Fostering a “Feeling of Worth” Among Vulnerable HIV Populations: The Role of Linkage to Care Specialists

Michelle R. Broaddus, PhD,¹ Jill Owczarzak, PhD,²
Casey Schumann, MS,³ and Kimberly A. Koester, MA⁴

Abstract

To address barriers to adequate engagement in medical care among people living with HIV, Wisconsin's AIDS/HIV Program created a new position, the Linkage to Care (LTC) Specialist. Specialists provide intensive, short-term case management and patient navigation services for small caseloads of individuals at high risk of disengaging with medical care. Clients are eligible if they are newly diagnosed with HIV or new to medical care, recently released from incarceration, recently out of care, nonadherent to scheduled medical care visits, or have detectable viral load while in care. Interviews with 30 clients of Specialists were conducted to understand experiences with the program and medical care. Common themes included the ability of Specialists to navigate complex systems of care and support services, the unique role Specialists played in their clients' lives, and the challenges of transitioning out of the program. Although the primary goal of Specialists is to address barriers to medical care, they often adopted a holistic approach that also included housing, financial assistance, and other social determinants of health. Descriptions of the Specialist's role in implementation manuals focus on their functional roles and the services provided. However, clients often discussed the emotional support they received, especially for clients without strong social support networks. Many clients also desired an ongoing relationship with their Specialists even after discharge, but had been able to establish independence and self-efficacy. The LTC Specialists are resource-intensive considering their small caseloads, but fill an important gap in existing, often overtaxed case management systems.

Keywords: medical care engagement, case management, patient navigation, people living with HIV

Introduction

IN 2010, THE WHITE HOUSE OFFICE OF National AIDS Policy released the first National HIV/AIDS Strategy with specific goals for testing, linkage, retention, and viral suppression.¹ Known together as the treatment cascade or the HIV care continuum, improving these processes is critical to reducing HIV transmission.² Of the people living with HIV (PLWH) in the United States, 45% are not retained in care and only 25% have suppressed viral load.³ Effective linkage to and engagement in HIV care have positive health effects both for individuals and for the population. Positive CD4 count and viral load responses to antiretroviral therapy (ART)

initiation may result in life expectancies for PLWH compared with the general population.⁴ Viral suppression among PLWH is a key component of current treatment as prevention efforts: studies show that HIV transmission rates are near zero for those on ART and with undetectable viral load.⁵ However, sustained viral suppression cannot be achieved without persistence and sustained engagement in care.^{6,7}

For many individuals, HIV linkage to and retention in care are cyclical processes of engagement, disengagement, and reengagement in HIV care (i.e., cascade churn).^{7,8} Linking to HIV care after an initial diagnosis, reconnecting with care, and transitioning from one system of care to another (e.g., when moving to a new state or city or transitioning from

¹Center for AIDS Intervention Research, Department of Psychiatry and Behavioral Medicine, Medical College of Wisconsin, Milwaukee, Wisconsin.

²Bloomberg School of Public Health, Department of Health, Behavior, and Society, Johns Hopkins University, Baltimore, Maryland.

³AIDS/HIV Program, Wisconsin Department of Health Services, Madison, Wisconsin.

⁴Center for AIDS Prevention Studies, University of California, Department of Medicine, San Francisco, San Francisco, California.

prison to the community) can be particularly challenging. Barriers to linkage to HIV care include unstable housing, competing subsistence needs, denial of HIV status, stigma, previous negative experiences or mistrust of healthcare and medical professionals, lack of social support systems, mental health or other illness comorbidities, and substance abuse. HIV-positive people who are released from incarceration are particularly vulnerable. The first few weeks after release are characterized by increased risk of both HIV transmission and substance use, as well as difficulties establishing health insurance and community ties.⁹ These challenges translate to worse outcomes on the continuum of care postincarceration.¹⁰

A number of different approaches to improving linkage to care (LTC) have been developed. Evidence-based strategies for increasing engagement in care include linkage case management such as medical case management, patient navigation, intensive and targeted outreach to vulnerable communities, and clinic-level messaging advertising the importance of engagement in care.¹¹ The CDC Antiretroviral Treatment Access Study (ARTAS) LTC intervention is a strengths-based case management intervention designed for persons newly diagnosed with HIV.¹² This program has been successful in linking clients to services that include mental healthcare, housing, transportation, and financial or employment assistance and referring clients to Ryan White-funded clinics responsible for longer term care.

Other LTC programs use patient navigation in which navigators assist patients with making better use of available resources, developing effective communication with providers, and navigating multi-disciplinary treatment. Within HIV care, navigators typically do not have social work or nursing degrees, unlike case managers and early iterations of navigator programs from fields such as cancer care.^{12–14} Additionally, linkage interventions specifically for postincarcerated individuals are particularly needed and some have been developed.^{15,16} However, effectiveness of these programs is unclear as one prospective study found no difference between an intensive case management program compared with standard prerelease information.¹²

In this article, we explore clients' experiences in Wisconsin's LTC program, developed as part of the 2011 Health Resources and Services Administration-funded Special Projects of National Significance (SPNS). With this SPNS initiative—entitled Systems Linkages and Access to Care for Populations at High Risk of HIV Infection—six states (Louisiana, Massachusetts, New York, North Carolina, Virginia, and Wisconsin) developed and implemented interventions aimed at increasing linkage and retention in care and reducing HIV-related health disparities. In Wisconsin, the LTC program was conceptualized as a way to increase access to HIV care and optimize health outcomes with intensive short-term assistance in identifying and overcoming barriers to accessing and maintaining engagement in HIV care. Detailed information regarding the development of the program, further structural specifics, and initial lessons learned is published elsewhere.¹⁷

