The HIV Care Continuum in Small Cities of Southern New England: Perspectives of People Living with HIV/AIDS, Public Health Experts, and HIV Service Providers

Lauretta E. Grau[1,2], **Sarah Brothers**[3], **Ja Young Kim**[4], **Arnaaz Khwaja**[5], **Robert Heimer**[1], **Thomas J. Stopka**[4]

[1]Yale School of Public Health, Department of Epidemiology of Microbial Diseases, New Haven, CT 06520-8034, USA

[2]Corresponding author Yale School of Public Health PO Box 208034 New Haven, CT 06520-8034, USA 203-785-2904 (phone) 203-764-4353 (FAX) lauretta.grau@yale.edu

[3]Yale University, Department of Sociology, New Haven, CT 06511

[4]Tufts University School of Medicine, Department of Public Health & Community Medicine, Boston, MA 02111, USA

[5]University of Chicago, Department of Anthropology, Chicago, IL 60637, USA

Abstract

The HIV care continuum (HCC), comprised of five steps (screening, linkage to care, treatment initiation, retention, and viral suppression), is used to monitor treatment delivery to people living with HIV (PLWH). The HCC has primarily focused on large urban or metropolitan areas where the situation may differ from that in smaller cities. Three themes (i.e., knowledge, stigma, stability) that shaped HCC outcomes were identified from analysis of two qualitative studies involving HIV service providers, public health experts, and PLWH in smaller cities of southern New England. The findings suggest that enhancing HCC outcomes require a multiprong approach that targets both the individual and organizational levels and includes interventions to increase health literacy, staff communication skills, universal screening to assess patients' religiosity/spirituality and supplemental service needs. Interventions that further ensure patient confidentiality and the co-location and coordination of HIV and other healthcare services are particularly important in smaller cities.

Abstract

El cuidado continuo de VIH (HCC), constado de cinco etapas (pruebas, vinculación al cuidado, inico del tratamiento, retención, y supresión viral), se emplea para monitorizar la entrega de tratamientos a las personas que vivien con VIH (PLWH). El HCC ha enfocado principalmente en

áreas grandes y urbanas o áreas metropolitanas, donde la situación podría ser diferente que la de las ciudades más pequeñas. Tres temas (i.e., conocimiento, estigma, estabilidad) que formaron los resultados de HCC fueron identificados con análisis de dos estudios cualitativos que involucraron los proveedores de servicios de VIH, expertos de la salud pública, y PLWH en ciudades más pequeñas en las partes sureñas de Nueva Inglaterra. Los hallazgos sugieren que la mejora de los resultados de HCC requiere un enfoque multidimensional que se dirigen a ambos niveles del individuo y organización, y que incluyen intervenciones para aumentar la alfabetización sanitaria, la habilidad de comunicación del personal, la prueba universal para evaluar la religiosidad/espiritualidad de los pacientes y la necesidad de servicios suplementarios. Intervenciones que aseguran aún más la confidencialidad de los pacientes y el co-ubicación y coordinación de los servicios de VIH y otras asistencias medicas son particularmente importantes en ciudades pequeñas.

Keywords

HIV/AIDS; HIV Care Continuum; HIV Treatment Cascade; religiosity/spirituality

Introduction

The HIV care continuum (HCC), comprised of five steps (HIV screening, linkage to care, treatment initiation, retention, and viral suppression), is used by local, state, and federal agencies and healthcare organizations to monitor treatment delivery to people living with HIV/AIDS (PLWH) and progress toward achieving the public health goal of ending the epidemic. A similar model from the World Health Organization is based on having 90% of those infected receive their diagnosis, 90% of those diagnosed receive antiretroviral therapy (ART), and 90% of those on ART achieve and sustain viral suppression. It was thought that if this 90–90-90 goal were achieved by 2020, the epidemic could end by 2030 [1]. Since this goal will not be met, however, the Joint United Nations Program on HIV/AIDS, using a similar model, seeks to set goals to combat the global HIV/AIDS epidemic for the period of 2021 – 2030 [2].

There are approximately 38,000 new HIV infections per year in the U.S. In 2016 and based upon the estimated HIV prevalence at the time, 86% of those who tested positive for HIV had received their diagnosis (i.e., 14% either had not been tested or never received their positive test results), and 63% were virally suppressed [3]. In southern New England, 50,000 HIV cases have been reported in Connecticut, Massachusetts, and Rhode Island. In 2018, the proportion of PLWH living in southern New England who were virally suppressed was 73% in Connecticut [4], 65% in Massachusetts [5], and 68% in Rhode Island [6].

Several factors have prevented our ability to reach the 90–90-90 goal. These include barriers to HIV testing and treatment, sociodemographic risk factors such as belonging to marginalized communities (e.g., men who have sex with men, people who inject drugs, sex workers, or individuals without health insurance), and the burdens of HIV stigma and/or discrimination [7–9]. Co-morbidities such as mental health or substance use disorders can also pose another barrier to reaching the 90–90-90 goal. Cha and Cohen (2018) reported that

the number of co-morbidities was positively associated with non-adherence [10]. Other studies have reported that stigma was associated with not initiating ART, not being retained in healthcare, and non-adherence to ART [9, 11–13]. Younger age, crack cocaine use, food insecurity, economic and housing instability have also been associated with poorer retention rates [14–16]. Linkage to care rates were found to higher in rural than in urban or metropolitan jurisdictions but retention and viral suppression rates significantly lower in rural and metropolitan jurisdictions [17]. Despite the 2006 CDC recommendation to screen all individuals aged 13–64 years for HIV, screening rates remain low, thereby reducing the possibility of people receiving their diagnosis and subsequent linkage to treatment [18,19]. In part, routine screening and testing appear less likely to occur in private, non-urban, or understaffed clinics or when staff attitudes do not support routine screening and testing [20–24]. Late diagnosis is another barrier that delays timely initiation of ART [8].

