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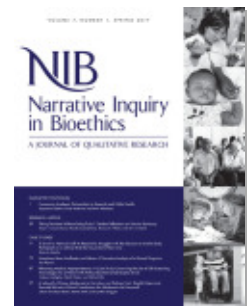
Developing Trust, Multiple Identities, and Participatory Research: Select Examples

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Narrative Inquiry in Bioethics, Volume 7, Number 1, Spring 2017, pp. E12-E14
(Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2017.0027>



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with the community organizations, I pondered about how true equity could be realized in such a project, and to what degree communities should be empowered to deal with substance use problems and I found the answer to this question to be quite complex. Therefore, in future research, I'd particularly prefer to work with a general welfare organization or a treatment center instead of an organization linked to or aimed at a group of people with specific migration backgrounds: because after all, are we studying epidemiology and health inequity of an ethnic group, or is it rather inequity in welfare, health and treatment organizations we want to study?



Developing Trust, Multiple Identities, and Participatory Research: Select Examples

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In community-based participatory research (CBPR), trust among participating individuals and groups is paramount to achieving goals. Trust is an ever-changing and evolving concept implying increasing willingness to take risks with potentially delicate information, an assumption that promises will be kept, and a belief in the good will of the other. When outside researchers enter a community, they are greeted by community members and organizations who have often had prior experience with outside researchers. A critical aspect of this process is the value of outside researchers developing what clinical psychologist James Kelly called an "eco-identity" or a way of becoming known in the local community that helps community members "locate" the researcher in the community context and provides a basis for relationship development and subsequent trust. In this paper, I will describe the development of trusting relationships involving genetic studies with Alaska Native communities.

The Center for Alaska Native Health Research (CANHR) located at the University of Alaska

Fairbanks was funded in 2001 by the National Institutes of Health (NIH) as a Center of Biomedical Research Excellence (COBRE) focusing on obesity and cardiometabolic disease in Yup'ik Alaska Native people in rural southwestern Alaska. Initially, it was comprised of three multidisciplinary research studies including genetics of obesity, nutrition and physical activity, and cultural understandings of health. Now, CANHR includes behavioral health and nutritional research as well as epigenomic and pharmacogenomic research to address health disparities in Alaska Native people.

As a Registered Nurse, I am interested in health disparities in Alaska Native people and the influence of culture on health beliefs, behavior and outcomes. I began working with CANHR in 2002, first as a graduate student in cultural anthropology, then as a research coordinator, and now leading the Community Engagement and Clinical Support Core. One of my responsibilities as a graduate student was initial contact with potential communities who had been selected by the Yukon-Kuskokwim Health Corporation (YKHC), the native health entity providing medical services and overseeing health research in this region. These initial contacts included several visits to the communities to meet with Tribal Governments and community members to discuss the research and gain approval. These first visits were the beginning of trusting and sustained partnerships spanning a 15-year period with over 1,800 Yup'ik participants in our genetic studies.

It is important to reflect on and document how trust develops in community research, particularly when it involves basic science rather than community interventions intending to have direct community impact. In the 15 years that I have been involved in multiple projects involving multiple communities, my primary role has been to facilitate the relationship between the university research project team members while simultaneously being involved in recruitment of participants, data collection and dissemination of research progress and findings. During these years, I have come to understand how my various identities have played a role in allowing and promoting relationships with community members. These identities involve my

southern upbringing, being a mid-aged woman with a family, a clinical background in nursing, and my role as a researcher.

Initially, I was very nervous, but also very excited about my first visits to these communities. I was not sure what to expect, how I would be received, and what I should or should not do to be culturally respectful. I had read much of the ethnographic literature about Yup'ik people to prepare myself. However, I felt the best and most genuine approach was to just be myself. Being brought up in the South, I was taught to be friendly and greet everyone, whether I knew him or her or not. In each Yup'ik community, I would smile and nod or say hello when passing. I found Yup'ik people were very friendly and welcoming to me. When appropriate, I would introduce myself, and share why I was in their community. I think my excitement over being in their community and my eagerness to learn about their culture was evident. Over time, I got to know many individuals in the communities by name, learned much about their lives and their families, and shared aspects of my own life, much as I would have done had I remained in a small southern town.

