AIDS DOESN’T KILL ITS CUSTOMER: UNDERSTANDING BARRIERS TO ACCESS AND ADHERENCE TO HIV TREATMENT AMONG YOUNG PEOPLE LIVING IN PERI-URBAN UGANDA

by

SIMONE CARTER

B.A., University of British Columbia, 2007

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE

in

THE FACULTY OF GRADUATE STUDIES

(Health Care and Epidemiology)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

August 2009

© Simone Carter, 2009
ABSTRACT

Introduction: Uganda’s current success story in its battle against the HIV/AIDS epidemic is being questioned as recent research has estimated a possible increase in both prevalence and incidence across the country, specifically within the rural southwest. Rakai district has long been recognized as the Ugandan epicentre of HIV/AIDS and appears to again be in a vulnerable positive. As universal care to free HIV treatment has only been available in Uganda in 2004, there remains a paucity of literature understanding the current barriers to access and adherence to HIV treatment programs, especially among young people living in the heavily affected southwestern community of Lyantonde. Therefore, objectives of this thesis were to: 1. Investigate the current barriers young men and women experience when attempting to access HIV treatment and care in town; (2) Document the barriers young women and men living in this peri-urban setting experience when attempting to adhere to HIV treatment while living in town; (3) Develop community appropriate recommendations to address the results found within this study. Results: Participants not accessing treatment identified three barriers to treatment access: relationship-based fears, workplace-based fears and food insecurity leading to treatment attrition. None of the participants who were accessing treatment at the time of the study were able to remain adherent to their treatment, all of which reported that food insecurity was their only barrier to adherence. Discussion: these data indicate that the conditions for young people living with HIV/AIDS in Lyantonde remain incredibly difficult and, despite free treatment availability, many are not able to access care and those who are, face such food security-related barriers that they are unable to adhere to their treatment. Recommended actions include community based farming programs for young people living with HIV/AIDS, small household farming workshops, micro-credit groups for young people and finally the training of couples to offer dual counselling for both concordant and discordant couples during HIV/AIDS educational workshops and testing times.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>v</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>vi</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td></td>
</tr>
<tr>
<td>CO-AUTHORSHIP STATEMENT</td>
<td></td>
</tr>
<tr>
<td>1.0 INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>1.1 INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>1.1.1 Young People Living with HIV/AIDS in Peri-urban Uganda</td>
<td>1</td>
</tr>
<tr>
<td>1.1.2 HIV Treatment in a Peri-urban Truck Stop Town</td>
<td>3</td>
</tr>
<tr>
<td>1.2 LITERATURE REVIEW: SOCIO-ECONOMIC BARRIERS TO ACCESS AND ADHERENCE HIV/AIDS TREATMENT</td>
<td>3</td>
</tr>
<tr>
<td>1.2.1 Barriers to HIV/AIDS Treatment Access</td>
<td>4</td>
</tr>
<tr>
<td>1.2.2 Barriers to HIV/AIDS Treatment Adherence</td>
<td>5</td>
</tr>
<tr>
<td>1.3 THESIS OBJECTIVES</td>
<td>8</td>
</tr>
<tr>
<td>1.4 THESIS OUTLINE</td>
<td>9</td>
</tr>
<tr>
<td>1.5 REFERENCES</td>
<td>10</td>
</tr>
<tr>
<td>2.0 UNDERSTANDING BARRIERS TO HIV TREATMENT ACCESS: A CASE STUDY FROM A PERI-URBAN UGANDAN TRADING CENTRE</td>
<td>16</td>
</tr>
<tr>
<td>2.1 INTRODUCTION</td>
<td>17</td>
</tr>
<tr>
<td>2.2 METHODS</td>
<td>18</td>
</tr>
<tr>
<td>2.2.1 Study Setting</td>
<td>18</td>
</tr>
<tr>
<td>2.2.2 Data Collection and Analysis</td>
<td>20</td>
</tr>
<tr>
<td>2.3 RESULTS</td>
<td>23</td>
</tr>
<tr>
<td>2.3.1 Sample Characteristics</td>
<td>23</td>
</tr>
<tr>
<td>2.3.2 Barriers to HIV Treatment Access Among Young People in Lyantonde</td>
<td>24</td>
</tr>
<tr>
<td>2.3.2.1 Job loss</td>
<td>24</td>
</tr>
<tr>
<td>2.3.2.2 Partner fears</td>
<td>25</td>
</tr>
<tr>
<td>2.3.2.3 Food insecurity, failure to adhere and attrition</td>
<td>28</td>
</tr>
<tr>
<td>2.4 DISCUSSION</td>
<td>29</td>
</tr>
<tr>
<td>2.4.1 Strengths and Limitations</td>
<td>33</td>
</tr>
<tr>
<td>2.5 CONCLUSION</td>
<td>34</td>
</tr>
<tr>
<td>2.6 REFERENCES</td>
<td>37</td>
</tr>
<tr>
<td>3.0 BARRIERS TO HIV TREATMENT ADHERENCE: STARVING TO SURVIVE IN PERI-URBAN UGANDA</td>
<td>40</td>
</tr>
<tr>
<td>3.1 INTRODUCTION</td>
<td>40</td>
</tr>
<tr>
<td>3.1.1 Barriers to Adherence to HIV Treatment</td>
<td>41</td>
</tr>
<tr>
<td>3.1.2 Research Objectives</td>
<td>41</td>
</tr>
<tr>
<td>3.2 METHODS</td>
<td>41</td>
</tr>
</tbody>
</table>
3.2.1 Study Setting .................................................................................................................... 41
3.2.2 Data Collection and Analysis: Phase 1 ............................................................................ 43
3.2.3 Data Collection and Analysis: Phase 2 ............................................................................ 45
3.3 RESULTS .................................................................................................................................. 46
3.3.1 Sample Characteristics ...................................................................................................... 46
3.3.2 HIV Treatment Adherence Among Youth in Lyantonde .................................................. 47
  3.3.2.1 Town living: without land ownership or subsistence farming .................................... 47
  3.3.2.2 Lack of income potential to purchase food ................................................................. 49
  3.3.2.3 Inability to meet dietary requirements to take HIV treatment .................................. 52
  3.3.2.4 HIV treatment and water supply .............................................................................. 55
  3.3.2.5 Seasons, food insecurity and treatment adherence ..................................................... 56
3.4 DISCUSSION .......................................................................................................................... 57
  3.4.1 Strengths and Limitations ............................................................................................... 61
  3.4.1 Corresponding Actions ..................................................................................................... 63
3.5 CONCLUSION ....................................................................................................................... 64
3.6 REFERENCES ........................................................................................................................ 66

4.0 DISCUSSION .......................................................................................................................... 72
4.1 DISCUSSION .......................................................................................................................... 72
  4.1.1 Barriers to Access to HIV Treatment and Care ............................................................... 72
  4.1.2 Barriers to HIV Treatment Adherence .......................................................................... 73
  4.1.3 Lyantonde: 15 Years Later ............................................................................................. 74
4.2 DIRECTIONS FOR FUTURE RESEARCH ........................................................................ 75
4.3 KNOWLEDGE TRANSLATION ACTIVITIES ..................................................................... 77
4.4 REFERENCES ....................................................................................................................... 80

5.0 APPENDICES ........................................................................................................................ 83
5.1 APPENDIX A: UBC BREB ORIGINAL ETHICS APPROVAL CERTIFICATE ................. 83
5.2 APPENDIX B: UBC BREB AMMENDED ETHICS APPROVAL ....................................... 84
5.3 APPENDIX C: UNCST ETHICS APPROVAL-RESEARCHER PERMIT AND RECEIPT .... 85
5.4 APPENDIX D: ENGLISH CONSENT FORM ................................................................. 86
5.5 APPENDIX E: LUGANDA CONSENT FORM ................................................................. 90
5.6 APPENDIX F: TOPIC GUIDES NOT ON TREATMENT ...................................................... 93
5.7 APPENDIX G: CONSENT FORM FOR FOCUS GROUPS .................................................. 103
5.8 APPENDIX H: TOPIC GUIDE FOR FOCUS GROUPS ...................................................... 107
5.9 APPENDIX I: TOPIC GUIDE FOR THOSE SEEKING TREATMENT ................................ 110
5.10 APPENDIX J: SAMPLE ADHERENCE CALENDAR ......................................................... 119
This study is not mine, there are so many it would not be without....
It would not have been possible without the dedicated time and commitment of our participants; willing to share their lives, stories, families and sometimes even breakfast with us.

Without the help of the Salama SHIELD Foundation staff, without the never-ending support and guidance of Kenneth Mugabo, for whom I will always owe my “proper” Ugandan education to.

Without the late night calls, long talks and never ending guidance of my supervisor, Dr. Patricia Spittal. I cannot express my gratitude for the opportunity you have given me, for the faith you have had in me and for the care you have taken to teach me.

Without the knowledge and strong guidance that time and again astounds me, of Dr. Nelson Sewakambo. Words fail me in my thanks.

Without my thesis committee and all your replies to my millions of questions....

Without the love and support of my family, my Ugandan sisters, my long distance friends who never feel that far away; the ones who will always take me back no matter how often I leave.... Shawn, Sheetal and Jessica, where would I be without you?

And without the patience, understanding and support of my other half, who stayed up, just to keep me company while I worked, who flew across the world to understand who I am, who challenges me and loves me even when my heart stays in Uganda.

Ugandans are, by far, the most friendly, wonderful and inviting community within which I have ever lived or worked. I cannot wait to go back.....
CO-AUTHORSHIP STATEMENT

Under the supervision of Dr. Patricia Spittal (PhD, UBC) and co-supervision of Drs. Martin Schechter (MD, PhD, UBC) and Dr. Nelson Sewankambo (MD, PhD, Makerere University, Kampala), Carter designed and implemented this study, including all aspects of data collection and analysis.

Identification and deigns of research program: the research proposal was drafted by Carter, with editorial and substantive input from Drs. Spittal, Schechter, and Sewankambo.

Performing the research: the research was conducted by Carter and two research assistants; Barnabas Magambo and Harriet Birungi. The research team was also assisted by Kenneth Mugabo.

Data Analyses: The data were primarily analyzed by Carter, Magambo, Birungi and Mugabo. Carter then consulted with and incorporated the input of Drs. Spittal, Schechter and Sewankambo into her data analysis.

Manuscript preparation: The two manuscripts contained in this thesis were primarily written by Carter. Carter consulted with Drs. Spittal, Schechter and Sewankambo during manuscript preparation and incorporated input from the three co-authors into later drafts.
1.0 INTRODUCTION

1.1 INTRODUCTION

1.1.1 Young People Living with HIV/AIDS in Peri-urban Uganda

HIV/AIDS was first reported in Uganda in 1982 and was presumed to have originated in two sites in the Rakai District (UAC, 2006).\(^1\) By the late 1980s, the virus had reached all corners of the country, resulting in a severe epidemic. In the early onset of the disease, studies found that, in Lyantonde Town, 35 percent of truck drivers (Carswell, 1989) and 76 percent of sex workers were living with HIV/AIDS (Kulis et al., 2004). While the rest of the country saw a serious decline in prevalence to approximately six percent, in Rakai district, it remained, in 2000, a reported 16.1 percent (USAID, 2002), leaving this small, peri-urban trading town facing a much greater battle against the epidemic.

Uganda has been recognized worldwide as a success story in its battle against the HIV/AIDS epidemic. Such success has been partially attributed to the immediate response made by President Yoweri Museveni in 1986 (Okware et al., 2001). During a time when HIV prevalence in Uganda was quickly rising to its peak of 30.1 percent (UNAIDS, 2004), Museveni embarked on a nationwide campaign addressing HIV/AIDS. Early programming focused on education, promotion of safe sex, condom distribution, decreasing the age of first sexual debut, encouraging monogamy and the use of safe blood products. In less than four years, in 1990, free HIV/AIDS testing was initiated and by 1999 the government had begun to offer free door-to-door at home HIV/AIDS tests (Okware et al., 2001).

Antiretroviral (ARV) drugs are an important part of a comprehensive approach to addressing this epidemic. They do not cure HIV/AIDS but, when taken consistently, they can improve a patient’s quality of life and prolong survival time. As a result of dramatic price reductions in the the 21\(^{st}\) century, combined with multiple treatment access initiatives through various non-governmental organizations (NGOs), in June 2004 the Ministry of Health was able to launch an integrated program for Universal Access to Free Antiretroviral Treatment in

\(^1\) Lyantonde Town was, in 2006 made part of Lyantonde District, however, at the time of the most recent 2004-2005 National Sero-survey, it remained part of Rakai District and was the major stop along the trucking route running through the district.
Uganda and the government was able to negotiate free antiretroviral therapy (ART) distribution in the country (UNGASS, 2008, UAC, 2006).

Since its introduction in the mid-1990s, the benefits of ART in Sub-Saharan Africa for the management of HIV/AIDS have been well established (Palella, 1998; Hogg, 1998). New antiretroviral regimens have demonstrated significant viral load reductions in people living with HIV/AIDS (PLWHA) and have, in low-income regions including Uganda, been found to decrease HIV transmission by up to 53 percent (Gray et al., 2003; Chi-Tai et al., 2004; Spacek et al., 2006). Treatment has proved to be effective in improving CD4 cell counts, and has substantially altered the natural history of HIV infection (Phenix et al., 2000; Tedaldi et al., 2006). As a result, substantial improvements in HIV-related morbidity and mortality have been documented among persons receiving appropriate antiretroviral regimens, and in many areas of the world, HIV infection is increasingly being viewed as a chronic and manageable illness (Ledergerber et al., 1999). In Uganda, the use of ART has been associated with a 95 percent reduction in mortality in HIV infected populations (Mermin et al., 2008). In addition, the use of ART plays a significant role in decreasing mother-to-child transmission in Uganda. As a result, ART not only extends the lives of those infected, but can prevent the spread of new infections (Musoke et al., 1999; Bajunirwe et al., 2004).

Despite such treatment inroads, Uganda’s successes in battling the HIV/AIDS epidemic have been coming into question (Parkhurst, 2001; Green et al. 2006). Recently, it has been estimated that, in the southwest of the country, and among rural populations, the rate of new infections is on the rise again (Shafer et al., 2008; Wakabi, 2006; WHO/UNAIDS/UNICEF 2008). Given the southwestern location of Rakai and Lyantonde Districts, where HIV/AIDS has left the most devastating effects since the early 1980s (Sewankambo et al., 2004; Nalugoda et al., 1997), it is alarming to see such a potential increase and there is need to investigate such claims as efficiently as possible. Special attention to young people within these peri-urban communities must be paid, as this group living in Lyantonde remain increasingly more vulnerable to HIV/AIDS related risks as a result of the transient trucking industry (Sewankambo, 2008). Furthermore, disproportionately affected by HIV/AIDS (Sewankambo et al., 2000), young people face great difficulties in their attempts to support their families while ill and, for young women in child-bearing years, the importance of accessing and adhering to
treatment is not only crucial for their lives, but for that of their children (Uganda Ministry of Health, 2006; USAID, 2002).

1.1.2 HIV Treatment in a Peri-urban Truck Stop Town

Peri-urban areas are those outside formal urban boundaries and urban jurisdictions which are in a process of urbanisation and which therefore progressively assume many of the characteristics of urban areas (Iaquinta & Drescher 2000). Lyantonde presents a compelling case for HIV/AIDS treatment research. As previously discussed, the town holds a history with the epidemic and remains home to a highly HIV/AIDS-vulnerable population (e.g. sex workers, transient truckers, orphans and vulnerable children). Despite its development and the availability of free HIV/AIDS treatment and care, there remain limited economic opportunities and the majority of employment surrounds agriculture (as is typical in rural areas). Furthermore, while free access is available (as is similar in large urban centres) there is no possibility of hiding access to treatment, as small town dynamics eliminate any hope of anonymity.

1.2 LITERATURE REVIEW: SOCIO-ECONOMIC BARRIERS TO ACCESS AND ADHERENCE HIV/AIDS TREATMENT

While the majority of HIV/AIDS related research in Uganda has, to date, focused on HIV/AIDS related vulnerabilities, since the introduction of free HIV treatment and care, there remains a paucity of literature investigating the success of such new programs, notably among vulnerable young people outside the major urban centres and the capital city of Kampala. This thesis will address the HIV/AIDS epidemic from a treatment based perspective. We will investigate the barriers to accessing and adhering to HIV/AIDS treatment among peri-urban young people in order to better understand the health impacts that socio-cultural, structural, gender and place related barriers have on access and adherence to HIV treatment and care.
1.2.1 Barriers to HIV/AIDS Treatment Access

The global movement to expand access to ART for PLWA as part of a comprehensive response to the HIV pandemic is grounded in both the human right to health and in evidence on public-health outcomes. However, for many individuals in low income regions, despite the availability of free treatment, there remain barriers which hinder their ability to access care.

A wide range of barriers have been explored in the literature; including health system-level barriers (e.g. lack of resources, insufficient supply of human resources) and population-level barriers (e.g. lack of information about ART). However, there is little structured insight into those barriers that prevent or restrict access to ART, and limited research has been performed. In a recent systematic review of both qualitative and quantitative studies addressing barriers to access ART published between 1996 and 2007, a considerable number of barriers were identified; both population and health system-level barriers (Alker et al. 2004; Dimbuguet al., 2004; International HIV/AIDS Alliance 2004; Khonyongwa 2004; Kwalombota & Shumba 2004; Mshana et al., 2006; Campero et al., 2007; McKoy 2007; Ramachandani et al., 2007). The other studies identified either population-level barriers (Lertpiriyasuwat et al., 2004; Mafigiri et al., 2004; Gamanya 2005; Kitajima et al., 2005; Sangowana et al., 2005; Adeneye et al., 2006; Grant et al., 2006) or health system-level barriers (Gichoya-Wawira & Ernest 2005). At the population level, barriers cited were enabling factors such as the lack of awareness about ART, stigma, perceived high costs for ARVs and/or related services and the lack of financial means. Pre-disposing factors such as the fear of side effects and husband's permission (relationship barriers) to start ART were also cited. At the health system level, the most frequently mentioned barriers were resource factors such as the length of the travel time to the health facility and the limited involvement of the community in the programme planning process.

The greatest access-based barrier found during this study’s literature review was regarding partner-related (gender-based) fears. In the context of the global HIV/AIDS epidemic, gender is an important underlying factor in HIV risk perception, risk of infection, access to HIV testing, care, and support, and the ability to cope when infected or affected by HIV. Although integrating gender issues into HIV/AIDS programs can be challenging, the effectiveness of such programs are greatly enhanced when gender-specific needs of men and women are considered (Gijsbers van Wilk et al. 1996, Standing; 1997). Impediments include women's responsibilities
to take care of the home and children and, also, women often do not have adequate money and resources for transportation to and from health care facilities. In some circumstances, going to the clinic (reproductive health, maternal and child health, antenatal clinic) is the only moment a woman is entitled to go out alone and meet other women for socializing. Many women prefer to be assessed by female health care providers; however, in many parts of the region, there are limited numbers of female care providers. Moreover, women often need to obtain permission from a male, either husband or other family member, before they can go to the clinic. Most of the time rejection is related to the behaviour leading to the state of vulnerability to HIV rather than HIV itself. Therefore, HIV infection is viewed as a punishment, a result of morally, socially, and religiously unacceptable behaviour (Amowitz et al, 2004; Hasnain, 2005). As a result of such fears, the WHO estimates that, in sub-Saharan Africa only 17-32 percent of women who test positive reveal their status to their partners. With such estimates, the battle against the HIV/AIDS epidemic in Africa appears increasingly challenging (WHO, 2008).

1.2.2 Barriers to HIV/AIDS Treatment Adherence

For PLWHA, strict adherence to HIV treatment medication is required for optimal ART response. Optimal ART adherence has been established as greater than or equal to 95 percent (Bangsberg, 2000; Montaner et al., 1998; Paterson et al., 2000). In addition, it has been identified that minor lapses in treatment adherence may compromise the efficacy of HIV treatment, leading to morbidity and mortality (Bangsberg et al., 2003, Laurence, 2001). Despite the National Health Institute’s (NHI) and the World Health Organization’s (WHO) commitment to understand and promote ART adherence, to date, there remains limited progress to developing strategies to decrease the prevalence of non-adherence (Simoni et al., 2006).

In the past decade, there has been a marked expansion in the distribution of highly active antiretroviral therapy (HAART) in resource-limited countries, as a result of international initiatives such as the US government’s President’s Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria. Studies from low-resource settings have reported adherence rates that are equivalent to or higher than those in resource-rich countries (Hardon et al. 2007; Laurent et al. 2002; Mills et al. 2006; Orrell et al. 2003;
Oyugi et al. 2004; Rosen et al. 2007). Such high levels of adherence have been reported, in contrast to research documenting experienced structural and socio-economic burdens for PLWHA in sub-Saharan Africa (Byakika-Tusiime et al. 2005; Crane et al. 2006; Weiser et al. 2003).

Some experts however, have cautioned that high levels of adherence may not be sustainable in the long term (Gill et al. 2005). In a recent review of studies examining patient retention in ART programmes in Africa, researchers found that, after only two years, an estimated 40 percent of patients had been lost to the programme (Rosen et al., 2007). Another study examining data on 5491 patients beginning ART in 15 treatment programmes in Africa, South America and Asia, found 21 percent of patients became lost to follow-up within six months, including four percent who were not seen since receiving their first prescription of ART (Brinkhof et al., 2008). Several African studies conducted in Botswana, Tanzania, Democratic Republic of Congo (DRC) and Rwanda have highlighted barriers to adherence including stigma, transport costs, opportunity costs of time spent at clinics and inadequate nutrition as reasons for non-adherence (Au et al., 2006; Byakika-Tusiime et al., 2005; Weiser et al., 2008; Roura et al., 2009).

Conversely, the majority of adherence research conducted in Uganda has reported high rates of adherence (AIDS Healthcare Foundation, 2008). These studies however, focused largely on hospital recruitment and self-reported adherence rates, and were conducted within urban centres (Byakika-Tusiime et al., 2005; Oyugi et al., 2004). In rural Uganda, a home-based ART care programme was initiated, enrolling 987 patients, and found, after one year that all the patients retained high levels of adherence. Adherence measurements were taken using self-reports, pill counts, CD4 and viral load tests (Weidle et al., 2006). Only recently have two adherence studies emerged from peri-urban Uganda investigating barriers to treatment adherence. Weiser et al. (2008) and Tuller et al. (2009) demonstrate, using qualitative research methods (in-depth interviews and focus groups), that significant barriers to adherence may exist within such areas of Uganda. Within Weiser et al.’s study food insecurity was commonly reported as both a barrier to accessing medical care and to ART adherence; as food was found to increase appetite, creating intolerable hunger and leaving patients with terrible side effects from taking their medication without food (Weiser et al., 2008). Transport fees, for those living
in areas without immediate access to treatment, was a second noted barrier in peri-urban treatment adherence; the difficulty that transportation costs imposed on efforts to adhere to a regular medication schedules was key and for those who reported strict compliance, transportation costs caused significant concerns and anxieties about whether or not they would be able to successfully adhere in the following month and into the future (Tuller et al. 2009).

These most recent studies highlight a growing need to continue to use qualitative methods to better inform understandings of current adherence measurements in peri-urban Uganda. As universal HIV treatment has only been available here for the past four years, there remains much to be understood about the barriers the young, vulnerable population encounters within such communities.
1.3 THESIS OBJECTIVES

To measure the success of current HIV treatment programs available to young people living in peri-urban Uganda that reflect their needs in ways that are both socio-culturally and structurally appropriate. The existing public community health systems require detailed information from the perspectives of community young people and service providers. Thus, an in-depth examination of the barriers that these young men and women are facing in their attempts to access and adhere to HIV treatment programs currently offered is warranted. Ethnographic research techniques (e.g. in-depth interviews, focus groups) are ideal for elucidating social and structural conditions from the perspectives of this vulnerable group, especially regarding stigmatized topics such as sexual health (Wolcott, 1999; Day, 2001; Desmond et al., 2005; Sankar et al., 2006). By gathering such information within this peri-urban trading centre, interventions for HIV treatment care programs can be developed that are tailored and targeted to the needs of young people within this setting.

