THE BENEFITS AND LIMITATIONS OF INTENSIVE ADHERENCE COUNSELLING:
A CASE STUDY OF PLWHAs IN LUWERO HEALTH CENTRE IV ART CLINIC

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DECLARATION

I, NABACHWA JANE hereby declare that this dissertation is a product of my efforts and has not been presented to any institution before for an academic reward.

Signature: 

Date: 27/11/2018
APPROVAL

This dissertation has been submitted to Makerere University in partial fulfilment of the requirements for the award of a Bachelors of Social Work and Social Administration with the approval of:

ASSOC. PROF. EDDY. J. WAJAKIRA.

ACADEMIC SUPERVISOR

[Signature]

DATE 27/11/2018
DEDICATION

This dissertation is dedicated to MR. MUWANGA HENRY BOGERE and MS. NABULO ZAM.

For even a journey of a thousand miles starts with a step.
ACKNOWLEDGEMENT

I humbly extend my sincere gratitude to the Almighty for seeing me through this.

I extend my sincere appreciation to my dear parents Mr and Mrs Muwanga for the unconditional love given to me. For all the support, more than morale and financial. My entire family for the sacrifices they have had to make to see to the completion of my Education. May God bless them for me

I also extend my gratitude to my academic supervisor for the wonderful support offered through out to the end

I would be a liar to say that I came to the completion of this project without support from friends. I therefore send my regards to all of them that sacrificed their time and rendered to help me.

It was such a long journey. I thank myself too.
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Figure 1 Relationship between cumulative adherence counselling hours and antiretroviral adherence 9
The study analysed the benefits and limitations of intensive adherence counselling for people living with HIV in Luwero Health Centre IV ART clinic. It was guided by specific objectives which included; explanation of the meaning of intensive adherence counselling to PLWHAs and health workers; finding out the role of IAC towards adherence to ART, understanding the experiences of clients on IAC, including the benefits of intensive adherence counselling to the people living with HIV and AIDS and the factors hindering its success. Comparison of experiences of patients on IAC and those that were not on IAC was also made. Data was collected using a case study design, underpinned by use of qualitative methods. The study comprised of 10 participants who included seven case study participants (PLWHAs) of which five participants had or were still receiving IAC while two were not on IAC, but had received ordinary counselling services that patients on ART received. Other participants included 3 Key Informants (a social worker and two counsellors). In-depth interviews and key informant interviews were used to collect data from the study participants.

The study's findings included IAC being described as a program that was recommended by the ministry of health in a bid to see to suppression of each and every HIV patient, a description that was rather given by the health workers at the ART clinic, Luwero Health Centre IV. the major role of IAC was to ensure suppression by the patient, where suppression meant a viral load less than 1000 copies/ml. Experiences of all the patients interviewed were obtained. The increased use of IAC as revealed by counsellors showed that suppression of the virus was becoming common after being on IAC, and there was vivid behavioural modification among the clients, this was not only drawn from the views from the health workers but from the clients’ experiences as well when they told their stories, which came from different dimensions but rounded up to almost being the same, most especially when it came to the compromises. On the downside, IAC was limited by factors such as poverty (being the major barrier), shortage of manpower, traditional beliefs and less male involvement. The study related to a number of other studies like that of Nina (2012), Gugulethu (2007), Sentebale (2017), Michael (2011) and more.

Given the above findings, it is recommended that in order for clients to benefit from IAC, they need to be provided with necessary information about the IAC concept. Financial empowerment would also be key for example provision of transport to those that have to move long distances to
come for the IAC sessions, male involvement and enhancement of components that make up
IAC would also be so instrumental especially in differentiating it from other forms of
counselling. Health workers would have to create more time with their clients and keep up the
spirit of seeing to their clients’ wellbeing.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>HIV</td>
<td>Human Immune Virus</td>
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<td>AIDs</td>
<td>Acquired Immune Deficiency syndrome</td>
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<td>IAC</td>
<td>Intensive Adherence Counselling</td>
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<td>ARVs</td>
<td>Anti-Retrovirals</td>
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<td>ART</td>
<td>Antiretroviral Therapy</td>
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<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
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<td>PLWHAs</td>
<td>People Living with HIV and AIDS</td>
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<td>VL</td>
<td>Viral Load</td>
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<td>ML</td>
<td>Millilitres</td>
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CHAPTER ONE: INTRODUCTION

1.1 Introduction
The chapter presents the background of the study, the problem statement, and purpose of the study, objectives, and research questions, scope of the study, justification of the study and definition of key terms.

1.2 Background of the study
HIV/AIDS is a major public health problem and cause of trauma in most parts of Africa. Global statistics according to UNAIDS (2018) indicate that 36.9 million people are living with HIV/AIDS world over. Of these, 2.1 million are children below fifteen years of age. 1.8 million Become newly infected in 2016 and there are normally about 5,000 new infections each new day. Seventy percent (70%) of people living with HIV/AIDS knew their status in 2016. This is partial achievement of the 2nd of 90-90-90 UNAIDS strategy by 2020. However, 35 million people passed on due to the pandemic and sub-Saharan Africa has the greatest number of positives. “The vast majority of people living with HIV are in low and middle income countries.” (UNAIDS 2016, page 2). Sixty-nine percent (69%) of the world’s population of people living with HIV (PLWHAS) is in Sub-Saharan Africa, with South Africa ranked number one in high HIV/AIDS rates (World Bank, 2011) and 70% of these that have died were in Africa as well.

According to Cleophas et al. (2018) antiretroviral care is a lifelong commitment and a push with adherence counselling wouldn’t do any harm. This is majorly because antiretroviral therapy (ART) and highly active Antiretroviral Therapy (HAART) have long term effects. UNICEF (2014) however revealed that 10 million people were receiving ART by the end of 2012. More success of ART will depend on improving our understanding of when to initiate ART therapy, creating continuity of care, and ensuring high treatment adherence (Cohen, 2011 and Tanser, 2013)

Adherence is the extent to which a person uses medication according to medical recommendations, inclusive of trimming, dosing and consistency. Without good adherence, treatment failure is bound to happen and this leads to avoidable HIV-related morbidity and mortality. Additionally, poor adherence increases the risk of developing resistant HIV strains and spreading the virus to other
(Press, 2002). Adherence patterns therefore influence an individual’s treatment response and future treatment options, hence the need to improve and sustain ART adherence. People living with HIV and their care providers often face challenges in ensuring good adherence. Given these difficulties effective, efficient, feasible and acceptable interventions to enhance ART adherence are urgently needed to ensure success, clinical and financial sustainability of the global ART scale-up (USAID, 2018 and Sentebale, 2017).

Uganda Adopted HIV viral load monitoring as the gold standard for measuring the efficacy of ART in HIV positive clients. The main goal of ART is to achieve suppression which is in line with the 3rd of the 90-90-90 strategy by 2020. To ensure viral load suppression, intensive adherence counselling (IAC) was introduced in Uganda by the Infectious Disease Institute in Makerere University, adopted by the Ministry of Health and mentorships were done at Health centre IVs like Orum, Luwero and hospitals like Mulago. (Sustain, 2016).

1.3 Problem statement
HIV/AIDS is a serious pandemic in Africa, Uganda and in such districts as Luwero. “Developing countries such as Kenya and Uganda have established comprehensive programmes for HIV/AIDS care and support, but there remains a large gap between the of people who actually need drugs and other medical support and the number who have access to them. Anomalies of ART adherence is known to result in the rapid development of drug resistance…” (Quinn, 2003 page 37).

The government of Uganda adopted the WHO’s recommendations and the IAC program was implemented as stipulated by MoH guidelines (2016); to perform viral load measurement for all adults and children that have been receiving ART for at least six months. Individuals with viral load above 1000 copies/ml, undergo three adherence counselling sessions each one month apart, after which a viral load test is repeated. If the post-IAC viral load is suppressed, the clients continue with the current treatment and repeat the viral load test after one year. If viral load is unsuppressed, clients are considered for a switch to a second line regimen after ensuring that adherence issues have been addressed. Resistance testing is only done for those who have suspected failure on a second line regimen before switch to a third regimen (Nina, 2012). Immediate initiation on ART (at diagnosis) was therefore recommended in order to see more success in viral load suppression.
The young people have however continuously exhibited lower rates of ART adherence and viral suppression (Danel, et al 2005). The same report indicates that this is because young people often face multiple psychosocial and other barriers to adherence. Intensive adherence counselling is however a program that is run for everyone that is not suppressing.

Infectious Disease Institute (2015) encourages enrolment on IAC especially for the young people, adolescents but there are barely any follow-ups. The most recent survey which was carried out in late 2015 by Bakalu (2015), indicates that the HIV/AIDS prevalence rate in Luwero increased from 9.7% to 10.3% the AIDS indicator survey was carried out at Kasana –Luwero catholic diocese

There is need to examine the challenges, and benefits that have come as a result of intensive adherence counselling in health centre IVs in Uganda. Luwero health Centre if ART clinic is among these, and specific concern is to be put on the role of intensive adherence counselling, the effects of intensive adherence counselling, the benefits resulting from intensive adherence counselling and the limitations of intensive adherence counselling among the people living with HIV and AIDS.

