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Bringing Lived Experience to Research on Health and Homelessness: Perspectives of Researchers and Lived Experience Partners

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Abstract

Improving health and healthcare for people experiencing homelessness (PEH) has become a national research priority. It is critical for research related to homelessness to be guided by input from PEH themselves. We are a group of researchers and individuals who have personally experienced homelessness collaborating on a study focused on homelessness and housing. In this *Fresh Focus*, we describe our partnership, lessons learned from our work together, what we have gained from our collaboration, and considerations for future homelessness research-lived experience partnerships.

Keywords Homelessness · Patient engagement · Patient-centered research · Research methods

Background

Homelessness is a growing social and public health crisis in the United States (U.S.), as approximately 580,000 individuals experienced homelessness on a given night in 2020 (U.S. Department of Housing and Urban Development,

2021). Compared to their housed counterparts, people experiencing homelessness (PEH) have elevated risk for serious health problems such as infectious disease (National Health Care for the Homeless Council – NHCH, 2019; Zlotnick, & Zerger, 2009; Zlotnick et al., 2013), behavioral health disorders (Fazel et al., 2008; Greenberg & Rosenheck, 2010;

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Zlotnick & Zerger, 2009), and multimorbidities (Vickery et al., 2021). Furthermore, the material hardships of homelessness accelerate aging, leading to the onset of geriatric conditions and medical conditions more typical of individuals 10–20 years older (Adams et al., 2007; Brown et al., 2012; Gelberg et al., 1990).

These issues are compounded by the fact that homelessness brings about significant barriers to consistent quality healthcare (Baggett et al., 2010; Zlotnick et al., 2013). Most PEH lack access to routine basic medical and behavioral services, and stigma and discrimination decrease treatment quality on the rare occasions they receive care (Baggett et al., 2010; Gilmer & Buccieri 2020; Jones et al., 2017; Jones et al., 2018; Mejia-Lancheros et al., 2020). The combination of increased risk, low access to services, and poor care quality has dire consequences. On average, individuals experiencing homelessness die 12 years younger than the rest of the U.S. population (NHCH, 2019).

The crisis of homelessness and health has spurred action, with the U.S. National Institutes of Health (2022) reporting that it is currently spending over \$195 million to support 191 research projects related to homelessness as of August 2022, and other funders investing significantly in research on healthcare and homelessness. For this research to be impactful, it needs to be rooted in a solid understanding of the practical challenges homelessness brings. Basic necessities that are often taken for granted in the industrialized world—physical safety, private restrooms, and access to hygienic supplies, medication, food, and water—are rare luxuries when experiencing homelessness. Public responses to homelessness exacerbate these challenges. Ordinances prohibiting sleeping, resting, eating, panhandling, or sitting in public places lead to a de-facto criminalization of homelessness, causing constant stress and dislocation for PEH (Robinson, 2019; Tars, 2021). Forced evictions and law enforcement sweeps of encampments and tent communities frequently result in the loss or destruction of the few possessions PEH own (Tars, 2021). The impacts that these harsh realities have on well-being and ability to access services need to be incorporated into research on health and healthcare for populations experiencing homelessness.

Research on homelessness also needs to account for contextual factors that may inhibit participation in studies. Increasingly research utilizes digital platforms to collect data, but many PEH lack reliable access to the equipment or data plans needed to engage consistently as research participants (Humphry, 2019). Individuals living in encampments, shelters, and other congregate settings also lack privacy or quiet spaces needed to complete surveys and interviews. These factors are exacerbated by the fact that many studies do not recruit PEH directly, instead partnering with other homeless-interfacing institutions (e.g. housing programs,

social service programs) to find and engage participants (Gordon, Baker, & Steffens, 2022). Many of these institutions have failed individuals experiencing homelessness in the past (Hoolachan, 2016; Woodhall-Melnik et al., 2018; Woodhall-Melnik et al., 2022), and studies' association with them may compromise their trustworthiness in the eyes of potential participants, causing downstream problems for study recruitment, retention, and data quality.

