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Enhancing Patient Retention in HIV Care: A Quality Improvement Project of the Emory Infectious Diseases Clinic Ryan White HIV/AIDS Program

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Abstract

Enhancing Patient Retention in HIV Care: A Quality Improvement Project of the Emory Infectious Diseases Clinic Ryan White HIV/AIDS Program

By Ajay Walther

Background: While HIV is no longer considered a death sentence due to the availability of highly effective treatments such as Antiretroviral Therapy (ART), patients today still face significant psychosocial barriers to care, particularly those who live in poverty or are of lower socioeconomic status. Retaining these patients in care is critical to achieving viral suppression and slowing the spread of the virus. The Ryan White HIV/AIDS Program at the Emory Infectious Disease clinic aims to provide patients with HIV care and social services if they meet certain criteria. To achieve this aim, traditional methods of patient retention such as phone-based interventions must be analyzed for their effectiveness, which is what this study aims to explore as a quasi-experimental quantitative study.

Methods: The methods used in this study involved chart extractions to examine the differences in patient attendances for HIV care visits between July and October of 2022. Phone calls were made to patients to assess why they missed appointments and comments were qualitatively recorded. Additionally, reminder calls were made to patients for appointments the next day. A numerical code was used during three separate analyses to highlight the frequencies of reasons for missed appointments.

Results: From July to October, the first analysis showed that a majority of patients contacted did not answer the phone (46.15%, 57%, 43.14% and 41.18% for each month). A second analysis conducted only focused on patients who did answer the phone and found that many patients had already canceled or rescheduled their appointments before the call, as well as that patients were either sick or had medical issues that prevented them from showing up. The no-show and appointment attendance rates did fluctuate from month to month, though several clinic staff anecdotally noted that the no-show rate fell during the course of the intervention.

Conclusion: The data collected over the course of four months at the Emory Infectious Disease Clinic in Midtown Atlanta gives a somewhat clearer picture of the kinds of barriers that patients face to being retained in care, but also more importantly shows how many patients are unreachable by phone.

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Abbreviations

HIV: Human Immunodeficiency Virus

ART: Antiretroviral Therapy

AIDS: Acquired Immuno-Deficiency Syndrome

CDC: Centers for Disease Control & Prevention

MMWR: Morbidity and Mortality Weekly Report

FPL: Federal Poverty Line

LVR: Latent Viral Reservoir

VHA: Veterans Health Administration

SMS: Short Messaging Service

MSM: Men who have Sex with Men

NIH: National Institute of Health

MRN: Medical Record Number

DOB: Date of Birth

EMR: Electronic Medical Record

MARTA: Metropolitan Atlanta Rapid Transit Authority

Chapter 1: Introduction

Overview of The Problem

One of the trickiest diseases in the field of infectious diseases isn't a typical virus spread by coughs between people, but rather through fluids such as blood or sperm (Visseaux et al. 2019). Known as Human Immunodeficiency Virus, or HIV for short, this disease has been around since the 1980s and is still considered a threat to human health around the globe. The first two decades of the HIV epidemic particularly wreaked havoc and brought death upon hundreds of thousands of people, many of whom had very little time between diagnosis and death (Agarwal-Jans 2020). The epidemic was also defined by fear, stigma and insensitivity against the people most vulnerable to HIV's spread ("World Health Organization," n.d.).

At the time of the epidemic, there was no effective treatment for HIV and there currently is no vaccine or immediate cure available (Pace and Frater 2014). Fortunately, however, contracting HIV today is no longer considered the death-sentence it once was due to the development of highly effective treatments (Pace and Frater 2014; (De Cock, Jaffe, and Curran 2012). Thanks to rapid advances in drug discovery, antiretroviral therapy (ART) has proved to be highly effective in suppressing HIV inside a person's immune system, which considerably improves a patient's chances of survival and offers a longer, quality life (De Cock, Jaffe and Curran 2012). Nevertheless, the success of ART for people living with HIV depends on adherence to treatment and retention in medical care over the course of treatment ("HIV Care Continuum" 2022). Given that many people living with HIV today still face significant challenges, which include stigma as well as socioeconomic and psychosocial barriers to care, much work needs to be done in coming closer to HIV elimination (Dasgupta et al. 2021).

In particular, individuals living with HIV in the United States who have no medical insurance or are homeless have significant trouble staying in care long enough to achieve viral suppression (Dasgupta et al. 2021). Sometimes these factors result in patients not adhering to their treatment regimen. For patients who receive services from the Ryan White Program for HIV in Atlanta, Georgia, ensuring those patients remain in care and adhere to their treatment regimen is critical to achieving viral suppression. ("HIV Treatment Overview" 2022). Additionally, it's important to consider the psychosocial barriers that these patients may face. Since a qualification for services in the program in Fulton County Eligible Metropolitan Area in Georgia includes being 400% or below the Federal Poverty Line, lower-income patients may naturally experience barriers to care such as lack of access to transportation or technology, heavy stigma amongst family members or friends regarding HIV diagnosis, or food insecurity (Prabhu et al. 2020; "Department for HIV Elimination: Fulton County," n.d.).

Overview of The Project

Despite advances in technology that have made human capital less important, a traditional aspect of supporting patients to remain in care (retention) are phone calls to remind patients of appointments and follow-up phone calls to assess and address barriers to care among people who have missed HIV care appointments. With many hospital systems, including Emory in Atlanta, relying more and more on patient portal notifications (which can include text-messages or emails), having an empathetic, compassionate human voice to reach out to patients to remind them of appointments or make no-show calls is advantageous as well. Such calls have shown in studies to have a positive effect on provider-patient interactions and are likely to encourage patients to remain in care long-term (Finnegan 2016).

This study is a quality improvement project which will assess the effectiveness of patient retention efforts in the Ryan White Program of the Emory Infectious Disease Clinic in Atlanta. This project will analyze the effect of the implementation of pre-visit reminder phone calls over time on rates of missed visits for HIV patients. It will also explore the various reasons for missed visits through follow-up calls for those who missed appointments.

Chapter 2: Literature Review

What is HIV & What is The Ryan White Program?

HIV

Human Immunodeficiency Virus (HIV) is a virus that targets the human immune system and its working components and cells, which fight off infection and sickness. Isolates of HIV can be categorized into two groups - HIV-type 1 (HIV-1) and HIV-type 2 (HIV-2). HIV-1 is most commonly found around the world, while HIV-2's prevalence is limited to parts of Western and Central Africa (Fanales-Belasio et al. 2010). Upon invasion of the CD4 cell, a type of white blood cell that makes up the immune system, the virus replicates and kills the cell while new copies find other CD4 cells to kill. This pattern of invasion and replication renders the immune system defenseless when CD4 cells are killed overtime (Fanales-Belasio et al. 2010; Chatterjee 2010). Moreover, HIV-1 has been cited as the responsible factor for the onset and development of Acquired Immuno-Deficiency Syndrome (AIDS), the combination of both which had been, at a time, one of the leading causes of mortality among infectious diseases (Chatterjee 2010). While the viruses themselves aren't responsible for death, they weaken the immune system enough to render the human body completely vulnerable to other infections or conditions. Currently, no cure or vaccine exists for HIV elimination within the human body (Ng'uni, Chasara, and Ndhlovu 2020). However, effective treatments can prevent HIV from progressing to AIDS, which typically can happen around 10-15 years after initial infection without such treatment (Ng'uni, Chasara, and Ndhlovu 2020).

Since the 1980s, HIV has been one of the most challenging public health issues to tackle. Even well before the virus emerged, decades of globalization, urbanization and evolving patterns

of sexual contact contributed to rising transmission rates of various diseases (Padamsee 2020). June of 1981 saw the first cases of HIV and AIDS in Los Angeles, California among several gay men who showed signs of infection ("Centers for Disease Control & Prevention: National Prevention Information Network," n.d.). Since then, an explosion of cases around the United States and the world, resulting in what became a full-scale pandemic. Urban gay communities all around the U.S. bore the brunt of the disease (Padamsee 2020). Additionally, such communities showed differences in HIV-related health outcomes when intersecting with race. In Atlanta, Georgia, the location of this thesis study, studies show that black individuals living with HIV are more likely than their white counterparts to suffer from barriers to accessing care and structural racism than their white counterparts (Sullivan et al. 2021). All in all, from 1981 to 1990, state, local and territorial health departments reported 100,777 deaths among persons with AIDS to the Centers for Disease Control (C.D.C.), according to a Morbidity and Mortality Weekly Report (MMWR) from 1991 ("CDC Morbidity & Mortality Weekly Report" 1991). Among these deaths was a boy from the Midwest.