Eligibility for participating in the LTC program included being newly diagnosed with HIV, initiating HIV care for the first time, having been out of care for 60 days, being released from incarceration, or at risk of falling out of care (defined as missing two or more consecutive HIV medical appointments or having detectable viral load while prescribed antiretroviral therapy). The Wisconsin LTC program was designed to be a 9-month service, in line with a linkage case management model

aimed at fostering client independence. It also incorporated some aspects of patient navigation and medical case management such as standardized intake, assessment, service plan development and implementation, and transition planning. These approaches have a high degree of overlap, but generally linkage case management is distinguished by its short-term intensive focus on specific barriers to care engagement in comparison with longer-term medical case management that addresses all client needs for supportive services. Patient navigation is distinguished by its focus on advocating for clients within complex systems and identifying and coordinating existing resources to meet client needs.¹¹

The Wisconsin program was delivered by interventionists called Linkage to Care Specialists (herein referred to as Specialists). LTC Specialists represent a diversity of backgrounds, including individuals with bachelor's degrees and licensed clinical social workers. Their training program was developed during the pilot phase and included HIV counseling, testing, and referral; motivational interviewing; case management; insurance and benefits programs; and screening, brief intervention, and referral to treatment. Specialists maintained small caseloads of 15–20, resulting in more intensive and proactive service delivery.

The LTC program is client centered and, as a result, each client has a personalized service plan based on individual needs. Therefore, Specialists do not have a specific set of services that they need to provide or number of sessions to complete. Specialists are distinct from case management, in which the case managers assist their clients with a wide variety of needs; do not have a time limit; and have significantly larger caseloads. In theory, Specialists were charged focusing primarily on client barriers that prevent linkage to or engagement in HIV medical care. Specialists were to refer clients to existing case managers for assistance with needs that did not affect medical care. After discharge from the program, clients were transitioned to self-management or standard case management. In general, the LTC program operated on the idea that a dedicated Specialist can—in a time-limited framework—provide clients with the knowledge and skills necessary to actively participate in their healthcare and maintain engagement in care after discharge from the program.

The LTC Specialist position is a program; however, the qualitative study described here was designed to be able to contribute to generalizable knowledge and was under the oversight of an Instructional Review Board (IRB) as human subjects' research. Therefore, participation in the interviews was designated as human research, but participation in the program itself was not. However, to avoid confusion, we refer to participants as clients.

Methods

Procedures

In-person interviews were conducted with 30 clients of Wisconsin's LTC program in collaboration with the SPNS project's Evaluation and Technical Assistance Center (ETAC) team. A broadly standardized interview guide was developed as part of the ETAC cross-site qualitative evaluation aimed at understanding effects of linkage interventions conducted across the six states. This analysis focuses only on Wisconsin clients. Interviews lasted between 45 and 75 min

and probed clients' determinants for lack of engagement in care; previous HIV medical care experiences, including HIV diagnosis; their experiences in the LTC program; and expectations for transitioning out of the program.

Although an eligibility criterion for participation in this qualitative research study included being a current or former client of the program, participation in the study was independent of participation in the LTC program. Clients were invited to take part in interviews through their Specialists. Study personnel asked the Specialists to consider their clients and refer multiple clients representing a range of engagements in terms of client contact and services provided, from those highly engaged with their Specialists to those less engaged. One agency provides services primarily to a Latino/Hispanic population in Milwaukee; therefore, Spanish-speaking participants were also invited to participate and were interviewed by a member of the ETAC fluent in Spanish. Interviews were conducted at the agency where the client received services from a local qualitative evaluation team member or ETAC interviewer. Interviews were conducted in private rooms and audio recorded, and participants provided informed consent before interviews began. Procedures were approved by the local Medical College of Wisconsin IRB as well as the ETAC University of California, San Francisco IRB.

Participants

The 30 interviewed participants represented a range of ages, genders, races, and client types. Sixteen participants identified as African American, nine as white/Caucasian, three as Latino/Hispanic, one as African, and one as Indian. The age range was 22–68 years (mean = 39.7 years, median = 42 years). Eight participants identified as female and 12 as male. Three interviews were conducted in Spanish. At the time that interviews were conducted (winter/spring, 2013–2014), there were 10 Specialists housed across seven agencies, two in Madison, and five in Milwaukee. Between two and four clients per Specialist were interviewed. Eight clients were classified as at risk of disengaging from care, six were newly diagnosed, seven had been out of care, eight were postincarcerated, and one indicated that he was both newly diagnosed and postincarcerated.

