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### Authors

Fuller, Shannon M  
Koester, Kimberly A  
Maiorana, Andres  
[et al.](#)

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# “I don’t have to do this all by myself”: Systems Navigation to Ensure Continuity of HIV Care for Persons Leaving Prison

Shannon M. Fuller<sup>1</sup> · Kimberly A. Koester<sup>1</sup> · Andres Maiorana<sup>1</sup> · Wayne T. Steward<sup>1</sup> · Michelle R. Broaddus<sup>2</sup> · Katie Lass<sup>3</sup> · Sophia Zamudio-Haas<sup>1</sup> · Evelyn Byrd Quinlivan<sup>4</sup> · Janet J. Myers<sup>1</sup>

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## Abstract

Ensuring continuity of and retention in care after release from prison is critical for optimizing health outcomes among people living with HIV. As part of a large federal initiative, we conducted qualitative interviews ( $n = 24$ ) with individuals living with HIV and recently released from prison in four states to understand their experiences in different navigation interventions to improve access to HIV care post-release. Interventions were delivered only in prison, only in the community, or in both settings. While the interventions varied by design, overall, participants appreciated the breadth of support received from interventionists, including health system navigation, case management and social support. Even when individuals leaving prison were returning to clinics that they were familiar with, systems navigation supported continuity of care. Our findings elucidate why navigational support was instrumental, and underscore the value of a variety of types of navigation programs in facilitating continuity of care and reintegration post-prison.

**Keywords** HIV · Incarceration · HIV care continuum · Navigation · Qualitative research

## Introduction

An estimated one in seven people living with HIV (PLWH) leave correctional facilities each year in the US [1], and many struggle to access care and treatment upon release [2–5]. One study found that only five percent of individuals leaving prison filled antiretroviral (ART) prescriptions soon enough to avoid a gap in HIV treatment [3], placing them at risk of poorer health outcomes and reducing the preventive benefits of sustained treatment [6]. However, meeting basic needs like housing, food, safety, and, in many cases, finding treatment for mental illness and substance use, present

difficulties for people attempting successful reintegration into society while managing HIV care [7, 8].

In this paper, we present findings from qualitative interviews with individuals who had been recently released from prison, and who were enrolled in navigation interventions through the *Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative*, henceforth called the “Systems Linkages Initiative.” The 5-year initiative was funded in 2011 by the Health Resources and Services Administration (HRSA) as a Special Project of National Significance, which funded state health departments to develop and implement interventions to address challenges with linking and retaining vulnerable populations in HIV care [9]. The University of California, San Francisco (UCSF) received separate funding to conduct a cross-state evaluation of all implemented interventions. In total, the initiative encompassed 18 unique interventions across six US states that aimed to improve care outcomes among persons newly diagnosed with HIV, out of care, and at risk of being out of care by connecting different sectors of the public health system such as surveillance, counseling, and testing to improve linkages between these systems across each state [10]. The states had broad flexibility to design and implement programs tailored to the epidemic and populations at

✉ Shannon M. Fuller  
shannon.fuller@ucsf.edu

<sup>1</sup> Center for AIDS Prevention Studies, University of California, San Francisco, 550 16th Street, 3rd Floor, UCSF Mailcode 0886, San Francisco, CA 94158, USA

<sup>2</sup> Center for AIDS Intervention Research, Medical College of Wisconsin, Milwaukee, WI, USA

<sup>3</sup> The Policy and Research Group, New Orleans, LA, USA

<sup>4</sup> Institute for Global Health and Infectious Diseases, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

risk in their jurisdictions. We characterized the “systems navigation” interventions as those that relied on individuals such as patient navigators, linkage to care specialists, and case managers to help clients link between various services and remain engaged in HIV care.

Although we previously discussed a larger set of navigation interventions within the initiative [10], we have chosen here to focus specifically on the experiences and perspectives of people transitioning from prison back to community life because their needs were potentially different than other clients in the initiative. For intervention clients who were not corrections-involved, a navigation intervention was usually deployed because the individual had either never linked to HIV care or had fallen out of care. By contrast, many of the individuals leaving prison were actively engaged in care while incarcerated. They were offered navigation services because the transition back to community life is a point of high vulnerability, during which there is a distinct risk a person may disengage from HIV services. Services for these individuals are also relatively unique in terms of their overall objective. Fundamentally, a navigator assisting a client leaving prison is trying to maximize the likelihood the client will stay in care (what we traditionally would label as “retention” in studies focused on the HIV care continuum). But doing so requires transitioning the client to a new care system (which is more akin to linkage or re-engagement in care continuum work in that it involves initiating care at a new facility). The analyses we present in this paper help us to understand the factors influencing these individuals’ transition to care in the community and to characterize how the navigation interventions helped to address the barriers clients encountered after leaving prison.