1.4 Objectives

1.4.1 General objective
To find out the benefits and limitations of IAC (Intensive Adherence Counselling) to the people living with HIV/AIDS.

1.4.2 Specific objectives
1. To describe the meaning of intensive adherence counselling from the perspective of clients and health workers at ART clinic Luwero Health Centre IV.
2. To establish the role of intensive adherence counselling to adherence to ART.
3. To explore the experiences of patients enrolled on IAC
4. To find out the benefits of intensive adherence counselling to the people living with HIV and AIDS and factors that limit its success.

1.5 Research questions
1. How is the concept of IAC understood by the patients and health workers at the ART Clinic Luwero Health Centre IV?
2. What is the role of intensive adherence counselling towards adherence to ART?
3. What is the difference between experiences of patients on IAC and those that are not on IAC?
4. What factors hinder the success of IAC?
5. How have patients on IAC gained from the program?

1.6 Scope of the study

1.6.1 Content scope
The study focused on the benefits and limitations of intensive adherence counselling to the people living with HIV and AIDS.

1.6.2 Geographical scope
The study considered HIV and AIDS patients on antiretroviral therapy and on IAC (Intensive Adherence Counselling) at Luwero Health Centre IV ART Clinic in Luwero District. The study also considered a few key health workers in this particular field. These included two Counsellors and a social worker.

1.6.3 Time scope
The study took a period of four months and this included time for data collection and time for analysis of data.

1.7 Justification of the study
This study provides a deep insight into the views of the recipients’ views about psychosocial support towards their lives and how it’s provided. It further directed psychosocial supporters on what else to do for the betterment of their clients.

The study provided room for an assessment of IAC to show if its main target of ensuring complete suppression by 2020 will be attained or is achievable.

The study gives a complete picture on what it is like, the concept of intensive adherence counselling (IAC) to those receiving it and how they view it. That is; how far they either understand or not understand it. It also opens other scholar’s eyes to discovering more about intensive adherence counselling, since it is a new field as it was only put into place in Uganda in 2016 (USAID, 2018)
The study acts as an update on the available information on Intensive Adherence Counselling especially the role, effects, benefits and challenges of the research topic in question. This is specific especially to Luwero Health Centre IV ART clinic.

It acts as an illustration of how effective HIV services are provided.

1.8 Definition of key terms

**Psychosocial support**: Refers to the provision of psychological and social resources to a person by a supporter intended for the benefit of the receiver’s ability to cope with problems solved.

**IAC**: Intensive Adherence counselling is a program under psychosocial support that is run for non-suppressing HIV/AIDS clients in order to suppress.

**Benefit**: This refers to an advantage or profit.

**Limitations**: A factor that stops something from happening.

**Adherence**: Adherence is the extent to which a person uses a medication according to medical recommendations, inclusive of timing, dosing, and consistency.

**PLWHAs**: People living with HIV and AIDS.
2.0 Introduction
This chapter presents the role of intensive adherence counselling, the limitations of carrying out intensive adherence counselling and benefits derived from intensive adherence counselling and challenge (limitations) of intensive adherence counselling.

2.1 The Birth of IAC (Intensive Adherence Counselling)

2.1.1 The HIV/AIDS pandemic
A number of theories came up in a bid to explain the origin of HIV and AIDS. According to UNAIDS and WHO (2003) however, the Human Immune Virus and the Acquired Immune Deficiency Syndrome was first traced among homosexual men in the United States of America. Another study however states that the virus was first traced in modern day Democratic Republic of Congo in 1995, a virus that was spread from monkeys to Humans (Anne et al., 2011). This plus many other assumptions, in most studies reviewed however, the syndrome hits Sub-Saharan Africa more than any other states. Sixty-nine percent (69%) of all people living with HIV/AIDS are in Africa and 70% of all these succumbed to death due to the syndrome in Africa as well (World Bank, 2011). Counselling was introduced came after the Second World War in the 1950’s in America, at a time when psychosocial distress was pretty much (Tutor Ltd, 2018) and one of the greatest psychologists and counsellors is Sigmund Freud.

According to the World Health Organisation (WHO, 2013) HIV testing and counselling services are a gateway to HIV prevention, care and treatment. Adherence is key in handling this infection.

Adherence refers to the process of choosing, starting, managing and maintaining a given therapeutic medical regimen to control HIV viral replication and improve the function of the immune system (Fong, 2003).

On the other hand, non-adherence is the discontinuity or cessation of part or all of the treatment such as dosage missing, under dosing, over dosing and drug holidays.

Intensive adherence counselling is a program under psychosocial support that is run for non-suppressing HIV/AIDs patients, here in Uganda and a number of Sub Saharan African states. In
Uganda, the program was introduced by the ministry of Health, was born at IDI (infectious Disease Institute) Makerere University and was first practiced at Orum Health Centre IV (Sustain Uganda), all in 2016.

2.2 Role of Intensive adherence counselling

Those who follow antiretroviral therapy (ART) know that patient adherence counselling is a central pillar of Uganda’s strategy against HIV/AIDS. Why is it so critical? To understand this, one must remember that the cornerstone of the UNAIDS’s 90-90-90 strategy, developed in the 2014, included a very important and practical recommendation-- to “directly observe” every dose of AIDS medication throughout a patient’s treatment. In resource limited settings, this directly observed therapy is prioritized during the intensive phase for drug-susceptible AIDS, which normally lasts three months (USAID, 2017 and Jamieson, 2016)

In some countries, however, directly observed therapy is not implemented in a consistent fashion, mostly due to the shortage of human resources. There is also increased complexity for implementing 90 suppression level strategy in resource-limited settings, since AIDS drugs are taken on daily for all of the patient’s life. It would be wonderful if 90% suppression by using Intensive Adherence Counselling could reach every AIDS and HIV patient in rural Uganda. But if that is not possible, other ways must be paved to directly reach AIDS patients so that they themselves understand the critical importance of taking every dose and staying on drugs. In this context, it also becomes clear that engaging health care providers to train them on effective adherence counselling is crucial -- reinforcing “doctor-patient” communication to improve adherence, even if the doctors themselves cannot observe every single dose. (USAID, 2017)

UNAIDS (2016) notes that adherence counselling is one of the most effective methods directed to addressing the problems faced by HIV and AIDS patients. That this is true because it targets behavioural change which is key in fighting the syndrome and seeing to HIV/AIDS drugs treatment success. For this reason, UNAID, USAID, government of Uganda considered the development of strong and long standing counselling programs, with a particular focus on AIDS peer counsellors. The goal is to make clear why patients must adhere to their treatment, how to prevent infection of others, and how to win the fight against the disease.
(USAID’s prioritization of adherence counselling also underlies the commitment to leveraging the emerging social media platforms and mobile communication tools that create new ways of forming connections with AIDS patients. The stronger the patient counselling strategy, the more effective the fight to eliminate AIDS, (USAID, 2017).

2.3 The benefits of using intensive adherence counselling

One of the benefits is that in poor countries it has been found to be an inexpensive intervention that has been designed to help patients comply with treatment. This is because the patients are counselled on the importance of following their treatment protocol. This method is highly effective and highly relevant to HIV clinics caring for large numbers of patients in Sub Saharan Africa (Michael, 2014).

According to Michael (2014), patients that received counselling in Sub Saharan African states were 29% less likely to adhere poorly to their treatment compared to those that received no counselling at all. That even those that received early intensive adherence counselling were 59% chances less likely to have viral failure. Viral failure refers to when the virus is no longer adequately suppressed.

Nina (2012) reveals that there is a significant relationship between cumulative adherence counselling hours and antiretroviral adherence; each additional counselling hour leads to 20% increase in adherence. It is elaborated in the figure below;
According to Nina (2012), there is less likely to be a relationship between intensive adherence counselling hours and adherence.

In studies like that by Michael (2011), intensive adherence counselling has been effective in fighting virological failure in Sub Saharan Africa.

**2.4 Limitations of intensive adherence counselling.**

There is no significant difference in CD4 counts- a measure of disease progression. In a research carried out in Kenya, an eighteen month follow according to Michael (2014), between those who received counselling and those that didn’t, there was no significant difference in adherence, CD4 count, time to viral failure and mortality.
2.4.1 Failure among the adolescents.
Intensive adherence counselling among adolescents is generally lower and treatment failure rates are higher than in any other age brackets (Press, 2002). This research states that psychosocial factors surrounding adolescents; stigma, peer influence, limited personal resources and dependence on care givers and the health centres which are unprepared to address the specific needs of adolescents living with HIV (ALHIV) (Sentebale, 2017).