HCC studies have primarily been conducted in large urban or metropolitan areas. An assumption underlying our study was that smaller cities may have unique HIV treatment and resource needs, and that structural and sociodemographic factors may vary considerably, thereby decreasing the applicability of HCC study findings from large urban regions. By combining data from two qualitative studies, we sought to understand the key elements that can shape HCC outcomes from the perspectives of HIV service providers, public health experts, and PLWH in smaller cities of southern New England.

Methods

Qualitative data from two studies are included in the current analysis. The first occurred in November 2015 - June 2016 and included interviews with HIV service providers and public health experts in the nine southern New England cities of Bridgeport, New Haven, and Waterbury in Connecticut; Lowell, New Bedford, Springfield, and Worcester in Massachusetts; and Providence, Rhode Island [25]. The cities had populations of 100,000 – 200,000 and relatively high HIV prevalence, particularly among people who use drugs, men who have sex with men, and racial/ethnic minority groups. Due to time and resource limitations, the second occurred in September 2018 – April 2019 and included interviews with PLWH only in Waterbury and Worcester. The research question in both studies explored the barriers and facilitators that can shape the HCC.

First Study

Details concerning research design and methods can be found in Grau et al. [25]. The study sample included 49 participants, recruited via purposive sampling. The inclusion criteria were staff who (1) provided HCC-related services or conducted HIV surveillance in any of the nine cities; (2) had   five years of experience in the HIV field; and (3) were English speaking. Semistructured, face-to-face interviews assessed the perceived barriers and facilitators to improving HCC outcomes. They were audio-recorded, transcribed verbatim, and thematically analyzed.

Participants received a $25 gift card as reimbursement for their time, and their quotations are identified by Participant number in the current study. The Institutional Review Boards (IRB) of Yale and Tufts granted an exemption for the first study.

Second Study

We conducted 34 interviews with PLWH. The sampling strategy included posting recruitment flyers at local HIV clinics, shelters and harm reduction agencies, attending HIV support group sessions in the two cities to recruit directly, and having local departments of health and AIDS service organizations refer people to our study. Inclusion criteria for participation were: (1) self-reported diagnosis of HIV/AIDS; (2) at least 18 years old; (3) Waterbury or Worcester resident; and (4) English or Spanish speaker. We had initially proposed to interview PLWH in each city, stratified by either being currently in or out of care. However, the early interviews indicated that many of those who were classified as in care also had previously fallen out of care and could provide valuable information about the context and circumstances surrounding their lapse in and resumption of care. Therefore, the stratification requirement was abandoned. To diminish potential recall bias concerning their experience or reasons for stopping as well as resuming treatment, we modified our inclusion criteria to include anyone who had been in uninterrupted treatment (i.e., in care) or had been out of treatment for at least three months but returned to care within the past year (i.e., interrupted care).

Following informed consent discussion and enrolment, all interviews were individual, face-to-face, audio-recorded, and lasted approximately 60 minutes. Interviewers had previous training in qualitative interviewing. All interviews were professionally transcribed verbatim except for the five conducted in Spanish. The audio-recordings for those were reviewed by research team members proficient in both languages and the specific contents summarized for data analysis.

The interview guide, developed in the first study, was adapted to focus more specifically on the beliefs and experiences of PLWH concerning HIV testing and diagnosis, treatment linkage and retention, and achieving and sustaining viral suppression. The coding team independently coded four transcripts and met regularly to adapt the existing codebook, refine code definitions, and add codes for new content. Coding discrepancies were resolved by consensus. The meetings continued until data saturation and acceptable inter-coder reliability were achieved. The remaining transcripts were then independently coded (by LG, SB or JK) and entered into ATLAS.ti (Version 7.1.7). Codes pertaining to HCC barriers and facilitators from both studies (e.g., coping, disclosure, stigma, co-morbidities) were analyzed thematically [26,27] in an iterative fashion, grouped into themes which were then compared across the two datasets. As part of the confirmability process [28], we sought negative instances where the data did not fit the existing themes. Quotations in the second study are identified by PLWH number, gender, and race/ethnicity; since no thematic differences were noted by age or city, these have been omitted since to ensure confidentiality. Colloquialisms and non-verbal utterances have been removed to improve readability of the quotes.

Participants in the second study received $40 as reimbursement for their time. The Yale IRB approved the study as part of the Single IRB Provision.

Results

Study sample

Details concerning the study sample in the first study can be found in Grau et al. [25]. Briefly, there were 49 participants, with an average of four participants per city and two at the regional/state level in each state. Approximately half the sample was male (53%), and over a quarter (29%) were direct service providers (i.e., medical or case management).

Table 1 provides demographic information for participants in the second study. Over 80% of the sample identified as people of color. The mean age was in the mid-forties but with a substantial range. Time since diagnosis ranged from two years to approximately 30 years, and although many acknowledged their history of illicit drug use, most believed that their infection had been sexually acquired. Almost half the sample had returned to HIV care within the past year after a hiatus of at least 3 months duration.

Results of the Thematic Analysis

Participants in the first study identified potential HCC barriers and facilitators at the individual, interpersonal, organizational, and community levels [25]. We chose to focus only on the individual (i.e., the PLWH) and organizational levels in the current analysis because they are the most logical and tractable to target when developing interventions to improve HCC outcomes. The interpersonal level has been subsumed within the organizational level to address both human (i.e., staff) and non-human (i.e., physical layout, branding, policies) elements that may influence HCC outcomes.

Figure 1 depicts a conceptual model of the major themes that emerged across the two studies. Consistent with theoretical models concerning health behaviors associated with HIV risk and treatment [29–31], individuals' level of motivation is key to performing targeted behaviors—in this case that of seeking and being retained in HIV care—which, in turn, will lead to ending the epidemic. Three themes emerged that appeared to directly or indirectly influence motivation: knowledge, stigma, and stability. Subthemes were identified at both the individual and organizational levels within each theme.

