Medium-Term Quality of Life Outcomes for Patients on HIV Treatment in Western Uganda

by

Catherine Alice Paulsen

A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Science

in

Global Health

School of Public Health
University of Alberta

© Catherine Alice Paulsen, 2016

Abstract

Background:

A pilot community-based antiretroviral therapy (CBART) program in western Uganda was previously shown to significantly improve quality of life outcomes among HIV patients in their first year of treatment, though certain psychosocial challenges and issues remained. What is not known is whether these issues diminish and if new issues arise with more time.

Objectives:

This study builds on previous research evaluating health-related quality of life outcomes of patients in the CBART program. This study aimed to explore the physical and psychosocial challenges faced by patients five to six years after the initiation of antiretroviral treatment.

Methods:

In-depth semi-structured interviews were conducted in Uganda in 2012 with 25 purposefully selected CBART patients who had undetectable viral loads just prior to the interviews. Interviews explored the topics of death and dying, hope, physical functioning, financial well-being, stigma, social and family relations, sexual relations and childbearing in relation to HIV infection and HIV treatment. Data were analyzed using thematic analysis.

Results:

Income had improved for all participants, compared with pre-treatment levels. As participants' health improved and their strength returned, they felt a pressing need to establish and secure their

family's future, while their health remained strong. However, given their baseline poverty and the sale of assets to fund medical care, improvements were slow. Additionally, reduced strength meant participants needed to look outside of subsistence farming alone to meet their financial needs.

Social relationships have largely been re-established. A return to good health meant that participants were once again able to engage in social activities in meaningful ways. Most patients were able to forgive those who treated them poorly. Similarly, once the initial fear that the patient would die had passed, family and community members were once again welcoming. Occasionally, past disputes proved too great to overcome and participants elected to dissolve these relationships instead. The ability to engage with others about HIV in a positive manner was important to participants. This included both discussing life-challenges and support with their peers, as well as helping newly diagnosed patients adapt to life with HIV. These acts of engagement both helped patients to feel less alone, and allowed them to contribute positively to their community.

Attitudes around child-bearing revealed many conflicting priorities for people living with HIV/AIDS (PLWHA). While children were highly valued, patients had many reservations regarding continued reproduction. Desire to provide well financially for all children, HIV-related risks to the health of the mother and child, and social pressure that PLWHA should limit family size discouraged reproduction. Those who did choose to reproduce were at times reluctant to seek advice from health care staff.

Conclusions:

Physical and psychosocial issues have reduced over time, which suggests treatment continues to improve quality of life; however, many challenges remain. As antiretroviral therapy (ART) improved patients' physical functioning, and with it their physical capacity and self-confidence, they were able to resume normal activities. However, patients could not simply return to their old lives. Adjustments had to be made, and a 'new normal' established.

PLWHA require more than the provision of ART alone to rebuild their lives. Patients need financial and social support to help adjust into this new sense of 'normal'. The most pressing issue for this population is their reduced physical work capacity, and the resulting loss of income earning ability. Skills training and assistance accessing local development programs could help alleviate this burden. Peer counselling and support should be facilitated for PLWHA, in order to help patients to adapt and live in a new normal with HIV. Increased inclusion of patients in community support and outreach programs could benefit all parties involved. There is a desire to have smaller families because of the challenges inherent to living with HIV/AIDS. However, for those without children, the desire to reproduce remains. More support is needed to counsel patients and help them find safer methods of conception.

Preface

(Mandatory due to research ethics approval)

This thesis is an original work by Catherine Paulsen. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board: "Medium-term outcomes in patients on HAART in Western Uganda", No. Pro00029522, May 2, 2012.

Dedication

To my Parents

for their endless love & support

without whom none of my success would be possible.

Acknowledgements

I am deeply indebted to a great many people for the support and guidance I have received throughout my studies, and throughout this research project. This work would not have been possible without it.

Firstly, I would like to thank my study participants, who graciously welcomed my team into their homes, and so openly and candidly discussed their experiences.

I would like to thank my Supervisory Committee for their endless guidance and encouragement throughout this process: Duncan Saunders, Arif Alibhai, Amy Kaler and Gian Jhangri. I am grateful for your expertise and for your continued involvement in my academic development. Your guidance and insight have made me a better researcher and writer.

I am grateful to our Ugandan collaborators at Makerere University and the Kabarole Health Department for their support during my fieldwork: Joseph Konde-Lule, Tom Rubaale and Peter Rwakilembe. This project would not have been possible without the help of my hard working Research Assistants: Lilian Banura, Janepher Birungi, Rose Tusiime, and Regina Aliraake.

Lastly I would like to thank my family and friends for their ongoing love and encouragement, especially: my parents Grant and Marlene Paulsen; my family Lorraine, Rick, and Nadia Dawe; and my good friends Westerly Luth and Tara Pidborochynski.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

AIDS: Acquired Immunodeficiency Syndrome

ART: Antiretroviral Therapy

ARV: Antiretroviral

CBART: Community-Based Antiretroviral Treatment program

CD4: T-lymphocyte cell bearing CD4 receptor

HAART: Highly Active Antiretroviral Therapy

HBV: Hepatitis B virus

HIV: Human Immunodeficiency Virus

HRQoL: Health-Related Quality of Life

PI: Primary Investigator

PLWHA: People Living with HIV/AIDS

PMTCT: Prevention of Mother to Child Transmission

QoL: Quality of Life

RA: Research Assistant

TB: Tuberculosis

WHO: World Health Organization

1. Introduction

1.1 Background

The widespread use of antiretroviral therapy (ART) has dramatically improved medical outcomes of people living with HIV/AIDS (PLWHA) in both high and low income settings (Braitstein et al., 2006). Studies in high income settings have suggested that with successful treatment, mortality rates for PLWHA are comparable to those with other chronic conditions, and approach that of the general population (Jensen-Fangel et al., 2004; Samji et al., 2013). In sub-Saharan Africa, mortality among PLWHA remains higher than that of the general population; however much of this excess may be due to delayed initiation of treatment. For those who are able to initiate ART earlier, mortality rates drop to levels comparable to other chronic conditions after two years on treatment (Brinkhof et al., 2009).

Access to ART has traditionally been limited in sub-Saharan Africa. A shortage of trained health care workers means that many health care systems struggle to provide even routine care (Van Damme, Kober & Laga, 2006). ART is most frequently made available in hospital-based programs in urban centres. This often poses difficulties for poor, rural patients, who lack the financial means to travel to the city for treatment (Kipp et al., 2010). However, with task shifting and alternate delivery methods being explored, ART is increasingly available to those in need of treatment (Chang et al, 2009; Kipp et al., 2010; Weidle et al., 2006)

At the end of 2013, an estimated 9.1 million people, or 37% of all people living with HIV in the World Health Organization (WHO) Africa Region, were receiving ART (WHO, 2014). However, changes in treatment guidelines are increasing the number of patients eligible for ART. The 2013 WHO clinical recommendations expanded eligibility for ART to include those with a CD4 count of 500 cells/mm^3 or less for adults, adolescents and older children. This was an increase from the 2010 WHO recommendations, which advised initiating treatment for those with a CD4 count of 350 cells/mm^3 (WHO, 2013a). Initiation of ART is recommended regardless of CD4 count for PLWHA and either active tuberculosis (TB) or hepatitis B virus (HBV) infection with severe chronic liver disease. Immediate initiation of ART is also recommended for HIV-positive partners in sero-discordant couples, pregnant and breastfeeding women, and children under five years of age, regardless of clinical measures (WHO, 2013a). Following the 2013 guidelines, the number of people eligible for ART is estimated to be approximately 85% of all people living with HIV. In low and middle income settings, this corresponds to an increase from 16.7 million people to 25.9 million people living with HIV who are eligible for treatment (WHO, 2013b). As ART services continue to expand in Africa, particularly in eastern and southern Africa, the number of individuals obtaining ART is expected to increase further.

While ART can significantly increase the life expectancy of HIV infected patients, this is not the only measure of life worth considering. Health-related quality of life (HRQoL) is a multi-dimensional concept that extends beyond more direct measures of health, such as life expectancy and mortality rate, and instead focuses on the impact health status has on quality of life (Andresen & Meyers, 2000). HRQoL includes various aspects related to physical, mental, emotional, and social functioning. A similar concept to this is well-being, which examines the positive aspects of a person's life, such as positive emotions and life satisfaction. Well-being relates HRQoL to the ability to live a full, satisfying, and productive life (Kobau, Sniezek, Zack, Lucas, & Burns, 2010).

The importance of quality of life (QoL) and well-being as part of overall health is not new. For over 60 years, the WHO has defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. As more and more PLWHA access treatment, it is important for researchers and policy makers to adapt the way they look at health, to move beyond causes of death and morbidity, and to examine the relationship of health to the quality of an individual’s life (Dybul, Fauci, Bartlett, Kaplan, & Pau, 2002; Murri et al., 2003; Wu, 2000).

While progression from HIV infection to active AIDS disease brings with it many physiological difficulties, many psychosocial issues arise as well. This is particularly true among patients who have difficulties or delays in obtaining treatment, as is often the case for patients in low and middle income settings. Inability to work, paired with ever increasing medical costs can quickly deplete any assets the patient and their family may possess, leading to anxiety and stress (Bedingfield, 2008). Extended illness and the need for ongoing care can put strain and pressure on family relationships (Bedingfield, 2008). Fear and social stigma can leave patients isolated from their family and communities (Bedingfield, 2008). Chronic pain, shame, and fear of death are emotionally taxing. While ART can help mitigate some of the physical effects of HIV infection, these psychosocial issues can be more difficult to resolve (Bedingfield, 2008; Beard, Feeley & Rosen, 2009; Russell et al., 2007; Russell & Seeley, 2010).

QoL studies have shown that initiation of ART is associated with improved QoL outcomes in early treatment (Alibhai et al., 2010; Beard et al., 2009; Bedingfield, 2008; Mwesigire, Wu, Martin, Katamba, & Seely, 2015; Wubshet, Berhane, Worku, & Kebede, 2014). Patients consistently show marked improvement after one year on ART, as compared with baseline/pre-treatment levels. However, a recent study in Kenya suggests some of the QoL gains made early in treatment may not be maintained; this cross-sectional study found that amongst patients on ART, duration of treatment was inversely associated with QoL (Mûnene & Ekman, 2014). Patients in this study had been on treatment between 2.6 and 6.5 years, with those who had been on treatment longer reporting lower QoL scores. Thus, further research is needed to better understand the long-term QoL implications of treatment.

1.2 Context

My study was conducted in the rural farming community of Rwimi, in southwestern Uganda. HIV prevalence in the area is high, and access to treatment is often hindered by poverty (Kipp et al., 2010). In 2006, a pilot project was introduced wherein patients could access ART from a local, lower-level health centre rather than having to travel to an urban hospital for care. Their treatment was further supported by local volunteers who delivered drugs, offered support, and monitored adverse events. This community-based antiretroviral treatment (CBART) program achieved positive clinical outcomes, comparable to hospital-based programs in the district (Kipp et al., 2012). During the first year of treatment, dramatic improvements in QoL were observed in both quantitative and qualitative studies of the CBART population (Alibhai et al., 2010; Bedingfield, 2008). Bedingfield (2008) noted however, that while ART relieves many AIDS-related difficulties, there are some psychosocial challenges that persist. My study was embedded within this overarching project, and my study participants were drawn from CBART patients still active in the program. My study examines QoL issues of CBART patients after five to six years of treatment.

1.3 Research Objectives

This study builds on previous research evaluating the HRQoL outcomes of patients in the CBART program. Specifically, this study aims to evaluate the psychosocial challenges of patients five to six years following initiation of ART, amongst those with current viral suppression. This study used methods similar to those used by Bedingfield (2008) who looked at psychosocial issues of CBART patients in the first year of treatment.

The overall objective of this study is to assess the medium-term HRQoL outcomes of patients on long-term ART, with a specific focus on the:

1) Medium-term impacts of ART on patients' ability to work
2) Medium-term impacts of ART on the social relationships of patients
3) Medium-term impacts of ART on patients' attitudes towards reproduction

1.4 Justification of the Study

ART can significantly increase the life expectancy of HIV infected patients; however, these patients often continue to face a variety of psychosocial difficulties. It has been proposed that ART programs should aim not only to extend life, but also to improve the QoL of patients. As the scale-ups of ART services continues and the guidelines for treatment initiation are relaxed, more people are starting treatment and living longer with HIV than ever before. In this context, the social and psychological aspects of being on treatment will become more prominent.

The current literature on the impact of ART on QoL in low and middle income countries is limited, and has focused largely on the first year of treatment. In a 2008 study, Bedingfield identified several psychosocial benefits of ART in this cohort, such as decreased fear of death and increased self-esteem. She also identified some of the challenges patients face during their first year of treatment, including ongoing family instability and delicate health. As participants adjust to their new lives on ART, the significance placed on these issues may shift. Previous research has shown that predictors of improved QoL early in treatment become less significant the longer the patient is on treatment (Stangl, Wamai, Mermin, Awor, & Bunnel, 2007). The current study will provide insight into the ongoing physical and psychosocial issues and challenges faced by ART recipients, five to six years after the initiation of treatment. A better understanding of the physical and psychosocial challenges associated with ongoing treatment would allow for the identification and tailoring of services to better meet the non-medical needs of patients and increase positive outcomes.

2. Literature Review

A literature review was completed with assistance from a University of Alberta health sciences librarian. The review examined the medium to long-term impact of highly active anti-retroviral therapy (HAART) on the QoL of PLWHA with a focus on the impact of HAART on patients' ability to work, social relationships, and reproduction. The databases searched included Medline, EMBASE, CINAHL, Global Health, PsychInfo, and Web of Science. Search headings and key words included: HIV; AIDS; HIV infections; HIV long term survivors; HAART; highly active antiretroviral therapy; quality of life; psychosocial; social adjustment; activities of daily living; reintegration; well-being; mental health; work; return to work; work schedule tolerance; physical functioning; social support; support system; social environment; fertility desire; reproductive behaviour; fertility; and family planning. Results were geographically restricted using the headings: sub-Saharan Africa, eastern Africa, Uganda, Kenya, Rwanda, Tanzania, and Burundi. Grey literature from the WHO and the Ugandan Ministry of Health was also included.

2.1 HAART & Quality of Life

ART has been shown to improve QoL among PLWHA. In 2009, Beard, Feeley and Rosen conducted a literature review examining the impact of ART on QoL outcomes in developing countries. They found that patients on ART in developing countries reported significant improvements in physical, emotional, and mental health. Patients experienced a dramatic improvement in the first three months of treatment, after which QoL leveled off. Subsequent studies have again found that ART significantly improves QoL over the first six to 12 months of treatment (Mwesigire, et al., 2015; Wubshet et al., 2014), and that QoL is notably higher among PLWHA on ART than those not yet on treatment (Martin, Russell & Seeley, 2014). Alibhai and colleagues (2010) conducted a quantitative study in which they examined changes in QoL in the CBART population over the first year of treatment. QoL was assessed using the MOS-HIV questionnaire. The authors found a significant increase in both mean physical health and mental health scores, as well as across all sub-scales. Improvements during the first year, however, were not uniform. After 12 months of treatment, 72% of patients had improved physical health scores and 84% had improved mental health scores. By contrast, 12% of patients experienced decreases in both mean physical health and mental health scores of five points or more; decreases that were considered clinically meaningful. The authors also found no associations between clinical outcomes and improved QoL, highlighting the importance of additional non-clinical issues in QoL outcomes. The literature on QoL beyond the first year of treatment is limited in sub-Saharan Africa. However, a recent study suggests some of the QoL gains made early in treatment are not maintained. A cross-sectional study in Kenya found that amongst patients on ART, duration of treatment was inversely associated with QoL (Mûnene & Ekman, 2014). Patients in this study had been on treatment between 2.6 and 6.5 years, with those who had been on treatment longer reporting lower QoL scores.

In a 2008 study, Bedingfield identified a number of the psychosocial benefits of ART, as well as some of the challenges faced by CBART patients during their first year of treatment. Bedingfield found that reduced fear of death and renewed hope was common. While patients had not returned to their pre-HIV level of health, most were able to work again, which gave them a sense of accomplishment and pride, and also helped eased some of their financial difficulties. Stigma was a major concern for most subjects and decisions around disclosure of status were weighed carefully (Bedingfield, 2008). These findings are consistent with much of the current literature (Beard et al., 2009; Russell & Seeley, 2010; Vetter & Donnelly, 2006).

Additionally, Bedingfield (2008) made several observations that are less frequently discussed. Interestingly, she found that patients in her study had extreme and unwavering faith in their drugs, with no concern regarding long-term effectiveness or resistance. The only drug-related fear observed related to concerns over continued supply. She also found that disclosure of status was often done in order to encourage others to go for HIV testing and/or treatment, as many patients identified 'being a positive role model' as an important role they played in the community. Finally, she found that family instability brought on by the patient's previous poor health was not easily rectified; many participants continued to have strained familial relationships. Of note, in her study there was limited discussion of social support, and at that time subjects expressed little interest in sexual relationships or having additional children; issues that have been identified as important in other studies (Russell et al., 2007; Bajunirwe et al., 2009; Seeley & Russell, 2010).

2.2 HAART & Ability to Work

The huge physical health improvements that HIV patients on ART can achieve have been well documented. Dubbed 'the Lazarus effect' (Koenig, Leandre, & Farmer, 2004) these changes are often quick and dramatic. In as little as six months, a patient who was previously bedridden and on the brink of death can see their symptoms resolve and their health return (Braitstein et al., 2006).

This improved physical well-being typically means that patients can return to work as well. In a study of Kenyan agriculture workers, Larson and colleagues (2008) estimated that patients receiving ART worked at least twice as many days each month as they would have in the absence of treatment. Additional studies have shown that employment rates among HIV patients on ART are often comparable to their pre-HIV employment rates (Bor, Tanser, Newell, & Bärnighausen, 2012; Wagner, Ryan, Huynh, Kityo, & Mugyenyi, 2009).

While physical capacity improves and employment rates return to pre-infection levels, patients' work output and the income generated do not improve as much. Studies have found that the incoming earning potential of ART patients is consistently less than it was before they contracted HIV (Amoran, Sholeye, Salako, & Fatungase, 2014; Ngo, Wagner, Huynh, Ryan, & Musisi, 2013; Wagner et al., 2009). A study of Ugandan ART patients found that six to 12 months following the initiation of treatment 38% of patients still required economic support from their families, whereas only 13% of those same patients had needed support prior to HIV infection (Wagner et al., 2009). A study of Kenyan tea plantation workers found that one year after the initiation of treatment female ART patients worked 30% fewer days plucking tea and 100% more days on lower-paying non-plucking tasks, compared to the HIV-negative control group (Larson et al., 2008).

Studies have shown that even with ART, it is difficult for PLWHA to re-establish themselves financially in an African context (Holmes, Winskell, Hennink, & Chidiac, 2011; Wagner et al., 2009). Holmes and colleagues (2011) proposed that ART patients find themselves in a cyclical pattern, wherein their limited access to resources leads to poor drug adherence, leading to poor health and reduced work capacity, which again leads to limited access to resources. The authors proposed that without an external influx of assistance, it can be difficult to generate more positive change. Given the reduced income of most patients, Wagner and colleagues (2009) found that despite returning to work after initiating ART, few HIV patients were able to buy back the assets they previously sold when they were sick.

