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RIBEIRÃO PRETO COLLEGE OF NURSING

NICOLA ALICEEN NERO

Length of survival of people living with HIV/AIDS in Guyana from 2003 to 2015

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NICOLA ALICEEN NERO

Length of survival of people living with HIV/AIDS in Guyana from 2003 to 2015

Thesis presented to the Graduate Program in
(Fundamental Nursing) of the University of
São Paulo at Ribeirão Preto College of
Nursing, for Doctoral level.

Line of Research: **Care Process for Adults
and Elderly People**

Candidate: **Nicola Aliceen Nero**

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ABSTRACT

Name: Nicola Aliceen Nero. Title of the thesis/dissertation. Length of survival of people living with HIV/AIDS in Guyana from 2003 to 2015. Doctoral thesis 2022. Presented to the University of São Paulo at Ribeirão Preto College of Nursing. Concentration area: Fundamental Nursing.

Introduction: Human immunodeficiency virus (HIV) is an infection that affects the body's immune system, specifically the white blood cells called CD4 count (WHO, 2022). As a global health concern, HIV/AIDS has been around for decades and to date, there is no known cure for the disease, however, with good health seeking behaviours, treatment, care and support, many persons affected are continuing to live long, comfortable and adoptable lives. **Objective:** The main objective of this study was to analyze the survival of people living with HIV and AIDS in Guyana from 2003 to 2015. **Method:** A retrospective cohort study was done of individuals with HIV/AIDS, notified and in care at seventeen (17) HIV Care and Treatment Sites, Ministry of Health, Guyana, from 2003 to 2015. The study took the form of a desk review of a cohort of individuals entered in the registry, consisting of clinical and treatment information that assisted to answer the proposed questions. **Result:** Of the 17 HIV Care and Treatment Sites assessed, the final bank produced a total of 1,067 (one thousand and sixty-seven patients) for analysis. Fifty six (56%) female and forty four 44% male. Eight variables were evaluated for this study that provided specific results as per analysis. **Conclusion:** Overall, patients with a high category of the CD4 variable have less risk of death and a good overall survival state and co-morbidities do contribute to an early death, especially if the ARV treatment regimen is not adhered to. Guyana's priority purposes are to reduce the transmission of HIV and improve the quality of life of persons living with HIV/AIDS. With great efforts and collaboration, several strategies are combined to improve access to adequate and high quality treatment care and support to all persons living with HIV/AIDS.

Keywords: AIDS, Anti-retroviral, HIV testing, Variables, Survival

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-Retroviral
CDC	Center for Disease Control
ERC	Ethnical Review Committee
ESC	English-speaking Caribbean Countries
HAART	Highly Active Anti-Retroviral Treatment
HIV	Human Immunodeficiency Virus
IDU	Intravenous Drug Users
MPH	Ministry of Health
NAPS	National AIDS Programme Secretariat
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to child Transmission
QoL	Quality of Life
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

DEFINITION OF TERMS

AIDS - Acquired immunodeficiency syndrome (AIDS) is a term which applies to the most advanced stages of HIV infection. An AIDS case is defined as an HIV-infected individual who has any one of more than 20 opportunistic infections or HIV-related cancer at the time of the study (WHO, 2017).

ARV - Antiretroviral therapy (ART) is treatment of people infected with human immunodeficiency virus (HIV) using anti-HIV drugs. The standard treatment consists of a combination of at least three drugs (often called “highly active antiretroviral therapy” or HAART) that suppress HIV replication (WHO, 2017).

HIV - The human immunodeficiency virus (HIV) is a retrovirus that affects cells of the immune system, destroying or impairing their function. As the infection progresses, the immune system becomes weaker, and the person becomes more susceptible to infections (WHO, 2019). HIV positive case definition was adopted as the current definition in Guyana at the time of the study, that is “ every individual with positive HIV results for two screening tests (ELISA) and sequentially positive for a third confirmatory test (Western-Blot, Indirect Immunofluorescence or PCR) according to the criteria proposed by the Ministry of Public Health (GUYANA, 2017).

Survival – The English oxford Living dictionary 2018 defined Survival as “The state or fact of continuing to live or exist typically in spite of an accident, ordeal or difficult circumstances”.

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INTRODUCTION

1 Introduction

Human immunodeficiency virus (HIV) is an infection that affects the body's immune system, specifically the white blood cells called CD4 cell/count (WHO, 2022).

As a global health concern, HIV/AIDS has been around for decades and to date, there is no known cure for the disease, however, with good health seeking behaviours, treatment, care and support, many persons affected are continuing to live long, comfortable and adoptable lives.

In 2021, worldwide there were 38.4 million people living with HIV, both adults - 15 years and over and children, below 15 years, 79% knew their HIV status and about 8.1% of people did not know that they were living with HIV (UNAIDS, 2022). Approximately 4,000 people are infected with HIV every day. Following this trend, by 2025, an estimated 1.2 million people will be infected with HIV (UNAIDS, 2022). Notably also, is that the risk for acquiring HIV is 22 times higher among men who have sex with men and among people who inject drugs (UNAIDS, 2019).

However, the epidemic in Guyana is considered generalized as an HIV prevalence greater than 1.0% has been consistently found among the general population (GUYANA, 2019). At the end of December 2018 across all the 22 HIV care and treatment sites, a total of 5,557 patients were having treatment and support. This total comprised of 5,450 adults and 107 children (children 0-14 age group and adults 15 years and above). The majority of the patient population; (i.e 94.5%) are receiving antiretroviral therapy (ART) and being managed based on the revised National Guidelines for Management of HIV-infected and HIV exposed adults and children 2014/2015 (GUYANA, 2019).

The proportion of all deaths in Guyana attributable to AIDS has been declining from 2002 when it was 9.5% as compared to 4.2% in 2009 (GUYANA, 2011). Increase survivability and reduced AIDS related deaths continue due to the expansion of programs, new interventions and robust implementation efforts.

Patients are surviving much longer with HIV, given that there is continuous availability of medications, strict adherence and clinic attendance. AIDS came to be recognized as a chronic disease. A study entitled "The end of AIDS: HIV infection as a chronic disease" was one of the pioneers to address this issue and opens discussions about the possible end of AIDS. This possibility arose with the success of antiretroviral treatment (DEEKS; LEWIN; HAVLIR, 2013). In addition, researchers

have shown that people living with HIV find antiretroviral treatment easier and more effective when compared to treating other chronic diseases such as cancer, hypertension and diabetes (MOJOLA et al., 2020). Also, survival time depends significantly on the interaction of the type of tuberculosis (TB) with age, gender and WHO stages of the patient (VARSHNEY et al., 2016). There are four (4) WHO clinical stage and immunological classification of HIV related disease in adults and children. Here, in Guyana physicians categorize patients using the four WHO clinical stage.

Another study expanded on the introduction of antiretroviral (ARV) treatments and other types of resources, such as legal agreements for access to treatment and protection against discrimination, can alter the way society deals with AIDS and its related stigma (AYRES et al., 2006). In Brazil, both strategies have been used and shown to have significant effects on prevention, access to counseling and treatment. However, in Brazil, people living with HIV who are hospitalized face difficulties in adhering to treatment, such as socioeconomic issues, family support and adverse effects resulting from antiretroviral drugs (FREITAS et al., 2018).

For Guyana, persons living with HIV can now live with ease with the disease and positively achieve normal life expectancy with effective antiretroviral therapy (ART). Since the introduction of highly active antiretroviral therapy (HAART) in Guyana in 2003, a steady increase of HIV cases is documented of persons being placed on HAART (GUYANA, 2019). HAART is "highly active antiretroviral therapy," a term used to describe the effectiveness of combination drug therapies used to treat HIV (CICHOCKI, 2019). The rate of CD4 cell destruction depends on the viral load, with higher viral loads leading to more rapid CD4 cell loss. Symptomatic HIV infection (Acquired Immunodeficiency Syndrome or AIDS) results when CD4 counts have fallen below 200 cells/mm³. This is marked by weight loss, the development of opportunistic infections, and end-organ disease such as neurologic complications or renal failure (GUYANA, 2016).

HAART is hardly ever an emergency and life-long ARV therapy should seldom be started without assurance of adherence readiness and support, a strategic follow-up plan and psychosocial support, since patient preparation and participation are critical to success. While ARVs cannot remove HIV virus from infected cells, they can lead to a near cessation of measurable viral activity which is the driver of disease progression (GROVER et al., 2014). There are currently five major classes of ARV

drugs: nucleoside reverse transcriptase inhibitors (NRTI), non-nucleoside transcriptase inhibitors (NNRTI), protease inhibitors (PI), entry inhibitors, and integrase inhibitors. NRTI, NNRTI, and PI are all available in Guyana and part of the treatment strategies for individuals living with HIV infection (GUYANA, 2016).

Guyana's priority purposes are to reduce the transmission of HIV and improve the quality of life of persons living with HIV/AIDS. With great efforts and collaboration, several strategies are combined to improve access to adequate and high quality treatment care and support to all persons living with HIV/AIDS (GUYANA, 2019).

Testing for HIV is generally offered to clients when seeking health care, the standard method is the voluntary counselling and testing (VCT). All tests done at public health institution and through civil society organizations (CSO) as recommended in the HIV treatment guidelines are free of cost, whereas at the private health facilities, minimal cost incurred to offset the consumables. In this way, persons are enrolled in the public and private health system, notified and managed accordingly if found to be HIV positive.

Guyana introduced its first HIV self-testing kit known as the "OraQuick" to its citizen in March, 2022, with test kits being available at public and private clinics. (DPI GUYANA, 2022). Monitoring of the distribution is in place, especially for those who may have tested positive to access care and treatment.

Clinical management of HIV cases at all the treatment sites are done following updated recommended guidelines adopted from WHO, UNICEF, CDC among others. Treatment, support and care are free at all the public health facilities, due to the Government of Guyana signing to the political will of providing adequate, reliable and continuous medications for all affected.

At the HIV Care and Treatment Sites, information taken from the patients are generally collected and stored in the patient's record/chart/register and to a minimal extent electronically to be used for patient management at every clinic visits.

The overall objective of this research was to estimate the length and time of people living with HIV (PLHIV) while in care and/or on treatment. This study took the form of a retrospective cohort analysis of HIV infected persons registered in care at 17 out of the 22 HIV Care and Treatment Sites around the country from 2003 to 2015.

1.1 Justification of the study

No such documented study in this area has been done in Guyana with the cohort of patients for the specified time period; therefore, the researcher embarked in conducting this research to have evidence based information to implement change and for future reference. To estimated whether persons on treatment survival meets minimum expectation according to international definitions, identified what services offered and the effectiveness of the programs. Along with identifying gaps and determine what changes may need to be instituted to address those gaps to improve patients' survival.

1. 2 Epidemiological aspects of HIV/AIDS infection

HIV is a virus spread through certain body fluids that attacks the body's immune system, specifically the CD4 cells, often called T cells. Over time, HIV can destroy so many of these cells that the body can't fight off infections and disease (CDC, 2017). There are two main groups of HIV and many subtypes of HIV, the HIV-1 and HIV-2 are the main types, while the HIV-1 is responsible for over 95% of infections (AIDSMAP, 2021).

