SOCIO-ECONOMIC AND INSTITUTIONAL CHALLENGES EXPERIENCED BY PATIENTS RECEIVING ANTI-RETROVIRAL TREATMENT AT KIRYANDONGO GENERAL HOSPITAL

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A RESEARCH REPORT SUBMITTED TO FACULTY OF CLINICAL MEDICINE AND DENTISTRY IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF BACHELOR OF MEDICINE AND SURGERY AT KAMPALA INTERNATIONAL UNIVERSITY

APRIL, 2019

DECLARATION

I hereby declare that this report; Socio-economic and Institutional challenges experienced by patients receiving anti-retroviral treatment at Kiryandongo General Hospital, is a product of my own effort, to the best of my knowledge, this study has never been submitted anywhere for the award of bachelor of medicine and bachelor of surgery. Where the works of other people have been included, due acknowledgement to this has been made in accordance with the appropriate referencing and citations.

Researcher: ATUKUNDA JONATHAN, BMS/0001/141/DU

SignatureDate

APPROVAL

This is to certify that this research report has been prepared under my close supervision and guidance and has never been presented anywhere for any other purpose and I therefore recommend the researcher to submit it to the Faculty of Clinical Medicine and Dentistry of Kampala International University for further consideration.

Supervisor: Dr. KIGGUNDU THOMAS

	151
Signed	
Date OISt MAY 2015	

DEDICATION

This research report is dedicated to my family (Rev.William and Mrs Noredah Habimaana family) and my sponsors (Mr. Thomas Nelson and Dr. Prudence Barrett Nelson) for being my greatest blessing and source of encouragement throughout the research work. May God bless them richly and abundantly

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I am grateful to the Almighty God the most Merciful for his unfailing love, provision, protection and unmerited mercy and grace. My sincere thanks go to all lecturers and staff of Kampala International University, throughout the Undergraduate program in general and in particular in relation to this research report.

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Table of Contents	
DECLARATION	i
DEDICATION	iii
ACKNOWLEDGEMENT	iv
LIST OF FIGURES	viii
LIST OF TABLES	ix
LIST OF ABBREVIATIONS	x
OPERATIONAL DEFINITIONS	xi
ABSTRACT	xii
CHAPTER ONE: INTRODUCTION	1
1.0 BACKGROUND	1
1.1 PROBLEM STATEMENT	2
1.2 OBJECTIVE OF THE STUDY	3
1.2.1 BROAD OBJECTIVE	3
1.2.2 SPECIFIC OBJECTIVES	3
1.3 RESEARCH QUESTIONS	4
1.4 JUSTIFICATION OF STUDY	4
1.5 STUDY SCOPE	4
1.5.1 GEOGRAPHICAL SCOPE	4
1.5.2 CONTENT SCOPE	5
1.5.3 TIME SCOPE	5
1.6 CONCEPTUAL FRAME WORK	6
CHAPTER TWO: LITERATURE REVIEW	7
2.1 SOCIAL CHALLENGES EXPERIENCED BY PATIENTS RECEIVING ART	7
2.2 ECONOMIC CHALLENGES EXPERIENCED BY PATIENTS RECEIVING ART	

2.3 INSTITUTIONAL CHALLENGES EXPERIENCED BY PATIENTS RECEIVING ART 9
CHAPTER THREE: METHODOLGY 11
3.0 INTRODUCTION
3.1 STUDY DESIGN
3.2 STUDY SETTING
3.3. STUDY POPULATION
3.4 ELIGIBILITY CRITERIA
3.4.1 INCLUSION CRITERIA
3.4.2 EXCLUSION CRITERIA 11
3.5 SAMPLE SIZE DETERMINATION
3.6 SAMPLE STRATEGY
3.7 DATA COLLECTION METHOD 12
3.8 DATA COLLECTION TOOL
3.9 DATA QUALITY CONTROL 12
3.10 DATA ANALYSIS
3.10.1 ETHICAL CONSIDERATION
3.10.2 RIGHT TO CONFIDENTIALITY AND ANONYMITY
3.10.3 STUDY LIMITATION AND DELIMITATION
3.10.4 DISSEMINATION OF STUDY FINDINGS
CHAPTER FOUR: RESULTS
4.0 INTRODUCTION
4.1 DEMOGRAPHIC CHARACTERISTICS
4.2 SOCIAL CHALLENGES
4.3 ECONOMIC CHALLENGES
4.4 INSTITIONAL CHALLENGES

CHAPTER FIVE: DICUSSION, CONCLUSION AND RECOMMENDATIONS	27
5.0 INTRODUCTION	27
5.1 DEMOGRAPHIC CHARACTERISTICS	27
5.2 SOCIAL CHALLENGES	28
5.3 ECONOMIC CHALLENGES	30
5.4 INSTITUTIONAL CHALLENGES	31
CONCLUSIONS	34
RECOMMENDATIONS	34
REFERENCES	36
APPENDIX I: STATEMENT OF CONSENT FOR THE RESPONDENTS	40
APPENDIX II: DATA COLLECTION TOOL-QUESTIONNAIRE	40
APPENDIX III: INTRODUCTORY LETTER	44
APPENDIX IV: MAP OF UGANDA	45
APPENDIX V: MAP OF KIRYANDONGO DISTRICT	46

LIST OF FIGURES

Figure 1: Conceptual Frame work on socio-economic and institutional challenges exp	erienced by
HIV/AIDS patients receiving ART	18
Figure 2: Source of discrimination of HIV/AIDS patients	31
Figure 3: Treatment after disclosure of HIV positive status	32
Figure 4: Sexual problems after ART initiation	33
Figure 5: Respondents' feelings on being seen at the ART clinic	35
Figure 6: Responses on forms of financial burden due to HIV/AIDS	36
Figure 7: Expenditure on transport	38
Figure 8: Number of meals per day among respondents	38
Figure 9: Showing how long respondents waited before being offered the services	39
Figure 10: Distance travelled by respondents to the hospital every visit	40
Figure 11: After how long respondents had to come back for refill of ART	42

LIST OF TABLES

Table1; Demographic Characteristics of respondents	.28&29
Table 2; Responses on whether respondents felt stressed or depressed at times	.30
Table 3; Monthly income and Monthly HIV/AIDS related expenditure of respondents	.36
Table 4; Showing responses on medication/ART stock outs on clinic visits	37
Table 5; Responses on treatment by Hospital ART clinic staffs	40
Table 6; Specific responses on inadequate space at the hospital ART clinic	41

LIST OF ABBREVIATIONS

AIDS	:	Acquired immune deficiency syndrome
HIV	:	Human immune deficiency virus
UN AIDS	:	United Nations program on AIDS
WHO	:	World Health Organization
PLWHAS	:	People living with HIV/AIDS
ART	:	Antiretroviral therapy
AVERT	:	Averting HIV/AIDS Organization
HAART	:	Highly active antiretroviral Therapy
KIU	:	Kampala International University
KI	:	Key informant

OPERATIONAL DEFINITIONS

Pandemic	: A disease prevalent through an entire country, continent or the whole		
	world over a large area		
Social	: An aspect that connects to the society and the way it's organized		
Institutional	: An aspect that connects to a center or organization that provides services		
	to patients		
Stigmatization	: The severe disapproval of or discontent with a person on grounds of		
	characteristics that distinguish him or her from other members of the		
	society.		
Discrimination	: prejudicial treatment of an individual based on his/her membership or		
	Perceived membership in a certain group or category.		
Stress	: body's reaction to a change which requires a physical, mental or		
	emotional adjustment or response.		

ABSTRACT

Background: There are over 36.9 million people globally living with HIV/AIDS, 35.4 million people have died from AIDS-related illnesses since the start of the epidemic and Sub-Saharan Africa carries 70% of the global burden of infection. While there has been a gradual increase in the number of HIV/AIDS patients accessing treatment, 33% of adults living with HIV/AIDS are still not on Antiretro-viral treatment. It's possible that the challenges faced by HIV/AIDS patients are probably not yet fully addressed beyond provision of ART since a significant proportion of patients legible for ART are still not enrolled on treatment and the of HIV/AIDS related morbidity and mortality continue to be severe. The study therefore thought to establish whether socio-economic and institutional factors have a bearing on challenges faced by patients receiving ART at Kiryandongo general hospital.

Methods: Between January 2018 and December 2018, a cross-sectional study, descriptive in nature and employing both qualitative and quantitative research designs was conducted at Kiryandongo general Hospital ART clinic with 201 respondents. Interviewer administered questionnaires were used to ascertain socio-economic and institutional challenges experienced by patients receiving ART

Results; A total of 201 participants were consecutively enrolled into the study. Majority of the respondents were in the age bracket of 26-35 years and peasants. The findings indicated that depression, Stress, stigma, discrimination, lack of family support, disclosure of sero-positivity and sexual problems were social challenges experienced by patients receiving ART. Economic challenges reported were; Low monthly income, transport expenses, food expense, inadequate general life economic demands like basic needs. The Institutional challenges identified were Medication/ART stock outs, long patient waiting hours, poor attitude of some staffs, inadequate clerking and counseling rooms, short intervals of ART refill and lack of community based ART services.

Conclusion; Socio-economic and institutional challenges are real among HIV/AIDS patients. There is need to empower patients and communities with better sustainable incomes through poverty eradication programs as well as improving health provision services.

xii

CHAPTER ONE: INTRODUCTION 1.0 BACKGROUND

The human immunodeficiency virus (HIV) infects cells of the immune system, destroying or impairing their function resulting into progressive deterioration of the immune system and eventually leading to immune deficiency. The immune system is considered deficient when it can no longer fulfill its role of fighting infection and disease. Infections associated with severe immunodeficiency are known as opportunistic infections since they take advantage of a weakened immune system. Acquired immunodeficiency syndrome (AIDS) applies to the most advanced stage of HIV infection and its defined by the occurrence of any of more than 20 opportunistic infections or HIV - related cancers (Avert, 2017). According to (UNAIDS Global HIV & AIDS statistics report, 2018) 36.9 million people globally were living with HIV in 2017 of whom 1.8 million were children under the age of 15 years, 1.8 million people became newly infected with HIV and 940 000 people died from AIDS-related illnesses in the same year, The HIV epidemic has resulted into 77.3 million people being infected since its onset and approximately 35.4 million people have died from AIDS-related illnesses since the start of the epidemic in the early 1980s. Approximately 75% of people leaving with HIV knew their HIV status in 2017 and about 9.4 million people did not know that they were leaving with HIV(U.S. Department of Health & Human Services, 2017).