In sum, research on homelessness and health is complex and nuanced, and researchers need to consider the aforementioned issues in all phases of study design and implementation. One way to do this is to engage people who have lived experience with homelessness as research partners (Franco et al., 2021; Kiser & Hulton 2018; Fletcher et al., 2022). Across healthcare and health services research, partnership with people with lived experience can contribute to the development of questions and outcomes that are more meaningful to patients and caregivers, and it is associated with higher levels of study enrollment and participant retention (Forsythe et al., 2019). With growing awareness of the importance of stakeholder partnership in research studies, funding agencies such as the National Institutes of Health and the Patient-Centered Outcomes Research Institute (PCORI) are increasingly providing research support to studies that rigorously incorporate stakeholder partnerships (Baker, 2022; Selby et al., 2012). In this paper, we—a group of homelessness researchers and individuals who have personally experienced homelessness—describe early phases of a study on homelessness and housing has brought us together. We share perspectives on what we have learned from our collaboration, what we have gained from our partnership, and lay out considerations for future efforts to integrate lived experience into research on homelessness.

Lived Experience and the Person-Centered Housing Options, Outcomes, Services, & Environment (PCHOOSE) Study

We formed our partnership to guide the Person-Centered Housing Options, Outcomes, Services, & Environment (PCHOOSE) study, a mixed-methods project examining the comparative effectiveness of different permanent supportive housing (PSH) configurations in improving housing, health, well-being, mental health, substance use, and healthcare utilization during the COVID-19 pandemic. The two models being studied are place-based PSH, which houses individuals in congregate settings where most residents are transitioning out of homelessness and supportive services are delivered onsite, and scattered-site PSH, which houses participants in apartments rented from private landlords and provides mobile case management services.

Our core investigative team consists of ten researchers from multiple disciplines, none of whom have personally experienced homelessness. To bring perspectives of individuals who have experienced homelessness and received housing services such as PSH to the project, the researchers organized a Lived Experience Group (LEG), consisting of eleven individuals with homelessness histories who have gone through the process of attaining and maintaining housing. LEG members were identified and recruited through pre-existing relationships that study investigators had with them from other projects and collaborations. Approximately half of LEG members (6/11) identify as male, and the majority of them (8/11) identify as Black or African American. The mean age of LEG members is 49 years old ($SD=15$), and on average, they experienced 13.6 years of homelessness ($SD=11.9$). LEG members are compensated for their time and expertise at the same rate as other project advisors and stakeholders (e.g. homelessness service advocates, policymakers, subject matter experts) who have been hired as study consultants.

We convene in meetings that bring together our core investigative team and our LEG roughly five times per year. LEG meetings occur on Zoom and generally last between 90 and 120 min. There have been twelve LEG meetings since July 2021. A member of the investigative team facilitates LEG meetings with support from other members of the research team. We organize LEG meetings around several principles of Community-Based Participatory Research (CBPR), including openness to influence from LEG members who do not have formal research training and recognition that LEG members' strengths, resources, and experiences are invaluable assets for the research team (Israel et al., 2017; Wells et al., 2006). As described below, researchers made many decisions concerning study design and implementation based on recommendations from LEG members given their intimate, real-world knowledge of homelessness, the housing process, and mistrust PEH may have of researchers and the research process. Acknowledging the structural disparities and inequalities between professional researchers and LEG members, the facilitator explicitly focuses on emphasizing and empowering the knowledge and expertise of LEG members, and making them equal partners in group discussions. Issues of race, ethnicity, and class often emerge during meetings, and both researchers and LEG members all discuss their own experiences, prejudices, and assumptions during meetings (Israel et al., 2017). To encourage honesty and trust, the group facilitator checks in with LEG members between meetings through surveys and one-to-one correspondence, eliciting feedback on how they feel about group meetings and ways that they could be improved.

The results presented below are a summary of how we have experienced this collaboration. The lead author—who

is also the LEG group facilitator—wrote an outline of this summary based on detailed notes other team members took during LEG meetings, his own recollections of LEG discussions, and input he received from LEG members themselves. He then verified the trustworthiness of the notes and his interpretation of them through member-checking, having other investigators and LEG members review findings, and discuss them during a LEG meeting (Candela, 2019; Thomas, 2017). Next, LEG members shared their perspectives on the study and their experience with the lead author over email. The lead author analyzed respondent emails using content analysis (Hsieh & Shannon, 2005), produced an outline summary of key themes and results that used direct quotes from LEG participants' emails, and verified them through member-checking. All members of the core investigative team and the LEG are co-authors on this paper, and we all agree that the summary below is an accurate reflection of our experience and perspectives.

