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Reaching and re-engaging people living with HIV who are out of care: A mixed-methods exploration of strategies to enhance clinic communication and outreach

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An abstract of

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Abstract

Reaching and re-engaging people living with HIV who are out of care: A mixed-methods
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By Emma Nedell

Half of all people living with HIV (PLWH) in the United States are not retained in HIV medical care. Clinics often encounter challenges reaching PLWH who are out-of-care (PLWH-OOC) to remind them of upcoming medical appointments due to factors such as lack of access to a working phone number and unstable housing. This mixed-methods study aimed to describe the preferences of PLWH-OOC for communication and outreach from clinics, as well as to gather perspectives from other clinic stakeholders on how best to reach and engage PLWH-OOC. From June 2019 to May 2021, 50 surveys were conducted with PLWH-OOC, and in-depth interviews were conducted with three PLWH-OOC, two PLWH retained in care, six PLWH serving as Ryan White Clinic Community Advisory Board members, and 14 HIV clinic staff. Phone calls (58%), text messages (54%), and calling a secondary contact (50%) were the most preferred methods of communication among the 50 survey participants. Three-fifths (60%) felt highly comfortable with a peer navigator visiting them at home or somewhere they hang out. Interviews highlighted trust, privacy, support, and community as considerations in choosing effective communication and outreach methods for better reaching PLWH-OOC. In conclusion, communication and outreach preferences vary at the individual level. Study findings highlight the need for clinics to offer a suite of communication and outreach models to patients at each clinic visit, record their preferences, and utilize this information to more effectively reach, re-engage, and ultimately retain those who are out-of-care.

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Chapter I: Introduction

In 2019, the Centers for Disease Control and Prevention (CDC) estimated that there were nearly 1.2 million people living with HIV (PLWH) in the United States. An estimated 87% of these PLWH had received a diagnosed of HIV, 81% were linked to HIV medical care within one month of their diagnosis, 66% had received HIV medical care, 50% were retained in HIV medical care, and 57% had achieved viral suppression (1). The epicenter of the current US HIV epidemic is the Southeastern region, which possesses the highest burden of both HIV cases and HIV/AIDS-related deaths in the US. Fewer PLWH in the South are aware of their HIV status compared to other regions, and therefore are less likely to be linked to HIV medical care or receive treatment with antiretroviral therapy (ART). This disparate burden of HIV in the South is explained by high rates of poverty and unemployment, widespread lack of insurance coverage, and pervasive stigma surrounding HIV, sexual orientation, substance use, and sex work (2).

Half of all PLWH in the US are out-of-care (1). There are demonstrated individual and public health implications of being unretained in HIV medical care. Missing HIV medical care appointments is a predictor of HIV disease progression on the metrics of both CD4 cell count and viral load (3), and is associated with increased all-cause mortality among PLWH (4) and high rates of opportunistic infections (5). Furthermore, 69% of all new HIV infections in the US are transmitted by people living with HIV who are out-of-care (PLWH-OOC), representing a major driver of the US HIV epidemic (6). Conversely, retention in HIV care leads to viral suppression and better health via the initiation and sustainment of ART combined with access to non-medical support services such as enrollment in the AIDS Drug Assistance Program (7, 8). Linkage to, receipt of, and retention in HIV medical care therefore not only improve individual outcomes among PLWH, but also benefit public health by slowing the spread of HIV.

Despite extensive research into the HIV care continuum in the past decade, little is known about the preferences of PLWH-OOC in the US with respect to communication and outreach from clinics regarding their HIV care. Methods of contact may include phone calls, text messages, mailed letters, social media or mobile application messages, contacting a family member or friend, and reminder visits to the patient's home. Commonly used methods of appointment reminders and other outreach attempts may not fit the preferences and needs of PLWH-OOC. For example, PLWH-OOC may be less likely to have consistent access to a working phone number and data plan (9) and more cautious of communication from the HIV clinic as household members may be less aware and accepting of their HIV diagnosis. Additionally, PLWH-OOC tend to be harder to reach than PLWH who are well-retained in care, making studying how to reach them challenging.

Studies of communication preferences and engagement in HIV care that sample from the general population or PLWH who are retained in care are likely not representative of the subpopulation of PLWH-OOC, who face a different or magnified barriers to linkage, engagement, and retention in care. These barriers to care engagement are well-studied: PLWH-OOC are more likely to be actively using drugs (10), experience housing insecurity or inability to pay rent (9), have difficulty scheduling appointments, and experience stigma (11) compared to PLWH who are retained in care. Other barriers to engaging in HIV medical care among PLWH-OOC include transportation, competing life priorities (11), insurance and financial concerns (12), and experiencing intimate partner violence (13). Taking these barriers into consideration, PLWH-OOC may be more likely to prefer communication and outreach strategies which help them navigate the health system and get to the clinic, do not rely on stable housing, finances, or access to technology, and minimize stigma and risk of unintentional disclosure of their HIV status.

Additionally, much of the current research on improving HIV care continuum metrics focuses on the success or acceptability of interventions aimed at increasing engagement and retention in care, without addressing the fundamental first step of successfully contacting PLWH-OOC. Without effective communication and outreach, PLWH-OOC will remain unable to access not only HIV medical care, but also the non-medical services offered by clinics (such as support for housing, insurance, food, transportation, mental health, etc.) which facilitate continued engagement in care and improve overall quality of life. Thus, there is a clear need to better understand the communication and outreach preferences of PLWH-OOC in order to improve re-engagement, and ultimately retention, in HIV care in the US.

The purpose of this study is to explore the preferences of PLWH-OOC, and the perspectives of PLWH and other key stakeholders in HIV care, with respect to communication and outreach strategies utilized by clinics to reach and re-engage patients who have fallen out of HIV care. Specifically, this analysis will investigate the following research questions:

1) What methods of contacting patients to remind them of their HIV care appointments are most preferred by PLWH-OOC, and do preferences differ by demographic and personal characteristics?
2) How comfortable are PLWH-OOC with peer navigator visits as a form of reminding them about HIV care appointments, and why?

3) What are the perspectives of PLWH and HIV clinic staff regarding effective individual and community communication and outreach strategies to reach and re-engage PLWH-OOC in HIV care?

The results of this analysis will help guide how HIV clinics communicate and conduct outreach with patients who have fallen out of care or who are at risk of falling out of care. This can ultimately improve re-engagement and retention in HIV care among this subpopulation of PLWH, as the implementation of the preferences and considerations for being contacted identified in this study could enable clinics to better reach patients and connect them with resources to get to the clinic. Increased retention in care among PLWH-OOC has potential to not only improve individual health outcomes, but also slow the US HIV epidemic by increasing the number of PLWH who are in care and virally suppressed. Finally, the centering of PLWH-OOC in this study will hopefully serve as a model for future research into the HIV care continuum and strategies for re-engagement and retention for PLWH who are out of care or at risk of falling out of care.

Chapter II: Literature Review

HIV in the United States

In 2019, the Centers for Disease Control and Prevention (CDC) estimated that there were nearly 1.2 million people living with HIV (PLWH) in the United States. Of these, 50% were retained in HIV care (defined as documentation of two or more CD4 or viral load tests performed three or more months apart in 2019) and 57% had achieved viral suppression (defined as viral load of less than 200 copies per milliliter at most recent check). There were approximately 34,000 new HIV diagnoses in 2019, 69% of which were among men who have sex with men (MSM). The group with the highest rate of new HIV diagnoses was Black/African American MSM. Black/African Americans also exhibit the lowest rates of linkage to HIV care and viral suppression of all racial or ethnic groups in the US population (1).

The Southeastern US is currently the epicenter of the US HIV epidemic. HIV diagnoses in Southern states make up 51% of all new cases each year, despite only 38% of the US population residing in these states. The region possesses the highest burden of both HIV cases and HIV/AIDS-related deaths in the US, however fewer PLWH in the South are aware of their HIV status and therefore are less likely to be linked to HIV medical care or on antiretroviral therapy (ART) compared to PLWH in other regions. The disparate burden of HIV in the South is explained in part by high rates of poverty and unemployment, widespread lack of insurance coverage, and pervasive stigma surrounding HIV, sexual orientation, substance use, and sex work (2).

The US Department of Health and Human Services proposed a new strategic initiative, "Ending the HIV Epidemic," to address the US HIV epidemic in February 2019. Through four pillars – early HIV diagnosis after infection, timely and effective treatment to achieve viral suppression, preventing at-risk individuals from HIV infection, and rapidly detecting and responding to new clusters of HIV cases – the goal is to reduce the number of new HIV cases by 75% by 2025 and by 90% by 2030 (14).

The HIV Care Continuum

The concept of a continuum of engagement in HIV care was first introduced in 2011 by Gardner et al. and included the following stages: unaware of HIV infection, aware of HIV infection but not in care, receiving some medical care but not HIV care, entered HIV care but lost to follow-up, cyclical or intermittent user of HIV care, and fully engaged in HIV care. Their analysis found that incomplete engagement in HIV care was common in the US, and that the majority of viremic PLWH exhibited incomplete engagement in care (5). The current iteration of the HIV care continuum features five stages: diagnosis of HIV infection, linkage to HIV medical care, receipt of HIV medical care, retention in HIV medical care, and achievement and maintenance of viral suppression. As of 2019, 87% of PLWH in the US had been diagnosed with HIV, 81% were linked to care within one month of diagnosis, 66% had received care, 50% were retained in care, and 57% had achieved viral suppression (1).

The care continuum has been used to structure progress goals for ending the global HIV epidemic. In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) announced their 90-90-90 targets: by 2020, 90% of PLWH would know their status, 90% of diagnosed PLWH would be on ART for treatment of HIV, and 90% of all PLWH on ART would achieve viral suppression. UNAIDS estimates that achieving these three targets would lead to 73% of all PLWH globally being virally suppressed (15). In 2019, 81% of all PLWH worldwide knew their HIV status, 67% were on ART, and 59% had achieved viral suppression (16). Though the 90-90-90 targets were not successfully reached by 2020, these statistics represent remarkable progress in the HIV care continuum globally. Treatment with ART prevents HIV-related morbidity, AIDS-related mortality, and new HIV infections; thus, increased access to and uptake of ART in high-burden low- and middle-income countries has led to a decline in AIDS-related mortality and an increase in life expectancy at the country level (15, 17).

The research and programmatic interest in the HIV care continuum, and especially the retention stage, is driven by a large body of evidence demonstrating the implications of being unretained in care. One primary impact is poorer health outcomes for unretained PLWH: in a study of 995 PLWH at an urban community health center in the US, missing HIV medical care appointments was found to be a predictor of HIV progression by both decreased CD4 count and increased viral load (3). Furthermore, a multisite study of 3,672 PLWH initiating ART from 2000 to 2010 found that missing HIV medical care visits was associated with increased all-cause, non-HIV-specific mortality (4). Opportunistic infections, a hallmark of AIDS due to the body's severely weakened immune system, are most common among unretained PLWH and PLWH who are not aware of their status (5). At a population level, low diagnosis and retention rates are a major driver of the national HIV epidemic. It is estimated that 69% of new HIV infections in the US are transmitted by PLWH who are not retained in care and 23% are transmitted by PLWH who have not received a diagnosis, totaling over 90% of all new HIV cases (6). These metrics can be attributed to the fact that continuous retention in HIV medical care is associated with achieving viral suppression, and therefore much lower probability of transmitting HIV, and that individuals who are retained in HIV care exhibit lower rates of sexual risk behaviors like unprotected vaginal or anal sex (18, 19). Retention in care leads to viral suppression via the initiation and sustainment of treatment with ART, as well as via accessing non-medical services such as facilitated enrollment in the AIDS Drug Assistance Program (7, 8).

Factors Impacting HIV Care Retention

Numerous interrelated factors, ranging from individual to societal, impact an individual's ability to stay retained in their HIV medical care. Substance use is one factor which can negatively impact an individual's retention in HIV care. In fact, a systematic review of 16 studies of HIV care retention conducted in high-income countries found that substance use was the most cited predictor of poor retention in care (20). A cross-sectional analysis of 1,133 PLWH found that PLWH-OOC were significantly more likely to be actively using drugs than PLWH who were retained in care ($p < 0.01$) (10). One mechanism by which substance use impacts retention in care is that when PLWH are actively using drugs, they report forgetting or dismissing thoughts about their scheduled HIV appointments (11).

Another closely related driver of suboptimal HIV care retention is poor mental health. Mental health conditions are more common among PLWH compared to the general population; a 2001 study which screened 2,864 PLWH for psychiatric disorders found that the prevalence of major depressive disorder and generalized anxiety disorder among PLWH were 36% and 16% respectively, compared to 6.7% and 2.1% respectively in the general US population (21). Furthermore, a 2014 study in Ontario, Canada found that 41% of PLWH had one or more mental health conditions compared to 22% of adults without HIV (22). Mental health struggles can impact engagement in HIV care in a variety of ways; for example, in a qualitative study of barriers to retention in HIV care, PLWH with depression reported sleeping through their appointments, not wanting to go through the effort of traveling to their appointment, and feeling apathetic about their health generally (11).

Having a history of traumatic experiences can also affect retention in HIV medical care. PLWH experience physical, emotional, and sexual trauma at disproportionate rates compared to the general population; for example, the prevalence of both childhood abuse and intimate partner violence is estimated to be twice as high among PLWH. History of trauma is associated with negative HIV care outcomes such as poor retention in care, increased viral load, and increased risk of AIDS-related morbidity and mortality (23). A cohort study of 251 PLWH in Virginia discovered that the rate of missed HIV care appointments among PLWH who had been threatened by a partner in the past year was significantly higher compared to those who had not been threatened by a partner. The authors suggest that the mechanisms driving this interaction include the partner withholding access to money or transportation, fear of retribution, and poor general health state (13).

The financial burden of HIV care – both the cost of appointments and medications, which is impacted by insurance coverage, and the cost to travel to and from the clinic – is another salient barrier to retention. Both lower household income and lack of health insurance coverage are associated with more missed HIV care appointments (24). In a study of 247 PLWH in Washington state who were unlinked to HIV care, 30% reported experiencing financial barriers to HIV care and 50% reported lack of insurance as a barrier to HIV care (12). Furthermore, in a study of 300 PLWH in North Carolina, 21% reported they perceived HIV care to be unaffordable and 27% experienced transportation costs as a barrier to retention in HIV care and/or their adherence to ART (25).

