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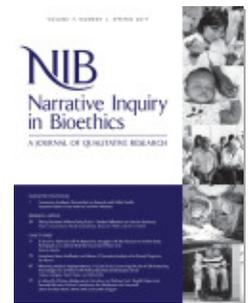
Be Careful What You Wish for: A Community–Academic Student Partnership Story

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The development of Afghan Women's Breast Health Program required extensive negotiation, flexibility, and constantly open communication, and from it grew a trusting relationship that allowed us all to address a serious concern from a sustainable place; and was an education in the development of long-term, effective programming on both sides of the partnership. Several of our early participants have been hired as health facilitators, and programming continues to focus on a holistic model of individual and community health. The community partners knew that this was their program that was benefitting their community, and that ownership was a powerful motivator.

Acknowledgements. This narrative is intended as a composite of the work done by our partnership, particularly Rona Popal executive director of the Afghan Coalition, Joan Bloom of UC Berkeley Public Health, Aida Shirazi of UC Berkeley, and the women of the Afghan community who shared their stories with us.

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Be Careful What You Wish for: A Community–Academic Student Partnership Story

Trina C. Salm Ward, Mary C. Mazul,
Martha L. Barry, and Amy E. Harley

Background

Milwaukee, Wisconsin is a unique Midwestern city. Situated on the western shore of Lake Michigan and the southeast corner of the state, it is Wisconsin's largest city. Milwaukee has a reputation for a diverse culture, cuisine, music, higher

education, and an incredible park system. These attributes make it a desirable city for over a half a million people in the Midwest. However, while steeped in rich history and culture, the city has some significant issues. While many urban cities in the United States suffer with racial tension and disparities, Milwaukee is considered one of the most segregated US cities and unfortunately has the largest racial disparities in some major health outcomes. One of the most significant disparities is in our infant mortality rate with African American babies dying at a rate nearly three times that of White babies.

In the fall of 2009, two doctoral students, Salm Ward and Mazul, enrolled in a newly formed public health course entitled Social and Environmental Justice in Public Health at the University of Wisconsin–Milwaukee taught by a public health professor, Dr. Harley. One student, a Master-prepared social worker and the other a Certified Nurse Midwife, joined together to complete a project assignment. The project consisted of designing a research proposal and presenting it to a community partner for feedback. The aim of this project was to provide students with the experience of engaging community partners in research. At the time, both students were involved in the Milwaukee Fetal/Infant Mortality Review (FIMR) committee and were vested in improving birth outcomes for African American babies. The FIMR data indicated that a much larger percentage of African American mothers received less than adequate prenatal care. The students were interested in understanding African American women's perceptions of prenatal care, including perceptions of racial discrimination, with the long-term goal of informing prenatal care providers.

The students created a proposal to undertake a qualitative study that would investigate the prenatal care experiences of low-income African-American women in Milwaukee with special interest in experiences of discrimination. They chose the YWCA Southeast Wisconsin (the YWCA) because of its mission to eliminate racism and the services the agency provided in the community with African American families and childbearing women,

predominantly from lower income neighborhoods. The students contacted the YWCA and were invited to meet and present the proposal. Proud of their well-thought out PowerPoint presentation, they entered a small room and presented to three people, none of whom they had really met before and oblivious to the fact that they were addressing the highest-level leaders of the organization—the COO, the Racial Justice Director (Dr. Barry), and a program coordinator—the students proceeded to accomplish their exercise of ‘presenting’ the study and asking for feedback.

