The effects of antiretroviral therapy on HIV-positive individuals in Wakiso District, Uganda

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ABSTRACT

AIM
The aim was to explore the experiences of HIV-positive individuals before and after gaining access to antiretroviral therapy in Wakiso District, Uganda and how antiretroviral therapy impacts certain aspects of those living with HIV, such as sexual behavior, support systems, faith and personal identity.

METHODS
Based on secondary data analysis of “Life On Antiretroviral Therapy: People’s Adaptive Coping And Adjustment To Living With HIV As A Chronic Condition In Wakiso District, Uganda” by Steven Russell (2015). The data was reanalysed using the conceptual framework from Bronfenbrenner’s ecological systems model.

RESULTS
Six main themes will be presented including personal life after HIV diagnosis, acceptance of HIV status, disclosure of identity, changes in sexual behavior, different types of support systems, and increasing faith and strength from God. After receiving antiretroviral therapy, the quality of life seemed to improve for some of the participants. Participants described their experiences living with HIV/AIDS, such changes in personal goals and perception of self, immediate acceptance of positive HIV results, disclosure of identity to certain people, the different types of support offered from each support system they have, abstaining from sex and the use of contraceptives against future transmission. Furthermore, participants have also described an increase of faith and belief in God in order to cope with HIV/AIDS.

CONCLUSION
People living with HIV in Wakiso District, Uganda have described significant changes in their lives after receiving antiretroviral therapy. These changes affect them both physically and emotionally therefore more research must be done to investigate the influence of antiretroviral therapy on wellbeing.
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INTRODUCTION

HIV in Uganda

Human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) continues to be one of the world’s most significant public health challenges, especially in low- and middle-income countries. AIDS is the end-stage disease of HIV infection. According to the National Institutes of Health (NIH), HIV kills or damages cells of the body’s immune system, predominantly the CD4+ T-cells, which the body needs to fight off infection (2013). Essentially HIV destroys the body’s ability to fight infections and certain cancers.

Currently, 7.2% of the people in Uganda are living with HIV (UNAIDS, 2012). HIV prevalence has been rising since its lowest rate of 6.4% in 2006 (UNAIDS, 2012). Despite the increases, the life expectancy is about nine years higher than that in 2000. This is likely due to the greater access to treatment for people living with HIV (PLWH) (UNAIDS, 2012).

Although there is no cure for HIV, antiretroviral treatment (ART) has drastically changed the face of history. Currently, ART decreases the viral load to undetectable levels using standard laboratory techniques, in order to increase immunological recovery and decrease clinical development and fatalities from HIV infections (Moreno et al., 2010). Additional to the proved efficacy of ART in prolonging life, studies have suggested that greater access to ART has reduced people’s anxiety and pressure to get tested for HIV, thus increasing the probability of engaging in risky behavior (Tenywa, 2008). ART gives people the assurance of a long life despite the risky behaviors that led PLWH to start ART.

In 2003 national guidelines for the execution of ART in Uganda aspired to create high-quality ART programs and to guarantee suitable levels of care throughout the country (Katabira et al., 2003; Ministry of Health, 2005). By the end of 2005, there was enough funding to provide 55,000 patients (i.e. half of the 110,000
individuals in need of ART in Uganda) with ART (Ministry of Health, 2005). By 2006, the number on ART had increased to 80,000 patients and the estimated number in direct need of ART had grown to 165,000 (Larsson, Okong, Thorson, & Ekström, 2007).

A study by Larsson and colleagues (2007) examined health worker’s perceptions and the type of HIV care received in three different delivery models of ART at St Francis Hospital in Kampala, Uganda. External donors funded two of the clinics, while out-of-pocket payments funded the third clinic (Larsson, Okong, Thorson, & Ekström, 2007). Despite the fact that all three clinics were situated in the same hospital, care given and quality of care differed considerably. Health workers at all three clinics identified the absence of collaboration between other HIV programs and low patient adherence as the main challenges (Larsson, Okong, Thorson, & Ekström, 2007). Furthermore, more women than men obtained ART through the externally financed programs (Larsson, Okong, Thorson, & Ekström, 2007). Larsson and colleagues also found that externally funded programs provided more comprehensive care because of greater number of staff and more common laboratory monitoring compared to the private clinics (2007). Larsson stated that, “many patients chose to pay a monthly average equivalent of US$60 for ART in return for privacy and access to drugs without HIV disclosure requirements” (2007). According to Larsson and colleagues (2007), stigma and fear of abandonment seem to be the key barriers to ART accessibility.

Furthermore, PLWH play a vital role in the deterrence of HIV transmission if they employ safer sexual behaviors. A study conducted by Musinguzi and colleagues (2014) estimated the prevalence and factors associated with safer sexual behaviors amongst PLWH in Uganda, who were seeking care from civil society organizations. The study concluded that the prevalence of consistent condom use amongst the sexually active was 41.3% (Musinguzi et al., 2014). Consistent condom use was higher in PLWH who didn’t use alcohol, were educated about reinfection with a new strain of HIV, and had a regular sexual partner who was HIV negative (Musinguzi et al., 2014). Prevalence of abstinence
was 22.2% (Musinguzi et al., 2014). Abstinence increased with age from 9.4% among PLWH less than 25 years to 40.5% among those greater than 50 years. Abstinence was extremely low (2.5%) between PLWH who were married (Musinguzi et al., 2014). Therefore, effective interventions are needed to reduce alcohol consumption and more strategies are needed to accommodate PLWH who desire more children.

Uganda was one of the first and only countries in Africa to have clearly reversed its HIV epidemic (UNAIDS, 2012). Uganda developed the first and the strongest planned and best supported National AIDS program, which included the largest national and international staffing. Uganda was receiving $18 million in support, whereas other countries received between $1 million to $4 million (Mann & Tarantola, 1991). Slutkin and colleagues suggested that, “openness about AIDS, destigmatization, and promotion of care and compassion were also important components of the Ugandan program” (2006). Although there was no intrinsic difference between the Ugandan program and the programs in neighboring countries, there was a difference in implementation. The primary difference between Uganda’s program and that of the other countries was the concentration, depth, extensiveness of programming of its behavioral change campaign, the degree of involvement of all sectors, the practicality and expansion of the district level work deep into communities, including the involvement of local churches and mosques, and the high level of financial support (Slutkin et al., 2006).

**HIV Prevention**

Abstinence, committing to monogamous relationships, and condom use are collectively known as the ABC strategy for HIV prevention. This approach urges young adults to delay their age of first sexual intercourse or to abstain until marriage, in order to maintain Christian and Islamic ideals to prevent HIV infection. In addition to abstinence, this approach encouraged the population to eliminate casual sex and to participate in monogamous relationships. The final
component of the ABC approach is to promote correct and consistent condom use.