## Methods

### Study Context: Intervention Description

In Table 1 we provide brief descriptions of interventions from the four states that specifically provided navigation services to individuals who had been or were about to be recently released from prison: (1) Louisiana’s video conferencing program, (2) Massachusetts’ peer-nurse team, (3) North Carolina’s bridge counseling program, and (4) Wisconsin’s linkage to care program. Two of the navigation interventions (in Louisiana and Wisconsin) specifically assisted PLWH who were soon-to-be released from prison. The other two interventions (in Massachusetts and North Carolina) did not focus on a prison or post-prison population, but happened to include recently released individuals as clients if they were determined to be in need of retention support after they had established care in the community.

The interventions differed not only in terms of the setting (e.g., prison, community, or both), but also regarding who delivered the navigation services and for the extent of time. The video conferencing program in Louisiana involved a pre-release intake session between the client and a case manager at an agency serving the geographical region where the client was scheduled to be released. Technically the intervention ended with the completion of the video conferencing session, though many clients continued to work with the same case manager who had conducted the video conference once they were released to the community. The peer-nurse team in Massachusetts involved an HIV-positive peer and a nurse who collaborated to provide clients with medical case management and non-medical support services. The team worked with clients for 6–12 months, depending on the clients’ needs. Bridge counselors in North Carolina, who were former disease intervention specialist (DIS) workers, located clients in need of linkage and/or retention support, and offered services to assist with appointment attendance. In Wisconsin, linkage to care specialists provided enhanced medical case management and care engagement services to clients for up to 9 months after release.

For this analysis, we categorized the interventions based on their scope of work. Due to variations in program design, the four interventions focused on different components of the care cascade for PLWH leaving prison: transitioning care to community providers (Louisiana), retention in care among PLWH who had been recently released from prison but who had already established care at a community facility and were thought to be vulnerable to falling out of care (Massachusetts and North Carolina), or transitional care and retention in care (Wisconsin). We aimed to illustrate client experiences across all of the systems navigation interventions in the four states.

### Sample and Recruitment

As part of our larger cross-site evaluation, from January, 2014 to April, 2015, we interviewed 73 participants in the four states featured in Table 1. The subset of participants selected for this analysis ( $n = 24$ ) consists of those who had been released from prison within the previous 18 months. Most of the interviews excluded from this analysis had been conducted with individuals who had not been incarcerated ( $n = 45$ ). We also excluded 3 participants who only described experiences in jail and 1 participant who had been incarcerated but the setting and timeline were unclear.

Intervention staff from each state set up times and locations for investigators to meet with potential participants. In order to respect the privacy of individuals who were enrolled in interventions, researchers did not have access to these individuals’ names or contact information. State contacts were successful in referring a pool of participants

**Table 1** Description of Interventions

State	Setting	Description	Interventionist and training	Duration and intensity	Scope of work
Louisiana	Prison	Video conferencing session with the client prior to release from prison, aiming to build rapport with a local case manager and facilitate connection to medical care	Case managers working in agencies/clinics across the state, who received additional training to conduct intake sessions via video conferencing technology	One session of approximately 45-min session Supplement to existing Ryan White transitional case management services	Transitional care
Massachusetts	Community	Intensive medical case management and care engagement support services to clients who are newly diagnosed with HIV, out of care, or high acuity	Teams consisting of an HIV-positive peer and a nurse, who received training in case management and peer outreach	6–12 months of intensive services; minimum of bi-weekly contact by phone or in person, at or outside the clinic Small case load (about 20 clients per team) to facilitate close contact	Retention
North Carolina	Community	Case management services to identify and locate clients who are newly diagnosed, out of care, or at risk of falling out of care, and attempt to engage them in medical care via case management	“Bridge Counselors,” or former Disease Intervention Specialists (DIS), trained in Motivational Interviewing	Short-term case management; i.e., services end after client attends a medical appointment Most outreach occurs in the field, and clients may be accompanied to appointments	Retention
Wisconsin	Prison and community	HIV-positive individuals in prison are contacted by mail prior to release to facilitate connection to care, those who consent then receive intensive medical case management and care engagement support services upon release	“Linkage to Care Specialists,” whose backgrounds ranged from Bachelor’s degrees to Licensed Clinical Social Worker degrees; trained in HIV education, case management, and Motivational Interviewing	Invitation letter submitted to client, followed by up to 9 months of intensive services after release; frequent communication and face-to-face visits at or outside the clinic/agency Small case load (about 15–20 clients) to facilitate close contact	Transitional care+ Retention

