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Addressing Chronic Disease Within Supportive Housing Programs

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Abstract

Background—Tenants of supportive housing have a high burden of chronic health conditions.

Objectives—To examine the feasibility of developing a tenant-involved health promotion initiative within a “housing first” agency using a community-based participatory research (CBPR) framework.

Methods—Qualitative analyses of nine research capacity-building group meetings and fifteen individual pre- and post-interviews with those who completed a chronic disease self-management program, resulting in the development of several themes.

Results—Tenants of supportive housing successfully partnered with health care providers to implement a chronic disease self-management program, noting that “health care becomes ‘relevant’ with housing.”

Conclusions—Supportive housing organizations are well-situated to implement health promotion initiatives. Such publicly subsidized housing that is accompanied by comprehensive supports must also include self-management training to help people overcome both internal and external barriers to addressing chronic health needs.

Keywords

Homeless persons; health care disparities; housing; community-based participatory research

Homelessness is a complex social problem; publicly subsidized, affordable housing is fundamental to its solution.[1] Approaches to public housing can vary from large-scale housing developments to direct subsidies for individuals to be used in the private housing market, such as the Section 8 program.[2] Recognizing that individuals with psychiatric disabilities who are homeless need both publicly subsidized housing and supports, the Department of Housing and Urban Development developed Shelter Plus Care. This program provides rental assistance subsidies for housing with a requirement that the local community

match the dollar value of the rental assistance with an equal or greater amount of supportive services, which may be funded through public and private resources.[3]

Pathways' Housing First (PHF) is an evidence-based practice for individuals experiencing homelessness and co-occurring serious mental illness and addiction[4] that is funded by programs such as Shelter Plus Care. PHF programs provide immediate access to publicly subsidized housing rented from private landlords along with flexible supports designed specifically for individuals with serious mental illness who are living in the community.[5] Housing is considered "scattered site," meaning that apartments are located throughout the community based on affordability and tenant preference. Tenants are expected to pay 30% of their income toward rent (usually in the form of disability benefits), and have the same rights and responsibilities as their nondisabled, lease-holding neighbors. As program participants, tenants also need to engage with support services; however, the intensity of services is based on individual need.[6,7] A Housing First approach that combines housing and support services has led to significant advancements in ending homelessness among persons with serious mental illness.[8]

Despite public health research that demonstrates how poor-quality housing is associated with chronic illnesses, infectious diseases, and injuries, thus prompting efforts to improve housing conditions,[9,10] access to housing for those experiencing homelessness has been generally regarded as a social problem rather than as part of health intervention for this population. Perhaps because it is taken for granted, there is little research about the impact of housing on health outcomes and how to best address the significant health disparities experienced by the population described as "chronically homeless," whose mortality rates are three to four times higher than the general public.[11] Many people who are able to transition from homelessness to housing continue to face considerable challenges, one of the foremost being living with chronic health conditions.[12] For individuals who have experienced both homelessness and serious mental illness, integrating physical health care with ongoing mental health and housing supports is critical[13]; however, individuals must ultimately play a role in self-managing their multiple chronic health conditions.[14,15]

This paper describes a CBPR project consisting of two phases. The first phase was a prolonged team-building exercise to engage PHF participants in the project and build a partnership between tenants and health care professionals. The second phase directly addressed the chronic disease burden of tenants through implementation of the 6-week Stanford Chronic Disease Self-Management Program (CDSMP). Based on the experience and perspectives of tenants who participated in the project, we examined the feasibility of implementing a tenant-involved health promotion initiative within a Housing First setting. The study addresses the following questions: (1) What are the facilitators and barriers for people who have experienced homelessness to self-managing their care? (2) What activities engage people who have experienced homelessness in self-managing their care? (3) Does the Stanford CDSMP meet the needs of people who have experienced homelessness?