The transmission of HIV infection in adults and adolescent occurs mostly through sexual contact, though it can also be acquired through the use of contaminated blood products and from mother to child during breast feeding. The risks of transmission vary by the type of exposure and other factors such as the presence of other concomitant sexually transmitted infections (GUYANA, 2014/2015; COHEN; COUNCIL; CHEN, 2019).

While formerly the World Health Organization and United States Centers for Disease Control classification systems were developed prior to the advent of CD4 testing to help clinicians gauge the extent HIV disease progression and WHO continues to use the current and past illnesses to categorize patients into four stages ranging from clinical stage 1 (mild) asymptomatic HIV infection) to clinical stage 4 (AIDS) (GUYANA, 2014/2015). Guyana is moving forward in adopting more stringent measures to increase coverage and uptake of testing and treatment (UNAIDS/GOG, 2019).

The National AIDS Programme Secretariat has reported in 2021 that there continues to be efforts for intervention targeting key populations as a result of

increased funding allocation. These key populations (people living with HIV, men who have sex with men, sex workers and their clients, transgender persons, prisoners, miners and loggers) are most likely to be exposed to HIV infection or transmit it due to the number of partners they have or the risky behavior they engage in. (GUYANA, 2021)

According to WHO (2021), there were approximately 38.4 million people living with HIV at the end of 2021 with 1.5 million people becoming newly infected in 2021 globally. These are compared with earlier rates of 26.0 million in 2000 which indicates that people are continuously infected but the survival rates are also improved possibly attributed to access to antiretroviral (WHO, 2021).

There are a growing numbers of strategies that are proving to be effective in extending the life expectancy of an infected HIV individual (LEGG, 2016). In 1996, the total life expectancy for an infected 20-year old person was 39 years and in 2011, the total life expectancy bumped up to about 70 years. In 2020, HIV infected individuals continue to live long healthy lives comparable to HIV negative individuals even as far as having life expectancy of 70 years (WHO, 2020). Someone who is HIV positive, receiving treatment, and in optimal health (no history of drug use and are free of other infections) may live to be in the late 70s (LEGG, 2016). However, for persons in low and middle income countries, the picture is not as clear for the life expectancy (AVERT, 2017b). What is certain in population that have access to ARV is that there has been a marked decline in deaths from HIV, however there needs to be more studies in this area (AVERT, 2017a).

Particularly, the introduction of combination ART has been one of the great public health success stories of the past 40 years. The combination therapy has led to increased survival in people living with HIV and subsequently to individual and societal gains worldwide, this is because of the marked improvements in its potency, side-effect and simplicity of its use (KATZ; MAUGHAN-BROWN, 2017). The efforts to introduce various curative strategies included other measures other than ART such as sterilizing cure; shock and kill (attacking long lived cells that acts as HIV reservoir of the virus); broadly neutralizing antibodies (bNAbs); and anti- $\alpha 4\beta 7$ therapy (NIH, 2018).

A study from the US has found that some groups of people with HIV, especially those treated before their CD4 count falls below 350 cells/mm³, now have life expectancies equal to or even higher than the US general population. However, it also

finds that life expectancy for some other groups most notably women and non-white people is still considerably below comparable members of the general population and that for people who inject drugs, life expectancy in the era of antiretroviral therapy has not improved at all (CAIRNS, 2014).

More remarkably, the Colwell (2017) study found that more patients from 2008-2010 survived their first year of receiving ART than did those in the earlier years 1996-2007. Similarly, a study done by Tancredi, Waldman (2014) showed a strong impact of longevity in Brazil following the introduction of HAART in 1996 with decreased AIDS mortality, increased survival rates, and benefits with timely introduction of ART.

In another study done by Cairns (2017), researchers mentioned that the trends reflected superior antiretroviral agents, more options for people developing resistance, fewer drug interactions, better management of opportunistic infections and chronic diseases, and the introduction of screening and prevention programs for co-morbidities in people who benefited from treatment. It was also noted that a benign process has been happening whereby, because physicians now expect people with HIV to live near-normal lifespans, they monitor and treat conditions associated with age better, including cardiovascular disease, age-related cancers, dementia and type 2 diabetes, and may also be more likely to support people in making life-prolonging choices such as stopping smoking.

Reports have shown that HIV/AIDS patients face various psychological problems, such as stigma, poverty, depression, substance abuse, and cultural beliefs, which can affect their quality of life (QOL) not only from the view of physical health but also from that of mental and social health, which can cause problems that affect important activities and interests of the persons (OGUNTIBEJU, 2012).

The use of ART has become the cornerstone of the clinical intervention that is available to prevent transmission and slow progression of HIV infection in individuals living with HIV/AIDS. Interestingly, efforts have begun for a significant scaling up of the use of ART in developing countries, such as those in sub-Saharan Africa, where the epidemic has had its most devastating impact. However, questions have also been raised about the use of ART and how it affects the quality of life of people living with HIV and AIDS, either negatively or positively (OGUNTIBEJU, 2012).

In 2014, UNAIDS and partners launched the 95–95–95 targets; the aim is to diagnose 95% of all HIV-positive persons, offer antiretroviral therapy for 95% of the

people diagnosed, and achieve 95% viral load suppression for 95% of those treated by 2025. This is estimated to result in 73% of people with HIV achieving viral suppression, a crucial step in ending the AIDS epidemic by 2030 (HEATH . et al, 2021). The UNAIDS has been constantly in setting ambitious target culminating in today's call of ensuring access to treatment for all 38 million people living with HIV.

The World is also cognizant that tuberculosis (TB) remains a leading cause of death among people living with HIV, accounting for one in five AIDS-related deaths globally. However, between 2004 and 2014, TB deaths declined by 33% due to the rapid increase in antiretroviral treatment, which reduces the risk that a person living with HIV will develop TB by 65% (UNAIDS, 2015). By the year 2021, globally, deaths have been reduced to approximately 187, 000 HIV associated TB deaths (WHO, 2021).

Access to ARV across Latin America and the Caribbean is uneven. Treatment coverage was 72% among people living with HIV in Latin America in 2016 compared to 34% in 2011 (AVERT, 2018). Additionally, Latin America has the highest total spend on ART among low-and middle-income countries, with Argentina, Brazil, Chile, Cuba, Guyana and Mexico providing universal access to HIV treatment.

Sutherland (2014) noted, while many persons in small English-speaking Caribbean Countries (ESC) have not been tested for HIV, it is estimated that in excess of 250,000 persons are living with HIV/AIDS. In the Caribbean, the primary mode of HIV transmission is heterosexual contact (79.3%), followed by men who have sex with other men (MSM) accounting for 12.4%, and the remaining reported cases by hemophilia/coagulation (.1%), perinatal infection (7%), adult intravenous drug users "IDU" (.7%), and (.4%) blood transfusion.

Guyana discovered its first HIV case in 1987 and the first introduction of ARVs was in the year 2003, since then, there have been a yearly increase in the number of persons actively receiving ART (GUYANA, 2008). According to UNAIDS (2013) estimation, Guyana's adult HIV prevalence was 1.4 % at the end of 2014, a total of 751 cases of HIV were diagnosed compared to 1,176 HIV cases reported in 2009. Studies suggests that early initiation and consistence HAART is associated with improved CD4 counts and lower rates of mortality, for the reason lifelong Continuation of HAART after initiation is recommended (GUYANA, 2014/2015).

Ever since the introduction of voluntary counselling and testing (VCT) in Guyana in 1998, there has been a fluctuating trend in the number of HIV cases diagnosed with a peak of more than 1,200 infections being diagnosed in 2006. From 2009 to 2013, there was a continuous reduction in new cases both for HIV as well as AIDS. As noted in 2013, 751 HIV cases were reported as compared to 758 in 2014 (GUYANA, 2015a). As of December 2015, 4,551 persons were actively enrolled in care and on treatment (GUYANA, 2016). Overall, the National Care and Treatment Center (NCTC) had the largest proportion of persons on treatment (35.1%) nationally. Only 10.6% of the population on treatment are on second line therapy.

Annual report, Guyana (2015b) stated that, the longevity of an HIV infected individual is influenced by social, biological, economical and medical factors which either prolong or shorten the lifespan.

Further, in Guyana the 2013-2014 national cohort report revealed 536 persons were initiated on ART with 81.2% 12 months' survivability and retention on ART. This represents a slight increase from the 79.7% reported for the 2012-2013 cohorts. Notably, the 12 month survivability of persons initiated on treatment during 2015 went down to 76.5% nationally. However, in 2017 the percentage went up to 86 nationally and the outcomes of death, stopped treatment and loss to follow-up (LTFU) occurred at a rate of 6.3%, 3.8% and 13.4% respectively (GUYANA, 2018). Additionally, an assessment done in 2017 saw that, survivability among adults for the first time since the introduction of ART noted that the 12 months' survivability and retention in care is greater among the male cohort when compared to their female counterparts (GUYANA, 2018).

Guyana's HIV treatment programme continues to deliver the highest quality of care to persons living with HIV and AIDS with the great majority of those persons (92%) on antiretroviral therapy, achieving universal coverage for ART. There continues to be favorable treatment outcomes with increasing survivability and reduced AIDS related deaths (GUYANA, 2016). Below is a thirteen year trend of persons actively on ARV across all the HIV care and treatment sites in Guyana.

Table 1: showing the 13 years trend of persons actively on ARV (GUYANA 2015b)

CATEGORY	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
# of persons on ARV	123	497	1002	1611	1965	3473	3832	3059	3432	3717	4054	4295	4551

HIV continues to be one of the major diseases causing public health issues, claiming many lives and causing many people to fall sick, unable to effectively support their families and contribute to the development of their communities. Even though there is no cure for HIV, there is effective antiretroviral drugs that can help prevent the transmission and control of the virus, giving people a chance to live a longer and productive life.

1.3 Problem Statement

In the era of availability of highly active anti-retroviral therapy (HAART), patients are expected to live longer. No one knows the average length of time that persons living with HIV/AIDS that were enrolled and or placed on treatment at all HIV Care and Treatment Sites in Guyana from 2003 to 2015 are surviving and therefore, how effective is the National Care and Treatment Programms in Guyana?

1.4 Research Questions

- How are people with HIV and AIDS benefiting from antiretroviral therapy in Guyana?
- What are the potential factors (associated with survival of PLHIV and AIDS; type of treatment regimens, sociodemographic characteristics (transmission category, gender, and age) and clinical characteristics (base line CD4 count)?

1.5 Research Hypothesis

The survival time from HIV infection to death has been extended with the introduction of different antiretroviral therapy regimens, heterogeneously according to sex, age, calendar year and exposure categories.

1.6 Objectives

General objective:

To analyze the survival of people living with HIV and AIDS in Guyana from 2003 to 2015.