Bangsberg (2001), Ortego (2011) and USAID (2018) conclude that children have unique challenges in taking ART because of a multitude of factors such as total dependence on a care giver, lack of disclosure, stigma, living with non-biological care takers and childish forgetfulness. However, treatment failure among children is under diagnosed and given attention by HIV programs (Tanser, 2013) and (Michael, 2014). A study made by Kiran (2014) states however, that regardless of the age bracket, intensive adherence counselling has no impact on viral suppression.

2.4.2 Complexity in measuring adherence.
Another challenge is that counselling alone cannot show that patients are now adhering to the prescribed drugs. Measuring adherence is a bit complex as it doesn’t take one route for assessment. Others like pill counting, electronic monitoring devices, refill dates, client self-report and measurement of medication in the blood stream (MOH Kenya et al., 2014).

2.4.3 Overwhelming numbers of patients.
While adherence counselling is included as a core component of ART delivery, provision of high quality counselling is challenging when the number of patients overwhelm providers. In addition, counselling is influenced by the counsellors training and is difficult to standardise. An immediate opportunity exists to improve medication adherence by augmenting, monitoring and optimising adherence counselling. It is generally believed that if adherence is addressed, clients receiving ART will achieve viral suppression unless the ART regimen is failing (Sentebale, 2017).

The world health organisation (WHO) basing on a systematic review disclosed that 70% of clients achieves suppression after adherence interventions, recommended adherence interventions for clients with high viral load (Nina, 2012). With even 61000 children receiving ART in Uganda in 2016, the World Health Organisation, (2018) stated that the government of Uganda adopted WHO guidelines that each adult or child that had been receiving Antiretroviral drugs for more than six
months has his or her viral load measured through the VL test (Menon, 2007). All individuals with HIV viral loads more than 1000 copies/mL would then receive intensive adherence counselling which includes three sessions of monthly intensive adherence counselling.

2.5 Emerging gaps
Research was done to check on IAC (Intensive Adherence Counselling) at Orum Health Centre IV (USAID, 2018). It will only be justice to carry out a study at other health centres; like Luwero health centre
CHAPTER THREE: METHODOLOGY

3.0. Introduction
Mugenda and Mugenda (1999) states that this chapter should specify the research design, the study population or the area in which the study was conducted. The sampling design, the sample size, data sources, data collection instruments and the validity of collection instruments plus the ethics were put into consideration when carrying out the research.

3.1 Research design
The researcher used qualitative case study design for this study. Qualitative because the researcher’s intention sought to capture stories, experiences and challenges from the study participants and also to collect detailed information from the interviews with both key informants and the primary respondents. It is a case study because the researcher intends to use a few participants through in-depth yet comprehensive analysis of the phenomenon under investigation.

3.2 Study population
This researcher collected data from people living with HIV (both male and female) currently receiving intensive adherence counselling services at Luwero Health Centre IV in Luwero district. The researcher targeted the IAC clients because according to speculation the IAC services received by people living with HIV has both benefits and limitations a question the researcher sought clarity on. The study population also included three health workers and among these included one social worker and two counsellors in the ART department at the facility as key informants.

3.3 Sample size and Sampling procedure
3.3.1 Sample size
The sample size refers to the number of items to be selected from the universe to constitute a sample (Kothari 1990). A sample should neither be excessively large or small, it should be optimal; it must fulfil the reliability, flexibility, efficiency and representativeness principles.

Two broad categories of study participants were earmarked for this study, the primary respondents were the individuals receiving IAC at the health centre, key informants and two respondents who were patients that were not on IAC. Due to the qualitative nature of this study the researcher
considered a small sample size in order to have enough time to discuss the experiences of participants in great details. Therefore, the researcher interviewed seven cases of PLWHAs who served as the primary study participants. Five of the study participants had received or were still receiving IAC while two had never received IAC. The inclusion of the two who had not received IAC was to make it possible to compare the experiences between these two groups. Among those that received IAC, four were female and one was male. The two that had never received IAC included a male and a female. Three participants (3) were recruited into the study as Key Informants. These included; a social worker and two counsellors. Their inclusion in the study was intended to generate the perspectives of service providers particularly with regards to the description, role of IAC, the benefits and limitations of IAC to PLWHAs at the ART clinic Luwero Health centre IV.

3.3.2 Sampling procedure
The study used convenience random sampling to select the respondents. Convenience random sampling is where the sample is taken from a group of people easy to contact or to reach. (Saunders, 2012). Only patients within the catchment area were considered.

3.4 Methods of data collection

3.4.1 In-depth interviews
An in-depth interview with each of the participants was conducted using open-ended questions contained within the in-depth interview guide. The interview guide was developed in line with the study design that necessitated the collection of rich data from the primary study participants. The interview guide was subjected to review by the supervisor and the comments provided were considered when preparing the final guide. The participants felt free to converse and tell rich stories about their experiences regarding the benefits and challenges of IAC. Meanwhile full attention was paid to the respondents to obtain meaningful data. Each interview lasted at least 30 minutes and the language most suitable for each respondent was used. This tool was basically for the patients.

3.4.2 Key Informant Interviews
Key informant interviews were used to collect data qualitatively to elicit viable in-depth and detailed qualitative data from the key informants. Each key informant interview used 30 minutes,
to allow generation of in-depth and detailed information from key informants. A key informant guide as a tool was used to direct the interviews towards fulfilling the study objectives. The guide was designed using the key issues and questions around intensive adherence counselling for people living with HIV specifically focussing on the benefits and limitations of IAC.

3.4.3 Validity of research instruments
The term validity indicates the degree to which an instrument measured the construct under investigation. For a data collection instrument to be considered valid, the content selected and included must be relevant to the need. Before the actual study, the instruments were discussed with the supervisor. The feedback from the supervisor helped in modifying the instruments.

3.5 Data collection procedure
The researcher first went personally to conduct a pre-study tour of the study area and sought permission from the authorities of the health facility before coming back on appointed date to collect data. Interviews were then conducted by the researcher. The qualitative data in form of written material on note pads from the interviews was then transcribed and analysed thematically according to the objectives of the study.

3.5.1 Data analysis
Qualitative analysis of the data from the in-depth interviews with the primary respondents and the key informant interviews was done both during and after data collection. Thus data was edited from the field and subjected to further analysis after the field data collection. Data was grouped according to themes and thereafter subjected to content analysis. During analysis, focus was placed on the interpretations by the study participants, generation of the meaning of their views and comparing their responses with those given by the key informants and evidence around the subject. Each of the patients that were on IAC were given a unique code, this code was generated from the initials of the patients’ names. The key informants were coded using their initials plus their age, and those that were not on IAC were coded using the initial of initial of their names plus the first letter of their jobs.

3.6 Ethical considerations
To ensure adherence to the ethics of social research, the researcher sought permission from the department in charge of research related matters in Makerere University. A letter of acceptance
was obtained from the department upon approval of the research proposal. This letter was appendicised in the report for further details.

Permission was sought from the authorities at the health facility to allow the researcher to have access to the study participants. The researcher explained to the authorities at the health centre the purpose of the study. It made clear to the authorities that the collected information was for academic purposes and was expected to contribute less or nothing to the ART clinic in Luwero health centre IV and people living with HIV and AIDS.

Keeping in mind the sensitivity of this study topic, the research participants were assured of confidentiality and anonymity in order to keep the observed data private and not to reveal their identities.

With the target population, the researcher sought informed consent from the study participants on whether they were willing to participate in the study. In the process, willing participants were recruited and interviewed while those who were not interested in taking part in the study were also accorded their respect.

The researcher further informed the participants that there were no tangible benefits for respondents associated with their participation in the study.
CHAPTER FOUR: PRESENTATION AND DISCUSSION OF STUDY

FINDINGS

4.0 Introduction

This chapter presents the findings from the field research based on data gathered from 7 cases of PLWHAs. Five of these were enrolled on IAC and the two were not on IAC. The findings also bring out the views and or perspectives of a number of three health workers who were the key informants.

- Data obtained during interviews was based on the following objectives and the findings were presented basing on these:
  - To describe the meaning of intensive adherence counselling from the perspective of clients and health workers at ART clinic Luwero Health Centre IV
  - To establish the role of intensive adherence counselling to adherence to ART.
  - To explore the experiences of patients enrolled on IAC
  - To find out the benefits of IAC to the people living with HIV and AIDS and the factors that limit its success.

4.1 Demographic profiles of respondents

The data obtained from the study was drawn from a total of seven (7) respondents who are HIV positive (five of whom had been born with HIV/AIDS, and two had contracted the virus in their old age) and are clients at Luwero Health Centre IV ART Clinic. Five (5) of the study participants were on IAC and the remaining two (2) were not. These two were included in the sample to gauge if there were any differences in the experience of counselling services between those on IAC and those on ordinary counselling. The participants were mostly aged between 14 to 40 years. Of these, five (5) were female and two (2) were male. Most of the respondents were employed in blue collar jobs such as subsistence farming, tailoring and commercial sex and two (2) were unemployed. Majority of the respondents (6) had at least acquired an education, the highest level being Tertiary and the lowest being Primary. All the respondents were residents in Luwero district. Two (2) of the respondents were married while the rest were single.
4.2 Understanding of IAC from the perspective of patients and health workers.