In particular, the Yup'ik women were very friendly and expressed interest in the research studies, especially my study on women and healthy aging. Immediately, I was invited for coffee or tea, and we would get to know each other. I shared about the research, but surprisingly they were more interested in who I was as a woman, where I lived and my family. Yup'ik culture is very family focused and a woman's primarily role is to take care of her family. The women took care of me, making sure I was fed, had a safe place to sleep, and that I was able to do my research. Initially, they offered me Kass'aq (non-native) food, but as they got to know me they shared their traditional native foods, like dried fish, seal oil, and moose. I would help prepare food, including cutting up meat, plucking birds, or making agutak (Eskimo ice cream), and also help to clean up. This felt natural to me as I was taught as a southern woman that my primary role was to support and take care of my family. Women support each other through church functions and other social events, and in times of need, we pull together

to help each other. These relationships extended far beyond formal research roles and included such involvements and attending important community events such as church services, funerals, feasts to honor relatives who have passed on, feasts to celebrate birthdays, and "throwing parties" to celebrate a youths hunting success.

An additional vestige from my southern upbringing was that I learned at an early age to be considerate and respectful of elders. In my youth, I would sit and listen to my grandmothers and great-grandmothers talk for hours about their lives and what it was like to be a woman in that era. Their stories defined and modeled my role as a woman in my family and community. In Yup'ik culture, Elders are highly respected and their stories teach the traditional Yup'ik ways of living. Oftentimes, the answer to a question is embedded in the story being shared. During community meetings and other events, it was natural for me to listen attentively to the Elders and to learn from their stories.

As I became better known in the communities, my training as a nurse made me an informal resource for health information. Women would ask questions about their health, not necessarily questions related to the research studies, as I was someone they could have a one-on-one conversation about sensitive health issues. Oftentimes, the local community health aide was a relative or someone with whom they did not want to discuss certain personal issues. Women expressed concerns over reproductive health, stress, and family issues including domestic violence and parenting. I would provide general clinical information, but also referred them to the appropriate services at YKHC.

I believe my willingness to open myself to new ways of living, to share parts of my personal life, and to offer my nursing expertise facilitated lasting relationships and served as a major bridge between academia and the communities involved. The women were able to place me not only as a researcher, but also as a woman, with similar roles and life challenges and as a nurse with specialized knowledge not necessarily related to the ongoing research projects. These experiences illustrate how the community "made sense" of the researcher

through her multiples roles within their cultural construct and provide a perspective on participatory collaboration that reflect the notion of CBPR as a “world view” that affects both the quality of research and the researcher. This approach to research fosters trusting, sustained relationships in which the researcher and the community share in the research goals and negotiate the day-to-day process of planning and conducting research. Over time, these deepening relationships can cultivate research that more effectively addresses the needs of the community, thus providing additional benefit to the community and enhancing the quality of the research.

The issue of trust, in my experience, involved all of these aspects of my identity not only as a researcher but also as a southern-born woman, a nurse, and with a willingness to share my own life and experiences and immerse myself in the life, particularly of women, in the communities involved in the research projects.

I consider my ability to spend time in communities, get to know the people, and to learn about the Yup'ik way of life as a precious gift that has enriched my life.



Advance Care Planning for the Homeless: A Community Collaboration

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UCLA Medical Center, Santa Monica is an academic medical center that serves a large homeless patient population, many of whom have chronic and potentially life-limiting illnesses. Our emergency room sees approximately 50 homeless patients during an average 30-day period. Given the transitory patterns of this population as well as the complex needs, their healthcare goals and instructions are typically overlooked and or

unknown. By educating and engaging the homeless population in Advance Care Planning (ACP) we hope to aide in addressing the issues this complex population faces.

ACP conversations include exploring goals of care with the hope of completing an Advance Healthcare Directive (AHCD) for that patient. This allows the patient to have his/her healthcare wishes documented and respected by healthcare institutions. Without an AHCD, the patient is treated aggressively, which is the default when healthcare instructions are unknown. Research has found about 70% of Californian's would prefer to have a “peaceful death” at home. However, due to lack of advance care planning, over 60% die while being treated at healthcare facilities and 20% will spend more than 7 days in the ICU in their last 6 months of life. Homeless individuals surveyed expressed the same desires and goals for their end-of-life care to result in a ‘peaceful death.’ The Palliative Care Clinical Nurse Specialist (CNS), Chaplain and Social Worker at UCLA–Santa Monica Hospital observed the need for providing these ACP conversations with the homeless patients, as the conversations were rarely had.

In collaboration with a physician champion and the Spiritual Care Department, the Palliative Care Team obtained a grant from the Coalition for Compassionate Care of California (CCCC) in order to create an outreach plan with the goal of completing AHCDs within the homeless community. Initially, we collaborated with our own administration and trained hospital in-house staff on ACP. The stress of being in the hospital and being hospitalized for a short period did not allow for ACP conversation, much less AHCD completion. Therefore, we decided to explore other opportunities and collaboration for education and training with the local community agencies that worked with the homeless population.

Collaborating with community agencies has proved to be successful and instrumental in shaping our outreach efforts. We sought out collaboration with agencies that worked with our homeless community. We reached out and collaborated with The People Concern, St. Joseph's Center and Venice