The Ryan White Program

Originally from Kokomo, Indiana, Ryan White was a 13 year old boy who was diagnosed with AIDS following a blood transfusion. Having faced AIDS-related discrimination in school, White became the face of public education about the disease ("HRSA: Ryan White HIV/AIDS Program," n.d.). Although White was remarkably able to live 5 years longer than expected, he died in 1990 just before his high school graduation. Subsequently, a program was passed by the Congress of the United States called the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act of 1990 ("HRSA: Ryan White HIV/AIDS Program," n.d.). This program aimed to deliver HIV care to underserved communities across the United States by operating as a "payer

of last resort" (Bradley et al. 2016). The program provides funds directly to HIV-care clinics, which research suggests generally perform better than other facilities which provide HIV medical care without the program (Bradley et al. 2016; Valverde et al. 2004; Weiser et al. 2015). In fact, the program boasts high levels of achieving viral suppression particularly among retained patients, according to a 2011 study analyzing the U.S. HIV safety net system (Bradley et al. 2016; Hirschhorn et al. 2009; Doshi et al. 2015). The study found that 82.2% of patients who had at least 1 medical visit in 2011 had been retained in care - meaning the patients had at least 2 HIV medical care visits at least 90 days apart - and 72.6% achieved viral suppression (Doshi et al. 2015). However, funding levels from Ryan White depend on discretionary grants based on annual appropriations from Congress, which have remained somewhat stagnant from 2015 to 2021, but increased slightly in 2022 ("HRSA: Ryan White Program Budget," n.d.). These funds are ultimately necessary to keep these rates of retention and viral suppression high.

The Ryan White program aims to fill the gap of HIV medical coverage by serving people living with HIV who otherwise cannot afford, or do not qualify for, other kinds of medical insurance, whether it be Medicare, Medicaid, or private health insurance (Ginossar et al. 2019). More broadly speaking, the program has **four** specific goals: 1) Reduce new HIV infections, 2) Open more access to care and improve outcomes for people living with HIV, 3) Reduce HIV-related health disparities and inequities, and 4) Contribute to a more coordinated national HIV-epidemic response ("HRSA: Ryan White Program National Strategies" 2020). In order to be eligible to receive services through the Ryan White Part A program via the Fulton County Eligible Metropolitan Area funds, a patient must meet the following criteria:

- Have documentation for a positive HIV diagnosis
- Proof of residency in one of 20 designated counties making up the Atlanta Metro region:

    - Barrow, Bartow, Carroll, Cherokee, Clayton, Cobb, Coweta, DeKalb, Douglas, Fayette, Forsyth, Fulton, Gwinnett, Henry, Newton, Paulding, Pickens, Rockdale, Spalding and Walton
- Have an income of ≤ 400% of the most current Federal Poverty Level (FPL)

*Source: ("Department for HIV Elimination: Fulton County," n.d.)

Treatment Regimen and Continuum of Care for HIV

Antiretroviral Therapy

As previously mentioned, HIV is a disease which has no immediate remedy or vaccine. Decades of research and study of HIV has not been able to yield an effective instant cure-all because of the complicated nature of the disease (Pace & Frater 2014). Specifically, HIV-1 has the ability to integrate itself into the genomic DNA of host cells within the immune system and establish a Latent Viral Reservoir (LVR), enabling its permanent presence in the human body (Poon et al. 2018).

While HIV may not be able to be cured, research has come a long way in the development of effective therapies that have turned the disease from a death sentence into a manageable illness. The most notable form of therapy is known as Antiretroviral Therapy (ART). This form of therapy is a combination of medicines that are prescribed by an HIV patient's doctor and are taken over a period of time to the point where a patient reaches what is known as "viral suppression" - the virus can no longer replicate and is undetectable in the human body, therefore unable to spread to other individuals (Lozano and Domingo 2011; Antiretroviral Therapy Cohort Collaboration 2008). Mortality and morbidity are reduced greatly with ART intake due to the increase in CD4 cells - white blood cells that build the immune system - increasing (Mocroft et al. 2007). A study published in the Lancet medical journal found that even in communities with high levels of risky sexual behavior, the combination of ART usage is still effective (Velasco-Hernandez, Gershengorn, and Blower 2002). Among the gay community in

the San Francisco area, the value of R(0) (ART) - which signifies the average number of novel infections that a single HIV case produces during their lifetime when ART is available - stood at 0.90 (0.85-0.96) if risky sex decreased, 1.0 (0.94-1.05) if risky sex remained stable, and 1.16 (1.05-1.28) if risky sex increased. Additionally, the probability of epidemic eradication stood at a high level (p=0.85) in the decreased category, a moderate level (p=0.5) in the stable category, and a low level (p=0.13) in the increased category. Therefore, the researchers were able to conclude that intake of ART can still be effective and beneficial in preventing HIV transmission even among high levels of drug-resistance and risky sex (Velasco-Hernandez, Gershengorn and Blower 2002). Overall, the intake of ART has been shown to increase life-expectancy for people living with HIV. Another study published in the Lancet found that life-expectancy among 20 year old HIV patients increased starting ART increased by about 9 years in women and 10 years in men on average between the years 1996 and 2010, having analyzed data from 18 European and North-American HIV-1 cohorts (Trickey et al. 2017). Generally, once viral suppression is achieved, an HIV patient can live normal healthy lives even as much as their HIV-negative peers (Wandeler, Johnson, and Egger 2016).

The Continuum of Care

The usage of ART is only one part in what's known as the “continuum of care” - a five-step chain that HIV patients must follow to achieve the ultimate goal of viral suppression. The continuum starts with the **first** step of receiving a positive HIV diagnosis, which can only be achieved through testing. The **second** step involves linking the HIV-positive patient to appropriate medical care, which is often in the form of seeing a licensed medical physician. The **third** step involves receiving the appropriate medical care, often in the form of adhering to the treatment regimen. The **fourth** step involves being retained in care - ensuring that patients

continue to meet and consult their healthcare providers. The **fifth** and final step is achieving and maintaining viral suppression ("HIV Care Continuum" 2022). While each of these steps are critical in the chain of HIV care to achieving the ultimate goal of undetectability of the virus, one of the most challenging aspects involves retaining patients in medical care. An HIV surveillance supplemental report found that for all people reportedly living with HIV in the U.S. in 2019, the lowest category pertained to patients retained in care, standing at 50% ("CDC: HIV Surveillance Report" 2019). Improving these levels is a small but necessary step to limiting the spread of HIV, and the focus of the Ryan White program involves investing heavily in analyzing ways to keep patients retained in care.

Barriers & Facilitators to Retention in HIV Care

While much is known about retention for HIV patients overall, more research is likely needed to address psychosocial barriers to care. Whereas quantitative studies have been successful at describing demographic and clinical characteristics associated with retention of HIV patients, qualitative studies are needed to fill the gap of describing what specific barriers and facilitators patients face (Yehia et al. 2015).

What are the Barriers?

A barrier to care may be defined as "factors in a person's environment that, through their absence or presence, limit functioning and create disability" ("CDC: Disability Barriers," n.d.). A study published in the peer-reviewed journal BMC Infectious Diseases found, through semi-structured interviews that some of the most common barriers identified by HIV-infected individuals overall, a number of barriers which include (but are not limited to) competing life activities, feeling sick, stigma, depression and mental illness, forgetfulness and insufficient health insurance (Yehia et al. 2015). Other studies were able to probe further, and one study from

2017 found that retention of veterans living with HIV who received treatment from the Veterans Health Administration (VHA) depended heavily on their perceptions of the clinical experience (Wessinger et al. 2017). For example, participants who were not retained in care experienced barriers such as high clinic wait times, low confidence in clinicians and customer service concerns (Wessinger et al. 2017). Based on the criteria that must be met to receive services through the Ryan White program regarding income level and geographic location, one can assume that patients who meet such criteria face a host of additional barriers to staying linked to care. This thesis will expand on such barriers, which were found to include a lack of affordable or easily accessible transportation, homelessness, and lack of access to technology among others.

What are the Facilitators?

Indeed, patients who are successfully retained in HIV care have typically reported positive experiences associated with their clinical journey. Such experiences could include the inverse of many of the barriers described: having an easier time scheduling appointments, high quality customer service and positive perceptions of healthcare institutions (Wessinger et al. 2017). Additionally, socioeconomic factors such as higher levels of income, access to health insurance and social capital & support could all lead to a higher likelihood of being retained in care (Yehia et al. 2015). A case study examining barriers and facilitators from North Carolina found that patients with few financial problems are more likely to prioritize their care than those who have significant problems and must worry about other necessities, such as feeding families (Berger et al. 2016). Since the Ryan White program in Atlanta assists patients who struggle from such hardships by providing insurance and coverage for care, the primary facilitators to pay

attention to are those at a systematic and institutional level. One such facilitator involves interacting with patients over the phone to keep them retained in care.

The Power of Phone Calls & The Value of Human Interaction

Human vs. Non-Human

Interactions between patients and healthcare providers can come in a multitude of different forms. For the purposes of this study, these types of interactions can be split into two categories: human and non-human. Some examples of non-human interactions between provider and patient, which lie in the realm of automation and technology, can include text-message reminders, emails or patient portal messages. On the other hand, human interactions will often take the form of face-to-face interactions or, more conveniently, phone calls with a human voice on both ends as opposed to a human voice on one end of the phone and a robotic voice on the other.