Sub-Saharan Africa carries a disproportionate burden of HIV, accounting for more than 70% of the global burden of infection. Success in HIV prevention in sub-Saharan Africa has the potential to impact on the global burden of HIV since the region still accounts for 74% of the global AIDS related deaths. Of the estimated 6000 new infections that occur globally each day, two out of three are in sub-Saharan Africa with young women continuing to bear a disproportionate burden. Adolescent girls and young women aged 15-24 years have up to eight fold higher rates of HIV infection compared to their male peers (Kharsany & Karim, 2016).

Many studies from sub-Saharan Africa, have highlighted the critical role of antiretroviral therapy in reducing morbidity and mortality associated with HIV/AIDS. However, the greatest challenge for sub-Saharan Africa has been that most HIV-infected patients present late for Ant-retroviral treatment (ART) thereby increasing the risk of death in spite of the increasing availability of effective treatment (Phillips et al., 2017).

Uganda's HIV and AIDS epidemic continues to be severe, mature, generalized and heterogeneous with an estimated 1.5 million Ugandans infected with HIV and about 130,000 new HIV infections each year. The HIV and AIDS epidemic in Uganda is now at cross roads with increasing number of infection among adolescents and young adults despite the country having made significant progress in the national HIV response especially with the introduction and promotion of highly active antiretroviral therapy (HAART) (Uganda Ministry of Health, 2015).

Global trends in HIV infection demonstrate an overall increase in HIV prevalence and substantial declines in AIDS related deaths largely attributable to the survival benefits of antiretroviral treatment. However globally, only 21.7 million people were accessing antiretroviral therapy in 2017 (U.S. Department of Health & Human Services, 2017).

While there has been a gradual increase in the number of people living with HIV accessing treatment, as of 2016 around 33% of adults living with HIV and 53% of children living with HIV were still not on treatment. Persistent disparities still remain around who is accessing treatment and many people living with HIV experience stigma and discrimination (Avert, 2017).

Whereas there is still no cure for HIV/AIDS, treatment with Ant-retroviral drugs can considerably reduce the viral load and further retards replication of the HIV in the body and consequently retard progress of disease and enables suffers to live relating for longer periods symptomless. Whereas ART is changing the gloomy picture brought about by HIV/AIDS which could make it a manageable epidemic and hence reduce the morbidity and mortality, the situation does not much with the input as the global situation remain alarming (UNAIDS, 2017).

The AIDS epidemic may be the most devastating health disaster in human history. The epidemic has the potential to create serious impacts (Orner et al., 2014). Only persistent and constant provision of ART and continuous support to people living with HIV/AIDS (PLWHAS) can remove the social economic and institutional frustrations barricading access and use of the drugs for their good health (Kharsany & Karim, 2016).

1.1 PROBLEM STATEMENT

An estimated 36.9 million people globally are living with HIV, 1.8 million of who are children under the age of 15 and majority (70%) of whom live in Sub-Saharan Africa, 77.3 million people have been infected with HIV and approximately 35.4 million people have died from AIDS-

related illnesses since the start of the epidemic. Approximately 1.8 million people became newly infected with HIV and 940 000 people died from AIDS-related illnesses in 2017 alone (UNAIDS, 2017).

Robust treatment and prevention initiatives have been implemented in recent years, leading to improved conditions for people living with HIV/AIDS (PLWHAS). However, while there has been a gradual increase in the number of people living with HIV accessing treatment, as of 2016 around 33% of adults living with HIV and 53% of children living with HIV were still not on treatment. Persistent disparities still remain around who is accessing treatment and many people living with HIV still experience significant stigma and discrimination (UNAIDS, 2017).

Despite Uganda having made significant progress in the national HIV& AIDS response, the epidemic continues to be very severe; 33% of adults eligible for access to ART are not enrolled on treatment, an estimated 1.5 million Ugandans are infected with HIV and about 130,000 new HIV infections occurring each year and many patients risk development of HIV/AIDS related complications if not initiated on ART early in time (Uganda AIDS Comission, 2017).

Could the continued severity of HIV/AIDS together with failure to achieve maximum utilization of ART be due to social, economic or institutional challenges among People living with HIV/AIDS (PLWHAS)? If not addressed, high prevalence of opportunistic infections as well as AIDS related death to continue prevailing among HIV/AIDS patients

1.2 OBJECTIVE OF THE STUDY

1.2.1 BROAD OBJECTIVE

To establish the socio-economic and institutional challenges experienced by HIV/AIDS patients receiving ART at Kiryandongo general hospital in order to promote maximum utilization of ART and to reduce morbidity and mortality among HIV/AIDS patients

1.2.2 SPECIFIC OBJECTIVES

- To find out social challenges experienced by HIV patients receiving ART at Kiryandongo general hospital
- To assess economic challenges experienced by HIV patients receiving ART at Kiryandongo general hospital
- To find out institutional challenges experienced by HIV patients receiving ART at Kiryandongo General hospital

1.3 RESEARCH QUESTIONS

- 1) What are the social challenges experienced by HIV patients receiving ART at Kiryandongo general hospital?
- 2) What are the economic challenges experienced by HIV patients receiving ART at Kiryandongo general hospital?
- 3) What are the institutional challenges experienced by HIV patients receiving ART at Kiryandongo general hospital?

1.4 JUSTIFICATION OF STUDY

Currently, there is no cure to HIV/AIDS with ART providing a restrain to viral replication and maintenance of relatively good health in patients affected by the infection. Constant use of ART not only prevents early progression to AIDS but also lessens chances of development of resistance to available drugs.

Whereas HIV/AIDS has attracted the attention of many scholars around the world resulting into a lot of research being carried and new ideas developed to improve care offered to PLWHAS, socio-economic and institutional bottlenecks in access and utilization of ART still exist and as well, HIV/AIDS continues to be very severe. These bottlenecks should be removed or significantly minimized in order to maximize the number of HIV/AIDS patients on ART. Thus the reason for this study, no similar study has been carried out among PLWHAS receiving ART at Kiryandongo general hospital. The study findings will enable the hospital and Kiryandongo district health administration to design strategies to improve utilization of ART and therefore reduce HIV/AIDS associated morbidity and mortality. The findings will also serve as a source of information for researchers intending to carryout related studies.

1.5 STUDY SCOPE

1.5.1 GEOGRAPHICAL SCOPE

Kiryandongo District is located in Western Uganda and is 1 of the 5 districts that form the Bunyoro sub-region. Kiryandongo general hospital and the district headquarters are located in Kiryandongo town that lies approximately 225 kilometers (140 miles), by road, northwest of Kampala, Uganda's capital and largest city The coordinates of the district are:02 00N, 32 18E (Latitude:2.0000; Longitude:32.3000). The District total population as of 2012 was estimated at about 317,500. Kiryandongo District is bordered by Nwoya District to the north, Oyam District to the northeast, Apac District to the east, and Masindi District to the south and west.

1.5.2 CONTENT SCOPE

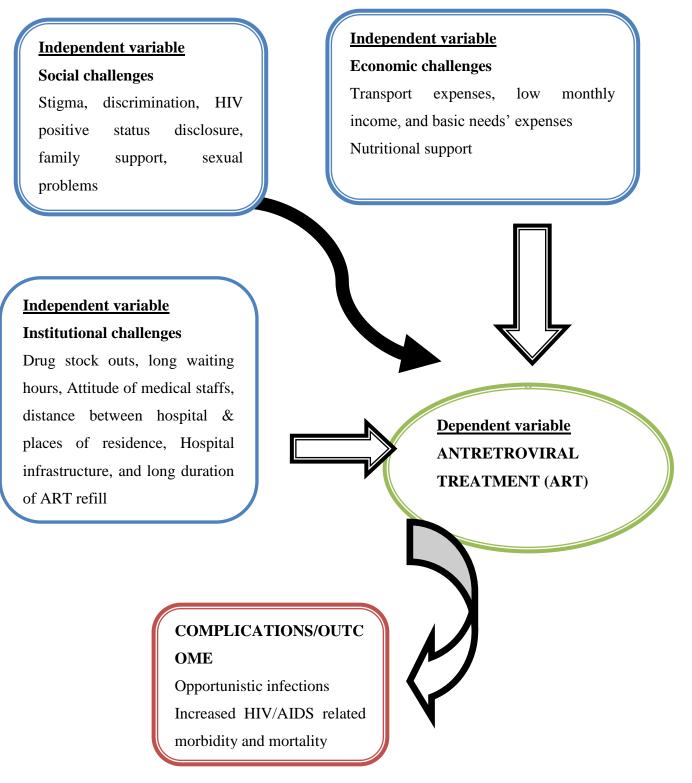
The study focused on identifying Socio-economic and institutional challenges experienced by patients receiving ART at Kiryandongo general hospital

1.5.3 TIME SCOPE

Ethical approval for this study was obtained in December 2018. Data was collected in the month of March 2019 and analyzed in April 2019. The final thesis was submitted for examination in April 2019.

1.6 CONCEPTUAL FRAME WORK

Figure I; Conceptual framework on socio-economic and institutional challenges experienced by HIV/AIDS patients receiving ART.



CHAPTER TWO: LITERATURE REVIEW

2.1 SOCIAL CHALLENGES EXPERIENCED BY PATIENTS RECEIVING ART

Among the major social challenges experienced by persons with HIV/AIDS in close to 35 years of the history of this pandemic is the social stigma and discrimination associated with the disease (UNAIDS, 2017).

HIV –related stigma and discrimination refers to prejudicial attitude and abuse directed at people living with HIV and AIDS. In 35% of countries with available data, over 50% of people are reported having discriminatory attitudes towards people living with HIV. Some people living with HIV and other key affected populations are shunned by family, peers and the wider community, while others face poor treatment in educational and work settings erosion of their rights, and psychological damage. These all limit the willingness to start and adhere to treatment and other HIV services (Avert, 2017).

