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Examining Geographic and Social Barriers to HIV Treatment Adherence in Kampala, Uganda

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Geography

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Abstract

With the rapid expansion of HIV treatment programs across sub-Saharan Africa, substantial progress has been made towards universal treatment accessibility in Uganda; however, new healthcare challenges have been emerging, such as the development of drug-resistant HIV, which threaten to undermine achievements made thus far. In order for HIV treatment to be effective, people living with HIV (PLWH) must be highly adherent without missing a single dose, which can be challenging for those also facing difficulties such as financial insecurity. In the context of Kampala, Uganda's urban capital, it has been suggested that healthcare accessibility is made difficult by several physical and social barriers. However, knowledge of the extent to which such barriers, especially geographical barriers might influence HIV treatment success is lacking. This is a mixed methods study which examines geographical barriers to adherence within the socio-economic context of Kampala. Using data from a survey administered to individuals on treatment at the Joint Clinical Research Center (JCRC) in Kampala (n=149), the study employs logistic regression to examine the association between geographical barriers and treatment outcomes. Semi-structured interviews (n=30) were also conducted to deepen our understanding of lived experiences with HIV treatment. Results were unexpected, suggesting that participants living more than two hours away from the treatment facility were actually less likely to miss their daily dose of medication (OR = 0.33, $p < 0.05$), compared to those living in proximity to the treatment center. Findings from the interviews helped to explain these paradoxical findings, as it was reported that PLWH prefer clinics further from their home to avoid being recognized. The effect of HIV stigma was reported to further impact adherence at home and in workspaces, as PLWH felt pressured to take medication in secrecy. The results of our regression suggested that high-income employment (OR = 3.82, $p < 0.05$) and partnered relationship status (OR =

4.28, $p < 0.05$) were predicted to increase the probability of missing doses. Challenges to HIV treatment adherence such as stigmatization and transportation costs must therefore be considered in conjunction with one another, as determinants of health are overlapping and inextricable.

Key Words: HIV treatment, Access to Healthcare, Accessibility, Transportation, Adherence, Antiretroviral therapy, Uganda, sub-Saharan Africa

Summary for Lay Audience

In recent decades, the development of HIV treatment medications has made it possible for those diagnosed with HIV to live longer and healthier lives. Treatment programs are now widespread across sub-Saharan Africa, including Uganda, with many programs offering medication for free. However, research shows that people living with HIV can face challenges which prevent them from accessing the medications, even though the medications are offered free of charge. For HIV treatment to be effective, the medication must be taken consistently, without missing any doses. Adherence can be defined as the degree to which someone takes their medication as prescribed. This research thus examines potential barriers to adherence, such as the distance to the treatment center. In this study, 30 people on HIV treatment at the Joint Clinical Research Center (JCRC) in Kampala, Uganda were interviewed about the challenges they face in adhering to treatment regimens. Surveys were also completed by 149 people on HIV treatment at the JCRC. Surprisingly, the survey data indicated that those who lived furthest from the clinic (over two hours away) actually had the lowest probability of reporting missed doses. These unexpected findings can be explained in the context of the results from the study's one-on-one interviews. It emerged from the interviews that those on HIV treatment prefer clinics further from their home to avoid being recognized. Further, based on survey data, those with high-income employment and a partner were most likely to report missing doses, compared to those who were unemployed and single. The effect of HIV stigma was reported in the interviews to impact adherence at home and in workspaces, as people on HIV treatment often feel pressured to take medication in secrecy. These results are significant in that they provide direction for public health policies which seek to maximize treatment success. The results suggest that stigma is an important challenge faced by people on HIV treatment. Initiatives in and around Kampala should therefore

seek to raise awareness surrounding HIV and HIV treatment, in order to minimize the stigmatization of people living with HIV.

Co-authorship statement

This dissertation is the product of an ongoing project developed by a large and interdisciplinary research team led primarily by Dr. Eric Arts and his colleagues at the Joint Clinical Research Center (JCRC). Thanks to the partnership between Western University and the JCRC, students completing the Master of Management of Applied Science (MMASc) in Global Health Systems have also had the opportunity to participate in this research project since its inception in 2017. These students, in addition to core JCRC staff, have helped to lay the foundation for the research project from which this thesis was produced. The data analyzed in this dissertation was collected in 2019 by myself, one MMASc student, and JCRC staff, under the auspices of my academic supervisor Dr. Isaac Luginaah and the principle investigators Dr. Eric Arts and Dr. Cissy Kityo. However, study instruments such as the questionnaire and consent forms were developed by the research team over the years and revised by myself in 2019. As such, two key members of the JCRC staff who enabled the data collection for my thesis were included as authors of the manuscripts in Chapters 4 and 5. The MMASc student has also been included, as she worked alongside myself and the JCRC team during the period of data collection. While I am the primary author of this dissertation and both manuscripts, Dr. Isaac Luginaah has contributed substantially to the development and the revision of both papers and this thesis. Dr. Eric Arts has also guided me throughout the research process and contributed to the revision of manuscripts. The authors of both manuscripts are as follows:

Chapter 4: Failure is not an Option: Barriers to HIV Treatment Adherence in Kampala, Uganda

Authors: Gabrielle Bruser, Ritah Katasi, Lily Ziyue Zhang, Eric Arts, Cissy Kityo, Isaac Luginaah

Chapter 5: “...So that's why we hide, we don't want them to know”— Challenges to Antiretroviral Therapy Adherence in Kampala, Uganda

Authors: Gabrielle Bruser, Isaac Luginaah, Ritah Katasi, Lily Ziyue Zhang, Miriam Namasinga, Eric Arts, Cissy Kityo

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Chapter 1: Introduction

This thesis examines experiences with the human immunodeficiency virus (HIV) and HIV-treatment in Uganda. While there are two types of viruses (HIV-1 and HIV-2), the majority of infections worldwide are caused by HIV-1 (World Health Organization, 2016). The focus of this dissertation is HIV-1, and from this point on, HIV-1 will be referred to as “HIV”, for simplicity. This chapter serves to introduce the research topic and define key processes related to our research questions. An overview of the broader context of HIV/AIDS in Uganda is provided, as well as a brief description of the main features of HIV treatment. The study’s research questions and the structure of this dissertation are also included in this chapter.

1.1 Study Background

The HIV/AIDS Epidemic

Beginning in the 1980s, the HIV/AIDS epidemic has devastated populations across the globe (Stoneburner, Sato, Burton, & Mertens, 1994). HIV is the retrovirus responsible for the progressive disease known as AIDS (acquired immunodeficiency syndrome). If left untreated, HIV compromises the immune system, leaving the body vulnerable to fatal opportunistic infections. Due to an initial lack of familiarity with human retroviruses, HIV proved incredibly difficult to manage clinically. Until the late 1990s, treatment options consisted largely of measures to prevent opportunistic infections (Arts & Hazuda, 2012; Broder, 2011; Yoshimura, 2017).

HIV can be contracted through sexual intercourse, injection drug-use, as well as mother-to-child transmission (Paquette, Demers, Gale-Rowe, & Wong, 2012). The risk of HIV transmission varies substantially by sex act, presenting the greatest risk for men who have sex

with men (MSM). Although MSM and injection drug-users have a higher risk of infection, heterosexual intercourse is the most common mode of transmission in regions where HIV is endemic, such as sub-Saharan Africa (Kharsany & Karim, 2016; Paquette et al., 2012). In heterosexual partnerships, biological vulnerability to HIV/AIDS is greater for the female sex as well as those with other sexually transmitted infections (STIs). Vulnerability to HIV can be further impacted by social factors such as gender and level of education (Chersich & Rees, 2008; Jukes, Simmons, & Bundy, 2008; Turmen, 2003).

From the beginning of the epidemic, it is estimated that over 32 million people have died from AIDS-related illnesses (UNAIDS, 2019). Despite the global scale of the HIV/AIDS epidemic, sub-Saharan Africa remains the most severely affected geographical region, bearing over 70% of the global burden of disease (Kharsany & Karim, 2016). Divergent patterns of HIV/AIDS prevalence exist within sub-Saharan Africa; Many countries in West Africa have an HIV prevalence of under 2%, while the prevalence of countries in East and Southern Africa have been estimated at as high as 27% (Bongaarts, Buettner, Heilig, & Pelletier, 2008; World Bank, 2018b). Drivers of this variation in global disease distribution are heavily debated, with potential factors including gender inequality, income disparity, and deficiencies in the quality of health services (Bongaarts et al., 2008; Lurie & Rosenthal, 2010; Piot, Greener, & Russell, 2007).

The state of the HIV epidemic in Uganda is unique in that the nation was one of the first to experience a drastic increase and subsequent reduction in HIV prevalence (Bessinger, Akwara, & Halperin, 2003). In response to HIV prevalence rates as high as 18% during the 1980s, public health initiatives were implemented in full force, including educational campaigns as well as the promotion of condom use (Bessinger et al., 2003; Kagaayi & Serwadda, 2016; Ministry of Health, 2019). With a prevalence of 5.7% in 2018, the country has made tremendous strides in

curbing disease transmission rates (World Bank, 2018b). Still, as of 2017, 1 in 7 households in Uganda were reported to have at least one HIV-positive household resident, with an estimated 1.2 million HIV-positive adults in the country (Ministry of Health, 2019).

Combination Antiretroviral Therapy

Despite hurdles encountered in the early development of HIV treatment, over 40 antiretroviral (ARV) medications are currently available to manage the illness (Broder, 2011; Yoshimura, 2017). However, ARVs cannot completely eliminate the HIV virus. Rather, a combination of ARVs from various drug classes are prescribed to inhibit viral replication, thus preventing the progression of the illness and the resultant immunosuppression (Arts & Hazuda, 2012; Zolopa, 2010). Laboratory tests help to gauge the progression of the virus by measuring viral load, generally measured as the number of copies of viral RNA per millilitre of blood (Hardon et al., 2006). With combination antiretroviral therapy (cART), HIV positive individuals are able to attain a high quality of life and a life expectancy that is only marginally shorter than those who are HIV negative (Yoshimura, 2017).

Uganda has also been a frontrunner in the scale-up of HIV treatment programs across the African continent. Beginning in the early 2000s, cART has been included in the nation's HIV/AIDS control program (Atuyambe et al., 2008; Ndembi et al., 2011). Treatment coverage rose steeply from around 200,000 individuals on treatment in 2009 to over one million as of 2018 (Ministry of Health, 2019; Ndembi et al., 2011). This progress has been met with skepticism as it was believed that low-income countries such as Uganda might not be able to meet the resource demands of long-term treatment programs (Byakika-Tusiime et al., 2005; Ndembi et al., 2011). While cART programs have made it possible to live with HIV, the prospect

of following a lifelong treatment regimen has created new challenges for Uganda's HIV positive population.

In order for treatment to be effective, individuals on cART must adhere to a strict medication regimen without missing any doses (Hardon et al., 2006). Whether or not someone takes their pills in a timely manner and at the prescribed dosage is termed 'adherence' (Ammon, Mason, & Corkery, 2018). Imperfect treatment adherence gives the HIV virus the opportunity to replicate and to compromise the immune system. Worse still, low levels of adherence can select for drug-resistant variants of HIV, making the virus more difficult to treat (Hamers, Sigaloff, Kityo, Mugenyi, & De Wit, 2013).

Based on experiences in the United States and Europe, it is expected that with the widespread implementation of cART programs, the prevalence of drug-resistant variants of HIV should rise initially, and then stabilize over time (Hamers et al., 2011). Due to the early timing of the cART roll-out, Uganda is currently experiencing a rapid increase in measured drug resistance. Issues such as the inconsistency of drug supplies and the lack of virological monitoring may exacerbate the emergence of drug resistance in resource-constrained nations (Hamers et al., 2011; Ndembi et al., 2011). If resistance continues to develop rapidly, large numbers of individuals on cART as well as newly diagnosed individuals will be forced to resort to alternative lines of treatment, which cost around ten times more than first-line treatments (Hardon et al., 2006). This will further marginalize patients struggling with adherence and result in additional strains on regional health facilities.

1.2 Research Problem

With the implementation of policies in 2011 which call for the free provision of cART at public facilities in Uganda, treatment costs should no longer hinder medication adherence (Church et al., 2015). However, other out-of-pocket expenses such transportation costs are often reported as a substantial burden (Hardon et al., 2006). Consequently, a disproportionately high level of drug resistance in Uganda, and in Kampala in particular, points to the need to investigate other potential barriers to treatment (Hamers et al., 2011).

There is a lack of consensus in the literature concerning the impact of issues of transportation and accessibility on treatment adherence in Uganda. As studies tend to focus on rural areas, in-depth analyses of geographical barriers in urban areas of Uganda have not been conducted. With the ever-changing urban landscape of Kampala and the evolution of treatment programs, there is a need for up-to-date studies examining challenges to treatment adherence such as accessibility.

In response, the overarching question for this thesis is “What are the barriers to cART treatment adherence in Kampala, Uganda?”. To answer this overarching question, we aim to answer the following specific research objectives:

- To examine the influence of geographical barriers, such as time spent traveling to the clinic, on treatment outcomes in the context of Kampala, Uganda.
- To determine the impact of socio-economic variables such as income on HIV treatment outcomes.
- To explore the perceptions of individuals on cART with regards to HIV treatment challenges in Kampala, Uganda.

1.3 Thesis Structure

This thesis is written in integrated article format, with the inclusion of two stand-alone manuscripts. The dissertation is organized into six main chapters: Chapter 1 introduces the research topic and provides key background information pertaining to HIV and HIV treatment. Chapter 2 presents an overview of dominant discourse surrounding HIV treatment challenges in Uganda, in addition to an outline of the evolution of UN global health objectives. The study's research methods are detailed in Chapter 3, including a summary of the theoretical perspectives that inform the study. Chapter 4 includes the first manuscript, which investigates the relationship between time spent travelling to the clinic and HIV treatment success in Kampala, Uganda. Chapter 5 contains the second manuscript which explores the experiences and perception of those on cART, regarding barriers to treatment success in Kampala. As both manuscripts are stand-alone, they each contain sections which also detail methodology and existing literature. As such, there is a degree of repetition in this dissertation. Lastly, Chapter 6 provides a brief discussion of the study results, tying together the conclusions drawn in both manuscripts.

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Chapter 2: Review of the Literature on Challenges Associated with HIV Treatment

2.1 Introduction

This chapter presents a review of the literature surrounding the challenges associated with HIV treatment, with a focus on experiences in Uganda. The chapter begins with an overview of the UN global health objectives related to HIV, and progress achieved thus far. The importance of adherence and the state of HIV treatment programs will then be established, followed by a summary of barriers to treatment adherence as seen in the literature. The review will then focus on how geography impacts HIV treatment adherence and accessibility. We will then situate treatment adherence challenges in the social context of Uganda, examining how gender shapes experiences with HIV.

2.2 United Nations Sustainable Development Goals and Global Health Objectives

For several decades, global health programs and partnerships headed by the United Nations (UN) have been established to work towards the ultimate objective of eradicating HIV/AIDS. Following the UN Millennium Summit in 2000, the eight Millennium Development Goals (MDGs) were established to be achieved by 2015. Goal 6, to combat HIV/AIDS, malaria and other diseases, included specific targets to achieve universal access to HIV treatment by 2010 (United Nations, 2008). The 3 by 5 initiative was established in 2003, with the goal of getting 3 million people living HIV/AIDS on treatment by 2005, specifically in developing countries. This objective was not met, with approximately 1.3 million people on treatment by the end of 2005 (Hardon et al., 2006). The UN estimate of the proportion of people living with HIV/AIDS in sub-Saharan Africa was approximately 37% in 2009 (United Nations, 2011).

The Sustainable Development Goals (SDGs) replaced the MDGs in 2015, comprised of 17 development goals meant to be reached by 2030. Goal 3, to ensure healthy lives and promote well-being for all at all ages, is the most closely related objective to HIV treatment. However, the SDGs acknowledge the multifaceted nature of HIV/AIDS, and emphasize how goals such as ending hunger are related to increasing positive treatment outcomes (United Nations, 2015; World Food Programme, 2019). The newest targets for HIV treatment were developed under the Joint United Nations Programme on HIV/AIDS (UNAIDS), aiming to have 90% of those diagnosed with HIV on treatment by 2020 (UNAIDS, 2014). UNAIDS estimated the proportion of people living with HIV on treatment to be 62% as of 2018 (World Bank, 2018a).

Unprecedented progress has been made to decrease morbidity and mortality associated with HIV/AIDS (Bain, Nkoke, & Noubiap, 2017). Globally, over 23 million HIV positive individuals were receiving treatment in 2018, with the majority living in Eastern and Southern Africa (UNAIDS, 2019). However, in addition to the goal of 90% treatment coverage, the ambitious 90-90-90 targets aim to diagnose 90% of all HIV-positive individuals, and to achieve viral suppression for 90% of those on treatment by 2020. The enormous amount of resources required to conduct continual virological monitoring and to ensure a consistent supply of ARVs continue to threaten the feasibility of these targets. Further, difficulties in the collection of data pertaining to HIV-treatment result in unreliable statistics, which make the evaluation of the success of the UNAIDS targets incredibly challenging. Continued research and development of HIV-treatment initiatives in low- to middle-income countries is crucial in order to maximize resource allocation and the efficiency of cART programs (Bain et al., 2017).

2.3 The importance of adherence to cART

Insufficient adherence to HIV treatment regimens is considered to be one of the main causes of HIV/AIDS-related mortality and morbidity (Tuller et al., 2010; Weiser et al., 2010, 2003). It has been well established that imperfect adherence can cause an increase in viral load, which can lead to immunosuppression (Bangsberg et al., 2000, 2001; Weiser et al., 2010). The benchmark of 95% adherence has been recommended to optimize treatment outcomes and maintain an undetectable viral load (at less than 50 copies/ml) (Paterson et al., 2000; World Health Organization, 2016). Although it is possible for viral suppression to occur at levels of adherence as low as 54%, it is recommended that those on cART to strive to take 100% of their medication, in order to minimize the occurrence of opportunistic infections and prevent the possibility of drug resistance (Bangsberg, 2006; Paterson et al., 2000).

In accordance with the latest WHO guidelines (2016), adults diagnosed with HIV should be initiated on cART as soon as possible, giving priority to those in the advanced clinical stages of HIV (i.e. with signs of a weakened immune system) (World Health Organization, 2016). It is recommended for newly diagnosed individuals to begin on the first-line treatment consisting of Tenofovir (TDF) + Lamivudine (3TC)/Emtricitabine (FTC) + Efavirenz (EFV). Alternative first-line medications may be substituted when these are unavailable although they may be less effective and result in increased side-effects. Unfortunately, many people living with HIV in Uganda are currently not using the most highly recommended combination of drugs (Ndashimye et al., 2018). Further, when resistance to first-line treatment occurs as a result of low adherence, individuals may be forced to begin second-line treatment. Second-line treatment can be ten times more costly than first-line medications as it includes a different class of drug called a protease inhibitor (Hardon et al., 2006). There is thus increased pressure to maintain high levels of

adherence in low-income countries, as the selection of medications is limited (Peltzer, Friend-Du Preez, Ramlagan, & Anderson, 2010; Weiser et al., 2010).

Contrary to concerns that low-income countries would not be able to support cART programs, levels of adherence observed in sub-Saharan African countries have often surpassed those observed in high-income countries (Mills et al., 2006). A systematic review conducted by Mills et al. (2006) reported that the proportion of those adherent (>95%) to their HIV treatment regimen throughout Uganda ranged from 68%-98% (Mills et al., 2006). Interestingly, the majority of the high-scoring studies were based in rural settings, and the study which reported 68% of individuals as adherent was based in Kampala (Byakika-Tusiime et al., 2005; Mills et al., 2006). Still, other studies within Kampala reported mean levels of adherence ranging from 82% to just under 95% (Oyugi et al., 2004, 2007). Although these levels of adherence meet and surpass those reported in high-income countries, levels of adherence in cART programs are expected to decline overtime, even when medication is provided free of charge (Nachega, Mills, & Schechter, 2010). Regionally variable challenges such as lack of drug availability demand for treatment initiatives to be tailored to the local context.

Recent studies have identified obstacles related to adherence which range from structural barriers such as health service deficiencies to individual (patient-level) challenges. Frequently cited barriers to adherence include food insecurity, stigma, side effects, waiting times, the inconsistency of drug supplies, and transport time and cost (Ammon et al., 2018; Byakika-Tusiime et al., 2005; Hardon et al., 2006; Weiser et al., 2010). While broad discussions of adherence across sub-Saharan Africa point to common barriers, the existence and importance of such barriers may vary substantially by factors such as age, cultural context, and geographical region (Ammon et al., 2018). Issues related to transportation and accessibility have been

repeatedly identified as prohibitive obstacles in several eastern and southern African countries including Botswana, Tanzania, Zimbabwe and Uganda (Chindedza, Mutseyekwa, & Chideme-Munodawafa, 2013; Hardon et al., 2006). Although, the extent to which transportation-related issues compromise HIV treatment success is often unclear. In addition to contextual variation, inconsistent methodology can result in a wide range of inferences about transportation challenges. The following section will explore geographical barriers to HIV treatment as well as the influence of social challenges on treatment outcomes.

