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"He Gave Me Spirit and Hope": Client Experiences with the Implementation of Community Health Worker Programs in HIV Care

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Abstract

Community health workers (CHWs) are members of the frontline health workforce who serve as intermediaries between health services and communities. In the United States, the role of CHWs has begun to expand as they have been shown to improve outcomes and reduce inequities in care for chronic conditions. This study used qualitative methods to explore the experiences of clients in CHW programs to inform their implementation in HIV care. Thirty clients from 6 Ryan White HIV/AIDS Program care settings across the United States participated in individual semistructured interviews to learn more about their experiences working with a CHW. Four key themes arose from the client perspective. First, CHWs embodied key qualities. Some of the qualities clients attributed to CHWs included being caring and supportive, along with capable of fostering personal connections. Second, CHWs met clients where they were. Clients described the CHW approach as more holistic compared with other care team members; they emphasized CHWs were able to focus on whatever was needed in that moment. Third, CHWs occupied a unique role in the HIV care team. Clients noted CHWs had more time to dedicate to their interactions; they also saw CHWs as representing a different level of authority. Finally, CHWs influenced how clients engaged with care and accessed resources. This included empowering clients to access resources independently in the future. Overall, clients' perceptions of CHWs in terms of their qualities, approach, role, and influence on the HIV care experience suggest they are a valuable resource on the care team.

Keywords: HIV care, community health workers, peer support, patient experience, qualitative research

Introduction

THERE HAS BEEN progress to date in the proportion of ■ people with HIV (PWH) who are in care and virally suppressed¹; however, inequities persist.^{2,3} Within HIV care in the United States, organizations often hire nonclinical staff

to carry out supportive activities focused on ensuring equity in care access, engagement, and retention.^{4–7} These ancillary staff members have titles such as patient navigator, linkage to care specialist, bridge counselor, outreach worker, promotora, peer counselor, or support specialist. 4,8-10 In international settings, the term community health worker (CHW)

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has typically been used to describe this role. 11-13 A CHW represents "a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served." CHWs serve as intermediaries between health services and the community, and in doing so, can enhance the quality and cultural competence of service delivery. 14

Although CHWs have been utilized in HIV care for over a decade, 15,76 CHW integration in HIV care settings across the United States has been limited. However, CHW programs have received increasing attention as an effective intervention to improve outcomes and reduce inequities in care for chronic conditions, ^{17–19} including HIV. ^{15,16,20,21} In particular, recent studies show a strong but underserved need for patient navigation in the HIV care system, 22 and CHW programs represent a promising intervention to meet this need. Therefore, as CHW programs are increasingly implemented within this field, understanding the experiences of PWH in these programs is essential. Since the relationship between patient and CHW represents a core element of these interventions, exploring the experiences of CHW program clients can help in understanding the mechanisms through which they impact health outcomes.²³

To improve linkage to care and health outcomes for PWH, from 2016 to 2019 the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau funded a project to support the integration of CHWs into Ryan White HIV/AIDS Program (RWHAP) care settings. ²⁴ Ten RWHAP sites across the United States were chosen to implement a CHW program and work toward integrating CHWs into their multidisciplinary care teams. Drawing on data collected for a multisite evaluation of the project, we report on findings from individual interviews with clients in the CHW programs.

Methods

Qualitative methods were used to explore the experiences of clients in CHW programs and their relationships with CHWs in HIV care settings.

Study design and setting

The goals of the overarching project were to: (1) increase the use of CHWs to improve access to and retention in care for PWH, and (2) improve health outcomes through strengthening the HIV care workforce. 21,25 To support integration of CHWs into their organizations, each RWHAP site received training, technical assistance, and coaching, which were guided by a shared implementation guide²⁶ and training curriculum²⁷ (targethiv.org/chw). These project resources incorporated the roles and competencies established by the CHW Core Consensus (C3) Project.²⁸ Training for CHWs across the sites was consistent and included 80 h of content, with two main components: CHW core competencies (64 h) and HIV knowledge base (16h).²⁷ Sites could incorporate their own additional training and supervision, and as an implementation project, each site had the opportunity to tailor their CHW program to their organizational context and needs of their patient population. More description of the overarching project and additional results of the multisite evaluation have been reported elsewhere. 21,25,29

Between March 2019 and June 2019, an evaluation team from Boston University visited each of the RWHAP sites.