The ABC approach was popular in Uganda before the mid-2000s, but by the mid-2000s, it was obvious that the simple ABC approach was not working. Interventions needed to account for socio-cultural, political, economical, legal and other related factors (UNAIDS, 2010).

Nowadays, combination prevention programs combine many different HIV prevention interventions into a single, all-inclusive program. Combination prevention programs consider issues specific to each location, such as levels of infrastructure, local culture and traditions and populations most influenced by HIV (UNAIDS, 2010). Combination prevention programs can be implemented at the individual, community and population levels (UNAIDS, 2010). Uganda united an assortment of biomedical, behavioral and structural strategies, including rigorous attempts to change social standards concerning partnerships outside marriage (Green et al., 2006), investment in condom endorsement, the involvement of leaders at all levels of society, and a obligation to the destigmatization of HIV and to the liberation of PLWH and affected populations (UNAIDS, 2001).

**HIV Stigma**

HIV-related stigma is changing due to the global scale up of ART, however, stigma remains to be an ongoing concern in Uganda (UNAIDS, 2010). A qualitative study conducted by Mburu and colleagues described the decline of stigma as a result of collective activities of groups of people living with HIV (PLWH); they found that gender, family, relationships, socioeconomic factors occurred to be key influencers of stigma (2013). ART and group-based approaches in the delivery of HIV services opened up new ways, for the joint cooperation of PLWH, to confront HIV stigma and become instruments of social transformation (Mburu et al., 2013). According to Mburu and colleagues, interventions for decreasing HIV stigma must be magnified beyond those that
intend to increase the strength and self-management strategies of individuals, to those that develop the capability of groups to collectively manage HIV stigma (Mburu et al., 2013). “Such interventions should be gender sensitive and should respond to contextual social, economic and structural factors that drive stigma” (Mburu et al., 2013).

**Religion in Uganda**

Religion has influenced how HIV/AIDS are viewed within their respective social contexts since the beginning of the pandemic. The rapport between religion and HIV/AIDS have been equivocal, split between religious principles in caring for PLWH/AIDS, and levying certain ‘ethical’ policies on society and social interactions in agreement with the corresponding religious beliefs. Furthermore, religion is also a vessel of coping mechanisms that provides PLWH/AIDS a way of continuing their lives (Park, 2005).

In sub-Saharan Africa, many people are religious and religious establishments have been documented as playing both supportive and harmful parts toward people living with HIV/AIDS (Mbonu, van den Borne, & De Vries, 2009). For instance, religion tends to stigmatize people as “saved” or “sinner”, “pure” or impure”, “us” or “them”, and reinforces the wide-ranging social stratifications where stigma develops (Mbonu, van den Borne, & De Vries, 2009). Although religion can strengthen stigmatization of PLWH/AIDS, many people living with HIV/AIDS express faith and religion as a valuable coping method; religion gives people a chance to accept they have sinned but through prayer they can be forgiven for their sins (Mbonu, van den Borne, & De Vries, 2009).

A study by Vanya Choumanova investigated how female cancer patients coped with breast cancer and how religion was used as a coping mechanism. Choumanova found that religious coping was an important coping mechanism for a majority of informants (2006). One participant reported that, “the only resources we have here are our beliefs and our faith. Religion and spiritual faith will help me bear my illness” (Choumanova, 2006). Although Chile is a different
country than Uganda, it can be deduced that since both are very religious countries and in the case of a life-threatening disease, the same would hold true for the Ugandans living with HIV/AIDS. For example, a study on women living with HIV in Uganda concluded that spirituality and faith were the main means of coping (Hodge & Roby, 2010). For these women, support from individuals whom they attended religious meetings with and a conviction that God provided them with the support to live their life, were supposed empowering factors for resolve in difficult situations they encounter in relation to their HIV status (Bakibinga, Vinje, Mittelmark, 2014).

As a foundation for one’s principles and ambitions, religious meaning may be an essential coping mechanism during stressful events (Park, 2005). Religion affects the way stressors are identified and the kinds of coping mechanisms used to counter the consequences of those stressors (Bakibinga, Vinje, Mittelmark, 2014).

**Overview of the Original Data**

This thesis is based on a research project conducted by Steven Russell in Wakiso District, Uganda. Russell’s research project analyzed people’s self-management of HIV following the access to ART and their quality of life. For people living with HIV (PLWH) in low-income countries like Uganda, the availability of effective treatment makes HIV a manageable condition. ART has restored people’s health, however challenges still remain. PLWH must take medicine daily for the remainder of their lives, along with living in harsh economic circumstances. The specific research objectives in the proposal were to (Russell, 2014):

- Document how patients access ART at three different service delivery sites, and their self-management strategies and reported adherence levels
- Analyze the alterations in ART patients’ lives and their self-management methods since
• Examine the factors illuminating a more radical change in people's identity, activities and outlook since becoming HIV positive and starting ART
• Assess people’s feelings of accomplishment (or disappointment) and self-esteem arising from their efforts
• Through qualitative data analysis, to investigate the implications of the above transformations in life, strategies and achievements through the course of change
• Through quantitative analysis, to measure outcomes indicative of change, notably mental health, physical health, and economic conclusions (asset portfolios and a food security index)
• Assess the factors affecting people’s transition through qualitative and quantitative data analysis
• Evaluate whether ART and the better health of PLWH modify cultural understanding of HIV and process of stigmatization

Conceptual Framework

Bronfenbrenner’s ecological systems model is used to frame this qualitative analysis. The model is used to explain factors influencing PLWH’s experiences and it recognizes the interlinking relationship between individuals and their environments. His model consisted of four environment levels - the microsystem, the mesosystem, the ecosystem, and the macrosystem – with each level having a unique influence on the development of a person (Bronfenbrenner, 1979). According to Bronfenbrenner (1979), the microsystem, which represents Level 1, was defined as “a pattern of activities roles, and interpersonal relationships experienced by the developing person in a given setting with particular physical and material characteristics” (p. 22). In Russell’s study, the microsystem can refer to the surrounding environment with which the individual closely interacted, such as a classroom, home, friends’ houses, and neighborhood.
Bronfenbrenner (1979) described the mesosystem, which represents Level 2, as “the interrelations among two or more settings in which the developing person actively participates” (p 25). The mesosystem is the association between Microsystems such as the relationship between family experiences and work experiences, between work experiences and peer experiences, and between home experiences and neighborhood experiences. For example, individuals who experience troubles at home may withdraw and perform badly at work.