who had all participated in the interventions; this sample precludes data on those who declined navigation services. Individuals who expressed interest in participating during the initial recruitment efforts met subsequently with the interviewer to discuss the procedures and provide verbal informed consent, which the interviewer documented on a tracking sheet. Participants received a \$40 VISA gift card as compensation for their time. The institutional review boards at UCSF and in the participating states approved all procedures.

### Interview Process

Interviews were conducted in a private space (e.g., at a clinic, case management agency, or at the participant's home). Interviews were conducted by qualitative cross-site research team members and by collaborating research colleagues from the state project teams. Collaborating colleagues within the states conducted interviews only if they had no direct involvement in implementation of the interventions. Interviews were audio recorded and transcribed verbatim, with any names or other personally identifying information redacted from the transcripts. Interviewers collected demographic information about each participant on a separate sheet. The interviews lasted 45 min on average. Interviewers wrote field notes after each interview to record an overall summary and general impressions.

### Analysis

We applied a Framework Analysis [11] to identify themes within the data set. Qualitative research team members (SF, KK, AM, SZH) coded the interviews, using *Dedoose* [12] to facilitate data management. The analysts read a sub-set of interview transcripts aloud as a team to develop the codebook, creating both in vivo and a priori codes. Following codebook development, each transcript was coded by a combination of two of the four analysts. If any discrepancy arose about coding application, the two analysts met to resolve it. The analysts also wrote a memo after coding each transcript to provide a summary of the participant's story and record any analytic ideas that emerged during the process of reading and coding the data. We analyzed excerpts under the following key codes: intervention impact, interactions with interventionist, corrections narrative, attitudes about HIV clinic/provider, and attitudes/understanding of HIV. The first author (SF) organized the analyses into a table that outlined the information for each participant. We then used the summary tables to identify and refine themes across and within cases.

## Results

### Characteristics of the Sample

Table 2 presents the demographic information of our participants. Note that given the specific design and intent of interventions in Louisiana and Wisconsin, the majority of the participants included in this analysis were recruited in those two states. Most identified as male and Black/African American (Black/AA), and were on average 46 years old (standard deviation (SD) = 10.1 years) at the time of the interviews. Most described stable housing situations.

All participants had received HIV care while in prison and were engaged in care at the time of the interviews. Participants had been living with HIV for an average of 13.5 years (SD = 8.3 years). The duration of the participants' most recent episode in prison ranged from eight months to 21 years, for a mean of 6.7 years (SD = 7.4 years). They had been released from prison an average of 6.0 months prior to the interviews (SD = 5.4 months; range 2 weeks–18 months). Participants had either completed or were enrolled in the intervention at the time of the interviews.

### Findings Observed Across All Interventions

Although the interventions differed in duration—from a 45-min session to up to 12 months of intensive services—participants described common features that they believed to be meaningful. Across all four interventions, participants appreciated having a designated person they could contact for assistance related to medical care or other services. Even clients who were enrolled in relatively short interventions believed that they could contact the interventionist beyond the time period of the intervention if necessary and found this to be comforting and novel.

Also, between the states, we consistently observed a difference in how participants valued the types of support offered through the interventions; specifically, assistance with non-medical support services was seen as more important to the participants than assistance with medical services such as adherence counseling. In order to explain this difference, it is important to understand the contextual factors involved when participants were exposed to the interventions. Most participants had experience in HIV care prior to their most recent incarceration, and were connected to the interventions at a time when they wanted to start anew. While they were motivated to engage in care post-release, they needed more assistance navigating the array of non-medical support services to facilitate their transitions into the community and minimize potential barriers to care.