Different views were given by both patients and health workers on what IAC was. It was described by patients that were on IAC as a program that was meant for those whose viral load was high. They referred to their health workers as the people to ask more about it. An example of NS, NA and KG insinuated the health workers were their superiors, so they knew more. For those that were not on IAC, it was a program for the non-suppressors and they thought it was an undesirable arrangement. RAFH, one of the patients that was not on IAC was quoted saying that she thought it was deadly to be part of the arrangement. All the patients however referred to it as, "bakanyiivu" meaning an arrangement for the non-suppressors. On the other hand, the health workers seemed to have a much clear understanding of intensive adherence counselling. It was introduced at the ART clinic by the ministry of health through Mild may and Uganda Cares through a Continuous Medical Education (CME). According to them, intensive adherence counselling is a medical program that was introduced in the bid to fulfil the third of the 90-90-90 UNAIDS strategy which states that by 2030, all HIV positive patients should have suppressed. Suppressing is a term used to mean that an HIV positive patient’s viral load is lower than 1000 MI/L.

IAC consists of three sessions and these comprise of intensive counselling sessions, monitoring, pill counting and follow up. After these, a patient is bound to go through a viral load test. If she or he has suppressed, that is what is read as a success story and if the viral load is still high, then they are retained on IAC for another IAC. After IAC has been done for six consecutive months and bleeding still produces poor results, that is; the patient has a viral load is still beyond 1000 copies/ml, and the blood is resisting the drugs, it is considered that the drug regimen rather than IAC has been a failure and the person is forwarded to another line of regimen. Switching or substitution is done for the patient (NK31 and TC27). Switching is when the whole drug combination is changed while substitution is where one of the drugs in the drug combination is changed for another. She further explained that in some cases failure is not considered entirely according to viral load count which is beyond 1000 copies, but resistance testing is carried out to find out if blood is resisting the drugs or it is rather correlating. In situations where the resistance test is negative (blood correlates with the given drug combination) yet viral load is high, then IAC is a failure since the burring factors are behavioural than medical. Relating to USAID (2017) that states IAC is supposed to take three sessions, health workers explained rather differently. They said that if a patient was put on IAC for three months, bled and their viral load was still high, they
would be retained on the program until they suppress so along as the burring factors were behavioural.

4.3 Experiences of patients on IAC

4.3.1 Case one
The researcher obtained information about NA, a thirty (30) year old widow. She is a primary seven dropout and really permanently employed. NA’s husband died at the beginning of 2017. She has a child aged four who was also enrolled on intensive adherence counselling. Unlike her child, NA was not on IAC at the time of the research but had an experience of it as she was there before. She doesn’t have a permanent home so she seeks refuge at NA's Auntie who resides in Dekabusa-Sakabusolo. The mother daughter pair were initiated on ART in 2015 in a month, date and ART numbers that have been withheld for purposes of confidentiality. Her story goes as follows; she engaged in sexual activity with a man who got her pregnant. She said the man was married, she knew it but didn't care mainly because she had pressure from home. Her Auntie always asked her to bring a man home, that she was getting old! When the Auntie found she was prime, she told her to go get married to whoever was responsible. KT (the late) rented for her in Kakooge but he was not providing as much as he had to provide especially to an inexperienced pregnant woman like NA. She didn't appear at any health facility to seek for Antenatal services. She said she was lazy to go. And besides, she never used to have transport.

"My in-laws always gave me herbs. Besides, this place was far from home."

She was brought to Kasana health centre IV when she was in her labour pains by her neighbour. (No PMTCT was done therefore). NA successfully gave birth to a baby girl. They left the centre and went back home. When the baby was six months, it got a wound on its left side cheek. In the meantime, NA had also been complaining about constant headaches to the neighbour. She (the neighbour) advised and helped the mother baby pair go to the facility for an examination. A blood sample of the mother was taken, tested and turned positive.

"Jesus!! I could never believe KT would be this heartless."

So, KT had never at any one time revealed to NA that he was HIV positive! She felt a sense of hopelessness through her blood but she decided to live for her child. So the pair was started on
ART. She decided not to tell the husband about it even. The family lived in pretence of each other's status until one fateful day when KT was announced dead after getting involved in an accident. It was a terrible experience. It was funny how everyone of the family members knew about the late's status apart from her. The relatives vowed to take care of all of the late's children but her child was left out. She wasn’t an official wife, so she has never benefited from her late husband's side. She stayed in Kakooge but time came when rent was due. She left and went back to the Auntie's place (Dekabusa-Sakabusolo) where she currently lives. Time had been tough before but it’s been tougher ever since then. She happens to have a few skills in tailoring, she does farming for people to earn sometimes. She and her baby were in a terrible state earlier. Immunity was low. The pair was always sickly. Their CD4 count was less. Mid 2017, their blood samples were taken and the counsellor said that their viral loads were beyond expected. After that day, a counsellor told her to always appear regularly at the health facility ART clinic every other month together with her child. She said she didn't know the essence of seeing a counsellor every time she came for her medicine but saw her any way. That the counsellor said they should be friends, partners in order to fight and see to the reduction of the virus in her blood and her baby's. She guided her on how to take care of her child. She thought to herself,

"I wasn't giving my child enough time I think. I quit my job at school to take care of my daughter."

NA stopped working as a cleaner in one school and settled down to see to her child's wellbeing. (this was rather a one sided way of looking at this whole situation). She meanwhile has no other provider apart from her). So they (the pair) started finding problems getting food as she sadly said sometimes she would take medicine without food but only water. She would then fear to give the child her dosage for fear of adverse effects. After the three months of intensive adherence counselling, NA suppressed but the child didn’t. She was therefore retained for another IAC which includes three sessions. To the child however there were quite number of burring factors to suppression and they were quite visible.NA was troubled and feared a lot for her child yet the child's welfare all depended on her and dosage missing was all because of her. The mother had a big burden load. Her situation was quite difficult and she also stood a chance of deteriorating again to a being a non-suppressor. Poverty is her major issue. There was no problem with the counsellor
that was handling her issue (she had a good relationship with her). She had no idea what IAC was but she knew was that it was meant to save her child.

4.3.2 Case two
NP, she is a fourteen-year-old female, resident of Kasoma zone and a pupil at Luwero SDA primary school. She is an orphan and has an Auntie for a caretaker. She has been positive since birth. Her mother died when she was three months old. She could never tell what went wrong. (but it can be suspected that her death was HIV related since NP has been positive since birth). She lived with her father and her other siblings. He was their caretaker until he also passed on in 2010. Responsibility was passed on to her paternal grandfather. He used to come for refills for them and on a few occasions he brought them along to the ART clinic. All was well then. At the end of 2017 however, NP was taken away from her grandfather and brought to her Auntie's place so that she can complete her primary seven. The Auntie didn't seem very much bothered about her situation although she knew about it. She was psychologically distressed and more often missed her dosage. The counsellor that monitors children took her for a viral load test because she had started constantly falling sick, a trend she hadn’t had in the past years. Her viral load was high and was therefore enrolled on IAC. NP confessed that she faced a number of problems as a child with a different status from all her fellow age mates at the Auntie's place.

"All was well, but now I fear my nieces. Am the different one at home even. When my colleagues are going to sleep, I sit waiting for the time (10:00pm) to take my drugs. At my grandfather's, we used to take it in a group but right now am alone."

She said that sometimes she used to actually forget her drugs and there was no one to remind him one could see the effects of non-adherence on her by looking at her. She was slowly wasting away, her performance at school was also not faring well too. She said she had got thirty-four (34) aggregates in her Mocks. She said she hardly had friends at school and was always in isolation for she felt different. She had gone through all her first IAC three sessions and a viral load test was done again. Her viral load was 51,600 copies/ml. She was briefed on why she was told to see a counsellor every time she appeared for her refill. Since she was taking full responsibility of her life, she was given guidelines on how to collect her medicine, be free with health workers and how to take care of her life. She has been seeing one counsellor. The one responsible for children and
youths. She admitted she sometimes forgot to take her medicine for lack of reminders, other times because she would be playing with her mates. This had been continuous although her counsellor always cautioned her on that. Surprisingly, when asked the challenges she has faced during IAC sessions, she couldn't list even one. She said as a teen she hasn't even involved in activities as other children do because she feels so alone. She wondered what her mother looked like and how fast death could be to snatch her father. But because of the IAC program she said,

"I at least let my Auntie let her children know about my status. The fear is not as much as it used to be in the beginning."

