FORTHCOMING IN PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP) 16.2 SUMMER 2022. ALL RIGHTS RESERVED.

Work in Progress and Lessons Learned

Engaging Vulnerable Populations in Community Based Participatory Research: Lessons Learned

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ABSTRACT

Background: Community based participatory research (CBPR) is effective in addressing health disparities. Lack of inclusion of vulnerable populations in research perpetuates systemic inequities. Community-academic partnership must represent the voices and experiences of marginalized populations.

Objective: To inform future research by sharing lessons learned from community-academic partnerships among three distinct vulnerable populations: Arab youth, Black girls and women, and sex workers.

Methods: Community based participatory researchers use reflexivity to identify and describe lessons learned when working with three vulnerable populations.

Lessons learned: Lessons learned focus on power sharing and community partnership which facilitated CBPR. We also describe how institutional roadblocks such as tenure and promotion timelines, institutional review board approval and erasure, stigmatization, and funding impede CBPR.

Conclusions: These lessons provide insight for future researchers to consider as they aim to develop strong and equitable community partnerships. Power sharing is required to maintain equitable community partnerships. Balancing community needs with academic expectations is essential to sustain funding. Emphasizing cultural safety and collaboration can address institutional roadblocks.

KEYWORDS: Vulnerable populations; community-based participatory research; health disparities

Background

Community-based participatory research (CBPR) is a collaborative approach equitably involving community members, researchers, and others in research processes. CBPR democratizes research aimed at sustainable change, empowering marginalized communities, and addressing inequities. Over 25 years, CBPR has contributed to reducing health disparities;[1] historically however, academics conducted research *on* vulnerable populations rather than *with* communities.[2]

CBPR principles were established to ensure that the rights, welfare, and dignity of community members are protected. Community-engaged research is most effective when these principles are followed. Prior to initiating formal research, CBPR researchers acknowledge that (1) community knowledge uniquely provides insights into data production; (2) community knowledge is valuable and legitimate; (3) communities should have equal inclusion and collaboration in the process and resolution of community issues; (4) research cannot lead to full understanding or resolution of complex social issues; and (5) interventions from non-community members frequently reap disappointing results.[3,4]

In this manuscript, we reflect on our community-academic partnerships and CBPR experiences with three distinct vulnerable populations: Arab youth, Black girls and women, and sex workers. We focus on lessons learned in the utilization of CBPR principles, power sharing, and describe the institutional obstacles faced by academic researchers while conducting CBPR.

Methods

Reflexivity, the process of self-reflection practices, positionality and acknowledgement of potential bias affecting research, is the methodology used.[5] Our positionality is influenced by expectations and guidelines of a research-intensive institution. SA, an Arab cisgender woman, and NC, a Black cisgender woman, are on the tenure track, and expected to establish independence and a reputation as experts in a particular content area as measured by funding and publications. RS, a Jewish white cisgender woman, is on the clinical track where research funding is not required. CP, a white cisgender woman, tenured professor and mentor also conducts CBPR research. We acknowledge our position as community insiders, outsiders, and somewhere in between.[6]

As newer faculty, we recognized our shared interests and engaged in conversations and reflections that helped us identify lessons learned and institutional obstacles. This collaboration is an effort to build community and support one another within the institution through knowledge sharing rather than opportunity hoarding. This paper centers the academic perspective of CBPR-engaged researchers. Although several reviewed and approved this work, no community members served as co-authors. Furthermore, the criminalization and stigma related to the research topics meant that some opted not to co-author. Despite working with disparate populations, we overlap in our goals to develop impactful work supporting health equity among vulnerable populations.

Findings

In our CBPR work with Arab youth (SA), Black girls and women (NC), and sex workers (RS) (Table 1), we describe lessons learned about how to share power, develop a community partnership, and navigate institutional barriers. We acknowledge the diverse range of lived experience, identities, and health outcomes within each population. This paper, however, speaks to the relationships built with our community partners. We have aligned our findings with the established principles of CBPR (Table 2).

Power Sharing

Aligning with CBPR principles 1, 2, and 3,[3] we recognize power imbalances exist between researchers and communities, and offer suggestions for how these imbalances can be addressed.[7]

To facilitate a more equitable partnership, SA centered youth needs in establishing the sexual violence prevention project. SA wanted youth involved in every aspect of the project. Although they were not involved in writing the initial proposal**,** members of the partner community-based organization leading the community assessment and youth programing did contribute and the findings informed proposal development aimed at meeting youth's needs. Two young adult Arab women were recruited to serve as research assistants and they collaboratively established a youth community advisory board. At regular meetings, expectations for equal involvement and roles for outreach, recruitment, data collection, analysis, and dissemination at community events were set. They were compensated for their commitment and contributed to the study's progress and process. For example, they suggested revising survey terminology by changing the word "dating" to "being in a relationship." Their rationale was that dating is not a socially accepted framing; so the wording was changed. Additionally, they guided successful community outreach and recruitment strategies. They also recommended organizing a community event to celebrate Arab Heritage month, where the team shared preliminary findings, recruited participants, organized educational sessions on intimate partner violence, and played community building games. For dissemination purposes, the youth community advisory board will collaborate to develop a pamphlet describing preliminary findings for community dissemination**.** After more than 18 months of shared decision making, the advisory board grew and they continue to work on this evolving project.

