Adherence to antiretroviral therapy (ART), self-stigma and depression among people living with HIV (PLWH) in rural Zambia

ザンビア共和国農村部における HIV 陽性者の抗レトロウィルス療法に対する服薬遵守及びセルフスティグマと抑うつ症状について

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Acronyms

ACTG	AIDS Clinical Trial Group
AIDS	Acquired Immune Deficiency Syndrome
AOR	Adjusted Odds Ratio
ART	Antiretroviral Therapy
ARV	Antiretroviral
CD4	Cluster of Differentiation Four
CES-D	Center for Epidemiological Studies in Depression Scale
CI	Confidence Interval
DH	District Hospital
DMO	District Medical Office
DOT	Directly Observed Therapy
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
ICW	International Community of Women Living with HIV/AIDS
IQR	Interquartile Range
JICA	Japan International Cooperation Agency
MEMS	Medication Event Monitoring System
MoH	Ministry of Health
NAC	National HIV/AIDS/STD/TB Council
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitors
PHC	Primary Health Care
PI	Protease Inhibitor
PLWH	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
PTSD	Post-Traumatic Stress Disorder
RHCs	Rural Health Centers
SD	Standard Deviation

SHIMA	Scaling up of Quality HIV/AIDS Care Service Management
SPSS	Statistical Package for the Social Sciences
STDs	Sexual Transmitted Diseases
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations for Children Fund
VCT	Voluntary Counseling and Testing
VS	Versus
WFP	World Food Programme
WHO	World Health Organization

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Abstract

Introduction: Sustaining high levels of adherence to antiretroviral therapy (ART) is a challenge in Zambia. This study aimed to identify the factors associated with ART adherence and to examine the relationship among ART adherence, self-stigma and depressive symptoms at the early months of treatment in rural Zambia.

Method: This is a field based observational longitudinal study in Mumbwa. Treatment naïve clients aged over 15 years, who initiated ART during September-November 2010, were enrolled. Clients were interviewed at the initiation of ART and at six weeks later. Clients' self-report was used for measuring ART adherence.

Result: Of 157 clients, 59.9% were fully adherent. In multivariable analysis, full adherence was associated with being female [Adjusted odds ratio (AOR), 6.4; 95% Confidence interval (CI), 1.7-23.5], experience of food insufficiency in the previous 30 days (AOR, 5.7; 95% CI, 1.6-21.2), spouse undergoing ART (AOR, 5.4; 95% CI, 1.4-19.9), self-stigma at the initiation of ART (AOR, 0.1; 95% CI, 0.02-0.6), being more depressed (AOR, 1.1; 95% CI, 1.0-1.3) and having less self-stigma (AOR, 0.6; 95% CI, 0.5-0.9) after six weeks compared with at the initiation of ART.

Conclusion: ART adherence continues to be a significant behavioral challenge in rural Zambia. Sex, food issues, spouse's ART use and mental health issues were associated with ART adherence. These are likely the issues that ART services will need to focus on in the future beyond current efforts such as increasing accessibility by expanding mobile ART services in rural Zambia.

Key words: HIV, Antiretroviral therapy (ART), Adherence, Self-stigma, Depression

Chapter 1: Introduction

1-1. HIV epidemic in Sub-Saharan Africa and Zambia

Sub-Saharan African countries have unique characteristics related to proportion of urban to rural population, prevailing religions, ethnicities and former colonial owners. For example, ethnic groups number in the hundreds, and religious communities in most parts of northern and eastern Africa are Muslim, while in the remaining regions, Christianity is the main religion (Velayati et al., 2007).

Although the region is not monotonous, AIDS is the leading cause of death in Sub-Saharan African countries. This area contains nearly 70% of the world's HIV infections. In 2009, the average number of people living with HIV (PLWH) reached 22.5 million (20.9 million–24.2 million) (Isaakidis et al., 2010; UNAIDS/WHO, 2010; WHO, 2005).

Zambia is one of the most severely affected countries in the region. Since Zambia's first reported AIDS diagnosis in 1984, the proportion of PLWH has rapidly increased, peaking in the mid 1990s at about 16% but reaching as high as 25% in some urban areas (Fylkesnes, Ndhlovu, Kasumba, Mubanga, & Sichone, 1998; UNAIDS/WHO, 2009). The Zambia HIV epidemic has been fairly stable over the last 15 years with a very modest decline after the initial peak prevalence (Ministry of Health, 2010). Although the rate of new HIV infections has decreased, the total number of PLWH continues to rise. An estimated average of 980,000

(890,000–1,100,000) people in a population of 12.9 million have been infected with HIV in Zambia. There were an average of 45,000 (30,000–60,000) estimated deaths due to AIDS in 2009 alone (Ministry of Health, 2010; UNAIDS, 2009). Adults aged 15–49 had an HIV prevalence of 13.5% in 2009, which was the 6th highest in Sub-Saharan countries (UNAIDS/WHO, 2010).

