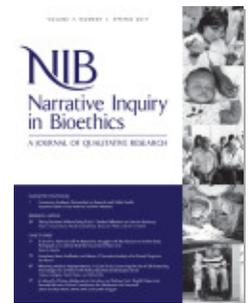




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Conclusion

Our primary goal with this symposium was to provide a platform for individuals engaged in community–academic partnerships to reflect on some of the more nuanced challenges of such work, as well as the ways in which they themselves had been personally affected by the partnership. The human stories of partnerships inevitably develop as teams meet, set specific aims and deadlines, complete project milestones, and write reports. Yet the human side of community–academic partnerships gets no more than a few lines in an academic publication—while human lives are profoundly affected. The fact that we received so many story proposals suggests that individuals engaged in community–academic partnerships have so much more to share than what is published in the traditional academic literature.

A list of references for publications that report findings from studies conducted by the community–academic partnerships detailed in the symposia in this issue are listed on the NIB website at <http://www.nibjournal.org/current/index.html>.

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Personal Narratives

Two Steps Forward, One Step Back: Dancing Toward Equitable Collaboration

Rosana Leos Bravo, Angela Gutierrez,
and Maria–Elena De Trinidad Young

Alma’s flustered voice burst out, “¡Pues, ya díganos! ¿Qué quieren que hagamos?” The outcry startled and confused us, breaking our attention and pulling us away from our facilitation notes—pages replete with our detailed plans for the meeting. It was a Friday evening after each of us had completed a full workday and fought the Los Angeles traffic. We were exhausted, to say the least. Furthermore, our meeting was taking place under time constraints because the East Los Angeles community center where we met was closing in an hour.

The members of our group—six *promotoras*—were antsy to move our collaborative project along. So were we. We were doggedly making our way through our plans to elicit discussion from the group to hone in the focus and objectives of the *promotoras*’ project. We were in our fourth meeting and had already spent the first hour attempting to lead a participatory decision-making process by asking the group our carefully crafted open-ended questions about their strengths and needs. The *promotoras*, who had formed a grassroots collective, had reached out to us in their efforts to develop the skills to initiate their own health promotion projects. On that hot, summer evening they had been politely, if somewhat listlessly, responding to our questions: What skills do you currently use? What skills would you like to gain? What types of research questions would you like to explore?

Alma’s words, “Okay, just tell us what you want us to do already!” marked the moment when we realized that our orchestrated recipe of participatory group processes was not helping us build a relationship with our community partners. It was not serving to move us towards an open exchange of ideas for the project. Alma pushing her chair away from the table where the nine of us were

sitting and, crossing her arms, continued, “We have a lot of skills. We can work on diabetes prevention, reproductive health, domestic violence; you name it. Just tell us already! What do you want us to do in this project?” Feeling the stare of our community partners as they awaited an adequate response, one of us sheepishly ventured in Spanish, “Well, we were hoping you’d decide what your project would be. It’s your project. You get to decide.” “Oh,” Yesenia, one of the *promotoras*, said. “We thought you were going to tell us what to do.” Another added, “I thought you were testing us on our skill level.” Quietly sitting and feeling the time slowly pass us by, we realized we had started on the wrong foot and inadvertently employed a deficit model of conducting our assessment with the group. Like learning a new dance, we had not only lost the steps but had lost track of how to take turns leading and following.

The three of us had won a small departmental grant that encouraged graduate students to engage in community partnerships. Our original idea was to collaborate with this group of seasoned *promotoras* on a research project of their own design. The members of the group had more experience than each of us working with a diverse range of nonprofit and public health institutions. We were newcomers to the public health field compared to their ten to almost twenty years each of experience. When we first met with them, they shared their desire to address the challenges that their fellow *promotores* faced personally and professionally in their health promotion work. Despite their experience, their work was poorly paid and rarely did they have a voice in the direction of the programs they implemented. When it came to research, they had only been treated as partners during the recruitment and data collection phases and had been dismissed at the latter stages of research.

As researchers committed to social justice, we saw the project as an antidote to the hierarchies in research and intervention programs we had so often observed in our work. The three of us had first-hand experiences with the stratified structures and often inequitable roles within academic organizations and studies, where voices and contributions of

less influential individuals could be discounted or undervalued. As Latina graduate students, we experienced being “tokenized,” had our voices disregarded or co-opted, and struggled with feelings of inadequacies and the lingering idea that “I only made it this far because of a ‘special program.’” We wanted to do things differently. We used the funds to provide each *promotora* with a stipend for her time and we wanted them to lead the direction of the project.

Perhaps we were too idealistic or naive. After the first meeting with them, it seemed like it would be easy to focus the project, impart some skills, and see a research project take off because the *promotoras* were full of ideas for their grassroots group. Silvia had wanted to work on a compilation of *promotores* stories. Marisa wanted to start a school to train other *promotoras*. All we had to do was direct their ideas and energy. In hindsight, however, what is clear is that despite our experiences of being subordinate in the research hierarchy, we did not know how challenging it is to dismantle those hierarchies.

Although we began our partnership with a sincere attempt to be collaborative, we perpetuated the research hierarchy by assuming that there were distinct functions between the researchers and the community partners. We assumed we had the “research” skills and they had the “community” skills. This perpetuated a false dichotomy of the abilities and values we each brought to the project and reinforced roles about who brings a researcher perspective and who brings a community voice. We saw ourselves as “consultants” to the community, where we planned to build capacity and step back to let them do the work. While our definition of these roles came from good intentions, from a desire to honor and recognize their wealth of experience and support them to gain new skills, we realized that we needed to drop our externally defined roles of “researcher” and “community” and collaboratively re-define new roles and project purposes for all of us.

We also had to challenge our concepts of what it meant to be “participatory.” Afraid of employing a banking model where we “dictated” and they “learned,” we applied what we assumed was an

open and fair approach to assessing and responding to their needs and interests. Thus, our initial meetings were awkward dances of questions, discussions, and group process activities—we thought we were letting them lead, but in actuality, we were leading them without sharing the steps to the dance. Our efforts to enact participatory processes felt collaborative to us because the questions were open-ended and we were looking to them to make decisions. Furthermore, we were mindful of the cultural context upon which we were developing this relationship. We wanted to be respectful due to their age and wisdom; however, we struggled to figure out how to best respect and foster their expertise, while also being cognizant that their formal training of research practices and methods was limited. On the one-hand, they had great working knowledge in their field, and on the other hand, they wanted to understand the research activities from which they were often excluded. What we quickly realized after Alma spoke up was that we did not give them the opportunity to lead, nor the research skills with which to do it.

We stopped trying to define the goals, objectives, and research questions and stepped back to focus on learning from one another. On our end, we developed interactive workshops to discuss research skills. The *promotoras* immediately started building from concepts already familiar to them—such as recruitment, interviewing skills, development of problem statements. As they started adapting these skills to the context of our research project, they shared with us their experiences in the field. We learned what it means to be a *promotora*. We were obtaining a deeper understanding of the role and experiences of *promotoras'* work.

As a result, we each started to foster each other's strengths. We began taking turns leading discussions on different phases of the research. Sometimes we as academics were the "experts" and sometimes the *promotoras* were the "experts." By switching off, we doubled our expertise. As our partnership progressed, each partner became increasingly comfortable in joining in the dialogue and challenging some of the assumptions or interpretations of the research we were conducting.

At one of our meetings, they each shared and spoke about the steps in the research process that they enjoyed the best. Alma loved losing herself in transcribing, while Yesenia felt her strongest when conducting interviews. During our last couple of meetings, the three of us sat back and enjoyed observing the *promotoras* develop codes and categories for their analysis, and discuss the results of their research. We relished in seeing our *promotora* partners successfully incorporate newly acquired research terminology and expand on the conceptual framework and recommendations of their completed research project, which captured the experiences of fellow *promotoras* in the field. We took their lead as the coding, analysis, and interpretation moved forward.

In the process, we have learned that being participatory also meant being honest and transparent about the many inequities that we could not directly address or change. As we became partners, colleagues, and equals within the context of our project, the glaring disparities within the research world have become more apparent. Although we are pleased that we have removed the rigid role of "researcher" and they the role of "*promotora*," these positions return the moment we step out of our meetings. The key to achieving, even if momentarily, an equal partnership is learning how to dance. We had to increase our sensitivity to reading the signs that indicated when it was our turn to lead and when it was our turn to follow. Although we recognize that community-partnership work is often accomplished within inequitable social hierarchies, at some level; we cannot fully resolve these systemic injustices. However, they need not negatively impact the relationship development between community-academic partners but we must be cognizant of their existence and its implications in our roles within the research.

As the project comes to a close, we plan to publish and disseminate our results. However, the real world of research, yet once again, confronts us with the challenge on how to be equitable. How can we ensure we respect *promotoras* as researchers? How do we ensure we equally share the benefits of our work? Then we are reminded that a partnership

must be maintained. Learning to dance is an art, not a science!

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Research Partnership Rather than Research on the Amish

Helen M Farrar

Personal Narrative

Gelassenheit. The first time I heard this word it sounded like a sneeze and I remember asking for the research participant, who I was interviewing, to translate. She paused, appeared thoughtful and said “for you it would be, it would be you being humble. That what you do is for God and you are grateful you can.” When I decided that I wanted to pursue doctoral education in nursing research almost ten years ago, I had no inkling how much this word, and my relationship with an Amish community would enrich my life. I knew that I wanted to do research with a population who was vulnerable. I knew that I wanted to learn how to listen to people’s stories and translate their perspective to the scientific community. I did not grasp how much I didn’t understand, and how reliant I would become on partnership to guide the research. My personal experience taught me that thinking you are humble and grateful, is not the same as being humble and grateful.

Research with groups who are considered minority, vulnerable, ethnically or racially diverse is a unique experience. There is a wealth of research about how the research community should interact

with these groups, all mindful of a less than savory history of how these groups were marginalized during the research process. When I first approached a member of an Amish community I knew this history, and I thought I was sensitive to the power differential. I assumed that as long as I was polite, there was no reason that they wouldn’t want to work with me.

I read literature about working with cultural groups, and most said to begin with a female Elder. When I first approached a female Elder of the Amish community about doing a research study, I asked her whether she thought there would be people in her community who might want to talk to me about mental health and aging. She was very polite and encouraging at the time, but never returned subsequent messages and when asked directly was evasive about getting started. I reflected that this may not have been the best strategy. This was the first of many missteps in my research relationship with this community that I made from a paternalistic and naïve perspective that of course they would want to talk to me, of course they would want to understand the same things I wanted to understand.