The exosystem, which represents Level 3, is “one or more settings that do not involve the developing person as an active participant, but in which events occur that affect or are affected by, what happens in the setting containing the developing person” (Bronfenbrenner, 1979, p. 25). The developing person refers to the individual that the researcher is examining. The exosystem could suggest connections between a social setting in which the person does not have an active role in and the person’s immediate context (Onwuegbuzie, Collins, & Frels, 2013). For instance, a person’s experience at work or school may influence their interactions at home. Onwuegbuzie, Collins, and Frels give an example where “a newborn baby might reduce the numbers of hours slept by the mother’s/father’s spouse/partner, which, in turn, might affect the productivity levels of the spouse/partner at work, which, in turn, might affect the relationship between the spouse/partner and his/her supervisor and/or colleagues, which, in turn, might affect the relationship between the couple at home” (2013, p. 5).

Lastly, the macrosystem, which represents Level 4, refers to “consistencies in the form and content of lower-order systems (micro-, meso-, and exo-) that exists, or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such inconsistencies” (Bronfenbrenner, 1979, p. 26). In other words, the macrosystem would involve the larger cultural context immediate to the individual. In Russell’s data, the macrosystem could include societal belief systems, ideologies, politics, and cultural traditions.
Significance of the Study

This thesis is highly relevant to global health and all persons interested in how HIV and ART affect relationships, sexual behavior, and personal identity. Through this thesis, information about how people live with HIV in a low-income country and how their experiences have changed throughout their treatment period can be highly educational to people in the healthcare field and highly motivating to others suffering from HIV/AIDS. Although there is data on coping
strategies for living with HIV, more in-depth analysis must be done on specific areas, in order to establish how HIV and ART transform one’s life.

This thesis attempts to analyze certain aspects of the data, which has not been presented before. It seeks to evaluate more detailed experiences of PLWH such as their sexual behaviors, support systems and how it influences their wellbeing, changes to personal life, goals, and choices, their openness with their HIV status, and how their faith has affected their life with HIV.

**Thesis Aim**

The aim of this study is to explore the experiences of HIV-positive individuals before and after gaining access to antiretroviral therapy in Wakiso District, Uganda and ART’s impact on PLWH’s sexual behavior, support systems, faith and personal identity.

**Specific Objectives**

1. Examine the sexual behavior of PLWH’s lives after HIV diagnosis
2. Consider the different types of support systems
3. Document shift in personal life
4. Assess PLWH’s openness of HIV status
5. Investigate their faith and religion after HIV diagnosis

**Research Question**

How do HIV and ART alter sexual behaviors, support systems, personal identity, disclosure of status, and religious faith?

**Methodology of original data**

Qualitative research is used to investigate and understand social phenomena. Interviews are one method of qualitative data collection, which involves direct
interaction with individuals in a small group or individual setting (Hancock, 1998). This thesis is based on qualitative secondary data analysis of the interviews from Russell’s data. His work has not been published in any peer-reviewed journal, however the qualitative data, the documents on study protocol, and the information sheet can be accessed online once a proposal for its use is approved.

**Research Design and Setting**

A quasi-experimental research design was used to evaluate people touched and untouched by HIV and ART (Russell, 2015). Using both qualitative and quantitative methods, researchers collected data on PLWH self-management approaches on ART, the reasons that facilitated or hindered their self-management and coping, and quality of life and mental health consequences suggesting effective self-management (Russell, 2015). Data was collected from January 2011 to March 2012 in Wakiso District, Uganda. Wakiso District was selected because of its close proximity to the capital city Kampala, the ease of access to the study population, and the existence of an established governments and non-governmental organizations (Russell, 2015).

**Participants and Sampling**

Participants were recruited from ART delivery sites in Wakiso District, including the HIV clinic at the government hospital in Entebbe, three government health centers that are associated with Entebbe hospital, and the Entebbe branch of a reputable NGO – The AIDS Support Organization (TASO) (Russell, 2015). Eligible participants had to have been on ART for more than one year (Russell, 2015).

The sampling process occurred in two steps and aimed to recruit 42 participants (16 from Entebbe hospital; 10 from the three Health centres; and 16 from TASO), however only 38 participants were recruited for the qualitative component
(Russell, 2015). A list of eligible patients was gathered at each location using patient files. The lists were then categorized by gender and age and a systematic random sample from each site was compiled (Russell, 2015). The sampling interval was purposefully set to choose a larger random sample than actually needed to account for refusals to participate, contact problems, and the need to recruit more participants to pre-test the qualitative tools (Russell, 2015). Overall, 94 possible participants were selected. From the list of 94, 42 participants for the study were purposively sampled to guarantee an equal number in males and females, a range of ages, a variety of patient experiences, and to ensure some participants (n=3) on a second-line ART regimen were included (Russell, 2015). After four people refused to participate 38 participants (18 male and 20 female) were interviewed (Russell, 2015). 13 were from HIV clinic, 11 were from the three associated health centers, and 14 were from TASO (Russell, 2015).

**Data Collection Methods**

For each of the 38 participants, two types of qualitative interviews were conducted:

1. The first type of interview was an unstructured interview, which asked for the participants' life history, especially emphasizing their experience with HIV illness, treatment and recovery (Russell, 2015). For many of the participants, the interview could not be completed within one session because of the time constraints, so the interviewer returned after a few days or weeks to continue the interview. If more than one visit was required to complete the interview, the visits would usually be completed within two months. These interviews were not recorded, but thorough notes were written after the interview by the interviewer (Russell, 2015). The original data does not explain why the interviews were not recorded.

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¹ Second-line ART regimen is for patients that have not seen positive results from the first line regimen. In Uganda, first line regimen includes AZT+3TC+NVP or EFV. Second line regimen includes ABC+ddl+LPV/r or TDF+3TC or FTC+LPV/r (USAID, 2012).
2. The second type of interview was done after the first was completed. It was a semi-structured interview that called for a comprehensive understanding of the key characteristics around HIV self-management (Russell, 2015). This interview was taped, then transcribed and translated into English.

These interviews sought to explore the changes in an ART patients’ lives and their coping strategies since becoming HIV positive and starting ART. For instance, interviewers would ask the participants about their openness to disclosure their status, work and daily activities, relationships, reflective and spiritual endeavors, support system, and connections to civil society organizations (Russell, 2015). Furthermore, sometimes the researchers would ask them to elaborate on how they felt about their life, what they thought the future would hold, hopes and motivations, and whether they were fulfilling the roles others expected of them.

**METHODOLOGY OF THESIS**

**Analysis of Secondary Data**

The aim of secondary analysis is to find new relationships and understanding that have not been previously stated in the original analysis. From the secondary data, relevant information was analyzed in order to find changes PLWH experience.

