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Bachelor of Arts

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Abstract

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By Srija Dutta

The Southern region of the US is home to the highest rates of HIV-related mortality and morbidity in the entire country. A lack of functional and coordinated integration between various systems of HIV-care delivery, coupled with the complexities of the healthcare system, continue to serve as primary barriers to providing quality, holistic, and highly effective care for people living with HIV (PLWH), and to re-engaging and retaining PLWH who are out-out-care (PLWH-OOC) into care. This qualitative study aimed to understand the relationship between care coordination and sub-specialty care throughout varying models of HIV care delivery – mobile clinics, home-based care programs, traditional fixed clinic – and to investigate if/how this relationship influences the health outcomes of PLWH-OOC. From October 2022 to March 2023, 18 in-depth-interviews were conducted with six HIV-care providers, three clinic administrative staff members, two social workers, and seven Community Advisory Board members who also identified themselves as PLWH. Primary results from this study reveal that care coordination plays a central and unequivocal role in the continuum of care, and also highlight that HIV care systems must be 1) equipped with a comprehensive range of services outside of traditional HIV-care and 2) organized in a way that allows HIV-care to be delivered and received as easily as possible if efforts to prevent PLWH from falling out of care and to re-engage PLWH-OOC are to succeed. In summary, findings from this study investigate current gaps/barriers that impede effective care delivery and coordination within models of HIV care delivery, and also offer strategies for how health systems can navigate these barriers/gaps and ultimately increase the number of individuals that are engaged and retained in care.

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Chapter I: Introduction

The Center for Disease Control and Prevention (CDC) estimates that there were nearly 1.2 million people living with HIV (PLWH) in the United States (US) in 2019 [1]. This 1.2 million includes approximately 34,000 new HIV diagnoses in 2019, 69% of which occurred among men who have sex with men (MSM) [2]. Among MSM, African American/Black MSM have the highest incidence of HIV diagnoses. Given the prevailing structural and societal barriers facing African American MSM, this population also exhibits the lowest rates of access and retention to HIV care compared to any other racial or ethnic group in the US population [1]. Investigating gaps in access and retention of HIV care is especially critical in Southern regions of the US, where an estimated one in five African American MSM are living with HIV [3].

The Southern region of the United States is primarily known for its hospitality and influence of rich Southern culture. However, driven mainly by overall poor healthcare access, extreme poverty rates, high levels of HIV-related stigma, and poor health outcomes for PLWH, the Southern region of the US is also home to states that have the highest rates of HIV infection [3], followed by some of the worst HIV death rates [4] in the entire country. Although only 38% of the US population resides in the South, HIV diagnoses in Southern states encompass over 50% of new cases every year [3].

Recent trends in the wider availability of antiretrovirals and antiretroviral therapy (ART) have prolonged life expectancies for PLWH and reduced mortality from HIV. Subsequently, over time, there has been a shift in the age demographic of the population living with HIV, with the majority of PLWH now being over the age of 50 [3]. This reduction in mortality has transformed HIV from a death-sentence to a chronic illness for many PLWH. Unfortunately, aging – both within and outside the contexts of HIV infection – is associated with a greater prevalence of non-communicable diseases (NCDs) [3]. While the longer lifespan associated with ART access is a significant step towards controlling the HIV epidemic, it has also introduced new concerns surrounding the management of HIV care, as providers must now acknowledge and effectively manage comorbidities and associated with aging. When compared to individuals who are HIV negative, PLWH develop comorbidities - such as cardiovascular (CV) diseases, hypertension, diabetes, bone fractures, and renal failure - at younger ages, largely due to the chronic immune activation and inflammation that results from HIV infection, both of which are known to be factors for accelerated aging [5,6]. As previously discussed, old age, in and of itself, accelerates the likelihood of being exposed to comorbidities. Coupled with underlying HIV infection and subsequent consequences of HIV-related treatment, PLWH become more susceptible to developing comorbidities as they age. The aging population of PLWH has resulted in a series of demands for health-care systems, with integration and coordination of specialty/clinical care (outside of HIV-related care) being two of the most salient necessities for the health and wellbeing of HIV-infected patients.

Given the socially and physically vulnerable circumstances PLWH live in, navigating the healthcare system can be overwhelming, often leaving individuals unable to access and retain the specialty care necessary to live a healthy life. Peer-reviewed scholarship from a 2012 sourcebook analyzing the effectiveness of US HIV care systems describes prompt utilization and access to clinical services (within and outside of HIV-related care) as the “second benchmark in HIV care” [7]. Given the limited amount of specialty care providers who are willing to provide care for uninsured patients, and the lack of consistent communication between specialists and clinics, referring patients to specialty care services off-site is especially challenging for HIV-care providers - ultimately posing a threat to the effective functioning of the healthcare system [8].

Effective and sustainable care coordination is critical if interventions aimed to re-engage and retain PLWH, as well as PLWH who are out-of-care (PLWH-OOC) are to succeed. Care coordination is highly associated with clinical outcomes [9], and a lack of coordination is reported to increase the risk of medication errors, unmet needs, duplicated tests, as well as both patient and provider dissatisfaction [10]. Care coordination has been reported as especially challenging to achieve for patients who have multiple chronic conditions that require services - and thus information exchange - from multiple providers. In addition, a wide range of existing research has noted that referrals from primary care physicians to specialists often include insufficient information, and consultation reports from specialists back to primary care physicians are often late and inadequate [11] – both of which impede the quality of care provided to patients. Furthermore, when patients are hospitalized, their primary care physicians may not be notified at the time of discharge, and discharge summaries may contain insufficient information or never reach the primary care practice at all [11].

With over 34,000 new diagnoses in 2019, it is evident that the HIV epidemic continues to jeopardize the health and quality of life for many individuals in the US. A lack of specialized and coordinated medical services, prevalence of stigma, and limited social support – mitigated by distance and isolation – are among the most exigent barriers that make Southern regions of the US especially vulnerable to the consequences of HIV infection. In addition, the prevailing presence of factors such as substance abuse, housing insecurity, financial and insurance barriers, systematic racism, and comorbidity leave PLWH in the South struggling to engage and be retained in care that addresses a wide range of health and psycho-social related concerns. Outside of HIV-related care, these barriers often prevent PLWH from accessing other forms of healthcare such as oncological, cardiovascular, and gastro-intestinal care. A significant lack of access, coupled with socio-cultural and structural barriers, are primary variables preventing patients from many forms of necessary non-HIV care.

PLWH diagnosed with comorbidities have unique health care needs as compared to individuals living with only one of these conditions, largely due to a heightened necessity for multiple medicine prescriptions, as well as regular monitoring of multiple forms of treatment to ensure medical adherence [12]. In order to effectively address these expanded needs, HIV care must go beyond a fixed, antiretroviral-focused approach, and extend to holistically address the dynamic and shifting elements of long-term infection, chronic disease and comorbidity management, and other patient-specific factors [13]. Despite ongoing and extensive HIV research in the past decade, little is known about the role of sub-specialty care and care coordination in the continuum of care. A lack of functional and coordinated integration between various systems of care, coupled with the complexities of the referral process, continue to serve as prevailing barriers to providing quality, highly effective care within and outside of traditional HIV care contexts. As such, there is an exigent need for multidimensional research regarding the relationship between HIV and coinfection/comorbidity across a variety of populations and psycho-social contexts. It is imperative to critically understand the relationship between HIV-care and other forms of healthcare, as a lack thereof has resulted in compromised levels of viral suppression (VS) and retention of HIV-care amongst PLWH.

The purpose of this study is to understand the relationship between care coordination, sub-specialty care, and the health outcomes of PLWH-OOC. More specifically, this study explores the role of care coordination and sub-specialty care in the context of a mobile-integrated health (MIH) HIV clinic developed and facilitated by Grady Hospital and the Ponce de Leon Center, both in Atlanta, GA. Although the MIH model was not initially designed for PLWH-OOC, as engagement and outreach have increased, it is now being explored as a model to reach/retain people who have faced challenges staying in routine clinic-based HIV care. While MIH has been instrumental in strengthening HIV care accessibility, the implementation and facilitation of this model may also pose additional challenges for HIV care coordination, specifically in relation to collaboration between sub-specialty care, routine/clinical care, and HIV support services. This analysis will compare gaps identified by patients and providers, ultimately illustrating how care coordination, sub-specialty care, and the MIH care model interplay when aiming to re-engage and retain PLWH-OOC into care. As such, this study aims to investigate the following research questions:

1) What is the role of mobile and home-based health care models in providing comprehensive care and HIV support services to PLWH-OOC?
2) How does care coordination throughout models of HIV care influence health outcomes among PLWH-OOC?
3) What are the perspectives and recommended strategies of PLWH and HIV clinic staff/providers to effectively integrate sub-specialty care and promote care coordination throughout the continuum of care?

The results of this analysis will highlight the dynamic perspectives of PLWH and HIV providers/key informants, specifically in relation to the integration and utilization of sub-specialty care with traditional forms of HIV care [in the context of a new HIV care model that is being explored to better reach PLWH-OOC]. In doing so, the study may identify potential strategies and areas of consideration when aiming to improve HIV care coordination and to provide holistic care more effectively for PLWH-OOC.

Chapter II: Literature Review

HIV in the United States

The Center for Disease Control and Prevention (CDC) estimates that there were nearly 1.2 million people living with HIV (PLWH) in the United States (US) in 2019 [1]. This 1.2 million includes approximately 34,000 new HIV diagnoses in 2019, 69% of which were in relation to men who have sex with men (MSM) [2]. Among MSM, the racial group with the highest incidence of HIV diagnoses was African American/Black MSM. Given the prevailing structural and societal barriers facing African American MSM, this population also exhibits the lowest rates of access and retention to HIV care compared to any other racial or ethnic group in the US population [1]. This gap in access and retention of HIV care is especially critical in the Southern regions of the US, where an estimated one in five African American MSM are living with HIV [3]. Currently, the majority of African Americans in the US reside in the South [3]. Also in the South, over 50% of individuals diagnosed with HIV in the country are African American [3]. African American PLWH – especially MSM – in Southern regions of the US face systemic barriers which continue to disproportionately influence the burden of HIV-related outcomes for this subgroup [4]. Additionally, the Southern region of the US is home to high levels of poverty and HIV-related stigma – both of which exacerbate rates of HIV incidence and mortality, ultimately leaving the South with the highest HIV-related mortality and morbidity rates in the entire country [3].

The Southern region of the United States is primarily known for its hospitality and influence of rich Southern culture. However, driven mainly by overall poor healthcare access, extreme poverty rates, and poor health outcomes for PLWH, the Southern region of the US is also home to states that have the highest rates of HIV infection [3], followed by some of the worst HIV death rates [4]. Among Southern states in the US, Georgia has the highest HIV incidence in the country, with four Atlanta Metropolitan Area Counties (Cobb, Fulton, Dekalb, and Gwinnett) identified as "emergency" areas with "priority jurisdictions" in the national *Ending the HIV Epidemic* (EHE) plan. The EHE plan outlines strategies to achieve a 90% reduction in new HIV infections by 2030 [14]. Racial and ethnic disparities, lack of community trust toward the health care system and public health initiatives, income inequality, and elevated levels of stigma and discrimination toward Lesbian, Gay, Bi, Trans and Queer (LGBTQ) communities are the most pressing challenges identified by EHE plans to lower HIV incidence in Georgia [14]. These salient challenges, coupled with historic and structural racism, leave PLWH (especially African American MSM) in Georgia particularly vulnerable to the consequences of the HIV epidemic. Although only 38% of the US population resides in the South, HIV diagnoses in Southern states encompass over 50% of new cases every year. Increasing rates of poverty and unemployment, lack of medical funding and insurance coverage, and dominating stigma surrounding HIV, leave the Southern region of the United States with the highest burden of HIV incidence and HIV-related mortality [3]. Additionally, fewer PLWH in the Southern region of the US are diagnosed with HIV, and consequently unaware of their vulnerable health status. Thus, fewer are likely to be engaged with HIV medical care and initiated or on antiretroviral therapy (ART) as compared to PLWH in other regions of the US [15]. Of those who are diagnosed and aware of their HIV status, 51% of PLWH in the Southern US are not retained in HIV care [16].

The widespread cultural conservatism in the Southern US heavily influences the perceptions and experiences of stigma among HIV-positive individuals [16]. This HIV-related stigma is a key risk factor for negative effects on preventive behaviors and health outcomes facing PLWH. Subsequently, laws and policies in Southern states have facilitated the spread of HIV, largely due to the utilization of abstinence-based sex education, which is proven to be ineffective in sexually transmitted disease (STD) prevention [16]. Additionally, pervasive through the Southern region of the US are laws that criminalize HIV-related sexual behaviors and prevent the implementation and utilization of interventions that have been proven effective in reducing transmission, such as targeting syringe exchange [16]. These outdated and ineffective laws not only further exploit populations that are highly vulnerable to acquiring HIV (such as sex workers, MSM, and injecting drug users), but also discourage HIV testing and access to care [4]. The disproportionate burden of HIV in the South is indicative of the critical necessity to address factors related to HIV-transmission and improve prevention in this region.

The HIV Care Continuum: Care Retention and Viral Suppression

The HIV care continuum, a concept of continuing engagement in HIV care, is composed of the following 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 [17]. Data from 2019 highlights that 87% of PLWH in the US were diagnosed with HIV, 81% of those were linked to appropriate HIV care, and 66% received care [1]. Of those who received care, 50% were retained in care, and 57% had achieved viral suppression [1]. From this data, it is evident that the latter stages of the HIV are continuum (i.e., retention in HIV care and achievement/maintenance of viral suppression) are the most pressing challenges when considering the effectiveness of HIV-related care. Retainment in HIV care is most commonly defined as documentation of two or more CD4 (viral load) tests performed three or more months apart; and viral suppression occurs only when a person with HIV has a viral load of less than 200 copies/milliliter during their most recent check [1].

A wide array of interrelated elements influence one's likelihood to stay retained in HIV care. Physical health factors, substance abuse, and psychosocial factors – such as psychiatric conditions and social welfare – are identified as some of the most prevailing barriers to HIV care retention [18]. A systematic review of 345 articles concluded that, among developing countries, substance abuse and demographic factors were found to be the most commonly cited indicators of poor retention to HIV care. Among demographic factors, individuals with poor mental health conditions were less likely to be retained in care, and presence of active psychiatric illnesses at last clinical visit was indicative of not returning for care [19,20]. In addition, the role of comorbidities among PLWH is especially pertinent when examining a person's capacity and likelihood to remain retained in HIV care. A systematic review analyzing HIV-disease progression and physical co-morbidities reported conflicting data [18]. One study concluded that those with Hepatitis C (HCV) coinfection and *higher* CD4 counts (350 9 106 /L) were less likely to be retained in care due to higher rates of disease progression [21]; another study, however, concluded that those with HCV coinfection and *lower* CD4 counts (350 9 106 /L) were less likely to be retained in care due to lower rates of disease progression [22]. This conflicting data emphasizes the necessity for context-specific research regarding the relationship between HIV and coinfection/comorbidity for people who are vulnerable to falling out of care. Additionally, individuals with HCV coinfections were identified as vulnerable to engaging in active substance abuse, which further interferes in retention to care [18].

