Lessons Learned from the Pathways to Community Health Study to Evaluate the Transition of Care from Jail to Community for Men with HIV

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Abstract

Time spent in jail can provide opportunities to deliver comprehensive medical care, including screening and treatment for HIV; however, engagement in HIV care postrelease is often fragmented. Identifying ways to improve the transition of care from jail to community for people with HIV (PWH) may help with engagement in HIV care postrelease. We evaluated the current HIV care transition processes of one jail in Massachusetts and identified change ideas to facilitate improving the transition of care from the jail to the community for PWH. We conducted qualitative interviews in 2018–2019 with incarcerated men with HIV \( (n=17) \), jail staff \( (n=7) \), and community providers \( (n=6) \) to understand the processes of HIV care prerelease from the jail and engagement in care on release. Data from these interviews and quality improvement tools were used to identify ways to improve the release process for PWH, such as using a release planning checklist, to help ensure that a 30-day supply of HIV medication and an appointment with a community provider within 30 days of release were provided. We identified communication process inefficiencies related to knowing release dates between the HIV care team and case managers that prevented providing HIV medications on release. We worked with jail administrators to find ways to improve the prerelease planning process, which is vital to the continuity of successful HIV care. The use of quality improvement methods generated a list of testable change ideas to improve the release planning process to better align with the Centers for Disease Control and Prevention guidelines, which has implications for PWH and public health.

Keywords: HIV, jail, adherence, transition of care

Introduction

The HIV burden has disproportionately affected incarcerated individuals\(^1\) where HIV prevalence estimates are almost 3.5 times higher in jail compared with the general population (1.3% vs. 0.4%)\(^1\) and 85% of individuals incarcerated in jails are substance involved.\(^2,3\) Time spent in jail can provide opportunities to deliver medical care, including screening and initiating treatment for HIV; however, the cascade of care deteriorates postrelease.\(^4\)

Approximately half of people who take HIV medications while incarcerated remained on HIV medications postrelease\(^4\) and 20% or fewer filled HIV prescriptions or visited HIV clinics within 30 days postrelease.\(^5\) Less than 50% of people released saw an HIV provider within 90 days and 33% had detectable viremia at the first visit.\(^6\) In addition, HIV care

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is not well linked between juvenile community supervision and community health care. To address the postrelease cascade of HIV care, it is essential to understand the challenges faced by jails and providers within the community.

People detained in jails move through the institution quickly, with a national mean incarceration period of 25 days and are, therefore, at high risk for fragmented HIV care in the community because of repeated re-entry in jail. In addition, incarcerated individuals with uncontrolled viremia can lead to transmissions in the community upon release. In the seminal article, “The Critical Link Between Health Care and Jails,” the authors cited connectivity between jails and community as one of eight policy recommendations necessary to build a comprehensive continuum of care. The Centers for Disease Control and Prevention (CDC) provided guidance to support the continuity of HIV care for incarcerated individuals, including planning for release, however, only ~17% of jails follow these guidelines.

There are challenges with care transitions from jail to the community given the need to coordinate care across organizational boundaries and the lack of systems to evaluate or improve these transitions. Despite published reports of successful interventions to increase postincarceration linkage to HIV care, to our knowledge, no available evaluation exists of prerelease processes to ensure quality postrelease care. Policies that organize HIV care on release from jails need to be examined, in addition to individual-level risk factors (such as health insurance access, mental health, and housing security), to develop effective interventions to improve the postrelease cascade of care. Studying the prerelease process using quality improvement methods is novel in this setting but has been applied to other health care settings with success.

The purpose of this pilot study was to evaluate the current prerelease HIV care processes of one jail in Massachusetts and identify change ideas to facilitate improving the transition of care from the jail to the community for people with HIV (PWH). Conducting this analysis in one jail allowed for an in-depth examination that could provide insight to additional jails in the future with regard to common ineffective processes and care barriers in jail-to-community transitions.

Methods

We conducted a multi-pronged study, PAthways To Community Health (PATCH), which included qualitative in-depth interviews of key stakeholders between July 2018 and June 2019 and quality improvement methods to understand the current prerelease process of care. Quality improvement involves a systematic way of testing out changes in a process to improve the overall outcome and level of performance. Quality improvement is often deployed in health care settings, but rarely in carceral environments. We used process mapping and developing a driver diagram as the quality improvement methods for this study.

**Study interviewees**

People with HIV. We recruited a purposive sample of men with HIV from one jail in Massachusetts, which only houses men. The detainee population at this jail is ~60% pretrial and 40% sentenced individuals. Eligibility criteria included having confirmed HIV diagnosis, current incarceration within this jail, estimated release from the jail within 30 days of enrollment, residing in Massachusetts after release, at least 18 years of age, and English speaking. We will refer to the participants with HIV as “participants” throughout the remainder of the article.