Analysis

All interviews were transcribed verbatim, translated into English if necessary, and entered into a computer-based text file. Transcripts were then transferred to the qualitative data analysis software program, MAXQDA,¹⁸ to be coded and sorted by the local evaluation team. Transcripts were analyzed by the first and second authors, who conducted a directed qualitative content analysis.¹⁹ That is, analysis not only took place deductively and inductively by exploring major domains related to the study's overall aims and prior research on this same SPNS project as well as other similar programs but also remained open to unanticipated themes, patterns, and relationships. The coding tree was developed using an iterative and collaborative process to ensure reliability and consistency.^{20,21}

Qualitative data analysis proceeded through a multi-step process that included open coding and axial coding. In open coding, the first two authors independently read the same transcript and identified preliminary coding categories. During this open coding process, both *a priori* and inductive codes were generated and applied. *A priori* codes included codes that re-

flected key topics and content area in the interview guide, such as evaluation strategies and organizational context. Inductive codes or themes that emerged from the data, but were not explicitly asked in the interview, included motivation to maintain health and independence. We then formed an initial coding tree and the first two authors each individually coded the same interview using this initial coding scheme. After discussion, the coding tree was revised and a different interview transcript was coded using the revised coding tree. The process was repeated until local evaluation team members were satisfied with the final coding tree. The first and second authors then independently coded the remaining transcripts with the final coding tree, periodically checking for consistent use of codes.

The first author has been conducting qualitative research for 7 years, has published multiple articles using qualitative methods, and served as the lead qualitative evaluator on this SPNS project. The second and third authors are trained medical anthropologists. Both have led and participated in numerous qualitative studies that draw on multiple types of qualitative data, including interviews, focus groups, observation, and text analysis. The second author has also trained students, faculty, and researchers in the collection and analysis of diverse forms of qualitative data.

Transcripts were first coded with document-level variables that included participant gender, race/ethnicity, education level, housing status (e.g., homeless, transitional housing, and assisted living), marital status, and client type (out of care, newly diagnosed, postincarcerated, and at risk). These document-level codes allowed for comparisons within and between different categories of clients (e.g., experiences of newly diagnosed clients with those of postincarcerated clients). Then, the documents were coded with text codes that reflected key analytic topics, including relationship with the Specialist, experiences with the Specialist compared with other case managers, perceptions of quality of care, transitioning out of the LTC program, and social support.

During axial coding, categories and themes were explored in relation to each other, and broader themes that transcended and combined existing codes were identified. Further analysis compared and contrasted experiences within and among categories of participants (e.g., recently out of care vs. newly diagnosed) around major themes such as ideas about personal responsibility and independence, experiences with bureaucratic systems, and the presence or absence of social support outside the LTC program. Data analysis also explored how an LTC program fits within clients' lives and how the program identifies and meets the needs of its clients.

Results

Specialists' role within the system of care and support services

Holistic management. Illustrating the client-centered patient navigation aspect of the Specialist role, clients discussed how Specialists helped them navigate the complex system of both HIV medical care and support services, including housing, mental health, and substance use treatment. Specialists helped clients understand what services were available within these systems and navigate the associated bureaucracy: obtaining and filling out forms, understanding eligibility criteria, and coordinating among different sources of service provision and support programs. While they still

prioritized medical engagement, Specialists approached their clients from a holistic perspective that took into account their broad health and social needs beyond HIV disease management. For example, a 33-year-old woman from Africa had been out of HIV care and suffered from multiple health conditions. She was in the process of looking for a new place to live. She described her Specialist as “concerned about my overall health and well-being”:

After meeting with [my Specialist], then—basically, she introduced me to the necessary things that I need to do, as far as dealin’ with the sickness. The clinics. She connected me with the clinics... She asked me if I needed food or help with food, residency, housing and—insurance, and stuff like that... She’s openin’ doors for me that otherwise, honestly speaking, I would have never known were available to me. So she’s been very useful to me and helpful. And I guess whenever she feels that I need anything, she brainstorms with me on how we can get this done and what we can do to get this done.

This quote illustrates that although Specialists were instructed to refer out to medical case managers for needs that did not have to do with medical care, what constituted a barrier to medical care was often unclear as support needs may impact care engagement.

Navigation of multiple systems. The Specialist can serve as a knowledge broker to help clients navigate through these multiple complex systems, even if only raising clients’ awareness about what programs and services exist, as illustrated above. Providing clients with this type of information was important because while multiple agencies may offer similar services, limitations or strict eligibility requirements forced clients to move between multiple systems to receive the necessary services or support. For example, one client received temporary housing through the Department of Corrections following his release from prison. However, he was required to become affiliated with another agency to access transportation assistance, vocational training, and more permanent housing (48 years old, white male, post-incarcerated).

Involvement in multiple systems can, at times, result in bureaucratic entanglements for clients. Specialists can play a key role in helping clients negotiate them. One LTC program client who had been incarcerated wanted to apply for Supplemental Security Income (SSI) before his release from prison. Below, he describes his inability to file the appropriate paperwork and the key role his Specialist played in the application process. [Note: this participant worked with both a Specialist and a prison-based social worker, whom he referred to as a case manager.]