These represented a variety of organizational settings funded by HRSA, including federally qualified health centers, AIDS service organizations, city public health departments, and HIV primary care clinics located in academic medical centers. The team conducted individual semistructured interviews with a subsample of program clients at 6 of the 10 sites to learn more about their experiences working with a CHW. Four sites with low client enrollment (<20) were excluded to protect client confidentiality. The included sites enrolled between 24 and 96 clients in their programs and were located in both rural and urban areas in six states (AL, LA, MD, NV, NJ, and NC). ^{21,25}

Recruitment and data collection

Clients were eligible for participation in interviews if they were enrolled in the overall multisite evaluation. Purposive sampling was used to recruit participants for the subsample, and an effort was made to ensure they were representative of the populations served at each site. Demographics for the subsample of interviewees were not collected to protect client confidentiality; however, those of all eligible participants from the sites included in recruitment (n=358) can be seen in Table 1. Further detail regarding the full multisite evaluation sample, as well as overall project recruitment and eligibility, can be seen in Drainoni et al.²¹

Flyers containing contact information for the evaluation team were posted at sites and/or distributed to clients by program staff, including CHWs. Clients interested in participating in the interviews could contact the evaluation team, who answered any questions and scheduled interviews. This recruitment process resulted in a final subsample of 30 clients. There was an average of five participants from each site (range: 4–8) where interviews took place.

The evaluation team developed a guide to conduct individual semistructured interviews focused on clients' experiences working with their CHWs. The full interview guide can be seen in the Supplementary Materials. Evaluation team members trained in qualitative data collection conducted the interviews in either English or Spanish, depending on the preference of participants. Interviews ranged from 30 to 60 min in length. Clients received a \$50 VISA gift card for participating, in accordance with the study protocol. The Institutional Review Boards of the Boston University Charles River Campus and Boston University Medical Center approved all study protocols.

Data analysis

Interviews were audio recorded, uploaded to a secure server, transcribed verbatim, and deidentified in the transcription process. Spanish language interviews were translated into English for analysis. Transcripts were reviewed for accuracy and imported into NVivo Version 12,³⁰ which was used to manage the data and facilitate the coding process. A codebook with a priori codes was initially developed based on theory underlying CHW program interventions and the content of the interview guide, consistent with the approach outlined by DeCuir-Gunby et al.³¹

Example theory-driven a priori codes included: client relationship with the CHW, HIV care experience before and after the program, program impact on areas outside of HIV care, and CHW activities. The evaluation team began with a

TABLE 1. CHARACTERISTICS OF ELIGIBLE PARTICIPANTS ACROSS THE SIX STUDY SITES AT BASELINE (N=358)

Variables	n	%	
Demographics			
Age (years)			
Mean (SD)		41.52 (12.46)	
Range	18	3–70	
Sex	2.45	60.00	
Male	247	68.80	
Female	109 2	30.36 0.56	
Other	2	0.30	
Transgender	0	2.22	
Yes (male to female) Yes (female to male)	8 2	2.23 0.56	
No	341	95.25	
	541	75.25	
Race Black	275	76.60	
White	44	12.26	
Hispanic	25	6.96	
Other/unknown	15	4.18	
Born in the United States	333	93.02	
English as primary language	342	95.26	
Employment status			
Émployed	101	28.13	
Unemployed	229	63.79	
Housing status			
Currently housed	311	86.63	
Not currently housed	41	11.42	
Unmet needs			
None	75	22.73	
1–2 unmet needs	113	34.24	
>3 unmet needs	142	43.03	
Clinical characteristics			
HIV primary care visit (past 6 months		50.00	
No visits recorded At least one visit recorded	179 179	50.00 50.00	
	179	30.00	
Active ART prescription	100	20.52	
No Yes	109 238	30.53 66.67	
Unknown	10	2.80	
	10	2.00	
Viral suppression No	171	47.77	
Yes	84	23.46	
No laboratory data	103	28.77	
Mental health diagnosis	116	32.40	
Substance use disorder diagnosis	109	30.45	
Hepatitis C diagnosis	50	13.97	

ART, antiretroviral.

pilot coding round in which four coders reviewed the same five transcripts, each from a different site. The four coders (M.D., M.C.R., M.S., and K.M.) assessed intercoder reliability and reached consensus through discussion and core view of each transcript. Any areas of disagreement were resolved among the coders, with input from the project director. During this process, the coders also discussed emerging concepts and updated the codebook to incorporate additional codes derived from the data. Example *inductive* codes included: CHW characteristics, client history, and subcodes

added under existing parent codes, such as depression and anxiety under mental health, transportation under concrete resources, etc.

Once the codebook was finalized, all transcripts were double coded. The study team then used a thematic analysis approach,³² which consisted of reviewing the content of each code and holding analysis meetings, to develop a set of key themes.

Results

Four prominent themes emerged from the client perspective. Clients expressed that: (1) CHWs embody key qualities, (2) CHWs meet clients where they are, (3) CHWs occupy a unique role in the HIV care team, and (4) CHWs influence how clients engage with care and access resources (Table 2). As clients discussed experiences in the programs and individual relationships with CHWs, comments centered around their qualities, approach, role, and influence.