Aging Population and HIV

Recent trends in wider availability of antiretrovirals and ART have prolonged life expectancies for PLWH and subsequently reduced mortality from HIV. Accordingly, over time, there has been a shift in the age demographic of the population living with HIV, with the majority of PLWH now being over age 50 years [23]. The reduction in mortality has transformed positive HIV status from a death-sentence to a chronic illness for many PLWH. Unfortunately, aging – both in and outside the context of HIV infection – is associated with greater prevalence of non-communicable diseases (NCDs) [24]. While the longer lifespan associated with ART access is a significant step towards controlling the HIV epidemic, it has also introduced new concerns surrounding the management of HIV care, as providers must now acknowledge and effectively manage comorbidities associated with aging. The increasing number of older individuals living with HIV has generated an exigent need for "medical care systems with the capacity to provide clinical services for a large cohort of older persons living with HIV" [3]. When compared to individuals who are HIV negative, PLWH develop comorbidities - such as CV diseases, hypertension, diabetes, bone fractures, and renal failure - at younger ages, largely due to the chronic immune activation and inflammation that results from HIV infection, both of which are known to be factors for accelerated aging [5,6]. Aside from inflammation, a positive HIV status is associated with inherent immune activation and altered coagulation – both of which are evident risk factors for the development of comorbidities [25].

In the US, over 50% of the 1.2 million PLWH are over 50 years old, with predictions estimating that over 70% of PLWH will be over 50 years old by 2030 [26]. Old age, in and of itself, accelerates the likelihood of being exposed to comorbidities. Coupled with underlying HIV infection and subsequent consequences of HIV-related treatment, PLWH become more susceptible to developing comorbidities as they age. While access to ART often allows PLWH to achieve viral suppression, numerous challenges continue to disproportionately influence treatment outcomes for older subgroups of PLWH. High rates of depression, coupled with low reports of quality of life, leave PLWH over the age of 50 vulnerable to comorbidity, limitations in activities, victimization, and compromised physical and mental health-related outcomes [27]. Aside from the effects of initial HIV infection, agents of ART have been associated with an increased risk of comorbidity – thus illustrating that exposure to ART is also a contributing factor to higher rates of comorbidities in PLWH [6]. In addition, middle-age and older adults have been subject to a variety of psycho-social issues, including stigma, loneliness, disclosure concerns, and financial challenges [7]. Aside from these issues, PLWH over 50 years old experience significant limitations surrounding the availability and access of social support services and HIV-related care [28]. The lower quality of life and high susceptibility to a wide range of illness has heightened the necessity for PLWH from older subgroups to be exposed and engaged in specialty care. A recent study concluded that "older adults tend to report different symptoms and receive less social support than young adults with HIV, which can affect clinical assessments and exacerbate psychological distress associated with the disease" [29].

The aging population of PLWH has resulted in a series of demands for health-care systems, with integration into specialty/clinical care (outside of HIV-related care) being one of the most exigent necessities for the health and wellbeing of HIV-infected patients. Drawing from existing literature, it is evident that management of care for PLWH will need to encompass a variety of medical disciplines, including oncology, cardiology, and geriatric medicine [24]. A 2022 study titled *"how health systems can adapt to a population ageing with HIV and comorbid disease"* concluded that as PLWH age and encounter increased age-related comorbidities, it is unclear whether current health/HIV- care systems can optimally and adequately respond to the health needs of ageing people with HIV [30].

HIV & Prevalent Comorbidities

Dr. Anthony Fauci of the National Institute of Allergy and Infectious Diseases recently concluded that PLWH “have a significant heightened risk of HIV-associated comorbidities that need to be addressed in order to improve the health and lives of PLWH” [31]. The pressing burden of comorbidities is especially influential when considering the significant increases of morbidity and mortality for PLWH, specifically in relation to kidney disease, obesity, diabetes, CV disease, liver disease, and neurocognitive disease [30]. While the prevalence of HIV-associated kidney diseases – such as HIV-associated nephropathy – in the US has decreased, kidney diseases associated with diabetes, hypertension, nephrotoxic medication effects, and aging are becoming increasingly prominent amongst PLWH who actively engage and are effectively treated with ART [31]. Similar to kidney disease, the relationship between HIV-related neurocognitive disorders and exposure to ART is continuously shifting. Despite a decreasing prevalence of HIV-associated dementia in light of ART, neurocognitive disorders and asymptomatic neurocognitive impairment continue to persist among PLWH, despite reaching viral suppression associated with ART [31].

Studies have concluded that PLWH are at higher risk of developing a myriad of chronic illnesses, including CV disease(s), hepatic and renal disease, osteoporosis and fractures, metabolic disorders, and several non-AIDS-defining cancers. Compared to HIV-negative individuals, PLWH have escalated rates of comorbidities, and the risk for developing these comorbidities is heavily influenced by older age [6]. Previous research highlights the significance of psycho-social and environmental factors as indicators of increased comorbidities among PLWH [32]. For example, existing habits of smoking and injectable drug use – both of which are primary drivers of CV disease – have been proven to be more common in HIV-infected individuals [33]. Additionally, among MSM, PLWH are associated with a greater risk of developing sexually transmitted infections and diseases – such as syphilis and gonorrhea – than their HIV-uninfected counterparts [34].

Barriers to HIV Care: Southeastern Contexts

Barriers to care inhibit PLWH from accessing and remaining in HIV-care, and are largely dependent on an individual's culture, community, geographic location, and additional psycho-social circumstances. In the Southern region of the US, lack of specialized medical services, prevalence of stigma, and limited social support – mitigated by distance and isolation – are among the most prevailing perceived barriers [35]. Evident through low CD4 T-cell counts and rapid disease progression, a lack of access to services, and the resulting poor retention in medical care, is reported to predict poor health outcomes for PLWH in the South [36]. Additionally, it is concluded that individuals who have missed medical appointments within the first year after initiating and engaging with ART have more than twice the risk of advancing HIV disease and navigating the subsequent consequences of doing so [37]. This is especially problematic in Southern areas with a high influx of PLWH living in rural regions, as rural residence is associated with delayed entry into care and increased mortality [35]. Poverty, coupled with the dependency of HIV-infected Southerners to rely on public assistance, are some of the most salient risk factors that influence delayed engagement in HIV medical care [38]. Of the ten states with the highest proportion of individuals living in poverty, the Southern region of the US is home to nine, ranging from 7.7% to 18.5% of the population [39]. In addition, approximately 17 million individuals living in the South are uninsured, leaving PLWH who rely on Medicaid, Medicare, disability insurance, the Ryan White CARE Act, or associated programs, with an exasperated burden associated with being uninsured – serving as a primary barrier to receiving necessary treatment [38].

In addition to the aforementioned individual and community-level barriers, structural and systemic barriers to health care – such as institutionalized racism – remain especially challenging in the Southern region of the US, which is evidenced by this region claiming the highest HIV diagnosis rates nationally [40]. In addition, recent data concludes that poverty, uninsurance, and rurality rates are disproportionate in the South when compared to other regions of the country [40]. These structural barriers heavily contribute to evident racial/ethnic disparities in the South. Almost 70% of PLWH in the South identify as Hispanic or African American/Black [41]. Once diagnosed, this subgroup is less likely to be linked to care [42], retained in care [37], or receive treatment [43]. Compared to PLWH in other regions, PLWH in the South are less likely to achieve viral suppression [44]. The influx of HIV-related barriers ultimately leave Southern states with some of the highest HIV fatality rates in the entire country [45].

Barriers to HIV Care

Given the socially and physically vulnerable circumstances PLWH live in, navigating the healthcare system can be overwhelming, often leaving PLWH unable to access and retain the specialty care necessary to live a healthy life [7]. Peer-reviewed scholarship from a 2012 sourcebook analyzing the effectiveness of US HIV care systems describes prompt utilization and access to clinical services – within and outside of HIV-related care – as the “second benchmark in HIV care” [7]. The success of clinical services relies heavily on the retention of HIV care and consistent viral suppression. A prevailing amount of research and evidence suggests that responses to HIV must “combine individual-level interventions with those that address structural or contextual factors that influence risks and health outcomes of infection” [46]. As such, it is critical to examine the social determinants of health and psycho-social factors that interplay as barriers for PLWH.

Housing is a unique barrier in that it is influential on an economic, social, and individual level. A systematic review on housing status, medical care, and health outcomes among PLWH in the US concluded that there is a correlation between housing status and HIV incidence. More specifically, people who are homeless or unstably housed are identified to have higher rates of HIV when compared to people with stable housing [46]. Of the those who are stably housed, PLWH are associated with an elevated risk for inadequate/unstable housing and housing loss [46]. Preexisting social disadvantages, loss of income, poor health, stigma, and policy restrictions on housing assistance for individuals with a history of substance abuse or incarceration are some of the most common factors that prevent many PLWH from accessing and maintaining adequate housing [46]. In addition, a meta-analysis of 152 studies identified lack of stable/secure housing as a prevailing barrier to consistent engagement with HIV care and sustained viral suppression [46]. Among those who have access to sustainable housing, many PLWH have noted that the neighborhoods in which they reside are often unsafe and prone to dangerous activities associated with gang violence, rape, or domestic violence – all of which deter one’s engagement in attending HIV-care appointments, and ultimately jeopardize their continuum of care at various stages [47].

Intertwined through many of the factors that influence one’s HIV care is stigma. The dominating role of stigma in one’s continuum of care is present in both the internalized and externalized ways in which stigma relates to an individual’s HIV status. A recent study found that among PLWH, women and older patients are at elevated risk of perceiving stigma, and subsequently associated with disengagement in HIV care due to stigma [48]. Among national strategies to prevent HIV incidence and ensure care retainment for PLWH, HIV-related stigma is identified as a paramount barrier to seeking and accessing HIV care [49]. In addition, HIV-related stigma is identified as a risk factor for decreased levels of HIV testing, pre-exposure prophylaxis (PrEP) exposure, medication adherence, and linkage to and retention of care – all of which serve as crucial components of the HIV care continuum [49]. A systematic review of HIV-related stigma by healthcare providers in the US illustrated the implicit ways in which stigma can be manifested, such as through racism, homophobia, transphobia, and negative perceptions of individuals who inject drugs/abuse substances. In turn, this stigma can construct uncomfortable environments for patients to receive care, ultimately acting as a barrier for HIV prevention, treatment, and care [49]. Additionally, it is hypothesized that a decrease in stigmatizing attitudes/behaviors by providers can be used as leverage in reducing the structural and social barriers to HIV care across the continuum [50].

Barriers to Subspecialty Care Access

The burden of HIV-associated comorbidities is heightened when considering restricted access to health care and increasing cost of treatment. The exorbitant cost of treatment is largely due to an increased demand for specialty outpatient services, which subsequently increase the use of health care resources, inpatient admissions, and require complicated and expensive treatment regimens. Aside from financing their HIV-related care, PLWH are responsible for costs related to the comorbidities that result from HIV infection and treatment. As such, it is concluded that PLWH with existing comorbidities have significantly higher health expenditures as compared to HIV-positive individuals without comorbidities. This relationship is especially prevalent in individuals simultaneously seeking care for HIV and chronic illnesses, such as kidney disease and cardiovascular disease [31] . Participants from a recent qualitative study on the social determinants of HIV treatment engagement explicitly mentioned the pertinent role of care-related costs in relation to engagement and retention of HIV care. When probed about barriers to care access, one participant noted that "it's hard because I get a check for $735.00 each month. And I have bills to pay. I have food to put in the house. So, it's like I can't pay for the things that I really need [HIV care]" [47]. The increase in health care usage and cost that results from HIV-associated comorbidities possesses a significant burden to not only the HIV-positive individuals engaging in care, but also to the US healthcare system as a whole, ultimately jeopardizing the availability and quality of healthcare.

Given the limited amount of specialty care providers who are willing to provide care for uninsured patients, and the lack of consistent communication between specialists and clinics, referring patients to specialty care services off-site is especially challenging for HIV-care providers, ultimately posing a threat to the effective functioning of the healthcare system [8]. As such, coupled with the existing and ongoing barriers surrounding HIV care, PLWH who require additional subspecialty care for multiple diagnoses are further disadvantaged in relation to engaging, access, and retaining in care.

Barriers to Care Coordination

In addition to the barriers that prevent PLWH from accessing care, it is important to consider the barriers that prevent effective and sustainable care coordination. Care coordination is highly associated with clinical outcomes [9], and a lack of coordination increases the risk of medication errors, unmet needs, duplicated tests, and patient and provider dissatisfaction [10]. Care coordination has been reported as especially challenging to achieve for patients who have multiple chronic conditions that require services - and thus information exchange - from multiple providers. For example, having multiple prescribing clinicians is a strong predictor of emergency room visits and hospitalization [51]. In addition, a wide range of existing research has noted that referrals from primary care physicians to specialists often include insufficient information, and consultation reports from specialists back to primary care physicians are often late and inadequate [51] – both of which impede the quality of care provided to patients. Furthermore, when patients are hospitalized, their primary care physicians may not be notified at the time of discharge, and discharge summaries may contain insufficient information or never reach the primary care practice at all [51]. A lack of functional and coordinated integration between various systems of care, coupled with the complexities of the referral process, continue to serve as primary barriers to providing quality, highly effective care to PLWH, both within and outside the contexts of traditional HIV care.

Healthcare providers guide PLWH through the care continuum, with the ultimate goal being to ensure effective prevention and care and reduce the likelihood of mortality and morbidity. Providing high-quality care is centered around a basis of trust between a patient and their provider, ultimately influencing a patient’s likelihood to stay retained in care. A multitude of research studies have identified stigmatizing attitudes, behaviors, and beliefs from providers toward PLWH as a primary risk factor for impeding progress in the continuum of care, specifically in relation to linking patients to care, identifying at-risk/undiagnosed individuals with HIV, administering HIV treatment, and increasing levels of viral suppression for PLWH [50].