My second attempt met with more success, because instead of just asking someone I knew who was Amish, I asked who I needed to talk to, and how I should talk to them. This male Elder of the community was also polite and encouraging but blunt in his opinion that, “no, no one will talk about that”. I was distressed. I hadn’t planned on him saying no. In the moment I was faced with a choice, walk away, and be thankful for his time or see if there was another way. I asked him what he thought people would want to talk about. Instead of giving me an answer, he told me a story. He told me about someone in the community who had taken their grandmother to the hospital because she was experiencing dizziness. He said that the hospital doctor ordered multiple medical tests and kept her in the hospital for several days. He shared that this was hard on her family who had to hire a driver to take them back and forth to the hospital, over 30 miles away. They were worried about the cost of the tests and the hospital stay, but wanted to help her. The grandmother had been sent home

with a diagnosis of syncope and instructions to stay hydrated, make position changes slowly, and no reason for why she was dizzy. Her medical bills were several thousand dollars.

Over time I would learn why these details were important to the Elder and why he wanted me to understand why this is something people in his community would want to talk about. That day I asked him to consider being my partner in a research study. He agreed and that was the beginning of a community based participatory research relationship. Over the next four years, myself, the community Elder, and his wife and 13 additional research participants would work together to explore the question “what is the lived experience caring for an Amish older adult and your interactions with Western healthcare providers”.

After those initial missteps, I was more cautious in my interactions and sought practical, real-world advice from my faculty with expertise in community partnerships. I recruited colleagues with experience doing research with Amish and Mennonite communities, and when unsure, asked the Elder and the participants themselves for direction. This attitude reflects the concept of *cultural safety*, where the research participant is the expert of what is or is not culturally safe. In other words, I gave as much power as possible to the Amish people I talked to, to tell me what I could say, what I should ask, and what I should think or understand about them. I moved from a place of polite interaction to real humility and gratefulness. Every interaction became an opportunity to learn, to listen to understand without trying to follow a textbook or my own assumptions.

Subtle differences in time orientation, level of comfort with geography, gender roles, and the value of food would influence every aspect of the study. For example, depending on which Amish community you are in, there may or may not be phone access in the home so messages are left on a community phone and may take several days to receive. Finding an Amish home in the dark, in rural area, where you have not been before, without the aid of a google mapped address, meant stopping and asking for directions, and learning to navigate by unusual

directions such as the third white barn on the left or past the turn off for the “*Smiths*”. One day when I arrived to see the Elder, he appeared to be frustrated with me. After some awkward conversation he asked me “why didn’t you take your husband’s last name”. I was not prepared to answer this question and immediately was concerned that my feminist preference would offend him and that this meant the study was over. I paused and considered what was true and what he might understand. I told him that I liked my maiden name, that my father was one of the most important people in my life, and as his only child with children, I wanted to preserve his name. I shared that changing your name while a student meant lots of paperwork with the University but I loved and honored my husband very much. He paused and laughed, “paper work, you *English* (Amish term for non-Amish) like paperwork”. He still teases me about this but somehow my answer was accepted and the study and our relationship continues. Every meeting with the Elder, every interview, and every interaction with the research participants from developing the questions, to the actual interviews and follow up interviews, and the analysis of the data involved food. Particularly sweets and home brewed mint tea. I learned to arrive hungry and bring my own contributions to these meetings. I learned the value of food as an ice breaker, how it binds us across differences in culture, age, gender and power differences. The time spent sharing food taught me to relax and enjoy the time spent talking about shared interests, listening to their stories with an open heart and mind, careful to ask for clarifications when I didn’t understand, when I needed translation of the low-German or Dutch words that would slip into their stories.

The research study took over four years to complete and during that time we all learned from each other. I was able to share with the Elder and his wife research done with the Amish in other Amish communities. Several participants showed me ways that they care for their Elders in the home without modern conveniences. The study revealed the significance of the Amish cultural value of *Gelassenheit* and how the spirit of humble sacrifice and love infused the relationship between

caregiver and older adults in every story. An aspect of the study that I did not anticipate, and fuels the research partnership we now have, is the lack of understanding of the Amish culture from Western healthcare providers. Every story had an aspect of cultural miscommunications, financial or transportation based barriers that was not appreciated. This information made me realize that there is still so much I don't understand.

During this period I became pregnant, my parents retired and my personal caregiving role began to shift. Normally you might think that these personal events might complicate the research relationship. However, because of the unique opportunity partnership with a community can have, my research partners are more than my research participants. We have more than an exchange of data and forms. In alignment with a key principle of participatory research, a sense of mutual growth pervades our research and our personal relationship. Several of the older adults who were being cared for during data collection passed on during the study, and I was grateful to be included in their funerals. My son enjoys the friendship of other Amish children born during the same time period, and I have new insight into the changing role of parent and child, as my own parent's age. I did not anticipate how much engaging in this partnership would affect my own life. I am humbled to be in this research relationship and I am grateful that I can do this work with this community.

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We Really Do Have the Same Goals: The Push and Pull of One Community– Academic Partnership to Support Congolese Refugee Women

Jyotika Saksena and Shannon McMorro

We never expected a mundane conversation about university curriculum to blossom into a community based participatory research endeavor. However, looking back, it seems natural that an international relations faculty member who had worked with a refugee organization for years and a public health faculty member who used Photovoice research with vulnerable populations found common ground. The main purpose of our project was to assess the needs of Congolese refugees coming into Indianapolis in order to improve the ability of refugee resettlement agencies and public policy makers to provide effective and, culturally appropriate services. Photovoice methodology was intentionally selected to give the women voice through the photographs and subsequent storytelling sessions, thus making them active participants in the study and providing a firsthand view of needs in their immediate environments through photos. Our initial conversation led to envisioning a Photovoice project with refugees, acquiring internal funding, securing an external grant associated with state public health funds, and utilizing Photovoice to understand perceptions and experiences of health and integration among Congolese refugee women living in Indianapolis.

Our community partner was a non-profit organization dedicated to refugee resettlement. From the outset, we strived to engage them in all facets of the project including choosing the specific refugee subpopulation, formulating research questions, recruitment, and implementation. We approached our partner with the idea of using Photovoice to better understand integration and health of refugees and asked two questions: 1) Is this something of interest and utility to you? 2) If so, which population of refugees do you feel would be most helpful to conduct Photovoice with? Their answer was yes and people fleeing the Democratic Republic of Congo,

Iraq and Syria were prioritized by the resettlement agency due to those being new refugee groups in the state.

We agreed the focus would be on women primarily due to alignment with an existing women's program at the agency.

Our partner was particularly excited about the use of Photovoice methodology to engage and give voice to refugee women, particularly the newer groups like the Syrians, Iraqi and Congolese that they had limited experience in serving. One curve ball that occurred was restriction of the study population to Congolese refugees only due to the funding agency's application of the U.S. Office of Management and Budget (OMB) definition of ethnic and racial groups. The OMB considers Iraqi and Syrian women as Caucasian and therefore do not count as minorities and had to be excluded from the study. This is a case where the OMB definitions were not helpful in serving the greater needs of refugees or refugee resettlement agency and all parties involved were dismayed about the shift in our project.

Initially, external funding was secured in close collaboration with the former executive director. During the course of the project, that initial executive director left the agency, so it was inherited by the next executive director. Later, we worked closely with two assigned personnel to flesh out the details of the project including working with our university's Institutional Review Board (IRB). Since we applied for the funding together, the amount was split between us, with the majority going to our community partner. The funding was limited in that it did not pay for our time as researchers, but simply for materials and supplies to conduct the project. This becomes relevant because we engaged in conducting the research in addition to our regular teaching and service responsibilities as opposed to buying out any time for the project.

One of several positive aspects of this partnership was generous investment of the community partner in terms of human resources, space, and transportation resources. They assigned their sole medical case manager to work as an interpreter for the Photovoice project. This was written into the budget, but in the end she invested more time than

she was compensated for. She was an invaluable resource as an insider of the community, ability to speak several languages and as a critical bridge in helping us recruit and retain the participants. It was also wonderful that we were able to use the space of the community partner to hold initial interviews. Additionally, the partner used their connections to find another, third partner to donate community space close to the homes of most of our participants where we held all Photovoice sessions. Finally, the partner provided their bus to transport participants to and from Photovoice meetings. This was instrumental for maximizing participation since the women did not have to rely on public transportation.

While we agreed in principle to the common goal of serving the refugee population, we faced multiple challenges. We differed throughout the project about the level of priority and significance of the project for the community partner and the women, lack of clarity in the point person with the partner institution, and appropriate use of funding. Though the new leadership appeared to be on board with the project, we felt the commitment to and context of the project was not sufficiently conveyed to staff assigned to work with us on the ground. We endeavored to communicate what we perceived as the relevance of the project for the day-to-day work of the agency, but we often missed the mark.

Sometimes, we felt perceived as stereotypical, leisurely academics conducting research. Other times, it appeared our partner personnel felt grudgingly required to help us out. They would not hesitate to ask us to wait if they had other work and sometimes changed appointment times and days at the last minute. Our perception was that the partner was not taking the project as seriously as us, viewing it as *our* research rather than a joint project. At different points, we were told that the project was taking too much time and commitment. This was disappointing to us because we thought the participatory process through which the agency had agreed the project was beneficial and had originally selected the priority population was evidence of their commitment. On the other hand, it seemed our community partner felt that

we did not sufficiently understand the day to day pressures of a non profit organization. While the project was important to them, serving their clients on a daily basis and dealing with emergency situations was clearly, understandably, their priority. A project that would help their clients in the future, therefore, could wait.

There were multiple challenges throughout the project that served as “ah ha!” moments and lessons learned for future work with partners. One such challenge was lack of a central point person from the partner agency. It was originally the “baby” of the first executive director who left for another organization before the project got off the ground. While the new director was interested, there suddenly were multiple things to manage such as adapting to the new position, and therefore, attention was clearly diverted. The previous executive director had committed to be the main point person, but the new director could not focus on the project in the same way. We were assigned two different personnel to work with us, an intern familiar with Photovoice and their medical case manager who was also an interpreter. The intern lived in another city and was available just two days per week and the health navigator had to divide the responsibility between what she saw as her “real job” that she was paid for at the organization and the research project, which felt like extra work for her. This meant that she was often unavailable and did not hesitate to back out if she had other commitments. Though the agency received funding to support part of her salary while assisting with the project, the intense time period of work for the study occurred on top of the regular workload and she justifiably, felt overworked. While we kept ourselves flexible outside of our regular university responsibilities and schedule, it became frustrating to constantly negotiate her availability with her or her supervisor. It was not clear who our point of contact was in the organization.

