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ORIGINAL PAPER

Lost to Care and Back Again: Patient and Navigator Perspectives on HIV Care Re-engagement

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Abstract Engagement in HIV care is critical to achieve viral suppression and ultimately improve health outcomes for people living with HIV (PLWH). However, maintaining their engagement in care is often a challenging goal. Utilizing patient navigators, trained in an adapted ARTAS intervention, to help re-engage out-of-care PLWH has proven to be a valuable resource. This qualitative study describes the encounters between PLWH (n = 11) and their care re-engagement navigators (n = 9). Participants were interviewed in-person; interviews were transcribed and analyzed using the strengths model of case management. PLWH shared how working with navigators increased their motivation to return to HIV care and assisted them to overcome barriers that were a hindrance to care engagement. Navigators described a strengths-based approach to working with their clients, thus helping facilitate PLWH care re-engagement goals and successes. Results from this study may inform the development of effective HIV navigation programs to re-engage out-of-care PLWH, often the hardest-to-engage.

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Introduction

Suppression of HIV replication leads to improved health outcomes for persons living with HIV (PLWH), reduced patient mortality, and transmission of infection to others [1]. To achieve viral suppression, engagement in HIV care is critical at each step of the care continuum, from diagnosis, to linkage, to sustained engagement in care, including the initiation and maintenance of antiretroviral therapy (ART) [2, 3]. Despite the known benefits of viral suppression, achieving this benchmark is challenging for many PLWH. The Centers for Disease Control and Prevention (CDC) estimated that of the 1.2 million PLWH in the United States (US) in 2011, only 40% had attended medical appointments during that calendar year, and less than one-third were virally suppressed [2]. Engagement in HIV medical care, defined as two visits in 12 months, > 90 days apart, is one of the strongest predictors of initiating ART [4] and achieving viral suppression [4–7], while missing HIV care visits increases morbidity and mortality [8–12].

To address low rates of engagement in care and increase viral suppression rates, strategies to improve retention in care represent a promising approach. One example is a strengths-informed approach which focuses on leveraging client strengths and recognizing the talents of each individual, rather than focusing on their perceived deficits, weaknesses, or illnesses [13, 14]. The strengths model of case management, as defined by Marty et al. is comprised of six domains: engagement; strengths assessment;

personal planning; resource acquisition; collective collaboration; and graduated disengagement [15]. The CDC utilized this strengths model approach to increase linkage-to-care for newly-diagnosed PLWH in their Antiretroviral Treatment and Access to Services (ARTAS) program, which demonstrated improved rates of linkage to care in two effectiveness studies [16, 17].

Patient navigation is one intervention showing promise for increasing engagement and retention in care for PLWH. Initially developed for cancer patients, patient navigation has been demonstrated to decrease barriers to retaining PLWH in consistent HIV care [18]. Other studies have also found that outreach interventions which incorporate aspects to help alleviate the cyclical nature of falling out of care and address additional barriers to medical care, such as patient navigation, can improve health outcomes and retention in care for PLWH [19]. However, within the research literature, interventions that focus on re-engaging HIV-infected individuals who are already out-of-care or lost-to-care are not as ubiquitous as linkage programs. In a systematic review of best practices using evidence-based interventions for linkage and retention programs for PLWH between 1996 and 2014, the authors found no evidence-informed re-engagement interventions qualified for inclusion in their review [20]. Since then, several papers have described the use of strengths case management for re-engagement, demonstrating limited success [21, 22].