**Table 2** Participant Demographics

	Sample (N = 24)	
	N	%
<i>Gender</i>		
Male	21	87.5
Female	3	12.5
Transgender (MTF or FTM)	0	0
<i>Race/Ethnicity</i>		
Black/African American	18	75
White (non-Latino)	6	25
<i>Highest level education</i>		
2-year college degree	1	4.2
Some college	2	8.3
High school/GED	12	50.0
Some high school	7	29.2
8 <sup>th</sup> grade or below	1	4.2
Unknown	1	4.2
<i>Housing status</i>		
Renting	3	12.5
Transitional housing	8	33.3
Living with family	10	41.7
Homeless	3	12.5
<i>State</i>		
Louisiana	14	58.3
Massachusetts	1	4.2
North Carolina	1	4.2
Wisconsin	8	33.3
	Mean (years)	SD (years)
Age (range 25–59 years)	45.9	10.09
Length of incarceration (range 8 months–21 years)	6.7	7.4

We organize the remainder of the findings into three main sections. First we discuss the *background factors that influenced the participants' response to the interventions*, then we describe the *benefits provided by the interventions*, and finally we present the *individual-level factors that reinforced the participants' engagement with the interventions*.

## Background Features that Influenced How Participants Responded to the Interventions

### Knowledge About HIV Treatment and a Desire to Continue Receiving Care Post-release

When recalling their attitudes in anticipation of release, many participants expressed that they had felt concerned about how they would access ART after leaving prison. One participant from Louisiana, a 48 year-old Black/AA male, released three months prior to the interview, reported, “my main concern was not the housing...first, my main concern

was, how was I going to get this medicine?” He went on to say, “I worried...I'm like, ‘Do I have to come back to prison to get medical care?’ Because if it came down to that, that's what I would've done.” He called the interventionist a “life saver” for helping him access ART. She helped him secure health insurance, set up medical appointments for when he was released, and connected him to a job readiness program and other supportive services.

Participants were, in general, highly knowledgeable about the importance of achieving an undetectable viral load, often because they learned about it through prison education programs and/or prior care experiences. Without any prompting, over half of participants stated that they were “undetectable.” Other participants who did not use that term said that their “numbers were good” or that their current health status was “fine.” Some participants knew that they were undetectable, and though they did not know exactly what that meant, they understood that it reflected well on their health status.

Participants not only spoke fluently about the importance of having undetectable viral loads, but also about

their treatment as routine and necessary for maintaining their health. Most participants had been living with HIV for a long time and were aware of the changes in the medications. In the quote below, one participant from Louisiana described his attitudes about ART and how he saw it as instrumental to keeping his viral load suppressed and managing his overall health:

“I’ve been diagnosed for 19 years now. I always was on top of where I had to go to get my medication, what I had to do to learn more...So it was just something that I know I had to do. And I had to learn, you know, what keeps me ticking. And the medication is going to keep you ticking. It’s simple.” (Black/AA male, age 56, 1.5 years post-incarceration)

### Feelings of Optimism and Desire to Start Anew After Prison

Many participants recalled that they left prison with a desire to start anew. This feeling of starting anew was often invoked when participants talked about connecting to care in the community and re-establishing their lives. One participant had spent 21 years in prison, and had been diagnosed with HIV in 2005, while incarcerated. When asked how he felt about the video conferencing session, which occurred prior to his release, he replied:

“Good, because it’s a new start. And, that’s what she was explaining to me. It’s helped. I mean, it’s a new start. Like I say, with housing, clothing, medication and all the stuff that would help me in the future, as far as coming home from 21 years [in prison]. I mean, I have help.” (Black/AA male, age 45, 5 months post-incarcerated)

Pre-release contact from the interventionist—in the form of video conferencing (Louisiana) or letter writing (Wisconsin)—was meaningful to participants and engendered feelings of hope. The pre-release contact not only facilitated the process of scheduling appointments for medical care in the community, but participants also characterized it as meaningful in terms of building rapport and showing them that someone cared. One participant reported that she saved the letters from the interventionist, along with personal letters she had received from friends while incarcerated. She explained that she treasured the letters as proof that someone in the outside world cared about her and wanted to offer support once she left prison.