We felt that partnership implied a commitment from our community partner but our sense was that they were doing us a favor by partnering with us. This became apparent from the way the assigned personnel dealt with us as well. There was friction

at different points due to their assumption that we did not know how to interact with refugees and unnecessary negotiations about resources like access to the bus, availability of drivers, or delivery of food without checking with the leadership structure. In frustration and trying to stick to a tighter timeline, we sometimes went to the leadership or executive director to get what we needed, which in turn led to more friction. We addressed this through conversations with the agency leadership and felt encouraged by a change and more amiable interactions during the remainder of the project. The assigned representatives from the resettlement agency became much more responsive and respectful of our requests regarding the project.

One major lesson learned was that we need to better communicate in advance about how both parties plan to use grant money. Our understanding was the agency would hire an additional interpreter or personnel. The community partner, like most nonprofits, wanted to use the grant money as an additional resource to support the organization. As a result, no new personnel were hired to assist with the project. Existing employees had to handle both their assigned work and additional work of the project. Therefore, for the duration of the two months that the project lasted, they were constantly torn in different directions. The organization did not want to pay them overtime, so there were restrictions on how many hours they could work. The employees wanted, and we felt they deserved, time off or extra pay to do the extra work for the Photovoice project. When they got neither, there was resentment towards us and the organization. We learned to keep in mind that for nonprofits, funding is always an issue and therefore, they are always going to be strategic about spending money. This means that it is up to us to ensure that we have a clear idea of how much time and commitment our project will require and convey it to our partner institution. We did not know how much time the project might take and therefore did not sufficiently communicate to our community partner how much time and resources the project might require. This led to the partner being overwhelmed to some extent by the obligation of the project.

Another key lesson learned was that prior to commencing the project, we needed to better communicate with the partner to identify one designated and committed staff person to be in charge of the project, to be our main point of contact, and responsible for all aspects of execution of the project. We spent a lot of time seeking input from various supervisor level staff and the executive director to negotiate the availability of the personnel, as well as the use of funding. At several times the personnel assigned to us did not know how to set their priorities. It also left us confused at times and questioning the commitment of the agency to the project.

A final lesson we will take with us for future partnerships is the need to build in more flexibility to project timelines to deal with unexpected situations, particularly when working with vulnerable populations such as refugees. For the women we were trying to engage, time was of the essence due to the urgency of trying to maintain consistent jobs. This means that the longer we took to implement our project, the more chance there was of losing participants. Due to many factors such as our inexperience in working with a refugee resettlement agency on a project of this nature, an intensive and lengthy IRB review, and the unusual pressures faced by our partner organization, the timeline for our project dragged on longer than anticipated. Luckily, due to the extraordinary assistance from our interpreter/research team member and unusual flexibility in our schedules we retained most participants. However, it is clear that in the future we need to build in the longer timeline as an expectation.

Overall, during the course of the project our partner organization experienced extraordinary change with sudden change in top leadership, engagement in a lawsuit against the state government, and planning an office move; all of which had impact on the project. In the end, we would absolutely do the project again with the same partner. We proudly worked together to share some of the photos and narratives at a local World Refugee Day event last summer. The friction that occurred during implementation faded away into satisfaction and pride in the shared accomplishment of giving voice to Congolese refugee women in our community. Moving forward, we foresee reuniting with our partner to

apply our lessons learned about how to better work together as the United States moves into times of great uncertainty and potential threat to refugees.

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Dual Relationships in Specialty Care: Reflections from the Field

Lewis Raynor and Amy Penkin

Introduction

The creation of the Oregon Health & Science University (OHSU) Transgender Health Program (THP) was a grassroots effort involving transgender and gender nonconforming (TGNC) community members, local organizations serving the TGNC community, clinicians, administrators, and researchers. The THP, which launched in January 2015, offers comprehensive, affirming, and competent healthcare to TGNC individuals across their lifespan. In 2015 the THP had over 500 referrals for TGNC patients and in 2016 that number grew to over 1500 referrals.

Amy Penkin is a cisgender, LGBTQ community member and licensed clinical social worker who was hired as the THP Program Coordinator in 2015. Her duties include, but are not limited to, workforce education, assisting patients with healthcare navigation, TGNC policy development, clinical alignment of departments offering gender affirming care, and community engagement to ensure program development and services align with community needs. During the first year Amy also helped establish a THP Volunteer program to ensure the program

continued to involve the voices of the community the program was serving. That program has also created opportunities to teach TGNC individuals about how to lead trainings for healthcare settings and providers about TGNC patient needs; thus, providing jobs and revenue to a community that faces disproportionate under/unemployment.

Dr. Lewis Raynor is an epidemiologist and a TGNC community member. He works as an Investigator at OCHIN and has affiliate faculty status at OHSU where he is helping build a program that addresses the healthcare disparities faced by sexual and gender minorities. He attends THP monthly meetings where he discusses what he is doing professionally; in addition, to providing his own community–based perspective on how the program can best serve the TGNC community.

Amy and Lewis have had many conversations about the overlap in identities and relationships with regards to the THP. Amy contributed to the creation of the THP and serves now as the program supervisor, but she also is a community member with personal ties to the TGNC community of Portland, Oregon where the THP is based. Lewis is a researcher that works with providers serving the TGNC community, but he is also a community member that advocates for improved healthcare access and utilization for community members in addition, to using the healthcare system himself. Lewis' recent utilization of healthcare at OHSU forced the both of us to move beyond abstract conversations to intentional ones around the ethical dilemmas our roles with each other and the systems we work within create. We believe that the issues we raise in this essay are experienced by other individuals that work with and coexist in small communities, and we hope this work will help guide other individuals from smaller communities in their attempts to bridge roles.

Program Supervisor and Community Member Amy Penkin's perspective

The THP program has experienced rapid growth since its onset and the success of this program would not be possible without the continued involvement of and relationships among community advocates

and organizations, patients, clinicians, and administrators. What I did not anticipate were the ethical issues that have arisen around my involvement in both the administration of this program and my membership in the community it serves. I have found that it is not unusual for me to engage with an individual who has overlapping personal and professional roles as a colleague, volunteer, community collaborator, friend, family member, and/or patient.

In April 2016, I was contacted by a close colleague of mine from an OHSU clinic who called to discuss a patient who came to the clinic for a consult regarding complications from a surgery received from a provider in another state. My colleague reported that the patient left before completing his appointment and appeared to be distressed, uttering a statement that was construed as a threat of self-harm. The patient's name and medical record number was provided, which led to the discovery this patient is an academic colleague, collaborator, and a personal friend, Dr. Lewis Raynor.

The context in which I met and built a relationship with Lewis was collegial and often informal. I knew he had encountered barriers to navigating healthcare; however, we never discussed those barriers in regards to his current utilization of OHSU healthcare services. He discussed personal healthcare experiences that are common to TGNC members, and we saw our discussions as a larger dialogue about creating a program that addressed those barriers and fostered trust between the provider/healthcare system and the patient. Our relationship was never based on him being in crisis.

After the clinic contacted me, I accessed Lewis' healthcare record and contacted him. We had a conversation where I let him know why I was reaching out and the professional capacity in which I was calling him. I directly asked if he was at risk and if he needed help. He let me know that he was not at risk, and I took him at his word, as we had established mutual trust in one another.

Later I reflected upon how my relationship with Lewis informed many elements of this interaction, for better and for worse. In the context of this crisis call, I was vulnerable to underestimating Lewis's true level of distress, as I relied on my knowledge

of him as a friend and colleague. I knew personally that Lewis was having complications and seeking care at OHSU; however, he had not asked for assistance navigating that care, nor had I considered the ways in which I could be intentionally or unintentionally involved in his healthcare. I had not anticipated that I would be accessing my colleague–friend’s medical record and documenting my assessment and conclusion.

Since this encounter the THP has hired a second employee who is also a social worker, which gives us greater flexibility around assigning an individual to meet patient needs, but this individual is also another member of the LGBTQ community in Portland. These dual relationships are the underpinning by which the THP functions, as it would be much more difficult to build trust with the community accessing the services and the community helping create and guide the program if the program were staffed by individuals that did not have a connection to the community being served.

Since April I have spent time reflecting on the countless individuals with whom I’ve worked with in more than one capacity but it was this particular interaction with Lewis that propelled me towards a change in my practice(s). I have become much more proactive in addressing and discussing roles, relationships, boundaries and privacy with anyone who has the potential to access healthcare with the THP.

TGNC Community Member and Healthcare Researcher Lewis Raynor’s Perspective

In an era of emerging transgender health programs and expanding care options there remains a dearth of healthcare providers serving TGNC patients in the United States. Patients often travel far from their homes, if not internationally, to access healthcare and obviously their support systems cannot travel with them. When they return to their homes to recover, they lose access to their healthcare providers. It is an unfair and unreasonable burden for patients, and their caretakers, and presents a questionable ethical landscape for providers who send physically vulnerable patients

across the country to recover without ensuring there is connected care.

My healthcare took place outside of the state in which I reside. I’m incredibly fortunate to be employed, to have insurance cover my transgender related healthcare needs, and to have the resources to pay to live out of state to receive medical care if necessary. However, my care is fragmented and largely driven by own well–developed knowledge of healthcare systems and my ability to advocate and oftentimes drive my own healthcare.

In April of 2016 I underwent a procedure in another state. Before I left that state I knew something was wrong. Fortunately, my relationship to the THP and my PhD in a healthcare field grants me both the awareness to know that I needed to get help and who I should contact in my state. In fact those relationships were formed by my involvement in the THP at OHSU. Consequently, I was able to contact a THP affiliated healthcare provider, discuss my concerns, and access care. I had very serious medical complications that necessitated surgical repairs and multiple hospitalizations.

The emotional burden of being a member of the TGNC community is sometimes beyond comprehension. We as a community fight for healthcare access and are frightened to push for measurement of how that healthcare is performing. We exhaust bank accounts and connections to physically get to the care we need. We sit in silence with our complications because we are afraid to talk about them lest we lose access to any care. We sit in silence with our complications because of the transphobia that makes us fearful to ask for support from the people in our lives that are not a part of our community. We sit in silence because we are scared.

