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Factors Associated with Retention in the Women's Interagency HIV Study Atlanta Cohort

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Factors Associated with Retention in the Women's Interagency HIV Study Atlanta Cohort

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2015

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Abstract

Factors Associated with Retention in the Women's Interagency HIV Study Atlanta Cohort

Poor retention in research studies threatens the validity of findings and has negative consequences on health justice. We identified predictors of retention in the Atlanta cohort of the Women's Interagency HIV Study (WIHS), a longitudinal observational cohort of women living with HIV and women at high-risk for HIV infection. Predictors of retention were determined through multivariable logistic regression analysis using baseline data, stratified by HIV status. With 'retained' defined as having attended all biannual study visits between 2013 and 2019, we found that 84% of women were retained in the cohort. Among the total cohort, history of incarceration (aOR: 4.77, CI: 1.86 – 12.22) and increased tangible social support score (aOR: 1.02, CI: 1.01 – 1.03) were predictors of retention, while drug use (aOR: 0.31) and income greater than $12,000 (aOR: 0.44, CI: 0.20 – 0.99) predicted poor retention. Among women living with HIV, only history of incarceration significantly predicted retention (aOR: 5.06, CI: 1.59 – 16.08). In a sensitivity analysis of retention among treatment-experienced participants living with HIV, history of incarceration predicted retention (aOR: 4.19, CI: 1.05 – 16.67). Among HIV-negative women, increased emotional wellbeing score predicted retention (aOR: 1.045, CI: 1.00 – 1.01) while income greater than $12,000 (aOR: 0.12, CI: 0.02 – 0.64) predicted poor retention. These results demonstrate that women of lower socioeconomic status were more likely to attend all visits than their higher income counterparts in the Atlanta WIHS cohort. These findings were contextualized through Maslow's hierarchy of needs describing behavior as an endeavor to meet unmet needs. In order to develop more tailored retention strategies, further research should include qualitative analysis to investigate the barriers and facilitators to retention in observational research among low-income women.

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INTRODUCTION

Project Context

The History of HIV Research and Introduction of WIHS

At the beginning of the HIV epidemic, AIDS research was focused primarily on gay and bisexual men who were known to be the population most at risk for AIDS. As the HIV epidemic progressed, the profile of people living with HIV (PLWH) shifted in ways indicative of underlying gender-based and racial inequality. Between 1990 and 1994, there was an 89% increase in AIDS cases among women and a 29% increase in AIDS cases among men [1]. Moreover, the new cases of AIDS among women occurred primarily in black women. As the population of PLWH became more gender diverse, it became clear that ongoing HIV research needed to include women, who experienced unique barriers to care and risk factors for acquiring HIV, and required unique prevention strategies. In 1993, the Women's Interagency HIV Study (WIHS) was established in order to fill this gap [2].

The WIHS is a national, multi-center prospective cohort study that enrolls women living with HIV (WLWH) as well as HIV-negative women who are at increased risk for HIV-infection. With over 3,000 participants, the WIHS is currently the largest cohort study of WLWH in the United States. The core WIHS research focuses on the current epidemiology of HIV infection among women, HIV treatment, and differences in treatment and clinical outcomes among women of different racial groups. The WIHS projects have contributed significantly to the understanding of HIV among women and in the United States in general.

Early HIV research focused primarily on prolonging life for PLWH. However as PLWH began to live longer, near-normal life spans, it became increasingly important to conduct research investigating co-morbidities and aging in PLWH. In addition to physical and clinical subjects associated with aging, it is important to understand psychosocial challenges and quality of life over time in PLWH. WIHS is uniquely suited to investigate the chronic physical and mental health conditions associated with living with HIV among American women due to the size of the cohort, the spatial and geographic diversity of the cohort, and the longitudinal nature of the project.

Atlanta WIHS and HIV in the South

The American South has become the epicenter of the HIV epidemic in the Unites States. While less than 40% of the American population lives in the South, more than half of new HIV cases occur in the South [3]. A group of nine Southern states (AL, FL, GA, LA, MS, NC, SC, TN, TX), referred to as the targeted states in HIV prevention, have experienced poorer HIV outcomes and increased incidence relative to other American states [4]. While the targeted states accounted for 28% of the population in 2013, the region accounted for 40% of new infections. Moreover, while most of the US is experiencing decreasing rates of HIV infection, the incidence of HIV in the South has not declined [3]. Southern states also have the highest HIV-related mortality and morbidity rates. High levels of concentrated poverty, HIV stigma and discrimination, and increased STI prevalence in the South have been proposed as mediators of the HIV epidemic in the South [4]. The 2020 National HIV/AIDS Strategy has named the South a priority region for interventions to reduce HIV incidence and reduce HIV-associated mortality and morbidity [5]. In order to bring these goals to fruition, a stronger understanding of the profile of HIV in the South

is required. This includes the social, cultural, and other population-level factors that contribute to the HIV epidemic in the Deep South.

In 2017, Georgia ranked 1st in HIV incidence among youth and 4th overall, with an incidence of 32.1 per 100,000 [6]. Over 65% of PLWH in Georgia are living in the Atlanta area [6]. This makes the Atlanta-WIHS site an essential institution for carrying out research to understand HIV infection and epidemiology the South. Furthermore, a large number of PLWH in the South migrate to Georgia following an HIV diagnosis. In fact, Georgia is home to the largest influx of PLWH post-diagnosis [7]. Not only is the Atlanta-WIHS site important for understanding HIV in Georgia, findings from Atlanta-WIHS research have implications for understanding the changing epidemiology of HIV in the United States in general.

Retention in Vulnerable Populations

There is a generalized need for improving cohort retention in longitudinal research studies [8]. Because longitudinal research requires that participants be enrolled for long periods of time, study attrition is to be expected, but ideally should be avoided. Poor retention reduces the validity of results by increasing risk of selection bias. Attrition is most problematic when factors influencing retention are related to study outcomes. Since loss-to-follow-up rarely occurs randomly [9], researchers should act to minimize study attrition as much as possible.

Poor retention also indicates that benefits of research are not being experienced by all sub-populations, particularly when variables relevant to retention are also relevant to social inequities. The NIH mandates inclusion of minorities and women in research in order to ensure that research can be generalizable to the entire population and that relevant differences among groups can be detected [10].

Among marginalized populations, such as women living with HIV and women at risk for HIV infection, retention in research becomes more complex since these populations often have several barriers to participation. Many of the factors associated with increased risk of HIV acquisition (such as drug and alcohol use, Black race, young age, and psychological distress) are associated with poor retention among women enrolled in HIV cohort studies [11, 12]. Yet, it is most important to retain these marginalized populations in research in order to understand risk factors for HIV incidence and poor outcomes. Additionally, understanding disparities between marginalized populations and those of higher socioeconomic status requires the retention of these marginalized populations in the study. Therefore, it is crucial to not only have a comprehensive understanding of risk factors for study attrition in HIV research projects such as WIHS, but to develop and implement retention strategies that cater to marginalized sub-populations as well as those with increased agency.

Problem Statement

While WIHS was established in 1993, the WIHS Atlanta site first began recruiting new participants in 2013. Analyses have been performed to determine retention rates for the complete multicenter WIHS cohort, most recently in 2009 [11]. However, not only was the Atlanta site not included in these analyses, but the Atlanta site has a distinct population profile, being located in a large metropolitan area in the South. Utilization of national retention figures in site-specific strategies would mask the unique characteristics of the Atlanta site, leading to retention strategies that are less applicable to the Atlanta cohort. High quality data from the Atlanta site is important to understanding the HIV epidemic in the South and in the country. This requires exceptional study retention. Rather than treating site location as a variable in retention, there is a need to assess retention specifically among the WIHS Atlanta site cohort.

Goal

The purpose of this project is to determine retention rates in the WIHS Atlanta cohort and to identify predictors of retention among the cohort in both WLWH and women living without HIV. Understanding risk factors for study attrition and developing retention strategies to address these unique issues remains a critical and ongoing goal for the WIHS Atlanta site, especially as the study population continues to shift.

We assessed overall study retention among the WIHS Atlanta site, as well as retention among participants living with HIV and the high-risk HIV-negative participants. Additionally, we identified predictors of retention among the Atlanta site for the overall populations, as well in the HIV-negative and HIV-positive populations separately.

Identifying predictors of retention will facilitate a stronger understanding of the population profile engaged in HIV research. This new understanding will allow the development of socially-relevant tools to revamp Atlanta-specific retention strategies in a way that takes into account the diversity of the population. This is part of an extensive effort to develop culturally-relevant and population-specific concepts into current and future retention strategies in order to retain all sub-populations in the study. Furthermore, these retention predictors may hold implications for other WIHS sites, particularly those in the South.