What We Have Learned So Far

We have learned that partnering with individuals who have personally experienced homelessness can enhance many phases of the research process, particularly ones that are challenging for scholars. For example, developing and implementing effective recruitment and retention strategies has historically been difficult in research on homelessness (Becker et al., 2014; North et al., 2012; Strehlau et al., 2017). When the researchers in our group asked LEG members how to address recruitment challenges, LEG members suggested that the study could be made more appealing if individuals who have personally experienced homelessness introduce the research and explain why it is important to potential participants. To do this, we created informational videos where LEG members introduced themselves, discussed their personal histories of homelessness, presented an overview of the study, explained why they believe the study is important, and emphasized that joining the study was a way for participants to make their voices heard. These videos were posted on the study's webpage to help publicize the project. To help boost retention, LEG members provided the investigative team with input on how to use study funds to compensate participants after they took monthly surveys, and project researchers used these insights to design an incentive schedule that helped the study reach target follow-up rates.

LEG members have also contributed key insights that have helped the investigative team consider new perspectives when interpreting data and adjust its qualitative data collection and analysis plans accordingly. For example, when early quantitative data showed lower-than-expected rates of substance use among the study sample, LEG

members suggested that study participants—all of whom had recently received PSH placements—could be underreporting substance use because they feared that if they disclosed alcohol or drug use the information could be used as “evidence” that could jeopardize their newly-secured housing. Based on this input, the study is emphasizing the confidentiality of all study data when asking participants about substance use, and considering the possibility that fear of disclosing substance use could be influencing the trends observed in quantitative and qualitative data. When investigators shared early data about health service utilization, LEG members helped contextualize findings by highlighting that many respondents may have reported about mental health and substance use services—not primary care—in response to this question. The LEG members in our group explained that this is because for many PEH, the first thing that comes to mind when asked about “healthcare” is behavioral healthcare, since they see mental health and substance use service providers for groups, counseling, and medication regularly, but they only see physical healthcare providers when they are sick or injured. Based on these insights, the investigative team has supplemented qualitative semi-structured interview scripts and the accompanying analytic plan to be mindful that participants may define “healthcare” differently from the research team.

In one case, our LEG member insights contributed to the addition of new methodological approaches to the project. When the investigative team presented initial quantitative findings concerning social activity, it shared the information by highlighting differences and similarities among participants in different types of housing programs (place-based, scattered-site) since that was the focus of the original study. After hearing this analysis, LEG members highlighted that for many individuals in PSH, the perceived safety of the neighborhood and attractiveness of amenities available to them (e.g. shopping, parks)—not just the type of housing itself—could account for observed differences in social activity. Based largely on this insight, study investigators adjusted the qualitative data collection and analysis plans, supplementing traditional semi-structured interviews with recently-housed participants with photo-elicitation interviews (PEIs - Clark-Ibanez, 2004; Padgett, Smith, Derejko, Henwood, & Tiderington, 2013). In our PEIs, participants are asked take photos that they believe capture the essence of their daily lives on study-issued cell phones (which they already had been issued to take surveys) and share them with qualitative interviewers, who then use them as prompts to start conversations about participants’ neighborhood and day-to-day activities. In addition to using PEI to facilitate interviews, the investigative team will also use the images themselves as a form of data (Richard & Lahman, 2015) that

it will analyze, interpret, and integrate with other quantitative and qualitative data.

While helping the study add new dimensions to the study, LEG input has also kept the research team from pursuing activities that could have potentially undermined project success. When thinking about how to better capture information about how PSH spend their time, the investigative team considered adding a supplement to the study where a subset of participants would be given an option to have their study-issued phones’ geolocation data tracking activated and share location information with the project. When presented with this idea, LEG members strongly opposed it for several reasons. First, they expressed concern that for individuals who were survivors of abuse, the idea of geographic tracking could trigger a post-traumatic stress response or cause serious emotional distress. Second, LEG members highlighted that many PEH and recently housed individuals are highly concerned about surveillance and tracking, so the collection of such data could be seen as an inappropriate and suspicious invasion of privacy. When researchers on the team explained that they would inform participants that this information would be secure and used only by the study team, LEG members maintained that even so, proposing the idea could have negative impacts on the study. Many LEG members cautioned that PEH often feel “misled” by researchers after they complete studies because they are told that their participation will lead to improved services, but they rarely see substantive change. By adding a potentially troubling “ask” to the research project after initially enrolling participants only to collect information about health and quality of life information, LEG members felt that the study could come across as doing a “bait and switch” with participants, thus irrevocably compromising their trust in the study and potentially jeopardizing retention. Based on this input, the research team opted not to go back to participants to obtain additional consent to add the geo-tracking component to data collection after the study had already started.