In addition to cost, other transportation-related factors like unreliability of transport services, the effect of weather on ability to travel to the clinic by foot, bike, or public transportation, and traffic are commonly reported barriers to care for PLWH-OOC (11). A spatial analysis of community-level access to transportation in Metro Atlanta found that in areas with high levels of poverty, car ownership and greater number of bus stops were associated with increased linkage to HIV care and viral suppression, respectively. This suggests access to a car facilitates initial engagement in HIV care, while access to public transportation is a facilitator of long-term retention in care (26).

There is a complex, bidirectional relationship between HIV and housing insecurity. Stable housing functions as more than physical shelter – it supports positive social, economic, and psychological environments. While people experiencing homelessness have higher rates of HIV than those who are stably housed, PLWH are also at increased risk for unstable housing due to poor health, low income, stigma, and social disadvantage. A meta-analysis of 152 studies found that lack of stable and secure housing was a major barrier to engaging in consistent HIV care and, in turn, sustained viral suppression (27). A study of 59 PLWH in Metro Atlanta found that PLWH-OOC exhibited higher rates of housing instability and inability to pay rent compared to their retained counterparts (9). Providing stable housing for PLWH is one avenue to support retention in HIV care and positive health outcomes; a qualitative study of 80 PLWH in New York City found that the provision of secure housing allowed PLWH to focus more on their health and showed that someone cared about them (28).

Another factor encompassing many of the previously named barriers like cost, housing security, and mental health which impacts retention is competing life priorities. Both PLWH-OOC and PLWH retained in care report competing priorities such as caring for family members, school, and work as a salient barrier to attending their HIV appointments (11). Additionally, medical and social service providers who work with transgender women with HIV in New York City identified that stressors like financial and housing stability are often prioritized over receiving HIV care among their patients. Many of these women “are just trying to survive”, a provider reported, adversely impacting their retention in care (29). Similarly, a longitudinal cohort study in Canada found that for recently incarcerated women living with HIV, competing aspects of re-integration like securing housing and employment, reuniting with family, and navigating society and the healthcare system led to poorer retention and ART adherence (30).

The relationship between a patient and their HIV care provider can also impact the likelihood of retention in care. Patients’ perception of a providers’ unwillingness to care for PLWH and an increased sense of stigma and/or shame in the clinical setting are associated with breaks in HIV medical care (31). In a study of 1,363 patients of an urban HIV clinic in Baltimore, Maryland, PLWH reported they are more likely to keep and attend their HIV care appointments if they are treated with respect, spoken to in a way they can understand, listened to carefully, and known personally by their provider (32). Furthermore, in a study of 413 PLWH and 45 of their HIV primary care providers, both patients and providers engaged in more rapport-building, social small talk, and positive talk during HIV medical appointments when providers reported higher respect for their patients (33).

Difficulty navigating the healthcare system presents another barrier to retention in HIV care. In a study of 64 women living with HIV in rural areas of California, 25% of participants reported difficulty navigating the healthcare system as a barrier to accessing HIV medical care. Nearly 40% of these women had missed an HIV care appointment in the last year (34). This barrier is salient in urban populations as well; HIV medical and social service providers who care for young MSM in Chicago identified lack of familiarity with seeking HIV services, lack of knowledge about what services were available, and not understanding the “process” to go through as reasons young MSM with HIV struggle to seek care (35). Difficulty with health system navigation closely relates to the barriers of cost and insurance coverage. More specifically, appointment scheduling is a noted barrier to HIV care engagement and retention. A qualitative study of 51 PLWH, half of whom were retained in care and half of whom were not, found that PLWH-OOC more often reported scheduling appointments (through both electronic patient portals and speaking to clinic staff over the phone) as a barrier to care compared to their retained counterparts. Participants identified difficulty navigating the appointment scheduling system, limited clinic hours, and privacy concerns as challenges to scheduling their HIV medical care appointments (11).

Underlying and connecting with many of the aforementioned factors impacting HIV care retention is stigma – both feeling internalized stigma and experiencing external stigma related to one’s HIV status. A 2017 study examining the impact of stigma on HIV care among 196 PLWH in Alabama found that higher levels of internalized stigma was associated with lower visit adherence, in patients both with and without depressive symptoms (36). Additionally, a qualitative study of 51 PLWH in Philadelphia, Pennsylvania found that feeling uncertainty and anxiety about disclosing one’s HIV status – either intentionally to friends and family, or unintentionally in clinic waiting rooms or pharmacies – negatively impacts the ability to regularly attend HIV care appointments. This concern was ranked higher as a barrier to retention among PLWH-OOC compared to PLWH who are retained in care (11). Lower perceived social support is also associated with more missed HIV medical care appointments (24). In addition to negatively impacting PLWH’s utilization of medical and social services, experiencing HIV-related stigma is associated with poorer adherence to ART (37). It is clear that stigma, in many forms and through many avenues, can impact retention in HIV care and in turn health outcomes.

Medical Appointment Reminders

Missed medical appointments of any kind are costly and inefficient for clinics and are associated with poorer health outcomes for patients. Appointment reminders offer one avenue to reduce the frequency of missed appointments, however patient-centered research in this area is fairly limited. A non-HIV-specific survey of 251 US adults (mean age of 43 years old; 84% White; 51% female) examining preferred attributes of general medical appointment reminders found that patients most preferred receiving a single reminder that comes by email, phone, or text message two weeks or less prior to their appointment. Social media reminders and electronic calendar reminders were relatively unpreferred reminder types. Mobile reminders like emails and text messages were preferred over static reminders like mailed letters, confirming previous research which found that three-quarters of people are willing to receive appointment reminders via mobile devices. However, participants did not uniformly prefer certain information to be included in the reminder message, indicating that customizable appointment reminders may be beneficial for clinics to offer. Transportation issues and forgetfulness were the most commonly stated reasons for missing medical appointments among participants (38).

Appointment reminders are used in HIV care delivery settings at high rates – a study of 1,234 HIV providers from 391 clinics (Ryan White funded and non-Ryan White funded) found that 89% worked in clinics which utilized some form of appointment reminder, and 82% worked in clinics that followed up on missed appointments (39). One unique reminder mechanism utilized in the HIV sphere is the use of pagers. A 2004 study of directly administered ART through a mobile clinic employed pagers to remind patients of the mobile clinic's visits, to take their ART doses, and of their upcoming medical appointments. Program participants liked the pagers; however, practical issues like device loss and battery changes were challenges to their use (40).

Communication and Outreach Strategies Supporting HIV Care Re-engagement and Retention

Clinics employ many strategies aimed at improving patients' retention in HIV care. One such strategy is case management, the coordination of both HIV medical care and non-medical services such as support for housing, insurance, food, substance use, and transportation for PLWH. In a study of 2,773 PLWH receiving care at a Ryan White-funded clinic in St. Louis, Missouri, engagement in medical case management services was found to improve HIV clinical outcomes (both CD4 count and viral load) significantly faster compared to those who did not engage in case management (41). By providing tailored assistance to patients' social and economic needs, case management helps lessen barriers to accessing HIV care and therefore facilitates retention in care. Offering case management services also improves clinic-level monitoring of retention; a study of 1,234 HIV care providers from 391 health facilities across the US showed that clinics without case management services were less likely to systematically monitor retention among their clients (39).

Another retention strategy is peer or patient navigation, in which another PLWH or a patient advocate representing the clinic helps facilitate health education, engagement in care, case management, and social support among patients. A review of four studies evaluating patient navigation interventions showed that retention in care improved from 64% at baseline to 87% after six months and remained high at 79% after 12 months. Furthermore, rates of viral suppression increased by 50% after 12 months of the navigation interventions (42). Similar to case management, peer/patient navigation succeeds as a retention strategy because it helps PLWH navigate and overcome barriers which may make it difficult to stay engaged in care. It also offers patients social support, friendship, and an experienced guide for engaging in HIV medical care and related services.

To be able to utilize these clinic-level retention strategies, there is a need to first adequately reach and engage PLWH-OOC. Characteristics of this population, such as the high rates of housing instability, substance use, and poverty, create barriers to traditional attempts at patient-clinic communication such as phone calls to follow up with patients who miss appointments. For example, in a study of 59 PLWH in Metro Atlanta, PLWH-OOC reported their phone number changed an average of 1.46 times in the past year (SD=1.58) – nearly four times more than PLWH who were retained in care (9). This, along with other barriers like not listing a secondary contact or having a stable mailing address, prevents clinics and other organizations from being able to reach PLWH who have fallen out of care or who are at risk of falling out of care.

Various strategies for outreach and communication specifically with PLWH-OOC exist, each with benefits and drawbacks. First, mailed communications like letters or postcards are a common method for clinics to attempt to reach patients who have fallen out of care. Mailed communication requires not only that the individual has a stable permanent address, which is not always the case due to housing instability and homelessness, but also one at which they can privately receive mail of a sensitive nature. Generally, mobile forms of patient-clinic communication are preferred to mailed letters (38).

Mobile technology-based communication strategies – phone calls, text messages, social media platforms, and mobile phone applications – represent another form of outreach. PLWH report the lack of a stable phone number as a barrier to receiving appointment reminder text messages and/or phone calls and to staying in communication with their HIV care provider (11).

This qualitative finding is supported quantitatively by the study previously introduced (9); the frequency with which PLWH-OOC change phone numbers or lack access to a phone clearly points to a need for alternate, non-technological communication methods in this population. Even for PLWH with a stable phone number and data plan, there are conflicting results regarding the impact of text message reminders on clinic attendance. A meta-analysis of seven studies found that text message reminders significantly reduced rates of HIV care appointment non-attendance (OR: 0.66, p=0.01) (43). However, a study conducted at an outpatient HIV clinic in Guadeloupe found that SMS reminders sent two days before appointments had no significant impact on clinic attendance rates (44). Phone-based communication also raises concerns about privacy and stigma. A qualitative study of young adults living with HIV aged 18 to 25 years old identified concerns about privacy and unintentional disclosure of HIV status by mobile phone notifications or social media activity, as participants reported they commonly share their phones with friends while hanging out and carefully manage their online presence. Participants showed interest in using a private app or website that would foster community among young PLWH and offer resources related to employment, education, health, and relationships (45). There is growing research into mobile phone apps for re-engagement of PLWH. For example, PositiveLinks is an app designed to improve engagement in HIV care that was developed using an iterative, user-driven process (46). In a study of its implementation among PLWH at a Ryan White-funded clinic in Virginia, PositiveLinks was shown to significantly improve both engagement in care and viral suppression after six months of using the app. These improvements were sustained throughout the two-year study period (47). Mobile phone apps present an exciting new opportunity for communication and re-engagement; however, their utility is limited to PLWH-OOC who have a smartphone or other compatible device and is subject to privacy and confidentiality concerns.

In addition to being a retention strategy, peer/patient navigation serves a way to reach PLWH-OOC. In the context of outreach, navigation may entail visiting the individual where they live or a place they frequent, helping them connect with resources to overcome barriers to engaging in care, and/or providing transportation to the clinic or pharmacy. A qualitative meta-analysis of PLWH's experiences with patient navigation reported that navigators help PLWH-OOC maneuver complex health and social service systems, emphasize the importance of re-engagement in care, increase self-efficacy, and provide assistance with non-medical needs like housing insecurity, substance use, mental health, insurance, and food insecurity. PLWH felt that social service assistance from their navigators was even more valuable than assistance with their HIV medical care. Navigator roles in this meta-analysis included peers, nurse guides, clinical social workers, and case managers (48). Additionally, a qualitative study with 11 PLWH found that working with navigators from the North Carolina State Bridge Counselors program increased PLWH's motivation to return to HIV care and their ability to overcome the barriers that had previously kept them out of care. Factors of navigation such as flexibility, having someone to understand what is going on their lives, and persistence were especially appreciated by PLWH in this study. Navigators engaged with PLWH-OOC through phone calls, home visits, transporting them to the clinic, and accompanying them to appointments (49). PLWH-OOC may be hesitant to utilize peer/patient navigation services due to concerns about privacy and confidentiality, as many models of navigation for reaching patients who have fallen out of care involve home visits or contact in the community.

Finally, data-to-care (DTC) initiatives use HIV surveillance data to locate and link PLWH-OOC to HIV medical care and support services. A DTC pilot in upstate New York successfully located 85% of PLWH presumed to be OOC, and subsequently relinked 71% of confirmed PLWH-

OOC to HIV medical care. Program advocates located presumed OOC patients through online searches, regional and government database searches, reviewing jail and prison directories, contacting patients' last known provider, contacting patients by phone call or letter, and/or visiting patients' last known residence. Advocates used motivational interviewing and support service referrals to encourage relinkage to HIV medical care. Among patients relinked to care, 95% re-engaged in care and 63% were retained in care six months later (50). Additionally, the Cooperative Re-Engagement Controlled trial (CoRECT) – a multi-state DTC study – found that PLWH-OOC who were randomized to receive active public health interventions after identification through DTC were more likely to re-engage in care, and to do so more quickly, compared to the standard of care. In the intervention arm, trained health department staff supported re-engagement in care through activities such as assistance with transportation, scheduling HIV care appointments and sending appointment reminders, referral to social support services, and linkage to community case management programs. However, despite this positive result, there was no effect on rates of viral suppression in any of the three states or on long-term retention in two of the three states (51). Despite its proven success at identifying and contacting PLWH-OOC, DTC programs may not overcome all of the barriers to accessing HIV medical care described previously. The CoRECT program intervention included assistance with appointment scheduling, arranging transportation, and linkage to social support services and case management, while the New York DTC pilot utilized motivational interviews and support service referrals for PLWH-OOC (50, 51).

Summary and Knowledge Gaps

In sum, the US HIV epidemic – of which the Southeastern US is the epicenter – continues to rage on. As of 2019, it is estimated that only half of PLWH in the US are retained in HIV medical care. Various intersecting factors affect the ability to PLWH to engage in care, including but not limited to poor mental health, substance use, history of trauma, financial and insurance barriers, competing life priorities, stigma, housing insecurity, and the quality of the patient-provider relationship. Missed HIV care appointments have dire implications for both the individual and community: missed appointments are associated with poorer clinical outcomes and higher risk of death, and PLWH-OOC contribute to the majority of new HIV infections in the US. Strategies for promoting retention in HIV care, such as case management and peer/patient navigation, are common practice in clinics. However, reaching PLWH-OOC to re-engage them in HIV care is the first step to employing these retention strategies.