LITERATURE REVIEW

Importance of Retention in Research

In clinical and public health research, retention is defined as the continued participation of research subjects over the projected study duration [13]. Conversely, attrition is defined as the failure of subjects to complete their participation in a study following enrollment [14]. Retention in research is a particularly challenging problem in longitudinal observational cohort studies. Because participants are expected to enroll over a long period, often several years, retention throughout the course of longitudinal observational studies requires significant effort from both the researchers and the participants [15].

Various retention analyses have reported rates from 5 - 96% [14, 16]. Some guidelines suggest that a retention rate of at least 80% should be the minimum standard [17, 18]. However, others argue that 60% to 80% is adequate for cohort studies [9]. Hewitt and colleagues argue that ensuring that retained participants are not characteristically different from those not retained is more important than the retention rate [19]. Furthermore, the characterization of retention in clinical research varies in the literature, and is often dependent on study design, making it difficult to compare study retention across projects [14]. While many studies define “retained” as the proportion of participants who completed follow-up throughout the study, others consider missed visits in study retention definitions [20].

In addition to producing financial loss and waste [21], poor retention in research reduces the internal validity and generalizability of the findings by increasing the risk of selection bias [22, 23]. This is particularly problematic if factors distinguishing the retained participants from other participants are related to study outcomes [24]. In addition to scientific validity, poor retention

elicits concerns of health justice. A major implication of poor research in clinical and observational research is the generation of findings that are not applicable to all sub-populations. If attrition occurs differentially between age groups, genders, racial and ethnic groups, or by other factors, then the resulting findings are generalizable only to a subset of these patients. In the history of public health and clinical research, this subset has generally been white males [25]. For this reason, the National Institutes of Health now mandates inclusion of women and minorities in health research [10]. Catalyzed by the NIH's Revitalization Act of 1993[26], justice in health research has moved from attempts to protect disadvantaged groups form harms of medical research towards a push for more rigorous inclusion of disadvantaged groups in research [27], to produce data that is useful to these groups.

As the US grows more diverse, the inclusion of minorities and low-socioeconomic status (SES) participants becomes increasingly important for developing national policy [28, 29]. This is particularly true if the research informs behavioral interventions, health promotion, or other socially-mediated interventions. However, lack of inclusivity in public health and medical research impacts the clinical management of minority populations as well. The omission of marginalized groups creates an inability to detect differences between groups or understand why differences exist between groups. It also weakens our ability to determine safety and effectiveness of interventions in all groups, and to determine which groups have highest disease burden [30]. Because clinical and epidemiological research informs policy and clinical guidelines, the exclusion of minorities and women in research directly impacts how the healthcare system interacts with these populations and affects the health of marginalized populations at macro levels. Non-random attrition reduces the translational value of research, and restricts evidence-based health policies and clinical guidelines to dominant social and ethnic

groups [31, 32]. The omission of racial minorities and low-SES groups from research also denies these populations the direct benefits of research participation, including counseling and improved knowledge, access to treatment and care, and incentives [27, 30, 33].

Conceptual Frameworks

Behavioral and conceptual frameworks have been employed to understand research retention and attrition in previous studies [12, 14, 34-37]. For example, ecological theories have been used to characterize research attrition and retention strategies. Marcellus described an ecological theory of attrition with nested layers representing retention factors at four levels: participant level, researcher level, study level, and environmental level [14]. Salihu and colleagues have used the social-ecological model to characterize and address attrition in minority and underserved population in the Southern United States. They showed that by using strategies acting at multiple levels, they could improve retention in clinical trials [37]. The Gelberg-Anderson Behavioral Model for Vulnerable Populations has also been used to characterize research retention. The Gelberg-Anderson Behavioral Model was used to characterize retention in an observational study of women at risk for HIV [12] and has informed an analysis of Alzheimer's research participation in Latino communities [34]. The model describes healthcare utilization, or clinical research participation in this case, as a function of enabling factors (factors that facilitate or impede health care utilization), predisposing factors (demographic factors that exist prior to illness), and need (perceived illness) [38].

Keller and colleagues used another framework, treatment theory, to address issues of retention in intervention-based clinical research [35]. Treatment theories describe and differentiate direct mechanisms of treatment or change from other less essential components of treatment delivery [39, 40]. In applying treatment theory, Keller and colleagues considered the critical aspects and

the mediating components of retention strategies to improve retention among low-income Latina women. Finally, Maslow's Hierarchy of Needs has been used to describe study retention factors in a longitudinal study with vulnerable families [36]. According to Maslow's hierarchy, motivation is driven first by immediate physiological needs, then safety and security needs, then belongingness, esteem needs, and finally self-actualization [41]. By this model, research participation that offered belongingness might be less attractive to participants struggling to meet basic physiological and safety needs such as food and shelter.

Factors Associated with Study Retention

Study retention is a function of study-specific characteristics, contextual and environmental characteristics, and participant characteristics [14]. Study-specific characteristics affecting study retention include participation burden, research staff skills, incentives for continued participation, and other study design structures [13, 42]. In particular, the burden/benefit ratio is strongly influences recruitment and retention [43]. Studies have found that greater travel, inconvenient or extraneous procedures, and frequent appointments can reduce study retention [22, 44, 45]. For example, a clinical trial of candidate HIV vaccines found that along with young age, more vaccinations and longer study duration were associated with poorer retention [45]. Meanwhile, perceived benefit and incentives for continued participation promote retention [13]. Other studies have emphasized the importance of research staff skills and demonstrated that increased research staff training can improve participant retention [13, 22, 46].

Contextual factors, such as environmental and community factors, are also important issues in research retention. In fact, in a qualitative analysis of retention in a community-based health study, Odierna suggested that participant factors were not the primary reason for attrition.

Rather, researchers could address the contextual factors and study factor to improve retention [47]. These contextual issues include political factors, geographic differences, and community practices [42]. For example, in a multistate Quality of Life study among women with lung cancer, sites in the Southern United States had the highest attrition rate (47%), as compared with the East (23%) and the West (5%). [48]. Other studies have found higher non-participation rates among urban communities compared to rural communities [49]. According to Groves and Couper cooperation rates may be greater in small rural communities due to stronger social cohesion if there is a strong relationship between the community and research team [20]. Other community factors relevant to retention overlap with race, ethnicity, and low SES. For example, mistrust of research government in minority communities has been known to reduce retention in these communities [50, 51].

Participant-specific factors include racial or ethnic minority status, age, gender, education, income and employment, substance use, residential stability, illness or health status, and psychological distress [13]. Participant-level factors for retention are expounded below, with special attention paid to HIV-related research.

Gender

Prior to the NIH Revitalization Act in 1993 mandating the inclusion of women and minorities in research, women were inadequately enrolled in clinical research. When studying disease and prevention, the standard patient was male and typically white [52]. In the decade after, there remained a significant differential in the recruitment of women and men in clinical research [53]. As progress is being achieved in the enrollment of women in research, women have been found to be better retained in research compared to men. This has been observed in numerous studies

and reviews of retention in research [13, 48, 54-56]. In the AIDS Clinical Trials Group (ACTG) Longitudinal Linked Randomized Trials (ALLRT) cohort, among treatment-naïve participants, male sex was associated with attrition. A second longitudinal cohort study of populations at high risk for HIV also found that women were better retained [57].

Women's increased retention in health research compared to their male counterparts fits within known patterns of health behavior among women. Women tend to have better health literacy [58], are more likely to seek health information [59], engage in less risky health behaviors [60-62], and have higher healthcare utilization[63]. Women's increased attendance and follow-up in research studies align with these other health-seeking behaviors.

Race and Ethnicity

Several studies have shown that minority racial and ethnic status is associated with poor study retention [12, 56, 64-67]. In a review of US panel studies comparing retention by racial/ethnic group, 85% of studies found that retention was poorer among racial and ethnic minorities [68]. The literature has also documented the sense of mistrust towards the medical community that many racial and ethnic minority communities hold [65-67]. This mistrust stems from a long history of exploitation and mistreatment of racial minorities by the medical community [66, 67, 69]. In addition to this mistrust, socioeconomic disadvantages, communication barriers between study staff and participants, and the lack of minority healthcare professionals continue to hinder the participation of racial and ethnic minorities in health research [70, 71]. In HIV-related research and care, this mistrust plays an even more significant role in how African Americans interact with the health system [72]. The circulation of theories blaming the government for the

increased rate of HIV in black communities increases mistrust in African American communities in the context of HIV-related research and care [72, 73].

Immigrant and Latinx populations in the US also tend to have poorer study retention [51]. In these populations, poor study retention may be related to increased mobility and residential instability [51], anxiety towards contact with unfamiliar institutions, and cultural or linguistic incongruence [74].

Age

Young age has been associated with poorer retention in HIV-related research [11, 75-78], as well as in other fields of research [79, 80]. Studies have found that younger participants have increased mobility and are more likely to relocate or migrate [76, 81, 82], negatively affecting retention. A second reason may be that older participants tend to participate in research for more altruistic reasons [83-85], and this altruism is associated with improved research retention [86]. Finally, older participants might be more aware of their mortality and concerned for future health [77]. While retention generally improves with age, among the oldest participants, increased age is associated with poorer retention due to the decreased cognitive function associated with elderly participants [87, 88].