What We Have Gained from Our Partnership

The researchers among us, while we had been highly cognizant of the challenges PEH face before, have gained a deeper understanding of what our LEG members term “the realism of homelessness, from real people” and the perspectives of “front-line soldiers who’ve lived and survived in that world (of homelessness)” through our collaboration. Getting to know the stories of misery, hardship, resilience, and recovery from LEG members with whom we have developed strong working relationships has added emotional depth and nuance to our understandings of individuals’ journeys through homelessness. Moreover, partnering

with people with lived experience—and not just collecting data from them—has forced us to consider the perspectives of our participants first and foremost as we have designed and implemented the study. Consequently, we have taken information that is, as one LEG member writes, “very often overlooked or not seen as valid” seriously, and proactively tailored the study to be as cognizant of and responsive to the realities of homelessness as possible.

For the LEG members among us, collaborating with researchers has been an avenue for healing and empowerment. While LEG meetings are not specifically designed to be therapeutic, having a forum where we get to discuss some of our darkest and most vulnerable experiences from the past in a safe space bring us senses of emotional wellness and belonging. Using our past pain to help improve knowledge about homelessness and alleviate the suffering of our unsheltered and recently-housed neighbors makes us feel good, and that we are making a difference. For some of us, this research is one of the first opportunities we have had to contribute to something positive by making our voices heard. We also recognize that through this collaboration, we speak not only for ourselves, but for all of the people who are still suffering on the streets. We are empowered by the fact that when we contribute to this group and to research, and we are speaking for all of those who are suffering, but who have not yet found their voices or had a chance to be heard.

Considerations for Future Collaboration

Though our collaboration has been highly beneficial, we also recognize ways that future researcher-lived experience collaborative studies on homelessness and housing could be improved. First, the main question of our study—what is the comparative effectiveness of place-based and scattered-site housing—was generated by researchers based largely on a literature review. All of the LEG contributions discussed above occurred within the confines of a study that was already conceptualized by researchers who have not personally experienced homelessness, and chosen for funding by a scientific review committee that was likely mostly composed of individuals who had not experienced homelessness. If individuals with lived experience had played a more substantive role in conceptualizing our study, we may have designed it to better capture issues that LEG members believe are crucially important (such as the neighborhoods of PSH placements, and not just their configurations) from its outset. However, there are significant barriers—lack of resources to support the time of LEG members for conceptualizing studies that are not yet funded, not having the training and experience needed to design robust research

projects, and unfamiliarity with the peer-review process among them—that make it difficult to meaningfully involve PEH in the development of research ideas. There are ways that future projects can address this issue. CBPR provides a roadmap that researchers can use to partner with community members—including those who have experienced homelessness—to develop research questions that address the community’s priorities, and not just those of researchers and scientific review boards (Fletcher et al., 2022; Forsythe et al., 2019; Franco et al., 2021; Israel et al., 2017; Kiser & Hulton 2018; Selby et al., 2012; Wells et al., 2006; Woodhall-Melnik et al., 2018; Woodhall-Melnik et al., 2022). The LEG group facilitator recently received funding to implement the Stakeholder Engagement in question Development and prioritization (SEED) method—an approach that combines CBPR principles with scientific reviews of available evidence to develop rigorous, community-driven ideas for research (Rafie et al., 2019; Zimmerman 2017; Zimmerman & Cook, 2017; Zimmerman et al., 2020)—in collaboration with the LEG. Our hope is that this new project will continue bringing the benefits of CBPR to research on homelessness in the community, similar to how the U.S. Department of Veterans Affairs (VA) health system has been implementing CBPR with veterans who have experienced homelessness (Fletcher et al., 2022).