Kaler, Alibhai, Kipp, Rubaale, and Konde-Lule (2010) examined the impact of AIDS and ART initiation on household livelihood in the CBART population. Interviews were conducted with co-resident treatment partners of CBART patients roughly 14 months after the patients initiated treatment. The households' primary concern was labour for subsistence farming. Prior to initiating treatment, when the patients had been quite ill, households had lost not only the patients' ability to work but also that of their caregivers. As patients' health improved, the caregivers' ability to work rebounded to pre-HIV levels. Treatment partners expressed hope that smaller assets, such as livestock, that had been liquidated to fund patients' treatment could be restored in time. Patients' households however remained poorer than average, and treatment partners reported difficulty saving money. The past sale of larger assets, such as land, were considered unlikely to be regained. Additionally, the CBART patients themselves continued to experience weakness and lack of strength, which affected their productivity. It was unclear if the patients' strength would improve further with time, or if this debility would be permanent.

The literature on the longer-term implications of HIV and ART on patients' work capacity is limited. The majority of the current literature examines these issues within the confines of the first year of treatment. However, there were two studies which extended beyond this treatment period. A recent follow-up of the Kenyan tea plantation workers revealed that after two years, ART patients were still working at a reduced capacity and were earning less than their non-HIV counterparts (Larson et al., 2013). Another study found that in a follow-up after three years on treatment, 10% of patients still reported being unable to perform normal activities in the preceding five days (Rosen et al., 2010). While a small proportion, this is not negligible. These were both quantitative studies, and neither examined the ramifications this reduced income had on patients' lives. Little is known with regards to how patients are adapting to their reduced work capacity and income generating ability, or how these changes affect their long-term goals.

2.3 HAART & Social Relationships

Social support has repeatedly been shown to be a significant predictor of well-being among PLWHA (Bajunirwe et al., 2009; Russell et al., 2007). Strong social support is associated with better medical outcomes, lower levels of depression and mental illness, better drug adherence, and better QoL (Martin et al., 2014; Ware, Wyatt, & Tugenberg, 2006; Ware et al., 2009).

Community and family social networks are common and have historically acted as a safety net in sub-Saharan Africa. However, HIV/AIDS, high rates of dwindling resources, and increased expenses resulting from caring for ill family members or orphans have led to family and community breakdowns and increasing distrust (Dawson, 2013; Ndou, Risenga, & Maputle, 2013). High AIDS mortality and stigma have changed many family relationships and friendships; a situation that is only exacerbated by within-family lateral and vertical transmission. Studies have shown that people on treatment are often largely supported by their immediate family, but that some family tension can still exist. Tension with extended family is more common. The ongoing financial burden of HIV/AIDS on poor households overall undermines more distant family ties. As a result, extended family becomes more conditional, temporary, and at times destructive (Dawson, 2013; Muriisa & Jamil, 2011; Ndou et al., 2013; Russell et al., 2007).

Kaler, Alibhai, Kipp, Rubaale, and Konde-Lule (2012) examined the impact of AIDS on social interactions within the CBART population. Interviews were conducted with co-resident treatment partners of CBART patients roughly 14 months after the patients initiated treatment. While there has been significant normalization of HIV in the community since the 1980s, AIDS-related challenges persist for some patients. The impact of AIDS on patients' social relationships was varied: many reported support and kindness from their friends and neighbours, while others reported isolation and gossip. Amongst those experiencing social difficulties, the source of derision was the patient's impending and unavoidable death, rather than AIDS itself. This was further exacerbated by attempts to avoid requests for help; help that dying patients would be unable to repay. The authors postulated that as treatment provides a reprieve from this inevitable death sentence, as well as an opportunity to contribute to reciprocal networks, social interactions with friends and neighbours may improve as a result.

As patients' health returns, attempts are made to rebuild and normalize their lives. Seeley and Russell (2010) describe the process of either 'getting back to normal' or undergoing a 'rebirth'. This largely depends on whether or not the patients are still able to return to their 'old' lives; changing needs, social relationships, and family deaths sometimes make this impossible. For example, while a given patient may regain their own health, they may find themselves left with the memories of a partner or child who was less fortunate (Russel et al., 2007).

Engaging with other PLWHA has been described as a turning point for patients (Martin, Kiwanuka, Kawuma, Zalwango, & Seely, 2013; Medley, Kennedy, Lunyolo, & Sweat, 2009). Being able to discuss their issues openly and honestly with others who share their challenges helps create a feeling of solidarity, and decreases feelings of isolation among PLWHA. This allows patients to change their perceptions of their HIV diagnosis from something that sets them apart from others, to something they can successfully integrate into their self-identity. Thus, HIV infection becomes only one facet of their identity. Involvement in community HIV outreach activities can similarly help patients adapt to life with HIV/AIDS. Volunteering in these activities allows PLWHA to transition from a more passive role as service recipient, to a more active role as a service provider. Patients are able to contribute to their communities in meaningful ways and report being respected as sources of guidance, support and knowledge on HIV/AIDS.

How family and social relationships shift and change with returning health remains unclear. Jury and Nattrass (2013) found that adult patients initiating ART were more likely to be living with their parents than their HIV-negative counterparts. Once patients began treatment however, and their health returned, the proportion being cared for by their parents dropped to the same level as the control group. The authors theorized that as ART restores health and independence, patients once again choose to live on their own, but this was unconfirmed.

2.4 HAART & Reproduction

Fertility and reproduction among PLWHA are complex issues. Children are almost universally viewed as a blessing. Children bring joy and warmth to a family, they bring couples closer together, and they help support family activities and care for parents once they age. In many societies the social pressure to reproduce is strong, especially for women (Berhan & Berhan, 2013; Kaler, Alibhai, Kipp, Konde-Lule, et al., 2012). Those who contract HIV early in their adult life are often infected before they have finished child-bearing. As ART improves health and extends life, it offers patients of reproductive age the opportunity to expand their families. However this decision – whether to reproduce again or not – is not any easy one for PLWHA.

Choosing to reproduce as PLWHA involves risks. There are risks involved with any pregnancy, and fears abound that an HIV-positive mother, already in a weakened state, may die in this pursuit. Should the mother survive, there is the risk of transmission to the infant. Studies in Uganda have found that this is often accompanied by a social view that PLWHA should not reproduce, and that to do so would be reckless (Heys, Jhangri, Rubaale, & Kipp, 2012; Kaler, Alibhai, Kipp, Kondu-Lule, et al., 2012).

Previous studies regarding fertility desire have shown that the desire to reproduce drops dramatically following HIV infection (Heys, Kipp, Jhangri, Alibhai, & Rubaale, 2009; Johnson, Akwara, Rutstein, & Bernstein, 2009). Studies examining the effect of ART on patients' fertility desires in Uganda have shown mixed results. Snow, Mutumba, Resnicow, and Mugyenyi (2013) found lower fertility desire among women living with HIV, regardless of ART status. Similarly, Kipp, Heys, Jhangri, Alibhai, and Rubaale (2011) found that the initiation of HAART did not change patients' desire for more children. By contrast Maier and colleagues (2009) found increased fertility desires among patients on ART for nine months or more. In a multi-country study in sub-Saharan Africa, Myer and colleagues (2010) found ART was associated both with increased fertility desire and higher rates of pregnancy in women living with HIV. After four years of follow-up, the authors found that 33% of women on ART had become pregnant, compared with less than 20% in the non-ART group.

Interestingly, while studies on fertility desire often show a stated desire to stop reproducing, studies on contraception and condom use have suggested desire for children as a common reason preventative measures are not used (Awolude, Oladokun, Adesina, Adewole & Okunlola, 2009). While patients may claim to have ‘enough’ children already, their reluctance to take steps to prevent conception could indicate that they in fact desire more but are unwilling to acknowledge it (Kaler, Alibhai, Kipp, Kondu-Lule, et al., 2012). Kaler, Alibhai, Kipp, Kondu-Lule, and colleagues (2012) were quick to point out that an ‘accidental’ pregnancy is not necessarily the same as an ‘unwanted’ one. While patients may not be actively trying to reproduce, they may also not be actively avoiding it. In fact, the authors argue that fertility desire is such a convoluted issue for PLWHA, that they could not predict what the demand or uptake of contraceptives would be in their population, as more and more HIV-positive individuals begin ART. They proposed that the unmet need for family planning among PLWHA frequently discussed in the literature (Habte & Namasasu, 2015; Jhangri, Heys, Alibhai, Rubaale, & Kipp, 2012), may not be as unmet as assumed.

3. Methods

This study builds on previous research evaluating psychosocial stress in the CBART population. The aim of this study was to identify key physical and psychosocial challenges faced by ART patients, major psychosocial benefits of continued treatment, and how these factors impact patients' lives in the medium term. The current body of literature on medium-term psychosocial stress among ART patients remains limited, particularly in an African context. A variety of stressors have been identified as important to patients both prior to treatment, and shortly after the initiation of treatment. However, much less is understood regarding which factors continue to affect patients five to six years after treatment initiation. A qualitative approach was chosen to address these questions as qualitative research prioritizes preserving and describing the complexity of the participants' lived experience (Mayan, 2009).

3.1 Study Setting

This study was carried out from September to December 2012 in Kabarole district, western Uganda. In 2013, Uganda had an HIV prevalence of 7.4%. There were 1,600,000 people living with HIV in the country with 600,000 active on treatment (UNAIDS, 2014a). Based on the 2010 WHO guidelines for ART, 70% of ART-eligible people living with HIV were receiving treatment in 2013. However, with the new, more inclusive WHO guidelines, this proportion drops closer to 40% (UNAIDS, 2014b).

In 2014, only 21% of the Ugandan population lived in urban areas (Uganda Bureau of Statistics, 2016). Uganda has a young population with a median age of 15 years old (Uganda Bureau of Statistics, 2016). In 2011 the total fertility rate in Uganda was 6.2 children/per woman

(UNICEF, 2012), with a higher rate among rural residents (6.8) and a lower rate among urban residents (3.8) (Uganda Bureau of Statistics, 2012). Kabarole district is located in the south west of the country and has an estimated population of 470,000 (Uganda Bureau of Statistics, 2016). Kabarole is a predominantly rural district, with high levels of subsistence farming. Fort Portal, the major town in the district, has a population of 40,000. The district health services consist of three hospitals, all in Fort Portal, and 60 government health units. Seventy-five percent of the population live within five kilometers of a health unit (Uganda Government, 2005).

This study is one component of a larger prospective cohort study (see Kipp et al., 2010). In 2006, a CBART program was introduced in Rwimi, Uganda, to evaluate the ability to deliver effective HIV treatment from a lower-level rural health centre. Between March 2006 and May 2007, people living with HIV seeking ART at the Rwimi Health Centre III were sequentially enrolled in the CBART program. The enrollment criteria for participation included: residency in Rwimi sub-county, being 18 years of age or older, treatment naive, CD4 count less than or equal to 200/µL and/or WHO clinical stage 3 or 4 at initiation of treatment, unable to afford ART on their own, and willing to accept treatment support by family/friends and a community volunteer. Patients who were ineligible for the community-based program were referred to the hospital program. The first-line treatment, as provided by the Ugandan national HIV/AIDS program, consisted of stavudine, lamivudine, and nevirapine (or efavirenz for patients on rifampicin) to be taken twice daily. All patients were also prescribed daily cotrimoxazole. The CBART program was shown to achieve two-year clinical outcomes similar to a local best practice hospital program (Kipp et al., 2012).

3.2 Study Participants

3.2.1 Selection Criteria

As part of the CBART study, all patients continuing to receive ART in Rwimi sub-country were to be tested for HIV-1 RNA viral loads beginning in August 2012. Based on these results, I had intended to recruit approximately 15 patients who had achieved viral suppression (defined as HIV-1 RNA viral loads below 400 copies/ml) and 12 patients who had not achieved viral suppression (HIV-1 RNA viral loads above 400 copies/ml) for this study. A cut off of 400 copies/ml was chosen as this is the lowest viral load detectable with the Cobas Amplicor HIV-1 Monitor test used. As viral load tests were carried out, however, it became clear that there was near-universal viral suppression in the remaining CBART population. Only four participants had viral loads above 400 copies/ml. For this reason, I limited my recruitment to participants having a viral load below 400 copies/ml. Participants for my study were purposefully selected from those with undetectable viral loads in order to ensure diversity in demographic characteristics believed to be important (e.g. age, sex, etc.).

3.2.2 Saturation

It was originally hoped that data saturation would be reached with 10–15 participants per group. Bedingfield, in her 2008 study of this population, found that data saturation was reached with 13 participants and I expected my results to be similar. However, once interviews were underway, a decision was made that additional interviews were needed to better identify nuanced differences in experience among the group. In the end, 25 participants were recruited into the study.

3.2.3 Recruitment & Interview Process

Potential participants who met the inclusion criteria were initially contacted by one of the clinical officers from the CBART program. This approach was used as the patients already had a relationship with this CBART worker and this would avoid issues of disclosure without patient consent. A call or visit from this individual would draw no additional attention, whereas a visit from a research team member may lead to questions from neighbours. This allowed potential participants the opportunity to decline participation with minimal disclosure risk. It also allowed those who were interested in participating the option of choosing less a conspicuous meeting place, away from their home. Once patients had consented to participate, the research team was provided with their contact information and their preferred meeting location.

All 25 invited patients agreed to participate in the study. Participants were then contacted by the research team to schedule interviews. All participants were given the choice to meet the interviewers somewhere other than their home, with transportation costs reimbursed. One participant chose to be interviewed at the health centre. All others were interviewed at their homes. Each participant was provided with an information and consent form by the research team (see Appendix A), and written informed consent was obtained prior to the initiation of activities. Participants who were unable to sign the consent form due to illiteracy were permitted to use a thumbprint instead.

Each interview was carried out by two research assistants (RAs), who visited the participant together. One led the interview, while the other took detailed notes on what was said. At the end of the interview, the note-taker was given the opportunity to ask additional questions, or for clarification of earlier answers. The same pair of interviewers conducted all of the study interviews, although they alternated who led the interview and who took notes. Both interviewers were female. Previous work with this study population revealed that it is deemed culturally acceptable for women to interview respondents of either gender (Bedingfield, 2008).

The primary investigator (PI) attended only the first handful of interviews. The PI accompanied the research team in order to observe how the interviewers interacted with the participants and carried out the interviews, and to ask questions and provided feedback on the process as needed. This also provided the PI with useful contextual information on the living and working conditions of the participants. Overall, however, the presence of the PI was considered distracting. The PI's presence was minimized in order to help the participants feel more comfortable, and to limit the attention drawn by having a non-native researcher visit. Additionally, the PI's absence helped reduce the likelihood of the participants overemphasizing their poverty in the hopes of acquiring financial assistance from the foreign research team; an artifact colloquially referred to as 'the mzungu [foreigner] effect'.

3.3 Interview Content

Initial Interview

To provide a starting point for interviews, an interview guide was prepared (see Appendix B). The guiding questions were based on issues identified as important in the early stages of treatment in this population (Bedingfield, 2008) as well as current literature, and covered broad topics including drugs and treatment guidelines; death and dying; hope for the future; physical functioning; financial situation; stigma and status disclosure; family relationships and social support; and sexual relationships and future children. Areas of focus were further refined throughout the data collection and analysis processes, as key issues were identified by the participants.

Throughout the data collection process, additional questions identified as important in the interviews were added to the interview guide. RAs were encouraged to use the guide as an introduction only, and to focus instead on the issues and concerns that were most important to the participants. Emphasis was placed on using unstructured talk as much as possible, and thoroughly probing responses for detail and meaning. Throughout the interviews, participants repeatedly highlighted the importance of work capacity, social relationships, and fertility desire.

Follow-up Interview

In all cases, the original interview guide was covered in the first interview. Some participants were selected for a second interview, approximately one month after the first interview, to follow-up on specific comments from the first interview and to ask about issues identified as important by subsequent participants. Seventeen participants were selected for a second interview based on the follow-up questions generated by their first interview, their openness and detail during the first interview, and their availability for a second interview. The guide for the second interview was participant specific and included a combination of general questions addressing topics identified as important by other respondents, as well as participant specific questions to clarify earlier responses.

3.4 Data Collection

Two RAs conducted all interviews. Two other RAs helped with translation and transcription of the interview recordings. All four RAs were educated and fluent in both English and the local language of Rutooro. All had previous experience conducting qualitative research with investigators from the University of Alberta. Time was spent with the interviewing RAs reviewing the interview guide, and stressing the importance of probing questions. These RAs also participated in a series of mock interviews with the PI and each other in order to familiarize themselves with the interview questions and to practice probing responses.

Prior to beginning data collection, the two RAs responsible for the interviews also received a half-day of training from a local psychologist. The aim of the training session was to teach the interviewers how to answer common questions participants may ask during the interviews, and how to support participants if they became distressed during the interviews (note: no participants became distressed during the interviews). Additionally, a CBART clinical officer was available throughout the period of interviewing to provide advice on questions asked by participants.

Following the interview, demographic information was collected about the participant. This included information on age, sex, religion, marital status, occupation, family size, education or literacy level, and ownership of assets (land, animals, transportation). Information on the quality of the interview was also recorded (e.g. participant's openness; what appeared most important; possible misrepresentations/lies; emotional outbursts; rapport with interviewers; etc.). In order to ensure consistency, these field notes were very structured (see Appendix C). The field notes were written by the interviewer as soon as possible following the interview. The interviewer and PI then discussed the interview and the field notes, with the PI making additional notes as needed to maximize contextual understanding.

3.5 Transcription & Translation

Interviews were carried out in the local language of Rutooro and were digitally audio-recorded. Recordings were then translated into English and transcribed by three RAs (one interviewing RA and two other RAs). RAs listened to the interviews in Rutooro, and simultaneously translated and transcribed them in English. All RAs had previous experience translating and transcribing qualitative interviews. Moments of strong emotion (e.g. crying) or long periods of silences were noted in the transcripts as well. However, other subtleties of language were excluded. Identifying details, such as individual or community names, were omitted to protect the participants' privacy and confidentiality. Four interviews, or approximately 10% of the total, were transcribed a second time by a different RA. Transcripts were then compared for discrepancies. No significant inconsistencies were found.

3.6 Rigor

In order to ensure this research was both relevant and appropriate for the CBART population, the study topic and design were developed in collaboration with faculty from the University of Alberta (Drs. Arif Alibhai, Duncan Saunders, and Amy Kaler), as well as Makerere University in Uganda (Dr. Joseph Konde-Lule). These researchers all have extensive experience working with CBART patients. Furthermore, this study built upon previous work conducted in Rwimi sub-county. Feedback regarding the interview guide was sought from the above mentioned team, as well as from CBART staff (Peter Rwakilembe and Tom Rubaale), and the research team. The interview guide was also amended throughout the data collection process, to better reflect the relevant issues in participants' lives.

In order to ensure rigor throughout the study, and to mitigate the effect of multiple interviewers, there was ongoing and detailed interviewer training. This included practice interviews, as well as tips on rapport building and probing. This helped ensure that all members of the interviewing team had a clear understanding of how the interviews should ideally be conducted, the types of comments that should be probed, and the aim of the project. Additionally, interviews were translated and transcribed as quickly as possible. This allowed the PI the opportunity to review and discuss interview results with the research interviewers. It also allowed the PI to generate a participant-specific interview guide for the second interview, in order to follow-up on any comments that weren't fully probed or clarified the first time.