Grounded in racism, the mistrust generated from unethical research negatively affecting Black populations makes power sharing especially relevant today.[8,9] NC engages in CBPR with Black girls and women prior to the onset of her studies. Parental engagement and buy-in were essential to NC's work with Black youth and she included parents at every step of the research process by answering any and all questions (e.g., over the phone, text, email or in person), sharing results (e.g., presentations or papers) with participants, their families and Black communities. Through a community advisory board of Black women, they co-created study materials. NC ensured interviews took place in a space of participants choosing, enabling them to feel seen and empowered, and at the beginning of each interview acknowledges them as experts of their own experience. To further address power sharing, NC developed trusted relationships with older Black women who were community stakeholders (i.e., directors of community organizations). NC worked in partnership with community organizations to determine how her expertise could best support community needs. For example, when asked to contribute to summer programming, NC facilitated sexual health education. In presentations and publications, participant and community partners' contributions are acknowledged.

In her CBPR project with sex workers, RS centered the community and aimed to equitably distribute power. Prior to the onset of this CBPR project, RS worked with the community to develop the AIMS of the project, to establish guidelines for outreach, recruitment, and data collection, analysis, and dissemination. These formative conversations about roles and responsibilities, however, lacked a supervision plan because RS did not want to appear "as a boss." Consequently, study staff expressed discomfort with team dynamics and process. To resolve this, RS worked with a community advisory board leader with lived experience to facilitate a 3-part zoom gathering allowing team members to share their frustrations and identify ways to move forward with more clarity in purpose, protocols, involvement, and support. Conversations highlighted the importance of leadership and RS worked to improve the CBPR processes and recognized that she does, at times, have different types of power than other team members**.** She learned that transparent and direct conversations and clear definitions of roles and responsibilities are critical**.** Power sharing was eased with use of a protocol booklet, regular supervisory meetings, and a quarterly blog post where the team regularly and actively communicates expectations and concerns and shares successes and goals.

To encourage power sharing, we sought feedback from our community partners and other stakeholders such as mentors, care providers, and other community members. Community members were involved in creating interview guides, editing protocols, recruiting and facilitating interviews. We solicited community feedback at every phase of our projects. When discrepancies between partners and researchers arose, community stakeholders advised researchers. For example, all co-authors worked with trained community members to facilitate qualitative interviews. However, to respect schedules and acknowledge the possibility of cancellation, stakeholders advised that honoring the commitment made to the participant was also important. Stakeholders suggested that another trained research team member could conduct interviews if a community member could not. RS, for example, is now very transparent about this possibility, and explicitly shares this statement in the protocol with community partners: "If there is an interview scheduled and the community member interviewer cancels, a trained team member without lived experience may substitute as an interviewer if the participant desires to proceed with the planned interview despite the absence of an individual with lived experience". This one example illustrates how all authors create new or revised protocols based on community feedback to support iterative collaboration. To further distribute power, all authors also invite community partners to engage in dissemination activities.

Scholars describe how power and privilege are mitigated by early involvement of community members, trust, long-term relationships, and transparent and continous communication about project expectations and power and privilege.[1,2,4,7,10] Power sharing is critical within CBPR and is impacted by our own positionalities and identities. Similar to the work of Muhhamed et al. (2015)[7], we found that our ascribed and achieved identities influenced how we perceived ourselves and how our community partners and members perceived us as insiders, outsiders, and in the "space-between".[5,6] We learned that direct and explicit communication regarding our positionalities, power, and privileges helps to ensure power sharing and is critical to the community-academic partnership.

Community Partnership

To align with CBPR principles 3, 4, 5 and 8,[3] we define community partnership as equitable exchanges of ideas and shared decision making in all aspects of the study from inception, implementation, to dissemination.[11]

SA's identity as an Arab immigrant woman initially positioned her as an "insider" to the Arab community. SA recognized that she was actually navigating as an insider, outsider, and somewhere in between space depending on the context, setting, and which community members were present.[5,6] The two Arab women co-founders of the partner community-based organization had expressed early in the process that there was lack of trust because they had experienced exploitation from previous researchers and academic institutions. For SA, it took 1 year of meeting regularly with community members, attending community events, and collaborating on public presentations in order to gain the trust necessary to establish her position as an Arab woman who is an ethical researcher with honest motives and community centered priorities. SA successfully established trust and support for this community-academic partnership. Early and regular conversations between SA and community partners, including youth groups, ensured that every decision would facilitate an equitable community-academic partnership.