Jail staff. Jail health care providers, administrators, and case managers who were knowledgeable about the HIV care process and/or prerelease planning within the jail were recruited to participate.

Community health care providers. Community providers were identified by the participants as their HIV provider in the community, either before or postincarceration. Data from these providers helped to inform the community perspectives about the transition of health care from multiple jails to the community.

The Social, Behavioral and Educational Research Institutional Review Board of Tufts University approved this research study. All interviewees provided informed consent to participate.

**In-depth interviews**

Semistructured interview guides were developed based on findings in the literature and experiences by someone who medically treats PWH in jails (A.G.W.). A.G.W. did not conduct interviews or take part in the analysis.

Participants were interviewed longitudinally during three time points: while incarcerated (baseline visit), 30 days postrelease from jail (visit 2), and 90 days postrelease (final visit). If a participant was reincarcerated during the study, we conducted another interview at the jail to understand the transition of care process while they were in the community.

The baseline interviews collected experiential and process data to learn about participants’ perceived barriers and facilitators to health care before incarceration and anticipated issues on release, types of social support, knowledge of HIV care transition plans and processes, and motivation for engaging in HIV care on release. Process data at baseline were the sequence of activities in delivering health care for PWH while incarcerated. The baseline interviews for participants were conducted in a private room at the jail without officers or jail staff present. Each baseline participant interview was conducted with two research staff; one staff conducted the interview and the other took handwritten notes since audio recorders were not allowed in the jail.

The two postincarceration interviews focused on the process and quality of release planning, participants’ postrelease level of engagement with HIV care, experienced barriers and facilitators to accessing health care, and types of social support. For postincarceration interviews, the process data included the steps for prerelease for participants to achieve the outcomes of being released with a 30-day supply of HIV medications and an appointment to see their community HIV provider within 30 days of release. The two postrelease visits were either conducted in a private room at local clinic or through phone, based on the participant’s preferences. Transportation costs were provided if participants decided to do the interview at the clinic. Participants consented to have the postrelease interviews audio recorded while one research staff conducted the interview.
Participants did not receive a stipend for interviews in jail. For each postrelease interview, participants received $25, for a possible $50 for all visits.

Jail staff and community health care providers were interviewed once. Interviews with jail staff were conducted in a private room at the jail. These interviews were conducted by one researcher and captured through handwritten notes. Community health provider interviews were conducted over the phone by one researcher and audio recorded. Jail staff and community health providers did not receive a stipend.

All interviews that were recorded through handwritten notes were transcribed by the researcher who took the notes. These transcriptions were verified by the researcher who conducted the interview. Interviews that had audio files were transcribed verbatim by research staff. We present quotes from interviews that had audio recordings since they are verbatim from participants.

### Medical information

Participants signed a medical release form to allow research staff to contact their community HIV providers to provide information about HIV care, dates of visits, CD4 counts, viral load, and medication adherence. We followed up with community HIV providers once participants were released from jail to measure the length of time it took participants to see their providers and to provide pre- and post-release care information. In addition, data on CD4 counts and viral load postincarceration provided objective data of HIV suppression to triangulate participant reports of engagement with HIV care.

### Process maps

We developed a cross-functional process map to identify the current steps for providing HIV care in jail and a process map to identify the steps for medically releasing PWH, the discharge process that includes medical care and continuity in the community. Initial maps were developed by the research team based on interviews with staff and participants, and then refined after meeting with jail staff to ensure the processes were captured correctly. We present the final version from our collaboration.

### Driver diagram

Driver diagrams illustrate the structures, processes, and norms believed to require change in a system as well as how these could be changed through the implementation of specific strategies. It depicts the factors required to achieve an aim and strategies to influence those factors. Data gathered through interviews and the process maps informed the development of factors (key drivers) that might lead to improvements in the process of transitioning back into the community. Jail staff participated in refining the driver diagram and determining feasible and appropriate change strategies. Based on recommendations from the CDC and the National Commission on Correctional Health Care, a 30-day supply of HIV medications should be provided to bridge the transition from leaving the jail to seeing a community provider, which defined our primary aim for the driver

| Table 1. Characteristics of Men with HIV Incarcerated in a Massachusetts Jail (n = 17) at Baseline Visit, n (%) |
|---|---|---|---|
| Age (years) | 36.8 ± 11.1 | Race | |
| White, non-Hispanic | 8 (47.1) | Black, non-Hispanic | 3 (17.7) |
| Hispanic | 6 (35.3) | HIV diagnosis before incarceration | 15 (88.2) |
| Had an HIV provider before incarceration | 12 (70.6) | History of SUD | 17 (100.0) |

SD, standard deviation; SUD, substance use disorder.