The interviews were thoroughly read and analyzed using thematic analysis. The text from the dataset was developed into codes, and then the codes were expanded into themes. This method of analysis is based on Braun and Clark’s qualitative thematic analysis to give a fuller description of the investigated phenomenon, which in this case is the different experiences of HIV-positive individuals after gaining access to ART. There are six phases of analysis: familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and finally producing the report (Braun & Clarke, 2006).
Table 1: Example of the process from text to code to theme

<table>
<thead>
<tr>
<th>Text from dataset</th>
<th>Codes</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Most importantly, I did not disclose to my children and none of them is aware and because they were young, they do not know what their father died of.”</td>
<td>Will not tell children about HIV status</td>
<td>Disclosure of identity</td>
</tr>
<tr>
<td>“I took the courage and believed the results because I was very sick yet I wanted to have life.”</td>
<td>Immediate acceptance of HIV infection</td>
<td>Acceptance of status</td>
</tr>
<tr>
<td>“Since I am on the island and independent, I don’t have many people to support me and moreso, being the first born, I am the one who give the rest support.”</td>
<td>No other support</td>
<td>Lack of other support systems</td>
</tr>
</tbody>
</table>

Since there is an abundance of data, only recorded interviews with participants between the ages of 40-49 have been analyzed. This age group was chosen due to the nearly equal distribution between the genders and inclusive to employed individuals. Employed individuals were preferred in order to keep the analyzed group similar. Furthermore, the first interview was not considered since it was unrecorded and based on the researcher’s memory; it may be a biased account of the interview. Out of 38 participants, only these 12 interviews were examined:

Table 2: Demographics of selected interviewees

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age at 1st interview</th>
<th>Sex</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bridge</td>
<td>42 years</td>
<td>Male</td>
<td>Transporter</td>
</tr>
<tr>
<td>Fred</td>
<td>47 years</td>
<td>Male</td>
<td>Casual Laborer</td>
</tr>
<tr>
<td>Jerry</td>
<td>44 years</td>
<td>Male</td>
<td>Policeman</td>
</tr>
<tr>
<td>Aaron</td>
<td>40 years</td>
<td>Male</td>
<td>Primary School Teacher</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Gender</td>
<td>Occupation</td>
</tr>
<tr>
<td>--------</td>
<td>------</td>
<td>--------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>Angelo</td>
<td>47</td>
<td>Male</td>
<td>Fisherman</td>
</tr>
<tr>
<td>Davis</td>
<td>43</td>
<td>Male</td>
<td>Farming</td>
</tr>
<tr>
<td>Tom</td>
<td>44</td>
<td>Male</td>
<td>Guest House attendant</td>
</tr>
<tr>
<td>Suzan</td>
<td>43</td>
<td>Female</td>
<td>Grass weaving, stone breaking, petty business</td>
</tr>
<tr>
<td>Happy</td>
<td>46</td>
<td>Female</td>
<td>Bar business owner</td>
</tr>
<tr>
<td>Hannah</td>
<td>46</td>
<td>Female</td>
<td>Business</td>
</tr>
<tr>
<td>Dorcas</td>
<td>42</td>
<td>Female</td>
<td>Teacher</td>
</tr>
<tr>
<td>Nana</td>
<td>46</td>
<td>Female</td>
<td>Farmer</td>
</tr>
</tbody>
</table>

**Ethical Considerations**

The researcher obtained ethical approval for the study from the Uganda Virus Research Institute and the University of East Anglia, UK, however the Uganda National Council for Science and Technology granted the overall approval (Russell, 2015). Informed consent was then obtained from all the participants, the consent form included the purpose of the study and its procedures, the contact information for the researcher, a statement that participation is voluntary and that the respondent has the right to withdraw at any time, an assurance of confidentiality; and the risks and benefits associated with participation in the study (can be found in Annex 2). Pseudonyms were used to ensure confidentiality.

**RESULTS**

Through the secondary data analysis, six main themes were developed:

1. Personal life after HIV diagnosis.
5. Support systems.
6. Increasing Faith and Strength from God
Personal Life After HIV Diagnosis

This theme explores the changes to the participants’ personal life after gaining access to ART. It includes perception of self, changes in personal life, and changes to personal choices.

Participants have described changes in their appearance due to the ART. Some noted the darkening of their skin or the weight loss they have experienced, however none of the examined participants suggested that they are unhappy with their appearance or that they were unhappy with the ART.

Nana, a 46-year-old widow, was asked if her HIV status influenced how she perceived herself, she answered:

“I perceive myself as I used to do. However, the age has changed my appearance. But again, I was born a small woman and the only thing that has changed is that I was looking healthy but now, I have changed because I have to struggle on my own.”

Participants also described how HIV constantly made them sick or how ART was changing their physical appearance but Nana described how HIV made her stronger:

“Courage! Nowadays everyone is strong and determined because HIV is not a personal problem; it is universal so, you have to tell them.”

Individuals suggested that there was no change in their lives, however some of the participants explained how HIV has changed their daily activities, workload, or habits. Davis, a single 43-year-old male, who makes his living from farming stated:

“We were dealing in petty business like selling matooke, delivering milk and it is where I got problems and we were robbed and I had to quit the business and I came and got a friend and we started dealing in cows. I have been through very many problems of money much as I got this illness.”

When he was asked how work has changed, he said:
“I decided to sit home now because I do not have anything to do.”

In another interview, the interviewer asked Fred, a separated 47-year-old male who makes a living as a casual laborer, how his life has changed after his HIV diagnosis. Fred responded:

“My way of having fun changed... Going to disco, I no longer do that... The most important thing I have done is stopping to sleep around with women and also avoiding heavy work.”

Participants have also expressed their new life goals and their need to do different things after their diagnosis. Furthermore, participants described their need to leave monetary means or build a house for their children. When the researcher asked Fred, if there are things he does differently now, he responded:

“What I see is I mostly do things I used not to do.... Like to prepare for my children’s future. I have built a house for them, have taken them to school and to set up something they can develop after I die.”

Hannah, a 46-year-old widow, was infected by her late husband and passed on AIDS to their children. Before ART, she was adamant of not conceiving new children but things changed after receiving treatment.

“The only things that changed were; not having more children and also building a home where I will rest from. However, since my children have become a disappointment, I would like to get other children after all we were told that we were free to conceive. I so much want to have a child who will console me because for the time I have worked for these children, none of them has paid me back.”

Almost all of the twelve participants have described some kind of change in their lives. Some participants have described changes in their appearance, while others have described changes in their character. Participants believe that HIV has made them mentally stronger and put more pressure on their lives. Other participants have noted changes in their work schedule; the ART makes them more tired and they cannot accomplish the same amount of work as they use to. Furthermore, individuals have described how they lack sufficient financial resources to support themselves due to the fact that they can no longer work as much. Additionally,
others have described how their leisure activities have changed, such as not going out to parties and courting women. Other changes participants have expressed include the desire to create something or leave behind something for their children. Lastly, one participant conveyed the wish to have more children since ART will prevent them from dying and because her current children will not support her.