The HIV prevalence rate in Zambia varies significantly according to age and sex. The prevalence peaks at 23.6% for the age group 35–39 years. Females show a significantly higher prevalence than males at younger ages. The difference between female and male prevalence is very large in age groups 20–24, 25–29 and 30–34 years (Ministry of Health, 2010; UNAIDS/WB, 2009).

Heterosexual sex is the major mode of transmission of HIV in Zambia, accounting for 78% of new HIV infections (Ministry of Health, 2010). This mode of transmission is exacerbated by high risk sexual practices, socioeconomic and poverty inequalities between males and females, high prevalence of untreated sexually transmitted diseases (STDs) and tuberculosis (TB) (Ministry of Health, 2008). However, positive changes were observed in several behavioral indicators in adults and youths from 1992 to 2007. Fewer survey respondents reported multiple partners and non-cohabiting partners, more reported just one partner and condom users increased among married women aged 15–49 from 2% in 1992 to

6% in 2007 (Ministry of Health, 2009, 2010; UNAIDS/WB, 2009).

The National HIV/AIDS/STD/TB Council (NAC) in Zambia became operational in 2002 when parliament passed a national AIDS bill that made the NAC a legally-established body able to apply for funding. The NAC Intervention Strategic Plan 2002–2005 was developed. One of the priority interventions was to provide care, treatment and support to PLWH (WHO, 2005). The total treatment need for 2005 was estimated to be 140,000 people, and the target for the WHO '3 by 5' initiative, which aimed to provide 3 million PLWH in low- and middle-income countries with life-prolonging antiretroviral therapy (ART) by the end of 2005, was 70,000 people in Zambia.

1-2. National HIV strategy in Zambia

In 2004, the Ministry of Health (MoH) in Zambia offered ART at four clinics in Lusaka. The program expanded to 14 additional urban sites in 2005, and the government declared that the entire ART service package would be provided free of charge in the public sector, with a goal of universal access to HIV care and treatment in Zambia (Stringer et al., 2006). By the end of 2005, approximately 45,000 people had received ART, and the number reached more than 70,000 by September 2006 (UNAIDS/WHO, 2006; WHO/UNAIDS/UNICEF, 2007).

In the second strategic plan 2006–2010, access to ART for eligible people was expanded,

and 210,000 eligible people were expected to receive ART by 2010 (Ministry of Health, 2005). Because more than half of the population lives in rural areas where there is poor access to ART services (Ministry of Health, 2009), the MoH is eager to develop approaches to expand services by strengthening the existing public health care system. It has expressed its intention to expand HIV testing and treatment facilities to all districts and as close to households as possible (Nozaki, 2006). With this effort, 283,863 (68%) people out of an estimated total population of 416,533 who were in need of ART received it at 447 health facility sites throughout the country by 2009, and the number of sites is expanding (Ministry of Health, 2010). As a part of this strategy, mobile ART services were introduced to scale-up services for PLWH in 2007 in cooperation with the Japanese government through the Japan International Cooperation Agency (JICA). Rural health centers (RHCs) were selected as mobile ART sites according to geographical location, population coverage and existing resources including medical staff, space and community activities. A mobile ART team including a physician, clinical officer, nurse, laboratory staff and pharmacist visits the selected RHCs every two weeks. The mobile sites are expected to make it easier for PLWH and other clients to access ART services. While achievements have been remarkable, challenges remain related to universal coverage in Zambia.

1-3. Adherence to antiretroviral therapy (ART)

Standard ART uses at least three antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of HIV disease (WHO, 2011). Adherence to ART is crucial for treatment success among PLWH; it has improved the health of people who otherwise would have progressed to AIDS or died (Chi et al., 2009). A high level of adherence is needed to maintain viral suppression (Ferradini et al., 2006; Glass et al., 2008; Gross et al., 2006; Isaakidis et al., 2010; Muyingo et al., 2008) and lower the risk of drug resistance (Sethi, 2004), in turn reducing premature morbidity and mortality (Hong et al., 2011; Stringer et al., 2006). Poor adherence is associated with low CD4 lymphocyte count (Chi et al., 2009) and a high viral load that can increase the risk of HIV transmission to others (Wilson, Law, Grulich, Cooper, & Kaldor, 2008).