Therefore, objectives of the current thesis are to:

1. Investigate the current barriers young men and women experience when attempting to access HIV treatment and care in town.
2. Document the barriers young women and men living in this peri-urban setting experience when attempting to adhere to HIV treatment while living in town.
3. Develop community appropriate recommendations to address the results found within this study.
1.4 THESIS OUTLINE

The current thesis consists of two manuscripts, in addition to this introductory chapter (Chapter 1) and a concluding discussion chapter (Chapter 4). The first manuscript (Chapter 2), entitled “Understanding Barriers to HIV Treatment Access: A case study from a peri-urban Ugandan trading centre”, explores the current barriers young people are facing in their attempts to access HIV/AIDS treatment in town. The second paper (Chapter 3), “Barriers to HIV treatment adherence: starving to survive in peri-urban Uganda”, focuses on how food insecurity leads to HIV treatment non-adherence and eventual treatment attrition. The last chapter (Chapter 4) includes a discussion of the relationship between the two manuscripts and contextualizes these findings within the wider state HIV/AIDS treatment literature, highlighting key implications and suggesting directions for future research.
1.5 REFERENCES


Au JT, Kayitenkore K, Shutes E, et al., 2006. Access to adequate nutrition is a major potential obstacle to antiretroviral adherence among HIV-infected individuals in Rwanda. AIDS 20, 2116–2118.


Bangsberg DR, Charlebois ED, Grant R. 2003. High levels of adherence do not prevent the accumulation of drug resistance mutations to HIV antiretroviral therapy. AIDS 17,1925-1932.


Crane, J. T., Kawuma, A., Oyugi, J. H., Byakika, J. T., Moss, A., Bourgois, P., et al., 2006. The price of adherence: Qualitative findings from HIV positive individuals purchasing fixed-dose
combination generic HIV antiretroviral therapy in Kampala, Uganda. AIDS and Behavior, 10(4), 437–442.


Ramachandani SR, Mehta SH, Saple DG et al., 2007. Knowledge, attitudes, and practices of antiretroviral therapy among HIV-infected adults attending private and public clinics in India. AIDS Patient Care and STDs 21, 129–142.


Weiser S., Tuller D., Ware N., Sengkugu J., Frongillo E., Bangsberg D., 2008. Food security as a barrier to sustained antiretroviral therapy in Uganda. XVII International AIDS Conference. Abstract available online at:


WHO., 20008. Gender Inequalities and HIV. Available online at: http://www.who.int/gender/hiv_aids/en/

2.0 UNDERSTANDING BARRIERS TO HIV TREATMENT ACCESS: A CASE STUDY FROM A PERI-URBAN UGANDAN TRADING CENTRE

2.1 INTRODUCTION

Since the first case of HIV was diagnosed in 1982, Uganda has been internationally renowned for its decreasing prevalence and expanding access of HIV care; prevalences from the early 1990s estimated between 20-30 percent had dropped by 2004-2005 to an estimated six percent (Waly, 2000; UNAIDS, 2004; Okware, 2001). The rigorous country-wide campaign to fight HIV/AIDS was further strengthened in 2004, when the Ugandan Ministry of Health launched an integrated program for Universal Access to Free Antiretroviral Treatment, and the government was able to negotiate free HIV treatment (including ART and prophylaxis treatment) distribution across the country (UNGASS, 2008).

However, nearly two decades after Uganda managed to drastically reduce its HIV prevalence, the rate of new infections appears to be on the rise again (Shafer et al., 2008; Wakabi, 2006; UNAIDS/WHO 2007). Despite significant inroads made in prevention and treatment, recent studies show that the southwest of the country (which includes Rakai and Lyantonde districts) has seen notable increases in both HIV prevalences and incidence (Shafer et al., 2008). As well, there is an increasing amount of literature questioning the reliability of Uganda’s success story (Parkhurst, 2001; Green et al. 2006)

While there are a number of Ugandan studies that have demonstrated high levels of access to treatment and treatment adherence (Oyugi et al., 2004; Crane et al., 2006), the short period of time that free treatment has been available has limited the opportunity to research the current accessibility of treatment programs. This is especially the case outside the capital of Kampala, major cities, and among vulnerable young people living in peri-urban

---

2 A version of this chapter will be submitted for publication. Carter S., Spittal P., Sewankambo N., Mugabo K., Schechter M. Understanding barriers to HIV Treatment Access: a case study from a peri-urban Ugandan trading centre.

3 For the purposes of this study, high levels of adherence follow the standards defined by the World Health Organization, 2003 as ≥95 percent. WHO states that this is the level required to achieve durable suppression of viral load (Bangsberg, 2000; Montaner et al., 1998; Paterson et al., 2000) and recent studies have shown that suboptimal (lower than 95 percent) may lead to resistance, which can then be transmitted to a partner (Boden et al., 1999; Hecht et al., 1998; Little et al., 2000).

4 The term “young people” follows the Uganda National Youth Council Statute 1993 definition of “youth” as between the ages of 18-30 years.
regions. Consequently, there is virtually no literature examining the challenges young men and women may be experiencing as they attempt to access treatment in these areas. This understanding is particularly important for young women who are living in an era of PMTCT (Sewankambo et al. 2000; Uganda Ministry of Health, 2006) and for young, working age populations attempting to support their families (UNPFA, 2006).

2.1.1 Barriers to Access to HIV Treatment

2.1.2 Research Objectives

The current study aimed to: (1) document young men’s and women’s experiences when attempting to access HIV treatment and care; (2) gather healthcare workers’ perspectives on the barriers to treatment access in Lyantonde and other peri-urban areas; and (3) to develop recommendations to improve access to HIV treatment among young people living in peri urban areas of Uganda.

2.2 METHODS

2.2.1 Study Setting

Lyantonde Town Council, Uganda (population: approx. 8000) (Sewankambo, 2008) is the peri-urban heart of Lyantonde District, directly placed along the transport lines between Kampala, Uganda and Kigali, Rwanda. Formally part of the Rakai District, it has been heavily affected by HIV/AIDS, and has long been considered a Ugandan epicentre of HIV (Serwadda et al., 1992). Populations living in Lyantonde Town have been considered to be more vulnerable to HIV related risks as a result of the transient trucking industry which operates within the town (Sewankambo, 2008). The town is compiled of bars, hotels, bicycle and car shops, and small restaurants. Most bar/hotel employees are young females who work 12 hour shifts for little or no wages in hopes of finding a male customer who will ‘offer’ them money in exchange for sex at the end of their shift. The majority of customers are transient truck workers, however, townsmen also frequent the bars and hotels for similar purposes. As Lyantonde falls within the category of “Central Uganda” according to the sero-Survey, its prevalence is estimated at 11.8 percent (Uganda Ministry of Health, 2006). In 2000 however, Sewankambo
et al. calculated a prevalence of 16.1 percent (Sewankambo, 2000). Furthermore, personal communications with the District Medical Officer in Lyantonde have suggested that the prevalence in Lyantonde may be as great as 17-18 percent in town (Dr. Katumba, personal communication, 2009), almost three times greater than the national average of 6.1 percent (UAC, 2007).

With an annual budget of sh437m (the equivalent of approximately 200 000 Canadian dollars to spread over 70 000 people, the district cannot sufficiently meet its health care targets which are estimated at twice as much as the funds they have received) (PHR, 2008). During seven months of fieldwork, the district remained with acute shortages of staff; without an X-ray machine, a CT Scan, an ultrasound machine and was staffed with only 4 physicians and 4 registered nurses, an estimated one third of the minimum requirements to sustain the basic healthcare needs of the district. While the hospital did have a vehicle to transport patients (a pickup truck), it was often without petrol (during certain times of year, the town itself was without petrol) or the funds to pay an available driver to take the patient to the nearest facility (Mbarara 65 km away or Masaka 70 km away). The hospital remains with less than 50 percent of the Ministry of Health’s staffing guidelines. Furthermore, while the only hospital has electricity, there are frequent blackouts—part of the energy crisis facing all of Uganda, especially rural areas—and the hospital generators are unreliable, leaving many surgeries cancelled or completed in the dark (PHR, 2008).

According to the district directorate of production, Lyantonde also faces immense agricultural challenges. Although the district produces crops such as bananas, cassava, potatoes, maize, millet etc., the production levels are seriously affected by crop diseases, viruses, bacteria and fungi. The long drought every year often negatively affects output. As well, while the district is rich in animals (particularly cattle estimated at 83,700), the long dry spells make water and pasture scarce. Compounding this, the animals are often affected by foot and mouth disease. As the district faces long periods of power shortages and shutouts,

---

5 In 2000, Lyantonde remained part of the Rakai district (until 2006 when it became its own district) and the estimated prevalence of 16.1 is represents a smaller, more accurate description of the area within which Lyantonde is situated versus the sero-survey estimate where Lyantonde is incorporated into estimates including the capital, Kampala and a much larger region of the country.
the town is left with limited harvest management and only a few milk coolers and maize mills to support long term food storage or production (LDLG, 2002).

Lyantonde is also home to the second highest (following only the post-conflict northern region) orphaned population in the country; 11.8 percent (compared to the national average of six and a half percent) (Lyantonde District Local Government, 2002), the majority of whom have been orphaned by HIV/AIDS and are left to fend for themselves. The household responsibility often then falls on young women to care and provide for their siblings. With limited employment in town, bar and sex work remain rampant. Town poverty and resource limitations are exacerbated by the devastating effects of HIV/AIDS. Lyantonde remains, as it was in the early onset of the HIV/AIDS outbreak, described as a town of disease, death and self destruction:

“People in Lyantonde do not fear HIV at all. People will come to you, even if they know you have HIV and ask for sex... because they know that they too are going to die and like all those who died before what is the point of denying themselves pleasure? They say AIDS never kills its customer\(^6\)....when they say this they mean that when they continue having sex with other people and spreading the disease, that HIV won’t kill them. But when you stop having sex and start protecting yourself you are bound to die faster. It is safer to continue having lots of sex. And they say you are better off if you go looking for it.” -F13, 23 years old, not accessing treatment

“What I know of people in Lyantonde is everyone is positive. This is because as soon as one gains their health back and looks better, they go around killing others. Even if you were sick, if you are back to normal looking, no one will protect themselves from you... prostitution is rampant. It is everywhere and the women who engage in this sex are all infected. People in Lyantonde do not care about their health or protecting themselves...” –F11, 19 years old, not seeking treatment

\(^6\) This expression ‘AIDS never kills its customer’ was a common expression, reflected by many of our participants and often heard around town during SC’s fieldwork.

2.2.2 Data Collection and Analysis

The study was informed by ethnographic research techniques (Fetterman, 1998; Power, 2002; Schensul et al., 1999). Ethics approval was obtained from the University of British Columbia and by the Uganda National Council for Science and Technology (UNCST) (APPENDIX A, APPENDIX B, APPENDIX C). Data were collected by trained, Luganda and Runyankole
speaking research assistants. The research team conducted 47 in-depth interviews; 24 young women and 23 young men (ages 18-30), and led 2 focus groups; 1 with 4 HIV community counsellors (1 male and 1 female from each of the two sites in Lyantonde providing HIV treatment and care) and 1 with 4 healthcare service providers (nurses, medical assistants, 1 male and 1 female from each of the two HIV treatment sites in town). The current analysis includes a subsample of 22 participants (male N=12, female N=10). Fieldwork included observations and informal conversations with young people, service providers, and other adults, as well as attending functions relevant to sexual health (e.g., parent meetings on sex education; public health meetings; visiting community NGO fieldwork).

The research team’s collaboration with a community HIV/AIDS youth counsellor led to purposive sampling, ensuring that we had relatively equal numbers of participants both seeking and not seeking treatment (Women on treatment N=14, not on treatment N=10, Men on treatment N=11, not on treatment, N=12). Eligibility criteria were: 18-30 years old, either Luganda or Runyankole speaking (the two languages spoken in the district), living within the Lyantonde Town Council boundaries, and self-identifying as HIV positive at the time of the interview. Eligible focus group participants were healthcare service providers and HIV counsellors, and were both males and females working in one of the two HIV treatment provider locations. The focus groups with healthcare workers were separated into one focus group with HIV community counsellors and one focus group with medical service providers. (APPENDIX G-Consent form Focus groups, APPENDIX H-Topic Guide Focus groups)

In regards to participants accessing treatment, no distinction was made between treatment options (e.g. ART such as Nevirapine, or Cotrimoxazole prophylaxis such as Septrin) for several reasons. Foremost, treatment protocols for starting ARV therapy have been changing over time (e.g. in October 2008, Uganda changed their requirement from a CD4 count of 200 to a CD4 count of 250 to qualify for ART (personal communication, Sewankambo, 2008)). Secondly, Cotrimoxazole prophylaxis treatment remains part of Uganda’s HIV treatment protocol (both alone and in partnership with ART) (Uganda Ministry of Health, 2005). Thirdly, prophylaxes such as Cotrimoxazole, have been found to significantly improve the lives PLWHA in rural Uganda (Mermin et al., 2004; Watera et al., 2000). Finally, prophylaxis adherence measurements are generally lacking in the current HIV treatment literature, despite
World Health Organization (WHO) recognition of their role in HIV treatment and care (WHO, 2006). Finally, prophylaxis treatment has been recognized as an important portion of PMTCT and therefore, to exclude those on such treatment would potentially be excluding pregnant women seeking treatment (WHO, 2006). As a result, SC and the research team felt that, as prophylaxis remains part of the path to HIV treatment and care, not including such participants would limit the complete understandings of the barriers faced in treatment adherence among this vulnerable group.

On average, each in-depth interview took between two and two and a half hours. Interviewers were matched for gender and within a similar age category as our participants. Interviewers were from Kampala, so the participants felt comfortable knowing the interviews were not part of small town dynamics (e.g. gossip). Participants signed a confidentiality agreement in Luganda (oral consent was given when they could not read) explaining their right to leave the interview at any time and ensuring complete confidentiality (English version: APPENDIX D, Luganda Version: APPENDIX E). Interviews were semi-structured and consisted of open ended questions that were modified to pursue emergent concepts as data collection and analysis progressed (Glaser, 1978) (APPENDIX F). In this way, data collection and analysis advanced in an iterative fashion, with early interviews and analysis informing future decisions on sampling and interview questions. 10 pilot interviews were conducted (five male, five female) and inclusive coding and analysis was completed. This was done prior to proceeding with the remaining 37 interviews, focus groups and follow-up interviews. Pilot interviews were conducted, coded and analysed to ensure appropriate research techniques and progress before continuing with the study. Young people were asked about their childhoods (including families, education, health), their experiences through relationships, testing for HIV/AIDS, their experiences attempting to access treatment and their current living situations. Healthcare workers and HIV counsellors were asked about their perceptions as to the current barriers to accessing and adhering to treatment for both young men and women in town.

Follow up interviews were done with three female and two male participants who were willing to return for another one or two visits with the research team. These offered participants the opportunity to reflect on previously discussed issues and to update the team on their progress or regression with treatment, their livelihoods, current state of health and
living situations. Follow up interviews also allowed for clarification and discussion surrounding new concepts or themes that had emerged over the previous months of interviews.

Interviews were audio recorded in either Luganda or Runyankole, then translated and transcribed by the research assistant who conducted the interview. Transcripts were then checked by another Ugandan research team member for accuracy of translation against original audiotapes. Coding structure was created by the research team, led by SC. During analysis, an audit trail was kept to document how and why analytic decisions were made. All original interviews were kept on a CD accompanied by their typed transcripts and a second copy of their coded transcript. Analysis was conducted by reading through transcripts and field notes, and with regular meetings with HIV community social workers (research team members from Lyantonde, to offer a community perspective) in order to develop a set of codes that accurately described the depth of the data. As data collection and writing progressed, the data were analyzed to gain insight into the barriers experienced (e.g. social, structural, cultural, economic) when young people attempt to access and adhere to HIV treatment in Lyantonde.

2.3 RESULTS

2.3.1 Sample Characteristics

24 of the young participants were female; their average age was 26 years (ranging from 18 to 30). All but one had engaged in sexual intercourse before the age of 18, 16 of the women were widowed or single, and 19 had children. Five of the women were, at time of the interviews, engaged in sex for exchange and all but two of our female participants had, at some point engaged in sex for exchange. Of the 23 male participants, 13 were married or in a relationship, 12 had children and only two owned their own land.

Eight health care workers were interviews: four public health staff (doctor, nurses and medical assistants in the HIV clinic) and four HIV counsellors. The two groups (public health staff and counsellors) consisted of two males and two females each. Service providers were recruited through their place of work (sampling from each of the two HIV treatment centres in town).
2.3.2 Barriers to HIV Treatment Access Among Young People in Lyantonde

Ten of the 24 women and 12 of the 23 men were not accessing treatment. Our study participants identified fear of (1) job loss, (2) fear of spouse and (3) inability to adhere as a result of food insecurity as key barriers that were enabling them from seeking HIV treatment and care.

2.3.2.1 Job loss

Four of the ten women and seven of the 12 men not accessing treatment identified the fear of losing their job as their reason for not seeking treatment. Participants told stories of other employees in their positions whom they had seen fired when caught taking HIV treatment:

“my workmate told the headmaster the truth that he was positive and that he’s going to start treatment at Kasambya. The headmaster said no, I can’t use you when you are on medication, what you can do is to pack your things and go back home. What I heard from him and something that led to the discontinuation of my colleague was a good lesson to me and I had to keep quiet and not mention anything about being positive”

-Young man, working as a cook at an elementary school

Others had been told outright by their employers that if they were found with HIV treatment, they would lose their jobs:

“When I told her that I was to test for HIV, she said it was ok, but before I did she said that she didn’t want an employee who was on medication in her home. I asked her what should I do and she said, if I wish, then I should leave and go. But I do not want someone on medication in this home. So at the moment, that is my biggest problem. I do not take medication and luckily, I have not had any sickness attacking me. But I tested and was found positive, but I cannot bring medication into her home, where I stay”

-23 year old female, working as a “house girl” whose husband infected her with HIV and then left her for another woman, took the children and moved away while she was sick in the hospital.

The majority of those who faced workplace barriers lived onsite. Whether living in the house as a domestic worker, at a restaurant, school or shop, they often slept in small spaces with co-workers or family members of their employers. They regularly felt that their space and privacy would be invaded:

“That is hard because I can leave it [the medication] hidden between my personal things and she [the boss] goes through them and finds it. And if that happens before I
"get somewhere else to work then I will be left homeless” - 29 year old female domestic worker

“Her [the boss] and her children they go through my things and I think she sends them [the children] to confirm if I have ever gotten the medication” – 23 year old young female working as a “house girl”

As a result, until they could afford to live in a place on their own, those living with their employers felt unable to seek treatment. At the same time, because rent was covered as part of their payment, the average income among males and females who were not seeking treatment because of their employers was approximately 13 dollars a month; less than rent for a month and not enough to save in order to eventually pay for a place of their own.

These participants often described feelings of desperation, as they could never earn enough to improve their situation, to move out and begin medication:

“I was worried [when I went for testing] that if I am found positive I would die. And I also knew that I would not get any medication for it for my boss would not allow me” - 29 year old female participant

2.3.2.2 Partner fears
Four of the women who were not accessing treatment were unable to do so because they feared their husbands would find their treatment and would blame them for bringing HIV into their home and then leave them with no means of supporting themselves. They explained that their husbands would blame them for bringing HIV into their home, and accuse them of being the “trouble causer”. Many women in our study felt completely reliant on their husbands for support:

“When the landlord came, my husband would be gone and I would have no money, so we [the children and her] would sleep on the porch. When such things would happen he would go to another woman. Many times he would stay at their home and we would be thrown out. I had nowhere to go”. - 25 year old female describing life with her ex-husband, who had raped her at 13 years old, impregnated her and infected her with HIV.

The women unable to access treatment as a result of their husbands describe having little option without the support of their partner and that, if thrown out, they will have no means of survival in Lyantonde:
“Without say, [if I told my husband I was HIV positive] we would separate. Yet all the problems I have at the moment he takes care of. I may have a father, but he is also old. My mother was the first to die begins crying. But now, this man is like both my father and mother. Anything that happens, he takes care of. If I tell him, I will be left with a big challenge of how to survive. Where will I go? I have no one. That is why. Why I tested and got to know that I am positive, I kept it to myself”. -23 year old female

They did not feel that they could hide their medication in the house, similar to those whose bosses would sort through their personal belongings; these women feared that their husbands would also go through everything and find their medication:

“One day I was not around and had gone to the village to bury. When I came back I found he had searched the house and everywhere. I had hidden the key under the mattress but he had found it. He opened it and saw the tablets, we fought so hard that time... The tablet he had found he threw them away from then I have never gone back to Supreme” -29 year old female not seeking treatment because of her husband.

Many of these women felt that their husbands had several other women on the side; that it was their husbands who were bringing home infections. Often the men would not even hide their affairs, yet the women felt no choice but to stay in the relationship:

“He has a lot of girlfriends, he is a womanizer, but then, he does not want me to get on medication and I do not know what to do” -29 year old female

“When we were together for 3 years, life was not good. I was in a terrible condition he would show me pictures of women he was having affairs with. He would also bring some at home and I would have to keep quiet... I kept quiet and gave him time to do what he wanted. He would bring photos of these women and display them in the house... And one day I had gone to dig, I had chosen to go and dig because everything I would ask of him, he would not give me. So I said, if I dig and harvest, I would sell and be in a position to get what I want. But I had gone to dig and when I got back I found him in bed, asleep with another woman”. –Young female participant living with husband who has threatened to leave her if he finds her medication

The women often had very little control over their lives and had to lie when they went to get tested, attempted to find work and even when they came to attend the interview:

“When I told her [my mother] she said, you should always sneak out and access medication. And I asked her, how can I sneak out when he does not allow me to move?
To be able to move a little, I have to lie to him. Lie that I am going to see my mother etc. even going to the village, he does not allow me to”. –Young female participant not seeking treatment because of her husband

“You fear men. Men keep saying, I don’t want my wife to work, when a woman works, she becomes independent and they prefer to see women doing nothing, having to ask for anything we want but not working so as to keep us begging. So when I go to work to earn a little money, I sneak away”-30 year old female participant, on treatment but hides it from husband who is away a lot.

Furthermore, male participants also admitted to holding control in the relationship, deciding to keep quiet about their status until after marriage and a family, so that then their wives could not leave them:

“Now this one I am planning to get I will not tell her at the beginning. I can only tell her 4 years after marriage and it’s not good to tell her direct that myself, I tested positive, but I will do it in a form of bringing an idea of testing ourselves. If she doesn’t force me to test at the beginning I will not talk about it because she may not be positive and it can’t be possible for her to accept me. I will keep quiet for 3-4 years and after we have produced, but for all that period I will be taking the pills secretly without her knowing about it, but then she will not be able to leave once we have produced”. -26 year old male, regarding his plans to marry his current girlfriend.

With such great fear of testing, the women knew that they could not even attempt to seek treatment; their personal items would be searched, they would be beaten and left alone, with no means of supporting themselves if their husbands found out. Ironically, many of the women believed it was the men who had the affairs, that it had been the men who had brought HIV into their home. Several widows said that they suspected their husbands had been seeking treatment without telling them:

“When he learnt he was positive, he did not tell me. He kept quiet and went on to access medication. He used to take medicine alone, he never told me. One day I caught him taking tablets and asked what they were for. He said they were for treating ulcers. And every day he would complain of this and that he was always sick. Stomach every day. So I never felt bothered by that. It was not until he died that I realized what he had been suffering from... How could he have tested and got on medication without warning me. I could not have got pregnant many times I did, possibly he too, could not have died so soon. He used to take medication and have sex without considering me; to me it was like he wanted me dead” - 30 year old sex worker, not accessing treatment because cannot afford enough food to take while on treatment.
My biggest problem is the man having very many sexual partners and he does not want to test. Because of what he does I decided to go and test for HIV. I went to test without telling him and I do not want him to know. I know when he gets to know that I tested, the next thing will be beatings. -28 year old female not accessing because fears husband

Men and women in the study did however agree that, if both partners could openly discuss their HIV status, then they could seek treatment together and work towards living together happily:

“It can be easy if you and your husband have a good relationship. That is when you can know each others’ statuses. If you are all positive, and are on medication, you can ably remind each other when it is time to take medication. And that way, even when he has gone away you can come up with ways to remind him not to forget to take his medication. So women will not find any problems adhering when they have good relations with their men” -19 year old female not seeking treatment because scared that she will lose her husband’s support if he finds out.

2.3.2.3 Food insecurity, failure to adhere and attrition

Five of the 12 males not accessing treatment said that they had fallen off of their treatment because they were unable to adhere as a result of food insecurity. As well, 2 women during follow up interviews in December and January, who had previously been accessing treatment between September and November, had fallen off treatment completely as a result of food insecurity and their inability to take their medication without the proper nutrients.