It is that fear that I was steeped in that day in April. I had devastating results from my complications. I was struggling with how to take time off of work to recover, as I had fought for three years to find a job in my field after transitioning. I struggled with how to walk into another provider’s office and trust them with my body. I could not do it that day. That is what I expressed to the front desk staff at the clinic, and I think that they did the correct thing by calling Amy.

When Amy called that adrenaline and fear kicked in and led me to tell her everything was fine. It was decidedly not fine. But you learn early on in transitioning to try to grow the thickest shell possible. That colleagues and acquaintances will say unbelievable things to you regarding your body and mind and most importantly question your ability to make decisions about yourself. You simply forget how to trust anyone even the people you see as friends and allies.

Later that week I sat in my provider's office and discussed my case. I wondered afterward how my own healthcare advocacy would influence potential collaborations I had proposed with that department and that provider. I want OHSU to track and measure care for their TGNC patients as part of the THP. The publications around TGNC healthcare are largely found in Europe where the gender clinics and socialized medicine creates opportunities to assess care. The fragmented nature of healthcare in the United States means that most peer-reviewed research is community driven and published by clinics serving LGBTQ populations.

Conclusions

The event last year highlights some of the ethical issues faced by the both of us. Amy has established intentional practices on how to be more predictive about the potential for dual relationships between her personal and professional identities. Communication around her role in different scenarios is key, as the patients accessing care will continue to have personal and professional overlaps with THP staff.

Lewis is continuing to explore how best to navigate the thorny landscape of overlapping identities as well. He has been actively talking with a small group of TGNC healthcare professionals that also navigate this landscape. Trust was previously mentioned in this essay and that concept is key not only to the personal use of healthcare but also to the creation of research that evaluates that care. Fostering that trust as a professional while calling for healthcare accountability measures is a tightrope that Lewis and other TGNC healthcare researchers

walk with trepidation, always fearful of breaking the trust of the systems they are studying and/or the trust of the communities they are a part of that so desperately need this research.



A Storied Community: Piloting a Patient/Student Narrative Workshop at a Community Health Center

EmmaLee Pallai

The students enter the room unsure. They come from various health professions across the University: Pharmacy residents, Doctorate of Nursing Practice students, and medical students. For perhaps the first time they will be sitting with patients in a room that is not an exam room. They will be writing stories, not medical notes. Together, students and patients will be talking and writing about illness as people who have experienced it in their lives, not with their role in institutionalized medicine on their sleeves. The students have been instructed that, if asked, they may be called on to help the patients with the physical act of writing, serving as scribes. The patients are encouraged to ask for such help if needed. Together, over a communal meal, everyone in the room will begin to form a dialogue about illness and the road to health as a community.

The Community–University Health Care Center (CUHCC), housed within the Academic Health Center (AHC) of the University of Minnesota, is located in the Phillips Neighborhood in South Minneapolis. This neighborhood is one of the first places where new immigrants to Minnesota begin their journey in America. The patient mix at CUHCC reflects this as no ethnic group makes up over 20% of the patient community and 20% of the patients are uninsured. CUHCC services include medical, dental, behavioral health (which includes therapy, psychiatry, case management, care coordination, and Adult Rehabilitation Mental Health Services)

for both pediatric and adult patients. There is also a midwifery service, dermatology clinics, and pharmacy appointments. As part of the commitment to patient access and overall well-being of the patients, CUHCC also employs domestic abuse and sexual assault advocates and in-house interpreters for our patients who speak Hmong, Lao, Vietnamese, Spanish, and Somali. Legal aid is also available through a partnership with Stinson Leonard Street, who provided about 5,000 hours of pro bono services to patients last year.

As part of a large university, close to 300 students across the professional schools rotate through the site each year. These include students in social work, medical, nursing, pharmacy, psychiatry, legal, communication, and behavioral health programs as well as those interested in public, global, and community health who are undergraduates or in various master's programs. CUHCC also serves as the main continuity clinic site for Med-Peds, a combined internal medicine and pediatrics residency at the university. For their entire four years in their residency, they come to the clinic around one day a week to learn and build their patient base, allowing a continuity of care. They also spend special months at the clinic focused on projects to improve the quality of care. Residents from Psychiatry and Internal Medicine also hold continuity clinics at CUHCC, with Pharmacy residents spending about 90% of their residency on site. CUHCC serves as the bridge between the school and community, providing healthcare to those most in need. After 50 years providing primarily health care services, CUHCC is entering a new era with a revised mission, "Transforming Care and Education to Advance Health Equity" and a new goal to integrate education into everyday practice. Narrative workshops were born out of this new direction and a push toward person-centered care. If the patient and their community is the center of education and healthcare, then it's time to integrate them into an educational setting outside the exam room. Health Centers such as CUHCC are not only members of the academic institution that houses them, but also within and born from the geographic communities where they are located. As such,

students and patients need to be at the center of education and healthcare together.

The past year, we piloted narrative health sessions. Patients were recruited from the patient advisory group, which is comprised of a group of people who have been patients at CUHCC for a length of time around two years or more and wish to help guide the clinic on patient experience. They help with satisfaction surveys, create informational materials for patients, and help bring patient concerns to the greater CUHCC administration. We have also been working to integrate them into learner education and invited them to work side by side with students to gather stories to be used in the education of health professionals, for the patients to use to see their growth, and for a possible communal book of stories about the health journeys of those living in our community. I, along with the liaison to the patients, the Mental Health Director at CUHCC, explained that the sessions were structured for those who haven't written creatively before and meant to be a way for them to tell their stories.

On that first day, while everyone sat around the table eyeing both the pizza and myself, I explained the process. We were going to go through a guided writing exercise that focused on sensory recall. I've taught Creative Writing in communities, colleges, and medical schools and developed a process that helps alleviate the anxiety of writing stories. For this exercise everyone first listed five times when they were ill. Then they chose one and gridded a sheet of paper into four sections—each focused on a different part of the senses. They had 2 minutes for each of the four senses we were focusing on and were instructed to just write, not worrying about structure or full sentences. At that point most had already stepped into their stories and we began to write them more fully.

After twenty minutes of writing it was time to talk about the experience and share. A patient read his aloud. It was about the first time he came to CUHCC, how he was referred by a neighboring clinic and how scared he was to leave the people he knew and walk into one run by white men. If his people couldn't help him how could we? The waiting room was loud with people speaking all

sorts of languages he didn't understand. However, the patient service representative (PSR) who helped him smiled. She took her time and helped him and made him feel welcome. Then, later, she recognized him outside of the clinic and said hello. She saw him as a human and, he wrote, that made him realize CUHCC just might be able to help. He was welcomed into the community. Other patients shared their stories, but none of the students or the Mental Health Director shared theirs (although they did comment that the process really got them to their story).

After this session I debriefed with the students and patients separately in preparation for the next workshop. The idea of interacting with a patient outside the clinic became a point of discussion among the students and the clinic, and this is still being discussed. Is acknowledgment or greeting someone crossing a line? The patient spoke of no dialogue beyond pleasantries; this was important to him when so many other health providers who say they are part of the community never actually acknowledge its members outside of their clinics. The medical students and a provider argued that clinical distance, that ever present idea in medicine that to preserve oneself and emotions as well as objectivity they can't get too close to their patients, extends far beyond the exam room walls. This led to a debate about how the providers in a community health center can truly be part of the community they serve within the confines of professionalism that dictates a separation.

Meanwhile, the patient advisors said they enjoyed working with the students and began to feel the community growing and having agency in that growth. The students actually heard their stories during that session and, the patient advisors said, it felt like they could work with the students to help guide health care providers to learn to listen better and help create a new breed of health care workers.

The sessions grew in size but still no students shared their stories, despite dutifully writing during the writing time. The patients, however, were ready to be heard. One man told his story about the day he was diagnosed with a Traumatic Brain Injury (TBI) at the clinic. This story also focused on the waiting

room, where he shared Bugles corn chips and talked with a man in a wheelchair. One medicine student was confused and asked about his visit with the doctor. That wasn't what mattered to the patient, though. The day of his TBI diagnosis wasn't defined by the doctor telling him he had it, but the acts of humanity, of community, that occurred before he was told. Those were moments of life; the time in the exam room was a formula he'd been through at other hospitals in the area after his accident. They were routine. The student seemed confused, but ultimately noted how important the waiting room is to the patient experience.

I asked the students why they didn't feel like sharing and was told that they didn't feel they had actually been sick. Their answers were all similar—how could their health issues in any way match those of our patients, whose health issues are so complex? The students were not only downplaying their own past illness, but also identifying the patient advisors as the holders of 'true sickness.' It seemed the students were not comfortable with their own times of sickness, partly because of their developing roles as "controllers" of illness, people who help others. Students were expressing a kind of 'us and them' in terms of who is sick or holds the title of 'patient'. While we were creating a community of those who told and listened to stories of illness, there was a divide between the protectors of those who were sick and the holders of illness.

As a bridge between academic communities and the physical communities that surround them, CUHCC is a unique staging ground. Here we were, creating a community that wasn't focused on the university within whom we were housed, but rather part of the community the center had been embedded in for the past 50 years. There is also a community of illness, one that shouldn't be ignored, with CUHCC as an epicenter. Yet, there isn't a fully realized integration between these communities. The health care students and providers who joined the sessions seemed to be taught they weren't part of the community of the ill despite the patients talking at length about how important it is for their doctors to admit to getting sick, even if the flu or a cold. There was a denial of what being sick even meant

when compared to others. Is illness, by definition, diagnosed only in comparison? How much can a provider be involved in their community while still maintaining professionalism? With the days of the neighborhood doctor who knows the ins and outs of their community gone, it seemed almost against everything being taught to suggest you could connect to the patient as a person and with equal footing in humanity. These sessions just began to scratch the surface of the ideas and complications of person-centered care as it relates to the relationship between provider and patient—and then the sessions were halted. The Mental Health Director who led the patient advisor group, a driving force in the clinic for over a decade, took an extended leave of absence from the clinic.

When there is one person who can bring half of the group together, their absence can bring work to a standstill. With the mental health director on leave, we needed a new person to run the patient advisor group and were working on a transition plan. Our director had built trust with the patient advisors and I had met with them only a handful of times, and mainly for our writing sessions. Many meetings with the patient advisors in this transition phase to a new leader for the advisors had no attendees so setting up more narrative health sessions became difficult, if not impossible.