METHODS

Background and Recruitment

This project took place at a PHF program office that used the U.S. Department of Housing and Urban Development's Shelter Plus Care program to serve 125 individuals who met the federal definition of chronic homelessness and had an axis I diagnosis of serious mental illness. To address the challenge of engaging tenants in health services[5] and to facilitate their ability and interest in becoming more involved in their own care, the project adopted a CBPR framework[16] divided into two phases. During Phase 1, ten tenants were recruited via a flyer advertising a “health care project” focused on barriers and facilitators of healthier lifestyle choices to form a small workgroup and participate in team building. Because the first ten tenants who responded were men, an eleventh member who was female was also included. This subgroup overrepresented men, who constituted 60% of the overall tenant population in the program. These tenants formed a workgroup along with the program's clinical director, a primary care physician affiliated with the program, and an outside group facilitator who had a doctoral degree in social work and expertise in CBPR methodology.

The two provider–participants (the clinical director and physician) had initially proposed and acquired funding to conduct the study's nine group sessions, but the specifics of the study design were purposely left open to be determined by group consensus. The provider participants also described the intent of the study at the first meeting—that is, to better understand how tenants make health-related decisions to implement a health promotion initiative—and made clear that the tenant group members were expected to determine the ongoing agenda and shape the inquiry process. With guidance from the group facilitator, tenant group members determined the following procedures through consensus for the nine consecutive weekly meetings, which lasted 2 hours each: (1) Meet each week to brainstorm topics, starting with “what is good health?”, (2) record group discussions using audiotapes, notes, and meeting minutes, (3) review the content of each week's discussion to identify important themes and develop new ideas for inquiry, and (4) discuss appropriate next steps and outcomes from the project. The nine group meetings took place at the PHF program office, were audiorecorded, and were transcribed verbatim.

Based on this successful team-building exercise (as evidenced by ongoing tenant attendance, weekly tenant involvement, and tenant requests to continue working together), the ten male tenants agreed to participate in and evaluate the 6-week Stanford CDSMP for men's health promotion, which constituted Phase 2 of the project. The decision to include only male tenants in Phase 2 was based on the recognition by all group members that men and women have different health issues and that gender-specific groups may facilitate discussion of these issues. The Stanford model, which is perhaps the most well-studied self-management program in the United States,[17] addresses common and disease-specific factors across chronic health conditions through regular action planning and feedback, modeling of behaviors and problem-solving skills, and identification and reinterpretations of symptoms. Classes are interactive and include the development of personal action plans that outline healthy lifestyle activities to be attempted each week, with participants reporting back to the

group. The intervention has been standardized with facilitator trainings and a manual, as well as participant workbooks used each week and as an ongoing reference.[18]

The model was selected based on research showing that it can be effective for individuals with serious mental illnesses[16] and is intended to be led by two peer facilitators rather than health professionals. In this case, rather than training tenants to be the peer facilitators, which would have delayed the project and introduced issues of tenant nomination and selection, outside facilitators from a local community-based organization agreed to conduct the 6-week program at the Housing First program office. These facilitators, who were considered to be peers based solely on living with chronic physical health conditions, had previously implemented the CDSMP at a senior center serving older African Americans.[19] Based on their recommendation, the program was open to fifteen male tenants, which included those involved in the first phase plus several tenants who had inquired about the project after the first phase had begun. All tenants received a $20 incentive per session for their participation, including the nine Phase 1 sessions, the 6-week CDSMP, and two pre- and post-phase interviews. These incentives were consistent with the PHF agency protocols for tenant involvement in research, but also introduced the question of whether and to what extent participation was driven by these incentives. All research protocols were approved by multiple affiliated institutional review boards.

Data Collection Procedures

In addition to group transcripts derived from Phase 1, individual pre- and post-phase semistructured interviews were conducted during Phase 2 with the fifteen male participants by clinical researchers affiliated with the program. The goal of these interviews was to assess the receptivity of tenants to the CDSMP, both for themselves and other program participants. Baseline questions focused on why tenants chose to participate in the program and what they hoped to achieve. Follow-up interview questions addressed how the program affected tenants' lives, whether they would recommend the program to other tenants, and what suggestions they had to improve the program. Interviews lasted an average of 1 hour, and were audio-recorded and transcribed verbatim.