YWCA leadership provided excellent and thorough feedback and facilitated an open and transparent conversation about the importance of trying to understand African American women’s experiences and yet not behave as if they were ‘studying’ them. At the end of the presentation, both students felt relieved that they completed their assignment and had received valuable feedback. The only thing left to do was to ‘write up’ the project for their professor. Quite proud of themselves, they left the YWCA feeling exhilarated! On a late Friday afternoon, Dr. Barry called one of the students and said, “we want you to do the project.” There was a moment of terror as both students wondered where they went wrong and how they did not convey that this was only an exercise. Dr. Barry clarified, “we know this was only a proposed project, but we really think it is meaningful, and we’re willing to do whatever we can to support you in carrying it out.” Obviously, there was no budget, no concrete research proposal, and neither student had ever conducted qualitative research. Moreover, both students were working professionals pursuing PhD programs and had little time to carry out an extraneous project. In addition, the students were keenly aware of the racial tensions in Milwaukee, and neither student was sure how the project aims would be received among their community partners and the families they served. The terrified students sought advice from their professor, Dr. Harley, who strongly encouraged them to pursue the project, offering her expertise in community-based participatory research approaches and qualitative research.

The Partnership

The YWCA has a long-standing reputation in Milwaukee of trust with the African American community. The students were both honored and worried to learn that the YWCA had historically never conducted research in their agency, and that the CEO of the agency was strongly interested in this project. YWCA leadership provided ongoing feedback on research questions, methods, and interpretation of the results. Wanting to be true to their reputation as advocates, they provided valuable feedback as the students began to create focus group questions. The students immediately began to understand the complexity of conducting rigorous scientific inquiry with respectful deference to a community partner’s unique insight. While the students came to the table understanding the importance of consistency in eliciting responses, recruiting participants and conducting focus groups, the community partner was far more interested in how women would perceive the questions and how they would be treated during the focus groups.

One of the most interesting points of discussion was the utilization of the word racism. As in many US cities, there is a history of distrust among the African American community and the larger community. Both students had worked within the Milwaukee community for several years and understood the sensitivity around the racial tensions in Milwaukee. The students worked to balance a rigorous study design that explored broad perceptions of prenatal care without providing “leading” questions about racial discrimination with the YWCA’s comfort and directive of calling out and naming racism. The compromise was to lead with questions about broad experiences and perceptions of prenatal care with a follow-up question about perceptions of racism. The YWCA leadership pushed the students to not shy away from the specific focus of racial discrimination in the dissemination of their study results.

The students, under the direction of Dr. Harley, conducted inductive thematic analysis, peer debriefing, and member checking sessions. Preliminary results were presented to the YWCA, who provided feedback and insight to the findings and helped

shape the dissemination plan to both the scientific community and the Milwaukee community. While it might have been a bit of a dance to have our partner involved in the research question and the discussion guide, their input was invaluable and created a much stronger and well-informed product.

The students were fortunate to have a highly-respected and invested community partner who provided direct access to the population. The students created recruitment materials with approval from the YWCA, and the YWCA did much of the recruitment via a program for women with infants and within their own building. They coordinated scheduling of focus groups and provided space and childcare for the groups. The students received a small grant from a local children's health care plan to provide participant incentives and snacks, and the YWCA managed the funds, ordered the food, and managed other coordination tasks, allowing the students to focus on carrying out the focus groups.

Lessons Learned—

Student Researcher Perspective

The students were fortunate enough not to experience any overwhelming challenges or obstacles during this partnership. Perhaps as two novice researchers, they were in a good position to abdicate a portion of the ownership over their research. The students were learning, the community partner was learning, and they had a strong, mutual respect and admiration for each other. While the students struggled to put together a research proposal, create discussion questions, recruit women and facilitate focus groups, the community partner helped them handle the logistics of doing this work. The community partner also ensured that the students' research was respectful and appropriate.

The most important lesson the students learned from this work was to include a community partner from the very beginning. Serendipitously, the 'assignment' was set up in a way that facilitated partner involvement from the beginning. While the students did define the research problem, the community partner helped refine that definition and actually pushed the students into a bolder and more meaningful study. Their influence over the

discussion questions and the dissemination of the results helped create an incredible study, resulting in the students developing a reputation in the community of being true advocates and allies. This has provided the students with credibility to continue to conduct appropriate research.