Socioeconomic Status: Employment, Income, and Education

Employment: Employment is considered a positive predictor of retention [13]. As has been observed in HIV longitudinal studies, participants with full or part-time employment are more likely to complete follow up visits [11, 89]. While employment is typically considered a predictor of retention, research participants have described work and time management as a barrier to research retention [36]. As was found in a study of retention in an ethnically-diverse

multi-center study, employed participants could be expected to struggle with finding time for research appointments compared to their unemployed counterparts [90]. Another study of a hospital-based cohort study found similar findings, with employed participants being less likely to complete follow-up [91]. On the other hand, the positive relationship between employment and retention could be explained by the correlation between employment and mobility. Employment can serve as a proxy for stability, with employed participants being less likely to migrate [92, 93].

Income: While income has been identified as a factor in retention, the relationship between income and study retention is unclear [48]. Low-income has been identified in numerous studies as a risk factor for study attrition [15, 82, 87]. Income is such a concern in study retention that researchers have invested in adapting retention efforts towards low-income participants [30, 36, 94]. However, some studies have shown that increased income is a predictor of study *attrition* [11], or is not a significant factor [78]. Retention of low-income individuals is generally expected to be poorer because the burden of participation is heavier on low-income participants [85]. Yet, if tangible incentives are provided, the perceived benefits of research may be greater for low-income participants [12, 95]. It is likely that the effect of income is dependent on the population being studied. One study found that economic status was a better predictor for retention among those with poor health status compared to those with good health [48].

Education: Education is generally regarded as a positive predictor of retention [13]. Previous retention analyses in HIV longitudinal cohort studies have found that having at least some college education was a positive predictor for retention [77]. This effect has been attributed to an increased ability of educated participants to appreciate the indirect benefits of research [20].

Leak and colleagues demonstrated that in a large prospective cohort study, health literacy was a primary predictor for study retention [91].

Residential Stability

Residential instability and homelessness have been associated with attrition in research studies [11, 12, 78]. In longitudinal studies, housing stability is often a critical predictor for retention [56]. For example, in a mixed methods analysis of retention in a longitudinal study with vulnerable families, unstable housing was both quantitatively and qualitatively identified as a predictor of study attrition [36]. In a longitudinal study of low-income women at increased risk for HIV infection, unstable housing was associated with more missed visits [12]. Given the diversity of housing arrangements, many studies have defined residential stability to be having one's own residence while unstable housing is anything else [11, 56].

Individuals experiencing homelessness have been deemed "hard-to-reach" and are often excluded from research [96]. Factors such as incarceration, cognitive impairment, and substance abuse make it difficult to retain individuals experiencing homelessness [97]. Women who are experiencing abuse are also at increased risk for experiencing homelessness [36] and having poor retention. While the high attrition rates associated with individuals experiencing homelessness make researchers hesitant to engage with these populations [96], numerous projects have been able to successfully recruit and retain this population in research [98], using targeted strategies. Strategies are considerate of mistrust towards authority figures, mental illness, and collaboration with community partners [98, 99].

Substance and Tobacco Use

Substance Abuse: Substance use, including alcohol and illicit drug use is a risk factor for study attrition in longitudinal studies [100, 101]. Moreover, increased severity of drug use, and untreated substance dependence are strongly associated with study attrition[101]. Issues of substance use are largely issues of cognitive impairment and psychological distress, as well as residential instability [102] . While substance-abusing populations prioritize meeting basic needs over research appointments, researchers struggle to adapt study protocol to the transient and often unorganized lifestyles associated with substance- using populations [102]. Some studies have managed to overcome these issues and have successfully implementing longitudinal designs with drug-using populations. As HIV infection is strongly associated with drug use, substance use has been investigated as a predictor for retention in numerous HIV-related longitudinal studies [11, 103]. In a previous analysis of women living with and without HIV, individuals who injected drugs were associated with poor retention [103]. A second analysis of retention among women at risk found HIV found that use of crack, cocaine, or heroin was a significant predictor of nonattendance [11].

Smoking: Smoking is also associated with poor retention in longitudinal studies. A longitudinal study of smoking prevention found that individuals who smoked and used marijuana were less likely to be retained in the study [64]. A study of men with HIV or at risk for HIV found that smoking was a strong predictor of nonparticipation [77]. This trend was also observed among a sample of treatment-naïve, PLWH [104]. Smoking's relationship to retention may exist within the relationship between other risky behaviors and study attrition [64, 105, 106].

Mental Health and Psychological Distress

Psychological distress, which is often but not always a symptom of mental illness, presents obvious barriers to research retention. While psychological distress is seldom described as a distinct concept, defining attributes of psychological distress include perceived inability to cope effectively, change in emotional status, discomfort, and harm [107]. Mental illness or psychological distress can damage normal functioning and impede a participant's ability to arrange or complete study visits [99].

Acute or chronic psychological distress has been identified as a risk factor for poor retention in several studies [22, 108, 109]. For example, comorbid depressive and anxiety disorders and increased symptom severity were predictors for study attrition in a study of depression in the Netherlands [109]. Another European study analyzed retention in an online education program for individuals with bipolar disorder. In this study, Nicholas and colleagues found that not only were bipolar symptoms a reason for attrition, but a major reason for withdrawal was not wanting to think of one's illness, which could be understood as an avoidance of psychological distress [54]. In a longitudinal, multisite study of parents with infants in intensive-care units, depression and overall psychosocial distress were associated with study attrition [22]. Finally, in an analysis of retention among individuals at-risk for HIV, participants who dropped out were more likely to be depressed [108].

Illness and Physical Health

Illness and physical health status is a commonly cited reason for study attrition [48]. Qualitative investigations of attrition have identified health issues as a major reason participants are poorly retained [36, 53, 110]. Quantitative analyses have found similar results. In a retention analysis of

the Midlife in the United States (MIDUS) study, not only was good health status a predictor of retention, but this relationship was stronger among older participants compared to younger participants. In this same study, health was also a stronger predictor of retention among men compared to women [48]. Given that attrition is associated with unhealthy behaviors such as alcohol and tobacco use [64, 100], it is unsurprising that attrition is associated with poorer health outcomes. It is important to consider the health status of participants in retention efforts to ensure that the sample is not biased towards the healthiest participants.

HIV Serostatus: HIV infection is also an important factor in retention. Despite poor health being associated with poor retention, HIV infection has paradoxically been associated with improved retention in many longitudinal cohort studies. In the HIV Epidemiological Research (HER) study, a longitudinal cohort study of women living with and without HIV, being HIV-negative at enrollment was associated with poorer retention [103]. Another longitudinal cohort study of women living with and without HIV, the Women's Interagency HIV Study (WIHS), also found that HIV-seroprevalence was associated with improved retention [11]. In a five-year long observational cohort study of individuals with and without HIV-infection and substance dependence, HIV-seroprevalence was again found to be associated with study retention [101]. When the effect of HIV has been adjusted for other behavioral and socioeconomic factors, the effect of HIV status on retention was somewhat mitigated [101]. Increased retention in PLWH compared to populations living without HIV could be related to the reasons participants decide to participate in research [101]. PLWH have been noted to participate for altruistic reasons, access to care, and health opportunities [101, 111]. The increased study retention PLWH could be explained assuming these benefits were less important to HIV-negative women.

While HIV-infection is a significant health condition, it is not necessarily indicative of one's health status as PLWH can live healthy lives. Indicators of health status among PLWH include viral load and CD4 count, both of which have been identified as factors in study retention. In a longitudinal, international Europeans study of PLWH, low CD4 counts were associated with poor retention [112]. In ALLRT, another longitudinal study of PLWH, high viral loads (≥400 copies/ml) were associated with poor retention [104]. High viral load also predicted poor retention in the WIHS Study [11].

A related but distinct area of HIV health status is medication experience and adherence. Unlike CD4 count and viral load, treatment adherence can be both a marker of psychosocial wellbeing and a predictor of physical health status [113]. Treatment-experienced participants (those who had initiated HIV treatment at any point prior to enrollment) were more likely to be retained in a Europeans study of PLWH [112]. Participants in the ALLRT cohort were also more likely to be retained if they were treatment-experienced. Among these participants, those who were non-adherent to medication had higher rates of attrition [104].

There is significant overlap in retention factors laterally, between different participant-level factors, and vertically, between participant-level and community-level factors of retention. Additionally, the effect of many participant-level factors is not uniform across all populations. In some cases, these effects are unclear altogether. Therefore, it is necessary to perform retention analyses among current and existing research cohorts in order to understand the unique predictors of retention among different populations and develop appropriate retention strategies.