Clients focus on key qualities of CHWs

Clients' descriptions of their relationships with CHWs were intertwined with descriptions of CHWs' key qualities and characteristics. Clients characterized CHWs as caring and supportive, capable of fostering personal connections, committed to their role, persistent, and as having shared experiences. CHWs were viewed as particularly caring, especially with regard to their ability to empathize with the client experience. Clients described the supportive nature of the relationship, particularly in terms of CHWs' nonjudgmental approach.

[The CHW] is someone who is more personal, he is more conscious, has friendly relations with people, has a presence where you feel comfortable with him, a person who helps you emotionally, guides you in the steps you need to take. He is a person that, how should I say, emotionally, he makes you feel good. [Client 1]

Clients frequently emphasized feeling a personal connection with their CHWs. Some used language related to family to characterize their relationship, including seeing the CHW as like a sibling or parent. Clients described feeling taken care of, and this was particularly true in cases where clients also described lacking close personal connections who were aware of their HIV status and able to support them.

Only my mom out of my whole family knows that I have it [HIV], I can't tell my dad because he barely messes with me for being gay. .. That's why when [CHW] was like, 'This is my kid, take care [of] him,' I was like 'Oh!'. .. Because he's low key like a father to me because I can't talk to my dad about this. .. [CHW] helps a lot. [Client 2]

CHWs were also seen as particularly committed to their job and persistent in their interactions with clients.

[The CHW] does more than what she needs to and is supposed to. She has offered to look up things for me that I know she doesn't even have to or need to, she's offered to make phone calls for me that I know she doesn't need to or have to. She's even just sat there and listened to me, even on her lunch break, and she doesn't have to. Just to calm me down, to keep me from having a [panic]attack and having to go to the hospital. [Client 3]

TABLE 2. SUMMARY OF RESULTS FROM THE CLIENT PERSPECTIVE ON THEIR EXPERIENCES WITH COMMUNITY HEALTH WORKERS IN HIV CARE

Theme	Details
Qualities: CHWs embodied key qualities	CHWs employed a nonjudgmental approach Clients felt a personal connection with CHWs Clients saw CHWs as committed and persistent Clients appreciated CHWs having shared experiences
Approach: CHWs met clients where they were	Clients saw CHWs approach as holistic and interpersonal CHWs focused on whatever clients needed in the moment (e.g., emotional support, social support, coaching, and motivation)
Role: CHWs occupied a unique role in the HIV care team	Clients described CHWs as having more time Clients saw CHWs as a different level of authority CHWs provided a source of social support for clients who needed it most
Influence: CHWs influenced how clients engaged with care and accessed resources	CHWs helped clients build health literacy CHWs helped clients access additional supportive resources Clients emphasized the role of CHWs in supporting their mental health CHWs focused on empowering clients

CHWs, community health workers.

Finally, most sites did not require that CHWs have a diagnosis of HIV, and CHWs may have shared different types of lived experiences with clients, such gender identity, racial identity, or experiences with substance use or incarceration. However, in circumstances where CHWs did share the experience of living with HIV, clients emphasized the importance of that bond. This was particularly true in cases where clients were newly diagnosed.

We are on the same level, kind of, going through the same process, I guess, of discovering that you are HIV positive. .. When [the CHW] told me his story and what he went through, the same thoughts and feelings that I had gone through, and how, he's like, 'It's going to get better'. .. That's what helped a lot. .. My personal journey compared to his and listening to his journey, it kind of lets you know that it's okay, it's not as bad as it is. [Client 4]

CHWs meet clients where they are

Clients experienced their interactions with other care team members, such as physicians and case managers, as being more regimented, whereas they described CHWs as wanting to make sure their needs were met—whatever those needs may be. Clients saw the CHWs' approach as more holistic and interpersonal compared with other care team members.

What I like about the community health workers is they meet your needs where you at individually. .. Sometimes with case management is kind of a thing that you follow. Is they taking their medicine? Is they going to the doctor? Are you using condoms, whatever? But [with the] community health worker, those are things that they want to make sure that you're managing, but they kind of meet you with your needs. .. Instead of it being a standard medical, like the medical case management, the community [health] workers can go outside the box a little bit with you, so to speak. [Client 5]

Clients emphasized that CHWs were able to focus on whatever they needed in that moment, and most notably, what clients often needed was emotional support, social support, and coaching. Clients continually emphasized how CHWs provided emotional and social support, usually when they described

feeling depressed. They also described a sense of motivation that CHWs provided, such as when they needed an extra push to "fight" their HIV or seek out other types of services.

I learned a lot from the community health worker. Learned how to be responsible. I learned how to deal with life when life turns. I learned not to give up. I learned to keep fighting. .. I normally give up. But dealing with the community health worker I deal with, there's always some positive being said. [Client 6]

CHWs occupy a unique role in the HIV care team

Clients' descriptions of their experiences emphasized how they viewed the CHW as a distinct member of their HIV care team. First, they described CHWs as having more time to dedicate to them.