Currently, we are working to make the writing sessions a regular occurrence for the year, and just had our first of the newly structured sessions. In hindsight, had we had a more intentional and longitudinal plan in place first rather than irregularly based on when all our times coincided, then the momentum might have stayed and the transition from the Director to someone else might have been eased. Without having a firm structure for continuation, it was easy for these sessions to stop. Also, our pool of patients was small. By expanding beyond the patient advisors we have been able to obtain a larger, possibly more consistent, group. However, this has led back to the ethical questions raised earlier—where is the professional line between clinical distance and person-centered care? Can we, as a health center, be both in and of the community? While the goal is to create this community of

stories of illness, that central idea of sitting around the table, eating the same food, and speaking on the same level is still new and at times frightening. However, with a donation of journals and new fervor (along with requests from the patients and students to continue these sessions) we hope to plan out the future and see what stories will be told next.

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Community–Academic Partnerships to Improve Hispanic Immigrant Health: Perspectives from a Doctoral Student

J. Claire Schuch

During my doctoral degree, I worked as a research assistant on a five-year National Institutes of Minority Health and Health Disparities (NIMHD)–funded study with the interdisciplinary research group the Mecklenburg Area Partnership for Primary Care Research (MAPPR). MAPPR is a practice-based research network designed to enhance healthcare access for underserved and vulnerable populations in Charlotte–Mecklenburg, NC. The core research team includes social and health scientists from the University of North Carolina at Charlotte and Carolinas Health-Care System.

MAPPR applies a community based participatory research (CBPR) approach, which involves community members and other stakeholders throughout the research process. During my time with MAPPR, I was actively involved in a study identifying the social determinants of health affecting Hispanic immigrants in Charlotte–Mecklenburg. I assisted

with the design, implementation, and evaluation of interventions to decrease health disparities and enhance access to primary care for this group. Partners included health and social service providers, educators, Hispanic foreign–born residents and a Community Advisory Board (CAB), which included representatives from the local school system, the County Health Department, and the City of Charlotte. In this essay, I reflect on the experience of engaging in community–academic partnerships as part of the intervention phase and as a doctoral student working ‘on the ground’ as part of MAPPR.

The research team employed a variety of methods (key informant interviews, focus groups, a Photovoice project, and community forums) to develop the interventions in collaboration with community members and partners. The first part of the intervention consisted of nine neighborhood–based health interventions at two elementary schools in two high–need areas. These events offered free check–ups, education, and representatives from a wide variety of social and health services (all in Spanish), as well as childcare. The academic team collected data in the form of participant surveys and health outcomes data.¹ I recruited and trained over 50 volunteers that assisted in various capacities with the fairs—as interpreters, medical staff, in childcare, and as navigators, for instance. Without our community partners and committed volunteers, we would not have been able to hold these fairs. They were truly a collaborative effort that leveraged resources across sectors.

The community health interventions offered an opportunity for different groups to come together and learn from each other. Participants felt welcomed by friendly volunteers and volunteers reported learning more about the local Hispanic community. Volunteers and organizational representatives were also able to successfully connect

with others. “It just builds comradery to see others outside of regular work environment,” a volunteer mentioned. Interestingly, immigrant participants were typically more positive about the intervention than the providers and organizational representatives. Participants were grateful to receive a check–up, speak with a provider, and receive information and education. Though emphasis was placed on getting participants connected to health and social services—to enhance sustainability of the intervention—providers and organizational representatives often felt frustrated by persistent financial, health insurance, or documentation status barriers. There are limited services available for low–income families and undocumented immigrants, and those services are typically already stretched thin.

We also encountered push–back and skepticism from some organizational representatives about research and sustainability components of our intervention. In one of the evaluation focus groups I facilitated, an organizational representative asked me: “you were asking us for some feedback, but who sees the recommendations and where does that go? I mean, I know you are trying to use it for another grant to continue but what ultimately is the outcome?” Another said: “It’s great all the information and the data and the research, and it’s obviously showing the needs out there, so what are we doing about those needs? (. . .) I know you have to sometimes follow what the grant says. (. . .) But it makes me wonder if putting the research aspect of it should come as a second thing.” This points to the need for transparency when research teams are working with organizations and other partners. It also illustrates how the needs and goals of different stakeholders vary and meeting everyone’s objectives can be challenging. There was a tension between research and services goals of the intervention; community members and some of our partners saw us more as service providers, whereas other partners felt we focused too much on the research aspects and should be doing more for service provision and policy. Tensions with some partners challenged us to think critically about what/who MAPPR is and what our role(s) in the community are. Conversations among MAPPR members and the CAB in 2016 have

¹All study materials were approved by the Carolinas Health-care System Institutional Review Board (IRB). Participants enrolled in the study were compensated for their time in the form of gift cards.

resulted in a revised strategy for the research team.

Furthermore, though I see it as a strength that we conduct community–engaged research, this struggle returned as we sought out to disseminate our findings; our work has been well received at CBPR conferences and local avenues but we are challenged to make our work ‘academic’ enough in order to publish in health journals. Finding journals that publish interdisciplinary research that is different from the ‘traditional’ scientific approach is an ongoing challenge and I am continuously challenging myself to communicate my research more effectively to different audiences.

What made me hopeful was participants’ willingness to make changes in their health behaviors and lifestyle to improve their health, based on the information they received at the community health interventions. This astonished our providers: the “behavior change in that population is astounding; I can’t do that with primary patients in my own time.” An interpreter shared that: “Speaking not only as a volunteer but speaking as a Latino myself, I have to say that I didn’t give our people enough credit (. . .) I didn’t expect to see as much willingness to change and get those results and positive outcomes and actually getting to see it was impressive.” This reminds me there is a lot of room for education and health literacy in Hispanic immigrant communities.

The second component of the intervention involved establishing two Latina women’s groups, *Hispanos en Accion* (HA) and *Hispanos Unidos* (HU). We started incorporating opportunities for input, ownership, and leadership early on and throughout the 16–month engagement process. Participating community members drove the mission and goals of the groups. For HA, a colleague and I met with the women weekly, offered Zumba classes, and brought in speakers. Listening to the evaluation focus groups that took place 14 months after HA first started, participants reflect that they had a positive experience overall. They enjoyed the workout classes, learned a lot from the guest speakers, and became motivated to exercise and eat healthier.

However, HA faced several critical challenges in the formative and transition stages that prevented progression to a sustained group. For instance, while

we had a consistent space for our meetings, we were unable to hold Zumba classes there (due to noise and poor building structure) and we were unsure if we could continue meeting there. Participants and MAPPR members continued to contact potential meeting places. Still, it was very hard to find space to meet because most places were too expensive (at apartment complexes or the school), too far away (churches), or too small (people’s homes). We all felt some frustration that we were not able to find a space. Additionally, we struggled with timeliness and declining/fluctuating participation. In general, participants were willing to take more active roles in the group, but other, more immediate, tasks and responsibilities were (understandably) more pressing. In a sense, barriers to participating in community groups are often similar to barriers for accessing health services, e.g. transportation, work schedules (long/irregular/changing hours), and child care responsibilities. For many participants, juggling life responsibilities and daily tasks took up most of their time and energy. As a result, regular participation in an organized program was possible but difficult enough. The talks and exercise opportunities we offered were much appreciated, but taking a leadership role was not an option.

The other women’s group, HU, was also interested in education and exercise but was more outward–oriented in terms of wanting to participate in volunteer and health events in the city. As they developed, they also received more support outside of MAPPR. For example, a local elementary school allowed them to meet there every other week and during the summer they met at a local YMCA (all for free). Thanks to a strong and ongoing partnership with this local YMCA, HU continues to exist three years after its founding. The YMCA provides a meeting space and their community engagement director supports the group and led them through a leadership development training.

Looking back at our study interventions, I am proud of our diverse and mutually beneficial collaborations. CAB members informed the work of MAPPR and vice versa. The successes of these community–academic partnerships can partially be attributed to a MAPPR project manager who is excellent at building and maintaining such partnerships.

Some collaborations showed to be stronger and longer-term than others. I also learned how structural and institutional impediments can continue to negatively affect Hispanic immigrant health, even when all the ‘right’ local partners are aligned. We cannot change the exorbitant cost of health care or somebody’s documentation status, for instance.

Our study interventions emphasized the importance of communicating with and across participants, volunteers, providers, organizational representatives, and research team members. This is time-consuming but helps clarify roles and responsibilities, which ultimately can help the quality of the partnerships and the outcomes. Providing comprehensive health and social service coverage for all Hispanic immigrants is challenging, though information about services available, how to navigate systems (health care, education, e.g.), and a healthy lifestyle can make positive impacts in the health and wellbeing of underserved Hispanic immigrants.

I feel privileged to have had the opportunity to work with an outstanding team and a wide variety of community partners, and to continue to be involved with MAPPR as part of their CAB. Being part of all steps of the research process taught me the strengths and complexities of CBPR, and shaped me as a community-engaged scholar. It provided a foundation for new community–academic partnerships in my dissertation, postdoctoral fellowship and beyond. I hope other graduate students are provided similar hands-on training and mentorship.

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Reflections on Cultivating Community-based Participatory Research Partnerships with the Afghan Immigrant Community

Mehra Shirazi

Background

Using a community-based participatory research (CBPR) approach, we describe the process of a first-time campus–community partnership between UC Berkeley School of Public Health and the Afghan Coalition in California.

Objectives: We reflect on lessons learned in cultivating a unique community health partnership to provide a preliminary understanding of how Afghan immigrant women view their breast health, and to determine and assess their barriers to breast cancer screening. This story will emphasize the importance and challenges of (1) negotiating equitable collaborative relationships, (2) recruitment and retention of participants by community members and ways to overcome cultural and language barriers, (3) training of community members, and (4) data dissemination.

Conclusion

Conducting meaningful community partnerships should be driven by a social justice agenda where community has control over the production of knowledge and engaged in all phases of research. There is also a need for transparency and mutual agreement around roles and responsibilities where researchers take on facilitative roles and do not attempt to control the research process.