PLWH interact with a myriad of practitioners – nurses, physicians, social workers, administrative staff – through their care continuum, all of whom influence the likelihood of an individual's willingness to remain in care. As such, it is critical to understand the relationship between patients and providers in improving HIV-related outcomes on the individual level, as well as mitigating the negative consequences of the HIV epidemic on a societal level. Provider reactions to HIV-infected persons, coupled with patient perceptions of these reactions, have been identified as key indicators of whether patients remain retained in HIV care [48]. The dichotomy between patients' perceptions of providers' unwillingness to provide care for PLWH and increased levels of stigma associated with HIV in clinical settings is commonly responsible for dis-engagement in HIV medical care, concluded Magnus et. al [48]. The significance of the relationship between a patient and their provider is further illustrated in a study conducted in an HIV clinic in Maryland. Of the 1,363 patients interviewed, PLWH indicated their willingness to attend HIV care appointments is heavily dependent on whether they are spoken to and treated with respect, delivered information in a digestible manner that they can understand, listened to attentively, and have a personal relationship with their provider [52].

As mentioned previously, the relationship between a patient and a HIV-care provider transcends beyond routine HIV check-up visits. The increased risk of developing comorbidities – such as hypertension and diabetes – leaves PLWH reliant on their provider/care team to address and refer them to appropriate diagnosis and treatment options. PLWH diagnosed with comorbidities have unique health care needs as compared to individuals living with only one of these conditions, largely due to a heightened necessity for multiple medicine prescriptions, as well as regular monitoring of multiple forms of treatment to ensure medical adherence [12]. Although previous research has demonstrated that training and knowledge of HIV care providers to adequately handle comorbidities among patients is crucial through multiple stages of the continuum of care, the effectiveness of physician comorbidity training remains unclear [53]. A study by the *Journal of Academic Medicine* concluded that among the various forms of clinic training that HIV providers receive, “many physicians perceived their medical training for chronic illness to be inadequate” [54]. Adequate knowledge and training of providers in relation to chronic complications and comorbidities is crucial as the healthcare needs of PLWH expand [13]. In order to effectively address these expanded needs, HIV care must go beyond a fixed, antiretroviral-focused approach, and extend to holistically address thee dynamic and shifting elements of long-term infection, chronic disease and comorbidity management, and other patient-specific factors [13].

The HIV-related burden of disease, coupled with increases in HIV diagnoses, has significantly increased the demand for medical care. This increased demand intensifies the emotional, physical, and mental stress experienced by HIV care providers, often resulting in a shortage in the HIV workforce [55]. These shortages are exacerbated by several factors, such as challenging working conditions, high prevalence of comorbidities and NCDs, and an exodus of health workers [56]. Despite a continuous increase in demand for HIV-related health care, a recent study by the *American Academy of HIV Medicine* predicts a steady decline in the number of physicians – both primary care and infectious disease – managing and administering HIV care [56]. A similar study found that almost 70% of practices funded primarily for preliminary intervention services within the Ryan White HIV Program reported significant difficulties with recruiting primary care providers [57]. Additionally, a recent risk assessment of the HIV workforce conducted by the US federal government identified “severe workforce capacity challenges” as a primary barrier to effectively diagnose and retain PLWH [58]. Furthermore, a “HIV Screening and Access to Care” report issued by the former Institute of Medicine highlights that not enough HIV primary care physicians are trained to account for the increasing number of individuals in the US who require testing and/or treatment for HIV [59]. This report also emphasizes the necessity to increase HIV-related training opportunities for healthcare professionals, followed by a need to include health care specialists beyond primary care physicians and infectious disease specialists – such as nurse practitioners, physician assistants, dentists, pharmacists, social workers – throughout the continuum of care [59].

Specific barriers to effective care coordination range from a lack of technical capabilities to time and resource constraints. Despite the prevailing evidence that suggests a relationship between longer consultations are more preventative and holistic health advice and treatment, primary care doctors/general practitioners have highlighted lack of time as a significant barrier to providing care for patients with comorbidities [24]. A recent study surveyed primary care providers (PCPs) and primary managers (PMs) and concluded that the most common barriers to providing highly effective, coordinated care were: difficulty sending and receiving information electronically (81% of PMs and 74% of PCPs); a lack of provider and practice staff time (77% of PMs and 79% of PCPs); and complex required workflow changes (78% of PMs and 78% of PCPs) [60]. When asked how these barriers influence the provision of care, PCPs largely noted that addressing the aforementioned barriers would “have a positive effect on all dimensions of patient care coordination” [60]. PCPs who participated in this study highlighted that addressing the demanding barriers to primary care would improve their patients’ treatment (86% of respondents somewhat agreed or strongly agreed), help patients overall (85%), and ensure that doctors know about their patients' visits to other doctors (85%). In addition, PCPs anticipated a reduction in the number of hospitalizations (59%), reduced adverse drug events (72%), and improved specialist responsiveness (75%) as outcomes of enhanced primary care [60].

Necessity of Care Integration

Over time, HIV has evolved into a chronic infectious disease, allowing its prevention, treatment, and management to occur in both primary and specialty care settings [61]. The current continuum of care enforces a standardized approach to HIV-care that often prohibits access, coordination, and integration of HIV-care with subspecialty care, counseling/mental health services, and services required to live a high-quality life following HIV diagnosis. This lack of integration has not only compromised the health of PLWH, but also prevented available services in the healthcare system from being utilized by people who need them the most. The International Antiviral Society-USA (IAS-USA) has developed recommendations to provide practicing clinicians, physicians, public health experts, and policy makers with a framework to implement the most effective HIV prevention interventions. These recommendations highlight that "the integration of biomedical and behavioral approaches to HIV prevention, coupled with ART for those infected, represents the cornerstone of efforts to curb the spread of HIV infection" [62]. Additionally, the framework developed by IAS-USA illustrates that providing preventative and/or sustainable HIV-care for people living with or at risk for HIV infection requires a comprehensive model that elicits a combination of activities and strategies. Among the variety of recommendations developed by IAS-USA, the following were identified as crucial when aiming to prevent, diagnose, and effectively treat HIV: HIV testing and knowledge, access and retention to ART, counseling on risk reduction, disclosure of HIV status, and partner notification, linkage to HIV care, exposure to PrEP, routine screening and testing for STIs, and additional patient support services [62]. A traditional, fixed approach to HIV prevention and treatment jeopardizes the ability for PLWH to receive sufficient and efficacious care that extends past the continuum of HIV care and enables individuals to live a healthy life.

The US National HIV/AIDS Strategy (NHAS) also highlights the necessity for interdisciplinary, integrated care for PLWH on a federal level [63]. Additionally, when aiming to promote healthcare reform in the US, the Patient Protection and Affordable Care Act (ACA) has emphasized the fundamental need for community health centers to provide “comprehensive, interdisciplinary primary care for underserved populations, including PLWH” [64]. Of the clinics/community health centers that readily engage with PLWH, a vast majority of these sites are unable to provide all of the necessary health/medical services onsite and depend upon referrals to specialty care. The benefits of integrated HIV care transcend the boundaries of co-infection/specialty care. A systematic review published in *the Journal of the International AIDS Society* concluded that the advantages of care integration are commonly reported in relation to positive patient outcomes among PLWH, including the ability of integrated services to better enable patients to uptake and adhere to treatment [65]. Additionally, HIV providers/health professionals and staff noted there are also significant service/provision outcomes with integrated and coordinated approaches to care, specifically highlighting that integrated care made it easier to refer patients to mental health, social, and medical services [65].

Strategies for Care Integration

A recent mixed-methods study comprised of a systematic literature review and consultation with key informants (i.e., health clinics throughout the US, PLWH receiving services, etc.) identified the following themes as critical for successful integration of HIV-care: model of care, staffing and team structure, site culture, spectrum of services, communication, financing, and quality of care [8]. Respondents of the study uniformly noted that delivering interdisciplinary HIV care through a “one-stop shopping” model wherein a variety of services – within and outside the contexts of HIV care – are co-located and accessible within one building with uniform administrative procedures and cross-disciplinary data sharing as ideal. Successful interdisciplinary sites were described as “patient-centered and responsive to the unique needs of PLWH” [8]. PLWH who participated in this study further emphasized the necessity for interdisciplinary care to include a comprehensive array of services. Patients consistently noted that mental health and substance abuse treatment should be available at HIV sites, referencing the high prevalence of behavioral health issues among PLWH who are currently seeking care as evidence [8]. Additionally, all respondents in the study noted an overwhelming need for consistent and wholistic psychosocial – including care management, specialty care, and peer counseling – and medical adherence support. Treatment for co-infection – specifically for hepatitis C – availability of specialty services, and access to dental care were also identified as important for the provision of successful interdisciplinary HIV-care. Effective collaboration and communication between diverse healthcare providers (inside and outside of HIV-care) were identified as crucial to the coordination of services among providers and patients [8].

The necessity and effectiveness of HIV care integration was further emphasized through an initiative funded by the Health Resource and Service Administration’s HIV/AIDS Bureau [66]. Researchers conducted a narrative review and meta-analysis of interventions focused on behavioral health integration in HIV care settings in the US and concluded that effective treatment for behavioral health problems significantly increased the likelihood of viral suppression, thus making it a crucial tool for preventing HIV transmission and mitigating the consequences of the HIV epidemic [67]. This narrative review found that among patients receiving treatment for other chronic diseases – such as diabetes – integrating behavioral health services with primary care has been successful in improving both behavioral and physical health outcomes [68]. Similarly, if behavioral health programs are integrated into HIV-care treatment regimens, it is hypothesized that PLWH are likely to experience similar improvements in both behavioral health and HIV-related outcomes [66]. Care integration is particularly effective in settings that experience high HIV-related burdens and have limited resources. Within these areas, integrated care ensures that complex and dynamic health needs are addressed, while also strengthening care delivery and drug distribution system commonalities, facility sharing, and aligning funding mechanisms [65]. Given the restricted time limitations of care appointments, researchers have found that having robust practice systems in place to ensure appropriate monitoring with a practice nurse before the appointment with a general practitioner would facilitate the most efficient and effective use of both patients' and doctors' time [22].

Peer-driven interventions (PDIs) are increasingly being recognized as effective mechanisms to bridge gaps and barriers to HIV care and facilitate collaboration among a variety of healthcare services [69]. The foundation of PDI allows peers with HIV (commonly referred to as peer navigators) to draw from their own experiences and build close relationships with patients, with the goal being to educate, recruit, navigate, and retain patients in care through relationships with peer navigators [70]. A widely successful iteration of PDIs is the peer integration model, which "involves the integration of peers into multidisciplinary healthcare teams with the aim of linking hard-to-reach clients into care" [71]. In this model, the peer navigator serves as a bridge between PLWH who have trouble accessing care and retaining treatment, and healthcare teams/programs that may not have the capacity to adequately address social determinants that serve as barriers to HIV care and treatment. A recent qualitative study of a peer integration model identified that PLWH often felt more compelled to share sensitive health/personal information – inclusive of information on intimate partner and family relationships/violence, substance abuse, sexual risk behaviors, and housing – with peer navigators, as opposed to sharing this information directly with providers. This enabled peers to identify potential risk factors or "red flags" to treatment, retention, and adherence. In turn, peer navigators were able to collaborate with providers and health professionals/staff to address prevailing barriers and prevent them from adversely impacting patient retention and adherence [71]. As such, the crucial role of PDIs in the continuum of care is a testament to the usefulness of integrative models when aiming to engage and retain PLWH in care.

Mobile Integrated Health (MIH)

Given that systems of traditional HIV care – such as fixed clinics – often do not meet the dynamic, shifting, and complex needs of PLWH, recent interventions aimed to re-engage and retain PLWH-OOC into care have increasingly adopted and/or implemented unique models of care delivery, aiming to address existing barriers (transportation, stigma, etc.) that may prevent PLWH-OOC from accessing care. As new models of HIV care continue to develop, it is becoming increasingly evident that the potential success of these models [in re-engaging and retaining PLWH-OOC] is often dependent on how care is coordinated within them. One such model is the mobile-integrated health (MIH) HIV clinic developed and facilitated by Grady

Hospital and the Ponce de Leon Center, both in Atlanta, GA. The MIH program was first created in 2013, with a focus on coordinating and facilitating the efficient, targeted management of outpatient problems that would otherwise burden emergency departments, thus decreasing hospital admissions and improving quality of care [72]. While the MIH model was not initially designed to deliver HIV-care, as the COVID-19 pandemic progressed and consequently decreased rates of care engagement among PLWH, the model began to be used as a tool to provide HIV-care to those facing challenges receiving traditional HIV care in light of the pandemic. As such, this model started to be used to address COVID-related barriers – such as insufficient functioning of public transportation and shelter-in-place mandates – that could otherwise jeopardize one's ability to [stay] engage(d) in HIV care. As engagement and outreach have increased, this model is now being explored as a tool to reach/retain people who have faced challenges staying in routine clinic-based HIV care/PLWH-OOC. While MIH has been instrumental in strengthening HIV care accessibility, the implementation and facilitation of this model may also pose additional challenges for HIV care coordination, specifically in relation to collaboration between sub-specialty care, routine/clinical care, and HIV support services.

Summary and Gaps in the Literature

With over 34,000 new diagnoses in 2019, it is evident that the HIV epidemic continues to jeopardize the health and quality of life for many individuals in the US. A lack of specialized medical services, prevalence of stigma, and limited social support mitigated by distance and isolation are among the most exigent barriers that make Southern regions of the US especially vulnerable to the consequences of HIV infection. In addition, the prevailing presence of factors such as substance abuse, housing insecurity, financial and insurance barriers, systematic racism, and comorbidity leave PLWH in the South struggling to engage and be retained in care that addresses a wide range of health and psycho-social related concerns. Outside of HIV-related care, these barriers can impede the ability for PLWH to access other forms of healthcare – such as dental and oncological. A significant lack of access and sufficient coordination, coupled with socio-cultural and structural barriers, often prevent PLWH from accessing and retaining the comprehensive array of medical services – inclusive of care that is related to and outside of HIV care – required to live a healthy life.

Research focusing on predictors of delayed HIV diagnosis and delayed presentation to medical care in the Southern US is limited, and much of the existing literature in relation to HIV and comorbidity is generalized and not context specific. While previous scholarship confirms an association between the presence of comorbidities and elevated CD4 counts, it is unclear whether integrating sub-specialty care will holistically address this contributor to the compromised immunity of PLWH. Additionally, few studies have examined barriers to subspecialty care access by PLWH, despite growing rates of HIV and coinfection. As such, there is an exigent need for multidimensional research regarding the relationship between HIV care and other forms of healthcare (i.e., primary, sub-specialty) throughout different models of HIV care delivery, focusing specifically on how the coordination of care through these models may influence outcomes of care delivery.