Doctors and HIV workers at the clinics spend long periods of time explaining the importance of remaining adherent; they discuss the possibility of drug resistant HIV if treatment is not taken consistently, however the participants were clear that the requirements were not possible:

“I fear, I fear very much those pills because of the problems they cause to the health of my friends, those without food who use that medication. Some people are able to walk before starting HIV medication but once on the treatment and they have no food, they don’t have the same energy, they become weak, you can find someone unable to stand up on his two legs because of the medication. Someone like me who has to care for my siblings, who has little food and must support the family can’t start taking medication because when I get weak without food and I stop working my siblings can’t survive”. -18 year old male, not on treatment because of side effects when taking medication without food

“The medical officers after the last test told me to wait for some period before going back to the health centre and after that period I went back. When I went there at the
hospital I was given pills to take which pills I didn’t take for some good time because of food difficulties. I used to take these pills even when I have not eaten and the effects were bad and included lost energy and pain and dizziness. Some days the pills stopped me from going to work and without work I couldn’t get more food”. “Which pills were you on?” “Septrine....After the third visit they told me to go back to hospital after 2 weeks but at Supreme they didn’t give me the pills and I was referred to Kasambya as a place for the medication. After 2 weeks I went back for the Septrine which I stopped taking because of the effects when I didn’t have food”

-18 year old young man, fell off of treatment because of effects without food.

The difficulties the participants faced with adherence to treatment as a result of food insecurities led to attrition in several cases; for others it appeared imminent in the near future. While these patients have successfully negotiated through the various barriers that are posed in seeking testing and treatment, they remain unable to take the free medication available to them because of the economic barriers that inhibit their access to the required nutrition. Unable to remain adherent to treatment, patients eventually fall off of treatment completely, a phenomenon referred to as the attrition cascade. (26, 39, 58, 71-from Uganda ethics)

2.4 DISCUSSION

In this paper we documented 3 key barriers to HIV treatment access among young HIV positive people living in peri-urban Uganda. Our data are consistent with previous research on barriers to treatment access with regard to partner fears, however they illustrate an important gap in knowledge regarding the barriers imposed by workplace and food insecurity.

Partner Fears: researchers have long since found that young women in sub-Saharan Africa are more than twice as likely to have, and remain more vulnerable to, HIV/AIDS than men. This often results from lack of negotiating powers in relationships (including marriage) vulnerabilities (Remien et al., 2009; WHO/UNAIDS/UNICEF, 2008). The WHO estimates that, in sub-Saharan Africa only 17-32 percent of women who test positive for HIV reveal their status. Fear of violence and reprisals prevents many women from disclosing their status and receiving care, often resulting in their inability to access treatment for their children as well (WHO, 2008; Ganyani, 2007). A WHO reported study in Tanzania found that, while men independently sought HIV counselling and testing, women felt obliged to discuss the options of testing and
treatment with their partners before seeking services (WHO, 2003). Fear of abandonment and loss of economic support, lack of access to control over resources, child care responsibilities and restricted mobility and decision making power have all been found closely tied to women’s inability to disclose their status to their partners and access treatment (WHO 2004; WHO 2008). Women within our study described similar challenges. As both our male and female participants also suggested however, studies have demonstrated that disclosure of HIV test results to partners is often associated with increased support, especially for women (Matthews et al. 1999). What has yet to be addressed within the global community is how to amend such structural barriers in gender relations, so that women can feel safe disclosing their status, seeking treatment, in doing so, protect their children from HIV/AIDS.

**Job loss:** A UNAIDS study across seven sites found that men may often feel pressure to keep their HIV status a secret for fear of dismissal from work and then being unable to support themselves (WHO, 2003). While many studies have attempted to explain that HIV status disclosure may enhance the lives of PLWHA (Ehlers, 2006), this premise may be inapplicable in sub-Saharan Africa where studies have demonstrated that HIV status disclosure can lead to stigmatization and job loss (Barroso and Powell-Cope, 2000; Holzemer et al. 2006; Varas-Diaz et al. 2005). While an understanding of the role that fear, stigma and job security can play in HIV treatment access, there remains little discussion on possibilities for solutions in addressing such issues; what has been made eminent is that, at the root of fears of job loss, lies HIV/AIDS related stigma issues that remain unaddressed.

**Food security and treatment attrition:** To date, there has been a growing amount of research illustrating the complicated relationship between HIV/AIDS and food security. Studies have found that malnutrition alone can increase one’s susceptibility to HIV/AIDS (Blackburn, 2001; Blumberg, 1994) and that food insecurity itself is a risk factor for HIV/AIDS transmission (Scarlatti, 2004). Research has illustrated the devastating effects that malnutrition can play in the progression of illness and, at the same time, the toll the illness plays on one’s ability to absorb nutrients (WHO, 2003). Malnutrition leads to immune impairment and worsens the effects of HIV thus furthering the progression of the disease. As a result, malnutrition can both contribute to and result from HIV/AIDS. (Food and Nutrition Technical Assistance Project, 2004; Loevinsohn & Gillespie 2003). Despite Uganda claiming high rates of treatment
adherence, there are an increasing number of studies that are noting food security’s role in HIV treatment adherence (Mukherjee et al., 2006; Ndekha et al., 2005; Villamor et al., 2005; Fawzi et al., 2004). Most recently, a qualitative study conducted between Mbarara (65 km from Lyantonde) and Kampala (approximately 200 km from Lyantonde), using in-depth interviews and hospital recruitment found that food security was the number one factor in treatment non-adherence (Weiser et al. 2008). With increasing understanding of the effects that food security has on HIV treatment adherence, it leaves little surprise that such treatment non-adherence would resultantly lead to treatment attrition.

Increasingly, HIV/AIDS related programmes are attempting to incorporate food security into their agendas. For example, a program in the Democratic Republic of Congo (DRC) was able to demonstrate, that when multiple institutions can work together, societies can successfully diminish malnutrition and food insecurity and assist PLWHA. In 2003 in Bukavu, a city like many others in the DRC and across sub-Saharan Africa, Medicins Sans Frontieres (Doctors Without Borders) worked in correlation with the Food and Agricultural Organization of the United Nations and the World Food Programme of the UN to create a food security programme for PLWHA in town. The programme included seed distribution, tools and education for agricultural support as well as food rations and nutritionally-based education to over 200 families affected by the epidemic. As a result of such a program, community based research found an overall weight gain among those living with HIV taking part in the programme. If such multi-organizational initiatives, even, such as that in Bukavu, took place in small scale areas, such small steps could potentially lead to vast improvements in HIV treatment program success as PLWHA would overcome the increasing obstacle of meeting the nutritional requirements for treatment (Tu D. et al. 2004). While research has established the path that food insecurity paves in creating HIV/AIDS related vulnerabilities, there remains limited research investigating how this continues into decreased treatment adherence and finally, to HIV/AIDS treatment attrition.

**Summary:** Free HIV treatment and care in Uganda has been limited to the past 5 years. As a result, there remains a paucity of literature investigating the barriers to accessing treatment, especially outside of major city centres. When preparing for this study, literature
regarding barriers to access did result in research regarding the role of gender as a potential barrier to access (UNFPA, 2006). Job and food insecurity however, were not found as potential barriers within our literature review.

Participants and HIV community counsellors both stressed the role that stigma and HIV/AIDS knowledge played in creating workplace barriers. While it was the fear of job loss that stopped our participants from accessing treatment, it was evident that their employers still held negative stigmatic beliefs regarding HIV/AIDS. Some of our participants expressed feelings that HIV/AIDS related stigma had decreased in town over the years. However, the results of this demonstrated many still feared stigma. For example, our participants reliant on their workplace for survival (including for housing), felt unable to risk the potential threat of workplace stigma by disclosing their statuses and seeking treatment. Without initiatives addressing the core root of stigma, not only to PLWHA, but to peri-urban communities as a whole, those economically dependent on their workplace will remain unable to successfully access treatment.

The qualitative interview process used during this study highlighted potential concern regarding the current barriers young men and women living in peri-urban Uganda are facing in their abilities to access treatment. Economic insecurity, in the form of spousal reliance, workplace dependency, and food shortage pose a clear threat to young PLWHA’s ability to access treatment in Lyantonde Town. This study illustrates the importance of investigating the relationship between economic dependency (in the aforementioned three forms) and HIV treatment access.

These relationships may also need to be considered within the context of place; the peri-urban setting of Lyantonde leaves limited opportunities for women to find employment and they are possibly more reliant on their husbands. In a peri-urban setting, there are also limited work opportunities for all, and, with only two available options for HIV treatment access, fear of being seen by an employer may have a greater affect on the role that workplace barriers play within this community. Finally, rural town living left our participants without land for subsistence farming, however also without the economic opportunities to afford the price of town food; leaving them unable to adhere to their treatment because of food insecurity and eventually forcing them off of treatment. What remains are questions of whether other young
PLWHA living within other peri-urban areas across Uganda are facing similar barriers to adherence. While studies to date have largely focused on gender, stigma and food security and HIV/AIDS related vulnerabilities, there is an increasing need to investigate the relationship between these areas and their effects on treatment access, and to consider these barriers within the context of place.

### 2.4.1 Strengths and Limitations

The purpose of this study was not to generalize the findings to a larger population, but to elicit insights to develop action that is sensitive to local circumstances. Self-reported data in epidemiology are often cited as vulnerable to reporting and social desirability biases. However, the insights of young people and their counsellors are precisely what we were interested in. Since these are not easily uncovered by traditional epidemiological methods, we used in-depth interviews to gather the perspectives of youth and service providers. This enabled SC and the research team to develop trusting relationships with participants over seven months and to obtain insights about local realities (e.g., the team gained a good understanding of the workings of the local public health system by participating in local NGO and hospital community workshops).

Some key demographic composition in our sample should be understood in interpreting our results. The self-reported non-access of treatment was greater than expected in Lyantonde (upon arrival in town, the team was told that close to 90 percent of those who had tested positive were accessing treatment). Although we made many efforts to select a diverse group of young people to take part in the study, given the fear reported in being seen seeking treatment (by those facing gender and workplace barriers), it may be possible that the number of people not accessing is actually quite high. Furthermore, it should be considered that, if gender and workplace barriers exist in accessing treatment, they may also exist as barriers to testing.

During data collection, SC moved to Lyantonde, where her presence in the community provided a catalyst for discussion among community members, HIV counsellors and service providers (a Western presence in this community is immediately noticed). As a result, after preliminary interviews and intense coaching with her research assistants with regards to
probing, to ensure participant comfort, Carter was not present during interviews. Choosing young interviewers from outside Lyantonde, we believe helped ensure participant security, allowing the young men and women to feel comfortable talking with someone their own age and gender, but who was unfamiliar with the small town dynamics. The rich and detailed stories gathered suggest that using such techniques enabled us to tap into deeper insights than would have been documented using traditional methods.

Our analysis is based on interpretations of data. To address this, we kept an audit trail documenting data analysis; completed follow-up interviews, sought analytic consensus among the research team and SC’s thesis committee; and compared our data with previous and ongoing HIV treatment research among young people in other locations in Uganda. This study attempted to produce as much of a classical ethnography, which typically involved extended fieldwork for periods of months to years (Wolcott, 1999; Schensul et al. 1999), and to engage as much as possible with this community given the limitations of available resources.

2.5 CONCLUSION

In this study, we documented the barriers to treatment access in a peri-urban trading centre along a major trucking route in Uganda. We documented young peoples’ experiences attempting to access treatment and elicited health and social service providers’ perspectives on the circumstances surrounding treatment access.

Since young people in Lyantonde are clearly facing great barriers accessing treatment, community and hospital programs need to attempt to address current relationship, workplace, and food security barriers in their HIV/AIDS educational workshops and treatment program discussion. At the end of this study, the research team held a community forum, attended by over 75 community members (including the district medical officer, HIV counsellors, religious leaders and political officials) to discuss the results of the study and potential areas where the issues could be addressed. With only one NGO in town, external support is limited and, while unable to change issues surrounding the current barriers in one meeting, the community attempted to address these barriers and together begin to incorporate the findings into the current community and hospital counselling and educational programs. Our study participants
identified relationship, workplace and food insecurity based barriers to their ability to access HIV treatment and care.

The gender based barriers to access run deep within culture, community and structure, making recommendations difficult. Ultimately, the UN has suggested that the most powerful solutions to such barriers will be the ones that address the root cause of the problem itself: gender inequity. Promotion of equal access to education, economic opportunity, political power, property rights and fights against sexual and domestic violence may be one of the strongest ways to combat gender based barriers in HIV/AIDS and access to its treatment and care (UNDG 2004).

Workplace barriers lie within the greater issues of HIV/AIDS related stigma, another deeply rooted barrier surrounding all levels of HIV care (e.g. testing, access to treatment and adherence to treatment). The idea that HIV/AIDS is a stigmatised disease and that people with HIV/AIDS face discrimination remains commonplace. Indeed the stigma and discrimination associated with HIV/AIDS is so prevalent that UNAIDS regards this as one of the greatest barriers to combating the disease around the world (UNAIDS, 2003). Resultantly, guides to workplace responses to HIV/AIDS stress the importance of reducing the stigma of HIV/AIDS and preventing discrimination against those who are HIV positive (Dickinson, 2003). In reality this important element of a workplace response to HIV/AIDS is easier to talk about than to achieve; even where workplace HIV/AIDS programmes are in place, stigma often remains strong and discrimination, while hidden, continues (Dickinson, 2005).

Food security has also been found to be a root cause in HIV/AIDS related vulnerabilities. At the 2005 WHO conference on HIV/AIDS and Food and Nutrition Security in Durban, South Africa, evidence regarding the relationship between food security and HIV/AIDS were acknowledged and a call to integrate nutrition into treatment packages was made (WHO, 2004). At the same time, similar international bodies such as (i) the 2003 WHO Technical Consultation on Nutrient Requirements for PLWHA in Geneva, (ii) the May 2006 forum on food security, nutrition and HIV led by Project Concern International in Lusaka, (iii) the World Food Summit: five years later in 2002, (iv) the 2001 and 2003 sessions of the FAO Committee on Food Security and (v) the 2002 and 2004 African Regional Conferences (FAO, 2002, FAO 2004, FAO 2009) have also acknowledged the important relationship between the epidemic and food
security. Despite such a worldwide acceptance of the need to incorporate food security into HIV/AIDS treatment programs, in 2008, the United Nations World Food Program (UNWFP) began, due to lack of funding, withdrawing food aid to PLWHA in the north of Uganda, leaving approximately 1.5 million people devastatingly affected (UNWFP, 2007).

Although researchers are increasingly recognizing the roles that gender, stigma (in the case of this study demonstrated within the workplace) and food insecurity have in HIV/AIDS related vulnerabilities, future studies must investigate how these not only create vulnerability but become barriers to treatment access. Such barriers must also be considered within the context of place (e.g. peri-urban living) and among young men and women. Peri-urban living may pose specific challenges as young PLWHA remain within easy reach of clinics and free treatment, however also remain within a small town setting, whether their treatment seeking behaviour cannot go unnoticed. Furthermore, while a hub for truckers, there remain little opportunities for young people to find economic independence. As well, as young people begin caring for families of their own, despite their increasing weakness as a result of their HIV status, it furthers their inability to work, gain economic security and improve their overall living and health situations.

If HIV treatment is to deliver the promise of healthy living for young PLWHA in Uganda, future studies must also ensure a comprehensive understanding of the current barriers young people living in Uganda are facing in their attempts access to the available HIV/AIDS treatment programs. The findings of this study underscore the urgent need to fill these knowledge gaps and to refine adherence research for future program policy making for young PLWHA in peri-urban Uganda.
2.6 REFERENCES

Barroso J, and G.M. Powell-Cope., 2003. Metasynthesis of qualitative research on living with HIV infection, Qualitative Health Research 10 (33), 340-353.


USAID 2007. HIV/AIDS in Developing Countries and the Importance of Safe Water


3.0 BARRIERS TO HIV TREATMENT ADHERENCE: STARVING TO SURVIVE IN PERI-URBAN UGANDA

3.1 INTRODUCTION

Since the first case of HIV was diagnosed in 1982, Uganda has been internationally renowned for its decreasing prevalence and expanding access of HIV care. For example, in the early 1990s prevalence was estimated between 20-30 percent and by 2004-2005 had dropped to an estimated six percent (Waly, 2000; UNAIDS, 2004; Okware, 2001). The rigorous country-wide campaign to fight HIV/AIDS was further strengthened in 2004, when the Ministry of Health launched an integrated program for Universal Access to Free Antiretroviral Treatment in Uganda and the government was able to negotiate free HIV treatment (including antiretroviral therapies) distribution across the country (UNGASS, 2008).

However, nearly two decades after Uganda managed, despite meagre resources, to drastically reduce its HIV prevalence, the rate of new infections appears to be on the rise again (Shafer et al., 2008; Wakabi, 2006; UNAIDS/WHO 2007). Despite significant inroads made in prevention, recent studies show that the southwest of the country, (which includes Rakai and Lyantonde districts) has seen notable increases in incidence. As well, there is an increasing amount of literature questioning the reliability of Uganda’s success story (Parkhurst, 2001; Green et al. 2006)

While there are a number of Ugandan studies that have demonstrated high levels of treatment adherence (Oyugi et al., 2004; Crane et al., 2006) the short period of time that free treatment has been available has limited the opportunity to research its success. This is especially the case outside the capital, Kampala, major cities and among vulnerable, rural populations. Consequently, there is virtually no literature examining the treatment challenges experienced by young HIV positive people. This understanding is particularly important for

---

7 A version of this chapter will be submitted for publication. Carter S., Spittal P., Sewankambo N., Mugabo K., Schechter M. Barriers to HIV Treatment Adherence: starving to survive in peri-urban Uganda.
8 For the purposes of this study, high levels of adherence follow the standards defined by the World Health Organization, 2003 as ≥ 95 percent. WHO states that this is the level required to achieve durable suppression of viral load (Bangsberg, 2000; Montaner et al., 1998; Paterson et al., 2000) and recent studies have shown that suboptimal (lower than 95 percent) may lead to resistance, which can then be transmitted to a partner (Boden et al., 1999; Hecht et al., 1998; Little et al., 2000).
9 The term “young people” follows the Uganda National Youth Council Statute 1993 definition of “youth” as between the ages of 18-30 years.
young women who are living in an era of PMTCT (Sewankambo et al. 2000; Uganda Ministry of Health, 2006) and for young, working age populations attempting to support their families (UNPFA, 2006).

3.1.1 Barriers to Adherence to HIV Treatment

3.1.2 Research Objectives
The current study aimed to: (1) document young peoples’ experiences adhering to HIV treatment in Lyantonde; (2) gather health service workers’ perspectives on adherence experiences among young people with HIV in Lyantonde; and (3) develop recommendations to improve adherence to HIV treatment among young people living in rural trading centre towns in Uganda.

3.2 METHODS

3.2.1 Study Setting
Lyantonde Town Council, Uganda (population: approx. 8000) (Sewankambo, 2008) is the peri-urban heart of Lyantonde District, directly placed along the transport lines between Kampala, Uganda and Kigali, Rwanda. Formally part of the Rakai District, it has been heavily affected by HIV/AIDS, and has long been considered a Ugandan epicentre of HIV (Serwadda et al., 1992). Populations living in Lyantonde Town, as a result of the transient trucking industry that resides within, have been considered to be more vulnerable to HIV related risks (Sewankambo, 2008). The town is compiled of bars, hotels, bicycle and car shops and small restaurants. Most bar/hotel employees are young females who work 12 hour shifts for little or no wages in hopes of finding a male customer who will ‘offer’ them money in exchange for sex at the end of their shift. The majority of customers are transient truck workers, however, townsmen also frequent the bars and hotels for similar purposes. As Lyantonde falls within the category of “Central Uganda” according to the Sero-Survey, its prevalence is estimated at 11.8 percent (Uganda Ministry of Health, 2006). In 2000 however, Sewankambo et al. calculated a
prevalence of 16.1 percent (Sewankambo, 2000).10 Furthermore, personal communications with the District Medical Officer in Lyantonde have suggested that the prevalence in Lyantonde may be as great as 17-18 percent in town (Dr. Katumba, personal communication, 2009), almost three times greater than the national average of 6.1 percent (UAC, 2007).

With an annual budget of sh437m (the equivalent of approximately 200 000 Canadian dollars to spread over 70 000 people, the district cannot sufficiently meet its health care targets which are estimated at twice as much as the funds they have received) (PHR, 2008). During seven months of fieldwork, the district remained with acute shortages of staff; without an X-ray machine, a CT Scan, an ultrasound machine and was staffed with only 4 physicians and 4 registered nurses, an estimated one third of the minimum requirements to sustain the basic healthcare needs of the district. While the hospital does have a vehicle to transport patients (a pickup truck), it is often without petrol (during certain times of year, the town itself was without petrol) or without the available funds to pay a driver to transport a patient to the nearest facility (Mbarara 65 kms away or Masaka 70 kms away). The hospital remains with less than 50 percent of the Ministry of Health’s staffing guidelines. Furthermore, while the only hospital has electricity, there are frequent blackouts—part of the energy crisis facing all of Uganda, especially rural areas—and the hospital generators are unreliable, leaving many surgeries cancelled or completed in the dark (PHR, 2008).

According to the district directorate of production, Lyantonde also faces immense agricultural challenges. Although the district produces crops such as bananas, cassava, potatoes, maize, millet etc. the production levels are seriously affected by crop diseases, viruses, bacteria and fungi. The long drought every year often negatively affects output. As well, while the district is rich in animals (particularly cattle estimated at 83,700), the long dry spells make water and pasture scarce. Compounding this, the animals are often affected by foot and mouth disease. As the district faces long periods of power shortages and shutouts, the town is left with limited harvest management and only a few milk coolers and maize mills to support long term food storage or production (LDLG, 2002).

10 In 2000, Lyantonde remained part of the Rakai district (until 2006 when it became its own district) and the estimated prevalence of 16.1 is represents a smaller, more accurate description of the area within which Lyantonde is situated versus the sero-survey estimate where Lyantonde is incorporated into estimates including the capital, Kampala and a much larger region of the country.
Lyantonde is also home to the second highest (following only the post-conflict northern region) orphaned population in the country; 11.8 percent (compared to the national average of 6.5 percent) (Lyantonde District Local Government, 2002), the majority of whom have been orphaned by HIV/AIDS and are left to fend for themselves. The household responsibilities then, often fall on the young women, to care and provide for their siblings and, with limited employment in town, bar and sex work remain rampant. Town poverty and resource limitations are exacerbated by the devastating effects of HIV/AIDS. Lyantonde remains, as it was in the early onset of the HIV/AIDS outbreak, as a town of disease, death and self destruction:

“People in Lyantonde do not fear HIV at all. People will come to you, even if they know you have HIV and ask for sex... because they know that they too are going to die and like all those who died before what is the point of denying themselves pleasure? They say AIDS never kills its customer11 ....when they say this they mean that when they continue having sex with other people and spreading the disease, that HIV won’t kill them. But when you stop having sex and start protecting yourself you are bound to die faster. It is safer to continue having lots of sex. And they say you are better off if you go looking for it.” -23 year old female

“What I know of people in Lyantonde is everyone is positive. This is because as soon as one gains their health back and looks better, they go around killing others. Even if you were sick, if you are back to normal looking, no one will protect themselves from you... prostitution is rampant. It is everywhere and the women who engage in this sex are all infected. People in Lyantonde do not care about their health or protecting themselves...” –19 year old female

3.2.2 Data Collection and Analysis: Phase 1

The study was informed by ethnographic research techniques (Fetterman, 1998; Power, 2002; Schensul et al., 1999). Ethics approval was obtained from the University of British Columbia and by the Uganda National Council for Science and Technology (UNCST) (APPENDIX A & B, APPENDIX C). Data were collected by trained Luganda and Runyankole speaking research assistants. The research team conducted 47 in-depth interviews; 24 young women and 23 young men (ages 18-30), and led two focus groups; one with four HIV community counsellors (one male and one female from each of the two sites in Lyantonde providing HIV

---

11 This expression ‘AIDS never kills its customer’ was a common expression, reflected by many of our participants and often heard around town during SC’s fieldwork.
treatment and care) and one with four healthcare service providers (nurses, medical assistants, one male and one female from each of the two HIV treatment sites in town). The current analysis includes a subsample of 22 participants (male N=11, female N=14) Fieldwork included observations and informal conversations with young people, service providers, and other adults, as well as attending functions relevant to sexual health (e.g., parent meetings on sex education; public health meetings, visiting community NGO fieldwork).