Additional strategies for ensuring rigor in the project included ongoing discussion with the research team, as well as the CBART staff, to determine whether what the data suggested is consistent with what they have observed to be true. Following analysis, the results were again discussed with key informants and stakeholders in the district health department of Kabarole, as well as researchers at the University of Alberta.

3.7 Data Analysis

Preliminary data analysis was carried out concurrently with the data collection process. The PI met with members of the research team, or key informants from the CBART staff to discuss the emerging trends. These meetings provided the PI with important cultural context, and better understanding of key ideas. This ongoing analysis allowed issues identified by patients in early interviews to be incorporated into future interviews. It also allowed for clarification and/or further probing of results as needed.

Formal data analysis for this study was carried out using thematic analysis. This method was chosen as this study is largely exploratory. Thematic analysis allows for the identification of both the implicit and explicit ideas within a dataset, and generates a rich description of the given themes. This method focuses on participants' perceptions, feelings and experiences subjectively, and was expected to be able to capture intricacies of meaning within the data set (Mayan, 2009).

The process itself consisted of reading the transcripts, developing a coding framework, coding the data, identifying themes, and building a theoretical model. An inductive approach was used to generate the coding framework. With this approach, the creation of codes and categories was strongly data driven and based on the content of the interviews, rather than trying to fit the data into a pre-conceived model. Themes were similarly identified as they emerged from the coded data. The themes were then used to present a rich description of participants' experiences living with HIV on ART.

Data was coded and organized for analysis using Nvivo 10 software. Stratification by age and gender was considered, but did not illicit meaningful distinctions in the dataset. The coding framework can be found in Appendix D.

3.8 Ethics

Ethical approval for this study was obtained from the Human Research Ethics Board at the University of Alberta (Edmonton, Canada), the Internal Review Board at the Makerere School of Public Heath (Kampala, Uganda), and from the Ugandan National Council for Science and Technology. There were several important ethical considerations that needed to be taken into consideration with this research project. They are outlined below, accompanied by strategies for appropriate management.

Maintaining Privacy & Confidentiality

In order to minimize unwanted attention, prospective participants were initially approached by members of the CBART staff. Once recruited, they were given the option of completing the interviews either in their homes or at alternate locations. Participants were given unique identifiers and only key demographic information important for analysis was retained. Paper study documentation were kept in a locked cabinet in the Fort Portal CBART office during the data collection process, and stored there following the PI's return to Canada. All electronic files were encrypted. All RAs were required to sign a confidentiality agreement.

Language Barriers & Illiteracy

In order to ensure complete understanding, all information and consent documents were provided in the local language of Rutooro. The documents were read in full to all participants and any questions were answered by the RA. Participants who were unable to sign the consent form due to illiteracy were permitted to use a thumbprint to indicate their consent instead.

Coercion

Given the participants' level of poverty, incentives for participation could be coercive. For this reason, incentives were not offered. However, in appreciation and in recognition of the half-day of work participants lost for each interview, participants were provided with a small package containing sugar and soap (value: CAD$1.50). There was also a risk that patients from the CBART program may feel obligated to participate in the study. It was repeatedly stressed, both during the recruitment and informed consent process that participation was not mandatory and that non-participation would not jeopardize their access to treatment.

Potential to Identify Individuals that are Upset or Distressed

Participants were asked to discuss their experience living with HIV/AIDS, which had the potential to cause distress. The RAs had training and experience with these types of interviews and were able to provide comfort to participants if they became distressed.

4. Results

Study interviews addressed a variety of topics regarding the impact of ART on participants' physical, emotional and psychosocial well-being, and the implications this had for their QoL. These topics included feelings about death and dying; ARV drugs and treatment guidelines; physical functioning; financial status; social support; status disclosure; sexual relationships; and hope for the future. While interviews touched on a wide range of issues, as the research progressed it became increasingly clear that three areas were of great significance to participants and most associated with QoL: changes in work capacity; normalization of social relationships; and changing attitudes on reproduction.

The demographics of participants who were interviewed are summarized in Table 1. Of the 25 participants interviewed for this study, roughly half (48%) of study participants were male. Ages ranged from 35–68 years, with a median age of 42 (interquartile range: 40–50). The majority of participants (52%) had primary school education, 24% had no education, and 24% had secondary education or higher. Most participants (60%) were married, 36% were separated, divorced or widowed, and only one participant (4%) had never been married. All participants were working, with the majority of participants (72%) being subsistence farmers. Most participants were Catholic (52%), followed by Protestant (24%), Pentecostal (20%), and Muslim (4%).

Some demographic characteristics of my study participants were different from the original CBART cohort (Kipp et al., 2010). The median age was comparable. The CBART population had a median age of 35 at treatment initiation (2006–2007), thus we would expect a median age of 41 in 2012, after approximately six years on treatment. However, purposeful selection led to a more even gender distribution in my study than was originally observed. Similarly, participants with secondary education or higher were more common in my study, while those with no education and primary were less common. There were fewer unmarried participants in my study, particularly single/never married participants. Additionally, my study participants were all working, while 22% of the original cohort were not working at treatment initiation. These differences were not entirely unexpected. In a closed system where patients can leave the ‘single/never married’ group but not enter it, I would expect a decline. Similarly, I would expect an increase in employment once treatment is initiated and physical health improves.

My study population also differed from the general population in Uganda in several ways. The most notable difference was age. Uganda has a young population with a median age of 15 (Uganda Bureau of Statistics, 2016). While HIV prevalence is slightly lower than average among young adults (Uganda Ministry of Health, 2012), they represent a significant proportion of the HIV-positive population. The proportion of participants who were single/never married was also significantly less than in the general population, both among my study participants and the CBART cohort overall (Uganda Bureau of Statistics, 2016). This is likely due in part to the higher age of the CBART population. Muslim participants were slightly underrepresented in my study population. A little over 12% of the Ugandan population is Muslim (Uganda Bureau of Statistics, 2016), whereas only 4% of my participants identified as Muslim.

Table 1. ***Participant Demographics***

Characteristic	Study Population (2012) Count (%)	CBART Population (2006–2007) Count (%)	Ugandan Population (2014)* %
Gender			
Male	12 (48%)	76 (41%)	49%
Female	13 (52%)	109 (59%)	51%
Age at time of study			
Median (IQR)	42 (40–50)	35 (30–42)	15
Education at ART initiation			
None	6 (24%)	56 (31%)	19%
Primary	13 (52%)	105 (57%)	58%
Secondary or higher	6 (24%)	22 (12%)	23%
Marital status at time of study			
Single	1 (4%)	26 (14%)	22%
Married	15 (60%)	73 (40%)	65%
Separated/divorced/widowed	9 (36%)	84 (46%)	13%
Occupation at time of study			
Not working	0 (0%)	41 (22%)	29%
Subsistence farmer	18 (72%)	104 (56%)	46%
Small business/formal employment	7 (28%)	38 (21%)	25%
Religion at time of study			
Catholic	13 (52%)	83 (45%)	39%
Muslim	1 (4%)	14 (8%)	14%
Pentecostal	5 (20%)	9 (5%)	11%
Protestant	6 (24%)	68 (37%)	34%

*Source: Uganda Bureau of Statistics, 2016. Educational attainment reported for individuals six years of age and older. Marital status reported for adults 18 years of age and older.

4.1 Changes in Work Capacity

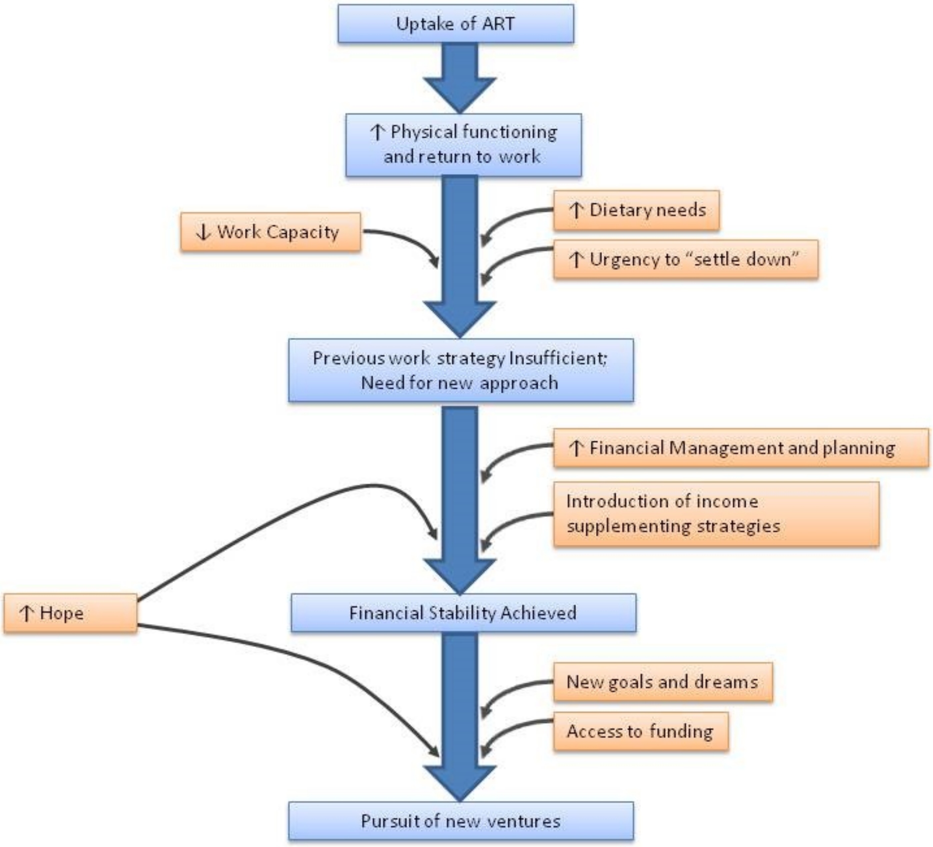

Figure 1. Participants' experiences returning to work.

Figure 1 details participants' experiences returning to work. After initiating ART, participants experienced a dramatic improvement in health as their AIDS-related symptoms resolved and their strength returned. Prior to treatment participants had been working very little, if at all. Their improved health allowed them the opportunity to return to work. However, their work capacity remained less than it had been prior to infection, as did their income earning potential. This reduced income, combined with increased costs for dietary needs and an increased desire to establish the family, meant participants struggled to meet their needs. This led participants to seek out new financial strategies. Through better budgeting and planning, as well as the addition of new income generating projects, most participants expressed that they were able to achieve financial stability. Throughout this process, participants' confidence in their renewed health and hope for the future increased, further prompting them to adjust to their new life. As participants became more financially secure, their plans for the future began to shift from those initiated for survival, to those initiated for personal preference and comfort. Participants began seeking out the means to pursue these new ventures.

The majority (72%) of participants in this study were subsistence farmers. Those who ran small businesses (16%) or were formally employed outside the home (12%) supplemented their income by farming as well. Working the land is physically taxing work and participants' livelihood was strongly tied to their physical strength; being physically weak meant being unable to work, and thus unable to secure food or income for themselves or their family.

When participants talked about changes in their health since initiating HAART, these changes were frequently framed in the context of returning to work, especially farming. Strong emphasis was repeatedly placed on their improved strength, which allowed them to return to work and once again be contributing household members.

> *R: There's an improvement because I go out and make money… by the work I do… I am making money. It's not like in the past where I would dig for a short while, and go back home due to a fever but now I can complete the work I am hired to do.*
>
> *- Participant 1, 50 year old male*

Like most rural subsidence farmers, participants' household's had been poor and marginal prior to infection. In poor households, the impact of having one member unable to work is strongly felt.

> *R: Eehh, the important change is that I am doing my work well… I don't have money. If I sit home, I don't have money.*
>
> *-Participant 8, 37 year old male*

Participants were relieved to return to work, and spoke often of the positive changes that came as a result.

Although HAART had allowed all participants to return to work and resume carrying out their household chores, most returned at a lesser capacity than before their illness. While participants had previously been capable of working long, hard hours in their homes and gardens, this was no longer possible.

> *R: We no longer possess that strength [we had] in the past, [when] we would dig for the whole day. But now, you work for six hours only [and] then retire. So, you find yourself reducing on the land tilled or the crops grown. Secondly, you won't be having money to hire the workers to… help you on the digging and [to provide relief].*
>
> *- Participant 2, 47 year old male*

Participants had to be careful to ensure that they did not overwork themselves and damage their health. If a participant did engage in overly strenuous or extended work, it now took much longer to bounce back from the exertion. In addition to the risk of long-term harm, the exhaustion from extra hours worked one day resulted in lost hours the next, and were thus not considered worthwhile.

> *R: If I overwork in a day, then the next day I don't work, just like that, [but] you know in the village you can't live without working.*
>
> *-Participant 18, 49 year old female*

As a result, participants frequently worked smaller pieces of land, for shorter hours. Some participants also avoided particularly arduous tasks. This lower productivity resulted in reduced income compared to pre-HIV infection levels. Interestingly, despite this reduced output, participants did not view themselves as less capable than others. Participants frequently reported that no one could tell that they were sick, and that they worked as well as others. It was only with further probing that they discussed any limitations.

> *R: I can't force myself to do something because I feel my life is lacking something. That's why I reduced on my working. [I am as healthy as others] because I see myself looking strong, healthy and better than those not on ARVs.*
>
> *- Participant 14, 35 year old female*

> *R: I feel free, happy because we are all equal, what they discuss, do is what I am doing. Whatever work they do I am capable of doing it too.*
>
> *-Participant 1, 50 year old male*

In addition to now working fewer hours, in order to maintain and protect their health, participants were also attempting to eat a more balanced diet. Participants were very aware that as PLWHA, nutrition was important. They had heard this repeatedly from health centre staff, and wanted to follow the appropriate guidelines. Following these nutritional recommendations, however, remained a challenge for some. Participants' concurrent reduced work capacity and increased health requirements were at times difficult to navigate. Participants often had little money with which to purchase food, and thus were largely limited to what they had grown themselves. This often meant there was little variability in their meal choices. In particular, meat and dairy could be hard to obtain.

> *I: Umm which things did they tell you and fail to follow?*
> *R: When they tell me to take milk and I fail to get money for example if I buy five cups then money goes into other things and decide to leave them; sometimes [I cannot afford] to eat meat.*
>
> *-Participant 12, 42 year old female*

> *R: I can manage my health but I have obstacles. I fail to do some of them. In the issue of food. At times [crops burn] and I fail to get what to eat. ... Money for buying food is scarce aahh, I get worried that if I fail to get money, I will not buy food from town.*
>
> *-Participant 24, 48 year old female*

While ART had allowed participants to return to work at a reduced capacity, at the same time living with HIV had given participants a heightened sense of their own mortality and a desire to work harder than before. Although participants felt confident in their renewed health and were hopeful that they could live for many years with the disease, they were also more cognizant of how rapidly their health could deteriorate.

> *R: Eehh, I have hope that I still have many more years to live in future, if I stay on my drugs.*
>
> *-Participant 13, 37 year old female*

> *R: I save for the children so that in case I am not around they will have where to start from. Because I know I have HIV/AIDS and I know I might die any time. I have to be prepared 24 hours.*
>
> *-Participant 13, 37 year old female*

As a result, participants felt an increased pressure to 'settle down' and establish themselves, both for their own future, and for that of their children. Participants' primary objectives - to educate their children, secure land, and build a home - were not new goals, but participants now felt a greater sense of urgency to complete them. Providing a secure future for their family was important to participants, and they were eager to achieve this while their health remained strong. Participants were afraid that if they died prematurely before achieving these goals, their family would struggle and have difficulty taking care of themselves.

> *R: My plans are many… educate children throughout all the levels and build a permanent house… because there is limited time. Though I am taking drugs, it doesn't mean that I will live for very many years... I plan more [so] at least you have something to leave behind.*
>
> \- Participant 2, 47 year old male

> *R: My children… I build for them… I have built them a house, I have my animals though I leave now they will not suffer.*
>
> *-Participant 18, 49 year old female*

While several participants acknowledged they would have liked to have had more children had they not been sick, this was considered less important than educating their current children, and ensuring they had sufficient land and a well-constructed home. Participants wanted to provide their children with a solid foundation in life, to help ensure future success.

> *R: I am praying to God to help me so that I educate my children. ...I never went to school. I make sure that my children have studied. I leave when every child has completed school and doing well. In my heart, that's what my plan says.*
>
> *-Participant 3, 40 year old male*

> *R: [I want] to educate them [my children]. To build for them. Such that I leave them somewhere and tell them "This is your home."*
>
> *-Participant 7, 40 year old female*

Participants' decreased work capacity and increased desire for financial stability led them to develop various strategies to compensate for their reduced income. Concern for the future combined with optimism that they weren't going to die led to action and allowed participants to progress with their goals. Participants had had limited income prior to be becoming sick, and their reduced work capacity exacerbated an already difficult position. In order to better meet their needs and goals, participants adopted a number of strategies to adjust to their lower earning potential. First and foremost, participants were more careful with their money. Degrees of unnecessary spending prior to acquiring HIV varied between participants. All, however, had now minimized impulse purchases and were careful to consider all their options when making purchases. Care was taken to determine the best use of their income.

> *R: Before I used to make money and spend it like someone who has stolen it. But now I have [my wife] counting it. ...I spend carefully ...I tell them to keep the money and use it later on ...It helps me buy stuff or use it for emergency.*
>
> *-Participant 25, 35 year old male*

Although not all could afford to do so, some participants had hired workers to help compensate for their reduced workload. This allowed them to work a larger piece of land than would otherwise be possible, and in turn produce greater yields.

> *R: I work sparingly. If there's a bush I can't afford to cut because my strength is little, I sell a bunch of banana get money to hire a worker who can do it... If I have money in my pockets I can say that "you work in my banana plantation." "You weed my maize garden or g-nut garden or a garden of beans."... I want to work, but you can't do all the work at the same time, you need to be having money aside and you hire someone to help you.*
>
> *-Participant 9, 68 year old male*

Still others began new income-generating activities. Most commonly participants incorporated rearing of animals, although other projects, such as small businesses and shops, were started as well.

> *R: After we planned and visited people keeping pigs and [they] told us they are benefitting and we decided to keep them and indeed we're benefitting too, those keeping chicken have benefitted and [when] we're sick we can eat eggs or slaughter a chicken and eat it then helps you then we planned to keep them, a cow when it produces you drink milk instead of spending money on milk from somewhere else you take your own milk.*
>
> *-Participant 4, 37 year old female*

> *R: Before I fell sick… I didn't have that business… I was digging, I am a farmer. Now when I became weak, I got plans of renting a house in the trading center, then conduct business since I am not very strong [and] that will provide income… I see I am doing well because I am not [wanting for] anything*
>
> *- Participant 19, 50 year old male*

With careful planning participants' income slowly grew, and most participants reported success in becoming financially stable. Of those participants with school-aged children/grandchildren, most reported current school enrollment. Some participants' children were even enrolled in secondary and post-secondary educational institutions. As participants' lives normalized most achieved a level of financial security comparable to their pre-HIV levels, and some had even managed to acquire assets. While it took considerable time and effort, some participants had successfully purchased land since their diagnosis, while others had either built a home or started to acquire building materials. Still others were purchasing new and useful household items (furniture, radio, bicycle, etc.).