Despite all that is known about the barriers PLWH-OOC face to accessing HIV medical care, there is a lack of research focusing on how best to reach and communicate with PLWH-OOC from their perspective. Studies of medical appointment reminders in the general population or of HIV care retention strategies in PLWH are not representative of the subpopulation of PLWH-OOC, who face a different set of barriers to linkage, engagement, and retention in care than those who are retained in care or people who are not living with HIV. Additionally, many studies in this realm of HIV research focus the success or acceptability of interventions aimed at increasing care engagement, without addressing the fundamental first step of successfully reaching PLWH-OOC. Most importantly, the preferences of PLWH-OOC – and the experiences and needs which drive them – are rarely centered in current research. In order to effectively employ the retention strategies in clinics’ toolboxes, we must first focus on ascertaining and understanding the preferences of PLWH-OOC for various communication, outreach, and reminder strategies. This differs from researching the advantages, disadvantages, and acceptability of such strategies individually, as it allows PLWH-OOC to compare multiple options and choose which strategy most appeals to them.

This analysis aims to identify the preferences of PLWH-OOC for various communication and outreach strategies and statistically examine what demographic and personal characteristics are associated with these preferences. Additionally, it aims to build on the existing literature on the preference for and acceptability of peer navigation as an outreach and re-engagement strategy for PLWH-OOC using a mixed-methods approach. Finally, this analysis aims to gather opinions and ideas on effective communication and outreach strategies for reaching PLWH-OOC from the perspectives of both PLWH and HIV clinical staff through qualitative interviews. Altogether, the findings will further patient-centered evidence to employ communication and outreach strategies that will successfully bring PLWH-OOC back into the clinic to re-engage with and stay retained in HIV medical care.

Chapter III: Manuscript

Reaching and re-engaging people living with HIV who are out of care: A mixed-methods exploration of strategies to enhance clinic communication and outreach

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Abstract

Half of all people living with HIV (PLWH) in the United States are not retained in HIV care. Clinics often encounter challenges reaching PLWH who are out-of-care (PLWH-OOC) to remind them of medical appointments due to factors such as lack of access to a working phone and unstable housing. This mixed-methods study aimed to describe the preferences of PLWH-OOC for communication and outreach from clinics, as well as to gather perspectives from other stakeholders on how best to reach and engage PLWH-OOC. From June 2019 to May 2021, 50 surveys were conducted with PLWH-OOC, and in-depth interviews were conducted with three PLWH-OOC, two PLWH retained in care, six PLWH serving as Ryan White Clinic Community Advisory Board members, and 14 HIV clinic staff. Phone calls (58%), text messages (54%), and calling a secondary contact (50%) were the most preferred methods of communication among the 50 survey participants. Three-fifths (60%) felt highly comfortable with a peer navigator visiting them at home or somewhere they hang out. Interviews highlighted trust, privacy, support, and community as considerations in choosing effective communication and outreach methods for better reaching PLWH-OOC. In conclusion, communication and outreach preferences vary at the individual level. Study findings highlight the need for clinics to offer a suite of communication and outreach models to patients at each clinic visit, record their preferences, and utilize this information to more effectively reach, re-engage, and ultimately retain those who are out-of-care.

Introduction

In 2019, the Centers for Disease Control and Prevention (CDC) estimated that there were nearly 1.2 million people living with HIV (PLWH) in the United States. An estimated 87% of these PLWH had received a diagnosed of HIV, 81% were linked to HIV medical care within one month of their diagnosis, 66% had received HIV medical care, 50% were retained in HIV medical care, and 57% had achieved viral suppression (1). The epicenter of the current US HIV epidemic is the Southeastern region, which possesses the highest burden of both HIV cases and HIV/AIDS-related deaths in the US. Fewer PLWH in the South are aware of their HIV status compared to other regions, and therefore are less likely to be linked to HIV medical care or receive treatment with antiretroviral therapy (ART). This disparate burden of HIV in the South is explained by high rates of poverty and unemployment, widespread lack of insurance coverage, and pervasive stigma surrounding HIV, sexual orientation, substance use, and sex work (2).

Half of all PLWH in the US are out-of-care (1). There are demonstrated individual and public health implications of being unretained in HIV medical care. Missing HIV medical care appointments is a predictor of HIV disease progression on the metrics of both CD4 cell count and viral load (3), and is associated with increased all-cause mortality among PLWH (4) and high rates of opportunistic infections (5). Furthermore, 69% of all new HIV infections in the US are transmitted by people living with HIV who are out of care (PLWH-OOC), representing a major driver of the US HIV epidemic (6). Conversely, retention in HIV care leads to viral suppression and better health via the initiation and sustainment of ART combined with access to non-medical support services such as enrollment in the AIDS Drug Assistance Program (7, 8). Linkage to, receipt of, and retention in HIV medical care therefore not only improve individual outcomes among PLWH, but also benefit public health by slowing the spread of HIV.

Despite extensive research into the HIV care continuum in the past decade, little is known about the preferences of PLWH-OOC in the US with respect to communication and outreach from clinics regarding their HIV care. Methods of contact may include phone calls, text messages, mailed letters, social media or mobile application messages, contacting a family member or friend, and reminder visits to the patient's home. Commonly used methods of appointment reminders and other outreach attempts may not fit the preferences and needs of PLWH-OOC. For example, PLWH-OOC may be less likely to have consistent access to a working phone number and data plan (9) and more cautious of communication from the HIV clinic as household members may be less aware and accepting of their HIV diagnosis. Additionally, PLWH-OOC tend to be harder to reach than PLWH who are well-retained in care, making studying how to reach them challenging.

Studies of communication preferences and engagement in HIV care that sample from the general population or PLWH who are retained in care are likely not representative of the subpopulation of PLWH-OOC, who face a different or magnified barriers to linkage, engagement, and retention in care. These barriers to care engagement are well-studied: PLWH-OOC are more likely to be actively using drugs (10), experience housing insecurity or inability to pay rent (9), have difficulty scheduling appointments, and experience stigma (11) compared to PLWH who are retained in care. Other barriers to engaging in HIV medical care among PLWH-OOC include transportation, competing life priorities (11), insurance and financial concerns (12), and experiencing intimate partner violence (13). Taking these barriers into consideration, PLWH-OOC may be more likely to prefer communication and outreach strategies which help them navigate the health system and get to the clinic, do not rely on stable housing, finances, or access to technology, and minimize stigma and risk of unintentional disclosure of their HIV status.

Additionally, much of the current research on improving HIV care continuum metrics focuses on the success or acceptability of interventions aimed at increasing engagement and retention in care, without addressing the fundamental first step of successfully contacting PLWH-OOC. Without effective communication and outreach, PLWH-OOC will remain unable to access not only HIV medical care, but also the non-medical services offered by clinics (such as support for housing, insurance, food, transportation, mental health, etc.) which facilitate continued engagement in care and improve overall quality of life. Thus, there is a clear need to better understand the communication and outreach preferences of PLWH-OOC in order to improve re-engagement, and ultimately retention, in HIV care in the US.

The purpose of this study is to explore the preferences of PLWH-OOC, and the perspectives of PLWH and other key stakeholders in HIV care, with respect to communication and outreach strategies utilized by clinics to reach and re-engage patients who have fallen out of HIV care. Specifically, this analysis will investigate the following three research questions: First, what methods of contacting patients to remind them of their HIV care appointments are most preferred by PLWH-OOC, and do preferences differ by demographic and personal characteristics? Second, how comfortable are PLWH-OOC with peer navigator visits as a form of reminding them about HIV care appointments, and why? Finally, what are the perspectives of PLWH and HIV clinic staff regarding effective individual and community communication and outreach strategies to reach and re-engage PLWH-OOC in HIV care?

The results of this analysis will help guide how HIV clinics communicate and conduct outreach with patients who have fallen out of care or who are at risk of falling out of care. This can ultimately improve re-engagement and retention in HIV care among this subpopulation of PLWH, as the implementation of the preferences and considerations for being contacted identified in this study could enable clinics to better reach patients and connect them with resources to get to the clinic. Increased retention in care among PLWH-OOC has potential to not only improve individual health outcomes, but also slow the US HIV epidemic by increasing the number of PLWH who are in care and virally suppressed. Finally, the centering of PLWH-OOC in this study will hopefully serve as a model for future research into the HIV care continuum and strategies for re-engagement and retention for PLWH who are out of care or at risk of falling out of care.

Methods

Overview

This mixed-methods analysis is nested within a larger research study that aimed to explore the perceived need for, and barriers and facilitators influencing, the implementation of a mobile HIV clinic to re-engage PLWH-OOC (52, 53). To inform enhanced communication and outreach to PLWH-OOC, this sub-study explores communication and outreach preferences of PLWH-OOC, as well as perspectives of PLWH who are engaged in care (PLWH-IC), PLWH serving as Ryan White clinic Community Advisory Board (CAB) members, and other clinic stakeholders (i.e., infectious disease physicians, mental health clinicians, nurses, social workers, and peer navigators). From June 2019 to May 2021, 50 surveys were conducted with PLWH-OOC and 25 in-depth interviews were conducted with PLWH-OOC (3), PLWH-IC (2), PLWH serving as Ryan White clinic CAB members (6), and HIV clinic providers and staff (14). All study protocols, survey questions, and interview guides were reviewed by Ryan White clinic CAB members and revised accordingly before data collection began.

Study Population

To be eligible for participation in the study, all potential survey and interview participants needed to be 18 years of age or older and fluent in English. PLWH-OOC were defined in this study as individuals with a diagnosis of HIV who had not received HIV care in the past six months and who had a viral load greater than 200 copies per milliliter at last check. PLWH-OOC were recruited for survey participation by convenience sampling through various channels: a Ryan White clinic "retention list" of patients who had fallen out of care, identification by inpatient HIV care providers and hospital social workers, and Ryan White clinic patient orientation sessions. Three PLWH-OOC who completed the survey completed a follow-up in-depth interview. PLWH-IC were recruited to participate in interviews by clinic-based convenience sampling. Ryan White clinic staff and HIV care providers were recruited to participate in interviews by email, phone calls, clinic-wide meetings, and snowball sampling. Ryan White clinic CAB members were recruited to participate in interviews by email, announcements at monthly CAB meetings, and snowball sampling.

Prior to the start of the data collection procedure, all participants were informed of the potential risks and benefits associated with their participation in the study and were provided with an opportunity to ask questions of study staff. Written or verbal informed consent was then obtained from each participant and documented by study staff before beginning each survey or interview.

Data Collection

Quantitative surveys were administered by trained study staff via SurveyGizmo and took place in hospital or clinic rooms. The 59-question survey featured questions assessing participant demographics, key considerations for acceptability of various community-based HIV care delivery models such as a mobile HIV clinic and telemedicine HIV visits, preferences for patient recruitment and contact strategies, and personal barriers and facilitators to engagement in HIV care. Questions designed to assess patients' communication preferences included, *"Of the list I will read you, please tell me which are the best three methods for us to reach patients who have fallen out of HIV care to remind them about their appointment and to see if we can help them reach their HIV care visit?"* and *"How okay would you be with a peer navigator (someone who works in the clinic and knows you well) visiting your home or a place you hang out to remind you about your HIV care visit and help you come back into HIV care? The peer would be careful to not mention HIV or your health information in front of other people."* Participants' responses to open-ended follow-up questions, such as why they would or would not be comfortable with a peer navigator visit, were paraphrased by research staff and recorded. Survey participants were compensated $25 for their time.

In-depth interviews were conducted by trained study staff and took place in private clinic rooms, at a convenient private location such as a public library or the participant's workplace, or via Zoom videoconferencing. Interviews were conducted using a semi-structured interview guide that was specific to the participant's role (PLWH-OOC/PLWH-IC, HIV care provider, PLWH/CAB member). PLWH-OOC were asked questions such as *"Describe how you would you feel if we reached out to you to remind you of your appointment to help you get back care.*", *"If we couldn't reach you by phone, how would you feel about a peer navigator (someone from our clinic who knows you well) visiting your home or a place you hang out to remind you of your appointment and help you come back into HIV care?",* and *"How would this method change the likelihood that you will make your HIV appointment?"*. HIV care providers and clinic staff were asked, *"Do you feel there is a need in finding alternative methods for re-engaging and retaining* *people who live with HIV who have fallen out of care?*" and *"Do you have ideas on new methods to re-engage and retain out of care patients?"*. Ryan White clinic CAB members were asked *"In what ways can we engage or encourage patients who have fallen out of care to get back into care?"* and "*What type of services or resources make it easier for someone to stay in care?*". All interviews were audio-recorded. In-depth interview participants were compensated $50 for their time.

Data Analysis

Survey data was exported from SurveyGizmo into SAS statistical software for analysis (SAS Institute, Cary NC). Participant demographic information, as well as survey questions asking about patients' preferred contact/outreach methods, perspectives on peer navigation visits, their HIV diagnosis, and barriers and facilitators they faced to engaging in HIV care were the primary focus of this analysis. First, descriptive statistics were calculated on participant demographics, preferred methods of reminding patients about their HIV care appointments, and acceptability of using peer navigation for their HIV care. Trends in participants' appointment reminder/communication preferences by age, race, gender, technological device access, experiencing housing instability, recent incarceration, and time living with HIV were explored descriptively using SAS. Frequency and percent of participants were calculated and compared across strata of these demographic and personal characteristics for each communication/outreach method, as well as for each level of comfort with a peer navigator visit. Participants were encouraged to choose three preferred forms of communication/outreach; however, they were given the option to select fewer if they did not prefer three methods.

In-depth interviews were transcribed verbatim and de-identified prior to analysis. Deductive codes were developed by the study team prior to data collection, and additional inductive codes specific to communication and outreach strategies were derived from review of the interview transcripts. Each interview transcript was coded and reviewed by two study team members using MAXQDA Plus 20.0.4 to achieve consistency and consensus in the qualitative data analysis (VERBI Software, 2019). When consensus was not reached between the two assigned coders, the transcript text and codes in question were discussed among the research team until consensus was achieved. For this analysis, segments of transcripts featuring the code "Clinic Engagement and Retention" and subcodes "General Communication" and "Peer Visits" were extracted, examined, and compared.