The research team’s collaboration with a community HIV/AIDS youth counsellor led to purposive sampling, ensuring that we had relatively equal numbers of participants both seeking and not seeking treatment (Females on treatment N=14, not on treatment N=10. Men on treatment N=11, not on treatment, N=12). Eligibility criteria were: 18-30 years old, either Luganda or Runyankole speaking (the two languages spoken in the district), living within the Lyantonde Town Council boundaries, and self-identifying as HIV positive at the time of the interview. Eligible focus group participants were healthcare service providers and HIV counsellors, were both males and females working in one of the two HIV treatment provider locations. The focus groups with healthcare workers were separated into one focus group with HIV community counsellors and one focus group with medical service providers.

In regards to participants accessing treatment, no distinction was made between treatment options (e.g. Antiretroviral Therapy (ART) such as Nevirapine, or Cotrimoxazole prophylaxis such as Septrin) for several reasons. Foremost, treatment protocols for starting ARV therapy have been changing over time (e.g. in October 2008, Uganda changed their requirement from a CD4 count of 200 to a CD4 count of 250 to qualify for ART (personal communication, Sewankambo, 2008)). Secondly, Cotrimoxazole prophylaxis treatment remains part of Uganda’s HIV treatment protocol (both alone and in partnership with ART) (Uganda Ministry of Health, 2005). Thirdly, prophylaxes such as Cotrimoxazole, have been found to significantly improve the lives PLWHA in rural Uganda (Mermin et al., 2004; Watera et al., 2000). Fourth, prophylaxis adherence measurements are generally lacking in the current HIV treatment literature, despite World Health Organization (WHO) recognition of their role in HIV treatment and care (WHO, 2006). Finally, prophylaxis treatment has been recognized as an important portion of PMTCT and therefore, to exclude those on such treatment would potentially be excluding pregnant women seeking treatment (WHO, 2006). As a result, SC and
the research team felt that, as prophylaxis remains part of the path to HIV treatment and care, not including such participants would limit the complete understandings of the barriers faced in treatment adherence among this vulnerable group.

On average, each in-depth interview took between two and two and a half hours. Participants were matched with interviewers based on gender and within a similar age category. Interviews were semi-structured and consisted of open ended questions that were modified to pursue emergent concepts as data collection and analysis progressed (Glaser, 1978) (APPENDIX I) Young people were asked about their childhoods (including families, education, health), their experiences through relationships, testing for HIV/AIDS, their experiences attempting to access treatment, and their current living situations. Healthcare workers and HIV counsellors were asked about their perceptions as to the current barriers to accessing and adhering to treatment for both young men and women in town.

3.2.3 Data Collection and Analysis: Phase 2

Interviews were modified to pursue emergent concepts as data collection and analysis progressed (Glaser, 1978). In this way, data collection and analysis advanced in an iterative fashion, with early interviews and analysis informing future decisions on sampling and interview questions. After 10 pilot interviews (5 male and 5 female) a complete coding and analysis was done for preliminary results. During this time, it became clear that the life stories and experiences with treatment that the participants were describing did not match their reports of adherence. During preliminary literature reviews conducted for ethics and thesis proposals, food security did not arise as a potential barrier to either access or adherence to HIV treatment in Uganda. During the preliminary interviews however, the majority of the participants spent the allotted time discussing the difficulties they had with the medication as a result of their inability to access enough food. Consequently, team meetings were held with the research assistants and community HIV counsellors. Community counsellors assured the research team that access and adherence to treatment were in fact, not taking place as a direct result of food insecurity. Despite this however, participants were unwilling to disclose their missed treatments for fear they would lose the free care they were receiving. At this point, changes were made to the topic guides and introduction and monthly adherence
calendars were introduced (APPENDIX J). The pilot interviews were revisited by the Community HIV Youth Counsellor and given a calendar to fill out in private. New interviews were given the opportunity to fill out the calendar at the end of the interview, under assurance that there was no connection to their adherence disclosure and their access to treatment. Monthly follow up calendars were administered by the counsellor in private with the participant and then returned to the research team. Missed treatment was marked with an “x” and the reason for missing was noted next to it.

Follow up interviews were done with three female and two male participants who were willing to return for another one or two visits with the research team. These offered participants the opportunity to reflect on previously discussed issues, to update the research team on their progress or regression with treatment, their livelihoods, or their health situation. They also allowed for clarification and discussion surrounding new concepts or themes that had emerged over the previous months of interviews.

Interviews were audio recorded in either Luganda or Runyankole, then translated and transcribed by the research assistant who conducted the interview. Transcripts were then checked by another team member for accuracy of translation against original audiotapes. Coding structure was created by the research team, led by SC. During analysis, an audit trail was kept to document how and why analytic decisions were made. All original interviews were kept on a CD accompanied by their typed transcripts and a second copy of their coded transcript. Analysis was conducted by reading through transcripts and field notes, and with regular meetings with HIV community social workers (research team members from Lyantonde, to offer a community perspective) in order to develop a set of codes that accurately described the depth of the data. As data collection and writing progressed, the data were analyzed to gain insight into the barriers experienced (e.g. social, structural, cultural, economic) when young people attempt to access and adhere to HIV treatment in Lyantonde.

3.3 RESULTS

3.3.1 Sample Characteristics
24 of the young participants were female; their average age was 26 years (ranging from 18 to 30). All but one had engaged in sexual intercourse before the age of 18, 16 of the women
were widowed or single and 19 had children. Five of the women were, at time of the interviews, engaged in sex for exchange and all but two had, at one point, engaged in sex for exchange. Of the 23 male participants, 13 were married or in a relationship, 12 had children and only two owned their own land.

Eight health care workers were interviewed: four public health staff (doctor, nurses and medical assistants in the HIV clinic) and four HIV counsellors. The two groups (public health staff and counsellors) consisted of two males and two females each. Service providers were recruited through their place of work (sampling from each of the two HIV treatment centres in town).

### 3.3.2 HIV Treatment Adherence Among Youth in Lyantonde

14 of the 24 women and 11 of the 23 men were accessing treatment, however all of those accessing were unable to adhere to their HIV treatment over the three month period that was measured. All participants identified food insecurity as their only reason being unable to adhere to treatment (both Septrine and Anti-retroviral therapy). There were also one female and three male participants who fell off treatment completely as a result of food insecurity.

When discussing the barriers to treatment adherence, 5 main themes arose: (1) lack of land ownership in town for subsistence farming, (2) lack of income potential to meet the costs of town food, (3) inability to meet dietary requirements to take HIV treatment, (4) the difficulties of taking treatment without water and (5) how the changes in season have significant affect on all of the aforementioned barriers, further amplifying the aforementioned barriers.

### 3.3.2.1 Town Living: without land ownership or subsistence farming

In the peri-urban living of Lyantonde town, many of the houses are small one or two roomed spaces on compounds shared with other, similar one or two roomed spaces. Cooking is done on the cement blocks (much like a patio) in front of the individual rooms and laundry is shared in the small communal dirt square in the centre. There are few large houses with land in town; those that do exist are owned by the very wealthy. The cement blocks are not owned,
rather they are rented out, to widows and children and even entire families unable to afford the cost of a home outside of their village.

Seven of 11 men and 11 of 14 women unable to adhere to treatment did not own their own land or the homes they lived in. They were renters, living in small apartments without plots of land to grow even subsistence food. They described their inability to farm anything to eat as a result of their current living situation. As a consequence of living in town, they had foregone their ability to live off the land and, were forced to purchase food from town, which was much more expensive than in the villages. Purchasing food left them dependent on the fluctuating costs of produce and with little hope of affording much variation in their diets. The high rent prices left them with little purchasing power to feed themselves or their children.

There were 3 participants who did own land in nearby villages and many spoke of others they knew in similar situations. However, for young people living with HIV/AIDS (PLWHA) returning to the village to live off the land would mean they could no longer afford to come to town and thus, as Lyantonde Town has the only supply of HIV treatment in the district, they could no longer access any HIV treatment whatsoever.

“...getting gardens became impossible for us. We have where we could farm, but the ground is all rocks and stones that nothing can grow. We have no land... Money to buy posho or flour is hard to get and varies with the season”
- 30 year old female, unable to adhere

While a few participants did have an option of returning to their villages to live off their land, this would again mean they could no longer access the free treatment that was only available in town:

“You could move back to the village but then you face transport problems. You may then have land that you can grow a little food. But it is not enough food to sell and earn a surplus, so you cannot afford transport back to town to get your medication”
-19 year old female participant, orphaned at age 12
3.3.2.2 Lack of income potential to purchase food

Many young described the cost of town living as too high and the lack of employment opportunities left them with little access to funds. For these young PLWHA, food is a luxury:

“To us, feeding or getting food at home is like a luxury. We cannot eat everyday as other people do. We only eat when we get the food and the other days we go to bed hungry. Even the children are used to it”-25 year old female

Of our female treatment seeking participants, five worked as diggers, five were unemployed, three engaged in sex for exchange and two were domestic workers. Of our male treatment seeking participants, seven were diggers, two worked in a meat shop or restaurant and two had odd jobs. Digging is notably a common job among young people living in Lyantonde, however it is incredibly unstable work. Those working as diggers (also referred to as farmers) do not own their own land, rather, they get up early each morning with their digging materials and hope to find someone who knows of someone who has land and needs people to work the land that day. They are paid at the end of a day’s work (where they take little or no break) and earn approximately seventy five cents to a dollar for nine hours of physical labour. There is no guarantee that they will find work each day and work is very seasonally dependent. Our young PLWHA described the difficulties they face when digging; since they are not paid until the work is completed, they wake up with an empty stomach, work in the hot sun for a whole day and only then are they paid. Finally, around 4 or 5 pm they able to purchase food and eat for the day. Participants that were on a twice daily dose regiment and working as diggers told us that they often missed their morning dose and could only take their medication after having worked, being paid and then finally getting to eat. Participants spoke of experiences when attempting to take their medication without enough food, and had then proceeded to dig all day and ended up fainting, nauseous and in excruciating pain as a result:

“I still try and dig, especially when I have eaten, but when I have not eaten anything I cannot dig. At such times, when I have nothing to eat and I cannot dig, all I can do is stay in bed hungry and weak”. -30 years old female

“My wife and I work we dig and look for money and we both come home late in the evening and the children are hungry and my wife tries to make food but there are times
we eat little or very late and I cannot take my medication. I can’t take my pills in the morning because I have yet to get money and yet to get food and so, because of the effects of the medication and what it causes, because I fear those, I skip taking the pills those days” -29 year old male orphaned by HIV/AIDS

“There is nothing else [but dig] I can do... and it’s important that I work for food because without that food I can’t use the medicine in time. When I fail to get food, I get weaker and cannot work. The medicine makes my appetite go up and I have to work harder, but I am weak” -27 years old male

All of our young participants described work as physically exhausting. They told us their bodies were too weak to dig, or cook and clean all day for others, or engage in long hours of aggressive sex, all to earn no more than a dollar. At the end of the day, they said they could feel the virus taking its toll on their bodies, but if they did not at least try and work, they would have no means of providing for themselves or their families. At the same time, when they would earn money, they felt that they had family responsibilities that should come before spending money on extra food to meet their treatment needs:

“I have children at school and they need school fees and they need food, I have to also care for my brother and my sister in the village. In the morning, after work, I can find myself with 1000 shillings [75 cents] which is just not enough. With HIV, I am too weak to work too hard and yet I need good feeding to be strong to work. I cannot afford the good feeding and caring for my family and paying the rent. I will try anything, even water that I can try and take the pills... many of the patients’ incomes are very low and they can’t afford meeting the treatment requirements for HIV medication and for living here [in town]”
-29 years old male, orphaned by HIV/AIDS at 11, caring for his 2 younger siblings, wife and 3 children

Young women engaged in sex for exchange spoke of the dangers they knew they took on by agreeing to have unprotected sex. They knew that they were increasing their chance of other infections, however, at the same time, they could earn enough to afford the required food in order to take their treatment, and feed their children:

“And when you say use a condom, he says with a condom, I will pay 5000 shillings [three dollars] and without a condom I am going to pay 15 000 shillings [approximately eight dollars CDN]. Because of the difference of how much he is willing to pay, I always
keep quiet first. I reflect on what counsellors have told me, but then I think of the state in which my home is in; my children are at home, they do not go to school, there is no food and I cannot take my pills, my children are hungry and rent is pending. So I close my eyes and accept to do that which the man has suggested so that I can get more money, this is how I survive”

-30 year old sex worker whose husband died in 2003 without telling her he was on ARVs, leaving her with three children, no land and no source of income

“I can’t remember the time I first had sex, I was very young... but then I married but he died and, I am someone illiterate who can’t easily get a job which can allow one to earn money so I am not supported by a husband, because of the fact that and I had these problems and no job I decided to resort to commercial sex work for a living.... it’s very hard for a man to give you any amount exceeding 10 000 shillings [approximately six dollars CDN] if I insist on a condom” -18 year old female bar maid and sex worker

“I have got all those difficulties simply because my husband died and before the death nutrition was not a problem in our house... before, he used to buy food by the plenty...now I may find a man paying me like 10 000 shillings [approximately six dollars CDN] but most times strings are attached such as not using a condom because of being paid more and if he’s paying me less he uses a condom...for 5000 shillings [approximately three dollars CDN] he will use one, but because I have money problems most of the time I accept the bigger amount without a condom which can push away my other problems..... I do have sex with those men who I fear especially if they do not use a condom and my worry is about getting a different type of virus on top of the type I am having and getting more weak. In that work we do as women you get other problems such as syphilis, gonorrhoea, especially without condom use and when a condom is used all the infections stop, but so does the money...some men do refuse to pay that money [the money they agreed upon] after using you. Men sometimes cancel the agreements when they get satisfied sexually. After sex he jumps you and goes away... after sex some men tell you stories after infecting you with STDs...I have just gone back to that business but I don’t do it so regularly anymore, so when I do I go two times in a week and then I stop for some time before I go back. I don’t sell my flesh every day because I don’t want to get weak. I realized that the more I do it the weaker I become so doing it all the time may put my life at risk. When I have sex with men I feel very bad and get weak...the reason why I went back it’s because I fail to get money to eat. When I work and get the money I stop going there for money from men and when the money gets over, I go back. I can’t sleep with men because of the little energy I have even yesterday I wanted to go there [to the bar where she meets men for sex] so that I could buy food, but I failed because I was too weak”

-30 year old female forced into sex work after her husband’s death

The cost of food in town is much greater than in the villages, and the affordability for our participants is largely impossible:
“Poverty and not having what to eat are the most pressing issues when you have to take medication. Almost, all of the time is spent discussing food. How to get food, what to do next, how you wish you had some place to plant or that you were strong or healthy to work”.

-30 year old female participant, fallen off of treatment because of lack of food.

3.3.2.3 Inability to meet dietary requirements to take HIV treatment

One of the greatest needs of PLWHA is adequate nutrition (WHO, 2005; Friis, 2006). HIV is often associated with poor nutrition, as a result of several factors, including increased energy needs, decreased appetite, symptoms of HIV that lead to malabsorption and finally, because of environmental factors such as lack of resources and inaccessibility of foods. In resource poor settings, food consumption has been found to drop by as much as 40 in households affected by HIV/AIDS (Topouzis, 1999). Furthermore research has found that those living in such conditions are often unable to meet the dietary requirements for HIV treatment regimens (WHO, 2003; Castleman et al., 2004). All of our treatment seeking participants expressed great concern for their ability to acquire not only enough food, but the right kinds of food (e.g. enough protein) to take with their medication. When they attempted to take their treatment without having eaten enough beforehand, they spoke of experiencing unbearable pain. Many also shared accounts of friends who had died from taking HIV treatment without enough food:

“I get side effects when I take it [Septrine] without eating. When I take it without food, I wake up and my head is beating too fast, my stomach is hurting too much, I cannot take it without food... most times, I can go days without food” -25 year old young woman

While they could not take their medication without enough food, the treatment itself was also reported to increase one’s appetite thus doubling the difficulty in meeting their nutritional needs:

“My main challenge is when I take the medicine I feel hungry and thirsty that I yearn for food something that was not there before [the medication started] but getting that food is a challenge, it does not come easily” –F4 30 years old, on ARVs
The participants reported strict nutritional guidelines that they had been told to follow while on treatment, however, they also explained that these requirements were far beyond attainable:

“We are told that only if you can feed properly, will the medication work in your body...though I do not get [food/drink] we are told to eat silver fish but there is no money to buy it. Also to eat fruits, but these all require money or land to grow them on and we have neither”.
-F2, 21 years old. Widow since 2007, left renting in town without land or earning potential

Most of our participants lived mainly off cassava (a starchy root) with little or no sauce (e.g.; meat, meat broth or nut sauce) and only a little salt. They drank tea without milk and could rarely afford the suggested dairy products of milk and yogurt (FAO and WHO, 2002). They could not meet the recommended requirements of regular ‘snacking’ (FAO and WHO, 2002) and would often begin their mornings hungry and, only after working for the day, have their first meal in the afternoon; one without protein, greens or much nutrients. In the evening, mothers often chose to feed their children any leftovers that were there while they survived off black tea.

“How often do you find yourself with nothing to eat and sick in a month?” “It has been like that for long, and more than before, what to eat and drink is no more. It has been long, it is more than one month with little food or drink” – young woman falling off treatment because of lack of work or food

Participants felt that the staff at the hospitals could not understand the difficulties they faced in accessing the required food. They felt great pressure to take their medication at all costs. Many had tried to take both Septrine (the Cotrimoxazole prophylaxis used in Lyantonde) and their ART (Nevirapine) without eating beforehand; for all who had tried, this resulted in extreme effects. Patients described “squeezing of their intestines”, nausea, passing out on the roadside, stomach pain leading them to believe they may die. After having had the side effects once, not one participant was willing to risk the combination of drug therapy without food again.

“When I went there at the hospital I was given pills to take, which pills I couldn’t take for some time because of food difficulties. I used to try to take these pills even when I
had not eaten and the effects were bad and painful, giving my stomach and intestines much pain. Some days the pills without food stopped me from working and without work I couldn’t get more food, so I stopped the pills”.

- 18 year old male participant who fell off of treatment last year because of food insecurity and his inability to adhere to treatment

“They [the recommended foods] are easy to get if one has money... the foods we are told to eat are very costly”

- 22 year old female adhering an average of seventy two percent over three months because of her inability to get enough food to eat.

“We are told what to eat, but it is what we cannot afford to get. They always tell us to get foods we cannot get... we are told to eat matooke, rice, g-nuts, beans and leafy vegetables and meat but all these we cannot get... I mean where would I get them from? We do not have the money to get them. Instead we eat cassava, we eat cassava with water.” “Can you continue taking medication with this type of feeding?” “You do not take medication then, because you know your stomach cannot be satisfied with just cassava. Should you force the medication, you end up getting so dizzy and so sick, so you cannot take your medication”

- 30 year old female falling off of treatment (less than 50 percent adherence in November)

With such little hope of ever affording the required nutrients to support their treatment needs, our participants felt tormented:

“My situation is completely undesirable, I have such poor feeding and it’s the feeding which stopped me from taking the pills. The money I get in a day can’t be enough to feed my children, pay the rent and meet the medical food requirements and now I am in danger for not being on medication...Feeding is very poor; this can psychologically torture you. The family demands meat, but there is no money to buy them what they need. I cannot afford it”.

- 27 year old male, fell off of treatment because could not get enough food to remain adherent.

Attrition eventually follows adherence failure. Patients are left too weak to work when taking the medication without food, and without work, they are unable to afford food, and are then forced to stop treatment:

“These pills [Septrine] I would take with little food and the effects were bad and I lost my energy and got pain and dizziness. The pills stopped me from going to work and without work I couldn’t afford more food... and I couldn’t take the pills without food and not get sick....i can’t afford that much for food each day and can’t work enough when I take the pills because I am too weak”
18 young man years, fell off of treatment because of food insecurity

3.3.2.4 HIV treatment and water supply

Reliable delivery of good quality water is critical in reducing exposure to pathogens to which HIV-positive people are particularly vulnerable. Where water services are inadequate or inaccessible, the time and monetary costs of accessing good quality water in sufficient quantities are high, particularly for HIV-infected people and their care-givers; PLWHA are more susceptible to opportunistic infections and diarrhoea; without clean drinking water their risk of both are immediately increased. At the same time, ARVs have been found to be better absorbed when taken with clean, treated drinking water (USAID 2007). For the impoverished young PLWHA of Lyantonde however, clean drinking water is often out of reach:

“[The water] appears brown like this floor, it is too dirty. The cows step in it and some of the water has vegetation covering it and it is too dirty. You try to sieve it, but it does not make it clean enough for drinking. And yet, I am supposed to take a lot of water a day, [the medication] they make me want to take 10 litres of water in a day.

–young woman unable to meet water requirements for medication.

“I do not think it [the water] is boiled. I heard rumours that it’s taken straight from the borehole and then packed without being boiled. It tastes salty when you drink it, but because we earn so little we’re forced to buy water that is not meant for drinking”

-18 year old young man

In Lyantonde Town there is a main market. There are water holes and water pumps, but when drought has hit and it’s been weeks without rain, running water stops and the price of food rises. Between August 2008 and January 2009 (the time SC spent in the field) there were never more than thirteen consecutive days with running water. When the taps are dry, water is sold at a water storage facility (there is a large tin roof with pipes on the side that collect rain water and filter them into a massive cement storage facility) for 50 cents per jerrycan (approximately eight litres, used for bathing, cooking and cleaning). For those, like many of our young participants, who cannot afford the 50 cents for the collected rain water that sits in the cement holder (and often collects worms as a result), there is a borehole which is also monopolized by townsmen who guard it and then charge 20 cents for a jerrycan. The borehole water is brown, often shared with cows and other animals and not only needs to be
boiled beforehand, but often also needs to be sieved before it can even be boiled. During the dry season, the water becomes undrinkable and the clean water becomes unaffordable; the increase in prices and the increasingly unsanitary water conditions furthered the difficulties our young participants encountered when trying to take their medication. Several women spoke of boiling the water with tea leaves, so that they could no longer taste the dirtiness of the water, and so that they would at least have something to quench their thirst. As mentioned, treatment increases PLWHA’s thirst and they are resultantly forced to drink more dirty water during the dry season than they would have been drinking off of treatment:

“Sometimes it [water] is not here and other times it is. Like just recently we did not have water. In such times we go to the well or buy from a borehole...It is a big ditch that was dug to collect water. But going to there is something that comes out of lack of alternatives. The cattle keepers bathe from it, cattle drink from it. But when we get it, we do not use it to cook food. We only use it to wash clothes and bathe. Then you ask from the neighbours a 5 litre jerrycan of clean water that can be used for drinking.”
-23 year old young woman

3.3.2.5 Seasons, food insecurity and treatment adherence

In September, all of our treatment seeking participants were waiting; waiting for the rains to fall, the crops to grow, the price of food to fall and finally, to be able to eat enough to meet their treatment requirements. They explained that the changing price of food directly impacted their ability to take their medication and thus, their overall health:

“This [September] is the hardest month for me because before I weighed 70 kg but yesterday when I stood on the scale at Supreme [the Muslim Health Centre] I found a reduction of 10 kg after weighing. The 10 kg is gone because of poor nutrition as I have been spending long periods without food. We can’t afford it right now”
-27 year old man

As the seasons change and summer arrives, crops dry out, the food supply dwindles and the price of food rises. Interview discussions were devoted to, (and adherence calendars confirmed) the gruelling food insecurity our participants faced in September (when food bundles were roughly five dollars); men reported an average adherence of 59 percent and women and average of 52 percent. In October the price of food began to drop (a food bundle cost approximately $3.50CDN) and fresh beans were available in large paper bags for just under a dollar; adding beans to their diets would completed most meals for our young PLWHA
and provide them with a more balanced diet and enough nutrients to take their pills; in October our male participants reported an average adherence of 73 percent and our young female participants reported an average of 69 percent. Finally, in November, as the price of food bundles fell to two dollars, the price of beans remained low and the prices of matooke and rice also fell, reported adherence rose. The average reported male adherence in November was 83 percent and that of women increased to an average of 72 percent. All of our participants faced severe difficulties as a result of seasonal changes and their adherence capabilities were directly affected by the changing seasons and changing prices in food:

“During the dry season there are no farming jobs to do and that is when life becomes harder. There is less to do, from which to earn money. You see, if it is the rainy season, people will call upon you to dig for them and they will pay you. But if it is the dry season, no one will call upon you to dig for them. You end up moving with a hoe on your shoulder, looking for work and when you do not get, you retire home, very tired and with nothing to eat and then you cannot take your medication. Sometimes, when we get some work we get money to use on transport to get the medication, so we end up with transport money but do not have any money for what to eat or drink for the whole day that we spend at the hospital”
—young woman struggling to support herself and her family seasonally.