Adherence in the adult population has been shown to range from 33 to 88% depending on the study design, study population and measurement tools in Sub-Saharan Africa and North America (Mills, Nachega, Buchan et al., 2006). There has been concern that PLWH in Sub-Saharan Africa, many of whom live in poverty and lack formal education, have suboptimal adherence to ART (Harries, Nyangulu, Hargreaves, Kaluwa, & Salaniponi, 2001; Stevens, Kaye, & Corrah, 2004). However, a meta-analysis of adherence studies done in Sub-Saharan Africa and North America showed that an estimated 77% of ART clients

achieved an adequate level of adherence in Sub-Saharan Africa compared with 55% in North America (Mills,Nachega, Buchan et al., 2006). While expectations of a poor level of adherence in Sub-Saharan Africa appeared to be unwarranted, studies in that region were conducted in clients with severely limited access to ART or early access to limited therapy, and are possibly not generalizable to the larger HIV epidemic in Sub-Saharan Africa (Mills, Nachega, Buchan et al., 2006). Given the relatively high level of adherence in Sub-Saharan Africa, the priority now is to increase access to ART and further improve the adherence rate as well as establish a reliable drug supply and distribution network.

Major factors related to ART adherence identified in the meta-analysis of Africa-based adherence studies were financial constraints, fear of disclosure/stigma, alcohol abuse and ART regimen complexity (Mills, Nachega, Buchan et al., 2006). Based on these results and other previous studies, factors influencing adherence can be divided into six key themes: demographic, economic, medication, physical health, interpersonal and mental health factors.

1-3-1. Demographic factors

Some studies have found associations between optimal adherence and older age, female gender, lower education level, higher income, and food support (Cantrell et al., 2008; Chi et al., 2009; Duran et al., 2001; El-Khatib et al., 2011; Franke et al., 2010; Li et al., 2005; Nilsson,

Williams, Ross, Bratt, & Keel, 2007; Nozaki, Dube, Kakimoto, Yamada, & Simpungwe, 2011; Puigventos et al., 2002; Raboud et al., 2010; Shah et al., 2007; Stringer et al., 2006; Unge et al., 2010; Uzochukwu et al., 2009). By contrast, others have found no such associations or have reported inconsistent findings (Bhat et al., 2010; Rougemont, Stoll, Elia, & Ngang, 2009; Stone et al., 2001; Uzochukwu et al., 2009; Weiser et al., 2003). Results are inconclusive as to the relationship between adherence and such demographic variables (Ammassari et al., 2002). These inconsistent associations may reflect the diversity of customs and environment related to the treatment across different studies.

1-3-2. Economic factors

Financial difficulties play a key role in suboptimal adherence (Brinkhof et al., 2008; El-Khatib et al., 2011; Nozaki et al., 2011; Weiser et al., 2003). The meta-analysis of Africa-based adherence studies introduced previously identified one of the important adherence factors to be cost (Mills, Nachega, Buchan et al., 2006). Out-of-pocket payment for ARV drugs represents an obvious barrier to adherence in resource-poor settings, even when medications are substantially subsidized (Brinkhof et al., 2008). Not only the cost for the drugs, but the cost of traveling to the clinic and lack of financial support from spouses or partners are also barriers to ART adherence (El-Khatib et al., 2011; Nozaki et al., 2011).

1-3-3. Medication factors

Adherence has been shown to be associated with type and level of regimen, daily schedule and duration of the treatment (Altice, Mostashari, & Friedland, 2001; Garang, Odoi, & Kalyango, 2009; Li et al., 2005; Martin et al., 2008; Nilsson et al., 2007; Puigventos et al., 2002; Raboud et al., 2010). Clients who received a protease inhibitor (PI)-based medication regimen were more likely to report lower levels of adherence to dose than those receiving nucleoside or non-nucleoside reverse transcriptase inhibitor (NNRTI) regimens (Altice et al., 2001; Li et al., 2005). Regarding dosing frequency, ART clients on once daily regimens were less likely to miss a dose than others (Raboud et al., 2010).