MANUSCRIPT

Introduction

Ending the HIV epidemic in the United States remains a major public health goal [114]. While there are more men living with HIV in the United States, women carry the greatest HIV burden worldwide [115]. In 2017, over 7,000 American women were diagnosed with HIV [116] . In the US, approximately one in four people living with HIV (PLWH) are women [116]. Of these women only 65% had received some HIV care. With the introduction of effective treatment, PLWH are living longer and healthier lives. However, only those aware of their HIV status and retained in care can experience these benefits. As PLWH age, understanding the complex social, behavioral, and clinical dynamics of women living with HIV is important is crucial to controlling the HIV epidemic and improving the lives of PLWH. In 1993, the National Institutes of Health established the Women's Interagency HIV Study (WIHS) in order to address this need.

The Women's Interagency HIV Study (WIHS) was established in 1993 in order to study the progression of HIV in women [117]. The WIHS is currently the largest prospective study of women living with HIV in the United States. With approximately 5,000 participants, the WIHS is a prospective longitudinal and observational study of women living with HIV and characteristically similar women who are HIV-negative. The WIHS has sites in ten sites, including cites in four Southern cities added in 2012: Chapel Hill, NC; Atlanta, GA; Birmingham, AL/Jackson, MS; and Miami, FL. The Southern sites were added most recently in order to understand the disproportionate epidemic of HIV in the Southern United States.

Given the significance of the WIHS, an understanding of the cohort profile is crucial to interpreting WIHS data and research. A representative sample with characteristics aligning with the target population is important goal of observational cohort allowing the valid extrapolation of result to the target population. Retaining participants in study is an essential component to achieving internal and external validity. African Americans, people who use drugs, and low-income participants have generally been considered difficult to retain in clinical research due to social, cultural, and economic barriers [13, 68, 101]. Yet, these populations have increased HIV prevalence and are at increased risk for HIV infection [118, 119]. This amplifies the need to effectively retain these populations.

Identifying predictors of study attrition or retention allows for the development of targeted retention strategies. Employing these strategies not only improves the participant experience, but enriches the resulting data and allows for more equitable distribution of research benefits. Our objective was to determine predictors of retention in the Atlanta WIHS cohort. We assessed demographic, behavioral, and clinical determinants of retention stratified by HIV status in the Atlanta WIHS cohort using logistic regression analysis. Maslow's theory of human motivation and associated hierarchy of needs were used to contextualize the findings [41].

Methods

Data and Population

The Women's Interagency HIV Study (WIHS) is a multisite prospective observational cohort of women living with HIV and women at risk for HIV infection. The WIHS cohort consists of sites in 10 American cities. Four of these cities are in the Southern United States and were added

most recently in 2013: Atlanta, GA; Birmingham, AL/Jackson, MS, Miami, FL, and Chapel Hill, NC [117]. Enrollment for these sites ended in 2015. At 6-month intervals, participants attend study visits that consist of physical and gynecological exams, laboratory testing, extensive histories, and structured interviews that include the Medical Outcomes Study (MOS) instrument. Per protocol, women who are incarcerated are asked to complete abbreviated visits over the phone rather than a complete visit.

The dataset used for this analysis consisted of women enrolled in the Atlanta site of the WIHS Study [120] and included all visits up to those initiated on or before March 31st 2019. For participants who had transferred into or out of the Atlanta site, only Atlanta visits were included in the dataset. A total of 286 women were included in the analysis, 191 of whom were WLWH, and 95 of whom were women living without HIV.

Outcome Measures

The primary outcome of interest was retention. We defined 'retained' as having never missed a biannual study visit, including abbreviated visits, at the Atlanta site. Participants who missed one or more visits were classified as 'not retained.' Missed visits were identified through the completion of a missed visit form. Participants who died within 12 months of their last visit were considered retained. Women who were currently incarcerated at time of visit were defined as retained if abbreviated visits were completed. The overall proportion retained was defined as the number of women classified as 'retained' divided by the total number of women in the sample.

Demographic and Socioeconomic Variables

Baseline demographic and socioeconomic variables from participants' enrollment visit were used in the retention analysis. Self-reported race/ethnicity categories were non-Hispanic African American/Black, non-Hispanic White, Hispanic, and Other. Annual income values were dichotomized into less than or equal to $12,000 vs greater than $12,000, to parallel the poverty threshold according to federal poverty guidelines [121]. Education levels were dichotomized into high school completion or less (high school or less) vs any tertiary education (some college education or more). Sexual orientation categories were heterosexual, bisexual, lesbian, and other. Participants were classified as having health insurance if they reported Ryan White Program enrollment, AIDS Drug Assistance Program, or other private or public health insurance. Country of birth was categorized into US-born or Non-US born. Marital status values were categorized into Married/Partnered, Divorced/Widowed/Separated, and Never Married/Other. Employment was categorized as full or part time employment (yes) vs unemployed (no). Age at baseline was analyzed as a continuous variable.

Behavioral Variables

Behavioral variables were also taken from participants' baseline visits. Alcohol use values were categorized as Abstainer, Moderate: 0-7 drinks per week, and Heavy: > 7 drinks per week, according to CDC definitions of moderate and heavy drinking [122]. Smoking status was defined as having never smoked cigarettes (never smoker), having smoked cigarettes previously but not currently (former smoker), or currently smoking cigarettes (current smoker). History of injecting drugs and history of crack, cocaine, or heroin use were dichotomized as yes vs no. A positive history of incarceration was defined as having spent time in jail or prison. A positive history of

pregnancy was determined from self-reporting of any previous pregnancy regardless of pregnancy outcome. Values for residential status were dichotomized into living in one's own house/apartment (has own residence) vs any other housing arrangement (temporary housing/other). Transactional sex was defined as having ever exchanged sex for money, drugs, or shelter.

Psychosocial Variables

Psychosocial variables were derived from participants' baseline visit. Presence of depressive symptoms was dichotomized according to CES-D score, CES-D of 16 or more (Yes) vs CES-D less than 16 (No) [123, 124]. Tangible and emotional/informational social support scores were determined according to the MOS Social Support Survey Instrument and scoring instructions, which is validated in populations living with HIV [125, 126]. Quality of Life Health Index score, emotional wellbeing score, and health rating score were determined from MOS Quality of Life Instrument and scoring instructions [126, 127]. Responses to health rating item (scale from 1 to 10) was analyzed continuously. In all analyses, these scores were analyzed as continuous variables.

HIV-Specific Variables

HIV status was defined as seronegative or seropositive at baseline visit. Among HIV seropositive participants, viral load was categorized unable to be detected (Undetectable), detectable and less than 1000 copies per ml (<1000 copies/ml) or detectable and 1000 copies per ml or greater (>=1000 copies/ml). Participants who had never began any HIV medication regimen were categorized as treatment-naïve, while all else were categorized as treatment-experienced. Among participants currently on treatment, adherence was assessed by asking how often the participant

took antiretroviral treatment as prescribed over the past 6 months. Adherence responses were categorized into less than 95% vs 95% or more.

Statistical Analysis

All analyses were conducted in the overall sample and also stratified by HIV status. Univariable analysis was conducted to assess the association of baseline clinical and demographic characteristics with retention status. Tests for differences of proportion among categorical variables were performed with chi-squared tests or Fisher's exact tests where necessary. For normally distributed continuous variables two-sample t-tests were performed, or Wilcoxon signed rank test where necessary. For HIV-specific variables (treatment adherence, treatment status, viral load), only participants living with HIV were analyzed. In addition, for the adherence variable, only treatment-experienced participants living with HIV were included in the analysis.

We performed multivariable logistic regression to identify independent predictors of being retained. Adjusted odds ratios and 95% confidence intervals (CI) were reported from the final models. All variables, were initially included in a backwards selection process with selection threshold $p < 0.2$. For the overall cohort model, age and HIV serostatus were forced into the model and HIV-specific variables were excluded. For the stratified models, only age was forced into the model. HIV-positive models additionally initially included HIV-specific variables (treatment status, viral load) for consideration. Since some participants living with HIV were treatment-naïve and therefore medication adherence could not be assessed, adherence could not be included as a potential covariate. Consequently, we performed a sensitivity analysis that incorporated adherence as a potential covariate for a subset of treatment-experienced participants

living with HIV. A further sensitivity analysis was performed among treatment experienced participants living with HIV with non-recent diagnosis (diagnosed at least five years prior to visit). Model fit was assessed by Hosmer-Lemeshow.

Significance level was set at $\alpha=0.05$ for all analyses. All statistical analyses were performed using SAS statistical software version 9.4 (SAS Institute, Cary, North Carolina).

Ethical Approval

Secondary analysis was performed using de-identified data. All consenting processes and ethical approval were obtained under original WIHS IRB and protocol approvals. All WIHS participants provided informed consent before study enrollment. The protocol was approved by the Emory University Institutional Review Board and the Grady Health System Research Oversight Committee.