“[In the dry season] life becomes harder, that everything needs money and if you do not have it, survival becomes harder than usual. On such days which the dams have dried up and there is no water flowing in the taps, the jerrycan at the borehole goes for 1000 shillings [75 cents CDN]. And even if you do not have that money but decide to go to the borehole in the middle of the night, there are men there, ready to make you pay”
—25 year old young woman, only able to adhere to treatment with food assistance during dry season

3.4 DISCUSSION
In order to better understand the barriers young people residing outside of the major urban centres in Uganda may be facing in their attempts to adhere to HIV treatment, our analysis demonstrated that food insecurity emerged within five thematic areas leading to treatment non-adherence among all of our participants.

The United Nations Standing Committee on Nutrition defines food insecurity as: “Uncertain or limited availability of nutritionally adequate or safe food, or the inability to procure food in socially acceptable ways” (UNSCN, 2001). The parameters around this
definition include: caloric intake; poor quality of food which can include lack of diversity or food groups; unsafe food (including food and/or water that may have been contaminated), and procuring food in a socially difficult manner (i.e. begging, stealing, or exchanging sex in exchange for food or money to purchase food).

The five areas discussed by our participants led through repeated paths to food insecurity:

**Town living and food insecurity:** Our young participants explained that peri-urban living poses challenges for PLWHA. Living in small rented rooms, they have no land to grow food for subsistence living, yet they cannot afford the cost of food in town. While returning to village living may offer the chance at subsistence farming, it would inhibit them from accessing treatment, which is not available all over the district. They would be able to farm enough to support themselves, however, participants described being unable to afford the transport costs to return to town and access their treatment. Previous qualitative studies in rural areas have supported the findings that living in rural areas can create a barrier to access to treatment resulting from transport costs (Weiser et al. 2003; Hillary, 2006). The barriers to adherence for town renters, who could not grow food, nor afford to buy it, yet were living close to a treatment centre however, remain unaddressed in the literature.

**Lack of employment and food insecurity:** The young PLWHA in our study were not only unable to grow their own food due to housing barriers, they were also facing employment difficulties and unable to meet the high costs of food in town (again, in comparison, the cost of food in the neighbouring villages was reportedly much cheaper). Previous studies have also encountered labour difficulties common among HIV/AIDS affected households (Loevinsohn and Gillespie, 2003). As a result of such labour shortages many young women in our study were forced into sex work in order to afford the food they needed for treatment and disclosed engaging in riskier sexual interactions for more money. Food insecurity has been previously associated with increased HIV related vulnerability; in Botswana and Swaziland, food insufficiency was found to be associated with inconsistent condom use and lack of control in sexual relationships (Weiser et. al. PLoS Med, 2007). In Nigeria, food insecurity has also been connected with entrance into commercial sex work (Oyefara (J Soc Aspects of HIV/AIDS, 2007). While with previous supporting research we can better understand the relationship between
HIV/AIDS related vulnerabilities and economic insecurities, there again remains little investigation into the path from job insecurity to treatment adherence in relation to food security.

**Inability to meet nutritional requirements to take medication:** To date, there has been a growing amount of research illustrating the complicated relationship between HIV/AIDS and food security. Studies have found that malnutrition alone can increase one’s susceptibility to HIV/AIDS (Blackburn, 2001; Blumberg, 1994). Research has illustrated the devastating effects that malnutrition can play in the progression of illness and, at the same time, the toll the illness plays on one’s ability to absorb nutrients (WHO, 2003). Malnutrition leads to immune impairment and worsens the effects of HIV thus furthering the progression of the disease. As a result, malnutrition can both contribute to and result from HIV/AIDS (Food and Nutrition Technical Assistance Project, 2004; Loevinsohn & Gillespie 2003). Despite Uganda claiming high rates of treatment adherence, there are an increasing number of studies that are noting the role of food security in HIV treatment adherence (Mukherjee et al., 2006; Ndekha et al., 2005; Villamor et al., 2005; Fawzi et al., 2004). Most recently, a qualitative study conducted between Mbarara (65 km from Lyantonde) and Kampala (approximately 200 km from Lyantonde), using in-depth interviews and hospital recruitment, found that food security was the number one factor in treatment non-adherence (Weiser et al. 2008).

**Water sanitation and treatment adherence:** The International Water and Sanitation Centre has documented the important role that easy access to safe and sufficient water plays for HIV/AIDS patients (IRC, 2005). Not only is safe drinking water necessary for taking medication, it is also required to maintain personal hygiene and the household cleanliness (e.g. bathing, cleaning). It is increasingly understood that, for PLWHA the burden of water is even greater when it must be collected far from home, or paid for, as was the case in Lyantonde, (Kgalushi, 2003). A case study in Limpopo, South Africa found that when public water services broke down, residents with already weak immune systems were forced to revert to unprotected water sources, despite the understood dangers of doing so given their HIV status (Kgalushi, 2003). With a gap in evidence linking water and HIV treatment adherence, there is a need for incorporation of water; sanitation and availability, into further HIV treatment adherence research.
**Seasonal changes and treatment adherence:** As the current decade brings increasing questions in climate change, researchers are acknowledging that many PLWHA in low income regions are seasonally affected, especially during times of drought. Recent qualitative findings from Kenya suggest that, as a result of such seasonal affects, HIV/AIDS affected households may only survive with the assistance of external support (Byron et al. 2008). Our participants were similarly affected by such seasonal affects on food prices, and without any external support, were left unable to adhere to their treatment programs during the dry seasons and times of drought and water shortages. Currently, Gillespie and Drimie are proposing that research investigate the role that seasonality plays in food security and potential spikes in HIV-related vulnerability in Eastern and Southern Africa (Gillespie and Drimie, 2008). Further adherence research and HIV treatment programs also need to consider incorporating the important effects that seasonal changes appear to have on treatment adherence.

**Summary:** Free HIV treatment and care in Uganda has been limited to the past 5 years. As a result, there remains a paucity of literature investigating the relationship between adherence rates and food insecurity. At the time of this study, most literature regarding adherence rates in Uganda reported high or near perfect adherence in previously studied areas (AIDS Healthcare Foundation, 2008). These quantitative studies however, focused largely on hospital recruitment and self-reported adherence rates, and were conducted within the urban centres (Byakika-Tusiime et al., 2005; Oyugi et al., 2004). It is also important to consider the preliminary barriers faced in this study when attempting to discuss non-adherence with patients and the fears that associated with disclosing adherence failure. Within this small qualitative data set, and especially during pilot interviews, it became apparent that, as a result of poor treatment and negative healthcare workers responses, patients feared admitting non-adherence. Instead they chose to respond based on what they felt was socially desirable behaviour (i.e. social desirability bias). Participants and HIV community counsellors both addressed negative hospital treatment as a serious barrier to patient self-reported adherence rates which resulted not only in false self-reported adherence rates, but also in pill-dumping. Furthermore, from fear of a potential relationship between SC’s study and the two treatment centres in town, participants initially felt compelled to swear by the adherence they had been claiming to the healthcare practitioners.
The qualitative interview process used during this study highlighted potential concern for current self-reported adherence rates in Uganda. In the early stages of free treatment, it is possible that patients, such as those in this study, are attempting as best as possible to remain on treatment and fear that any disclosure of non-adherence would compromise their access to potentially life-saving treatment. As well, this study illustrates the importance of investigating the relationship between the many facets leading to food insecurity and their effects on treatment adherence, and to recognize the role these may play in certain settings, within certain seasons and among certain age categories.

PLWHA require a greater than average amount of daily food and water; once on treatment, these requirements increase once again (WHO, 2003, WHO, 2005) Our young participants described that these increased requirements, coupled with the widespread agricultural challenges and compounded by poverty, job insecurity, and water shortages within Lyantonde made their attempts to adhere to HIV treatment nearly impossible. What remains are questions of whether other young PLWHA living within other peri-urban areas across Uganda are facing similar barriers to adherence. We know very little about the role of land ownership and subsistence farming and their importance in food procurement to meet the nutritional needs for treatment. While studies to date have largely focused on food security and HIV/AIDS related vulnerabilities, there is an increasing need to investigate the relationship between treatment and food and water insecurity and to consider this within the context of place and season.

3.4.1 Strengths and Limitations

The purpose of this study was not to generalize the findings to a larger population, but to elicit insights to develop action that is sensitive to local circumstances. Self-reported data in epidemiology are often cited as vulnerable to recall and reporting biases. However, the insights of young people and their counsellors are precisely what we were interested in. Since these are not easily uncovered by traditional epidemiological methods, we used in-depth interviews to gather the perspectives of youth and service providers. This enabled SC and the research team to develop trusting relationships with participants over seven months and to obtain insights about local realities (e.g., the team gained a good understanding of the workings of the local public health system by participating in local NGO and hospital community workshops).
Some key demographic composition in our sample should be understood in interpreting our results. The self-reported non-adherence average was greater than expected in Lyantonde (upon arrival in town, the team was told that the hospitals estimated a 95 percent adherence rate). Although we made many efforts to select a diverse group of young people to take part in the study, given the fear reported in acknowledging non-adherence, it may be possible that adherence was actually even lower than reported. As well, many participants spoke of other people who had fallen off treatment as a result of food insecurity, however only a small number of our sample reported such circumstances.

During data collection, SC moved to Lyantonde, where her presence in the community provided a catalyst for discussion among community members, HIV counsellors and service providers (a Western presence in this community is immediately noticed). As well her presence during preliminary interviews clearly affected self-reported adherence levels and thus, she removed herself from the remaining follow-ups and all further interviews. Choosing young interviewers, from outside Lyantonde, we believe helped ensure participant security, allowing the young men and women to feel comfortable talking with someone their own age and gender, but who was unfamiliar with the small town dynamics. The rich and detailed stories gathered suggest that using such techniques enabled us to tap into deeper insights than would have been documented using traditional methods. Furthermore, the added use of adherence calendars, filled in on a weekly basis, complemented the interview results and helped reduce recall bias.

Our analysis is based on interpretations of data. To address this, we kept an audit trail documenting data analysis; completed follow-up interviews, sought analytic consensus among the research team and SC’s thesis committee; and compared our data with previous and ongoing HIV treatment research among young people in other locations in Uganda. This study attempted to produce as much of a classical ethnography, which typically involved extended fieldwork for periods of months to years (Wolcott, 1999), and to engage as much as possible with this community given the limitations of available resources.
3.4.1 Corresponding Actions

Current service delivery models need to consider the role that food insecurity plays in treatment adherence. Since young people in Lyantonde are clearly facing great barriers accessing the needed nutrients to remain on regular treatment, not only do hospital and clinic programs need to consider including food security discussion as part of their treatment education programs, but community organizations that work with PLWHA in Lyantonde must also consider this important barrier in their implementations. At the end of this study, the research team held a community forum attended by over 75 community members (including the district medical officer, HIV counsellors, religious leaders and political officials) to discuss the results of the study and potential areas where the issues could be addressed. With less than a handful of NGOs in town, external support is limited. Thus, the small, community-feasible interventions discussed, while unable to address each barrier discussed, offered some significant public health benefits in light of the increasing challenges this community appears to be having with HIV treatment adherence and food insecurity.

In addressing peri-urban town living difficulties resulting from lack of land ownership, domestic produce growth was offered as a small, feasible solution to supplement nutrition. Community social workers explained that tomatoes and passion fruit could both be grown from plastic bags on the porch, or in a windowsill and that they could be used for meals or be sold and the money earned could be invested in beans or a protein.

To address the issues of job and economic insecurity that led to food insecurity, the Salama SHIELD Foundation offered examples of microcredit groups that could be started, among 5 or 10 HIV positive youth, investing a small amount of money each month and thus supporting each other. The Salama SHIELD Foundation currently assists nearby village women with this project and it has been incredibly successful. In Northern Tanzania, small plot sharing allowed vulnerable youth to afford the land together and grow vegetables both for subsistence farming and for market sales and profit (Loevinsohn & Gillespie, 2003).

In order to ensure that adherence reports were more accurate, hospital staff and patient relationships were addressed by the District Medical Officer. He insisted that patients not be punished for their non-adherence and that hospital staff work on their empathy and understanding. He stated the importance for research as well as program implementation that
the medical staff be able to accurately document real adherence rates within the community as well as understand the reasons for adherence failure.

3.5 CONCLUSION

In this study, we documented the barriers to treatment adherence in a rural trading centre along a major trucking route. We documented young peoples’ experiences attempting to adhere to treatment and elicited health and social service providers’ perspectives on the circumstances surrounding treatment and adherence. We also developed recommendations to improve the current food insecurity issues and discussion surrounding treatment non-adherence within the hospital and clinic. Study participants identified food insecurity as their only reason for missed treatment; they then described five areas that directly led to their food insecurity: lack of land ownership for subsistence farming, job and economic insecurities to afford the costs of town food, their inability to meet the nutritional requirements to take medication, their inabilities to take their medication without sufficient or sanitized water and finally, the difficulties they face seasonally as a result of changes in food and water availability and costs to remain adherent to treatment. The stress of land, job, nutrition, and water insecurity on their ability to meet the dietary requirements for treatment led many to attrition.

At the 2005 WHO conference on HIV/AIDS and Food and Nutrition Security in Durban, South Africa, evidence regarding the relationship between food security and HIV/AIDS were acknowledged, and a call to integrate nutrition into treatment packages was made (WHO, 2004). At the same time, similar international bodies such as (i) the 2003 WHO Technical Consultation on Nutrient Requirements for PLWHA in Geneva, (ii) the May 2006 forum on food security, nutrition and HIV led by Project Concern International in Lusaka, (iii) the World Food Summit: five years later in 2002, (iv) the 2001 and 2003 sessions of the FAO Committee on Food Security and (v) the 2002 and 2004 African Regional Conferences (FAO. 2002, FAO 2004, FAO 2009) have also acknowledged the important relationship between the epidemic and food security. Despite such a worldwide acceptance of the need to incorporate food security into HIV/AIDS treatment programs, in 2008, the United Nations World Food Program (UNWFP) began, due to lack of funding, withdrawing food aid to PLWHA in the north of Uganda, leaving approximately 1.5 million people devastatingly affected (UNWFP, 2007).
While current literature reports high levels of adherence to HIV treatment, the results of this study challenge such conclusions. Although researchers are increasingly recognizing the relationships between food security and HIV/AIDS vulnerabilities and disease progression, future studies must consider the role of place (e.g. peri-urban living), and the effects of economic instability, food insecurity, water shortages and seasonal changes. Studies should incorporate the use of multiple methods of adherence measurement to mitigate possibilities of fear based response in self-reports (as illustrated in the preliminary interviews of this study). They must also ensure a comprehensive understanding of the current barriers young people living in Uganda are facing in their attempts adhere to the available HIV/AIDS treatment programs.

If HIV treatment is to deliver the promise of treating young PLWHA in low income regions such as Uganda, a more comprehensive approach is required. Health workers, clinicians and researchers must document, monitor and attempt to understand the dynamics between place, food security, water availability, seasonal changes and HIV treatment programs, access and adherence (Cogill, 2005). Further research investigating land, economic, water and food insecurities and HIV treatment adherence is urgently needed to provide the scientific evidence base required for making appropriate HIV/AIDS treatment programs. The findings of this study underscore the urgent need to fill these knowledge gaps and to refine adherence research for future program policy making in peri-urban areas of Uganda.
3.6 REFERENCES


Gerry Hillary Mshana, Joyce Wamoyi, Joanna Busza, Basia Zaba, John Changalucha, Samuel Kaluvya, Mark Urassa. Barriers to Accessing Antiretroviral Therapy in Kisesa, Tanzania: A Qualitative Study of Early Rural Referrals to the National Program. AIDS Patient Care and STDs 20(9), 649-657.


Power, R., 2002. The application of qualitative research methods to the study of sexually transmitted infections. Sexually Transmitted Infections 78, 87-89.


UNWFP.,2007. WFP forced to cut food for nearly 1.5 million war displaced in Uganda. Available online at: http://www.wfp.org/node/414


Weiser S., Tuller D., Ware N., Sengkugu J., Frongillo E., Bangsberg D., 2008. Food security as a barrier to sustained antiretroviral therapy in Uganda. XVII International AIDS Conference. Abstract available online at:

file:///C:/Users/Simone/Documents/barriers%20to%20access%20and%20adherence/Simone%20HIVAIDS%20Food%20Security/food%20security%20as%20art%20barrier-weiser%20AIDS%20abstract.htm


4.0 DISCUSSION

4.1 DISCUSSION

This thesis demonstrated that, despite significant inroads made in HIV treatment development and availability in Uganda, there remains a paucity of literature investigating the success of such programs, and a lack of understanding regarding the barriers young people face in their attempts to access and adhere to HIV treatment in peri-urban settings. Findings were presented around community, gender and socio-economic based barriers that were experienced by youth (and witnessed by their service providers) in their attempts to access and adhere to HIV treatment and care.

4.1.1 Barriers to Access to HIV Treatment and Care

Chapter 2, “Understanding Barriers to HIV Treatment Access: A case study from a peri-urban Ugandan trading centre”, examined the current barriers young women and men living in Lyantonde experience as they attempt to access HIV treatment. These findings were supported by the focus groups held with HIV/AIDS community counsellors. Study participants identified fears surrounding losing their employment (stigma), relationship based fears (gender power imbalances) and food insecurity (non-adherence to attrition) as the key reasons for their inability to access treatment.

These findings identify that young people living in Lyantonde are still facing significant barriers surrounding stigma; as many feared that they would lose their job based on their employers’ perspectives surrounding HIV/AIDS. HIV/AIDS in Uganda has been a stigmatized illness since its onset in the early 1980s (Muyinda et al., 1997) and, these results highlight that such stigma has yet to dissipate. Across sub-Saharan Africa, there remain several studies that have found that HIV status disclosure can still lead to stigmatization and resulting job loss (Barroso and Powell-Cope, 2000; Holzemer et al., 2006; Varas-Diaz et al., 2005). Stigma, therefore, must remain at the forefront of HIV treatment programme implementation.
Gender-based fears as a barrier to treatment also underscore the already widespread literature regarding gender-based HIV/AIDS related vulnerabilities (Remien et al., 2009; WHO//UNAIDS/UNICEF, 2008). International institutions, scholars and policy experts have begun to focus on the role of gender equality in the spread of HIV; this human rights approach asserts that the marginal social location and low status of women in many societies explains their weakening ability to protect themselves from the virus (UNIFEM 2002; United Nations 1996; Mann and Tarantola 1996; Seidel 1993; Mann et al. 1992). Nonetheless, there remains a paucity of literature regarding the struggle women face in their attempts to seek HIV treatment given their vulnerabilities. Steps forward must be taken to empower women so that they are able to make their own choices in treatment access; for example, in Rwanda, a law was passed allowing women to inherit land, which would provide them with subsistence living if left widowed or orphaned (Kristoffersson, 2000). Such changes, although small, can begin to address the root issues of gender imbalances within the larger context of health and survival in sub-Saharan Africa.

4.1.2 Barriers to HIV Treatment Adherence

Chapter 3, ‘Barriers to HIV treatment adherence: starving to survive’, described young peoples’ great challenges with food insecurity and the role this plays in their inability to adhere to HIV treatment. Of all our young participants seeking treatment, not one of them was able to adhere to treatment over the three months that adherence calendars were administered. The only reason provided for treatment non-adherence was food insecurity. It is widely recognized that HIV impairs the immune system, as well as nutrient intake, absorption and use (Piwoz and Preble, 2000). Malnutrition can further exacerbate the effects of HIV and hasten the progression of AIDS. Food availability and nutrition are thus essential for keeping people living with HIV healthy for longer (Friis, 2006). Food security and nutrition are also fundamental to HIV treatment; there is emerging evidence that patients who begin ART without adequate nutrition have lower survival rates (Paton et al., 2006). Poor nutritional status may also increase the risk of mother to child HIV transmission (Gillespie & Kadiyala, 2005). While there is increasing research noting the potential for treatment non-adherence (Rosen et al., 2007), the
results of this study demonstrate an increasing need to further expand research to understand the relationship between food security and treatment adherence among young people and across various regions in Uganda.

4.1.3 Lyantonde: 15 Years Later

Since its onset in Uganda, HIV/AIDS has predominantly been greater within the urban centres (mainly, the capital Kampala), with one notable exception: Rakai District. Paradoxically, Rakai is a predominantly rural district and yet, those living within the region have experienced unprecedented levels of devastation due to HIV/AIDS. 25 years ago, the seroprevalence rates recorded in Rakai were the highest recorded for a general population living anywhere in rural Africa (Barnett & Blaikie, 1992). In the early 1990s, Lyantonde was home to transient truckers and a large sex work industry. Studies from the late 1980s reported an HIV prevalence of 35.3 percent among truckers (Carswell, 1989) and 76 percent among sex workers within Lyantonde (Namaara, 1988). In 1994, HIV related mortality in Rakai accounted for approximately 58 percent of all adult deaths (Sewankambo, 1994). Chin (1990) estimated that by the late 1980s at least 2.5 million women in Africa were infected with HIV. These women in turn gave birth to approximately 2 million infants, of whom, 500 000 were estimated to be infected with the virus. By the end of 1992, it was estimated that 4 million children would be born to HIV infected mothers and that at least a quarter of these children would be infected as well. Today, Lyantonde is home to the second largest orphan population (outside of the post-conflict northern region) in Uganda (Lyantonde District Government, 2002).

In 1995, Lyantonde was the site of a research project investigating the devastating effects of HIV/AIDS and the lives of the women forced into the sex trade.

“In Lyantonde today, many women, including bar girls, refer to themselves as the walking dead. Full of anguish and despair, this popular expression exposes one of the hidden truths of this HIV/AIDS epidemic in Uganda. Women know how to remain uninfected, but the conditions of their lives make it difficult to avoid HIV” (Spittal, 1995)

“As you know, women, we need so many things. When you look at yourself we need to eat, need soap; if you have a house you need rent... when people see us working in bars they call us Malaya [prostitute]. They think we go to the bars for men... we do not go for men, we for for money to support ourselves” –Betty’s story (Spittal, 1995)
15 years later, little has changed. Our female sex workers all entered the sex trade only after their husbands had died and left them infected with HIV/AIDS and they felt they had no other means of survival. They engaged in sex for exchange to feed their children and themselves.

“after my man died...you start thinking, I am positive possible the virus I had was causing wounds, now I have added on that [by engaging in sex for exchange] which causes you vomit and at the moment starting with the month of September people are poor. Money is scarce; you go three days with nothing to eat. You try to get someone who can pay you 2000 shillings [one dollar and 15 cents CDN] for sex, and then you go home, still with nothing for the children”.- Female sex worker, age 30.

In 15 years, the one thing that has changed has been the initiation of free HIV treatment. However, this may not have improved the lives of the young women living in town. Now seeking treatment, their hunger increases, yet the difficulties they face in supporting themselves remain the same. It seems the NGOs have left, gone up North to where the conflict remains, and Lyantonde has all but been forgotten. While prevalence has decreased somewhat, it remains one of the highest in the country. 15 years later I am reading the stories of the Lyantonde’s women in 1995 next to those in our current study and I see no distinction. The starvation, suffocation and despair exists today, just as it did 15 years ago.

4.2 DIRECTIONS FOR FUTURE RESEARCH

The example of Lyantonde Town was used in this thesis to illuminate those barriers to access and adherence to HIV treatment faced by young people living in peri-urban regions of Uganda. Although the results of the current qualitative study are not meant to be statistically generalizable, they are likely to be relevant to young people living other peri-urban communities, facing similar circumstances living in Uganda. The most recent example of this was demonstrated when the preliminary findings from a similar study conducted in Mbarara, a town approximately 70 km from Lyantonde, highlighted food insecurity as a commonly faced barrier to treatment adherence among participants (Weiser et al., 2008). To date however,

12 In Lyantonde, the Salama SHIELD Foundation and the Lutheran Foundation have limited funds to support orphans and vulnerable children. The Rakai Health Sciences Project however, no longer has funds in the area as Lyantonde has, since 2006, become its own district.
there remains little more investigation into how these vulnerable young people are attempting to negotiate across the barriers in order to seek and adhere to their HIV treatment regimens.