I had thought—I had signed up for [SSI] before me leavin’ prison, with some assistance from Linkage to Care, you know because I could never get the forms that I needed to even file.... And I’m beggin’ and pleadin’ with the—with the case manager there. [The Health Services Unit] is tellin’ me to go ahead and file. [My clinic] is tellin’ me, go ahead and file, they’re gonna support my claim, so at least you can get supplemental security income. The prison is kinda blockin’ it, even though [my clinic] has the knowledge of my illness... [My case manager] called [my Specialist] for me, and they [collaborated] together and got me the applications that I needed and I did manage to file it before I left prison, a month before I left prison, I did. And it’s crazy, because the rules say,

Social Security even acknowledged it, when they give you the pamphlet: 30 days before you leave prison, file! It’s right there on the sheet. But the prison was still tryin’ to be adverse and blockin’ it... but through Linkage to Care and [my clinic], I did manage to get it filed... What would I have been doin’ [without my Specialist]? I don’t know. I... probably would’ve been homeless. I don’t say that lightly at all. [53 years old, African American male, post-incarcerated]

Specialists as part of the larger system of care. Although Specialists were well poised to aid clients’ navigation of multiple service programs within the system of care, they themselves were also part of this complex system, which sometimes contributed to lack of clarity of the Specialists’ role. Some clients saw the Specialist as another representative of a relatively amorphous-seeming system of traditional medical case managers, HIV care providers, the criminal justice system (e.g., parole agents and probation officers), and housing case managers. Other clients did not distinguish between the Specialist and the clinic or organization that the Specialist was housed in. For example, the largest participating organization housing the highest number of Specialists is a designated medical home, with programs including medical case management, housing case management, behavioral health and substance use treatment, pharmacy, food pantry, and support groups.

As the exchange below illustrates, LTC program clients sometimes conflated the Specialist, the case manager, and the agency rather than viewing them as distinct services (often with very different funding streams to support them):

P: I’d been associated with [agency] before—before I got incarcerated ... I’d been with [agency] for almost two years... I think what I first just basically expected was a lot of help with my medical care. I didn’t expect that they would go to the extremes that [the agency] goes. I mean, they helped me with all aspects of my life. I never would have imagined that they would help me with some of the things they helped me with... I use the food pantry, I have an AODA counselor here, I have a social worker here, I have my case manager here. [48 years old, white male, post-incarcerated]

In this example, the client conflated the LTC program with the organization’s standard of care and package of services that it offers to all clients.

Clients’ past experiences with case management and other service systems may have led them to approach the prospect of working with a Specialist with hesitation and skepticism. For example, some participants thought that the Specialists would engage in a type of surveillance of their lives and behaviors rather than assistance. One participant described how his probation officer continually asked him questions about his living situation, required him to get permission to travel across state lines, and always needed to know the exact address and phone where he was staying. As a result, when asked if he wanted to enroll in the LTC program, he was concerned:

I was wondering, “What, are they gonna be checkin’ on me on every little thing I do?” I was just wondering. Concerned... I was just tryin’ to figure out, what is a case manager like? I was thinkin’ like... “Oh, this is gonna be a lady. She gonna be comin’ by to see me all the time!” I was thinkin’ kinda like that, but then I was like, I don’t know—it’s kinda different in

the situation. [23 years old, African American male, post-incarcerated and newly diagnosed]

After being in the LTC program, he realized that the Specialist was a resource to help with whatever was needed in a tough time rather than a monitor.

In general, the model of service provision that Specialists provided—as experienced by clients of the LTC program—blended roles typically relegated to a range of individuals: patient navigators (care coordination, advocacy within systems, and attending appointments with clients), linkage case managers (short-term narrow focus on medical care engagement barriers), medical case managers (use of individualized service plans, addressing psychosocial needs as related to medical engagement), and psychosocial support counselor. However, clients may struggle to fully understand how Specialists fit into the larger system that the Specialist themselves help the client to navigate.

Specialists' unique role: various aspects of social support

Functional support. As illustrated above, the Specialist role is conceptualized as very functional, providing clients with skills and coordinating services, with small caseloads that facilitate a high level of care. Indeed, the Specialist served a very practical role that clients recognize and appreciate, beyond scheduling appointments for them and helping them obtain, organize, and submit the paperwork required of various social welfare programs. However, this function-specific definition of the Specialist does not capture how clients perceived Specialists who helped them beyond service provision. From clients' perspective, Specialists were similar to case managers, but better, in that they were able to provide more support and pay more attention to them than other service providers. Clients also viewed Specialists as taking the initiative to check on their well-being and facilitate access to resources:

P: When I was in Milwaukee. I can't think of what his name was, but I had a case manager at [agency]... It was okay. It wasn't like—I only dealt with him like once a month. Whereas here [in the LTC program] they'll call me and remind me of things, when necessary, but sometimes they phone a couple times a week or—she'll call just because I haven't heard from her or she hasn't heard from me, she'll say, "What's goin' on?" I don't know. Maybe their caseloads were bigger down there, I would imagine. [45 years old, white male, out-of-care]

Emotional social support in the absence of traditional support systems. Some participants described situations in which they lacked emotional and other forms of social support from friends and family. The Specialist filled this role. A 61-year-old African American man had been diagnosed with HIV about a year before the interview. He recounted his experience getting on HIV medication and being hospitalized for a stroke. After being released from the hospital, he lived with his daughter until she could no longer take care of him due to her work schedule. He described his Specialist as finding him when he needed to be found. He was able to talk with his Specialist about the way his family treated him and described his Specialist as his "motivational speaker" who helped him get through a difficult time. His Specialist filled an important gap in social support that stemmed from his

inability to disclose his HIV status to his family (apart from his daughter) out of concern that they would react negatively and his children's already constrained ability to assist him financially. A Specialist could provide clients with a sense that someone cared about them, particularly when they struggled to find similar support from their family or friends:

She would call and ask how I was doing. And what was going on here? And did I like it? Or was I going to run away? I know it sounds silly but it made me feel better to think that somebody other than myself care about what happens to me. Especially when your own family is giving you such a raw time. Now I'm strong enough again, mentally and physically to handle it. Where before I don't think I could have took it without [my Specialist]. [61 years old, African American male, out of care]

Filling gaps in social support may be particularly important for clients who have been incarcerated. Upon release, the LTC program can fill gaps in supportive networks that may have deteriorated while clients were incarcerated:

I did let her know that my support system - had all but deteriorated. I've got some people out here, but they're not really in a position where they can really help me out... So I wasn't at the forefront no more but I wasn't mad at nobody because I did this to myself. But anyway, my relationship with them was kinda strained, so I didn't really have a support system out here at all. [53 years old, African American male, post-incarcerated]

Emotional social support and finding meaning. Often coupled with receiving emotional support from Specialists was the feeling of finding meaning as a result of working with the Specialists. In general, the LTC program clients explained that their Specialist and the program more generally gave clients a feeling of worth instead of a feeling of worthlessness, hope, and desire (54 years old, African American male, postincarcerated). As he summed up:

It makes me feel better knowing someone... [is] concerned about me because all of my life I've been an outcast. But [my Specialist] was calling me to give me some kind of better meaning. Sometime I might not even be feeling good that day and she would call and just hearing her voice—it's kind of putting me back in the state of mind where I'm being positive and stuff.

A 23-year-old African American woman recently diagnosed with HIV described herself as not having any support from her family. She had not disclosed her status to her family, saying that she felt ashamed to have HIV and was worried about how her family would react to her diagnosis. Her Specialist provided a source of support beyond helping her with her HIV-related care:

She was very uplifting at the point in time when I came in, when I first met her. She was very uplifting to me. So—I should give this a try, because I don't give a lot of—I don't go into a lot of programs. And I don't know how they be like, so I don't even bother to participate in anything. But I felt like at that point in time I needed help and I needed support to get through this and she was there for me at that point in time. So I felt like she was a real big help.

In summary, although clients described many instances of functional help with barriers to their medical care and other support needs, they often attributed the success of the

program to more intangible aspects of the unique relationship that clients had been able to forge with their Specialists.

Discharging clients and fostering independence

Client reluctance to discharge. By definition, the LTC program is time limited: clients are discharged by 9 months based on the assumption that their time with the Specialist prepared them to maintain their engagement in HIV medical care on their own or with the assistance of a traditional case manager. In line with a linkage case management model, Specialists aim to bolster skills that will enable clients to manage their care and support needs with increased independence. However, lack of clarity of the Specialist role within the extremely complicated system of care may result in confusion about why discharge is necessary if clients perceive little difference between their Specialist and the medical case manager to whom they are transferred:

P: If I could, I actually would do the whole entire thing over again, but I'm—from my understanding, I don't think I can, or I have to wait or something. I don't know. But she did tell me that regardless, it's not like she's leaving or anything like that, so if I had any problems or just wanted to stop by and say hi, she's here, or whatnot. So that was actually nice to hear, when she said that. Then the fact that the program that I'm going to be going in is pretty much similar, from my understanding. [27 years old, African American male, at risk of falling out of care]

Clients were generally aware that the LTC program was time limited. However, when some clients were asked how long they had been working with their Specialist and how much longer they were going to be in the program, they responded that they would like to work with the Specialist or maintain some sort of relationship (e.g., periodic check-ins) for as long as possible. For example, a 50-year-old African American man who had recently been diagnosed with HIV knew that the LTC program was of limited duration but also wished “she could always be there for me.”

For those clients who understood the time limitation on the program, some expressed anxiety about leaving, even if they seemed ready. One 27-year-old male client was newly diagnosed with HIV and had been working with his Specialist for several months. He understood that his time in the LTC program was limited, but felt somewhat ambivalent about no longer working closely with this particular Specialist: “I'm hoping I can still go to her and you know check in once in a while, but no I don't think so. I feel like we got things sorted out the messy part in the beginning the treatment and we were just talking and stuff. I feel like we got it.”

LTC program clients expressed anxiety about transitioning out of the program because they had invested time in telling their Specialist their story and establishing a rapport: “I definitely be nervous, definitely. Whenever I go to a new doctor somebody who doesn't know me, I don't like just going over everything again” (29 years old, white female, out of care). Likewise, a 44-year-old white man recently released from jail explained that he had built a relationship with his Specialist and was not looking forward to undergoing this process yet again. After describing that he felt anxious about leaving the LTC program and starting with someone new (such as a case manager), he explained why:

Well, because she knows my—and has talked to my probation agent... now she'll be gone so now I gotta get somebody in to be dealing with my probation agent and my attorney. I'd like to have her at least around till I find a place to live.

In other words, Specialists often know clients' stories within the context of a system (including healthcare system) that is often marked by a lack of continuity of care. Clients expressed an emotional burden of disclosing that story to more and more people over time (including doctors and other case managers). In a way, the Specialist became a repository of memory that countered the fractured nature of care that clients may have received in the past.