These are the reflections of the first community/campus partnership between the Afghan Coalition of Alameda County, CA and the UC Berkeley School of Public Health in an effort to provide a preliminary understanding of how Afghan women view their breast health. This was done through in-depth semi-structured interviews conducted with non-English speaking first-generation immigrant Afghan women above the age of 40. This narrative aims to describe the experience of engaging in community–academic partnerships that brought forth essential information pertaining to the breast health

screening practices of Afghan women which then led to a five-year breast health education intervention program funded by the National Institute of Health.

My mother, my sister, my aunt, my daughter . . .

In telling their stories, the women were speaking about their struggles, their pain and resilience. They painted an accurate picture of breast cancer in their communities, which remained a subject considered taboo in Afghan culture. It was clear this was more than a “make sure everyone gets a pamphlet” intervention. No intervention was going to work unless it was a part of the community itself; not for them or about them or even from them. In a refugee community struggling against the label of terrorist as the United States entered its second decade of war in Afghanistan, information and access to preventative healthcare, including breast cancer screening, was minimal. And the stories kept coming.

My niece, my daughter-in-law . . .

Working with the Afghan community of Alameda County, CA, the largest Afghan refugee population in the United States, two-thirds of whom are female, meant we were approaching a long-established community with its own politics, social and cultural norms, and community leaders. It can be easy, and expedient, to paint broad circles in the name of increased access, but it was clear that previous research on immigrant Muslim women and breast cancer hadn't addressed the scope of what we were facing. The women here were less literate, unaware of screening recommendations, and hampered by their immigrant status, cultural valuation of female modesty, and a necessary wariness of any dealings with officialdom in the age of the “War on Terror” wherein the community was consistently approached for informants.

My mother-in-law, my cousin, my wife . . .

Establishing any partnership is part act of faith and part extended learning curve, but the development of a true partnership across culture, language, religion, and deep societal mistrust required more

than good intentions. The high rates of breast cancer anecdotally reported in the population, as well as the lack of access to care still faced by an established community (mean residence in the US was 16 years) pointed to the need for a culturally based intervention program to establish and address attitudes toward breast cancer screening among a population with limited English language usage, high rates of illiteracy in any language, cultural concerns around female modesty, and limited access to healthcare providers. Two groups, from the UC Berkeley School of Public Health and the community via the non-profit Afghan Coalition came together for a pilot study and the goal of developing a sustainable community based intervention project.

A Community Advisory Board (CAB) was established to develop research questions, partner in the data collection, and development of future intervention programs. The CAB) was representative of the Afghan community and consisted of local community leaders, elders, nurses, teachers, breast cancer survivors, and community health advisors invited by the Afghan Coalition. Transparency, roles, budget, and procedures were all collectively agreed upon and written into the grant proposal to avoid conflict or confusion at a later date. While this process was lengthy, particularly in the eyes of the University partners who were not fully enmeshed in the community politics and behind the scenes negotiations necessary, it did ensure community buy in.

The importance of tea in Afghan culture cannot be overstated. If this project was going to go anywhere it would go there on the strength of the tea.

They come in. Suddenly, all your academic notions of cultural relevancy and community participatory research become very real. Our partnership made our plans for a project design that would foster a warm and inclusive atmosphere possible. The multi-lingual interviewers, the careful recruitment of a broad cross section of the community, the careful attention to religious and cultural norms, remembering to provide childcare; it all begins to fade into the narrative of women's stories. Our community partnership model helped contextualize our research within the historical and political

context of women’s lives—as refugees, as woman headed households, as trauma survivors, and as members of an incredibly close–knit tribal culture that has rebuilt a community as outsiders. Our community researchers were trained to conduct interviews both to overcome literacy issues and to make this project a truly shared experience. There was extensive follow up built into the project design to maximize retention. We wanted our partnership to have time to build on the conversations started over tea because that trust was the foundation for community–based intervention. Academic timetables being what they are the pace could feel particularly laborious at times, but the room built into our project, and funding, for talk was an essential part of its success.

And it was the stories that stuck. Women were interviewed one–on–on in one of several possible languages. As the tea flowed so did the stories. Some were unsurprising—trouble with transportation and a lack of interpreters—and others were more nuanced. By centering religion (the community 99.9% identifies as Muslim), we opened the doors to deep discussions of philosophy and identity, their community, and their role in Afghan life. These women viewed their bodies as divine gifts and felt a deep responsibility to care for them and do everything they can to be healthy and beat disease—a contrast to a more fatalist attitude we often expect to find in deeply religious communities in the West. Additionally, particularly as the US presents such a negative view of gender relations in Muslim societies, it was essential that we understand that our partners viewed their health as essential for the survival of the family and, by extension, the community. From this we began to build our intervention strategies.

“Islam doesn’t say we can’t go to a man doctor but I am Afghan and my culture says it’s not right”

One of the most powerful things to come out of our partnership was the development of intervention programming for men. Afghan culture is so often portrayed as profoundly segregated, and it initially seems counter–intuitive that in an attempt to empower women in their healthcare interactions

we needed to focus on men as well. However, the community’s men serve as guardians, gatekeepers, and links to the outside world; ninety percent of the women interviewed indicated that they were reliant on a male relative for transportation, coordination of appointments, and, more tellingly, as decision makers for women’s health screening decisions. Our partnership was with the community, not only the women, and a variety of outreach programs to men—primarily focusing on general health and the link between women’s health and the health of the community—were initiated. Without full partnership and the use of community–based participatory research this essential aspect of an effective intervention program could have been missed.

“. . . to listen to a woman and to let her tell you what is bothering her. To not just ignore her and make her feel small”; “. . . to be gentle, and caring’ and ‘Talk to her, explain everything . . .”

There are, of course, challenges to any partnership. When working cross culturally they serve to highlight the vastly different ways in which communities and cultures approach problems and make decisions. This project, by definition had to have a level of flexibility, which can be difficult when working with academic publishing timelines and grant reporting. We found the project to be a long–term process requiring patience and flexibility. Additionally we had to address clarity, even when speaking the same language, in a project operating with a minimum of three languages (English, Farsi, and Dari). As the academic partners it was essential that we move slowly and build trust in a community with a level of paranoia when faced with ‘official’ sources, both from their experiences in Afghanistan and the ongoing exploitation of the community by US agents looking for informants. As outsiders we were also working in a community with several waves of immigration experiences and complex social and cultural hierarchies of which we knew little. In this case face–to–face interactions through culturally meaningful ways such as ‘tea parties’ proved to create a welcoming and warm environment that paved the way for sustainable trusting relationships.

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.

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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

get from colleagues is sufficient.” And community members have their own pre-conceptions: “I think research projects are a scam. Researchers have a hidden agenda and just are trying to help themselves.” “Lots of researchers are white—they don’t want to hear my ideas.” “Research? Nope, I don’t want to be a guinea pig!” “Most researchers are uppity and just talk down to us.” And these are just the comments conveyed to our WINRS team directly. Obviously, other prejudices and stereotypes also divide us—based on how we dress, talk, our skin color, the condition of our teeth, etc.

Imagine trying to communicate in a room where these two worlds collide. On one side: I see you as less educated, less smart, and not able to offer me anything useful. On the other: I see you as sneaky, self-interested, arrogant and out to take advantage of me. How do we find common ground? How can researchers get the advice they need to make their projects more accessible, appropriate and engaging? How can we create a space where lay people feel free to share important feedback?

Two specific practices we use to break down divisive assumptions and stereotypes demonstrate the power of “The Personal.” The first practice is to start each CARDS® meeting with an opening question that everyone at the meeting answers. This may seem straightforward, but learning what makes an effective opening question has been an experience of considerable trial and error.

At one meeting, the guest was a young researcher who appeared very stiff and ill at ease at the outset. Our opening question was: “Think about a time when you took care of someone else—a child, relative or friend. Tell us what made you good at taking care of that person?” As we went around the room, we heard from a woman caring for her grandma, who described the patience (and humor!) required to deal with increasing forgetfulness. We heard about stepping up to be on call 24/7 for an ailing friend and making the decision to move in with aging parents. When it was the researcher’s turn, she started by simply holding up her hands. People shifted uncomfortably in their seats, wondering if she was giving up on the meeting before it had even started. Then she spoke: “I have 3 young children,”

she said gently. “I’ve always felt like human touch is one of the most caring gifts we can give each other. Every time I bathe my kids, wipe their noses or their tears, wash a scrape . . . touching them in a tender, loving way seems like one thing that makes me good at taking care of them.” By the time she finished this very short statement, there were plenty of damp eyes and warm smiles around the table, and we were all looking at each other with a very different perspective. The power of “The Personal.”

At another meeting, we asked, “Looking back on your childhood, what is one *good* memory that really sticks with you?” One of our CARDS® has struggled with drug addiction and shows many of the physical ravages of this difficult history. It would be hard for most people to look at this person and not jump to conclusions based on outward appearance. When it was his turn to answer the opening question, he said: “I grew up in New York. I had the best granny in the world. Every year, she got me all dressed up and took me to see the Christmas show with the Radio City Rockettes. Every single year! She said I would never miss a Rockettes Christmas show—and I never did.” The impact on the researcher (and the rest of us) was amazing. To see him glow with this happy memory and to unexpectedly glimpse the excited, dressed-up little boy still inside this grown man was transformative. The power of “The Personal.”

But not just any opening question works! Here are some lessons we’ve learned.

Some opening questions are simply boring, and do not help us connect with each other. When we had dementia researchers at a CARDS® meeting, we said, “Tonight we are going to talk about research on memory. What is one trick you have for remembering or keeping track of things?” Not surprisingly, the answers were all basically identical: “I write lists.” “I have a special place where I put important things, like my keys.” No one shared anything uniquely personal—so no personal connections were established and no stereotypes were really challenged.

We’ve also learned that while “The Personal” is powerful, it needs to be used thoughtfully. Some opening questions can unintentionally derail the

group with negative energy, making it harder to get on a productive track. One night we said, “We are going to talk about home care after surgery. That got us thinking about scars—we all have scars from accidents, injuries or wounds. Please tell us a story about one scar you have.” Although we prepared a staff member to model a light-hearted memory of a scar she got while playing with her beloved baby sister, the following stories took a darker turn. We heard about a stillborn baby, injuries from the Vietnam War and serious work-related accidents. Soon the group was extremely somber, with a palpable sadness around the table created by stories that led us into our own separate worlds of grief.