For participants who were diagnosed with HIV in prison or who had been receiving little to no care prior to incarceration, the improvement in their health resulting from consistent ART utilization during prison offered encouragement

for a new start and an incentive to continue treatment. One participant from Wisconsin summarized this well:

“[The prison healthcare providers] put me on a beautiful cocktail— my CD4 had been all the way down to like 220, and I was almost at a point where you get AIDS, below 200. They put me on a cocktail drug, and within a couple years, I was non-detectable. My CD4 count is like at 470 something. So that was beautiful, I loved the turnaround, so at last I got a zest for life again, I want to live now, but I want to live with more of a purpose now, not like I was before.” (Black/AA male, age 53, 1.5 months post-incarcerated)

### Benefits Provided by the Interventions

#### Support from Interventionists to Manage Care and Meet Basic Needs

Participants described an array of challenges post-release, often related to transitioning out of the structured environment of prison and back into the community. Common challenges expressed by participants included lack of access to housing, transportation, and employment, difficulty managing mental health needs, and avoiding triggers for substance misuse relapse. Interventionists, through their navigational services, helped participants access medical and support services to meet these basic needs by coordinating their care through case management-type activities (Massachusetts, North Carolina, Wisconsin), or by connecting clients to case managers in the community (Louisiana). For example, interventionists helped clients with a range of services, such as, completing paperwork for housing, insurance, and any legal issues; conducting job searches; securing transportation to and from medical appointments; and offering adherence counseling. Interventionists also helped participants arrange medical appointments, mental health care and/or substance use disorder treatment counseling, and obtain medication refills. Most participants worked with interventionists affiliated with clinics where they would receive HIV care. In a few cases (for five of our participants), the interventionist worked at a different agency, but helped to facilitate medical care and other services. In this situation, about half of the time, the client already had care established at another clinic and did not want to move services, and the other half of the time, the interventionist was based at an agency that did not provide medical care. In the latter cases, the clients each had a pre-existing relationship with their current clinic, so in this particular analysis we did not detect a difference in the impact on clients according to the interventionist’s location.

One of the key characteristics facilitating navigation's success was the easy access that participants had to the interventionists in each of the four states. Most participants commented on how they saved the interventionist's cell phone number and that they could call any time if they needed help or wanted to talk. Even if participants did not act on this opportunity to contact the interventionist by cell phone, simply having the phone number was comforting and made them feel like someone cared. When asked how he had been impacted by the intervention in North Carolina, one of the interventions of relatively lesser intensity than others in this study, the participant replied:

“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... if I feel that I get to the point where I need anything, I know that I always can call him, because I keep his number right in my phone.” (Black/AA male, age 57, four months post-incarceration)

Most participants also felt that they had learned skills that would be useful to them after the intervention concluded, e.g., job searching, accessing transportation, and knowing who to contact at the clinic. While most participants did not want the interventions to end, especially the more time-intensive ones such as those in Massachusetts and Wisconsin where clients formed particularly close bonds with the interventionists, participants in all states generally expressed confidence in their abilities to manage care in the future through the existing resources at the clinics. For example, one participant in Wisconsin (Black/AA male, age 53, incarcerated 20 years) explained, “[The interventionist] helped me to gain my independency. It's not just, knock on my door and let me know what you need. It's been about striving to motivate you to start doing things for yourself, too, which I appreciated.” When asked how long he would be working with her, he explained that it was a nine-month program and that “for two months right now with all she has been helping me out with, my wings will be spread and ready to fly before the nine months. I feel pretty positive right now.”

## Factors that Reinforced Engagement with the Interventions

### Positive Attitudes About the Clinic to Which They Were Referred, and Learning About the Array of Services Available

Overall, participants expressed positive attitudes about the clinics where they currently received care, seeing them as trusted places where they could receive both medical and non-medical support. This idea was echoed by participants

in our sample who had prior experience receiving HIV care in community clinics, as well as those who were diagnosed in prison and for whom this was their first opportunity receiving HIV care in the community.

Although many participants conveyed favorable experiences about their previous care and desire to return to the same place, many still experienced barriers to care such as managing mental health, substance use, and transportation issues. Most clinics had case management services on-site, making it possible for many participants to return to the clinic for assistance with housing or other basic needs. Participants frequently commented on the extensive wraparound services available at the clinic, for example, one participant from Louisiana (Black/AA male, age 56, 1.5 years post-incarceration) said the clinic was “my lead source for housing, and clothing, and places to sleep.”

Another participant, who was diagnosed with HIV about 1.5 years earlier while incarcerated, also described a “smooth transition” into care after his release. While he believed he would have been able to engage in care without the intervention, he felt that video conferencing program in Louisiana “sped up” his connection to care in the community, and that then the support available at the clinic—both from the intervention and from other services available—fostered his continued engagement in care. Importantly, he associated his improved health with the support system at the clinic.