Just how effective are these kinds of approaches compared to one another? Most available research paints a bit of a mixed picture. Automated forms of interaction certainly can be valuable in how efficiently patients can be contacted and reminded of appointments, reducing the burden on hospital offices and providers to do so. However, human forms of interaction are quite effective at retaining patients overall because of the ability of a compassionate human voice to establish trust (Finnegan 2016). A meta-analysis study of mobile phone reminders on HIV patients' retention to care found a roughly equal effectiveness between reminders using text messages and phone calls (Jong, Cuca and Thompson 2017). However, this finding was mostly limited to resource-limited settings spanning several nations in Africa, mostly among women with young infants, and was inconclusive about the impact of short messaging service (SMS) on clinical attendance across settings (Jong, Cuca, and Thompson 2017). The study makes a

reasonable assumption that mobile reminders, whether they be text or phone-based, will continue to be effective as long as mobile phone ownership increases across the globe. Another study utilizing a randomized control trial in the academic primary care division of the Geneva University Hospitals in Switzerland came to roughly the same conclusion of relatively equal effectiveness between text message reminders and phone call reminders (Junod Perron et al. 2013). While this study did reaffirm that text-messaging is less of a resource-demanding option that phone calls, the authors also noted another study which performed a prospective, randomized, parallel design clinical trial on patients of specialty outpatient practices (one of which included allergy/infectious disease) at the Robert Wood Johnson Medical School in New Jersey (Parikh et al. 2010). This study actually found that clinical phone reminders to patients was more effective than automated reminders, contrasting no-show rates of 13.6% and 17.3% respectively (Parikh et al. 2010). A clinical phone call also has the advantage of being able to communicate to and collect critical information from patients during reminders that automated information cannot, such as giving directions to the clinic, answering real-time questions, and perhaps collecting miscellaneous information of consequence.

A phone call can be a powerful tool in linking patients and providers and ensuring higher patient retention, but only if performed carefully. A study conducted by the Baird Group, a Wisconsin-based consulting group, found that 35% of callers may not return to a medical practice or appointment if they had a negative experience during the first call (Baird and Callahan 2016). The study recommended several strategies to create a good first impression:

- Introducing themselves in a friendly and reassuring manner
- Speaking slowly and clearly without interrupting the patient

- Scheduling appointments sooner than later (callers offered appointments more than 2 weeks out were 4.4 times less likely to stay within practice)

Aspects of Patient Retention - Two Types of Calls

As part of a quality improvement project, the Emory Infectious Diseases Ryan White HIV/AIDS Program initiated a pilot program including patient reminder calls regarding upcoming appointments and follow-up phone calls to assess/address barriers to care among people who missed clinic visits. Data in support of these approaches is provided in the sections below.

Pre-Visit Reminder Phone Calls

Before a patient is due for their appointment, a reminder call sometimes is made to remind the patient by specifying the time, date and location of their appointment. Much of the current literature has focused largely on examining how reminder calls affect patients' adherence to treatment as opposed to reducing no-show rates. One study conducted by researchers at Wake Forest University focused largely on how reminder calls and interventions positively affected medication adherence rates (West et al. 2012). Remarkably, it was found that patients had a higher average adherence rate when contacted by a traditional or automated phone call as opposed to a text message, with rates standing at 67.65% and 51.31% respectively. This finding reinforces conclusions from the previous study from New Jersey on the higher effectiveness of phone calls, though no distinction is made between human and automated calls (West et al. 2012; Parikh et al. 2009). The researchers acknowledged, however, that what exactly is being communicated through phone calls has a complex relationship with how likely a patient will adhere to treatment or come to their appointment. Pre-visit reminder calls are generally supposed to be simple and short, so as to not overly burden a patient with too much information. A

different randomized control trial, which focused on telemedicine HIV visits during the COVID-19 pandemic, found that simple standard reminders were adequate for patients reachable by phone and did not require a pre-visit intervention to assist with barriers to telemedicine (Hickey et al. 2023). This study, however, warned that additional interventions will be needed for patients experiencing homelessness or who have poorly-controlled HIV. Those additional interventions were not specified. Overall, the literature on pre-visit reminders shows that the overall effect of the practice is complicated and is based on a number of factors, from the content of the call to the needs and demographics of a specific patient. However, the literature also shows that simple pre-visit reminder calls make a meaningful difference for patients.

Follow-Up Calls for Missed Visits

The second type of call a provider's office or clinic can make to patients is a follow-up call. For the purpose of this study, follow-up calls are made to patients who miss their appointments, whether routinely or on a one-time basis. Follow-up calls can typically be made to inform patients of their missed appointments as well as to reschedule. The Ryan White Program's efforts for follow-up include asking patients why they missed their appointments for the purpose of addressing any potential barriers to care.

Research on the effect of follow-up calls for missed visits in reducing future no-show rates is currently very limited. Most literature focuses on varied aspects of follow-up such as potential to detect and mitigate unresolved problems or assessing clinical status (Houser et al. 2013; Zorc et al. 2003). One study, however, did highlight promising evidence of the effect of follow-up calls in increasing subsequent visits (Blank et al. 1996). The study focused on case managers' responses to failed appointments for 83 persons with mental health disorders in a rural community mental health center. The study found that patients who received follow-up calls or

letters were much more likely to attend subsequent appointments in the future than patients who received no follow-up at all, though equal likelihood was reported between follow-up calls and letters. Clients who received no follow-up were noted as being more likely to receive emergency services rather than a regular appointment as their next contact with their clinic. This is a scenario which the Emory Ryan White Program hopes to avoid by boosting efforts to patient retention through these calls.

Gaps in Literature

What More Must Be Done?

Plenty of literature currently exists across a plethora of dimensions regarding the HIV epidemic, built off work conducted battling the disease at its height in the 1980s and 90s. However, research becomes more and more limited as specificity to patient retention for HIV patients in the Ryan White program goes on. Phone calls to patients have been highlighted as an effective way to retain patients in care overall, yet more must be studied to clearly understand how these human-based interactions work among Ryan White patients in Atlanta, who have many psychosocial barriers to care that must be addressed. There is a need to understand these strategies better so that patients can remain linked to care and achieve their ultimate goal of viral suppression, thereby reducing the burden of HIV among poorer individuals in the metro Atlanta region.

The goal of this thesis is to assess the process and effectiveness of patient retention efforts (i.e., (1) appointment reminder phone calls and (2) calls to assess and address challenges faced to attending their clinic visit) in the Emory Infectious Diseases Clinic Ryan White HIV/AIDS Program between July and October 2022 when data was collected. This research will fulfill a previous knowledge gap of analyzing the quality of human-based forms of patient

interaction for Ryan White patients in reducing no-show rates, compared to the status quo of patient portal and automated reminders. The findings of this thesis could have implications for how these efforts can be similarly applied to Ryan White programs across the United States.

Chapter 3: Methodology

Overview of Methods

The main methods used in this study will involve chart extractions before and after the intervention calls (i.e., appointment reminder calls and calls assessing/addressing challenges to attending clinic visits) to evaluate whether there were differences in patient attendance of HIV care visits. This method will aim to examine several principal tenets. The first tenet will pertain to the implementation of pre-visit reminder phone calls, seeking to investigate if the percentage of missed visits declined overtime for patients who see specific providers. The second tenet will pertain to the pre- and post-implementation of follow-up calls for missed visits, seeking to understand the overall reasons for missed visits and how those reasons may or may not change overtime.

Basic Structure

Setting

The study took place in the city of Atlanta, Georgia, in the United States. Data was collected in the Emory Infectious Disease Clinic of the Emory University Hospital Midtown, located in the heart of the city. The clinic is located on the 7th floor of the Medical Office Tower and is where services for the Ryan White HIV/AIDS Program are delivered. The larger hospital serves residents of not only Atlanta, but also Georgia and the larger southeastern United States. This region has been characterized as a concentrated one in the HIV epidemic due to high levels of poverty, underinsured people, and MSM (men who have sex with men) populations as well as social drivers such as stigma, racism, and homophobia (Hixson et al. 2011). In fact, the Deep South - which was defined in a 2019 study from researchers at the National Institute of Health

(NIH) as the states of Texas, Louisiana, Mississippi, Alabama, Tennessee, Georgia, South Carolina, North Carolina and Florida - were higher than all other major regions of the United States despite a promising steady decline overtime (Watson et al. 2019). HIV diagnosis rates in the Deep South were 45% higher than other southern states - Arkansas, Delaware, District of Columbia, Kentucky, Maryland, Oklahoma, Virginia and West Virginia - which have a combined rate similar to that of the U.S. average of 17 per 100,000 persons (Watson et al. 2019). There's been no evidence to suggest that these trends have changed.