> *R: My real original land is small…, but when God helped me and I gained strength, now I am able to work and I have managed to buy more land there... I bought that farm… and I have bought another plot near the road.*
>
> *-Participant 21, 40 year old male*

> *R: Now, before I started taking drugs, I was badly off, but when I started taking drugs… I became well. ... I started doing my work very well, better than how I used to do it….I have done a lot of things. I bought those sofa sets when I was sick. Even the kitchen, porch, I constructed all of them when I was sick…. Even my bicycle, I bought it when I was already positive. Even the radio in my bedroom. What else do I want?*
>
> *-Participant 9, 68 year old male*

Participants' ability to return to work, and the financial independence that resulted, was integral to their sense of self-worth. The value participants placed on their renewed health and their corresponding ability to support themselves and their family financially was significant.

> *R: The change that has been important to me… is regaining strength. I became someone in society and I have a life to lead… The strength I regained helps me work for myself.*
>
> *- Participant 6, 40 year old female*

The desire to start more income generating projects was common amongst all participants. Participants were now looking to the future with hope and optimism. They discussed their dreams, and the various ideas and activities they would like to pursue, now that their lives had normalized. As mentioned previously, participants' ability to farm was hindered by their reduced physical strength. This was further complicated by less than ideal growing conditions. Seasons of drought or excessive rainfall and hail resulted in damaged crops and left many households with little to no return for their effort. Sub-optimal crop yields, in gardens that were already reduced in size, meant participants' incomes were twice affected. Plans to acquire more animals, as well as desires to open a shop or start a small business were frequently discussed. It was a common belief that running a shop was less hectic and demanding work than farming, and that it would be easier to carry out then their current work. The income generated from such work was also believed to be both greater and more consistent.

> *R: If I had money, I would have started a retail shop. I sit down, and get for my children food… and generating money for school fees … [Farming] reduces on your strength, you become weak, your health deteriorates, you can't gain weight. … In farming… there is no peace.*
>
> *-Participant 3, 40 year old male*

The most commonly cited challenge to initiating these ventures was lack of capital. While this is a common challenge amongst poor, rural subsistence farmers, it was more strongly felt by participants since their diagnosis. As participants' strength had not returned to pre-infection levels they were unable to earn the same income from farming as before. Living with HIV also meant increased self-care costs. As a result, participants were more eager than before to find alternative means of generating income. However, having spent much, if not all of their money seeking medical care, participants had little income available to invest in new projects. Once participants' incomes stabilized, any extra income was mainly focused on establishing themselves, rather than exploring new enterprises. Participants were aware of the various lending programs available in the area. Their new hope and optimism, however, did little to alleviate the fact that participation in these programs was viewed as both difficult and risky. For some, their poverty made them ineligible. For example, to acquire an animal from the National Agricultural Advisory Services program, one needed to have appropriate housing for the animal (chicken coop, pig pen, etc.). Participants who lacked the funds to build these structures were thus unable to participate in the program. While some considered getting a loan, they faced two barriers. Firstly, in order to acquire a bank loan they needed a bank account, which they found too costly to open. Secondly, they perceived the risks of getting a loan to be high. If the participant's venture failed and they were unable to repay the program, they risked losing their land or limited possessions.

> *R: I fear borrowing money or getting money from financial institutions. Those involved end up badly, they acquire loans and fail to pay them off. That's why I decided to stay the way I am now. I don't want to get worried because of loan repayments.*
>
> *-Participant 14, 35 year old female*

In the instances where participants might have been willing to take the risk, fear amongst other family members acted as a deterrent.

> *R: I do think about it but when I tell my wife to go and get a loan then she says aah when we get a loan they will confiscate our land, she refuses.*
>
> *-Participant 3, 40 year old male*

Still others were concerned that they lacked the knowledge and skills necessary to successfully run a business, having no experience or education outside of farming. This was viewed as a gamble that few were willing to make.

> *R: I am a farmer not a business woman who makes profits and accumulates money. We are farmers and I have to first wait for a season. If the crops yield well, God willing, I will, I will plan for my children.*
>
> *-Participant 24, 48 year old female*

Amongst my study participants, there was only one participant who had taken a sizable loan. She had purchased a cow, was able to care for it well, and was successfully paying down her loan. This particular participant was a widow whose children were grown. She was helping to put her grandchildren through school, and to secure employment for her children. Like all participants, her main concern was the financial well-being of her family. She was also concerned with protecting her health. The purchase of the cow allowed her to better care for her health (by consuming milk more frequently), and retain a valuable asset for her family. Helping improve her family's financial situation was important to the participant. Given her success with this loan, once it was repaid, the participant intended to take obtain a second loan to help her son gain employment as a motorcycle-taxi driver.

> *R: I, the hope I have is to work hard and acquire assets to make my living so that I be well in the future… [Recently] I acquired a loan and bought a cow. I am now drinking milk. …People think … "you're sick, you shouldn't [have done] such and such a thing." I am not concerned about them, what I know is that I am alive.*
>
> *-Participant 5, 52 year old female*

4.2 Normalization of Social Relationships

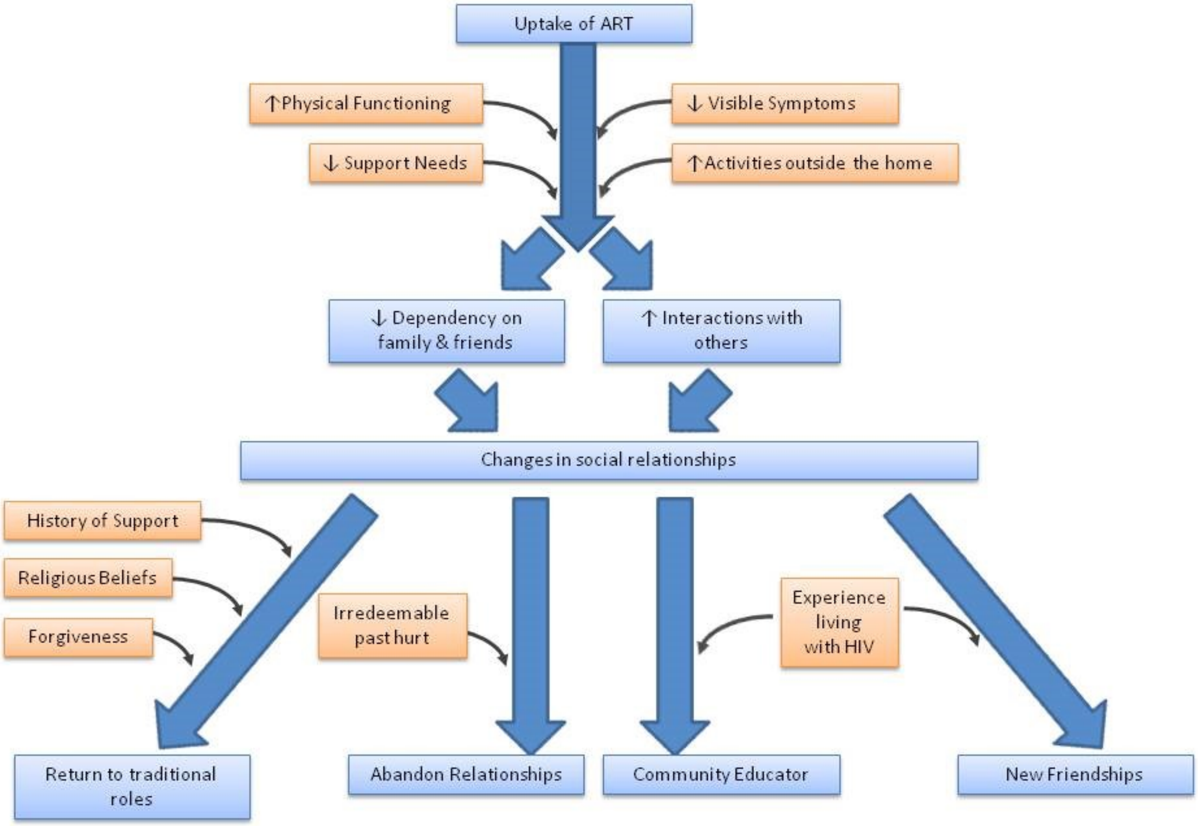

Figure 2. Participants' experiences with social relationships.

Figure 2 details participants' experiences with changing social relationships, as they adjust to life on ART. After initiating treatment, participants experienced a dramatic improvement in health as their AIDS-related symptoms resolved and their strength returned.

This improvement in health meant that participants required less care and support from their families, and were able to once again engage in social activities outside the home. As participants' dependency on their caregivers decreased and their interactions with others increased, social relationships began to change. The reliance on caregivers was largely eliminated from participants' lives. For those participants who had positive interactions with their caregivers, this meant a return to their former social roles and relationships. For those who experienced discord with their caregivers, outcomes varied. The desire to forgive, combined with religious beliefs meant many participants chose to re-establish traditional social relationships with these individuals. However, for some, past conflict and hurt was too great, and the relationship was abandoned. Relationships with neighbours and community members similarly changed. In addition, participants developed relationships related to their experience living with HIV. Participants formed close networks with other PLWHA to provide support to one another. Participants also frequently acted as community educators, sharing their knowledge and experience with HIV with those around them.

Impact of HIV on Family & Community Relationships

Good family relationships were important to all participants. Families were seen as a source of comfort and support in difficult times. Participants felt very grateful to their families for the emotional support and financial assistance they had received while they were sick.

> *R: They [my family] didn't segregate me as a sick person and they would help me to look for transport to take me to the hospital. Even when I was still bedridden and I would not be able to go to the sub-county to collect my drugs, they would buy for me these drugs locally.*

-Participant 11, 40 year old female

Overall, participants had received excellent care from their families while they had been sick, with many claiming never to have experienced conflict. Most said they were always well-treated when sick, that they were never abandoned, and that they were never made to feel like a burden. Participants reported instead that their families had worried about their health, and continued to be concerned for their well-being. One participant even reported that his wife, who had left their home prior to his infection, showed him great compassion and had returned once he fell sick.

> *R: She [my wife] also struggled to put in much effort to take care of me, to make sure that she nurses me. She wasn't at home by the time I fell sick, aahh, she had failed to cope up with this place and decided to go back to her home, but when I fell sick, she came. She came back here to take care of me.*
>
> *-Participant 3, 40 year old male*

The perception of being a non-contributing burden to their family while ill weighed heavily on participants. Despite being well-treated by their family, or perhaps because of it, participants often felt guilty about the time and money their family had had to spend on them. All of the participants had meager income and assets, and often large proportions of the household wealth had been spent treating the participant.

> *R: We used to fall sick most of the time and we spent a lot of money on medication and other things but now we no longer spend… Things we couldn't manage to buy because we were spending on medication, now we use the money to buy what we need since we no longer spend on medication or take it to the hospital.*
>
> *-Participant 4, 37 year old female*

Additionally, family members had been limited in their ability to work or pursue their own activities, while caring for the participant.

> *R: Sometimes I could feel [like a burden,] for instance one day my child missed exam because [he] was taking care of me in the hospital… They were going to begin exams like tomorrow then [I] was admitted to Buhinga hospital and no one was there to look after me, so I felt being a problem to them, my husband could spend money on transport going to Buhinga, Kabarole and on treatment, he could not invest in other developmental activities, only spending on my medication…. [But] he did not get tired [of me] because when I could fall sick [he was] there with me while comforting, even my mother and sisters/brothers were not tired of me.*
>
> *-Participant 23, 47 year old female*

Now that participants were on ART and their health had returned, these family interactions were able to shift from patient–caregiver dynamics back to more traditional exchanges. As their health improved, participants were able to take a more supportive and helpful role in the household and no longer had to be a burden to the family.

While most participants felt well cared for through their AIDS progression, there were some exceptions. There were seven participants who had received little support or experienced family discord. There were a small number of participants who did not have close family or friends nearby. Their families lived some distance away and made no effort to help them. This left the participants feeling alone and abandoned, and was clearly very difficult for them.

> *I: When they got to know that you're sick…They did not come, they didn't come to see you?*
> *R: They did not come at all, maybe if they tell them that I am dead.*
>
> *-Participant 17, 53 year old female*

> *R: My family members [stay far away]. (Interviewer: Do they take care of you?) To take care of me even they don't know that I am staying here.*
>
> *-Participant 16, 50 year old male*

There were also several participants who had negative experiences with family or community members who treated them poorly because of their illness. Typically, these interactions were with in-laws or neighbours – individuals less emotionally attached to the participant – although one participant reported significant conflict with her then-husband.

> *R: After him [my husband] knowing that I was HIV-positive, he started talking about me in public… He would go to drinking joints and start saying "my wife is HIV-positive", "My wife has infected me with HIV"… [Then] he dodged me and refused to…take care of me and my children. He started buying some items and using them alone. Now I came to realize that I will not manage…living with the man.*
>
> *-Participant 6, 40 year old female*

These experiences ranged from people saying hurtful things to the participants and gossiping behind their back, to actively avoiding and isolating the participants, to attempts to take the participants' land and/or assets. Again, these experiences caused the participants to feel alone and distressed.

> *R: He [my neighbour] used to say that I am suffering from HIV and I am going to die, then [he] will marry a woman in my house.*
>
> *-Participant 8, 37 year old male*

> *R: There's a time I was nursing my younger child. The child was badly off, when I was, I was at the clinic with the child by then the child was admitted. ... I was the only one with the child, when the [paternal] grandmother came. ... I said "you stay with the child and I go outside to wash clothes." Surprisingly I heard the old woman telling the health worker that "why are you disturbing yourself, you leave treating the child, we shall take him home and he dies from there, do you think HIV patients get cured."*
>
> *-Participant 13, 37 year old female*

Restoring Family & Community Relationships on HAART

Over time, a re-establishment of cooperative family relationships was one way people returned to 'normal'. As participants began feeling better and engaging in routine day-to-day activities, they once again started running into their neighbours, extended family, and community members. This re-establishment of contact and repeated interaction often led to reconciliation for those who had experienced conflict. Participants expressed being eager to put past differences behind them and re-establish their lives. Most chose, over time, to forgive their family, friends, and neighbours for any past disputes. Participants often expressed a belief that past conflicts had arisen due to fear or poor understanding of the situation. Additionally, participants' religious beliefs often promoted forgiveness of others. Most on-going conflicts in participants' lives were not HIV-related but rather land conflicts.

> *R: They used to say that "That one is already dead, he's useless, and he can't do anything productive." Aah, but now, they come to me for advice, help. Seeking advice from me. I just look at them and feel sorry. You know even us eehh in our religion they say that when someone wrongs you or talks ill of you, you respond to that person well. You talk to him/her gently, and forget the past. Forgive whoever wronged you… I forgave all of them.*
>
> *-Participant 9, 68 year old male*

> *R: We [now] cooperate well, we're friends, we don't hate each other. (Interviewer: Did you forgive them?). Very much so… I am not alone, even God said that if one slaps you on the right cheek then change the left one also and slaps you and forgive him/her…. Because they don't know what they're doing, they don't know what is ahead of them and there many things by the way.*
>
> *-Participant 17, 53 year old female*

> *R: Those who used to talk when I was badly off that, "so is going to die" came to me for advice when her husband started HIV drugs and failed to follow instructions… I went and explained to her husband how HIV drugs should be taken. We forgot the past and helped them in time of need.*
>
> *-Participant 6, 40 year old female*

While most participants chose to forgive past transgressors, there were exceptions. Participants' return to health and improved social support meant they no longer felt obligated to endure these taxing disputes. Participants thus had a choice to either forgive the offending individuals and re-establish the relationships, or cut these individuals out of their lives completely. For a few participants, the damage was too great, and the relationships were abandoned. The loss of these relationships did not seem to affect participants' perception of their QoL. In fact, many seemed relieved to be rid of toxic relationships as this allowed them to focus more on other, positive relationships in their lives.

> *R: Those who mistreated me, I left them…. At times I get thoughts when I am sleeping. I think badly. …I left them… They used to say that I was going to die…they talked badly. …I left them.*
>
> *-Participant 8, 37 year old male*

> *I: How is your relationship now?*
> *R: They just bypass my house and I also go my own way…. They go to their own churches and I also go to my church. And when we meet like at funerals, they sit in their own place and I also sit alone.*
>
> *-Participant 24, 48 year old female*

When participants had been sick, they had been unable to engage in many community activities, such as participating in church, funerals, saving groups, socializing in the marketplace, etc. Participants had felt guilt and shame at being unable to participate in socially significant activities. In particular, participants regretted being unable to attend church and the funerals of their friends/neighbours; activities they considered to be morally important. Participants were appreciative for the opportunity to support and interact with their friends and neighbours once again.

> *R: [Before ARVs] I used to feel bad because I could not sit in the public, … fever couldn't allow me to interact with people, … I would discuss with them during day like this, but in the evenings I wouldn't due to fever… I used to feel reluctant going to public places… I could not even attend funerals or sympathize with people who lost their loved ones in my village, when you insist on going there, you run back home immediately due to fever. You would rather stay home.*
>
> *-Participant 1, 50 year old male*

> *R: Do you think when I was still sick I would have gone to Church and start mixing up with other people? [No], but now I don't miss any Sunday without going to church, I have my clothes set aside purposely for going to Church, I go there and pray and then come back.*
>
> *-Participant 16, 50 year old male*

A return to good health meant that participants were once again able to engage in community activities in meaningful ways. Participants talked about becoming fully re-engaged in their communities, with some participants even leading groups and/or being recognized by the community.

> *R: When I am with other people, I do what they are doing… I am one of the church leaders… Village leaders recognize me to be a VHT (Village Health Team member) of this village, because I have regained my life, but before they did not have hope in me, now I am important.*
>
> *-Participant 22, 48 year old male*

In addition to being physically unable to venture frequently into the community, participants had also felt self-conscious when sick because they looked ill and did not feel like themselves. As their illness progressed the participant became increasingly visibly ill. Participants reported a variety of very visible signs, such as extreme weight loss and skin lesions. Unable to mask these signs, the participants were reluctant to go out. Participants feared being openly mocked or ostracized. The resolution of these signs gave participants both the physical ability, as well as the emotional confidence to once again engage in community activities.

> *R: I saw my skin getting spoiled, I suffered from boils then sat down having constant fevers. …I felt like I never fit in the community. I was isolating myself and felt like a portrait in public.*
>
> -Participant 12, 42 year old female

> *R: At first I was looking bad so I was fearing people, now I am looking good and I stay with people conversing.*
>
> *-Participant 8, 37 year old male*

However, living with HIV meant that some social activities needed to change. In order to protect their health, participants now actively avoided alcohol and tobacco consumption, casual sex and unnecessary spending. The importance of adhering to these guidelines was discussed by both male and female participants. However, with regards to drinking, smoking and extra-marital sex, it was predominantly men who discussed their past engagement in these activities while women typically discussed the necessity of good behaviour in more general terms.