In the study we describe here, in 2012, a state-level public health team of patient navigators, called State Bridge Counselors, was developed to address the need to link and re-engage PLWH in care [21]. As part of the development and standardization of the State Bridge Counselor intervention, components of the strengths-based ARTAS case management model were incorporated into State Bridge Counselors' work with newly-diagnosed and out-of-care HIV clients. The full ARTAS program requires extensive time and personnel resources. Thus, during the initial pilot phase of the intervention and implementation of ARTAS, an abridged version of ARTAS strengths-based case management was used. The abridged version of ARTAS included an emphasis on the engagement domain of the strengths-based model. The engagement domain focuses on the case manager (or navigator) utilizing various engagement techniques such as the navigator trying to meet the consumer at a time and place most comfortable to the consumer, as well as engaging the consumer in shared experiences while focusing on the consumers interests and abilities. (Please see Table 1 for the 11 components included in the engagement domain). Beginning in 2012, the engagement domain of the strengths-based case management model was included in all State Bridge Counselor trainings. After the initial pilot phase of the State Bridge Counselor intervention in 2012, it was expanded statewide and all State Bridge Counselors were trained in the abridged version of ARTAS emphasizing the engagement domain of the strengths case management model.

The research aims for this qualitative study were two-fold: To describe the encounters between PLWH who were lost-to-care and the State Bride Counselors working with these individuals to re-engage them in care; and to characterize the adaptation of and use of the engagement domain components included in ARTAS within these encounters.

Methods

Overview of the State Bridge Counselor Intervention

This study utilized a qualitative approach to explore the perspectives of HIV patients who had fallen out-of-care and the State Bridge Counselors, North Carolina Division of Public Health (NC DPH) employees, who located them and helped them re-engage in HIV care as part of the NC-LINK State Bridge Counselor intervention. Medical staff at HIV clinics referred HIV patients who were out-of-care to the State Bridge Counselors. Each clinic developed its own definition of what was considered out-of-care for patients, ranging from 6 to 9 months without attending a medical appointment. The clinics then created their own processes and procedures for creating out-of-care lists, attempting to locate patients, and sending referrals to the State Bridge Counselors for patients that they could not locate [23]. State Bridge Counselors worked with re-engaging PLWH to address barriers to health care; the goal of the program was achieved once the patient had attended one HIV medical visit. A full description of the NC-LINK State Bridge Counselor intervention is described in Swygard et al. [23]. State Bridge Counselors differ from case managers in the time-limited nature of their work. Generally, case managers follow their patients for an extended period of time, helping with various needs as they arise, while State Bridge Counselors, in a navigator role, focus on the short-term goal of helping the patient to re-engage in care and attending a HIV medical appointment. For the remainder of this paper, State Bridge Counselors will be referred to as "navigators".

Study Setting

In-depth, semi-structured in-person interviews were conducted with PLWH in 2014 and with navigators in 2015. Written informed consent was obtained from all subjects prior to their participation in the audio-recorded interviews, which lasted 45–60 min. All study procedures were

Table 1 Strengths model of case management-engagement. Adapted from: Marty et al. [15]

1	When a consumer describes him or herself or experiences, the case manager assists the consumer with identifying any achievement, interest, or aspiration embedded in the event
2	Case manager uses every opportunity to identify the consumer's interests, talents, abilities, and resources
3	Case manager discusses roles, responsibilities, and mutual expectations of the case manager-consumer relationship
4	Once service is requested, case manager does whatever it takes to meet with a new consumer
5	Case manager scheduled meetings at a time that is most comfortable for the consumer
6	Majority of contacts happens out of the office
7	Case manager and consumer are involved in an activity that is enjoyable to the consumer as a backdrop for getting to know each other (e.g., cup of coffee, shooting baskets, walking)
8	Case manager informs consumers of their rights as a client
9	If attempts to meet with consumer are unsuccessful, case manager discusses barriers in supervision
10	Case manager and consumer may discuss the interests and experiences they have in common
11	Consumers are encouraged to ask purposeful self-disclosing question of the case manager

conducted with the appropriate Institutional Review Board (IRB) approvals.

PLWH Recruitment

A purposive sampling technique was used to identify and recruit participants for the study. Inclusion criteria were: PLWH who were at least 18 years old; able to speak and read English; had worked with a navigator for care re-engagement; and were willing to participate in an interview. Per IRB requirements, PLWH were first approached by their designated navigator, who reviewed the study information and obtained verbal consent to be contacted by a research team member for follow-up. The research team then called PLWH to provide additional information, answer questions, and schedule a time and location for informed consent and interview processes.