Ethics Statement

This research was approved by the Institutional Review Board of Emory University (IRB00109937) and the Grady Health System Research Oversight Committee. All members of the study team completed training in the ethical conduct of research prior to the start of data collection.

Results

Participant Characteristics

Of the 50 survey participants, 76% (38/50) identified as cisgender men, 86% (43/50) were Black/African American, 10% (5/50) were Hispanic/Latino, and 56% (28/50) identified sexual minorities. The average age of participants was 45.5 years old (SD=12.6), and on average participants had been living with their HIV diagnosis for 15.8 years (SD=10.9). The majority of participants were unemployed (80%, 40/50) and reported an annual household income of less than

$10,000 (64%, 32/50). Participants paid for their HIV care in a variety of ways; the most common forms of payment were Medicaid (34%, 17/50) and the Ryan White Program and/or AIDS Drug Assistance Program (34%, 17/50). One-third (34%, 17/50) of participants were unhoused or unstably housed at the time the survey was conducted, and on average had spent eight nights (SD=27.5) in shelters and 38 nights (SD=69.5) on the street in the past six months. Two-thirds (66%, 33/50) of participants reported they had access to a smartphone, tablet, or computer (Table 1).

Table 1. Demographic characteristics of survey participants, people living with HIV who were out-of-care (N=50).

Age	**Mean (SD)**
	45.5 (12.6)
Sex assigned at birth	**n (%)**
Male	41 (82%)
Female	9 (18%)
Gender identity	
Cisgender woman	8 (16%)
Cisgender man	38 (76%)
Transgender woman	2 (4%)
Gender fluid/gender non-conforming	2 (4%)
Ethnicity	
Hispanic/Latino	5 (10%)
Race	
Black/African American	43 (86%)
White	2 (4%)
Asian/Pacific Islander	1 (2%)
Other	3 (6%)
Prefer not to answer	1 (2%)
Sexual orientation	
Heterosexual/straight	22 (44%)
Gay/lesbian/homosexual/same gender loving	20 (40%)
Bisexual	6 (12%)
Prefer to self-describe	2 (4%)
Highest level of education completed	

Less than high school	15 (30%)
High school diploma/GED	16 (32%)
Education beyond high school	19 (38%)
Annual household income	
Less than $10,000	32 (64%)
$10,000-19,999	13 (26%)
Greater than $20,000	0 (0%)
Prefer not to answer	5 (10%)
Employment status	
Employed, full-time	5 (10%)
Employed, part-time	5 (10%)
Unemployed	40 (80%)
Payment method for HIV care	
Medicare	7 (14%)
Medicaid	17 (34%)
Private insurance	7 (14%)
Ryan White Program/AIDS Drug Assistance Program	17 (34%)
Other	5 (10%)
None	3 (6%)
Incarcerated in the last year	
	7 (14%)
Access to smartphone, tablet, or computer	
	33 (66%)
Housing status	
Homeless or unstably housed at time of survey	17 (34%)
	Mean (SD)
Nights spent in shelter in past 6 months	8 (27.5)
Nights spent on street (unsheltered) in past 6 months	38 (69.5)
Years living with HIV diagnosis	
	15.8 (10.9)

The qualitative in-depth interview participants included 11 PLWH – six who were serving on Ryan White Clinic CABs, three who were out-of-care, and two who were retained in care at the time of the interview – and 14 HIV clinic staff including providers, nurses, social workers, and peer navigators. To protect the identities of these participants, no additional demographic information was collected.

Communication/Outreach Strategy Preferences of PLWH-OOC

When survey participants were asked to select their three highest preferences for receiving communication about upcoming appointments, 58% (29/50) preferred phone calls, 54% (27/50) preferred text messages, and 50% (25/50) preferred a call to a secondary contact listed on their medical record such as a friend or family member. Less popular options included a peer navigator visiting them where they live (26%, 13/50), receipt of a mailed letter (26%, 13/50), social media messaging (20%, 10/50), messaging through a mobile app (12%, 6/50), and a peer navigator visiting them somewhere they hang out (8%, 4/50) (Table 2).

Table 2. Proportion of participants selecting each communication/outreach method as one of their three most preferred methods for clinics to reach patients who have fallen out of HIV care (N=50).

Communication/Outreach Method	n (%)
Phone calls	29 (58%)
Text message	27 (54%)
Calling secondary contact (friend, family member)	25 (50%)
Visiting you where you live	13 (26%)
Mailed letter	13 (26%)
Message through social media	10 (20%)
Other	10 (20%)
Message through a mobile app	6 (12%)
Visiting you where you hang out	4 (8%)

If a participant selected the option of a peer navigator visiting them where they hang out, they were asked to specify ideal locations for these visits. Responses included convenience stores, in the neighborhood where they live, and encampments or other areas where people experiencing homelessness sleep. Probing on “other” responses (20%) most commonly yielded email as a preferred contact method, in addition to creative ideas like hosting a block party or community medical fair and organizing carpool groups to the clinic.

Participants' communication and outreach preferences were further examined by personal and demographic characteristics. When broken down by age, PLWH-OOC age 35 years and older most preferred phone calls and text messages. Participants aged 18 to 35 years most preferred calling a secondary contact (63.6%, 7/11) and were the age group most likely to prefer a peer navigator visit to their home (54.5%, 6/11). This age group also relatively disfavored phone calls (36.4% compared to greater than 50% in all other age groups). Interest in a peer navigator visit at home and social media messages decreased with age (54.5% and 36.4% respectively among 18- to 34-year-olds versus 0% and 7.1% respectively among those aged 55 and older), while interest in a peer navigator visit somewhere you hang out increased with age (0% among 18- to 34-year-olds versus 21.4% among those aged 55 and older). Phone calls were the most preferred method among Black/African American participants (60.5%, 26/43), while non-Black/African American participants most preferred text messages (57.1%, 4/7). Black/African American participants were less likely to prefer peer navigator visits to their home (23.3% versus 42.9%) and social media messages (16.3% versus 42.9%) and more likely to prefer calling a secondary contact (51.2% versus 42.9%) compared to those of other races. Cisgender women had a strong preference for phone calls (75%, 6/8), while cisgender men most preferred text messages (57.9%, 22/38) followed by phone calls (55.3%, 21/38). Participants who identified as a gender minority most preferred calling a secondary contact (75%, 3/4) and were the most likely to prefer social media messages (50%, 2/4) compared to cisgender men (15.8%, 6/38) and women (25%, 2/8).

Phone calls were the most preferred communication/outreach model among both participants with (57.6%, 19/33) and without (58.8%, 10/17) access to a device like a smartphone, tablet, or computer. However, participants with access to a smart device were more likely to prefer receiving a social media message compared to participants without a device (24.2% versus 11.8%).

Phone calls were also preferred with about equal likelihood between participants who were and were not unstably housed at the time of the survey. About half as many participants experiencing housing instability preferred a peer navigator visit to where they live (17.6% versus 31.3%), and about twice as many preferred a peer navigator visit to somewhere they hang out (11.8% versus 6.3%), compared to participants not experiencing housing instability. Phone calls and text messages were also the most preferred communication/outreach model among both participants who had and had not been incarcerated in the last year. Zero participants who had been incarcerated in the last year preferred a peer navigator visit at their home, while nearly one-third (30.2%, 13/43) of those who had not been incarcerated selected this model as one of their three most preferred.

Finally, preferred communication/outreach method differed slightly by participants' length of time living with HIV. For participants who received their HIV diagnosis in the last five years, phone calls and text messages were the most preferred methods (66.7%, 6/9). For participants who had been living with HIV for more than five years, phone calls were the most preferred method (56.1%, 23/41). Participants with newer HIV diagnoses were less likely to prefer calling a secondary contact (33.3% versus 53.7%) and social media messages (11.1% versus 22%) compared to those living with HIV for more than five years (Table 3).

Table 3. Distribution of top three communication/outreach method preferences of PLWH-OOC by personal and demographic characteristics. [1, 2]

	Number of participants	**n (%) of participants who selected model as one of three most preferred**							
		Phone calls	**Text messages**	**Calling secondary contact**	**Visit where you live**	**Mailed letter**	**Social media message**	**Message through an app**	**Visit where you hang out**
Age									
18-34 years old	11	4 (36.4%)	4 (36.4%)	***7 (63.6%)***	6 (54.5%)	2 (18.2%)	4 (36.4%)	1 (9.1%)	0
35-44 years old	10	***6 (60.0%)***	4 (40.0%)	5 (50.0%)	3 (30.0%)	4 (40.0%)	3 (30.0%)	1 (10.0%)	0
45-54 years old	15	***11 (73.3%)***	***11 (73.3%)***	6 (40.0%)	4 (26.7%)	4 (26.7%)	2 (13.3%)	2 (13.3%)	1 (6.7%)
> 55 years old	14	***8 (57.1%)***	***8 (57.1%)***	7 (50.0%)	0	3 (21.4%)	1 (7.1%)	2 (14.3%)	3 (21.4%)
Race									
Black/African American	43	***26 (60.5%)***	23 (53.5%)	22 (51.2%)	10 (23.3%)	11 (25.6%)	7 (16.3%)	6 (14.0%)	4 (9.3%)
Other	7	3 (42.9%)	***4 (57.1%)***	3 (42.9%)	3 (42.9%)	2 (28.6%)	3 (42.9%)	0	0
Gender									
Cisgender woman	8	***6 (75%)***	3 (37.5%)	5 (62.5%)	2 (25%)	4 (50%)	2 (25%)	0	0
Cisgender man	38	21 (55.3%)	***22 (57.9%)***	17 (44.7%)	10 (26.3%)	7 (18.4%)	6 (15.8%)	6 (15.8%)	4 (10.5%)
Transgender or gender fluid/gender non-conforming	4	2 (50%)	2 (50%)	***3 (75%)***	1 (25%)	2 (50%)	2 (50%)	0	0
Access to smartphone, tablet, or computer									
Yes	33	***19 (57.6%)***	18 (54.5%)	16 (48.5%)	10 (30.3%)	8 (24.2%)	8 (24.2%)	4 (12.1%)	1 (3.0%)
No	17	***10 (58.8%)***	9 (52.9%)	9 (52.9%)	3 (17.6%)	5 (29.4%)	2 (11.8%)	2 (11.8%)	3 (17.6%)
Unstably housed									
Yes	17	***10 (58.8%)***	9 (52.9%)	***10 (58.8%)***	3 (17.6%)	6 (25.3%)	2 (11.8%)	1 (5.9%)	2 (11.8%)
No	32	***18 (56.3%)***	17 (53.1%)	15 (46.9%)	10 (31.3%)	7 (21.9%)	8 (25.0%)	5 (15.6%)	2 (6.3%)
Incarceration in past year									
Yes	7	***4 (57.1%)***	***4 (57.1%)***	3 (42.9%)	0	3 (42.9%)	1 (14.3%)	0	1 (14.3%)
No	43	***25 (58.1%)***	23 (53.5%)	22 (51.2%)	13 (30.2%)	10 (23.3%)	9 (20.9%)	6 (14.0%)	3 (7.0%)
Length of time living with HIV									
5 years or less	9	***6 (66.7%)***	***6 (66.7%)***	3 (33.3%)	2 (22.2%)	2 (22.2%)	1 (11.1%)	1 (11.1%)	1 (11.1%)

More than 5 years	41	***23 (56.1%)***	21 (51.2%)	22 (53.7%)	11 (26.8%)	11 (26.8%)	9 (22.0%)	5 (12.2%)	3 (7.3%)

[1] *Participants were encouraged to choose their three most preferred communication/outreach models, however some participants elected to only choose one or two if they would not utilize the other models.*

[2] *Bolded, italicized cells represent the most preferred method among a group.*

Acceptability of Peer Navigation as a Communication/Outreach Strategy

Peer navigation was overall viewed positively among PLWH-OOC: 60% (30/50) of survey participants said they would be comfortable “to a great extent” with a peer navigator visiting their home or a place they hang out to help them re-engage in HIV care and remind them of their appointments, 20% (10/50) said they would be somewhat comfortable with this, 6% (3/50) would have “very little” comfort with this, and 14% (7/50) were not at all open to the peer navigation model. Compared to cisgender men (63.2%) and gender minorities (75%), cisgender women felt less comfortable with a peer navigator visiting them, with only 37.5% selecting “to a great extent”. Participants without access to a smartphone, tablet, or computer were more comfortable with a peer navigator visit than those with access to a device (76.5% versus 51.5%). Participants who had been incarcerated in the last year were less comfortable with peer navigator visits than those who had not been incarcerated (42.9% versus 62.8% answering “to a great extent”, 42.9% versus 16.3% answering “very little or not at all”). Participants who had been living with HIV for longer than five years expressed more comfort with peer navigation than those with diagnoses in the last five years (63.4% versus 44.4%) (Table 4).

Table 4. Level of personal acceptability of a peer navigator visiting one’s home or a place they hang out by personal and demographic characteristics (N=50).

	Number of participants	n (%) of participants		
		To a great extent	Somewhat	Very little or not at all
Full sample	50	30 (60%)	10 (20%)	10 (20%)
Age				
18-34 years old	11	7 (63.6%)	1 (9.1%)	3 (27.3%)
35-44 years old	10	5 (50%)	4 (40%)	1 (10%)
45-54 years old	15	9 (60%)	3 (20%)	3 (20%)
> 55 years old	14	9 (64.3%)	2 (14.3%)	3 (21.4%)
Race				

Black/African American	43	26 (60.47%)	9 (20.9%)	8 (18.6%)
Other	7	4 (57.1%)	1 (14.3%)	2 (28.6%)
Gender				
Cisgender woman	8	3 (37.5%)	2 (25%)	3 (37.5%)
Cisgender man	38	24 (63.2%)	7 (18.4%)	7 (18.4%)
Transgender or gender fluid/gender non-conforming	4	3 (75%)	1 (25%)	0 (0%)
Access to smartphone, tablet, or computer				
Yes	33	17 (51.5%)	7 (21.2%)	9 (27.3%)
No	17	13 (76.5%)	3 (17.7%)	1 (5.9%)
Unstably housed				
Yes	17	11 (64.7%)	2 (11.8%)	4 (23.5%)
No	32	19 (59.4%)	8 (25%)	5 (15.6%)
Incarceration in past year				
Yes	7	3 (42.9%)	1 (14.3%)	3 (42.9%)
No	43	27 (62.8%)	9 (20.9%)	7 (16.3%)
Length of time living with HIV				
5 years or less	9	4 (44.4%)	3 (33.3%)	2 (22.2%)
More than 5 years	41	26 (63.4%)	7 (17.1%)	8 (19.5%)

When asked to explain why they did or did not feel comfortable with a peer navigator visit, survey participants highlighted advantages and disadvantages of the model and provided input on how such a visit should be carried out. Participants who felt comfortable with a peer navigator visit cited the alleviation of transportation barriers, having someone to talk and relate to, and the display of care as reasons they were interested in the model. On the other hand, issues of privacy and confidentiality, stigma, and lack of trust of the navigator were commonly raised as concerns with the model. General considerations for peer navigation visits reported by participants included agreeing on a safe, neutral meeting place for community visits, ensuring the navigator does not mention any personal or health-related information, planning visits ahead of time if possible, and employing navigators who represent and “blend in” with the community.