The doctors don't really have time. They have a little time to hear your concerns but then they know where that's going to go, so they gone shortcut it, and 'Okay, we need to do this. I've got a limited amount to time to be with you and I've got another patient'. ... So, the community [health] worker, he can sit there. He kind of analyze what needs to be done. [Client 7]

CHWs were also seen as representing a different level of authority, which clients expressed in terms of feeling more "comfortable" in that relationship compared with other care team members. In one case, the client used the word father to describe a more paternalistic relationship with their physician. Whereas, their CHW represented someone with whom they could relate and interact with in a more helpful way.

I think of [my doctor] as a father... Because he just gives me a look, and I'm like, wow, I know that I've messed up... The community health worker talks with me, let me know, like, this is where your weak point at, this is where your strong point at. And I know you can do it. They push me to do better. [Client 6]

However, in another case, a client reported the CHW was not a key part of their HIV care experience. Analysis of this interview suggested the client had outside sources of social support that they could engage, rather than going to the CHW.

I don't just go to [the CHW] about problems and stuff because like I said, I guess because my sister and brother now, they constantly come by and come get me, and they always be asking me, 'You all right? You need anything?'. You know, and stuff like that. [Client 9]

This may indicate that CHWs represent a unique resource for clients within the context of the HIV care team, in that they provide a source of social support for those who need it most.

CHWs influence how clients engage with care and access resources

In this final theme, clients described how CHWs influenced both their HIV care experience and areas outside of health care. These changes were numerous, but could be summarized as: (1) building health literacy, (2) helping clients access additional supportive resources, and (3) empowering clients to engage with their care in a different way. CHWs helped build health literacy by working with clients on topics such as how to communicate and engage with providers. Other examples included helping clients talk to their physician about whether they could switch medications in response to side effects or reduce the number of pills in their regimen.

I have doctor's appointments, and I may be going through stuff, I'll call [the CHW] and ask her for tips on questions... 'Oh, is it okay if I asked them questions like that,' and she'll give me her input. [Client 10]

Clients also frequently cited CHWs helping them access additional supportive resources. These typically included concrete resources (e.g., assistance with housing, food, transportation, and insurance). However, support for mental health was also particularly important from the client's perspective. Examples of resources clients accessed included both the emotional support provided by CHWs along with referrals to professionals.

Definitely it would be the therapy, [the CHW] was the one that suggested I go to therapy and start talking to somebody. So that's one thing that helped me a lot mentally to get on the right state of mind. You think therapist, you think crazy, you know another stigma that goes with it, especially in the Hispanic community. .. You got an issue, you swallow your issue, and you deal with it, it's the Hispanic culture. But with [the CHW] saying it's really good, it's going to help you, give it a try and if you don't like it you don't have to go back. So, I did. .. [Client 4]

A key mechanism through which CHWs influenced clients' engagement in care and access to resources was their emphasis on empowerment. CHWs often began by helping clients access initial referrals to supportive services, but they also helped clients learn problem-solving skills to access resources on their own in the future. In addition, CHWs would often provide an initial push to engage in care and seek additional resources through focused encouragement.

I was on my deathbed last year, so I wasn't going to appointments, I wasn't taking medications, and I didn't really have a lot of self-esteem or motivation to do anything. I was in a bad place mentally. So, now it's like total opposite. .. It's really on the person, so it's really on me. But [the CHW] done all she could do to motivate me or push me or make sugges-

tions. So [the CHW] advised... I had a drug addiction problem as well. [The CHW] had advised me [about] different NAs [Narcotics Anonymous] I could go to... that turned out pretty good. [Client 11]

CHWs also helped some clients implement desired changes in nutrition, fitness, and overall quality of life through individual coaching and assistance with goal setting. However, CHWs were particularly influential in empowering clients to address mental health issues. Clients described instances of CHWs helping in their experiences with depression, anxiety, and suicidal ideation. A thread running through this assistance was CHWs helping clients to recognize that they were valued, important, and able to access professionals to help them with their negative thoughts and feelings.

And people see that. They tend to say, 'Well, they really care about me. This person really care[s] about me, so I'm going to do something.' It activates something in there, at least for myself. I can say personally it activate to say that I'm not alone in this. My case manager might not call me, but maybe once a month. Whereas [the CHW] calls me twice a week or something, you know what I mean? I'm just saying for example. So that makes a big difference. Because people want to hear that, especially if they isolated themselves or they depressed. [Client 12]

This was particularly true for individuals who were newly diagnosed and did not initially understand HIV was a treatable condition. These clients described CHWs helping them to understand that HIV was not a death sentence.