Due to historical atrocities Black communities have experienced in research, it was critical that NC establish trust. Being a Black woman and/or an "insider" within the Black community does not, in and of itself, automatically establish trust. NC still has to work to gain and sustain community partnerships. Because older Black women are viewed as trusted leaders and protectors in the community, NC has developed trusted relationships with these women including doctors, directors of Black community centers, and leaders of youth groups. Working in partnership with these older Black women paved the way for young Black girls to comfortably participate in sensitive research. Strategies NC uses to build trust within Black spaces include sharing/disclosing her identity as a Black female nurse with a PhD. Additionally, NC talks about her own upbringing, as this provides her community partners with context and background about who she is and where she comes from. NC found that sharing information about her identity helped to create a level of comfort and enabled communities and participants to open up about themselves and their needs regarding stigmatized topics.

As a marginalized and, for many, criminalized community, sex workers are leery of outside researchers. Some have had negative experiences and others worry that results could lead to harm and marginalization. RS was introduced as a trusted ally to the community by a community insider because of her work supporting LGBTQ+ health equity. As a nurse and a volunteer for over three years, RS offered mobile outreach and leveraged her role in an academic institution to begin to meet the needs of the community through grant writing and access to harm reduction supplies. Building community partnerships as an outsider takes perseverance. RS is an outsider who has not engaged in sex work. She fostered access to university resources, jobs, and public health community leaders. Her commitment to the community was made apparent through resource sharing and an ability to be reflexive about relationships. This trusted relationship allowed for partnering with sex worker community members to research HIV/STI risks.

The *lesson learned* is the precarious nature of trust and the value of reliability when working with vulnerable persons. This has been also shared elsewhere in the literature [12,13] and contributes to the all CBPR principles and successful partnerships.

Institutional Roadblocks

Although not new,[14–16] institutional roadblocks continue to serve as overarching barriers to all principles of CBPR[3] including our own work. Based on our experience, we provide examples for how we addressed some of these barriers.

Promotion. Researchers invested in community-academic partnership require institutional and leadership support to be successful. For example, a large proportion of time and effort is required to build trusting and successful community-academic partnerships. While research intensive institutions are invested in public health initiatives supported by groundbreaking CBPR research, the effort required is not accounted for in guidelines. These contradictory expectations cause SA and NC to constantly reflect on ways to meet community needs while securing a program of research. Fast turnaround for funding applications with short notices inhibits the ability to meaningfully involve community members. On the other hand, clinical track faculty are differently poised to conduct CBPR as they do not have the same promotion timeline and there is less expectation for major external funding. However, institutional barriers, such as the lack of a start-up package and fewer course releases, make conducting CBPR research equally challenging on the clinical track.

Institutional Review Boards. When questionable research ethics come to light at a university, approval for subsequent research with vulnerable populations becomes even more difficult. NC has met challenges getting her research with Black adolescent girls approved by the Institutional Review Board (IRB) as their age, race and gender make them particularly vulnerable. NC has met resistance with getting IRB approval on materials that are developmentally tailored, utilize culturally sensitive and reflect the literacy levels of Black youth. Even with the use of community advisory boards and asking youth about the components of the IRB materials, IRB reviewers pushed back asking NC to use language like “sexual physiology” which is not developmentally appropriate or responsive to literacy levels. Most recently, and since the start of COVID-19, all authors experienced difficulty transitioning their research online and making it accessible/user friendly for vulnerable populations without internet access. Although NC is an expert and has worked with this population for years, IRB reviewers rarely bring the same level of awareness and expertise about the history and current socio-political context of Black populations. Some strategies used by NC requiring additional time and emotional energy include calling the reviewers to detail the rationale and merits of the methods, utilizing other colleagues' approved IRB applications as exemplars, and providing IRB reviewers with evidence-based research supporting the methods.

Erasure, Stigmatization, and Funding. The authors spent several years prior to initiating research projects building authentic community-academic partnerships. This phase includes networking, community outreach, formal and informal meetings with multiple stakeholders, and establishing community advisory boards, to name a few. Historically, this phase is nearly impossible to fund through foundations or government institutes, especially when requesting financial support for both the community and academic team members. Although time spent building trust and fostering relationships is critical in establishing equitable CBPR partnerships, we address barriers, by population, to this essential CBPR component.

Faculty of color and faculty working with vulnerable populations face barriers when securing research funding from institutions with predominately white leadership,.[17,18] Since Arabs are classified as white, many funding institutions, including the National Institutes of Health, do not recognize them as a minority group with identifiable health disparities. Arabs, however, do not benefit from whiteness privilege.[19] This perpetuates a cycle of invisibility related to lack of data on their health disparities, and hence lack of funding since researchers (SA) cannot argue for existing visible disparities.

