Community-Engaged Research Partnerships as Healing Spaces for Health Professionals and Researchers

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ABSTRACT

Drawing from collective experiences in our capacity building project: Health Equity Activation Research Team (HEART) for Inclusion Health, we argue that while community-engaged partnerships tend to focus on understanding health inequities and developing solutions, they can be healing spaces for health professionals and researchers. Data were obtained from a 15-month participatory ethnography, including focus groups and interviews. Ethnographic notes and transcripts were coded and analyzed using both deductive and inductive coding. Practices of radical welcome, vulnerability, valuing the whole person, acknowledging how partnerships can cause harm, and centering lived experience expertise in knowledge creation processes were identified as key characteristics of healing spaces. Ultimately, health professionals and researchers work within the same social, political and economic contexts of populations with the worst health outcomes. Their own healing is critical for tackling larger systemic changes aimed at improving the well-being of communities harmed by legacies of exclusion.

KEYWORDS: Community-based practice; patient-centered research; community partnerships; stakeholder engaged research; CBPR

Despite tremendous information about the causes of health inequities, discovery of new knowledge has not always led to their elimination. Academic and health care institutions have historically controlled the processes of knowledge creation about health inequities, excluding communities impacted the most.[1] Organizations such as the Patient Centered Outcomes Research Institute (PCORI) are prioritizing community engagement and leadership in health equity research by investing resources to bring together stakeholders and supporting capacity building for conducting community-engaged research.[2] Community- based participatory research (CBPR) holds promise for this work.[3] In the broadest sense, CBPR is an approach that requires ongoing collaboration between researchers and communities impacted by the topic of research, and taking collaborative action for sustainable change.[4] Partnerships leverage research expertise of academic partners, insights into health services delivery that clinicians bring,[5] and the community's lived experiences[6] to address health inequities. In CBPR, community members or context experts – persons without formal training as researchers or clinicians – bring the expertise of their lived experiences into full participation— from conceptualization to implementation and dissemination. Lived experience expertise is critical for research design, delivery of care, and structural transformation.

The lived experiences of health professionals and researchers are also important. First, they typically work in systems with policies and practices that cause harm to the communities they serve. Second, their professional and personal lives are likely shaped by the same broad social, political and economic contexts that shape the health of communities. Third, positionality – how their identities, statuses and relationships with institutions can wield power over communities – influences their actions within these partnerships.[7] Much of what we know about the experiences of health professionals and researchers in community-engaged partnerships

centers their roles as facilitators of community participation, content-area experts, power and resource holders, and as persons who are responsible for fixing problems that prevent health equity.[8-10] Beyond existing as learning and action research communities, we argue that partnerships can be healing spaces for health professionals and researchers.

Objectives

Our CBPR partnership sought to examine how health care institutions can listen to, trust, accept, and support persons with stigmatizing conditions in Allentown, Pennsylvania. But as we reviewed data throughout the project, we realized that health professionals and researchers entered the partnership perceiving their own struggles as inappropriate to discuss within such a professional setting. They functioned in their professional roles, seeking only to generate solutions to health inequities in the community. Over time, the nature of participation of health professionals and researchers changed. The recurrent themes were about how the partnership improved their own well-being. The purpose of this manuscript is to describe what it means for a CBPR partnership to become a healing space for health professionals and researchers. We address two specific objectives: 1) Define healing spaces in the context of community-engaged research partnerships; and 2) Identify factors that characterize healing spaces. These can inform the design of partnerships that might strengthen relationships in which health professionals and researchers are able to engage deeply and authentically.

Methods

Our Partnership

The Health Equity Activation Research Team (HEART) for Inclusion Health is guided by the nine principles of CBPR partnerships[11] as shown on Table 1. Inclusion health is a

comprehensive approach to engage with and provide compassionate care specifically for people with stigmatizing conditions. It is about finding ways "to bring socially excluded populations in from the cold – literally and metaphorically – and to provide them with the opportunity to be part of a diverse and flourishing society."[12(p.187)] Participatory explorations of the experiences of people who use inclusion health services indicate that trust, acceptance, patience, deep listening, honesty and transparency from service providers are important for making them feel seen, included and supported, and enables full participation in decisions and processes about their own health.[13] The HEART project was designed based on the inclusion health framework and sought to understand how to break down barriers to trust between health care institutions and persons with specific stigmatizing conditions – people with experiences of homelessness, addiction, and/or a history of incarceration – in Allentown, Pennsylvania.