In a study to find out the challenges of treatment adherence by people living with HIV/ AIDS in Brazil, the participants spoke of difficulties concerning the stigma, life style and personal relationships. Some mentioned the need to hide the use of medication from friends, workmates and family. The stigma to live with HIV/AIDS was an important barrier according to many participants who Identified with strong need to hiding the disease(Hoffmann et al., 2016).

It is very common for communities to think that persons who have contracted HIV/AIDS must have been living a promiscuous life. Promiscuity among many communities is a shameful practice and highly condemned. Therefore, many persons living with HIV/AIDS are in perpetual fear or shame and feel guilty which further encourages the assimilation of restrictive rules that distance patients from those who are uninfected (Kalichman, 2014).

With HIV/AIDS comes stress and depression which occur after manifestations of opportunistic infection together and in association with ART pill burden. HIV/AIDS patients are exposed to chronic stress considered most toxic as it most likely result into long-term or permanent changes in emotional, psychological or behavior responses (Kalichman et al., 2015).

HIV/AIDS patients do not easily or sometimes never disclose their positive sero-status for HIV to their partners and community because of fear of breach of confidentiality, fear or anger and abandonment by partner, fear of being accused, destabilizing relationships, or being condemned and being avoided by those closer to them. Patients also find it difficult to deal with returning to

normal life after previous openness about the HIV positive status and may revert back to nonopenness about their status (Colombini, James, Ndwiga, Team, & Mayhew, 2016).

2.2 ECONOMIC CHALLENGES EXPERIENCED BY PATIENTS RECEIVING ART

In a study to identify barriers to adherence to antiretroviral treatment in a regional hospital in South Africa; the economic factors that were identified by respondents to interfere with their ability to be initiated and adhere to taking ART as prescribed were poverty and un employment, lack of money to buy food and eat properly before taking the medication (Azia, Mukumbang, & Van Wyk, 2016).

Literature reveals that patients with lower incomes unlike those with higher incomes face much difficulty with access and adherence to ART and life economic demands. Majority of persons and families affected by HIV/AIDS are also affected by poverty (Bigna, Plottel, & Koulla-Shiro, 2016). Daily life demands like food, housing, treatment etc. are viewed as more pressing to patients that are taking medication regularly (Sevelius, Patouhas, Keatley, & Johnson, 2014).

Poverty directly affects adherence to ART since medical facilities that provides ART do not cover travel expenses and thus ART services may not be readily accessible for HIV/AIDS patients who should attend clinic appointments coming from very distant residential communities. Therefore patients often have to walk or travel which may require considerable effort and yet some maybe unwell. The combined stress associated with poverty, such as inadequate housing and unemployment may obviate an acknowledgement of the importance of regular clinic visits and what may be perceived as rigid treatment regimens (Saal & Kagee, 2012).

In a qualitative study conducted among ART users in Uganda, Tanzania and Botswana, participants reported that they were unable to afford food needed to satisfy their increased appetites following commencement of treatment, especially in the early stages of treatment when their bodies needed extra nutrition to regain weight and strength. Food insecurity may affect the regularity of ART doses, as some patients have reported taking their medication only when they have food available (Vernooij, Mehlo, Hardon, & Reis, 2016).

In the context of high unemployment in many low income countries, many patients lack regular employment making themselves available as day laborers to employers willing to pay them a wage and this eclipses the potential benefit of clinic visits which only take place during day. In the event of frequent absences from work subsequently may lead to termination of employment especially if the employers do not know the reason for such absences. The threat of losing employment for this reason, therefore often impedes clinic attendance (Kagee, 2012).

Therefore, clinic visits cost money and may stretch an already stretched budget. Furthermore; there in is no medical insurance or disability pension for PLWHAS in developing countries Uganda inclusive (Reda & Biadgilign, 2012).

2.3 INSTITUTIONAL CHALLENGES EXPERIENCED BY PATIENTS RECEIVING ART

Inadequate medical supplies like ART and other adjunct medications pose a challenge to patients. The results from a case study on experiences of PLWHAs receiving care services according to united Nation Population Fund, UNFPA (2013), revealed that shortage of medical supplies is still a challenge. According to the results, there is abundant evidence that Uganda's health system, personnel and HIV/AIDS information strategy are still ill equipped to meet the care and treatment demands of PLWHAs. In addition, according to (Sabet Sarvestani, Bufumbo, Geiger, & Sienko, 2012), most Health facilities / pharmacies are faced with recurrent stock outs of some ART medications and other prescribed medications and as a result, some PLWHAS may spend some period without ART or other prescribed medications.

According to (Kagee, 2012) among patients receiving ART, logistical problems included having to line up outside ART clinics as early as 6 a. m and having to wait many hours before they could collect their medication. Some patients, in an attempt to reduce the time demanding-frequency of clinic visits, would decrease their doses so that their supplies would last longer. Thus, the way public health clinics are organized may determine the nature and level of access that patients have. Many ART clinics have long patient waiting times, inadequate infrastructure and facilities and severe staff shortages (Kagee, 2012)

The presence of uncooperative, impolite, inconsiderate or unsympathetic staffs in some of the health units affect patients desire to be initiated on ART and adherence onto it. Results from studies done in south Africa, revealed that 30% of study participants preferred to go to private or distant public ART clinic away from their areas of residence because they could not trust health workers at their local units, feared mistreatment from familiar health workers and this affected their adherence. In addition, most health centers lack outreach services to patients who cannot easily access health units for treatment (Njuguna, 2010).

According to (peter et al, 2014), PLWHAS face difficulties with ART replenishment, for just over half of PLWHAS, a prescription for ART lasts for 2 months in developed countries. Only 40% of PLWHAS in developing countries receive a prescription for 1 month and only 12% for 2months. Patients therefore have to frequent the health centers for treatment which has adverse implications onto other daily life activities.

CHAPTER THREE: METHODOLGY 3.0 INTRODUCTION

This chapter focuses on the methodology; the study design and rationale, study population inclusion criteria, exclusion criteria, sample size determination, sampling technique, data collection method, data collection tools, data collection procedure, quality control, data analysis, ethical considerations, right to confidentiality and anonymity, study limitation and delimitation and dissemination of study findings

3.1 STUDY DESIGN

The study was cross-sectional and descriptive in nature employing both qualitative methods of data collection and analysis. This design was considered appropriate considering the nature of the research and the researcher's limited time for carrying out the study.

3.2 STUDY SETTING

Kiryandongo general hospital ART clinic is located in the center of the hospital. The clinic was opened in February of 2005 and has since enrolled a total of 6022 adult patients on ART of whom 1904 are currently active as per the current quarter (Kiryandongo general hospital ART clinic data, 2019). The clinic opens every day (8 am -5 pm) from Monday to Friday.

3.3. STUDY POPULATION

The study targeted HIV/AIDS patients receiving ART at Kiryandongo general hospital ART clinic.

3.4 ELIGIBILITY CRITERIA

3.4.1 INCLUSION CRITERIA

Participants who took part in this study as respondents were;

1. Above 18 years

2. Had been receiving ART at the Kiryandongo general hospital ART clinic for at least 1 year

3. Had consented

3.4.2 EXCLUSION CRITERIA

This included HIV/AIDS patients attending Kiryandongo general hospital HIV clinic but with co-morbidities like Hypertension and Diabetes Mellitus.

3.5 SAMPLE SIZE DETERMINATION

Sample size was obtained through calculation by using the Kish Lesley (1965) formula: $n=z^2p$ (1-p) /E²; (Israel 1992) Where;

n= Estimated minimum sample size required,

p= prevalence of challenges experienced by HIV/AIDS patients (84.5%),

Z=1.96 (for 95% confidence Interval),

E = Margin of error set at 5%,

 $n=1.96x\ 1.96\ x\ 0.845(1\text{-}0.845)\div(0.05x0.05)=201$

A sample size of 201 was representative of the whole study population.

3.6 SAMPLE STRATEGY

All participants who met the inclusion criteria were selected consecutively meaning that, one patient out of 3 in a queue were selected

3.7 DATA COLLECTION METHOD

Data was collected only on working days from8th- 22nd of April 2019. The researcher and research assistants administered a structured interviewer administered questionnaire with English questions which were translated to the understandable languages; Runyoro, Alur, Kiswahili, Acholi and Langi, as most of the respondents were not comfortable with the English language. This was done by asking respondents translated questions, their responses were therefore applicable to both the literate and illiterate. Data was only collected from respondents who had consented and were eligible after having been screened by the researcher in respect to the interest of the research.

3.8 DATA COLLECTION TOOL

The interviewer administered questionnaires with multiple choice, open and close ended questions. Since most of the respondents were uncomfortable with the English language, the questions were translated into the understandable language and the responses were back translated to English and then recorded on the questionnaires. This made the research tool best applicable to even respondents who had not attained any formal education. The tool was developed based on the key research questions

3.9 DATA QUALITY CONTROL

Quality control procedures were emphasized in this study by; pre- testing the questionnaire and training of the research assistants.

The researcher made a pre-visit to the study area prior to carrying out the study, pre-visiting of the site ensured that the authorities concerned were briefed about the study and it made the researcher familiar with the study setting which made data collection easier.

The appropriateness of questions was assessed by pre-testing of the data collection tool at the ART clinic of Kiryandongo general hospital a week earlier before the actual study. Pre-testing was done on ten patients in form of practice in order to get used to the tool before real use.

Two research assistants were utilized in this study, they underwent some training by the researcher so as to make sure they were very conversant with research objectives and procedures which helped in ensuring that the best quality data was obtain from the respondents.

3.10 DATA ANALYSIS

The data collected was analyzed and reported using descriptive statistics and illustrated using; tables, graphs, pie-charts and statements; from all the questionnaires that had been used and was reviewed in relation to study objectives and variables. Analysis and discussion was done by establishing relationship between the independent and dependent variables.