Population & Timeframe

The individuals who were the focus of this quality assessment were patients in the Ryan White program who were linked to care in the Infectious Disease clinic at Emory University Hospital Midtown. In order to qualify to receive services through the Ryan White program, patients had to meet specific criteria: namely that they lived in the 20 designated counties surrounding the metro Atlanta region and that they were designated at or below 400% of the federal poverty line (refer to criteria on pages 6-7). Moreover, this study was conducted at the hospital from early July to late October of 2022. Therefore, only patients who attended, or were scheduled to attend appointments during this timeframe were considered participants for this quality assessment.

Study Design

The study carried out is designed as a quasi-experimental quantitative study because the analysis was conducted to examine patient retention in care pre- and post-implementation of the phone calls. For 3-4 days of the week, phone calls were made to patients who either missed their appointment from the previous day/couple of days or had an upcoming appointment the following day.

Intervention

For the first set of patients, a list was compiled by the office Supervisor of Business Operations which detailed which patients had missed their appointments on a particular day. The list would show their medical record number (MRN), date of birth (DOB), what time their appointment was supposed to be, and with which healthcare provider. Patients who missed appointments with nurses in the clinic were not counted for this study. Patients who were marked as "deceased" in the electronic medical record (EMR) system were also not counted. All other patients were contacted via office telephone. Calls would first be attempted on a patient's cell phone number, followed up by a home phone number if the cell was unsuccessful, although messages would be left regardless. If a patient answered the phone, their birthdate would first be verified. This step was critical to determine the identity of the patient on the phone, since a discussion of HIV-related material is subject to harmful stigmatization if other individuals related to the patient were to find out their diagnosis. Once verified, the patient would be notified of their missed appointment and would be asked to provide reasoning as to why they missed their appointment.

For the second set, another list was compiled for patients who had appointments the next day with the clinic's Physician Assistant. A similar phone call procedure was made to remind patients of their appointment for the next day. If a patient answered the phone, their identity would be verified by confirmation of their birthdate. Once this step is completed, the patient would be reminded of their appointment and asked to confirm that they will be present. If a patient says they will be, the caller will make sure the patient knows the location of the hospital and clinic, as well as identifying any potential transportation issues that may arise before the conversation ends. If a patient says they can't make it to their appointment, they will be

redirected to the call center for assistance in canceling or rescheduling their appointment. If a patient has foreseen transportation issues, they will be redirected to their social worker for assistance.

For both the first and second set of patients, specific scripts were drafted and adhered to as a way of guiding the caller through the initial interaction. Copies of these scripts for the first and second sets can be found in **Appendix A** and **Appendix B** respectively.

Data Collection

As phone calls were being made regarding both missed visits and appointment reminders, excel charts were made each day for compiling qualitative data for calls of each variety. The order of the columns were structured according to **Figures 1 and 2** below:

Figure 1: Column structure of excel charts for patients who missed their appointments

	A	B	C	D	E	F	G	H
1	**Name of Patient**	**Medical Record Number (MRN)**	**Date of Birth**	**Phone Number**	**Date of no-show**	**Provider**	**Date of Attempted Contact**	**Comments**

Figure 2: Column structure of excel charts for patients who were reminded of appointments

	A	B	C	D	E	F	G	H
1	**Name of Patient**	**Medical Record Number (MRN)**	**Date of Birth**	**Phone Number**	**Date/Time of Appointment**	**Provider**	**Date of Attempted Contact**	**Comments**

Under the “Comments” section, the caller would write down comments relevant to the content of the call. In the case of no-show calls, this content would largely include reasons why the patient missed their appointment. However, the content could also include (but is not limited to) patients who claim they rescheduled their appointments already, patients who are unsure of why they were being called, patients who had moved away, or patients who didn’t answer the phone and

received a message from the caller. In the case of reminder calls, the content written down in the comments section was more simplistic. If patients confirmed their appointment, such would be written that they knew of their appointment and were due in the office. However, some patients who couldn't make their appointments would have their reasons for not confirming their attendance written down.

For patients in both types of calls who didn't answer the phone, the comments would specify if a voicemail was left. If one wasn't left, further specification would include whether the mailbox was full or if the number was no longer functional. This specification could assist the clinic in identifying better ways to contact certain patients in the future, which could include updating their contact information based on changing phone numbers.

Finally, data showing the number of missed visits, the number of arrived appointments and the number of canceled appointments between 2 and 24 hours before the appointment was provided by the Patient Access Operations Manager. This data highlights the no-show rate of the Physician Assistant's patients on a monthly basis from April to September of 2022 to give a look into how the rate changed before and during the intervention.

Analysis Methods & Use of Numerical Codes

Analysis Methods of Psychosocial Barriers to Care

In order to analyze the frequency of psychosocial barriers to care and how they fluctuate overtime, the most commonly identified barriers were coded numerically as a way to have their frequency added up in proportion to how many total calls were made for each month. **Figure 3** below displays the numerical code, with different numbers assigned to different reasons:

Figure 3: Numerical code for reasons of missing visits

1 = "Patient didn't know appointment was today, thought it was a different day"
2 = "Patient didn't know he/she had an appointment today at all"
3 = "Patient tried to cancel/reschedule appointment but couldn't"
4 = "Patient showed up a bit late but they could not accommodate"
5 = "Patient has transportation issues"
6 = "Patient has shift in work schedule"
7 = "Patient was sick/having medical issues and could not make it"
8 = "Patient was out of town"
9 = "Patient knew of appointment but simply forgot"
10 = "Patient has busy hectic schedule"
11 = "Patient has moved out of state/service network"
12 = "Patient already canceled/rescheduled missed appointment/delay in system"
13 = "Patient had an accident"
14 = "Patient receives care from elsewhere"
15 = "Patient gives no coherent/good reason"
16 = "Patient did not answer phone"
17 = "Other reason"

These numbers were assigned to these reasons for missing appointments as a way to assess what the frequency of each barrier to care was for each month of the intervention. The numbers would be tallied by how many times they appeared in a particular month, and that tally would be divided by the total number of calls made for that month to come up with frequency in the form of a percentage. In particular, the top three reasons for missing appointments were scrutinized and highlighted. The intervention lasted for a total of 4 months, starting in July and lasting till October of 2022. While it was included in the numerical code to be representative of reasons that were unlisted, reason #17 showed a relatively high frequency in this secondary analysis. Some reasons listed in the recorded comments from the charts that were encompassed under 17 included (but are not limited to), *"....patient believed follow-up wasn't necessary...."* or *"....patient already spoke with provider..."* or *"....patient had family emergency...."* Because these reasons were wide-ranging, it was deemed best to have them condensed into one reason for the numerical code listed as "unlisted reason."

Analysis Methods for Non-Answering Patients

Because the largest share of patients who missed appointments didn't answer the phone, a third analysis was conducted to further scrutinize the nature of unanswered calls. Specifically, this analysis divided the unanswered calls into the following groups: patients who didn't have a working number, those for whom a voicemail was left, and those who had a full or unestablished mailbox.

In order to calculate the frequency of these categories, a similar numerical code was used in the charts to tally how many times each category arose throughout the course of the intervention only when reason #16 showed up. This new numerical code is shown in **Figure 4** below:

Figure 4: Numerical code for categories of unanswered calls

101 = "Patient didn't have a working phone/call couldn't be completed as dialed"
102 = "Patient had a working number but a voicemail was left"
103 = "Patient had a working number but mailbox was full"

Chapter 4: Results & Analysis

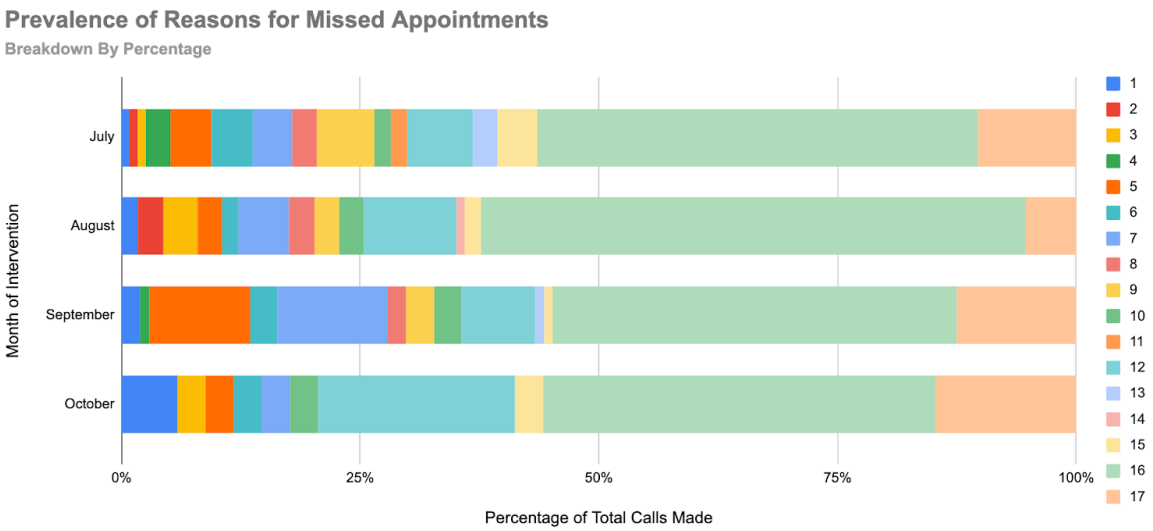
Effect of Pre-Visit Reminder Phone Calls