These themes were present and expanded upon in the qualitative interviews conducted with PLWH who were in care (IC) and out-of-care (OOC). Participants were generally open to the peer navigation model:

> "As long as I'm comfortable with that person, yes, I'd be all for it." – PLWH-OOC

One concern named by interview participants, like survey participants, was potential loss of privacy and confidentiality during a peer navigation visit – specifically, unintended disclosure of their HIV status.

> "Just being put out…people finding out about your condition, about your HIV status." – PLWH-OOC

In describing what they would like about the peer navigation model, many participants explained the importance of feeling like someone cares about them, will advocate for them, is there for them through their journey with HIV care.

> "You've got somebody in your corner. It's like…somebody else is there, they didn't give up on you but you gave up on yourself…you've got somebody there that didn't give up on you." – PLWH-OOC

> "It makes you feel like somebody actually cares…about whatever it is that is going – that you're going through that you're missing your appointments – that somebody's there and trying to help you stay up to date with your health." – PLWH-IC

> “And I think that a lot of people just really need support. I don't think it's so much money and food. I think they just need support, you know, just to let them know that if there's anything you could do or if it's anything I need to speak on or be their advocate because people need that.” – PLWH-OOC

> “I need somebody there when I need a shoulder to cry on, when I need somebody to talk to, because sometimes you can’t talk to your family. Not that you can’t talk, you just don’t know how, you know, so somebody that is neutral is better and that you feel has got an open mind and been there and know that’s what they do.” – PLWH-OOC

Participants further highlighted the need for a caring, trustworthy, and friend-like navigator when describing what they thought a peer navigation visit should ideally look like.

> “Ask them, ‘Is it anything I can do to help you that can make you come in, that will help you to get here? What is it that you need? What do you need us to do?’ But [the navigator] has to open up and show them that you're concerned.” – PLWH-OOC

> “I should be able to confide in them.” – PLWH-OOC

> “Just talking to you not basically, not really in in medical terms or anything, just basically like a friend…someone that’s not gonna talk at me and try to make me feel guilty about missing my appointment or why I’m not coming in, you know, putting that guilt trip on you.” – PLWH-IC

One participant described how interactions with a peer navigator taking place outside of an individual's home, such as at a hangout spot or nightclub, should be friendly, discreet, and casual.

> "Casual, nonchalant; not, 'Hey, you know you forgot your freaking appointment'…none of that. 'Look here, girl, let me talk to you real quick; we got important situations that we got to handle real quick', and pull me to the side, and be more discreet, confidential about it….'Come on, let's go to the bar; let's go have a drink real quick; we have to conversate about some things'; 'Oh, girl, I got some secrets to tell you or some tea with you to spill', or something like that." – PLWH-OOC

Finally, when asked how the peer navigation model might change the likelihood of attending their appointments and how they think about their HIV care, participants described the potential positive impacts such as increasing personal engagement and accountability.

> "It would change tenfold. It would make the person feel a lot more comfortable. It would make them want to feel more a part of their medical situation." – PLWH-OOC

> "It would give me a different outlook. It'll make me feel like, really somebody care, not just for me to come get medicine, you know. It'll make you really feel different about taking the medicine, about your life, knowing that if you don't this is something that's going to keep you here, you know, and it will really help me." – PLWH-OOC

> “I think it would hold people more accountable. Because you know, you don’t have – especially people who are by themselves, you don’t have nobody holding you accountable for your appointments.” – PLWH-IC

No negative impacts of peer navigation on participants’ engagement in or outlook on their HIV care were mentioned.

Patient and Clinic Staff Perspectives on Effectively Reaching PLWH-OOC

PLWH who were out-of-care, in care, and serving on a Ryan White Clinic CAB were also interviewed about their experiences with and opinions on clinic communication/outreach strategies for better reaching and re-engaging PLWH-OOC. A range of ideas regarding the best form of communication were expressed, from traditionally utilized methods like mailed letters and text messages to social media messages:

> “I would really be all for it via mail or social media, like [direct messages] and stuff like that.” – PLWH-OOC

> “For me, I mean phone is fine, but sometimes I’m not near – I don’t answer my phone. I’m more likely to answer a text than I am to answer the phone" – PLWH-IC

Others expressed concerns about potential loss of privacy when clinics use mailed letters to communicate with patients.

> "When you get something in the mail from [the clinic], I mean you could have a family member open your mail." – PLWH-IC

Reflecting on how others' knowledge of their HIV status affects how they would like to be contacted by the clinic, one participant explained that while he no longer is affected by this, younger individuals with newer HIV diagnoses might be more sensitive to forms of contact with higher risk of accidental disclosure.

> "Now, being 33, it doesn't affect me as much as it did when I was younger...The younger [me] would probably feel offended by it; but then again, as long as I'm getting contacted not in front of everybody in a group setting, that's fine. More or less over the phone or computer, stuff like that, I'll be comfortable; but the younger me, back then, I could not have – I would trip out when I see a confidential letter in the mail and be like, what the hell is this; I don't even want to open it up." – PLWH-OOC

Finally, participants were asked to identify ways in which they feel clinics could improve in reaching, re-engaging, and retaining patients. One participant answered that clinics could help people by simply cheering patients on and providing human connection:

> "Well, you know what, my self-esteem needed to be helped…I need some pep talk; you know what I mean, so to speak…I need somebody to tell me it's going to be OK, you know what I'm saying? You need that sometimes. It's just not – I mean I know God is there but still sometimes you need that human touch, you know?" – PLWH-OOC

Additionally, HIV clinic staff were asked to reflect on their clinics' strengths and weaknesses in reaching and engaging PLWH-OOC, as well as to think of avenues for improvement in these areas. One clinic staff member identified stronger logistics and patient follow-up procedures as an area the clinic could improve.

> "I would say the barriers would be a lot is a lack of consistency on the part of the clinic with regards to being consistent about enforcement of what happens when you fail to keep an appointment or you don't call or reschedule an appointment and consistent about following up with the patient. Who does that? Who calls to see why they missed an appointment? Who calls to remind them of an appointment?" – Nursing Staff

The Need for Individual and Community Outreach

One theme which emerged in interviews with PLWH and HIV clinic staff was the importance of strong outreach programs, both for individual patients and in the larger community. Clinic staff explained the need for patients who have fallen out of care to be better connected to resources, groups, or programs – HIV-related or otherwise – which may help support them in continuing to engage in their HIV care.

> "There's this cooking class that we do there, which is interesting because there is no HIV attached to it. You are just coming to get nutrition education skills. And so, brief story, I had a lady, and so she kind of whispered to me, 'Everybody in here is like me,' and I said, 'What do you mean?' And she was like, 'Everyone in here has HIV'…sometimes people

> are confused about what [PLWH] actually look like. So sometimes it's just programs like that that are maybe nonthreatening. They don't feel like the outcome in context is to come and talk about their medical diagnosis.” – Social Worker/Peer Navigator

> “If you can keep [PLWH-OOC] engaged, and then they meet other people who also have the same medical concerns, right, then maybe they will form a bond and they will do things outside of that when the clinic isn't open.” – Social Worker/Peer Navigator

Additionally, one PLWH-OOC shared a novel idea for how clinics can better engage and retain patients: hosting a meeting for people to get their questions about HIV care anonymously answered by experts.

> “I say maybe, like, every other month we have a gathering…like, we put on the board and say that on January the such-and-such we're having a group meeting and just put some little plates of food or hors d’oeuvres or something to bring the people so everybody can talk…once people start eating you'd be surprised. They get comfortable. They start talking. Then once everybody know what - everybody is going to write down what their problem is. They ain't got to put their name on the paper. Just write it down so the next time we meet in a month and a half or two months, then we'll have the doctor, the social worker, the case manager, everybody here. And everybody's question will be answered.” – PLWH-OOC

Zooming out, community outreach and relationship-building was also identified by HIV clinic staff as an area in which clinics currently fall short in reaching and serving PLWH-OOC.

> "I think they need to do more work in the community, especially the community that they provide services to. I think they need to do more in being out there and finding out what's available where they live…I don't think they do enough with having events about HIV, hosting events about HIV." – Nursing Staff

Discussion

Half of all PLWH in the US are not retained in HIV medical care, an issue that is magnified in the South, where fewer PLWH receive care and treatment with ART and HIV/AIDS-related mortality is high (1, 2). There is a clear need to improve engagement and retention in HIV care in the South and across the US in order to improve individual and public health. This study helps address a critical gap in the understanding of contact preferences of PLWH-OOC, a population that is difficult to reach with traditional engagement and retention methods. While there are several evidence-based interventions to retain PLWH in care, they are futile if we are unable to communicate with, reach, and re-engage those who are OOC. A critical strength of this study is its recruitment of and focus on PLWH-OOC. Our sample of 50 participants was generally representative of the population of PLWH in the Atlanta metropolitan area: mostly Black, male, and gay or bisexual (54).

The three most commonly preferred methods of contact regarding HIV care in the entire sample were phone calls, text messages, and calling a secondary contact. This aligns with the literature on general, non-HIV medical appointment reminder preferences, which shows that phone calls, texts, and emails are highly preferred contact methods (38). Most HIV clinics are already employing these methods to contact patients, but it is clear that these strategies on their own are not enough to effectively reach and retain PLWH-OOC. Less traditional methods like peer navigator home visits and social media messages were highly preferred by about a quarter of participants, indicating that these methods should be incorporated into regular clinic operations by creating or building out community-based peer outreach and navigation programs and asking patients if they would like to be contacted via social media. While past research has found that social media messages were strongly disfavored for general medical appointment reminders (38), PLWH-OOC appear to be more receptive to this method of communication than the general public. The least-preferred contact methods among PLWH-OOC in this study were messages through a mobile app and peer navigator visits where they hang out. There is a large body of recent research on the development of mobile apps for PLWH (45–47) with one recent study finding 17 apps available for HIV management (55); however, our findings may suggest low interest in or utilization of these apps among the PLWH-OOC subpopulation.

Though not the most highly preferred communication/outreach model, peer navigation was widely accepted by participants in this study, serving as evidence for the utilization of the peer navigation model to reach PLWH-OOC. The subgroup that expressed the most comfort with peer navigator visits was PLWH-OOC without a device like a phone, tablet, or computer, suggesting that lack of access to other methods of communication may influence willingness to engage in the peer navigation model. Recently incarcerated participants were the least comfortable with peer navigator visits – nearly half responded that they had very little or no comfort with the model, and none preferred a peer navigation visit to their home as one of their top three contact methods. Housing instability and experiences of stigma post-release may lead to concerns about peer navigation regarding trust and privacy; however, the complex set of challenges recently incarcerated PLWH face such as housing instability, lack of transportation, low social support, and competing priorities for reentry (56) suggest this population might benefit from peer navigation programs. Finally, compared to those not experiencing housing instability, twice as many participants experiencing housing instability preferred a peer navigator visit to somewhere they hang out. This suggests that offering peer navigation in the community can be an important tool for reaching PLWH-OOC experiencing housing instability.

Interview participants' ideas about what an ideal peer navigation visit would entail – agreeing on a neutral location, planning visits ahead of time, and meeting with a demographically representative navigator that blends in with the community – as well as their concerns about stigma and privacy should be used to shape clinics' peer navigation programs for PLWH-OOC. Descriptions of a peer navigator being a support system, advocate, friend, and confidant highlight that this communication/outreach model serves as more than simply an appointment reminder or ride to the clinic. Interview participants reported peer navigation would positively impact their outlook on and involvement in HIV medical care, reflecting an important mental transition; in a study of PLWH-IC and PLWH-OOC, IC patients wanted to proactively manage their HIV and stay informed about new treatments, while OOC patients did not want to be reminded of their disease and had other more important life priorities (57). By showing patients that someone cares about them and overcoming barriers such as lack of transportation or difficulty navigating the healthcare system, peer navigation can help bring PLWH-OOC back into HIV medical care.

HIV clinic staff frequently touched upon the importance of offering and linking PLWH-OOC to programs that foster connection and social support as a way to better serve this subpopulation of patients. These outreach programs present the opportunity to engage people in a way they may not have been engaged in the past, and in doing so allow clinics to capture PLWH-OOC in a non-clinical setting and ensure they have the support to re-engage and stay retained in care. Through fostering community, providing social support, and offering tangible resources, individual and community outreach programs have the potential to lessen the experience of stigma among PLWH-OOC and show that it is possible to live well with HIV. Even in the time of the COVID-19 pandemic, this type of programming is possible: when an HIV clinic offered an anonymous online support group for its patients, nearly two-thirds of users named connecting with others as a benefit of the community message board feature of the online group (58). By strengthening individual and community outreach efforts, HIV clinics would have the opportunity to meet PLWH-OOC where they are and support them in all aspects of life.