“I just transitioned straight from being incarcerated from enrolling in care without having to go through the initial interviews [intakes] once I got out... My status is undetectable at the moment, which is a good thing. CD4 count has risen dramatically, just by sticking around here in the support systems.” (Black/AA male, age 53, time post-incarceration unknown)

Those unaware of the kind of services they could obtain after release were surprised with the comprehensive care they could access at the clinics. When we asked another participant in Wisconsin how he felt about going to the clinic, he responded:

“This place is a godsend. I mean, they've helped me with my medical, and just about any other need I have. They try to help me to the best of their knowledge and extent... I mean, without [this clinic] I would be—whew! I'd be lost.” (White male, age 48, two weeks post-incarceration)

Many participants described the clinic as a place where they felt safe and respected. One participant from Wisconsin, a 53 year-old Black/AA male who had been incarcerated for 20 years and released approximately one month before the interview, explained that he often felt overwhelmed by his new environment, and turned to the clinic as a safe place.



One day he felt particularly overwhelmed and came to the clinic because he did not know where else to go—“I leave home sometimes and I get lost and confused, and it’s like this [clinic] is the only safe place I really knew to come to.” In the face of a stressful environment, the clinic was often seen as a source of security and familiarity, and this may have served as an additional motivator to engage in care.

### Emotional Support from the Interventionist

Participants consistently endorsed the value of the interventionist’s support, regardless of whether they had strong or limited social support networks. In cases when participants had limited support from friends or family, the interventionists often served as a primary source of support. For participants with strong networks, the support from the interventionist provided them more encouragement, as summarized by one woman from Louisiana (Black/AA, age 48, 1.5 years post-incarceration), who remarked, “That makes me feel good to know that somebody cares besides my family about me and my illness.”

Particularly among participants who served long sentences, support networks had often crumbled by the time of their release. Those who received family support for housing often wished that they could be more independent, but appreciated the stability offered by their families. In contrast, one participant with limited familial support, who was incarcerated for 17 years in Louisiana and living in transitional housing at the time of the interview, expressed concern about how he would secure stable housing once his temporary placement ended. In the quote below, he reflected on his lack of support and appreciation for the assistance offered through the clinic:

“Being locked up as long as I have, your family die off. You know, like my mother and my brother—my brother got killed. My mom died. My dad died. And, you know, my house was no longer there. So, I mean, I’d probably have been sleeping on the street if I didn’t know nothing about all these things [that the clinic offered].” (Black/AA male, age 56, one month post-incarceration)

Those with familial support tended to struggle less post-release than those who did not have such support. As summarized well by one participant from Louisiana (Black/AA male, age 59, 8 months post-incarceration) who received extensive support from his family and friends, “When you got people supporting you, it’s a lot easier to deal with the HIV program or your sickness.” By contrast, another participant from Wisconsin (White, female, age 43, 4 months post-incarceration) was incarcerated for a crime that she committed very far from her home. The terms of her parole required that she remain in the state in which she was convicted,

where she had no support network and did not know how to navigate her new city of residence. She described often feeling “lost” and deeply appreciated the support from the interventionist.

### Discussion

Our findings help to characterize the role of navigational services in the participants’ lives and provide recommendations for how other states could consider structuring services to meet the needs of PLWH leaving prison. Across all four states where this study occurred, participants in this sample were motivated to seek and maintain care for HIV after their release, and the interventions appeared to facilitate their successful engagement in care. The commonality of themes across the different states suggests that the types of interventions generated through the Systems Linkages Initiative and featured here (transitional care, retention, and transitional care + retention) can be well received among PLWH who are leaving prison.

A few best practices are worth highlighting. Participants who were part of interventions that involved video conferencing or letter writing prior to release appreciated these forms of communication. Beyond the practical support provided to them through health systems navigation, many participants described close relationships with the interventionists, even in interventions that were relatively short term. However, the time and intensity of many of the interventions appeared to facilitate close relationships between the interventionists and the participants. The depth of these relationships built in the context of the interventions was notable to people that we interviewed, and may have reinforced their motivations to continue in care.