Supporting clients' self-reliance. Raising awareness about available services and facilitating access to information and resources were seen as steps on a path toward independence and self-sufficiency. LTC program clients often described their Specialist as both motivating and helping:

As far as transition-wise, I'm tellin' you, she has really addressed the issues. She really has. While motivating me to do more... When you sit down with a person and they let you know what they gotta offer you and then they ask you on the other side, “Well, now how can I help you be independent, too?”.. That's something she's working on - askin' me my points of interest, like occupation-wise and stuff. And she even took it upon herself to gather certain information, which has been useful. [53 years old, African American male, post-incarcerated]

Later, in the interview, this client referenced the 9-month limit to the program and felt confident that with the help of the Specialist, he would be ready to successfully transition out of the program: “My wings will be spread and ready to fly before the 9 months.”

Discussion

Numerous LTC programs have been developed to address critical moments in the HIV care continuum in which those living with HIV are most vulnerable to disengagement from care. The LTC program described here helps clients address many factors that may undermine their ability to access and maintain HIV care and develop the skills necessary to remain engaged in HIV care over time.

The interviews with clients of Wisconsin's LTC program revealed several key points about what clients saw as the most valuable aspects of this program. First, many LTC program clients were enrolled in multiple programs and received services within a variety of bureaucratic systems. Their Specialists served as a centralized point of care that helped them navigate these often complex systems. Second, Specialists often provided necessary social and emotional support for clients, particularly in contexts in which they faced stigma about their HIV diagnosis or social relationships that may have eroded during periods of incarceration or instability. Finally, these aspects of the LTC model have led many clients to want to stay in the program, although they understood that the program was time limited. They generally thought that they had gained skills and confidence necessary to remain engaged in care after the program ended. This may be, in part, due to their increased healthcare empowerment or the degree to which individuals feel informed and collaboratively engaged as active participants in their healthcare,

which has been shown to be associated with medication adherence among PLWH.²²

These insights from this study have several implications for potential dissemination or expansion of this LTC program model. First, through their Specialists, clients felt important, uplifted, and a sense of hope. When they spoke of the benefits of the LTC program, clients often highlighted aspects of their relationship with their Specialist beyond meeting basic needs. In many ways, the LTC program underscored the precariousness of clients who lack other support systems. Clients' desire to remain in the LTC program raises the question of whether (and how) HIV care programs can attend to people's needs beyond immediate healthcare needs and basic subsistence, particularly for clients whose personal social ties may be weakened or absent. If the Wisconsin or other LTC programs are to be scaled up, consideration must be paid to patient needs such as adequate social support that providers can feasibly address. Additionally, given the intensive nature of some of these relationships, adequate support systems must also be in place for the Specialists so that they do not experience burnout.^{23,24}

Second, eligibility criteria for enrollment into the program ensured that clients were either currently not in care or at risk of not remaining engaged in medical care. Therefore, LTC clients represent those of highest acuity, and the embeddedness of these clients in multiple systems of care may represent unique issues not faced by the majority of PLWH. The experiences of these high-acuity clients highlight existing gaps in services within a context of already overtaxed case management systems. Therefore, these high-intensity services are needed, yet may require somewhat restrictive triage and continued review of eligibility criteria to assure enrollment of high-acuity clients. For such clients, Specialists are in a unique position to solve complicated problems within several bureaucracies and potentially alleviate some associated stress. Therefore, future LTC programs and their Specialists must be able to handle multiple appointments and services. Specialists must be highly trained and familiar with the available services within a given area, the eligibility criteria for these programs, and how to help clients access them.

Third, continued efforts to ensure clients understand the unique role of linkage interventions and Specialists who deliver these intense services are also needed. Qualitative research in the pilot phase of this same SPNS project suggested that clients often did not distinguish between Specialists and case managers.²⁵ Despite explicit differences defined in subsequently developed training manuals and other materials, participants in this study still did not make clear distinctions between the Specialist and traditional case manager or other systems' representatives. The LTC program, by definition, focuses primarily on addressing client barriers that prevent linkage to or engagement in HIV medical care. This is in contrast to case management, in which the case managers assist their clients with all needs, such as housing or food security. However, in practice, almost all client needs could conceivably affect engagement in care. Therefore, Specialists often did not refer out to case management, which may have contributed to confusion. Future LTC programs may benefit from additional refinement of role definitions.

Fourth, many clients also worked either previously or concurrently with medical case managers, housing case managers, social workers, and other service providers, which

may further complicate understanding of roles and expectations. Case management and LTC services are similar primarily in the processes used to serve clients, including conducting assessments, developing individualized service plans, and making referrals for services. However, Specialists have the ability to navigate complex systems and develop personal relationships that were highly valued by clients. It is unclear whether clients' positive experiences in the LTC program are artifacts of the small caseloads of LTC Specialists (15–20 clients, compared with 30 or more for case managers) or the uniqueness of the LTC program model, as they are confounded. Regardless, when clients work with other social service providers or transition to a longer term case manager, they may have elevated expectations of these individuals based on their positive experiences with the Specialist and intensity of services. Given that at least one client indicated that they anticipated needing case management essentially forever, this is not a trivial concern.

Finally, the degree of standardization across sites and clients has implications for how these programs are evaluated. Typical process assessments of successful program completion or LTC include number-based indicators such as the number of appointments kept, number of communications with the client (email, text messages, and letters), and time spent with clients. Additionally, preliminary quantitative outcome data collected as part of this same SPNS project indicate that clients in the LTC program were more likely to be engaged in care and have suppressed viral load than propensity score-matched controls while enrolled and at more than 12 months postintervention.²⁶ Publication of results is forthcoming, with 68% and 72% of LTC clients who were engaged in care and virally suppressed, respectively, compared with 38% and 44% of matched case-controls. However, while such indicators and outcomes are important, they may not fully reflect what clients value about the program or other dimensions of success, such as the program's ability to address social isolation and stigma that clients experience.