Results

A total of 286 women were included in the overall sample, and two-thirds were WLWH. The cohort was predominantly non-Hispanic African American and American-born (Table 1). The age range of the cohort was 25 to 60 years old, with 35% of women being at least 50 years of age and 7.7% of women being younger than 30 years of age (Table 1). Over half of the cohort had a positive history of crack cocaine or heroin use, did not have their own residence, and had a history of incarceration. Among WLWH, the median CD4 was 474 cells/mL and 57% had an undetectable viral load. We observed an overall retention rate of 84.97%, (having never missed a visit from enrollment through March 31, 2019). Of the women who had ever missed a visit, 58% missed only one visit. Less than 5% of the total cohort missed more than two visits.

Overall Analysis of Predictors of Retention

Univariable analysis demonstrated that the retained and not retained groups differed significantly by HIV status, income, and incarceration history (Table 1). Compared to participants who were not retained, retained participants were more likely to be living with HIV (69.5% vas 51.2%, p=0.018), have an income of $12,000 or less (57.5% vs 38.5%, p = 0.027), and have a positive history of incarceration (59.1% vs 37.8%, p=0.015). While history of pregnancy and increased tangible social support were associated with being retained in the study, these results were not statistically significant.

Among the entire cohort, the following variables were selected as important for retention: income, depressive symptoms, emotional wellbeing, social support scale, history of incarceration, history of pregnancy, and drug use (crack, cocaine, or heroin) (Table 2). Income of greater than $12,000 (aOR: 0.44, 95% CI: 0.20 - 0.99), increased tangible social support score (aOR: 1.02, 95% CI: 1.01 – 1.03), and history of crack, cocaine, or heroin use (aOR: 0.31, 95% CI: 0.11 - 0.83) were significant negative predictors of retention. Increased age (aOR: 1.05, 95% CI: 1.00 -1.10) and improved emotional wellbeing (aOR: 1.018, 95% CI: 0.99 – 1.04) trended towards positive prediction of study retention, but were not statistically significant. Having been pregnant trended toward association with poor retention (aOR: 0.33, 95% CI: 0.07 – 1.59), but was not significant. Depressive symptoms according to CES-D score also trended towards association with retention (aOR: 2.401, 95% CI: 0.86 – 6.75), but was not significant.

Sub-Analysis among WLWH

In the logistic regression model among WLWH, the following variables were selected: drinking behavior, marital status, education, and history of incarceration. Age was not significantly

associated with retention. Only history of incarceration was statistically significant, and was associated with substantially increased study retention (aOR: 5.06, 95% CI: 1.59 to 16.08). While not statistically significant, drinking (aOR: 0.25, 95% CI: 0.06 – 1.04) and being un-partnered (aOR: 0.27, 95% CI: 0.06 – 1.26) were associated with poor retention, while higher education level was associated with increased retention.

Among treatment-experienced participants living with HIV, logistic regression analysis showed that history of incarceration was significantly and positively associated with retention (aOR: 4.19, 95% CI: 1.05 to 16.67) (Table 4). Drinking showed a negative and non-significant association with study retention. Among the treatment-experienced, participants living with HIV, a further sub-analysis was performed among participants with non-recent HIV diagnosis (Table 5). Variables selected were health rating, history of incarceration and adherence as important factors for study retention. While none of these factors were significant, adherence was associated with increased retention (aOR: 4.90, 95% CI: 0.94 - 25.52). History of incarceration (aOR: 3.15, 95% CI: 0.77 - 12.82) was also associated with improved study retention. Increasing health rating showed a non-significant association with reduced study retention.

HIV-Negative Participants Sub-Analysis

Among the HIV-negative participants, depressive symptoms, income, education, history of incarceration, emotional wellbeing were selected for model inclusion (Table 6). Age was not significantly associated with retention. Emotional wellbeing showed a significant positive association with study retention (aOR: 1.05, 95% CI: 1.00 – 1.09). Income greater than $12,000 was a significant and negative predictor of retention (aOR: 0.12, 95% CI: 0.02 – 0.64). Increased

educational attainment was associated with poor retention (aOR: 0.37, 95% CI: 0.09 – 1.46), but was not significant.

Tables

Table 1. Demographic, Health, and Behavioral Baseline Characteristics of Study Population

	Overall (n=286)		Retained (n= 143)		Not Retained (n=43)		p-value
	N	%	N	%	N	%	
HIV Status*							**0.018**
Negative	95	33.2	74	30.5	21	48.8	
Positive	191	66.8	169	69.5	22	51.2	
Age	**Mean**	**Std dev**	**Mean**	**Std dev**	**Mean**	**Std dev**	
	44	9.2	44.5	9.1	43.3	9.8	0.414
Race							0.839[a]
White NH	19	6.7	16	6.6	3	7.1	
AA NH	250	87.7	214	88.1	36	85.7	
Hispanic	9	3.2	7	2.9	2	4.8	
Other NH	7	2.5	6	2.5	1	2.4	
Country of Birth							0.151[a]
US-Born	260	93.9	223	94.9	37	88.1	
Non-US Born	17	6.1	12	5.1	5	11.9	
Marital Status							0.923
Married/Partnered	77	27.2	67	27.6	10	25.0	
Divorced/Widowed/Separated	86	30.4	74	30.5	12	30.0	
Never Married/Other	120	42.4	102	42.0	18	45.0	
Sexual Orientation							0.827[a]
Heterosexual/Straight	246	86.3	210	86.4	36	85.7	
Bisexual	34	11.9	28	11.5	6	14.3	
Lesbian/Gay	3	1.1	3	1.2			
Other	2	0.7	2	0.8			
Education							0.376
High School or Less	167	58.6	145	59.7	22	52.4	
Some College or More	118	41.4	98	40.3	20	47.6	
Annual Household Income*							**0.027**
$0 - $12,000	149	54.8	134	57.5	15	38.5	
>$12,000	123	45.2	99	42.5	24	61.5	
Employment							0.645
No	211	74.3	181	74.8	30	71.4	
Yes	73	25.7	61	25.2	12	28.6	
Health Insurance							0.532
No	90	31.6	75	30.9	15	35.7	
Yes	195	68.4	168	69.1	27	64.3	
Housing							0.645
Has Own Residence	113	39.7	95	39.1	18	42.9	
Has Temporary Housing	172	60.4	148	60.9	24	57.1	
History of Incarceration *							**0.015**
No	120	43.8	97	40.9	23	62.2	
Yes	154	56.2	140	59.1	14	37.8	
History of Pregnancy							0.191[a]
No	32	11.2	30	12.3	2	4.7	
Yes	254	88.8	213	87.7	41	95.3	
Smoking Status							0.210
Never smoker	91	31.9	73	30.0	18	42.9	
Current smoker	151	53.0	131	53.9	20	47.6	
Former smoker	43	15.1	39	16.0	4	9.5	

Drinking							0.800
Abstainer	115	40.4	100	41.2	15	35.7	
Moderate: 0-7 drinks/wk	106	37.2	89	36.6	17	40.5	
Heavy: > 7 drinks /wk	64	22.5	54	22.2	10	23.8	
Crack, Cocaine, Heroin Use							0.463
No	121	42.5	101	41.6	20	47.6	
Yes	164	57.5	142	58.4	22	52.4	
Injection Drug Use							0.332[a]
No	264	92.6	223	91.8	41	97.6	
Yes	21	7.4	20	8.2	1	2.4	
Transactional Sex							0.247
No	153	53.7	127	52.3	26	61.9	
Yes	132	46.3	116	47.7	16	38.1	
Depressive symptoms (CES-D)							0.636
No	159	56.2	134	55.6	25	59.5	
Yes	124	43.8	107	44.4	17	40.5	
Health Rating							0.861
Low (30 or Below)	10	3.6	8	3.3	2	5.0	
Medium (30 to 70)	138	49.5	119	49.8	19	47.5	
High(Greater than 70)	131	47.0	112	46.9	19	47.5	
	Median	**IQR**	**Median**	**IQR**	**Median**	**IQR**	
Social Support Scale (Tangible)	75	50 - 100	75	50 - 100	75	25 - 87.5	0.077[b]
Social Support Scale (Emotional)	71.88	50 - 94	75	50-94	65.63	41 - 94	0.278[b]
Emotional Wellbeing	73.33	53 - 87	73.33	53.3 - 86.7	70	47- 80	0.497[b]
	Mean	**Std dev**	**Mean**	**Std dev**	**Mean**	**Std dev**	
Quality of Life Index	65.38	21.12	21.44	21.44	64.53	19.33	0.787
HIV Specific Measures							
Viral Load							0.182
Undetectable	104	57.46	92	57.9	12	54.5	
<1000 copies/ml	27	14.92	21	13.2	6	27.3	
>=1000 copies/ml	50	27.62	46	28.9	4	18.2	
HIV Treatment Status							0.674
Treatment Experienced	145	76.32	129	76.8	16	72.7	
Treatment Naïve	45	23.68	39	23.2	6	27.3	
Adherence							0.238[a]
<95%	27	19.42	22	17.74	5	33.3	
>95%	112	80.58	102	82.26	10	66.6	

a: Fisher's exact test used; b: Wilcoxon signed rank test used.* p<0.05. NH: Non-Hispanic. CES-D: Center for Epidemiological Studies Depression Scale.