Results of Psychosocial Barriers to Care

The analysis of the most prevalent reasons for missing appointments showed some consistencies and some fluctuations over the course of the intervention. In the month of July, the top three reasons with the highest frequency were 16 (46.15%, *n* = 117), 17 (10.26%, *n* = 117) and 12 (6.84%, *n* = 117). This means that out of 117 total calls made for that month, 46.15% of patients did not answer the phone, 10.26% of patients missed their appointments for another unlisted reason (i.e. family emergency, technology issues, etc.), and 6.84% of patients had already canceled or rescheduled their appointments ahead of the call. In the month of August, the top three reasons with the highest frequency were 16 (57%, *n* = 114), 12 (9.6%, *n* = 114) and a tie between 7 and 17 (5.26%, *n* = 114). This means that out of 114 total calls made for that month, 57% of patients did not answer the phone, 9.6% of patients had already canceled or rescheduled their appointments ahead of the call, and 5.26% of patients either had medical issues or couldn't make it for an unlisted reason. In the month of September, the top three reasons with the highest frequency were 16 (43.14%, *n* = 102), 17 (12.75%, *n* = 102) and 7 (11.76%, *n* = 102). This means that out of 102 total calls made for that month, 43.14% of patients did not answer the phone, 12.75% of patients missed for an unlisted reason, and 11.76% of patients were sick or had medical issues. It's important to note that while 102 calls were made for September, 2 of the calls listed more than one reason for a patient missing an appointment. Finally, in the month of October, the top three reasons with the highest frequency were 16 (41.18%, *n* = 34), 12 (20.59%, *n* = 34) and 17 (14.71%, *n* = 34). This means that out of 34 total calls made for that month,

41.18% of patients did not answer the phone, 20.59% of patients had already canceled or rescheduled their appointments ahead of the call, and 14.71% of patients missed due to an unlisted reason. **Figure 5** below gives a breakdown of this analysis by percentage for each month:

Figure 5: Breakdown of Analysis #1 which considers unanswered calls



*Note: Colored boxes to right of chart signify the numerical codes of reasons from Figure 5

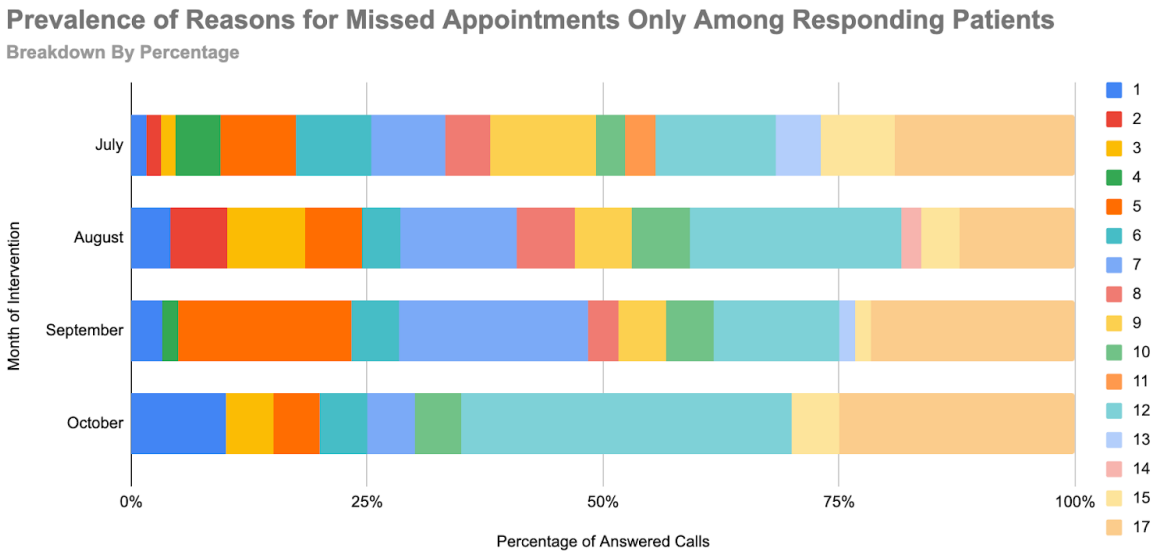
As the data shows, reason #16 shows most consistently to be the most prevalent across all 4 months of the intervention. The majority of patients contacted did not answer the phone. This reason was followed by other reasons of high frequency, such as having already canceled or rescheduled appointments before the call, indicating that there might be a delay in the system since these patients are still counted as no-shows. Some of the least prevalent reasons include reasons like #11 (patients moved out of the state or service network) and #15 (patient gave no good or coherent reason).

Because reason #16 was consistently ranked the most prevalent reason, a second analysis was performed to further analyze the frequency of reasons in which patients who didn't answer the phone were not included. This was done to solely consider reasons for missing appointments that were actually provided to the clinic, since patients who didn't answer the phone were very unlikely to respond unless they contacted the call center to reschedule their missed appointments. This secondary analysis highlights a high frequency of additional reasons that have not yet been considered.

In the month of July for the secondary analysis which didn't include reason #16, the top three reasons with the highest frequency were 17 (19%, $n = 63$), 12 (12.7%, $n = 63$) and 9 (11.11%, $n = 63$). This means that out of 63 total calls in which patients answered the phone for that month, 19% of patients missed for an unlisted reason, 12.7% of patients had already canceled or rescheduled their appointments ahead of the call, and 11.11% of patients knew of their appointment but simply forgot about it. In the month of August for the secondary analysis, the top three reasons which had the highest frequency were 12 (22.4%, $n = 49$), a tie between 7 and 17 (12.2%, $n = 49$) and 3 (8.2%, $n = 49$). This means that out of 49 total calls in which patients answered the phone for that month, 22.4% of patients had already canceled or rescheduled their appointments ahead of the call, 12.2% of patients either had medical issues or couldn't make it for an unlisted reason, and 8.2% of patients tried to cancel or reschedule their appointment ahead of time but couldn't (possibly due to long wait times at the call center or some other reason). In the month of September for the secondary analysis, the top three reasons with the highest frequency were 17 (22.41%, $n = 58$), 7 (20.7%, $n = 58$) and 5 (19%, $n = 58$). This means that out of 58 total calls in which patients answered the phone, 22.41% of patients missed their appointment due to an unlisted reason, 20.7% of patients were sick or had medical

issues, and 5% of patients had issues related to transportation. Finally, in the month of October for the secondary analysis, the top three reasons with the highest frequency were 12 (35%, *n* = 20), 17 (25%, *n* = 20) and 1 (10%, *n* = 20). This means that out of 20 total calls in which patients answered the phone, 35% of patients had already canceled or rescheduled their appointments ahead of the call, 25% of patients missed their appointments due to an unlisted reason, and 10% of patients thought their appointment was scheduled for a different day instead of the actual day. **Figure 6** gives a breakdown of the results of this secondary analysis by percentage for each month:

Figure 6: Breakdown of Analysis #2 which does not consider unanswered calls



*Note: Colored boxes to right of chart signify the numerical codes of reasons from Figure 6

The data here shows that reasons #12 and #17 largely dominate the field in higher frequency. However, this chart shows more clearly the importance of other barriers to care such as a lack of

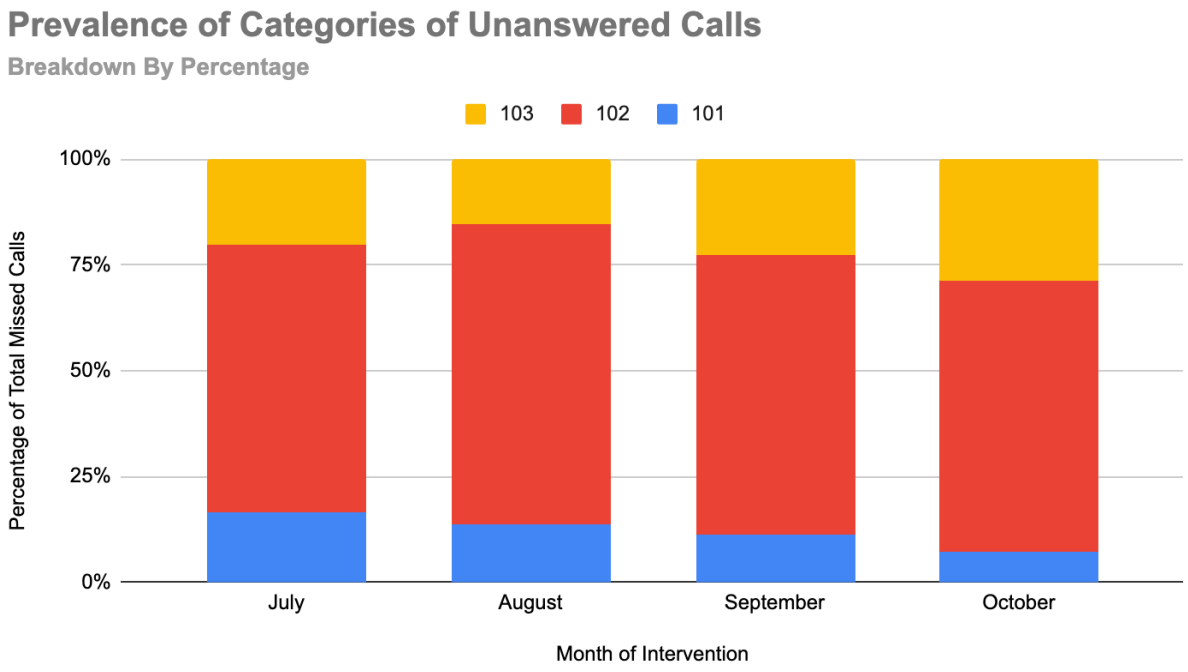
transportation or medical issues, which make it more difficult for patients to attend their appointments.