Specific Objectives:

- To estimate the median survival time of PLHIV with or without HAART;
- Estimate the median survival time by type of ARV received by PLHIV;
- Investigate potential factors associated with survival of PLHIV by exposures of, the types of treatment regimens available by calendar period, according to sociodemographic characteristics (transmission categories, gender, age) and clinical characteristics (baseline CD4 count) performed during follow-up;
- To estimate the mortality rate of PLHIV and AIDS.

METHOD

2 Method

Data collected prospectively from patient's chart/registers and entered into an excel spread sheet developed specifically for data extraction. Variables, such as demographics, behavior and characteristics related to diagnosis and treatment were part of the data collection.

The outcome of the study intends to act as supplementary knowledge to the disease and provide details on the disease trends with a scientific point of view. Permission was granted from the Institutional Review Board, Guyana to access patients records at various HIV care and treatment sites, following all protocol in relation to confidentiality and protecting the records.

2.1 Study Design

A retrospective cohort study was done of individuals with HIV and AIDS, notified and in care at seventeen (17) HIV Care and Treatment Sites, Ministry of Health, Guyana, from 2003 to 2015. The researcher examined secondary data of a cohort of patients entered in the registry from 2003 to 2015, consisting of clinical and treatment information that assisted to answer the proposed questions. The data was extracted and inputted in a computer-generated spread sheet for entering data. A new data extraction tool was developed by the researcher to collect the information from the patient's records.

Records of all the patients enrolled and notified for the period 2003 to 2015 at 17 HIV care and treatment sites were reviewed and extraction of key variables such as; , date of birth, gender, ethnicity, region, treatment site, category of exposure, date of HIV diagnosed, baseline CD4 count, treatment modality, co-morbid condition, and date of death for the study accordingly.

Below is a table showing years of HIV/AIDS cases, also number of death related cases. The numbers are inclusive of all ages from 2003 to 2015.

Table 2: HIV/AIDS cases and number of death related cases from 2003 to 2015 (GUYANA, 2011; GUYANA, 2016; GUYANA 2017)

Year	HIV cases	AIDS cases	Total HIV/AIDS cases	AIDS related death
2003	762	417	1,179	399
2004	837	348	1,185	356
2005	809	142	951	360
2006	1,258	172	1,430	298
2007	993	130	1,123	289
2008	959	24	983	239
2009	1,176	43	1,219	192
2010	1,039	146	1,185	194
2011	972	62	1,034	230
2012	820	105	925	226
2013	758	88	846	67
2014	751	158	909	73
2015	789	105	894	81
Total	11,923	1,940	13,863	3,004

2.2 Inclusion criteria:

Only registered cases of PLHIV and AIDS from all the HIV care and treatment sites in the country from 2003 to 2015.

2.3 Exclusion criteria:

People with follow-up time of less than 30 days (including deaths and single visit).

Censoring criteria. The “censoring” occurred in three situations:

- i) Patients who at 12/31/2019, the study's closing date, were alive and in follow-up (administrative censoring).
- ii) Patients who died from a cause other than AIDS related, in this case the censoring was recorded on the date of death.

iii) Patients who were lost to follow-up, that is, those who did not return to the service one year after the last appointment and, in this case, the censoring was recorded on the date of the last appointment.

2.4 Research Setting

Guyana has a population of approximately 747,884 (POPULATION & HOUSING CENSUS, 2012) with a land mass of 215,000 km² extending along the north-eastern coast of South America. It is the only English speaking country in South America and is bordered by Suriname, Brazil and Venezuela (GUYANA, 2015a).

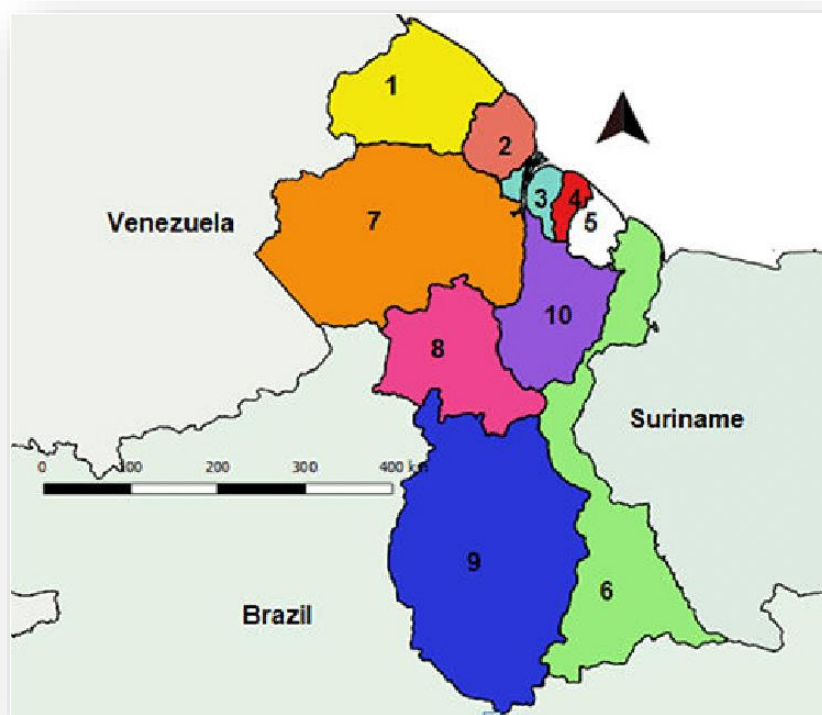


Figure 1: Map of Guyana showing the 10 administrative regions

As shown above, there are 10 Administrative regions (1-10) in Guyana (POPULATION & HOUSING CENSUS, 2012), with general primary health care services and a robust well outlined referral system available in each region. The country is further divided into coastland and hinterland regions where most of the population (89.1%) is concentrated in the coastal areas (regions 2, 3, 4, 5, 6 and 10) (POPULATION & HOUSING CENSUS, 2012). There are six (6) ethnic groups in

Guyana, including Indo-Guyanese, Afro-Guyanese and Amerindian of which Indo-Guyanese account for the largest population.

The hinterland regions (regions 1,7,8 and 9) are the hard to reach areas, with rough terrains and sparsely populated, hence preventing readily access to essential health care services. The Amerindians are the descendants of the indigenous people of Guyana. There are 9 indigenous nations settled across the 10 administrative regions of Guyana. Most of the indigenous nations inhabit the hinterland regions, which together are the home of almost 80 percent of that population. The hinterlands are covered by dense forestlands and mountain ranges and marked also by a multitude of hills and rivers. Despite the large landmass of the hinterland regions, when compared with the coastland, they are sparsely populated due to the barriers set by the geographical terrains (UNICEF, 2017).

There is limited empirical data on HIV/AIDS among the Indigenous Peoples in Guyana. Nonetheless, the populations that are more at risk of contracting HIV, are sex workers, miners and loggers. Many of the hinterlands regions gain financial support through farming, mining and logging. Study suggests that there are persons living with HIV/AIDS in the villages based on a sample of tests conducted in 2014 found that 15 out of 50 people were HIV positive (UNICEF, 2017). The limited data on the number of persons living with HIV/AIDS in these communities contributes to the challenges in testing and reporting of cases. Additionally, based on a study, indigenous women have less comprehensive knowledge on HIV/AIDS among different socioeconomic groups while the indigenous males have the second-lowest level of knowledge on HIV/AIDS. (UNICEF, 2017)

There are five levels of health care in Guyana, ranging from health posts to national referral hospitals and each of the regional health systems has its own independent health care service that caters for the general population with health needs residing in and around its environs. The key personnel of the regional health services ensure the linkages along the different levels of health care as necessary for continuity of care.

Region # 4, with 41.3% of the general population, is the largest of the 10 administrative regions and continues to be disproportionately affected by HIV, accounting for 72.7% in 2016 (GUYANA, 2016). There are 22 HIV Care and Treatment

sites in the country, fourteen (14) in the coastland regions (2, 3, 4, 5, 6 and 10) and 8 from the hinterland regions (1, 7, 8 and 9), two of the sites are from private hospitals.

Coastland Regions (2, 3, 4, 5, 6 and 10)

1. Public Hospital Suddie
2. West Demerara Regional Hospital
3. National Care and Treatment Centre
4. Saint Joseph Mercy Hospital
5. Davis Memorial Hospital
6. Dorothy Bailey Health Centre
7. Campbelville Health Centre
8. Georgetown Chest Clinic
9. Beterverwagting Health Centre
10. Enmore Poly Clinic
11. East La Penitence Health Centre
12. Rosignol Health Centre
13. New Amsterdam Family Health Clinic
14. Skeldon Hospital
15. Wismar, Upper Demerara Hospital
16. Mabaruma Hospital

Hinterland Regions (1, 7, 8 and 9)

17. Matthews Ridge Hospital
18. Port Kaituma Hospital
19. Kamarang Hospital
20. Bartica Hospital
21. Mahdia Hospital
22. Lethem Hospital

Overall, the HIV National Care and Treatment Centre, Region 4 has the largest proportion of persons in care and on treatment 35.1% nationally. Reporting of information/all notified cases is done through the central body of the National AIDS Programme Secretariat (NAPS) and the Ministry of Health (MoH) respectively.

2.5 Data collection Tool (appendix 2)

All the data/information collected was done using a new tool developed by the researcher specifically for the data entry of the variables required for the study.

2.6 Data Management and Analysis

All data were collected using the data extraction tool generated by the researcher and stored on a computer that is password protected. Strict protocol was followed when entering data to prevent error and miss information.

Cleaning of the data collected was accomplished by, checking for spelling mistake, accurate information, completeness and double counting, to avoid simple data collection errors and avoid making incorrect conclusion. The researcher also examine the data for outliers, additionally variables were checked for interaction and other biases. Stored information was backed up on a flash drive for safety precaution or data loss.

All analysis were performed using the statistical software R, version 4.2.2, which can be freely obtained from the following electronic address: www.r-project.org. The packages readxl, survival, dplyr and ggfortify were used to read, visualize, process and model the data.

Fisher's exact test was used for the purpose of comparing the numerical variables Age and Initial baseline CD4.

The nonparametric statistical test (Kruskal-Wallis test) was use to process the independent variables against regions, since the data is not normally distributed.