Knowledge Theme

Knowledge deficits, although substantively different, were noted at both the individual and organizational levels. Three sub-themes were identified: (1) HIV knowledge at the individual level, (2) knowledge about relevant services and resources at both levels, and (3) communication skills knowledge at the organizational level.

At the individual level, some PLWH did not appear to fully understand their HIV treatment which appeared to influence their motivation to seek and be retained in HIV care. For example, some participants appeared to believe that low values on all lab results (e.g., viral load, CD4) were desirable. The term "undetectable" was misinterpreted by several PLWH to mean that there was no need to initiate or continue ART treatment. Clearly, this has important implications for achieving viral suppression and treatment as prevention. One participant noted that she was "Undetectable. I didn't need it [ART]." and later implied that

HIV could be transmitted through kissing. In addition, although less frequently noted, some PLWH delayed or discontinued the HIV care based on their feeling quite healthy and further illustrated how inaccurate knowledge can influence motivation.

> I think that, by me being undetectable, that was one of the main reasons where I stopped taking the medication, too. 'Cuz I felt like me stopping taking the medication, I'm good. I feel like I don't have the virus no more so I'm good. Let me just stop for a little bit.
>
> (PLWH #9, male, Latinx)

> I didn't want to be on medication yet. You know, my body was healthy still. You know? So why start medication when you're so healthy?
>
> (PLWH #10, male, Latinx)

Another knowledge deficit was inferred from several participants' comments about having scrupulously adhered to their HIV treatment while pregnant, and none of the children had been vertically infected. However, they also reported having stopped their HIV treatment postpartum. No reasons were given for stopping their ART.

Lack of awareness of the services and resources available to PLWH was noted at both the individual and organizational levels. It often took time for PLWH to find the appropriate services and resources after moving to a new location, another factor that could influence motivation.

> …they asked me if I was taking any medication and I was, like, no, since I came into the country, I haven't been because I don't know which avenues to get on and I don't have medical insurance or anything.
>
> (PLWH #29, female, Black)

> She told me, "Go the welfare office", and I went there and they didn't know what the hell I was talking about but it was a client who told me about [a medical assistance program]. And that's when I came back and I told her, "How can you work at an AIDS service organization and you don't know the resources?" And I think that's a challenge, a struggle when you have staff that are at these agencies that don't what the hell what they're doing.
>
> (PLWH #14, female, Black)

PLWH did not complain that HIV staff lacked knowledge about the disease, but several wished that staff could provide information about local resources such as yoga, meditation centers, and support groups as these helped some to cope with their infection and motivated them to seek care. PLWH often identified religiosity/spirituality as another critical element in coping with their infection. However, it appeared that organizations and their staff had limited knowledge or awareness of religiosity/spirituality as a valuable coping resource, awareness of their local availability, and rarely, if ever, referred clients to such services.

> I had to get back on track spiritually, my spiritual beliefs and my spirituality was, I feel is what saved me in the overall.
>
> (PLWH #8; female, Black)

Data from both studies suggested the importance of good communication skills and an "appropriate [staff] attitude," particularly when interacting with individuals from minority or marginalized populations. HIV staff and providers, no matter how well-intentioned, conveyed concerns in ways that could sometimes dissuade patients from returning. The importance of positive and supportive interactions with staff appeared to be critical to being retained in HIV care by indirectly providing socioemotional support that could motivate PLWH to continue their HIV care. Positive and supportive interactions are more likely to happen when staff are knowledgeable about the elements of good communication and cultural competence.

> [The HIV doctor said,] "I don't understand why you stopped taking your med." He didn't even ask me, first of all, why. He basically [said] "I see you haven't been here since blah, blah, blah." By my chart and everything. To me, it was hostile...I realize I made a mistake, and I need to do this. It's not like it was something I wanted to do. I just wanted him to be empathetic to the fact that I was going through some things…And that's how I felt. So I didn't go back.
>
> (PLWH #28, female, White)

It appeared that most HIV service staff and public health experts understood the importance of cultural competence in motivating PLWH to have sought and been retained in HIV care, but it was most often identified as staff racial/ethnic diversity and multilingual capabilities. Only one participant in the first study identified it as having an appropriate attitude and good communication skills.

> For me, the surface of culturally competent care is care delivered in the language that the person feels most comfortable speaking and… coming from a similar background…[but] it's more about just withholding judgment…without being condescending or without the appearance of being rude or without making the person feel like they are stupid.
>
> (Participant #42, Male, ASO administrator)

In marked contrast, only one PLWH mentioned preferring a provider from the same racial and cultural background. All others spoke in terms of their provider understanding and valuing them as a person. This valuing or feeling of "specialness" is best created through positive interactions with staff who are knowledgeable about good communication skills, and it appeared to be more important in motivating PLWH to continue their treatment than did organizational efficiency, multilingual capabilities, or racial/ethnic diversity.

> I'm the baby of the health department, the special one.
>
> (PLWH #27, male, Black)

> I've been with her [healthcare provider], she calls me her star pupil.
>
> (PLWH #17, male, Black)

> I wasn't just some number or whatever. I was a person. And that made me feel more comfortable.
>
> (PLWH #28, female, White)

Stigma Theme

The potential effects of stigma on HCC outcomes was evident at both the individual and organizational levels. PLWH and providers also noted how HIV stigma could be compounded by stigma concerning substance use or mental health problems.