This study aims to investigate the role of care coordination in the continuum of care, focusing specifically on the ways in which care is coordinated throughout models of HIV care, clinical settings, and hospital systems. This analysis will compare gaps identified by patients and providers, ultimately illustrating how care coordination, sub-specialty care, and the MIH care model interplay when aiming to re-engage and retain PLWH-OOC into care. Finally, this analysis intends to highlight care coordination experiences among a variety of individuals that interact with the continuum of care in different ways, ranging from PLWH and HIV care providers, to social workers and program coordinators. Ultimately, findings from this study will reveal whether care coordination and integration are key factors that influence care delivery outcomes within various models of HIV care. In addition, this study will employ rich participant-centered data to further understand the ways in which we can most effectively provide coordinated and comprehensive HIV-care for PLWH-OOC.

Chapter III: Manuscript

Care coordination outcomes in diverse models of HIV care: An analysis of patient and provider identified gaps in the continuum of care

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Abstract

The Southern region of the US is home to the highest rates of HIV-related mortality and morbidity in the entire country. A lack of functional and coordinated integration between various systems of HIV-care delivery, coupled with the complexities of the healthcare system, continue to serve as primary barriers to providing quality, holistic, and highly effective care for people living with HIV (PLWH), and to re-engaging and retaining PLWH who are out-out-care (PLWH-OOC) into care. This qualitative study aimed to understand the relationship between care coordination and sub-specialty care throughout varying models of HIV care delivery – mobile clinics, home-based care programs, traditional fixed clinic – and to investigate if/how this relationship influences the health outcomes of PLWH-OOC. From October 2022 to March 2023, 18 in-depth-interviews were conducted with six HIV-care providers, three clinic administrative staff members, two social workers, and seven Community Advisory Board members who also identified themselves as PLWH. Primary results from this study reveal that care coordination plays a central and unequivocal role in the continuum of care, and also highlight that HIV care systems must be 1) equipped with a comprehensive range of services outside of traditional HIV-care and 2) organized in a way that allows HIV-care to be delivered and received as easily as possible if efforts to prevent PLWH from falling out of care and to re-engage PLWH-OOC are to succeed. In summary, findings from this study investigate current gaps/barriers that impede effective care delivery and coordination within models of HIV care delivery, and also offer strategies for how health systems can navigate these barriers/gaps and ultimately increase the number of individuals that are engaged and retained in care.

Introduction

The Center for Disease Control and Prevention (CDC) estimates that there were nearly 1.2 million people living with HIV (PLWH) in the United States (US) in 2019 [1]. This 1.2 million includes approximately 34,000 new HIV diagnoses in 2019, 69% of which occurred among men who have sex with men (MSM) [2]. Among MSM, African American/Black MSM have the highest incidence of HIV diagnoses. Given the prevailing structural and societal barriers facing African American MSM, this population also exhibits the lowest rates of access and retention to HIV care compared to any other racial or ethnic group in the US population [1]. Investigating gaps in access and retention of HIV care is especially critical in Southern regions of the US, where an estimated one in five African American MSM are living with HIV [3].

The Southern region of the United States is primarily known for its hospitality and influence of rich Southern culture. However, driven mainly by overall poor healthcare access, extreme poverty rates, high levels of HIV-related stigma, and poor health outcomes for PLWH, the Southern region of the US is also home to states that have the highest rates of HIV infection [3], followed by some of the worst HIV death rates [4] in the entire country. Although only 38% of the US population resides in the South, HIV diagnoses in Southern states encompass over 50% of new cases every year [3].

Recent trends in the wider availability of antiretrovirals and antiretroviral therapy (ART) have prolonged life expectancies for PLWH and reduced mortality from HIV. Subsequently, over time, there has been a shift in the age demographic of the population living with HIV, with the majority of PLWH now being over the age of 50 [3]. This reduction in mortality has transformed HIV from a death-sentence to a chronic illness for many PLWH. Unfortunately, aging – both within and outside the contexts of HIV infection – is associated with a greater prevalence of non-communicable diseases (NCDs) [3]. While the longer lifespan associated with ART access is a significant step towards controlling the HIV epidemic, it has also introduced new concerns surrounding the management of HIV care, as providers must now acknowledge and effectively manage comorbidities and associated with aging. When compared to individuals who are HIV negative, PLWH develop comorbidities - such as cardiovascular (CV) diseases, hypertension, diabetes, bone fractures, and renal failure - at younger ages, largely due to the chronic immune activation and inflammation that results from HIV infection, both of which are known to be factors for accelerated aging [5,6]. As previously discussed, old age, in and of itself, accelerates the likelihood of being exposed to comorbidities. Coupled with underlying HIV infection and subsequent consequences of HIV-related treatment, PLWH become more susceptible to developing comorbidities as they age. The aging population of PLWH has resulted in a series of demands for health-care systems, with integration and coordination of specialty/clinical care (outside of HIV-related care) being two of the most salient necessities for the health and wellbeing of HIV-infected patients.

Given the socially and physically vulnerable circumstances PLWH live in, navigating the healthcare system can be overwhelming, often leaving individuals unable to access and retain the specialty care necessary to live a healthy life. Peer-reviewed scholarship from a 2012 sourcebook analyzing the effectiveness of US HIV care systems describes prompt utilization and access to clinical services (within and outside of HIV-related care) as the "second benchmark in HIV care" [7]. Given the limited amount of specialty care providers who are willing to provide care for uninsured patients, and the lack of consistent communication between specialists and clinics, referring patients to specialty care services off-site is especially challenging for HIV-care providers - ultimately posing a threat to the effective functioning of the healthcare system [8].

Effective and sustainable care coordination is critical if interventions aimed to re-engage and retain PLWH, as well as PLWH who are out-of-care (PLWH-OOC) are to succeed. Care coordination is highly associated with clinical outcomes [9], and a lack of coordination is reported to increase the risk of medication errors, unmet needs, duplicated tests, as well as both patient and provider dissatisfaction [10]. Care coordination has been reported as especially challenging to achieve for patients who have multiple chronic conditions that require services - and thus information exchange - from multiple providers. In addition, a wide range of existing research has noted that referrals from primary care physicians to specialists often include insufficient information, and consultation reports from specialists back to primary care physicians are often late and inadequate [11] – both of which impede the quality of care provided to patients. Furthermore, when patients are hospitalized, their primary care physicians may not be notified at the time of discharge, and discharge summaries may contain insufficient information or never reach the primary care practice at all [11].

With over 34,000 new diagnoses in 2019, it is evident that the HIV epidemic continues to jeopardize the health and quality of life for many individuals in the US. A lack of specialized and coordinated medical services, prevalence of stigma, and limited social support – mitigated by distance and isolation – are among the most exigent barriers that make Southern regions of the US especially vulnerable to the consequences of HIV infection. In addition, the prevailing presence of factors such as substance abuse, housing insecurity, financial and insurance barriers, systematic racism, and comorbidity leave PLWH in the South struggling to engage and be retained in care that addresses a wide range of health and psycho-social related concerns. Outside of HIV-related care, these barriers often prevent PLWH from accessing other forms of healthcare such as oncological, cardiovascular, and gastro-intestinal care. A significant lack of access, coupled with socio-cultural and structural barriers, are primary variables preventing patients from many forms of necessary non-HIV care.

PLWH diagnosed with comorbidities have unique health care needs as compared to individuals living with only one of these conditions, largely due to a heightened necessity for multiple medicine prescriptions, as well as regular monitoring of multiple forms of treatment to ensure medical adherence [12]. In order to effectively address these expanded needs, HIV care must go beyond a fixed, antiretroviral-focused approach, and extend to holistically address the dynamic and shifting elements of long-term infection, chronic disease and comorbidity management, and other patient-specific factors [13]. Despite ongoing and extensive HIV research in the past decade, little is known about the role of sub-specialty care and care coordination in the continuum of care. A lack of functional and coordinated integration between various systems of care, coupled with the complexities of the referral process, continue to serve as prevailing barriers to providing quality, highly effective care within and outside of traditional HIV care contexts. As such, there is an exigent need for multidimensional research regarding the relationship between HIV and coinfection/comorbidity across a variety of populations and psycho-social contexts. It is imperative to critically understand the relationship between HIV-care and other forms of healthcare, as a lack thereof has resulted in compromised levels of viral suppression (VS) and retention of HIV-care amongst PLWH.

The purpose of this study is to understand the relationship between care coordination, sub-specialty care, and the health outcomes of PLWH-OOC. More specifically, this study explores the role of care coordination and sub-specialty care in the context of a mobile-integrated health (MIH) HIV clinic developed and facilitated by Grady Hospital and the Ponce de Leon Center, both in Atlanta, GA. Although the MIH model was not initially designed for PLWH-

OOC, as engagement and outreach have increased, it is now being explored as a model to reach/retain people who have faced challenges staying in routine clinic-based HIV care. While MIH has been instrumental in strengthening HIV care accessibility, the implementation and facilitation of this model may also pose additional challenges for HIV care coordination, specifically in relation to collaboration between sub-specialty care, routine/clinical care, and HIV support services. This analysis will compare gaps identified by patients and providers, ultimately illustrating how care coordination, sub-specialty care, and the MIH care model interplay when aiming to re-engage and retain PLWH-OOC into care. As such, this study aims to investigate the following research questions:

1) What is the role of mobile and home-based health care models in providing comprehensive care and HIV support services to PLWH-OOC?
2) How does care coordination throughout models of HIV care influence health outcomes among PLWH-OOC?
3) What are the perspectives and recommended strategies of PLWH and HIV clinic staff/providers to effectively integrate sub-specialty care and promote care coordination throughout the continuum of care?

The results of this analysis will highlight the dynamic perspectives of PLWH and HIV providers/key informants, specifically in relation to the integration and utilization of sub-specialty care with traditional forms of HIV care [in the context of a new HIV care model that is being explored to better reach PLWH-OOC]. In doing so, the study may identify potential strategies and areas of consideration when aiming to improve HIV care coordination and to provide holistic care more effectively for PLWH-OOC.

Methods

Overview

This qualitative analysis is embedded within a larger mixed-methods research study that aims to identify the necessity and/or effectiveness of a mobile clinic and home-based care program to re-engage PLWH-OOC, and to explore the barriers and facilitators which influence the implementation and success of these care models [73,74]. Formative research from this study illustrated that, in order to effectively reach, re-engage, and retain PLWH-OOC through different models of care, we must better understand the relationship between care integration, sub-specialty services, and potential psycho-social factors that influence care outcomes. As such, this sub-study explores the role of care coordination in the continuum of care through the perspectives of PLWH-OOC, care providers, healthcare personnel, and administrative staff. More specifically, this study investigates the role of care coordination among differing models of HIV care delivery – home-based care, mobile-integrated health (MIH), as well as mobile-clinics – and seeks to evaluate whether care coordination influences outcomes of the care delivered and received through these models.

The unique cross-examination of perspectives from a myriad of key informants who interact and engage with HIV-care allows this study to highlight emerging themes and areas of improvement throughout a wide spectrum of HIV care experience. In addition, this study explores barriers and facilitators of integrating sub-specialty care/HIV support services throughout varying contexts and models of HIV care – guided largely by recommendations from PLWH, Community Advisory Board (CAB) members, and other clinic stakeholders, such as infectious disease physicians, attendings, nurses, social workers, program coordinators, and executive directors. From November 2022 to March 2023, 18 in-depth-interviews (IDIs) were conducted. All study protocols and interview guides were reviewed by Ryan White clinic CAB members and revised in accordance with recommendations from the CAB prior to data collection and analysis.

Development of IDI Guide

Community partners, THRIVESS and LOTUS, established a Community Advisory Board (CAB) composed of PLWH who were either presently out-of-care or had, in the past, faced challenges with staying engaged in HIV care. THRIVESS and LOTUS primarily work to build collective advocacy and create community development initiatives among PLWH in Atlanta [75]. CAB members represent a variety of racial, ethnic, gender, and sexual minority subgroups. Many have experienced being out-of-care during previous periods of their lives and can share strategies they used to overcome challenges they encountered. The opportunity to share their stories, lived experiences, and diverse fields of knowledge allowed CAB members to exercise their agency throughout this project, and also highlighted the importance of community partnership in considering programs to enhance patient engagement along the continuum of care. CAB members were involved in all phases of this project, their contributions ranging from providing vital knowledge and feedback throughout the protocol and instrument development phases, to serving as key informants/participants in the study.

Interview guides were developed based on themes generated from previous qualitative research performed by the study team. For this thesis study, the guide included questions to investigate the perceived effectiveness, barriers, and facilitators of care coordination and sub-specialty care throughout the continuum of care – in the context of HIV care for PLWH-OOC in general, as well as specifically in relation to home-based care programs, such as MIH. Interview guides were tailored to each stakeholder group – providers/administrators and CAB members – and probes that followed questions were also unique to each stakeholder group. All interview guides included questions about barriers and facilitators to care for PLWH-OOC, and also asked participants for relevant strategies/suggestions to improve care coordination and sub-specialty care integration across various models of providing HIV care (ie., MIH, traditional fixed clinic, etc.). Updates, insights, and recommendations from completed IDIs were shared at weekly research team meetings and guides were subsequently revised with probes for future interviews. All IDI guides were vetted by CAB members and revised upon receiving feedback from co-investigators.

Study Population

The eligibility criteria for this study required all potential participants to be 18 years of age or older and fluent in English. Participants included PLWH who were out-of-care (PLWH-OOC), defined as individuals with a diagnosis of HIV who 1) have not received any form of HIV care (i.e., fixed clinic, mobile clinic, home-based care, etc.) in the past six months, and 2) had a viral load greater than 200 copies per milliliter at last check. Convenience sampling was used to recruit PLWH-OOC through a variety of mediums: identification by inpatient HIV care providers and hospital workers, a Ryan White clinic "retention list" of patients who had fallen out of care, as well as chart review of recently hospitalized PLWH. Other key informants – infectious disease physicians, nurses, mobile clinic personnel, Ryan White clinic staff – were identified as stakeholders in the home-based HIV care program, and recruited by email, phone call, and clinic-wide meetings. CAB members were informed about the study by email, engagement at monthly CAB meetings, and through snowball sampling. Prior to data collection, all participants were provided information regarding potential risks, benefits, and confidentiality procedures associated with their participation in the study and given the opportunity to ask questions and withhold their consent if necessary. Written or verbal consent was obtained and documented by study staff prior to administering data collection through the IDIs.

Data Collection

IDIs were administered by trained study staff in private, hospital/clinic settings, or conducted virtually via Zoom. After receiving participant consent, IDIs were recorded to ensure accuracy of data collection and transcription. IDIs were conducted following semi-structured interview guides that were specific to the role of the participant (PLWH, HIV Care Providers). IDI questions aimed to explore the following variables: participant involvement with HIV care, key considerations for acceptability of HIV-care delivery models (i.e., mobile HIV clinics and home-based care programs), barriers and facilitators to the integration of specialty care, current gaps in traditional HIV-care, the role of care coordination in HIV care delivery, and strategies to retain and re-engage PLWH-OOC into care. Questions started out broad and open-ended, focusing on participants' current engagement and satisfaction (or a lack thereof) with HIV care, and eventually focused on specific considerations and strategies in relation to care integration and coordination, driven largely through the lens of home-based HIV care.