4.3.3 Case three
KP, thirty-two (32) years, single, a sex worker, totally illiterate, resides in Kiwogozi and has two positive children (set of twins). Right from the start, she was torn between the difficulty to talk about her experience to an age inferior and the ease that came with talking to an education superior. Anyone could read this through her gestures and facial expressions. KP ran away from home in her youthful days. She left Nabutaka, come to Kasana town to start a new life with a one SF who had promised to marry her. It was unfortunate how things didn't go well between them, she decided to leave. Whatever separated them, she wasn't comfortable talking about it. She was illiterate, single and unemployed yet she had to take care of herself. This is how she started sleeping around. It is a thing she learnt to do as she says it was a bit uncomfortable in the beginning. KP found she was HIV positive in 2009. It was at an outreach around Kasana market. She was then advised to initiate on ART but she refused.

"The idea of swallowing medicine every day."

She resorted to the church because she had heard rumour that in the born again church, one could get HIV and AIDS cured for good. She became born again, but continued with her sex work. She then narrated of a day she heard of a crusade at the town centre. It was hosted by a pastor X where she went and got prayed for. She said she paid Ugshs 20,000 for the prayer. She believed she was healed. She always got infections in her private parts but thought these were effects of her job. She received different kinds of clients and some never want to use protection. Apart from that she had never got any other serious illness that could maybe have driven her to hospital until in 2014. She
got pregnant, tried to abort and failed. She was brought to the maternity ward for help. When she was tested, she was HIV positive. She was counselled to keep her pregnancy and also got her initiated on ART. She didn't adhere though. She never appeared at the facility for all the period between her pregnancy and birth. She gave birth at her home,

"My sister helped me deliver my twins. I only took them to the health centre for immunization in late 2015 and then took them to their grandmother’s place in Lutuula."

KP only came back to the clinic last year, she was sickly. Her file was rejuvenated and updated. She was in clinical stage II and her viral load was high. She was enrolled on IAC. She claimed that ever since that day, she had decided to take care of her life. She was remorseful. She felt stupid for having been reckless when she was pregnant, that she could have been able to save her children. She felt lonely. She claimed she took her medicine right but didn’t know why she wasn’t suppressing. She was resigned and appreciated this program but had a sensitive complaint as well;

“If this program used to fund us, then there would be changes but the counsellor just tells you sex work is risky yet it is my only source of income”

This insinuated that she could be able to change but situation could never let her do. IAC had done quite some work on her. She said she had reduced on the number of men she was sexually engaging with, that she didn’t want to kill any more people. She had felt the impact of living with this disease. Her other issue was that she found it a bit inconveniencing to talk to especially a younger person about her problem. She confessed there was a lot more that she couldn’t share because it wasn’t appropriate.

4.3.4 Case four
KG is a twenty-year-old male. Works in a garage. He resides in Galuweru, single with no children. His caretaker is NF (her mother) and he is on ART file number xxxx. KG was born HIV positive he however never got to understand this until he was fourteen years of age. He is born of MK to SF of Lumonde in Butuntumula subcounty Luwero district. He went to Kasaala moslem primary school, Kasaala moslem secondary school and thereafter due to the lack of school fees for continuation to Advanced level, he went to a technical school where he attained skills in repairing cars and motorcycles. Throughout his school time, there are things he never got to understand. He
grew curious about why especially he was entitled to taking a pill or two everyday throughout. Due to children stupidity, he asked his friends at school if they also swallowed medicine when they went back home and in the morning before coming to school. When they said no, he decided to run to his mother and ask him. He was fourteen then. The mother explained to him why and that was the beginning of all the catastrophe. He got angry at his mother for quite some time, he didn’t want anything to do with his life. He started isolating himself because he always felt different from his mates. He started hating the idea of going to school. His mother talked him into going to the clinic for his refills. That’s how he started taking full charge of his life. He was welcomed by a counsellor for the children and youths and she is the one he has been seeing ever since. When his viral load was taken later, at a time he couldn’t remember, he had graduated from a suppressor to a non-suppressor. He was enrolled on IAC, but still saw the same counsellor. He claimed he had gained quite a lot ever since.

“I thought am positive, so there was nothing left to save but of late, I have learnt that I can still do a lot. Iam no longer angry at my mother. Iam getting more courage to manage my life.”

He said a lot of information had been given to him especially through health talks about protection his life and he was appreciative. He faced no constraints and that he would check in at a counsellor’s call because for the counsellor, his life had been renewed.

4.3.5 Case five

One of the few patients that were interviewed was NS, a twenty-one-year-old single illiterate young woman. She resides in Kavule and is prime. Her caretaker was AP who also happens to be her mother. She could never have noticed she was HIV positive if she hadn't got pregnant. But for the pregnancy, she went to seek antenatal services at the facility and one of the services offered is compulsory HIV testing for every pregnant mother. It was unfortunate that she turned positive. She was referred to the ART clinic, a confirmatory test was done, she was counselled, enrolled on ARVs and PMTCT. For a pregnant woman, under the PMTCT program, a viral load test is taken immediately at discovery that the mother's status is positive. It was taken therefore. Her viral load was higher than expected hence being my put to IAC. She could never explain anything. NS looked puzzled by her situation, like she lost control over her life and left for fate to drive. She was shabby and her clothes were half rugged. She admitted she didn't know the father of the child she was
expecting. Reason was she had engaged in sexual activity with a number of men. She seemed very scared. Throughout the conversation she was remorseful. She kept saying she wishes she saves her baby. She many times insinuated she didn't about her own life but she would rather do anything and everything to save her child. She was all about her child. She seemed like one who would change if certain conditions were made better for her. For example, she said she wouldn't miss her appointments but it's expensive for her to make it to the facility every month. Her only sources of income are her mother's "toninyila" business and her boyfriends.

"I have attended four sessions so far. But I see a different counsellor every time I come."

It was followed by a blatant laughter. Was this supposed to mean some clients are not comfortable with sharing with just anyone but rather find a confidant? She on top of this added that this whole "thing of putting her on IAC had got her on pressure. She had talked to her mother about the pregnancy and she comforted her but the whole Idea of being ART was intimidating and now seeing a counsellor every time she showed up at the clinic was making things worse.

"I am on pressure. It has put me on pressure. I'm pregnant. The health worker tells me to swallow medicine, I will infect my baby. I don't know. How will I take care of my baby"?

NS was confusing, she seemed like she didn't like the idea of counsellors but she said she implemented many of the things they have always told her, for example; when asked about the changes she had made as a result of seeing a counsellor, she said;

"Counsellor X told me it's not a good idea to sleep with many men, and I saw it. She also gave me some condoms. I didn't use them at first, but now I use them."

She felt like her other colleagues, "bakasanyufu" were in a much better position than where she was. That they don't even have the burden of having to come around every time and see a counsellor. But she had learnt to adopt anyway, for she was already in trouble and she had to find a way of her saving baby. She had been equipped with the knowledge that the reason she was enrolled on IAC was to get her viral load suppressed. NS cried and wished there was a way the
clinic supported her and other people that fell in her category. Support that was beyond just giving them refills and counselling them-financial support.

4.4 Experiences of patients that were not on IAC

4.4.1 Case one

BRF, a forty-nine-year-old male married farmer. He resides in kakokolo, has six children who all tested negative, positive wife (caretaker) with his highest level of education being form six. BRF discovered was HIV positive in 2017. He could never have tested for HIV if it wasn't for the consistent fevers he always got. When the fever was constant, he one time decided to visit Luwero Health Centre IV for an examination and probably get some medication. A blood sample was taken and then BRF tested HIV positive. It must have been hard for him to take in from the way he winced at speaking and remembering that moment. A sense of self disappointment must have run through his blood at that very moment:

"I kind of always suspected it, I had an affair with another woman around Christmas time in 2016. so I had infected my wife too. It was hard... "

Using APN (Assisted Partner Notification), he was advised to bring his wife as well for testing and also get to inform her about the changes in their status in the calmest way possible. He did as advised, brought his woman and they were both counselled. His wife was told. She got frustrated of course. They even had fights at home visits and when they didn't go back on the appointed date to see the counsellor, they rather received a home visit from one of counsellors at the clinic. It didn't take one day or two but after some time, they came to an agreement. They decided to be each other's keeper, take their medication and never miss appointments. They did this because they felt their children but especially the youngest who had twelve years only hurt them. They decided to live a new life for them. He doesn't see a counsellor often as he used to before when things were still very difficult to figure out but he is grateful his life is now what it is;

"When I found out I was positive, I was worried and I was the one at fault. A counsellor helped me make a lot of certain decisions. "

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He didn't know any particular kinds of counselling but he knew it was very important talking to a person especially when in trouble. He looked strong and brave. No wonder he had taken the bull by its horns. But what if he hadn't got any support from any counsellors, would things be as good as they are now? Probably no. This was why he said he valued whatever the counsellors had to tell him. Regardless of size sex and age, he believed they only intended good. He didn't face any challenges with them.