A total of 41 PLWH potential participants were contacted by navigators, 20 (49%) of whom were unable to be reached by the navigators after multiple attempts and three (7%) who declined follow-up by research staff. The remaining 18 PLWH (44%) agreed to be contacted by the researchers; of these, seven were unable to be reached and 11 (61%) were consented and interviewed by research staff.

Navigator Recruitment

Navigators were contacted via email or phone for individual interviews by a member of the research team. Inclusion criteria included being employed as a state-level navigator and willing to participate in a qualitative interview. All nine NC navigators provided their written consent and agreed to participate.

Procedures

PLWH interviews were conducted by a pair of researchers at a location of the participant's choice. Interview topics covered included social history, HIV medical history (e.g., experiences with HIV care, diagnosis, and psychosocial needs) and intervention experiences (e.g., experiences with navigator, services received from navigator, and strengths and weaknesses of navigator program). At the conclusion, participants received a $40 gift card to compensate them for their time.

Individual navigator interviews were conducted by a research team member in a private office. The purpose of the navigator interviews was to elucidate their perspectives on: re-engagement efforts and the modified ARTAS intervention; interactions with and services provided to clients; common barriers experienced by clients; and overall challenges and successes in their work as navigators. Navigators were not provided an incentive, per state employee guidelines.

Data Analyses

All interviews were professionally transcribed verbatim and the transcriptions were compared to the original recordings to ensure accuracy. Identifying information was removed from transcripts prior to analyses. Analyses were conducted on each dataset separately (PLWH interviews as one group; navigator interviews as another group) using an iterative process. Due to the small numbers of interviewed PLWH, it was thus not feasible to analyze the data in terms of navigator/PLWH pairs. All interviews were double-coded by two independent researchers using QSR International NVivo® 10 software for the PLWH interviews and NVivo® 11 software for the navigator interviews. Upon

completion, analysts of the research team reconvened to identify characteristics of the data that aligned with the engagement domain of the strengths based model. The experiences in engagement in care as described by PLWH and navigators were then analyzed within the context of the components of the engagement domain of the strengths model of case management (Table 1) [15]. When presenting these data, the engagement model describes "case managers" and "consumers," referred to as "navigators" and "PLWH," respectively, in this study. To ensure participant confidentiality, individual demographic information is not presented within quotes.

Results

Participant Demographics

Demographic data, including age, gender, race, education and sexual orientation, were collected for the PLWH and the navigators, with the exception of sexual orientation which could not be obtained for the navigators due to their status as state employees. Among the 11 PLWH, there were five males, five females, and one transgender woman, with a median age of 39 years old and a range of 24–57 years old (Table 2). The majority of PLWH participants were African American (73%), identified as heterosexual (73%) and did not have any post-high school education (64%). Among the nine navigators, the median age was 37 years old, with a range 29–54 years. Seven out of the nine navigators (78%) were female, over half (56%) were African American and two navigators had an ethnicity of Latino/a. Per navigator job requirements, all nine navigators possessed a minimum of a Bachelor's degree.

Table 2 Demographic characteristics of study participants

	PLWH n = 11	State bridge counselors n = 9
Age (median)	39	37
Gender		
Male	45.5%	22.2%
Female	45.5%	77.8%
Transgender	9.0%	–
Race		
Black/African American	72.7%	55.6%
White	18.2%	44.4%
Other	9.1%	–
Highest level of education completed		
Some high school	36.4%	–
High school	27.2%	–
Some college	36.4%	–
College graduate	–	100%
Sexual orientation		
Heterosexual	72.7%	na
Gay/bi-sexual	18.2%	na
Did not identify	9.1%	na

na not available

Strengths Model of Case Management-Engagement

The *first* component of the engagement domain states that navigators work with PLWH to identify successes, interests, or goals within PLWH experiences. Several of the navigators shared that they practice active listening to PLWH stories to identify interests.