> There's a lot of judgmental people. I know a lot of clients that are still using drugs would rather try to pop their own or heal their own abscess instead of going to the medical [clinic] to have it done.
>
> (PLWH #14, female, Black)

> There's stigma about HIV. There's stigma about mental illness. There's stigma about addiction. There's stigma about a number of things. So it seems sort of multi-layered issues.
>
> (Participant #39; Male, Medical provider)

At the individual level and often based on fear of rejection or loss of status within the community, many PLWH hid their HIV status from family, friends, and even non-HIV healthcare providers. They did not seem to recognize how this could possibly deprive them of important socioemotional or instrumental support that could serve as important motivators for seeking and being retained in HIV care. Some tried to prevent disclosure by travelling to other cities for their HIV care—often time-consuming or expensive—or by hiding their medications in a manner that could compromise their HIV treatment.

> [I get my HIV care in another city.] I'm doing it because of my privacy. I'm doing it so I can have a discrete life where I don't have to feel ashamed or feel like I have to hide or be scrutinized."
>
> (PLWH #26, male, bi-racial)

> I was staying at the shelter, and I didn't want them to know so I hid the [HIV] medication in my suitcase and I just been forgetting to take it because every day I would have to leave or do this or try to find a job.
>
> (PLWH #15, female, Black)

Disclosure of HIV status to one's family was often a difficult decision. One participant, diagnosed 20 years ago, said that she still had not disclosed to family.

> Nobody knows, my sister, nobody. I don't know how to tell them nothing...they might not want me no more, and I don't know. It's hard. It's so hard…I don't do none of the groups because...if I associate with people [with HIV] and [others] see me…I think everybody won't want to talk to me no more.
>
> (PLWH #6, female, Latinx)

> When people start pushing me away, I don't know how everyone feels [about HIV/AIDS], but if some of the family were to be, "Oh no, don't invite her over."…I'm not willing to take that chance. 'Cuz I love my family, and I would hate to know that somebody is feeling a certain kind of way about me because I know they love me now.
>
> (PLWH #22, female, White)

Although many avoided disclosure due to concerns about potential stigmatization, others reported actual stigma experiences. One participant with vertically acquired HIV infection was shunned by his classmates after he disclosed his HIV status when correcting inaccurate HIV transmission information provided during a school assembly. Another complained that, despite having lived with HIV for 30 years, he continues to experience "being treated like the AIDS leper within the gay community."

Only a few participants appeared oblivious to stigma. Some spoke of their refusal to be defined by their HIV infection, stating that it wasn't a sign of a moral or character flaw. Others considered HIV a disease like any other.

> Just like having cancer. It's a treatment. You have to treat it. If you don't treat it, it will take you.
>
> (PLWH #17, male, Black)

> You gotta detach yourself from things that you don't need to be hearing.
>
> (PLWH #24, female, Latinx)

Regardless of whether an organization provided HIV or another health or social service, several PLWH noted how negative interactions with staff could be perceived as stigmatizing.

> The first thing the vascular surgeon asked me when he walked into the exam room was, "How did you catch HIV?"…Now knowing that I'm HIV-positive does make a difference in prescribing a course of treatment, but knowing the mode of transmission has nothing to do with treatment. It only tells me that the person asking that question has a bias, and he wants to know if I fit into that bias group.
>
> (PLWH #19, male, White)

> Why I couldn't [be] retain[ed] in care, stay on my meds? It has a lot to do with providers, too...You don't seem like you want to help me. You're judgmental.
>
> (PLWH #14, female, Black)

In addition to negative staff interactions, other elements at the organizational level were identified as stigmatizing and could alter motivation to seek and be retained in HIV treatment. Examples included providing HIV services in a separate space apart from other healthcare services within the same building and including "HIV," "AIDS," or HIV/AIDS" in the organization's name; these could potentially identify someone as an HIV patient to any passerby.

> Stigma. They don't want people to see—in a small city, people know each other...That is big. People will see them going into a clinic.
>
> (Participant #29; Female, ASO administrator and clinician)

> Where [the infectious disease doctor] is, everybody knows. When you go in that building, you're going for HIV. So I never wanted to involve myself in that.
>
> (PLWH #11, female, Black)

Worries about stigma sometimes concerned the potential negative consequences to their uninfected loved ones (i.e., "second-hand stigma").

> …people were so cruel to my kids. They used to come up to my kids, they used to get in fights in school and on the streets. "Oh, your mother's got AIDS. She's dying."
>
> (PLWH #7, female, White)

> I remember one time, one time my daughter came home from school and… somebody had told her that "Your mother has AIDS."…And then, my daughter was just hurt because she was talking about her mother. You don't want nobody to say nothing about your mother. And I told her, I said, "it's okay because, you know, words don't hurt you." But yeah, she was very upset. She didn't want to go back to that school.
>
> (PLWH #4 female, White)

Stability Theme

The degree to which the lives of PLWH were stable appeared to strongly influence treatment retention. Stable lifestyles and routines provided the instrumental support (i.e., tangible assistance such as transportation or assistance with taking medications) and social support that indirectly served to motivate PLWH to more easily incorporate and adhere to HIV treatment in their daily schedules. Three sub-themes emerged from the data: (1) satisfying one's basic needs, (2) having good socioemotional support, and (3) having a sense of purpose in life or reason for living. These sub-themes were noted at both the individual and organizational levels.

Consistent with Maslow's hierarchy of needs [32,33], basic needs (e.g., housing, food, transportation) must be met in order to mitigate potential stressors that can interfere with treatment. This issue was recognized by both the PLWH and HIV staff.

> [The case manager] ended up helping me. I ended up moving to a new apartment. You know, everything was starting new and fresh. I have doctors now, I'm taking my medications, I'm in a new apartment. I'm going good. I'm undetectable now 'cuz I'm taking my pills.
>
> (PLWH #9, male, Latinx)

> The reasons why I wasn't in care—my mental health, my fear, my disclosure, the substance use, the homelessness.
>
> (PLWH #14, female, Black)

> Everything just piggybacks each other, housing, transportation, food, income, medication, doctors' appointments, everything just piggybacks each other.
>
> (Participant #47; Female, Case worker)

Some PLWH, particularly those with multiple co-morbidities, may require more intensive services as part of addressing their basic and healthcare needs. One participant recognized the importance of having a healthcare worker continue to come to her home daily to provide

directly observed therapy of her psychiatric medications. She understood that the daily visits provided her with social support from her nurse and a stable routine that enabled her to adhere to her mental health and HIV treatments.