The following variables were used for analyses:

- i. DAYS (Total days in treatment)
- ii. GENDER (/Sex/Gender)
- iii. AGE (Age)
- iv. AGEGROUP2 (Age categorized according to the second classification 'Age Group 2' in the database)
- v. RACE (Ethnicity)
- vi. CD4 (Cell count, with results already presented in previous spreadsheets)
- vii. CD4CAT (Categorized cell count, with results already presented in previous spreadsheets, but which will also be used here for survival analysis)
- viii. COMORB (Presence of any comorbidity)

The reliability and safety of the data collected for the research were key for the provision of correct and safe information for the general audience. Methods for the data collections were ensured and protected, only authorized persons had access to the data as necessary; and was only used for the purpose of the intended study by the research team. Safety of the data was ensured by the following procedures:

- All data entry occurred on site by the principle researcher and the assistant on a password protected computer.
- Identifying variables from individual patient's records and recording was done by using numbers ranging in sequence on order of entry.
- Any clarification or verification of data during the process was sought from senior personnel within the organisation at the site in review.
- All the data/information collected was stored on one computer designated by the principle researcher for the entire data collection process.
- There wasn't any knowingly breach of data security, since the researcher made every effort to secure the data.
- Confidentiality and data protection were of outmost importance to the research team due to sensitive information.
- The quality of this research was maintained through standardised and precise definitions of the disease.
- Standardized procedure was also followed in the data collection process, so as to reduce missing data and minimise errors.
- Minimal error occurred during the collection process, however cleaning of the data was done to arrive at the final document.
- The researcher utilized authentic references during the literature review process and maintained the quality of the research contents.

2.7 Ethical Consideration

The clinical review of patients' charts and registers were conducted by the researcher and a research assistant who followed direct protocol as it relates to confidentiality and coding of information.

The research assistant played an important role is assisting in gathering the data for the study at some of the sites. She was aware of the confidentiality of patients

records and protecting same. A confidentiality form was signed before the data collection started and a formal introduction of her to the personnel onsite was done before accessing patients records.

Patients' names were not recorded and only pertinent information were extracted from the charts using the data extraction tool. All completed forms with extracted data was secured and only the principal assessor and the assistant had direct access to the data since it was secured on a password protected computer.

No written document needed for inform consent since the collection of data was secondary in nature, however permission was sought from the Institutional Review Board (IRB), Ministry of Health, Guyana for approval to access patient's record without seeking consent from the patients directly and to utilize the information for research purposes. The proposal was reviewed, analyzed and approval was given to conduct the research with approval protocol # 605/2019 (copy attached). The researcher sought permission from NAPS and key personnel from the respective HIV care and treatment sites to access the patient's records to extract the needed information.

RESULTS

3 Results

When analyzed, the final bank produced a total of 1,067 (one thousand and sixty-seven patients) for analysis. Fifty six (56%) were female and forty four 44% were males.

A total of 17 out of 22 HIV Care and Treatment Sites were included in the study. The remaining 5 sites were not accessed due to varying circumstances. Eight variables were assessed for this study that provides specific result as per analysis.

Appendix 3 gives detail on the description of the data used in the study.

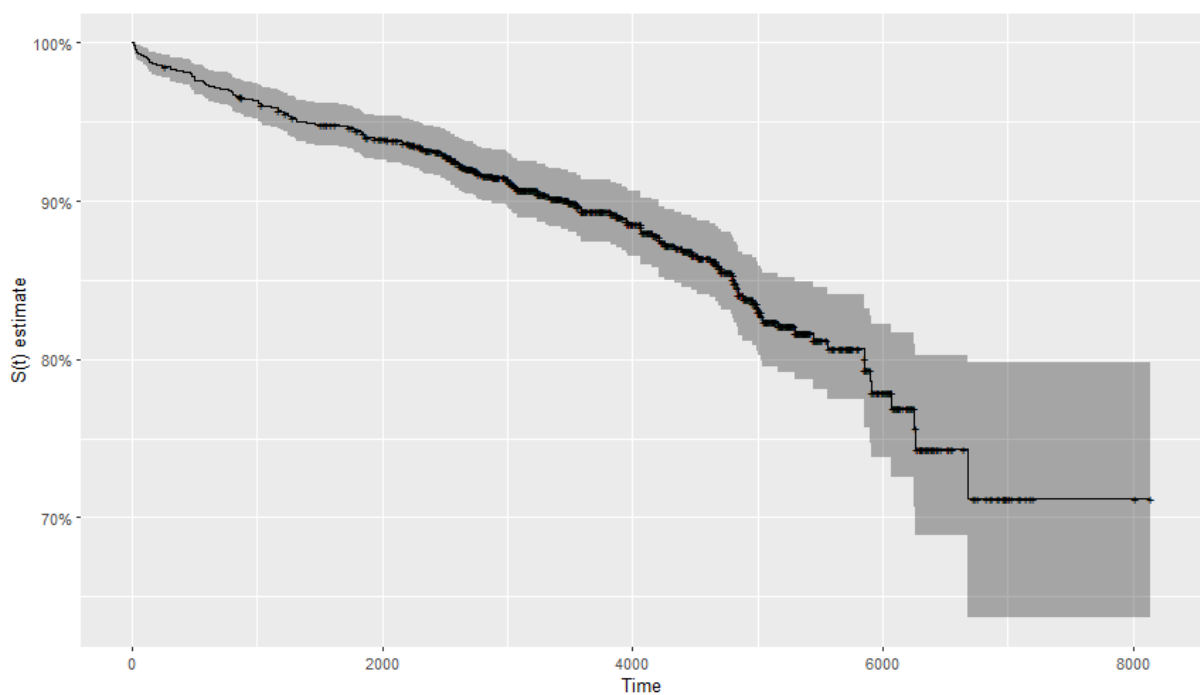


Figure 2: Kaplan-Meier curve for all study subjects.

From these records, then, the Kaplan-Meier curves and the adjustment of the Cox Model were estimated, with a view to analyzing the survival of patients undergoing ARV treatment since the beginning of its use. Initially, it appears that, on average, the individuals in the study, except for those who died, have been under ARV treatment for approximately 3,986 days. Thus, additional results are presented below. The adjustment of the Kaplan-Meier Curve for all individuals is shown in figure 2. The results show that from the 6000th day of treatment, there is a more accentuated decrease in the survival of individuals on ARV treatment.

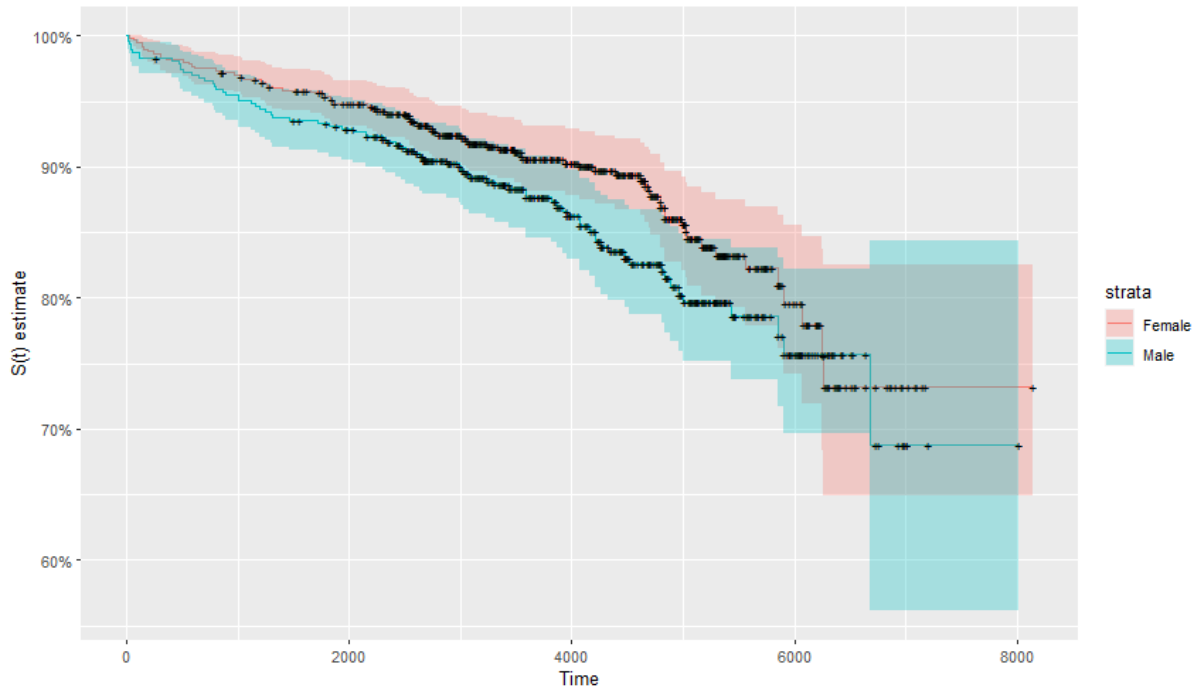


Figure 3: Kaplan-Meier curve for all patients according to sex/gender.

When considering the patient's sex/gender (Figure 3), the data provide evidence that female patients have a longer survival up to approximately the 6000th day of treatment, when compared to male patients. From the 6000th day, patients of both genders are equivalent in terms of the drop in the survival curve, but with an unfavorable trend for the group of male patients. This unfavourable trend for the male group might be as a result of delayed health seeking behaviours, none compliance of the treatment or lack of support from family members or health care institutions.

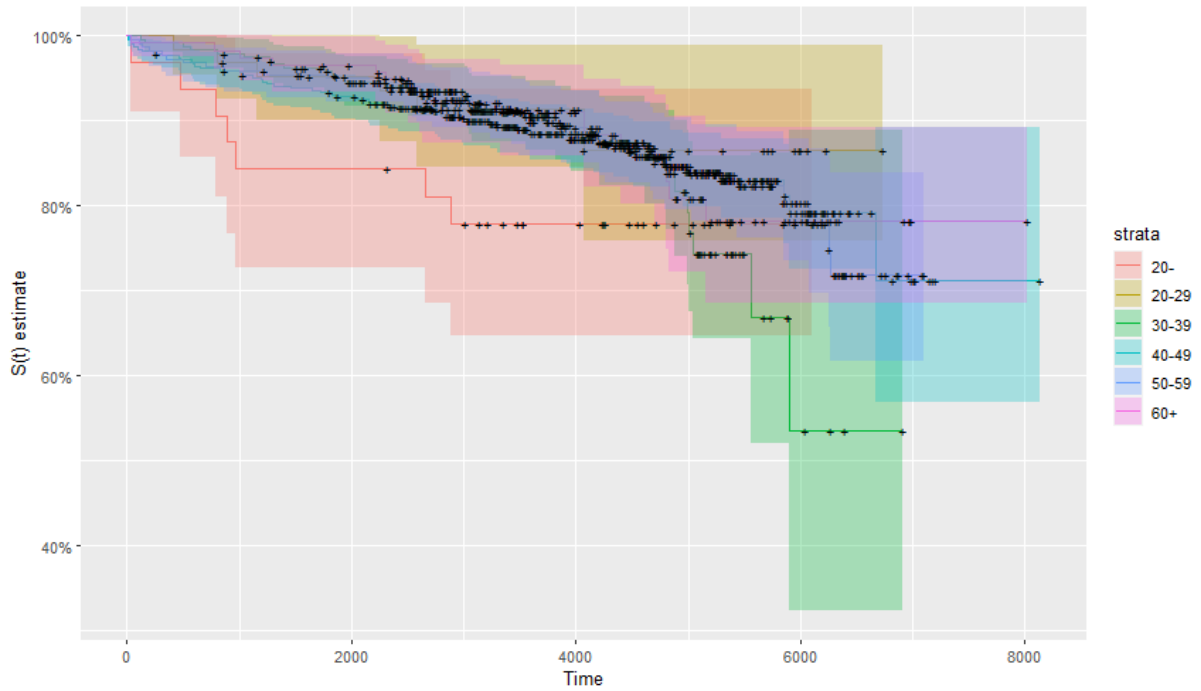


Figure 4: Kaplan-Meier curve according to the patients age group

When considering the age group of the patient (Figure 4), the data provide evidence that patients age 20 years or less have a shorter survival state in most of the number of days since the beginning of ARV treatment. From approximately the 6000th day of treatment, patients aged 30 to 39 years and patients aged 40 to 49 years or less tend to have a lower survival curve when compared to other age groups. The age group mostly affected might be as a result of poor treatment compliance due to work priority, delayed health care, shame or denial of being ill. The older age group tend to accept illnesses and work towards altering lifestyle changes/habits.