The diversity of preferences identified in this study demonstrate that one size does not fit all when it comes to effective communication regarding HIV medical care. Even the most widely preferred contact method among the sample of PLWH-OOC – phone calls – was only selected as a top three most-preferred method by 58% of participants. Preferences varied by individual demographic, personal, and social characteristics; these findings highlight a need for many communication and outreach options to be in place at clinics in order for PLWH-OOC to be successfully reached and re-engaged. Clinics also need to implement administrative strategies which support effective communication/outreach with PLWH-OOC. At patient intake, clinic staff should ensure that contact information of friends or family members is collected and consent to contact these individuals is obtained. Additionally, clinic staff should ask all patients how they would prefer to be reached based on what methods the clinic offers, obtain consent for all selected forms of communication, and note these preferences in their chart. Finally, clinics should dedicate resources to create or expand an individual role or team dedicated to standardizing, monitoring, and conducting communication and outreach with patients who have fallen out of care. HIV clinic staff interviewed in this study identified a need for increased consistency and responsibility for contacting patients who miss appointments. The Retention Coordinator, often charged with reaching out and re-engaging PLWH-OOC, could also be responsible for tracking which forms of communication are most appropriate or effective to reach an individual patient and conduct outreach accordingly. This intervention is proven to be successful: at a Ryan White HIV clinic in South Carolina, the creation of an "outreach coordinator" who contacted patients using a stepwise, multifaceted approach – phone calls to the patient and their secondary contacts, mailed letters, and finally a home visit – led 44% of PLWH-OOC to re-engage in care, 50% of whom remained retained in care (59).

This study is not without limitations. First, the population of PLWH-OOC in Atlanta may not be representative of PLWH-OOC in other cities, non-urban areas, or outside of the Southeastern US. While our sample of 50 survey participants was representative of PLWH-OOC in Atlanta, the low number of participants who were non-Black, gender minorities, or young adults limits the generalizability of our findings. For example, the lower relative preference for social media and mobile app messages may be due to the older average age in our sample; younger PLWH might be more amenable to these communication models. Additionally, the average time living with HIV among survey participants was nearly 16 years; the communication and outreach preferences of PLWH-OOC who have accepted their diagnosis and are possibly more familiar with HIV care system may differ from the preferences of newly diagnosed PLWH. This study's findings should therefore be validated in other settings outside of the urban Southeast with different populations of PLWH-OOC. Additionally, it is important to mention a methodological limitation of preference identification. Survey participants were asked to select their top three most preferred communication/outreach models, but they did not have an opportunity to indicate which models they would not consider using. It is important to remember that the lack of selection of a model in this study does not necessarily indicate that the participant actively disliked the model, it may have just ranked lower than third on their preference list. Finally, the small sample size of survey participants limited our ability to conduct statistical analyses on communication and outreach preference data such as assessing for confounding and multivariate analysis. Future research should aim to quantify the associations between preferences and demographic/personal characteristics, as well as qualitatively explore the factors influencing these preferences across subgroups.

In conclusion, while standard contact methods such as phone calls and text messages are most commonly preferred by PLWH-OOC, non-traditional methods like peer navigation and social media messages are also strongly preferred by a portion of the population. Individual characteristics like age, experiencing housing instability, access to technology, being recently incarcerated, and length of time living with HIV may be associated with differences in preferences and comfort with the various models. These findings highlight the need for clinics to offer a suite of communication and outreach options to reach PLWH-OOC. Knowing that someone cares has been identified as a motivator for patients to stay retained in HIV medical care (57), and PLWH and HIV clinic staff alike identified a need for increased support for PLWH-OOC. The findings of this study should be used to shape clinics' communication strategies, peer navigation programs, and community outreach efforts aimed at reaching PLWH-OOC. This will allow more PLWH-OOC to re-engage in care, leading to better individual health outcomes and the eventual slow of the US HIV epidemic.

Chapter IV: Conclusion & Recommendations

Conclusion

Fifty percent of PLWH in the US are unretained in HIV medical care (1). Using a representative sample of PLWH-OOC in the urban Southeast, the epicenter of the US HIV epidemic (2), this study aimed to increase understanding of how best to contact PLWH-OOC in order to increase engagement in care and employ clinic retention strategies. We found that one size does not fit all when it comes to the communication and outreach preferences of PLWH-OOC. Most participants highly preferred phone calls and text messages, but other methods such as peer navigator visits and social media messages also ranked highly for a substantial portion of participants. Current retention trends demonstrate that phone-based communication methods, which are currently utilized by clinics, are not enough to effectively reach all PLWH-OOC. Peer navigation, which can help PLWH-OOC overcome barriers to accessing care such as lack of transportation, difficulty navigating the health system, and low social support, was found to be widely accepted by PLWH-OOC in this study. Finally, clinic-run individual and community outreach programs not related to HIV medical care may be an innovative way to reach and engage PLWH-OOC. The individual variation in preferences suggests that no one communication or outreach method is preferred or accepted by all. In conclusion, in order to reach PLWH-OOC effectively in a way that works for them, HIV clinics should employ a range of communication and outreach strategies and allow patients to indicate their preference and consent to any methods they would be comfortable with. The findings of this study have implications for HIV clinics, PLWH-OOC, and the US HIV epidemic.

Public Health Implications

This study's findings offer many ways for HIV clinics to improve their communication and outreach with PLWH-OOC. First, clinics should aim to offer a variety of different communication and outreach methods – phone calls, texts, calling a secondary contact, emails, letters, peer navigation visits, social media and mobile app messages – to patients. By encouraging patients to select and consent to as many of the methods as they are comfortable with, there is a higher chance of successfully reaching them. These efforts could be overseen by a dedicated outreach coordinator, building on the role of retention coordinator that many clinics already have. This role would involve closely tracking missed appointments, communication attempts, and engagement interactions with PLWH-OOC and PLWH who are at risk of falling out of care. Additionally, the high level of comfort among participants with peer navigation as a communication/outreach strategy suggest clinics' allocation of resources to beginning or expanding peer navigation programs would be worthwhile. The qualitative findings can help inform the design or peer navigation programs that consider the perspectives and needs of PLWH-OOC, such as hiring demographically representative navigators, having the option to plan visits at home or in the community, and developing a friend- or mentor-like relationship between navigator and patient. Finally, novel outreach programs suggested by study participants such as clinic question and answer nights, non-HIV-related life skill classes, or community medical fairs would offer the opportunity for clinics to meet PLWH-OOC where they are and engage them in familiar, non-clinical settings. Taken altogether, our findings highlight that HIV clinics have room to grow in the communication and outreach strategies they offer specifically for PLWH-OOC.

If clinics implement these changes and policies that reflect the diversity of preferences and needs of PLWH-OOC, successful communication and outreach may help facilitate re-engagement in HIV medical care. After re-engaging in care, PLWH-OOC would gain access to the proven retention tools and programs clinics offer to help them stay in care, adhere to ART, and achieve viral suppression. This will allow PLWH who are currently out of care to improve their short-term health outcomes and live a longer, healthier life. Furthermore, increasing the number of PLWH who are in care and virally suppressed would reduce the spread of HIV. PLWH-OOC disproportionately contribute to new HIV infections due to having a detectable viral load; therefore, targeting this population for increased retention through first effectively contacting them and facilitating their re-engagement in care may ultimately improve the state of the US HIV epidemic.

Future Directions

To continue increasing the understanding of communication and outreach strategies for reaching PLWH-OOC, future research should aim to validate and build upon this study's findings in populations of PLWH-OOC outside of the urban Southeast. Additionally, larger samples of PLWH-OOC should be recruited in future studies in order to elucidate meaningful associations between demographic and personal characteristics and preferences for certain communication and outreach methods. Future directions should also include communication and outreach program implementation and evaluation research. For example, the creation or expansion of a clinic outreach coordinator role or peer navigation program should involve assessments of patients' experiences with their services and an analysis of how rates of successful contact and re-engagement have changed. In general, more research in the field of HIV should include the voices of PLWH-OOC, who make up half of all PLWH in the US. The findings and strategies shared in this study can also be applied to reaching PLWH-OOC for recruitment into research studies.

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Appendix A:
Quantitative Survey Tool

Interviewer to read aloud: *Thank you again for participating in the study. We recognize that many people have a hard time making it to their HIV care visits and taking HIV medicine. Our goal as a program is to make it easier for you and others in the clinic to stay in HIV care and be healthy. The questions that follow will help us develop a community-based program to better meet the needs of the people we serve. As we work through the questions, please let me know if there is a question you want me to explain further or repeat and also if there are questions you don't feel comfortable answering and prefer to skip. Are you ready to begin?*

1. **Participant ID number: __ __ __**
2. **Date of interview: __ __/ __ __ / ___**
3. **Time of interview: __ __ : __ __ AM/PM**
4. **Interviewer initials: __ __ __**

Community-based HIV Care Models

I am going to first ask you some questions about the Emory Ryan White Program and Infectious Diseases Clinic. Our clinic is concerned because 200-300 patients each month fall out of HIV care. We know that many people experience barriers to coming to the clinic. So, we need to come up with new creative ways to better reach patients, particularly those who have fallen out of care.

Now, I am going to share with you some ideas we have that involve our clinic providing more direct care in the community rather than at Emory Midtown Hospital. After I read the descriptions to you I am going to ask you to summarize the option. I also want to hear your thoughts on what might work best.

Mobile HIV Treatment Clinic

Our first idea is a mobile HIV treatment clinic. This would mean that a large medical van would come directly to the community where patients live to provide them with HIV care and support services. Patients would directly walk into the mobile van where they would be seen and examined by their HIV care team. Can you summarize the mobile HIV treatment clinic option?

(Interviewer show visual aide #1)

5. **How likely do you think patients who have fallen out of care would be to use a <u>mobile HIV treatment clinic</u> for their HIV care?**
   - ☐ Not likely
   - ☐ Somewhat likely
   - ☐ Very likely
6. **How likely do you think <u>you</u> would be to use a <u>mobile HIV treatment clinic</u> for your HIV care?**
   - ☐ Not likely
   - ☐ Somewhat likely
   - ☐ Very likely
7. **Specify why: ____**

8. **To protect the privacy of patients using the mobile van for HIV treatment, we want to be careful with how we name it. We want to put a name on the outside of the van so that Emory patients would know that it is for their HIV care, but others would not. The name should discourage other people from using the van services as we can only provide HIV care to patients who are enrolled at Emory at this time. What ideas do you have for naming the van?**
    - ☐ Specify ________________________
9. **The van won't be too big, so we can't have too many care providers on the van at one time. Knowing that, what are the minimum services you think that should be part of the care Emory provides on the mobile van:** *(Interviewer to read all options aloud. Multiple answers okay).*
    - ☐ HIV clinical services
    - ☐ Mental health services
    - ☐ Substance abuse services
    - ☐ Social work and case management services
    - ☐ Nutrition services
    - ☐ Laboratory services
    - ☐ HIV medication (ARV) adherence nurse or counselor
    - ☐ Other _____________________________
10. **Thinking about yourself, if in the future you were to receive HIV care via a mobile HIV treatment clinic, would you prefer the HIV treatment van be parked:**
    - ☐ In front of your home
    - ☐ A nearby empty parking lot
    - ☐ A nearby grocery store
    - ☐ A nearby school parking lot
    - ☐ A nearby church parking lot
    - ☐ Somewhere else (specify): __________________________
11. **Thinking about yourself, if in the future you were to receive HIV care via a mobile HIV treatment clinic, what time would you prefer your HIV care appointment:**
    - ☐ Between 7-9am, Monday-Friday
    - ☐ Between 9-12pm, Monday-Friday
    - ☐ Between 12-4pm, Monday-Friday
    - ☐ Between 4-7pm, Monday-Friday
    - ☐ On a Saturday
    - ☐ On a Sunday
12. **What excites you about the possibility of using a mobile HIV treatment clinic for your HIV care? (specify):____________________________**

13. **What things would keep you from using a mobile HIV treatment clinic for your HIV care? Specify: ____**

Community-based Peer Navigator

Our second idea is to hire a community-based peer navigator. The peer navigator would bring the patients from their home to their HIV care visits, help provide transportation, show the patient to and around the hospital (i.e. take him/her to the doctor, social worker, labs, *pharmacy) and help make sure all their questions and concerns were answered along the way. Can you summarize the community-based peer navigator option?*

(Interviewer show visual aide #2)

14. **How likely do you think patients who have fallen out of care would be to use a community-based peer navigator to bring them to the Emory Infectious Diseases Clinic as part of their HIV care?**
    - ☐ Not likely
    - ☐ Somewhat likely
    - ☐ Very likely
15. **How likely do you think you would be to use a community-based peer navigator who would bring you to the Emory Infectious Diseases Clinic as part of your HIV care?**
    - ☐ Not likely
    - ☐ Somewhat likely
    - ☐ Very likely
16. **Specify why: ____**

HIV Telemedicine

The third idea is HIV telemedicine. This would mean that patients could receive some aspects of their medical care by videoconference. For example, we could provide mental health support, social work support, and address some medical concerns through video-chatting (i.e. through a program like Facetime, Google Hangouts, Skype, imo, or Whatsapp). Can you summarize the HIV telemedicine option?

(Interviewer show visual aide #3)

17. **How likely do you think patients who have fallen out of care would be to use HIV Telemedicine as part of their HIV care?**
    - ☐ Not likely
    - ☐ Somewhat likely
    - ☐ Very likely
18. **How likely do you think you would be to use HIV Telemedicine as part of your HIV care?**
    - ☐ Not likely
    - ☐ Somewhat likely
    - ☐ Very likely
19. **Specify why: ____**

20. **Do you have a smart phone, tablet, or computer?**
    - ☐ Yes
    - ☐ No
    - ☐ Other (specify): ____________
21. **Do you have regular access to internet?**
    - ☐ Yes
    - ☐ No

☐ Other (specify): _____________

Primary Care Clinics

The fourth idea is to provide HIV care through local primary care clinics. This would mean that patients could go to a primary care doctor (i.e. a family physician) in the area in which the patient lives for HIV medical care. The patient would not be directly seen by an HIV care/infectious diseases specialist, but the HIV care specialist would train the primary care doctor and work with him/her by phone to provide the patient with HIV care. Can you summarize the local primary care clinic option?
(Interviewer show visual aide #4)

22. How likely do you think patients who have fallen out of care would be to use local primary care clinics for their HIV care?

☐ Not likely
☐ Somewhat likely
☐ Very likely

23. How likely do you think you would be to use a local primary care clinic for your HIV care?

☐ Not likely
☐ Somewhat likely
☐ Very likely

24. Specify why: ____

Shelters, Transitional Housing Facilities, and Drug Treatment Centers

Our last idea is to provide HIV care at shelters, transitional housing facilities, and drug treatment centers where patients may be living. This means providing HIV care alongside the mental health and substance use services at these facilities. Can you summarize the shelter, transitional housing, and drug treatment center option?
(Interviewer show visual aide #5)

25. How likely do you think patients who have fallen out of care would be to use HIV Care Services if they were provided at a shelter or transitional housing facility along with mental health and substance use support services?