4.4.2 Case two
A story from a twenty-three (23) year old RAFH. She is a senior two dropout, married to MSD and has no child yet. She was initiated on ART in 2015 on ART number xxxx, is a full time housewife and resides in kasana-modern commonly known as "Mukyimodern" RAFH started dating MSD in 2008.

"I was out of school, I had no job yet I wanted some things as a girl. “

She didn't know MSD was a widower. She started hearing rumours that MSD had lost his wife to AIDS. She didn't believe because she had never seen any signs. A sick man could never have looked like her lover. They soon started cohabiting but there was no evidence still. She never saw him swallowing any medicine.

A "moon light" however was held one day around Kasana market. (a moonlight is an outreach meant for HIV testing in a highly risky population. It is called moonlight because it is carried out between evening and night. Never during day). Out of curiosity RAFH decided to go testing and the unfortunate bit is that she turned out to be HIV positive. That's when she proved all the rumours she had been hearing right. She cried but later noticed it was not going to help her. She didn't start on ARVs at that time though.

"I took Septrin for four years. I feared the idea of swallowing ARVs."

The idea of initiation on ART only hit her in 2015 when she felt careless for her life. Meanwhile she had never told the lover about it. She started ART at Luwero Health Centre IV ART clinic. With the help of the counsellor she managed to reveal to her husband that she was on ART. She showed the drugs to the husband, told him she was infected and she was sure it was him that infected her, therefore she wasn't going anywhere. They then sought counselling as a couple. They
decided to put the past behind, been taking their ARVs since then and life hasn't been that bad. She said it is very difficult to open up to someone but she is glad she did, then admitted that she didn't know allot of things but she was sure whatever the health workers did was for the good of them (people that are positive like her). She was a loyal woman, very honest and trusting. One could tell from the way she talked about her experience before and while being a client at the clinic with her husband. Though not in a very comfortable state health wise and economically, RAFH had an assurance of a positive living. She said she would not hesitate seeing a counsellor if she sad she needed to see her, but it would rather be hard for her to approach one if she had a problem. She had a vague idea about the differences between the kinds of counselling services that were offered at the clinic. At least she mentioned counselling for the non-suppressors.

"bakanyiivu, the health workers always talk about it during the health talks. I think its deadly to be a non-suppressor. "

She didn't have a lot of information about it because she had never been there but she believed whatever was done under this program was not for any bad intention and it was really vital for those that received it plus a number of people in the environment surrounding them for example; their families, friends because saving a life that is loved by some people or changing their character was a very kind act. She insinuated that even though counselling might be as direct as expected (problem discussion procedure), it’s still vital that a counsellor and a patient meet at least once in a while.

"I can't tell you this or that, but there are times a counsellor talks about something. You don't open up to her but inside you tell your heart to change. "

That personally she had cleared a lot of mess she had never talked about to the counsellor but because she indirectly talks about it. She also thought the idea of seeing a counsellor was brilliant for it restored hope into people,

"Some people lose hope the moment they notice they are positive."

She could however not tell the difference between the kinds of counselling offered by the clinic to clients but she thought that only if either the counsellor or the client is bad is when the counselling sessions would yield negative results.
4.5 Views on the role, benefits and limitations of IAC from the key informants

These were three. They were coded using their initials and age. They were; NK31, NJ23 and TC27. The following was the information they provided putting emphasis on the role, benefits and limitations of IAC.

4.5.1 On the role

Key informants revealed that the major role of intensive adherence counselling is to ensure suppression of the virus to make sure that the copies/ml are less than 1000 copies. Here NK31 said;

“Once a client is not suppressing they are eligible for IAC” NK31 she stressed this by saying “Suppression is when an HIV patient’s viral load is less than 1000 copies/ml. ‘sometimes a patient just needs a little push and then they will do better to suppress the virus’”

Another role which was revealed by a key informant was that IAC is key in working towards the last 90 in the 90-90-90 strategy which requires suppression by all HIV patients by 2020. TC27 said that “both of government and nongovernmental organizations are working hand in hand to implement the last 90 of the 90-90-90 strategy.”

A role of identifying the different barriers which limit adherence on the drugs to ensure suppression of the viral was stressed by one of the key informants. TC27 said that

“Very many problems stop clients from taking their ARVs and sometimes they are petty, that they can be addressed and one can live normally again.”

Another role that was identified by the key informants was to monitor, evaluate treatment for patients in order to adjust in the model of treatment if possible. For example, TC27 said

“our clients on IAC can only be treated under Facility Based Management where a client always has to show up at the clinic for refills and not send any other person for much more than just refilling is needed.”
4.5.2 On the benefits

Key informants revealed that many clients had started to suppress and were taken off IAC for example TC27 said that

“Clients have suppressed their viral load because of this program”. This statement is further supported by NJ31 who acknowledged that many peoples had become first trackers and were taken off IAC she said “It is very unusual for a client to be on IAC and you find that they are clinical stage I, most of them are in II and III”

The key informants revealed that IAC had provided alternatives on how to handle people living with HIV in order for the drugs to be effective. Here NK31 said

“it has in a sort of way helped us to know who were dealing with, so our work is eased in a way for example, the way I handle a first tracker is so different from the way I will handle a client on IAC.” It was further reinforced by another key informant NJ23 who said “It has led to a more proper of handling and guiding such clients as those that are no IAC.”

Key informants revealed that that IAC had created new methods of treating or testing for HIV/AIDS, for example resistance testing. The leader of the viral load camp NJ31 said;

“Because of IAC, there is direct and specific treatment of HIV according to its capacity. IAC has) born a number of tests that are more specific to what she/he is treating hence producing more efficient results, for example less misallocation of resources (drugs) and a stronger hand on the pandemic.” For TC27 said that “It gives a clear picture of what the doctors and clinicians are supposed to treat in form of dispensing drug and handling clients.”

4.5.3 On the limitations

Though IAC has created all those benefits, counsellors revealed that it was also in a sort of way creating environment of having people who are hopeless in life for example, NK31 said “some clients you talk to them, but they have given up on life already. They say “musawo ndiwakanyiivu, ngendakufa” if is absolutely right to guess that they pick this from their colleagues that are not on
this program or from the way we separate them. We have nothing to do about this, because truth is they need special attention.’

It was revealed by key informants that there no male involvement in counsellor at Luwero Health Centre IV Art Clinic. Here the problem was more apparent when the leader of viral load camp (NK31) said;

“A male patient kept a wound on his private part for a year yet he used to see a counsellor but he couldn’t disclose the condition to the counsellor since the counsellor was a female. It was only when the situation was serious that he disclosed the condition to a doctor later on.”

All counsellors revealed that there was limited manpower in form of counsellors who would attend to the patients on IAC, yet it was the same counsellors carrying out all the other forms of counselling like health talks, triaging, drug dispensing and more. as a result, there was a tendency of working to get rid of the work load than to create impact.

IAC has born has created stigma among patients which is proving deadly among patients themselves where they feel like they have nothing left but to die. The leader of the viral camp (NK31) said;

“Some patients you talk to them, but they have given up on life already, they say musawo ndiwa kanyiivu ngenda kufa which literally means ‘doctor am going to die’”

One of the clients that were interviewed and were not in IAC insinuated it was terrible being a part of the program.

Poverty among clients. Clients on IAC are scheduled to show up at the clinic every once a month, but some clients don’t show up because of transport issues, so their situation gets worse.

Non-disclosure. “a client will tell you only what they want you to hear and other stories. So you have actually been addressing a lie for an issue.” This of course complicates the sessions and bars it from progressing.
Tradition and religion. Here, the health worker gave an example of a teenager mother who was presented at the clinic when she was prime, she was given all the care and education on PMTCT but surprisingly the PCR, the baby last was positive and an on-suppressor. IAC was initiated and was given a next appointment which she missed, she appeared after she found the baby’s files were put in the lost to follow shelf (six months) with a story. That when her baby got something like a burn on her left side chin, she consulted a traditional doctor who said her baby was bewitched. The death of her baby was a wakeup call to her.

4.6 Discussion of the Findings

4.6.1 The role of intensive adherence counselling
Participants were interviewed to find out the role of IAC to people living with HIV and AIDS. Based on the findings of the study, different reasons were given according to different patients and health workers. Some of the respondents said that the reason as to why they had been put on IAC was to reduce the viral load. Another respondent said that the role of IAC was to make sure their loved ones never got infected with the disease. For others, beyond knowing that they were enrolled on IAC didn’t have any other information regarding its role. All counsellors’ major say was that intensive adherence counselling was to ensure that every HIV positive patient at the ART clinic suppressed (that every patient’s viral load was below 1000Acopies/mL). This was supposed to be done through intensive counselling sessions, monitoring and evaluating treatment for patients, because it is scheduled that patients on IAC are intensively monitored through pill counting, confirming evaluating them according to the number of sessions and bleeding them which includes having viral load and resistance tests done for them. The researcher wrapped up that all the views from the patients put together with those of the key informants drove to one point; that is suppression. This is in correlation with UNAIDS (2014) which talks about the 90-90-90 strategy and USAID, 2017 that clears elaborates IAC, its role and how long it’s supposed to take.