2.4 The impact of geography on HIV treatment outcomes

Health geographers have been at the forefront of the studies of access and utilization of health care services (Rosenberg & Hanlon, 1996). Many related studies have investigated geographical challenges such the association between transportation and cART adherence, though results range considerably depending on the manner in which transportation barriers were assessed. Overall, transportation barriers have often been shown to negatively impact adherence in sub-Saharan Africa; however, other studies exist which show a lack of association between geographical challenges and treatment success. For instance, a study by Billioux et al. (2018) calculated the distance traveled to cART facilities in rural Uganda, using online maps. By comparing distances traveled by those who are virally suppressed and those who are virally unsuppressed, Billioux et al. (2018) found no significant difference between the two groups. Byakika-Tusiime et al. (2005) also found no association between distance traveled to clinic and adherence to cART in Kampala. A few studies even indicated a reverse relationship, whereby those who reported geographic barriers were more likely to report an increase in positive HIV care and treatment outcomes (Lankowski, Siedner, Bangsberg, & Tsai, 2014). Linking measurable indicators of treatment success to quantitative measures of geographical barriers has

proven to be quite challenging. However, qualitative and descriptive studies continue to identify such issues as primary barriers to HIV care and treatment in Uganda (Hardon et al., 2006; Lankowski et al., 2014; Tuller et al., 2010). There is thus a need to further investigate the effects of transportation challenges on treatment adherence by situating quantitative findings in the context of the lived experiences of people living with HIV in Uganda.

In Uganda, the costs associated with transport to HIV treatment facilities are substantial in comparison to the cost of living expenses (Tuller et al., 2010). Although income levels tend to be higher in urban areas of Uganda, transportation charges are proportionately raised (Uganda Bureau of Statistics, 2018b). Compounding issues of cost, transportation through Kampala can be time consuming and even dangerous, considering the high incidence of road traffic accidents in the region (Balikuddembe, Ardalan, Khorasani-Zavareh, Nejati & Munanura, 2017). Several studies have identified transportation as one of the main reasons people in Uganda failed to get tested or even initiated on cART (Lankowski et al., 2014). Those on cART in Uganda reportedly struggle to come up with the transportation costs to travel to medical appointments or to pick up medications. Compounding these issues, sickness related to HIV/AIDS may interfere with someone's ability to earn their wages in order to save for transportation costs (Tuller et al., 2010). Transportation challenges have been especially well documented in rural regions of Uganda (Bajunirwe et al., 2009; Siedner et al., 2013; Tuller et al., 2010). For populations living in remote areas, it can be difficult to obtain any form of transportation, especially during heavy rains which complicates the use of boda bodas (Hardon et al., 2006). In three treatment centers across urban Kampala, while distance to clinic was not identified as a predictor of non-adherence, travel away from home *was* mentioned by those on cART as a reason for their lack of adherence. This suggests that the relationship between adherence and geography may be

complicated by other aspects of geographic mobility (Byakika-Tusiime et al., 2005; Taylor et al., 2014).

Geographic mobility has been broached as a predictor of retention in HIV treatment and care (Taylor et al., 2011, 2014). While transportation constitutes a specific aspect of mobility, mobility itself may be viewed more broadly, including migration to and from other countries. The United Nations definition of a mobile population includes those “who move from one place to another temporarily, seasonally, or permanently for a host of voluntary and/or involuntary reasons” (International Organization for Migration. & UNAIDS., 2001). As Kampala is the nation’s economic hub, its job market attracts permanent and temporary workers from across Uganda, and from other countries. Kampala’s resident population has been estimated to be half the size of the total population which occupies the city during the day (Nyakaana & Sengendo, 2004). This suggests that the city is subject to unique patterns of geographic mobility, with half its population constantly in transit.

Mobility is multifaceted, and can thus influence HIV treatment outcomes in several ways: Frequent travel can result in treatment interruptions due to limited drug supplies (Taylor et al., 2014). For instance, month-long travel plans can be problematic when HIV-treatment facilities experiencing drug shortages can only provide two weeks’ supply of ARVs (Oyugi et al., 2007). Some people on cART actually view mobility as beneficial to HIV treatment, because they believe the quality of care they will receive will be higher where they are travelling to. However, mobility is generally seen as an impediment to treatment success (Taylor et al., 2014). Some of those on cART even skip their medication during travel due to the fear of experiencing side-effects in transit. Non-disclosure of one’s HIV status can also restrict engagement with care during travel and at destinations, due to concerns of stigmatization.

2.5 The social context of HIV treatment in Uganda

One's social context may either alleviate or increase pressures on those who are already struggling to adhere to their HIV treatment regimen. In Uganda, notable socioeconomic challenges which compound difficulties on cART include gender inequality, financial insecurity and HIV-related stigma (Schulkind, Mbonye, Watts, & Seeley, 2016; Tsai, Bangsberg, Kegeles, et al., 2013; Tsai, Bangsberg, & Weiser, 2013). Globally, HIV is highly stigmatized. This makes it challenging for people living with HIV to disclose their status, which can increase population-level transmission risks (Tsai, Bangsberg, Kegeles, et al., 2013). Stigma is enacted whereby individuals are subject to hostility and discrimination based on an attribute they possess which is deemed shameful. Stigma greatly affects the well-being of people living with HIV, who can develop *internalized* stigma if they come to accept their society's negative view of themselves. This internalized stigmatization has deleterious effects on their mental health, as well as their adherence to HIV treatment (Tsai, Bangsberg, & Weiser, 2013). Friends and family may also experience *felt stigma* for remaining in connection with someone who has HIV (Takada et al., 2014; Tsai, Bangsberg, & Weiser, 2013). This can further erode social networks which are critical for the well-being of people living with HIV as well as their likelihood of success on treatment (Ncama et al., 2008).

With cART, people living with HIV can manage the symptoms of the infection, making it easier integrate into society without judgement (Tsai, Bangsberg, Bwana, et al., 2013). However, those who are unable to disclose their status to their peers and their family experience great difficulty adhering to treatment in secrecy. Social support has been shown to be of great importance for people living on cART, particularly in low-income nations such as Uganda. In this context, a strong support system can help to counter financial hurdles such as food

insecurity, which is a notable impediment to adherence (Tsai, Bangsberg, Kegeles, et al., 2013). In contrast, feeling stigmatized in social situations has been shown to cause those on cART to delay taking their medication or to skip a dose rather than risk being disclosed to their peers (Ammon et al., 2018). Further, stigmatization interacts with pre-existing vulnerabilities such as poverty and gendered inequities (Goudge & Ngoma, 2011). Stigma can thus be conceived as a social process which reproduces existing societal inequalities, thus further marginalizing disadvantaged groups (Tsai, Bangsberg, & Weiser, 2013).

Gender and HIV/AIDS

Gender inequality is intertwined with stigmatization in Uganda. With the association of the HIV infection with promiscuity, women often face intensified discrimination (Turmen, 2003). Women are often reluctant to disclose their HIV status due to their fear of intimate partner violence, which is common in Uganda (Karamagi, Tumwine, Tylleskar, & Heggenhougen, 2006). Existing gender norms characterize women's expression of sexuality as taboo while normalizing men who have several sexual partners (Jewkes, Levin, & Penn-Kekana, 2003; Mburu et al., 2014; Nattrass, 2008). Thus, in cases of HIV transmission, blame may be placed on women (Petros, Airhihenbuwa, Simbayi, Ramlagan, & Brown, 2006). Sexual coercion and intimate partner violence also make it difficult for women to refuse sex or advocate for condom use, thus increasing the risk of HIV infection (Ramjee & Daniels, 2013). These social inequalities can increase the psychological burden of HIV and make it difficult to openly discuss the infection and access treatment. Patriarchal views of gender encourage men to assume the role of the provider, while women are expected to bear children (Goudge, Ngoma, Manderson, & Schneider, 2009; Mburu et al., 2014). In this context, this frequently results in women's financial

dependency on men, which has been shown to undermine self-esteem and treatment adherence (Goudge & Ngoma, 2011).

Expectations of masculinity can also negatively affect men's engagement with HIV care, as the same gender norms which contribute to the oppression of women also dictate how men should behave in the face of illness (Mburu et al., 2014; Nattrass, 2008). The male identity has been constructed as strong, powerful, independent and in control, while illness is perceived to be a sign of weakness, which can discourage men from seeking health services or discussing their HIV status (Nattrass, 2008; Mburu et al., 2014). Studies in South Africa show that while women are more vulnerable to HIV, men are less likely to access treatment services (Nattrass, 2008). The association of masculinity with risk-taking has implications for HIV transmission, as well as health-seeking behaviors. Men may be less likely to seek counselling and treatment due to the fear that health workers will advise against risky behaviors such as concurrent partnerships (Mburu et al., 2014). Thus, both female and male gender norms erode the potential of HIV treatment initiatives. Social challenges such as gender inequality can thus create an environment where vulnerable populations are structurally exposed to health disadvantages including higher HIV prevalence and limited usage of HIV testing facilities. The following section discusses theoretical approaches to assessing healthcare utilization, taking into consideration the wide range of factors which impact health.

2.6 Theoretical considerations and approach:

Models of access and utilization of healthcare

Health phenomena have been studied from different angles across countless disciplines, including biology, sociology as well as geography. Early thinkers understood health as the

outcome of the simplistic relationship between disease incidence and healthcare provision (Evans & Stoddart, 1990). Under this linear model of health care utilization, an increase in health services corresponds directly to a proportionate decrease in illness. Similar to the model of supply and demand, such conceptions of health fail to consider the social determinants which influence health and well-being. Rejecting the consideration of health as the absence of disease, the WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 2020, p. 1). We have thus sought to understand health and function as mediated by one’s social and physical environment and not solely biology (Evans & Stoddart, 1990).

In the late 1970s, the biomedical model of disease which was dominant at the time was critiqued by Engel (1977) as being overly focussed on the biological processes within the human body. The biomedical model asserts that medical sciences need not consider issues related to society and even psychology (Engel, 1977). Today, it is suggested that this model of disease remains dominant, and that this model continues to devalue the role and the experiences of the patient (Gilbert & Walker, 2009). This dissertation is intended to contribute to the growing body of literature which explores the social complexities of HIV and HIV treatment. Treatment success is contingent on adherence, and adherence has been shown to be heavily influenced by social, cultural and geographical factors. The biomedical model will thus fall short in identifying predictors of treatment failure, and a more holistic approach is therefore necessary (Gilbert & Walker, 2009).

Medical and health geographers have been contributing to the study of HIV/AIDS since the onset of the epidemic. Geographers began by mapping the spread of the disease, eventually progressing to the investigation of underlying causes of infection (Rosenberg, 1998). In this

dissertation we have employed perspectives in health geography which give importance to the socio-economic conditions which impact health and well-being. These perspectives have frequently been employed to understand the spread of the infection and predictors of risk-taking behaviors which increase the probability of HIV transmission. In this thesis, we have used this approach to investigate predictors of HIV treatment outcomes (Rosenberg, 1998).

In Chapter 4, the objective was to examine geographical barriers to treatment success, therefore we employed the model of health service accessibility developed by Andersen (1995). This model, shown in Figure 1, is intended to represent the relationship between health and healthcare as multidimensional and systemic. Earlier conceptions of healthcare accessibility feature linear relations between need and use of health services. The model proposed by Andersen (1995) explains healthcare as several interrelated feedback loops which include enabling resources such as attributes of the person's community (Aday & Andersen, 1974). This analysis will thus consider demographic variables such as income and relationship status which may influence engagement with health services. Andersen's (1995) model also incorporates the perception of one's health as a factor which in turn influences health practices and thus the use of health services. Health perceptions and associated theories were further explored in the second manuscript.

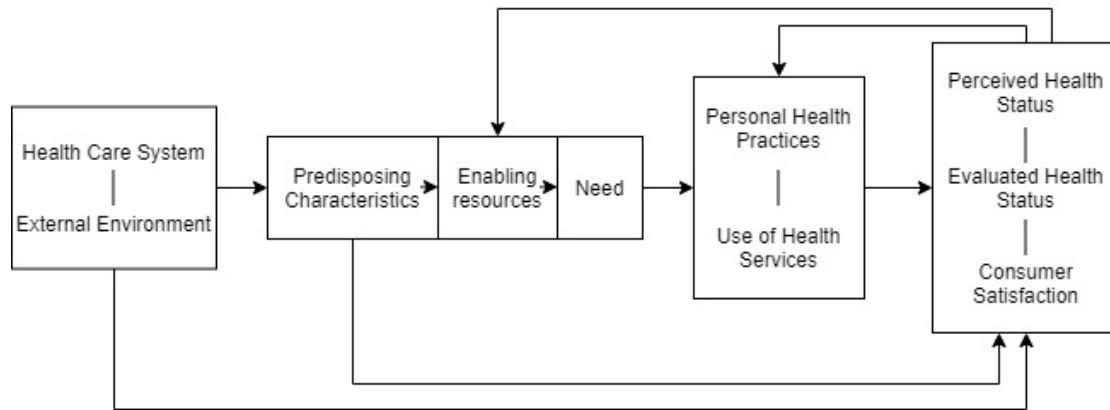


Figure 1: Behavioral Model of Health Service Use developed by Andersen (1995)

Chapter 5 addresses the research objective of understanding HIV treatment barriers from the perspective of people on treatment. Hence, we employed the Health Belief Model (HBM) to understand adherence behaviors based on the perceptions of those on cART (see Figure 2) (Hochbaum, Rosenstock, & Kegels, 1952). Explained in detail in Chapter 5, this model builds on early psychological theories which explained behavioural responses to stimuli. The HBM incorporates cognitive theory which acknowledges an individual's capacity for reasoning, in the face of health challenges (Champion & Skinner, 2008; Rosenstock, Strecher, & Becker, 1988). The HBM asserts that in addition to stimuli (i.e. punishment or reward), an individuals' beliefs motivate their health-related actions. These beliefs are in turn influenced by modifying factors such one's socioeconomic status (Champion & Skinner, 2008). In the context of cART adherence, the model's key constructs have been adapted as follows, using the guiding format published by Champion & Skinner (2008):

- **Perceived susceptibility:** The extent to which someone on treatment believes they are susceptible to the effects of HIV if they do not adhere to their treatment regimen.
- **Perceived severity:** The perceived gravity of the consequences of poor adherence.

- **Perceived benefit:** The degree to which someone believes they will benefit from strictly adhering to their treatment.
- **Perceived barriers:** The perception of challenges associated with remaining adherent to treatment.
- **Perceived self-efficacy:** The extent to which someone believes they are capable of being highly adherent to treatment.

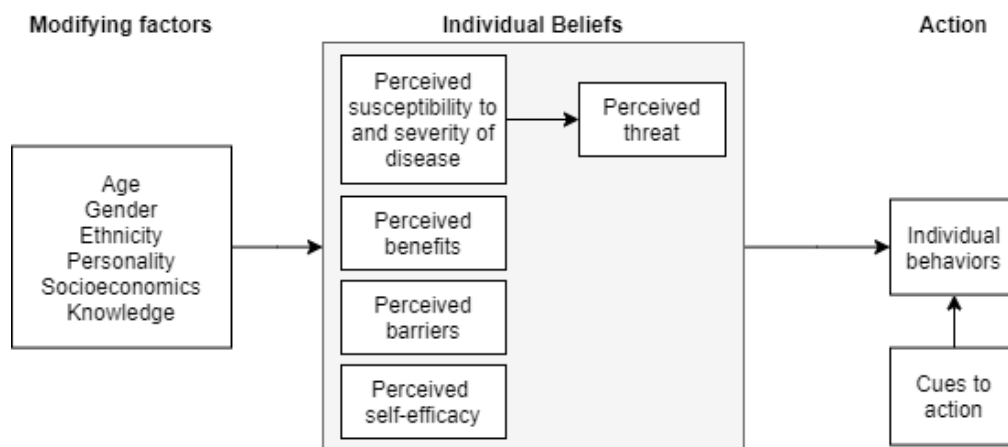


Figure 2: Health Belief Model adapted from Champion & Skinner (2008)

2.7 Chapter Summary

In the face of debilitating obstacles such as financial insecurity, people on cART in Uganda struggle to take life-saving medications. This chapter has shown the individual and population-level risks of suboptimal adherence, as well as key factors which impact treatment success. While substantial progress has been made toward the SDGs and the newest targets for universal HIV treatment coverage, several existing barriers threaten to undermine the enormous potential of cART programs in Uganda. Geographical barriers have often been identified as a substantial issue associated with HIV treatment; however, the extent to which geography compromises treatment success is still unclear. Structural barriers to treatment accessibility also

exist within the context of socioeconomic processes such as poverty, stigmatization and gender inequality, which cannot be considered separately. Andersen's (1995) model of healthcare utilization and the Health Belief Model are two conceptual frameworks which are frequently used to examine deficiencies in the public health system and predictors of health-related behaviours. These two overlapping models of health and healthcare were employed in the manuscripts found in the following chapters. Andersen's (1995) model of healthcare accessibility was used in Chapter 4, which considers the influence of factors such as one's external environment and perceived health status on health service utilization (Andersen, 1995). Health perceptions were further explored in Chapter 5, where we used the Health Belief Model to analyze predictors of HIV treatment adherence.

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Chapter 3: Research Methodology

3.1 Introduction

This chapter outlines the methodology employed in this dissertation. The chapter begins with a summary of the study's context in Uganda, to provide the reader with a broader context in which to situate our research results. An overview of ontological and epistemological considerations is provided, in addition to a statement regarding the positionality of the authors. The proceeding section introduces the study design, including the roles of the research team, the data collection procedure, and the analytic strategy.

3.2 Study Context

Uganda is a landlocked country located in East Africa, sharing a border with Rwanda, Tanzania, Kenya, South Sudan and the Democratic Republic of the Congo (Figure 3). Straddling the equator, the country has a tropical, rainy climate, with two dry seasons (Central Intelligence Agency, 2020). Kampala, the nation's rapidly growing capital city, is located towards the south of the country, near the shores of Lake Victoria (Vermeiren, Van Rompaey, Loopmans, Serwajja, & Mukwaya, 2012). Kampala had its origins as the royal capital of the Buganda Kingdom, and as such, the Bagandas are dominant ethnic group (Nkurunziza, 2006). The dominant religions include Protestant (45.1%), Roman Catholic (39.3%) and Muslim (13.7%). The most commonly spoken languages include Luganda as well as English, which is the language officially taught in schools (Atuyambe et al., 2008; Central Intelligence Agency, 2020). Other local languages spoken within Kampala include Runyankole-Rukiga, and Lusoga.

Kampala has a population estimated at around 1.5 million as of 2014 (Uganda Bureau of Statistics, 2018a). Kampala city's neighboring districts include Mukono, Luweero and Wakiso,

the location of the study site (see Figure 3). Inclusive of the neighboring districts which are often considered part of the Greater Kampala Metropolitan Area, official population estimates reach over 4.5 million (Kiggundu & Mukiibi, 2013; Uganda Bureau of Statistics, 2018a; Vermeiren et al., 2012). As previously mentioned, the city's population doubles during daytime hours with the arrival of temporary workers and residents (Nyakaana & Sengendo, 2004). An estimated 60% of Kampala's residents live in informal settlements, otherwise known as slums, which are characterized by high population densities and inadequate infrastructure for health and safety (Kulabako, Nalubega, Wozzi, & Thunvik, 2010).

Within Kampala, 5.1% of females and 7.8% of males are estimated to have completed secondary school. 63.1% of women in Kampala were employed in 2016, with the largest proportion (43.3%) working in sales and services. As of 2016, 90.3% of men in Kampala were employed, with 24.1% in professional, managerial or technical positions and 24.0% working in sales and services (Uganda Bureau of Statistics & ICF, 2018). The median monthly earnings for those employed in Kampala was calculated at 300,000 Ugandan shillings (approximately \$112.00 CAD) during the 2016/17 fiscal year. Income estimates in urban areas such as Kampala are estimated to be over twice as high as earnings in rural regions (Uganda Bureau of Statistics, 2018b).

In Kampala as well as the rest of Uganda, health insurance is uncommon, with 7.6% of women and 9.9% of men reporting some kind of insurance plan (i.e. employer based, privately purchased, etc.) (Uganda Bureau of Statistics & ICF, 2018). The majority of medical costs in Uganda are paid for out-of-pocket. For HIV/AIDS care in particular, cART programs have received a substantial amount of funding to minimize out-of-pocket payments. However, the

majority of this funding comes from donor sources (Agaba, 2009; Kwesiga, Zikusooka, & Ataguba, 2015).