**Acceptance of HIV status**

Participants seemed to immediately accept their diagnosis with HIV. When they received their test results, they predicted that HIV could be the culprit behind their recent episodes of sickness. Dorcas, a 42-year-old female, reported that:

“I took the courage and believed the results because I was very sick yet I wanted to have life.”

Hannah stated:

“I believed them because I had lost two children and I came to believe that my children had died of AIDS... when I also remembered my husband’s sexual relationships, I couldn’t doubt the result but to get courage.”

Tom, a separated 44-year-old male, said:

“I accepted that I am HIV positive and thus a person living with HIV. This is the most important thing. When you know your status then life goes on and you know you are living positively...”

Aaron, a cohabiting 40-year-old male, disclosed:

“I accepted the results without any doubt.”

Lastly, Angelo, a married 47-year-old male, explained:

“For me I was not taking it as an issue to go for an HIV test but now when I went to have a test and they told me that I am positive, I remained firm and did not get any fear... I accepted.”
Participants described how they immediately accepted their diagnosis because they were sick or they had kin that died of AIDS. Acceptance was common in this group of participants and none of them were in denial. Acceptance of HIV-status may be due to encouraging clinicians and confidantes as well as a promotion of hope and acceptance of HIV-status in the community. These circumstances may have helped the participants in Russell’s study to immediately come to terms with their sickness and develop a positive therapy relationship with ART by making the necessary lifestyle changes that promoted adherence and acceptance.

**Disclosure of Identity**

Participants differed in their preferences of disclosure, from whom they told to how much they told. Some participants have disclosed their status to the people close to them, health workers, or people from their support groups. Some individuals do not openly disclose their status but some like Dorcas, was not worried if people find out about her status.

“I did not tell her (friend) but I am sure she is aware because there are times when I sleep at her place if I am to go to hospital... At times I get to think that they probably know I am on treatment...I am always free with them and it doesn’t affect me at all.”

Others seem to openly disclose their status, such as Fred:

“Yes, I disclosed to most of my people.”

When asked why he disclosed to more people such as his friends, he explained that:

“Because of the things I have gone through. I tell my friends whether infected or not yet test and if they ask me why, I tell them to test. I tell them that testing is good; if they test negative, they continue to take care of themselves not to catch the illness. And if they test positive, to start treatment and live longer and I also encourage them.”

Another participant, Aaron, told more people about his status as time passed:
“... Some of the people who did not know now know because I told them that I am infected with HIV. This is because at first, I told a few but I later told others.”

It should be noted that while some participants did not openly admit their status to their children, others were fairly open about it to his kin but not to others. Tom stated that:

“By the time I got to know, I had my daughters and they are the people who were close to me because I had already separated with the woman I had... She got to know and she understands because I told her everything and she told me that... I do not involve many people in my business.”

Only one of the 12 interviewees did not disclose their HIV status to anyone. Davis does not want anyone to know his status, when asked if any of his relationships has changed with other people, he responded:

“It has never changed because I have never told them my secret.”

When asked why he wouldn’t disclose his status, he explained that:

“What stops me from telling other people is the rumor mongering... So when you go to one corner and you find they are talking about you, you start getting worried and you lose weight and you start developing high blood pressure but if you know that you kept your secret well and it is your doctor and your treatment supporter who know your status, no one else should know.”

Another interviewee, Nana, did not disclose her HIV status to her children:

“Most importantly, I did not disclose to my children and none of them is aware and because they were young, they do not know what their father died of.”

She also said:

“I wouldn’t want people to know my status, in fact I don’t want them to know apart from a few who already know.”

Responses varied between each participant; while some participants chose to openly disclose their status, others chose to only tell their close family members
or not tell anyone at all. Similarly, the reasons for disclosure also varied between each participant. While some stated that they revealed their identity to potential partners because they want to make sure neither of them contracts another infection, others divulged their status so they can get treatment or they can get help from their family members. While some of the participants did not want to disclose their status to the whole community, they never strayed from getting the treatment needed for their survival. The participants have also stated that the stigma associated with HIV is not as bad as it use to be due to the fact that ART can decrease transmission and increase life span.

Every participant was asked if they believed that people with HIV should disclose their status if they enter a new relationship. Below are some examples of what the participants have said.

Tom said:

“Yes because when you know, because for us when we get to know, we have to be ambassadors. You have to protect the one is not infected from getting infected. The other thing is that if they are all infected, there are other infections that one of them may not be having, so you make sure that it is not transmitted to the other party.”

Aaron said:

“What motivated me to tell others is to get help like my family on the side of my children; I had to tell other people that are related to me to see that they help me in my situation.”

Bridge, a single 42-year-old male, said:

“It would be good to disclose to this partner and then use condoms if she is not infected. If she is infected and have decided to have children, then you could go back to the Basawo and get to know the conditions in which you will have them.”

Happy, a 46-year-old widow, explained:

“Yes, it is good because if you hide this how will you take your drugs?”
Lastly, Suzan, a 43-year-old widow, stated:

“They should tell them their status... So that they get themselves entangled into that problem knowingly, instead of realizing it later and cursing that they were infected without them knowing and they get to know about it through rumours and that affects you so much.”

**Changes in Sexual Behavior**

Participants experienced a change in their sexual behavior whether they started abstaining from sex, avoiding sexual relationships, or practicing safe sex.

Happy described that she no longer has relationships with anyone:

“My body changed a lot because I got a rash and I stopped relationships with men. From the time I got to know that I have HIV I abstained from having sex with men, I do not drink alcohol.”

Bridge described a similar situation, except he had someone to go back to:

“My life really changed; I gave up on getting into relationship with a woman. I realized that getting into the relationship had no benefit and I had been through these times. I decided to give up on this. Then I decided to get back with one of the women, who had my children. But after getting back together, I realized that she was moving too fast and I felt like I wanted to leave her. I was heart broken by this and it seems that is the problem I have.”

Jerry explained that he and his wife don’t normally have sex anymore but when they do, they use condoms:

“I have a wife at home but still we use a condom and at times we don’t do have sex and I come back here. It is like this; at first, my wife told me that she tested from her home because I had asked her to go and test and she told me that she had tested at her home and that she was found negative. I said that is nice; that is why you see I tested we start using condoms and that is what we have been using.”

While some of the participants did not elaborate on their sexual activities, they did tell the researchers whether they were engaging in sexual relations, abstaining, or practicing safe sex. Some participants were abstaining from sex
altogether and were avoiding relationships but others had a significant other whom they regularly practice safe sex with. Contrastingly, there was one participant who did not disclose his HIV status to anyone; therefore, he would still engage in risky sexual behaviors with multiple partners.