> People like me with PTSD and bipolar, I can't have a different person coming to my house every day. I gotta have the same thing every day...When I think that I'm doing well, when my meds is working and I feel like I need meds no more. I fall out of care. So that's why I gotta [have] a nurse.
>
> (PLWH #12, female, 56 years, Black)

Social networks were important for providing transportation to healthcare visits, helping obtain needed resources, reminding PLWH about medications, and serving as positive emotional support. These sources of material and social support served to alleviate uncertainties that could arise in the lives of PLWH and decrease their motivation to adhere to their HIV treatment. Reference to social networks primarily occurred at the individual level, with PLWH talking about supportive relationships with friends, family, or a spiritual community.

> I was very open with [my church community], telling them of my past history [HIV, drug use], what got to where I am, and I was not looked at any different. They actually embraced me like family and everything. And that was really my foundation, my recovery.
>
> (PLWH #5, male, Black)

> …with the help of [my husband] I'm able to deal with HIV. So, I have a good relationship with my family. They know that I'm positive and only my family know.
>
> (PLWH #3, female, Black)

It was also clear that staff at HIV organizations were well-liked, trusted, and seen as important sources of support. They promoted stability in patients' lives by not only providing access to care and resources but also by being supportive listeners.

> I started to eliminate outsider people. And just if I need to talk, I come here and talk to [staff name] or talk to anybody in this building.
>
> (PLWH #7, female, White)

> I think everybody at the health center, everybody on the team, the HIV team, has been super supportive and amazing. It's like I couldn't have done it without all of the support.
>
> (PLWH #21, male, Other)

This participant also noted how being more forthcoming with others about his HIV disease improved the quality of his healthcare and "actually got [him] further, in better relationships with people." Previously, he had not discussed his history of risk behaviors with healthcare providers which may have resulted in incomplete care.

Having a reason to live, exclusively noted by PLWH, can be an important component of establishing stability and motivating them to adhere to their HIV treatment. For example, several participants cited their desire to continue to take care of their children. One participant sent her rebellious teenage child to live with the father because the stress of parenting this child interfered with caring for her other child and her ART schedule. Once departed, she was able to establish a routine around her young child's schedule that also ensured that she adhered to her ART.

> …the bus gets there at 7:05 and [returns] at 3:20, not tired at all, hungry …[and when asked about how the child's schedule affects her own medication schedule] once I say it's time to go bed, when I take my pills, I drink a cup of water so they can [go] down. And I tell him time to go to bed. I give him his sippy cup and he goes to his bed. I go to mine and I don't see him until next day.
>
> (PLWH #1, female, Latinx)

Spirituality and religion provide some participants with an important source of stability and purpose in life that motivated them to adhere to HIV treatment. Their religious community was a highly valued social support and positive coping mechanism for some. Others noted how their spiritual or religious beliefs motivated them to adhere to their HIV treatment.

> I tell my daughter I'm trying to stay alive…So if it wasn't for my spirituality and my faith and my belief, I don't think I would have got, I wouldn't have made it.
>
> (PLWH #8, female, 55 years, Black)

> I know that god heals, he's the same yesterday, today, and forever more. So, my beliefs are more in that than any medicine because he is the healer. So I do take them, because god also made the science and made the medicines.
>
> (PLWH #24, female, Latinx, 58 years)

Although most reasons for living were based upon strong and positive socioemotional or spiritual/religious relationships, one participant's antipathy and resentment motivated him to adhere to his HIV treatment.

> I have a giant revenge plan against my mother...So my mother told me that I was, that I'm a monster and all this stuff. I want to prove to her that I am better than she is on every single level. And in order for that to happen, I need to be healthy and alive.
>
> (PLWH #20, male, Black)

Discussion

By considering the potential barriers and facilitators to HIV treatment linkage and adherence from the perspectives of HIV providers/experts and PLWH, the study findings identify how the themes of knowledge, stigma, and stability can manifest and possibly be addressed. The findings are generally consistent with other studies that examined treatment linkage and adherence [16,34,35]. However, those did not consider the important interplay between the individual and organizational levels or how residing in a smaller city might influence PLWH

motivation to seek and be retained in HIV care. Motivation is influenced by not only the HIV patients' unique situation but also the context in which they find themselves.

With respect to knowledge deficits, the finding of PLWHs' misinterpretation of the meaning of "undetectable" may be related, in part, to staff communication skills deficits when explaining about viral load and "undetectable." This misunderstanding may apply to only a few patients, but staff may need to verify that patients correctly understand the concepts of viral load and being undetectable as the implications of misunderstanding appeared to provide some with a rationale for postponing or stopping ART. Post-partum challenges such as increased family and child-caring responsibilities, managing their home and work schedules, and newborns' follow-up care appeared to represent substantial barriers to mothers continuing their own ART [36–38]. Similarly, the fact that some new mothers stopped their HIV treatment post-partum suggests that the importance of continuing ART post-partum was another knowledge deficit. It is possible that the responsibilities of caring for a newborn may have interfered with the mother's ART schedule. It is recommended that new mothers be encouraged to continue their HIV treatment and that implementation of interventions that promote care coordination and co-location of pediatric, obstetrics/ gynecology, and HIV services [39,40] should be considered.