By 2007, cART programs had been established in 140 accredited health facilities, including regional referral hospitals, district hospitals and district health centers across Uganda (Hardon et al., 2006). Namely, the Mulago National Referral hospital in central Kampala has provided HIV treatment services to tens of thousands of people living with HIV. Non-governmental organizations such as The Aids Support Organization (TASO) and Mildmay Uganda (MUg) also have locations in Kampala which offer cART (Hardon et al., 2006). The JCRC is Uganda's main HIV treatment provider, estimated to have provided treatment to over 200,000 people (Joint Clinical Research Centre, 2019; Poon et al., 2019). In Kampala alone, the JCRC provides cART to 15-20,000 people living with HIV (Kyeyune et al., 2016, 2013). The JCRC was one of Uganda's first HIV treatment centers, established with government support in response to the escalating HIV/AIDS epidemic in the 1990s. While the JCRC is a private medical research institute, it provides free ARVs in its public facilities in addition to medications offered at a cost through its private wing (Hardon et al., 2006).

The study was conducted at the JCRC headquarters which are located approximately 10km from the city center, in the Lubowa suburb of the Wakiso district. This JCRC is accessible using the main highway called Entebbe road, which travels towards the city center in one direction and the airport in the other. Uganda's mass transit system consists mainly of privately-owned intercity buses, minibuses (also known as *matatus*) and motorcycle taxis called *boda bodas* (Muni et al., 2020; Raynor, 2014). A high volume of vehicles regularly filter through Kampala, Uganda's capital city, resulting in traffic jams (Vermeiren et al., 2012). With their small-sized vehicles called 'boda bodas' which can weave through traffic jams and send their

clients directly to their destination. The ‘matatus’ (shuttle transport) travel consistently along Entebbe road, and while they generally cost less than ‘boda bodas’, the price may fluctuate. However, they run on regular routes which often exclude more remote areas.

Features of the study site, such as the configuration of road network and the distribution of treatment centres, have a great bearing on our research results. There are an incalculable number of variables which impact HIV treatment success in Kampala, and it is not possible to account for them all in statistical models or thematic analyses. We have attempted to design our study to represent the most salient predictors of treatment success. The purpose of this overview of the study site is to further situate our findings into the local context.

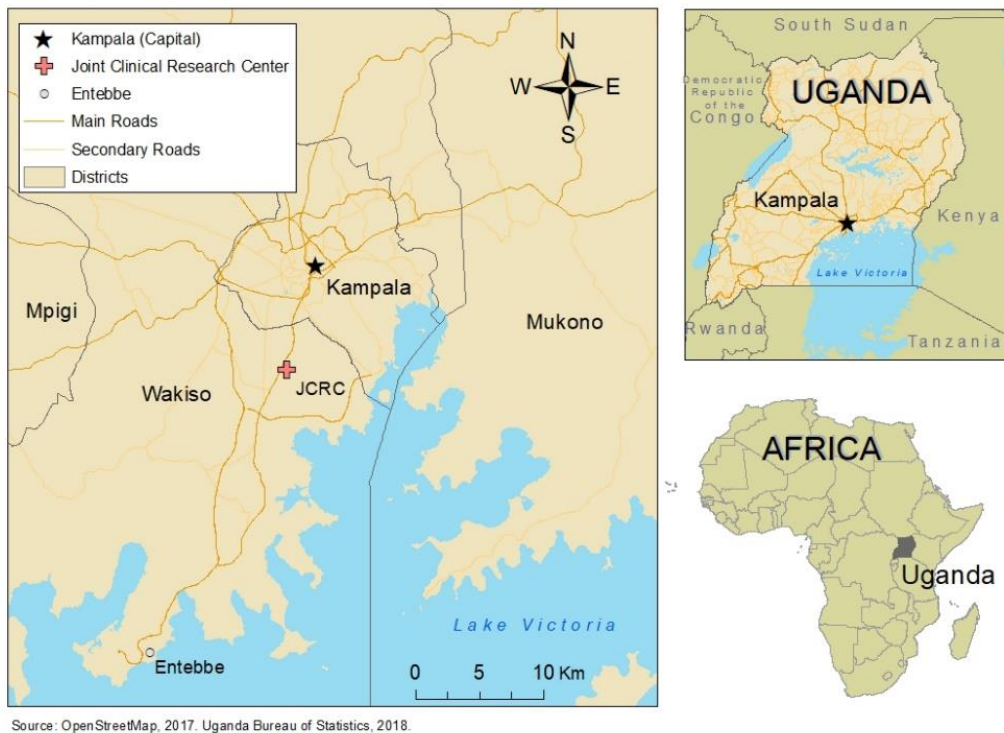


Figure 3: Map of Kampala, Uganda and the location of the JCRC

3.3 Methodological perspectives

Etic and Emic Perspective:

The factors which prevent and enable an individual to take their medication are exceedingly complex. Such complexities are rooted in local belief systems and cultural constructions of illness which are often misinterpreted by the ‘outsider’ (Bonner & Tolhurst, 2002; Hardon et al., 2006). The primary author’s status as an outsider may present limitations in terms of the interpretation of the study’s results; however, outsider status can also lend a degree of objectivity to the study. Still, the ultimate goal of this research is to present the perspectives of people on HIV treatment in Kampala, therefore the author has endeavored to do so while acknowledging their own preconceptions and biases.

An etic perspective was adopted during this research, as the main author does not identify as a part of the community under study. An *emic* perspective is adopted when the researcher is a member of the community in question, and an *etic* perspective is used when the researcher is considered to be an ‘outsider’ (Naaeke, Grabowski, Linton, & Radford, 2012). The identification of the researchers’ insider or outsider status is particularly important in qualitative research, where meaning is recognized to be socially constructed and thus subject to biases. Even in quantitative research, the researcher is a ‘positioned subject’ who exists relative to the study participants, makes conscious decisions about the manner in which research is conducted (Baxter & Eyles, 1997). In this dissertation the primary author strives to remain conscious of their outsider status and the role that this status plays in knowledge construction. The reader is urged to interpret the study’s findings bearing in mind the main author’s positionality.

Ontology and epistemology of research design

Inevitably, research methods are developed within existing knowledge paradigms, which guide the way researchers see and understand the world (Phoenix et al., 2013). Philosophical theories about the nature of reality and knowledge are implicit in any research design, regardless of the discipline. Where *ontology* relates to the question of how we conceive of reality, *epistemology* relates to the question of what constitutes valid knowledge (Aitken & Valentine, 2014). Research paradigms are composed of ontological and epistemological theories, and they have not remained constant over time. For instance, the biomedical model of disease which was dominant in the 20th century is derived from positivist philosophies, as the model contends that it is purely scientific and apolitical (Goldenberg, 2006). The ontological stance of positivism asserts that there is one true reality. Positivist epistemology maintains that reality can and must be objectively measured. This methodology has been criticized as reductionist. Claims that positivist research can possibly be objective are also often rejected on the basis that such an approach leads to unintentional biases. Interpretivism, which is found at the opposite end of the spectrum from positivism, asserts that reality is constructed and cannot be measured. However, this philosophy can create challenges for policy development which often relies on measurable evidence (Lincoln, Lynham, & Guba, 2011; Phoenix et al., 2013).

Post-positivism, which differs from positivism in its ontological and epistemological assumptions, emerged as a response to these critiques. Post-positivism works with a similar notion of one existing reality, but maintains that research cannot fully understand that reality, it can only approximate it. Post-positivists also acknowledge a degree of subjectivity which is inseparable from scientific research. Rather, post-positivist researchers strive towards objectivity while acknowledging their own biases (Lincoln et al., 2011; Phoenix et al., 2013). In this dissertation, we have adopted a post-positivist approach to Health Geography, with the

understanding that human experiences are inexplicably complex. We employed mixed research methods, including surveys as well as semi-structured interviews. Chapter 4 features a study which attempts to express the relationship between treatment adherence and geography using statistical measures. In acknowledgement of the short comings of quantitative research methods, the study found in Chapter 5 serves to represent the lived experiences of those on treatment, with the incorporation of the participants' testimonies. The use of qualitative and quantitative methods has been debated, with the categorization of quantitative research as positivist and qualitative research as interpretivist. However, this post-positivist study design allows us to gain a broader understanding of our research problem while maintaining the robustness of findings to inform policy development (Teye, 2012)

3.4 Study Design

This study evolved from a larger interdisciplinary research project, which has been progressing for several years under Dr. Arts in the Department of Immunology and Microbiology at Western University and the Joint Clinical Research Centre (JCRC) in Kampala, Uganda. This study was deemed necessary to bring a geographic approach to address issues of treatment accessibility. The lead researchers of this study include representatives of both Western University and the JCRC, thus ensuring that the interests of the main stakeholders are represented throughout the research process.

Ethics approval

Ethics approval was obtained from the Institutional Review Board/Research Ethics Committee (IRB/REC) in Kampala, Uganda, in addition to approval from the non-medical Research Ethics Board (REB) at the University of Western Ontario in Canada.

Research Team

At the JCRC, a team of healthcare workers and administrators were assigned to the study to assist with the field work conducted between May and August 2019. Intake nurses were responsible for identifying potential participants and inquiring as to whether those identified were interested in participating in the study. The nurses received training sessions on the selection criteria and study protocol, and remained in constant contact with the primary researcher (myself) throughout the data collection period. Luganda-speaking participants were assisted by one of three JCRC staff members assigned to the project. A graduate student enrolled in the Master of Management of Applied Sciences (MMASc) Program in Global Health Systems in Africa, contributed to the practical components of the study. This student was selected for this study based on their interest and competency in geography and health research. Several undergraduate students were also selected to work alongside myself at Western University after the field work was completed. These students assisted with tasks such as data entry and cleaning.

As the main author of this dissertation, I had multiple roles throughout the research project. Prior to the field work in Kampala, I was responsible for leading the design of the study and study tools (i.e. questionnaire) and the submission of the ethics application. Upon arrival to the JCRC, I coordinated our project team, provide training sessions and liaising with the JCRC staff to ensure that the project was in line with the mission and vision of the clinic and the local community. When participants were comfortable in English, I conducted interviews and administered questionnaires. If participants were most comfortable in Luganda, I played a supporting role while a member of the JCRC staff spoke with the participant. With some assistance from research assistants, I also completed the data entry, including the transcription of

English interviews. Lastly, I was primarily responsible for all data analyses. This was conducted in Canada, along with the writeup of this dissertation.

Study Tools:

Tools used during data collection included the enrollment consent form, the questionnaire, and the semi-structured interview guide. It should be noted that this thesis is only a component of a larger research project which is ongoing at the JCRC. Thus, the consent form details future analyses and a larger sample size than that which is used in this thesis. The questionnaire was developed to record demographic and geographic variables, travel patterns, and health/medical history. It also included the Duke Health Profile, a standardized instrument used to assess health, although the analysis of this data was not the focus of this thesis. The interview guide was developed to assist the interviewer in the structuring of the semi-structured interviews, and to maintain consistency. It contains guiding questions as well as probes to use when responses are unclear or vague. Where the questionnaire required specific and concrete responses, the interview guide was designed to be flexible, and encourage discussion. All three study instruments were developed in English by the research team and translated into Luganda by JCRC staff. The forms in Luganda were verified by the IRB/REC for any translation errors. The English forms were also reviewed by JCRC staff to ensure they were free of jargon or phrases which are particular to Canadian English. All three study tools were reviewed and approved by the ethics committee. The English consent form, questionnaire and interview guide are included in Appendix A, B and C, respectively.

Data collection

Within the JCRC, intake nurses identified HIV-positive patients both successfully treated on first-line cART for three or more years and those who have failed first-line treatment within two years. Participant selection criteria are illustrated in Figure 4. Treatment failure constitutes a substantial increase in viral load (≥ 1000 copies/mL) or immune failure as measured by CD4+ cell count. The association of early virological failure with HIV drug resistance lends importance to the investigation of early years on treatment (Metzner et al., 2009; Ruel et al., 2011). Thus, our study included those who experienced treatment failure in the first two years of treatment.

Potential participants were provided with a brief overview of the project and an outline of any associated risks and benefits. Those who expressed interest in participating were asked to contact the lead researcher. Participants were then guided through a consent form in their preferred language. As detailed in the consent form, participants were guaranteed the confidentiality of research results, which was a frequent concern of the participants due to the sensitive nature of our research topic. It was emphasized that participants were free to withdraw from the study at any time or to decline to answer any questions with which they were not comfortable. After thorough briefing, participants were asked to complete the 13-page questionnaire. In order to minimize the social conformity of responses, participants were also reminded that we were not looking for any particular answers. Those who completed the questionnaire were compensated for their time with 20,000 Ugandan shillings (the equivalent of about \$7.00 CAD).

Survey respondents were selected for semi-structured interviews based on key characteristics and the relevance of their survey responses to the objective of the study, with the goal of obtaining deeper insight with regards to a diverse range of cases. The interviews, which were approximately 25 minutes on average, were audio-recorded using a recording device. In

addition to the consent form, the use of the audio-recording device was explained verbally to ensure the participant's consent was fully informed. Both the interview and questionnaire were completed privately in JCRC's research wing. Again, participants were reminded of the confidentiality of the discussion. Interviewers explained their role in the study and emphasized that their objective was to understand the participant's experiences without judgement. It was important to explain the role of the researchers to alleviate any concerns that participants would face negative repercussions if they spoke of negative health behaviors (i.e. lack of condom use). This helped to put the participant at ease and to increase the depth of the discussion.

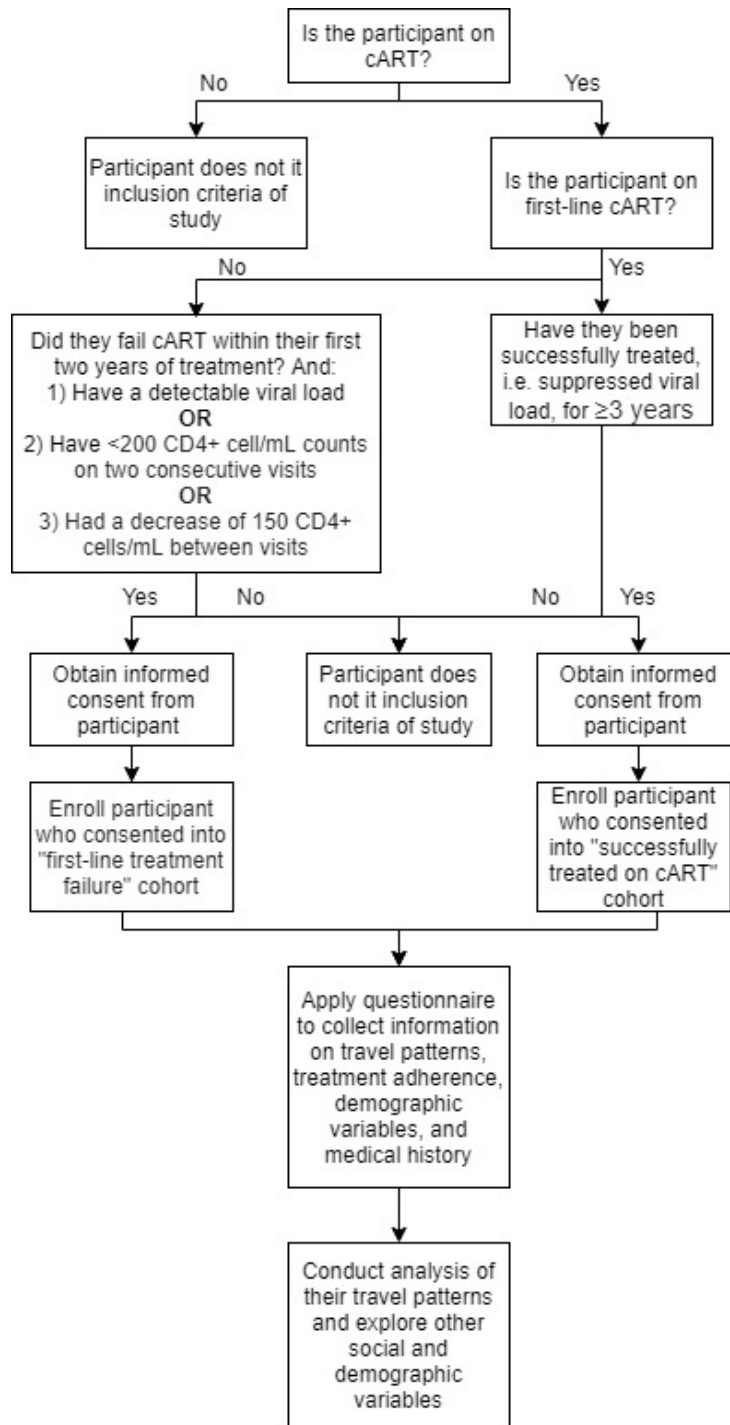


Figure 4: Flow chart of study's selection criteria for participants

Sample size

Treatment failure is categorized as the least probable outcome, compared to treatment success, as the majority of those on cART generally maintain viral suppression in early years (Jaffar et al., 2009). Although there is no clear requirement for sample size, the general rule of thumb suggests 10 cases of the least probable outcome per predictive variable (Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996). As our statistical models include a maximum of six independent variables, this suggests a minimum of 60 treatment failure cases. It has been further suggested that the ratio of 10:1 may even be overly conservative, where sample sizes with a smaller ratio have produced substantive findings (Vittinghoff & McCulloch, 2007). Still, our study included a total of 149 participants, with 93 in the treatment success group and 56 in the treatment failure group, approaching the 10:1 recommendation. A total of 30 participants were interviewed, with 15 in each of the treatment failure and treatment success groups. Purposive (non-probability) sampling was employed in the selection of all study participants. Given the manner in which participants were recruited, the exact questionnaire response rate was difficult to calculate. It has therefore been omitted from this dissertation.

Data entry and analysis

The interview audio files were uploaded onto a computer and transcribed verbatim, excluding any mention of the participant's name. Luganda transcriptions were translated into English for analysis. Content analysis was conducted using Nvivo version 12, a computer software package designed for the analysis of qualitative data. Interview transcripts were thus analyzed for recurring themes and patterns of communication, using manual coding. In Nvivo, the coding process helps to organize interview themes into a hierarchy of importance. Frequently mentioned ideas were coded into nodes, and the relative importance of each idea was established

based on the frequency with which a topic is discussed during the interview. We did not employ previously defined coding categories, rather the categories were developed based on information from the transcripts. As such, our content analysis approach was primarily exploratory. We used inductive reasoning to formulate general conclusions based on our interview transcripts (Hyde, 2000). The content analysis procedure is further elaborated upon in Chapter 5.

Survey data was manually entered into IBM Statistical Package for Social Sciences (SPSS) Statistics version 25 and cleaned. Data cleaning included the recategorization and recoding of variables to facilitate statistical analysis. Due to our limited sample size, dropping cases due to missing data was not recommended. As the questionnaires were completed with the help of the research team, we were able to maintain a relatively high response rate. In the event of missing data, values were imputed based on the most frequently occurring response.

The software package Stata 16 was used to conduct the statistical analyses of variables derived from survey data. Multivariate logistic regression was used to investigate the relationship between HIV treatment outcomes and social, geographic and demographic variables. We used logistic regression analysis to predict treatment failure, as well as a measure of adherence. The key independent variable was the self-reported time taken to reach the clinic. We initially hypothesized that increasingly substantial geographic barriers would hinder treatment success. We estimated self-reported travel time to be representative of a key geographic barrier experienced by those on cART. This portion of the study was mainly confirmative, as we set out to prove or disprove our hypothesis. Deductive reasoning was used to test existing theories that geographical barriers have a negative impact on treatment outcomes (Hyde, 2000). Further detail on regression analyses can be found in Chapter 4.

Although the extent to which inductive and deductive reasoning was used differs in the two manuscripts, both papers are rooted in similar ontological and epistemological perspectives. Our regression analyses serves to provide evidence to support or oppose claims about the impact of travel time on treatment outcomes. Similarly, content analysis provides a rough estimate of the challenges which are most important to those on cART. However, conclusions made throughout both manuscripts do not purport to be definitive by any means.

3.5 Chapter Summary

In efforts to move past reductionist approaches to the study of health and illness, a post-positivist perspective was adopted throughout this research. The primary author's status as an outsider offers benefits and drawbacks in terms of the validity of the study. Regardless, conscious awareness of the researcher's "outsider" frame of reference is critical for the interpretation of our results. This chapter has given an overview of the research methods employed in this mixed methods study, including the logistic regression of treatment outcomes and content analysis of interview transcripts. Further detail on methodology can be found in Chapters 4 and 5.