Lesson learned—craft a thoughtful opening question likely to draw out stories and experiences that engender positive emotions and reinforce human connections. This not only helps us to see past the stereotypes and assumptions that divide us, it also reduces our own barriers of discomfort, nervousness and feeling out of place. It’s hard to connect with a stereotype. It’s hard *not* to connect with a good personal story. As one of our CARDS® told us, “I love the opening questions. They help us accept the researcher. When we share life experiences, we see each other as human.”

The second personal practice that breaks down stereotypes is using five minutes of meeting time for guest researchers to explain their personal motivation for their research. The CARDS® have repeatedly told us how critical it is to understand why a researcher is focused on a specific topic: “Are they just doing this for the money or do they actually care about this problem?” The fundamental truth we’ve learned is “people don’t care how much you know until they know how much you care.” However, when we first started asking researchers to comment on what motivates them to do their research, they generally discussed “gaps in the literature” or the “iterative nature” of the research process. Researchers are trained to be objective and scientific—not to talk from the heart when discussing their program of research. But we have found that with some individualized coaching, researchers of all kinds can benefit from the power of “The Personal.”

Now we specifically ask researchers to reflect on why they are passionate about their research and to answer this question in a short survey before coming to a CARDS® meeting. We follow up with each researcher and together prepare a short “script” for the researcher to share at the meeting—expressing in 2–3 sentences why they have a personal stake in their research topic. Consider the difference between “I’m part of a multidisciplinary team facilitating innovative science, targeting the prevention and treatment of this disease with novel research projects . . .” versus “This research is important to me because of my own family history with this disease. I am personally committed to making a difference in the prevention and treatment of this disease.” OR “I focus on this research because scientists still don’t understand the most cost-effective way to treat this condition . . .” versus “I am a physician who treats people with this condition. I have seen my patients struggle with both the terrible symptoms of this disease and with the high costs to treat it. I hope what we learn in this project will help my patients and the many others whose lives are damaged by this condition.”

Some of the most poignant comments we have heard in evaluations with the CARDS® are about how their attitudes towards researchers have shifted as a result of the power of “The Personal.” As one of the CARDS® put it, “I get really moved when researchers tell us why they study what they do—the stories of grandparents, other family members, patients and so on. You can see that they genuinely want to make the world a better place.” Another said, “I used to think that researchers were ‘off in another universe,’ but now I see them as decent, caring human beings who are trying to do good things.”

Researchers also have shared touching comments about being able to connect with these “hard to reach” people: “The single best thing about meeting with the CARDS® was getting feedback from community members we normally wouldn’t have the opportunity to talk with.” “Getting advice from people with ‘lived experience’ is more critical than we realized. Many researchers don’t consider the perspective of participants. I really didn’t

think about this issue seriously, but this meeting improved my materials *and* changed my attitude!”

These two practices, thoughtfully and consistently followed, enable us to harness the power of “The Personal”—breaking down barriers and building human connections that empower all stakeholders to participate in reducing health disparities and improving health outcomes for everyone.

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Stigma as a Facet of Community–Academic Partnership

Sally Mason

The Positive Families Project is a partnership between parents living with HIV, service providers, and myself, an academic at a public university. Our projects investigate the need for and develop social services with HIV-affected families. Often services focus only on the person living with HIV. Our mission is to support people living with HIV who are also parents so that families with an HIV+ member can be healthy and productive. Stigma reduction is key to our approach as

stigma can contribute to multiple risks for parents and their children.

The partnership has encompassed several projects, starting with pilot studies in 2006–2010 on the stigma experiences of non-HIV+ teens living with HIV+ parents. Parents and community-based service providers originally were research participants and the data analysis team. The team reviewed transcripts, identifying themes and making recommendations for future services. Currently parents and service providers meet monthly to develop ideas for family-focused services and review funding possibilities. Recently, we received funding to implement psychoeducational group sessions for parents with HIV. Parents and service providers recruited participants, co-facilitated groups, and reviewed evaluation data. Originally my role was researcher and a program coordinator/facilitator. Now I convene and facilitate the planning group, assist with programming when funded, and provide resources such as meeting space, writing skills, and supplies.

I was drawn to partnership and participatory methods through our pilot studies on stigma. One finding about stigma was that positive parents and their non-positive but HIV-affected children used silence as a form of protection from stigma. They identified wanting to find “safe others” who they could trust with their secret. If we, as researchers, asked them to open up, to be less vigilant for an hour or two in an interview, first, how could we reduce (and not reproduce) stigma for them during this process and, second, what was our responsibility to give them a safe place to talk in the future?

Coincidentally, I was meeting regularly with researchers committed to community collaboration and participatory methods. I became increasingly convinced that participatory methods have the potential to, at least, not reproduce stigma and, at most, reduce stigma’s impact. By leveling the power differential between researchers, service providers, and families (a difference which may be exacerbated by stigma), participation can be an antidote to stigma, by engaging families, as Paolo Freire would say, in “the struggle for their redemption.”

As a service provider, I had experienced courtesy stigma as described by Goffman or stigma-by-association with people living with HIV. Due to my status—race, class—and with support from educated family and friends, I was able to thwart efforts to label me as less than “normal” or to be silenced in my work. What I had not anticipated was how, as boundaries between academic and community members blur, parents’ stigma situations became part of the process, immersing me in their experience and confronting me with fresh personal and professional dilemmas.

A prime example occurred while convening a community group to help with the analysis of data collected during focus groups with HIV+ parents and their non-infected adolescent children. Sandy (pseudonym) was an African–American woman who had been engaged with our projects over the years. She had known her HIV status for at least 15 years and had often been a peer facilitator in our parenting groups. She called me one day saying that she had told a church member about our project. This church member was a graduate student in community psychology and was intrigued by our recent research. Sandy thought this young woman would be an asset to our process providing some assistance as we prepared the final reports and articles. Sandy was excited to involve the student and asked if she could give this young woman my number. As we always need more resources, I heartily agreed.

After hanging up the phone, I realized that I did not know if the graduate student or anyone at Sandy’s church knew Sandy’s HIV status. I called Sandy back. She said that only the minister at her church knew; she had intentionally not told anyone else in order to protect herself and her daughter. Her church was an important part of her life and she was not sure that all church members could be as trusted as her minister. She had not told the graduate student that this was a “community-based” project or how Sandy became involved so had not indirectly disclosed her HIV status.

Sandy offered to tell the graduate student but I was reluctant for her to do so. I knew enough about disclosure of stigmatized information to want Sandy to do this if and when she felt it was useful

to her and to prepare for it, rather than to have her do it on the spur of the moment for the purposes of this project alone. Sandy decided to wait. We talked about how the student’s involvement, without disclosure, might affect the group process; we would have to be careful how we presented the project to the graduate student and what other HIV+ group members might want her to know about them. We agreed that I would talk with the graduate student and then we could assess further.

The student called me the next day. As I explained the project, I felt constrained, watching every word, as I was careful not to “out” Sandy. The student was eager and, when I as part of usual business, explained confidentiality, she indicated that she understood its importance. We arranged a meeting time.

This interaction went round and round in my head for the next few days. Had I been dishonest? How did my carefulness with words affect our interaction and her perception of me? Did I seem disingenuous (I felt that way). As I reviewed it, I was struck by the knowledge that my friends and colleagues who were HIV+ dealt with this every day.

The next day Sandy called me and said she had told the graduate student about her HIV status. I expressed concern that she did this for the project rather than what was best for her. She said that she was comfortable with the decision. She asked the student to maintain confidentiality at church. I debated with myself how to handle the next communication with the student, as she would know that I had not been forthcoming in our initial phone call. I decided to be honest and, in our meeting, acknowledged that Sandy had told her and that I was concerned about how she interpreted our phone call based on this new information. She expressed understanding of the dilemma and assured me that she was still interested.

The student attended one meeting of the board and then did not return nor call. Sandy said that nothing changed at her church and she occasionally saw this young woman and everything seemed fine; Sandy did not ask her about her decision not to attend any more. We were left wondering if she was

too uncomfortable, whether with the group's status or knowing Sandy's status. I wondered if I should have handled something differently—questioning my abilities and actions in a way that made me feel tentative and ineffective.

More recently, Daniel, a member of our consumer advisory board, asked to speak to me privately. He had been an active member in our parenting groups and our advisory board for several years. Daniel's daughter was receiving mental health services in the outpatient clinic in our building. As part of those services, his daughter was seeing a mental health clinician for psychotherapy whose office was close to mine.

Daniel asked what the clinician knew about our relationship. I told him that I had not talked to the clinician about Daniel or his daughter. Daniel explained that when he mentioned that he knew me, he thought the clinician "made a face". Daniel expressed concern that the clinician now knew that Daniel was living with HIV and that he did not want to work with Daniel's daughter any more.

Daniel and I spent a few minutes talking about how he interpreted the clinician's reaction. I assured him that the clinician was thoughtful and caring. I suggested that the clinician could have been confused, assuming that I had worked with Daniel's daughter in our clinic but wondering why none of the chart notes reflected this. We discussed ways that Daniel might manage the situation so that he felt comfortable. Afterwards, I did not know what to say to my colleague. Did I acknowledge that I knew Daniel or not? Did I hint at how I knew Daniel based on what this colleague knew about my work in the community? I chose not to say anything. I see this colleague often and each time have a touch of doubt about what he is thinking and how I might allay my own concerns without doing a disservice to Daniel.

I was struck by how one small moment—a "face"—could trigger apprehension for Daniel and his daughter's welfare. I was reminded of Sandy, her courage, and my feelings of guilt, dishonesty, and confusion. People with HIV anticipate these situations daily. I say "anticipate" as the literature says that people living with HIV who have access to medication experience "hidden" stigma—they

do not have to let anyone know their HIV status, as they look healthy, but they anticipate the possibility of being "found out" in many encounters. Similar to people living with HIV, I had two small situations with the student and the clinician which I had to manage, internally, through my perceptions and feelings, and externally, through interpersonal interactions. What if it was multiplied with every day holding the possibility that someone would think I was "abnormal"? I felt a subtle but substantial shift in my understanding of my colleagues living with HIV. I had felt the day-to-day tension of keeping a secret, being cautious but still wanting to connect, the constraints of not being genuine.

So perhaps I have learned more about stigma through this partnership than my community-based colleagues. I hope that community members have learned about the process of research and service development. I hear their frustrations with funding changes over the years as HIV has become a lower priority. I explain that as they live longer, new social issues, such as veterans' mental health or gun violence, become more pressing. They respond that their worries are different but still substantial—concern for their children, for their chronic (rather than terminal) illness. Stigma continues but is more covert.