Data Analysis

After Phase 1, the provider–participants met with the tenants as a group to discuss the nature of qualitative analysis and the process of coding transcripts. Using an inductive approach, participants developed several codes related to varying definitions of health, the nature of transitioning from homelessness, and factors that influence health-related decisions based on ideas that emerged during the team-building meetings. The two provider–participants and six tenants then template-coded[20] Phase 1 transcripts using these developed codes. Passages of text "earned" their way into thematic development[21] through identification by at least three coders, with priority given to those sections most frequently identified by the eight coders. Individual interviews were reviewed and coded by the first two authors only because consent forms indicated that these interviews would not be shared outside of the researchers identified in the institutional review board application.

Based on constant comparative analysis[22] of the coded materials that pertained to the feasibility of conducting a tenant-involved health promotion initiative, general themes were developed and presented to the tenant group members for validation. This took place before and after Phase 2, when the provider participants met with tenants as a group to present themes. Tenants mostly validated the themes, although some clarifying phrases or sentences were added. An example included in the themes below was the need to clarify that good health was never irrelevant, as an initial theme suggested, but that "experiencing homelessness implied other competing priorities related to immediate survival." Validation and member checking of the themes also occurred when this group of providers and tenants prepared to present the project to audiences at local and national conferences related to health care.

Several strategies for rigor in qualitative methods were employed, including prolonged engagement, peer debriefing, and member checking during the data collection and analytic processes; independent coding of transcripts; and memo writing to aid the development of ideas and provide a decisional audit trail.[21]

RESULTS

Implementing a tenant-involved health promotion initiative within a Housing First setting was determined to be feasible, although several important lessons were learned. These lessons are presented within the following five themes (see Table 1 for illustrative quotes) arranged according to study questions.

(1a) What Are Facilitators to People Who Have Experienced Homelessness in Managing Their Care?

Health care becomes "relevant" with housing. Tenants described how having a place to live fundamentally changed their outlook on both health and health care. Participants reflected that when living on the streets, the primary goal was survival. Within that context, they framed their understanding of health:

> I knew that that wasn't a place that I wanted to be, but I tried to be like, 'It's what I have to do now.' The 'so what' attitude. Or, I'm gonna just survive. So, that was good health to me as far as I was concerned.

It was not that good health was ever truly irrelevant, but that experiencing homelessness involved other competing priorities related to immediate survival: Staying safe, eating, and sleeping.

Once participants received housing, the ability to reorient their priorities from survival to more typical daily activities opened up new choices and opportunities related to being healthy and accessing care. Some of the benefits related to housing were simply logistical, although nonetheless profound; their apartment provided a stable base from which to manage their health care, such as having a place to keep track of appointments and store medications. Housing provided both the means and motivation for pursuing better health. As one tenant put it, "You get in that bed, you start pursuing those things because it's relevant." The changing priorities of tenants, once housed, implied that access to housing acts as a

health intervention, reorienting daily decisions to include health concerns and enabling the pursuit of improved health. It should be noted that housing is only a first step.

This theme demonstrates that rather than thinking of supportive housing as a venue for health promotion initiatives, more attention should be paid to supportive housing itself as way to promote health. This finding resulted in the development of a multimedia video production by the project group that has been presented at several local, regional, and national conferences, and was competitively selected and broadcasted on a local television network highlighting local filmmakers.[23] The main message of the video (which can be accessed at http://www.youtube.com/watch?v=3VNZGEpuKBY) is that housing should be the first line of intervention when addressing the health care needs of people experiencing homelessness, because it has the potential to profoundly change how people perceive their health care priorities. Additionally, the video notes that access to health care may have a limited impact on the health of individuals experiencing homelessness, except in the case of painful, life-threatening conditions.

(1b) What Are Barriers to People Who Have Experienced Homelessness in Managing Their Care?