3.6 References

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Chapter 4: Failure is not an Option: Barriers to HIV-1 Treatment Adherence in Kampala, Uganda

Introduction and Background:

The introduction of combined antiretroviral therapy (cART) has made it possible to slow the progression of the human immunodeficiency virus type 1 (HIV-1), thereby improving the health and well-being of millions of HIV-positive individuals (Reda & Biadgilign, 2012). Sub-Saharan Africa shoulders the majority of the burden of the HIV epidemic, with 1.4 million people living with HIV in Uganda alone (Lange, Perriens, Kuritzkes, & Zewdie, 2004; UNAIDS, 2018a). Within the last decades, treatment programs have become widespread across the continent with the assistance of financing organizations such as The US President's Emergency Plan For AIDS Relief (PEPFAR), Global Fund to Fight AIDS, Tuberculosis and Malaria, as well as strategic partnerships with pharmaceutical companies and foundations (Hardon et al., 2006; Reda & Biadgilign, 2012). As a result, it was estimated that 72% of people diagnosed with HIV in Uganda were on treatment as of 2018 (World Bank, 2018a).

cART consists of several drugs taken in combination to target the virus at various stages of its life-cycle, in order to prevent replication (Zolopa, 2010). Patients who are successfully treated on cART are considered to be virally suppressed, with an undetectable viral load (i.e. less than 20 copies of the virus). However, for cART to be most effective, patients must adhere to strict medication regimens, ideally without missing a single dose (i.e. perfect adherence) (Hardon et al., 2006). While no standard definition exists for adherence, it generally refers to whether or not a medication has been taken in a timely manner and at the prescribed dosage. High levels of adherence ($\geq 95\%$) to cART are necessary for treatment success as well as the prevention of the development of drug-resistant strains of HIV (Hardon et al., 2006; Tuller et al., 2010). While

drug resistance has stabilized in high-income countries, low- to middle-income countries are experiencing increased prevalence of circulating and transmitted HIV drug resistant strains. Frequency of treatment failure based on a rebound of circulating HIV and the emergence of drug resistant HIV following the initiation of first line cART remains higher in Uganda (5% failure/year of cART) than observed in high income countries, despite Uganda being one of the first East African countries to implement the scale-up of antiretroviral programs (Author, 2013; Author et al., 2013; Pham, Wilson, Law, Kelleher, & Zhang, 2014; Author et al., 2019).

While cART adherence reported in African countries has often been shown to surpass levels of adherence in North American countries, study results tend to vary greatly depending on the research context. In Uganda, estimates of the proportion of patients who reported optimal cART adherence ranged from 68% to 98% (Mills et al., 2006). Adherence rates have also been shown to decline over time in long-standing treatment programs (Nachega et al., 2010). Those who miss more than one dose of their medication in a week are already at risk of treatment failure, and thus the development of drug resistance (Hardon et al., 2006). Patients generally begin on first-line cART (the most effective and low-cost medication), which is often available through many treatment programs in low-income countries such as Uganda, free of charge. However, drug-resistant HIV may require treatment with second- or third-line cART which can be costly, require more treatment monitoring, have greater adverse events, and involve more complicated treatment regimens (Bacha, Tilahun, & Worku, 2012). Patients experiencing virological failure in Uganda may therefore have limited access to second- and third-line cART, highlighting the need for the identification of predictors of treatment failure and barriers to adherence (Boender et al., 2015; Hardon et al., 2006).

Frequently cited barriers to adherence include: food security, transportation, stigma, side-effects, waiting times, forgetfulness, lack of community support, and cost (Byakika-Tusiime et al., 2005; Hardon et al., 2006; Weiser et al., 2003). It is debated whether sub-optimal adherence in Uganda can be attributed to difficulties *accessing* the medication rather than an inability to follow the drug regimen (the former requiring structural rather than behavioral interventions) (Crane et al., 2006). Accessibility can refer to spatial and temporal attributes such as the distance and transit time to the clinic (Andersen, 1995). However, access can also be conceptualized by examining whether characteristics of the population such as income and social class, create barriers to obtaining proper healthcare, and thus impacting treatment adherence. The framework proposed by Andersen (1995) addresses healthcare accessibility by considering a myriad of factors which affect the accessibility of health services beyond supply and demand. While it is critical that the population's needs be met with a proportional supply of health services, characterization of the population in a given service area helps us to understand factors that motivate the initial visit to a health facility, as well as the reasons for continued adherence. It is therefore necessary for attempts at spatial predictions of accessibility to consider the range of pressures experienced by those on cART, and not just the characteristics of the health delivery system i.e. the number of facilities (Andersen, 1995; Luo & Qi, 2009).

Studies have presented contradictory evidence as to whether or not the distance to treatment facilities in Uganda is in fact a significant predictor of treatment failure (Ammon et al., 2018). Those on cART frequently cite their inability to pay for transport costs as a reason for non-adherence, yet it is often shown that there is no substantial association between treatment outcomes and geographical mobility (Billieux et al., 2018; Byakika-Tusiime et al., 2005; Hardon et al., 2006). The objective of this study is therefore to determine whether geospatial barriers (i.e.

travel time) have a negative impact on HIV treatment (cART) outcomes in Kampala, Uganda. Secondly, we sought to identify other predictors of cART adherence and treatment failure. We tested the hypothesis that those with a greater burden of mobility would experience lower levels of adherence and therefore be more susceptible to treatment failure, compared to those who travel minimally, after controlling for demographic characteristics.

Methods

Study Site:

This project was conducted in partnership with the Joint Clinical Research center (JCRC) in the greater Kampala region, who have provided HIV treatment services for over 200,000 patients in Uganda, in addition to other services such as tuberculosis care and treatment. Antiretrovirals are available at the JCRC free of charge. The treatment facility is located in the Wakiso district, approximately 10 kilometers away from Kampala's city center (see Figure 3). Kampala is Uganda's capital city, located in central region of Uganda bordering Lake Victoria (Vermeiren et al., 2012). As Kampala is found within the Buganda Kingdom, the most commonly spoken language is Luganda (Brisset-Foucault, 2013). However, the city's rapid urban expansion and increased commercial activity has drawn settlers from various regions of Uganda, with a variety of native languages. Paved roads in Kampala funnel traffic through the densely populated city, resulting in severe traffic jams (Vermeiren et al., 2012).

Study Design:

Data was collected from patients receiving routine care and treatment from the JCRC, under an agreement of confidentiality. In-country ethics approval was obtained from the Institutional Review Board/Research Ethics Committee (IRB/REC) in addition to approval from

the Research Ethics Board (REB) at the University of Western Ontario in Canada. From the JCRC's HIV treatment department, eligible patients who arrived for their regular clinic visits were asked if they were interested in participating in the study. Patients who expressed interest were given a consent form in their preferred language (either English or Luganda). Patients who agreed to participate completed a structured questionnaire specifying demographic, geographic and behavioral characteristics. As stated in the consent form, participants were reminded that they are free to withdraw from the study at any time without fear of repercussion. Participants were also assured that their data would remain confidential. Upon completion of the questionnaire, participants were compensated for their time and transportation costs.

In order to evaluate predictors of divergent treatment outcomes, the study included two cohorts of patients: those who had been successfully treated on first line cART for a period of three years and those who have experienced treatment failure on first-line cART within two years. All patients receiving cART pass through the same intake department, no matter which line of treatment they are on, therefore both cohorts were recruited from the same pool of patients. As treatment failure represents the least frequent treatment outcome, the treatment success cohort consisted of 93 individuals, while the treatment failure cohort consisted of 56 individuals. Treatment 'failure' was determined based on clinical parameters (i.e. detectable viral load) obtained from the JCRC patient database, and adherence to cART was assessed with respect to missed appointments and discontinuity of drug regimen (using self-reported data & JCRC patient logs). Patients' treatment regimen (i.e. first-line, second-line, etc.) was recorded using the patient database.

Data and Measurement:

The focal dependant variable was treatment failure (failure = 1 and success = 0), in addition to indicators of treatment adherence such as missed doses (yes/missed = 1 and no/never missed = 0). Adherence was assessed from when the patient was initiated on first-line treatment. To measure adherence, participants were asked if they have ever 1) missed a dose of their cART medication, 2) missed an appointment, 3) stopped taking their medication intentionally, and 4) unable to refill their medication. All four variables were coded as either 1 = yes or 0 = no. All demographic information was drawn from the study questionnaire, with the exception of age which was recorded from the patient database. Age was categorized into intervals of approximately ten years, aggregating the upper and lower limits to ensure the relative equality of group sizes. Only patients over the age of 18 qualified for the study. Gender and parenthood (i.e. whether they have children) were also determined based on the participants responses to the questionnaire. Participants were then asked to identify which income range they correspond to. Income figures correspond to the amount of Ugandan shillings (UGX) earned per month. As salaries in Uganda tend to be inconsistent, participants' responses represent estimates of their average income (Hardon et al., 2006). Participants originally selected one of five ranges of income; however, the three higher income ranges were merged due to the small number of individuals in each group. An income of 100,000 UGX corresponds to approximately \$36.00 CAD, and 350,000 UGX corresponds to \$126.00 CAD. Participants were categorized as either below 100,000 UGX per month, over 350,000 UGX, or between 100,000 and 350,000 UGX. An income of 350,000 UGX is considered to be relatively high in the Ugandan context, accounting for purchasing power (Wanyenze et al., 2006). Those who identified themselves as unemployed were aggregated into the category of under 100,000 UGX.

Participants indicated their current relationship status. Those who reported that they are single (i.e. never married) were grouped into one category. Those who indicated that they are currently married or have a boyfriend/girlfriend were grouped into the category “with partner,” and those who indicated that they were previously married (now either widowed or separated/divorced) were grouped together. This categorization of relationship status follows the general method employed by Wanyenze et al. (2006), adjusted slightly to assess the impact of partnership on adherence, rather than marital status. Finally, patients indicated the time they spent in transit on the way to the clinic where they receive HIV treatment (JCRC). Original categories were as follows: 1) less than 10 minutes, 2) 10 to 30 minutes, 3) 30 minutes to one hour, 4) one to two hours, 5) greater than two hours. This variable was re-categorized to 1) less than one hour, 2) one to two hours, and 3) greater than two hours, to ensure the adequacy of group sizes per category for the regression analysis. Accounting for the urban context of Kampala, travel times were taken into consideration rather than travel distances, as movement through the city is often restricted due to traffic rather than kilometer distance (Vermeiren et al., 2012).

Statistical Analysis:

The statistical analysis was conducted in various stages. All survey data was initially entered into IBM SPSS Statistics 25, and then analyzed using the statistical software package Stata 16. Descriptive statistics were first calculated for all theoretically relevant demographic and clinical variables, indicating counts and sample percentages for categorical variables (seen in Table 1 and Table 4). The mean and standard deviation of viral load was computed, as this measure is a continuous variable. In Table 2 and Table 5, bivariate logistic regression was used to assess the influence of each independent variable, including transportation time, on the key

dependent variables (treatment failure and missing a dose). Lastly, multivariate logistic regression was conducted (Table 2 and Table 5) to determine the relative influence of transit time when controlling for demographic variables. We evaluated potential demographic variables that may influence adherence including family composition, gender, wealth and age. Results were presented with odds ratios (OR) derived from regression coefficients.

Logistic regression was the most appropriate choice for analysis, as the data satisfies key assumptions. Both outcome variables are binary (whether or not one failed on treatment, and whether or not one missed a dose), observations are independent of one-another, and there is no multicollinearity between independent variables. The study's sample size approaches the suggested minimum observation-predictor ratio: A minimum of ten cases representing the least probable outcome should be included per independent variable (Peng, Lee, & Ingersoll, 2002). The least probable outcome was treatment failure, with a probability of 0.38. With a total of six independent variables included in statistical models, the suggested minimum sample size is 158.

Results:

Table 1: Demographic and health characteristics of treatment failure and treatment success cohorts

Covariates	Treatment Success Cohort (n=93)	Treatment Failure Cohort (n=56)
Time to Clinic		
Less than one hour	41 (44.09%)	23 (41.07%)
One to two hours	20 (21.51%)	20 (35.71%)
Greater than two hours	32 (34.41%)	13 (23.21%)
Viral Load (copies/ml)	<20 (SD 0)	260,525.93 (SD 840102.75)
Age		
18-30	14 (15.05%)	17 (30.36%)
31-40	22 (23.66%)	17 (30.36%)
41-50	34 (36.56%)	8 (14.29%)
51+	23 (24.73%)	14 (25.00%)
Gender		
Female	60 (64.52%)	36 (64.29%)
Male	33 (35.48%)	20 (35.71%)
Income (UGX)		
<100,000 (including unemployed)	40 (43.01%)	24 (42.86%)
100,000-350,000	33 (35.48%)	21 (37.50%)
> 350,000	20 (21.51%)	11 (19.64%)
Relationship Status		
Single	16 (17.20%)	13 (23.21%)
With Partner	56 (60.22%)	31 (55.36%)
Separated or Widowed	21 (22.58%)	12 (21.43%)
Children		
Has children	80 (86.02%)	43 (76.79%)
Does not have children	13 (13.98%)	13 (23.21%)

Mean (SD) or n (%), Sample size = 149.

As shown in Table 1, all participants in the treatment success cohort have an undetectable viral load (below 20 copies of viral RNA per ml of plasma) and therefore standard deviation was zero. This was expected, as anyone who is successful on cART will have suppressed the virus to the point where it is undetected by standard viral load tests. The mean viral load for the treatment failure cohort was approximately 260,500 copies of RNA/ml of plasma, with a detectable viral load classified as >1000 copies/ml. However standard deviation was comparatively high, at approximately 840,000 (Table 1).

In the sample, the largest proportion of participants fell into the 40-50 year age range. The mean age for the success cohort was approximately 43 and the mean for the failure cohort was 40. Although mean ages are similar, the distribution across age categories differs. In the treatment failure cohort, the 41-50 age range contained the *smallest* proportion of participants. However, the largest proportion of the treatment success cohort fell between ages 41-50. The proportion of males and females is relatively equal in both groups, although the majority of the sample were women. This was expected as women are both more likely to seek out treatment and more vulnerable to HIV due to biological and cultural factors (Türmen, 2003; Mills, Beyrer, Birungi, & Dybul, 2012).

In Table 2, Model 1 assesses the bivariate association between transit time to clinic and treatment failure, in addition to an analysis of the relationship between demographic variables (age, gender, income, parenthood and relationship status) and treatment failure. Model 2 in Table 2 assesses the association between transit time and treatment failure when controlling for demographic variables. In terms of the variables of interest, the treatment failure and success cohorts seem remarkably similar. The maximum log likelihood for Model 2 (-91.02) barely increases from the baseline of -98.64 which was calculated for the intercept-only model, with no

covariates (Peng et al., 2002). A substantial increase in the value of log likelihood would have hinted at the fit of our model's coefficients. Both models are weak predictors of treatment failure, as the only significant association is seen in the 40-50 age range, suggesting that compared to patients aged 18-30, patients aged 41-50 had a 61% decrease in their probability of treatment failure.

Table 2: Bivariate (Model 1) and multivariate (Model 2) and regression of treatment failure (OR)

Covariates	Model 1: <i>OR (SE)</i>	Model 2: <i>OR (SE)</i>
Time to Clinic		
Less than one hour		(reference)
One to two hours	1.78 (.73)	1.76 (.77)
Greater than two hours	.72 (.30)	.79 (.37)
Age		
18-30		(reference)
31-40	.64 (.30)	.66 (.34)
41-50	.19 (.10)**	.18 (.11)**
51+	.50 (.25)	.50 (.27)
Female	.99 (.35)	.50 (.32)
Relationship Status		
Single		(reference)
With Partner	.68 (.30)	.65 (.32)
Separated or Widowed	.70 (.36)	.80 (.45)
Have Children	.54 (.23)	.83 (.44)
Income (UGX)		
<100,000		(reference)
100,000-350,000	1.06 (.40)	.99 (.42)
>350,000	.92 (.42)	1.02 (.44)

**p < .01. Sample size = 149. SE: Standard Error.

Model 2 Maximum Log Likelihood: -91.02
 Model 1 Maximum Log Likelihood: -96.57

Table 3: Logistic regression of treatment outcome (bivariate)

Covariates	OR (SE)
Missing doses (unintentionally)	2.10 (.72)*
Missing appointments	1.01 (0.40)
Stopped taking medication intentionally	2.93 (1.75) [†]
Unable to refill medication	3.71 (2.37)*

[†]p < .10. *p < .05. Sample size = 149. SE: Standard Error.

A bivariate analysis of adherence indicators was conducted to gauge their importance as predictors of treatment failure (Table 3). Expectedly, a lack of adherence was a significant predictor of treatment failure. Those who miss a dose were more than twice as likely to fail (OR = 2.10, p < .05). Similarly, those who reported an inability to refill their medication were approximately 3.7 times more likely to fail treatment (OR = 3.71, p < .05). Those who indicated that they intentionally stopped taking their medication were also more likely to fail, although this association was noted with little statistical significance and should thus be interpreted with caution (OR = 2.93, p < .10). In total, 42% of participants reported having missed at least one dose of their medication (n=63), the majority of which reflected on *periods* of low adherence rather than simply missing one dose. Compared to other measures of adherence, missing a dose was the most statistically significant predictor of treatment failure (p = .03), and the most frequently occurring indicator of sub-optimal adherence. This measure was further examined in a separate logistic regression in order to gauge the influence of our predictor variables on the likelihood of missing doses.

As shown in Table 4, of those who reported missing doses of cART, over 55% travel under one hour to reach the treatment facility, with approximately 25% traveling between one and two hours and 19% of participants traveling over two hours. Of those who reported never missing doses, approximately 34% travel under one hour, with 28% traveling between one and two hours and over 38% traveling over two hours to reach the treatment facility. Among both

those who reported missing and those who reported never missing, the greatest proportion of participants fell into the low-income employment category (including those who are unemployed). Amongst those who reported never missing, approximately 48% were either unemployed or had low-income employment. Approximately 37% of those who reported missing doses fell into the lowest income category of our sample. Amongst those who reported never missing, and those who reported missing, approximately 57% and 60% had a partner, respectively. Additional descriptive statistics for groups reporting missed doses and groups reporting no missed doses can be seen in Table 4.

Table 4: Demographic and Health Characteristics of HIV-positive individuals with self-reported optimal and sub-optimal adherence to ART

	Self-reported missed doses (n=63)	Self-reported never missed doses (n=86)
Time to Clinic		
Less than one hour	35 (55.56%)	29 (33.72%)
One to two hours	16 (25.40%)	24 (27.91%)
Greater than two hours	12 (19.05%)	33 (38.37%)
Time to Failure (days)	255.25 (SD 306.51)	147.55 (SD 255.63)
Viral Load (copies/ml)	44,845.91 (SD 178,132.32)	136,814.19 (SD 676,623.40)
Age		
18-30	20 (31.75%)	11 (12.79%)
31-40	15 (23.81%)	24 (27.91%)
41-50	12 (19.05%)	30 (34.88%)
51+	16 (25.40%)	21 (24.42%)
Gender		
Female	39 (61.90%)	57 (66.28%)
Male	24 (38.10%)	29 (33.72%)
Income (UGX)		
<100,000 (including unemployed)	23 (36.51%)	41 (47.67%)
100,000-350,000	23 (36.51%)	31 (36.05%)
> 350,000	17 (26.98%)	14 (16.28%)
Relationship Status		
Single	8 (12.70%)	21 (24.42%)
With partner	38 (60.32%)	49 (56.98%)
Separated or widowed	17 (26.98%)	16 (18.60%)
Children		
Has children	46 (73.02%)	77 (89.53%)
Does not have children	17 (26.98%)	9 (10.47%)

Mean (SD) or n (%), Sample size = 149.

Table 5: Bivariate (Model 1) and multivariate (Model 2) and regression of missing doses (OR)

Covariates	Model 1: OR (SE)	Model 2: OR (SE)
Time to Clinic		
Less than one hour		(reference)
One to two hours	.55 (.23)	.40 (.20) [†]
Greater than two hours	.30 (.13)**	.33 (.16)*
Age		
18-30		(reference)
31-40	.34 (.17)*	.20 (.12)**
41-50	.22 (.11)**	.18 (.11)**
51+	.42 (.21) [†]	.40 (.23)
Female	.83 (.29)	1.42 (.71)
Relationship Status		
Single		(reference)
With Partner	2.04 (.95)	4.28 (2.60)*
Separated or Widowed	2.79 (1.51) [†]	8.28 (5.76)**
Have Children	3.16 (1.43)*	3.64 (2.24)*
Income (UGX)		
<100,000 (including unemployed)		(reference)
100,000-350,000	1.32 (.50)	1.53 (.70)
>350,000	2.16 (.96) [†]	3.82 (2.42)*

[†]p < .10. *p < .05. **p < .01.

Sample size = 149. SE: Standard Error.