Results for Non-Answering Patients

For the month of July, it was found that patients who had a working number but had a voicemail left made up the largest fraction of unanswered calls (62.97%, $n = 54$) and total calls overall (29.1%, $n = 117$). The category of patients who had a working number but a full mailbox made up the next highest percentage of both total missed calls (20.36%, $n = 54$) and total calls overall (9.35%, $n = 117$). The category of patients who didn't have a working phone or the call couldn't go through made up the lowest frequency of the three categories for both total missed calls (16.67%, $n = 54$) and total calls overall (7.7%, $n = 117$). For the month of August, it was found that patients who had a working number but had a voicemail left for them made up the highest frequency of both total missed calls (70.8%, $n = 65$) and total calls overall (40.4%, $n = 114$). The category of patients who had a working number but a full mailbox made up the next highest frequency of both total missed calls (15.4%, $n = 65$) and total calls overall (8.7%, $n = 114$). The category of patients who didn't have a working phone or the call couldn't go through made up the lowest frequency of the three categories for both total missed calls (13.8%, $n = 65$) and total calls overall (7.9%, $n = 114$). For the month of September, it was found that patients who had a working number but had a voicemail left for them made up the highest frequency of both total missed calls (65.9%, $n = 44$) and total calls overall (28.44%, $n = 102$). The category of patients who had a working number but a full mailbox made up the next highest frequency of both total missed calls (22.7%, $n = 44$) and total calls overall (9.8%, $n = 102$). The category of patients who didn't have a working phone or the call couldn't go through made up the lowest frequency of the three categories for both total missed calls (11.36%, $n = 44$) and total calls

overall (4.9%, *n* = 102). Finally, for the month of October, it was found that patients who had a working number but had a voicemail left for them made up the highest frequency of both total missed calls (64.28%, *n* = 14) and total calls overall (26.47%, *n* = 34). The category of patients who had a working number but a full mailbox made up the next highest frequency of both total missed calls (28.57%, *n* = 14) and total calls overall (11.77%, *n* = 34). The category of patients who didn't have a working phone or the call couldn't go through made up the lowest frequency of the three categories for both total missed calls (7.14%, *n* = 14) and total calls overall (2.94%, *n* = 34). **Figure 7** below visualizes these trends across the duration of the intervention, which remarkable stay fairly consistent:

Figure 7: Breakdown of Analysis #3 which solely examines unanswered calls



*Note: Colored boxes on top of chart signify the numerical codes of reasons from Figure 7

This data clearly shows category #102 consistently maintaining the highest frequency throughout the duration of the intervention, followed by category #103 and then category #101. The majority of patients who did not answer the phone were left a voicemail by the office, whereas the lowest proportion of patients who did not answer the phone did not have a working number to reach or the call couldn't be completed as dialed.

Effect of Intervention on Appointment Attendance Rates

Rate of No-Shows

Data provided by the Patient Access Operations Manager shows the no-show rate from April to September 2022 for the Physician Assistant's patients. It's important to note that the number of no-shows are defined as the number of times patients didn't show up to appointments, as opposed to the number of patients total who missed appointments. This means that a patient could have missed an appointment multiple times in a single month. In April, there were 27 no-shows. In May, there were 44 no-shows. In June, there were 41 no-shows. In July (when the intervention started), there were 37 no-shows. In August, there were 47 no-shows. In September, there were 57 no-shows.

Rate of Arrived Appointments

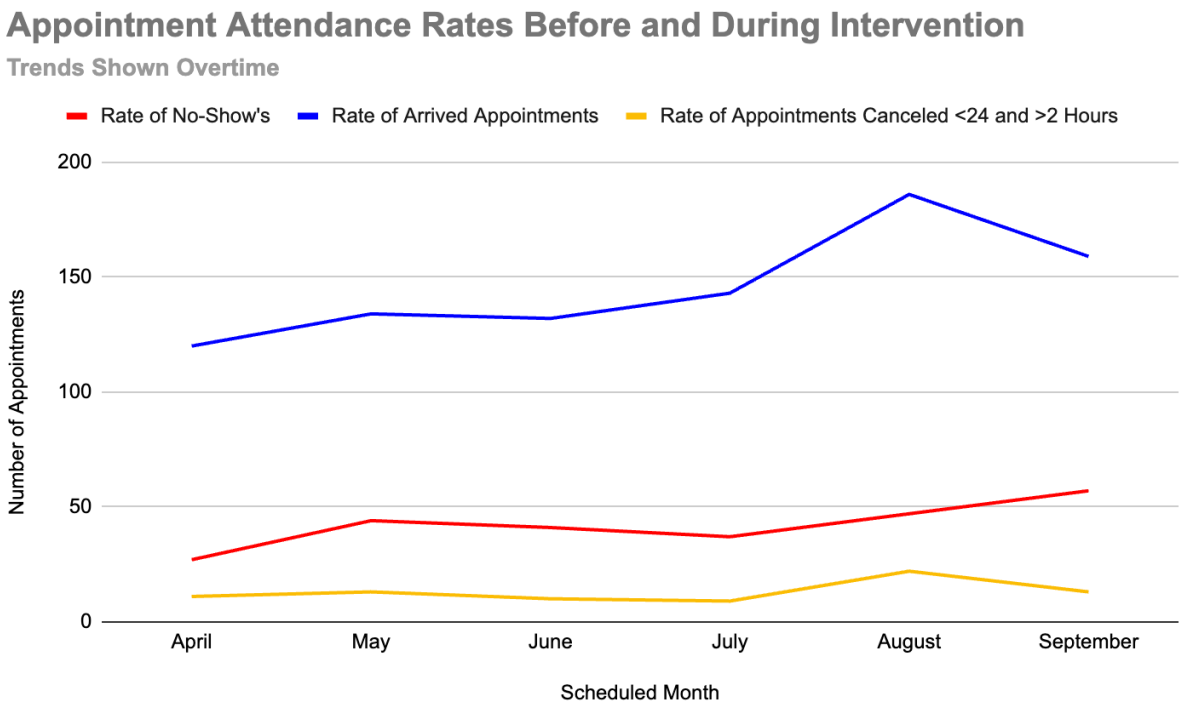
Data provided by the Patient Access Operations Manager also shows the rate of "arrived appointments" - defined as the number of appointments which patients attended on-time - from April to September 2022 for the Physician Assistant's patients. In April, there were 120 arrived appointments. In May, there were 134 arrived appointments. In June, there were 132 arrived appointments. In July, there were 143 arrived appointments. In August, there were 186 arrived appointments. In September, there were 159 arrived appointments. Like the no-show rate, a patient could have attended multiple appointments in a single month.

Rate of Appointments Canceled Between 2 and 24 Hours Beforehand

Data provided by the Patient Access Operations Manager finally shows the rate of appointments which were canceled between 2 and 24 hours before the appointment was scheduled to take place for the Physician Assistant's patients. In April, there were 11 canceled appointments. In May, there were 13 canceled appointments. In June, there were 10 canceled appointments. In July, there were 9 canceled appointments. In August, there were 22 canceled appointments. In September, there were 13 canceled appointments.

Overall, **Figure 8** shows the trends of the no-show, arrived appointment, and canceled appointment rates below for the Physician Assistant's patients:

Figure 8: Rates of Appointment Attendance and No-Show's



Chapter 5: Discussion & Public Health Implications

Discussion

Summary of the Results

HIV as a disease has progressed a long way from being a death sentence to becoming a disease with which people can still live long, healthy lives. People living with HIV face a whole host of barriers to care that could prevent them from adhering to their treatment regimen, not just in Atlanta but across the nation and around the world. Such barriers to care are seen more frequently among individuals of lower socioeconomic status, including those who are homeless or have no medical insurance to afford care (Dasgupta et al. 2021). Ensuring that these patients are retained in care is critical to achieving viral suppression, and thus highlights the importance of identifying strategies, traditional or otherwise, to retain patients in care.