> I get there, I really do listen a lot… I really listen to that person, I would say, for the first, however long that takes… (Navigator01)

Quite a few PLWH stated that although they were initially hesitant to open up, the navigators' eagerness to listen made it easier to share their experiences, as one PLWH commented:

> When I see that you really care, then when you're talkin' to me, I'm ready to listen. (PLWH02)

One PLWH described enjoying walking around the yard during a home visit from the navigator:

> It was awesome. [Navigator] was a very nice [person], very concerned, just – [navigator] just made me feel very comfortable. It was easy to talk to [navigator]…We walked around the yard and talked and – [navigator] just made me feel comfortable. (PLWH08)

A majority of navigators discussed how they framed their conversations with PLWH within a strengths context. One navigator explained this approach:

> Even though they're not in [HIV] care for five years…but still seeing, 'Okay, this is something I can pat you on the back for because you did this. Now, if I can get you to see the good in this, let's kind of move past this to the next step, to get you to value getting into care.' (Navigator02)

PLWH echoed this and described that when navigators reacted positively and addressed their apprehension to return to HIV care, they felt more open to returning to care:

> The impact to me [of navigator] is encouragement. I don't have a loss of hope today. (PLWH01)

> I was just at a point where it really didn't matter to me. And when [navigator] called, I don't know, it was just something in the way that [navigator] talked to me, like [navigator] was concerned. [Navigator] didn't even really know me, and – it made me say, 'Okay.' (PLWH03)

The *second* component of the engagement domain focuses on navigators leveraging resources, opportunities, and interests to help PLWH. PLWH expressed that navigators emphasized that care re-engagement was the ultimate goal, but they were there to provide support and other resources:

> [Navigator] did make it clear that getting me back into seeing another doctor was the most important thing, but [navigator] has helped with other things. (PLWH06)
>
> Knowing that there's someone that you can call to help you when you're in need, basically, and knowing that I don't have to do this all by myself. I just have to use my resources. (PLWH07)

Navigators also described tailoring their work with clients to identify individual needs and targeted behaviors to improve PLWH care engagement and health outcomes. One navigator summarized this approach:

> What is it that I can actually say or what barrier that they're saying they have that I can kind of get them to overcome? So I may not be able to get them to overcome that family piece…. But maybe I can talk about the getting-on-meds piece. So it's just kind of tailoring it to that individual. (Navigator07)

PLWH described a variety of approaches utilized by navigators that they thought enhanced their interest in returning to HIV care, namely the navigators' understanding of their priorities in life. As one PLWH stated simply: *"[Navigator] knows the things that I care about."(PLWH02)* Another PLWH shared that the navigator stressed the importance of care engagement to remain healthy and involved as a parent:

> [It] just says there are people out here that care, and [navigator] was sayin' that I need to – for my kids and for myself - to be healthy…. And [navigator] just said, 'Once you go do it, you'll feel good about yourself.' And when I went back [to care] with [navigator], I felt kinda good. I felt I could do it. I felt motivated. (PLWH04)

Navigators echoed the importance of family as a motivation for care engagement, as was described by this navigator who leveraged a PLWH's interest in being reunited with his/her children:

> [PLWH] really cares about his/her children. So let me try to swing it to say, 'Okay. Let's get you into care because we want you to be well enough to fight to get your children back…but you can't do that if you're not well… So kind of keying in on some buzzwords to say, 'Okay. This is something that they really care about.' (Navigator07)

The *third* component of the engagement domain involves the navigator clearly explaining to the PLWH expectations for their working relationship, including delineating roles and responsibilities of both parties. In addition, the *eighth* component focuses on the importance of navigators informing PLWH of their rights. Several navigators shared that during their initial meetings with clients, they inform PLWH of the goals of their interactions. One navigator described this process by saying:

> Letting you [the PLWH] talk, tell me where you've been, what's going on, and what's keeping you from getting into care. Then we try to address those as you tell me. We're just trying to find out what can we do to get you back into care. That's my goal, to get you back into care. (Navigator02)

PLWH also stated that navigators introduced themselves and their role in trying to re-engage the PLWH in care, as evidenced by this PLWH's comments:

> [Navigator] told me [their] job description…is…helps bring people back into care, that's been out, because – like I was sayin', I went off my medicine and I wasn't goin' to my appointments. [Navigator] called to see how [they] could help. And I'm glad that [navigator] called… (PLWH03)

Navigators shared that they often need to explain patient/consumer rights, as many PLWH do not know that they are entitled to switch medical providers:

> I've had some who are out of care who I've called and they're like, 'Well, I didn't like going to that provider.' It's like, 'Okay, that's fine. I can give you somebody else…' and they're like, 'Okay, I'll do that,' and they actually go. (Navigator05)

Navigators also shared that it is their role to explain the rights of PLWH to choose not to engage in medical care. Although the goal of the navigators' work with PLWH is care re-engagement and they try to exhaust every resource to achieve this objective, PLWH ultimately possess the autonomy to decide whether to return to HIV care. One navigator summed this up as follows:

> A lot of times, though, you do have those patients that nobody can do anything right… So I'm going to treat them just as respectfully as I can. I understand that

> that's where they're at right now… I'm still going to make sure that if something does come up, just remember I'm here. (Navigator01)

Navigators spoke about their need to establish and share expectations for maintaining boundaries with clients, but also allowing PLWH to call when it was convenient for them, as this navigator explained:

> What I tell them is, 'I do have a state cell phone and it really doesn't matter what time you call me… If I can't [answer], just leave me a message and I'll get back to you as soon as possible.' (Navigator01)

Another navigator described redirecting clients to maintain appropriate boundaries:

> I'm about a rapport and getting people to feel comfortable to talk to me, but when I feel like it's crossed the line between professionalism and my personal life, I'm like 'Okay…Let's shift this back over here.'…Because I want my clients to feel like they can tell me anything and they feel comfortable, but there are limits. I don't want to cross that line. (Navigator02)

Navigators also discussed their termination process with PLWH. Almost all navigators explained that though they typically end their interactions with PLWH when at least one medical visit is attended, they generally leave the opportunity open for PLWH to contact them in the future. One navigator explained:

> I kind of always leave the door open on their side. That's important to me. 'If anything were to come up in the future that would make it hard for you, I want you to know I'm still here. So this is my number. Here's my card. (Navigator01)

A few of the PLWH were aware of this transition and felt ready to manage without regular support from the navigator, as evidenced by this PLWH's comments:

> I hate – [navigator] is leavin' me! [Laughs]… [Navigator] said, 'I just want to get you consistently doing this, to where I can just let you go. I'll be there but I have to let you go.' And this is the initiative that I'm taking, to be more responsible, doing things that I need to do, positive things that I need to do, to keep my mind clear, I'm doing. (PLWH01)

However, about half of the PLWH stated they were unaware that their relationship with the navigator would end.

The *fourth* and *fifth* components of the engagement domain describe that navigators should do whatever it takes to meet with PLWH once they have identified a patient in need of services, and to be flexible with times to work with them. One navigator explained the effort it takes to engage some PLWH who are mistrustful when initially contacted:

> If [PLWH] don't answer, I leave a message, and if they haven't called back in a day or two, then I go out to the address and look for them. If they're not at home, I'll leave a confidential letter and then I'll try calling again… (Navigator05)

Several PLWH also referenced the persistence of navigators—that navigators contacted them repeatedly until they were ready to talk—and that this persistence often motivated them to return to care, as described by this PLWH:

> Like I say, [navigator] motivated me to make that appointment, and the help… It was just – okay, [the navigator] keeps calling, keeps calling, keeps calling! I need to call my doctor, or I need to get to where I usually go, so that way I can tell [navigator] I've been to the doctor. (PLWH05)

PLWH also shared the persistence of the navigators to address dissatisfaction PLWH had with their medical care and the importance of navigators helping to find solutions that addressed their needs. One PLWH described how the navigator helped to change doctors:

> [Navigator] listened to my concerns about [institution 1], and [navigator] hooked me up with [institution 2]. [Navigator] made the initial appointment. … [Navigator] didn't say, 'Oh, you've missed your appointments and you need to' – [navigator] didn't just run in and scream and yell and then leave again. [Navigator] stayed there to help me… (PLWH06)

Another PLWH described the flexibility in navigator contacts:

> And when I first talked to [them], I told [them], I said…you need to call me back later 'cause I don't wanna talk right now. And [navigator] did. [Navigator] didn't give up on me. (PLWH01)

The *sixth* engagement domain component references that the majority of contacts between navigator and PLWH should take place outside of the office. Many PLWH discussed the importance of navigators transporting them to their medical appointments, which addressed their immediate transportation needs and provided an opportunity for social connection and support. As one PLWH described,

> While I'm in the car, and then we get here, we talk. We talked so long the last time [navigator] passed the house! [Laughs] (PLWH04)

Navigators also made home visits where HIV-related information was provided:

> My first time meeting [navigator] was actually when [navigator] came to my house to get me to come to [institution]. [Navigator] came to the house and [navigator] wanted to talk to me about it and [navigator] gave me a little bit of information and some cards and pamphlets… (PLWH08)

PLWH also described the advantages of attending appointments with navigators and that this played a vital role in helping to navigate health systems, as this PLWH described checking out more than one clinic:

> [Navigator] told me that [navigator] would make an appointment for me for [institution], and even go with me. [Navigator] said that we could go to [institution 2] together, and we would walk around and look and check it out and see how things are. (PLWH05)

Although the engagement domain consists of eleven components, analyses revealed that not all components were relevant to the navigator-PLWH relationship. The *seventh* component of the engagement domain states that navigators and PLWH get to know one other while involved an enjoyable activity. This was not an element that was included in the program due to the short and highly-focused nature of the intervention. The *ninth* component addresses the need for supervision. Clinical supervision is not part of the program structure. However, several navigators described seeking and receiving supervisory support for any difficulties that arose. The *tenth* and *eleventh* components address personal sharing between the case manager and the client. This was not an expectation in the program training and most navigators came from roles in state government with an emphasis on professional boundaries. As previously mentioned, the navigators described taking steps to maintain these boundaries. Thus, the absence of these four components are the main way in which this navigator program diverged from the strengths-based model components.

Discussion

This qualitative study explores the perspectives of recently re-engaged PLWH and the team of State Bridge Counselors who served as their care navigators and who were trained in a modified ARTAS method, utilizing the engagement domain. To our knowledge, this is the first study that assesses the perspectives of PLWH and their care navigators about their experiences working with one another through the HIV care re-engagement process. In addition, the State Bridge Counselors interviewed were navigators, who experienced and reported the work first-hand, unlike other studies that have focused on interviewing medical providers rather than the case managers or navigators conducting linkage and retention work [24, 25].

PLWH shared that working with the navigators increased their motivation to return to HIV care and their ability to overcome barriers that kept them out-of-care. Navigators explained that a strengths-based approach to listening to PLWH and meeting PLWH where they were in life helped facilitate care re-engagement goals. These findings are similar to those of Brun and Rapp [26], which was the first to examine the perspectives of clients receiving strengths-based case management [26]. Their investigation also found clients possessed positive perceptions of strengths-based case management and highlighted the importance of stressing client strengths and the positive impacts of relationships between case managers and clients [26]. Wohl et al. [22] also demonstrated that the ARTAS strengths-based approach was successful in re-engaging out-of-care PLWH, with 85% of participants re-engaged in care within 6 months and 94% within 12 months. Additionally, 82% of the participants were retained in care, defined as attending a second appointment within 3–12 months after initial re-engagement [22]. The implementation and outcomes of the State Bridge Counselor intervention are published in Swygard et al. [23] and Seña et al. [27].