3.10.1 ETHICAL CONSIDERATION

Ethical approval was sought from the Health Research Ethics Committee of KIU. Permission to conduct the study was obtained from the hospital medical superintendent Kiryandongo general hospital and subsequently from the hospital ART clinic in-charge. Informed consent was obtained from respondents before enrolling them into the study and all the information obtained was kept confidential. All legal protocols were followed in collecting, analyzing and processing the data and no administrator was asked for any unlawful favor of any form. The data was analyzed in correspondence to the study design used as required by research ethics.

3.10.2 RIGHT TO CONFIDENTIALITY AND ANONYMITY

Confidentiality and anonymity was maintained throughout the study. Only the researcher, supervisor, and statistician had access to any information and data obtained for the purpose of this study.

3.10.3 STUDY LIMITATION AND DELIMITATION

The limitations of the study are the biases inherent to any questionnaire survey based study which may be as follows:

Selection Bias: In spite of taking adequate care to follow the scientifically valid methods of representative samples, selection bias cannot be ruled out entirely as only a small proportion of the total target population was studied.

3.10.4 DISSEMINATION OF STUDY FINDINGS

Results from the study was shared between the researcher, the supervisor, the examiners, and the hospital administration.

CHAPTER FOUR: RESULTS 4.0 INTRODUCTION

This chapter involves critical analysis of data from the questionnaires and its systematic presentation in table, statements, charts and graphs. From this chapter, deductions were made on socio-economic and institutional challenges experienced by patients receiving ART at Kiryandongo general hospital, Kiryandongo district. Qualitative findings have been presented descriptively while quantitative findings presented in table and figures

4.1 DEMOGRAPHIC CHARACTERISTICS

Variable	Category	No.	Percentage (%)
		respondents(N=201)	
Age	18-25 years	26	12.9
	26-35 year	121	60.2
	36 years and above	54	26.9
Level of formal	None	6	3.0
education	Primary	102	50.7
	Secondary	61	30.3
	Tertiary	32	16.0
Occupation	Civil servant	27	13.4
	Business person	42	20.9
	Peasant	113	56.2
	Not employed	19	9.5
Gender	Male	72	35.8
	Female	129	64.2
Marital status	Married	71	35.3
	Single	59	29.4

 Table 1: Demographic characteristics of respondents

	Widowed	43	21.4
	Divorced	28	13.9
Tribe	Alur	76	37.8
	Munyoro	87	43.3
	Acholi	14	7.0
	Langi	7	3.5
	Others	17	8.5
Religion	Catholic	68	33.8
	Protestant	54	26.9
	Muslim	32	15.9
	Born Again	29	14.4
	Others	18	9.0
Place of residence	Rural	144	71.6
	Sub-urban	21	10.5
	Urban	36	17.9

Majority, 121 (60.2%) of the respondents were in the age bracket of 26-35 years, 54(26.9%) 36 years and above, and 26(12.9%) were in the age bracket 18-25 years. Almost half of the respondents 102(50.7%) had attained primary education, 61(30.3%) secondary education, 32(16%) tertiary education and the smallest proportion, 6(3%) had not attained any level of formal education

The largest proportion 113(56.2%) of the respondents were peasants, 42(20.9%) did business, 27 (13.4%) were civil servants and the smallest proportion 19(9.5%) were not employed

Majority 129(64.2%) of the respondents were females and 72(35.8%) were males of whom; 71(35.3%) were married, 59(29.4%) single, 43(21.4%) widowed and 28(13.9%) were divorced.

The largest proportion 87(43.3%) of respondents were Banyoro, 76(37.8%) were Alur and the remaining proportion comprised of; Acholi, Langi and others. Majority 144(71.6%) of respondents reported living in rural areas, 21(10.5%) lived in sub-urban areas and the rest

36(17.9%) lived in urban areas. Majority 68(33.8%) of respondents were Catholics, 54(26.9%) protestants, 32(15.9%) Muslims, 29(14.4%) Born again and 18(9%) formed a proportion of other religions

4.2 SOCIAL CHALLENGES

In this study, efforts were made to find out the social challenges experienced by patients receiving ART

Respondents were asked whether they at times felt stressed or depressed by the condition (HIV/AIDS) and its management and whether they had ever been discriminated against due to the condition.

Table 2; Responses on whether respondents felt stressed or depressed at times

Response	Frequency(n=201)	Percentage (%)
Yes	156	77.6
No	45	22.4

Majority 156(77.6%) of respondents were experiencing stress and depression as a result of their status and the condition, only 45(22.4%) of the respondents reported not experiencing any stress or depression.

Majority 151(75.1%) of the respondents had faced discrimination at some point due to HIV/AIDS, only 50(24.9%) reported having not experienced discrimination due to their condition

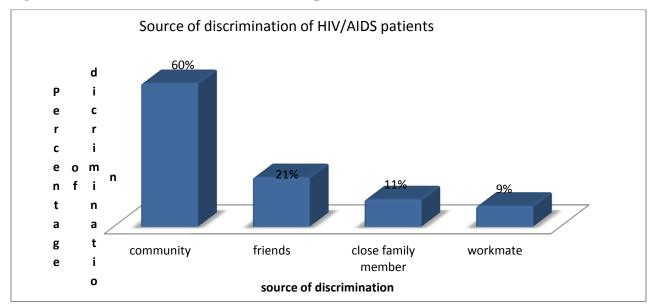


Fig 2; Source of discrimination of HIVAIDS patients (n=151)

Respondents were most discriminated against by community 90(60%), the other sources of discrimination were; 31(21%) friends, 17(11.3%) close family member and 13(8.6%) workmates.

Respondents were asked whether their spouses, families and people in community knew their HIV status and how they were treated towards their HIV/AIDS condition.

Majority 130 (65%) reported their spouses, families and community being aware of their HIV status, 71 (35%) had not disclosed their status.

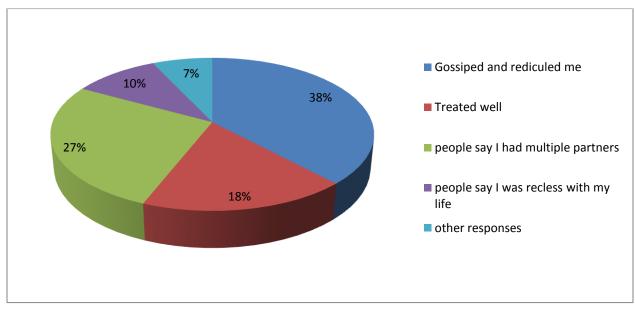
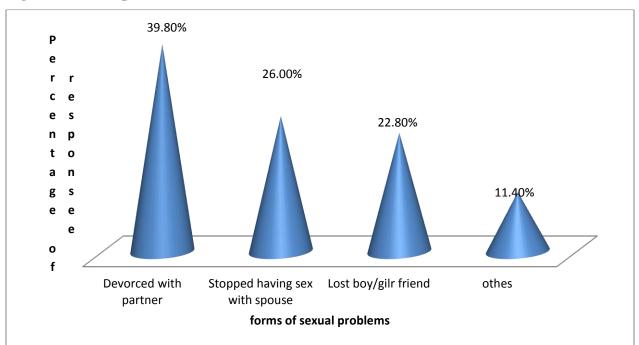


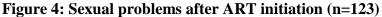
Figure 3: Treatment after disclosure of HIV positive status (n=130)

Majority 49(38%) of those who had disclosed their sero HIV positive status reported being gossiped and ridiculed, 35(27%) reported people saying they had had multiple sexual partners, 23(18%) being treated well, 13(10%) reported people saying that they had lived a reckless life and 9(7%) represented other responses

Respondents were asked whether they had faced any sexual problems after ART initiation, how they responded to being seen at the ART clinic and when taking ART and whether they got any support from their families.

Majority 123(60.2%) of respondents reported having experienced sexual problems after ART initiation, 78(38.8%) did not report these problems





Majority 49(39.8%) of respondents reported having divorced with their partners, 32(26.0%) having stopped having sex with their spouses, 28(22.8%) having lost their boy/girlfriends and 11(11.4%) reported other responses

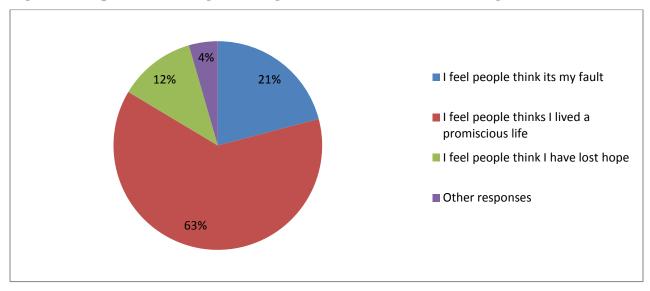


Figure 5: Respondents feelings on being seen at the ART clinic or taking ART (N=201)

Majority 123(62.7%) felt that people thought they had lived a promiscuous life, 42 (20.9%) reported feeling that HIV/AIDS was their fault, 24(11.9%) reported feeling like people thought they had lost hope, 9(4.5%) represented other forms of responses.

Majority 148(73.6%) of the respondents reported having been receiving family support while a small proportion 53(26.4%) represented those were not receiving family support.

4.3 ECONOMIC CHALLENGES

In this study, efforts were made to assess the economic challenges experienced by patients receiving ART among respondents.

Respondents were asked whether the condition (HIV/AIDS) posed a financial burden to them, how much money they earned per month and the amount spent on AIDS related expenses per month, the amount they spent on transport per visit to the hospital ART clinic and the means of transport they used to get to the health centre.

All respondents 201 (100%) were experiencing some degree of financial burden as a result of the condition (HIV/AIDS)

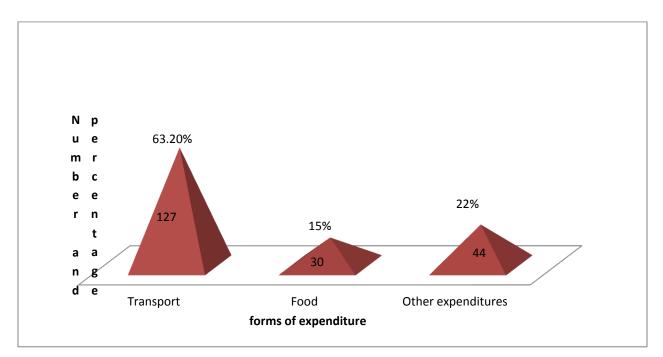


Figure 6: Showing Reponses on forms of financial burden due to HIV/AIDS (n=201)

Majority 127(63.2%) of respondents reported spending money on transport, 30(15%) on food and 44(22%) reported other forms of financial burdens.