Perhaps since the students were such novices at the beginning of this research project, they didn't need to 'know' anything about working with community partners. Therein is the primary lesson, forget what you know about conducting research. Bring your expertise and knowledge to the table but don't own the research. True community engaged research is a co-ownership. The students as researchers recognize that they conducted a far more meaningful project with their partner's input than they would have on their own. An additional lesson learned was to maintain ongoing communication with the community partner. In retrospect, the students let several months elapse between communications with the YWCA, and could have been more proactive with communicating about their ongoing dissemination plans.

Also, as students, we were very reluctant to use the term "racism." The YWCA helped us gain confidence in our use of the term and how they described the study results. We ultimately applied Camara Phyllis Jones' theoretical framework for defining levels of racism, published in 2000 in the *American Journal of Public Health*.

The students reported project results in two publications in the *Journal of Racial and Ethnic Health Disparities* and the *Maternal and Child Health Journal*, at several national professional meetings (American Public Health Association; CityMatCH), state level professional meetings (Wisconsin Association for Perinatal Care; Southeastern Wisconsin Nursing Research Conference; Wisconsin Public Health Association), and at local venues such as health care system and university learning sessions.

Lessons Learned—

Community Partner Perspective

YWCA leadership was excited to collaborate with these two enthusiastic students on this research. It fit well within the agency mission, and leadership

saw an opportunity to help shape the learning of two budding researchers while also addressing an important issue in the Milwaukee community. YWCA leadership appreciated the ability to help shape the study design and questions, and believed the research was much more meaningful because of the value placed on the agency’s experience with the community. YWCA leadership encouraged the students to not only identify opportunities to share research results in their academic circles, but also with local community partners to ensure a strong impact in our community.

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The Power of The Personal: Breaking Down Stereotypes and Building Human Connections

Gay R. Thomas, Betty L. Kaiser,
and Kaitlin Svabek

On a weekday night, every month, twelve people meet around a table at a community center in Madison, Wisconsin. The group includes people who are homeless, previously-incarcerated, unemployed, handling chronic mental or physical challenges and several health science researchers. Someone walking by the room might notice the intense energy, lively debate, engaged participation, reams of flip chart paper, and wonder, “What’s going on??”

This has been our reality every month for over six years. The people *giving* advice are the

Community Advisors on Research Design and Strategies (CARDS)[®], community members from diverse racial, socioeconomic, and educational backgrounds. The people *getting* advice are researchers who want candid feedback about how to make their materials more engaging, easier to understand and more actionable from people often labelled “hard-to-reach.” And the people planning the meetings are our staff with the Wisconsin Network for Research Support (WINRS), a patient and community engagement resource.

We started the CARDS[®] in 2010 as a partnership between the University of Wisconsin–Madison School of Nursing, Lussier Community Education Center, and Goodman Community Center. With initial funding from a 3-year National Institutes of Health grant, our project was a response to the painful reality of persistent health disparities in our country and to the fact that health sciences research has not successfully engaged the full breadth of our country’s wonderful diversity. What’s the connection, we wondered? How can research appeal to a broader group of people? If all Americans did participate equally in health sciences research, would this move the needle on health inequality? With our community partners, we deliberately recruited CARDS[®] from groups of people most affected by health disparities and least represented in research projects. We provide an interactive orientation for all CARDS[®] and pay members for each meeting they attend. We also compensate the community centers for staff time and meeting space.

In the process of bringing unheard voices into the research enterprise, we have learned a lot about how to revise research activities and materials to engage a broader audience. We’ve also learned some interesting things about the stereotypes and assumptions that researchers make about “hard to reach” people, the assumptions that lay people make about researchers, and how to overcome prejudices that make it hard to connect with each other.

What are some common researcher assumptions? “I’ve spent my whole professional life researching this disease, what can I learn from people who don’t really know anything about this topic?” “I know what I will get—people telling me to ‘dumb down’ my materials.” “The feedback I