Questions for providers/HIV care teams included: "*On a scale from 1-10, where 1 is the least effective and 10 is the most effective, how effective is [mobile HIV clinic or home-based HIV care program] in providing non-fragmented HIV care (i.e., care that is integrated into the larger health system)? Why? How could this be improved via this model?"* Participants who identified as PLWH/CAB Members were asked questions such as "*Please describe what the* *ideal place or way would be for you to receive HIV care,"* and "*On a scale of 1-10, where 1 is extremely difficult and 10 is extremely easy, how easy was it for you to access HIV support services (like case management, social work support, housing, food vouchers, mental health services) when you needed it? Why?"* All participants were asked questions about the role of care coordination in the continuum of care, namely for PLWH-OOC, and were also asked for suggestions/strategies that may strengthen care coordination outcomes. Questions of this nature included *"Do you think that care coordination, throughout different systems of HIV care, can influence care engagement and retention outcomes among PLWH-OOC? Why or why not?"* and *"What are some ways that HIV care models can deliver and coordinate care in a way that is most accessible for PLWH-OOC?"* Participants were often probed with follow-up questions to further investigate key themes and generate a better understanding of responses from previous questions. All IDI participants had the ability to skip any questions that did not apply to them/they were not comfortable answering and were compensated $50 for their participation.

Data Analysis

All IDIs were transcribed verbatim using the TranscriptDivas transcription software (TranscriptDivas Delaware). Transcripts were checked by a member of the study team for quality, and for assurance that they were devoid of any identifying information prior to analysis. Trained members of the study team coded transcripts in parallel with conduct of the IDIs, allowing inductive codes to be further probed in subsequent interviews. The codebook was developed after 3 initial interviews were conducted. Deductive codes developed for the codebook addressed the following themes: 1) the role of care coordination within various models of HIV-care delivery, 2) the ways in which care coordination can influence outcomes for PLWH-

OOC, 3) the effectiveness of home-based care programs and mobile clinics in providing non-fragmented HIV care, 4) barriers/facilitators of integrating and coordinating sub-specialty care within these care models, and 5) strategies to improve care coordination to better meet the needs of PLWH-OOC. Inductive codes emerged throughout interviews and aimed to further investigate themes of interest. The codebook was revised throughout analysis to account for additional themes revealed through the interviews as they were being transcribed. Each interview was then coded using MAXQDA Plus 20.0.4, independently, by two members of the study team. This analysis primarily extracted, investigated, and compared the code "Care Coordination" and the subcodes "Identification and Referral Process," "Strategies to Improve Care Integration/Coordination for PLWH-OOC," and "Strengths/Weaknesses of Care Coordination in MIH." When discrepancies arose, they were discussed with a third study team member until consensus was reached.

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

This study included participants from the following subgroups: infectious disease physicians, social workers (SWs), physician's assistants (PAs), nurse practitioners (NPs), executive directors (EDs), program coordinators, and Community Advisory Board (CAB) members (Table 1). As PLWH in the community, CAB members represent dynamic and diverse experiences of engaging with HIV care across a broad range of contexts. Often, PLWH join the CAB to leverage their past [negative] experiences receiving or staying retained in HIV care in efforts to strengthen systems of care delivery for others who may face similar challenges. Of the 18 IDI participants, 6 identified themselves as HIV care providers (33%, 6/18), 2 identified themselves as SWs (11%, 2/18), 3 were administrative staff (17%, 3/18), and 7 identified themselves as members of the CAB (39%, 7/18). To protect the identities of participants, no additional demographic/identifying information was collected. Additionally, it is important to note that participants in this study work across the hospital-to-clinic linkage system. As such, some providers/SWs may help bridge patients from hospital-to-clinic or hospital-to-MIH; others work in the clinic or with MIH directly.

Table 1. Characteristics of In-Depth-Interview Participants (N=18).

Characteristic	**Category**	**n**	**%**
Role			
	HIV Care Provider	6	33%
	*Administrative Staff**	3	17%
	Social Worker	2	11%
	Community Advisory Board (CAB) Member	7	39%
Tenure			
	1-3 years	5	27%
	4-6 years	7	39%
	7-10 years	2	11%
	10+ years	4	23%

*Administrative staff include executive directors and program coordinators

Barriers to Care Coordination

All participants were asked about the role of care coordination in the continuum of care, specifically in relation to PLWH-OOC. In addition, participants were asked to identify barriers that may impede care coordination. Responses ranged from concerns about current HIV care being fragmented, to an overall insufficient understanding of the pertinent role that care coordination plays in outcomes for PLWH-OOC. Moreover, participants highlighted the complexity behind systems/processes of receiving HIV care and reported that the complex nature of HIV care systems, in and of itself, can serve as a preliminary barrier preventing individuals from accessing and receiving the care they need. This theme had the highest number of responses, suggesting that care coordination is a salient factor when considering care outcomes for both patients and practitioners:

> “Transportation, co-pays. They haven't said it like this, but the executive functioning involved in making sure that you're signed up for the right programs, like that you're on, ADAP, that your Ryan White is up to date. You know, and then remembering to call in your prescription three to five days before it's due so that you can either come pick it up or get it mailed. Like these are things that take a lot for some patients to be able to do every month, for example, for the meds. And also some people just don't remember appointments, don't have a way to keep track of appointments, or are too disorganized – well, to, you know, do that.” – Administrative Staff

> "The patient doesn't come into the clinic because, you know, I mean they don't have transportation or they, you know, there's all this paperwork that needed to be done that is not, wasn't done and they didn't know they were supposed to do it." – HIV Care Provider

Some participants noted that a lack of systematic processes/approaches to determining why patients fall out of care often serves as a salient barrier to effective care coordination and retention.

> "There is no structured process to assess as to why somebody fell through the gaps. There is no concerted effort, structure, or process, and I think that that is the first step that we've got to take. Now, do I know some of the key indicators that would tell us that either somebody is about to fall out of care or has fallen out of care? Yes, which means potential red flags that a patient is falling out of care, and let me preface this with falling out of care could also mean I am still somewhat engaged and coming to the clinic, but I'm not participating in my care." – HIV Care Provider

Participant responses also emphasized a lack of hospital-to-clinic coordination for patients with complex care needs as a salient barrier:

> "I would say there is a lack of support in some of the follow-up. We've had some people fall through the cracks. It's complicated, right, because we have patients, like, one is really sick and then she's a really – she's got 20,000 meds, and she's got some post-stroke changes, and just can't remember particularly well, and she ended up going to the

> hospital, and so we missed one pill tray because she was hospitalized. But then no one was tracking her getting back on the schedule, so then she was off her meds, because nobody was doing the pill tray…so, there was no tracking, and, yeah, she fell through the cracks." – HIV Care Provider

In addition, many participants identified a lack of flexibility and ease within systems of HIV care as a barrier that can impede the way care is coordinated and delivered:

> "I think everybody has some level of a logistical barrier, whether it's financial or transportation or geographic. But underlying all of that in the vast majority of patients that fall, tend to fall out of care – like truly fall out of care, I think is – one is access to the clinic in terms like lack of ease. Like an easy way for them to get an appointment. Straightforward, you know, timely, whatever." – Administrative Staff

Coupled with the already-complex nature of receiving HIV-care, participants also noted how existing systems of HIV care are typically not forgiving, thus making it difficult for one to re-engage and retain care after being disengaged:

> "We can start off with lacking access to transportation or reliable transportation. What I mean by that is even public transportation can be a challenge. Delays will cause the patient to be late for an in-person appointment, and then that appointment gets cancelled, and then the provider is not available and they have to try again, which then gets frustrating. The patient, then, ultimately gives up." – Administrative Staff

Some participants highlighted a lack of HIV awareness among medical providers as a primary barrier that compromises outcomes of care coordination and retention:

> “But again most – sometimes it’s the people who are caring for you that comes with the stigma, that stigmatize you. It’s not the people in the grocery store. A lot of times it’s the people who are taking care of you. I’ve heard some of the most idiotic stuff come out of the mouths of the medical professional with regard to my HIV care. So I’ll throw this all the way back to our educational system, our educational/political system. Because HIV isn’t going anywhere I personally don’t believe not a single medical professional should graduate from a college without beyond basic knowledge of HIV and HIV care.” - CAB Member

Others explained how insufficient and un-coordinated appointment scheduling/follow-up can negatively influence care outcomes:

> “And you know, Hep B and Hepatitis A vaccines have to be delivered. It's a series, right, and you get one at baseline and then you get one in one month and one in six months. I can't even tell you the number of times that patients never show up for subsequent appointments, because they just forget, or providers forget to order the vaccine or make them an appointment. And – if you come to me and you get a vaccine today, but I don't need to see you for five months from now, what happens is that you miss your – you might forget to come back in one month to get another vaccine. Because they don't make

> an appointment. There's no vaccine appointment in the system. And you can't just expect patients to remember." – HIV Care Provider

Participants also emphasized how the complex nature of referral systems between hospitals and clinics often stands as a barrier to effective care coordination between various modes of care. More specifically, responses noted how a lack of patient hospitalization communication/notification between hospitals and HIV care systems can further exasperate the negative outcomes of already un-forgiving systems of HIV care:

> "So, the in-patient provider is, like who the patient is hospitalized with, for example, and you – you caught them for the first time in six months. And as a provider with a full schedule, you just can't see everyone and at some point you – you would have to refer them to someone else or with MIH, but, like, then like who is the person that is following up with that? That would be their – their primary doctor. And they might not even know the patient was hospitalized right away." – HIV Care Provider

When asked about how – if at all – care coordination can impact the care delivered to patients, one participant noted that a lack of communicated health records can stand as a salient barrier to effective care coordination:

> "And I think that that's when I'm going to get the best care when my doctor can pull up and see everything, whether he works for [hospital] or [university] or [additional hospital] or whoever, he can see and they can discuss my care as a team. 'Cause I feel

> disconnected. I don’t feel like I have a full team. I feel disconnected ‘cause I’ve got to run all over the place to get you connected to my care. So that bugs me out.” - CAB Member

In addition to a lack of communication, participant responses also explained how referrals not being sent in from providers can also compromise the quality of care coordination:

> “I think it’s, like, very good once they have been put in, like, they will try to call them, and all of the numbers are available. But the referral not being put in is difficult because of their – there be like not many patients who get the referral, even though they might meet the criteria.” – HIV Care Provider

Care Coordination within MIH

Participants were also asked more specific questions about the state of care coordination within the MIH model. Additionally, they were asked about potential impacts that this state of care coordination may have in how the model functions, and in providing care to PLWH-OOC:

> “I think there are certain situations where I feel like it has worked out and then others where I've had the – I've thought that maybe they could help, but in general I think it hasn't really. Just because the coordination of care has been very choppy.” – HIV Care Provider

Some reported that MIH – in and of itself – can offer an additional encounter/interaction between a patient and a provider, and thus may increase the likelihood of a patient following up/continuing with care after an MIH visit. However, this additional interaction can often increase the burden of care coordination within clinics:

> “But – but it’s also, like, gives the patient – like, in that encounter, patients a lot of time have to, like, get labs, for example, and blood tests done. And just – just by the – having the tests done, the provider will have to call them, because they did the labs. Somebody will have to check those labs and tell them that either come back in or – or – or continue what they’re doing. So, I think it forces, like, an extra encounter, as well.” – HIV Care Provider

Several barriers to MIH care coordination were noted, including inadequate communication between mobile health providers and fixed clinic providers. These barriers were noted to compromise the way care is coordinated through the MIH model and, in some instances, also compromised the quality of care that patients receive. In addition, participants expressed that a lack of sufficient communication between clinics and MIH providers can also negatively influence the ability to reach and engage patients.

> “But then the second time around it turns out that they couldn't reach her. And part of the problem is, they were supposed to go monthly to also deliver her medications. So they couldn’t reach her and then I just didn't know about it...so then it just turns out that like she just wasn't getting her meds, which again, this sort of lack of communication was

> something that – that second visit that they couldn't get through to her to drop off even her medications [in the very least], like then I needed to know about it. So there is definitely some lack of communication that's going back and forth between sort of the providers that are delivering mobile health and the main providers who ware physically located only at [the HIV clinic].” – HIV Care Provider

> “There's a bit of a disconnect sometimes between me and the patient and the provider. If the patient needs to say, get their mammogram or just the routine screenings that we do for primary care, not HIV related necessarily, is that all getting done? Is it getting reported and communicated?” – HIV Care Provider

When asked about barriers that may have prevented successful care coordination, many participants reported that, in addition to inadequate communication, a lack of clear organization and leadership is likely to produce fragmented care through MIH:

> “Because I feel like even now, we’re struggling with tracking. We have people that are getting pill trays every month, but we don’t know how many. There is no clear leadership in the MIH program. It was basically kind of do this and no clarity about who’s coordinating or what the goal is. There was no coordination.” – HIV Care Provider

Finally, some participants emphasized how a lack of strategic/organized coordination can often pose a tremendous burden on patients, providers, and health systems:

> "So, I think that there's not been a clear organization or communication of, like, what is a routine follow-up, how often do they need appointments, who's making the appointments, who's putting in the referrals?" – Administrative Staff

One participant expressed how a lack of sufficient staff dedicated to MIH has posed a burden on already-exhausted providers within HIV care systems:

> "There's a lot of disjointedness because you have referring providers, you have mobile health providers doing the work during the day, but they also have clinic days and full clinic…So, I'm a little – labs roll in, and then I'm like – wait, I've got a full panel, and then I've got all these labs to address, and I get a little bit of a pushback from the others that, like, what are you doing with this patient? I was like well, like, technically, they're not my patient, this wasn't my lab, you know, but now it's falling on me to handle it because their provider, like, works a half-day clinic and can't here, or they're not looking it up, you know, because they're at [medical facility], you know? Like, so, it's – there's – there's been some – and I think that's one of the reasons the other providers don't necessarily wanna do mobile health." – HIV Care Provider

> "I think the referral system is OK. I just think that the follow-up system, once a patient has been referred into MIH, needs to be a little bit better." – HIV Care Provider

> "Getting a referral to MIH but then not getting, like, their phone number not working in their chart. That's a problem we have all the time." – HIV Care Provider

Strengths of MIH

While the complex systems in which models to deliver HIV care exist can often prevent the potential impact of these models, results from this study largely highlighted how models of HIV care delivery – such as MIH – can eliminate barriers that commonly impede care coordination, thus enhancing the quality of care delivered and received.