When I was first diagnosed with this, I was very unwell and he gave me spirit and hope. When they diagnose you, you think that you're going to die right away, but he is someone who helps you with moral support, which is the most important thing, [Client 1]

Discussion

Our findings illustrate that from the client perspective, CHWs possess key qualities, meet clients where they are, occupy a unique role in the HIV care team, and influence how clients engage with care and access resources. Clients in our sample described their CHWs in consistent ways, and the qualities identified align with those outlined in the literature on CHWs. 7.28,33 The sites in our study based implementation of their programs in a set of core roles and competencies for CHWs across all fields established by the C3 Project. 28 The C3 Project focused their work on CHW skills and competencies, such as communication and interpersonal skills, but they also emphasized that qualities have long been valued in helping to "facilitate the trust and relationships CHWs need to be effective in their work." 28

The C3 Project endorsed prior work from the New York State CHW Initiative and National Community Health Advisory Study, which identified qualities of CHWs to include: caring, empathetic, committed, dedicated, dependable, persistent, and resourceful, among others.^{33–35} In a review of client experiences with HIV patient navigation in the United States, Roland et al. found that clients attributed the success of navigation to dimensions of their relationship with their navigator, which they described as comfortable and familial.^{7,36} In our study, we found that when CHWs were HIV-positive peers, clients emphasized the importance of having that shared experience. This also aligns with the findings of

Roland et al., who suggest navigators sharing the experience of HIV may help buffer against perceptions and experiences of HIV stigma, and that greater levels of acceptance of one's HIV diagnosis can improve engagement in care.⁷

Clients in our study also described CHWs as meeting them where they were. Overall, they saw the CHW approach as more holistic compared with other care team members, which aligns with prior studies from both CHW and client perspectives, as well as the concept of patient-centered care. 33,37,38 The C3 Project encourages the widest possible scope of practice for CHW services. 28 This allows for what we found in our study, wherein clients emphasized how CHWs were able to focus on whatever was needed in the moment, with emotional and social support as well as coaching and motivation coming across as key activities. The C3 Project notes the key role of "providing coaching and social support," and motivation has been found to be important in improving HIV care engagement, with the presence of external social support as a key factor providing ongoing motivation to return to care. ^{28,33,39,40} Emotional support also has been found to be an essential element of the CHW role, and this aligns with prior findings on how the emotional and social connection that CHWs provide may be most important for clients without other stable sources of support. 7,36–38,40,41

Clients clearly emphasized the importance of having the CHW as a presence on their care team. Specifically, they valued having a care team member who had more time and represented a different level of authority. Broaddus et al. concluded that traditional case managers may not have the ability to build as close of bonds based on their large caseloads and administrative burdens, whereas with more time, the patient experience can be personalized; therefore, they suggest developing strategies to triage clients into different levels of service intensity.³⁶ The topic of authority relates to prior findings that suggest clients who have fallen out of care may have previous negative experiences with providers in which they were not in control of their care decisions, and their desire to have health care personnel with whom they can relate and establish trust.^{37,39} These findings emphasize how CHWs can translate between clients' lived experiences and the clinical world.

This is echoed in clients' descriptions of the influence of CHWs on their HIV care, which suggest they represent a valuable resource. CHWs helped clients build health literacy and empowered clients to engage with their care and access the additional supportive services they needed, particularly in terms of mental health. To do so, CHWs wore multiple hats, providing health education and cultural mediation, ^{28,39} the practical element of system navigation, ^{7,9,28,38} and social support, particularly in terms of helping clients seek out the care they needed to address feelings of depression and social isolation. ^{12,39,42}

Empowerment as the mechanism through which CHWs influence the care experience is supported by prior literature, with studies discussing how CHWs build patients' skills, ³⁹ self-management, ⁹ and self-efficacy, ⁷ as well as provide emotional and social support that translates to feelings of meaning and hope. ^{7,38} Results from this study suggest organizations can support CHWs in promoting client empowerment through training, coaching, and consistent supervision. The training program for this project was grounded in popular

education, a social movement founded by Paolo Freire, a Brazilian educator with a focus on empowerment and social justice. ^{43,44} Each training session was designed with learner-centered and learner-engaged principles to deliver content and build CHW skills to support clients with: (1) obtaining resources to address their social and medical unmet needs, (2) managing their life with HIV, and (3) making decisions about their health care. ⁴³

Our findings regarding CHWs parallel those from the extant literature on patient navigators, linkage-to-care specialists, and other support specialists in HIV care. Regardless of job title, the elements of the role appear to be the embodiment of key qualities, employing a holistic approach, providing emotional and social support, and having smaller caseloads that allow for more time dedicated to each client. What sets CHWs apart is a focus on shared experiences, specifically a connection to the community being served, however, that community is defined. We found shared experience was an important element in both the qualities and role of the CHW; clients felt they represented a different level of authority within the health care system with whom they could relate.