**Support System**

Countless support systems have been documented for the participants. Support systems ranged from family, friends, church, groups, health workers, etc.; however not all the participants had support systems. Some of them lacked any type of support system while others lost their support system.

Familial support seemed to be the most common type of support amongst the participants. The families offered them emotional, financial, and/or child support.

Nana stated that:

“My relatives have really supported me and my children. They give me money when I don’t have and some of my older children stay with some of my relatives.”

Dorcas also described her family as being her major supporters:

“There is only one and that is my husband. I also have a brother who supports me though I have never disclosed to him. He helps me oversee the construction of my house since it is on the mainland.”

Tom explained that his sister was his financial supporter:

“... Sometimes I get a prescription of high blood pressure and it is not available at the clinic and doctors write it on a paper and I tell her that I do not have money but I need to buy medicine. She tells me to go to the clinic or pharmacy and establish how much it is. I then call her and tell her the price and she then tells me where to find and pick the money to buy the medicine. Just like recently, the house I am renting was increased and I wanted her to help me top up about thirty thousand. She asked me when I needed the money and I told her that same month and she said
that it was okay when time comes for payment, I should go and pick it and things like that.”

He also described that his family is what motivates him to keep going:

“What gives me courage to move forward, is my family, my children give me a lot of courage. They tell me that daddy we shall study, finish school and help you, you will be okay.”

Happy also turned to her sister for help, but more for advice and emotional support:

“Yes, when I have problems I can talk about them with my sisters and they give me advice or comfort.”

Bridge also stated that his mother and sister help him but he provided them with monetary means:

“When you visited the last time, you saw the children at my mother’s place. I take there some money to help them but it is mainly for food. The rest of the support for them comes from my mother. There is another child who stays with my sister but I just send only money for school fees; I do not buy food or clothes for him. Though I do not buy for them clothes, I have to do the rest like paying school fees and feeding them. The burden of those near falls on me, and I have no one to lend the helping hand.”

Another participant, Aaron, explained how his family helps take care of his children:

“My family members help me on the side of the children. There I mean like my Dad, my grand mother, and brothers and sister have contributed much.”

Suzan named her daughter as her support system, however she supports herself financially:

“I have a daughter who can take me to hospital when I am sick.”

Angelo explained that he did not have any other support besides his wife:
“It is only my wife and I. We try to diverse means as you know like growing food for us to eat, looking for money to buy cloths, taking us to the hospital when we fall sick and we live/survive like that.”

Although family is commonly mentioned, many of the participants were religious, however only one of the interviewees named the church as a support system. When asked about support systems, Happy said she had none, however, she only seemed to be interested in financial support. When further questioned, she described how her sisters and the church have helped her:

“When I was sick and bedridden they used to pray for me and the reverend would come to my home. He used to preach to me the word and that gave me encouragement.”

While work does not provide a foundation for emotional support, it usually gives the interviewees a way to take their mind off their illness. Dorcas described how work is beneficial to her health:

“My work helps me because it keeps me active thus allowing me exercise by lifting things. Another thing is that because I am busy most of the times, I forget about the illness.”

Other support systems were also mentioned by one interviewee, Hannah, described a number of support systems, such as TASO, previous business partners, and her interviewer.

“TASO gives me medication and for financial support, apart from those friends who give me merchandise on credit I have no one else. There is a certain businessman whom I owe 850,000 shillings and whenever I explain to him, he listens. I also owe Mr. Mayega 900,000 shillings and bags of sugar and also owe another one 400,000 shillings and those are the ones who have been supporting me via business… It’s you who brought me a bar of soap and also supported me when my father was sick because I was overwhelmed and confused. Apart from you, no one else supported me and also encouraged me until my father passed on.”

The interviewer and the interviewee did not previously know each other, however because they spent so much time together during the interview, the interviewee seemed to have established a connection with the interviewer.
Some of the interviewees lack any kind of support system, although this does not mean they are suffering more emotionally or financially. There does not seem to be a difference between the emotional states and the quality of life between interviewees who have a support system and interviewees who don’t. Fred stated that:

“No support… I support myself. Most people don’t know I have HIV.”

Happy also described her current lack of support:

“I do not have any support and I am taking on the responsibility for my children on my own.”

She explained that she used to have support but she had lost it:

“I had female friends that abandoned me because they were very scared. Well, I did not blame them because I was indeed scary so I did not get angry at them.”

Another individual that described a lost of support was Tom:

“The situation is that when I was working in a hotel, I reached a point when I was helping many friends, getting for them jobs or their relatives but when I lost my job, the other person who was supposed to be close to me was my wife. She also abandoned when I lost my job. Even those I used to help; I thought that they would help me but they also abandoned me so I remained alone.”

Support systems included familial support, spousal support, support from church, support groups, work, and other support systems. Family support seemed to be the most common support group for many of the participants. The participants’ families would help them financially, caring for the children, and/or emotionally. Oddly, none of the participants directly mentioned support from their friends, however they did mentioned support from the people from church (through prayers), group support – where they would meet to discuss their situation and clear their minds, and how work provided a way to forget about the illness. Lastly, one participant said that she also thought of the interviewer as one of her main supporters because the interviewer had been there for her when her
father had passed. The same participant also described the men who lent her money and the TASO who gave her medication as her supporters. Some participants have also described how they do not have any support systems or how they have lost their support system. One participant described how her infection has scared off her friends but she did not blame them for leaving her.

**Increasing Faith and Strength from God**

All of the 12 participants were religious and they also described an increase in faith. Some of their accounts are listed below.

Nana described her relationship with God:

“I had faith even before however, after knowing my status, it somehow increased and I started asking God to give me life and also thank him for the time I have so far lived.”

Tom also described his support from God and the increase of his faith:

“My faith has increased. I see every day I am alive, every morning, I see something new coming and I say a prayer, I see myself going through difficult situations and I see every thing moving on well. So my faith just increases.”

Fred described the strength God has given him and how God guided his life:

“It’s God who gives me strength... It is only God who strengthens me and also the drugs that I take that enable me to work... It is God who gives us strength because He’s the one who created us. If you don’t pray to Him when going to bed it’s bad but if you pray to him, he gives you the courage and power. You can’t know that you are to get this amount of money but it’s God who does everything, He makes us travel safely, He decides whether you will get an accident or not.”