Internal and external factors constrain healthier living. Once they received housing and were able to address health issues, participants described a realization that there were many problems that had gone untreated. One participant explained:

> I believe that now, ‘Oh, I excelled. I got better health now.’ Only for me to start physically on focusing in on all the physical. ‘My back hurts, my leg, I gotta get my knee done. I gotta get my foot operated on. I gotta get my neck done. I gotta get this ear removed.’ And I had this shit for years—20, 30 years. But all of a sudden now the physical became more important.

Years of experiencing chronic, deteriorating conditions while on the streets had taken its toll, with one tenant describing the lingering effects of life of the streets: “I'm in pain and sick almost every day. Good health doesn't even reach me.”

Some attributed delays in addressing their physical health to their mental health symptoms, particularly depression or a lack of motivation to change habitual patterns. Others focused more on dealing with external constraints, such as difficulty navigating a complicated health system. Even obtaining health insurance presented new problems for tenants who attempted to find providers that would take their specific Medicaid or Medicare plan. One tenant expressed, “You gotta search and look and get a referral and get somebody else to sign on it. It's like, ‘damn.’”

Both external and internal barriers meant that improving one's health, even with housing, was not easy; however, one tenant stated that housing made it possible: “With the trying to get to healthy, when you're doing it the right way and aren't in the streets. It's a long process.” This theme demonstrates that, although tenants’ personal choices and behaviors impacted their health, external and systemic obstacles existed despite their efforts to make healthier decisions.

(2) How Do You Engage People in Self-Managing Their Care?

Importance of Meeting Basic Needs—As noted, public hous ing can serve as an important health intervention to address the needs of those with histories of homelessness and unstable housing, because tenants' perception and attitudes toward health are shaped primarily by their housing status, a consistent theme throughout both phases of the project. In addition to providing a location to store needed medication, an apartment also afforded people a greater ability to organize and keep appointments. During Phase 1, absences from group sessions rarely occurred (there were fewer than five occasions when a person missed a session), and more than half of those who participated in the CDSMP attended at least five of the six weekly sessions. Providing public transportation tokens to tenants was identified as important, given their limited income.

A Process of Participation and Activation—One of the main findings of this project was that tenants, even those considered most vulnerable, can engage in sustained partnerships, including research endeavors, if given adequate time and input, a feature that is often missing from both clinical and research encounters. Recognizing the need for an ongoing process of involvement and negotiation within clinical and research settings was viewed as a necessary step for subsequent efforts to self-manage care. In this case, a core group of tenants continue to be involved in ongoing health promotion and remain supportive of continuing research activities that have a direct impact on their lives. Tenants have engaged in additional activities designed to share the project's findings with a larger audience, including the development of the video referenced. Tenants reported that this process gave them a sense of ownership of the group activities and provided them with a voice. This is consistent with the purpose of CBPR and relevant to empowering people to become actively involved in their own care (i.e., activated patient). In this case, tenants chose to continue working together and engage in the CDSMP.

(3) Does the Stanford CDSMP Meet the Needs of People Who Have Experienced Homelessness?

Tools for Healthier Living—Participants during the CDSMP phase universally agreed that it was helpful in providing tools to better address ongoing health concerns, although it was acknowledged that, "You get out of it what you put in." Some of the participants expressed interest in being trained as a peer facilitator for future groups, and many identified the group format as beneficial: "Again, the sharing is extremely important, that you're not an island alone. You don't have to suffer in pain alone." Sharing a similar background and being with peers was important to the group process: "Uh, we all come in with the same common denominator. We all have pain. We all have some malady that we're gonna share a story about."

By attending weekly meetings and developing ongoing action plans, tenants identified a process of learning new skills and feeling more empowered to address their health and alleviate symptoms. There was a focus on learning about better nutrition; providing accurate information was seen as an important contribution. Equally important was discussion about physical activity specific to the daily routines of participants. Tenants also identified learning to speak with their doctors and stated they became aware that they had choices

within the health system. Nevertheless, tenants determined that more time was needed to jointly discuss the experience of transitioning from homelessness to housing, as well as the complexity of living with ongoing physical and mental health conditions. Extending the length or frequency of the group meetings or increasing participation in a preparatory group such as the one featured in Phase 1 are possible options.