As in any partnership, attendance at meetings can be sporadic. Without funding, we regularly remind ourselves of our purpose and its value. Community members see me as the person with concrete resources; I see the resources as increasingly scarce, especially at a State university as I am asked to do more with the same amount of time and compensation. For community members, the majority of whom are low-income, my statement that the university lacks resources seems implausible as they see how little they have compared to the university.

I draw strength from the examples of Sandy, Daniel and others, as I consider more carefully how to use my privilege and access to contribute to our discussions and decision-making. Some days, it would be easy for me to let go of the project, especially when stretched by work responsibilities and discouraged by funding constraints. In the past, as I was frustrated or impatient, I may have allowed my opinions to take over in our meetings

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.

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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.

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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.*"

The study took place in Beaufort SC, a primarily rural southern coastal county with several small towns. Both perceived and actual differences between racial equality among African Americans and Whites are more strongly felt in the “deep South” than in other parts of the country. This is especially strongly felt in South Carolina; over 40% of African slaves were brought in to the US through this State, and during the Civil War, Beaufort County was a focal point of secessionist sentiment. Although a significant portion of the White population in Beaufort County are direct descendants of the early European settlers, or long–time residents of the area, there has been a large influx of affluent retirees who have settled in nearby Hilton Head and surrounding areas. The majority of the African American population have been in the county since they were brought over during slavery, and due to the relative geographic isolation (parts of Beaufort County includes several islands) have maintained the Gullah subculture, which includes a strong retention of indigenous African cultural elements. There is a high rate of poverty and unemployment, and associated health disparities within the African American community of Beaufort County.

Building trust within the community was the first goal of our academic palliative care research team (Study PI, two co–investigators, a palliative care physician and a research assistant.) Forming a partnership with the local hospital in which the last phase of the study would take place was the first step. The hospital’s outreach coordinator, Ms. C., had developed strong ties with many community organizations and members, both African American and White, and was deeply trusted and respected. She was instrumental in helping us invite community members, African American and White, to form a Community Advisory Group (CAG) that would guide the first phase of this study. The 14 members, equal numbers of African American and White, all residents of Beaufort County, comprised primarily of community leaders and gatekeepers. Also included were those who had recently lost a loved one, two hospital staff members not involved in the project, and two “regular” community members. These members were recommended by the

hospital outreach worker familiar with all community groups and organizations, and chosen based on an attempt to balance the group by race/ethnicity, and educational and financial level.

As study PI, I began by sharing aspects of my personal story that directly related to this study. Growing up as the child of an Israeli diplomat, I had lived in many different countries, attended many schools with diverse groups of peoples, who spoke different languages, and had varying histories, backgrounds and cultures. This had given me a deep understanding, and appreciation of, respecting the uniqueness of each culture. Later in life, I witnessed both my parents and husband become very ill and die, all within a very short time. Following a period of intense grief, I became determined to use the remainder of my career to help those who are ill or dying and their families to live the remainder of their life receiving the care that they, their families and communities wanted. My vision for this study therefore, was to create a program not only to alleviate suffering in those who are very ill or dying, but to provide the care their families, and communities wanted for them. And who better to determine how to do so, than members of the African American and White community members who lived in Beaufort, SC.

This first strong recommendation was made by the African American members of the CAG: *“If you want our people to tell you that which is in their hearts, you can’t put them in the same [focus group] with the Whites.”* We therefore planned separate focus groups. Based on recognized and justified distrust of research within the African American community, we shared our concern with the CAG that too few African Americans than we needed (10) would want to participate in the focus groups. The CAG’s recommendations for appropriate wording and artwork for the invitation to community members to participate, as well as their personal outreach in their community resulted in a higher number of eligible African American community members who wanted to participate (15) than we had planned for. Because of the strong community interest in this topic, we expanded the two focus groups to 15 members per group, and both groups

met twice in a neutral community-based setting that the CAG had recommended.

Analysis of the data (using thematic analysis, where themes are identified in each group) indicated that several aspects of preferred care for their loved ones were the same for both racial groups. For example, both groups reported confusion about pain medication provided to their loved ones, and both expressed a preference for there to be clear and easily understood communication about this. There were several key aspects of preferred care that differed between the two groups. For example, African American group members strongly appreciated doctors invoking God or a higher being, an issue not raised in the White group. Discussion of prognosis by the physician was another aspect on which the groups differed. White members wanted family members to be consulted as to whether the physician should reveal the prognosis to the patient, and their requests followed. African American members, on the other hand, did not want the prognosis to be shared—unless the family specifically asked for it—with God (not the physician) as the final determiner of impending death.

Phase 2, in which the culturally based palliative care consult program was developed, is where our story truly comes alive. To help build the program, a second Community Advisory Group of 8 members was convened. This was done in order to include some members of the focus groups, and to make the number of members more manageable. Half were members of the original CAG, and the other half were members from each of the focus groups. Two focus group members per group were chosen based on their ability to express their own opinions and reflect what the focus group had said, and the other two were members who had expressed concern or doubt about the study in order to gain a broader perspective. Here too, the group consisted of equal numbers of African American and White community members. These 8 community members, together with the team of palliative care researchers, met at the same local hospital for two hours after work one Thursday a month, for a period of *two and a half years* to develop the culturally-based palliative care protocol. Very rarely did any member

miss a meeting, most did not even miss one. Each member received a folder with the thematic results of the focus groups, and over the entire time, no one ever forgot to bring their folder to the meeting. We sat around a big table with our folders, and on the other table, a finger dinner of sandwiches, vegetables, fruit and cookies was tastefully laid out by the study coordinator. At the beginning of this phase, members were a little uncomfortable, and often sat beside other members of the same race. Over time however, a ritual developed: Ms. J, an African American retired banker who had lost her husband the previous year, became responsible for the members' sign-in sheet and gave each member the envelope with their study fees (\$25 per meeting and a \$25 gas voucher.) A natural leader, she would get up to cut up the circular sandwich wheel and everyone would then fill their plates with food and fruit and bring it to the table. Members sat wherever there was a space, no longer with regard to race, and lively conversations would begin.

Work of the group also took on a rhythm. Following an overview of all the results, at each meeting we would review one finding from Phase 1 in detail, and the group would then discuss and determine the programmatic implication of the finding. If the finding applied to both groups, the entire group discussed the recommendations and if it applied to one or other groups, that group were the primary discussants of the recommendation. Opinions were widely expressed, and although at times differences of opinions arose between members, these were always respectfully discussed. An example of recommendations made that was the same for both groups was the importance of the physician to be compassionate.

... the doctors were just so caring and so giving and he was up one time and it was close to the end of life ... and the doctors and the nurses were just crying with him and hugging him. . . just because he felt so bad and they were doing everything they could. . . . When you have wonderful caring doctors and nurses, it makes it a lot easier to go through this.

Several recommendations were made that differed between the groups. For example, African Americans strongly recommended that their loved

ones remain at home and receive care from the family only, “ . . . as a family unit we had to know in our hearts that this was the right thing to do,” and “We take care of our own.” This was also one of the reasons provided for why African American family members did not want hospice staff to come to their homes to help, “ . . . it’s taken us a while to get to where we allow other people to come into our homes and do because we have always provided the care at all costs.” On the other hand, White community members appreciated the assistance of home hospice and nursing home, recognizing that taking care of a loved one at home alone, can be overwhelming and taxing.

It was apparent that although in the beginning, some White CAG members were completely unaware of several of the cultural nuances in the African American members, for example, when the concept of eternal hope and the possibility of miracles was raised, I noticed several members express surprise. Over time however, it was apparent that there was an increase in awareness and respect of, the culturally–determined wishes of the African American group, an unexpected benefit of working together.

One of the other positive outcomes of these meetings was the development of a strong sense of support among the group. On many occasions, members spoke of how participating in these sessions and working to help others, helped ease their own grief. Mr. M. a young African American man, shed tears over the loss of his beloved grandparents. Although initially embarrassed by these outward displays of feeling, he later shared with the group the support he felt in expressing these. Ms. B, a White woman in her late 60s had cared for both her dying husband and mother at home at the same time, and had experienced many instances of poor medical care, and at times rude and disrespectful communication by the physician. As a result, this gentle, dainty woman who lived in a home in the country came to the first meetings frustrated and angry. The groups’ recognition of these events, and their wish to turn it into something positive for others, as well as their ongoing support in her healing when she developed severe neck pains, was obviously very important to her. Despite her continued

pain, Ms. B drove the hour to the meeting and the hour back in order to continue to participate. When Ms. R, an affluent White woman in her late 60s whose husband had died the previous year, met a widower at church, she shared this news with the group, and when she later got engaged, the entire group exclaimed over the beauty of her large diamond ring. Ms. G., a highly respected retired Gullah nurse always made sure to call Pastor M. before the meeting to ensure his attendance. Over time, friendships began to develop across the color line. The first time I saw this was the sharing of a recipe by Ms. J. with Ms. R. and B. resulted in a discussion of various options for creating this dish.

During phase 3 of the study, we implemented the community–developed, culturally based palliative care consult program, in order to test patient and family acceptability of it. Concern was expressed by African American CAG members that African American patients and family members may not be willing to participate in a research study, and therefore recommended that they be the first to meet the patient and family and introduce the study to them, sharing that they co–created this study. In order to keep the process the same in both groups, it was decided that a CAG member would be the first to meet the patient, with African American members meeting African American patients and/or White patients, and White CAG members meeting White patients/family.

Following the completion of this phase, a study completion ceremony was held. CAG members brought their loved ones, and hospital staff and community members also attended. Following my final report of the study’s progress, CAG members in turn each spoke of how meaningful it had been to them to be a part of developing this program, and how it would help future members of their community. “This program is a legacy to our loved ones who have passed,” and “We’re like the community of people that have been there before, you know, we’ve walked in these shoes before . . . This program was developed by people . . . who got together and with expert guidance, they developed a program. That’s why it’s helpful for community members to be instrumental in the program. ‘Cos palliative care happens when

somebody's in a great deal of stress . . . you're exposed and you're dependent."

We ended the meeting with my announcement to the group of information that I had shared in the last CAG meeting; I had submitted a large, multi-state grant, based on the work of this community, and for which CAG members would serve as consultants. If and when funded, the work of this community would expand beyond their town to other rural southern states. *A program by the community for the community; work that would hopefully be expanding.*

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