Our study was not without its limitations. First, there may have been some risk of selection bias. This applies in terms of which clients agreed to participate in the interviews, as well as in terms of the sites. Data were not collected to determine the interview acceptance rate among participants who were invited, and at the site level, four of the six were excluded from sampling. This decision was made to protect client confidentiality, since these sites had low client enrollment (range: 3–17), although it is possible these sites may have differed from those included in the subsample. Second, there was the potential for social desirability bias in clients' responses; however, this was mitigated by having external evaluation team members conduct the interviews. Finally, since this project was focused on implementation of CHW programs in different HIV care settings, each site was able to implement their program in a manner tailored to their needs. Therefore, given the rolling nature of enrollment and differential level of engagement of clients, it was not clear how long clients interviewed were engaged with their CHW. In addition, since CHW programs were not standardized across sites, clients across the sites likely had a variety of different experiences; however, the role and activities of the CHWs were similar across sites based on the use of a shared training curriculum²⁷ and implementation guide.²⁶ Despite these limitations, the findings of this study still provide important insights. We believe our purposive sampling of 30 clients and combined deductive/inductive approach to analysis allowed us to identify key aspects of the client experience shared across a variety of HIV care settings, despite any site- or program-specific differences, and these results may be transferrable to other organizations implementing CHW programs.

Findings regarding client experiences in CHW programs have important implications for their implementation in HIV care, and as such, may inform how organizations choose to hire and train CHWs as well as establish their roles within the care team. For example, results from this study emphasize the importance of establishing organizational policies and procedures that allow CHWs to engage in a holistic and client-centered approach to service provision, such as those that facilitate CHWs' ability to engage in outreach and conduct

home visits. These findings may also help guide organizations with implementation, including determining the size of CHW caseloads along with priority populations for their program. For example, results on the importance of shared experiences between clients and CHWs suggest these programs may be helpful in addressing the unmet needs of particular communities, such as transgender and gender nonconforming individuals, 45,46 racial/ethnic minorities, 47,48 and youth. 49,50 Finally, the relationship between client and CHW represents a core element of CHW program interventions and are likely fundamental to their effectiveness. Therefore, these results may be used in future research to help in understanding the mechanisms through which CHW programs impact health outcomes.

Overall, clients' perceptions of CHWs in terms of their qualities, approach, role, and influence on the HIV care experience suggest these health workforce members play a unique and valuable role on the care team.

Authors' Contributions

M.L.D., L.S.M., A.B., S.R., T.E., K.R.D., and L.T. led project implementation and evaluation. M.L.D., L.S.M., A.B., M.C.R., and M.S. conducted the interviews. M.C.R., K.M., M.S., and M.D. coded the data. M.D. led data analysis and drafted the article. All authors contributed to interpreting results and editing the article. All authors read and approved the final article.

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Ethics Approval

The Institutional Review Boards of the Boston University Charles River Campus and Boston University Medical Center approved all study protocols.

Consent to Participate

Informed consent was obtained from all individual participants included in the study.

Availability of Data and Materials

The data used for this study are available upon reasonable request to the corresponding author.

Author Disclosure Statement

L.S.M. is an external evaluator with the Boston Public Health Commission and a youth engagement consultant for America's Promise Alliance. The additional authors declare that they have no competing interests.

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Supplementary Material

Supplementary Material

References

- The Office of National AIDS Policy. National HIV/AIDS Strategy: Updated to 2020. 2015. Available at: https://www .hiv.gov/federal-response/hiv-national-strategic-plan/ national-hiv-aids-strategies-2010-2020 (Last accessed July 24, 2021).
- Drainoni M-L, Carey KM, Morgan JR, et al. An interrupted continuum of care? What are the risk factors and comorbidities related to long-term engagement and retention in HIV care? J AIDS Clin Res 2015;06. [Epub ahead of print]; DOI: 10.4172/2155-6113.1000468.
- Anderson AN, Higgins CM, Haardörfer R, Holstad MM, Nguyen MLT, Waldrop-Valverde D. Disparities in retention in care among adults living with HIV/AIDS: A systematic review. AIDS Behav 2020;24:985–997.
- Genberg BL, Shangani S, Sabatino K, et al. Improving engagement in the HIV care cascade: A systematic review of interventions involving people living with HIV/AIDS as peers. AIDS Behav 2016;20:2452–2463.
- Risher KA, Kapoor S, Daramola AM, et al. Challenges in the evaluation of interventions to improve engagement along the HIV care continuum in the United States: A systematic review. AIDS Behav 2017;21:2101–2123.
- Higa DH, Crepaz N, Mullins MM. Identifying best practices for increasing linkage to, retention, and re-engagement in HIV medical care: Findings from a systematic review, 1996–2014. AIDS Behav 2016;20:951–966.
- Roland KB, Higa DH, Leighton CA, Mizuno Y, DeLuca JB, Koenig LJ. Client perspectives and experiences with HIV patient navigation in the United States: A qualitative meta-synthesis. Health Promot Pract 2020;21:25–36.
- Cabral HJ, Davis-Plourde K, Sarango M, Fox J, Palmisano J, Rajabiun S. Peer support and the HIV continuum of care: Results from a multi-site randomized clinical trial in three urban clinics in the United States. AIDS Behav 2018;22:2627–2639.
- 9. Sarango M, de Groot A, Hirschi M, Umeh CA, Rajabiun S. The role of patient navigators in building a medical home for multiply diagnosed HIV-positive homeless populations. J Public Health Manag Pract 2017;23:276–282.
- Maulsby C, Charles V, Kinsky S, Riordan M, Jain K, Holtgrave D. Positive charge: Filling the gaps in the U.S. HIV continuum of care. AIDS Behav 2015;19:2097–2107.
- Scott K, Beckham SW, Gross M, et al. What do we know about community-based health programs? A systematic review of existing reviews on community health workers and their integration with health systems. Hum Resour Health 2018;16:1–17.
- Mwai GW, Mburu G, Torpey K, Frost P, Ford N, Seeley J. Role and outcomes of community health workers in HIV care in sub-Saharan Africa: A systematic review. J Int AIDS Soc 2013;16. [Epub ahead of print]; DOI: 10.7448/IAS.16.1.18586.
- Han HR, Kim K, Murphy J, et al. Community health worker interventions to promote psychosocial outcomes among people living with HIV—A systematic review. PLoS One 2018;13:1–18.
- American Public Health Association. Community Health Workers. 2020. Available at: https://www.apha.org/aphacommunities/member-sections/community-health-workers (Last accessed July 24, 2021).