(Insert Table 1 about here)

HEART partners are Lehigh Valley Health Network (LVHN)'s Department of Family Medicine; Promise Neighborhoods of the Lehigh Valley (PNLV) – a grassroots organization that focuses on community development, violence prevention, re-entry, health equity, and wellness; Ripple Community, Inc. – a housing service provider and community building organization; Valley Health Partners – a community health center that provides a range of services including addiction treatment; and the Health Justice Collaborative at Lehigh University. Having collaborated in health equity issues for over five years, the HEART core team designed this project to center people experiencing homelessness, addiction, and/or who have a history of incarceration because they face enormous stigma within health care settings, constantly lose relationships that could stabilize safe housing, are more likely to be criminalized, and are significantly negatively impacted by COVID-19.

PNLV is the leading community partner in HEART. As a Black-led, anti-racist, liberation-based grassroots organization, PNLV has built a coalition of trusted messengers who generate community engagement in solutions designed by and for the people most affected by structural inequities. Trusted messengers are context experts who are often self-recruited to work with PNLV. They are known in their communities as influencers and dedicate their time and talents to build healthier, stronger connections, and to generate knowledge. Our existing partnership facilitated the involvement of a trusted messenger context expert on the HEART core team as essential personnel with major contributions in design, planning, execution, evaluation and dissemination. Other context experts, invited based on existing relationships, also participated in planning sessions that were scheduled for four-hour morning blocks and hosted as open houses. These planning sessions, along with multiple informal conversations to reach those who could not attend, were instrumental in defining and refining the project design.

Once funding was obtained from PCORI, the project was reviewed and approved by LVHN's Institutional Review Board (IRB). Lehigh University approved a request to rely on LVHN's review. We then recruited ten context experts – people with experiences of homelessness, addiction and incarceration, and eight content experts – health professionals, researchers and social service providers – through personal connections within our networks and from PNLV's coalition of trusted messengers. These experts worked together as a learning community for 15 months. Community gatherings included three-hour monthly story-healing events on zoom, 90-minute monthly health equity webinars, and a cumulative 15 hours of action group meetings that identified collective action for system change.

In story-healing sessions, the learning community focused on connecting to their own purpose and to each other by sharing stories about their work, personal lives, health, and health care. Health equity webinars were opportunities to collectively learn about core concepts together and to tackle difficult local issues and social determinants of health from different perspectives. They were three action groups, each co-directed by a context and content expert. The research action group focused on identifying key health inequities and how to design implementation research that involves full participation and power from people most impacted. The advocacy action group designed and launched a community media campaign to reduce health care stigma that people who experience addiction, homelessness and incarceration face. This group also focuses on building a movement of people most affected by these issues and working with local institutions that are ready to implement change. The replication action group developed materials to replicate HEART for inclusion health.

All HEART gatherings – story-healing meetings, health equity webinars, and action group meetings – were co-facilitated by a context and a content expert who used the ethical practice of radical welcome to lay the groundwork for participation and mutual trust between health professionals and researchers with formal knowledge (content experts) and context experts— community members with experiential knowledge. Radical welcome engages participants by recognizing that exclusion, discounting lived experiences, and rejection are a form of violence that disrupt the healing process, and that welcome is the cure.[14]

Data

Data were collected through observations made by the evaluation team in the process of participatory ethnography, and through focus groups and interviews. Evaluation team members

consisted of three content experts, two context experts, and two project personnel. The team attended story-healing meetings, health equity webinars, and action group meetings, and observed dialogue and behaviors that help build or corrode trust. The learning community was often encouraged to share their reflections about the process and content of each event at the end of the event. All events were recorded via zoom. A context expert facilitated two focus groups with other context experts and a content expert facilitated two focus groups with other content experts. Content experts were individually interviewed at least twice by research personnel who were neither members of the learning community nor participated in gatherings. Context experts were also interviewed individually at least once by a content expert or a context expert on the evaluation team because there were concerns from context experts about "starting over with new people," engaging superficially or potentially sharing sensitive issues with persons who were not part of the learning community. Focus groups and interviews were also recorded via zoom. They elicited data on the experiences, perceived impact, challenges, successes and evolution of the project.