Both gender and food insecurity arose as significant barriers in the scope of this study. An important step when further investigating the role of food insecurity on treatment access and adherence is the incorporation of gender as a factor that may further vulnerability to both food insecurity and to treatment non-adherence (or non-access). Women are biologically, socially and economically more vulnerable to HIV than men (FAO, 2001). Young women in sub-Saharan Africa are left (often as a result of being orphaned by HIV), without access to adequate food, income or land and are thus increasingly likely to engage in risky behaviours to earn enough to feed themselves and their families. Such high-risk situations include commercial sex work, but also include remaining in high-risk or abusive relationships due to economic or social dependency (Weiser, 2007; WFP, 2006; Strickland, 2004). The results from integrating gender-specific investigations during access and adherence studies would assist in future programme implementation, to ensure that women’s issues are given their own address.

The use of qualitative methods in this study helped to gather rich, in-depth information about human experience. The methods of qualitative research provide powerful tools to increase our understanding of combination ART adherence (e.g. inquiry regarding, patients beliefs about access, stigma, reasons for non-adherence, patterns of medication taking and intervention measurement) (Sankar et al., 2006; Pequegnat et al. 1995). Sankar et al. (2006) argue that a variety of experiences cannot be accounted for during standardized quantitative methods and that it is with examples of data that are provided through qualitative methods that inform narratives. With regards to adherence measurement, current quantitative findings in Uganda have reported high or near perfect adherence (Byakika-Tusiime et al., 2005; Oyugi et al., 2004), however Weiser et al. (2008) and this study, through the use of qualitative measures question the accuracy of quantitative methods used for adherence measurement. The 2004 Institute of Medicine (“Scaling up Treatment for the Global AIDS Pandemic: Challenges and Opportunities”) named (1) adherence research as a priority, including gaining the perspectives of community representatives and HIV community workers and (2) “scaling up” treatment in a “learning by doing” method as part of its priorities within low-income regions (Curran et al., 2004). The future use of qualitative methods can assist in such goals firstly by indentifying and
describing local culture relevant to adherence practice and meaning (this may also assist in how best to support a community). Secondly, by gaining the perspectives of individuals and the health service providers through in-depth interviews, qualitative methods can assess the cultural validity of constructs identified through earlier adherence research in other settings and the acceptability of such technologies within new settings (Sankar et al., 2006).

Finally, there is a knowledge gap investigating the barriers that young people are facing in other areas of Uganda; especially within the context of food security and HIV treatment access and adherence. In 2008, as a result of funding cuts, the United Nations World Food Programme (UNWFP) cut funding to HIV positive people living in Uganda. Those expected to be most severely affected are the young people living in the post-conflict North (WNFP, 2007; IRIN, 2009). The young people in this region have lived a lifetime of war, they have grown up without land ownership, or economic independence and now, as food aid is relinquished, their ability to remain on the free treatment that has been provided requires immediate examination. As such UNWFP changes occur, the dearth of knowledge on the relationship between food insecurity and HIV/AIDS within displaced and conflict settings, leaves little available to offer solutions to those now struggling.

4.3 KNOWLEDGE TRANSLATION ACTIVITIES

One of the most integral components of this research project was the community forum held in Lyantonde in January 2009. The forum was presented as an opportunity to inform the community of the study results as well as to, with the support of community leaders, offer small, feasible solutions to some of the challenges that had been presented in the study. The forum was attended by over 70 community members, including the district medical officer, leading religious officials, educational workers, HIV clinical staff, HIV community counsellors, local government representatives and the public. It was held at the Salama SHIELD Foundation hall, a community centre open to all the public. The data were presented via slideshow, in Luganda and was supported with images and diagrams for ease of understanding. The forum was not simply an opportunity for the research team to present their findings, it also provided members of the hospital, counsellors and the community to express their concerns, needs and thoughts.
As study results demonstrated a gap in understanding and communication between health care workers and PLWHA attempting to adhere to treatment, this was one of the first challenges addressed. The research team explained that our participants had experienced great fear in disclosing non-adherence to treatment; that they felt scolded and in trouble when they returned to the hospital or clinic with their pill box still full and resultantly would pill drop, sell their pills or not return to the clinic. The district medical officer was the first to speak after the research team, demanding judgement-free HIV treatment centres. The importance of reporting accurate adherence rates was explained and the community members were assured that if they continued to feel judgement when unable to adhere to treatment that they were to contact the hospital director immediately. The research team thanked the participants who were willing to come forward to explain the food related difficulties they faced in attempting to adhere to treatment and they were assured that it was as a result of their testimonies that changes could begin to be implemented.

While attempts to deal with deep-rooted issues of gender and workplace imbalances were discussed, they were more difficult to address in the short term. The research team, along with the assistance of social workers from the Salama SHIELD Foundation, were however able to offer solutions to economic and food insecurity and related barriers to treatment:

- **Growing produce within town housing:** small tomato and passion-fruit plants can be grown inside plastic bags on windowsills, porches or patios. Both could be used for nutritional purposes or for sales to increase income.
- **Forming small, micro-credit groups:** Salama SHIELD Foundation employees explained how they created their own micro-credit support group whereby each member puts in a small amount of money per month and at the end of the month a lump sum is given to one member, this allows members to save for something larger, without affecting their weekly earnings by a large amount.
- **Building a community garden:** some participants mentioned their inability to garden more than once per week. A shared small plot of land among young PLWHA would ensure that no one would have to work too often to maintain the produce and the proceeds could be divided among the owners for either subsistence farming or resale.
Finally, in an attempt to address the relationship-based fears that stopped many of our female participants from seeking treatment, we, along with the support of Dr. Sewankambo (director of the Rakai Health Sciences Project, the largest cohort study in Uganda), suggested the implementation of using couples to offer pre and post test HIV counselling to other couples. The Rakai Project has both concordant and discordant couples on staff, aware of each others’ statuses, to offer counselling to new couples coming to test for HIV/AIDS. Introducing this new form of counselling and education in Lyantonde would allow couples to witness successful relationships (both concordant and discordant), and how they could help each other seek treatment and stay healthy, irrespective of their HIV status. During the forum, we had two couples come forward who were willing to be trained in counselling and to offer not only counselling at the clinic and hospital, but also to take part in later town hall meetings to discuss relationship-based fears surrounding HIV/AIDS.

The community forum lasted approximately three and a half hours. It was amazing to witness the community involvement and interactions, across disciplines and social backgrounds. Everyone received a chance to speak, and the counsellors, medical workers and district medical officer made assurances that the results of this study would be considered in their daily efforts to allow ease of access and adherence to young PLWHA in Lyantonde.
4.4 REFERENCES

Barroso J, and G.M. Powell-Cope., 2003. Metasynthesis of qualitative research on living with HIV infection, Qualitative Health Research 10 (33), 340-353.


UNWFP., 2007. WFP forced to cut food for nearly 1.5 million war displaced in Uganda. Available online at: http://www.wfp.org/node/414

Weiser SD et al., 2007. Food insufficiency is associated with high-risk sexual behaviour among women in Btoswana and Swaziland. PLoS 4(10), 1589-1598.


WFP., 2006. HIV/AIDS and transporters: putting the brakes on transmission.


5.0 APPENDICES

5.1 APPENDIX A: UBC BREB ORIGINAL ETHICS APPROVAL CERTIFICATE

The University of British Columbia  
Office of Research Services  
Behavioural Research Ethics Board  
Suite 102, 6190 Agronomy Road, Vancouver,  
B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - MINIMAL RISK RENEWAL

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR:</th>
<th>DEPARTMENT:</th>
<th>UBC BREB NUMBER:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patricia M. Spittal</td>
<td>UBC/Medicine, Faculty of/School of Population and Public Health/Epidemiology &amp; Biostatistics</td>
<td>H08-00669</td>
</tr>
</tbody>
</table>

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

<table>
<thead>
<tr>
<th>Institution</th>
<th>Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Other locations where the research will be conducted:
The Salama SHIELD Community Development Center (CDC) in Lyantonde, Uganda. This location is central within the community and provides participants with a neutral and confidential location to meet. The organization has been working in the community for over 10 years and the residents are familiar with the centre (youth come to the centre to use the sports courts and others also come to use the business and internet centre). The CDC has private offices for interviews as well as large, private rooms for focus groups.

CO-INVESTIGATOR(S):
Simone Carter

SPONSORING AGENCIES:
N/A

PROJECT TITLE:
Barriers to Accessing and Adhering to Antiretroviral Therapy: A case study from a rural truck stop in Uganda

EXPIRY DATE OF THIS APPROVAL: April 7, 2010  
APPROVAL DATE: April 7, 2009

The Annual Renewal for Study have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board

Dr. M. Judith Lynam, Chair  
Dr. Ken Craig, Chair  
Dr. Jim Rupert, Associate Chair  
Dr. Laurie Ford, Associate Chair  
Dr. Anita Ho, Associate Chair
5.2 APPENDIX B: UBC BREB AMENDED ETHICS APPROVAL

CERTIFICATE OF APPROVAL - MINIMAL RISK RENEWAL

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR:</th>
<th>DEPARTMENT:</th>
<th>UBC BREB NUMBER:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patricia M. Spittal</td>
<td>UBC/Medicine, Faculty of/School of Population and Public Health/Epidemiology &amp; Biostatistics</td>
<td>H08-00669</td>
</tr>
</tbody>
</table>

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

<table>
<thead>
<tr>
<th>Institution</th>
<th>Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Other locations where the research will be conducted:
The Salama SHIELD Community Development Center (CDC) in Lyantonde, Uganda. This location is central within the community and provides participants with a neutral and confidential location to meet. The organization has been working in the community for over 10 years and the residents are familiar with the centre (youth come to the centre to use the sports courts and others also come to use the business and internet centre). The CDC has private offices for interviews as well as large, private rooms for focus groups.

CO-INVESTIGATOR(S): Simone Carter

SPONSORING AGENCIES: N/A

PROJECT TITLE:
Barriers to Accessing and Adhering to Antiretroviral Therapy: A case study from a rural truck stop in Uganda

EXPIRY DATE OF THIS APPROVAL: April 7, 2010 APPROVAL DATE: April 7, 2009

The Annual Renewal for Study have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board

Dr. M. Judith Lynam, Chair
Dr. Ken Craig, Chair
Dr. Jim Rupert, Associate Chair
Dr. Laurie Ford, Associate Chair
Dr. Anita Ho, Associate Chair
5.3 APPENDIX C: UNCST ETHICS APPROVAL-RESEARCHER PERMIT AND RECEIPT
Barriers to Accessing and Adhering to Antiretroviral Therapy:
A case study from a rural truck stop in Uganda
(Informed Consent: In-depth Interviews)

INFORMED CONSENT FORM: June 4, 2008 (page 1 of 4)

The investigators in this study are:
Simone Carter, MSc Health Care and Epidemiology, University of British Columbia
Dr. Patricia Spittal, BC Centre for Excellence in HIV/AIDS
Dr. N.K. Sewankambo, Dean, Makerere University Medical School, Kampala, Uganda

Sponsor: Salama SHIELD Foundation

Introduction

You are being invited to participate in a qualitative research study because, although Lyantonde makes up a small part of the population in Uganda, access and adherence to HIV medications (antiretroviral therapy) is necessary throughout the country in order to successfully fight HIV/AIDS. In Uganda, HIV is increasing among young people, thus this study will focus on young people’s barriers to accessing and adhering to treatment. Two of the major hurdles to fighting HIV/AIDS in Uganda are 1) access to treatment for all those who are positive as well as 2) ensuring that those who are on treatment are able to remain this way. Little is known about the barriers that people in Lyantonde are facing to access and adhere to treatment and, we are therefore inviting you to participate in this research study designed to explore the barriers to access and adherence to HIV medication (antiretroviral therapy).
Study design and method

We are interviewing both young men and women ages 18-24 and if you agree to help, all information will be kept confidential. This means that your name will never be attached to or placed on any of the transcribed data. All study information will be kept in a secure database and accessed only by study staff and investigators. Your name and other identifying information will not be recorded in any of our files. All data for the study (tapes, transcriptions etc.) are kept within locked offices with both day and night watch-person. Qualitative data sets are made anonymous through use of numerical ID’s and held at the Salama SHIELD Foundation Community Development Centre in Lyantonde, until they can be transferred to the data management Centre at Makerere University Medical School in Kampala within secure, password protected computer systems.

In order to gain breadth of understanding of different barriers, the meanings, experiences and views of study participants are sometimes best captured via in depth interviews. Your interview will be audio-recorded. This recording will not include your name.

If you agree to participate, you will be asked to spend one hour or one and a half hours with us. Through an in-depth interview, we would like to learn more about your life, your experience with accessing antiretrovirals, what problems you face accessing them or adhering to them or what problems you fear you may face in the future. We would also like to know why you think you face these problems and where the roots of the problems stem from. We would also like your advice on how you feel that these barriers could best be overcome in your community and what you feel would need to happen in order to make these changes.

The in depth interviews will explore research questions such as i) length of time since HIV positive; ii) length of time on or attempting to seek treatment; iii) where you might currently access (or would if you were on treatment) treatment; iv) perceived barriers to accessing treatment; v) perceived barriers to adhering to treatment; vi) perceived view of community perceptions to accessing treatment; vii) perceptions of required change in order to eliminate barriers.

If you are willing to participate, we will ask you to:
1. Allow an interviewer to spend some time with you and conduct one interview with you. The researcher will interview you wherever you feel most comfortable.
2. The interview will be like having a conversation. This conversation may last up to one and a half hours and will be recorded on tape. Information collected in the interview is transcribed by someone who does not know you, and then your interview data is entered into a software program designed to help evaluate in-depth interviews. Confidentiality is guaranteed at all times, and your name is not linked to the information analyzed. When the study is over, all recordings will be destroyed.
Benefits to you:
There is no direct benefit to you in participating in this study. Your participation will help us to understand the barriers that young people face in accessing and adhering to HIV treatment and your input may help us to understand better how to plan more appropriate distribution and accessible treatment programs.

Additional costs and compensation:
No compensation will be provided.

Risks and discomforts:
There is no direct risk associated with the study. However, discussing HIV/AIDS related experiences and may be difficult for you. We will be conducting focus groups separately for women and for men, however, if you have difficulties discussing sensitive topics in group situations this may not be the best way to discuss these issues with us. We have made arrangements to gain fast access to counseling (at the Salama SHIELD Community Centre), and if you wish have any other health related concerns we can help to make appropriate and confidential referrals on your behalf. Researchers will be available to be contacted at the Salama SHIELD Community Development Centre located at PO BOX 19 Lyantonde, Uganda. Miss Simone Carter will be available to discuss the project if any further questions arise.

Confidentiality:
It is important for you to know that we keep all data completely confidential. All information collected will remain confidential at all times, and will only be used for the research purposes of this study. Researchers are committing themselves not to divulge your name at any point, and to take all the necessary precautions during the interviews to preserve their anonymous character in order to make sure that you will not be recognized. Results of this study are only for scientific communications.

Your rights and obligations:
The subject matter is not politically sensitive; therefore the project itself will not put you at enhanced risk. The project will follow operational guidelines from humanitarian operational mechanisms in emergency situations. You can refuse to participate in this study if you wish. If you choose not to participate, you will still have full access to any social programs or health care services you are currently using. You may choose not to participate or to withdraw from the study at any time with no consequence.
CONSENT TO PARTICIPATE IN THIS STUDY (page 4 of 4)

I voluntarily consent to participate in this study. I have read the consent form entirely, or it has been have read to me, and I have understood the technical language used. I have been able to ask all my questions to the researcher, and understand that I will be able to communicate with him or her later if I have additional questions during the course of the study. I can withdraw from the study at any time without any prejudice to me.

A copy of the consent has been given to me. If I wish further information about this study, it is my right as a participant. If I have any questions about my participation to this study, I can contact Simone Carter, at Salama SHIELD Foundation, Lyantonde (0754617031), Dr. Patricia Spittal (0001 604 806 8779 in Vancouver) or Dr. Nelson Sewamnkambo, Dean of Medicine at Makerere University, Kampala at sewankam@infocom.co.ug. If I have questions about my rights as a participant in the study, before, during or after my participation, I can contact the Uganda National Council for Science and Technology Ethics Board at 256-414-250 499 (email directly online at:http://www.uncst.go.ug/site/index.php?option=com_contact&Itemid=23), If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

____________________       ______________________       ___________
Signed                                                 Print Name                         Date

____________________       ______________________       ___________
Witness                                               Print Name                         Date

____________________       ______________________       ___________
Primary Investigator                       Print Name                         Date
Emiziziko/obuzibu obuli mu kufuna n’okukozesa enkola
eweeweeza ku kawuka ka siriimu. Okunoonyereza kuno
kukoleddwa awakunganira lukululana mu bimu ku bitundu
bya Uganda.
Ebibuuzo bya ssekinoomu.

Awomye omutwe mu kunoonyereza kuno:
Simone Carter, MSc Health Care and Epidemiology, University of British Columbia
Dr. Patricia Spittal, BC Centre for Excellence in HIV/AIDS
Dr. N.K Sewankambo, Dean, Makerere University Medical School, Kampala, Uganda

Baakolaganye nabo: Salama SHIELD Foundation

ENYANJULA

Oyitibwa okwetaba mu kunoonyereza kubujanjaba n’okufuna eddagala lya kawuka
kamukenya. Wadde nga ekitundu kye Lyantonde mulimu abantu batono bw’ogrageranya
n’eggwanga lyonna, okunoonyereza kuno kwamugaso wonna okutwalira awamu kubanga buli
kitundu kyettanira enkola eyokukozesza eddagala okukendeeza amanyi ga siriimu. Mu ggwanga
lyonna, kati kimanyikidwa nti akawuka ka siriimu keyongedde naddala mu bavubuka,
y’ensonga lwaki okunooyereza kuno essira kulitadde ku bavubuka okusobola okuzuula
emiziziko mu kufuna ate n’enkozesza y’eddagala eriziyiza akawuka ka siriimu. Obuzibu bwa
mirundi biri 1) obusobozi bw’okufuna obujanjabi eri bonna abalwadde ate 2) N’abo abafuna
obujanjabi basigala babufuna. Kitono ekimanyikidwa ekikwata ku biremesa abantu be
Lyantonde okufuna ate n’okukozesa eddagala lino, kale osabiddwa okwetaba mu kawefube
ono nga tunonyereza ku miziziko gino mu kulwanyisa akawuka ka siriimu.

ENKOLA N’EMITENDERERA
Ebibuuzo bibuuzibwa abakyala n’abaami abeteeufuteefu okutuyamba era ebyo byonna ebitutegezebwa bya kyama ddala nga kino kitezeeza nti erinnya ly’addamu teriragibwa wantu wonna era byonna bigenda kukuumbwa mu kyuma kikalimagezi ate mu negeri entuufu. Tewali muntu yenna okuijako abakulembera SSF na banonyereza agenda kumanyisibwa ebinaaba bivuddem. N’ebyo ebinakwateebwa mu maloboozi nabyo byakukuumbwa mungeri entuufu ate wala ddala. Ebibuuzo by’empapula bya nnamba era bireeteewa butereevu ku CDC ate oluvannyuma bitwalibwe ku kitebe kye Makerere ekikulu eky’eddagala.

Olwokwagala okumanya ebizibu eby’enjawulo, amakulu, ebitytamwumu mu kufuna n’okukoza eddagala, tweyambisa enkola ey’ebibuuzo okufuna ebyetaagisa era amaloboozi gano gakwatibwa wabula erinnya teriulikutika wantu wonna.

Ng’okirize okutwetabako, osabibwa akadde ka ssaawa emu abu n’ekitundu nga oli naffe. Ekigendererera nga tubuuza ebibuuzo bino, kwe kwagala okumanya ebifa ku bulamu bwo, by’oyiseemu ng’ofuna eddagala eriziiza akawuka ka siriiu, ebibuze by’osanga mu ku lifuna ate no’kulikokozes ob’obuzibu bw’otya okusanga mu maasoo singa obeera okozoza eddagala eryo. Tusaba otutegeeze nti lwaki olowooho oja kufuna obuzibu obwo era ensibuko yaabwo eri wa? Mu negeri y’emu tusaba otoo ku ndwozayo ku negeri obuzibu gyebuyinza okumalibawo mu kitundu kino ara, ne kisuubirisa okukolebwa enkyukakyuka okusobola okubaawo.

Ebibuuzo bino bigenderera okututegeza ku bibuuzo; 1) ebbanga ly’omaze n’obulwadde 2) Ebbanga ly’omaze ng’onoonya obujjanjabi/ ofuna 3) wa w’osuubira okufuna eddagala oba obujjanjabi 4) Okumanya kwo ku bizibu ebiri mu bujjanjabi obwo 5) By’omanyi ku bikugaana okukozaa obujjanjabi obwo 6) Okumanya kwo ku negeri abantu b’ekitundu gye bategeeremu obujjanjabi obwo 7) ate n’okumanya kwo ku nkyukakyuka ezisaanidde okweyambisibwa okumalawo obuzibu obwo.

Bw’oba nga wetegese okwetwba mu kunoonyereza kuno, tujja kukusaba:

1. okkiriza okuwa akubuuza ebibuuzo obudde obumala wakati w’essaawa emu ne emu ne kitundu. Tewagenda kubaawo kutaatakaganyizibwa nga obuzibu ebibuuzo.
2. Ebibuuzo bino biri mu negeri ya kunyumya era emboozho eno esuubiriwa okumala akabanga ka ssaawa emu oba ssaawa emu n’ekitundu wabula amaloboozi gakwatibwa. Era ataputa amaloboozi ajja kuba nga takumanyi. Ebilowoozo Oluvannyuma gateekebewe mu byuma okwekennenyezibwa era mu negeri eno erinnya siryeyambisibwa. Okunoonyereza nga kuwedde, amaloboozi agaakwatibwa ku ntambi gagyibweko.

OKUSASULWA:

Tetulina kusasulwa kugenda kukuweebwa olw’okutuwa ebilowoozo byo. Okwetaba kwo kujja kutuyamba okumanya ebizibu abavubuka bye basanga mu kufuna ate n’enkoza y’eddagala eriziiza akawuka ka sirimu. Ebilowoozo byo bijjakutuwa enteekateeka entuufu ey’okubatuusaako obujjanjabi.

OKULIWA:

Tetusuubira kuliyrirwa muntu yenna.
OBUZIBU /EBYERALIKIRIZA:
Tewali buzibu bwonna mu musomo guno. Newakubadde, okwogera ku ku kawuka ka siriimu ne by’oyiseemu biyinza okubeera ebizibu gyoli. Tujja kukozeza enkola ey’okubuuza abantu nga bali wamu abaami na bakyala wadde ng’oyinza okusanga obuzibu okutwegattako mu kubaganya ebirowoozo ku bimu. Waliwo enkola ey’okubudaabuda abantu nga tubuulirira era bw’oba n’obuzibu bwonn naddala nga bwekuusa ku bulamu, oli wa ddembe. Waliwo enteekateeka okukuwereza ewali obujanjabi mu kyama. Abakola okunonyereza webali ku CDC PO BOX19 Lyantonde. Omukyala Simone Carter okukunnyonnyola kubikwata ku nteeketeeka eno singa wabaawo ebitategeerekese.

OKUKUUMA EBYAAMA
Kirungi omanye nti ebirowoozo byo tugenda kubikuuma nga bya kyama. Ebirowoozo byo bigenda kweyambisibwa mu byakunonyereza kwokka era abanonyereza tebagenda kulaga linnya lyo mungeri yonna oba mu ngeri yonna eraga nti ono yali gundi oba ggwe.

EDDEMBE LYO:
Okunoonyereza kuno tekwekuusa ku bya bufuzi era tewali kabi konna kakulimu kyoka kugoberera emitendera gy’ekikula ky’abantu mu biseera omuli ebigwa bitalaze. Okyayinza okutwegattako mu ngeri eyo mu kunoonyereza kuno singa ob’oyagadde, so singa oba toyagadde era oli wa ddembe era obutetaba naffe tebulina buzibu bwonna gyoli ate oli waddembe okugenda mu maaso ng’okozeza ebyo byonna ebiyamba obulamu bwo ate n’enteekateeka zonna ez’ebyobulamu mu kitundu kyo. Osobola okusalawo okuka naffe oba obutaberera naaffe era tewali buzibu.

OKUKUKIRIZA OKUBEERA NNAFFE MU KUNOONYEREZA

Ekiwandiiko kino kimpeereddwa kale nya kusobola okufuna ebisingawo ebikwata ku kunoonyereza kuno nga ndi mu bwetaavu bwo kwongera okumanya nga ntuukirira (Simone Carter) ku Salama Shield Foundation, e’Lyantonde.