Strengths Model

In the State Bridge Counselor program, ARTAS was used as the basis for the strengths model of re-engagement. Although the strengths model contains six domains: engagement; strengths assessment; personal planning; resource acquisition; collective collaboration; and graduated disengagement, due to the time-limited nature of the navigator role, ARTAS was abbreviated to include key components from the engagement domain [15]. The components of the engagement domain that were not included in the training were also not reported by the navigators. These included clinical supervision, personal disclosure, and discussions of common interests. Additionally, large caseloads in vast geographic areas and additional navigator work tasks meant that, in general, shared activities between the navigators and PLWH, as one of the components of the engagement domain, was limited to providing transportation.

Although the navigator strengths approach did not include all components of the engagement model, these results suggest that those components that were included in the trainings were actively adopted by the navigator. This is consistent with other findings that the full ARTAS intervention is not necessary for every PLWH and shorter

use of the intervention is still effective [22]. Navigator focus on leveraging PLWH experiences and strengths to help motivate them to return to care was a successful approach to re-engage lost-to-care PLWH. The State Bridge Counselor program also focuses on enhancing the qualities of a navigator that improve PLWH engagement in care, an important component of HIV care retention programs that has been well-documented in the literature [18, 28–30]. Navigators and PLWH alike spoke of navigator persistence and tailoring of services and resources provided to address the unique needs of PLWH.

This study demonstrated many positive aspects of the navigator program and relationships between navigators and PLWH; however, areas for improvement were identified, namely the process of transitioning out of working with the navigators after re-engagement in care was achieved. Almost all navigators spoke of their perception of clear communication of time-limited work with PLWH and their goal to transition PLWH to clinical care, but PLWH often seemed unaware of the finite nature of the relationship. One explanation for this is that although navigators stated they share the transition process with clients, clients did not feel the relationship had concluded because they were told the navigator was available in the future for help. A more clear transition plan established from the beginning may help PLWH better understand the goals of the State Bridge Counselor program.

Limitations

Despite its strengths, this study is not without limitations, namely selection bias on the part of the PLWH who participated and social desirability bias for PLWH and navigators in their responses. Among the navigators, this was mitigated by interviews being conducted by personnel from outside of the health department. In addition, despite all nine State Bridge Counselors volunteering to be interviewed, their length of time in their positions varied. Thus, not all navigators were reflected evenly in the analyses phase, depending on their in-depth knowledge and length of employment as a state-level navigator. On the client side, PLWH were reminded of confidentiality and interviewers were trained to maintain a neutral interviewing approach. In addition, the sample size of 11 PLWH is not representative of all out-of-care PLWH receiving navigator services; however, saturation of themes was reached [31]. The small sample size of PLWH and low interview enrollment is another limitation, perhaps due to the nature of this hard-to-reach population.

Conclusions

Despite these limitations, this study provides an important contribution to the literature on HIV care engagement programs. Results from this study may inform the development of effective HIV navigation programs to re-engage PLWH who have fallen out of care, who often need different approaches for effective re-engagement. These approaches live outside of standard communication of mail or phone calls that are generally used for reaching and engaging individuals in HIV care. It is particularly important to locate and connect these individuals back to care due to the negative clinical and public health consequences for those who do not maintain ART and medical care regimens or sustain viral suppression. The State Bridge Counselor intervention seemed accepted by the interviewed PLWH and the program continues, even after the conclusion of the NC-LINK project. Further research is necessary that explores qualitative client and provider experiences and quantitative assessments of short and long-term outcomes of interventions that aim to improve HIV care retention and re-engagement.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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

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