Analyses

Supervised by the HEART evaluation team lead, an external research team consisting of two graduate students (who conducted interviews with content experts), an undergraduate student and a postdoctoral fellow watched all meeting recordings, focus group and interview videos, reviewed and coded transcripts, and identified recurring themes through content analysis. These were done independently first, and then collectively as team. Deductive and inductive approaches to coding were employed. Deductively, HEART objectives – barriers to trust between context experts and health care institutions – were used as organizing categories for

coding. Inductively, new categories of codes emerged from unexpected patterns in group and individual experiences within the learning community. The themes that were identified by the external research team were brought to the HEART evaluation team that met every two weeks and to the core team that met weekly for discussions, clarification, member-checking and process improvement. These themes were also shared with the entire learning community several times over the course of project for member-checking and collective validation. This manuscript focuses on findings specific to the inductive broad theme of healing spaces. We discuss these results as lessons learned.

Lessons Learned

Healing Spaces

Healing spaces encompass the practices, ideas, values, beliefs, and attitudes that enable people to see themselves and each other as fully human, whole and valid. Healing spaces promote wellness through authentic relationships. Content experts struggled to build personal relationships in a partnership that they were recruited into because of their professional roles. Encouraged by context experts to extend their participation beyond these professional roles, content experts shared more personal experiences that further humanized them to and connected them with context experts. These processes were validating and healing for content experts who enthusiastically looked forward to the healing spaces that had become of HEART gatherings. Health professionals, for example, could:

> "*Talk about things that [they]'ve never talked about. Like how [their] mental health is impacted by work. In forever, I've felt like I've got to choose between being isolated at work or toe the line, joining in with institutional bullies to cause harm. It's like I'm a*

failure for not just quitting. That's why I've cherished this space, learning how to navigate it and talk about it. 'You're only as sick as your secrets,' right? I'll never forget when [name removed] said this last week."

HEART served as a space for open exchange of ideas and beliefs that enable people to process their own experiences and to begin to heal.

Characteristics of Healing Spaces

1. Radical welcome: Like one context expert said:

> *"Welcome is a lifestyle not just a greeting."*

Radical welcome is a practice that acknowledges that people are simultaneously healing and carrying pain, and inviting and embracing the whole person is healing. In moments when content experts hid behind professional roles to avoid sharing aspects of their lives that impact their ability to trust, undesirable characteristics, or fell short of letting go of the need to find quick solutions, context experts modeled patience and acceptance. They welcomed content experts into their most private experiences by telling stories of profound pain from stigma and exclusion by health care institutions. These were humbling lessons for context experts who later collectively identified them as pivotal to their embrace of vulnerability.

2. Vulnerability: In the process of facilitating a meeting, a context expert empathized:

> *"This is a place where we assume good intentions, regardless of how anyone expresses their feelings or shares their stories."*

This statement reflects what undergirds vulnerability within HEART partnership. Practicing vulnerability is practicing courage, honesty and open communication. It requires time and patience. Story-healing sessions provided space for people to get to know each other better and

for content experts to get to the point where they could reciprocate vulnerability. Indeed, during one story-healing meeting, a physician stated:

> *"I'm extremely appreciative of this space. I feel like some of these sessions are you know, super high highs and some of them super emotional, you know, low lows. For myself and for everyone to be vulnerable enough to share their personal journeys and their challenges, I think is what has made this experience so monumental for me in my life. I feel like a different person after participating in this. I don't know how I would have gotten through anything without this group."*

3. Valuing everyone wholistically: This is the understanding that every individual is more than their histories and the titles, experiences, or identities we perceive as necessary for the partnership. This excerpt describes the experience of one content expert:

> *"It takes me a lot to even accept that I have a disability, that I need help. I've always felt I needed to show this front that I'm strong and okay. I think this group, the stories along the lines of feeling and being enough, being valued for just who you are, not to have to put up this front, all are part of building collective power...... I think being a part of this in a lot of ways has healed, humbled me and empowered me at the same time.*"

Being intentional about acknowledging the multiple levels and layers to all members of the learning community can expose researchers and health professionals to the care, clarity, and healing that they might need.

4. Acknowledging the harm caused in partnerships: We learned that explicitly naming harms is important. Health care professionals acknowledged that:

> *"The health care system was designed to cyclically oppress marginalized folks."*

We identified potentials for oppression within HEART and were intentional about not replicating harmful patterns. For example, given that the participation and stories of community members in these kinds of partnerships can be exploited, we made sure that everyone had control over the extent of their participation and personal stories. Reassurances like this were common:

> *"It's about our stories. It's about how we share them and how we tell them…… it's about you and how you feel. And today you might be having a bad day. Tomorrow you might have an even worse day. But it's still yours to tell and we shouldn't allow no one else to tell you anything or tell you how to express yourself. You know your story is part of your self-care of who you are."*