☐ Not likely
☐ Somewhat likely
☐ Very likely

26. How likely do you think you would be to use HIV Care Services if the HIV care services were provided at a shelter or transitional housing facility along with mental health and substance abuse support services?

☐ Not likely
☐ Somewhat likely
☐ Very likely
☐ Does not apply to me, and I would never consider it
☐ Does not apply to me, but I would consider it if it did

27. How likely do you think patients who have fallen out of care would be to use <u>HIV Care Services if they were provided at a drug treatment center along with mental health and substance use support services</u>?

(Interviewer show visual aide #6)

☐ Not likely
☐ Somewhat likely
☐ Very likely

28. How likely do you think <u>you</u> would be to use <u>HIV Care Services if the HIV care services were provided at a drug treatment center along with mental health and substance abuse support services</u>?

☐ Not likely
☐ Somewhat likely
☐ Very likely
☐ Does not apply to me, and I would never consider it
☐ Does not apply to me, but I would consider it if it did

29. Specify why: ____

30. Now that we've finished describing all of the ideas we have for community-based HIV care, can you summarize each option? *(Interviewer listen to patient summary and clarify as needed based on the description below)*

Please rank the ideas in the order in which you think you would be likely use them. (Starting with 1=most likely). Leave blank the ideas you would never consider using for your HIV care.

_ <u>A Mobile HIV Treatment Clinic:</u> a large medical van would come directly to the community where you live to provide you with HIV care and support services. You would directly walk onto the mobile van where you would be seen and examined by an HIV care team. *(Interviewer show visual aide #1)*

_ <u>A Community-based Peer Navigator</u>: A peer navigator would bring you from home to your HIV care visit, help provide you with transportation, show you to and around the hospital (i.e. take you to the doctor, social worker, labs, pharmacy) and help make sure all your questions and concerns are answered along the way. *(Interviewer show visual aide #2)*

_ <u>HIV Telemedicine:</u> You would receive some aspects of your medical care by videoconference. For example, you could get mental health support, social work support, and have some medical concerns addressed through video-chatting (i.e. through a program like Facetime, Google Hangouts, Skype, imo, or Whatsapp) *(Interviewer show visual aide #3)*

_ <u>Primary Care Clinics</u>: You could go to a primary care doctor (i.e. a family physician) in the area where you live for your HIV medical care. You <u>would</u> <u>not</u> be directly seen by an HIV care/infectious diseases specialist. Rather, an HIV care specialist would train your primary care doctor and work with him/her by phone to provide you with HIV care. *(Interviewer show visual aide #4)*

_ HIV care provided at shelters or transitional housing facilities: You would get HIV care at the shelter or transitional housing facility where you live. If you were receiving mental health and/or substance abuse counseling services, you would get HIV care alongside these services at the facility. *(Interviewer show visual aide #5)*

_ HIV care provided at a drug treatment center: You would get HIV care at a drug treatment center. If you were receiving mental health and/or substance abuse counseling services, you would get HIV care alongside these services at the drug treatment facility. *(Interviewer show visual aide #6)*

_ Emory Infectious Diseases Clinic at Emory University Hospital Midtown. You would continue to receive HIV care at the Emory Infectious Diseases clinic at Emory University Hospital Midtown as you have in the past. *(Interviewer show visual aide #7)*

Patient Recruitment Strategies

Next, we are going to talk about how our clinic contacts patients who have fallen out of HIV care. Every month we try to call our patients who have fallen out of care to remind them of their appointments and to see if there are ways we can help them make their appointments (i.e. setting up transportation). But, when we call them, many of their phones are disconnected, voice mailboxes are full, or patients simply don't answer their phones. In the next section I will ask your opinion on how our clinic can best reach patients who have fallen out of care.

***31.* Of the list I will read you, please tell me which are the best three methods for us to reach patients who have fallen out of HIV care to remind them about their appointment and to see if we can help them reach their HIV care visit?**

☐ Call the patient's phone multiple times
☐ Request contact phone numbers of the patient's friends or family members they trust. Then, call the secondary contact number and have that person remind the patient of their appointment.
☐ Visit the patient where they live
☐ Visit the patient at places where they usually hang out: (specify) ___________
☐ Send the patient a letter
☐ Send the patient a text message on their phone
☐ Send a message through a phone app
☐ Send an inbox message to the patient's social networking site (i.e. Facebook or Instagram inbox)
☐ Other ideas: (specify) ___________________

32. Our clinic recently hired two peer navigators. How acceptable (okay) do you think it would for a peer navigator (someone who works in the clinic and knows patients well) to visit a patient's home or a place they have told us they hang out to remind them about their HIV care visit and to help them come back into HIV care? The peer would be careful to not mention HIV or health information in front of other people.

☐ Not at all
☐ Very little
☐ Somewhat
☐ To a great extent

☐ Prefer to not answer

33. How okay would <u>you</u> be with a peer navigator (someone who works in the clinic and knows <u>you</u> well) visiting your home or a place you hang out to remind you about your HIV care visit and help you come back into HIV care? The peer would be careful to not mention HIV or your health information in front of other people.

☐ Not at all
☐ Very little
☐ Somewhat
☐ To a great extent
☐ Prefer to not answer

34. Explain: ______________________________

Demographics

I am next going to ask some basic questions about you. We ask these questions of everyone to help make sure we are getting a good representation of the views of all people living with HIV (i.e. by age, gender, race, income and education level).

35. What is your current age (years)? ____

☐ Prefer to not answer

36. What was your assigned sex at birth?

☐ Female
☐ Male
☐ Prefer to not answer

37. Which gender do you identify as?

☐ female
☐ male
☐ transgender female
☐ transgender male
☐ gender fluid/gender non-conforming
☐ other, specify ________________
☐ Prefer to not answer

38. Do you identify as Latino/Hispanic?

☐ no
☐ yes

39. What other races do you identify as? (may select more than one)

☐ Black/African American
☐ White
☐ Asian/Pacific Islander
☐ Multiracial
☐ Other ____________________________
☐ None
☐ Prefer to not answer

40. Which best describes your sexual orientation?

☐ heterosexual/straight

☐ gay or lesbian/homosexual/same gender loving (SGL)
☐ bisexual
☐ queer
☐ prefer to self-describe ______________________
☐ prefer not to answer

41. What is the highest level of education you have completed?

☐ Less than 9th grade
☐ Some high school
☐ High school diploma or GED
☐ Education beyond high school
☐ Prefer to not answer

42. What is your annual household income?

☐ <$10,000
☐ $10,000-19,999
☐ $20,000-39,999
☐ $40,000-59,999
☐ >$60,000
☐ Prefer to not answer

43. Which best describes your current employment status?

☐ Employed, Full-time
☐ Employed, Part-time
☐ Unemployed
☐ Other, specify _____________
☐ Prefer to not answer

44. We have a few questions about where you are living. In what type of place do you currently live? ***Select the one option that best describes your current housing status.***

☐ Own or rent home/apartment
☐ Staying at home of family member(s)
☐ Staying at home of friend(s)/other
☐ Group / foster home
☐ In a rooming, boarding, halfway house
☐ Shelter
☐ On the street(s) (vacant lot, abandoned building, park, etc.)
☐ Other (specify): ________________
☐ Don't know / prefer not to answer

45. During the past 6 months, how many nights have you spent …?

a. In an overnight shelter
  ☐ Response: ___ ___ *nights (0-180)*
  ☐ Don't know / prefer not to answer

b. On the street, without shelter
  ☐ Response: ___ ___ *nights (0-180)*
  ☐ Don't know / prefer not to answer

46. In the past 30 days was there any time when you didn’t get anything, or barely anything, to eat for two or more days?

- ☐ Yes
- ☐ No
- ☐ Prefer to not answer

HIV Care & Barriers to HIV Care

I am now going to end with some personal questions related to your HIV care and about things that may have kept you from coming in for HIV care as well as motivated you to seek HIV care. Some of these questions are sensitive – please know that you don’t have to answer anything that you don’t want to – just tell us to skip the question. Also if something doesn’t apply to you, let us know that as well.

47. In what year were you diagnosed with HIV?

- ☐ Year: ___________
- ☐ Prefer to not answer

48. Which of the following best describes how you pay for your HIV care? *(may select more than one)*

- ☐ *Medicare*
- ☐ *Medicaid*
- ☐ *Private insurance*
- ☐ *Ryan White Program/ADAP (AIDS Drug Assistance Program)*
- ☐ *None*
- ☐ *Other, specify* ____________
- ☐ Prefer to not answer

49. In the past 12 months, were you ever in jail or prison?

- ☐ Yes
- ☐ No
- ☐ Prefer to not answer

[If biologic sex=male, then skip to #49]

50. In the past 7 days, how many times did you have more than 3 drinks of alcohol in one sitting?

- ☐ Never
- ☐ Once
- ☐ More than once
- ☐ Prefer to not answer

[If biologic sex=female, skip to #50]

51. In the past 7 days, how many times did you have more than 4 drinks of alcohol in one sitting?

- ☐ Never
- ☐ Once
- ☐ More than once
- ☐ Prefer to not answer

52. In the past 7 days, how many total drinks of alcohol did you have?

- ☐ None
- ☐ 7 alcoholic drinks or less

☐ 8-14 alcoholic drinks
☐ More than 14 alcoholic drinks
☐ Prefer to not answer

53. In the past 7 days, which of the following best describes how frequently you used crack or cocaine?

☐ Never
☐ Once
☐ More than once
☐ Not in the past week, but I did use I in the past 3 months
☐ Prefer to not answer

54. In the past 7 days, which of the following best describes how frequently you used heroin or opiates that weren't prescribed for you by a doctor? Examples of opiates include Vicodin, Dilaudid, Percocet, and Darvocet.

☐ Never
☐ Once
☐ More than once
☐ Not in the past week, but I did use I in the past 3 months
☐ Prefer to not answer

55. In the past 7 days, which of the following best describes how frequently you used marijuana?

☐ Never
☐ Once
☐ More than once
☐ Not in the past week, but I did use I in the past 3 months
☐ Prefer to not answer

56. In the past 7 days, which of the following best describes how frequently you used methamphetamines such as crystal meth?

☐ Never
☐ Once
☐ More than once
☐ Not in the past week, but I did use I in the past 3 months
☐ Prefer to not answer

57. In the past 7 days, which of the following best describes how frequently you used other non-prescription, illegal drugs or substances? Examples include hallucinogens like LSD or Ecstasy.

☐ Never
☐ Once
☐ More than once
☐ Not in the past week, but I did use I in the past 3 months
☐ Prefer to not answer

58. In the past 12 months, how much did transportation problems keep you from coming to your HIV care visits?

☐ Not at all
☐ Very little

- ☐ Somewhat
- ☐ To a great extent
- ☐ Prefer to not answer

Safety is an issue that keeps some patients from coming to the clinic. For example, some people experience abuse at home or violence in the communities where they live.

59. In the past 12 months, how much did concern for your personal safety keep you from coming to your HIV care visits?

- ☐ Not at all
- ☐ Very little
- ☐ Somewhat
- ☐ To a great extent
- ☐ Prefer to not answer

60. Poor mental health can include feeling sad, down, depressed, or anxious. In the past 12 months, how much has poor mental health kept you from coming to your HIV care visits?

- ☐ Not at all
- ☐ Very little
- ☐ Somewhat
- ☐ To a great extent
- ☐ Prefer to not answer

61. How much do you trust your HIV doctor or clinic to offer you the best medical care they can provide?

- ☐ Not at all
- ☐ Very little
- ☐ Somewhat
- ☐ To a great extent
- ☐ Prefer to not answer

62. What is the single biggest reason that kept you from coming to your HIV care visits?(specify)

____
____
____

Thinking about a time when you regularly made your HIV care appointments and took your HIV medicine, what was the single biggest reason you were able to do so?____
____
____

63. Thank you for your participation in this survey. We really appreciate your answers and will be using them to develop new community programs for our clinic. Do you have anything else that you would like to add? (specify):

____

64. Would you be willing to participate in one more interview to ask your opinion on community-based HIV care in more detail, either now or at another time more convenient to you? It would take approximately 45 minutes.

☐ **Yes**
☐ **No**

65. As our clinic plans future community-based HIV care strategies, we will be involving doctors, nurses, social workers, and patients in the planning meetings. Would you like to be involved?

☐ **Yes** *(interviewer to verify contact information is correct)*
☐ **No**

Appendix B:
In-Depth Interview Guide – PLWH

<u>Introduction</u>:
The Emory Infectious Diseases Clinic and Ryan White Program are exploring ways to bring HIV care into the community. We understand patients may fall out of HIV care for several reasons. We are interested in understanding why patients falls out of care and hearing your thoughts about some ideas we have on how the Emory Clinic can provide more accessible services to patients who have fallen out of care.

I'm going to record our conversation in order to best capture your responses, but when we transcribe the interview, we will be sure to remove any identifying information. Please take a minute to put your cell phone on silent. Do you have any questions before we begin? Ok, let's get started. May I begin the recording?

Tell me about your life right now. (General question to build rapport. Probe: what do you do in Atlanta for fun? Where are you from originally?)

State: Let's transition into some questions about HIV care.

Please describe the ideal way for you to get HIV Care. *(Probe: where would it be? Preference of setting (community or clinical), characteristics of person to deliver care, services provided, time/day and frequency)*

Why are these things the most important to you?

How would this make it easier for you to stay in care?

Thinking about the HIV care you have gotten in the past, what things made it difficult for you to get care and to stay in HIV care? *(Probe: distance, other priorities, bad experience with clinic provider/staff, safety, didn't want to think about HIV, didn't want others to find out, fear, drug use, depression)*

What are some ways the Emory clinic could help you overcome these barriers?

State: *We'd like to explore what it might look like if we provided HIV care to patients within their own communities. As you heard about in the survey, some possible alternatives we came up with include a mobile HIV treatment clinic, a Peer Navigator to provide transportation to and from appointments, HIV telemedicine, incorporating HIV care into primary care clinics, providing HIV care at shelters or transitional housing facilities, and providing HIV care at drug treatment centers. We'd like to hear your thoughts on some of these potential programs.*

<u>***NOTE:** Staff should have response cards available and have participant paraphrase each option to ensure they remember what each option is and how it works.*</u>

Which programs would you have concerns about? *(Probe: Why?)*

Which of these ideas stand out to you as a program that might help you stay in care? (Probe: why?)