Income (Ug	Frequency (201)	Percent	HIV/AIDS	Frequency	Perc
shilling)		age (%)	related	(n=201)	enta
			Expenditure		ge
			Ug shillings		(%)
10,000-50,000	76	37.8	Less than 10,000/=	34	16.9
50,000-100,000	61	30.4	10,000- 30,000/=	93	46.3
100,000-150,000/=	24	11.9	30,000-50,000/=	41	20.4
150,000/= and above	32	15.9	More than	17	8.5
			50,000/=		
Never earned	8	4.0	Never spent	16	8.0

Majority 76(37.8%) of the respondents earned 10000-50000/= on average per month, 61 (30.4%) 50000-100,000/=, 24(11.9%) 100,000-150,000/=, 32(15.9%) 150,000/= and above, 8(4%) never earned.

A large proportion of respondents 93(46.5%) made HIV/AIDS related expenses of between 10,000-30,000/=, 41(20.4%) between 30,000-50,000/=, 17(8.5%) more than 50,000/=, 34(16.9%) spent less than 10,000/=, while only 16(8.0%) never made any expenses

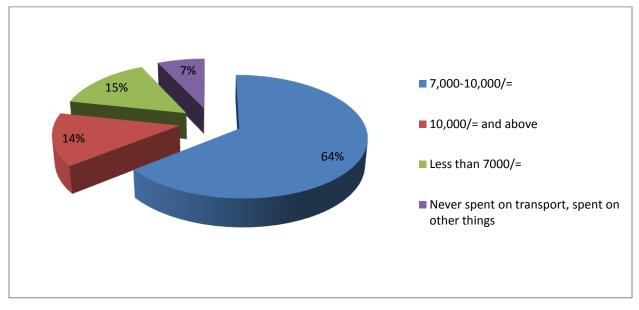


Figure 7: Expenditure on transport expenditure per visit (n=185)

Majority 119(64.3%) of respondents spent between 7000-10000/= on transport (to and from) every visit, 26(14%) 10000/= and above, 27 (14.6%) less than 7000/= and 13(7%) who never spent on transport but spent on other things

Majority 102(50.7%) of respondents reported motorcycles as a means of transport to the hospital, 44(21.9%) reported motor vehicles (Tax), 42(20.9%) reported bicycle and 13(6.5%) footed to the ART clinic.

Respondents were asked whether they always had enough supplies for their general life demands e.g. basic needs and the number of meals they got in a day.

Majority of the respondents 146 (72.6%) never always had enough supplies compared to 55 (27.4%) who reported always having enough supplies

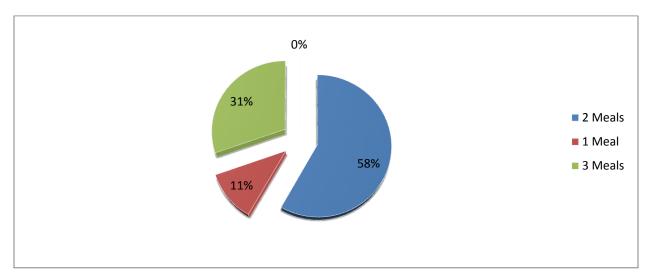


Figure 8: Showing number of meals per day among Respondents (n=201)

Majority 117(58.2%) reported always having 2 meals per day, 23(11.44%),1 meal per day and 61 (30.4%) 3 meals per day

4.4 INSTITIONAL CHALLENGES

In this study, efforts were made to find out the institutional challenges experienced by patients receiving ART at Kiryandongo general hospital ART clinic

Respondents were asked whether there were times they ever attended the clinic and some prescribed medications/ART were out of stock

Response	Frequency(N=201)	Percentage (%)
Yes	107	53.2
No	94	46.8

Majority 107(53.2%) of respondents reported at times failing to get all prescribed medication compared to 94(46.8%) who reported finding all the medication they needed most times.

Respondents were asked whether; they at times had to line long hours before being offered the services and how long they had to wait, how health workers treated them on visits, whether they ever had experienced difficulty receiving services due to inadequate medical infrastructure and how far it was from their homes to the clinic.

All respondents 201 (100%) were experiencing long hours of waiting before being offered the services.

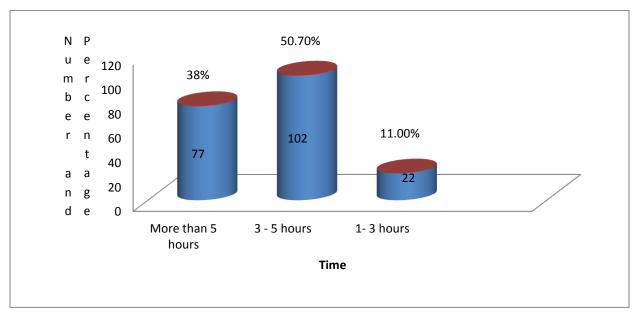


Figure 9; Showing how long respondents waited before being offered the services on a visit (n=201)

Majority 102(50.7%) waited for 3-5 hours, 77(38.3%) reported usually waiting for more than 5 hours, 22(11.0%) waited for 1-3 hour

Response	Frequency(n=201)	Percentage (%)
Treated me well	131	65.2
Rude to me at times	13	6.5
Impolite at times	41	20.4

16

Other responses

Majority 131(65.2%) reported being treated well, 41(20.4%) reported some health workers being impolite at times, 13(6.5%) reported staffs being rude to them at times and remaining proportion 16(8.0%) of respondents represented other responses

8.0

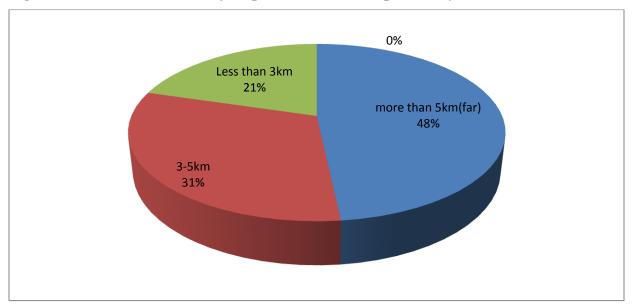


Figure 10: Distance travelled by respondents to the hospital every visit (n=201)

Majority 97(48 %) of the respondents lived more than 5km from the hospital, (Interpreted as far in this study) 63(31%) 3-5 km and 41 (21%) lived less than 3km from the hospital Majority 152 (75.6%) of respondents reported having faced no difficulty with space at the ART clinic while the remaining proportion 49(24.4%) reported inadequate space being a challenge at times

Response	Frequency(n=49)	Percentage (%)
-Lack of enough waiting space	12	24.5
-Absence of privacy at times	8	16.3
-lack of enough counseling and clerking rooms	23	47.0
-Other responses	6	12.2

Table 6; Specific responses about inadequate space at the hospital ART clinic

Majority 23(47%) reported lack of enough counseling and clerking rooms, 8 (16.3%) absence of privacy at times, 12(24.5%) lack of enough waiting space and 6(12.2%) reported other responses.

Respondents were asked after how long they had to come back for refill of ART, whether the clinic had ever closed without them being worked on and how often health workers provided ART services near them in villages or homes

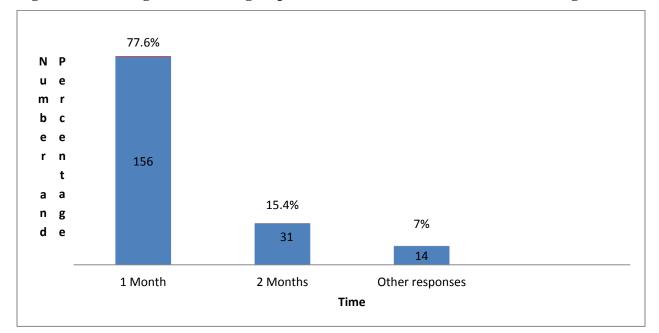


Figure 11: Showing after how long respondents had to come back for refill of drugs(n=201)

Majority 156 (77.6%) came back for refill of ART after 1 month 31 (15.4%) after 2 months, all respondents 201 (100%) reported the ART clinic having never closed without them being attended to and as well all respondents 201(100) reported receiving ART services only at the hospital

Information from key informants

In this study, two Health workers used as key informants (KI) were interviewed, one, a nursing officer who is the longest serving staff of the ART clinic since its opening in 2005 and the other the in-charge ART clinic.

Both KIs (2) reported the clinic having inadequate ART supplies only on a few occasions, while the stock outs of other medications which patients on ART may occasionally need like Antibiotics and Antifungal was a serious problem since they are out of stock most times. Some of other socio-economic and institutional challenges experienced by patients as reported by KIs included, stigmatization and discrimination, depression and stress, transportation costs, long waiting hours at the hospital, poor nutrition, difficult reproductive decision making, lack of family support among others

CHAPTER FIVE: DICUSSION, CONCLUSION AND RECOMMENDATIONS 5.0 INTRODUCTION

This chapter critically discusses the results of compiled data relating to objectives of the study, comparing and contrasting with the findings of other researchers elsewhere. Final conclusion is drawn and recommendations made.

5.1 DEMOGRAPHIC CHARACTERISTICS

The study findings revealed that majority 121 (60.2%) of the respondents were in the age bracket of 26-35 years. This is in agreement with (Kahana et al., 2015) who found out that although there were continued challenges with successful treatment of youth after HIV diagnosis, majority of HIV/AIDS patients enrolled on ART were in the youth age bracket of less than 35 years. The findings correspond with record review from the Kiryandongo hospital ART clinic where majority of the patients were in the youth bracket of 24-35 years (Kiryandongo hospital ART clinic records, 2019)

Half of the respondents 102(50.7%) had attained primary education; this could probably be attributed to low monthly income of most of the respondents who could probably find it difficult to afford scholastic materials and school fees. More than half of the respondents 113(56.2%) were peasants, this could be attributed to the fact that the catchment area for this hospital ART clinic is mainly rural communities in which subsistence farming is the main source of livelihood or this probably could be attributed to low education ability in rural areas making majority population resort to peasant farming.