> *R: Drinking alcohol then getting drunk and, and I spoil the drugs I am on….You know alcohol can lead you to do something bad. You may take alcohol and it disorganizes your brains and you forget to take medicine then you sleep like that.*
>
> *-Participant 6, 40 year old female*

> *R: When I got HIV then stopped having sex outside [my marriage], I only have my wife.*
>
> *-Participant 3, 40 year old male*

For some, these were relatively minor adjustments; for others however it was a big change. There were some participants whose social activities had frequently involved drinking with friends in the marketplace. These participants therefore needed to develop new methods of connecting with their social network.

> *R: I had to economize my income to school fees and home necessities, and I gave up on side expenditures....We used to spend on drinks and women.*
>
> *-Participant 21, 40 year old male*

Additionally, care had to be taken now to ensure that pills were not missed. If a participant wished to stay out with friends rather than go home for their evening dose, it was imperative that they remember to pack their pills when leaving in the morning. If the pills were forgotten, then the participant would have to skip the social activity and go home instead. All things considered however, these adjustments were viewed as relatively straightforward and a small price to pay for continued health.

While participants experienced a loss of some social interactions, they gained some new ones as well. Many participants now found themselves with a new role within the community: the role of HIV educator. Participants were now supporting their community through HIV knowledge sharing; a task they considered important. Participants were exceedingly grateful to have had the opportunity to receive treatment. Participants reported that they now felt it was their duty to help receptive friends and neighbours seek out treatment as well.

> *R: To me [advising others to seek testing] is an important thing… If I let you die, you see I would have committed a crime in the presence of God.*
>
> *-Participant 3, 40 year old male*

> *R: When I see [someone] looking unhealthy then encourage him/her to go and test. I have to first ask him have you ever tested if he says no or tested negative then [I] advise him that I was like you but when I tested positive and started drugs now I am okay, do you see! You can also test and feel better, you will stop suffering.*
>
> *-Participant 15, 53 year old female*

Participants claimed to encourage testing to friends, family, or neighbours they thought might be sick. In addition, they were also willing to help those close to them adjust to life with HIV, by offering their support on dealing with adherence, adverse side effects of the HIV drugs, and other issues that arose.

> *R: Now me I can [talk about my HIV status], because they always say that you can't leave your friend to fall into a ditch you are seeing….You have to advise that person and say "my friend, the action you are going to do is bad. You should avoid it in such and such a way."*
>
> *-Participant 10, 36 year old male*

In addition to acting as an informal HIV educator to the community, participants had also developed strong social networks with other people living with HIV/AIDS (PLWHA) in the area. While participants reported being able to interact and engage with anyone in their community, regardless of that person's HIV status, they did acknowledge that there were times they felt more comfortable with other HIV-positive friends.

> *R: Positive patients know that we are one and we belong in the same group but negative people are different even if they help me in times of need, they can't understand me at times.*
>
> *-Participant 14, 35 year old female*

In particular, when it came to discussing the challenges and complexities of living with HIV, participants felt most comfortable with other PLWHA. Having these HIV-positive friends was important to participants, as they were able to share all aspects of their day-to-day lives with them.

> *R: I am free to disclose my secrets to HIV-positive people because we understand each other's problems; have you heard. If I have made a mistake, my colleague will tell me that, "my friend, you have made this and this mistake, do it like this and that or my friend you take drugs at the wrong time, you adjust." That's how we interact.*
>
> *-Participant 6, 40 year old female*

Participants had been able to make connections with other PLWHA in the community in later years of the ART program when they started to pick up their own drugs from the health centre. While a post-test club had existed in Rwimi when participants initiated treatment, few had chosen to join and their interest in such groups remained minimal. Participants did however deeply value their friendships with other PLWHA. These new connections were able to offer participants help and support with adjusting to life with HIV, and addressing HIV-related concerns. Participants felt they could be truly open and free with other patients, and often described them as being like family.

> *R: You see when I am with people who have HIV/AIDS we are like we are in one family and you cannot hide anything from them.*
>
> *-Participant 13, 37 year old female*

4.3 Attitudes Towards Reproduction

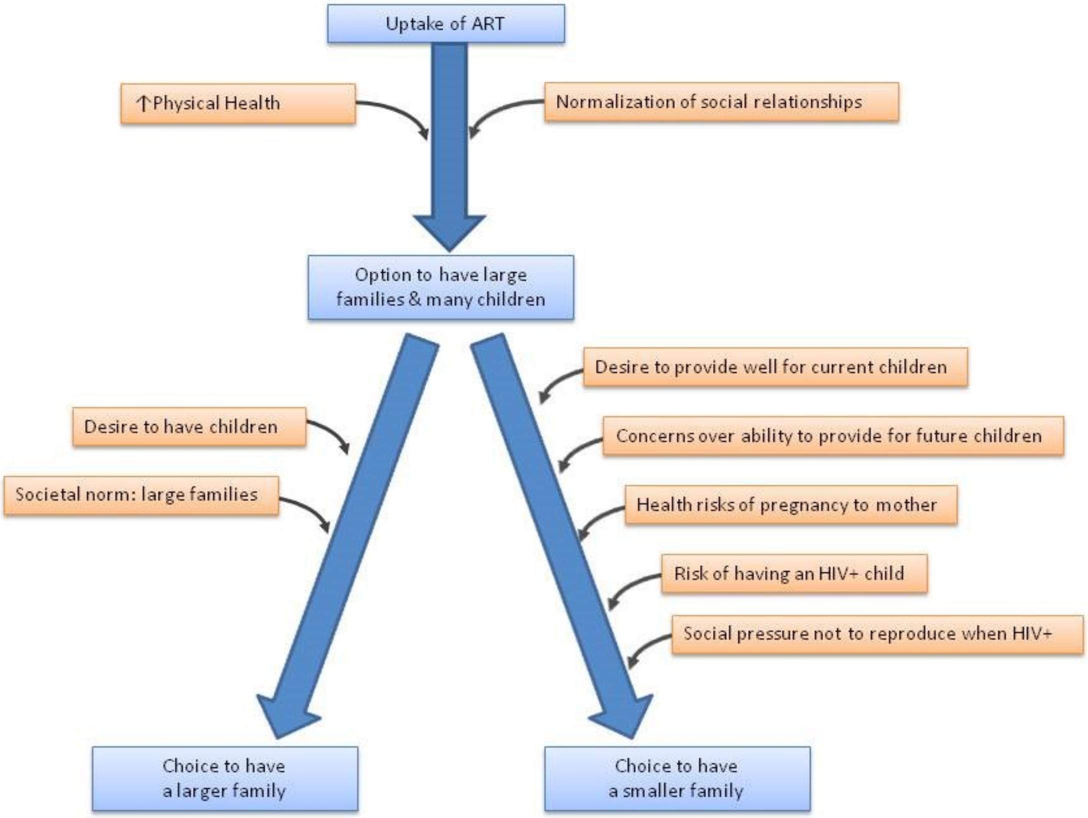

Figure 3. Participants' attitudes towards child-bearing.

Figure 3 details participants' attitudes towards child-bearing. After initiating ART, participants experienced a dramatic improvement in health as their AIDS-related symptoms resolved and their strength returned. Social relationships normalized, and participants were able to reintegrate into society. At this point participants could potentially expand their family and have more children. The decision to reproduce is not determined by HIV-related issues alone, and it is likely that other factors such as older age and changes in marital status affected study participants' individual choices. However, participants expressed similar attitudes and beliefs with regards to child-bearing, both for themselves personally and for PLWHA as a whole. There are many conflicting priorities surrounding the decision to reproduce. Personal desire for more children, as well as social norms that favour large families encourage patients to have more children. By contrast, a desire to financially provide for all children, HIV-related risks to the health of the mother and child, and social pressure that PLWHA should limit family size discourage further reproduction.

As is typical in Ugandan culture, having children was viewed as important by all participants. Male children were valued as heirs and family members who would grow and expand the clan. Female children were valued for the support they would provide to their families. All children were considered to bring joy and happiness. Children were also seen as a means of strengthening a couple's relationship.

> *I: Uumm, now how do you think of a situation whereby you are HIV-positive without children? What do you think of that life?*
> *R: You have nothing at all.*
>
> *-Participant 1, 50 year old male*

> *R: It's important for a family to get children… This family has children and they keep it warm most of the time.*
>
> *-Participant 5, 52 year old female*

> *R: To confirm that a woman belongs to a certain man is to produce a child with that man…That is when you strengthen your love with your husband.*
>
> *-Participant 11, 40 year old female*

In Uganda, the societal norm is to have large families with many children. The majority of study participants, however, reported that PLWHA should limit their family sizes. Those who had had no children or few children prior to infection expressed a desire to keep their family size smaller than normal. Similarly, most participants advised that young HIV-positive couples should limit the number of children they have. Participants discussed a shift in priorities, wherein they favoured limiting the number of children in the family in order to ensure those children were well provided for. Most participants felt that the financial cost and potential health risks to both mother and child strongly outweighed any benefits of many children.

Almost all of the study participants had had children prior to being diagnosed with HIV, and were now older in age. Participants' main concern at this point was taking care of the children they already had. Having been so close to death, participants now had an increased awareness of their own mortality; this led participants to focus on preparing for their current children's future, rather than expanding their family.

> *R: I no longer want more children. I told you those children, I told you those children are enough for me. Because producing a child without meeting all their basic needs, it's bad.*
>
> *-Participant 3, 40 year old male*

> *R: What is the use of having many children whom you cannot manage to look after? What is the use of getting children and you end up making them suffer; a child doesn't go to a good school, they need good feeding and you are unable to provide for them, there you find yourself in a fix. You cannot be happy when you have many children but when you have few children you can manage to bring them up in a good way.*
>
> *-Participant 13, 37 year old female*

Participants were concerned that with the limitations of HIV, they might struggle to provide financially for their family if they had more children. Participants feared that their resources would be stretched too thin and that all of their children would suffer. The idea of providing well for their children's future was integral to participants' idea of what it meant to be a good parent. Now participants had to address these realities in the face of HIV-related limitations.

> *R: You may go on producing, producing yet you are weak and you fail to take care of those children, you, you only focus on producing more. And yet the children's needs are not provided satisfactorily. Because what you would be needing, the needs are so many. They instruct HIV-positive patients to feed well, drink well. Now, will you get money to take children to school at the same time feed on it?*
>
> *-Participant 3, 40 year old male*

Additionally, the health risk pregnancy posed to mothers' health, as well as the possibility of having an HIV-positive child further deterred participants. Participants were particularly aware of the risks associated with labour, and feared leaving current children motherless, should a subsequent pregnancy/delivery end poorly.

> *R: When women conceive their health weakens, when we were still negative, we used to suffer with our pregnancies, we would vomit, feel dizzy, get heart attacks plus many other signs. At times we wouldn't even work. So, I make a flashback and compare with the situation I am in now, if I conceive my health will be at risk that's why I don't advise positive mothers to conceive.*
>
> *-Participant 6, 40 year old female*

> *R: I would not like to hear that one is HIV positive and is producing more children, may produce [a] child [that is] also infected, I wouldn't wish that.*
>
> *-Participant 20, 41 year old male*

> *R: It's necessary to stay with the children you have, you first look after them. The children you have, but not producing more because it weakens the woman's body. And it's not necessary, you should take care of the children you have.*
>
> *-Participant 1, 50 year old male*

The idea that HIV-positive patients should not have many children was prevalent. When asked about hypothetical patients who did not yet have children, participants repeatedly recommended that they should limit their family size, typically to between two and four children, and that those children would be enough.

> *I: If these [HIV-positive] people insisted to produce children, how many children would you have wanted them to produce?*
> *R: They can produce one or two children; those would be enough.*
>
> *-Participant 13, 37 year old female*

> *I: Those who marry and want to produce, what advice would you give them? Or they may produce like how many?*
> *R: About 2, they are enough and this applies to the couple whom have not yet produced any child, at least they produce about two instead of staying without any child.*
>
> *-Participant 23, 47 year old female*

At times it was even proposed that HIV-positive individuals should avoid producing children entirely. However, it was recognized that young people without children would be unlikely to forgo parenthood entirely, in which case a small number of children would be reasonable.

> *R: Uuhh, producing children! They advised us not to produce children while on drugs, they should stop at that.... You leave producing.*
> *I: [what if] someone has not yet produced and he/she wishes to have one?*
> *R: Uumm, when someone has never given birth, he/she insists on having one... They ought to produce like two to three children that's all.*
>
> *Participant 3, 40 year old male*

When asked how many children an HIV-negative person could/should have, the answer was consistently higher than for HIV-positive individuals. Not one participant suggested that a PLWHA could or should have the same number of children as an HIV-negative individual, nor did any of the participants suggested that a PLWHA could care for their children as well as an HIV-negative individual.

> *R: They are supposed to be four children [in HIV-positive families]... (Interviewer: Now if you're not sick, how many would you produce?). Like five or six children.*
>
> *-Participant 8, 37 year old male*

Similarly, amongst the few participants who were actively choosing to have more children, the intention was to keep the family size small. These participants had no children prior to their HIV diagnosis or initiation of ART, and for them the pain of a life without children meant that they were willing to accept the risks. There were only two participants who were choosing to have children, both of whom had been recently married. These participants were limiting themselves to two and three children respectively; low counts in a Ugandan context. When asked about their reasoning, both participants expressed concerns regarding their ability to properly provide for their children as the reason for the reduced number.

> *R: I had told my wife…that we should produce a child. (Interviewer: You had planned for it?) Yes… I need only two children.*
>
> *-Participant 8, 37 year old male*

> *I: You and her, did you first talk about it then decided to have a baby?...*
> *R: ...[Yes]. If she produces that baby, we will make three children…they are the only ones I want to have.*
>
> *-Participant 25, 35 year old male*

How to safely conceive and deliver children while living with HIV was not part of the research questions and as such, was not purposefully discussed with participants. Four participants, however, volunteered information on this topic. It was interesting to note that only one of the couples choosing to reproduce sought out the advice of the health centre staff prior to conceiving. This may be an indication that they struggled with the pervasive attitude that HIV-positive individuals should not be having children. The idea that health centre staff would disapprove of a pregnancy was also mentioned on occasion. One participant reported having asked staff about having another child and was told his income was insufficient; another participant mentioned that health centre staff could yell at you if you have too many children. It is unclear how common a belief it is that health staff disapprove of PLWHA reproducing. Regardless of its validity, the potential consequences of not seeking prevention of mother to child transmission (PMTCT) services, particularly among sero-discordant couples, is of concern.

4.4 Summary

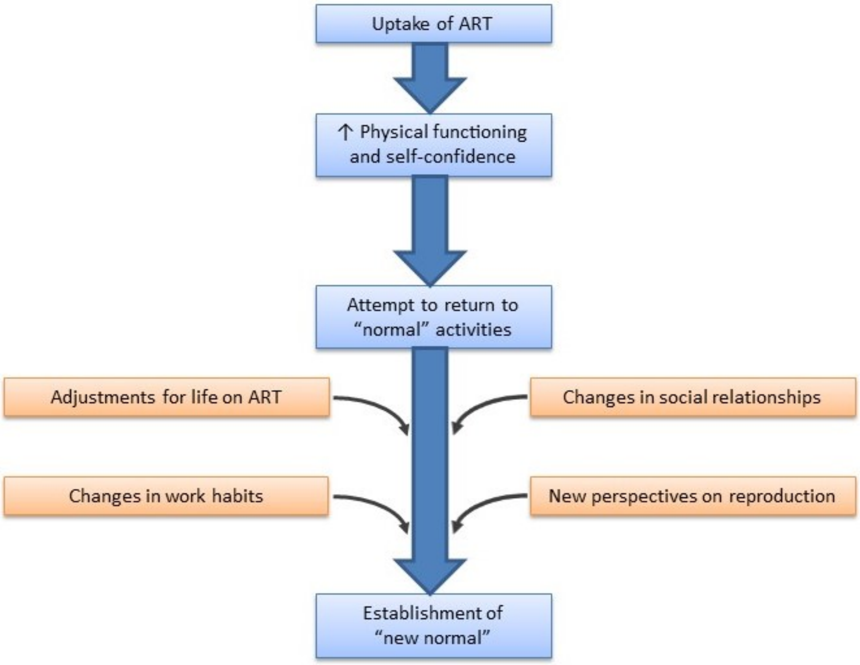

Figure 4. Participants' experiences adjusting to life on ART and developing a new normal.

Figure 4 depicts participants' experiences as they return to typical day-to-day activities, make adjustments for life on ART, and establish a new routine and a new sense of 'normal'. After initiating ART, participants experienced a dramatic improvement in health as their AIDS-related symptoms resolved and their strength returned. As participants' physical functioning improved, and with it their self-confidence and sense of self-worth, they began once again engaging in routine activities.

Participants, however, were unable to simply return to the same life they had known before. Life on ART required that adjustments be made to many aspects of their lives. While ART allowed participants to return to work, new strategies were needed to address changes in work capacity and shifting financial priorities. As participants began to once again engage in social activities outside the home, social relationships changed as well. While many relationships were re-established as they were before, some relationships were deemed irreconcilable and abandoned. New relationships were also forged with other PLWHA.

As participants adapted to life on ART, their lives began to normalize. Work and social relationships once again conformed to social norms. By contrast, attitudes towards reproduction continued to deviate from the cultural norm. ART allows PLWHA the opportunity to engage in normal activities again, including the option to have children and expand their family. However, my study participants all expressed a belief that PLWHA should limit childbearing. Participants felt it was important for PLWHA to focus on providing well for their children and establishing the family, rather than expanding it. This shift in priorities favored smaller family sizes over larger ones, and was in direct conflict with traditional beliefs in their community. While participants were able to establish a 'new normal' that was consistent with typical work and social activities, beliefs regarding family size remained distinctly different.

5. Discussion

The overarching theme, expressed again and again in all of the interviews was the idea of ‘returning to normal’. Participants’ HIV infection and subsequent progression to AIDS disease had been significant hurdles in their lives. However, the availability of treatment and the health improvements that resulted allowed participants a second chance at life. Participants were eager to move past their illness, and rebuild their lives.

For the last two decades, western researchers have framed HIV as a manageable chronic condition. In high income settings this has largely been true. Yet in low and middle income settings, where access to reliable health care in general and ART in particular has been limited, HIV has typically remained an acute and poorly managed issue (Kendall & Hill, 2010; McGrath et al., 2014; Scandlyn, 2000). For rural patients in particular, accessing both care and treatment can be difficult (Kipp et al., 2010). It was only with the introduction of the CBART program in 2006 that study participants were able to reliably access ART. Traditionally, research and resources in sub-Saharan Africa have focused largely on the immediate need to increasing ART availability, through efforts such as establishing and strengthening drug distribution systems, training and education programs, and counseling and monitoring systems. Comparatively little attention has been paid to understanding or addressing the economic and social challenges PLWHA continue to face, once the immediate risk of death has passed (Russell et al., 2007). However, as ART rollouts continue and access to treatment expands, understanding these issues and how patients adapt to HIV as a chronic condition is becoming increasingly relevant.

With temporary, acute illnesses, patients will alternate between a ‘sick role’ and a ‘normal role’ (McGrath et al., 2014). During a period of illness, patients are relieved of their normal responsibilities while they focus on recovery. There is an expectation that normal functioning will resume, and when it does, the individual resumes their former roles and duties. With chronic conditions however, pre-illness conditions never return. Patients can claim neither to be ‘sick’ nor ‘normal’. Instead, the shift from acute to chronic disease presents a new role entirely, that of ‘being sick while normal’ (McGrath et al., 2014). For HIV-infected patients, physical symptoms resolve and good health returns with ART. However, patients must continue to engage in many of the health-seeking behaviours they did while in the acute stage, such as adhering to drug regimes, monitoring disease progression, and being mindful of diet and physical exertion.