Furthermore, Suzan described how God helped her through her sickness and improved her emotional health:

“During such times I leave it up to God because it is from him that all good things come from, he brings both the good and the bad, I give it all to God and I ask him to give me courage to go through the problem. Then
Participants described God being a major part of their lives and how their faith has changed after their diagnosis with HIV. Some participants have described how God has given them strength to move forward in their lives and how God makes the decisions for everyone. Furthermore, another participant has explained how seeing himself alive everyday and overcoming the obstacles in his life has made his faith stronger. Another participant has stated her faith increased because she didn’t believe she’d live that long but with God’s protection she has hope that she will be alive. The participants in Russell’s study did not perceive HIV as a punishment from God but rather an obstacle from God that they will overcome with the help of their faith. The believed that their path was chosen for them by God, thus HIV was a part of what God intended for them.

**DISCUSSION**

The thesis offers insight into how PLWH describe their experiences after gaining access to ART. This analysis provided a broader understanding of how Ugandan PLWH have experienced changes in their lifestyle, in order to support or challenge previous knowledge and findings from other studies.

**Discussion of Results**

The aim of this thesis was to explore the experiences of PLWH before and after gaining access to ART in Wakiso District, Uganda. Specific aims included examining the sexual behavior of PLWH after HIV diagnosis, considering the different types of support systems, investigating any shifts in personal life, assessing openness and disclosure of HIV status, and studying PLWH’s relationship with God after their HIV diagnosis. After detailed secondary data analysis, six main themes were established. The main themes include personal
life after HIV diagnosis, acceptance of HIV status, disclosure of identity, changes in sexual behavior, support system, and increasing faith and strength from God.

Overall, the themes suggest that after receiving antiretroviral therapy (ART), the quality of life seemed to improve for some of the participants. Participants described their experiences with living with HIV/AIDS, such changes in personal goals and perception of self, immediate acceptance of positive HIV results, disclosure of identity to certain people in their lives, the different types of support offered from each support system they have and abstaining from sex and the use of contraceptives against future transmission. Furthermore, participants have also described an increase of faith and belief in God in order to cope with HIV/AIDS.

Although the participants mention stigma, it was clearly evident that some participants are at ease when disclosing their status. A study by Nattabi et al., concluded that PLWH in Uganda continue to experience HIV-related stigma and this has a negative impact on their quality of life (2011). Verbal abuse and negative self-image are the major forms of stigma in this region, while less PLWH experienced healthcare neglect, social isolation, fear of contagion, and workplace stigma (Nattabi et al., 2011). The participants in Russell’s study support this idea since they noted that the healthcare workers were more viewed as support systems. Furthermore, a study by Tsai et al., concluded that internalized stigma inhibited disclose of seropositivity to intimate social ties other than sexual partners (2013). While the Russell’s participants believed that it was imperative to disclose to their intimate partners, some participants refused to disclose to their family members and friends. This may be due to internalized stigma, however none of the interviewees have stigmatized themselves or thought that their lives were over after their HIV diagnosis. This may also be due to the theory that ART can attenuate the stigma of HIV. Tsai et al. also investigated this phenomenon by specifying internalized stigma as the dependent variable, adjusting for time of therapy and additionally socio-demographic, medical and psychosocial aspects (2013). Researchers concluded that over the course of
treatment internalized stigma gradually decreased, with the largest decline detected during the first two years of treatment (Tsai et al., 2013). The decline seemed to be due to ART-influenced improvements on HIV symptoms, physical and psychological health and depression severity (Tsai et al., 2013). Lastly, improved social support may have been a protective influence against future and internalized stigma (Takada et al., 2014) on the participants in Russell’s study. The material and emotional resources provided by support systems are critical for the wellbeing of people living with HIV.

Infants of HIV-positive mothers are at a higher risk for HIV infection and when children are born with HIV, the disease develops rapidly (Sofolahan & Airhihenbuwa, 2012). With the increased accessibility of ART, the fear of death or the inability to have healthy children has largely decreased. Kastner et al., found that access to ART and the knowledge of reduced chances of mortality, morbidity and HIV transmission has improved experiences of HIV-positive women to childbearing, as well as discretely managing conflicting social expectations and clinical recommendations regarding conception (2014). One of the participants in Russell’s study portrays this conclusion by initially fearing to conceive more children, but decided to try and have more children once she gained access to ART and received the knowledge that creating a healthy child was possible. Realizing that they could give birth to a HIV-negative baby and sustain their own wellbeing to provide for their children gave them hope for the future (Kastner et al., 2014).

A study by Shuper et al. (2013), on HIV-positive women and men receiving ART in KwaZulu-Natal, South Africa, concluded that most sexually active participants engaged in unprotected sex during the four weeks before the study. 46.9% of women and 35.4% of men reported that they had unprotected sex with an HIV-negative or HIV status unknown partner (Shuper et al., 2013). This is very different than the responses from the participants gathered from Russell’s study; nearly all of the participants were practicing safe sex or abstaining from sex. Shuper described the reason for the copious amount of unprotected sex in HIV-
positive women, correlated to possessing little HIV prevention knowledge and being in a relationship characterized by low perceived power, receiving threats and experiencing abuse by partners, nondisclosure of HIV to one’s partner, and being unmarried or living separate from their partners (2013). HIV-positive men participated in risky behaviors due to negative attitudes toward condoms, experiencing depression, seeking help for infection from traditional healers, poor ART adherence, and younger age (Shuper et al., 2013). These notable differences can most likely be attributed to the ample supply of education and support given to the participants in Russell’s study. They were instructed on the importance of containing HIV, methods of prevention, and reduction transmission rates by proper condom use and abstinence.

**Connecting Analysis with Conceptual Framework**

Bronfenbrenner’s ecological systems were previously presented to guide the secondary data analysis. The framework has helped the author to analyze and establish relationships within the secondary data. These systems were used to categorize the participants’ responses, as a way to organize the themes in the results. A number of participants provided information that would fall into one of Bronfenbrenner’s systems. Furthermore, the model made it more feasible to understand the different levels of interconnectivity between the systems. Bronfenbrenner’s model provided multiple analyses on individual, interpersonal, organization, community and societal aspects.

A number of participants described experiences similar to that of Bronfenbrenner’s systems. Some participants described their daily activities and interactions with their surrounding environment, such as their workspace, neighborhood, and homes. These experiences are referred to as the participants’ microsystem. At the micro level, participants have explained changes in their daily life, interactions with family and friends, as well as connections with clinicians and health workers.
Some participants also described the association between their microsystem, such as how their clinical experiences contribute to their work or how their home experiences affect their relationships with family members or peers. For example, one individual described how troubles with their test results and symptoms of HIV have caused them to decrease their workload. These experiences are collectively known as the mesosystem.