Table 2. Adjusted Effects of Selected Baseline Variables on Study Retention

Variable	Adjusted Odds Ratio	(95% Confidence Limits)	p-value
Age	1.05	(1.00 - 1.10)	0.055
Annual Household Income *			
$0 to $12,000	Ref		
$12001 or greater	0.44	(0.20 - 0.99)	**0.049**
Depressive symptoms (CES-D)			
No	Ref		
Yes	2.40	(0.86 - 6.75)	0.096
Emotional Wellbeing Scale	1.02	(0.99 - 1.04)	0.127
Social Support Scale (Tangible)	1.02	(1.01 - 1.03)	**0.005**
Crack, Cocaine, Heroin Use *			
No	Ref		
Yes	0.31	(0.11 - 0.83)	**0.021**
History of Incarceration *			
No	Ref		
Yes	4.77	(1.86 - 12.22)	**0.001**
Pregnancies			
No	Ref		
Yes	0.33	(0.07 - 1.59)	0.165
HIV Status			
HIV-Negative	Ref		
HIV-Positive	1.15	(0.51 - 2.62)	0.738

* p<0.05, CES-D: Center for Epidemiological Studies Depression Scale

Table 3. Adjusted Effects of Selected Baseline Variables on Study Retention Among HIV-Positive Participants

Variable	Adjusted Odds Ratio	(95% Confidence Limits)	p-value
Age	1.03	(0.98 - 1.10)	0.247
Drinking Behavior			
Abstainer	Ref		
Moderate: 0-7 drinks/wk	0.48	(0.15 - 1.59)	
Heavy: >7 drinks/wk	0.25	(0.01 - 1.04)	0.157
History of Incarceration *			
No	Ref		
Yes	5.05	(1.59 - 16.12)	**0.006**
Marital Status			
Married/Partnered	Ref		
Divorced/ Widowed/ Separated	0.27	(0.06 - 1.26)	
Never Married/Other	0.42	(0.10 - 1.80)	0.248
Education			
High School or Less	Ref		
Some College or More	2.20	(0.77 - 6.22)	0.139

* p<0.05

Table 4. Adjusted Effects of Selected Baseline Variables on Study Retention Among HIV-Positive, Treatment Experienced Participants

Variable	adjusted Odds Ratios	(95% Confidence Limits)	p-value
Age	1.00	(0.94 - 1.071)	0.916
History of Incarceration *			
No	Ref		**0.042**
Yes	4.18	(1.05 - 16.67)	
Drinking Behavior			
Abstainer	Ref		
Moderate 0-7 drinks/wk	0.21	(0.04 - 1.10)	
Heavy: >7 drinks/wk	0.11	(0.02 - 0.73)	0.066

* p<0.05

Table 5. Adjusted Effects of Selected Baseline Variables on Study Retention Among HIV-Positive, Treatment Experienced Participants with Non-Recent Diagnosis

Variable	adjusted Odds Ratio	95% Confidence Limits	p-value
Age	0.99	(0.91 - 1.08)	0.863
Health Rating	0.96	(0.92 - 1.01)	0.115
History of Incarceration			
No	Ref		
Yes	3.15	(0.77 - 12.82)	0.110
Adherence			
<95%	Ref		
≥95%	4.90	(0.94 - 25.52)	0.059

Table 6. Adjusted Effects of Selected Baseline Variables on Study Retention Among HIV-Negative Participants

Variable	Adjusted Odds Ratio	(95% Confidence Limits)	p-value
Age	0.99	(0.93 - 1.06)	0.856
Education			
HS or Less	Ref		
Some College or More	0.37	(0.09 - 1.46)	0.150
Income*			
$0 to $12,000	Ref		
Greater than $12,000	0.12	(0.02 - 0.64)	**0.014**
Depressive symptoms by CES-D			
No	Ref		.
Yes	2.12	(0.34 - 13.08)	0.418
History of Incarceration			
No	Ref		
Yes	1.86	(0.45 - 7.63)	0.391
Emotional Wellbeing*	1.05	(1.00 - 1.09)	**0.040**

* p<0.05. CES-D: Center for Epidemiological Studies Depression Scale

Discussion

Cohort Description

The Atlanta WIHS cohort consists of women between the ages of 25 and 60 living with HIV or at high risk for HIV infection [117].The Atlanta WIHS cohort, both the women living with and without HIV, represents a population with very low socioeconomic status (SES) compared to many population cohort studies. For example, over 50% of women lived below the poverty line designated for a single-person household. Approximately half of the women had a history of incarceration. The majority of the cohort had no tertiary education and had unstable housing. Many of the risk factors for research attrition (such as drug use, experiencing homelessness, young age, and African American race) are also risk factors for HIV infection. However, given the pre-disposition for attrition, the retention rate among the WIHS–Atlanta cohort was impressive. Approximately 85% of the women in the cohort were retained, having never missed a visit. Less than 5% of the women missed more than two visits.

Retention Factors

The recruitment of the Atlanta WIHS cohort ended in 2015 and our analysis included data up to March 2019. With participants having only two visits per year, we defined “not retained’ to be having one or more missed visits. Even one missed visit would be a significant proportion of missed visits, given the relatively few visits possible in this analysis. This very sensitive definition of ‘not retained’ provides us with the most conservative estimates of retention.

Trends from the univariable analysis described a profile of women where retained participants had lower educational attainment, had lower income, were more likely to have engaged in transactional sex, and were more likely to have a history of incarceration. Additionally, women

who were retained tended to have increased substance use, have more depressive symptoms, were more likely to be HIV-positive, and had higher viral loads. While only income, history of incarceration, and emotional wellbeing were statistically significant, in this relatively low-SES population, our findings suggest that the subgroup of more socially and economically advantaged populations were more likely to miss visits. This could be explained by increased mobility among the relatively higher-SES participants or lower regard for observational research and retention incentives.

HIV Status: Previous analysis among low-SES cohorts have shown that HIV is associated with *improved* retention [11, 101, 103]. This has been attributed to greater health needs or more altruistic reasons for participation [101, 111]. Our unadjusted analysis demonstrated that HIV seroprevalence was associated with retention (69.5% HIV- positive in the retained group vs 51.2% HIV-positive in the poorly retained group). However, in the logistic regression analysis, after adjustment for other confounders, the effect of HIV status on retention was mitigated. This suggests that other sociodemographic or psychosocial conditions may explain observed differences by HIV status.

Race and Ethnicity: Several studies have shown that racial and ethnic minorities, namely African Americans and Latino populations, are poorly retained in research [12, 56, 64-67]. In this analysis, African Americans were well retained in the cohort, contrasting with other findings. The relationship is between race/ethnicity and retention is mediated through cultural incongruence, mistrust for institutions, and other contextual factors [65-67]. In principle, if research projects are integrated within community relationships, many of the barriers to retention among minority groups should dissolve. These community relationships are a defining aspect of the WIHS cohort, as every site has a local Community Advisory Board comprised of community

members who act as advocates on behalf of the community and participants [78, 128]. WIHS also employs other research retention strategies that focus on social cohesion and partnership, such as disseminating community newsletters and hosting social events for WIHS participants. In this analysis and an older retention analysis of WIHS that did not include the Atlanta site [11], the retention of minority participants indicates the effectiveness of participatory and culturally-sensitive research strategies in retaining African American women in research.

Age: Age approached significance in the regression model of the total cohort ($p = 0.055$) as a positive predictor of retention. This mirrors what has been described in other longitudinal cohort studies Younger people have been considered more difficult to retain in research due to increased mobility [76, 81, 82]. Older individuals might also perceive greater benefit from research participation due to greater health needs or greater prioritization of one's health.

Marital Status: Marital status was only important among HIV-positive participants. While not significant, being single or un-partnered reduced likelihood of retention among HIV-positive participants. This has been observed in other longitudinal research studies [48, 82]. Marriage is known to improve health-seeking behaviors [129]. Additionally, marriage offers interpersonal support which may act as a buffer against everyday stigma in HIV-positive populations, increasing their quality of life and facilitating healthier behavioral functioning.

Education: Among HIV-positive participants, having some level of college education tended to improve retention in the cohort. Education was also selected in the HIV-negative model, however was associated with *reduced* likelihood of retention. Given the relationship between health literacy and education, more educated participants may perceive greater benefits from research [20]. This might be especially true for HIV-positive participants, who receive HIV-specific laboratory testing and investigation. As WIHS is designed to study the aging with HIV

and the progression of HIV, HIV-negative participants might perceive WIHS visits to be less beneficial than their HIV-positive counterparts. Additionally, if educated participants are more likely to be employed, then educated HIV-negative participants may deprioritize WIHS visits due to work schedules and time management.