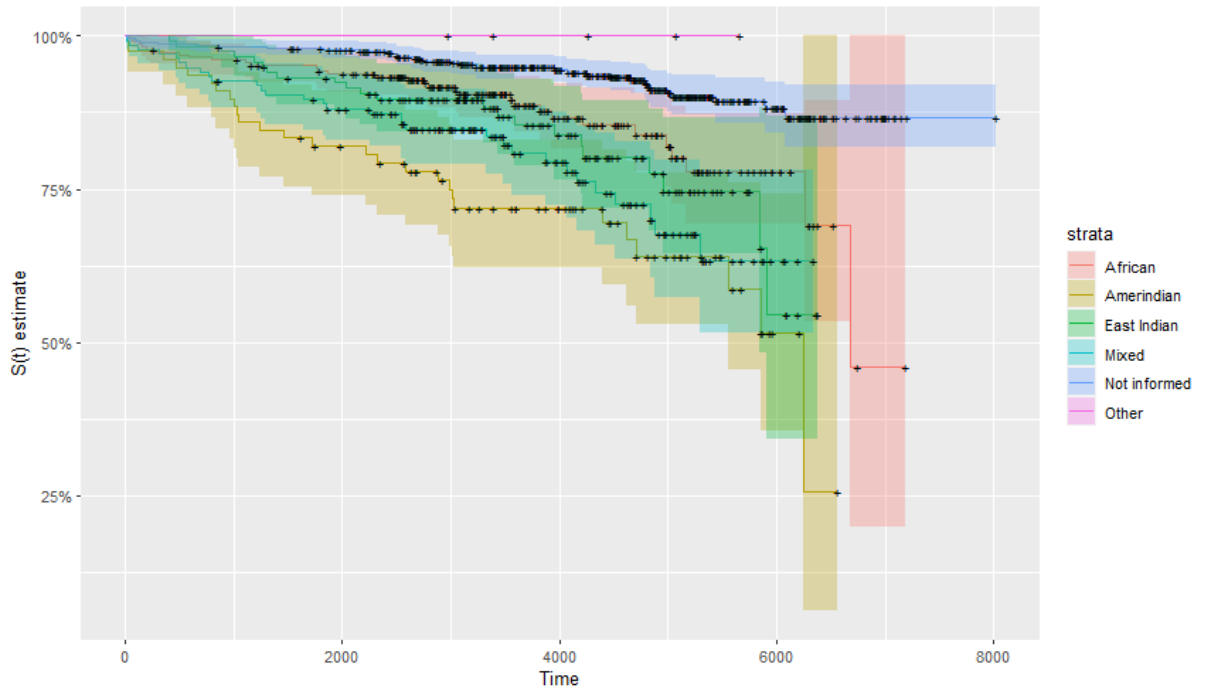


Figure 5: Kaplan-Meier curve accoring to patients ethnicity.

When considering the patient's ethnicity (Figure 5), the data provide evidence that patients with “East Indian” and “Amerindian” ethnicities have a lower survival in most of the number of days from the beginning of ARV treatment. From approximately the 6000th day of treatment, patients with “Amerindian” ethnicity and patients with “African” ethnicity tend to have a lower survival curve when compared to other ethnic groups.

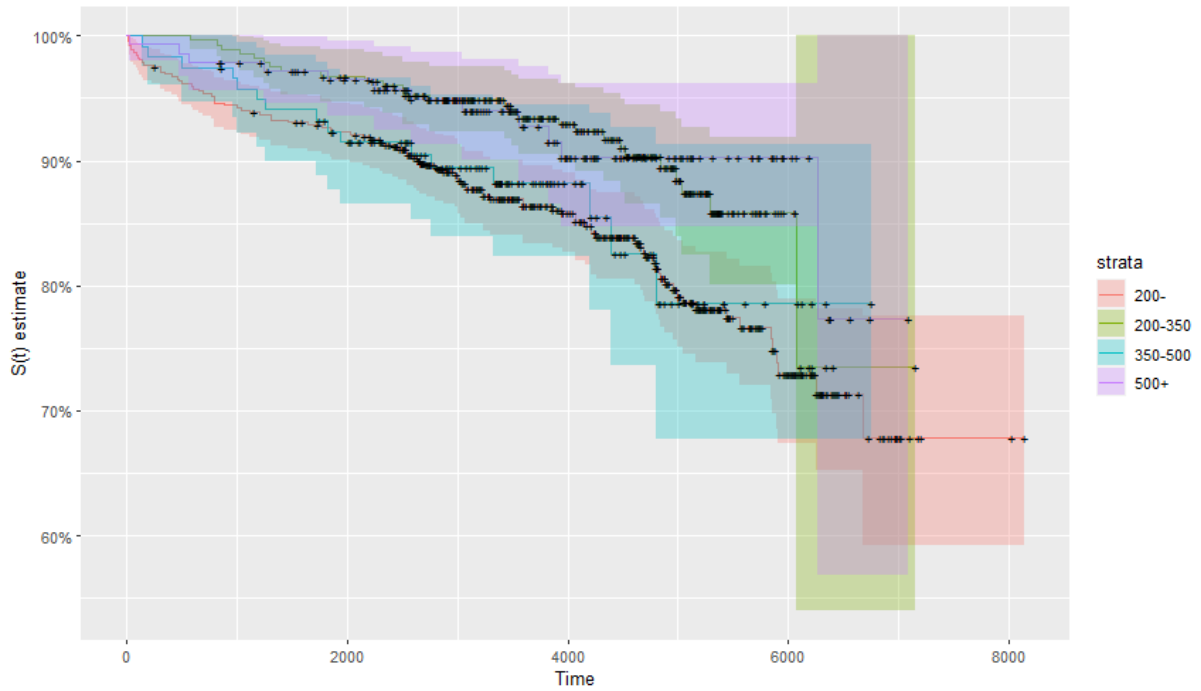


Figure 6: Kaplan-Meier curve according to the patients CD4 count levels.

When considering the patient's CD4 count levels (Figure 6), the data provide evidence that patients with levels below 200 and between 200 and 350 have a lower survival for most of the number of days from the start of ARV treatment. From approximately the 6000th day of treatment, patients with levels lower than 200 begin to provide evidence of shorter survival.

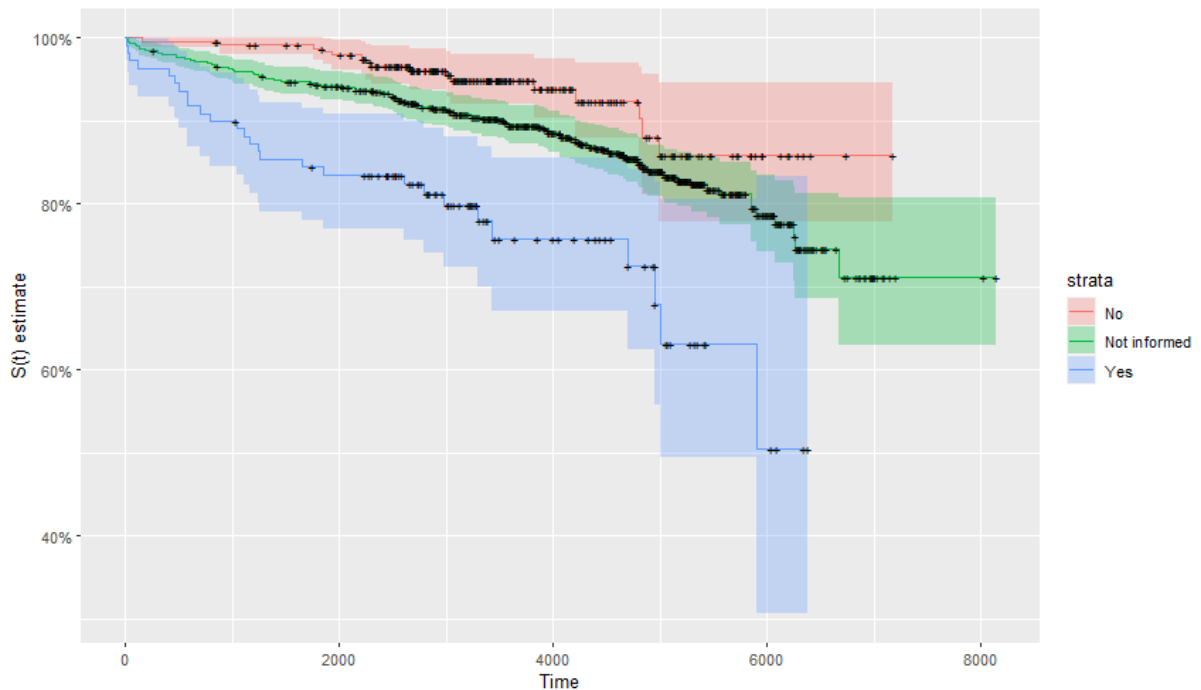


Figure 7: Kaplan-Meier curve according to the patients co-morbidity.

When considering the information on the presence of patient comorbidities (Figure 7), the data provide evidence that patients with at least one comorbidity have a shorter survival curve throughout the period in which they underwent ARV treatment, when compared to the others groups. It is also possible to observe that the survival curve for patients who do not have comorbidities have a smooth decay when compared with the other survival curves of the groups of patients with comorbidities and who did not report on comorbidities.

Adjustment of the Cox Survival Model

Cox regression, also known as proportional hazards model, is an extension of the Kaplan-Meier results with the introduction of regression concepts, in order to incorporate effects of explanatory variables called covariates. It is a semiparametric technique intended for studies aimed at investigating the relationship between the covariates and the time until the occurrence of the event of interest.

With this technique, based on the assumption of proportionality, it is possible to estimate the effects of the covariates without having to make any assumptions regarding the distribution of survival time, that is, whether an individual at the beginning of the study has a death rate equal to twice that of a second individual, then this ratio is the same for the entire follow-up period.

To assess the risk factors related to death, the relative risks and their respective confidence intervals (95% CI) were calculated, according to the Cox model. Significant covariates at the 5% level were used in the final model, and the results of this adjustment are shown in Tables 1 and 2.