Health professionals and researchers later acknowledged that they too worried that their stories could be exploited:

> *"Once I understood that I had control about whether and how my story and experiences will be used or shared, it was much easier for me to engage and share. The whole thing reminded me that I have power. I want my story out there to be used so that it can have impact in the community."*

5. Centering knowledge production in lived experiences: This means creating room for individuals with lived experiences to provide leadership around what needs to be done and how it should be done. Health professionals and researchers understood that the implications of their practice and research are based on lived experiences, including theirs. One physician stated that the partnership helped her:

"Practice hearing about people's negative relationships with healthcare and um, not being defensive about that, or not making excuses for their experiences or the system. This has made me a better doctor and an even better person."

Content experts also checked in often with the core team and the general learning community to ensure that the work and any subsequent changes were foremost about addressing issues that were of interest to context experts.

Conclusion

Community engaged partnerships can be spaces where health professionals and researchers build authentic relationships with communities and with each other, and where they experience moments that provide validation and healing. Often, the possibility that marginalized communities can teach, and catalyze and support the healing and well-being of researchers and health professionals is obscured. We learned that healing goes both ways.

The things that are normalized in health care such as dismissing lived experiences of patients, justifying why they may have been treated poorly, and stereotyping them based on stigmatizing health and social conditions do not only prevent health professionals from seeing patients as people who are valued and whole. They also prevent professionals from acknowledging their own full selves as valid and whole, leading content experts to evaluate their own value and contributions to community partnerships purely on their professional roles. This likely makes it harder to develop authentic relationships that are necessary for CBRP efforts to be successful.

In future partnerships that take on health equity as a priority, we will intentionally cultivate healing spaces to identify and address the things we normalize that continue to cause harm. We will practice vulnerability, look where we have trained ourselves and each other to look away, and sit in discomfort without expecting closure, knowing that these actions are needed for collective healing and for building collective power.

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Table 1: Application of the Nine Principles of Good Community Health Partnerships

Principle	Evidence of Application
1.Recognizes community as a unit of identity	HEART centered context experts: people with specific stigmatizing conditions —with experiences of homelessness, addiction, and/or with a history of incarceration.
2.Builds on strengths and resources within the community	The work would not have existed without context experts' knowledge that informed design, their influence and strong connections with marginalized groups, their lived experience expertise about incarceration, homelessness and addiction, their knowledge of utilizing health care and other health-related social services, their knowledge about what works for them, and their time and skills such as relationship building, deep listening, patience, empathy and tireless advocacy.
3.Facilitates collaborative partnerships in all phases of the research	HEART built on existing relationships to explore ideas, write the proposal and grant application, design, implementation, evaluation, analysis and dissemination approaches. These were all collaborative. Decisions were made collectively.
4.Integrates knowledge and action for mutual benefit of all partners	Key activities of HEART were grounded in the production, exchange and application of knowledge in ways that benefit all partners. Story healing and health equity webinars enabled partners to connect to their own purpose and to each other. In action groups, everyone shared and co-created skills for leading, planning and implementing change.
5.Promotes a co-learning and empowering process that attends to social inequalities	We focused on collective learning, healing and power. Each context and content expert had at least one turn to facilitate a HEART gathering, or a portion of the gathering. Everyone belonged to at least one action group. We constantly had conversations about inequalities, encouraged and created processes where some participants stepped into power and where others relinquished power. Agendas for each meeting were set by the core team that included one dedicated context expert and others with context expert experiences. Meeting agendas were flexible, depending on interest of the larger learning community.
6.Involves a cyclical and iterative process	Planning, implementation and evaluation were ongoing. The core team met weekly. Evaluation team with context experts met twice a month. The entire learning community meetings that were held twice a month (health equity discussion and story healing) incorporated the collection of feedback for process improvement discussions and decisions.
7.Addresses health from both positive and ecological perspectives	Partners represented distinct sectors. HEART created formal processes to address health from different perspectives: diverse personal and life course experiences, policies and systems. Health equity webinars specifically tackled social determinants of health.
8.Disseminates findings and knowledge gained to all partners	All partners were involved member-checking. All data and findings belong to all partners. All partners made decisions about ways to disseminate findings and knowledge gained. Action group activities also a part of dissemination.
9.Establish a long-term commitment to the process.	Partners have been committed to the work for years, doing it without support. Content and context experts were recruited in part because of their long-term commitment to the goals of the partnership. The personal and collective benefits of healing from participation, as well as the establishment of action groups facilitated long term commitment.