Limitations

Although Specialists were instructed to invite clients who varied in their level of engagement in the LTC program, it is likely that more highly engaged and motivated clients agreed to be interviewed. Similarly, attempts were made to recruit individuals who had been offered LTC services and had declined, but these were unsuccessful. In addition, participants were still enrolled in the program at the time of the interview. Therefore, these data cannot provide perspective regarding possible longer term effects or why individuals may enroll in the program, but then become lost to follow-up (10–15% of enrollees). We also did not capture data regarding how long participants had been living with HIV, which would have added additional context to their work with the Specialists.

Additionally, most Specialists were housed within clinics that specifically catered to HIV specialty care, and previous research indicates increased screening and other positive primary care outcomes for PLWH seeing providers with a high volume of HIV-positive patients.²⁷ Therefore, further research should also attempt to generalize the LTC model to individuals seeing nonspecialist providers and include additional positive health outcomes in addition to viral load. It is also currently unclear what makes LTC programs effective:

dosage, length, intensity, specific services, or interpersonal relationships, for example.

Postincarcerated clients referred to several challenges unique to their situation, including limited housing options, variable existing social support networks, transportation difficulties, and complicated histories with healthcare. Previous research also suggests similar challenges to linkage and viral suppression postincarceration and that patient navigation can aid in relinkage.^{28,29} However, the limited number of postincarcerated clients limited the ability to do deep analysis on this subsample.

Future cross-site evaluation efforts of this SPNS initiative conducted by the ETAC will attempt to answer some of these questions as they will have the ability to compare different dosages of interventions across multiple sites and can pool together postincarcerated clients. Finally, although the interview guide did not specifically probe for comorbidities such as substance use, many participants spontaneously discussed their histories of substance use. Some drew direct connections between substance use and engagement in care, and others discussed substance use within a constellation of difficult life circumstances as well as coping strategies. Additional inquiry into these connections is a ripe area for future work.

Conclusions

Clients of the LTC program highly valued the Specialists' ability and flexibility to address their unique needs, whether communicating with a child welfare specialist, filing paperwork for social security benefits, or simply calling to ask how they were doing. Other studies of LTC programs have similarly highlighted that these programs offer highly individualized service plans without standard operating procedures or specific guidelines regarding type, frequency, and duration of contact with clients.^{12,30} The original ARTAS structured the case management around five specific sessions for relationship building, identifying needs and addressing barriers, and encouraging and/or attending clinic appointments, all to be completed within 90 days with no further contact.³¹ In a similar study based upon ARTAS, the number of sessions was increased to 10, structured around relationship building, assessment, linkage to resources, and disengagement. In both of these ARTASs, many clients did not attend all of their scheduled visits, but this did not necessarily lead to negative outcomes. Wohl et al. concluded that the use of one size fits all LTC strategies may be unnecessarily resource-intensive and not sufficiently client centered.¹² Our results bolster this claim.

Specialists engaged in relationship building, linkage to resources, encouraging and supporting medical care engagement, and transition into regular case management or self-management, yet these aspects of the role were structured around client readiness and ongoing communication rather than a certain number of sessions. This also allowed some clients to remain in the Specialists' caseloads for a short amount of time if needs were met easily (e.g., a newly diagnosed individual who had good support and only needed initial LTC). In contrast, some clients remained in caseloads for longer periods if they had more complex needs (e.g., lack of housing). In summary, allowing for the Specialists to tailor their approach to each client meant a wide variety of levels of engagement in the program, but service relationships were centered on clients' needs rather than a structured progression of steps.

Acknowledgments

Funding for this study was provided by Health Resources and Services Administration Special Projects of National Significance, "Systems Linkages and Access to Care for Populations at High Risk of HIV Infection," (grant number H97HA22698). Manuscript preparation was supported, in part, by a National Institute of Mental Health Center Grant (grant number P30MH052776). The authors extend many thanks to the Linkage to Care Specialists and participants who shared their experiences with them.

Author Disclosure Statement

No competing financial interests exist.