The study attracted more females (64.2%) than male (35.8%) respondents probably because females are associated with a better health seeking behavior and are more concerned about their health than males who normally refuse their status or fail to disclose it. This is agreement with(Ham, Lin, Newman, Wijesooriya, & Kamb, 2015) who found out that, Women were more prone to accepting their condition as part of themselves and thus would easily seek health care compared to their male counterparts.

A significant proportion (35.3%) of the respondents were married, the married probably support each other while on treatment, this probably is not the case with the single, divorced and the widowed respondents whose percentages were lower. The largest proportion of the respondents (43.3%) were Banyoro, this is probably because the study area is located in the heart of Kiryandongo district which is part of the Bunyoro Sub-region that is inhabited by many tribes but mainly Banyoro. The largest proportion of respondents (71.6%) were residents in rural areas, this is probably because Kiryandongo district is mainly made up of rural communities with only 3 town councils

5.2 SOCIAL CHALLENGES

Whereas mechanisms to cope with HIV/AIDS have been put in place by different sectors, HIV/AIDS patients still experience significant stress and depression associated with the condition. The study findings showed that majority (77.6%) of the respondents were experiencing stress and depression as a result of their status and condition. This is probably because the condition being chronic and its association with complications, PLWHAS may lose hope of the future and additionally are burdened by stressors like daily life demands, the future of their families and bereavement for their lost or threatened loss of loved ones. In line with the findings, (Saadat et al., 2015) found out that HIV/AIDS was associated with Psychiatric manifestations like stress and depression and that finding out that one had HIV/AIDS leads to fear (of illness or dying), worry, concern about what other people will think, guilt, shame, embarrassment, anger and sadness after a diagnosis. Also in agreement with this study are Sheldon et al. (2014) who found out that stress and HIV/AIDS were inseparable and that an accumulation of stressful negative life events over several years predicted worse AIDS-related outcomes.

Study findings showed that majority (75.1%) of the respondents had faced stigma and discrimination at one point as result of the HIV/AIDS condition from mainly community (60%), friends (21%) family (11%) and workmates (9%). This could probably be attributed to the perceived and real effects of the disease onto the lives of infected individuals, the condition being highly fatal in long term and its high risk of transmission. According to (Avert, 2017), there is a cyclical relationship between stigma and HIV; most people with HIV/AIDS experience stigma and discrimination and this makes them more marginalized. Some people living with HIVAIDS and other key affected populations are shunned by family, peers and the wider community, while others face poor treatment in educational and work settings, erosion of their rights, and psychological damage and these all negatively affect adherence to ART and consequently, poor outcome of treatment (Avert, 2017).

According to (Neuman & Obermeyer, 2013) some HIV/AIDS patients are isolated by community and their families for fear of contamination by direct contact through sharing utensils, clothes and direct body contact.

This study findings revealed that the community discriminated HIV/AIDS patients most (60%). This can probably be explained by this same study findings which indicated that majority of the respondents (71.6%) lived in rural communities which are best known to have malevolent rumors, misconception and negative beliefs about HIV/AIDS. The findings are in agreement with (Oduro & Otsin, 2013) who in their study found out that that fear and secrecy associated with the HIV/AIDS was majorly due to stigmatization and discrimination and that once one was identified to be suffering from HIV/AIDS, he/she was at risk of suffering a number of public sanctions including discrimination abuse and neglect which were more evident in rural communities and highly affected patients' adherence to treatment.

On assessment of the outcome of HIV sero positive disclosure, Majority (65%) had disclosed their status to their spouse, friends and community. This is in disagreement with Tesfaye et al., 2017 whose study findings indicated that the disclosure of HIV positive sero - status were very low even after initiation of HAART and several factors affected sero-positive status disclosure including educational status, WHO clinical staging at start of HAART, length of time stayed on HAART, presence of co-morbidities, presence of any clinical symptoms for HIV/AIDS and the general or overall quality of life status. The disagreement is probably due to the limitation of the study to only patients above 18 years of age.

More than half of the respondents of those who had disclosed their HIV/AIDS status,38% reported being gossiped and ridiculed, other respondents reported people saying that they had had multiple sexual partners and that they had lived a reckless life. In line with the above findings, (Drummond et al., 2015) reported that that communities think that persons who have contracted HIV must have lived a promiscuous life and therefore direct different forms of prejudice towards these patients and that these discriminatory attitudes toward PLWHA are mainly due to negative public perceptions about HIV/AIDS and local cultural beliefs

HIV/AIDS is not without associated sexual challenges, the study findings revealed that majority (60.2%) of the respondents had experienced sexual problems due to their HIV/AIDS condition, a significant percentage (26%) of whom had stopped having sex with their partners while other respondents reported having divorced their partners or lost their boyfriend/girlfriends. In

agreement with this study, (Sandfort, Bos, Knox, & Reddy, 2016) reported that sexual problems were common among HIV/AIDS patients and that in some cases, it led to total avoidance of sex. Majority of PLWHAS no longer had sex for fear of infecting their HIV sero negative partners while others had seized relationships with their partners.

5.3 ECONOMIC CHALLENGES

In resource-limited settings, illness can impose a major financial burden on patients and their families. It was evident from this study findings that all study participants 201 (100%) were experiencing some degree of financial burden associated with the condition (HIV/AIDS) with examples of reported expenditures being on transport (63.2%), food (15%) and other expense (22%). This could be attributed to the fact that being chronic HIV/AIDS requires regular care and treatment aimed at keeping the viral load down and to avoid opportunistic infections which strongly retard the progress of these patients . In line with the above findings, Kose et al.,2016 in their study among PLWHAS found out that more than half of the respondents reported difficulty in meeting the costs of daily living and that most of the respondents (61%) did not have any medical insurance or disability pension yet clinic visits, sometimes medications and some other services cost money which meant that patients faced harsh financial circumstances.

The study finding revealed that majority (63.2%) of the respondents were spending on transport with the remainder spending on food (15%) and other expenses (22%). The study findings also further revealed that almost half (46.3%) of the respondents spent Uganda shillings 10,000-30,000 on HIV/AIDS related expenditures on a Monthly basis. The above expenditure is equivalent to more than a half of what majority (37.8%) of respondents earned on average per month (Ug.sh. 10,000-50,000/=) which means that a significant proportion of the respondents were spending more than a half of their income on HIV/AIDS related expenses. This concurs with the study carried out in Tanzania which found out that patient costs pose a challenge in accessing ART for people living with HIV especially in sub-Saharan Africa and that out of pocket costs among respondents in this study were up \$ 50 per year which made patients less likely to seek regular health care unless they were in dire need and this even worsened the expenditure (Mnzava, Mmari, & Berruti, 2018).

Transport expenses were the most pronounced as reported by majority (63.2%) of the respondents and almost a half of these respondents (45.8%) spent on motorcycle charges to and from the hospital. Motorcycles, the reported means of transport by majority of the respondents

together with motor vehicle (16.9%) are expensive for the low income earners who formed the majority of the respondents. It therefore possible that difficulties in accessing adequate income to cater for transport expenses to and from the ART clinic affects utilization of offered services.

This concurs with the study carried out in South Africa which revealed that while ART for HIV/AIDS was made free of charge in order to increase access for poorer patients and promote adherence, non-drug costs of obtaining treatment continue to significantly limit access to treatment citing transport as an example where ninety-one per cent (91%) of respondents paid for transport to attend the ART clinic (Rosen et al., 2016)

HIV/AIDS patients do not live in isolation from the rest of the community and therefore face expenses associated with basic needs of life. Indeed, the study findings revealed that majority (72.6%) did not always have enough supplies for their basic needs. This probably can be attributed to the fact that majority of the respondents interviewed were peasants with very low monthly income. The findings concur with Taraphdar et al., 2016 who stated that patients with lower income levels had difficulties with meeting daily life economic demands which in the end led poor to adherence to ART

According to(Jordan et al., 2017), most HIV/AIDS patients on ART do not receive nutritional support from the ART clinics that they attend even when access to a balanced diet is perceived as a key to improved health in the comprehensive AIDS care package. In this study, majority (58.2%) of the respondents received only 2 meals per day. Poor and inadequate nutrition increases the susceptibility to opportunistic infection, malnutrition, and may accelerate poor adherence and progress of HIV/AIDS.

5.4 INSTITUTIONAL CHALLENGES

The role of health institutions is pivotal in regard to adherence to ART among PLWHAS (Azia et al., 2016). The study findings showed that more than half (53.2%) of the respondents had at times failed to get all prescribed medication/ART during their visit to the ART clinic. This can probably be attributed to inadequate medical supplies from the central medical stores or overwhelming HIV/AIDS patient numbers at the hospital. In agreement with the findings by (Mori & Owenya, 2014)in their study in Kinondoni District in Tanzania found out that Stock-out of antiretroviral drugs and other occasionally required medications was reported in 16 out of the 20 ART clinics causing HIV/AIDS patients to change their ART regimens often which increases the risk of the emergence of drug-resistant HIV strains. (Windisch, Waiswa, Neuhann, Scheibe,

& de Savigny, 2011) in their study in Uganda also concur with the above, they explain that ART stock outs and other medication shortages were still a huge challenge in Ugandan ART clinics and this had an effect on primary care in general. A significant percentage (46.8%) of the respondents that had always found the medication/ART available probably represent a proportion of patients who had until the time of the study been visiting the clinic for only HAART medications whose stock out only occur occasionally according to the ART clinic Incharge (Key informant in this study)

There was a time lag between arrival of the respondents and receiving of medical attention/complete reception of services. The study findings showed that all the respondents 201(100%) were experiencing long hours of waiting before being offered the services with more than a half (50.7%) of the respondents waiting for up to 5 hours before fully receiving the services. This probably could be due to few staffs and integrated ART services of health education, counseling, regular consultation, laboratory workup, records and file retrieval and sometimes the need for a specialist consultation. (Orner et al., 2014)are in agreement with this study findings, in their study at 3 ART clinics in Uganda, they found out that there was heavy congestion with a long waiting time at all the ART clinics and that this was a challenge that could affect patient satisfaction and retention. In their study, they attributed patient load as one of the factors leading to a long waiting time but also stressed that the number of providers seen by a patient on each visit was also a major bottleneck to reduction of waiting time at the ART clinics with supportive findings where patients in all the three clinics saw three to four providers on each visit which kept them longer at the clinics on each visit.