Elinnya omukono ennaku z’omwezi
................................................. ................................................. .................................................
Omujulizi omukono ennaku z’omwezi
.................................................... .................................................... ....................................................
Omunonyereza omukono ennaku z’omwezi
.................................................... .................................................... ....................................................

............................

................................................. ................................................. .................................................
5.6 APPENDIX F: TOPIC GUIDES NOT ON TREATMENT

Barriers to Accessing and Adhering to Antiretroviral Therapy: A case study from a rural truck stop in Uganda

Unstructured In-depth Interview Topic Guide: NO TREATMENT

This discussion we are going to have is called an open-ended interview. There are no set questions, only subjects and types of questions I would like to talk about. At any point, if you feel that you would rather not answer the question, please say so and we will move on. We want you to tell us your story. About being HIV positive and how you access and adhere to your treatment, we want to you to feel comfortable, remember that everything said here is confidential and your identity will never be revealed. WE WOULD LIKE TO MAKE SURE YOU KNOW THAT WE HAVE NO CONNECTION TO THE HOSPITAL AND ANYTHING DISCUSSED WITH US WILL NOT BE GIVEN TO THEM. YOUR DISCUSSION WITH US WILL HAVE NO NEGATIVE IMPACT ON YOUR ABILITY TO ACCESS ANY MEDICAL TREATMENT AT ANY CENTRE IN THE FUTURE.

To begin, we do not have to record your name, however, can you tell me your age, the sub-county that you are from and the parish?

A. Let’s start with your family.....

What is your age? Olina emyaka emeka?

Place of birth of participant: where were you born? Ozaalibwa wa?

Description of family of origin (adoptive or foster family) can you describe for me your family (who lives/lived in your home? Are there your parents/in-laws?)

And your childhood/place of origin? Nnyonnyola ebikwata ku maka gammwe?

Can you tell me about your house now? Who do you live with (where?)

How far away from the nearest school are you? (do your kids go there?) how about from water are you? (WHAT IS THIS WATER SOURCE LIKE? CLEAN? DOES IT VARY WITH SEASON) how far are you from the hospital? Clinic? obuwanvu bwo’lugendo okutuka ku ssomero bwenkana ki? Ate okuva wojja amazzi?

B. School & Community

Did you ever study? What level of schooling did you complete? What age were you?

What were your reasons for stopping? Were you ever taught about sex in school?-(Wali osomeseedwako kubikwatagana n’okwegata?) how much was taught? (if yes, what were you
taught? If no, why do you think not?) Were you ever taught about HIV/AIDS in school? (if yes, what were you taught?) IF NOT TAUGHT!!! WHERE DID YOU LEARN????

Wasomako? Wakoma kuddaala ki? Walina emyaka emmeka? Lwaki wakoma awo?
Oba wakoma-owo? Kiki kyo’jjukira ku ssomero eryo?

**EMPLOYMENT**

Are you currently working? What do you do? Can you tell me some more about that? Do you feel that this is enough for you and your family?

How much do you earn a day/week/month? How much does this vary?
(if no,) what is missing?

Okola mulimu ki? Nnyonnyola; osuubira nti omuliimu ogwo gukumatiza wamu n’ amakaago? Oba nedda, kiki ekibulako?

What does your spouse do? (if kids are grown, what do they do? If not in school do they work?)

(together/alone) how do you pay rent (if you have) or school fees or for other essentials?

C. Let’s talk a little bit about your relationship

**TRANSITIONS OF RISK: WOULD LIKE TO LOOK AT THE ISSUE TEMPORALLY – SEARCHING FOR CONTEXT AND LIVED EXPERIENCES**

Are you currently married? How long? Are you in a relationship now? How long have you been in this relationship? when was your first relationship? Oli mufumbo? Kumala bbanga ki? Olina muganziwo?

Nature of sexual relationships –friends, sugar daddy’s, sex for exchange. (omukwano gwansimbi oba bilabo?)

Have you ever had sex in exchange for anything? Gifts? Were these relationships, Regular?

How did you feel about this? wali wegasse mu mukwano ng’ogenderera ebyenfuna? (e.g. money gifts)

Do you distinguish between a relationship and a man you have sex with? Do you have just one or the other?

Omanyi enjawulo wakati w’omukwano ogwa ddala n’omuntu gwe wegatta naye? Olinayo omu oba abalala?

What types of gifts have you received from your partners? (Specifically sex for exchange for, food, shelter or clothing)

D. Reproductive and Sexual health

Do you discuss HIV/AIDS or STDs with your partner? Oyogera ku bikwata ku kawuka kasiriimu ne’ndwadde z’obukaba ne muganzi wo?
**What was it like telling your partner? Can you tell me that story.**
IFI THEY DON’T TALK: why not? Are you planning?
Do you discuss sex with your husband/family? Oyogera ku by’okwegatta ne balo/mukyala wo?
Do you know the status of your partner? Who are the people that know of your status? Omanyi obulamu bw’omwagalwa wo? baani ablala abamanyi ebifa ku bulamu bwo?

Have you ever used a condom? Do you use a condom when you have sex? When was the first time using a condom? (Was this the same as the first time having sex?)
Do you have difficulty using one? Does your partner have difficulty using one? Why do/don’t you use a condom?
Wali okozeseko kukapila kakuma bulamu?

Does the type of relationship you are in effect whether or not you use a condom?
Do you discuss using a condom before sex? Is it difficult to discuss? Muteesa ku kukoza akapiira nga temunnegatta? Kikaluubiriza okukyogerako?

E. Ok, can we talk a little bit about your history with HIV
How long have you been positive? Omaze bbanga ki ng’oli n’obulwadde?
What prompted you to get tested? Kiki ekyakusikiriza okwekebeza?
How do you think you contracted HIV? Osuubira obulwadde wabufuna otya?

**HISTORY WITH TESTING**
What was that experience (getting tested) like? Can you tell me about the time(s) you were tested? Has it been more than once?
Wawuulira otya nga ogenda okwekezeba?
Wakekebeza emirundi emmeka?

Do you feel that there are any barriers to getting tested? (Is this difficult? Were you scared?)
Before you were tested, did you feel that you knew a lot or a little about HIV?
Olowooza waliwo obuzibu bwonna mu kwekebeza? Wali otidde?
Olina ky’ewali omanyi ku kikwata ku siriimu bwe wali tonnaba kwekebeza?

**HISTORY WITH TREATMENT**
How about treatment? Have you ever been on treatment? (if not, are you on a prophylaxis/septrine (CD4>200) what treatment? Any other treatment?)
how long were you on it?
What type of treatment were you on? (probe: fears/reactions to treatment)
Bw’obeera ofuna objujjanjabi, omaze bbanga ki?
Obujjanjabu bwa kikula ki kati bw’ofuna? (ebitiisa ku bujjanjabi/byofuna)

If you were on but stopped, can you tell me what it was like when you were on?
Why did you stop?
* if NEVER on, what made you decide NOT to seek treatment?
WE WANT THE WHOLE STORY- LOTS AND LOTS OF PROBING!!!!!
- why do you feel that way?
- what makes you think that?
- why do others think that?
- where did you get that information?
***remember NO JUDGEMENT HERE!!! NONE!!!!
REMIND THEM AGAIN THAT THIS IS CONFIDENTIAL:
- HOW DO THEY FEEL THAT SOMEONE ELSE IS CONTROLLING THEIR ACCESS TO MEDICATION? DO THEY AGREE WITH THIER BOSS/SPouse/WHOEVER FOR HOW THEY FEEL ABOUT TREATMENT?
- WHAT WOULD HAPPEN IF THIS PERSON FOUND OUT ABOUT THEIR TREATMENT?
- WHAT WOULD THIS MEAN? HOW WOULD THIS CHANGE AFFECT THEIR LIFE?

Did ever you pay anything (even small amount) for any treatment?

Did you know much about treatment before you found out your status?
How did you find out about treatment?
Nga tonnategeera mbeera gy’olimu kati, wali omanyi obujjanjabi buno? Wamanya otya enzijanjaba eno era wagisanga otya?

Have you had your CD4 count measured/tested? How often? Where? When was the last time?
Wekebeza obutaffaali bwo? Kumala bbanga ki? Ate ddi lwewasembayo okwekebeza?

Are people in your family on treatment?
Abantu bammeka abafuna obujjanjabi mu mmakaago?
****if more than one:
Can you always get treatment for all? Who gets first?
Osobola okubafunira bona eddagala? Ani asooka okufuna obujjanjabi?

Where is the nearest health centre from you? eddwaliro erikuli okumpi liri wa? What types of services are offered at this centre? Ligaba bujanjabi ki? Can you get ARVs there?Osobola okufunawo eddagala eriweweeza ku kawuka ka siriimu?

**MEANINGS OF THE DIAGNOSIS OF HIV IN LYANTONDE**
What does it mean to you to be HIV positive in Lyantonde?
Gy’oli kitegeezaaaki okuba ng’oli mulwadde mu Lyantonde?

How do people in Lyantonde react to HIV positive people?
Ngeri ki abantu be Lyantonde gye bayisaamu abalwadde ba siriimu
Are there judgements about being HIV positive in this community?
Olowooza abnatsu be kintunda basalira abalwadde/omusango oba okubanenya?

Do you think where you live can affect how you feel about your status?
What is the hardest/best part about living in this community and being positive?

Kizibuki ekisinga ku kubena mu kiteundu kino ng’oli mulwadde?

How does the district treat those with HIV? How does your sub-county treat those with HIV?

Ngori ki district gye yisaamu abalina sirimu? Ste eggombololayo eyisa etya abantu abaliirra akawuka ka sirimu?

**COMMUNITY EXPERIENCE OF HIV/AIDS**

Do you have fears about being HIV positive? (e.g. passing it to your kids, people finding out, dying, being unable to care for your family, having trouble finding a partner) Olina obwerarikirivu okuba nti oli mulwadde?

How has the diagnosis affected your family life and living? (More vulnerable?)

Olowooza kibadde kizibu okwogerak u mbeeraayo?

(Do they know? Do you talk about it? Does it affect your family life? Kids?)

Banatu b’omumakago balina kyebamanyi? Okyogerako? Kikosa amakago? Ate abaana?

Has it been difficult talking about your status? How did you tell those people (husband/wife/partner/kids= most important)

Embeeraayo ogyoerako ki ne mukyalawo, muganziwo oba abaana?

Has being positive affected the way the community or your extended family treats you OR your family? Has it affected your place in your extended family? Or your place in the community? Do you or your family feel stigmatized as a result of your diagnosis?

Obwooza okuba omulwadde kireese enkyukakyuka kun gen abantu b’ekitundu ob’abenyyanda gye bakuyisaamu oba aba makaago?

**SOCIAL/FRIENDS AND DIAGNOSIS**

What about your friends? Are you friends with others who are HIV positive? Are you part of any type of HIV support group? If yes, how does that work? How do you like that?

Mikwano gyo babeena n’abalwadde ba siriumu?

Oli omu kw’abo oba ebiibina ebiwigira/ebirahirera abalwadde?

Oba yee, mukola mutya? Okyagala otya?

DO YOU HAVE ANY FRIEND WHO YOU SPEAK A LOT WITH ABOUT YOUR STATUS? SOMEONE WHO YOU WOULD GO TO HOSPITAL WITH? OR WHO WOULD HELP WHEN YOU ARE SICK?

G. let’s talk about your ability to get health information and services.

Where do you get health – related information in this area?

Ofuna tya ebikwata ku byobulamu mu kitundu kyo?

Who/what/when/how often/ who do you go with?

ARE YOU ABLE TO MEET THE REQUIREMENTS THE DOCTORS TELL YOU?
The treatment that you are/were on, where do you/have you access it/them?
Obujjanjabi bw’ofuna oba bwe wali ofuna wali oba kati obujjawa?

Do you always access them from this place?
If no, where else/why/how often/ differences
Olowooza ofuna obujjanjabi buli w’obwagalidde mu kitundu kyo?

Do you feel that it is easy to access your treatment? Getting there AND once there
Olowooza kyangu okufuna obujjanjabi?

Is it more difficult to access medication at certain times of the year? (SEASONAL?)

**TESTING AND COUNSELLING AVAILABILITY**

Do you feel that there is adequate HIV testing and counselling in your community/sub-county/district? (is there enough information about HIV/testing/counselling)
Olowooza okukebeera era n’okubudaabudde abantu mu kitundukyo kumatiza?

Do you think it is widely available?
Waliwo amawulire gamala ku bifa ku siriiimu/okwekebeza/okubu-daabudda?

How do you feel about counselling before testing?
Owulira otya okubudaabudilibwa nga tonaba kwekebeza?
How do you feel about counselling after testing?
Ate owulina otya omuntu okubudaabudib wa nglamaze okukeberebwa?

What role do you feel counselling and education plays in ARV access/adherence?
Okubudaabudibwa n’okusomesebw a birina mugaso ki mu kufuna era n’okukozesa eddage la eri weweeza ku kawuka ka siriiimu?

What is missing from counselling and testing?
Biki ebitamatiza mu kubudaabuda wamu n’okwekebeza omusaayi?

**ATTITUDES TOWARD TESTING IN HOME COMMUNITIES**

How do you feel about accessing counselling/testing or any HIV/STD services in town? Or close to home (or work)?

Do you think that accessing in your town/village/community or home provides enough confidentiality? Olowooza abantu abo nga bakusanze mu kitundu kyo kiyamba okukuuma ebyama?

**TREATMENT EXPERIENCES WITH THE HEALTH CARE SYSTEM TO DATE**

Can you tell me how treatment was (if they were ever on it)? What has your experience been like?
Nsaba ombuulire okufuni obujjanabi bwe bubadde?

Can you tell me how you feel when you go to the hospital/clinic (wherever they seek treatment) Owulira otya ng’ogenze mu ddwaliro okufuna obujjanabi?

What do you think being on treatment would change? How would it affect you? (physically, emotionally, economically, social/stigma)

Ok, let’s talk a bit about taking your pills every day.... **ADHERENCE**

If ever took medication, when did you take the medication? you are on? Odi lwe watandika eddagala? Oli kuddagale okuya lwewakeberebwa?

How long after diagnosis did you begin treatment Wmalae bbanga ki oluvannyuma lwokukeberebwa lwe watandiko eddagale?

Can you tell me what happened that changed this?? (If they have been on/off treatment) did the medication have any effects (if was on, but stopped) Biki ebikulemeseza okukozess eddagale mu biseera ebiyisa?

What effects do you think being on the drugs would have on your daily life? If you were to take them? Buzibu ki edagala bye lireta ku bulamubwo obwabulijo?

****IF THEY WERE ON TREATMENT:
Can you tell me about some of the times when it was difficult to access/adhere to your treatment? (DOES THIS CHANGE WITH SEASON/WEATHER?)

Olowooza ddi kwe kiba ekizibu okufuna oba okukozesi obulungi eddagala?

Can you give me some examples?

How often do these happen? When was the last time? How long will this last?

Do others know you face similar difficulties? Other difficulties? Can you tell me What difficulties do you perceive others facing? Abalala bamayi nti mufuna obuzibu bwebumu? Osobola okuntegeeza ku buzibu abalala bwe basanga?

Stigma associated with seeking treatment
How did you feel when you seek treatment? (do others know? Husband? Family?) or going to hospital? Owulira otya ng’ogenze okufuna obujjanabi?
How did you take your medication? When did you take it? were others around? What if you’re not at home when you need to take it?

Eddagala olikuzesa otya? Ddi lw’olikoze? Wbaawo abalala ng’olimira? Ate nga toil waka ddi lwoyagala?

Did you ever pay for treatment? How? (Is this similar to how you get money for school fees?)

Obujjanjabi bw’ofuna bwakusasulira?

What are the other costs associated with your treatment?

COST OF GETTING TESTED/STARTED? PASSPORT PHOTOS???

Bizibu ki by’osanga my kufuna obujjanjabi?
how do you come up with this money?

Osobola otya okufuna ensimibi ozo?

**PERCEIVED INSTITUTIONAL BARRIERS TO CARE AND SUPPORT **

Do you feel that (the place where they seek treatment) is welcoming for those in need of treatment? Do you feel comfortable there?

Olowooza ekifo wlofuna obujjanjabi kikwaniriza bulungi?

What do you think are the institutional (clinic/hospital/government) barriers for people seeking HIV treatment and counselling/information?

Buzibu ki bw’osuubira obulemesa abalwadde okufuna eddagale uga bwekussa ku bifo ebibaamu obujjanjabi?

**PERCEIVED ECONOMIC BARRIERS TO CARE AND SUPPORT **

What do you feel are the biggest financial constraints in seeking treatment? (Cost of transport/lost work because sick/ may be others we don’t think of)

Bizibu ki ebikulu nga bikwata ku ssente ebinemesa abalwadde nga bagezaako okufuna eddagala?

How about other requirements? Have these changed since becoming positive? How has being HIV positive affected your requirements?

Have you been able to meet these requirements?

Why/why not? What changes did you have to make to meet these new requirements?

And how about being on treatment? Has this changed your requirements? Are you able to meet them? Why/why not

Ate emeere n’amazzi biri bitya? Olowooza bikyuse okuva lwe walwala?
Waliwo ebyefaago ebyenjawalo ebyeetaagisa ngolo kubujjanjabi?

**PERCEIVED SOCIAL BARRIERS TO CARE AND SUPPORT**

Do you feel any the social barriers to accessing treatment?

Olowooza bizibu ki ebyabulijjo ebiremesa okufuna obajjanjabi?
Do these social barriers exist when trying to access information about HIV or information about treatment? Are these social barriers present in accessing sexual health information? Or sexual health services (STDs)

Ebizibu/oba obuzibu buno obusanga mu kufuna ebifa ku kawuka ka siriimu oba ebifa ku bujjanjabi?

**PERCEIVED GENDER BARRIERS TO CARE AND SUPPORT **
Do you feel that you face different barriers in accessing treatment because you are female/male?

Olowooza obuzibu bw’osanga bwa nsawulo ku balala kubanga oli musajja?
Is being HIV positive different for women/men? Is it harder to talk about because you are a man/woman?

Do you think it may be different for men? Do you feel that there are difficulties adhering to treatment based on your gender?

Olowooza ekyoo kiyinza okukwawula ku bakazi? Kino kikulemesa obulungi eddagala kuba oli musajja?

**PERCEIVED AGE BARRIERS TO CARE AND SUPPORT **
Do you feel that there are barriers to accessing or adhering to treatment because of your age? How does your age affect your ability to access/adhere?

Olowooza waliwo ebizibu ebikulemesa okufuna oba okukozesa eddagala nga bwekuusa ku myaka gyo
Emyaka gikesa gitya obujjanjabi bunoo?
Does being HIV positive as a youth have a different affect than on older people? Is it harder/easier? (to talk about/ to be/ to get assistance?)
Does the younger/new generation perceive HIV differently than the previous?
What are these differences?

H. We’d like to get your thoughts on change... Determine the ideal kind of support and care and where it might be delivered

Can you tell me a bit about what changes you think need to be in place in order to ensure access to everyone in your community who needs it?

Oymza okumbuulira ku nkyukakyuka eziyiriza okukolebwa okusoboza mu muntu okufuna eddagla mu kitundu kyo?

Do you think different changes are required for town versus rural areas?

Olowooza buli ggombolola yandibadde efiibwako mu b=ngen ya njawulo naddala mu kukola enkyukakyukn zino?

Do you think these changes would be possible?
Olowwoza enkyukakayuka zino ziyinza okusoboka?
Is there anything else you would like to tell us? About accessing treatment? Adhering to treatment? Feelings of being HIV positive in your community?

Olina kyewandyagadda okututegeezza ekirala? Kubikwala ku kufuna obujjanjabi okukozesa obulungi eddagala? Bw’owulira ng’oli n’abantu mu kitundu kyo?
Barriers to Accessing and Adhering to Antiretroviral Therapy: A case study from a rural truck stop in Uganda

(Informed Consent: Focus Group Interviews)

INFORMED CONSENT FORM: June 04, 2008 (page 1 of 4)

The investigators in this study are:
Simone Carter, MSc Health Care and Epidemiology, University of British Columbia
Dr. Patricia Spittal, BC Centre for Excellence in HIV/AIDS
Dr. N.K Sewankambo, Dean, Makerere University Medical School, Kampala, Uganda

Sponsor: Salama SHIELD Foundation

Introduction

You are being invited to participate in a qualitative research study because, although Lyantonde makes up a small part of the population in Uganda, access and adherence to HIV medications (antiretroviral therapy) is necessary throughout the country in order to successfully fight HIV/AIDS. In Uganda, HIV is increasing among young people, thus this study will focus on young people’s barriers to accessing and adhering to treatment. Two of the major hurdles to fighting HIV/AIDS in Uganda are 1) access to treatment for all those who are positive as well as 2) ensuring that those who are on treatment are able to remain this way. Little is known about the barriers that people in Lyantonde are facing to access and adhere to treatment and, we are therefore inviting you to participate in this research study designed to explore the barriers to access and adherence to HIV medication (antiretroviral therapy).
Study design and method

We are interviewing both young men and women ages 18-24 and if you agree to help, all information will be kept confidential. This means that your name will never be attached to or placed on any of the transcribed data. All study information will be kept in a secure database and accessed only by study staff and investigators. Your name and other identifying information will not be recorded in any of our files. All data for the study (tapes, transcriptions etc.) are kept within locked offices with both day and night watch-person. Qualitative data sets are made anonymous through use of numerical ID’s and held at the Salama SHIELD Foundation Community Development Centre in Lyantonde, until they can be transferred to the data management Centre at Makerere University Medical School in Kampala within secure, password protected computer systems.

In order to gain breadth of understanding of different barriers, the meanings, experiences and views of study participants are sometimes best captured via in depth interviews.

In order to gain breadth of understanding of different barriers to antiretroviral access and adherence that young people face, we had a number of conversations with various young people affected by HIV/AIDS in Lyantonde. In order to confirm our findings and identify common or different themes that emerged in the in-depth interviewing process we are inviting you to join us in a group discussion to discuss similar topics.

If you agree to participate, you will be asked to spend one hour or one and a half hours with us. Through an in-depth interview, we would like to learn more about your life, your experience with accessing antiretrovirals, what problems you face accessing them or adhering to them or what problems you fear you may face in the future. We would also like to know why you think you face these problems and where the roots of the problems stem from. We would also like your advice on how you feel that these barriers could best be overcome in your community and what you feel would need to happen in order to make these changes. This group session will be audio-recorded for the entire 1-1.5 hours.

The in depth interviews will explore research questions such as i) length of time since HIV positive; ii) length of time on or attempting to seek treatment; iii) where you might currently access (or would if you were on treatment) treatment; iv) perceived barriers to accessing treatment; v) perceived barriers to adhering to treatment; vi) perceived view of community perceptions to accessing treatment; vii) perceptions of required change in order to eliminate barriers.

If you are willing to participate, we will ask you to:

3. Allow an interviewer to spend some time with you and 5-6 other people and conduct a group discussion that will typically last 1-1.5 hours. The researcher will interview you wherever is convenient for all to participate. You can pull out of this process at any time and we will ensure that your contributions will be immediately destroyed.
4. The group discussion will be like having a conversation. This conversation may last up to two hours and will be recorded on tape. Information collected in the interview is transcribed by someone who does not know you, and then the data is entered into a software program designed to help evaluate the data collected in the focus group. Confidentiality is guaranteed at all times, and your name is not linked to the information analyzed. When the study is over, all recordings will be destroyed.

**Benefits to you:**
There is no direct benefit to you in participating in this study. Your participation will help us to understand the barriers that young people face in accessing and adhering to HIV treatment and your input may help us to understand better how to plan more appropriate distribution and accessible treatment programs.