References

- Office of National AIDS Policy (ONAP). National HIV/AIDS Strategy for the United States, 2015. Available at: <https://obamawhitehouse.archives.gov/sites/default/files/uploads/NHAS.pdf> (Last accessed May 19, 2016).
- Gardner EM, McLees MP, Steiner JF, del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis* 2011;52:793–800.
- Skarbinski J, Rosenberg E, Paz-Bailey G, et al. Human immunodeficiency virus transmission at each step of the care continuum in the United States. *JAMA Intern Med* 2015;175:588–596.
- May MT, Gompels M, Delpech V, et al. Impact on life expectancy of HIV-1 positive individuals of CD4+ cell count and viral load response to antiretroviral therapy. *AIDS* 2014;28:1193–1202.
- Attia S, Egger M, Müller M, Zwahlen M, Low N. Sexual transmission of HIV according to viral load and antiretroviral therapy: Systematic review and meta-analysis. *AIDS* 2009;23:1397–1404.
- Hall HI, Holtgrave DR, Maulsby C. HIV transmission rates from persons living with HIV who are aware and unaware of their infection. *AIDS* 2012;26:893–896.
- Nosyk B, Lourenço L, Min JE, Shopin D, Lima VD, Montaner JS. Characterizing retention in HAART as a recurrent event process: Insights into 'cascade churn'. *AIDS* 2015;29:1681–1689.
- Rebeiro P, Althoff KN, Buchacz K, et al. Retention among North American HIV-infected persons in clinical care, 2000–2008. *J Acquir Immune Defic Syndr* 2013;62:356–362.
- Westergaard RP, Hess T, Astemborski J, Mehta SH, Kirk GD. Longitudinal changes in engagement in care and viral suppression for HIV-infected injection drug users. *AIDS* 2013;27:2559–2566.
- Iroh PA, Mayo H, Nijhawan AE. The HIV care cascade before, during, and after incarceration: A systematic review and data synthesis. *Am J Public Health* 2015;105:e5–e16.
- Mugavero MJ, Amico KR, Horn T, Thompson MA. The state of engagement in HIV care in the United States: From cascade to continuum to control. *Clin Infect Dis* 2013;57:1164–1171.
- Wohl AR, Dierst-Davies R, Victoroff A, et al. Implementation and operational research: The navigation program: An intervention to reengage lost patients at 7 HIV clinics in Los Angeles county, 2012–2014. *J Acquir Immune Defic Syndr* 2016;71:e44–e50.
- Ali-Faisal SF, Colella TJ, Medina-Jaudes N, Scott LB. The effectiveness of patient navigation to improve healthcare

- utilization outcomes: A meta-analysis of randomized controlled trials. *Patient Educ Couns* 2017;100:436–448.
14. Bradford JB, Coleman S, Cunningham W. HIV system navigation: An emerging model to improve HIV care access. *AIDS Patient Care STDS* 2007;21(S1):S49–S58.
 15. Booker CA, Flygare CT, Solomon L, et al. Linkage to HIV care for jail detainees: Findings from detention to the first 30 days after release. *AIDS Behav* 2013;17:128–136.
 16. Nunn A, Cornwall A, Fu J, Bazerman L, Loewenthal H, Beckwith C. Linking HIV-positive jail inmates to treatment, care, and social services after release: Results from a qualitative assessment of the COMPASS program. *J Urban Health* 2010;87:954–968.
 17. Schumann CL, Westergaard RP, Meier AE, Ruetten ML, Vergeront JM. Developing a patient navigation program to improve engagement in HIV medical care and viral suppression: A demonstration project protocol. *AIDS Behav* 2017; [Epub ahead of print]; DOI: 10.1007/s10461-017-1727-4.
 18. MAXQDA, software for qualitative data analysis, 1989–2017, VERBI Software–Consult–Sozialforschung GmbH, Berlin, Germany.
 19. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–1288.
 20. Carey JW, Morgan M, Oxtoby MJ. Inter-coder agreement in analysis of responses to open-ended interview questions: Examples from tuberculosis research. *CAM J* 1996;8:1–5.
 21. Ryan G. Measuring the typicality of text: Using multiple coders for more than just reliability and validity checks. *Hum Organ* 1999;58:313–322.
 22. van den Berg JJ, Neilands TB, Johnson MO, Chen B, Sabeti P. Using path analysis to evaluate the healthcare empowerment model among persons living with HIV for antiretroviral therapy adherence. *AIDS Patient Care STDS* 2016;30:497–505.
 23. Ginossar T, Oetzel J, Hill R, Avila M, Archiopoli A, Wilcox B. HIV health-care providers' burnout: Can organizational culture make a difference? *AIDS Care* 2014;26:1605–1608.
 24. Rowan D, Lynch S, Randall E, Johnson H. Deconstructing burnout in HIV service providers. *J HIV/AIDS Soc Serv* 2015; 14:58–73.
 25. 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.
 26. Schumann C. Improved linkage, engagement and viral suppression: Preliminary findings from a patient navigation demonstration project. Paper presented at: National Ryan White Conference on HIV Care and Treatment, Washington, D.C., 2016.
 27. Landovitz RJ, Desmond KA, Gildner JL, Leibowitz AA. Quality of care for HIV/AIDS and for primary prevention by HIV specialists and nonspecialists. *AIDS Patient Care STDS* 2016;30:395–408.
 28. Montague BT, Rosen DL, Sammartino C, et al. Systematic assessment of linkage to care for persons with HIV released from corrections facilities using existing datasets. *AIDS Patient Care STDS* 2016;30:84–91.
 29. Koester KA, Morewitz M, Pearson C, et al. Patient navigation facilitates medical and social services engagement among HIV-infected individuals leaving jail and returning to the community. *AIDS Patient Care STDS* 2014;28:82–90.
 30. Maulsby C, Kinsky S, Jain KM, et al. Unpacking linkage and reengagement in HIV care: A day in the life of a positive charge care coordinator. *AIDS Educ Prev* 2015;27:405–417.
 31. Gardner LI, Metsch LR, Anderson-Mahoney P, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS* 2005;19:423–431.

Address correspondence to:
 Michelle R. Broaddus, PhD
 Center for AIDS Intervention Research
 Medical College of Wisconsin
 2071 N. Summit Ave
 Milwaukee, WI 53202

E-mail: mbroaddus@mcw.edu