Whereas majority (65.2%) of the respondents in this study reported being treated well by health care staffs during their visits to the ART clinic, however, a significant proportion (34.7% in total) of the respondents demonstrated their dissatisfaction with the way clinic staffs were occasionally treating them during visits with some reporting staffs being at times impolite or rude to them. This probably implies that some patients experienced some difficulty dealing with some health workers at the clinic which probably affects their adherence to ART and utilization of the other services at the ART clinic. In agreement with this study, Jonathan (2016) in his study in Nigeria found that in the ART clinics, the nurses, councilors and Doctors often embraced HIV/AIDS patient and also welcomed clients with a smile and had a welcoming attitude during the provision of the services. However, his study findings also revealed that behaviors and attitudes

of some health staff were very poor and contrary to ethics of practice citing some examples of Poor Communication skills, condemnation and Abusive behavior, poor skills in controlling Clients and discriminatory treatment as reported by some of the study respondents. Such behaviors and attitude could have a negative impact of adherence to ART and health seeking behavior of patients

In this study, majority 152 (75.6%) of the respondents were satisfied with the infrastructure of the hospital ART clinic with only 49 (24.4%) of the respondents reporting inadequate space being a challenge at times, significant proportion 23(47%) of whom reported lack of enough counseling and clerking rooms as the main problem. The researcher observed that the clinic had only one counseling room and 2 consultation rooms. (Patrice et al., 2017) concurs with these study findings with their study whose results revealed that concerns about confidentiality and privacy in ART clinics among during PLWHAS were due to inadequate and limited space at the health facilities which is a de-motivating factor to Patients towards regular attendance of the ART clinic and adherence to ART. They further noted that Inadequate or lack counseling and clerking rooms leads to poor or lack of privacy and confidentiality which greatly affect the quality of the services offered to HIV/AIDS patients and could determine whether a patient adheres or regularly attends the clinic.

The study findings revealed that majority (77.6%) of the respondents received a prescription for 1 Month compared to 15.4% who were receiving a prescription for 2 months. This implies that patients have to frequent the hospital for ART refill and other services at least every month and this not only has implications on quality of institutional service delivery but also on patients' expenditure. (Tsitsi et al., 2017) in their study suggested that reduction of ART clinic visits and ART medication pick-ups may improve clinical outcomes and that It's a viable option to relieve health systems and reduce burden of care for PLWHAS. However, they stress that the above should focus on stable patients who are virally suppressed, tolerant to their drug regimen and fully adherent in whom ART refills interval can be even up to 6 months. This however may not be very practical in this study setting where there are occasional medication shortages which would be better solved by distributing available medications equitably among patients and reducing intervals between clinic visits in order to avoid scenarios where one patients returns home with long tern medication and another goes with no medication at all.

According to (Mukherjee et al.,2016), community-based ART programs have achieved remarkable results in expanding access to ART in resource-poor settings. These programmes have also promoted retention in care and catalyzed efforts to build health systems that respond effectively to the complete burden of disease. The study finding suggested otherwise in relation to the above, all respondents (100%) were receiving ART services only from the hospital ART clinic on a full time basis. In areas where Community based ART services have been rolled out, they have proved their worth through decentralization of services and excellent retention of patients through the application of an accompaniment model that engages community health workers in the delivery of medicines, the provision of social support and education and the linkage between communities and clinics(Mukherjee et al.,2016). It's probably the factor of limited finances that has delayed the initiation of this program in this particular study area and it will be something worth undertaking in the future

CONCLUSIONS

Socio-economic and institutional challenges are significant bottlenecks among HIV/AIDS patients and should be addressed. In this study Social challenges such as, stigma, discrimination depression, stress, lack of or poor family support, sexual problems, disclosure of sero-positivity affected patients receiving ART treatment at the hospital ART clinic.

Economic challenges such as; low monthly income with high expenditure on transport, food and other basic needs and other nonspecific expenses were reported among respondents and these had a bearing on how they adhere to ART

Study findings revealed that; Medication and sometimes ART stock outs, lack of enough consultation and counseling rooms, long waiting time, poor attitude of some staff and lack of community ART services were some of the institutional challenges that were affecting patients receiving ART at the Kiryandongo hospital ART clinic,

RECOMMENDATIONS

In reference to the study findings above, the researcher has made the following suggestions in a bid to ensure enhancement of quality of care for HIV/AIDS patients

To the government of Uganda

The government should continue to launch more educational programmes to allow dissemination of accurate facts about HIV/AIDS in order to eliminate misconceptions about HIV/AIDS in order to tackle stigma and discrimination and related social challenges

34

There should be substantial increment in funding of HIV/AIDS care to address challenges like medication stock outs, understaffing, inadequate infrastructure etc.

To Kiryandongo hospital

The hospital administration and health staffs should mobilize the community to form HIV/AIDS community initiatives/based organizations and social support groups for fighting stigma and motivational strategies and continuous counseling for positive living should also be done

The HIV/AIDS patients should be given appointment dates and specific hours of the day when to come to the clinic in order to address long waiting hour at the clinic

Community sensitization using motivation advocacy messages should also be done in order to increase the number of HIV/AIDS patients on ART

To the community

Communities should be fully involved in initiation and implementation of health programmes Communities should also be involved in identifying traditional practices that worsen social and economic challenges among HIV/AIDS patients.

REFERENCES

- Avert. (2017). Global HIV and AIDS statistics | AVERT. Avert. https://doi.org/10.1596/1813-9450-6869
- Azia, I. N., Mukumbang, F. C., & Van Wyk, B. (2016). Barriers to adherence to antiretroviral treatment in a regional hospital in Vredenburg, Western Cape, South Africa. Southern African Journal of HIV Medicine. https://doi.org/10.4102/sajhivmed.v17i1.476
- Bigna, J. J. R., Plottel, C. S., & Koulla-Shiro, S. (2016). Challenges in initiating antiretroviral therapy for all HIV-infected people regardless of CD4 cell count. *Infectious Diseases of Poverty*. https://doi.org/10.1186/s40249-016-0179-9
- Colombini, M., James, C., Ndwiga, C., Team, I., & Mayhew, S. H. (2016). The risks of partner violence following HIV status disclosure, and health service responses: Narratives of women attending reproductive health services in Kenya. *Journal of the International AIDS Society*. https://doi.org/10.7448/IAS.19.1.20766
- Drummond, I., Pinto, J. A., Mesquita, J. D., Schall, V. T., Mutahar, R., Masoudnia, E., ... Norr, K. F. (2015). Global HIV & AIDS statistics — 2018 fact sheet. *Indian Journal of Sexually Transmitted Diseases and AIDS*. https://doi.org/27367846293461
- Ham, D. C., Lin, C., Newman, L., Wijesooriya, N. S., & Kamb, M. (2015). Improving global estimates of syphilis in pregnancy by diagnostic test type: A systematic review and metaanalysis. *International Journal of Gynecology and Obstetrics*. https://doi.org/10.1016/j.ijgo.2015.04.012
- Hoffmann, M., Maccarthy, S., Batson, A., Crawford-Roberts, A., Rasanathan, J., Nunn, A., ... Dourado, I. (2016). Barriers along the care cascade of HIV-infected men in a large urban center of Brazil. AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV. https://doi.org/10.1080/09540121.2015.1062462
- Jordan, M. R., Penazzato, M., Cournil, A., Vubil, A., Jani, I., Hunt, G., ... Bertagnolio, S. (2017). Human Immunodeficiency Virus (HIV) Drug Resistance in African Infants and Young Children Newly Diagnosed With HIV: A Multicountry Analysis. *Clinical Infectious Diseases*, 65(12), 2018–2025. https://doi.org/10.1093/cid/cix698
- Kagee, A. (2012). Addressing psychosocial problems among persons living with HIV. *African Journal of Psychiatry*. https://doi.org/10.4314/ajpsy.v15i6.53
- Kahana, S. Y., Fernandez, M. I., Wilson, P. A., Bauermeister, J. A., Lee, S., Wilson, C. M., &

Hightow-Weidman, L. B. (2015). Rates and correlates of antiretroviral therapy use and virologic suppression among perinatally and behaviorally HIV-infected youth linked to care in the United States. *Journal of Acquired Immune Deficiency Syndromes*. https://doi.org/10.1097/QAI.000000000000408

- Kalichman, S. C. (2014). The Causes and Consequences of HIV-Related Enacted and Internalized Stigma: a Comment on Takada et al. Annals of Behavioral Medicine. https://doi.org/10.1007/s12160-014-9620-0
- Kalichman, S. C., Hernandez, D., Kegler, C., Cherry, C., Kalichman, M. O., & Grebler, T. (2015). Dimensions of poverty and health outcomes among people living with HIV infection: Limited resources and competing needs. *Journal of Community Health*. https://doi.org/10.1007/s10900-014-9988-6
- Kharsany, A. B. M., & Karim, Q. A. (2016). HIV Infection and AIDS in Sub-Saharan Africa: Current Status, Challenges and Opportunities. *The Open AIDS Journal*. https://doi.org/10.2174/1874613601610010034
- Mnzava, T., Mmari, E., & Berruti, A. (2018). Drivers of Patient Costs in Accessing HIV/AIDS Services in Tanzania. Journal of the International Association of Providers of AIDS Care (JIAPAC), 17, 232595821877477. https://doi.org/10.1177/2325958218774775
- Mori, A. T., & Owenya, J. (2014). Stock-outs of antiretroviral drugs and coping strategies used to prevent changes in treatment regimens in Kinondoni District, Tanzania: A cross-sectional study. *Journal of Pharmaceutical Policy and Practice*. https://doi.org/10.1186/2052-3211-7-3
- Neuman, M., & Obermeyer, C. M. (2013). Experiences of stigma, discrimination, care and support among people living with HIV: A four country study. *AIDS and Behavior*. https://doi.org/10.1007/s10461-013-0432-1
- Njuguna, W. (2010). ADHERENCE TO HIGHLY ACTIVE ANTIRETROVIRAL THERAPY AMONG PATIENTS IN THE THERAPY PROGRAMME, NAMIBIA Supervisor : Dr Brian Van Wyk March 2010.
- Oduro, G. Y., & Otsin, M. (2013). Perspectives on HIV/AIDS stigma and discrimination: voices of some young people in Ghana. *Sex Education*, *13*(2), 146–158. https://doi.org/10.1080/14681811.2012.678941
- Orner, P., de Bruyn, M., Cooper, D., Gomez-Suarez, M., Figueiredo, R., Duncan, S., ... Castilla,