The results of this study show several interesting trends overtime. One notable trend is that a high percentage of patients contacted during each month did not answer the phone, which is concerning considering that the purpose of phone contact is to engage with patients in a conventional, clear and human way. Patients understandably have busy lives and may not be able to attend to phone calls depending on the time of day, particularly if they work, were in a private place, didn't recognize the number or simply didn't want to be bothered by the clinic. However, ensuring that patients are at least able to be contacted via phone, as well as receive voicemails, is vital to reminding patients of appointments, missed or otherwise, and identifying any obstacles to care that they may face. When looking at the secondary analysis to further investigate these obstacles, the data reveals several other reasons for missing appointments that commonly appear throughout the months. Some of these reasons appear very sparsely throughout the intervention,

such as having family emergencies or believing, on the patient's own accord, that a follow-up appointment wasn't necessary for them. Due to their scattered pattern in the data, these reasons were marked as "unlisted" and clustered under reason #17. Another highly prevalent reason was that patients had already canceled or rescheduled their appointments before the call was made, which may indicate a delay in communication between the call center and the clinic since these patients were still counted as no-shows regardless. Identifying these disconnects or delays are important, since patients who have already done the work of being rescheduled might not want multiple calls from the clinic that are redundant in nature. Finally, patients being sick or having medical issues that make appointment attendance difficult was noted by the data as recurring throughout the months. All other reasons listed showed relatively modest prevalence, though they were still considered important to the clinic.

The data regarding the no-show and appointment arrival rates did show some shifts in trends overtime, particularly as it pertained to appointment attendance which peaked in August before declining a bit in September. Overall, the rate of arrived appointments appeared to climb from April to August, which initially might suggest that the intervention succeeded. However, the slight decline in the rate in September might suggest otherwise, in addition to the fact that the no-show rate actually climbed as the summer months turned to fall. There aren't any clear explanations as to why this might be, though the trends suggest that the pool of patients overall increased during the intervention, which would explain the higher rate of both appointment attendances and no-shows. The number of canceled appointments between 2 and 24 hours, meanwhile, stayed relatively stagnant. However, a peak in August similar to that of the arrived appointment rate was followed by a slight decline in September. Coinciding with a slight increase in the no-show rate in this same period, this trend is also confirmed by a decrease in

frequency of reason #12 - that the patient already canceled/rescheduled appointment ahead of call - from August to September (refer to Figure 6 to note the difference).

Results in Context of the Literature

The results found in this study have expanded upon barriers that were highlighted in previous studies. A peer-reviewed journal BMC Infectious Diseases highlighted through semi-structured interviews a number of barriers that HIV patients faced, which included (but are not limited to) competing life activities, sickness, stigma, mental illness, forgetfulness and a lack of health insurance (Yehia et al. 2015). The data from this quasi-experimental quantitative study was able to further shine a brighter light on the prevalence of some of these barriers, such as sickness and forgetfulness (reasons #7 and #9 respectively) while also expanding on other barriers including a lack of adequate transportation or having shifts in work schedules that were not previously considered. While many of these barriers are well-cited in literature, the clinic understood that some patients may not have been comfortable sharing certain barriers with someone they didn't know over the phone. The data was not able to draw conclusions about the effectiveness of phone calls vs. text-message reminders. However, several employees of the clinic have noted anecdotally that the phone-based interventions have had a substantial impact in reducing the no-show rate at the clinic as opposed to the more electronic methods of patient contact such as text-messages or portal emails, which have the disadvantage of not being able to identify barriers to patients' care. In reducing the no-show rate, the study employed several strategies for phone-based interventions that were in fact recommended by the study conducted by the Baird Group to keep experiences positive for patients over the phone, including speaking in a friendly and professional manner, speaking clearly and slowly without interruption and scheduling appointments sooner than later through the call center (Baird and Callahan 2016).

Finally, the results expanded on the gap in literature of the effect of follow-up calls on reducing the rate of no-shows in the clinic. Research on this topic is currently very limited, since most available literature pays attention to different aspects of follow-up such as potential to detect and mitigate unresolved problems or assessing clinical status (Houser et al. 2014; Zorc et al. 2003). The data had focused on the fluctuating no-show and appointment attendance rates to see how they might have been affected by the intervention, though future studies will need a longer timeframe to truly assess the impact.

Implications for the Emory Infectious Disease Clinic

The research conducted in the clinic has certain implications for the Ryan White Program and how patients are connected to, and retained in, care. It's certainly alarming that a significant number of patients do not answer the clinic's calls, even if some of them do manage to respond eventually. This could potentially highlight the importance of patients having alternate systems of contact available, such as email addresses or alternate phone numbers. For patients who are left voicemails, the clinic must be particularly careful in delivering appropriate messages. For example, the clinic should refrain from directly reminding the patient of their missed appointment, since the clinic cannot verify that the patient will be the one listening to the voicemail and not a family member or friend who might accidentally discover the patient's HIV diagnosis. This is why the clinic only leaves a callback number, in addition to mentioning the name of the clinic calling as the Emory Clinic in Midtown.

In voicemails, two callback numbers are left. One number is for the senior Patient Support Specialist in the clinic, who would relay the reasons a patient missed their appointment to the researcher should that patient call back. The other number left is the patient's assigned social worker, who is able to provide assistance to patients regarding their barriers to care such as

cards for Kroger, Metropolitan Atlanta Rapid Transit Authority (MARTA), or housing assistance. Some patients do call back, however, many of them don't. For the ones who don't call back, this can be a sign of some other underlying problem or issue with the patient. If the patient is listed on the patient portal, the clinic can follow-up later with a written communication via the portal reminding them to reschedule their missed appointment. There is no guarantee, however, that the patient will do so or even read the message. For patients who have a full mailbox or one that has not been set up yet, this could still indicate a working number that simply doesn't receive messages. Perhaps the patient could be made aware of this so as to set up or clear out the mailbox so that the clinic can leave messages if need be. For patients who don't have working numbers, it would be worthwhile to collect a valid working number for that patient during their next appointment. The clinic can still leave a written communication only if the patient is on the portal. If they are not, there isn't much that can be done to reach the patient.

Due to the high frequency of patients who had also rescheduled or canceled appointments ahead of being contacted, it is further recommended that the clinic adopts an enhanced line of connection with the call center so that these patients can avoid being placed on the no-show list (though this may or may not have happened in October during Emory's transition to EPIC for EMR documentation). Overall, many patients contacted didn't know who their social worker was when asked over the phone and/or did not have their social worker's contact information. A necessary step toward attaining services to combat barriers to care is linking patients to their social workers, should they require assistance. This step was a key component of this work and should be continued under the role of the Patient Retention Specialist.

Reducing the no-show rate was a goal of the researcher's work, particularly in justifying the need for the clinic to adopt a permanent Patient Retention Specialist position. While the data

obtained on the no-show rate is unfortunately limited in its scope, the overall perceptions amongst staff at the clinic were that fewer no-shows were being reported each month.

Limitations of Study

Like other studies on this topic, the work of this study bore its own shortcomings. For example, while the data gives a decent picture of the reasons as to why people miss their appointments, it is clear there are several limitations that might blur its accuracy. One limitation comes from the fact that many patients simply do not answer the phone, and those who we leave messages for are asked to call back the Patient Support Specialist. At times, reasons for missing appointments might be lost between the Patient Support Specialist and the researcher due to a high volume of calls to be made and a high workload done in the clinic overall. Additionally, not every patient spoken to is someone coming to the clinic for HIV care (although the majority of patients coming to see the Physician Assistant are). Many patients are not necessarily coming to the clinic for HIV treatment. The researcher's lack of access to the electronic medical record unfortunately means that the researcher cannot distinguish who is a patient coming for HIV care versus for other reasons. This might affect the data since the focus was on Ryan White patients specifically. A lack of access to certain electronic medical record systems for the researcher was also reflected in the month of October, when the Emory Clinic made the transition to EPIC's new EMR system. This switch hindered the number of calls that could be made in October by the researcher, as is demonstrated in the fact that only 34 total calls were made that month as compared to 117, 114 and 102 for July, August and September respectively. Moreover, another limitation of this study is a lack of longitudinal follow-up; data from the last month of the intervention and a few months following the intervention's completion was not able to be obtained. The researcher had aimed to obtain data all the way through January 2023 to see how

the rates fluctuate before, during and after the intervention, which would have helped assess whether the effects on appointment attendance extinguished with discontinuance of the reminder calls. However, the data provided only covered before and during most of the intervention from April to September of 2022. Finally, and perhaps most importantly, the clinic acknowledges that not all patients are forthcoming in their responses to our calls. Some patients have given reasons that don't add up when corroborated with social workers or peer navigators who have worked with these patients in the past. This is somewhat understandable, given that patients may not feel comfortable talking to a perceived stranger on the phone. Thus in the future, the clinic could consider ensuring the phone calls were made by an staff member with establish rapport with the patients

Conclusion of Discussion

The data collected over the course of four months at the Emory Infectious Disease Clinic in Midtown Atlanta gives a somewhat clearer picture of the kinds of barriers that patients face to being retained in care, but also more importantly shows how many patients are unreachable by phone. With some literature suggesting that patient retention is improved through more traditional methods of phone-calling instead of text-messaging, there are several recommendations for the clinic that could strengthen reachability to patients by phone (Nedell et al. 2023).