DISCUSSION

Results from this project support integrating the CDSMP within supportive housing organizations. This is consistent with and further supports the key role of housing to promote better care at lower costs for people with multiple health and social needs.[24] Supportive housing provides a unique venue for health promotion because, as these findings indicate, a change in housing status resulted in a revised understanding of what it meant to be healthy. As articulated by tenants, urgent health needs related to survival (such as eating, sleeping, and remaining safe) were replaced by the need to address ongoing health conditions once they received housing.

Although housing was viewed as a necessary condition for engaging in health promotion, it was not seen as sufficient. Within this project, successful implementation of a more structured self-management program depended on building trust and a cohesive group process. This was accomplished in Phase 1, during which tenants had an opportunity to make decisions about the overall project trajectory. This additional meeting time before the self-management program also gave tenants the time to process the complex transition from homelessness, an important step before they could begin addressing their health needs. Tenants suggested that the length of the self-management program should be extended to allow for more processing time, noting that transitioning from homelessness involves a multidimensional process of redefining oneself in relationship to one's environment.

As seen within this project, participatory methods represent a way to engage tenants, an important lesson for other supportive housing programs attempting to promote health and reduce health disparities experienced by their tenants. Moreover, this study demonstrated that tenants can provide valuable insights into the development of holistic health care models for individuals experiencing homelessness and psychiatric disabilities. The endorsement of peer involvement within this group context, for example, is consistent with other promising practices, such as a peer health navigator model, which is intended to complement formal systems integration and promote “activated” health consumers.[25]

Although this project demonstrates that housing programs can serve as an effective venue to implement various health initiatives, including peer-run self-management programs, there remain issues related to feasibility. First, financial incentives were substantial (as much as $340 per participant), which may help to explain participation levels and could be necessary to sustain tenant involvement in other programs. Second, although most tenants acknowledged the benefits of a group approach to addressing chronic disease, there are some health-related issues, including the high prevalence of trauma in this population, that may be better served through one-on-one encounters.[26] Third, this project did not directly address the feasibility of conducting a women's health group, whose participants may be

more impacted by trauma. Last, the peer facilitators in this case were not from supportive housing programs; whether tenants can be trained to successfully facilitate future CDSMP projects remains to be seen.

CONCLUSION

Publicly subsidized housing programs can serve as an effective venue to implement various health initiatives, including peer-run self-management programs. However, such efforts must take into account the housing environment and tenants' individual backgrounds, because histories of homelessness, serious mental illness, and addiction may require a tailored approach.[27] Housing authorities and public housing programs could form partnerships with public health and medical providers as well as tenants to help people overcome the internal and external barriers to addressing health needs and improving the overall health of disadvantaged populations.