Income: Lower income was a significant predictor of retention in the total cohort and among HIV-negative participants. Participants with an annual household income of $12,000 or less were more likely to attend all visits compared to higher income participants. Hessol and colleagues reported similar findings their 2009 analysis of retention in the total multi-center WIHS cohort [11].

If research participation and retention in this cohort is driven by tangible incentives and remuneration, then our findings could be explained by considering the effect that these remunerations would have on the research burden-to-benefit ratios for different SES populations. As the entire cohort is generally poor, including those with annual household incomes greater than $12,000, remunerations would be expected to play a significant role in recruitment and retention. This is especially true among HIV-negative participants who may perceive fewer non-tangible benefits for participation in HIV-related research [130]. The effect of financial and other tangible retention gifts would be greater among the lower-income participants of the cohort who are more likely to have unmet financial needs. In this lower-income subset, financial remunerations would reduce the research burden-to-benefit ratio more so than in the higher-income subset, explaining their increased retention rate.

Pregnancy: History of pregnancy was associated with poorer retention among the Atlanta WIHS cohort. As these women would have more dependent children, women with history of pregnancy

may struggle to incorporate research visits into their schedules. In this case, the research burden-to-benefit ratio might be higher amongst women with dependent children.

Incarceration: History of incarceration was the most consistent predictor of retention across all analyses. The odds of being retained among participants with a positive history of incarceration were 4.8 times higher than the odds among participants who had never been incarcerated. Given that incarceration is associated with unstable housing and poor retention in health care [131], this effect is surprising. While this relationship is perplexing, the findings fit within the observed pattern of socioeconomically disadvantaged participants being better retained. One potential explanation is that those with history of recent incarceration may have less mobility due to legal restrictions, keeping them within necessary proximity to complete WIHS visits.

A second explanation might be the provision of more rigorous case management for criminal justice populations who are transitioning back into the community. Case management has been shown to play a significant role in liking formerly incarcerated individuals to HIV care and increasing healthcare utilization [132, 133]. Those transitioning from incarceration may experience more rigorous follow-up and management from case managers acting to facilitate post-incarceration barriers to care and social services. In an analysis of retention in care among criminal justice-involved PLWH, retention in care three years post release was significantly associated with case management [133]. Compared to a similarly disadvantaged population, an increased presence of case managers or more rigorous case management among criminal justice-involved populations may facilitate WIHS visit attendance.

Depressive Symptoms: Although not statistically significant, presence of depressive symptoms was associated with retention among the total Atlanta cohort. Depression was also selected and in the HIV-negative sub-analysis. These findings contrast with what is found in the literature

regarding retention and psychological distress [22, 108, 109]. However, these findings match the trend of increased retention among socially disadvantaged participants.

Substance Use: Substance use variables were selected in the total cohort regression analysis and the HIV-positive sub-analyses. Use of crack, cocaine or heroin was a significant predictor of having a missed visit in the general Atlanta cohort. Similarly, In HIV-positive analysis, increased alcohol use predicted poor retention. Other longitudinal HIV-related research have found similar findings [104]. Substance use is associated with erratic lifestyles which conflict with the structured nature of research [102], leading to poorer retention.

Emotional Wellbeing: While quality of life was not selected in any model, HIV-negative participants with increased emotional wellbeing scores were significantly more likely to attend visits than those with lower scores. This supports claims in the literature liking psychological distress to poor retention [22, 108, 109]. Improved emotional wellbeing facilitates normal daily functioning increasing the capacity of participants to attend visits [99].

Treatment Adherence: We performed a sensitivity analysis with treatment-experienced HIV-positive participants in order to consider effects of treatment adherence. Adherence was only important among those with a non-recent diagnosis (diagnosis five or more years prior to visit). Adherence of 95% or greater was associated with improved retention, matching what has been described in the literature [104]. Among participants, poor adherence to medication may be a marker with non-adherence to other components of healthcare, which might be associated with poor retention in research.

Conceptual Framework

Maslow's Hierarchy of Needs is a conceptual framework developed by Abraham Maslow in 1943 to describe human motivation and behavior [41]. This framework has previously been used to describe the behavior of women living with HIV [134], and has been used to contextualize retention in research [36]. Maslow's theory posited that human behavior is shaped by the need to satisfy five levels of necessity. These necessities are hierarchical and shape human behavior in a stepwise manner (Figure 1). According to the model, humans act to first meet their physiological needs. This set of needs takes highest priority, is innately driven, and includes needs such as water and food. Safety and security needs are the next most important set of needs in defining behavior. This includes physical safety and wellbeing as well as emotional and economic security and other needs to remove anxiety and stress. Afterwards is the social level, which includes needs for belongingness. After this has been satisfied, the need to achieve status and self-esteem dominates behavior. Finally self-actualization, the need to achieve and be one's best perceived self, dominates behavior. Maslow's Hierarchy of Needs will be used help to inform our understanding of retention and attrition in the Atlanta WIHS cohort and which retention strategies are most appropriate for various sub-populations. According to Maslow's theory, participants struggling to meet basic physiological needs, such as shelter, might not prioritize behaviors that meet higher level needs. Additionally, the behavior of participants who have satisfied lower level needs such as economic security should no longer be dominated by these needs. Rather, their behavior should be shaped by the need to achieve self-esteem and self-actualization.

Since the WIHS is not a clinical trial, motivation for participation in WIHS must be understood in a manner distinct from other research in which participants receive a novel or otherwise

inaccessible intervention. *Previous characterizations of retention informed by Maslow's hierarchy of needs assumed that the research offers some health intervention or service, that participation in the research was a health behavior and driven by the need or desire of the intervention service, and that the need was low priority for low-SES populations struggling to meet basic physiological needs. However, the WIHS is not designed as an interventional study [117] and participation is not primarily driven by needs for treatment or intervention.* Rather, as an ongoing longitudinal, observational cohort study not offering clinical or mental health treatment, WIHS retention strategies rely on social cohesion and tangible and intangible incentives[11]. According to Maslow's conceptualization of motivation, Atlanta WIHS participants would seek benefits from attending WIHS visits as a means of satisfy unmet needs. With this understanding, we can further investigate the retention profile of the WIHS Atlanta cohort.

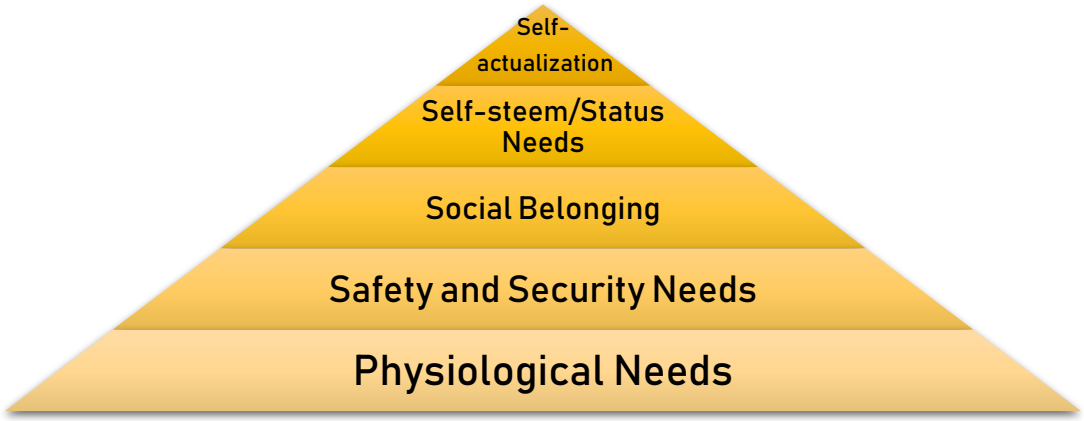

Figure 1. Maslow's Hierarchy of Needs

The Atlanta WIHS site provides financial remunerations and retention gifts such as cosmetics and personal hygiene kits to its participants. At all visits, snacks are also provided for participants to take freely. These snacks can be consumed at visits or afterwards. If needed, WIHS also offers transportation to and from visits via public transportation passes or money for

fuel so that visit attendance does not require any financial sacrifice. These incentives act to promote and sustain retention in the cohort. They can also address participants' physiological needs as described by Maslow, such as immediate hunger, thirst, and other needs that can be alleviated through small amounts of money. Therefore we can expect participants whose behaviors are being motivated by physiological necessities to value these incentives more and attend visits. These participants are likely to be low-income or unemployed.