Implications for Public Health

Implications for Future Research

Despite the pool of research that has already been conducted on the intersection of HIV care and patient retention, and how this study has expanded the pool, more research needs to be conducted to further determine the likelihood of patients being rescheduled for future follow-up

appointments and the likelihood of follow-up for subsequent visits in the future as a result of the interventions conducted in this thesis study. This was difficult to analyze in this study due to limitations of time. While anecdotally the phone-based intervention has been said by clinic staff to have worked in reducing the no-show rate, more studies like these are needed over longer periods of time to determine if this is in fact true. Additionally, future research needs to focus on the efficacies of different patient retention strategies, such as phone calls, text-messages, emails or other automated reminders and how these strategies all compare to one another.

Implications for Future Practice

While acknowledging that not every patient may ultimately be reached or retained in care, the findings of this study and the overall trends demonstrated show the importance of having a patient retention specialist with established patient rapport who can employ a variety of methods to keep patients engaged. These methods can include phone-calling to patients to remind them of appointments and further identify barriers to care for patients who repeatedly miss appointments, as well as text-messaging and writing electronic communications (such as emails) or sending written letters to patients who might not otherwise have a working number. A study from a Ryan White clinic in South Carolina found that having an outreach coordinator performing similar duties to a patient retention specialist "may be an effective intervention to re-engage patients in care." Of the 51% of patients among the out-of-care population who were lost to care, around 44% of these patients were reengaged in care (Bean et al. 2017).

Social workers at the Emory clinic often have to deal with the needs of hundreds of patients, which means that the added task of keeping track of their appointment attendance may be too much to handle. Having a patient retention specialist working alongside social workers to

make sure patients don't fall through the gaps will be beneficial to reducing the no-show rate at the clinic and keeping patients on the path toward achieving viral suppression.

Implications for Future Policy

Ultimately, the success of the Ryan White program at Emory or elsewhere boils down to funding from the federal government. Such funding is critical to expanding patient retention efforts for HIV patients who live in poverty so that they can live healthier, more dignified lives. The good news is that the funding levels for Ryan White's budget have been increasing modestly each year by around 5%, an indication the policy on this issue is headed in the right direction ("HRSA: Ryan White Program Budget," n.d.). An increase in Ryan White's budget means that more clinics such as Emory's can hire patient retention specialists to identify barriers to care, which will ensure that resources of the clinic are allocated toward addressing patients' needs in a more efficient manner. Retaining more patients in care will mean reducing the spread of HIV across the South and beyond. Thus, if future effectiveness studies support use of a patient retention specialist to make reminder and follow-up calls, Ryan White policy could be amended to make this a requirement (or at least strong recommendation) of each Ryan White funded clinic.

Chapter 6: Conclusion

HIV is undoubtedly one of the most complicated public health issues faced by the world today, with no immediate cure or vaccine available. However, the virus no longer has the same capability of mass mortality as it once did in the 1980s and 90s. Today, many individuals who contract HIV can still live dignified lives so long as they have access to testing, care and treatment.

Unfortunately, many people living with HIV in the world today have access to only some or none of these things. People who live in poverty or live paycheck-to-paycheck sometimes can't afford insurance to cover their care or the time dedicated to adhere to their treatment regimens to achieve viral suppression. Given how stigmatized HIV still is, particularly in areas such as the Southeastern United States with a high prevalence of HIV, people face a whole host of barriers to care such as homelessness, lack of transportation, lack of insurance, poor access to technology or food insecurity, among others. Patients in the Ryan White program, which delivers HIV care to people living 400% or below the Federal Poverty Line, are particularly prone to facing such barriers. Finding intuitive ways to keep them retained in care is critical to slowing the spread of HIV and helping these patients live long, healthy lives.

The aim of this thesis is to identify the most frequent barriers to care that patients face and analyze the effect of a phone-based intervention on the rate of attendance of HIV patients at the Emory Infectious Disease clinic in Midtown. Through chart extractions and analysis based on numerical coding, the data concluded that many patients did not answer the phone and that a majority of these patients were left with voicemails. A secondary analysis concluded that many patients had canceled or rescheduled their missed appointments ahead of time, or that they had medical issues and could not make their appointment. Other barriers such as a lack of

transportation access were also highlighted as significant. While staff of the Emory clinic had observed the no-show rate of patients drop during the course of the intervention, the data could not effectively conclude whether or not the intervention was ultimately successful due to several unexpected variations in trends and a time frame deemed too short. Ultimately, more research will be needed on this topic to assess the value of phone-based interventions, especially as they compare to more automated forms of patient retention such as text-messaging or portal reminders.

Finally, this thesis makes a strong case for the necessity of a Patient Retention Specialist position in the clinic to handle all forms of patient retention, including linking patients more effectively to their social workers and further addressing their needs. Having such a specialist operate in every clinic will help ensure that appointment slots for healthcare providers are filled, and that fewer appointment slots are wasted due to patients not showing up.

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Appendix A

Script for Calling Patients Who Missed Appointments

How to Talk to No-Show Patients:

- Hi, am I speaking with Mr./Ms.?
- Hi, my name is Ajay Walther, I'm calling from the Emory Clinic, how're you doing this morning/afternoon/evening?
- Good, good. Before we proceed, may I verify your date of birth?
- Perfect. The reason for my call is that we noticed you had an appointment with Dr. _____ yesterday (date) that you missed. Because of this, we were a little concerned and wanted to reach out to you to ask why you weren't able to make it?
- Okay, I see. Are you on the patient portal?
    - **(IF NO):** So the patient portal allows you to keep track of all your medical appointments with Emory so that you don't have to rely on memory. It will also allow you to cancel your appointments if need be, that way you won't be charged for not being able to make it as opposed to missing your appointment. If you'd like, I can send you an invitation for access to the portal, I'll just need your email address.
        - If they give email address, write down to send a portal invitation to patient
    - **(IF YES):** Okay, perfect. That's good since it allows you to keep track of your Emory appointments. Also keep in mind that if you're not able to make your appointment ahead of time for whatever reason, you can use the portal to cancel your appointment, that way you won't be charged.
- So, we will need you to reschedule your missed appointment at your earliest convenience. If you have a pen and paper on hand, I can give you the number you'll need to call to do so.
    - (404)-686-8114

If Leaving a Message for No-Show's:

- Hi Mr./Ms. ___, this is Ajay Walther calling from the Emory clinic. If you get a chance, please call us back at *(404)-617-4522, thank you and have a great day!

*(404)-617-4522 is Patient Support Specialist's work-cell, I leave this as a callback # and coordinate with them….but if you have your own work-cell, leave that number in the message so they can call you back directly

Additional Notes:

- If patient has transportation, food issues or anything else and requires assistance, give them their social worker's number/email address (only if they are a Ryan White patient)
- If a patient is rude or nasty, don't engage in similar behavior. Try to reason with patient but if this isn't possible, simply say "okay, have a nice day" and hang up phone

- Always remember that establishing patient confidentiality (as per HIPPA) is extremely important. If another individual answers the phone, attempt to ask if you can speak to the patient, otherwise don't engage as this could endanger patient's HIV status to family members or friends (basically just be careful about what information you give/don't give)
    - This also includes leaving messages, don't mention doctors' or social workers' names but just ask patient to call back

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Appendix B

Script for Calling Patients to Remind of Appointments

How to Talk to Patients for Appointment Reminders:

- Hi, am I speaking with Mr./Ms.?
- Hi, my name is Ajay Walther, I'm calling from the Emory Clinic, how're you doing this morning/afternoon?
- Good, good. Before we proceed, may I verify your date of birth?
- Perfect. The reason for my call is to remind you of your upcoming appointment with Dr.___ for ___ on (date) at (time). Will you be able to make it?
    - If YES: perfect! We'll see you then! We're located at 550 Peachtree Street NE, on the 7th floor of the hospital.
    - If NO: okay, would you then like to reschedule or cancel your appointment?
        - Here's the number to do so: (404)-686-8114
- Amazing, well you have yourself a great day alright?

How to Leave Messages for Appointment Reminders:

- Hi Mr./Ms., this is Ajay Walther calling from the Emory clinic in Midtown. We just wanted to remind you of your upcoming appointment with us for tomorrow (date) at (time). Your visit will be in-person/virtual, and we're located on the 7th floor of the Emory Hospital Midtown at 550 Peachtree Street NE. We're also walking distance from the Civic Center MARTA railway station off the red and gold lines if you're coming by train. If you're not able to make it and would like to cancel or reschedule your appointment, please call (404)-686-8114. Have yourself a great day and we'll hopefully see you tomorrow!
