Academic Institutional Barriers and Facilitators to Community-Based Participatory Research

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ABSTRACT:

Background: Collaborative research between researchers and community members can meaningfully address public health concerns. Collaboration can be complicated, however, due to unanticipated challenges stemming from academic institutions. This article describes how academic institutions can hinder and facilitate community-based research.

Objectives: We evaluated a research partnership focused on structural determinants of COVID-19 vaccine hesitancy among Latinx people who: 1) have a precarious immigration status; 2) are sexual and gender minorities; and 3) can become pregnant.

Methods: We completed a process evaluation with community organization partners who collaborated on the study. We asked community partners to describe benefits and challenges of collaborating with academic institutions.

Lessons Learned: Our evaluation revealed institutional challenges to successful community-based partnerships, including IRB delays and institutional expectations that failed to understand grassroots community organizations. Using the concept of bureaucratic violence, we describe how academic institutions can constrain community-based research and provide suggestions for how academic partners might overcome institutional hurdles.

KEYWORDS: Community-based research, Community-academic partnerships, COVID-19, vaccine hesitancy, Vulnerable populations

Introduction

Community-based participatory (CBPR) research can improve health outcomes for minoritized people and advance health equity (Wallerstein & Duran, 2006). However, few studies describe unexpected barriers to advancing CBPR that are caused by academic instititions themselves (Gholipour et al., 2023; Hallmark, Bohn, Hallberg, & Croisant, 2022). In this article, we describe a process evaluation of a study aimed to reduce COVID-19 vaccination disparities among Latinx individuals in the Dallas-Fort Worth region—the 4th most populous region in the US. Our evaluation focused on barriers and facilitors to advancing the study, which focused on Latinx individuals who: 1) were sexual and gender minorities; 2) had precarious immigration statuses (e.g. undocumented, DACA recipient, etc); or 3) could experience pregnancy. These groups are prioritiy populations for our community partners and experience elevated vaccine-related vulneabilitites due to their unique social positions (Bhattacharya, Siddiquea, Shetty, Afroz, & Billah, 2022; Eichelberger, 2007; Gim, 2023; Hsu, Johnson, Phillips, & Nelson, 2022; Markel & Stern, 2002; Rocha & Dil, 2022).

We experienced challenges advancing our study due to numerous barriers associated with the academic partners' institution. As we describe here, these challenges included IRB inefficiencies and institutional processes that were not designed for grassroots organizations. Our strengths included commitment to CBPR values and attempting to educate academic institution staff about CBPR. We provide suggestions for similar partnerships and caution that some academic institutional processes may perpetuate what anthropologists refer to as "bureaucratic violence" (Heckert, 2020): harm created through management procedures within institutional systems.

The Public Health Problem

In 2023, Latinx individuals represented 18.9% of the US population (U.S. Census Bureau, 2022), but accounted for 25.6% of adults who received a primary series and booster dose of COVID-19 vaccinations, compared to 37.5% of white and 29.3% of Black individuals (Centers for Disease Control and Prevention, 2023). Our team of researchers and community partners suspected there were structural determinants (Brown et al., 2019) of COVID-19 vaccination disparities beyond individual and behavioral factors documented in existing literature.

In focusing on structural factors, we were interested in how intersecting forms of social marginalization (Aguayo-Romero, 2021; Bowleg, 2012; Young, Ayiasi, Shung-King, & Morgan, 2020) related to immigration status, sexual and gender minority identity, and pregnancy capability, could shape COVID-19 inequalities. We chose these foci because they respond to our existing community partners' priority populations and we sought to center our collaborative work on the very communitites our partners prioritize. Further, these populations experience elevated risk of vaccine-related vulnerabilitites: immigration status is a social determinant of health that structures access to health services (Castañeda et al., 2015), and sexual and gender minorities face constrained access to culturally appropriate care (Nowaskie & Sowinski, 2018). Immigrants and sexual and gender minorities have also historically been scapegoated during epidemics (Eichelberger, 2007; Gim, 2023; Markel & Stern, 2002; Rocha & Dil, 2022). Lastly, we focused on pregnancy since pregnancy is a time of vulnerability and pregnant people may be hesitant about vaccination due to concerns about potential adverse birth outcomes (Bhattacharya et al., 2022; Hsu et al., 2022).