A second consideration for future collaboration is that our lived experience partners likely differ from much of the population experiencing homelessness in significant ways. In large part, this is because our LEG was formed by researchers who recruited members through pre-existing networks they had. Consequently, most LEG members have previously been involved in activities—such as volunteering for research projects, speaking at conferences, or working as peer advocates in PSH programs—that are not typically pursued by most people who experience homelessness. Many individuals exiting homelessness continue to experience a lack of meaningful activity and social integration, (Harris et al., 2019; Hawkins & Abrams, 2007; Pilla & Park-Taylor, 2022), and it is likely that that our LEG members are more active and engaged in their community than most people who are experiencing homelessness or transitioning to housing. Furthermore, in our study, lived experience contributions were confined to the perspectives of people who had *previously* experienced homelessness. No LEG members are *currently* unhoused, so their lived experience contributions of the LEG are based on retrospection—memory of the experience of homelessness in the past. The homelessness experience of LEG members is somewhat distal, with some individuals having been housed for over five years, so their understanding of homelessness could differ substantively from homelessness as it is today due to changes in the economy, society, and housing policy. If the

LEG included people who are currently experiencing homelessness and/or received housing placements more recently, it could have potentially offered a different perspective to the project.

However, it is not clear if advising a research group would be a priority, or feasible, for people currently experiencing homelessness or who have been recently housed. The instability of being unhoused and logistical issues that often intersect with homelessness (e.g. lack of communication devices, transportation challenges, participation in residential behavioral health programs) make it difficult for PEH to engage with research teams and sustain these relationships (Fletcher et al., 2022). The same material and contextual factors that can affect their health and research participation also inhibit participation in academic-community collaborations. Furthermore, for most PEH, exiting homelessness and meeting basic needs for survival are pressing priorities, leaving them with little time or mental energy to dedicate to research (Fletcher et al., 2022). Even when partnering with people who had experienced homelessness but are currently housed this is an issue since individuals exiting homelessness tend to be under-employed and still struggle financially (Poremski et al., 2016). Several ongoing initiatives, including efforts being spearheaded by the National Health Care for the Homeless Council (National Health Care for the Homeless Council, 2022) and the VA (Fletcher et al., 2022), include individuals who are currently unhoused as research stakeholders. However, some of these efforts have encountered significant obstacles sustaining partnerships (Fletcher et al., 2022). Further research is needed to identify effective strategies and best practices not only for bringing people currently experiencing homelessness into research partnerships, but also to sustain these relationships.

It is notable that beyond improving the study, the LEG members among us have found partnership with researchers to be healing and empowering on a personal level. Homelessness can lead to experiences of trauma, marginalization, dehumanization, and exclusion (Hamilton et al., 2011; Magwood et al., 2019; Tsai et al., 2020), and activities that support empowerment, resilience, and a sense of personal mastery help facilitate the process of healing and recovery during the transition out of homelessness (Magwood et al., 2019; Manning & Greenwood 2019). The personal fulfillment and sense of meaning LEG members are deriving from this research partnership highlights how having individuals with lived experience join research teams can advance not only research, but also the process of healing and growth for PEH themselves. Finding purpose (conducting meaningful daily activities) and community (having relationships and social networks that provide support, friendship, love, and hope) are key dimensions of recovery (SAMHSA, 2023), and based on our experience, it seems that research partnerships

can foster both. Future documentation of PEH's experience in research partnerships, and its contributions to their senses of purpose and fulfillment, can help develop understanding of the role that partnering in research on homelessness can have for individuals who have experienced homelessness as they proceed on their own recovery journeys. At the same time, the limitations of research collaborations also need to be considered and better understood.

Conclusion

The Person-Centered Housing Options, Outcomes, Services, & Environment (PCHOOSE) study has benefited tremendously from the input of individuals who have lived experience with homelessness, underscoring the importance of bringing their voices to research. Our experience has shown how partnering with PEH can help investigators conduct research that is better informed by and aligned with the real-world experience of homelessness. At the same time, partnering with researchers seems to provide individuals with lived experience with opportunities for healing and empowerment, furthering their recovery from homelessness. Though these partnerships require a significant investment of time and resources, they can be critical to ensuring that research generates knowledge that improves clinical practice and policy, and contributes to the broader goal of improving the lives of individuals impacted by our nation's homelessness crisis.

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