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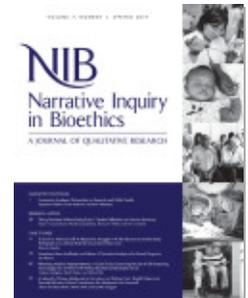
Community-Academic Partnerships to Improve Hispanic
Immigrant Health: Perspectives from a Doctoral Student

J. Claire Schuch

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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