4.6.2 The benefits of intensive adherence counselling to PLWHAS
As a result of implementing intensive adherence counselling, there has been an increase in the number of first trackers at the ART clinic. A first tracker as described by the viral load camp leader, NK31 referred to an HIV/AIDs patient who has a suppressed viral load, such patients were also described as being in clinical stage one; they are not sick both physically and most especially psychologically. This is in partial fulfilment of the UNAIDS, 2014 target of having all HIV
positive patients suppress by 2030. This study finding proves wrong a study done by Kiran (2014) which concluded that regardless of the age differences, there was not any impact of IAC on adherence and viral suppression. The above study on the contrary revealed that there were really impressing results brought about by the implementation of IAC. Health workers NK31 and NJ23 concluded that despite the many limitations, IAC at the ART clinic at Luwero Health Centre IV has culminated into a number of success stories.

The study also revealed that patients had as a result of being on intensive adherence counselling changed a number of things, especially to do with their habits for example, in the way they fed, sex lives, drinking habits, and also brought about a sense of remorse among them that pushed for betterment of the way they were handling their lives. For example, KP who stopped having unprotected sexual affairs. This finding was all about behavioural change. Behavioural factors are a key factor towards improving adherence to treatment and consequently suppression. According to research the factors that determine the success and failure are either medical or behavioural and if IAC has been able to bring about such changes as those discussed and revealed by the PLWHAs when narrating their experiences, then the program is a success and this finding is proves true by Gugulethu (2007); who concluded that there were no positive changes that would be expected when dealing with people living with HIV unless their psychosocial context is put under consideration.

All the three health workers revealed that IAC had born a number of tests that helped a health worker be more specific to what she/he was treating like resistance testing, viral load testing which had been added to the previous tests which was causing more efficient results for example TC27 said that the tests help them know if modal that suits a patient very well so that treatment becomes a little easier, patients on second and third lines are given different attention from those on the first line and patients are put on exact drug combinations, there is less guess work done. There has also been improvement in the health workers’ quality of treatment. IAC has provided them with more information on how to deal with different patients and this is all to the benefit of the HIV/AIDs service recipients.
4.6.3 The limitations of Intensive adherence counselling

Poverty among clients. Clients on IAC are scheduled to show up at the clinic every once a month but some clients don’t show up because of transport issues, causing limited monitoring of the progress of the patients. Poverty could be exhibited when without them talking, one could read from their stories, they could be in a better position if their economic conditions were bettered. A number of them complained about transport costs and food shortage, for example NA’s case and KP who wished the program used to fund them rather than just providing them with advice. One counsellor explained and said that there are problems that go beyond them, for example a scenario where a counsellor advises a client to feed well and a client says she/he doesn’t have the food. The counsellor is torn with hopelessness for all they can offer is not more than counselling and facilitating these people with the necessary medication. On the contrary to Michael (2014)’s study that proved IAC as an appropriate program for a resource limited setting like this that the study covered, it’s unfortunate that the issue of limited resources was still complicating its success. It turns out to be one of the major limitations.

Another challenge encountered by PLWHAs was limited manpower in form of counsellors to attend to them. It was the same counsellors carrying out all the other forms of counselling like health talks, triaging, drug dispensing and had to have IAC sessions with these patients as well. This forced the counsellors into working to get rid of the work load rather than to create impact onto those that were worked on. IAC clients received limited time therefore, or ended up seeing a counsellor that wasn’t of their preference. This finding is in correlation with that of Sentebale (2017) who talked about the overwhelming numbers of patients against the number of counsellors. This makes it difficult to produce effective results just as found by the study.

There also seemed to be a challenge of privacy. Different patients preferred differently how and when they see their counsellors. This was an aspect that the counsellors were aware of, TC27 reported that they did but due to the fact that there was a mismatch between labour and work load, they had less say over it. Patients found trouble seeing a counsellor of their preference. Such came with a lot of repercussions for example inconsistency in storytelling, turning up on their appointed returning dates and creating rapport between the patients and their counsellors was harder.
Lack of male involvement, all the counsellors said there was need for male counsellors to attend to IAC patients. There was apparently no male counsellor at Luwero Health Centre IV ART clinic. Such left no option to especially the men who would as a result keep silent with pressing issues. An example was provided by the viral load camp leader about a patient who kept a wound on his private part a secret. It was after a very long time when he was in a terrible state that he whispered to the doctor who reached out to the counsellor for his rescue. When he was asked why he didn’t speak all that while, he said he felt embarrassed to talk about it to a female. It was then that he was referred to Mulago for a test. May be it wouldn’t have gone that far if there was a male counsellor in place. This was a serious challenge.

From the findings of all patient respondents, very few clearly saw the impact of what IAC was helping them to achieve because over 4 respondents said they saw no difference before they came to IAC and when they were on IAC. None of the patients could clearly describe the concept IAC insinuating that there was less if no education about intensive adherence counselling which turned to be a burring factor to the success to the implementation of the program.

Another challenge that came with receiving IAC was stigma. This was proving deadly to patients. The program made some of them feel like they had nothing left but to die so they rather lived in isolation. They compared themselves to their colleagues who were not on IAC. They felt like they were in a better position, for example NC who in her experience said that she knew that since she was told to join the program, she is badly off and she was going to die. She was hopeless. Such problems were the ones found out during the research. This finding correlates with that of Seyles, J et al., (2009). This study concluded that stigma is very common among people grouped together with a similar problem.

4.6.4 Comparison of patients on IAC with those were not on IAC

Non suppressors are HIV/AIDs patients that have their viral load more than 1000 copies/ml of their blood while suppressors are those that have less than 1000 copies/ml. According to the health worker NK31, those that were on IAC were in a relatively much worse position than those that were not on IAC. This was the reason they separated them. They needed special attention, for the more the virus multiplies in a human body, the frailer they become.
Both the groups had very limited information about this program (Intensive Adherence Counselling). When BRF and RAFH were asked to spot the difference between the counselling they received and IAC, they could barely talk. All they knew was that IAC was a counselling program for those that weren't suppressing. As for the clients on IAC, they knew they were on the program but majority could only tell why. Beyond this, one could hardly get information from such clients about IAC.

Their stories were different of course, that is; there were different ways in which they had contacted the syndrome. Some were born with it and others contacted it in their later stages of life. They seemed to have a common cause though. Poverty and ignorance were outstanding issues in their stories. Referring to their stories, it can be concluded that those that got infected at their later stages in life were pushed by factors revolving around lack, apart from one respondent. Regardless of whether a patient suppressed, is still on the program or was there but suppressed, there is much more to be done beyond IAC, for there are more common causes.
CHAPTER FIVE: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction
This chapter presents summary, conclusion and recommendations drawn from the findings of the research conducted. The study was conducted to find the benefits and limitations of intensive adherence counselling in Luwero health centre IV ART clinic.

5.1 Summary
Intensive adherence counselling as a program recommended by the ministry of health has been taken in by the health workers at the ART clinic Luwero health centre IV. It is supposed to ensure that the 90-90-90 strategy of ensuring that all HIV patients in Uganda have suppressed by 2030. The concept has been understood by the health workers at the facility that was under study; that is; they described it according to the UNAIDS strategy of 2030 On the other hand, patients hardly can comprehend it but rather heed to what their health workers said, for the belief that they know better. The patients referred the researcher to their health workers for information about the concept. Its role is to ensure that each of the HIV patients suppresses (his/ her) viral load. After description of IAC and different views on its role were given by both the health workers and the patients.

Another positive impact which was revealed by the patients was modification of behaviour as a result of intensive adherence counselling for example, respondent KP testified that she had started using condoms which she never used before, that she went back on her tendency of having unprotected sexual affairs with men regardless with an "I don't care attitude" after all she was positive. Because of the IAC sessions, she didn't want to kill people's sons as she put it.

It was revealed that a number of tests that help a health worker to be specific to what she/he is treating like resistance testing viral load testing started as a result of IAC in Luwero Health IV ART clinic and has also improved the quality of the services they provide to their clients.
Some of the challenges encountered by the PLWHAs as recipients of IAC was lack of male counsellors at the ART clinic in Luwero Health Centre. This was a serious limitation as it caused
a lot of absenteeism especially when it came to the men. An example of this was the story narrated by the viral load camp leader where a man kept a wound around his private part. He feared to discuss it with a female counsellor. Another challenge that was revealed from the study was that results were slow coming which made the patients not to see the effects of IAC on individual basis early in time so most of the patients saw that there was no change in their health. Also the major challenge of poverty among patients revealed by the respondents made some to miss showing up at the clinic for counselling and other related services.