- Kenya S, Jones J, Arheart K, et al. Using community health workers to improve clinical outcomes among people living with HIV: A randomized controlled trial. AIDS Behav 2013;17:2927–2934.
- Kenya S, Chida N, Symes S, Shor-Posner G. Can community health workers improve adherence to highly active antiretroviral therapy in the USA? A review of the literature. HIV Med 2011;12:525–534.
- Islam N, Nadkarni SK, Zahn D, Skillman M, Kwon SC, Trinh-Shevrin C. Integrating community health workers within patient protection and affordable care act implementation. J Public Health Manag Pract 2015;21:42–50.
- Kangovi S, Grande D, Trinh-Shevrin C. From rhetoric to reality—Community health workers in post-reform U.S. Health Care. N Engl J Med 2015;372:2277–2279.
- 19. Vasan A, Morgan JW, Mitra N, et al. Effects of a standardized community health worker intervention on hospitalization among disadvantaged patients with multiple chronic conditions: A pooled analysis of three clinical trials. Health Serv Res 2020:1–8. [Epub ahead of print]; DOI: 10.1111/1475-6773.13321.
- Dave S, Peter T, Fogarty C, Karatzas N, Belinsky N, Pai NP. Which community-based HIV initiatives are effective in achieving UNAIDS 90-90-90 targets? A systematic review and meta-analysis of evidence (2007–2018). PLoS One 2019;14:1–18.
- Drainoni M-L, Baughman AL, Bachman SS, et al. Integrating community health workers into HIV care teams: Impact on HIV care outcomes. J HIV AIDS Soc Serv 2020; 19:204–219.
- 22. Mizuno Y, Fagan J, Tie Y, Padilla M. Is patient navigation used by people with HIV who need it? An assessment from the Medical Monitoring Project, 2015–2017. AIDS Patient Care STDS 2020:34:452–459.
- Arvey SR, Fernandez ME. Identifying the core elements of effective community health worker programs: A research agenda. Am J Public Health 2012;102:1633–1637.
- Using Community Health Workers to Improve Linkage and Retention in Care. 2020. Available at: https://targethiv.org/chw (Last accessed July 24, 2021).
- 25. Sprague Martinez L, Davoust M, Rajabiun S, et al. "Part of Getting to Where We Are is Because We Have Been Open to Change": Integrating community health workers on care teams at ten Ryan White HIV/AIDS program recipient sites. BMC Public Health 2021. [Epub ahead of print]; DOI: 10.21203/rs.3.rs-144645/v1.
- 26. Boston University School of Social Work, Center for Innovation in Social Work and Health. A Guide to Implementing a Community Health Worker (CHW) Program in the Context of HIV Care. 2020. Available at: https://targethiv.org/library/hiv-chw-program-guide (Last accessed July 24, 2021).
- Boston University School of Social Work, Center for Innovation in Social Work and Health. Community Health Workers in HIV Care Curriculum | Un Plan de Capacitación Para Las Promotoras de Salud. 2020. Available at: https://targethiv.org/library/chw-curricula (Last accessed July 24, 2021).
- Rosenthal EL, Menking P, John J St. The Community Health Worker Core Consensus (C3) Project: A Report of the C3 Project Phase 1 and 2, Together Leaning Toward the Sky. 2018. Available at: https://www.c3project.org/resources (Last accessed July 24, 2021).
- Wolfe HL, Baughman A, Davoust M, Sprague Martinez LS, Rajabiun S, Drainoni M-L. Client satisfaction with com-