Managing any chronic condition in rural Africa is difficult (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). In order for patients to control their illness effectively, it is imperative that they both recognize the lifelong nature of their disease and commit to integrating disease management into their day-to-day lives (McGrath et al., 2014). This transition of incorporating the illness, its treatment, and its various lifestyle accommodations into everyday life often requires that the patient develop a new or adjusted identity that includes these attributes. This is not a passive transition, but rather an active process, that occurs as patients adjust their lives to fit their new reality (Kralik, 2002; Pierret, 2007). Through active coping strategies, such as returning to work or engaging in community activities, patients are able to regain a sense of order and control over their lives, and develop these new identities (Russell & Seeley, 2010).

With ART becoming increasingly accessible and the treatment guidelines becoming more inclusive, a growing proportion of PLWHA in sub-Saharan Africa now have the opportunity to rebuild their lives despite this once terminal diagnosis (Matovu & Hemmingsson, 2012; Wouters & De Wet, 2015). While access to ART can dramatically reduce mortality and morbidity among those receiving treatment, considerable challenges remain (Russell et al., 2007). ART cannot directly address economic difficulties or challenging social relationships. However, it does provide a means to counteract some of these processes by improving physical health, appearance, and life expectancy. Restored health enables people to return to work, reengage with family, and participate in social activities.

Recovery of health on ART has significant implications for patients' social and economic lives. This in turn, has significant effects on their identity, and their sense of self. Adjustment to life on ART still poses significant medical, economic, and social challenges for patients, but also brings about new outlooks, new personal aims, and new social roles as patients develop new hope for life and the future (Russell, Seeley & Whiteside, 2010).

Study participants repeatedly indicated that while their HIV status was a serious condition that required careful management, they were cautiously optimistic that they could live a long life with it. Similarly, while participants acknowledge being ostensibly ill with HIV at all times, they only really felt ill when they were physically symptomatic, either from AIDS or another illness. Wouters and De Wet (2015) noted similar outcomes in a cohort of South African women.

As has been previously noted in the literature, returning to their old lives was frequently not possible for participants (Seeley & Russell, 2010). In fact, all study participants needed to make some accommodations for their changed health status. However, most participants found they were able to adjust and adapt their behaviour, and build lives with purpose. Participants were keen to engage with the world around them in meaningful ways; so long as this was possible, they felt ‘normal’ (Medely et al., 2009).

5.1 Return to Work

Russell and Seeley (2010) have suggested that returning to work serves as a key means by which patients are able to begin restoring order and control to their lives. This was readily evident in my study population. Returning to work allowed participants to resume their expected roles. It provided participants the opportunity to engage with family and community members as equals. Most importantly, returning to work allowed participants to earn income again, and thus increase their independence. Being less dependent on others was an important step in adapting to life on ART. Creating budgets and initiating new income generating activities gave participants an opportunity to take back control of their situation. Being able to plan and work for themselves and their families gave participants comfort and improved their self-esteem. Contributing to the household income was considered a key indicator for what it meant to be a partner, a parent, and an adult. By returning to work, participants were able to begin reclaiming these elements of their identity.

Participants often framed the burden of HIV in terms of economic costs; both in terms of the increased financial costs necessary to protect their health, as well as the loss of income from their reduced physical strength. Participants cited financial problems and the desire to reestablish the household economy as their greatest concern. Given participants' baseline poverty, as well as the lack of government support structures, it is not surprising that returning to work was so highly valued. Previous studies in similar contexts have shown that as patients adjust to life on ART, financial and economic challenges are their biggest concern (McGrath et al., 2014; Wouters & De Wet, 2015). Where subsistence farming constitutes a large proportion of the household food, the economic necessity of returning to work is strongly felt (Kaler et al., 2010; Russell & Seeley, 2010). Returning to work, however, was not as straightforward as simply resuming their pre-infection duties. The work capacity of PLWHA is consistently less than it was before they became ill, a reality that has been observed across a variety of populations (Amoran et al., 2014; Kaler et al., 2010; Ngo et al., 2013; Wagner et al., 2009). Even after many years on treatment, this remained an issue for my study participants. Participants were still unable to work as many hours or engage in as physically taxing work as they were before they fell ill.

This decrease in work capacity was met with a concurrent increase in participants' sense of urgency to provide for their family. It was important to participants that their family have the means to care for themselves, even if the participant were to die. Participants had a heightened awareness of how quickly one's health status can change and wanted to prepare for their family's future while their health remained strong. This was a novel finding that the PI did not find reported in the current literature. While it was expected that people on treatment would return to work as their health improved, the participants' desire to establish themselves and provide for their future and that of their children was less predictable. This increased urgency to establish the family combined with decreased income earning potential only increased the degree to which their current income fell short.

Adapting to meet their changing needs was challenging for participants. However, while Larson and colleagues (2008) found that PLWHA were forced to take on lower paying work as a result of their reduced physical functioning, my study suggests that over time some PLWHA are able to begin new higher-income generating activities to help compensate. While the process was slow, and at times difficult, some participants were able to supplement their income with new side projects, particularly with the addition of animals. These projects were further complemented by changes in spending habits, which helped participants to curtail the effects of their reduced income. As a result, while physical work capacity was reduced, some participants were generally still able to earn sufficient income to meet their needs.

As has been previously noted however, beginning new income generating projects can be very difficult without external assistance (Holmes et al., 2009; McGrath et al., 2014; Russell & Seeley, 2010). This was a common challenge for participants. While some participants had managed to successfully obtain the necessary funds to begin their projects, lack of start-up capital was a common difficulty. Amongst those who were successful, projects typically progressed slowly, as participants were dependent on a good growing season and few other expenses in order to pursue the activity. By contrast, a poor growing season or unexpected need could halt a project, if funds needed to be reallocated elsewhere. Russell and Seeley (2010) have noted that uncontrollable events, like poor weather and harvests, can significantly disrupt patients' progress in rebuilding their lives, and in so doing, demoralize patients, undermine their motivation to cope, and thus threaten their ability to adapt to life with HIV. Participants repeatedly expressed interest in new income generating opportunities, but were reluctant to invest their limited assets in ventures that may fail. Low-risk options would be beneficial in helping patients adjust to their new work capabilities.

These challenges notwithstanding, some participants were successfully implementing a variety of projects. Participants' experiences living with HIV reflected both a renewed hope for the future, but also a degree of uncertainty. Participants were cautiously optimistic, both working hard to establish themselves now because the future is uncertain, while at times still hopefully planning longer-term projects for a more positive future. This duality, of trying to both live in the moment, but not forsake the future has been observed among other PLWHA (Russell & Seeley, 2010). As my study participants' activities progressed, they were able to buy land and build homes, send their children to school, and begin new work ventures. Participants were able to regain their independence and grow their families' wealth. While these endeavors took considerable time and effort, they were not impossible, as has been previously suggested (Wagner et al., 2009). Furthermore, as time progressed some participants began to shift away from projects initiated for financial necessity, and towards ones pursued for personal preference. In these cases, participants had achieved financial security, and were now interested in projects that would offer them more comfort.

Certain economic difficulties remained, particularly with regards to affording to eat a balanced diet year-round. Food insecurity is a challenge among rural Ugandan subsistence farmers, regardless of HIV status. Food costs in Uganda have significantly increased in recent years. In 2011, the annual food crop inflation was 29.1% and the Food Prices Index increased 32% nationwide (Uganda Bureau of Statistics, 2012; quoted in McGrath et al., 2014). However, for PLWHA, food insecurity provides additional challenges. It has been observed in other studies that economic difficulties, and the food insecurity that results, can give rise to non-adherence issues (Russell et al., 2007). In interviews with health care workers, Wekesa and Coast (2013) identified the side-effects of taking ART on an empty stomach lead those without food to skip their medication. They also found that concerns over food security prevented some PLWHA from starting treatment entirely. As my study participants were recruited from successful participants in the CBART program, all displayed good drug adherence (Kipp et al., 2012). However, given the need for high adherence to ART, as well as the desire to start eligible patients on treatment, it is important to ensure patients are able to meet these basic needs. While better health and work meant that all participants had improved their economic situation, the routine concerns and difficulties of living in poverty and struggling to earn a living in a resource poor setting remained.

5.2 Social Relationships

ART allows patients to return to work and their day-to-day activities. In so doing, it can strengthen a patient's sense of identity and self-worth, as well as their social relationships. As patients resume their social roles in supporting the family, they are able to restore these social relationships (Wekesa & Coast, 2013). Previous research conducted with the CBART population (Bedingfield, 2008) indicated that family difficulties and conflict due to HIV can persist, even after six to 12 months on treatment. By contrast, my research suggested that after several years on treatment, HIV-related disputes were no longer a pressing issue. Throughout their interviews, participants frequently expressed the desire to engage with people 'normally'. Once participants' health returned, they were eager for their social relationships to shift from patient-caregiver dynamics to more traditional ones. To this end, the majority of participants had been willing to forgive those with whom they had had conflicts. Similarly, participants who had previously avoided community gatherings were once again able to engage with their friends and neighbours in meaningful ways. Occasionally, in relationships that were deemed too toxic, participants elected to cut ties instead. No one, however, had ongoing disputes related to their HIV-status.

Getting back to normal was less challenging for participants with good social support. For those with supportive friends and family, as ART restored their health, they were able to return to a social environment that was very similar to their life before HIV. By contrast those with less social support often had to develop new social circles and support systems. For some participants, this need arose after relationships ended as a result HIV; either due to conflict and abandonment or AIDS-related deaths. For others adhering to ART meant avoiding certain social activities, such as drinking, thus limiting interactions with certain friends. Supporting patients as they make these necessary social adjustments is important, as a return to their previous 'normal' activities would be detrimental for their health (Seeley & Russell, 2010; Ware et al., 2006).

It has previously been theorized that community acceptance for ART patients will increase as the patient's health improves and they are no longer perceived as inevitably dying (Kaler, Alibhai, Kipp, Rubaale, et al., 2012). My participants' experiences reflected this, with social relationships normalizing as participants' symptoms abated and they were able to once again participate in routine activities. Additionally, participants' return to health offered them the opportunity to end relationships as well. Participants on treatment now had the social freedom to choose either to reconcile with people who had treated them badly as a result of their illness, or to leave those people entirely.

The value of social support for PLWHA has been well documented (Martin et al., 2013; Medley et al., 2009). Social networks provide patients with support and help navigating the psychological distress that can arise from HIV-infection (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). They play an important role in helping patients to create and maintain a new identity with HIV, and to 'live positively' (Wekesa & Coast, 2013). Social support groups also facilitate retention in care and adherence to ART (Ware et al., 2009). HIV post-test clubs in particular have been heralded as a valuable, and almost critical, resource for helping patients to adjust to life with HIV (Seeley & Russell, 2010; Weseka & Coast, 2013). My study participants deeply valued the support offered to them by other PLWHA and considered it a key element in adapting to life with HIV. Having other PLWHA to talk to, to share challenges with, and to seek advice from helped participants to feel that they were not alone in dealing this issue. These connections helped participants to regain strength and hope. Participants would often describe their HIV-positive network as being 'like family'. Interestingly however, few had been involved with organized social support groups. Rwimi had once hosted a post-test club as a means of offering support to patients in the area, however it had subsequently collapsed. Few of my study participants had been members, and interest in re-establishing such a group was minimal. Instead, participants seem to have been able to successfully carve out their own social support network from patients they met at the health clinic.

For many, there was now a desire to educate and inform others about HIV/AIDS. Helping newly diagnosed PLWHA was considered important. This reaction has been observed in both high and low income settings (Derlega, Winstead Greene, Serovich, &

Elwood, 2004; Russell & Seeley, 2010; Wekesa & Coast, 2013). By helping others in their community, participants were able to incorporate their HIV status into their identity in a manner that was not entirely negative. While they are still HIV-positive, they are able to offer insight and help to others because of it. They became HIV experts. They became counselors and advisors to family, friends, and the wider community. Being able to support their community in this way gave participants a sense of purpose, and provided participants with greater order and control over their lives. Participants felt valuable and useful, and were proud of the assistance they provided. Kielmann and Cataldo (2010) have discussed the value added to organizations by including PLWHA in their efforts, but the value this adds to the lives of the volunteers as well should not be forgotten. The rise of the 'expert patient' provides PLWHA the opportunity to forge new individual and group identities as responsible patients and public health citizens (Kielmann & Cataldo, 2010).

It is worth noting that in an income-poor environment where many struggle to make ends meet, rebuilding social relationships is also an essential means of survival (Seeley & Russell, 2010). Family and friends provide not only emotional support, but also financial support in times of need. As has been previously noted, the safety net provided by extended family has been eroded in the face of HIV/AIDS (Dawson, 2013; Muriisa & Jamil, 2011). However, with ART and the health improvements that result, patients and families are able to rebuild these relationships.

5.3 Attitudes Towards Reproduction

As participants began to forge new lives for themselves on ART they were able to create new work and social routines that, while perhaps different for them personally, still reflected typical Ugandan values and social norms. By and large, their work and social activities were characteristically ‘normal’, and did not differ significantly from the general population. By contrast, participants’ attitudes and beliefs with regards to child-bearing were markedly different for people living with HIV than for those who are HIV-negative. Despite participants’ successful reintegration into regular life, all now expressed a belief that PLWHA should limit their number of children.

For many people, a key component of a ‘normal life’ includes childbearing (McGrath et al., 2014). The role of parenthood in identity has been well established. Pregnancy, childbearing, and motherhood are often integral parts of the female identity, and symbolically significant (Wouters & De Wet, 2015). Women often face pressure from men to have children to strengthen the relationship and provide heirs. Similarly, men feel pressure to expand and grow the family line (Barnett & Whiteside, 2002). My study participants reiterated many of these views, with some going so far as to suggest a life without children would be worthless. That participants placed great value on parenthood cannot be questioned. Thus by disrupting an individual’s sexual and reproductive life, HIV can severely affect an individual’s identity and sense of self.

Reproductive decision making was viewed as a complex issue by study participants. PLWHA face a wide range of competing pressures, from the inherent social rewards of childbearing to the challenges of poverty and the potential risk of illness. With an overall fertility rate of 6.2 children per woman, large families are typical in Uganda (UNICEF, 2012). It is both the desire and expectation that one will have many children. This is particularly true in rural communities. However, participants were also acutely aware of the risks involved with child-bearing. There are increased physical health risks, for both mother and child. Living with HIV meant additional challenges to parents' ability to care for their children. PLWHA face tradeoffs between caring well for themselves and their family, or expanding their family size, with limited financial ability to do both. Transmission reduction strategies also discouraged reproduction. When presented with these realities, participants claimed a more moderate position was best: a small family size, which offers both the opportunity to parent, as well as some risk reduction.

Studies examining the reproductive goals of PLWHA have seen mixed results. Decreased fertility desire has been noted previously in a number of studies (Heys et al., 2009; Johnson et al., 2009), however other research has suggested that with access to ART, it might increase again (Maier et al., 2009; Myer et al., 2010). Almost all my participants on long-term ART claimed they personally wished to stop producing children. While their personal decisions were likely affected by other factors as well, such as age, my study participants also consistently expressed a belief that HIV-positive individuals should have fewer children, if any, than HIV-negative individuals. Regardless of their income or family support, PLWHA were presented as being less able to care and provide for their children. It has been noted in previous research however, that a claimed intention to restrict family size is not necessarily as hard and fast as it might appear (Kaler, Alibhai, Kipp, Konde-Lule, et al., 2012). Individuals may state a desire to cease childbearing and yet make no effort to prevent pregnancy. Given the many conflicting desires PLWHA face with regards to child-bearing, it is important to remember that an ‘unplanned’ pregnancy is not inherently an ‘unwanted’ one.

While the overwhelming majority of my study participants expressed being content with their current number of children, there were two participants who were actively choosing to reproduce. These participants were both younger in age and newly married. Creating a family together was viewed as important to both participants. It is interesting to note that while they were actively interested in reproducing, there was some reluctance to seek out medical advice. Some participants claimed that health care workers strongly discouraged PLWHA from having children, which may explain some of hesitation exhibited with regards to seeking care.

With ART, the future opportunities of PLWHA can change, including those related to reproductive health. However, despite the availability of drugs to prevent mother-to-child transmission, some patients still feel forced to abandon the notion of having children because of their HIV status (Wouters & De Wet, 2015). It is important that health services professionals support the choice of PLWHA to pursue their fertility goals, while minimizing transmission risk. As has been noted previously, PLWHA would benefit from counseling that addresses sexuality as a whole, not simply risk reduction, as is often the case (Wekesa & Coast, 2013).

5.4 Strengths & Limitations of the Study

There were a number of methodological strengths to this study. Participants were recruited into the study using purposeful selection. This maximized variability across important demographic characteristics and diversity of experiences. Prior to data collection, the interview guide was discussed with the Ugandan research team to ensure that all questions were clear and culturally appropriate. The first few interviews were then spaced far apart and served as pilot tests for the interview guide. Throughout the data collection process, interviews were translated and transcribed quickly to allow for ongoing adjustments to the interview guide. In order to enhance their interviewing skills, RAs received training that included mock interviews, lessons in probing, and sensitivity training for handling distress prior to beginning data collection. To maximize participant comfort and openness, interviews were conducted by local RAs, in the local language. The PI was absent from most interviews in order to minimize any social desirability bias her presence might introduce. Multiple interviews were conducted with tailored interview guides that allowed for clarification of previous answers and exploration of topics not previously discussed.

There were a number of limitations in my study as well. My study participants were recruited from successful patients in the CBART program. This sample is unlikely to be representative of all PLWHA in this setting, as many do not go for testing, access treatment, or survive (Russell & Seeley, 2010). Patient groups who do not initiate treatment, do not adhere to treatment, or who refuse to participate in a research study might have different illness experiences. Furthermore, while my participants were purposefully selected for a variety of characteristics, there are certain groups who were either underrepresented or missed entirely. Only one participant who was single (never married) was recruited into my study. Only one Muslim participant was recruited. There were no participants under the age of 35 years. It is not unlikely that these demographic groups would have different concerns than those raised by my study participants.

There is also a risk that participants may provide inaccurate information, either deliberately or inadvertently. The majority of CBART patients are very grateful for the opportunity to participate in the program, which may limit their willingness to speak negatively about it. There is also a local belief that negative thoughts can cause physical harm, which could prevent participants from revealing the full extent of their difficulties (Bedingfield, 2008). By contrast, there is also the potential for some participants to exaggerate their difficulties in the hopes of securing additional support (Bedingfield, 2008). Detailed field notes of the interviews and discussions with the research team were used in an attempt to evaluation participant reliability, but their effectiveness is uncertain.

Finally, the PI on this project is foreign born. She comes to this study with her own biases and assumptions which could impact her understanding of the issues and their significance. While she consulted with local advisors in Uganda, as well as Canadian researchers familiar with the Ugandan context, her understanding remains limited. Her absence from most interviews, while considered important for patient comfort, also limited her ability to become more sensitized with the context and the research setting. As she is unfamiliar with the local language, interviews for this study were translated into English for analysis. While care was taken to ensure the content was translated accurately, subtle nuances of language were undoubtedly lost.