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Table 1

Emergent Themes and Illustrative Quotes

Theme	Quote
Health Care Becomes 'Relevant' With Housing	"Like he said, it goes back to priorities. When you're in the streets, it's survival. My back does hurt. My vision's not well. But, right now, they're feeding that 4 o'clock [referring to a food line at a local church]. With my apartment instead of surviving, you get to living. You start prioritizing. I wanna eat, but instead of me buying a pack of cookies, why don't I buy something nutritious. You literally, we got handed like a second chance in life to get back to what god wanted us to do." "I have a place now. I can go home. I have my dresser and 14 vials on there. There's no way I would've walked around the street with my medicine." "I was sick when I was in the streets. You gave me a key, I'm still sick, but I'm in a better position to do something about it. The healing process begins every time you put that key in the door." "I knew that that wasn't a place that I wanted to be, but I tried to be like, 'It's what I have to do now.' The 'so what' attitude. Or, I'm gonna just survive. So, that was good health to me as far as I was concerned." "You get in that bed, you start pursuing those things because it's relevant."
Internal and External Factors Constrain Healthier Living	"Even though I know to get up and keep doing something but, I don't want to. And plus, I'm a little older now, and I just, just ready to ride out. I ain't super excited or nothing, but I just wanna just ride out. I'm tired. I don't like, been through too much stuff, just tired. That's it." "After being diagnosed with the depression, I um, I slumped, it seems like, into another, I don't know, I don't know, some sort of, another world it seems like. You know, it's like I can just sit there and things go on, and I'm gonna do things. It's like a procrastination world, you know. I just procrastinate and nothing happens but time goes by." "You think that when you get a place everything was gonna fall in place. And, it doesn't work that way...Before, there were small hoops to jump through, but now you got more. You gotta get insurance, because now you have a mailing address. You got the phone... It does get a little easier, but it's still the same stuff." "I got the A, B, D, whatever the letters are [referring to Medicare]. And, I found out, I couldn't get a decent pair of eye glasses. So, I had to switch insurance, drop that, pick up this other insurance, get the eye glasses I need, drop that insurance, go back to my insurance." "I believe that now, 'Oh, I excelled. I got better health now.' Only for me to start physically on focusing in on all the physical. 'My back hurts, my leg, I gotta get my knee done. I gotta get my foot operated on. I gotta get my neck done. I gotta get this ear removed.' And, I had this shit for years—20-30 years. But, all of a sudden now the physical became more important." "I'm in pain and sick almost everyday. Good health doesn't even reach me." "You gotta search and look and get a referral and get somebody else to sign on it. It's like, 'damn.'" "With the trying to get to healthy, when you're doing it the right way and aren't in the streets. It's a long process."
Importance of Meeting Basic Needs	"You have a life, but it takes a little a little bit more to live life. And I thank God that I really feel like I'm living life today [with housing]." "Our health has gotten better because we have a place to go, to keep our meds. I make my appointments, I take my meds, I eat better because I have my own food."
A Process of Participation and Activation	"We was treated like human beings. And not like numbers, like on a case study or something. They talked to us like we were human and it made you feel good to be able to express yourself. And then the people that was in the group, most of them I was out on the street with so it made it easier to be able to talk. I saw, all of us know what we went through out there so it was easy to express yourself." "It started, like I say, it started making me go to the doctor more and find out the things that's wrong with me and if I had a situation, then I learned that I could go back and follow up on it. You told me something while I was out on the street, I didn't follow up on nothing I just chased right to the bottle. Now I know that I have to follow up on things in order to get better."
Tools for Healthier Living Can Be Developed	"In the beginning it kinda felt like a classroom. It felt like they're just gonna teach us, you know, until I think a lot of us just finally realized that, you know, we need to participate in this and tell them what we're going through because they have, I don't know the skills, but they have the knowledge of things that you can do." "Um, I learned how to eat better. Now I know I have to eat my three meals a day. I have (to) nourish the body in order to maintain it...Then also in the book, booklet that they gave us, the manual on certain foods that are not as fatty. We had a big debate over which type of bread we should or could be eating." "They'd give me tips on, trying to get to sleep earlier. Uh, then I remember one was my walking regiment and uh, it was suggested that if I walk the same length at the same time every day, at the same pace, that (I'm) not actually working the muscles. So I have to challenge my muscles." "This program really teaches that you can do it yourself, just need the knowledge; and they showed me, yea, you're right, I can do it. Don't be afraid to talk to your doctor, um. I used to be shy about talking to my doctor. Let them do the talking. I figured they know it all. No, not necessarily, I have an agenda. I'm gonna see her Tuesday, I'm gonna have to ask her a few questions. I have a list of questions that I have to ask her." "You get out of it what you put in." "Again, the sharing is extremely important, that you're not an island alone. You don't have to suffer in pain alone." "Uh, we all come in with the same common denominator. We all have pain. We all have some malady that we're gonna share a story about."