FIG. 1. Map of study visits for men with HIV incarcerated in a Massachusetts jail and the number of participants who completed each study visit. This figure highlights the flow of study visits and how many participants completed each visit. The boxes highlighted in gray are the visits where individual in-depth interviews were conducted. One individual who was reincarcerated was released during the time of the study. Of the 17 participants, 13 (76.5%) were released from jail and eligible for follow-up study visits. Three participants were reincarcerated during their time in the study and interviewed about their experiences with postrelease health care before being reincarcerated. One participant who was reincarcerated was released during the study period and provided one postrelease interview. Five participants were lost to follow-up; however, medical information for four of these participants were provided from their community health care providers. Of the participants released from jail, six participated in interviews at 30 days postrelease and four at 90 days postrelease.
diagram. Jail administration and providers identified that provision of a 30-day supply of HIV medications on release was also their goal for standard practice.

**Data analysis**

We used a qualitative thematic analytic approach to code the interviews.20,21 For each stakeholder, we developed an initial codebook based on our semistructured interview guide. All transcripts were double coded. K.R.D. coded every transcript and four were coded by S.K., and A.G. coded the remaining. K.R.D. met with both S.K. and A.G. regarding any disagreements with coding. Codebooks were edited as needed to include additional codes. After the coding, we identified themes based on patterns in the data. NVivo software version 15 (QSR International) was used to code the interviews.

**Results**

Seventeen participants, seven jail staff, and six community providers were enrolled in this study. Three incarcerated men declined to participate. Table 1 lists the characteristics of the participants during their baseline visit. Participants had an average age of 36.8 years, were predominantly White (47%), diagnosed with HIV before this incarceration (88%), had an HIV provider before incarceration (71%), and had a history of substance use disorder (SUD; 100%). Figure 1 depicts the number of participants per follow-up visit.

We obtained medical information from the community HIV providers of 10 of our participants who were released (77%) to learn more about their postrelease engagement with HIV care (Table 2). We did not have medical information from three of our participants since their community HIV providers did not respond to our requests for information. The median number of days it took these 10 participants to see their community HIV provider postrelease was 26.5 and 70% of this subgroup saw their HIV provider within 30 days of release. The postrelease median CD4 count was 594 and 20% had an undetectable viral load.

**Qualitative interviews**

Jail staff and participants reported that HIV medications were not commonly provided on release. According to jail staff, providing a month supply of HIV medications on release was particularly an issue for pretrial PWH because it was challenging to know release dates, but better for sentenced men since release dates were more predictable.

**Table 2. Medical Information for Men with HIV who were Incarcerated from Health Care Providers to Show Postrelease HIV Care (n = 10)**

| Metric                                      | Median (25th/75th percentile) |
|---------------------------------------------|-------------------------------|
| Number of days postrelease to visiting HIV provider | 26.5 (16, 48)                |
| 30 days postrelease CD4 count               | 594 (224, 858)               |
| Viral load (copies per milliliter of blood) | 40 (27.5, 174)               |

*aIf viral load was <20, the data were analyzed as viral load=0.*

However, some participants who were sentenced disagreed since they were not provided HIV medications on release. Most community providers confirmed that PWH often did not receive medications on release. Participants who were provided a 30-day supply of HIV medications were most often released to an SUD or HIV treatment program. Table 3 depicts salient quotes from the qualitative interviews.

Community providers and participants both recognized strong pre-existing patient–provider relationships influenced engagement in HIV care postrelease. Participants with a strong provider relationship felt comfortable dropping by or scheduling appointments. Several community providers recognized how critical it was to engage patients in care postrelease. They reported that the health insurance and the Massachusetts HIV Drug Assistance Program (HDAP) insurance were not often activated on release so PWH would get turned away from clinics. These clinics reported implementing workarounds to ensure their patients link to HIV care immediately, including providing care without activated insurances and assist with reactivating insurances. Some clinics also implemented extra walk-in hours to remove appointment barriers. In addition, many community providers mentioned they wanted carceral medical records to improve continuity of care but often did not know who to contact for this information.

Participants reported drug use, predominantly opioids, as the main barrier to engaging in postrelease HIV care. Many participants reported that HIV was a worry, but that the intensity of addiction overshadowed concern of HIV. This experience was predominantly emphasized by men who were not engaged in HIV care and SUD treatment before incarceration. Other identified barriers to HIV care included lack of transportation, perceived stigma at health care centers, and the uncertainty of housing postrelease.