As the number of PLWHA on ART increases, my study participants will become less representative of those initiating treatment. My study participants began ART at a time when accessing treatment in rural communities was difficult. As a result, most participants had progressed to active AIDS disease, and had been sick for a considerable period of time before obtaining treatment. This extended period of illness depleted household assets, strained family relationships, and caused permanent physical damage. With improved access to testing and treatment, PLWHA are now able to start treatment earlier. For patients who are able to initiate treatment before their physical health deteriorates, many of the financial and social implications of HIV will be reduced.

6. Conclusion

An HIV diagnosis, particularly in a low or middle income setting, is often framed as an overwhelming obstacle, if not a death sentence. While participants clearly faced many challenges related to their health status, my study participants were largely able to adjust and adapt to life with HIV. Provision of ART was critically important, as participants would not have otherwise been able to afford treatment. However, while access to ART was the starting point for rebuilding lives, participants' experiences involve much more change than simply improved CD4 count or decreased viral load. The challenges of rebuilding economic livelihoods and social relationships affected by HIV were considerable, and often required significant changes in participants' lifestyles.

This study highlights that while ART can significantly increase life expectancy, many physical and psychosocial challenges remain. PLWHA require more than the provision of ART alone to rebuild their lives. Participants need financial and social support to help adjust and create a new sense of 'normal'. These are complex issues without easy solutions. This study identified several ways to help support participants' non-medical needs as they adapt to their lives on ART, though implementation of these recommendations may be limited by practical difficulties inherent in the context of a low-income setting.

1) ART programs need to include financial assistance and support for income generating programs, in addition to drug delivery. By seeking partnerships with organizations that provide financial and social support, ART programs can better help PLWHA to reestablish themselves, and recover from the financial difficulties caused by their illness.

2) Peer counselling and support should be facilitated for PLWHA in order to help them to adapt and live positively with HIV. As the post-test club was not particularly well received by the CBART population, further research to understand why could be useful in helping develop a more appropriate program. Research into less formal support organizations could also offer alternative approaches to providing these services. Given the pride participants took in their ability to offer knowledge and support to recently diagnosed PLWHA, it is possible that increased inclusion of patients into informal community support and outreach programs could benefit all parties involved.

3) It is important that patients be encouraged to seek out PMTCT care if choosing to reproduce. Counseling must be expanded beyond safer sex and family planning messages to include options for safe and healthy reproduction. Further research to determine both health workers' attitudes towards child-bearing among PLWHA, and patients' perceptions of health worker's attitudes could help identify how best to address this issue.

References

Alibhai, A. J., Martin, L., Kipp, W., Konde-Lule, Saunders, D., Rubaale, L., . . . Okech-Ojony, J. (2010). Quality of life of HIV patients in a rural area of western Uganda: Impact of a community-based antiretroviral treatment program. *Current HIV Research, 8*(5), 370-378.

Amoran, O. E., Sholeye, A. O., Salako, A. A., & Fatungase, O. M. (2014). Determinants of self-reported health related quality of life among people living with HIV/AIDS attending clinic in a tertiary hospital in Sagamu, south-western Nigeria. *British Journal of Applied Science & Technology*, *4*(8), 1296.

Andresen, E. M., & Meyers, A. R. (2000). Health-related quality of life outcomes measures. *Archives of Physical Medicine and Rehabilitation, 81*, S30-S45.

Awolude, O., Oladokun, A., Adesina, O., Adewole, I., & Okunlola, B. (2009). O69 Fertility desire and unsafe sexual practice among people living with HIV. *International Journal of Gynecology & Obstetrics*, *107*, S112-S113.

Bajunirwe, F., Tisch, D. J., King, C. H., Arts, E. J., Debanne, S. M., & Sethi, A. K. (2009). Quality of life and social support among patients receiving antiretroviral therapy in Western Uganda. *AIDS Care*, *21*(3), 271-279.

Barnett, T., & Whiteside, A. (2002). *AIDS in the twenty-first century: Disease and globalization* (2nd ed.). Basingstoke, UK: Palgrave Macmillan.

Beard, J., Feeley, F., & Rosen, S. (2009). Economic and quality of life outcomes of antiretroviral therapy for HIV/AIDS in developing countries: A systematic literature review. *AIDS Care*, *21*(11), 1343-1356.

Bedingfield, N. J. (2008). *The psychosocial impact of highly active antiretroviral therapy on patients and caregivers in western Uganda: A qualitative study* (Master's Thesis). Retrieved from ProQuest Dissertations & Theses Global (304435755).

Berhan, Y., & Berhan, A. (2013). Meta-analyses of fertility desires of people living with HIV. *BMC Public Health*, *13*(1), 409.

Bor, J., Tanser, F., Newell, M. L., & Bärnighausen, T. (2012). In a study of a population cohort in South Africa, HIV patients on antiretrovirals had nearly full recovery of employment. *Health Affairs*, *31*(7), 1459-1469.

Braitstein, P., Brinkhof, M. W., Dabis, F., Schechter, M., Boulle, A., Miotti, P., . . . Bangsberg, D. R. (2006). Mortality of HIV-1-infected patients in the first year of antiretroviral therapy: Comparison between low-income and high-income countries. *The Lancet*, *367*(9513), 817-824.

Brinkhof, M. W., Boulle, A., Weigel, R., Messou, E., Mathers, C., Orrell, C., . . . International epidemiological Databases to Evaluate AIDS (IeDEA). (2009). Mortality of HIV-infected patients starting antiretroviral therapy in sub-Saharan Africa: Comparison with HIV-unrelated mortality. *PLoS Med*,*6*(4), 1-10.

Chang, L. W., Alamo, S., Guma, S., Christopher, J., Suntoke, T., Omasete, R., . . . Reynolds, S. J. (2009). Two year virologic outcomes of an alternative AIDS care model: Evaluation of a peer health worker and nurse-staffed community-based program in Uganda. *Journal of Acquired Immune Deficiency Syndromes*, *50*(3), 276-282.

Dawson, H. (2013). HIV/AIDS, the erosion of social capital and the collapse of rural livelihoods in the Nkomazi district of South Africa. *African Journal of AIDS Research*, *12*(4), 185-194.

Derlega, V. J., Winstead, B. A., Greene, K., Serovich, J., & Elwood, W. N. (2004). Reasons for HIV disclosure/nondisclosure in close relationships: Testing a model of HIV–disclosure decision making. *Journal of Social and Clinical Psychology*, *23*(6), 747-767.

Dybul, M., Fauci, A. S., Bartlett, J. G., Kaplan, J. E., & Pau, A. K. (2002). Guidelines for using antiretroviral agents among HIV-infected adults and adolescents: The panel on clinical practices for treatment of HIV*. *Annals of Internal Medicine*, *137*(5Part2), 381-433.

Epping-Jordan, J. E., Pruitt, S. D., Bengoa, R., & Wagner, E. H. (2004). Improving the quality of health care for chronic conditions. *Quality and Safety in Health Care*, *13*(4), 299-305.

Habte, D., & Namasasu, J. (2015). Family planning use among women living with HIV: Knowing HIV positive status helps-results from a national survey. *Reproductive Health*, *12*(1), 41.

Heys, J., Jhangri, G., Rubaale, T., & Kipp, W. (2012). Infection with the human immunodeficiency virus and fertility desires: Results from a qualitative study in rural Uganda. *World Health & Population*, *13*(3), 5-17.

Heys, J., Kipp, W., Jhangri, G. S., Alibhai, A., & Rubaale, T. (2009). Fertility desires and infection with the HIV: Results from a survey in rural Uganda. *AIDS*, *23*, S37-S45.

Holmes, K., Winskell, K., Hennink, M., & Chidiac, S. (2011). Microfinance and HIV mitigation among people living with HIV in the era of anti-retroviral therapy: Emerging lessons from Côte d'Ivoire. *Global Public Health*, *6*(4), 447-461.

Jensen-Fangel, S., Pedersen, L., Larsen, C. S., Tauris, P., Møller, A., Sørensen, H. T., & Obel, N. (2004). Low mortality in HIV-infected patients starting highly active antiretroviral therapy: A comparison with the general population. *AIDS*, *18*(1), 89-97.

Jhangri, G. S., Heys, J., Alibhai, A., Rubaale, T., & Kipp, W. (2012). Unmet need for effective family planning in HIV-infected individuals: Results from a survey in rural Uganda. *Journal of Family Planning and Reproductive Health Care*, *38*(1), 23-29.

Johnson, K. B., Akwara, P., Rutstein, S. O., & Bernstein, S. (2009). Fertility preferences and the need for contraception among women living with HIV: The basis for a joint action agenda. *AIDS*, *23*, S7-S17.

Jury, C., & Nattrass, N. (2013). Parental presence within households and the impact of antiretroviral therapy in Khayelitsha, Cape Town. *Southern African Journal of HIV Medicine*, *14*(2), 70-74.

Kaler, A., Alibhai, A., Kipp, W., Konde-Lule, J., & Rubaale, T. (2012). Enough children: Reproduction, risk and “unmet need” among people receiving antiretroviral treatment in western Uganda. *African Journal of Reproductive Health*, *16*(1), 133-134.

Kaler, A., Alibhai, A., Kipp, W., Rubaale, T., & Konde-Lule, J. (2010). “Living by the hoe” in the age of treatment: Perceptions of household well-being after antiretroviral treatment among family members of persons with AIDS. *AIDS Care*, *22*(4), 509-519.

Kaler, A., Alibhai, A., Kipp, W., Rubaale, T., & Konde-Lule, J. (2012). Walking corpses and kindly neighbours: Retrospective accounts of AIDS stigma in western Uganda. *World Journal of AIDS*, *2*(3), 174.

Kalichman, S. C., DiMarco, M., Austin, J., Luke, W., & DiFonzo, K. (2003). Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behavioral Medicine*, *26*(4), 315-332.

Kendall, C., & Hill, Z. (2010). Chronicity and AIDS in three South African communities. *Chronic conditions, fluid states: Chronicity and the anthropology of illness* (pp. 175-194). Piscataway, NJ: Rutgers University Press.

Kielmann, K., & Cataldo, F. (2010). Tracking the rise of the “expert patient” in evolving paradigms of HIV care. *AIDS Care*, *22*(S1), 21-28.

Kipp, W., Heys, J., Jhangri, G. S., Alibhai, A., & Rubaale, T. (2011). Impact of antiretroviral therapy on fertility desires among HIV-infected persons in rural Uganda. *Reproductive Health*, *8*(1), 27-37.

Kipp, W., Konde-Lule, J., Saunders, L. D., Alibhai, A., Houston, S., Rubaale, T., . . . Kiweewa, F. (2010). Results of a community-based antiretroviral treatment program for HIV-1 infection in Western Uganda. *Current HIV Research*, *8*(2), 179-185.

Kipp, W., Konde-Lule, J., Saunders, L. D., Alibhai, A., Houston, S., Rubaale, T., ... & Okech-Ojony, J. (2012). Antiretroviral treatment for HIV in rural Uganda: Two-year treatment outcomes of a prospective health centre/community-based and hospital-based cohort. *PloS One*, *7*(7), e40902.

Kobau, R., Sniezek, J., Zack, M. M., Lucas, R. E., & Burns, A. (2010). Well-being assessment: An evaluation of well-being scales for public health and population estimates of well-being among US adults. *Applied Psychology: Health and Well-Being*, *2*(3), 272-297.

Koenig, S. P., Leandre, F., & Farmer, P. E. (2004). Scaling-up HIV treatment programmes in resource-limited settings: The rural Haiti experience. *AIDS*, *18*, S21-S25.

Kralik, D. (2002). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, *39*(2), 146-154.

Larson, B. A., Fox, M. P., Margaret, B. I. I., Rosen, S., Julia, R. O. H. R., Shaffer, D., . . . Simon, J. L. (2013). Antiretroviral therapy, labor productivity, and gender: A longitudinal cohort study of tea pluckers in Kenya. *AIDS, 27*(1), 115.

Larson, B. A., Fox, M. P., Rosen, S., Bii, M., Sigei, C., Shaffer, D., . . . Simon, J. L. (2008). Early effects of antiretroviral therapy on work performance: Preliminary results from a cohort study of Kenyan agricultural workers. *AIDS*, *22*(3), 421-425.

Maier, M., Andia, I., Emenyonu, N., Guzman, D., Kaida, A., Pepper, L., . . . Bangsberg, D. R. (2009). Antiretroviral therapy is associated with increased fertility desire, but not pregnancy or live birth, among HIV+ women in an early HIV treatment program in rural Uganda. *AIDS and Behavior*, *13*(1), 28-37.

Martin, F., Kiwanuka, T., Kawuma, R., Zalwango, F., & Seeley, J. (2013). Tasks and strategies of self-management of living with antiretroviral therapy in Uganda. *AIDS Patient Care and STDs*, *27*(12), 697-706.

Martin, F., Russell, S., & Seeley, J. (2014). Higher quality of life and lower depression for people on ART in Uganda as compared to a community control group. *PloS One*, *9*(8), e105154.

Matovu, S. N., & Hemmingsson, H. (2012). Narratives of Ugandan women adhering to HIV/AIDS medication. *Occupational Therapy International*, *19*(4), 176-184.

Mayan, M. J. (2009). *Essentials of qualitative inquiry*. Walnut Creek, USA: Left Coast Press.

McGrath, J. W., Winchester, M. S., Kaawa-Mafigiri, D., Walakira, E., Namutiibwa, F., Birungi, J., . . . Ayebazibwe, N. (2014). Challenging the paradigm: Anthropological perspectives on HIV as a chronic disease. *Medical Anthropology*, *33*(4), 303-317.

Medley, A. M., Kennedy, C. E., Lunyolo, S., & Sweat, M. D. (2009). Disclosure outcomes, coping strategies, and life changes among women living with HIV in Uganda. *Qualitative Health Research*, *19*(12), 1744-1754.

Mûnene, E., & Ekman, B. (2014). Does duration on antiretroviral therapy determine health-related quality of life in people living with HIV? A cross-sectional study in a regional referral hospital in Kenya. *Global Health Action*, *7*. doi: http://dx.doi.org/10.3402/gha.v7.23554

Muriisa, R. K., & Jamil, I. (2011). Addressing HIV/AIDS challenges in Uganda: Does social capital generation by NGOs matter? *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *8*(1), 2-12.

Murri, R., Fantoni, M., Del Borgo, C., Visona, R., Barracco, A., Zambelli, A., . . . Wu, A. W. (2003). Determinants of health-related quality of life in HIV-infected patients. *AIDS Care*, *15*(4), 581-590.

Mwesigire, D. M., Wu, A. W., Martin, F., Katamba, A., & Seeley, J. (2015). Quality of life in patients treated with first-line antiretroviral therapy containing nevirapine or efavirenz in Uganda: A prospective non-randomized study. *BMC Health Services Research*, *15*(1), 1.

Myer, L., Carter, R. J., Katyal, M., Toro, P., El-Sadr, W. M., & Abrams, E. J. (2010). Impact of antiretroviral therapy on incidence of pregnancy among HIV-infected women in Sub-Saharan Africa: A cohort study. *PLoS Med*, *7*(2), e1000229.

Ndou, T. V., Risenga, P. R., & Maputle, M. S. (2013). Experiences of HIV positive patients on ARV treatment at the Thulamela Municipality in the Vhembe District of Limpopo Province, South Africa. *Journal of Antivirals & Antiretrovirals*, *5*(5), 123-131.

Ngo, V. K., Wagner, G. J., Huynh, A., Ryan, G., & Musisi, S. (2013). A qualitative analysis of the effects of depression and antidepressants on physical and work functioning among antiretroviral therapy clients in Uganda. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*,*12*(6), 414-422.

Pierret, J. (2007). An analysis over time (1990–2000) of the experiences of living with HIV. *Social Science & Medicine*, *65*(8), 1595-1605.

Rosen, S., Larson, B., Brennan, A., Long, L., Fox, M., Mongwenyana, C., . . . Sanne, I. (2010). Economic outcomes of patients receiving antiretroviral therapy for HIV/AIDS in South Africa are sustained through three years on treatment. *PLoS One*, *5*(9), e12731.

Russell, S., & Seeley, J. (2010). The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy. *Social Science & Medicine*, *70*(3), 375-382.

Russell, S., Seeley, J., Ezati, E., Wamai, N., Were, W., & Bunnell, R. (2007). Coming back from the dead: Living with HIV as a chronic condition in rural Africa. *Health Policy and Planning*, *22*(5), 344-347.

Russell, S., Seeley, J., & Whiteside, A. (2010). Expanding antiretroviral therapy provision in resource-constrained settings: Social processes and their policy challenges. *AIDS Care*, *22*(S1), 1-5.

Samji, H., Cescon, A., Hogg, R. S., Modur, S. P., Althoff, K. N., Buchacz, K., . . . Justice, A. (2013). Closing the gap: Increases in life expectancy among treated HIV-positive individuals in the United States and Canada. *PloS One*, *8*(12), e81355.

Scandlyn, J. (2000). "When AIDS became a chronic disease." *Western Journal of Medicine, 172*(2), 130-133.

Seeley, J., & Russell, S. (2010). Social rebirth and social transformation? Rebuilding social lives after ART in rural Uganda. *AIDS Care*, *22*(S1), 44-50.

Snow, R. C., Mutumba, M., Resnicow, K., & Mugyenyi, G. (2013). The social legacy of AIDS: Fertility aspirations among HIV-affected women in Uganda. *American Journal of Public Health*, *103*(2), 278-285.

Stangl, A. L., Wamai, N., Mermin, J., Awor, A. C., & Bunnell, R. E. (2007). Trends and predictors of quality of life among HIV-infected adults taking highly active antiretroviral therapy in rural Uganda. *AIDS Care*, *19*(5), 626-636.

Uganda Bureau of Statistics. (2012) *Uganda Demographic and Health Survey 2011.*Retrieved from http://ubos.org/onlinefiles/uploads/ubos/UDHS/UDHS2011.pdf

Uganda Bureau of Statistics. (2016). *The National Population and Housing Census 2014 – Main report.* Retrieved from http://www.ubos.org/2014-census/census-2014-final-results/

Uganda Government. (2005). *Uganda district information handbook*. Kampala, UGA: Foundation Publishers.

Uganda Ministry of Health. (2012) *Uganda AIDS Indicator Survey 2011*. Retrieved from http://health.go.ug/docs/UAIS_2011_REPORT.pdf

UNICEF. (2012). *UNICEF in Uganda. Keeping children alive | safe | learning.* Retrieved from www.unicef.org/uganda/UNICEF_Uganda_Keeping_Children_Alive_Safe_and_Learning_2012(1).pdf

UNAIDS. (2014a). *The gap report.* Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf

UNAIDS. (2014b). The *HIV and AIDS Uganda Country progress report; 2013.* Retrieved from http://www.unaids.org/sites/default/files/country/documents/UGA_narrative_report_2014.pdf

Van Damme, W., Kober, K., & Laga, M. (2006). The real challenges for scaling up ART in sub-Saharan Africa. *AIDS*, *20*(5), 653-656.