Our findings support previous qualitative research that identified individual attitudes, supportive personal and professional relationships [13, 14], and coping strategies as facilitators to HIV medical care among individuals recently released from jails and prisons [15]. Participants in our post-prison sample, all of whom were engaged in medical care at the time of the interviews, appeared to be doing well in terms of individual attitudes and coping strategies, and many described supportive relationships from the interventionists, clinic staff, friends and family. Additionally, our findings underscore the importance of having services such as enhanced case management and retention support to assist participants in meeting needs outside of HIV medical care. Addressing needs such as substance use treatment, mental health care, housing, and food assistance is essential to successful engagement in HIV care [16]. Though participants in this study did not appear to require significant encouragement to engage in care post-release, they still expressed a need and appreciation for the support from the

interventionists to help them to become re-established outside of prison. In fact, the importance of case management and other holistic, supportive services for this population is well documented [7, 14].

Our study adds further nuance to this literature by exploring why, from a client perspective, support services are so valuable for PLWH leaving prison, and illustrating how different types of systems navigations can be perceived as useful for a set of relatively well engaged clients. Most participants met the navigators after they already knew about HIV medical care and, in many cases, had previously received such care outside of prison, which another study found to be associated with shorter linkage times to care in the community compared to individuals who had not previously received care in Ryan White settings [17]. Participants were also coming to the navigator at a time that they were seeking to start anew. The problems they encountered after release had less to do with medical services and more to do with living life on the outside, yet those challenges can also be barriers to medical care. The navigators were able to link clients to, and facilitate usage of, a variety of support services with which the participants had less familiarity, offering them the stability to effectively engage in HIV medical care. It was the successful linkages to the diversity of services, along with the emotional bond to the navigator, that reinforced engagement in the intervention and in HIV medical care. This type of intervention model was especially important for those who lacked family resources that could serve as a buffer or safety net.

We found that those without support from friends or family struggled more post-release than those who had strong support networks, according to their own reports. Though it may seem obvious, it bears repeating that familial support is instrumental when it comes to enhancing quality of life. Families are positioned to help with food, shelter, and a base from which people can rebuild their lives. Negative and positive familial support can impact the mental health, substance use and treatment adherence of individuals post-release from prison [18, 19]. Soon-to-be-released individuals with limited or inhospitable support networks may need to be prioritized for receiving intensive services, whereas those with more familial support as well as higher degrees of health literacy may not need such intensive services in order to stay engaged in care.

The interventions featured in this study varied in terms of scope and intensity, and offer examples of three general strategies that states could use to improve continuity and retention in care for PLWH post-prison. On one end of the spectrum, there is the program in Wisconsin that begins working with participants prior to release and continues offering intensive services for up to 9 months after release. At the other end of the spectrum are the examples from Massachusetts and North Carolina, both of which worked

with clients for relatively extended periods of time, but only after release from prison, as those two interventions were not developed specifically to target those leaving prison. In the middle of the spectrum is Louisiana, which facilitated pre-release communication via a video conferencing session, then relied on existing case management services to promote further retention and engagement in care. Our description of the interventions is based on our findings from the patient interviews reported in this manuscript and previously published findings from our key informant interviews across the larger Systems Linkages Initiative [10]. We have limited data on the impact of the Massachusetts and North Carolina interventions for PLWH post-prison given our small sample size from those interventions in this particular analysis. However, the experiences of the limited set of clients included in our analyses suggest that such programs have the potential to benefit PLWH with post-release retention in care, especially in states that already have strong pre-release discharge planning efforts. Otherwise, developing programs so that interventionists can communicate with clients prior to release seems to be a key element for success, as reflected from the stories of participants in the interventions based in Louisiana and Wisconsin, which included pre-release contact as part of the intervention design. Participants generally liked that kind of continuity, and felt that it established rapport and gave them something to look forward to upon release.

For programs focused on transitioning a client from a prison setting to the community, a decision must be made as to whether the individual facilitating the transition will continue to offer retention and engagement assistance longer-term (e.g., Wisconsin) or refer the client to other case management services (e.g., Louisiana). One factor that may influence the decision is the characteristics of the clients, themselves. For those with prior experience receiving care from the same clinic and established support networks, longer-term services from any interventionist may not make a substantial difference in terms of their retention in care. Our data suggest that these clients already have the support they need to remain in care. A second factor is geography. If an interventionist is transitioning clients to many communities distant from one another and the prison site, it would be challenging for the individual to continue to see clients longer-term. Maintaining extended contact with clients after release is easier when the interventionist's work is focused in geographic areas proximal to one another. A third factor is the availability of services in the region. A model like the program implemented in Louisiana requires that there be adequate existing case management services to which clients can be referred. In the absence of such services, a state or locality intent of improving engagement in care among those released from prison may need to commit to more extended services. Given these realities, we recommend that states

consider the needs of the clients they serve, geography, and the characteristics of the HIV care delivery systems when developing a program or set of programs to improve continuity of care for PLWH leaving prison. Further research needs to be done to understand the most cost-effective choices for delivery and allocation of services.