**Additional costs and compensation:**
No compensation will be provided.

**Risks and discomforts:**
There is no direct risk associated with the study. However, discussing HIV/AIDS related experiences and may be difficult for you. We will be conducting focus groups separately for women and for men, however, if you have difficulties discussing sensitive topics in group situations this may not be the best way to discuss these issues with us. We have made arrangements to gain fast access to counseling (at the Salama SHIELD Community Centre), and if you wish have any other health related concerns we can help to make appropriate and confidential referrals on your behalf. Focus group participants are asked to use discretion outside of the interview, however, although the research team honours confidentiality with all data collected, we are unable to guarantee confidentiality on behalf of the other participants. **Researchers will be available to be contacted at the Salama SHIELD Community Development Centre located at PO BOX 19 Lyantonde, Uganda. Miss Simone Carter will be available to discuss the project if any further questions arise.**

**Confidentiality:**
It is important for you to know that we keep all data completely confidential. All information collected will remain confidential at all times, and will only be used for the research purposes of this study. Researchers are committing themselves not to divulge your name at any point, and to take all the necessary precautions during the interviews to preserve their anonymous character in order to make sure that you will not be recognized. Results of this study are only for scientific communications. Although focus group participants are asked to use discretion outside of the interview, however, although the research team honours confidentiality with all data collected, we are unable to guarantee confidentiality on behalf of the other participants.
Your rights and obligations:
The subject matter is not politically sensitive; therefore the project itself will not put you at enhanced risk. The project will follow operational guidelines from humanitarian operational mechanisms in emergency situations. You can refuse to participate in this study if you wish. If you choose not to participate, you will still have full access to any social programs or health care services you are currently using. You may choose not to participate or to withdraw from the study at any time with no consequence.

CONSENT TO PARTICIPATE IN THIS STUDY

I voluntarily consent to participate in this study. I have read the consent form entirely, or it has been read to me, and I have understood the technical language used. I have been able to ask all my questions to the researcher, and understand that I will be able to communicate with him or her later if I have additional questions during the course of the study. I can withdraw from the study at any time without any prejudice to me.

A copy of the consent has been given to me. If I wish further information about this study, it is my right as a participant. If I have any questions about my participation to this study, I can contact Simone Carter, at Salama SHIELD Foundation, Lyantonde, Dr. Nelson Sewankambo at Makerere University Medical School, 41 530020, Patricia Spittal at 001 604 806 8779 in Vancouver. If I have questions about my rights as a participant in the study, before, during or after my participation, I can contact the Uganda National Council for Science and Technology Ethics Board at 256-414-250 499 (email directly online at: http://www.uncst.go.ug/site/index.php?option=com_contact&Itemid=23), Dr. Nelson Sewankambo, Dean of Medicine at Makerere University, Kampala at sewankam@infocom.co.ug, or 011 256 41 53 0020. If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

____________________       ______________________       ___________
Signed                                                 Print Name                         Date

____________________       ______________________       ___________
Witness                                               Print Name                         Date

____________________       ______________________       ___________
Primary Investigator                       Print Name                           Date
5.8 APPENDIX H: TOPIC GUIDE FOR FOCUS GROUPS

Barriers to Accessing and Adhering to Antiretroviral Therapy: A case study from a rural truck stop in Uganda

Unstructured Focus Group Topic Guide

Remind them we want to finish in 1.5 hours, let everyone talk, all confidential and let us know if they agree or disagree.

A. COMMUNITY/FAMILY DAILY CHALLENGES

WHAT ARE THE MAIN CHALLENGES FACED BY THOSE LIVING IN LYANTONDE?
- schooling, school fees, uniforms, books, agricultural lives, access to food/cash, food aid dependency etc.

B. CONFIRM HISTORIES WITH LIVING WITH HIV FROM A COMMUNITY PERSPECTIVE

WHAT ARE THE MAJOR CHALLENGES OF THOSE LIVING WITH HIV IN LYANTONDE?

- particular challenges living with HIV
- costs of HIV
- effect on community
- stigma surrounding HIV
- marriage and HIV (one partner positive before marriage)
- how they perceive HIV related vulnerabilities/fears
- cultural practice including wife inheritance?

C. HEALTH SEEKING BEHAVIOUR AND HIV ACCESS:

*IS TREATMENT EASILY AVAILABLE?

What do most people know about treatment?
Do most people in town know about treatment?
What are the common MISPERCEPTIONS about treatment or it’s requirements?
What is known about treatment?
what are the requirements (perceived) to access treatment? CAN THEY MEET THESE?

*WHO HAS THE MOST TROUBLE ACCESSING TREATMENT? WHY????

How does STIGMA affect peoples’ ability to access treatment?
How does GENDER affect peoples’ ability to access treatment?
How does SEASON affect peoples’ ability to access treatment
How does BEING A YOUTH affect peoples’ ability to access treatment?

*WHAT ARE THE REQUIREMENTS TO BE ON TREATMENT? (FOOD/WATER/REST ETC)

Do you feel most people can meet these requirements?
If not, why not? What’s missing?
*WHAT ARE THE MOST COMMON BARRIERS TO ACCESSING TREATMENT?*

Do these vary with time of year/season?
Do these vary with gender?
Do these vary with age?

**DO 15-18 FACE DIFFERENT CHALLENGES THAN 18-24, OR 24-30?**

**ADHERENCE:**

*WHAT ARE THE MOST COMMON BARRIERS TO ADHERING TO TREATMENT?*

Do these vary with time of year/season?
Do these vary with gender?
Do these vary with age?

**WHO FACES THE MOST CHALLENGES ADHERING (WOMEN? MEN? YOUTH?)**

**WHY DO PEOPLE FACE BARRIERS ADHERING? (WHY EACH GROUP SPECIFICALLY)**

**DOES ADHERENCE VARY WITH SEASON?**

How does STIGMA affect peoples’ ability to adhere to treatment?
How does GENDER affect peoples’ ability to adhere to treatment?
How does SEASON affect peoples’ ability to adhere to treatment?
How does BEING A YOUTH affect peoples’ ability to adhere to treatment?

**DO 15-18 FACE DIFFERENT CHALLENGES THAN 18-24, OR 24-30?**

**D. ACCESS TO INFORMATION/EDUCATION/COUNSELLING AND TESTING:**

*HOW EASY IS IT TO ACCESS SEXUAL HEALTH INFORMATION IN LYANTONDE? IS IT SCARY? A LOT OF STIGMA ATTACHED?*

How confidential is testing? Counselling? Treatment access?
What is the general level of HIV knowledge in the community?
What is taught about sex to HIV positive people?
Is it easy/confidential and comfortable for young people to come into where you work and access information or get tested? Will they be comfortable?
do you feel most young people have the appropriate information about HIV in Lyantonde?
Why do young people fear telling their partners? What can be done to resolve this?

**HOW AVAILABLE DO YOU FEEL HIV COUNSELING AND TESTING IS IN LYANTONDE? WHAT’S MISSING? HOW CONFIDENTIAL DO YOU FIND IT?**

- meanings of the diagnosis of HIV in Lyantonde
- the possibility to go home to one's community with an HIV diagnosis
- experience of chronic disease in family including HIV/AIDS
- ramifications of HIV positive diagnosis on life and living
- perceptions of what it means in terms of family, support, stigma in respective place of residence, home or community
- perceived difficulties with disclosing to partner, family, friends
- treatment experiences with the health care system to date
- perceived institutional barriers to care and support
- determine the ideal kind of support and care and where it might be delivered

E. RECOMMENDATIONS:

**WHAT DO YOU SUGGEST TO IMPROVE**
- Food problem
- Gender problem
- Any other problem mentioned in discussion (repeat the problem to them)
5.9 APPENDIX I: TOPIC GUIDE FOR THOSE SEEKING TREATMENT

Barriers to Accessing and Adhering to Antiretroviral Therapy: A case study from a rural truck stop in Uganda
Unstructured In-depth Interview Topic Guide

So, this discussion we are going to have is called an open-ended interview. There are no set questions, only subjects and types of questions I would like to talk about. At any point, if you feel that you would rather not answer the question, please say so and we will move on. We want you to tell us your story. About being HIV positive and how you access and adhere to your treatment, we want you to feel comfortable, remember that everything said here is confidential and your identity will never be revealed.

To begin, we do not have to record your name, however, can you tell me your age, the sub-county that you are from and the parish?

A. Let’s start with your family.....

What is your age? Olina emyaka emeka?

Place of birth of participant: where were you born? Ozaalibwa wa?

Description of family of origin (adoptive or foster family) can you describe for me your family (who lives/lived in your home? Are there your parents/in-laws?) And your childhood/place of origin? Nnyonnyola ebikwata ku maka gammwe?

Can you tell me about your house now? Who do you live with (where?)

How far away from the nearest school are you? (do your kids go there?) how about from water are you? (WHAT IS THIS WATER SOURCE LIKE? CLEAN?) how far are you from the hospital? Clinic? obuwanvu bwo’lugendo okutuka ku ssomero bwenkana ki? Ate okuva wojja amazzi?

B. School & Community

Did you ever study? What level of schooling did you complete? What age were you? What were your reasons for stopping? Were you ever taught about sex in school? (Wali osomesedwako kubikwatagana n’okwegata?) how much was taught? (if yes, what were you taught? If no, why do you think not?) Were you ever taught about HIV/AIDS in school? (if yes, what were you taught?) Wasomako? Wakoma kuddaala ki? Walina emyaka emmeka? Lwaki wakoma awo? Oba wakoma-owo? Kiki kyo’jjukira ku ssomero eryo?
**EMPLOYMENT**

Are you currently working? What do you do? Can you tell me some more about that? Do you feel that this is enough for you and your family? (if no,) what is missing?

*Okola mulimu ki? Nnyonnyola; osuubira nti omuliimu ogwo gukumatiza wamu n’amakaago? Oba nedda, kiki ekibulako?*

C. Let’s talk a little bit about your relationship

**TRANSITIONS OF RISK: WOULD LIKE TO LOOK AT THE ISSUE TEMPORALLY – SEARCHING FOR CONTEXT AND LIVED EXPERIENCES**

Are you currently married? How long? Are you in a relationship now? How long have you been in this relationship? when was your first relationship? *Oli mufumbo? Kumala bbanga ki? Olina muganziwo?*

Nature of sexual relationships –friends, sugar daddy’s, sex for exchange. (*omukwano gwansimbi oba bilabo?*)

Have you ever had sex in exchange for anything? Gifts? Were these relationships, Regular? How did you feel about this? *wali wegasse mu mukwano ng’ogenderera ebyenfuna?* (e.g. money gifts)

Do you distinguish between a relationship and a man you have sex with? Do you have just one or the other?

*Omanyi enjawulo wakati w’omukwano ogwa ddala n’omuntu gwe wegatta naye? Olinayo omu oba abalala?*

What types of gifts have you received from your partners? (Specifically sex for exchange for, food, shelter or clothing)

D. Reproductive and Sexual health


Do you discuss HIV/AIDS or STDs with your partner? *Oyogera ku bikwata ku kawuka kasiriimu ne’ndwadde z’obukaba ne muganzi wo?*

Do you discuss sex with your husband/family? *oyogera ku by’okwegatta ne balo/mukyala wo?*

Do you know the status of your partner? *Who are the people that know of your status? omanyi obulamu bw’omwagalwa wo? baani ablala abamanyi ebifa ku bulamu bwo?*
Have you ever used a condom? Do you use a condom when you have sex? When was the first time using a condom? (Was this the same as the first time having sex?)
Do you have difficulty using one? Does your partner have difficulty using one? Why do/don’t you use a condom?

Wali okozeseko kukapila kakuma bulamu?

Does the type of relationship you are in effect whether or not you use a condom?
Do you discuss using a condom before sex? Is it difficult to discuss? muteesa ku kukoza akapiira nga temunnegatta? Kikaluubiriza okukyogerako?

E. Ok, can we talk a little bit about your history with HIV

How long have you been positive? Omaze bbanga ki ng’oli n’obulwadde?
What prompted you to get tested? Kiki ekyakusikiriza okwekebeza?
How do you think you contracted HIV? Osuubira obulwadde wabufuna otya?

Do you have fears about being HIV positive? (e.g. passing it to your kids, people finding out, dying, being unable to care for your family, having trouble finding a partner) Olina obwerarikirivu okuba nti oli mulwadde?

**HISTORY WITH TESTING**

What was that experience (getting tested) like? Can you tell me about the time(s) you were tested? Has it been more than once?
Wawuulira otya nga ogenda okwekezeba?
Wakwesizu emirundi emmeka?

Do you feel that there are any barriers to getting tested? (Is this difficult? Were you scared?)
Before you were tested, did you feel that you knew a lot or a little about HIV?
Olowooza waliwo obuzibu bwonna mu kwekebeza? Wali otidde?
Olina ky’ewali omanyi ku kikwata ku siriimu bwe wali tonnoba kwekebeza?

**HISTORY WITH TREATMENT**

How about treatment? What type of treatment are you on? (if not, are you on a prophylaxis/seroprine/septrine (CD4>200) treatment? Any other treatment?)
Kati oli ku bujanjaba bwa kikula ki? Oba nedda, okola tya okwejanjaba?

If you’re on treatment, how long have you been on it?
What type of treatment are you on? (probe: fears/reactions to treatment)
Bw’obeera ofuna obujjanjabi, omaze bbanga ki?
Obujjanjabi bwa kikula ki kati bw’ofuna? (ebitiisa ku bujjanjabi/byofuna)
Did you know much about treatment before you found out your status? How did you find out about treatment? 

_Nga tonnategeera mbeera gy’oolimu kati, wali omanyi obujjanjabi buno? Wamanya otya enzijanjaba eno era wagisanga otya?_

Have you had your CD4 count measured/tested? How often? Where? When was the last time? 

_Wekebeza obutaffaali bwo? Kumala bbanga ki? Ate ddi lwewasembayo okwekebeza?_

How many people in your family are on treatment? 

_Abantu bammeka abafuna obujjanjabi mu mmakaago?_

****If more than one:

Can you always get treatment for all? Who gets first? 

_Osobola okubafunira bona eddagala? Ani asooka okufuna obujjanjabi?_

Where is the nearest health centre from you? eddwaliro erikuli okumpi liri wa? What types of services are offered at this centre? Ligaba bujanjabi ki? Can you get ARVs there? Osobola okufunawo eddagala eriweweeza ku kawuka ka siriimu? 

Do you all go on the same date to pick up treatment? 

_Mugenda wamu okufuna obujjanjabi/ mwenna mugendera wamu okufuna obujjanjabi?_

**MEANINGS OF THE DIAGNOSIS OF HIV IN LYANTONDE** 

What does it mean to you to be HIV positive in Lyantonde? 

_Gy’oli kitegezaaki okuba ng’oli mulwadde mu Lyantonde?_

How do people in Lyantonde react to HIV positive people? 

_Ngeri ki abantu be Lyantonde gye bayisaamu abalwadde ba siriimu_ 

_Are there judgements about being HIV positive in this community?_ 

_Olowooza abnatu be kintunda basalira abalwadde/omusango oba okubanenya?_

Do you think where you live can affect how you feel about your status? 

_What is the hardest/best part about living in this community and being positive?_ 

_Kizibuki ekisinga ku kubena mu kiteitundu kino ng’oli mulwadde?_

How does the district treat those with HIV? How does your sub-county treat those with HIV? 

_Ngori ki district gye yisaamu abalina siriimu? Ste eggombololayo eyisa etya abantu abaliira akawuka ka siriimu?_

**COMMUNITY EXPERIENCE OF HIV/AIDS **

How has the diagnosis affected your family life and living? (More vulnerable?) 

_Olowooza kibadde kizibu okwogera ku mbeeraayo?_ 

(Do they know? Do you talk about it? Does it affect your family life? Kids?)
*Banatu b’omumakago balina kyebamanyi? Okyogerako? Kikosa amakago? Ate abaana?*

Has it been difficult talking about your status? How did you tell those people (husband/wife/partner/kids= most important)

*Embeeraayo ogyoogerako ki ne mukyalawo, muganziwo oba abaana?*

Has being positive affected the way the community or your extended family treats you OR your family? Has it affected your place in your extended family? Or your place in the community? Do you or your family feel stigmatized as a result of your diagnosis?

*Obwooza okuba omulwadde kireese enkyukakyuka kun gen abantu b’ekitundu ob’abenyyanda gye bakuyisaamu oba aba makaago?*

**SOCIAL/FRIENDS AND DIAGNOSIS**

What about your friends? Are you friends with others who are HIV positive? Are you part of any type of HIV support group? If yes, how does that work? How do you like that?


G. let’s talk about your ability to get health information and services.

*Where do you get health – related information in this area? Ofuna tya ebikwata ku byobulamu mu kitundu kyo?*

*The treatment that you are/were on, where do you/have you access it/them? Obujjanjabi bw’ofuna oba bwe wali ofuna wali oba kati obujjawa?*

*Do you always access them from this place? Olowooza ofuna obujjanjabi buli w’obwagalidde mu kitundu kyo?*

*Do you feel that it is easy to access your treatment? Olowooza kyangu okufuna obujjanjabi?*

**TESTING AND COUNSELLING AVAILABILITY**

*Do you feel that there is adequate HIV testing and counselling in your community/sub-county/district? (is there enough information about HIV/testing/counselling) Olowooza okukebeera era n’okubudaabudde abantu mu kitundukyo kumatiza?*

*Do you think it is widely available? Waliwo amawulire gamala ku bifa ku siriimu/okwekebeza/okubu-daabudda?*
What is missing from counselling and testing?
Biki ebitamatiza mu kubudaabuda wamu n’okwekebeza omusaayi?

**ATTITUDES TOWARD TESTING IN HOME COMMUNITIES**

How do you feel about people coming to your town/village/community or home and doing counselling and testing or providing treatment?
Gy’owulira otya ng’otuukiriddwa abantu mu kitundukyo nga bagezaako okubuddabuda, okukebera era n’okugaba obujjanjabi?

Do you think that coming to your town/village/community or home provides enough confidentiality? Olowooza abantu abo nga bakusanze mu kitundu kyo kiyamba okukuuma ebyama?

How do you feel about counselling before testing?
Owulira otya okubudaabudilibwa nga tonaba kwekebeza?
How do you feel about counselling after testing?
Ate owulina otya omuntu okubudaabudib wa nglamaze okukeberebwa?

What role do you feel counselling and education plays in ARV access/adherence?
Okubudaabudibwa n’okusomesebwa birina mugaso ki mu kufuna era n’okukozaesa eddage la eri weweeza ku kawuka ka sirimu?

**TREATMENT EXPERIENCES WITH THE HEALTH CARE SYSTEM TO DATE**

Can you tell me how it has been getting treatment so far?
Nsaba ombuulire okufuni obujjanjabi bwe bubadde?

Can you tell me how you feel when you go to the hospital/clinic (wherever they seek treatment)
Owulira otya ng’ogenze mu ddwaliro okufuna obujjanjabi?

**ADHERENCE**

When did you start the treatment you are on?
Odi lwe watandika eddagala? Oli kuddagale okuya lwewakeberebwa?
Have you remained on treatment since diagnosis? How long after diagnosis did treatment start?
Wmalae bbanga ki oluvannyuma lwokukeberebwa lwe watandiko eddagale?
(If they have remained on treatment) what could happen that would change this?
(If they have been on/off treatment) what has affected your adherence to treatment in the past?

*Biki ebikulemeseza okukozess eddagale mu biseera ebiyisa?*

What effects do the drugs have on your daily life?

*Buzibu ki edagala bye lireta ku bulamubwo obwabulijjo?*

What difficulties do you face accessing?

*Buzibu ki bwlosanga my kufuna eddagala?*

Do you face these difficulties adhering to treatment? Other difficulties?

*Osanga ebizibu ebyo mu nkozesya y’eddagala? Ate ebizibu ebirrala?*

Can you tell me about some of the times when it has been difficult to access/adhere to your treatment?

*Olowooza ddi kwe kiba ekizibu okufuna oba okukozesa obulungi eddagala?*

Do others know you face similar difficulties? Other difficulties? Can you tell me What difficulties do you perceive others facing?

*Abalala bamayi nti mufuna obuzibu bwebumu? Osobola okuntegeeza ku buzibu abalala bwe basanga?*

**Stigma associated with seeking treatment**
How do you feel when you seek treatment? (do others know? Husband? Family?)

*Owulirra otya ng’ogenze okufuna obujjanjabi?*

How do you take your medication? When do you take it? Are others around? What if you’re not at home when you need to take it?

*Eddagal a olikuzesa otya? Ddi lw’olikoze? Wbaawo abalala ng’olimira? Ate nga toil waka ddi lwoyagala?*

Do you pay for treatment? How? (Is this similar to how you get money for school fees?)

*Obujjanjabi bw’ofuna bwakusasulira?*

What are the other costs associated with your treatment?

*Bizibu ki by’osanga my kufuna obujjanjabi?*  
how do you come up with this money?

*Osobola otya okufuna ensimibi ozo?*
**PERCEIVED INSTITUTIONAL BARRIERS TO CARE AND SUPPORT**

Do you feel that (the place where they seek treatment) is welcoming for those in need of treatment? Do you feel comfortable there?

_Olowooza ekifo wlofuna obujjanabi kikwaniriza bulungi?_

What do you think are the institutional (clinic/hospital/government) barriers for people seeking HIV treatment and counselling/information?

_Buzibu ki bw’osuubira obulemesa abalwadde okufuna eddagale uga bwekussa ku bifo ebibaamu obujjanabi?_

**PERCEIVED ECONOMIC BARRIERS TO CARE AND SUPPORT**

What do you feel are the biggest financial constraints in seeking treatment? (Cost of transport/lost work because sick/ may be others we don’t think of)

_Bizibu ki ebikulu nga bikwata ku ssente ebinemesa abalwadde nga bagezaako okufuna eddagala?_

How about food and water costs/requirements? Have these changed since becoming positive? Or since being on ARVs? Are there different requirements when you are on treatment?

_Ate emeere n’amazzi biri bitya? Olowooza bikyuse okuva lwe walwala? Waliwo ebyefaago ebyenjawalo ebyeetaagisa ngolo kubujjanabi?_

**PERCEIVED SOCIAL BARRIERS TO CARE AND SUPPORT**

What do you feel are the social barriers to accessing treatment?

_Olowooza bizibu ki ebyabulijjo ebiremesa okufuna obajjanabi?_

Do these social barriers exist when trying to access information about HIV or information about treatment? Are these social barriers present in accessing sexual health information? Or sexual health services (STDs)

_Ebizibu/oba obuzibu buno obusanga mu kufuna ebifa ku kawuka ka sirimu oba ebifa ku bujjanjabi?_

**PERCEIVED GENDER BARRIERS TO CARE AND SUPPORT**

Do you feel that you face different barriers in accessing treatment because you are female/male?

_Olowooza obuzibu bw’osanga bwa nsawulo ku balala kubanga oli musajja?_

Do you think it may be different for men? Do you feel that there are difficulties adhering to treatment based on your gender?

_Olowooza ekyo kiyinza okukwawula ku bakazi? Kino kikulemesa obulungi eddagala kuba oli musajja?_
**PERCEIVED AGE BARRIERS TO CARE AND SUPPORT**
Do you feel that there are barriers to accessing or adhering to treatment because of your age?
How does your age affect your ability to access/adhere?
Olowooza waliwo ebizibu ebikulemesa okufuna oba okukozaesa eddagala nga bwekuusa ku myaka gyo?
Emyaka gikesa gitya obujjanjabi buno?

H. We’d like to get your thoughts on change... Determine the ideal kind of support and care and where it might be delivered

Can you tell me a bit about what changes you think need to be in place in order to ensure access to everyone in your community who needs it?
Oymza okumbuulira ku nkyukakyuka eziyiriza okukolebwa okusobozaesa buli muntu okufuna eddagla mu kitundu kyo?

Do you think different changes are required for a different sub-county?
Olowooza buli ggombolola yandibadde efiibwako mu b=ngen ya njawulo naddala mu kukola enkyukakyukn zino?

Do you think these changes would be possible?
Olowwoza enkyukakayuka zino ziyinza okusoboka?

Is there anything else you would like to tell us? About accessing treatment? Adhering to treatment? Feelings of being HIV positive in your community?
Olina kyewandyagadda okututegeezza ekirala? Kubikwala ku kufuna obujjanjabi okukozaesa obulungi eddagala? Bw’owulira ng’oli n’abantu mu kitundu kyz
5.10 APPENDIX J: SAMPLE ADHERENCE CALENDAR

<table>
<thead>
<tr>
<th>Sun</th>
<th>Mon</th>
<th>Tue</th>
<th>Wed</th>
<th>Thu</th>
<th>Fri</th>
<th>Sat</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>11</td>
<td>12</td>
<td>13</td>
<td>14</td>
<td>15</td>
<td>16</td>
<td>17</td>
</tr>
<tr>
<td>18</td>
<td>19</td>
<td>20</td>
<td>21</td>
<td>22</td>
<td>23</td>
<td>24</td>
</tr>
<tr>
<td>25</td>
<td>26</td>
<td>27</td>
<td>28</td>
<td>29</td>
<td>30</td>
<td>31</td>
</tr>
</tbody>
</table>