The results also suggest that HIV patients desire staff to be better informed about nonmedical supports (e.g., yoga, meditation, guided imagery, supportive apps) and eligibility criteria to qualify for each locally available supplemental service or resource of potential benefit to patients [41]. That several PLWH discussed how religiosity/spirituality services were extremely important to their seeking and being retained in HIV care is consistent with some but not all studies [42–45]. Given the cultural diversity of PLWH in the U.S., our findings suggest that it is necessary to ask all patients about the importance of religiosity/ spirituality and assess whether their beliefs serve as potential barriers or facilitators to their HIV treatment.

The issue of stigma arose early in the epidemic and has diminished little over time [11]. The vast majority of stigmatizing experiences were reported by PLWH participants, and by contrast, HIV staff rarely mentioned stigma as an important factor influencing HIV care. Consistent with the literature, anticipated and internalized stigma [46,47] can be reduced by positive interactions with the healthcare system [8,13,48,49]. The study findings suggest several actions at the organizational level to reduce the potential for stigma. First, it is recommended that all staff should receive communication skills training and periodic "refresher" sessions to learn techniques that promote positive interactions. Renaming the organization, clinic, or department to omit any reference to HIV/AIDS and combining HIV and non-HIV services within the same physical space can minimize ways in which people could be identified as HIV patients, a concern that may be more common in smaller cities where ensuring anonymity or confidentiality may be challenging. These interventions can help decrease anticipated and internalized stigma by increasing HIV patients' sense of self-worth and trust in the organization as a "safe" environment [50]. This, in turn, can motivate patients to adhere to their HIV care [51].

The data indicated that PLWH whose basic needs were met and had stable lifestyles with adequate social support were better able to seek and be retained in HIV care. The study highlighted the importance of family, social networks or religious/spiritual communites as a means of providing stability, social support, and motivation for some PLWH to engage in the behaviors of seeking and being retained in HIV care. This suggests the need for universal screening for religious/spiritual needs and staff awareness of available religious/spiritual resources within the local community. Mental health and substance use disorders often were associated with sporadic or total discontinuation of ART. Consistent with other studies [25,52,53], co-locating these services may improve HCC outcomes by addressing these co-morbidities and merits further exploration in future studies. Satisfying housing, food security, and transportation needs may also improve HCC outcomes. The findings also suggest that patients' refusal to disclose their HIV status should be explored to determine whether their HIV care and quality of life could be improved by encouraging such disclosures to some members of their social networks.

Several study limitations should be noted. Potential biases may have been introduced, including participant reports on program strengths rather than weaknesses in the first study, self-report bias in the second study, and recall bias across both studies. In addition, relevant quotes from providers and experts in the first study include some from cities beyond Waterbury and Worcester. However, no thematic differences were noted in the themes across the cities in the first study. Finally, the qualitative findings and recommendations derive from a limited number of interviews and may not apply to HIV care in small cities in other regions of the country.

Conclusions

The study findings suggest that a multipronged approach that targets both the individual and organizational levels can improve HCC outcomes for PLWH who reside in smaller cities. At the individual level, these include interventions that increase HIV health literacy and awareness of available supplemental resources, ensure that basic needs are met, promote stable and positive social support networks, and give purpose or meaning to the person's life. At the organizational level, the potential for stigma may be reduced by implementing initiatives to improve staff communication skills and by omitting HIV/AIDS from the name of the organization or clinic. The latter is particularly important in smaller cities where ensuring patient confidentiality may be more challenging. A universal screening policy to assess patients' religiosity/spirituality and supplemental service needs is also recommended. Finally, strategies that ease time and transportation burdens for post-partum mothers and individuals with co-morbid conditions are recommended and include care coordination and co-location of HIV, pediatric, primary care, mental health, and substance abuse services.

Acknowledgements

The HIV Care Continuum in Small Cities of Southern New England: Perspectives of People Living with HIV/AIDS, Public Health Experts, and HIV Service Providers

Acknowledgements

References

1. UNAIDS. 90–90-90: An ambitious treatment target to help end the AIDS epidemic. 2014 https://www.unaids.org/en/resources/909090 Accessed March 16, 2020.

2. UNAIDS. 2025 Target setting and 2020–2030 resource needs and impact estimation. 2020 https://unaids.org/en/topics/2025_target_setting Accessed March 15, 2020.

3. Centers for Disease Control and Prevention. HIV Care Continuum. https:www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum Accessed July 1, 2020.

4. Connecticut Department of Public Health. HIV continuum of care, Connecticut, 2018. 2018 https://portal.ct.gov/-/media/Departments-and-Agencies/DPH/AIDS--Chronic-Diseases/Surveillance/statewide/graph_hiv_continuum_care.pdf?la=en Accessed March 15, 2020.

5. Massachusetts Department of Public Health. 2018 Massacusetts HIV/AIDS epidemiologic profile. The Massachusetts HIV care continuum. 2018 https://www.mass.gov/lists/hivaidsepidemiologic-profiles Accessed March 15, 2020.

6. Rhode Island Department of Health. HIV, sexually transmitted diseases, viral hepatitis, and tuberculosis surveillance report, 2018. 2018 https://health.ri.gov/publications/surveillance/2018/HIVSTD.pdf Accessed March 15, 2020.

7. Burnett JC, Broz D, Spiller MW, Wejnert C, Paz-Bailey G. HIV infection and HIV-associated behaviors among persons who inject drugs—20 cities, United States, 2012. MMWR Morbid Mortal Wkly Rep. 2015;67(1):23–28.

8. 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. [PubMed: 28340589]

9. Risher K, Mayer K, Beyrer C. The HIV treatment cascade in men who have sex with men, people who inject drugs and sex workers. Curr Opin HIV AIDS. 2015;10(6):420–429. [PubMed: 26352393]

10. Cha AE, Cohen RA. QuickStats: percentage of adults aged 18 years who did not take their medication as prescribed or asked for lower-cost medication to save money among those prescribed medication in the past 12 months, by number of chronic conditions — National Health Interview Survey, 2018. MMWR Morb Mortal Wkly Rep. 2019;68:990. [PubMed: 31671081]

11. Davtyan M, Olshansky EF, Brown B, Lakon C. A grounded theory study of HIV-related stigma in U.S.-based care settings. J Assoc Nurse AIDS Care. 2017;28(6):907–922.