> “Patients left to their own devices I feel are more confused about the way they should care for themselves when they're not in a hospital or a medical setting. When they're home and they have to sort their pills out themselves or inject themselves with their medication, they appreciate a medical individual or EMT or somebody coming to them showing them how to do these things, doing them for them, giving them that information that they just would not have gotten, or the clarity that they would have not gotten if they went and did it on a Google search engine, you know?” – Administrative Staff

Many participants revealed the ways that MIH has promoted holistic and comprehensive care that is better suited to meet the dynamic needs of PLWH:

> “So I think we do a good job of making sure that that industry gets the holistic care opportunities. Because I mean it's all up to them on whether or not they want it. Because we can see something and we can put it in the referral and we can make those connections. But the patient might not be willing to go through all of that.” – HIV Care Provider

Other responses noted how the MIH model has been a preliminary facilitator to providing care for those who would otherwise be out of care due to existing barriers, such as transportation and financial constraints:

> “I think that it's like highly necessary, especially just because we have such a poor public transportation system in Atlanta or in Georgia in general. And we have a lot of patients that live further out who have transportations difficulties and/or are not able to like take multiple MARTA buses or trains or whatever just to get here. And so I just think that this actually allows us the flexibility of particularly seeing people who are much more vulnerable. Maybe they have like, they have some disability that prevents them from coming in and/or age-related issues. – HIV Care Provider

> “But even for our patients that are dealing with fixed incomes, some may have to pay for transportation if they came to the clinic. Well, MIH, we're avoiding them spending money on going to spend on transportation, they can put it on their bill or food, because they're coming out to them.” – Administrative Staff

> An advantage is transportation, no worries about transportation, which as you know is an issue that a lot of our patients face. And then there's the whole stigma piece. And then there's the sort of meeting patients where they are. I think those are all, you know, ways to keep people engaged in care or get them back into care. – HIV Care Provider

One participant mentioned that by eliminating some of these existing barriers, MIH also allows for more accountability and thus may strengthen the likelihood of an individual staying in care:

> “Because it makes it two-sided, but it gives the patient just a little bit more accountability. Because now, okay, you missed so many appointments because of transportation. Now we're bringing it to you. All you have to do is wake up and get dressed and have your appointment. So you've already had so many excuses, we're here now. So it just gives them – hold them more accountable.” – HIV Care Provider

> I think we do a very good job with keeping those that are in care within care. – HIV Care Provider

Some HIV care providers highlighted how MIH visits have prevented existing patient conditions/illnesses from further escalating:

> “And you know, sometimes it's like really simple things that we will kind of encounter that could potentially lead to better health outcomes like you know, maybe their just house is really cluttery and we just help them find a place to keep their meds or, you know, have a little bit of a semblance of organization that might potentially help them stay a little bit more, you know, on track in terms of their endurance to care. And from a patient perspective I think it just, you know, I think the just convenience of not having to come out – you know, most of our patients have transportation challenges whether that's, you know, they have to take Marta and you know, several Marta lines, and that can be

> hours of their time. And you know, some people just financially it's tough with, you know, gas prices going higher and, you know, that kind of thing. And so it's, you know, it's a nice perk to have somebody actually come to their homes. So I think in general the overarching theme of, or you know, reception of it, has been positive, a positive experience for both sides." – HIV Care Provider

One provider highlighted the influential role that MIH has had on patients:

> "The patients that I have referred over have benefited significantly from it. To be more specific, there have been some benefits related to HIV and then not related to HIV care. So for the HIV related care, the MIH has helped with making sure that patients have their pill tray set up and correctly set up…Then we can also do control, monitor their response to ARVs in people who have limited transportation or who have, you know, cognitive impairment or live by themselves, that can't come to clinic that easily. Related to non-HIV care, I have two specific examples. One is this patient who had a very bad insufficiency ulcer that had gotten infected. And he needed very close wound care. And usually we do that at clinic but it's hard for him to come three times a week to the clinic just to do wound care. So I asked MIH if they could do that and they did. And they did an even better job in terms of wound care than what I think we could have provided in clinic. The provider who saw this patient put, it's called a uniboot, to improve the healing of the ulcer. And it worked. So and then she took a picture. She put it on the media tab. I'm able to see it from the clinic, to see how it's looking, the progression of the ulcer. So that's one specific example. The other is this patient who has PML and it's very hard for

> him to speak. But in one of the visits from MIH the provider, his speech was even worse, which triggered hospital admission and then which required, you know, steroids because he was developing immune reconstitution syndrome from the PLM. Without the MIH provider’s constant visits and noticing this change, it would have been missed, because we wouldn't have seen him so early.” – HIV Care Provider

Another HIV Care Provider noted how MIH has been a critical asset for providers with heavy case-loads and demanding schedules:

> “I think it just makes my life much easier...I feel more at ease that, you know, someone is looking after my patient when I can’t.” – HIV Care Provider

Many providers emphasized how MIH has enhanced care coordination by helping patients stay caught up with the extensive paper-work and administrative work required to remain engaged in HIV care:

> “One of the providers that I know well has like brought patients documents back to clinic so that they can enroll in, or do their financial counseling, or has gone out and said this is what you're going to need. But I think there has definitely been some like bringing documents back to help patients enroll in things, or Project Open Hand forms, things like that. Which is good.” – HIV Care Provider

> “So some of our patients – well, all of our patients, in order to come to the clinic have to submit Ryan White documents; they have to certify once a year. And because MIH is going out to the home, they collect some of those documents and bring them back to the clinic. So we have never had an issue where documents were misplaced or lost. Once they finish with the patients for the day they immediately bring the documentation back to either the education department or they give it to the social workers to file.” – HIV Care Provider

Others shared that MIH offers a more holistic approach to care delivery than traditional fixed clinics. As such, participants emphasized how this model has been especially beneficial among patients who have co-infections or additional illnesses un-related to HIV, such as diabetes:

> “I think it's great for diabetes monitoring and people who can't come in. Hypertension monitoring. Post-hospital follow-ups, when people are too weak to come into clinic but really need to be checked out, you know, have a physical exam and get their vitals done.” – HIV Care Provider

> “Yes. Huge, huge intervention with diabetes. Like, I mean, you show somebody how to use their insulin or how to store it or find out that they’re not storing it correctly – that can be a game-changer.” – HIV Care Provider

When asked about MIH services that have been especially effective and useful, many participants expressed that pill-trays administered through MIH have positively influenced medication adherence:

> “Yes. I mean I definitely think that the pill trays are super-helpful…Because you know, we have pill tray services at the clinic, but you have to have an appointment and you have to – the way it works is, you make your appointment with the nurse educator and then you have to pick up your meds the day of your appointment. You have to stand in line at the pharmacy. You have to have called them in.” – HIV Care Provider

> “Like, it can be helpful to have a creative solution to problems with adherence.” – HIV Care Provider

> “So I think that pill trays are immensely helpful. And I also think that when an MIH provider goes out and looks at pills, if patients on pill trays looks at them, or even just asks to see their meds, they can pretty quickly figure out how a patient's adherence is, even before they get the viremic labs back. You know?” – MIH Care Provider

In addition, participants highlighted how MIH visits can make care more convenient for patients and enhance the ability for patients to connect with their providers – both of which are often difficult to achieve in traditional fixed clinics:

> “By not being in a clinic setting, it's less likely that a provider will get pulled away, or there is something that happens in the clinic that interrupts the care. Making it more convenient is probably part of that patient-centered piece.” – CAB Member

One-stop Shops Enable Care Coordination

Responses from interview participants emphasized the importance of providing and coordinating care that is 1) feasible/easily accessible and 2) comprehensive, inclusive of services outside of traditional HIV-care. Participants commonly referred to this idea of comprehensive, feasible HIV care as a “one-stop-shop,” and also noted how this “one-stop-shop” model is especially useful given the complex, shifting circumstances in which PLWH-OOC often live.

> “Because I feel like it's so important to put it all together for people, especially with this population. They can't just go walking and bouncing around to all these different offices.” – Administrative Staff

> “And the other thing about providing HIV care is that so many of my patients would never been in primary care. Some people really say like, ‘the best thing that ever happened to me in a weird way was that I got HIV. Because now I'm getting like my diabetes checked and I'm getting my cancer screenings and I'm getting all the other things that I never – I'm getting my vaccines’. So yes, so I think – I love the model that we have at the [HIV clinic]. I can't imagine really just working in a – like a practice that only does HIV.” – HIV Care Provider

> “Like one thing about [health center] is they handle other stuff too like mental situations and they have dentists there. And so you don’t know why I’m there.” - CAB Member

One participant noted how the complexities of providing and receiving HIV care, such as within the referral system, can be minimized by using models that function as a “one-stop-shop,” such as through mobile clinics:

> “I think referral, if not done correctly or in a timely fashion, could definitely be causing a disadvantage…It’s a lot of referrals to a lot of places and a lot of appointments to keep up with versus having the mobile clinic which can create a process where you can be able to see all of that in one day. You eliminate a barrier of missed appointments. You can’t expect and make the appointment for me to see the doctor and assume I’ll just see the case management another day or…So referral process and the many times referrals can get lost in the transition. So that’s something else that you can count as a barrier. Me personally I also feel like in clinic the referral process is a lot easier.” - CAB Member

Co-localizing services was also a prevalent suggestion for enabling holistic, “one-stop-shop” systems of care:

> “I think the more that you can try to co-localize specific services, you'll find that people are, I think, willing – because it's just – it becomes a one stop shop, right? It's convenient.” – HIV Care Provider

> “And so I think that certainly co-localizing services helps, right?” – Administrative Staff

Coordination of HIV and Non-HIV Care

Additionally, participants were asked specific questions about how – if at all – the integration of HIV care and other services/forms of care (i.e., primary care, specialty care, etc.) can influence outcomes of care coordination, specifically for PLWH-OOC. Responses namely expressed the necessity to integrate forms of sub-specialty care into traditional HIV care, and also identified specific sub-specialty services that they reported as being the most salient for PLWH-OOC:

> “That's one that I do have issues with in a lot of people where their HIV is not the problem; it's other things like diabetes.” – HIV Care Provider

Some participants expressed how, in a potential HIV-care visit, exposure to forms of care outside of traditional HIV care can often positively influence the comfortability of patients receiving care:

> “We need to think about dentists and eye doctors. The one thing that could be most valuable on a mobile clinic or anything like that, just even if it’s like an exam done and then they provide you a referral to a specialist, is vision. A lot of us don’t understand how blind or our vision isn’t the best until we take an exam…I’ll say for myself it took a really long time until I was able to go to my doctor and get the eye exam done. I just started wearing glasses last year. So I was like wow. All these years I’ve been not able to

> be able to see. But you don’t know until the doctor – until you’ll be able to get an exam. Same for the dentist, even if it’s a check in its just on your teeth and your gums, things like that they will be able to provide you a level of kind of like they care more about me than just my HIV. Not a full exam but just an eye exam, just an examination of like the mouth, ear, the joints making sure like your movement, just something like a physical basically pretty much.” - CAB member

When asked about integrating and coordinating sub-specialty/primary care with HIV care, participants highlighted how an influx of services may pose an additional burden on already over-exhausted systems of HIV care, and that we must be intentional about integrating services that are of the most importance for PLWH:

> “I think like I was mentioning and we talked about the limited space kind of…So as long as they’re able to do all the vitals or in depth test, I know they won’t do EKGs or dental or anything like that. But as long as they’re able to do the vitals, collect blood, able to blood sugar levels, all those things that I – ‘cause loading it too much can kind of have people jumping up on top of each other and stuff like that.” - CAB member

One participant noted how care for PLWH has shifted drastically over the past decade – transforming from an emphasis solely on infectious disease, to a focus on services required to manage chronic illness:

> “In fact, when I first started at the [HIV clinic], it was really, it was very much infectious disease. And now the model – not the model, but the patients have shifted to where for many, many people their primary problem is not their HIV; it's their diabetes or their heart failure or whatever. So we've become a lot more internal medicine-y than we ever were before.” – HIV Care Provider

Strategies to Improve the Coordination and Delivery of Care for PLWH-OOC

Throughout the IDI, participants were asked to provide any feedback, suggestions, or recommend strategies that could be used to improve care coordination and delivery outcomes for PLWH-OOC. Responses highlighted specific ideas about how to enhance care coordination and delivery relative to specific models of HIV care - such as the MIH program, mobile clinics, home-based care programs, as well as traditional fixed clinics.

> “Follow-up and outreach. Pretty much that. Now, if someone maybe is delegated to do that – I know maybe the medical staff may not be able to reach out to every patient or nurse practitioner may not be able to reach out to every patient, but there should be someone – maybe a liaison or someone in between – that could say, ‘Hey. Oh, wow. Mister [name] hasn't been back. He's supposed to be back – okay.’" - CAB Member

Many participants highlighted the influential role that peer navigators can play in engaging and retaining PLWH-OOC in care.