Team Background and Study Context

We designed a study to identify structural factors that perpetuate COVID-19 vaccination disparities. Our study was guided by CBPR principles for public health interventions, which emphasize establishing equal partnerships between community members and researchers to design effective interventions tailored for marginalized communities (National Institute of Minority Health and Health Disparities, 2018). Our team comprised three community-based organizations in the Dallas-Fort Worth Metroplex: Prism Health North Texas (PHNTX), a health service provider focused on LGBTQ+ populations; 2) ICE Out of Tarrant (IOT), a grassroots immigrant justice organization; and 3) Health Equity Alliance of Tarrant County (HEAL), a non-profit organization focused on birth equity and maternal and child health.

PHNTX is the largest LGBTQ+ health clinic in the Dallas-Fort Worth area, and since its inception in 1986, the organization has linked individuals living with HIV to essential care and services across North Texas. Approximately 30% of people living with HIV in North Texas receive medical care and support from one of the four health centers operated by PHNTX. HEAL formed in 2003, and is a network of public health experts, local agencies and community leaders united on a mission to end health, socio-economic and racial disparities and address disproportionate death rates for mothers and infants in Tarrant County, Texas. IOT is the newest organization of the three partners. It formed in 2018 to protect immigrant rights in Tarrant County, and is led by and for immigrants with precarious immigration statuses. The community and academic partners co-developed the study goals and instruments.

Our study was funded by the National Institutes of Health (NIH) Community Engagement Alliance Against COVID-19 (CEAL) Texas consortium. The NIH's CEAL effort was designed to focus on the communities most impacted by COVID-19, with particular emphasis on expanding community engagement, enhancing diverse participation in clinical

trials, and increasing COVID-19 education and awareness (National Institute of Health, 2023). To advance this effort, NIH funded CEAL teams, or consortiums, across the United States, including one in Texas. The Texas CEAL consortium comprises multiple researchers at different universities. Our study team was one of several different teams within the Texas CEAL consortium, and we focused on the Dallas Fort Worth area. As part of our team, we as reseaarchers and community members developed our study examining structural factors influencing COVID-19 vaccination that were unique to each subpopulation the organizations focused on and planned to disseminate findings to our partners' organizational membership.

Academic and Community Partner Relationships

The community partners and researchers had established relationships prior to this study. Author 1 and IOT leader (Name removed for review) have collaborated on community panels focused on immigrant health equity, and Author 2 (name removed for review) has been an executive board member of HEAL since 2019 and has partnered on studies related to prenatal care and maternal health. The newest relationship was with PHNTX, when co-authors (names removed for review) met with PHNTX leaders (names removed for review) in the summer of 2021 to discuss potential collaborations and PHNTX's priorities.

Although our relationships predated this particular project, our collaboration on this study formed in December of 2021, when a call for CEAL proposals in Texas circulated the researchers' institution. Studies were limited to one year. Given our prior relationshps and knowledge of mutual interests, the academic team and community partners were able to quickly collaborate on a proposal related to Latinx COVID-19 vaccination vulnerabilities.

The Study: Original Design and Changed Plans

Together, we designed a study that included surveys (n=150), and semi-structured interviews (n=24) with key stakeholders who can speak to structural factors shaping vaccine hesitancy and vaccination disparities among these populations. The study was approved by the (omitted for review) Institutional Review Board. To recruit survey participants, we developed digital flyers to post on community partners' websites and paper flyers with QR codes to scan for immediate access to an eligibility screener. Upon collecting data, we planned to summarize the data and report it to community members associated with each organization through a community forum process. For these efforts, PHNTX, HEAL, and IOT all received funds to compensate them for posting study links to their websites, and in the case of IOT, completing surveys with participants who have precarious immigration statuses and may prefer completing surveys with IOT staff.

Our study plans, however, changed due to unforeseen challenges that we describe here. As a result of our delays, we ultimately contracted with a survey data collection consultant to complete data collection for surveys, resulting in 140 completed responses. We also completed a total of 14 of interviews with key stakeholders. Rather than reporting study findings, the purpose of this paper is to report challenges in achieving our desired goals with our community partners. Our study began in March 2022 and was to be completed in the one year timeframe required by the Texas CEAL consortium. However, by January 2023, we had made progress towards completing interviews but had not received IRB approval for the surveys.