Model 1 Maximum Log Likelihood: -97.10

Model 2 Maximum Log Likelihood: -83.62

In Table 5, Model 1 presents the association between our predictor variables and the likelihood of missing doses. Surprisingly, participants who traveled over two hours to get to the JCRC were approximately 70% *less* likely to miss a dose relative to those who traveled less than one hour, both before (OR = 0.30, p < .01) and after (OR = 0.33, p < .05) controlling for demographic variables (Table 5, Model 2). Controlling for demographic variables, significance begins to emerge for other categories of transit time: Those who traveled one to two hours to get to the clinic were also 60% less likely to miss doses compared to those who traveled less than

one hour (OR = 0.40, $p < .10$). Therefore, the trend of decreasing probability of missing doses in those with longer travel times is consistent across transit time categories.

The association between treatment failure and the 41-50 age range holds in the second analysis predicting missed doses. In the bivariate analysis, those between the ages of 41 and 50 are least likely to miss a dose, compared to the 18-30 age range (OR = 0.18, $p < .05$). Further, those in the 31-40 age range are 80% less likely to miss a dose (OR = 0.20, $p < .05$). Gender remained unrelated to adherence throughout the analysis. However, relationship status became increasingly significant when controlling for demographic variables. Those who have a partner were approximately 4.3 times more likely to miss a dose, compared to their single counterparts (OR = 4.28, $p < .05$). This has been previously reported and may be associated with partner stigma and concerns in sharing HIV infection status (Dlamini et al., 2009). Further, those who reported having children were more than three times more likely to miss their medication, both before and after controlling for demographic variables (OR = 3.64, $p < .05$). Finally, those who corresponded to the higher-income category of >350,000 were more likely to miss doses compared to those who make less than 100,000 (including those who are unemployed). The bivariate regression suggests that high-income individuals are over twice as likely to miss a dose (OR = 2.16, $p < .10$), and the association is amplified after controlling for demographic variables in Table 5. In Table 5, Model 2, high-income patients were nearly 4 times more likely to miss their medication (OR = 3.82, $p < .05$).

Model 2 appears to be the best fit, with a maximum log likelihood of -83.62, compared to the baseline value of -101.50 for the intercept-only model. Akaike’s Information Criterion (AIC), and Schwarz’s Bayesian Information Criterion (BIC)

Table 6: Akaike’s Information Criterion (AIC) and Schwarz’s Bayesian Information Criterion (BIC)

Model	df	AIC	BIC
Null Model	1	204.99	208.00
Model 2	12	191.24	227.28

Model 2 found in Table 5. df: Degrees of freedom

provide a further indication of the fit of the model (Table 6). AIC decreases by approximately 14, suggesting that Model 2 is a better fit than the null model. The BIC, however, is more resistant to change, and suggests a negative difference. It should be noted that these metrics are a function of the number of model parameters and the sample size. For moderate sample sizes, the BIC tends to point to the model which is most parsimonious, therefore this metric may not be appropriate for this study (Burnham & Anderson, 2004).

Discussion:

The key findings of this study are portrayed in Figure 5, which illustrates the relative predicted probability that a range of individuals would miss a dose of their medication. Unexpectedly, the person with the lowest probability of missing a dose is predicted to be single, unemployed (or low income), and live over two hours away from the treatment facility. Conversely, someone who has a high paying job, a partner, and lives close to the facility is predicted to have an 80% chance of missing their medication. Across all four types of individuals, those who live more than two hours away are much less likely to miss a dose, compared to someone who lives nearby.

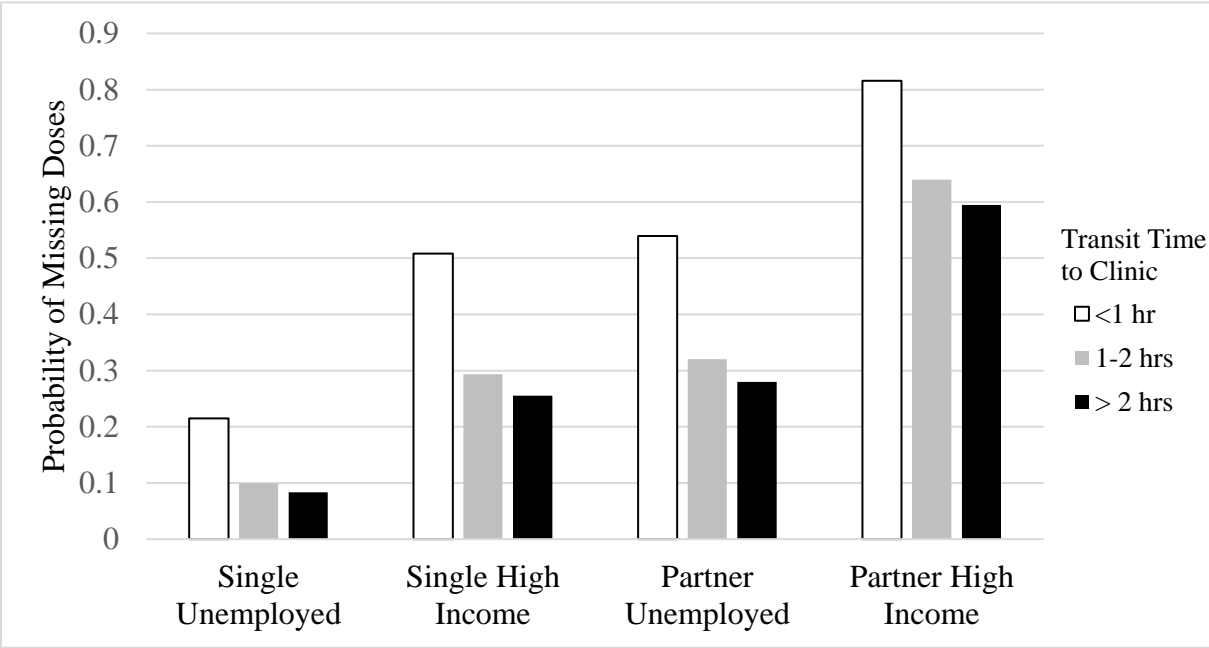


Figure 5: Probability of missing doses for individuals with and without a partner and with and without employment

Note: Probabilities predicted from Table 5, Model 2. Association between missing doses and partnership, compared to those who are single ($p < .05$), high-income employment compared to unemployed ($p < .05$). Association between missing doses and time to clinic of one to two hours ($p < .10$) and over two hours ($p < .05$), compared to less than one hour.

Transport time and cost have been identified in the literature as an important barrier for adherence, although the degree of influence of transit time on cART adherence and treatment outcomes is not agreed upon (Ammon et al., 2018; Hardon et al., 2006). Those on cART frequently cite transport cost as a challenge with cART. However, our results suggest that transportation time may actually have a positive relationship with treatment adherence. The findings show that those further away from the clinic (at least two hours) were actually less likely to report missing their medication. This may be explained by confounding factors that were not accounted for in our models. For instance, those who decide to receive treatment from a facility far from their home may be more invested in treatment outcomes than those who visit a treatment facility nearby. In Kampala, the JCRC is considered to be a high-quality treatment

facility, which guarantees a constant supply of drugs and minimal waiting times. It is possible that those who plan to get their medication from the JCRC, and are willing to travel hours to get there, could be more invested in treatment adherence. Another explanation could be that people prefer to go to clinics further away because of the deep-seated stigma associated with HIV/AIDS in Uganda (Hardon et al., 2006). Those on cART in Uganda tend to choose treatment facilities which are isolated from their home community, in order to avoid contact with friends, family and acquaintances (Hardon et al., 2006). Such encounters put them at a risk of publicizing their HIV status and thus facing stigmatization and discrimination.

Further, while it was expected that stable relationships and employment would be positive predictors of adherence, this study's results show otherwise. This may be attributed to the influence of stigma in both their work and family lives. Due to the high prevalence and importance of HIV/AIDS in Uganda, it is assumed that someone who is taking daily medication must be taking antiretrovirals and is therefore HIV-positive. Those on cART have expressed the fear of losing their jobs if they are seen taking medication at work (Hardon et al., 2006). They mention that their employers believe that someone with HIV has a low life-expectancy and is therefore not worth the investment of resources such as time and money. The fear of stigma in the workplace pressures individuals to take their medication in secret, which may prevent someone from taking their medication at the correct time, which is necessary for cART to be effective (Hardon et al., 2006). This might be even more so the case for those with high-paying employment, and thus a higher social status. In these cases, there may be an increased perception of risk if someone is seen taking their medication.

Stigmatization has also been an issue within communities and households (Ammon et al., 2018). While we expected family and partner support to improve cART adherence, our

results suggest the reverse. At the family level, a lack of disclosure of one's HIV status may result in poor adherence. Status disclosure often results in abandonment and poor treatment by one's spouse, thus prompting many of those on cART to secretly take their medication (Hardon et al., 2006). Those who were either separated or widowed were also more likely to miss doses compared to their single counterparts. As this study is retrospective, it is possible that at that the time of failure, these participants were still in a relationship, making them vulnerable to stigma. Those with children were also more likely to miss doses, which may be attributed to busier schedules and/or non-disclosure of HIV status.

In general, the degree of discomfort that those on cART feel when taking their medication in shared spaces may have a substantial influence on their adherence. The effect of this discomfort may even be additive if someone experiences stigma or discrimination at home as well as at work. In the context of health geography, Kearns (1993) refers to space as “the local context of health, disease and social process” (p. 140). By using this approach to health research, we can understand the interactions between those on cART and the places they frequent. The level of stigma experienced at home, at work and around health facilities may have a stronger influence on adherence than the time spent in transit to the clinic. If the fear of status disclosure is pervasive in the lives of those on cART, structural interventions such as increasing the number of treatment facilities will not be effective in improving treatment outcomes. In order to improve the utilization of treatment services, interventions must consider the experiences of the HIV-positive population within their local contexts, as well as the healthcare system itself (Andersen, 1995).

Limitations:

Variability in measurements of adherence may produce divergent results. For instance, participants were asked if they have ever missed doses on treatment. However, if a participant has been on cART for years, it is probable that they have missed at least one dose. As previously mentioned, those who reported missing doses tended to have experienced a prolonged period of low adherence, rather than a single dose. Still, self-reported measures of adherence have been shown to be consistent with more objective measures of adherence (i.e. electronic drug monitoring) (Author et al., 2004). Regardless, the development of standardized measurements of adherence will facilitate future analyses. Quantitative studies should take into consideration the variability of the lived experiences of those on cART. To conduct a comprehensive evaluation of the relationship between geospatial variables and treatment adherence, quantitative measures of geographic mobility should be analyzed in conjunction with qualitative measures (i.e. via semi-structured interviews with participants). These interviews were conducted with participants as part of this research project and results will be analyzed in a forthcoming study.

Finally, the study's moderate sample size must be taken into account in the interpretation of results. The sample may not be representative of all those in Uganda who are on HIV treatment. Rather, the study should be considered within the context of Kampala, and at the JCRC. Our results suggest a degree of internal validity as our measures of adherence were negatively correlated with treatment success, which is consistent with academic literature (Hardon et al., 2006; Lange et al., 2004). The study's sample size of 149 may present certain limitations in terms of potential statistical significance, however, related studies have used similar sample sizes and produced meaningful analyses (Mills et al., 2006; Siedner et al., 2013). Further research is required to increase the study's sample size and make more definitive conclusions about barriers faced throughout the city of Kampala.

Conclusion:

Adherence greater than 95% to cART is necessary for treatment success, and high rates of adherence are necessary to minimize drug resistance. Although those on cART are highly motivated to follow their treatment plan, challenges such as stigma undermine their best efforts to do so. It is therefore crucial that factors influencing adherence are identified and evaluated. Resource-constrained regions require a context-specific approach to maximize treatment adherence and combat drug resistance. The identification of barriers to ARV treatment adherence will provide guidance for future public health initiatives targeting the HIV/AIDS epidemic in Uganda.

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Chapter 5: “...So that's why we hide, we don't want them to know”— Challenges to Antiretroviral Therapy Adherence in Kampala, Uganda

Introduction:

Due to the introduction of combination antiretroviral therapy (cART), human immunodeficiency virus type 1 (HIV-1) is no longer a terminal illness, making it possible for millions of HIV-positive individuals to live long and healthy lives (Midtbø, Shirima, Skovdal, & Daniel, 2012; Reda & Biadgilign, 2012). Efforts to combat the HIV epidemic now necessarily include interventions which target the improvement of treatment services, in addition to the prevention of disease transmission. Although HIV is now considered a manageable chronic disease, treatment programs place substantial demands on treatment facilities as well as PLWH. Antiretroviral therapy inhibits viral replication, thus preventing the progression of the disease towards acquired immunodeficiency syndrome (AIDS). However, this inhibition of viral replication, commonly referred to as ‘viral suppression,’ only occurs when cART users are highly adherent to their treatment regimen. Failure to adhere to cART can result in immunosuppression, and even the development of drug-resistant HIV (Hardon et al., 2006).

In resource-constrained contexts such as Uganda, access to cART is inequitable and often inconsistent due to underfunded treatment facilities, travel costs and other systemic barriers (Gilbert & Walker, 2009; Hardon et al., 2006; Weiser et al., 2003). The importance of the cost of medication has diminished with the implementation of policies in 2011 which mandate the free provision of cART in public facilities in Uganda. Funding from financing institutions such as the Global Fund to Fight AIDS has further alleviated short term financial concerns (Gill, Hamer, Simon, Thea, & Sabin, 2005). However, common challenges to cART adherence including food insecurity, accessibility and stigmatization, threaten to undermine the HIV treatment successes

that have been achieved to date (Gilbert & Walker, 2009; Hardon et al., 2006; Tsai, Bangsberg, Bwana, et al., 2013).

Consistent with the United Nations targets, Uganda aims to achieve viral suppression in 90% of PLWH by 2020 (where viral suppression equates to under 1000 copies/ml). As of 2018, the prevalence of viral suppression was reported at 64% (UNAIDS, 2018b). In order to reach this goal, it is crucial to gain insight into the manner in which affected populations experience HIV and the resultant economic and societal pressures, as these experiences shape the ability of PLWH to adhere to treatment. The term adherence is intended to simply address whether or not such instructions have been followed, rather than place blame on the patient or health care provider (Hardon et al., 2006). Adherence, previously referred to as ‘compliance,’ can be defined in this context as the extent to which people on cART follow the instructions given to them by a physician. Under the concept of adherence, it is acknowledged that patients are independent and intelligent individuals who play an active role in their medical treatment with their cultural, psychosocial and political context. While the term compliance tends to focus strictly on medical objectives such as viral suppression, the notion of adherence as explored in the paper encourages us to examine the nuanced nature of health-related behaviors as they are influenced by social and personal challenges (Lutfey & Wishner, 1999).

Theoretical Context

We used theoretical constructs from the Health Belief Model to understand the challenges to cART adherence in Uganda. In the examination of treatment adherence, the importance of patients’ perception of health challenges is made evident by the Health Belief Model (HBM) (Hochbaum et al., 1952). Developed in the 1950s by social psychologists, the HBM seeks to explain the manner in which individuals respond to health concerns (Champion & Skinner,

2008). The model explains that an individual's actions related to illness and healthcare are influenced by a set of core beliefs, including one's perception of susceptibility to illness, situational severity, and the barriers and benefits of actions. Self-efficacy was later incorporated into the framework, referring to the degree to which someone believes they have control over health outcomes (Rosenstock et al., 1988). These core beliefs are in turn influenced by external variables such as socioeconomic status, education and knowledge. For instance, general knowledge about HIV/AIDS and treatment is an important determinant of medication adherence (Reda & Biadgilign, 2012). According to Uganda's Demographic Health Survey published in 2016, only 48% of women and 49% of men have a comprehensive understanding of HIV transmission and prevention (Uganda Bureau of Statistics & ICF, 2018).

The HBM is one of the most widely used models for the analysis of treatment adherence (Gao, Nau, Rosenbluth, Scott, & Woodward, 2000; Vitalis, 2017). The model has been specifically applied for the study of ART adherence in a variety of contexts including Botswana and the United States (Gao et al., 2000; Kip, Ehlers, & Van Der Wal, 2009). Generally, the HBM is used to explain that cART adherence may be influenced by the perception of the severity of consequences i.e. whether or not someone believes they will become ill if they fail to take their medication. The framework also informs the importance of understanding the *perception* of benefits and barriers to cART adherence. For instance, the cost of transportation to the clinic may be perceived as an insurmountable barrier by some, and as a necessary burden by others. Further, the evaluation of self-efficacy is particularly relevant in the context of chronic illnesses requiring long-term treatment such as cART. Understanding the severity of poor adherence may not be an effective motivator if the individual does not believe themselves to be capable of making the substantial lifestyle changes required. The HBM thus provides the underpinning that

can be used to effectively explain prevailing cultural, social political belief systems associated with varying degrees of cART adherence in the study context. Specifically, this paper aims to advance our understanding of the social, geographical and economic complexities which impact the effectiveness of HIV treatment within the urban context of Kampala, Uganda.

Methodology:

Study Site:

The study took place within the Joint Clinical Research Center (JCRC), a health facility and research center known for the provision of cART. The JCRC has been operating for over 27 years, providing both public and private HIV treatment services, including first, second, and third-line treatment. The center is financed by funding agencies such as the Center for Disease Control and Prevention (CDC), in addition to other funding streams. The JCRC has established seven regional clinical research centers across the country, with the headquarters located in Lubowa, a suburb of Kampala, Uganda's capital city. This study was conducted at the Lubowa location.

Data Collection:

Ethics approval for the study was obtained in-country via the Institutional Review Board/Research Ethics Committee (IRB/REC), as well as the Research Ethics Board (REB) at the University of Western Ontario in Canada. Field work was conducted between May 2019 and August 2019. Purposive sampling was employed in order to ensure that a range of perspectives were considered. Participants on arrival at the JCRC, were first contacted by intake nurses who explained the purpose of the study. Those who expressed interest were then provided with the contact information for the lead researcher. HIV-positive individuals qualified for the study if

they had 1) been virally suppressed for at least three years on *first-line* treatment or 2) failed *first-line* treatment with a viral load exceeding 1000 copies/ml, within their first two years on first-line treatment. Participants were categorized into one of these two groups with reference to patient charts as well as the digital patient database.

Participants who expressed interest in the study were given a consent form in their preferred language (either Luganda or English), which detailed the nature of the research. A total of 30 participants consented to take part in the study, with 15 in the treatment failure group and 15 in the treatment success group. Semi-structured interviews were conducted, using an interview guide in either English or Luganda which detailed the main questions of interest, in addition to potential probes to be used by the interviewer. Participants were interviewed by either JCRC staff (in the case of Luganda speakers) or the research team (in the case of English speakers). Interviews were audio-recorded and transcribed verbatim.

In addition, participants completed a written questionnaire which included questions on cART adherence, transportation networks, demographic variables and other relevant topics. Participants who spoke only Luganda were assisted by the JCRC staff. In the case of both the semi-structured interview and the questionnaire responses, participants were assured that their responses would remain confidential, and that their names would not be disclosed. Participants were compensated for both the interview and the completion of the questionnaire. Throughout the data collection process, participants were also reminded that their participation is voluntary and that they are free to withdraw from the study at anytime, without fear of any repercussion.

Analysis:

Interview transcriptions were uploaded and analyzed using Nvivo 12, a software package used for qualitative analyses, in order to identify salient themes and common experiences amongst respondents. The interviews were coded by categorizing statements made by respondents into various ‘nodes,’ depending on the subject matter discussed. Common nodes were then grouped together and related to one-another hierarchically. Each interview, or case, was classified as either ‘Failure’ or ‘Success,’ and analyzed as such. The analytic strategy was two-fold: to establish broad areas of consensus and differences amongst ‘success’ and ‘failure’ respondents on various topics, and to draw attention to areas of difference between men and women in terms of cART adherence. Direct quotations from the transcripts are used to illustrate the themes and contextualize responses from the study participants. The participant's sex, designation as treatment success or failure, and age are provided at the end of each quotation.

Results:

Sample Characteristics:

The sample was mostly female (63.33%) and employed (70.00%), with a mean age of 41 years old (Table 7). The majority of the sample (66.67%) reported missing doses of their medication, and 20.00% reported that they intentionally stopped taking their medication at some point. Participants tend to travel much further to reach the clinic than they do to work, with approximately 17% of the sample traveling over two hours to reach the JCRC. Over 83% of respondents have children, with 63.33% of the sample indicating that they are currently in a relationship.