Furthermore, participants may describe situations that refer to their exosystem. For instance, financial problems might reduce the amount of resources the family has, which in turn, might cause the head of the family to be anxious, which in turn can affect that participants relationship with the head of the family. Since experiences with the exosystem are not frequently described, the analysis tends to disregard the exosystem.

Lastly, some participants’ experiences commonly fall into the macrosystem, which involves the larger cultural context immediate to the individual. The macrosystem that participants described includes the stigmatization of HIV within the community, abiding to their faith, and ethnical principles of the community.

This thesis mainly focuses on the experiences within the microsystem or the macrosystem due to the abundance of data within that area and the ease of systematic correlation.

**Reflexivity & Limitations**

According to Green and Thorogood (2004), “reflexivity is the recognition that the researcher is part of the process of producing the data and their meanings, and a conscious reflection on that process” (p. 194). Qualitative research requires reflexivity about how the background and cultural attributes of the researchers affect the data produced. Addressing the element of reflexivity will help produce credible analysis that addresses the issues of subjectivity (Green & Thorogood, 2004. In an ideal world, the researchers would be invisible, removing any
potential bias that the individual may bring to the data collection or analysis, however, since this is not an ideal situation, other measures must be taken to counteract bias. One strategy is to overtly account for subjectivity by considering how the researchers had an impact on the research and data (Green & Thorogood, 2004).

Overall, the original data provided a wealth of useful data however the study was still subject to various limitations. The authors of the original data did not provide a complete and thorough description of how they did the interviews and why they did it in that way. For instance, the researchers did not disclose information on themselves and why they did not record the first interview. Moreover, the identity of the original researcher as a professional who has previously worked and studied in the research area might have influenced the quality and the type of responses given by the participants. Although we cannot account for bias within the original researchers, we can scrutinize the subjectivity of the current thesis writer. The writer is an American student with no prior knowledge of Ugandan culture and society. This may impact the interpretation of the interviews due to her lack of knowledge in the area and the preconceptions she may hold about HIV/AIDS.

The use of secondary data also may impact the analysis of the data since the original researcher and the thesis writer may have different views on the subject and different ways of interpreting the data. Also the use of secondary data makes it difficult to contextualize the selected quotes. The writer acknowledges the causes of bias and has a constant awareness of how this may impact the data analysis. Furthermore, the writer has explicitly described the steps taken, including how the analysis will be pursued and how a theoretical framework helped shape her analysis of the interviews.

Furthermore, the original interview was conducted in the native language of the Wakiso District and was translated into English. The translation may not have captured the complete scope of what the participant intended to express. Lastly,
the writer’s lack of contact with the researcher and the participants may have impacted the level of analysis. Also by not partaking in the data collection, the writer may have missed out on the opportunity to observe non-verbal communication, which can be very important to the analysis of the interview.

**CONCLUSION**

The participants have described their experiences of living with HIV/AIDS after receiving access to ART. Participants have described the positive effects on their wellbeing, notably on their physical health. Participants described changes in their sexual behavior, such as adhering to safe sex or abstaining from sexual relations. Moreover, they have also described changes in personal goals and perception of self, such as a positive self-image as well as the desire to provide for their children. Furthermore, the participants explained their immediate acceptance of positive HIV results and their disclosure of identity to certain people in their lives. The participants have also expressed the variety of resources provided by different types support systems. Furthermore, participants have also described an increase of faith and turning to God in order to cope with HIV/AIDS. Further research should be done on the implications of these experiences in order for humanitarian organizations to try and improve the conditions of people living with HIV/AIDS.

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Annex 1: Information Sheet

A. Information sheet for the study: 'Living on ART'
(For adult ART participants: qualitative component - cases)

Hello, my name is …………………………………I am a social science interviewer from the Medical Research Council.

What is this study about?
This study will look at the lives of people who have been taking ART for more than 1 year.

The study will ask people about events and changes in their lives that happened earlier as a result of illness, and also about their lives since they started taking ART. The study will ask people about the health services they use and the support arrangements available to them. It will also ask people about their health, their family circumstances, their friends and social activities, and the work they do. The study is also interested to hear about people’s hopes and fears for the future, and their feelings about the changes that have happened to them. The study aims to improve our understanding of how people are managing on ART, and how to improve support services for people living with HIV. This part of the study will consist of three or four visits over the next 12 months.

Why do we want to include you in the study?
You have been asked to participate in this study because you are accessing ART from (a) TASO, (b) the Entebbe A hospital or (c) a government health centre.

What’s involved in taking part in the study?
Your participation in the study is voluntary. You can decide freely whether to participate or not. If you do agree to take part, you can still decide to withdraw at any stage of the study without any penalty.

I am requesting you to take part in this study which will involve three or four visits by me over the next 12 months. I can meet you at the facility / hospital or somewhere else you find convenient or at your home.

What are the risks and benefits of your participation?
There is little if any risk to you from taking part in this study. We will not take any blood, give any drugs, or conduct any medical procedure. We will only ask questions and make observations about your experiences. You may find some questions sensitive or embarrassing. You can refuse to answer any question asked.

There are no direct benefits to you from participating in this study. However, I hope that this study will provide information to improve support services for
people living with HIV. You will receive a small token of thanks after each visit (a bar of laundry soap or a kilogram of salt).

**What happens to the information you give?**
Your answers will be written down by the interviewer during the interview. Afterwards they will be added together with all the information from the other people taking part in the study. We will write-up the results, they will be given to the people in charge of health services, and they may be published in research journals.

**Will the information you give me be kept confidential?**
Yes, all information collected from you (and other participants) will be kept in strict confidence. Your name will not be written on the interview sheets or the account of the visit. Your name, and any details by which you could be identified, will not be used in any reports.

**What happens now?**
If you agree to take part we can arrange a time for our first meeting/visit. If you are not ready to decide now, I will contact you in the next few days to see if you are interested in taking part.

**Who can you contact for more information?**
If you have any questions or would like any more information before deciding to take part, please feel free to contact Dr Janet Seeley or Ms Flavia Zalwango on telephone 0417-704000. If you have questions about your rights as a research participant, you can contact the Uganda Virus Research Institute (Ethics Committee Chairperson) on telephone number 0414321962.
Annex 2: Consent Form

Consent form for the study: ‘Living on ART'
(For adult ART participants: qualitative component - cases)

Consenting to participate in this study

☐ I have read and understood the information sheet that describes this study, or I have understood the explanation offered, and I agree to take part and I understand that I do not need to respond to questions if I do not want to and can withdraw from the study at any time without penalty.

☐ I give permission for short extracts from my interview to be used for research purposes (including publications and reports), so long as they are strictly anonymous.

Name of participant:

_____________________________________________________

Signature / finger print of participant:

_____________________________________________ Date: _____________

Signature of investigator/ interviewer:

_____________________________________________ Date: _____________