Participants identified several facilitators to accessing HIV care in the community. Although SUD was a barrier to accessing health care for some, others mentioned that being engaged in SUD treatment catalyzed HIV-care postrelease. For many, this was not the first time they were incarcerated and over time they became engaged with HIV care through treatment for SUD. Avoiding triggers and negative social influences were common strategies to remain engaged in HIV care and prioritize health and recovery. Additional motivators to engaging in HIV care included the fear of getting sick, having confidence in their treatment plans, employment, and fear of reincarceration. Participants also highlighted if HIV care providers sent appointment reminders and/or provided empathy, this improved willingness to engage in HIV care. Having a regular pharmacy was identified by participants as helpful for getting HIV medications.

Essential community support that participants identified included more compassion for PWH, additional HIV programs, such as support groups and needle exchange programs, and increased testing centers to address the recent community spike in HIV infections related to injection drug use. While in jail, participants had time to reflect and most were motivated to seek HIV care at the time of release. The participants who successfully engaged in HIV care post-release were able to find positive social support (either from family, friends, or a treatment program) and, therefore, more likely to stay in recovery and retained in HIV care.

Table 4 compares common themes about the re-entry planning process that influences HIV outcomes. For the success themes, a participant who received a 30-day supply...
The failure themes highlight a participant who was not provided HIV medications on release from the jail and had low CD4 and high viral load counts postrelease in the community.

Process maps

The cross-functional map identified issues around inefficient communication of HIV status and breakdowns with care coordination (Fig. 2). There was confusion about whether case managers could know HIV status or if that fell under protected information. Case workers reported learning about HIV status usually through self-report instead of the jail HIV care team, making release planning difficult. In addition, the role of the ID nurse was vacant during the study’s data collection, leaving this coordination function to be provided by other health services unit staff. The position was eventually filled but staff identified actual and potential care coordination handoff problems with a key role vacancy.

The jail staff and researchers examined the process to understand the issues around clear and consistent release planning (Fig. 3). Clear communication is needed between the reintegration coordinator and the case worker. The reintegration coordinator is tasked with ordering the 30-day supply of HIV medications for release but reviews the release list monthly. The case worker regularly tracks exact court

| Qualitative interview results | Quote | Interviewee |
|-----------------------------|-------|-------------|
| Issues with not receiving 30-day supply of HIV medications on release from jail | “I got out and they gave me no medicine...They said the only medication they give people, are people that are going into a program...If they prescribed me a medication and I have 20 days left of a 30-day supply, I believe they should give that to you whenever you leave so you’re not just out there with nothing.” “That’s the other things that’s so challenging. When they’re released from court unexpectedly...their meds are at the prison...I wish that the meds could always go with them to court in case they’re released.” | 58-year-old White male with HIV, 30 days postrelease |
| Engagement in HIV care postrelease | “What I’ve seen is that people that are able to get on Suboxone through our clinic, those people are like pretty regularly taking the Suboxone and actively are on treatment with us...so even if their main priority is not HIV, their priority is getting their medications. We’re able to sort of wrap around and take advantage of them being at the clinic.” | Community provider |
| Barriers to engaging in HIV care postrelease | “I didn’t take [HIV medications] I want to say for like a week and a half to two weeks. Due to me going from detox to [redacted] and then I run out. And me personally, I know it’s like confidential or whatever, but I’m still struggling with the idea of me having HIV so it’s really hard for me to just be open to like people about it. I just feel there’s still stigma about it. Um, like any time, a conversation has come up about HIV or whatever, like, just people always make faces, or like, people who are not educated on it.” | 26-year-old Hispanic male, 30 days postrelease |
| Facilitators to engaging in HIV care postrelease | “Honestly, it’s the program I went to, going from jail into a program—a substance use program—it changed my way of thinking. I think that PWH usually suffer from substance abuse, whether or not some people deal with them having it subconsciously, it might be like you’re gonna try to block it out a little bit so you might get high. Everybody deals with it differently.” “I thought about it but I decided not to succumb to [cocaine] because I just...think about all the consequences. I don’t want to go through that anymore.” | 31-year-old Black male, 90 days postrelease |
| Social support | “I got some friendships. But just having that atmosphere and knowing that people around you are trying to stay clean, it’s helpful, because I get in a lot of trouble by myself. So the main point of me getting a program was getting like a support group of friends in recovery so if I ever got bored, I’d have somebody to call.” | 36-year-old Black male, 30 days postrelease |

PWH, people with HIV.
FIG. 2. Cross-functional map showing the process of the current system for identifying and treating PWH who are in jail. This figure outlines the steps of the current HIV care process in jail and the role of each team member and points of interaction. PWH, people with HIV.
Current system in jail for medically discharging people with HIV

![Process Map](image)

FIG. 3. Process map showing the current process of releasing PWH who are in jail. This figure depicts the role of each team member to successfully provide HIV medications on release.