Table: 3 Cox Model Fit Results

Variables	Coefficient		Standard error	p-value
	Estimate	Risk		
RACE-new, Amerindian	0,642	1,901	0,273	0,019
RACE-new, Not informed	-1,279	0,278	0,267	0,000*
CD4 cat-new 200-350	-0,617	0,540	0,220	0,005
CD4 cat-new 500+	-0,872	0,418	0,313	0,005
COMORBID-new, Not informed	1,069	2,912	0,286	0,000*
COMORBID-new, Yes	1,250	3,492	0,320	0,000*

*p-value less than 0.001

Table 4: Test, Statistics for the final model

Test	Statistics	Degree of Freedom	p-value
Likelihood Ration Test	105,7	10	0,000*
Test the wald	100,7	10	0,000*
Test the Log Rank	118,8	10	0,000*

*p-value less than 0.001

DISCUSSION

4 Discussion

Participants in this study were at risk of dying from HIV/AIDS. The following characteristics of the studied population were associated with an increased risk of death: being an Amerindian and having comorbidities such as hypertension and diabetes mellitus. These data open spaces for discussions on the formulation of strategies that seek to reduce the risk of death and improve the health conditions of people living with HIV/AIDS in Guyana.

The epidemic of HIV infection can be controlled through advances in early diagnosis and antiretroviral treatment. It is understood as a chronic disease and people living with HIV who are on antiretroviral treatment can live with the same standards as HIV-seronegative people (JOHNSON et al., 2013; UNAIDS, 2019). However, some populations (amerindians) and specific groups (gays) have unequal access to health services and are disproportionately affected by the infection.

International health bodies propose a nomenclature for specific groups more vulnerable to infection, currently the most appropriate denominations are “key populations” and “priority populations”. Key populations include gays and other men who have sex with men, sex workers, transgender people, people deprived of their liberty, and users of alcohol and other drugs. Priority populations defined by international health institutions, such as Ministries of Health in other countries, include indigenous people, black people and young populations (BRAZIL, 2019).

Such definitions, identification of these populations, identification of risk factors for infection and increased risk of death due to AIDS are important for directing health actions and elaborating broader prevention strategies. The efforts of researchers and health agencies over the years of the epidemic resulted in a growing number of strategies that are proving to be effective in extending the life expectancy of an individual infected with HIV (LEGG, 2016).

Since 2011, significant increases in the life expectancy of people living with HIV have been reported. In 2020, these people will continue to live long and healthy lives, comparable to HIV-seronegative people (WHO, 2020). In this sense, a person who is HIV seropositive receiving treatment and in excellent health (with no history of drug use and free from other infections) has a life expectancy similar to the general population (LEGG, 2016). However, precarious social and economic conditions, especially for people living in low- and middle-income countries, life expectancy may

not be the same as projected for those people in better social conditions and living in high-income countries (AVERT, 2017b).

The results of the study leads to an in-depth discussion of the many variables assessed.

It was found in this study that the ethnicity of patients influences the survivability of a patient with HIV. More so, that Amerindian have 1.901 chance higher of the risk of dying when compared to the African ethnicity. It is difficult to compare this result with regional countries since the ethnic background of other countries are not so diverse in its major ethnic breakdown.

However, as noted in the few articles which speaks to HIV related mortality in Africans, Afzar –e- Alam Siddiqi et al noted that there is a 3-year survival of African infected with HIV as compared to other ethnic groups with longer lifespan. This study further reported that those who are in the 'not informed 'category actually have a triple rate (3.597) times higher risk of death when compared against Africans.

A study carried out in Central Brazil with indigenous peoples identified that 38.8% of the participants died and 62.5% of the deaths occurred within less than one year of the diagnosis of HIV/AIDS infection. The authors of the Brazilian study highlight the difficulties faced by indigenous populations in accessing information on prevention and treatment of the infection. Other factors deserve to be highlighted in the context of this population and the tragic consequences of HIV, such as the cultural oppression experienced since the time of the arrival of colonizers in the Americas, conflicts over land and poor access to health services (GRAEFF et al., 2021).

Another Brazilian study identified an increase in the number of HIV cases among indigenous populations. As of 2007, a continuous increase in AIDS cases was observed and the authors identified higher mortality and lethality among a specific ethnic group, the Kaiowá. The highest mortality and lethality rates were identified in regions with greater social and economic needs (GRAEFF et al., 2019). In this sense, public policy makers for the prevention and control of infection must consider ethical, social and economic aspects, especially indigenous populations in social and economic vulnerability.

The analysis process showed a significant difference ($p < 0.001$) between the sectors (sites) for both variables and non-significant between the Regions. Eight administrative regions (1, 2, 4, 5, 6, 7, 8, and 9) were part of the study, with 17 HIV

Care and Treatment sites (Mabaruma, Port Kaituma, Matthews Ridge, Public Hospital Suddie, National Care and Treatment Centre, Dorothy Bailey Health Centre, Georgetown Chest Clinic, Enmore Polly Clinic, Beterverwagting Health Centre, East La Penitence Health Centre, Rosignol Health Centre, New Amsterdam Family Health Clinic, Skeldon Hospital, Kamarang Hospital, Bartica Hospital, Mahdia Hospital, and Lethem Hospital) located in those 8 regions. Region # 4 had the highest number of patient's records reviewed totaling 989. The nonparametric test was chosen because the variables did not present a normal distribution (see Kolmogorov-Smirnov Normality Test).

From the analyzed data (figure 4), it is evident that patients 20 years and less have a shorter survival state in most of the days since the beginning of the ARV treatment, when compared to the 30-39 and 40-49 age groups. This might be as a result of poor treatment compliance, stigma and discrimination. From the 6000th day of treatment, the study saw a lower survival curve when compared to the other age groups.

According to a cited document (GUYANA, 2019), comparable to early years, there was no major shift in the age group affected by new infection and that the risks of transmission vary by the type of exposure and other factors such as the presence of other concomitant sexually transmitted infections.

Evidence from the data (figure 3) shows that the female patients have a longer survival, up to the 6000th day of treatment when compared to the male patients. Notably, as mentioned in a document (GUYANA, 2018), survivability among adults for the first time since the introduction of ART in 2003 noted that the 12 months' survivability and retention in care is greater among the male cohort when compared to their female counterparts. However, from the 6000th day both male and female are equal in terms of the drop in the survival curve, but with an unfavorable trend for the male patients group

The results also provide evidence, at the 95% confidence level, that: Patients belonging to the "Not informed" ethnicity category have a 3.597 times lower risk (1/0.278) of death (overall survival) when compared to patients belonging to the "African" category.

The AIDS epidemic is a complex and multifactorial public health problem that must be analyzed from different aspects. Some population groups are

disproportionately affected compared to the general population. The uneven rates of HIV infection and AIDS are due to the vulnerability (Ayres et al., 2004) of some groups. Within the individual dimension, it is possible to identify race/color as one of the vulnerabilities to HIV. Other studies have already identified this vulnerability to AIDS.

In high-income countries such as the United States, the highest rates of HIV infection are concentrated in black people (TOWNES et al., 2022). Studies have identified factors associated with this difference: structural barriers to HIV prevention, treatment, and care, stigma, lack of health insurance, and lower socioeconomic status (CDC, 2019; REIF et al., 2017). It is noted that a set of factors add up and influence the insistence on the high rates of notification of HIV cases among the black population and is reflected in the disproportionate burden. This problem must be faced through different strategies, from expanding access to prevention and treatment services to improving social and economic conditions.

Patients who belong to the “200-350” category of the CD4 variable have 1.852 times less risk of death (overall survival) when compared to patients who belong to the “< 200” category of CD4.

Monitoring of immune system cells among people living with HIV is important. Similar to the results presented in the present study, an epidemiological research that investigated 80 cases of deaths resulting from AIDS identified that the T-CD4+ lymphocyte count, opportunistic diseases and clinical manifestations were strongly associated with the risk stratification associated with death from AIDS. (LEADEBAL et al., 2019).

Monitoring viral load among people living with HIV is an important indicator, as it evaluates the effectiveness of treatment and may indicate possible failures in the therapeutic scheme or problems with adherence to treatment (ALENCAR; COISAK, 2016). Other studies have already indicated an increase in viral load was associated with a negative prognosis (LEADBAL et al., 2016).

Patients who belong to the “500+” category of the CD4 variable have 2.392 times less risk of death (overall survival) when compared to patients who belong to the “< 200” category of CD4; Importantly to note that, as mentioned by CICHOCKI, the rate of CD4 cell destruction depends on the viral load, a high viral loads leads to more rapid CD4 cell loss. Symptomatic AIDS results when the CD4 counts have fallen below 200 cells/mm³. This is marked by weight loss, the development of opportunistic infections,

and end-organ disease such as neurologic complications or renal failure (CICHOCKI, 2019).

Patients belonging to the “Not informed” category regarding the Comorbidity variable have a 2.912 times greater risk of death (overall survival) compared to the “No” category.

Based on the information as it relates to the presence of patient comorbidities (Figure 7), Patients belonging to the “Yes” category referring to the Comorbidity variable have a 3.492 times greater risk of death (overall survival) compared to the “No” category. At least one comorbidity have a shorter survival curve throughout the period of ARV administration, when compared to the others groups. To note, the survival curve for patients who do not have comorbidities has a smooth line when compared with the other survival curves of the groups of patients with comorbidities and who did not report on comorbidities.

The presence of comorbidities among people living with HIV/AIDS are well reported in the literature. A Brazilian study identified the main comorbidities among people living with HIV/AIDS living in a city in the interior of São Paulo, Brazil: dyslipidemia, triglyceridemia, hepatitis C, oral candidiasis, sexually transmitted diseases and tuberculosis (RIGUETTO et al., 2014).

In a more comprehensive study carried out in Japan with 28,089 people living with HIV, it was identified that 81.5% had at least one chronic comorbidity. The same study identified that comorbidities were more prevalent in older patients (NAITO et al., 2022).

4.1 Challenges Encountered

- The data collection and reporting system is mostly paper based at the reviewed sites.
- Some of the patient’s chart were partially completed with key information missing.
- Illegible hand written documents at some sites, causing the inability to utilize some records.
- Some records for the patients were lost or destroyed due to flood or fire, hence, limited information available for use at some sites.

- The researcher had to cross check many supporting records (registers/ledgers/charts) for verification and accuracy of information as the need arises.
- As many individuals did not have information on the date of initiation of ARV treatment available, it was decided to eliminate these individuals from the database.
- Due to the COVID-19 restrictions, many sites were closed during the 2020-2021 period. Also, time spent at the sites were limited due to social distancing and time limit.

4.2 Recommendations

- Recommendation is strongly noted for an electronic data base at all the HIV care and treatment sites for inputting information, monitoring and evaluation of patient's information as it relates to the management and care.
- Standardization at all the sites of information required to complete the patient's chart.
- Also, the provision of timely and equitably services needed, especially in the hinterland regions of Guyana.
- A follow-up study is recommended, possibly utilizing a second cohort period, independent variables and different approaches.