Vetter, C. J., & Donnelly, J. P. (2006). Living long-term with HIV/AIDS: Exploring impact in psychosocial and vocational domains. *Work*, *27*(3), 277-286.

Wagner, G., Ryan, G., Huynh, A., Kityo, C., & Mugyenyi, P. (2009). A qualitative analysis of the economic impact of HIV and antiretroviral therapy on individuals and households in Uganda. *AIDS Patient Care and STDs*,*23*(9), 793-798.

Ware, N. C., Idoko, J., Kaaya, S., Biraro, I. A., Wyatt, M. A., Agbaji, O., ... & Bangsberg, D. R. (2009). Explaining adherence success in sub-Saharan Africa: An ethnographic study. *PLoS Med*, *6*(1), 39-47

Ware, N. C., Wyatt, M. A., & Tugenberg, T. (2006). Social relationships, stigma and adherence to antiretroviral therapy for HIV/AIDS. *AIDS Care*, *18*(8), 904-910.

Weidle, P. J., Wamai, N., Solberg, P., Liechty, C., Sendagala, S., Were, W., . . . Bunnell, R. (2006). Adherence to antiretroviral therapy in a home-based AIDS care programme in rural Uganda. *The Lancet*, *368*(9547), 1587-1594.

Wekesa, E., & Coast, E. (2013). Living with HIV postdiagnosis: A qualitative study of the experiences of Nairobi slum residents. *BMJ Open*, *3*(5), e002399.

World Health Organization. (2013a). *Consolidated guidelines on general HIV care and the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach*. Geneva, SUI: WHO Press.

World Health Organization. (2013b). *Global update on HIV treatment 2013: Results, impact and opportunities.* Geneva, SUI: WHO Press.

World Health Organization. (2014). *HIV Reporting. Global health update on the health sector response to HIV.* Geneva, SUI: WHO Press.

Wouters, E., & De Wet, K. (2015). Women's experience of HIV as a chronic illness in South Africa: Hard-earned lives, biographical disruption and moral career. *Sociology of Health & Illness*, *38(*4), 521-542.

Wu, A. W. (2000). Quality of life assessment comes of age in the era of highly active antiretroviral therapy. *AIDS*, *14*(10), 1449-1451.

Wubshet, M., Berhane, Y., Worku, A., & Kebede, Y. (2014). Perception and predictors of quality of life among HIV patients attending art clinics in northwest Ethiopia: A prospective longitudinal study. *Ethiopian Medical Journal*, *52*(3), 119-127.

Appendix A. Information Letter and Informed Consent Form

MAKERERE UNIVERSITY
SCHOOL OF PUBLIC HEALTH

UNIVERSITY OF ALBERTA

Consent form for Individual Interview

Title of Research Study: Medium-term outcomes in patients on HAART in Western Uganda
Principal Investigator: Dr. L. Duncan Saunders, University of Alberta, Canada (duncan.saunders@ualberta.ca)
Co-Investigator Catherine Paulsen, University of Alberta, Canada (cpaulsen@ualberta.ca)
Uganda Researcher: Professor Joseph Konde-Lule, Makerere University, Tel: 0772-418451
Local Project Manager: Mr. Tom Rubaale, Fort Portal, Uganda, Tel: 0777-912866
Makerere University School of Public Health IRB Chair: Prof. Fred Wabwire Mangen, Tel: 0772 -732206

Study Purpose: The purpose of this study is to learn more about people's lives after they have been taking Highly Active Antiretroviral Treatment (HAART) for several years. We hope that this information will help the people who run HAART Programs to better help patients like you.

Procedure: If you join the study we will ask you some questions about your life. We would like to talk to you two different times. It will take about one and a half hours each time. If it is okay with you, we would like to tape record what is said. You can choose if you would like to talk to us at your house or in another place. If you would like to talk to us in another place, we will pay for you to get to that place. We will ask if your feeling have changed since you started the medication. We will also ask you about your worries and thoughts about the future. We would also like to know about how you spend time with other people.

Benefits: It may help you to talk about what is happening in your life. It may also help the clinic staff to help you better.

Risks: It may make you upset to think back to when you were sick or into the future when you may die. It is also possible that having stranger visit your home will may people wonder if you have HIV. We do not know of any other bad things that could happen. It is very important that you know that nothing you do in this study can affect your medication supply. If you do not participate you will still get the medications. If you say bad things about the medications or the program, you will still get the medications.

Confidentiality: To make sure your answers are kept confidential, we will:

1. Ensure that your name will not be shared by us at any time, to anyone.
2. The research team will be asked to sign a document stating that they will keep all information confidential.
3. Any reports published as a result of this study will not identify anyone by name.
4. The information provided will be kept in a safe place for at least five years after the study is done. It will be kept in a locked cabinet in the offices of Mr. Tom Rubaale in Fort Portal.

Freedom to withdraw: You do not have to participate in this study if you do not wish to. You can withdraw from the study at any time.

Contact: If you have any questions or concerns, you may contact Professor Joseph Konde-Lule at Makerere University at telephone 0414-545002 or Tom Rubaale, Project Manager in Fort Portal at 0777-912866. Concerns or questions about participant rights regarding this study can be forwarded to the Makerere University School of Public Health IRB Chair: Prof. Fred Wabwire Mangen, Tel: 0772 -732206

To be completed by the research participant:	**Yes**	**No**
Do you understand that you have been asked to be in a research study?	☐	☐
Did you receive and read the study Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable health information?	☐	☐
Who explained this study to you? ____		

I agree to take part in this study: YES ☐ NO ☐

Signature (or thumbprint) of Research Participant: ______________________________

Printed Name of Participant: ____

Date: ______________________

Signature (or thumbprint) of Witness (if available): ______________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee: ____________________ Date: __________

A COPY OF THIS DOCUMENT IS TO BE GIVEN TO THE RESEARCH SUBJECT

Appendix B. Interview Guide

(Intro & Background – Ask all participants)

Just to get to know you a little better can you tell me a little about who you live with here?

How are they related to you?

What is your occupation?

Can you tell me a story that would help us to understand how things were for you before you started taking ARV's?

Now that you've been on ARVs for several years, how are things for you?

Probe into:
reasons for their response

Do you think that your life has gone back to being the same as it was before you became sick or is it different in some ways?

Probe into:
changes in priorities for life and reasons for life being different/same

What have been the most important changes in your life since starting on ARVs?

Probe into:
Why these are important
How they've changed life

If the participant can't list anything specific, ask:

Do people treat you differently because they know you have HIV/AIDS?

Do you have concerns about accessing drugs and whether they will continue working?

Do you fear dying more than you would have if you were not HIV positive?

Are there times when you don't feel strong enough to do all the things you want to do?

Has HIV and treatment affected your financial earnings

Do you worry about your children's future (being able to provide for them/teach them/etc)?

Do you want to have more children, but worry because of HIV/AIDS?

Do you worry about HIV/AIDS in terms of love and relationships with your (husband/boyfriend/wife/girlfriend)?

Are your family relationships different, now that you're on ARVs?

How do you feel about telling family/friends about your status?

Do you think it's important to 'live positively'?

Do you find you have more hope for the future, now that you're on treatment?

Which of these has been most important to you?

Area Specific Questions:

DRUGS /TREATMENT GUIDELINES – page 2
DEATH / DYING – page 3
HOPE FOR THE FUTURE – page 3
PHYSICAL FUNCTIONING – page 3
FINANCIAL SITUATION – page 4
STIGMA / STATUS DISCLOSURE – page 4
FAMILY RELATIONSHIPS / SOCIAL SUPPORT – page 6
SEXUAL RELATIONSHIPS / FUTURE CHILDREN – page 7

(DRUGS / TREATMENT GUIDELINES)

Now that you've been on ARVs for several years, what are your thoughts about the drugs?

Probe into:
Adherence
Effectiveness of the drug
Side effects and harmful effects of drugs
On-going availability of the drugs
Future cure for HIV/AIDS

How do you think being on ARV's has changed how long you will live?

Probe into:
Number of additional years of life

Is it important for those with HIV not to worry?

Probe into:
Types of worries they have

Do you ever hear contradicting advice from the clinic staff and others (friends/family/ church group/ traditional healers) about how you should care for yourself?

Probe into:
Feelings about contradictory advice
How they decide whose advice to follow

Do you feel like you have all of the knowledge about ARV's and HIV that you need to manage your health?

If no, probe into:
knowledge they need

Do you feel like the improvement in your health could disappear at any time or do you feel that it is secure and you can rely upon your health?

If health is fragile, probe into:
Impact of fragile health on life

(DEATH & DYING)

Do you think that people with HIV die with more suffering than those without HIV?

Probe into:
Personal fear of this before ARVs and now

Now that you've been on ARVs for several years, what are your thoughts about death?

Probe into:
Frequency of thoughts of dying
Dying with family or alone
What people would think or say
Impact on family (relate to HIV/AIDS and ARVs)

(HOPE FOR THE FUTURE)

Before you started ARVs, did you feel hopeful for the future?

Explain

Now that you've been on ARVs for several years, do you feel hopeful for the future?

Explain

<u>Probe into:</u>
Activities related to hope
Impact on relationships with others

Do you have a plan about what kinds of things you would like to accomplish before you die?

<u>Probe into:</u>
Things done now to prepare
Who plan will benefit
How this will impact family
What things they feel they cannot plan or prepare for and why

(PHYSICAL FUNCTIONING)

Are you able to physically do the things you want?

<u>Probe into:</u>
What can't be done
Feelings about limitations
How limitations have affected life
Perceptions around whether limitations are temporary or permanent

Have you been able to resume your normal work and home activities?

<u>Probe into:</u>
Types of activities
Feelings about limitations
How limitations have affected life
Perceptions around whether limitations are temporary or permanent

Have you had to modify your activities (are you unable to do as much as you could before you became sick)?

<u>Probe into:</u>
Types of activities
Feelings about limitations
How limitations have affected life
Perceptions around whether modifications are temporary or permanent

Do you feel as strong/healthy as other members of your community?

Explain

Do you feel you must be extra careful to protect your health?

Probe into:
Types of extra precautions
Feelings about these extra precautions
Impact on life

(FINANCIAL SITUATION)

Has your income increased, decreased or stayed the same since starting ARVs?

Probe into:
Reasons for change
Impact on decisions and choices they've had to make
Impact on household

****If the subject has children****
How have ARVs affected your children's schooling?

Probe into:
Leaving school and returning back to school

(STIGMA / STATUS DISCLOSURE)

Can you tell me about how you experience HIV stigma in your community?

What do you think that others in the community think about people who are in treatment for HIV?

As a person living with HIV/AIDS, how do you feel about being in public? How did you feel before you started ARVs?

Is it hard sometimes?

Do you ever avoid certain activities because of the way people treat you/talk about you?

If yes, probe into:
Types of activities avoided
Feelings about avoiding activities
How avoiding activities has affected life

Are people ever unkind to your family/friends, because of your illness?

If yes, probe into:
How this is dealt with

Impact on relationships

Do many people know about your illness, or just a few?

How did they come to know about your illness?

Do you wish fewer people knew about your illness?

Why?

Do you ever have to explain to people about your illness (before ARVs)?

If you do have to explain your illness (before you started on ARV's) to others, what do you choose to tell them?

Why?

Do you think that being on drugs makes it easier to tell people that you are HIV positive?

(if yes) Why do you think these drugs give you courage to tell others about your status?

Is there a difference in telling people who you are very close with and people who you are not so close with?

How do you decide who you will tell about your HIV status and who you will not tell about your HIV status?

(If the person is open about their status) How did you find the courage to be truthful with people about your status?

Do you think that looking healthy gives you a choice about who you will tell and who you will not tell about your status?

Is this important to you?

Why is this important?

What does it mean to "live positively"?

Do you think you are an example of "living positively"?

Why?

Probe into:
Importance of being in public
Fears faced and why

Do you ever feel pressure to share your experience with others (e.g. to encourage others to get tested)?

Probe into:
Types of pressure
Feelings about this pressure
Perceived value of sharing these experiences

Thinking back to your first year on ARVs, are you more likely or less likely to disclose your HIV status now than you were then?

Explain

Do you think you have more courage because you made a choice to live with HIV and others have chosen to die rather than know their status?

Explain

(FAMILY RELATIONSHIPS / SOCIAL SUPPORT)

How do you think your HIV status affected your family?

Probe into:
Impact on family
Impact on relationship with family
Changes in impact after being on ARVs

When you were sick, who cared for you?

Probe into:
How this affected relationships with these people

Did you ever feel like a burden to your family?

Probe into:
Types of burdens
Feelings of abandonment by family

How are your family relationships now that you're on ARVs?

Explain

Probe into:
Anything that had to be done to repair relationships

Do you feel any resentment for the way your family treated you?

Explain

Does your family feel any resentment over your past need for care?

Explain

How has being on ARV's changed your interest in being around other people?

<u>Probe into:</u>
Who they now spend time with and why
New acquaintances based on experience with HIV and ARVs
How others understand their experience with HIV and ARVs
Involvement in social activities (bars, visiting neighbours, friends)
Involvement in sports
Involvement in religious activities
Involvement in volunteer activities

Are there people you no longer spend time with because of your illness?

<u>Probe into:</u>
Types of individuals and why
Feelings about this
Hope for restoring these relationships

(SEXUAL RELATIONSHIPS / FUTURE CHILDREN)

How do you feel about people on ARVs being sexually active?

What do you think about people on ARVs having more children?

<u>Probe into:</u>
Importance of having children
Appropriate number of children for a family
Perceptions of life without children

Are you currently sexually active?

<u>If no, Probe into:</u>
Interest in sexual relations
What prevents sexual activity
How this affects their life

<u>If yes, Probe into:</u>
Impact of ARVs on decision to become sexually active

Do you want (more) children?

<u>Probe into:</u>
Importance of having more children
Number of children desired
Concerns about having more children
Preparations being made to have more children

(Closing – Ask all participants)

What do you think has been the biggest challenge(s) in 'getting back to normal'?

If you could change one thing (excluding becoming disease-free), what would it be?

Do you feel like you've been able to come to terms with the disease?

Explain

Is there anything else you would like to share?

Appendix C. Field Note Collection Form

Form for the Collection of Field Notes

Date of Interview: ________________________

ID Number of Interviewee: _________________

Direction to Home:

____
____
____

Notes on Interview:

How were you received by the interviewee?

____
____
____

What was her or his demeanour in the interview? (reserved, open, shy, nervous jovial?)

____
____
____

What do you think was the most important topic that the interviewee discussed? (to the interviewee)

____
____
____
____
____
____

How could you tell that this was the most important topic to the interviewee?

____

____

____

____

Did the person become emotional at any time? (What were they talking about? What emotion were they displaying?)

____

____

____

____

How do you think the relationship is between the patient and the caregiver? Was there anything that you noticed (that was not said) that told you about the relationship?

____

____

____

____

Describe the conditions of the home (crowded, dirty, clean, what was it made of, was there furniture)

____

____

____

____

Describe the condition of the interviewee, did the person appear strong, weak, any skin rashes, what was the person doing when you arrived?

____

____

____

____

Did you have to work very hard to get the patient to talk? (If so, what did you do to get the patient to talk?)

Do you think that the person was telling any lies? ____________________________

What do you think she or he was lying about?

Why do you think that they were lying?

Do you think that the person was always telling the whole truth? Why do you think that?

Were there a lot of interruptions in the interview?

Can you describe the area where the interview took place?

Do you think that there were people around that could hear the interview?

Can you briefly summarize the important points of the interview?

(what were the comments on **emotional changes,** changes inside the **family,** how the person feels about **socializing,** how he or she deals with **stigma,** how does he or she **compare themselves to others** in the community? What are the person's **future** goals? Are there **any new problems** experienced by the interviewee because of ARV's) (Why is this the most important?)

Demographic Information:

Age: ____________________ Occupation: ___________________________________

Marital Status: ____________ Religion: _____________________________________

Number of Children: _______ Land Ownership or Rental: _______________________

Ages and Gender of Children:

____

____

____

Who do these children belong to?

____

____

Other Household Members:

____

____

Construction Material of Home: ____

Ownership of any means of Communication: (Radio, phone?): __________________________________

Ownership of any means of Transportation: ____

Ownership of Animals: ____

Researcher's Impression of Literacy Level: ____

Appendix D. Coding Framework

- 1.0 Health & Physical Functioning
  - 1.1 Changes in health
  - 1.2 Changes in strength
  - 1.3 Confidence in current health status
  - 1.4 Negative experiences of treatment
  - 1.5 Ongoing physical issues
  - 1.6 Looking good; can't tell I'm sick
  - 1.7 Feeling cured
  - 1.8 Caring for health
  - 1.9 Other
- 2.0 Death
  - 2.1 Fear of death
  - 2.2 Dying before children are self-sufficient
  - 2.3 Death is inevitable; can't control death
  - 2.4 Will not die of HIV; HIV- die while HIV+ live
  - 2.5 Increased survival; life expectancy
  - 2.6 other
- 3.0 Financial Status & Income
  - 3.1 Ability to work; hiring workers
  - 3.2 Ability to meet needs
  - 3.3 Changes in financial status
  - 3.4 Spending habits and savings
  - 3.5 Sources of income
  - 3.6 New income generating projects
  - 3.7 Concerns or goals
    - 3.7.1 Basic needs; paraffin, soap, etc
    - 3.7.2 Preparing for children's future
    - 3.7.3 Increased cost of caring for self
    - 3.7.4 Building for family
    - 3.7.5 Garden; Animals; Land
    - 3.7.6 Business; Rental property
    - 3.7.7 Emergency fund
    - 3.7.8 Other
  - 3.8 Participation in saving and credit groups
  - 3.9 Participation in National Agricultural Advisory Services group
  - 3.10 Experience with loans
  - 3.11 Desire for Assistance
  - 3.12 Crop failure

- 3.13 Other
- 4.0 Relationships & Children
  - 4.1 Relationship type
    - 4.1.1 Close family
    - 4.1.2 Extended family
    - 4.1.3 Friends
    - 4.1.4 Community
    - 4.1.5 Sexual (close)
    - 4.1.6 Sexual (casual)
    - 4.1.7 Health workers
    - 4.1.8 General
  - 4.2 Support
  - 4.3 Conflict
  - 4.4 HIV+ friends
  - 4.5 HIV- friends
  - 4.6 Engaging with others; socializing; avoiding public
  - 4.7 Involvement in clubs, community
  - 4.8 Interest in HIV group
  - 4.9 Changes in marital status
  - 4.10 Attitudes regarding sex
  - 4.11 Attitudes around reproducing; desire for children
  - 4.12 Forgiveness
  - 4.13 Other
- 5.0 Outlook & Perspective
  - 5.1 Everything is good
  - 5.2 Feeling equal to others
  - 5.3 Acceptance of HIV
  - 5.4 Openness or reservation about status disclosure
  - 5.5 Worries
  - 5.6 Moving forward; progressing in life
  - 5.7 Planning for the future; limited time; leave something behind
  - 5.8 Desire to see children grow
  - 5.9 Helping others; Being valued by the community
  - 5.10 Dedicated to god
  - 5.11 Hope
  - 5.12 Desire for cure
  - 5.13 Priorities
  - 5.14 Other
- 6.0 Modifiers
  - 6.1 Positive statement

6.2 Negative statement
6.3 Good quote
6.4 Flag