“And peer navigators I think could also play a really big role in – and I do think they have the bandwidth to do so at [the HIV clinic]. They could play a really big role in looking at those patients, finding those patients that have been out of care.” – HIV Care Provider

“I would say the first steps would be – I would say start with a peer to make you feel like you have someone to be able to support you along the way. Also you can have easier conversations up front with them to help identify barriers, help identify treatment plans or support plans, have people that are there so that when it do come time to see the care team you already are in a sense of a level of being comfortable. You’re in a sense of being ready for treatment. And then you’re able to explore a different route with your peer to where they can like navigate these other services so it might be mental health services and things like that. So I feel like the introduction at home to be always with maybe that first appointment being with a peer or someone from the care team besides the doctor.” - CAB Member

“I think MIH or any home-based care should definitely have a patient or peer navigator, a linkage patient navigator would be beneficial to have to the team. Because the person who scheduled appointments and made the calls, he's the coordinator, but he doesn't do all the follow up like a navigator could do. And that would also allow the social worker to focus on the intense cases, kind of what we do at [the HIV clinic] now; my social workers do the intense cases, my patient navigators do the cases that just need support.” - Social Worker

In addition, participants namely reinforced the importance of including services outside of traditional HIV care in mobile clinics, home-based programs, or mobile-integrated models of health:

> "Again – and the mobile clinic, it cannot just be for, I feel like, HIV. It could be for whatever your health condition, and you feel like you don't feel a certain way, 'We can refer you here. While you're here though, let me take some vitals, okay?' That type of care." - CAB Member

> "Some of the most important aspects if being able to have members from different teams present so that you can still have that feeling everyone is involved in my treatment plan. So being able to have different members present, different options for different exams there. Maybe information, pamphlets or information booklets or things that will make you aware to help you with like living stigma and things like that that can be present at the clinics." - CAB Member

One participant provided feedback about how home-based care models can systematically improve care coordination outcomes:

> "I think that home-based people should process these patients in the system so that they will know which doctors they went to before, prior to the doctor they're going to now, so that they can keep together the medical information for each patient." - CAB Member

Other participants stressed the importance of having a systematic plan/approach to care, and also highlighted the potential benefits in doing so:

> "I think one of the things that could really make a difference, is having a, either an assessment or a plan. Me personally I am a planning person. So if I have a plan and it's written down or I could have or just be knowing that I'm a part of the plan. So creating a support plan that would look like something that's not just about what the provider thinks is the best treatment. It should be like, 'well what do you think about this? How do you feel about x, y and z?' So I feel like that would be the biggest thing to make you feel like somebody in the office, mobile clinic, at home that 'this is my plan and I'm a part of it' kind of thing versus like 'this is the plan. This is what we're going to do.' I think it gives people the ability to feel more comfortable, feel more willing to be a part of it and feel more, just more free to be able to say 'I'm getting care. I'm doing well. My care is important to the team but also they made it how, they have made it feel like its important to me as well.'" - CAB Member

> "I think you can, like, try to make it standard of care. Like, you can make a, like, an idea you could have, for example that, oh, if a person has had two visits in two months, you can have, like, a pop-up that says, 'how often have you thought about this patient's visiting MIH?' or integrating it into the EMR. And then, as I said, like, awareness but, like, in multiple, like, avenues, like, having, like, in-person awareness, emails, fliers, things like that. One option could be screening patients, like, as part of the EMR. If they haven't been in care in the past six months, you can have a pop-up in the EMR, as well,

> that says, oh, have you considered MIH for this patient as an option?" – HIV Care Provider

In describing potential approaches to re-engaging PLWH-OOC into care, participants explained the importance of understanding why individuals fell out of care before determining which model of care would be best-suited for them:

> "Well I think we first have to – if we know that the person is out of care I guess we have to have one approach for those people we know who are out of care and then another approach for those people who we want to know that, if you're out of care we're here for you. Give us a call. Let us know how is best for us to help you. We want to know – something kind of way where people, we involve people in their decision making and we're just not saying – 'cause people are so funny. You know what I mean? So sometimes you have to feed them with the long handle spoon and make them feel like they're the ones making decisions but you know that in a sense you're guiding them to the decision." - CAB Member

One participant stressed the importance of equipping PLWH-OOC with knowledge of services, resources, and support systems during their initial re-integration into care:

> "Yes. I actually think when people first – even when people first get into care they just should have a sheet of paper with a list of who you should contact first and what services that they have to offer. Because that way they know. And they can keep that piece of

> paper with them for as long as they want or need, even if they aren't in care anymore" - CAB Member

Similarly, another participant emphasized how, given the complex circumstances that PLWH-OOC often live within, it is unrealistic to expect everyone to be able to coordinate their own care following initial exposure to HIV care - thus further validating the perceived usefulness of giving patients an information sheet that provides contacts and resources for essential services.

> "Right. And that's why a lot of people are not in care because it's just about impossible. I mean because if I'm homeless you have to travel with what little bit is possible from point A to point B and I for one ain't writing down in no journal about no appointment or nothing else that somebody else can read. Especially if I'm a very private person. Yeah. That's kind of hard." - CAB Member

Finally, one participant highlighted the importance of completing all forms of paperwork and/or documentation prior to the end of a care visit as a primary strategy for ensuring care coordination and increasing the likelihood of follow-up visits:

> "Yep. If an appointment is being scheduled while on the mobile clinic, that should be reverted to telehealth while that person is sitting there. The provider referring should make sure that all the paperwork for that next appointment is filled out. It makes it easier for the person. They can just pull up the screen and start that telehealth." - CAB Member

Discussion

The Southern region of the United States is primarily known for its hospitality and influence of rich Southern culture. However, driven mainly by overall poor healthcare access, extreme poverty rates, high levels of HIV-related stigma, and poor health outcomes for PLWH, the Southern region of the US is also home to states that have the highest rates of HIV infection [3], followed by some of the worst HIV death rates [4] in the entire country. As such, it is critical that HIV care systems are structured and facilitated in a manner that prioritizes the needs of PLWH, inclusive of PLWH-OOC. This study helps address a critical gap in understanding the role of care coordination and integration in the continuum of care, ultimately revealing perspectives and strategies that intend to improve outcomes for PLWH-OOC. Our sample of 18 participants – including HIV care providers, PLWH, CAB members, social workers, and program coordinators – represents perspectives from a diverse range of individuals that interact with the HIV care system in different ways. As such, the sample for this study allows for a deeper, more nuanced understanding of the dynamic ways in which care coordination can influence outcomes throughout various models of HIV care.

The most prominent results from this study reveal that care coordination plays a central role in outcomes for PLWH-OOC. An emphasis on the role of care coordination was evident throughout all major themes uncovered in this study, which included: factors influencing care coordination, the integration of HIV care, and strategies to improve care coordination. This finding is not novel, as existing literature has continuously highlighted the ways in which fragmented systems of care can negatively influence one’s ability to engage and retain HIV-care [76]. Findings from this study reveal that although most individuals who interact with systems of HIV care are aware of and affected by insufficient care coordination. Strategies addressing existing systems of care coordination need to be improved. Results revealed that this may largely be due to a lack of leadership, structural organization, and understanding about the aspects of care that are compromised when systems of care delivery are fragmented. In addition, a vast majority of the existing research within the diaspora of HIV care has aimed to investigate the impact of using diverse models of HIV- care as tools to re-engage PLWH-OOC. Participants in this study, however, uniformly noted that these models – or any – by themselves, are not sufficient in reaching, engaging, and retaining PLWH-OOC in care. Although there is a rich variety of research analyzing the impacts of varying models of HIV-care, there is a clear gap in understanding pertaining to how the implementation of these models influences the care delivered to patients. More specifically, it is clear that innovative models of delivering HIV-care – MIH, mobile clinics – are effective in and necessary to re-engage and retain PLWH-OOC, but findings from this study highlight that they require additional analysis/attention, staffing, and resources to maximize their impacts and ensure care coordination occurs effectively.

Participants provided valuable suggestions on how to improve the way care is coordinated in HIV care systems, one of the most common being through peer navigation. The idea of having a peer navigator throughout the continuum of care was widely encouraged by participants in this study, serving as evidence of the critical role that peer navigators can play in helping individuals navigate and stay engaged in care. Participants namely expressed the importance of peer navigation in models of HIV-care that are outside of traditional fixed clinics, as these models can require interaction between different health systems, which can be complex and often increase the chances of falling out of care. This finding is supported by the current literature, which highlights how peer-driven interventions (PDIs) are increasingly being recognized as effective mechanisms to bridge gaps and barriers to HIV care and facilitate collaboration among a variety of healthcare services [69]. A widely successful iteration of PDIs is the peer integration model, which involves integrating peers into multidisciplinary healthcare teams with the aim of linking hard-to-reach clients into care [71]. In this model, the peer navigator serves as a bridge between PLWH who have trouble accessing care and retaining treatment, and healthcare teams/programs that may not have the capacity to adequately address social determinants that serve as barriers to HIV care and treatment [71]. The existing literature surrounding peer navigation, coupled with the findings from this study, reinforce that integrating systems of peer navigation into HIV care systems can strengthen the coordination and delivery of care, and ultimately prevent an individual from falling out of care.

Another primary finding from this study reveals the importance of offering a comprehensive range of medical and social services [that are not just exclusive to HIV-care] in models of HIV care delivery, especially when aiming to prevent individuals from falling out-of-care, or when re-engaging those that are already out of care. This aligns with the existing literature surrounding care retention outcomes among PLWH-OOC, as it is reported that the likelihood of falling out-of-care is higher among those who have previously engaged with and discontinued care [18], and thus care models must be designed to address the barriers that may have initially influenced falling out of care. Participants in this study also highlighted how, given the shifting age demographic of PLWH, – largely due to recent trends of significantly increasing the availability of ARVs during the past decade – HIV is no longer the primary health condition of concern for many PLWH. This finding is widely addressed in existing literature, and it has been reported that as people with HIV age, they often require services and care for co-existing chronic illnesses and health issues outside of HIV-care [5].

It is important to note that the complex nature of HIV care systems has a foundational and primary role in determining the success of models of care delivery, such as in MIH. MIH, in and of itself, has proven to effectively eliminate a large variety of barriers that may prevent PLWH-OOC from receiving care – transportation, stigma, comfortability – and also has the potential to serve as a tool to enhance care coordination. However, the fragmented HIV care systems in which models like MIH exist often impedes the ability of these model to function and deliver care as they were designed to do so. For example, this study revealed that a common care coordination barrier in the MIH model lies within the referral system. The referral system is not exclusive to MIH and requires coordinated functioning throughout varying systems of care delivery, such as hospitals, HIV clinics, and providers putting in and/or receiving referrals. As such, we cannot accurately analyze the success of models like MIH without first analyzing the role/impact of the systems in which they exist. This finding is directly supported by the existing literature, as it is widely noted that although varying levels of integration exist within and between HIV service delivery organizations and funding agencies that provide prevention, medical, and support services, the vast majority of these activities are uncoordinated. Experts in the field explain the detrimental effect that this insufficient coordination can have in systems of care delivery when stating that "fragmentation and disparate approaches to these critical activities and surveillance methods undoubtedly hinder effective engagement in HIV care efforts and lead to suboptimal use of limited funds and resources" [77]. In addition, although current research initiatives often aim to evolve and strengthen coordination between modes of care delivery for PLWH-OOC, there is little research pertaining to the relationship between the reason that an individual is out of care, and the effectiveness of the care model they use to re-engage in care – which may also heavily influence the perceived success of models like MIH.

Interview participants’ ideas about ideal systems of care to re-engage and retain PLWH-OOC highlighted the need for models to include care for medical needs/conditions that are outside of HIV, such as for co-infections, chronic illnesses, and routine check-ups. Study respondents stressed the necessity of developing HIV care models to be seen as a “one-stop-shop” in which individuals are able to receive all their care in without having to go back and forth between clinics, hospitals, and health systems. Not only does the idea of this “one-stop-shop” concept support results from this study, but it is also supported by existing literature, which states that offering a comprehensive array of health services can eliminate the barrier of having to seek different forms of care, which can often prevent individuals from giving their HIV care the attention that it needs [45]. When asked which forms of care would be most salient to integrate into HIV care models, participants shared that basic care for diabetes (such as blood tests), dental hygiene checks, eye exams, and mental health services would all be valuable components to an HIV-care model designed for PLWH-OOC. By offering services outside of traditional HIV-care, these models can incentivize PLWH-OOC to seek care for other conditions through the model and simultaneously expose individuals to the potential of re-engaging in HIV-care. Moreover, participants in this study highlighted that models of HIV-care should be developed relative to the people they intend to serve.

Although this study employs perspectives from a diverse range of individuals that interact with the continuum of care, this study population may not be representative of individuals that receive or provide HIV-care in other cities, clinics, or hospital systems outside of Atlanta. While our sample of 18 participants aimed to encompass those who engage with HIV-care in Atlanta, the limited number of participants who were gender minorities or young adults limits the generalizability of study findings. For example, younger adults with HIV may be more likely to engage with non-traditional, unique models of care delivery, whereas middle-aged and older individuals may be more inclined to support and continue using models that are well established and more standard. Therefore, the results of this study may not be indicative of how models of HIV care delivery and coordination are perceived among PLWH of all ages. Additionally, the participants in this study that identified themselves as PLWH were all currently engaged and receiving care at the time of this study. While many of these participants shared their experiences of falling out-of-care in the past, the preferences of those *currently* out-of-care may be different from those who *previously* struggled to remain retained in care. Additionally, it is important to mention the methodological limitations of convenience and snowball sampling. Using convenience and snowball sampling allowed this study to reach a diverse range of individuals and extend the variety in participant characteristics/roles, but it may have prevented this study sample from reaching and including key informants who are not necessarily in the same network as members of this study.

A critical strength of this study is its in-depth analysis and focus on PLWH-OOC, a population that often bears the highest burden in accessing health care and maintaining positive health outcomes. On a broader level, future research should aim to further understand how different models of HIV-care influence retention and engagement outcomes for PLWH-OOC. More specifically, future research initiatives should aim to expand the scope of understanding care coordination by developing research projects that include additional key informants, such as emergency medical technicians (EMTs), financial administrators, and linkage specialists. In addition, future studies should investigate the relationship between the implementation of HIV-care models and how/if implementation can influence care coordination outcomes within these models of care delivery. While this study offers rich insights about the critical role of care coordination in the continuum of care, – especially for PLWH-OOC – future research much further evaluate how care is coordinated in a diverse range of HIV care delivery models, and seek to understand differences in outcomes for PLWH-OOC among these different models of care. Finally, it is paramount that future research in the HIV care field formatively understands and analyzes the ways in which existing HIV care/health systems function, as well as the extent to which the foundational makeup of these HIV care systems may influence outcomes of models of HIV care delivery.

Chapter IV: Conclusion & Recommendations

Conclusion

Fifty percent of PLWH in the US are not engaged or retained in HIV-related medical care [1]. The Southeast region of the US is considered to be the epicenter of the US HIV epidemic, largely due to widespread rates of HIV incidence and prevalence, coupled with existing systems of oppression. Using a representative sample of PLWH, HIV care providers, administrative staff, and CAB members, this study aimed to 1) understand the role of care coordination and sub-specialty care within multiple modes of HIV-care – such as mobile-integrated health, mobile clinics, home-based care, and traditional fixed clinics – and 2) identify strategies to improve care coordination and strengthen HIV care engagement and retainment among PLWH-OOC. Given the dynamic and shifting needs of HIV care systems, coupled with the unique experiences of individuals who receive and provide HIV care, this study found that there is no "perfect solution" or "one-size-fits-all" approach to delivering comprehensive and coordinated HIV care. Although most participants considered the integration of sub-specialty care into HIV care as crucial in ensuring sustainable health outcomes across diverse contexts, some also emphasized the necessity to address and develop long-term solutions to coordination challenges within the existing HIV care system before taking steps to expand and include more services.

Despite these differences, participants uniformly expressed the exigent role of care coordination in engaging and retaining PLWH-OOC into HIV care, and also highlighted that health systems must be organized in a way that allows HIV care to be delivered and received as easily as possible if efforts to prevent individuals from falling out of care are to succeed. In conclusion, this study found that HIV care systems must employ strategies to address *both* the existing discrepancies in HIV care coordination, as well as the pertinent role of comprehensive/ sub-specialty care in meeting the needs of PLWH-OOC. Moreover, this study highlighted the salient interplay of care coordination and sub-specialty care in relation to HIV care retainment outcomes among PLWH-OOC. The findings of this study have implications for US healthcare systems, HIV clinics, PLWH-OOC, and the US HIV epidemic.