CONCLUSION

5 CONCLUSION

Overall, due to the improvement of the effectiveness of treatment with HIV medication, patients who are diagnosed early, stay on treatment and have a high category of the CD4 have less risk of death due to the suppressed virus and have a good overall survival state. Co-morbidities such as tuberculosis, diabetes and heart conditions put persons at higher risk for an early/premature death, especially if they are not on the ARV regimen. Also, the Amerindian population when compared to the other groups have a decreased survival rate when diagnosed with HIV/AIDS, possibly due to their health seeking behaviours, limited access to testing, treatment and care. Therefore, it is very important for people diagnosed with HIV to be linked to HIV Care and Treatment centres early and have access to support services to help them stay healthy and remain engaged in HIV care.

Treatment and care for HIV/AIDS should be readily available to the general public at strategic health ports within the country and greater efforts are needed to reach the key population in providing effective services in a timely manner.

For Guyana, its priority purposes are to reduce the transmission of HIV and improve the quality of life of persons living with HIV/AIDS. With great efforts and collaboration, several strategies are combined to improve access to adequate and high quality treatment care and support to all persons living with HIV/AIDS.

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APPENDICES

Appendix 1: Duration and timeline of the research project.

ACTIVITY	2019	2020		2021		2022	2023
	Sept- Dec Sem 2	Jan - June Sem 1	Jul - Dec Sem 2	Jan - June Sem 1		Jul - Dec Sem 2	Jan - Dec Sem 1-4
Technical visit to Brazil	X		X		X		
Meetings with Advisor (s)	X	X	X	X	X	X	X
Proposal Development/Literature	X	X	X	X	X		X
ERC Submission/Approval	X						
Qualifying Exam	X						
Data collection procedure		X	X	X	X	X	
Article Related to Research Project/publication	X	X				X	
Data cleansing, coding and analysis				X	X	X	
Thesis writing					X	X	
Attend Conferences/Scientific events	X	X	X	X	X	X	
Final editing of Thesis and presentation of Report					X	X	
Defense							X

Appendix 2: Data collection tool template.

	A	B	C	D	E	F	G
	Chart number	Date of birth	Gender	Ethnicity	Region	Date of HIV Diagnosis	Category of Exposure
1							
2							
3							
4							
5							
6							
7							

Appendix 3: Variables Assessed

Variables		Initial baseline CD4						Confidence Interval for sample mean (95%)			
		n	Mean	Standard Deviation	Standard Error of Mean	Median	Percentile 75	Percentile 25	Lower Limit	Upper Limit	
Administrative region	1	40	404.10	269.03	48.32	367.00	586.00	148.00	306.36	501.83	
	2	357	345.16	282.75	20.73	297.50	487.00	115.00	304.38	385.93	
	4	988	356.40	314.39	11.80	282.00	488.00	140.00	333.24	379.55	
	5	103	319.11	304.49	33.03	232.00	456.00	73.00	253.60	384.62	
	6	117	400.56	486.25	45.54	302.00	519.00	163.00	310.36	490.76	
	7	145	296.39	200.27	19.10	267.50	386.00	156.00	258.65	334.13	
	8	10	385.00	12.73	9.00	385.00	394.00	376.00	364.64	405.36	
	9	20	244.57	117.89	31.51	222.50	302.00	159.00	178.63	310.51	
	Setor	Reg 1 Mabaruma	17	420.47	272.45	66.08	381.00	684.00	152.00	280.39	560.55
Reg 1 Port Kaituma		17	383.00	308.12	97.44	296.50	586.00	93.00	176.44	589.56	
Reg 1 Matthews Ridge		6	387.25	199.28	99.64	442.50	536.50	238.00	131.12	643.38	
Reg 2		357	345.16	282.75	20.73	297.50	487.00	115.00	304.38	385.93	
Reg 4 BV		153	433.20	333.02	28.45	361.00	567.00	214.00	376.98	489.41	
Reg 4 EL		56	437.92	329.21	45.65	359.00	607.50	202.50	346.43	529.41	
Reg 4 NCTC		352	226.41	208.45	13.96	178.00	318.00	61.00	198.95	253.86	
Reg 4 DBHC		261	434.46	358.05	24.03	305.00	597.00	216.00	387.14	481.78	
Reg 4 EPC		88	317.12	274.37	35.72	277.00	447.00	103.00	246.12	388.12	
Reg 4 GCC		79	309.00	206.26	48.62	301.50	483.00	159.00	212.21	405.79	
Reg 5		103	319.11	304.49	33.03	232.00	456.00	73.00	253.60	384.62	
Reg 6 SKL		12	303.18	165.35	49.85	292.00	444.00	178.00	193.45	412.91	
Reg 6 NFHC		105	410.96	508.06	50.06	311.00	524.00	152.00	311.69	510.23	
Reg 7 KAM		14	427.62	240.51	66.71	390.00	515.00	271.00	283.51	571.72	
Reg 7 BCA		131	278.80	188.85	19.18	248.00	350.00	139.00	240.87	316.74	
Reg 8		10	385.00	12.73	9.00	385.00	394.00	376.00	364.64	405.36	
Reg 9		20	244.57	117.89	31.51	222.50	302.00	159.00	178.63	310.51	
Region	1	40	404.10	269.03	48.32	367.00	586.00	148.00	306.36	501.83	
	2	357	345.16	282.75	20.73	297.50	487.00	115.00	304.38	385.93	
	4	989	356.30	314.18	11.78	283.00	488.00	140.00	333.18	379.42	
	5	103	319.11	304.49	33.03	232.00	456.00	73.00	253.60	384.62	
	6	117	400.56	486.25	45.54	302.00	519.00	163.00	310.36	490.76	
	7	145	296.39	200.27	19.10	267.50	386.00	156.00	258.65	334.13	
	8	10	385.00	12.73	9.00	385.00	394.00	376.00	364.64	405.36	
	9	20	244.57	117.89	31.51	222.50	302.00	159.00	178.63	310.51	
	HIV Care & Treatment Site	1	17	420.47	272.45	66.08	381.00	684.00	152.00	280.39	560.55
		2	8	359.00	183.78	82.19	360.00	525.00	246.00	164.66	553.34
		3	17	383.00	308.12	97.44	296.50	586.00	93.00	176.44	589.56
		4	355	345.69	283.42	20.84	300.00	487.00	115.00	304.71	386.67
		6	351	226.41	208.45	13.96	178.00	318.00	61.00	198.95	253.86
		9	262	434.46	358.05	24.03	305.00	597.00	216.00	387.14	481.78
		11	79	309.00	206.26	48.62	301.50	483.00	159.00	212.21	405.79
		12	88	317.12	274.37	35.72	277.00	447.00	103.00	246.12	388.12
		13	153	433.20	333.02	28.45	361.00	567.00	214.00	376.98	489.41
14		56	437.92	329.21	45.65	359.00	607.50	202.50	346.43	529.41	
15		103	319.11	304.49	33.03	232.00	456.00	73.00	253.60	384.62	
16		105	410.96	508.06	50.06	311.00	524.00	152.00	311.69	510.23	
17		12	303.18	165.35	49.85	292.00	444.00	178.00	193.45	412.91	
18		14	427.62	240.51	66.71	390.00	515.00	271.00	283.51	571.72	
19		130	278.80	188.85	19.18	248.00	350.00	139.00	240.87	316.74	
20		10	385.00	12.73	9.00	385.00	394.00	376.00	364.64	405.36	
21		20	244.57	117.89	31.51	222.50	302.00	159.00	178.63	310.51	
Gender Identity		1	786	300.24	265.70	11.69	256.00	418.00	101.00	277.30	323.18
		2	994	386.19	346.95	12.80	301.00	530.00	163.00	361.08	411.30
FaixaEtaria_1		<20	49	852.66	932.68	164.88	585.00	1260.00	203.50	521.15	1184.16
		20-29	107	441.39	322.32	40.29	374.50	643.00	190.00	361.51	521.27
	30-39	408	398.42	301.60	17.24	327.50	568.00	180.00	364.53	432.32	
	40-49	630	316.34	247.63	11.65	276.00	428.00	138.00	293.46	339.21	
	50-59	376	302.29	263.86	16.06	247.00	408.00	114.00	270.71	333.86	
	60-69	141	280.55	227.25	23.19	243.00	350.00	102.00	234.70	326.41	
	70-79	42	336.42	367.47	72.07	305.50	472.00	114.00	190.88	481.97	
	780	6	280.75	150.98	75.49	276.50	402.00	159.50	86.70	474.80	
	FaixaEtaria	<20	49	852.66	932.68	164.88	585.00	1260.00	203.50	521.15	1184.16
		20-29	107	441.39	322.32	40.29	374.50	643.00	190.00	361.51	521.27
30-39		408	398.42	301.60	17.24	327.50	568.00	180.00	364.53	432.32	
40-49		630	316.34	247.63	11.65	276.00	428.00	138.00	293.46	339.21	
50-59		376	302.29	263.86	16.06	247.00	408.00	114.00	270.71	333.86	
60-69		141	280.55	227.25	23.19	243.00	350.00	102.00	234.70	326.41	
70-79		42	336.42	367.47	72.07	305.50	472.00	114.00	190.88	481.97	
780		6	280.75	150.98	75.49	276.50	402.00	159.50	86.70	474.80	
Race/Ethnicity		1	182	419.70	347.40	29.90	362.00	576.00	170.00	360.70	478.69
		2	333	365.06	264.21	16.88	311.00	524.00	152.00	331.86	398.27
	3	119	294.31	197.03	23.55	255.00	402.00	146.00	247.68	340.95	
	4	243	404.89	459.93	36.48	299.00	533.00	152.00	333.04	476.74	
	5	4	670.75	658.20	329.10	544.50	1113.00	228.50	-376.60	1718.10	
WHO classification of HIV infection	1	587	429.43	363.52	15.88	332.50	534.50	230.00	398.24	460.62	
	2	188	313.51	244.99	18.90	261.50	453.00	148.50	276.22	350.80	
	3	208	237.19	254.77	19.60	156.00	328.00	63.00	198.55	275.83	
	4	74	151.26	206.18	26.18	77.00	206.00	29.00	99.07	203.44	
On ART regimen	1	1080	312.79	302.08	10.08	261.00	398.00	124.00	293.01	332.57	
	2	57	437.09	320.69	47.81	448.00	613.00	191.00	341.32	532.85	
Comorbid	Yes	175	250.01	219.31	21.40	215.00	348.00	79.00	207.77	292.25	
	No	285	443.31	413.18	25.43	363.50	580.00	200.50	393.26	493.37	
Smoking/drugs (including illicit drugs)	1	104	336.84	261.11	26.51	296.00	519.00	118.00	284.25	389.42	
	2	182	465.49	458.37	36.01	377.00	592.00	213.00	394.43	536.55	
Patient status	1	352	382.98	368.72	20.18	296.50	520.00	163.00	343.30	422.66	
	2	177	478.00	338.63	27.38	398.00	701.00	213.00	423.97	532.03	
	3	9	372.00	362.37	120.79	234.00	379.00	201.00	93.46	650.54	
	4	310	248.37	252.54	18.72	180.00	351.00	60.00	211.53	285.20	
	5	21	445.50	168.60	53.32	480.00	580.00	329.00	334.28	556.72	