Societally, Black bodies are not valued and historically have been excluded from research as most models, theories and frameworks are created for and by a heteronormative white population.[20] Often in NC's research, funders compare their sexual experiences as white female bodies, to that of Black girls and women, saying that these things happen to white girls and women too. These responses fail to acknowledge the history of racism, discrimination and sexualization of Black bodies, thus minimizing their experiences. As researchers we also work within institutions and can perpetuate systematic oppression and structural racism in our research. Therefore, we must advocate for vulnerable populations at the conception of our research.

Current HIV prevention and sexual health promotion interventions for sex workers in the United States are inadequate,[21] ignore the impact of structural violence, and have not included sex workers as experts. Only recently have lessons learned for effective CBPR HIV prevention and treatment from low and middle-income countries been used in the US.[22,23] Despite the need for increased access to care, sex workers remain an understudied and underfunded population.[24,25] When discussing funding opportunities to support the sexual health needs of sex workers, RS was often asked the same question, "*But how will you find them*?". This question represents a widespread belief that "*they*," the sex workers, are different from everyone else. This question reflects assumptions about who sex workers are, and implies that sex workers are not our colleagues, our friends, or our employers. Sex work stigma and misconceptions negatively fuel disparities in funding for sex work research.

Conclusion

Our experiences highlight the importance of conducting CBPR with vulnerable populations and how much time, effort and energy is required to establish an equitable and ethical community-academic partnership. The benefits of CBPR do not come without interpersonal and institutional challenges. Power sharing and community building present opportunities for lessons learned regardless of population. In order to deconstruct existing institutional roadblocks, we must acknowledge that many of the barriers experienced are rooted in a history of mistrust of research, researchers and academic institutions. Placing institutional value on the time needed to build equitable community academic partnerships would serve to secure future funding by centering the needs of the community.

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Table 1. Principles of CBPR include (Israel et al., 2013, p. 523)
1. Recognizes community as a unit of identity.
2. Builds on strengths and resources within the community.
3. Facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities.
4. Fosters co-learning and capacity building among all partners.
5. Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners.
6. Focuses on the local relevance of public health problems and on ecological perspectives that attend to the multiple determinants of health.
7. Involves systems development using a cyclical and iterative process.
8. Disseminates results to all partners and involves them in the wider dissemination of results.
9. Involves a long-term process and commitment to sustainability.

Table 2. Distinct Vulnerable Populations

Vulnerable Population	**History of Inequality**	**Sample Health Disparities**	**Root causes of vulnerability**	**Lessons Learned**
Arab youth (SA)	• Immigrant population • Racial misclassification • “White” without white privilege • Lack of research • History of invisibility and hypervisibility	• Intimate partner violence • Mental health (PTSD, depression, anxiety, etc.) • Smoking and cancer • Diabetes	• Xenophobia (especially post 9-11) • Invisibility; not recognized as a minority (classified as white) • Islamophobia • Orientalism • US-Middle East political relationships • Anti-immigration policies • Government and medical mistrust • Language barriers	• **Understanding unique historical and current context of community’s lived experiences** • **Recognition and reflexivity related to privilege and power** • **Work with community leaders to utilize existing community resources and build on community strengths** • **Early and continued involvement of community members and leaders** • **Clear expectations of roles and responsibilities** • **Leveraging resources to foster capacity building and reciprocity** • **Invite community members to participate in conceptualization and/or authorship of manuscripts and presentations** • **Disseminate academic literature and project results to community (pamphlets, local community presentations, etc.)** • **Developng effective communication strategies to support sustainability with partners and future interventions**
Black girls and women (NC)	• Slavery • Mass incarceration • Black Lives Matter Movement • Jim Crow Laws • Redlining • Police Brutality • School to prison Pipeline	• 97.9 Blacks vs. 46.6 whites (per 100,000) dying of COVID-19 [26] • Black adolescents 7 times more likely to be in juvenile justice system than whites • Black adolescents between the ages of 15-19 are 4.5 times more likely to get Chlamydia than whites [27]	• Structural racism • Historical mistrust • Discrimination • Healthcare access and utilization • Educational, income, and wealth gaps • Housing	
Sex workers(RS)	• Criminality • Violence • Sexual Assault • Police Abuse	• Sex Workers among five “key populations” at increased risk for HIV.[28,29] • Sex Workers are 12 times more likely to acquire HIV [30] • Stigma/discrimination prevent sex workers from receiving HIV/STI prevention information, services, and treatment[23,29,31]	• Criminalization • Whorephobia • Stigma • Harassment • Discrimination within healthcare settings	