On comparison of patients on IAC and those not on IAC, it was revealed that those on IAC had a viral load of more than 1000 copies/ml than those not on IAC who were below 1000 copies/ml. Also through observation it was clear that patients who were not on IAC were more comfortable, confident and looked better physically compared to those that were on the IAC program. The ones that received normal counselling found it easier talking about their experiences than those that were on the program. There was a relatively small difference between the two categories.

5.2 Conclusions

From the finding of the study conducted, it was concluded that intensive adherence counselling is a good program. This is because of the impact its presence and implementation has caused onto the people living with HIV and AIDS and their health workers at Luwero Health Centre IV ART clinic. Its intended role right from its birth and implementation by the infectious disease institute and the ministry of health remains the same which is called suppression. However, broken down into the small assumed roles by the health workers and patients, the role is still one. Experiences of the patients were obtained which were all different but seemed to relate in a certain way… for example in terms of the challenges they faced due to the syndrome, and the IAC program in general. IAC has come with a number of benefits which have been mentioned and analysed earlier to both the PLWHAS and their health workers for example the success stories, behavioural change among the clients and self-satisfaction and quality improvement among health workers. However, the program has and is still facing a number of challenges and most of these emanated from the fact that resources were also limited both at the ART clinic and among the PLWHAS themselves. These are really strong, many and seem to multiply day in day out (the problems) and if not handled with justice, they would further put the programs to halt.
5.3 Recommendations

Based on the findings from the study carried out, the following recommendations are made; Intensive adherence counselling is a very good program. From the study above, it is revealed by the health workers (the counsellors) that a number of success stories have been obtained as a result of the program. This is due to the production of a number of the resistance and the viral load tests which give rather clearer results than the former CD4 count method which had a number of weaknesses.

Components that make up Intensive Adherence Counselling could be enhanced. More can be done to make it more efficient and also to demarcate it. That is; to differentiate it from other types of counselling. There seems to be a problem spotting the differentiate the kind of counselling under study from the others considering that all the forms especially those that are carried out in relation to HIV/AIDS are all directed towards adherence.

The male involvement factor should be taken into consideration. All the concerned bodies should work towards enrolling male counsellors. It might partly solve the problem of absence when it comes to men. It might also increase the number of success stories not only because it might encourage men to turn up but because it will leave space for choice. That is; maybe not all the females would want to see a female counsellor.

5.4 Suggestions for future research

There is need to carry out assessment studies on IAC (Intensive adherence counselling) in many other health units all over the country. This will enable the ministry of health and other Nongovernmental organizations in monitoring and evaluating the progress or regress of the program and how far it has dug in combating non suppression.

More research needs to be carried out basing on the kind of gender imbalances exhibited in the above conducted research. Reasons as for why there is reluctance in turning up for ART when it comes to men as stated by one of the key informants in this research when asked whether it’s a common tendency for men on IAC to miss appointments
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Appendix I: Key informant interview

Hello, my name is Nabachwa Jane, a 22 year old female Ugandan third year student of Makerere University pursuing a Bachelor's degree in Social Work and Social Administration. As part of my requirements for my degree, I am carrying out a study research on the benefits and limitations of intensive adherence counselling for PLWHAS. I would like to discuss with you a few questions about the mentioned topic. Be assured that this information will be for academic purposes only and your identities will not be disclosed. The session will take at most thirty minutes, there are no specific benefits attached to it and therefore it will take only your willingness to take part of it.

Unique identifier.................................................................

Sex.........................................................................................

Name of interviewer.............................................................

Date.........................................................................................

Time started.............................................................................

Time ended............................................................................... 

SECTION A

Profile of respondent

1. State your level of education

2. State the nature/type of your job

3. How often do you have patients on Intensive adherence counselling?

4. What is the procedure that is undertaken when the patient is on intensive adherence counselling?

5. How many times do you carry out Intensive adherence counselling in a month?
SECTION B

To find out the role of intensive counselling

5. What is the role of intensive adherence counselling to the different stakeholders like the patients, health workers, and government?

6. When do we tell that a patient needs Intensive adherence counselling?

7. How do we know that intensive adherence is a success?

9. What are the parameters for considering that intensive adherence counselling is a failure

SECTION C

To find out the benefits of intensive adherence counselling

10. How is IAC impacting in the way HIV treatment is being administered?

11. What are the benefits of being on intensive adherence counselling by the patient?

SECTION D

To find out the limitations of intensive adherence counselling

12. What are the challenges that hinder the success of intensive adherence?

THANK YOU VERY MUCH FOR YOUR COOPERATION
Appendix II: In-depth Interview guide

Hello, my name is Nabachwa Jane, a 22-year-old female Ugandan third year student of Makerere University pursuing a Bachelor's degree in Social Work and Social Administration. As part of my requirements for my degree, I am carrying out a study research on the benefits and limitations of intensive adherence counselling for PLWHAS. I would like to discuss with you a few questions about the mentioned topic. Be assured that this information will be for academic purposes only and your identities will not be disclosed. The session will take at most thirty minutes, there are no specific benefits attached to it and therefore it will take only your willingness to take part of it.

Unique identifier..........................................................................................

Sex.............................................................................................................

Name of interviewer..................................................................................

Date...........................................................................................................

Time started.............................................................................................

Time ended..............................................................................................

PROFILE
Name: .................................................................

Sex: .................................................................

Age: .................................................................

Session number: ..................................................

SECTION A
Social demographics of the respondents

1. What is your level of education?
2. What do you do to earn a living?
3. Do you get any form of support from any organisation in terms of basics for example food, medication and so on?
4. Are you married?
5. When did you find out you were HIV positive?
6. When did you start medication?
7. When did you start going for counselling?
8. What were the initial reasons for seeing a counsellor?
9. Do you still see the counsellor? And how often?

SECTION B

To find out the role of intensive adherence

10. Why do you think you need intensive adherence counselling?
11. Have you ever had failure of adherence? and how many times has this happened?
12. What was your prior condition before you joined Intensive Adherence counselling?

SECTION C

To find out the benefits of intensive adherence counselling

13. What has been the result of intensive adherence counselling to you as an individual?
14. How has intensive adherence counselling been different from the prior counselling you had?
15. What changes have you had to do as a result of intensive adherence counselling?

SECTION D

To find out the limitations of intensive adherence counselling

16. What are some of the challenges that you have found during the sessions of intensive adherence counselling?
17. What have you done to overcome these challenges?

THANK YOU VERY MUCH FOR YOUR COOPERATION
Appendix III Interview Guide

Interview guide for PLWHAS and are not on IAC but rather on normal Adherence Counselling.

Hello, my name is Nabachwa Jane, a 22 year old female Ugandan third year student of Makerere University pursuing a Bachelor's degree in Social Work and Social Administration. As part of my requirements for my degree, I am carrying out a study research on the benefits and limitations of intensive adherence counselling for PLWHAS. I would like to discuss with you a few questions about the mentioned topic. Be assured that this information will be for academic purposes only and your identities will not be disclosed. The session will take at most thirty minutes, there are no specific benefits attached to it and therefore it will take only your willingness to take part of it.

This tool is to be filled by PLWHAS that are on normal adherence counselling. To be filled, the respondent must have consented. This interview guide is to provide views about counselling as a whole, and what they think about intensive adherence counselling.

Unique identifier........................................................................

Sex....................................................................................................

Name of interviewer........................................................................

Date..................................................................................................

Time started..................................................................................

Time ended..................................................................................

SECTION A

General questions

1. When did you find out that your status had changed?
2. How did you find out? (Probe to get a story)
3. When did you start on ARVs?
4. Who is your caretaker?
5. Are you a member of any HIV/AIDs association?
6. Do you obtain any form of assistance in form of basic needs; food, shelter, ARVs?
7. Have you received any counselling services?
8. Do you still receive them?
9. How often do you see a counsellor?
10. Before you enrolled on counselling, what was your prior condition?

**SECTION B**

**To find out the role of IAC**

11. Which kinds of counselling do you know which are carried out at this clinic?
12. Have you heard of intensive adherence counselling?
13. How would you differentiate it from the kind of counselling that you obtain?
14. Some of your colleagues are part of this program, can you mention some of the reasons they get from this kind of counselling

**SECTION C**

**Benefits and limitations**

15. What are the good things that come as a result of?
   (i) You receiving counselling
   (ii) Your colleague receiving IAC

16. Do you think this kind of counselling benefits any other group of people apart from the patient?
   a) Yes
   b) No.

If no, skip part B and proceed to Section D.

17. If yes, which other group, please mention it and give reasons why?

**SECTION D**

18. What do you think has changed as a result of providing this kind of counselling?
   (i) Good changes
   (ii) Bad changes
   (iii) No effect

19. Please mention what you see would bring this kind of counselling from being effective.

**THANK YOU FOR YOUR COOPERATION**