- munity health workers in HIV care teams. J Community Health. 2021. [Epub ahead of print]; DOI: 10.1007/s10900-021-00978-1.
- QSR International. NVivo Qualitative Analysis Software Version 12. 2018. Available at: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software (Last accessed July 24, 2021).
- 31. DeCuir-Gunby JT, Marshall PL, McCulloch AW. Developing and using a codebook for the analysis of interview data: An example from a Professional Development Research Project. Field Methods 2011;23:136–155.
- 32. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.
- 33. Parnell HE, Berger MB, Gichane MW, et al. Lost to care and back again: Patient and navigator perspectives on HIV care re-engagement. AIDS Behav 2019;23:61–69.
- 34. New York State Community Health Work Initiative. Paving a Path to Advance the Community Health Worker Workforce in New York State. 2011. Available at: https://nyshealthfoundation.org/resource/paving-a-path-to-advance-the-community-health-worker-workforce-in-new-york (Last accessed July 24, 2021).
- 35. Rosenthal EL. A Summary of the National Community Health Advisor Study: Weaving the Future. 1998. Available at: https://crh.arizona.edu/publications/studies-reports/cha (Last accessed July 24, 2021).
- 36. Broaddus MR, Hanna CR, Schumann C, Meier A. "She makes me feel that I'm not alone": Linkage to Care Specialists provide social support to people living with HIV. AIDS Care 2015;27:1104–1107.
- 37. Kangovi S, Grande D, Carter T, et al. The use of participatory action research to design a patient-centered community health worker care transitions intervention. Healthcare 2014;2:136–144.
- Broaddus MR, Owczarzak J, Schumann C, Koester KA. Fostering a "Feeling of Worth" among vulnerable HIV populations: The role of linkage to care specialists. AIDS Patient Care STDS 2017;31:438–446.
- Rajabiun S, Mallinson RK, McCoy K, et al. "Getting Me Back on Track": The role of outreach interventions in engaging and retaining people Living with HIV/AIDS in medical care. AIDS Patient Care STDS 2007;21:S20–S29.
- 40. Fuller SM, Koester KA, Maiorana A, et al. "I don't have to do this all by myself": Systems navigation to ensure continuity of HIV care for persons leaving prison. AIDS Behav 2019;23:S14–S24.
- 41. Sullivan KA, Schultz K, Ramaiya M, Berger M, Parnell H, Quinlivan EB. Experiences of women of color with a Nurse Patient Navigation Program for linkage and engagement in HIV care. AIDS Patient Care STDS 2015;29:S49–S54.
- 42. Westergaard RP, Genz A, Panico K, et al. Acceptability of a mobile health intervention to enhance HIV care coordination for patients with substance use disorders. Addict Sci Clin Pract 2017;12:11.
- 43. Rajabiun S, Baughman A, Sullivan M, et al. A participatory training curricula for CHWs and supervisors to increase HIV health outcomes. Front Public Health 2021;9:964. doi: 10.3389/fpubh.2021.689798.
- 44. Freire P. The adult literacy process as cultural action for freedom. Harv Educ Rev 1970;40:205–225.
- 45. Harper GW, Jadwin-Cakmak LA, Popoff E, et al. Transgender and other gender-diverse youth's progression through the HIV continuum of care: Socioecological system barriers. AIDS Patient Care STDS 2019;33:32–43.

46. Auerbach JD, Moran L, Watson C, Weber S, Keatley J, Sevelius J. We are all women: Barriers and facilitators to inclusion of transgender women in HIV treatment and support services designed for cisgender women. AIDS Patient Care STDS 2020;34:392–398.

- 47. Freeman R, Gwadz MV, Silverman E, et al. Critical race theory as a tool for understanding poor engagement along the HIV care continuum among African American/Black and Hispanic persons living with HIV in the United States: A qualitative exploration. Int J Equity Health 2017; 16:54.
- Levison JH, Levinson JK, Alegría M. A critical review and commentary on the challenges in engaging HIV-infected Latinos in the continuum of HIV care. AIDS Behav 2018; 22:2500–2512.
- 49. Saberi P, Ming K, Dawson Rose C. What does it mean to be youth-friendly? Results from qualitative interviews with health care providers and clinic staff serving youth and

- young adults living with HIV. Adolesc Health Med Ther 2018;9:65-75.
- Casale M, Carlqvist A, Cluver L. Recent interventions to improve retention in HIV care and adherence to antiretroviral treatment among adolescents and youth: A systematic review. AIDS Patient Care STDS 2019;33:237– 252

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