Safety and security, the second stage of Maslow's hierarchy, includes security of health. The WIHS offers a structured method for some participants to keep up with their health. WIHS offers physical and gynecological exams as well as laboratory testing at each visit. While participants do not receive treatment, they can be referred to appropriate care if necessary. Participants with little or no access to care who are looking to ensure physical wellbeing may be interested in visits due to the exams and tests offered. For participants living with HIV in particular, the CD4 and viral load measurements can motivate attendance among participants who are seeking security of health. This could explain why education is a predictor of attendance among HIV-positive participants but not for HIV-negative participants.

Belongingness is the third stage of Maslow's hierarchy. WIHS participation seeks to foster community and social support. WIHS staff members provide safe and comfortable environments for participants and give each participant personalized attention. The Community Advisory Board advocates on behalf of the community and patients and works to foster social cohesion. The Atlanta site also hosts WIHS retention events. These community events are often social and/or educational events designed to strengthen the relationship between participants and staff as well as among the participants themselves. The WIHS has local and national branding strategies, complete with logos and color schemes. Branding helps to create a sense of identity

among those associated with the program [46, 135]. These retention strategies can help participants achieve satisfy the need for social belongingness. The need for belongingness might be higher in populations with history of incarceration compared those without, and participants with depressive symptoms compared to those without.

While satisfying the first three stages of the hierarchy can indirectly facilitate satisfaction of later stages, WIHS retention strategies do not directly address self-actualization, social status, or other aspects of the later stages. Therefore participants who have reached these stages might perceive low value in attending WIHS visits. Higher income participants, and educated HIV-negative participants compared to uneducated HIV-negative participants were more likely to miss visits.

In summary, using Maslow's hierarchy of needs, we can explain why low-income women were more likely to attend visits. Women who are more likely to have unmet needs in realms of physiological needs and safety and security are more likely to attend WIHS visits seeking benefits that meet these needs. In our sample, these were women with income of $12,000 or less and women with criminal justice involvement. There are undoubtedly other factors at play, such as capacity and self-efficacy, which are required for participants to actually attend visits. In accordance with this, we also found that emotional wellbeing is significantly associated with retention, while substance use is associated with missed visits.

Limitations

Limitations of this study include the smaller sample size among HIV-negative women in the Atlanta WIHS. Our sample included only 95 HIV-negative women, which reduced our capacity to include more variables in the HIV-negative regression model. A second limitation is the self-

reporting of baseline behaviors. Behavioral measures such as smoking, drug use, transactional sex, history of incarceration, and treatment adherence are based on responses of a single interview. While participants are made to feel as comfortable as possible, responses are still subject to social desirability bias. Further, responses to these variables may change over time, and affect missed visits over time. Accounting for time-varying variables and consideration of missed visits as a time-varying outcome will be the focus of future analyses of retention to study visits in this cohort. Finally, our reporting of income, which proved to a significant factor in this retention analysis, did not incorporate household size. Annual household incomes were reported and used for analysis without regard to varying household sizes or number of dependents.

In conclusion, our analysis demonstrates that a large cohort of women living with and without HIV with low SES can be effectively retained in a longitudinal observational research study over at least 5 years. Women who were retained were generally of lower SES than those who missed visits and incarceration was the strongest predictor of retention across all models. In this sample, predictors of retention in HIV-research did not correspond with predictors of retention in HIV care. As the WIHS is an observational cohort, the motivations for attending WIHS visits may be oriented around incentives and support rather than healthcare utilization. Maslow's hierarchy of needs would then explain why low-income participants have better attendance. Researchers should bear in mind that visit attendance and retention profiles observed in research cohorts may not be predictive of retention in care or healthcare utilization behaviors in that same population. Further investigation should employ qualitative methods to address the facilitators and motivations of research participation among low-income PLWH in order to design more effective retention strategies for research studies and for clinical interventions

PUBLIC HEALTH IMPLICATIONS

While historical arguments in health justice implied that research incentives could prevent low-agency populations from effectively considering risks of participation, current trends in health justice emphasize the importance of including marginalized populations in research [27]. Mandated by the NIH, the inclusion of marginalized populations in health research is a pre-requisite to the equitable distribution of research benefits. In particular, a complete understanding of HIV in the United States cannot occur without the involvement of African American populations, low-income populations, people who use drugs, and poorly educated populations. These groups, across all genders and sexualities, experience the highest incidence of HIV [136, 137].

Our findings suggest that populations with lower socioeconomic status were more likely to attend all WIHS visits. As the WIHS is not an interventional study, participant attendance is driven by perceived benefits of participation. Other studies have found that perceived benefits of participation include increased health knowledge, receiving an intervention or health service, financial and other tangible incentives, and altruism or the desire to give back [71, 138]. Low-income and criminal justice involvement were significant predictors of retention, implying that WIHS benefits appealed more strongly to these populations. Increased depressive symptoms were also associated with retention.

Other studies have identified low-income and depressive symptoms as predictors for study *attrition* [15, 82, 87, 99], as these participants might de-prioritize research visits due to other barriers. However, considering that the WIHS is an observational research study, the predictors of retention we identified can be understood under Maslow's hierarchy of needs. This framework

describes human behavior as endeavors to meet unmet needs, where basic physiological needs, safety and security, and needs for belongingness take priority. The financial incentives and social support offered by the WIHS can be a method of at least partially satisfying these needs. Meanwhile, participants who have met these lower-level needs might perceive less benefit in participation and therefore be more likely to miss visits, even if they are more likely to attend HIV care follow-up visits. In the case of participants with history of incarceration, increased utilization of case management services could be another factor accounting for their improved attendance compared to other participants.

Retention in HIV care has been investigated in depth. However, retention in HIV research has received less attention, but is critical to optimize the generalizability of research findings. While participants with better medication adherence were more likely to attend visits, the predictors of retention in HIV care do not immediately apply to retention in research. In clinical care, low-income and depressive symptoms are typically associated with poor retention, while these factors predicted improved retention in our study. Understanding this discrepancy is important for investigators involved in HIV research since the profile of participants who regularly attend research visits does not always reflect those who are most strongly engaged in care. Rather, individuals who are poorly retained in care could be better retained in HIV research, such as the WIHS, because the incentives provide a way to meet lower-level needs. This adds important context to the interpretation of findings.

In general, retention strategies should be guided by principles of respect for persons, maximizing benefits for participants, and intensive tracking and follow-up [46]. Several studies have investigated retention strategies for low-income or vulnerable populations [13, 29, 42, 139-142]. A summary of retention strategies identified by Robinson and colleagues can be found in Table 7

[135]; many of these are utilized by the Atlanta WIHS as noted in the examples, and others may be adapted based on the findings of this analysis to further optimize cohort retention.

Understanding the profile of participants who miss visits allows for targeted strategies to aid in the retention of these populations. For the Atlanta WIHS cohort, where women of higher socioeconomic status are more likely to miss visits, the Atlanta site should consider incorporating retention strategies to target these higher-SES populations. For example, having flexible scheduling and appointment slots, such as having a few evening or weekend appointment times, to accommodate the work or school schedule of participants. A second would be improving tracking methods for women who move, including social media and email, for which higher-SES women are more likely to engage with.

In conclusion, we have described the predictors of retention among a generally low-SES population of women living with HIV or at increased risk for HIV infection. The retention in the cohort was impressive given the behavioral and demographic characteristics of the cohort. African American and low-income women were well-retained demonstrating that these populations can be effectively retained with appropriate retention strategies. Our findings suggested that low-SES women and women with histories of incarceration were more likely to attend all visits than those with higher incomes. In observational HIV studies, in which attendance does not always indicate a health-seeking behavior, investigators should consider the inconsistencies between determinants of research participation and the determinants of retention in care. These determinants should be incorporated into a flexible and comprehensive retention plan to improve retention.

Table 7. Summarized Retention Strategies		
Goal	**Theme**	**Examples**
Strengthening trust	Community involvement	Advise with a community advisory panel in study design implementation, and retention and recruitment Use community sites for retention events
	Study identity	Develop study logo, slogan, and color schemes to be printed on gifts and study materials
	Study personnel	Keep continuity in study staff so that participants interact with the same individuals Train staff extensively Engage culturally-sensitive and empathetic staff
	Study description	Be transparent when describing requirements of study while emphasizing benefits
Address study level retention barriers	Contact and scheduling methods	Mail newsletters periodically Contact participants in between visits Collect multiple phone numbers if possible
	Reminders	Remind participants by phone and email one week before appointment
	Visit characteristics	Be flexible in scheduling Minimize wait times
	Special tracking methods	Conduct clinic and community outreach for LTFU participants
Maximizing perceived benefits	Benefits of study	Provide educational resources and free examinations
	Financial incentives	Provide incentives for control and intervention groups Increase incentives for later visits
	Reimbursement	Provide transportation passes or compensation for fuel
	Nonfinancial incentives	Provide retention gifts relevant to population

Table of summarized retention strategies (Robinson et al.)[135]

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