Table 7: Demographic and Health Characteristics of HIV-positive individuals (n=30)

Variable	Percentage of Sample
Treatment outcome	
Failure	50%
Success	50%
Gender	
Males	36.67%
Females	63.33%
Age	
50+	23.33%
40-49	26.67%
30-39	23.33%
18-29	26.67%
Asset ownership	
Vehicle	10.00%
TV	76.67%
Computer	23.33%
Radio	60.00%
Fridge	40.00%
Running water	56.67%
Electricity	86.67%
Livestock	40.00%
Employed	70.00%
Hours worked per week (mean)	63 (SD=21.15)
Monthly Income (UGX)	
Less than 100,000 (about 26.00 USD)	6.67%
100,000 – 350,000	33.33%
350,000 – 750,000	20.00%
750,000 – 1,000,000	6.67%
Over 1,000,000	3.33%
In school	3.33%
Have children	83.33%
Have a partner	63.33%
Time to clinic	
Less than 10 min	6.67%
10 min – 30 min	13.33%
30 min – 1 hr	36.67%
1 hr – 2 hrs	26.67%
Over 2 hrs	16.67%
Adherence throughout duration of treatment	
Missed one or more appointment(s)	26.67%
Completely stopped taking medication	20.00%
Failed to refill medication	20.00%
Missed taking one or more dose(s)	66.67%

A majority of the sample reported a monthly income between 100,000 and 750,000 Ugandan shillings (equivalent to between \$26-\$198 USD), with 40% of participants making under \$198.00 per month. All participants own a mobile phone and the majority own a television and radio. Although, not all participants have electricity at home, and just over half have running water. While some participants are financially well-off, with a laptop and a car and a high-paying job, some participants live in low-income households. The main themes that emerged from the analysis were: Knowledge and perception of HIV/AIDS, cART Knowledge and Perception, Challenges with cART adherence and Patient's suggestions for improvement.

Knowledge and perception of HIV/AIDS

Within the lifespan of most of the respondents, HIV has progressed from a death sentence to a chronic disease (Hermann et al., 2009). However, participants reports suggest that knowledge and attitudes towards HIV have not yet shifted. Many participants use the terms HIV and AIDS interchangeably, particularly when referring to interactions with community members. This indicates a lack of differentiation between HIV (the viral infection) and AIDS (the fatal condition). During the interviews, many participants explained that in their communities the consideration of "HIV as a death sentence" persists despite the development of medications, as well as the dominant belief that PLWH "will soon succumb to the illness".

It is important to note that while the interview questions were centered on HIV treatment, it emerged from the interviews that testing and transmission were considered to be important topics for the respondents. Participants suggested that the public's inadequate understanding of HIV transmission routes greatly affects how PLWH are perceived in their communities. The participants were in agreement that many people still hold the belief that HIV can be transmitted through saliva (i.e. sharing dishes), as mentioned in the following quotation:

If they get to know that you are sick, they may even refuse to eat on the same plate you have eaten from. – (Female, Treatment Success Group, Age 28)

A participant offered the insight that this lack of HIV knowledge was the result of family members' low level of educational attainment. Another respondent echoed this sentiment, suggesting that misconceptions about HIV transmission can be attributed to illiteracy. This participant explained that although they “weren't the first in their family to be diagnosed with HIV, family members were reluctant to change their understanding of the illness”. Some participants also explained that some community members still believe that people contract HIV as a result of “bad behaviour or low social status”. Overall, several interviewees talked about the persistent misconception as to whether HIV is a disease or the result of witchcraft. A respondent reported experiencing the passing of a family member with HIV whose death was attributed to witchcraft. They emphasized that such cultural beliefs and misconceptions still prevent some people from seeking out treatment:

Some people still think that HIV can be sent to you through bewitching. You may find that someone has HIV but they are just in bed thinking that someone has bewitched them because they have land issues, yet they are HIV positive.

– (Female, Treatment Success Group, Age 29)

The study's participants also spoke of the discrepancy between the willingness of men and women to go for testing. Several female respondents described the reluctance of men to do HIV tests, often pointing to their partner as an example. Approximately 63% of the study sample were female, supporting the gendered nature of both the testing and treatment and of HIV. Still, several of the study's participants noted that they discovered they were HIV positive because

they were pregnant and made to undergo tests. Other male and female participants indicated that they only got tested after becoming seriously ill, or after other treatments (i.e. malaria medication) were not working.

In most villages, even in the city, women get tested. We do get tested because when you get pregnant the first thing they do is test and the man, he cannot escort you. You go there alone, and when you find out that you are HIV positive, you cannot go back and tell your husband you went and tested HIV positive, you cannot. You will wait for his time to go get tested, and he won't go, and then he will die. Here, women we get tested, but men in Uganda don't, they fear. – (Female, Treatment Success Group, Age 36)

Reportedly, through the 'test and treat' approach, Uganda has been making efforts to encourage the general public to get tested and to immediately initiate those diagnosed with HIV on cART. However, public knowledge and perceptions about cART remain unclear.

cART Knowledge and Perception

Some participants explained that community members are gradually beginning to understand that treatment can help those diagnosed with HIV. They suggested that people "have realized when they take the drugs, they can live longer." However, participants emphasized that many community members still do not understand that "it is now possible to live with HIV, if you are taking cART". Several participants talked about how in their communities, people still believe that "taking the medication itself is what will kill them or make them ill," while other participants mentioned that some people believe that if you have HIV, you will die regardless of the medication you are taking. Some participants reported that at times, within the local

community it is believed that there are particular drugs which when prescribed to someone, are meant to kill them:

If you go to the clinic and they give you that particular drug [second-line medication], people think they are trying to kill you, because they think you are spreading the virus. So people back there [in the village], when they are changed to this particular medication, they just stop taking it. – (Male, Treatment Success Group, Age 41)

Further, many participants talked about community members who believed in alternative cures for HIV, including herbs, witchcraft and prayer. A participant agreed that she had also believed she could be cured through prayers, but later decided to begin cART. These perceptions were reinforced by other respondents as indicated in the comment below.

There are some who are dissuaded by friends that tell them to go to pastors and Sheiks to pray for them to heal, others to go to shrines...others prefer traditional herbs only to find that it doesn't work and yet now it's too late to get treatment. – (Female, Treatment Success Group, Age 44)

Despite the existing misconceptions about HIV, most participants acknowledged that there is no cure for HIV, and that cART does not eliminate the virus completely, rather it prevents it from multiplying. Although, one participant did suggest that if you take your medication well, the virus can disappear.

Somebody even told me that if you really take it [cART] every day, that in the future, the time can even come when you are totally at zero [viral load]. So I don't know if it was true or she just wanted to console me, but she said that it's good to take [cART]. You may

reach a time where the virus completely disappears from your body. – (Female, Treatment Failure Group, Age 58)

Most respondents explained that cART can allow you to function normally by suppressing the virus. However, many respondents alluded to having had a lower understanding when they first started treatment. Participants often reported experiencing difficulties following their treatment regimen due in part to an incomplete understanding of the level of adherence necessary.

With regards to what happens when someone taking cART misses a dose, every participant explained that this would negatively affect their health. The extent of the negative effect did vary noticeably, with some participants suggesting that you would become ill after missing about a week, and others stating that you would die immediately. Many participants specifically mentioned that missing doses could render the treatment ineffective (due to drug resistance). Several others mentioned that the virus would become even stronger than when you began on treatment:

Well, the virus proves to us that it is very intelligent. Every time you miss, it may adapt to the drugs within the missed gaps, making it resist medication. – (Male, Treatment Failure Group, Age 66)

The research also sought to explore participants' level of understanding of the term 'adherence,' as it applies to their cART regimen. When prompted to define the concept, nearly all participants emphasized the importance of not only taking your medication daily, but taking it at the same time every day.

Good adherence is taking your drugs daily at the right time such as seven o'clock. Or if it's eight instead, let it be eight and stick to it. – (Female, Treatment Success Group, Age 50)

Here the notion of having an established routine is crucial. One participant boasts that taking their medication is akin to brushing ones teeth. Several participants also specifically stated that showing up to clinic appointments is a part of good adherence.

Challenges with cART adherence

Participants elaborated upon various challenges associated with cART adherence, including the burden of the drug regimen, side effects, food insecurity, accessibility and stigma.

Burden of Drug Regimen

One of the principle challenges associated with cART is the burden of the drug regimen as the treatment is a lifelong commitment and PLWH must take several pills daily. Most of the study's participants reported struggling with side effects, the timing of medication and/or the size and number of pills. Many respondents explained their aversion to swallowing medication, with many participants specifically mentioning that it is the size of the pills which makes it difficult to swallow. Participants often spoke of medication side effects they experienced at some point on their treatment regimen. Side effects mentioned included dizziness, weakness, nausea and vomiting, among others. Often, participants explained that side effects only occurred when they were first initiated on cART, or when they were taking the medication on an empty stomach.

Food Insecurity and Finance

Although the introduction of cART treatment programs which offer the medication free of charge at public facilities has taken away the cost of the drugs as a significant barrier, several participants raised issues related to food and financial insecurity. A respondent commented on how food insecurity can influence someone's adherence to cART:

Some people don't take their pills due to absence of food as it can cause bad side effects such as nausea. This happened to me as well, but ever since I learnt that I have to eat before I take the medication, I no longer get those effects. – (Female, Treatment Failure Group, Age 45)

In this study context, food security goes hand in hand with financial security. Those who reported financial insecurity discussed how this affects cART adherence primarily due to the need to take the medication after having eaten.

With that medication, your family must be kind of well-off, and support you with food. Sometimes at home I didn't have anything to eat but I decided to take the medication and deal with the side effects, but there are persons who are doing worse than me. You must have a source of food and good sanitation at home. – (Male, Treatment Success group, Age 27)

The need for proper nutrition and clean drinking water was mentioned by most participants, who emphasized the debilitating side effects which occur if the medication is taken on an empty stomach. Approximately 43% of our sample reported that they do not have access to running water, despite Kampala's rapid urbanization and infrastructure development (Vermeiren et al., 2012). Discussions surrounding food insecurity were slightly more extensive within the treatment failure group, compared to the treatment success group.

Despite difficulties paying for daily meals, some participants opt to avoid public treatment facilities and pay for their medication instead. Some respondents reported the motivation to obtain treatment from private clinics due to the perceived sense of privacy offered at such places, and the quality of services, among other reasons. Participants who began treatment from a private clinic reported missing several doses of medication due to the cost of the drugs.

I thought if I could economize the drugs, I'd take it today and tomorrow I wouldn't.

Mainly, by doing that, I would prolong the drugs to last me for like a month. I thought that would help me. – (Female, Treatment Failure Group, Age 54)

Thus, even with the provision of free ARVs, costs associated with HIV-treatment remain a burden. In addition to the cost of regular meals, people on cART must pay for transport to their medical appointments and to pick up their medications.

Transport and Travel

Overall, participants agreed that transportation and travel related to cART has been a challenge, especially the time it takes to travel to the clinic and the cost travel. One participant pointed to accessibility as the biggest challenge:

The main challenge is access, to the proper medication, and to the quickest medication.

Someone might be on ARVs, getting the medication far from where they stay, and you might find that sometimes they miss their appointment, which is so bad for the treatment.

– (Male, Treatment Success, Age 37)

Popular modes of transportation typically include privately operated buses that run within the city of Kampala. Motorcycle taxis are also often used to travel to destinations where the buses

don't reach. The majority of participants use the buses as well as the motorcycles to reach the clinic, apart from the few respondents who have access to their own vehicles. As the buses run along Entebbe road and are less costly than the motorcycles, it is common to use a motorcycle to reach the bus park, and board a bus to the clinic.

You might find that someone traveling to that health center, will have to pay like 10,000 [Ugandan shillings] for transport. And you can use 10,000 shillings for a daily meal, so if the medication was available at the village center, it would cost only 2,000 shillings to access the medication, so I think it would be easier. – (Male, Treatment Success, Age 37)

Due to the heavy traffic which accumulates along Kampala's main roads, participants indicated that it takes several hours to reach the JCRC, obliging clients to take the day off work on the day of their appointments, which may result in an additional loss of income.

Despite issues with transportation, participants still acknowledge the importance of traveling to get their medication, as it is necessary for their health. However, issues of travel and transport are further complicated by the persistent stigmatization of PLWH.

Stigmatization

The stigmatization of HIV-positive individuals creates challenges which exacerbate all other barriers to treatment adherence. All participants frequently emphasized the negative effects of stigma on their daily lives, whether at work, at home or in transit. A respondent described his experience of considerable stigmatization and discrimination even within his household, which eventually forced him to leave home and live elsewhere.

So I was discriminated by my stepmother, who made my [HIV] stigma rise to a level that I couldn't even imagine. So I decided to quit taking my drugs ... My stepmother would

isolate my dishes, fork, plate, cup, basin, everything, as if I was in the ICU! – (Male, Treatment Success Group, Age 27)

Both the success and failure groups of participants spoke at a length about the effects of stigma. Stigma seemed to have a direct relationship to adherence, as people on cART feel they must take their medication without being seen, which is increasingly difficult when they are expected to take several pills per day. In the context of Uganda, it is uncommon for someone to be taking daily medication. Thus, if someone takes a pill in public, it is often assumed that they are taking medication for HIV. Due to the taboo associated with the illness, PLWH fear disclosure of their status.

Some people are negative [towards us], others are positive. There are people who talk badly about HIV patients. Some people, you find them talking badly about us... so that's why we hide, we don't want them to know our HIV status. – (Female, Treatment Failure Group, Age 42)

Participants mentioned that they intentionally chose a clinic far from their home so that they won't be seen picking up their medication. Participants agreed that locating treatment facilities near their homes would not be favorable, as they would not like to be seen going into treatment facilities in their home communities. Several participants also explained that simply carrying the medication alone poses the risk of exposing their status.

The workers especially, people who work in distant places, they say they fear moving with the drug because they don't want [their status] to be disclosed ... So you find the time can come when they are scheduled to take their medication but they are traveling to work, so they miss [taking] the medication. – (Female, Treatment Failure Group, Age 42)

Many participants fear to disclose their status, and experience great difficulty in taking their medication when they are constantly surrounded by people. Many of the respondents explained their fear that their children would discover their HIV status and face stigma at school or develop the worry of losing their parents. As 83% of respondents also have children, participants often struggle to their medication in secrecy. A similar reluctance was conveyed about disclosure to other family members such as parents or siblings. Some participants are reluctant to disclose their status because they don't want to be perceived negatively, and others don't want their family to think they are dying (a lasting misconception of HIV/AIDS). While some participants proudly mention the support they receive from their relatives, many others don't feel comfortable taking their medication at home or telling their families that they are going to a medical appointment.

Due to pervasive stigma within their communities, many respondents struggle to disclose their status to their partners. The majority of participants were either presently or previously in a relationship, with 63% reporting that they currently have a partner. Respondents in our sample who are single similarly expressed frustration at the negative reaction they receive when disclosing their status to potential partners, and one participant suggested that it is best to remain single.

A participant reported that they currently have not disclosed their status to their partner, and other participants reported instances in the past where they hid their HIV status from their partner. This was suggested to be a greater challenge among women, who face more serious repercussions if their partner discover they are HIV positive. Women often fear that their partner will leave them or react violently. As indicated in following comment, respondents tend to avoid status disclosure for fear of repercussions.

I hide my HIV status because if I tell my husband to come and get tested and they find him to be HIV negative when I'm HIV positive, definitely we are going to separate because his family is going to be like 'why are you with that woman'? They would say my sickness would affect him. So [if he finds out] he is going to hate me or he's going to chuck me, after chucking me I'd hate myself and say ha! Now what am I doing? Let me die, because women we need support from men. -5166 (Female, Treatment Success Group, Age 36)

Within our sample, employed respondents reportedly spend an average of 63 hours per week at work. Unfortunately, some respondents reported marked discrimination from employers and colleagues. Several respondents were fired from their jobs because their employer discovered their HIV-status. When participants openly took their medication or asked for time off to attend their appointments, people within their workplace would then learn that they are HIV-positive.

...out there the world perceives people [with HIV] differently. In my first job, I was stigmatized, I would say... My boss found out that I was sick, so I was chased away from work. So if you get such cases [where someone is fired from their job]—and there are many out there by the way—someone cannot easily move on with their lives. – (Female, Treatment Failure Group, Age 29)

Despite long hours spent at work, those employed often fear taking their medication at work, further complicating their adherence schedule. The respondents explained that much of the population in Uganda still view HIV as a death sentence, and employers often hold similar beliefs. According the participants, employers think that someone who is HIV positive is not worth an investment of time and capital because of the incorrect presumption that such a person will soon succumb to the illness. Due to this stigmatization within the workplace, many

participants reported a fear of being seen with medication at work, and a reluctance to disclose their HIV status to their colleagues.

Patients' suggestions for improving cART adherence

Participants discussed at a length on what they thought might improve cART adherence and accessibility, from their perspectives. In general, participants were satisfied with the services offered at the JCRC. When asked what would improve treatment accessibility across Kampala, they suggested that the JCRC should open more branches across Uganda. There were also many requests for an increase in the quality of treatment facilities, and not just the number. Specifically, respondents valued the care and friendliness of health service workers. They often explained that positive interactions with health service workers encouraged them to adhere to their treatment regimen. As many participants gained a lot of clarity on the subject of adherence through counselling sessions, they suggested that this service should be increased within the JCRC and at other facilities.

The counsellors should actually encourage the patients and talk to them, because when they talked to me, I adjusted the time I am scheduled to take my medicine. That is what worked for me. What works is when the counsellors talk to you, street talk, hip talk... to encourage you, not shout at you. Because when they shout at someone, they'll never take their medicine. Even me, when someone shouts at me, I can even leave the medicine there and not take it. – (Female, Treatment Failure Group, Age 36)

Many participants also highlighted the need for government support, with one respondent specifically concerned about the overreliance of the healthcare system on donor funding. Others requested government support in the form of job security, health programs and increases in the

quality of treatment services. It was often mentioned that the best way to increase accessibility to treatment is to improve upon the general public's knowledge of HIV and HIV treatment.

Participants suggested various methods for accomplishing this objective, including sensitization via television, radio, social media, church leaders and advocacy through local parishes. The use of social media was particularly recommended, since Uganda has a strong social media culture. Specifically, it was requested that information about ARVs should be expressed in layman's terms so that the population can understand the particularities of the medication regardless of their educational background and mother tongue.

Not everyone understands all the ifs and buts about HIV treatment, because it is a science, and to some extent it is not localized in our language so that everyone can understand. Even if I did go to school, I still might not understand. So to some extent, not everyone has someone to explain the science and break it down ... so some of them understand, but some of them do not. – (Female, Treatment Success Group, Age 24)

The value of quality healthcare services was made evident by the study respondents, who emphasized the importance of knowledge translation to patients and within their communities. In addition to the burden of a strict medication regimen, those on cART must navigate a social context which is still unfamiliar with HIV treatment. A summary of the common themes discussed during semi-structured interviews is provided on Table 8.

Table 8: Common themes discussed during semi-structured interviews (n=30)

Thematic Coding: Number of participants (number of mentions)

HIV/AIDS knowledge

Testing: 12 (39)

- Got tested because they were ill
- Got tested because they were pregnant
- Men are reluctant to test
- People (in general) don't want to get tested

Transmission: 14 (24)

- People think HIV is caused by witchcraft
- People think you can get HIV by sharing dishes
- Guilt associated with HIV transmission
- Confusion about modes of transmission

cART Knowledge/Perception

Community's perception: 26 (76)

- People don't understand
- People are beginning to understand
- People think...*
 - HIV is still a death sentence
 - cART will kill you
 - You will die even if you take cART
 - There are alternative treatments

Participant's understanding: 30 (156)

- cART...*
 - Allows you to live
 - Cannot cure
 - Fights the virus to weaken it
 - Reduces symptoms
 - Decreases the viral load
 - Makes the virus dormant

Consequence of low adherence: 28 (78)

- If you miss...*
 - You become ill/your immune system weakens
 - The medication will stop working
 - The virus becomes stronger
 - You will die

Adherence definition: 27 (58)

- Take cART at the same time every day
- Keep appointments

Challenges with cART adherence: 30 (661)

Behavioural characteristics: 20 (25)

- People miss because they are...*
 - Forgetful
 - Lazy/complacent

Careless/negligent
Hopeless
Uncommitted

Burden of drug regimen: 27 (152)

The pills are too big
Timing is difficult
Symptoms and side effects are intolerable

Food security and finance: 25 (86)

Need to take medication with food/water
Cost of drugs is a burden
Financial insecurity is an issue

Health service deficiencies: 20 (30)

Drugs not available
Waiting time used to be an issue
Waiting times are long
Waiting times are reasonable

Transport and travel challenges: 27 (64)

Cost of transport is too much
Clinic is too far
There is too much traffic
Transport is not an important barrier
Frequent travel is a barrier

Stigmatization: 30 (272)

Intentionally go to clinic far from home
Fear of being seen at clinic
Fear of being seen taking medication
Negative perception of PLWH
Stigma at work
Stigma at home/with family
Stigma with friends
Stigma with partner
Stigma is not an important barrier

Participant Suggestions: 27 (103)

Increased advertisement and sensitization
Increase the number of clinics
Increase availability of drugs
Increased counselling
Drug development
Need for government support

Discussion and Conclusion:

Overall, the findings from this study reveal that there are several persistent challenges to cART adherence. Although the study's participants demonstrated a relatively thorough understanding of the illness at the time of the interviews, their in-depth comprehension reflects the efforts of years of counselling and personal experience with cART. A low understanding of cART in early stages of treatment can result in treatment failure due to low adherence, with long-term implications for drug resistance and treatment success. Further, the level of knowledge alluded to within the general public was lacking. This low level of knowledge of HIV is consistent with studies based in Malawi which demonstrate the persistence of misconceptions surrounding HIV, decades after the peak of the epidemic (Antabe, Sano, Anfaara, & Luginaah, 2020; Sano et al., 2016). Misconceptions about cART play a formative role in the perception of control over treatment outcomes. Personal beliefs that HIV is the result of witchcraft or that it can be cured by religion may negate any willingness to adhere to treatment. Further, PLWH develop normative beliefs based on their community's consensus on treatment options. For instance, internalized beliefs that HIV is a death sentence may delay or discourage people from starting treatment. Knowledge levels amongst community members thus have a wide-reaching effect, with the potential to prevent or encourage positive adherence behaviors (Champion & Skinner, 2008).