Appendix 4: Confidentiality and None Disclosure Form

CONFIDENTIALITY AND NONE DISCLOSURE FROM
STUDENT PROJECT

UNIVERSITY OF SÃO PAULO

RIBEIRÃO PRETO COLLEGE OF NURSING

Agreement between the Research Student (Ms Nicola Nero) and National AIDS Programme Secretariat (NAPS), Georgetown, Guyana

Research title: *Length of survival of people living with HIV/AIDS in Guyana from 2003 to 2015 and followed until 2019*

In order to maintain confidentiality, I agree to:

1. Keep all research information that is shared with me (e.g. flash drives, notes, transcripts, data, etc.) confidential by not discussing or sharing this information verbally or in any format with anyone other than the Advisor (s) of this study;
 2. Ensure the security of research information while it is in my possession. This may include:
 - Keeping all documents and/or data related to the research study on a password protected computer with password protected files;
 - Closing any programs, documents, or data files related to the research study when away from the computer;
 - Keeping any printed documents and/or data related to the research study in a secure location such as a locked filing cabinet;
 - Permanently deleting any digital communication containing documents and/or data related to the research study.
 3. Not make copies of documents and/or data related to the research study unless specifically instructed to do so by the Advisor (s);
-

By signing this form I acknowledge that I have reviewed, understand, and agree to adhere to the expectations for a research student described above. I agree to maintain confidentiality while performing my duties and recognize that failure to comply with these expectations may result in disciplinary action.

Research staff/Student

Print Name: Nicola Nero

Date: 05/10/2020

Appendix 5: Permission letter for Georgetown Public Hospital Cooperation



Georgetown Public Hospital Corporation

Director of Medical & Professional Services

New Market Street, Georgetown, Guyana
Tel: 226-6712; Fax: 225-3346; Email: medicaldjefgphc@gmail.com



5th January, 2022

Ms. Nicola Nero
Coordinator,
National Tuberculosis Programme,
Ministry of Health

Dear Ms. Nero

I hereby confirm that approval has been granted for you to access records to carry out your research paper entitled.

“Length of survival of people living with HIV/AIDS in Guyana from 2003 to 2015 and followed until 2019.”.

Dr. Kampta Prashad, Doctor -in-Charge, Campbellville Health Centre will supervise this research on behalf of the Georgetown Public Hospital Corporation.

Dr. Nicole Need-Jerrick, Doctor -in-Charge, Enmore Poly Clinic will supervise this research on behalf of the Georgetown Public Hospital Corporation.

Please be reminded of the following:

- that permission needs to be sought for any publication of information gathered using our data.
- Copies of the **final** research papers **must** be submitted to the hospital through my office upon completion of the research.

Regards,


Dr. Pawcett Jeffrey
Director, Medical & Professional Services

Copy: Mr. Robbie Rambaran, C.E.O (ag)
Dr. Narine Singh, Chief Medical Officer, Ministry of Health
Ms. Shivani Ramdihol, Assistant Director Nursing Services
Ms. Leslyn Holder, Assistant Director (ag) Nursing Services
Dr. Kampta Prashad, Doctor-in-Charge, Campbellville Health Centre
Dr. Nicole Nedd-Jerrick, Doctor -in-Charge, Enmore Poly Clinic
Advisor: Professor Elucir Gir, University of Sao Paulo, Brazil.

Institutional Review Board FWA00030719

Ministry of Health

Brickdam, Georgetown, GUYANA

Telephone: 592-226-1224

E-mail: guyanamohirb@gmail.com

Memo

To: Nicola Nero
From: Chair, Institutional Review Board
Date: November 17, 2021
Subject: IRB Approval – New Protocol # 605/2019

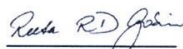
The Ministry of Public Health's Institutional Review Board (IRB) has reviewed the request for approval of protocol # 605/2019 entitled "*Length of survival of people living with HIV/AIDS in Guyana from 2003-2017*" and has approved further extension of the protocol for the maximum allowable period of **one year**. This IRB approval expires **November, 2022**.

As a reminder, the IRB must review and approve all human subjects' research protocols at intervals appropriate to the degree of risk, but not less than once per year. There is no grace period beyond one year from the last IRB approval date. It is ultimately your responsibility to submit your research protocol for continuation review and approval by the IRB. Please keep this approval in your protocol files as proof of IRB approval and as a reminder of the expiration date. To avoid lapses in approval of your research and the possible suspension of subject enrolment and/or termination of the protocol please submit your continuance request at least six weeks before the protocol expiration date.

Upon completion of your research an **electronic Report MUST** be submitted to the Board.

Any problems of a serious nature should be brought to the immediate attention of the IRB and any proposed changes to the protocol should be submitted as an amendment to the protocol for IRB approval before they are implemented.

Should you have any questions please contact the **IRB Administrator** or the **IRB Chair** via email or telephone at the email address or telephone number listed above.



Dr. Reeta Gobin

Institutional Review Board FWA00030719

Ministry of Health

Brickdam, Georgetown, GUYANA

Telephone: 592-226-1224

E-mail: guyanamohirb@gmail.com

Regulation in accordance with the MOH Act

**ETHICAL PRINCIPLES & POLICIES GOVERNING RESEARCH INVOLVING
HUMAN SUBJECTS**

The Guyana Institutional Review Board, Ministry of Health requires that all research projects or studies involving human subjects comply with the principles and procedures for protecting human research subjects specified below.

1. Ethical Principles Governing Human Subjects Research

The Guyana Institutional Review Board, Ministry of Health is guided by the ethical principles regarding research involving human subjects set forth in the Declaration of Helsinki. These ethical principles must guide individuals, groups and institutions in the conduct of all studies in which human subjects participate.

2. Policies Governing Human Subjects Research

The policies below are to be complied with by all Researchers.

- a) Researchers acknowledge and accept their responsibilities for protecting the rights and welfare of all human subjects involved in research which they sponsor or conduct.
- b) Researchers encourage and promote a research atmosphere that safeguards the rights and welfare of human subjects.
- c) Researchers agree that before human subjects are involved in research which they sponsor or conduct, proper consideration must be given to:
 1. Risks to the subjects
 2. Anticipated benefits to the subjects and others
 3. Importance of the knowledge that may reasonably be expected to result
 4. Informed consent process to be employed

Institutional Review Board FWA00030719

Ministry of Health

Brickdam, Georgetown, GUYANA

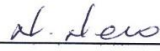
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- d) Researchers agree that, whenever appropriate, they will consider special safeguards for protecting research subjects who may be vulnerable to coercion or undue influence, such as children, prisoners, pregnant women, refugees, mentally disabled persons, rural populations and economically or educationally disadvantaged persons.
- e) Researchers agree to provide appropriate administrative overview to ensure that these principles are applied effectively.
3. The Guyana IRB, Ministry of Health may implement appropriate mechanisms to ensure that these regulations are complied with.



Chair, IRB



Investigator(s)

Date: 17th Nov 2021

Date: 22 Nov, 2021

Appendix 7: Coding for Variables

No	Variable	Definition	Code
1	Charts	1, 2.....n	1..n
2	Administrative Region	1	1
		2	2
		3	3
		4	4
		5	5
		6	6
		7	7
		8	8
		9	9
		10	10
			Missing = 0
3	HIV Care and Treatment site	Mabaruma Hospital	1
		Matthews Ridge Hospital	2
		Port Kaituma Hospital	3
		Public Hospital Suddie	4
		West Demerara Regional Hospital	5
		National Care and Treatment Centre/Gum Clinic	6
		Saint Joseph Mercy Hospital	7
		Davis Memorial Hospital	8
		Dorothy Bailey Health Centre	9
		Campbelville Health Centre	10
		Georgetown Chest Clinic	11
		Enmore Poly Clinic	12

		Betervewagting Health Centre	13
		East La Penitence Health Centre	14
		Rosignol Health Centre	15
		New Amsterdam Family Health Clinic	16
		Skeldon Hospital	17
		Kamarang Hospital	18
		Bartica Hospital	19
		Mahdia Hospital	20
		Lethem Hospital	21
		Wismar, Upper Demerara Hospital	22
			Missing = 0
4	Identification	Case number	000-9999
			Missing = 0
5	Gender Identity	Male	1
		Female	2
		Transgender Female	3
		Transgender Male	4
			Missing = 0
6	Date of Birth	Date	dd/mm/yyyy
			Missing = 0
7	Race/Ethnicity	East Indian	1
		African	2
		Amerindian	3
		Mixed	4
		Other	5
			Missing = 0
8	Catogery of exposure	Sex with male	1
		Sex with female	2
		Sex with commercial sex worker	3
		Sex with known HIV infected person	4
		Multiple sex partners (more than 2)	5
		Been a commercial worker	6
		Share needles	7

		Blood transfusion	8
		Exposure to needle stick	9
		Pre natal exposure	10
		Victim of sexual assault	11
			Missing = 0
9	Date of HIV diagnosis	Date	dd/mm/yyyy
			Missing = 0
	Date of Enrolment in clinic	Date	dd/mm/yyyy
			Missing = 0
10	WHO classification of HIV infection	Stage (Initial)	1
			2
			3
			4
			Missing = 0
11	Initial baseline CD4	First CD4 count-Value	000-1000
		Date	dd/mm/yyyy
			Missing = 0
12	On ART drug regimen	Yes	1
		No	2
			Missing = 0
13	Date of ARV initiated	Date	dd/mm/yyyy
			Missing = 0
14	ARV drug regimen	1a,1b,1c, 1d,1e,1f,1g/4a,4b,4c,4d,4e,4f	1
		2a,2b/5a	2
			Missing = 0
15	Viral load	First/Initial test	High value
			Low value
			Missing = 0
16	Co-morbid conditions	Tuberculosis	1
		Diabetes Mellitus	2
		Hypertension	3
		Respiratory lung disease	4
		Heart condition	5
		More than one of the above	6

		None	7
			Missing = 0
17	Support Service	Counsellig/support group	1
		Family/friend support	2
		Care packages/hampers/finincial	3
		1 and 2	4
		1, 2 and 3	5
			Missing = 0
			Missing = 0
18	Smoking (including illicit drugs)/Alcohol	Yes	1
		No	2
			Missing = 0
19	Patient status	On treatment	1
		Drop treatment	2
		Stop treatment	3
		Dead	4
		In care, not on Rx	5
			Missing = 0
20	Date of drop treatment	Date	dd/mm/yyyy
			Missing = 0
21	Date of stop treatment	Date	dd/mm/yyyy
			Missing = 0
22	Date of death	Date	dd/mm/yyyy
			Missing = 0