12. Earnshaw VA, Reed NM, Watson RJ, Maksut JL, Allen AM, Eaton LA. Intersectional internalized stigma among Black gay and bisexual men: A longitudinal analsyis spanning HIV/sexually transmitted infection diagnosis. J Health Psychol. 2019;28(8):1083–1089.

13. Earnshaw VA, Smith LR, Chaudoir SR, Amico KR, Copenhaver MM. HIV Stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. AIDS Behav. 2013;17(5):1785–1795. [PubMed: 23456594]

14. Bauman LJ, Braunstein S, Calderon Y, et al. Barriers and facilitators of linkage to HIV primary care in New York City. J Acquir Immune Defic Syndr 2013;64(Suppl 1):S20–26. [PubMed: 24126445]

15. Beattie CM, Wiewel EW, Zhong Y, et al. Multilevel factors associated with a lack of viral suppression among person living with HIV in a Federally funded housing program. AIDS Behav. 2019;23(3):784–791. [PubMed: 30680539]

16. Colasanti J, Stahl N, Farber EW, del Rio C, Armstrong WS. An exploratory study to assess individual and structural level barriers associated with poor retention and re-engagement in care among person living with HIV/AIDS. J Acquir Immune Defic Syndr. 2017;74(Supp 2):S113–120. [PubMed: 28079721]

17. Nelson JA, Kinder A, Johnson AS, et al. Differences in selected HIV care continuum outcomes among people residing in rural, urban, and metropolitan areas—28 US jurisdictions. J Rural Health. 2018;34(1):63–70. [PubMed: 27620836]

18. Diepstra KL, Cunningham T, Rhodes AG, Yerkes LE, Buyu CA. Prevalence and predictors of provider-initiated offers among heterosexual persons at increased risk for acquiring HIV infection – Virginia, 2016. MMWR Morbid Mortal Wkly Rep. 2018;67(25):714–717.

19. Pitasi MA, Delaney KP, Brooks JT, DiNenno EA, Johnson SD, Prejean J. HIV testing in 50 local jurisdictions accounting for the majority of new HIV diagnoses and seven states with disproportionate occurrence of HIV in rural areas, 2016–2017. MMWR Morb Mortal Wkly Rep. 2019;68:561–567.

20. Henderson ER, Subramaniam DS, Chen J. Rural-urban differences in human immunodeficiency virus testing among US adults: findings from the behavioral risk factor surveillance survey. Sex Transm Dis. 2018;45(12):808–812. [PubMed: 29965946]

21. Messer LC, Quinlivan EB, Parnell H, et al. Barriers and facilitators to testing, treatment entry, and engagement in care by HIV-positive women of color. AIDS Patient Care and STDs. 2013;27(7):398–407. [PubMed: 23829330]

22. Mgbere O, Khuwaja S, Bell TK et al. Managing the personal side of health care among patients with HIV/AIDS: A pilot study of providers' perspectives. J Int Assoc Provid AIDS Care. 2017;16(2):149–160. [PubMed: 25331218]

23. Sutherland JL, Spencer GA. HIV screening intentions, behaviors, and practices among nurse practitioners. J Am Assoc Nurse Pract. 2017;29:264–271. [PubMed: 27860463]

24. Sutherland JL, Spencer GA. U.S. nurse practitioner beliefs about routine HIV screening: Predicting behaviors. J Assoc Nurses AIDS Care. 2019;30(3):270–278. [PubMed: 30601203]

25. Grau LE, Griffiths-Kundishora A, Heimer R, et al. Barriers and facilitators of the HIV care continuum in Southern New England for people with drug or alcohol use and living with HIV/AIDS: Perspectives of HIV surveillance experts and service providers. Addict Sci Clin Pract. 2017;12:24. [PubMed: 28965489]

26. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.

27. Braun V, Clarke V. Successful Qualitative Research: A Practical Guide for Beginners. 1st ed. Thousand Oaks CA: SAGE Publications Ltd; 2013.

28. Henwood K, Pidgeon NF. Qualitative research and psychological theorizing. Br J Psychol. 1992;83(1):97–111. [PubMed: 1559146]

29. Fisher JD, Fisher WA, Amico KR, Harman JJ. An information-motivation-behavioral skills model of adherence to antiretroviral therapy. Health Psychol. 2006;25(4):462–473. [PubMed: 16846321]

30. Hargreaves JR, Delany-Moretlwe S, Hallett TB, et al. The HIV prevention cascade: integrating theories of epidemiological, behavioural, and social science into programme design and monitoring. Lancet HIV. 2016;3(7):e318–322. [PubMed: 27365206]

31. Rosenstock IM, Strecher VJ, Becker MH. Social learning theory and the health belief model. Health Educ Q. 1988;15(2):175–183. [PubMed: 3378902]

32. Barroso J, Leblanc NM, Flores D. It's not just the pills: A qualitative meta-synthesis of HIV antiretroviral adherence research. J Assoc Nurses AIDS Care. 2017;28(4):462–478. [PubMed: 28286006]

33. Maslow AH. Motivation and Personality. 2 ed. New York, NY: Harper and Row; 1970.

34. Rochon D, Ross MW, Looney C, Nepal VP, Price AJ, Giordano TP. Communication strategies to improve HIV treatment adherence. Health Commun. 2011;26:461–467. [PubMed: 21432703]

35. Taylor BS, Fornos L, Tarbutton J, et al. Improving HIV care engagement in the South for the patient and provider perspective: the role of stigma, social support, and shared decision-making. AIDS Patient Care STDs. 2018;32(9):368–378. [PubMed: 30179530]

36. Adams JW, Brady KA, Michael YL, Yehia BR, Momplaisir FM. Postpartum engagement in HIV care: An important predictor of long-term retention in care and viral suppression. Clin Infect Dis. 2015;61:1880–1887. [PubMed: 26265499]

37. Rana AI, Gillani FS, Flanigan TP, Nash BT, Beckwith CG. Follow-up care among HIV-infected pregnant women in Mississippi. J Womens Health. 2010;19:1863–1867.