Emerging from the findings here is the fact that after several decades of the HIV epidemic, stigma has remained deep-seated in this study context. The stigmatization of PLWH was one of the most salient themes which emerged in relation to adherence. A growing body of evidence suggests that stigma in sub-Saharan African countries has a considerable impact on the likelihood of missing doses of ARVs (Dlamini et al., 2009). Stigma was expected to decrease as

the public became increasingly aware of existing treatment options and medical advancement. However, there is evidence to suggest that HIV stigma may even be increasing (Chan et al., 2015; Maughan-Brown, 2010). Consequently, the perceived stigmatization (whether warranted or unfounded) reported has a serious impact on adherence behaviors, whereby people choose to go to clinics which are located far away from their homes in order to avoid being seen accessing treatment centres.

Consistent with previous work by Turmen (2003), although stigmatization affects all genders, it is seen as having a disproportionate impact on women, particularly in the context of intimate relationships. HIV is considered to be a gendered illness, as women are more at risk to infection due to biology as well as social, cultural and economic factors. In patriarchal societies which often dominate regions in sub-Saharan Africa, women are unable to play an active role in decision-making. For example, violence and forced sexual activity can affect women's ability to exercise preventative measures (Ramjee & Daniels, 2013; Turmen, 2003). Women who became widowed due the HIV/AIDS epidemic also face extraordinary challenges as they have to take care of their families in the context of sociocultural issues which tend to be made worse by stigma (Luginaah, Elkins, Maticka-Tyndale, Landry, & Mathui, 2005). This study's results echoed the effect of gender disparities on experiences with HIV treatment. During the interviews, participants described challenges faced by women such as violence in response to HIV status disclosure. Although women are affected disproportionately, both male and female gender norms play a role in undermining efforts to combat the HIV epidemic. As alluded to by the study's participants, a greater number of women seek out testing and treatment in Uganda, compared to men (Uganda Bureau of Statistics & ICF, 2018). Some studies in sub-Saharan Africa suggest that women are more comfortable in a clinical setting than men, and that seeking

out medical care can be viewed as a sign of weakness for men (Shand, Thomson-de Boor, van den Berg, Peacock, & Pascoe, 2014; Treves-Kagan et al., 2017). The gendered nature of HIV must therefore be considered in the planning and implementation of treatment programs.

In the sub-Saharan African cultures, communal living and close family ties are common and in most cases an expectation (Baskind & Birbeck, 2005). Hence, most participants have strong social networks, which are supposed to contribute positively to their quality of life. Yet, in addition to challenges faced in intimate relationships, PLWH can also experience difficulties amongst friends and relatives. Positive support from friends, family and community members can increase adherence to treatment and improve the lives of those living with HIV (Ncama et al., 2008). However, due to the fear of judgement and social ostracization, those living with HIV are often reluctant to disclose their status to the people around them. Consequently, friends and family members who surround PLWH in some cases are frequently unaware of their HIV status, thereby forcing people on cART to take their medication in secrecy. This fear of status disclosure adds another barrier thus resulting in low adherence, as participants struggle to find an appropriate time and place to take their medication.

The secrecy that patients must live under has led to a situation where they must go to clinics located very far from where they live to access cART. Hence, travel and geographic mobility influence HIV treatment in two main ways. Firstly, frequent or extended travel can make it challenging to adhere to a regular treatment schedule and to carry the necessary stock of medication, particularly considering the country's drug shortages (Hardon et al., 2006). Secondly, concerns of stigmatization in transit and at the destination can result in a reluctance to take medication (Taylor et al., 2014). Ultimately, the reason some people would forgo the convenience of traveling to a nearby clinic is to retrieve medication from a distant community

where they will not be recognized. These findings are consistent with studies based in South Africa, the Dominican Republic, and the United States, whereby the fear of stigma in home communities has pressured people on cART to seek treatment from farther health facilities (Mills, 2006; Taylor et al., 2014). Clinics such as the JCRC have a reputation for being HIV treatment facilities and providing services to PLWH. Those who visit the clinic are cognisant of this reputation and prefer to travel outside of their home community. Given the fact that participants frequently opted for farther away treatment facilities, it is interesting that some participants called for more treatment facilities to ease the challenges they face when trying to access cART. Such facilities may only end up helping to redistribute those on cART but may not necessarily ease transportation challenges unless the stigma of HIV improves.

As we attempt to untangle the relationship between accessibility and treatment success, social processes such as stigmatization in public places must be considered. Social support continues to be important for overall health and well-being. However, efforts towards public sensitization can help to create social settings which allow cART users to take their medication without fear of judgement. As requested by the study's participants, the use of tools such as social media can improve education surrounding HIV and cART, and inform the population about the treatment options available. PLWH in Uganda are burdened by multiple overlapping challenges which exacerbate one another. Challenges such as food insecurity, stigma, transportation, and financial insecurity cannot be considered individually, as they are deeply embedded in the fabric of society. As per the Health Belief Model, the perception of such barriers should be viewed as competing with the perceived benefits of treatment. Knowledge of HIV/AIDS and cART is often incomplete and muddled by social biases; therefore, treatment success hinges on the health beliefs which motivate the behavior of PLWH.

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Chapter 6: Summary and Conclusions

6.1 Introduction

This study's research objectives are united by the common goal of identifying and evaluating challenges associated with HIV treatment in the context of Kampala, Uganda. Each objective was approached using appropriate research methodology, in order to contribute the overarching goal of this dissertation. The following section will summarize the key findings of each manuscript as they relate to our research questions and hypothesis. The chapter will then examine how the research objectives intertwine, followed by a summary of the implications of this research for policy development and future research.

6.2 Discussion of key findings

The following research questions were addressed in the first manuscript found in Chapter 4: *Failure is not an Option: Barriers to HIV Treatment Adherence in Kampala, Uganda.*

Research question (1):

Do geographical barriers such as time spent traveling to the clinic have a negative impact on treatment outcomes in the context of Kampala, Uganda?

Research question (2):

What is the impact of socio-economic variables such as income on HIV treatment outcomes?

We hypothesized that *those with a greater burden of mobility will experience lower levels of adherence and therefore be more susceptible to treatment failure, compared to those who travel minimally, after controlling for demographic characteristics.* Our findings from Chapter 4 surprisingly contradictory, suggesting that those who traveled the longest distances to reach the

clinic reported the highest adherence. This association remained true after controlling for demographic variables. Many quantitative studies have failed to establish a statistically significant association between geographic variables and treatment success (Billieux et al., 2018; Byakika-Tusiime et al., 2005). The results from this research actually showed the reverse, reporting a statistically significant *negative* relationship between the distance travelled to the clinic and the likelihood of reporting missed doses of medication. Although geographical barriers are often identified as an obvious impediment to treatment adherence, the literature which has sought to evaluate this association has been divisive (Hardon et al., 2006; Lankowski et al., 2014; Tuller et al., 2010).

Our results can potentially be explained by the interaction of geographic variables with extraneous variables which were not accounted for in our models. Although we accounted for basic socioeconomic and demographic factors, there may be aspects of the social context in Kampala which further complicate the relationship between geography and treatment success. The unique geographical position of the JCRC, which is far from the city center but still within the greater Kampala region, gives this study an interesting angle to approach this research problem. The topic of stigma was broached as a potential explanation for an aspect of the study's findings: Those on cART often choose to pick up their medication from treatment facilities which are far from their homes, in order to avoid being seen at an HIV treatment center (Hardon et al., 2006; Taylor et al., 2014). Those living in proximity to the treatment center may feel a substantial amount of stigma but may not have the resources to reach a distant treatment facility. Those who live hours away who decide to invest the resources necessary to reach the JCRC – which is considered a high-quality treatment center – may be the most invested in treatment adherence. A similar theory was advanced by Lankowski et al. (2014), in their explanation of

paradoxical findings whereby greater geographical barriers actually led to positive HIV treatment outcomes.

In response to the second research question which seeks to assess the relative impact of demographic variables, our research delivered further counterintuitive findings. From our statistical models it emerged that the theoretical individual with the highest likelihood of reporting missed doses lives less than one hour from the treatment facility, has a partner and high-income employment. The prevalence of HIV stigma also serves as a potential explanation for these findings. Although stable employment and relationships are considered to be beneficial for those with chronic conditions such as HIV, non-disclosure of one's status may negate potential benefits (Ncama et al., 2008). Those who perceive substantial HIV stigmatization at home or within their workplaces may not feel comfortable taking their medication, thus compromising adherence.

Research question (3):

What do individuals on cART perceive to be the main barriers to HIV treatment and treatment adherence in Kampala, Uganda?

From our interviews with those receiving HIV treatment from the JCRC, it emerged that the following are notable challenges associated with cART adherence: The community's knowledge and perception of HIV and HIV treatment, the burden of the drug regimen, food insecurity and financial issues, transport and travel, and stigmatization. In general, these principle barriers were consistent with existing literature on HIV treatment challenges in Uganda as well as other sub-Saharan African countries such as South Africa (Gilbert & Walker, 2009; Hardon et al., 2006).

As described by the participants, the burden of the medication regimen includes the number and size of pills, the life-long duration of treatment, regimen complexity and resultant side-effects. This has been difficult to address as side-effects can differ drastically between individuals (Gilbert & Walker, 2009). This challenge associated with cART intersects clearly with HIV stigma, as many individuals are motivated to take the medication in order to reduce visible symptoms of the illness in efforts to conceal their HIV status (Schulkind et al., 2016). Side-effects are also worsened by food insecurity, which is a serious issue in Uganda: A study in southwestern Uganda found 78.5% of their study participants who were on cART to be food insecure (Weiser et al., 2010). Food insecurity is generally intertwined with financial insecurity, whereby those on HIV treatment are often forced to distribute limited funds between the cost of food, shelter and children's education, as well as the cost of transportation to the clinic (Tuller et al., 2010). Indeed, the study's participants often cited the substantial cost of transportation in comparison to their living expenses.

6.3 Interrelation of key findings from manuscripts

We advanced several possible explanations for the paradoxical findings from our quantitative study in Chapter 4. The narrative which emerged from the interviews conducted with those on cART helps to shed light on the complex relationship between geography and HIV treatment success. The topic of geographic barriers to treatment adherence was embedded in several interview questions. However, under the direction of the respondents, it did not remain the focus of discussion. Rather, the topic of travel and transportation was often re-introduced when participants discussed fears of stigmatization when taking their medication in transit. As is commonly identified in qualitative literature, many participants reportedly struggled with the burden of transportation and geographic mobility (Gilbert & Walker, 2009; Tuller et al., 2010).

However, the manner in which they dealt with this barrier was not clear cut, and thus, attempts to measure the association between geography and treatment success may deliver inconsistent findings. As suggested by the participants, experiences with stigma in transit occurred not only with travel to treatment facilities, but also during frequent visits to friends and relatives, with regular travel to home villages, and with jobs which demand high mobility. These are measures of geographic mobility that have been largely neglected in the literature.

Interview participants also spoke of substantial discrimination within their workplaces. Many respondents conceal their HIV status at work, and those who disclosed their status faced severe repercussions such as ostracism and even job loss. These findings in conjunction with the results of our regression analysis help to explain how employment can actually threaten treatment adherence. A steady source of income is evidently essential for basic health and well-being; however, HIV stigma and discrimination have made it increasingly difficult for people living with HIV to find employment. People are often forced to take their medication or attend clinic appointments in secrecy. A study conducted in Kenya and Zambia reported similar findings, whereby people living with HIV experienced discrimination in hiring, the reception of promotions, and job loss (Sprague, Simon, & Sprague, 2011).

Lastly, the findings from Chapter 4 suggest that those with a partner were actually more likely to report missing doses of medication. Although it has been suggested that support from a significant other should increase treatment adherence, people on cART who haven't disclosed their status or are simply uncomfortable with their status can feel pressured to engage in HIV treatment and care in private (Tsai, Bangsberg, Kegeles, et al., 2013). This emerged from the interviews as a problem frequently experienced with a particular severity early on in treatment. People on cART may become more comfortable over time, particularly when the burden of HIV-

related symptoms are reduced (Tsai, Bangsberg, Bwana, et al., 2013). However, early experiences on cART and initial levels of adherence have implications for long-term treatment success (Metzner et al., 2009; Ruel et al., 2011). These findings are supported by a study on treatment adherence in Kampala by Byakika-Tusiime et al. (2005), who found that those who were single were actually more likely to adhere to treatment.

6.4 Contributions of this dissertation

Literature examining the impact of geographical barriers in urban Uganda has been very limited, as issues of accessibility in rural areas have often been the focus of study (Lankowski et al., 2014; Siedner et al., 2013; Tuller et al., 2010). Generally, the specific use of a geographic approach to examining HIV treatment adherence is rare, regardless of urban or rural context. Our investigation of predictors of treatment adherence in Kampala contributes to the bridging of this research gap. This dissertation also contributes to a growing body of literature which endeavors to incorporate the lived experiences of those on cART into the evaluation of treatment programs. Our findings help to show how experiences on HIV treatment cannot be understood using a purely biomedical approach, as such approaches fail to acknowledge the effects of one's environment, community and economy on treatment outcomes. By employing perspectives from health geography, we have provided a holistic interpretation of barriers to treatment success.

This dissertation employed the distinctive approach of coupling regression models with content analysis, which gives a unique perspective on HIV treatment experiences. Several of our key findings from Chapter 4 were unexpected, and the perspectives of our interview respondents allowed us to investigate the social mechanisms which underly our statistical results. This thesis sheds light on the intersection of social interactions and stigma (at home and in the workplace), and its negative impact on adherence in Kampala. We have shown how stigmatization can often

arbitrate the relationship between geography and treatment adherence. Our qualitative findings also suggest that knowledge levels surrounding HIV and HIV treatment have a powerful influence on the community's perception of people living with HIV, and thus, the enactment of stigmatization.

6.5 Limitations of the study

This thesis has limitations which should be noted. The robustness of findings is heavily impacted by a study's sample size (Bohrstedt & Carter, 1971). As previously discussed, our sample approaches the minimum expected sample size for logistic regression. Related studies have also conducted robust analyses using comparable sample sizes (Siedner et al., 2013; Weiser et al., 2003). However, for future research, a larger sample size could increase the generalizability of the research in the context of Kampala. Due to time constraints which required data collection to be complete within four months, probability sampling was not feasible. However, purposive (non-probability) sampling did allow us to maximize our sample size during our timeframe and thus optimize the robustness of findings. The purposive sampling strategy for the selection of interview participants also helped to maximize the richness of information derived from each case (Palinkas et al., 2015).

Several other limitations should be acknowledged in the consideration of the study's findings. Notably, as the majority of the analyses were conducted by the main author of this dissertation, who is Canadian, our interpretation of findings may be limited. To reduce the likelihood of misinterpretation, our Ugandan partners were consulted continually throughout the research process. Still, the influence of the researcher's positionality and unintentional bias on research design and analysis should be considered (Phoenix et al., 2013). At various points throughout the research process, translations between Luganda and English occur. There is

therefore the possibility of mistranslation, despite the research team's best efforts. The social conformity of interview and questionnaire responses also presents a potential limitation, as participants can feel pressured to give desirable answers, despite assurances that there are no right or wrong answers. These limitations should be considered in the interpretation of the findings presented in this dissertation.

6.6 Policy implications

Worldwide, healthcare systems are increasingly adopting models of patient-centered care, which focus on the unique needs of the patient rather than employing a one-size-fits-all treatment strategy. This model of healthcare is proposed to have the potential to greatly improve levels of adherence and thus reduce the development of drug-resistant HIV. Under this model, HIV treatment patients would be empowered through regular support and counselling (O'Donnell et al., 2016). One of the findings from this research emphasized the importance of the kindness and compassion of health personnel for those on cART (pointing to the need for the reinforcement of professional development), given that several participants explained how they are discouraged to visit clinics for their medication when they are treated badly in a health facility. The participants' experiences of stigmatization in the general community can be either alleviated or exacerbated by their perceived sense of acceptance around health professionals as well as their HIV-positive peers. Participants expressed a desire to connect with other HIV-positive community members, with the knowledge that a sense of community can help them to manage the stigma and stress associated with HIV treatment. These findings point to the need for peer support groups within the HIV-positive community.

HIV treatment facilities in Uganda have begun to adopt a patient-centered approach and are therefore working towards increasing the efficiency of healthcare systems (USAID, 2012).

The JCRC itself strives to employ a differentiated service delivery model (DSDM), which tailors the cART drug regimen to each patient, providing six months of refills for those with stable suppressed viral loads (JCRC, 2018). The findings from this study support the application of this service model in Uganda. However, this treatment strategy can be further improved. For instance, under current policies, those who experience treatment failure are automatically given shorter refill periods, requiring them to return to the health center more frequently to be monitored. For those struggling for transportation costs, this can increase the financial burden and potentially worsen treatment outcomes. It is therefore recommended for treatment regimens to be tailored to each individual, with the consideration of the potential influence of factors such as accessibility on treatment success.

Community-based treatment programs focussed on DSDM have also been shown to reduce HIV stigma, as those on cART became more open about their HIV status with adequate support from counsellors (Duffy et al., 2019). Hence, community sensitization should continue to encourage the public to be increasingly receptive to discussions of HIV and HIV treatment. Our findings draw attention to the need for increased awareness within the greater community in Uganda. As confirmed by Uganda's latest Demographic Health Survey, knowledge levels surrounding HIV are inadequate: under 50% of the population was assessed as having a comprehensive understanding of HIV (Uganda Bureau of Statistics & ICF, 2018). The findings from this study suggest that knowledge levels of HIV treatment are also inadequate. Persistent misconceptions of HIV and HIV treatment encourage the development of negative stereotypes of those living with HIV. HIV testing and treatment initiatives have made great strides towards the goals of achieving universal treatment accessibility and eventually eradicating the virus. Health education policies should strive to inform the public about HIV risk as well as HIV treatment, as

this study's findings suggest that a substantial proportion of the community is unaware that HIV is now a manageable chronic condition. Community sensitization can help to reduce the high levels of stigmatization felt by those on HIV treatment.

6.7 Future directions

This research has provided direction for future studies which may endeavor to explain the complex relationship between geography and HIV treatment outcomes. Firstly, treatment outcomes inevitably fluctuate over time, and the personal circumstances of those on treatment do not necessarily remain constant. Consequently, a longitudinal study which follows participants on cART will get a clearer picture of factors which impact treatment success. Time-sensitive analyses are particularly important in this context as adherence to life-long treatment regimens is suggested to decline over time.

The results of this study have identified stigma as a persistent problem within the HIV/AIDS epidemic. As health service models in Uganda continue to improve, further research is needed to assess the degree to which HIV stigma impacts treatment adherence. Additionally, future studies should endeavour to consider complex social variables that underpin stigmatization in order to devise appropriate context-based tools for community-level educational programs aimed at improving public knowledge on HIV treatment.

Lastly, given the importance of the geographical locations of treatment centers, a location-allocation analysis could be conducted to evaluate the attributes (e.g., transportation, topography and population characteristics) of potential service areas in order to choose an optimal location for future treatment clinics. People on HIV treatment in Kampala grapple with the burden of transportation challenges, but are reluctant to visit treatment centers near their

home community. A simple model of supply and demand will therefore be inadequate to address the needs of the population. The development of a comprehensive location-allocation model for location health facilities will support the advancement of the public health system in the Kampala region.