J. (2014). IUD use in HIV-positive women. *Contraception*, 14(1), 34. https://doi.org/10.7448/IAS.19.6.21264

- Phillips, A. N., Stover, J., Cambiano, V., Nakagawa, F., Jordan, M. R., Pillay, D., ... Bertagnolio, S. (2017). Impact of HIV drug resistance on HIV/AIDS-associated mortality, new infections, and antiretroviral therapy program costs in Sub-Saharan Africa. *Journal of Infectious Diseases*, 215(9), 1362–1365. https://doi.org/10.1093/infdis/jix089
- Reda, A. A., & Biadgilign, S. (2012). Determinants of Adherence to Antiretroviral Therapy among HIV-Infected Patients in Africa. *AIDS Research and Treatment*. https://doi.org/10.1155/2012/574656
- Saal, W., & Kagee, A. (2012). The applicability of the Theory of Planned Behaviour in predicting adherence to ART among a South African sample. *Journal of Health Psychology*. https://doi.org/10.1177/1359105311416875
- Sabet Sarvestani, A., Bufumbo, L., Geiger, J. D., & Sienko, K. H. (2012). Traditional Male Circumcision in Uganda: A Qualitative Focus Group Discussion Analysis. *PLoS ONE*, 7(10). https://doi.org/10.1371/journal.pone.0045316
- Sandfort, T., Bos, H., Knox, J., & Reddy, V. (2016). Gender Nonconformity, Discrimination, and Mental Health Among Black South African Men Who Have Sex with Men: A Further Exploration of Unexpected Findings. *Archives of Sexual Behavior*, 45(3), 661–670. https://doi.org/10.1007/s10508-015-0565-6
- Sevelius, J. M., Patouhas, E., Keatley, J. G., & Johnson, M. O. (2014). Barriers and facilitators to engagement and retention in care among transgender women living with human immunodeficiency virus. *Annals of Behavioral Medicine*. https://doi.org/10.1007/s12160-013-9565-8
- U.S. Department of Health & Human Services. (2017). Global Statistics | HIV.gov.
- Uganda AIDS Comission. (2017). Uganda Hiv / Aids Country Progress Report July 2016-June 2017. Kampala, Uganda.
- Uganda Ministry of Health. (2015). *The HIV and AIDS Uganda country progress report 2014*. 73.
- UNAIDS, W. (2017). UNAIDS FACT SHEET REGIONAL HIV STATISTICS 2016.
- Vernooij, E., Mehlo, M., Hardon, A., & Reis, R. (2016). Access for all: contextualising HIV treatment as prevention in Swaziland. *AIDS Care*, 28(sup3), 7–13.

https://doi.org/10.1080/09540121.2016.1178954

Windisch, R., Waiswa, P., Neuhann, F., Scheibe, F., & de Savigny, D. (2011). Scaling up antiretroviral therapy in Uganda: Using supply chain management to appraise health systems strengthening. *Globalization and Health*. https://doi.org/10.1186/1744-8603-7-25

APPENDIX I: STATEMENT OF CONSENT FOR THE RESPONDENTS

I	have been requested to
participate in the above research study. I ha	we understood the main purpose of the study to the
best of my knowledge and based on the way	the researcher has explained to me. I have accepted
to participate in the study.	
Signature/Thumbprint	Date
Researcher/Research	
Assistant	Date

APPENDIX II: DATA COLLECTION TOOL-QUESTIONNAIRE

Study Title: Socio-economic and institutional challenges experienced by patients receiving ART at Kiryandongo general hospital

Confidentiality: I am **ATUKUNDA JONATHAN**, a fifth year medical student at Kampala International University – Western Campus carrying out the above research. The information rendered to me will be accorded with utmost confidentiality, your participation is voluntary, and you can choose to participate or not.

Instruction: please complete the questions below by ticking in the boxes provided and filling in the spaces against each question

Section A: Demographic characteristics

1. Age (in years)	(a) 18-25 (b) 26 – 35 (c) 36 and above
2. Gender (a) Male	(b) Female
3. Tribe; (a) Alur	(b) Munyoro (c) Acholi d) Langi
(e) Others (Specify)	
4. Level of Education (a) Prim	ary (b) Secondary (c) Tertiary
(d) None	
5. Occupation (a) Civil servan	t (b) Business person (c) Peasant
(d) Not employe	ed
6. Marital status (a) Married	(b) Single (c) Widowed (d) Divorced

7. Religion; (a) Protestant (b) Catholic (c) Muslim	
Others (Specify)	
8. Place of residence (a) Urban (b)Sub-urban (b) Rural	
Section B; Social challenges experienced by patients receiving ART at Kiryandongo	
general hospital	
9. Have you experienced any stress related to the condition (HIV/AIDS) or its management?	
(a) Yes (b) No	
10. Have you face any discrimination due to your HIV status or your HIV/AIDS condition?	
(a) Yes (b) No	
(i) If yes, by who?	
(a) Close family member(b) Friends(c) Community	
(d) Workmates	
11. Does your spouse, family and people in community know about your HIV status?	
(a) Yes (b) No	
If yes, how do they treat you or react towards your HIV/AIDS condition?	
(a) They gossip and redicule me (b) Treat me well	
(c) People say I had multiple sexual partners	
(d) People say I was reckless with my life	
(e) Other (specify)	
12. Have you faced any sexual problems ever since you initiated treatment?	
(a) Yes (b) No	
(i) If yes, which problems?	
(a) My partner has divorced me	
(b) I have stopped having sex with my spouse (b) I have lost my girl/boy friend	
(c) Others (specify)	
13. What are your feelings about being seen on the ART clinic or taking ART	
(a) I feel people think it's my fault (b) I feel people think I lived a promiscuous life	
(c) I feel people think I have lost hope (d) other responses	
14. Do you get family support?	

(a) Yes		(b) No	
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Section C: Economic challenges experienced by patient receiving ART at Kiryandongo general hospital

14. Does this condition stretch you and family financially?
(a) Yes (b)
If yes, how?
a) I spent a lot of money on transport
b) I spend money on food
(a) Other expenses
15 (i) What is your average income per month?
(a) 10,000- 50,000/= (b) 50,000-100,000/= (c) 100,000-150,000/= (c) 100,000/= (c) 100
(d) > 150,000/= (e) I don't earn
(ii)What is your average expenditure per month?
(a)< 10,000/= (b) 10,000- 30,000/= (c) $30,000-50,000/=$ (d) > $50,000/=$ (d)
(e) I don't spend others (specify)
(iii) How much do you spend on transport on every visit?
(a) 7,000- 10,000/= (b) > 10,000/= (c) $<7,000/=$
(d) I don't spend
16. Do you always get enough supplies for your general life demands for example drugs soap,
food etc.?
(a) Yes (b) No
17. Are there prescribed medication(s) stock outs sometimes other than ART?
(a) Yes (b) No
18. (i) Do you get any nutritional support from the ART clinic? (a) Yes b) No
(ii) How many meal(s) do you eat a day? (a) 1 Meal (b) 2 Meals
(c)3 meals
Section D: Institutional challenges experienced by patients receiving ART at Kiryandongo
general hospital
19. Are there times when prescribed medication / ART is lacking?
(a) Yes (b) No
20. Do you at times have to lineup for long hours for medication/ART on your clinic visits?
(a) Yes (b) No

If yes, approximately how long do you have to wait before being worked on?
(a) More than 5 hours (b) 3-5 hours (c) 1-3 hours
21. How do the health workers in this clinic treat you on your clinic visits?
(a) They treat me well (b) They are rude to me
(c) They at times are impolite to me
(f) Other responses (specify)
22. (i) How far is it from your home to this hospital?
(a) < 3 km (b) 3-5 km (c) > 5 km (c)
23. Have you faced any difficulty due to inadequate space in this hospital during your regular
visits?
(a) Yes (b) No
If yes, please explain, how difficult it has been
24. After how long do you have to come back for refill of drugs medication/ART?
(a) 2 weeks (b) 1 month (c) More than 1 Month

APPENDIX III: INTRODUCTORY LETTER



P O BOX 71, ISHAKA UGANDA Tel: +256 200923534 www.kiu.ac,ug

Kiryand

OFFICE OF THE DEAN FACULTY OF CLINICAL MEDICINE & DENTISTRY Accord hum the necessary assortance

19/03/2019

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

RE: ATUKUNDA JONATHAN (BMS/0001/141/DU)

The above named person is a fifth year student at Kampala International pursuing a Bachelor of Medicine, Bachelor of Surgery (MBChB) Programme), O. Box 128, Kigumba

He wishes to conduct his student research in your hospital.

Topic: Social economic and institutional challenges experienced by Receiving ART at Kiryandongo General Hospital

Supervisor: Dr. Kiggundu Thomas

Any assistance given will be appreciated ING 0 Yours Sincerely, 2 1 MAR 2019 5-0 Dr. Akib Surat

Deputy Executive Director/Assoc Dean I

44

"Exploring the Heights" Assoc. Prof Ssebuufu Robinson, Dean (FCM & D) 0772 507248 email: rssebuufu@gmail.com Dr. Akib Surat Associate Dean FCM & D) 0752574699email: doctorakib@yahoo.com

APPENDIX IV: MAP OF UGANDA



APPENDIX V: MAP OF KIRYANDONGO DISTRICT