38. Swain CA, Smith LC, Nash D, et al. Postpartum loss to HIV care and HIV viral suppression among previously diagnosed HIV-infected women with a live birth in New York State. PLoS One 2016;11:e0160775. [PubMed: 27513953]

39. Anderson EA, Momplaisir FM, Corson C, Brady KA. Assessing the impact of perinatal HIV case management on outcomes along the HIV care continuum for pregnant and postpartum women living with HIV, Philadelphia 2005 – 2013. AIDS Behav. 2017;21:2670–2681. [PubMed: 28176167]

40. Momplaisir FM, Storm DS, Nkwohoreze H, Jayeola O, Jemmott JB. Improving postpartum retention in care for women living with HIV in the United States. AIDS. 2018;32:133–142. [PubMed: 29194122]

41. Pinto RM, Witte SS, Filippone PL, Baird KL, Whitman WR. Factors that influence linkages to HIV continuum of care services: Implications for multi-level interventions. Int J Environ Res Public Health. 2017;14:1355–1366.

42. Dalmida SG, McCoy K, Koenig HG, et al. Examination of the role of religious and psychosocial factors in HIV medication adherence rates. J Relig Health. 2017;56:2144–2161. [PubMed: 28285439]

43. Doolittle BR, Justice AC, Fiellin DA. Religion, spirituality, and HIV clinical outcomes: a systematice review of the literature. AIDS Behav. 2018;22(6):1792–1801. [PubMed: 28004218]

44. Finccharo-Kessler S, Catley D, Berkley-Patton J, et al. Baseline predictors of ninety percent or higher antiretroviral therapy adherence in a diverse urban sample: The role of patient autonomy and fatalistic religious beliefs. AIDS Patient Care STDs. 2011;25(2):103–111. [PubMed: 21235403]

45. Kendrick HM. Are religion and spirituality barriers or facilitators to treatment for HIV: a systematic review of the literature. AIDS Care. 2017;29(1):1–13. [PubMed: 27410058]

46. Earnshaw VA, Chaudoir SR. From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. AIDS Behav. 2009;13:1160–1177. [PubMed: 19636699]

47. Turan B, Budhwani H, Fazeli PL, et al. How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. AIDS Behav. 2017;21 (1):283–291. [PubMed: 27272742]

48. Eaton LA, Earnshaw VA, Maksut JL, Thorson KR, Watson RJ, Baumeister JA. Experience of stigma and health care engagement among Black MSM newly diagnosed with HIV/STI. J Behav Med. 2018;41:458–466. [PubMed: 29626312]

49. Rice WS, Turan B, Fletcher FE, et al. A mixed methods study of anticipated and experienced stigma in health care settings among women living with HIV in the United States. AIDS Patient Care STDs. 2019;33(4):184–195. [PubMed: 30932700]

50. Dang BN, Westbrook RA, Njue SM, Giordano TP. Building trust and rapport early in the new doctor-patient relationship: A longitudinal qualitative study. BMC Med Educ. 2017;17(1):32. [PubMed: 28148254]

51. Dang B, Westbrook R, Hartman C, Giordano T. Retaining patients in care: The role of initial patient care experiences. AIDS Behav. 2016;20(10):2477–2487. [PubMed: 26910339]

52. Castel AD, Tang W, Peterson J, et al. Sorting through the lost and found: Are patient perceptions of engagement in care consistent with standard continuum of care measures? J Acquir Immune Defic Syndr. 2015;69(S1):S44–55. [PubMed: 25867778]

53. Risher K, Mayer KH, Beyrer C. HIV treatment cascade in MSM, people who inject drugs, and sex workers. Curr Opin HIV AIDS. 2015;10(6):420–429. [PubMed: 26352393]
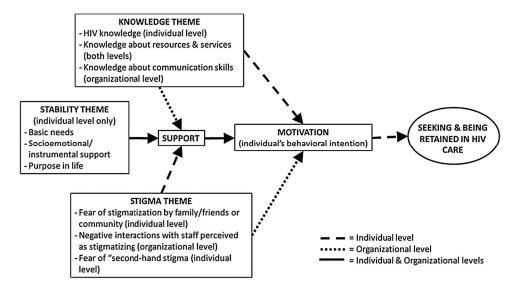
Figure 1.
Elements that Shape the HIV Care Continuum: Three themes and their sub-themes were identified that were thought to influence motivation to engage in the behaviors of seeking HIV care and being retained in care. These specific behaviors are critical to improving HIV Care Continuum outcomes and helping end the HIV epidemic.

Table I

Description of the PLWH sample in the second study

	Waterbury (N = 16)	Worcester (N = 18)	Total (N = 34)
Sex (male)[a]	5 (31.3)	9 (50.0)	14 (41.2)
Race/Ethnicity[a]			
Black	10 (62.5)	6 (33.3)	16 (47.1)
Latinx	4 (25.0)	8 (44.4)	12 (35.3)
White	2 (12.5)	2 (11.1)	4 (11.8)
Other	0	2 (11.1)	2 (5.9)
Age (years)[b]	46.3 (11.8); 25–68	45.4 (11.8); 21–63	45.8 (11.7); 21–68

[a]N (%)

[b]Mean (S.D.); Range