Process Evaluation: Methods for Learning what Went Wrong

To identify challenges related to making progress on our study, we conducted a low-barrier process evaluation for understanding our study's implementation. We convened the community organization leaders (Author names omitted for review) to collectively identify the

barriers and facilitators they experienced to advancing the study aims. This process occurred via virtual meetings in which community organization leaders were given prompts about the study and asked to anonymously post responses using Google JamBoard. Participants were invited to discuss their responses.

JamBoard replicates whiteboards and can be shared in real-time, facilitating participatory discussion activities, which is how we used it as process evaluation tool. Specifically, we replicated discussion and learning activities in which users post sticky notes representing individual ideas to a corresponding prompt. For our study, we created a digital concept mapping activity for participants to use digital sticky notes to respond to the following prompts:

1. Think about a time when you collaborated with academic institutions. What were some of the benefits? What were some of the challenges?
2. Think about our project. How does the timeline compare to projects you have worked on in the past?
3. Thinking about our project, how have expectations of paperwork compared to others?
4. Looking back to when we first started, what do you wish you had known then? What surprised you or what was unexpected?
5. What are some possible approaches/solutions that will allow us to better cater to local community organizations?

Three community partner participants (one from each organization) participated in the evaluation activity. They were given as much time needed to respond to prompts and were allowed to submit an unlimited number of responses.

Lessons Learned:

As part of the process evaluation, community partner participants described that implementing our study was challenging and delayed due to unexpected institutional barriers. These challenges included: 1) encountering IRB inefficiencies that are designed around clinical research; and 2) institutional processes that do not consider grassroots organizations' structure or staffing capacities. The benefits included the CBPR approach, or as one community partner explained, doing "real collaboration."

Challenge: IRB inefficiencies

The researcher authors all worked at the same academic institution and encountered significant hurdles advancing the study. The academic institution's IRB was accustomed to biomedical proposals without community collaborations, which made the relationship of the project participants difficult for IRB reviewers to grasp and slowed the review process. Overall, full IRB approval took 8 rounds of revisions and 8 months. This timeline delayed the study and missed the urgency with which we hoped to respond to community partners' needs and interests. As a result, community partners shared that COVID-19 no longer remained a top priority for their organizations and was difficult to discuss. As one community partner wrote in a JamBoard reply "[there's] less willingness to discuss COVID-19 –[it's] become a 'taboo' subject."

Delayed IRB approval stalled data collection and also changed our study design. We intended to host community forums to report findings and collect community input. As IRB approval delays continued and COVID-19 no longer became a priority for community partners, forums on COVID-19 seemed out of step with community needs. Accordingly, we removed this element of the study.

Challenge: Institutional processes not designed for grassroots organizations

Institutional processes that formed a barrier to advancing this work included necessary institutional paperwork to process payments for grassroots organizations in particular. All community partners were paid for assisting with advertising and recruitment, and processing payment was a multi-step process. Processes included obtaining bank and tax information from organizations, invoices in a university-preferred format, having documents reviewed and approved at a university level, and then having documents reviewed at a system level (comprising all universities that our institution is a part of) and entered into a centralized vendor contracting and payment software system. These are standard institutional processes but created delays for all community partners and capacity challenges for one partner. Specifically, IOT is a grassroots organization that values its grassroots structure. When the paperwork was requested, IOT did not have a formal address, an official tax status, or a bank account with their organization name on it. Organization leaders were unsure of how to complete required tax and bank account information, and when the researchers and community partners asked the academic institution for guidance on how to meet these needs, institutional officials declined to assist them. As one academic staff member told Author 1, "they should know how to do this—it's outside of our purview to assist with these matters."

IOT is also led by first generation immigrants, some of whom were attending undergraduate institutions or were recent graduates working at an academic institution. These experiences are vastly differently than the professional backgrounds of PHNTX and HEAL leaders, who have had more time in their careers and more experience in collaborating with hospitals, academic institutions, and other entitites with large bureaucracies. Staff at the academic institution were unwilling to guide IOT on how to complete this work or provide examples of what the university considered acceptably formatted documents. Accordingly, the

study PI and organization leader, a queer Latinx person and first generation college graduate, met and worked together to complete the tax documents and other required paperwork.