Public Health Implications

Findings from this study provide diverse insights regarding the role of care coordination, specialty care, and models of care delivery in the continuum of care, specifically for PLWH-OOC. The unique experiences and perspectives revealed from participants in this study offer a variety of strategies for healthcare systems and HIV clinics to improve HIV care delivery and reach/retain PLWH-OOC. First, clinics should ensure that HIV care is delivered in a manner that promotes integration and coordination, ultimately leaving little to no room for someone to fall out of care. As such, effective care coordination can serve as a preventative measure for individuals vulnerable to falling out of care. Furthermore, HIV clinics and models of HIV-care delivery can employ a large range of strategies – creating a system of standardized communication among providers, patients, and administrators, offering a comprehensive array of medical and social services outside of traditional HIV-care, developing a systematic approach to identifying and reaching individuals who are out-of-care – to improve the coordination and delivery of HIV care, ultimately aiming to re-engage and retain PLWH-OOC into care.

In addition, the emphasis on care feasibility and comfortability revealed through participant interviews suggests that clinics' and health systems' allocation of resources to strengthen care coordination or offer a more comprehensive array of medical services would be worthwhile. The qualitative findings from this study can inform the design of care coordination within health systems and also allow HIV clinics to deliver care in a manner that corresponds with the perspectives of PLWH-OOC. Finally, the unique and novel suggestions for care delivery/coordination suggested by study participants – ranging from integrating peer navigation into HIV-care systems to offering dental services – provide clinics the opportunity to maximize their existing resources/systems in a strategic way that accounts for the pertinent needs of PLWH-OOC. In summary, findings from this study highlight current gaps/barriers that impede effective care delivery and coordination within models of HIV care delivery, and also offer strategies for how health systems can navigate these barriers/gaps and ultimately increase the number of individuals that are engaged and retained in care.

If HIV clinics implement the strategies suggested from this study, successful care coordination – equipped with a comprehensive array of specialty services – may prevent individuals from falling out of care, and also re-engage those who have already fallen out of care. After being reintegrated into care, PLWH-OOC would have the ability to interact with coordinated, holistic forms of HIV care and be exposed to retention tools that allow them to stay in care, adhere to ART, and ultimately achieve and maintain viral suppression. By doing so, PLWH-OOC will be able to access HIV care that is coordinated and successful in addressing a variety of health needs, thus increasing the amount of PLWH who are in care and virally suppressed, and consequently reducing HIV transmission throughout communities. Given the prevailing and disproportionate role that PLWH-OOC have in the HIV epidemic, specifically in relation to accelerating the likelihood of HIV infection, identifying and implementing strategies that improve the coordination and holistic delivery of HIV care may ultimately lead to improved outcomes within and throughout the HIV epidemic in the US.

Future Directions

Given the dynamic and interdisciplinary needs of PLWH-OOC, future research should continue to investigate the ways in which care coordination outcomes differ among models of HIV-care delivery, and how these coordination outcomes influence the care delivered to and received by PLWH-OOC. As such, future research should aim to further analyze how different models of HIV-care influence retention and engagement outcomes for PLWH-OOC. In addition, research in the future should further validate and critique findings from this study by implementing studies of this nature in contexts outside of the Southeastern US, and with differing models of HIV-care. Doing so will not only increase the external validity of study findings, but also ensure that HIV care coordination and access to sub-specialty care are targeted to address the individual/prospective contexts in which they exist. Finally, future research initiatives should employ perspectives and experiences from larger and more diverse populations if efforts to standardize HIV care coordination and ultimately increase retention among PLWH-OOC are to succeed. Irrevocably, prospective studies aimed at re-engaging and retaining PLWH-OOC should account for the foundational role of care coordination and access to sub-specialty care in influencing health outcomes for PLWH and PLWH-OOC. The findings and strategies shared in this study can also be applied to future research that investigates barriers to care retention among PLWH-OOC.

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Appendix A:
In-Depth Interview Guide – Providers/Administrative Staff

Introduction

As you know, patients fall out of HIV care for several reasons. This study aims to explore the feasibility and acceptance of two new models of community-based HIV care, home-based HIV care and mobile HIV care, and their effectiveness in retaining people with HIV relative to traditional fixed clinic models like the Grady IDP or Emory ID Clinic. Given your role as a healthcare provider/administrator involved in [insert model: home-based HIV care or mobile clinic care], we are interested in hearing your perceptions of how well this model works and how we can make it work better to meet the needs of people with HIV who are out of care, help retain them in HIV care, and improve their overall health and wellbeing.

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 mention patient/individual identifying information, 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?

[Turn on e-recorders]

Warm-up Questions

What is your current role at Emory/Grady?
- How long have you worked in this capacity?
- Have you worked in any other capacity for the same organization?

What is your role as it relates to the [insert: mobile HIV clinic or home-based HIV care program (MIH)]?
- How long have you worked in this capacity?

Community-based Care Model: General

Tell me your general thoughts about providing HIV care via [home-based care/mobile HIV clinic].
- Probe: capacity/role in addressing acute care needs like opportunistic infections, HIV treatment, primary care (inclusive of co-morbidities like hypertension, diabetes), vaccinations and other preventative primary care

Do you think it is more or less effective than providing HIV care via the fixed clinic [The Ponce Center/Emory ID Clinic] to people living with HIV who are out-of-care? Why? What do you see as advantages and disadvantages?

- Effectiveness in reengaging and retaining PLWH who are out-of-care in care? Effectiveness in achieving/maintaining viral suppression?
- Are there subgroups (i.e., unstably housed, with mental health disorders, substance use disorders, physical challenges, high/low community support, high/low HIV diagnosis acceptance) that you have found this model works better for than traditional fixed clinic models? Are there subgroups that this model works less well for relative to the fixed clinic model? Who and why?
- How could this model be improved to better help PLWH stay in HIV care and achieve and maintain viral suppression?
- How has the COVID pandemic impacted the care provided via this model over time?

What are some of the most common barriers to HIV care access/retention that patients have reported to you?

How effective is this model [mobile HIV clinic or home-based HIV care] in overcoming commonly cited barriers to HIV care retention and viral suppression? How could this model be improved to better address common barriers?

Community-based Care Model: Specifics

I'm now going to ask you more specific questions about this care model. In our prior work, we heard from several key stakeholders that for community HIV care models to be effective their environments must be physically and emotionally safe for patients and care providers, enable provision of private, confidential, compassionate, and coordinated care, foster patient support, and be convenient and accessible. My next set of questions will ask you to reflect on how well [home-based HIV care or mobile HIV care] exhibits these characteristics and how we can improve them to do so.

On a scale of 1-10, where 1 is the least effective and 10 is the most effective, how effective is [mobile HIV clinic or home-based HIV care program] in…

- ensuring patient physical safety, emotional safety and/or comfort? Why? How could this be improved via this model?
- ensuring provider and staff physical safety, emotional safety and/or comfort? Why? How could this be improved via this model?
- ensuring privacy/confidentiality of HIV care? Why? How could this be improved via this model?
- providing convenient, easy, and accessible care? Why? How could this be improved via this model?
- demonstrating and providing support to patients? Why? How could this be improved via this model?

- demonstrating compassion and providing compassionate care? Why? How could this be improved via this model?
- building trust/rapport and a personal relationship with patients? Why? How could this be improved via this model?
- providing non-fragmented HIV care (i.e., care that is integrated into the larger health system?) Why? How could this be improved via this model?
- providing HIV support services? Why? How could this be improved via this model?
- fostering provider and staff understanding of patient's home situation/environment inclusive of barriers and facilitators of care? Why? How could this be improved via this model?
- scheduling, reaching, and notifying patients who were previously out-of-care of upcoming appointments? Why? How could this be improved via this model?
- reducing the stigma associated with HIV encountered by the patients served via this model? Why? Reducing the stigma associated with HIV in the community? Why? How could this be improved via this model?

Community-based Care Model: Challenges

What have been some of the more major challenges you or others have faced providing HIV care via [mobile HIV clinic or home-based HIV care]?

    - Probe: technology, data availability, resource/staff availability, vehicle function/maintenance, care coordination

Concluding Section

How has providing HIV care via the [mobile HIV clinic or home-based HIV care] impacted you? How has providing HIV care via the [mobile HIV clinic or home-based HIV care] impacted your approach to HIV care or the patients/people you serve?

What else could be done by your health system, university, or community to help you and your team provide HIV care via the [mobile HIV clinic or home-based HIV care] more easily or more effectively?

Are there other models of care (i.e., the fixed clinic, peer navigation, telemedicine, community health workers) you would combine this HIV care model with? How and why?

Do you have anything else you would like to add about providing HIV care via the [mobile HIV clinic or home-based HIV care] to people who are out-of-care? Or in general?

Thank you for sharing your thoughts and detailed feedback. We will use your feedback and the feedback from others to continue to enhance these models of care to better reach those who face challenges staying in HIV care.

[Turn off e-recorders]

Appendix B:
In-Depth Interview Guide – Community Advisory Board (CAB) Members

Introduction

As you may know, the Emory Infectious Diseases Clinic and Grady Ponce de Leon Center are exploring new ways of bringing HIV care into the community to make care more accessible for patients who have challenges reaching the clinics. Two ways are through providing HIV care in people's homes and through providing HIV care through a mobile clinic. Given your engagement with the Community Advisory Board (CAB), we are interested in hearing what you think about the ***home-based care program and the mobile clinic****, and how we could improve the HIV care delivered to better reach people who face difficulty with receiving HIV care at their regular clinic. Your insights, perspectives, feedback, and experiences will allow us to develop a model that works to meet the needs of people with HIV and improve their overall health and well- being.*

I'm going to record our conversation to best capture your responses. When we transcribe (type up) this 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?

[Turn on e-recorder]

Warm-up Questions

Can you tell me about your role as a member of the Community Advisory Board (CAB)? What led you to join the CAB? What do you like/dislike about being a CAB member?

Where are you currently receiving HIV care?

What do you like most about your HIV care?

Please describe what the ideal place or way would be for you to receive HIV care.

- Probe: place (in the community versus clinic), characteristics of providers, services included, frequency/timing, etc.
- Probe: why would this design make it easier for you to stay engaged in care?

Community-based Care Model (General)

The next set of questions I will be asking are about ***the [home-based HIV care program and the mobile clinic]. I'm going to ask you to think about both of these ways of receiving care, and ask you to compare, and contrast them****. Through the home-based care program, members of the care team go to a patient's home (or place where they stay) to provide HIV care in the patient's home. For the mobile clinic, HIV care is provided by members of the care team on a mobile* *clinic (a big coach or van) in the community in which the individual lives. Can you briefly summarize the two programs to me before we move on?*

Tell me your general thoughts about individuals receiving HIV care through **the home-based HIV care program.** Tell me your general thoughts about individuals receiving HIV care through **the mobile clinic.**

- Probe: difference from traditional clinic-based HIV care? Like it more/less? Why?
- Probe: Advantages/disadvantages versus traditional clinic; **Advantage/disadvantages of mobile clinic versus home-based HIV care**
- Probe: For people who have fallen out of HIV care (missed many appointments), do you think receiving HIV care through the [home-based HIV care program], [mobile clinic] or in the clinic is better or worse? Why?
- Probe: How do you think **the home-based HIV care program versus the mobile clinic** could make a difference for an individual being able to stay on HIV treatment [antiretroviral treatment, ART, ARVs] as directed? Why?
-

What are the characteristics of people who might choose or be appropriate for **the home-based care program versus the mobile clinic versus the traditional clinic** for HIV care? Why?

- Probe: individuals who are unstably housed; with mental health disorders; substance use disorders; physical challenges; high/low community support; high/low HIV diagnosis acceptance

Thinking about your past HIV care history, what are some barriers, or things that made it difficult for you to *access* HIV care? Also thinking of your past, what are some barriers that made it difficult to *stay* in HIV care?

- Probe: distance, other priorities, poor provider experiences, safety, didn't want to think about HIV, didn't want others to find out HIV status, fear, drug use, depression

How well do you think the **home-based care program** might address these barriers? How well do you think the **mobile clinic** might address these barriers?

- Probe: Are there any barriers you faced that you don't think would be addressed through the home-based HIV care program or mobile clinic for HIV care?

Community-based Care Model: Specifics

Thank you. I'm now going to ask you a few more specific questions about receiving HIV care via ***[the home-based care program] vs. [mobile clinic].*** *As you think through these questions, I really want you to think about the differences, if any, between these two ways of receiving care.*

When thinking of some of the most important aspects of the **home-based care program** what factors come to mind? When thinking of some of the most important aspects of the **mobile clinic** what factors come to mind? To you, what are some of the important differences between the two programs?

- Probe: scheduling/reaching PLWH-OOC, safety, comfort, confidentiality, transportation, population served, etc.

People sometimes report discrimination, stigma or feeling judged when they seek HIV care. Do you think accessing HIV care via [the home-based HIV care program] would change an individual's experience of HIV-associated stigma? If so, how? Do you think accessing HIV care via [the mobile clinic] would change an individual's experience of HIV-associated stigma? If so, how? Are there differences in how the two programs would affect stigma? Why?

- Probe: how could we better ensure people don't feel judged when they receive HIV care via the mobile clinic or home-based care program?
- Probe: work that could be done with the surrounding community?

How do you think the home-based HIV care program would fit into the larger health system? How do you think mobile clinic would fit into the larger health system?

- Probe: accessing sub-specialty care, providing non-fragmented care, document sharing, patient portals, etc.
- Probe: do you think it would make it easier or harder to do these things?
- Probe: what strategies could help ensure all aspects of care (i.e., HIV care, non-HIV care, support services) are coordinated for people who use these models?

Concluding Section

We have come to the last set of questions.

Are there any other challenges you think someone might face when receiving care through [the home-based HIV care program]? Are there any other challenges you think someone might face when receiving care through [the mobile clinic]?

- Probe: relationship building, resource/staff availability, vehicle, home/space issues?

If *you* could design the home-based care program from scratch to reach people who face challenges staying in traditional HIV care what would it look like? If *you* could design the mobile clinic from scratch to reach people who face challenges staying in traditional HIV care what would it look like?

- Probe: location, staff/providers (who/what qualities), services provided

Is there anything else you would like to add about how receiving HIV care via [the home-based HIV care program vs. mobile clinic] might impact PLWH who face challenges receiving HIV care?

What else could be done by your health system or community to help you and others living with HIV receive HIV care via the [the home-based HIV care program]? What else could be done by your health system or community to help you and others living with HIV receive HIV care via the [the mobile clinic]?

Thank you for sharing your thoughts and detailed feedback. We will use your feedback and the feedback from others to continue to enhance these models of HIV care. We hope to better address barriers to HIV care so that more people will be able to access and remain in care.

[Turn off e-recorders]