Discussion

Health care systems in jails are complex, adding to the challenges of providing coordinated HIV care and release planning. Our study highlights the importance of prerelease planning to ensure successful continuation of HIV care during the transition from jail to the community. Our project exemplifies strong collaborations with jail administration to make changes.

Many of the community providers we interviewed reported developing clinic workarounds to assist with re-entry HIV care, such as allowing visits without an appointment, assisting with reactivating health care insurance, and providing HIV medications until insurance was restarted. Although these workarounds are helpful, we recognize that not every clinic can do this; it required PWH to have a strong pre-existing relationship with their providers, and these workarounds may not be sustainable solutions. In addition, we acknowledge that there is a need for SUD and HIV treatment programs, but availability is limited. Our study focused on working with the jail administrators to identify ways during prerelease to improve the care transition process to improve HIV outcomes. Through our process maps, we identified places for systems strengthening to assist with provision of a 30-day supply of HIV medications and an appointment with a community HIV provider on release. Our next steps for future study include working with jail administrators and staff to
prioritize some of the proposed change ideas from the driver diagram and developing implementation plans.

Data to systematically monitor the cascade of care for PWH after release from corrections have demonstrated gaps in the linkage to care and can be a mechanism to monitor trends over time and provide information to support interventions6; however, these data from correctional facilities and community health care providers may not always be readily accessible (only data from North Carolina and Rhode Island were provided in this study) so more work toward developing a nationally comprehensive surveillance system should be considered. Most prior research has focused on services in the community to help PWH as they transition from jails. Qualitative research has identified themes to understand the barriers and facilitators to accessing postrelease HIV care. Mental illness, SUD, and unstable housing are barriers to HIV care.13,14 Facilitators include comprehensive release planning with specific linkages and appointments, supplies of medications, access to health care benefits, including reactivation on release, and postincarceration case management to assist with housing and transportation.5,15 Interventions based on these qualitative findings have been tested with some promising results,22,23 and in conjunction with improving prerelease planning, similar to our study, could synergistically work to have more successful transitions of care. In addition, upstream policies are being proposed to help with postrelease engagement in care as bipartisan members of Congress are working on legislation to re-start Medicaid benefits for incarcerated individuals 30 days prerelease.24

Our study had many strengths, including the use of quality improvement methods, which are novel in this setting. These methods helped to understand the complex systems and allowed stakeholders to develop a shared understanding of the HIV care and release process. Understanding the process allowed us to identify areas at greatest risk for failure and to develop strategies to address these failures. Another strength of our study was having multiple stakeholder viewpoints to evaluate the current transition of care and to identify ways to improve this process. Because our study was conducted in one jail in Massachusetts, we recognize the limitations with generalizing our study findings to other settings; however, our study provided in-depth context in this jail to help strengthen their services.

We may be able to extrapolate some of our evaluation methods and findings to other carceral settings to initiate improving the prerelease process in other facilities in the future. Our findings around communication issues, including
improving knowledge of release dates, and change ideas, such as developing a discharge planning checklist, may be useful in other jails. But other facilities may first need to use similar quality improvement tools to identify the barriers specific to their facility and the strategies needed to improve their prerelease process for PWH.

Conclusions

Working with jail administrators to improve the prerelease planning for PWH as they transition from jail to the community is key to continuing successful HIV care. Including multiple stakeholders, such as PWH, jail administration and staff, and community providers, is helpful to provide insight into the current process. The use of quality improvement methods generated a list of testable change ideas to improve the release planning process and better align with the CDC guidelines. This has implications both for improving the health of PWH by helping them receive consistent access to medication and remain HIV undetectable, and improving public health by reducing the risk for transmission of HIV in communities.

Authors’ Contributions

Study conception by K.R.D. and A.G.W. Protocol development by K.R.D., P.J.K., K.S., and A.G.W. Study activities and follow-up by K.R.D., A.G., and S.K. Article conceptual development and preparation by K.R.D., D.H.D., and A.C. Data analysis by K.R.D., D.H.D., A.C., O.P., A.G., and S.K. Article review and contributions by all authors.

Disclaimer

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

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Author Disclosure Statement

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