As a qualitative, exploratory study, our findings do not aim to produce generalizations for all PLWH leaving correctional settings, nor among those in the Systems Linkages Initiative. Our participants were incarcerated in different settings across four states, and the majority of our participants came from two of those states (Wisconsin and Louisiana). Participants were referred to us by the interventionists, which may have introduced sampling bias (with interventionists, perhaps, more likely to recruit those they knew had favorable experiences in the program). It is also worth noting that most participants in our sample had been living with HIV for a long time and had received care in Ryan White settings prior to incarceration. National-level data from the Medical Monitoring Project demonstrate that patients receiving assistance from Ryan White funding have better care outcomes than patients who do not receive support from Ryan White [20]. Additionally, all participants in our study self-reported that they were taking ART at the time of release and described their housing situation as at least “comfortable.” Both of those factors are associated with primary care utilization after release from prison [21], although these factors may have been influenced by the services provided by the interventions. We did not gather perspectives from participants who were unable to link to care or were re-incarcerated. Future studies to understand why some people and not others are able to successfully engage in care will be critical in designing programs to best meet the needs of PLWH leaving prison settings. Knowing that our participants generally appreciated communication from the interventionist via video conferencing or letter writing while they still incarcerated, future studies could also examine the most effective means of pre-release contact to facilitate engagement in services after release.

Based on our findings, a key implication for efforts to improve outcomes along the HIV care continuum is to recognize that a linkage-to-care program for PLWH leaving prison may need to focus more heavily on the provision of support services, and less so on adherence counseling. Participants across all four states expressed high levels of motivation to attend appointments and take ART, and these habits were likely established before participants began working with the interventionists. Reinforcing the importance of adherence can still be productive, but may not need to be the focus for some clients. While other populations in need of linkage-to-care services (e.g., individuals who are newly diagnosed or out of care) may require more encouragement to buy into the idea of seeking care in addition

to assistance with support services, the post-prison population is not necessarily defined by an unfamiliarity with care or historical disengagement from HIV medical care. Rather, it is a group that faces a unique set of salient vulnerabilities that can preclude a person from getting care even if the importance of the care is recognized. Our findings underscore this reality by highlighting the clients’ existing knowledge about HIV, juxtaposed with the need they had for social support services to overcome the daily challenges accompanying life after release.

## Conclusions

Our findings suggest that the navigation interventions can offer both social and practical support, and these components may assist persons recently released from prison with re-entry to HIV care. Interventions can be situated in prison, in the community, or in both settings, and various designs hold unique strengths and weaknesses. Some individuals may need to be prioritized for more intensive services like those offered in Wisconsin, where interventionists started working with clients before release and for up to 9 months in the community. Other individuals, such as those with prior experience receiving care in the community and with strong support networks may not require such extensive navigational services. Our sample captures some of this variation in level of need. Our participants overwhelmingly wanted to be in care and understood the value of ART, yet some did not know how to access those resources. In those cases, the interventionists could steer and support them appropriately. In other cases, the interventionist offered the participants support and encouragement, reinforcing the participants’ own motivations to remain in care. Our findings highlight the importance of pre- and post-release support from navigators (i.e., interventionists), families, and friends. Furthermore, the importance of the federal Ryan White Program, with its ability to offer, as a payor of last resort, comprehensive health support services for PLWH needs to be emphasized. Clinics funded by Ryan White offer medical case management and on-site social support services that benefit not only those who are recently released from prison, but the general patient population as well. The consistency and ease of access to a variety of critical services can provide a safe space for those who face numerous stressors in their daily lives. Successful continuity of care requires interventions like those in the Systems Linkages Initiative, which facilitated linkage to comprehensive care, and provided consistent, consumer-friendly support services.

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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 involving human participants were in accordance with the ethical standards for the institutional review board 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. No personal identifying information is included in the manuscript.

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