These practices, though innocuous to academic institutions, can have the effect of insufficiently meeting the urgency of community organizations' needs to respond to pressing public health issues, and are designed around organizations with more formal structures than grassroots organizations may intentionally want to have. Grassroots organizations often approach decisions from a collective decision-making and mobilization process rather than a hierarchical method, and institutional forms may be designed in ways that normalize hierarchies and fail to consider other types of entities. IOT leaders described working with the university as "chaotic" and wished the university "had more of an understanding of how to work with grassroots organizations for future collaborations." Moreover, IOT received payment for their services one year after they were supposed to, delaying their ability to start work for the study.

Strengths: Dedication to CBPR Goals

Despite the challenges, our study's CBPR approach remained consistent and was a considerable strength of our collaboration. Understanding study challenges and seeking feedback, for example, led one community partner to comment that other researchers were comparatively "not looking for real collaboration," and instead looking to use the organization "primarily for participants in clinical trials but not collaborators in driving hypotheses or testing them, which is frustrating." Accordingly, our team's intentional CBPR approach is a strength of a study.

CBPR approaches prioritize sustainability, and our intervention had a similar goal. Maintaining positive relationships is inherent to sustainability, and institutional delays can potentially threaten partnerships. To address this shortcoming, we suggest academic institutions

build upon the strength of CBPR approaches that foster collaboration. This can take the form of finance offices providing internal support for grassroots organizations that are unaccustomed to institutional requirements and IRBs staff familiarizing themselves with CBPR approaches that may differ from clinical research proposals. As such, researchers who partner with community organizations may need to increase their institution's capacity for understanding authentic community partnerships and suggest revising processes that can inhibit authentic partnership.

In the case of our partnership, another strength of our collaboration was that the academic co-authors attempted to educate their institution on CBPR through suggestions for IRB and finance staff about how to foster CBPR. Although these efforts were met with researchers being told "we're not able to provide that level of assistance," and similar comments, they may nevertheless begin building groundwork for future CBPR attempts.

Bureaucratic Violence

Borrowing from anthropological literature on bureaucratic violence (Heckert, 2020), or the harms created by bureaucracies, our study underscores unexpected and unintentional institutional challenges that can complicate CBPR research to reduce health disparities. Bureaucratic violence is not an outcome, but rather a series of processes that can include paperwork and decision-making (Eldridge & Reinke, 2018, p. 95). For anthropologists and other social scientists, the term extends social and health science concepts of stuructural violence that considers how social structures themselves can produce harm (see, for example:Farmer, 2004; Herrick & Bell, 2022). Bureaucratic violence can be understood as processes that work together to produce types of harm that are directly designed by institutions that can wield bureaucratic

power and authority. Such power and concomitant mechanisms may work to serve a particular institutional bureaucracy, but may inadvertently harm other entities.

For our study, bureaucratic violence that manifested in IRB approval delays resulted in the study no longer being relevant to community partners. This IRB approval lag resulted in a shift in what was important and relevant to our community partners. Similarly, the paperwork hurdles created layers of bureaucracy for IOT that added to their already over-worked leadership. These factors led us to revise our data collection methods with two community partners in order to complete data collection within a rigid timeline set by the funder. In many ways, the funder deadline itself, with limited flexibility, further imposed an artificial urgency necessitating revising our approach.

When examined through the lens of bureaucratic violence, the revised approaches to our study and the associated challenges our partners faced, raise important questions about how community-based research can be effective if academic partners' institutions impose their own norms upon community groups with limited flexibility.

Conclusions

A goal of public health research and practice is to address the health needs of particular populations. As such, academic institutional processes must support successful community collaborations in public health research, especially when responding to rapidly evolving health issues. The delays with our study that perpetaute bureaucratic violence reveal how academic institutions may not thoughtfully serve community organizations. As many academic institutions purport to champion community partnerships, the challenges described here highlight how some institutions may only be paying lip service to collaborations with community-based organizations. Indeed, while some research has demonstrated the challenges of conducting

community-based research in academic settings, our example framed through bureaucratic violence, directly emphasizes the harms that academic institutions can inadvertently perpetuate, ultimately undermining efforts for partnering to addressing pressing public health problems.

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Conflicts of Interest

None to disclose.

Human Participant Protection

This study received approval from the (removed for peer review) Institutional Review Board.

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