You mentioned that *[selected program]* stood out to you as a better way of getting HIV care. Tell me how you think *[selected program]* would work or what it would look like:

- *If **peer navigator**, Probe: confidentiality concerns and strategies for overcoming concerns, peer characteristics, where to meet peer, what peer would do for you pre-, during, and post-visit, how peer would contact you,*
- *If **HIV telemedicine**, Probe: confidentiality concerns and strategies for overcoming concerns, location (home, office, CBO, church), method (phone/tablet/computer, software), what services (mental health, substance use counseling, HIV medication counseling, social work), characteristics of care provider*
- *If **primary care**, Probe: confidentiality concerns and strategies for overcoming concerns, knowledge of/existing relationship with primary care doctor, concern of doctor's knowledge of HIV treatment, concern of lack of colocation of social work and mental health services, characteristics of care provider*
- *If **shelters or transitional housing facilities**, Probe: confidentiality concerns and strategies for overcoming concerns, frequency/timing of visits, what services, characteristics of care provider*
- *If **drug treatment center**, Probe: confidentiality concerns and strategies for overcoming concerns, frequency/timing of visits, what services, characteristics of care provider*
- *If **mobile HIV treatment clinic**, skip to next question*

Tell me about the people in your life who know your HIV status.

How does this affect what type of care you would like to receive?

State: *Now we would like to hear more about what you think about the HIV mobile treatment clinic. Just a reminder, this would mean that a large medical van would come directly to the community where patients live to provide them with HIV care and support services. Patients would directly walk into the mobile van where they would be seen and examined by their HIV care team.*

Describe how interested you would be in accessing your HIV care in your own community through a HIV mobile treatment clinic. *(Probe: What makes you most interested? What makes you least interested? In what ways could this idea help someone stay in care?)*

In what ways does the HIV Mobile Treatment clinic idea compare with the others you heard about today?

How does the HIV Mobile Treatment clinic compare to the usual HIV care you receive at Emory University Hospital Midtown?

What would your concerns be about accessing HIV care in in this way?

What factors might make you feel safe or unsafe and comfortable or uncomfortable receiving HIV care in a mobile treatment clinic? *(Probe: location to park/access the van, confidentiality concerns and strategies for overcoming concerns)*

If you were able to access mobile HIV treatments services within your own community, how would you prefer the mobile clinic to look? (Probe: how should the inside look? How should the outside look?)

What are the minimal services you would want to be provided on the mobile HIV clinic and why? *(Probe: HIV care, social work, mental health/substance abuse counselor, blood work, peer counselor, medication educator)*

Thinking about convenience and your privacy, when would be the best time for you to use the HIV mobile treatment clinic for care? *(Probe: time, day, frequency)*

State: *Every month we try to call our patients who have fallen out of care to remind them of their appointments and to see if there are ways we can help them make their appointments (i.e. setting up transportation). But, when we call them, many of their phones are disconnected, voice mailboxes are full, or patients simply don't answer their phones. In the next section I will ask your opinion on how we can best reach you if you miss your appointments and we can't reach you by phone.*

Describe how you would you feel if we reached out to you to remind you of your appointment to help you get back care.

How does the likelihood of someone knowing your HIV status affect how you feel about being contacted? *(Probe: The person you live with? Your friends? Community?)*

If we couldn't reach you by phone, how would you feel about a peer navigator (someone from our clinic who knows you well) visiting your home or a place you hang out to remind you of your appointment and help you come back into HIV care?

What concerns would you have about this type of visit? (*Probe: what would you like about this visit?)*

What should this visit look like to you? *(Probe: Where i.e. home, hang out spots, other? Who would you trust make the visit? Where should the visit NOT take place?)*

How would this method change the likelihood that you will make your HIV appointment?

State: *Thank you for participating in the interview. We will use your responses to help build a community-based HIV care program for patients who have fallen out of care.* **Do you have any final comments you want to share about your needs or preferences in receiving HIV care either on or off recording?**

In-Depth Interview Guide – Ryan White Clinic Community Advisory Board (CAB) Members

Introduction:
At the Emory Infectious Diseases Clinic and Ryan White Program, approximately 250 patients each month remain out of care, so we are exploring new ways to bring HIV services to patients that have fallen out of care. Nationally, common interventions to retain patients, such as patient navigators, case managers, transportation assistance, appointment reminders, and contingency management, have demonstrated some efficacy but still fall short of national targets for HIV care retention. We are interested in understanding the needs, barriers, and facilitators to implementation of new community-based HIV care models for patients who are out of HIV care.

I'm going to record our conversation in order to best capture your responses. To maintain confidentiality, I ask that you please try to avoid providing information that may identify specific patients or other people. If by accident you do, we will be sure to remove any identifying information when we transcribe the interview. Please take a minute to put your cell phone on silent. Do you have any questions before we begin?

Ok, let's get started. May I begin the recording?

Tell me why and how you got involved with the Emory Midtown Community Advisory Board?

State: We understand that there are many reasons a patient may fall out of care or stay in care.

What are the main barriers that make it hard for someone to stay in care?

What type of services or resources make it easier for someone to stay in care?

Describe a time when you had challenges remaining in care. (Probe: What made it easier for you to stay in care?)

Describe your ideal way for you to get HIV care. (Probe: Location. Time of day. Characteristics of person to deliver care. Services provided. Etc.)

Can you describe the areas you feel the Emory ID Clinic/RWP is falling short in keeping patients in care?

In what ways can we engage, or encourage patients who have fallen out of care to get back into care?

State: Now we will explore your thoughts on a few specific novel community-based models of HIV care. These are represented on the response card in front of you and include:

- A mobile HIV treatment clinic. In this case, a large medical van would come directly to the community where patients live to provide them with HIV care and support services.

They would walk directly into the mobile van where they would be seen by an HIV care team.

- A community-based Peer Navigator, who would bring patients to and from home to their HIV care visit, show them around the hospital, and make sure all their questions and concerns were answered along the way.
- HIV telemedicine, where patients could receive some aspects of their medical care such as mental health support, social work support, and have some medical concerns addressed through video conference.
- Incorporating HIV care into primary care clinics. Patients would not be directly seen by an HIV care/infectious diseases specialist, rather an HIV care specialist would train a patient's primary care doctor and work with them by phone to provide their HIV care.
- Providing HIV care at shelters or transitional housing facilities where patients live. If they were receiving mental health or substance abuse counseling services, patients would get HIV care alongside these services at the facility.
- And finally, providing HIV care at a drug treatment center. If they were receiving mental health or substance abuse counseling services, patients would get HIV care alongside those services at the drug treatment facility.

Which of these ideas stand out to you as potentially being effective? *(Probe: Why?)*

Tell me more about what you think this (selected) model of care should look like.
(Probe: services to be provided, characteristics of care providers, characteristics of patients, timing/frequency of care, barriers, facilitators, advantages/disadvantages, confidentiality/safety concerns and strategies to overcome them)

Imagine you were one of the patients utilizing this *[selected new model for care]*. Describe what your care visit would look like? (Probe: What happens when you arrive? What services do you receive? Who do you interact with? How long is the visit?)

What barriers would you face to delivering care?

What would make you most likely to use [Selected mode of care]?
(Probe: technology, personnel, support, safety)?

CAB perceptions of mobile HIV treatment clinic

State: We'd now like ask you questions about delivering care in an HIV mobile treatment clinic.

What is your opinion on utilizing a mobile HIV treatment clinic?
(Probe: Potential effectiveness? Advantages/weaknesses?)

How does mobile HIV care compare to other possible models of alternative HIV care?

What challenges may we have with trying to deliver care using the mobile HIV care clinic?

(Probe: safety, confidentiality, time, support, technology)

What type of services are needed to provide adequate care on a mobile HIV care clinic?

What do you think our clinic can do to increase the safety, comfort, and confidentiality/privacy of our patients if we provided care in this setting?
(Probe: naming/branding of van (so that only Emory patients living with HIV would access services – while maintaining confidentiality), location/timing of van, considerations in provision of care to multiple patients from one community, approach of patients in community to bring them into and remind them of mobile care)

What other thoughts do you have on how we could make mobile HIV treatment more acceptable and safe?

What other thoughts or concerns do you have about feasibility of mobile HIV treatment?

What role do you see the CAB having in developing and implementing the mobile HIV treatment model?

Would you be interested in helping the ID clinic further plan and develop a model for community-based care to be implemented by the clinic? *(if yes, take contact information)*

State: Thank you for participating in the interview. We will use your responses to help build a community-based HIV care program for patients who have fallen out of care. **Do you have any final comments you want to share about your needs or preferences in delivering HIV care either on or off recording?**

In-Depth Interview Guide – HIV Clinic Staff and Providers

Introduction:
At the Emory Infectious Diseases Clinic and Ryan White Program, approximately 250 patients each month remain out of care, so we are exploring new ways to bring HIV services to patients that have fallen out of care. Nationally, common interventions to retain patients, such as patient navigators, case managers, transportation assistance, appointment reminders, and contingency management, have demonstrated some efficacy but still fall short of national targets for HIV care retention. So, we are interested in understanding the needs, barriers, and facilitators to implementation of new community-based HIV care models for patients who are out of HIV care.

I'm going to record our conversation in order to best capture your responses. To maintain confidentiality, I ask that you please try to avoid providing information that may identify specific patients or other people. If by accident you do, we will be sure to remove any identifying information when we transcribe the interview. Please take a minute to put your cell phone on silent. Do you have any questions before we begin?

Ok, let's get started. May I begin the recording?

What is your role in the Emory Infectious Diseases Clinic or Ryan White program at present?

View of barriers and facilitators to PLWHIV-OOC staying in care

State: There are many reasons a patient may fall out of care or stay in care.

What are the main barriers contributing to your patients falling out of care?

What are the main facilitators to your patients remaining in care?

Thinking about the patients we have the most difficult time retaining in care, what strategies have been most effective in retaining or re-engaging these patients? *(Probe: Individual strategy as a provider, clinic-level strategies)*

State: Health care environment can contribute to retention in HIV care.

Can you describe the areas you feel the Emory ID Clinic/RWP is strong in retaining patients?

Can you describe the areas you feel the Emory ID Clinic/RWP is falling short in retaining patients?

Do you feel there is a need in finding alternative methods for re-engaging and retaining people who live with HIV who have fallen out of care?
(Probe: Why or why not?)

Do you have ideas on new methods to re-engage and retain out of care patients?

State: We'd now like to explore your thoughts on a few specific novel community-based models of HIV care. These are represented on the response card in front of you and include:

- A mobile HIV treatment clinic. In this case, a large medical van would come directly to the community where patients live to provide them with HIV care and support services. They would walk directly into the mobile van where they would be seen by an HIV care team.
- A community-based Peer Navigator, who would bring patients to and from home to their HIV care visit, show them around the hospital, and make sure all their questions and concerns were answered along the way.
- HIV telemedicine, where patients could receive some aspects of their medical care such as mental health support, social work support, and have some medical concerns addressed through video conference.
- Incorporating HIV care into primary care clinics. Patients would not be directly seen by an HIV care/infectious diseases specialist, rather an HIV care specialist would train a patient's primary care doctor and work with them by phone to provide their HIV care.
- Providing HIV care at shelters or transitional housing facilities where patients live. If they were receiving mental health or substance abuse counseling services, patients would get HIV care alongside these services at the facility.
- And finally, providing HIV care at a drug treatment center. If they were receiving mental health or substance abuse counseling services, patients would get HIV care alongside those services at the drug treatment facility.

State: We'd like to hear your thoughts on some of these potential programs.

Do any of these ideas stand out to you as potentially being effective?
(Probe: Which one(s)? Why?)

Thinking about *[insert effective strategy mentioned by participant]*, tell me more about what you think this model of care should look like.
(Probe: services to be provided, characteristics of care providers, characteristics of patients, timing/frequency of care, barriers, facilitators, advantages/disadvantages, confidentiality/safety concerns and strategies to overcome them)

How would you prioritize patients to receive this strategy of care?
(Probe: characteristics of patients, strategies)

Imagine you were one of the *[insert participant clinic role]* involved in the *[selected new model for care]*. How would operating within this new model of care change the quality of care you could give?

What barriers would you face to delivering care?

What would facilitate your provision of HIV care using this strategy?

(<u>Probe</u>: technology, personnel, support, safety)?

<u>Provider viewpoint on mobile HIV treatment clinic</u>

State: We'd now like to explore more the safety, feasibility, and efficacy of delivering care in an HIV mobile treatment clinic.

What is your opinion on this specific alternative care option?
(<u>Probe</u>: Potential effectiveness? Advantages/weaknesses?)

How does mobile HIV care compare to other possible models of alternative HIV care?

What barriers as a *[insert role]* do you see to your provision of care using the mobile HIV care clinic?
(<u>Probe</u>: safety, confidentiality, time, support, technology)

What would you need to provide adequate care as a *[insert role]* on a mobile HIV care clinic?
(<u>Probe</u>: van outfitting (minimal clinical instruments, setup), technology, personnel, support, safety)

What do you think our clinic can do to increase the safety, comfort, and maintenance of confidentiality/privacy of our patients if we provided care in this setting?
(<u>Probe</u>: naming/branding of van (so that only Emory patients living with HIV would access services – while maintaining confidentiality), location/timing of van, considerations in provision of care to multiple patients from one community, approach of patients in community to bring them into and remind them of mobile care)

Other thoughts on how we could make mobile HIV treatment more effective, acceptable, and safe?
(<u>Probe</u>: minimal services provided (clinical, social work/case management, mental health, substance abuse counseling, peer counseling, medication adherence, laboratories), patient prioritization, patient incentives, characteristics of HIV care providers)

Other thoughts or concerns about feasibility of mobile HIV treatment?
(<u>Probe</u>: billing, medical record keeping, patient tracking, frequency of visits, sustainability, legal/compliance concerns, cost, staffing)

State: Thank you for participating in the interview. We will use your responses to help build a community-based HIV care program for patients who have fallen out of care. **Do you have any final comments you want to share about your needs or preferences in delivering HIV care either on or off recording?**

Would you be interested in helping the ID clinic further plan and develop a model for community-based care to be implemented by the clinic? *(if yes, take contact information)*