6.8 References

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Appendix A

Geography and Health Questionnaire

Name of interviewer: _____

Date and time: _____

ID Number: _____

General Demographic Questions

1. Please circle your identified gender: male female other (specify): _____

2. Are you currently enrolled in a research protocol or clinical trial at the JCRC? Y N

3. Do you receive a refund for the cost of your transportation to the JCRC?.....Y N

4. Where do you live in Kampala? Exact address and/or location based on landmarks:

5. Has your residence changed since you started ART treatment?.....Y N
If YES, specify the location(s) of your previous home(s):

Employment and Assets

6. Do you own or have use of a car, truck, motorcycle, or bicycle that you use every day for transportation?.....Y N

If YES, circle the type of transport: car, truck, motorcycle, or bicycle

If NO, circle the transport you use most often: private hire, bus, taxi, boda, bicycle, walk

7. Please indicate which of the following items your household owns (circle your choices).

- a. Television
- b. Mobile phone
- c. Computer
- d. Radio
- e. Refrigerator
- f. Sewing machine
- g. Bed
- h. Table
- i. Running water
- j. Electricity

8. Does your household own any livestock?..... Y N

If **YES**, how many of the following animals does your household own?

- _____ Cow(s)
- _____ Goat(s)
- _____ Chicken(s)
- _____ Pig(s)
- _____ Sheep
- _____ Other (specify):

9. Are you employed? Y N

If **NO**, proceed to sub-section **Education and Transportation**

10. How many days per week do you work? _____ days

11. How many hours per day do you work? _____ hours

12. What is the location of your normal place of work? Exact address and/or location based on landmarks:

13. How much do you earn (UGX) per month?

- a. Below 100,000
- b. 100,000 - 349,000
- c. 350,000 - 699,000
- d. 700,000 - 1,000,000
- e. 1,000,000+

14. On average, how long does it take you to get to work? (Circle one option below)

- a. Less than 10 min
- b. 10 min to 30 min
- c. 30 min to 1 hr
- d. 1 hr to 2 hrs
- e. Greater than 2 hrs

15. What are your typical means of transportation to and from work?

Circle ALL that apply: car, truck, motorcycle, bicycle, private hire, bus, taxi, boda, walk

16. Please list the order of transport and how much time you spend on each transport to/from work and include waiting times for each transport. (e.g. walk for 10 min to motorcycle, take motorcycle for 5 min to Shell on Entebbe Rd, wait 15 min for taxi, take taxi for 20 min to taxi park, wait 5 min for new taxi to take to Wandegeya/work):

To:

From:

17. Has your workplace changed since you started ART treatment? Y N

If **YES**, specify the location(s) of your previous workplace(s):

Education and Transportation

18. Are you in school? That is, secondary, college, vocational, professional, or university?Y N
If **NO**, proceed to sub-section **Transportation and Children**

19. How many days per week do you attend school? _____days

20. How many hours per day do you attend school? _____hours

21. What school do you attend?

22. What is the location of your school? Exact address and/or location based on landmarks:

23. Have you changed school(s) since you started ART treatment?Y N
If **YES**, specify the location(s) of your previous school(s):

24. On average, how long does it take you to get to school? (Circle one option below)

- a. Less than 10 min
- b. 10 min to 30 min
- c. 30 min to 1 hr
- d. 1 hr to 2 hrs
- e. Greater than 2 hrs

25. What are your typical means of transportation to school?

Circle ALL that apply: car, truck, motorcycle, bicycle, private hire, bus, taxi, boda, walk

26. Please list order of transport and how much time you spend on each transport to/from school and include waiting times for each transport.

To:

From:

Transportation and Children

27. Do you have children?.....Y N

If **NO**, proceed to sub-section **Appointments and HIV-Related Care**

28. What school does your child/children attend?

29. What is the location of your child/children's school? Exact address and/or location based on landmarks:

30. Do you transport your children TO school?.....Y N

If **YES**, how many times per week? _____

31. On average, how much time does it take to drive TO your child/children's school? (Circle one option)

- a. Less than 10 min
- b. 10 min to 30 min
- c. 30 min to 1 hr
- d. 1 hr to 2 hrs
- e. Greater than 2 hrs

32. Do you transport your children FROM school?.....Y N

If **YES**, how many times per week? _____

33. On average, how much time does it take to drive FROM your child/children's school? (Circle one option)

- a. Less than 10 min
- b. 10 min to 30 min
- c. 30 min to 1 hr
- d. 1 hr to 2 hrs
- e. Greater than 2 hrs

34. What are your typical means of transportation to and from your children's school?

Circle ALL that apply: car, truck, motorcycle, bicycle, private hire, bus, taxi, boda, walk

35. Please list order of transport and how much time you spend on each transport to/from your children's school and include waiting times for each transport.

To:

From:

Appointments and HIV-Related Care

36. Is the JCRC your primary clinic for HIV-related care?..... Y N

If NO, where is your primary medical clinic? Exact address and/or location based on landmarks:

37. How long does it take you to get to your HIV care-related clinic (JCRC or other)?

- a. Less than 10 min
- b. 10 min to 30 min
- c. 30 min to 1 hr
- d. 1 hr to 2 hrs
- e. Greater than 2 hrs

38. From which of the following places do you leave *most often* when heading to the clinic for HIV-related care? Select one.

- a. Home
- b. Work
- c. School
- d. Other (specify): _____

39. What are your typical means of transportation to/from this clinic?

Circle ALL that apply: car, truck, motorcycle, bicycle, private hire, bus, taxi, boda, walk

40. Please list order of transport and how much time you spend on each transport to/from this clinic and include waiting times for each transport.

To:

From:

41. How many times per year do you have scheduled clinic visits (at the JCRC or another clinic)? _____ visits

42. Do you ever take the day off of work (or school) to attend your clinic appointments?.....Y N

43. Have you ever missed one of your scheduled clinic visits (at the JCRC or another clinic) while on firstline treatment? Y N

If **YES**, how many scheduled clinic visits have you missed in that period? _____ visits

If **YES**, what was the main reason for missing a clinic visit? Select ONE option.

- a. You did not think it was necessary
- b. You could not get time off work
- c. You needed to fetch your children from school
- d. The distance was too far
- e. You did not have money for transport there
- f. Other (please specify): _____

44. Have you changed the clinic you receive your ART drugs from since you started treatment?.....Y N

If **YES**, specify the location of your previous clinic(s):

If **YES**, why did you change your clinic to the current one?

45. Do you get your HIV **medications** from the same clinic mentioned in questions 36?..... Y N

If **YES**, proceed to sub-section **Treatment Adherence**

If **NO**, where do you pick up your HIV medications from?

46. What are your typical means of transportation to/from this clinic?

Circle ALL that apply: car, truck, motorcycle, bicycle, private hire, bus, taxi, boda, walk

47. Please list order of transport and how much time you spend on each transport to/from this clinic and include waiting times for each transport.

To:

From:

48. How long does it take you to get to the clinic to pick up your medications?

- a. Less than 10 min
- b. 10 min to 30 min
- c. 30 min to 1 hr
- d. 1 hr to 2 hrs
- e. Greater than 2 hrs

49. From which of the following places do you leave *most often* when heading to the clinic to pick up your medication? Select one.

- a. Home
- b. Work
- c. School
- d. Other (please specify): _____

Treatment Adherence

50. How often are you scheduled to pick up your HIV medications in a year? _____ times/year

51. Do you ever take the day off of work (or school) to pick up your ART medications?.....Y N

52. Have you ever stopped taking your HIV medicine (intentionally)?..... Y N

If **YES**, how long did you stop taking them for? _____ days

If **YES**, what is the *main* reason you stopped taking them? Select one option.

- a. You felt sick when taking them
- b. You feared side-effects
- c. You did not feel they were working
- d. You feared dependence on the medication
- e. You felt better
- f. Social stigma
- g. Can't take them everyday for the rest of my life
- h. Other (please specify): _____

53. Have you ever been unable to refill your HIV medicine?.....Y N

If **YES**,

How many times per year have you been unable to refill them? _____ times/year

On average, for how long did you not take your pills because you were unable to refill them?
_____ days

What is the *main* reason you were unable to refill your HIV medicine? Select one option.

- a. You could not get time off work
- b. You needed to fetch your children from school
- c. The distance was too far
- d. You did not have money for transport there
- e. Your medication was not available at the pharmacy/clinic
- f. Other (please specify): _____

54. Have you ever missed a dose of your medication?.....Y N

If **YES**, what is the *main* reason you failed to take your pills? Select one option.

- a. You were at an important event such as a wedding or funeral
- b. You were traveling
- c. You were on vacation
- d. Your treatment regimen is too complicated
- e. You shared or sold your medication
- f. You forgot to take it
- g. You lost the medication
- h. You were hospitalized
- i. Other (please specify): _____

Partner-Related Questions

55. Do you have a primary partner? That is, your husband/wife/boyfriend/girlfriend?Y N

If **NO**, proceed to sub-section **Mental and Physical Health**

56. What is your marital status? Circle one option.

- a. Married
- b. Separated
- c. Widowed
- d. With girlfriend/boyfriend

57. Does your partner know your HIV status?.....Y N

58. Is your partner aware that you are taking ARVs?.....Y N

59. What is your partner's HIV status?

- a. Positive
- b. Negative
- c. Don't know

60. Is your partner on ART?.....Y N
 If **YES**, does your partner get their medications from the same place as you?.....Y N

Mental and Physical Health (Adapted from the Duke Health Profile)

Instructions: Here are some questions about your health and feelings. Please read each question carefully and check (✓) your best answer. You should answer the questions in your own way. There are no right or wrong answers.

	Yes, describes me exactly	Somewhat describes me	No, doesn't describe me at all
61. I like who I am			
62. I am not an easy person to get along with			
63. I am basically a healthy person			
64. I give up too easily			

Mental and Physical Health (Adapted from the Duke Health Profile)

Instructions: Here are some questions about your health and feelings. Please read each question carefully and check (✓) your best answer. You should answer the questions in your own way. There are no right or wrong answers.

	Yes, describes me exactly	Somewhat describes me	No, doesn't describe me at all
65. I have difficulty concentrating			
66. I am happy with my family relationships			
67. I am comfortable being around people			

TODAY would you have any physical trouble or difficulty:

	None	Some	A Lot
68. Walking up a flight of stairs			
69. Running the length of a football field			

DURING THE PAST WEEK how much trouble have you had with:

	None	Some	A Lot
70. Sleeping			
71. Hurting/aching in any part of your body			
72. Getting tired easily			

Mental and Physical Health (Adapted from the Duke Health Profile)

Instructions: Here are some questions about your health and feelings. Please read each question carefully and check (√) your best answer. You should answer the questions in your own way. There are no right or wrong answers.

	Yes, describes me exactly	Somewhat describes me	No, doesn't describe me at all
73. Feeling depressed or sad			
74. Nervousness			

DURING THE PAST WEEK how often did you:

	None	Some	A Lot
75. Socialize with other people (talk or visit with friends or relatives)			
76. Take part in social, religious or recreation activities (meetings, church, sports, parties)			

DURING THE PAST WEEK how often did you:

	None	1-4 Days	5-7 Days
77. Stay in your home, a nursing home, or hospital because of sickness, injury, or other health problem			

Appendix B

Consent Form

TITLE OF THE RESEARCH:

Geospatial patterns of HIV antiretroviral therapy treatment facility use, work location, and viral suppression in Kampala, Uganda

PRINCIPAL INVESTIGATOR:

Dr. Cissy Kityo, Joint Clinical Research Centre, Kampala, Uganda

Dr. Eric Arts, The University of Western Ontario, London, Canada

INTRODUCTION:

You are being asked to take part in the research study named above. Before you decide whether to join this study, we would like to explain the purpose of the study, any risks to you, and what will be expected of you if you decide to participate.

This informed consent document gives you information about the study that will be discussed with you. Once you understand the study, and if you agree to take part in it, you will be asked to sign this consent form or make your mark in front of someone. You will be given a copy to keep.

Please note that your participation in this research is entirely voluntary. You may decide not to take part or to withdraw at any time without losing the benefits of your standard medical care.

PURPOSE OF THE STUDY:

Studies have shown that with the use of repeat clinic visits in Ugandan HIV-infected cohorts the adherence rates for HIV-infected Ugandans are higher than that of HIV-infected individuals in North America. Despite this, roughly 10% of Ugandan HIV-infected patients fail first-line cART which is more than double that of HIV-infected North Americans on cART. The purpose of this study is to find out whether the geospatial situation of HIV-infected individuals on ARV has an impact on treatment outcomes

A total of 400 HIV-infected patients from the Kampala district will be in this study. Equal numbers of patients successful on cART for 3+ years and those who have failed first line cART within 2 years will be asked to take part in this study.

Procedures:

If you agree to join this study, after you sign this consent form you will be asked questions about your pattern of transportation use, location of your home and workplace, location of the pharmacy you receive your ARV drugs from, mental and physical health status and history of ART adherence. Based on your answers to the survey questions, you may be selected to answer additional questions about your experience on ART. These additional questions and responses will be audio recorded and put into writing. We will also review your current clinic charts.

Potential Benefits:

You will receive UGX 20,000/= (Twenty thousand shillings only) for your transportation costs to and from the clinic, and for the time you may have lost from work.

Costs to you:

There is no cost to you for taking part in this study.

Confidentiality:

Your research records will be confidential to the extent permitted by law. You will be identified by a code, and personal information from your records will not be released without your written permission. You will not be personally identified in any publication about this study. If you are selected to answer additional questions, your responses will remain confidential. GPS coordinates will be taken within a 300 m radius of your home to keep anonymity of the exact location of your home.

Your records may be reviewed by the NIH and the study monitors.

Persons to contact for problems or questions:

If you ever have questions about this study, you should contact Dr. Cissy Kityo at the Joint Clinical Research Centre in Kampala, Uganda. Tel number xxx xxx-xxx-xxx

If you ever have questions about your rights as a research subject you may call Dr. Jess Kagimba, Chairman JCRC IRB/REC, Tel number xxx xxx-xxx-xxx or JCRC IRB/REC office on xxx xxx-xxx-xxx

SIGNATURE PAGE

If you have read the informed consent or had it read and explained to you and understand the information, and you voluntarily agree to join the study, please sign your name or make your mark below.

_____	_____	_____
Volunteer's name	Volunteer's signature	Date
_____	_____	_____
Witness' name	Witness' signature	Date

Appendix C:

Semi-Structured Interview Guide with ARV User

Name of interviewer: _____

Date and time of interview _____

ID Number: _____

Introduction:

- Introduce interviewer and researchers and reiterate purpose of discussion: We want to learn from participants, to hear their thoughts on ART and understand challenges that exist for people who take ARVs
- Ask for participant's consent to respond to additional questions which will be audio-recorded and transcribed
- Thank participants for agreeing to participate, and ensure confidentiality of results

Script: Thank you for accepting to be interviewed for this study, my name is _____, at the jcrc my role is _____, the purpose of the interview is to try to learn from participants, to hear their thoughts about ART and understand challenges that exist for people who take ARVs. During the interview, we ask that you give us as much detail as possible. There are no right or wrong answers—all answers are welcome. The interview is going to be audio-recorded to help me take good notes, however, whatever you have said here will only be accessed by the research team and your names will never be mentioned anywhere outside the interview. After the study, an analysis will be done and all recordings will be destroyed. Feel free to ask any questions at any point during the interview. You should also feel free to ask for any clarification you need during the discussion.

Explore participant's knowledge of ART:

We would like to understand what people know about HIV/AIDS medicines.

1. Could you help us with this by telling me what you know about antiretroviral therapy (or ART)?
 - Allow patient to say what they want, then probe on the following: how it works, costs, side effects, how long you have to take it.
 - Probe as to whether or not the patient believes ART is a treatment that cures HIV
2. Could you describe what you think may happen when someone on ART misses several doses of their medication?
 - Allow patient to say what they want, then probe on the following: do they become sick? Do they continue taking this medication?

Understand participant's experience on ART:

We would like to hear more about your personal experiences on ART. Please feel free to be open about the problems you face with this. Everything you say here will remain confidential and will not be shared with anyone at the clinic.

3. What would you say are the main challenges faced by people on ART?
 - Allow patient to say what they want, then probe on the following: side effects, lack of food, adherence, lifestyle issues, pill burden.

Understand challenges to ART adherence:

We would like to understand how people manage to take their medications – for some people it’s not a problem but we also know that others don’t always find it easy.

4. Could you tell me what you understand about good adherence?
 - Probe: how do you define good adherence?
5. Why do some people have good adherence?
 - Probe: what are the sources of motivation for adherence?
6. Why do others have poor adherence?
 - Probe: because they forgot to take it? Because they can’t get to the pharmacy?
7. What would you say can be done to help people adhere more easily to their treatment?
 - Probe: reminders? Social support?

Quality of HIV/AIDS care and treatment services:

We want to hear your thoughts on the services provided at the JCRC and in Kampala in general.

8. How would you describe the services provided by the JCRC?
 - Probe: privacy, confidentiality, respect, being listened to, time spent with patient, waiting time, integration with other services
9. What support are you given by the health workers to help you adhere better to your medications?
 - Probe especially on counselling about adherence, regular appointments, longer duration of prescription refill
10. How can existing infrastructure be modified and strengthened to increase access to ART, in Kampala?
 - Probe: transportation, pharmacies.

Community Perception and Access:

Now we want to hear your experiences with ART in your specific community.

11. What kind of support do you receive from your community, your family, and your workplace?
 - Probe: encouragement from family members? Any negative social support or stigma? Added stress?
 - Specify which family member offers support, probe: boyfriend, husband, children

12. What are the beliefs and perceptions of your community on HIV/AIDS treatment?
 - Probe for why they think those beliefs and perceptions exist.
 - Probe especially on the existence of stigma or discrimination.

13. What resources are needed to make antiretrovirals widely available in *your specific area*?
 - Probe: more clinics? Improved public transportation?

***Ask follow-up questions based on participant's responses to questionnaire**

Conclude Interview

14. Do you have any questions or feedback for me?
15. Thank the participant and invite them to provide any additional commentary.

Appendix D: Curriculum Vitae

Name : Gabrielle Bruser, BA (Hons), MSc Candidate

Education:

Degree	Discipline	Institution	Year	Location
MSc	Geography, Global Health Systems in Africa	Western University	2020	London, Ontario
BA	Human Environment (Hons) Thesis: Assessing Uncertainty in the Calculation of Flood Zones in the Pierrefonds Region of Montreal, QC	Concordia University	2018	Montreal, Quebec

Relevant Employment History:

Position and Responsibilities	Location	Date
Teaching Assistant Courses: Environmental Hazards and Human Health, Public Health and Environment, Geography of Hazards	Department of Geography, Western University, London, ON	September 2018 – April 2020
Internship Coordinator with CEED Concordia	Concordia University, Montreal, QC and Gulu, Uganda	November 2017 – September 2018
Intern with CEED Concordia	Concordia University, Montreal, QC and Gulu, Uganda	May 2017 – August 2017
Administrator	Réseau Access Network, Sudbury, ON	May 2013 – August 2013

Honors and Awards:

	Date
Received Ontario Graduate Scholarship	2019/20
SSHRC Canada Graduate Scholarship – Master’s Award	2018/19
Dean’s List	2015/16-2018/19
Arts & Science Scholar	2015/16-2018/19
TD Insurance Meloche Monnex Scholarship	2018
Faculty of Arts and Science Entrance Scholarship	2012/13

Manuscripts (Under Review):

Sano, Y., Kansanga, M., Kwon, E., Konkor, I., Bruser, G., Umar, H. Time availability as a determinant of health: Evidence from the 2015 Canada General Social Survey. Under Review.

Bruser, G. Katasi, R., Zhang, L. Z., Namasinga, M., Arts, E., Kityo, C., Luginaah, I. Failure is not an Option: Barriers to HIV Treatment Adherence in Kampala, Uganda. *Health and Place*. Under Review.

Bruser, G., Luginaah, I., Katasi, R., Zhang, L. Z., Namasinga, M., Arts, E., Kityo. "...So that's why we hide, we don't want them to know"— Challenges to Antiretroviral Therapy Adherence in Kampala, Uganda. *Social Science & Medicine*. Under Review.

Guest Lectures:

Lecture	Location	Date
Course: GEOG 2131B – The Natural Environment Lectures: - Planet Earth in Profile - Global Climates and Climate Change	Western University, London, ON	February 2020
Course: GEOG 3432B – Environmental Hazards and Human Health Lecture: - Barriers to HIV Treatment in Kampala, Uganda	Western University, London, ON	May 2020
Course: LOYC 398 – Orientation to International Community Engagement - Sustainability of International Development Projects	Concordia University, Montreal, QC	February 2018

Presentations at professional meetings:

Event	Presentation	Location	Date
Africa-Western Collaborations Day 2019	Failure is Not an Option: Barriers to HIV Treatment in Kampala, Uganda	Western University, London, ON	November 13, 2019
Africa-Western Collaborations Day 2018	Poster Presentation: The Impact of Geospatial Barriers on Adherence to HIV Treatment in Kampala, Uganda	Western University, London, ON	November 15, 2018
GIS Day 2018	Flood Mapping in Montreal	Western University, London, ON	November 16, 2018
Sustainability Across Disciplines Conference	Resilience and environmental sustainability in Uganda	Concordia University, Montreal, QC	March 8-9, 2018