In addition, having reminders or reminder tools for taking medication have been positively associated with ART adherence (Nozaki et al., 2011; Shah et al., 2007; Wang et al., 2008; Wang & Wu, 2007). Nozaki showed that 'remembering when to take ARV drugs based on the position of the sun' was negatively associated with adherence, and noted the need for effective and practical strategies for remembering and cuing dose times to offer clients in accordance with their living conditions (Nozaki et al., 2011).

1-3-4. Physical health factors

There are no conclusive results regarding physical health factors. Some studies have

documented lower adherence in persons with lower CD4 lymphocyte counts at treatment entry (Brinkhof et al., 2008; Stringer et al., 2006). In contrast, others have shown that clients with higher CD4 lymphocyte counts at entry were more likely to have lower adherence (Chi et al., 2009). Findings have also been inconsistent in defining the relationship of TB conditions to ART adherence (Birbeck et al., 2009; Chi et al., 2009; Shah et al., 2007; Stringer et al., 2006). Some studies showed that TB comorbidity was associated with high adherence (Chi et al., 2009; Shah et al., 2007) , while it was not related in other studies (Birbeck et al., 2009; Stringer et al., 2006).

Clients with adverse side effects and little experience with HIV disease symptoms were likely to have lower adherence (Altice et al., 2001; Johnson, Dilworth, Taylor, & Neilands, 2011; Nilsson Schonnesson et al., 2007; Shah et al., 2007; Weiser et al., 2003), while Rougemont et al. (2009) found that those in severe disease stages had higher risks of becoming lost to follow-up compared with asymptomatic clients. Johnson et al. (2011) showed that counseling sessions relevant to ART side effect coping were positively associated with ART adherence and treatment continuation.

Moreover, substance abuse and alcohol consumption have been associated with decreased adherence (Bhat et al., 2010; Duran et al., 2001; Palepu, Milloy, Kerr, Zhang, & Wood, 2011; Raboud et al., 2010; Wang et al., 2008). Integration of addiction treatment with HIV care is

known to be a challenge. In a study in Canada, methadone maintenance therapy was positively associated with ART adherence (Palepu et al., 2011).

1-3-5. Interpersonal factors

Good patient-provider relationships such as clients' trust and confidence in their doctor, and social and emotional support from surroundings have been positively correlated with ART adherence (Altice et al., 2001; Chi et al., 2009; Duran et al., 2001; Franke et al., 2010; Garang et al., 2009; Mostashari, Riley, Selwyn, & Altice, 1998; Nozaki et al., 2011; Raboud et al., 2010; Shah et al., 2007; Unge et al., 2010). Intervention strategies to support ART adherence have also been found to be important in the achievement of positive outcomes. Previous studies showed that clients' having a buddy increased ART adherence (Chi et al., 2009; Nozaki et al., 2011).

Disclosure of one's HIV status has been associated with better adherence (Birbeck et al., 2009; Unge et al., 2010; Weiser et al., 2003). On the one hand, disclosure has the potential to yield much-needed social support. On the other hand, it may result in stigmatization, discrimination or abandonment. A study in Botswana showed that 69% of clients kept their HIV status a secret from their families, and 94% kept their status a secret from people in their community because of the negative repercussions for the clients, including broken marriages

and relationships, rejection by family, ostracism by the community and loss of employment (Weiser et al., 2003).

1-3-6. Mental health factors

There have been several studies on mental health issues among PLWH that have identified significant barriers to ART adherence (Byakika-Tusiime et al., 2009; Dlamini et al., 2009; Franke et al., 2010; Kacanek et al., 2010; Li et al., 2005; Nilsson et al., 2007; Nozaki et al., 2011; Peltzer, Sikwane, & Majaja, 2011; Puigventos et al., 2002; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006). Some recent studies have linked HIV/AIDS stigma to poor adherence to ART (Dlamini et al., 2009; Peltzer & Ramlagan, 2011; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Rintamaki et al., 2006; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). Rintamaki et al. (2006) found that people in the United States with high HIV stigma concerns were 3.3 times more likely to be non-adherent to their medication regimens than those with low concerns. Rao et al. (2007) identified in a focus group discussion that the fear of stigma from friends or family leads to skipping doses among adolescent and young adult ART clients in the United States. A prospective study in South Africa indicated that self-stigma is negatively associated with ART adherence, and the proportion of clients who had self-stigma, depressive symptoms and experiences of discrimination remained high

after initiation of ART (Peltzer & Ramlagan, 2011). Dlamini et al. (2009) found not only a significant relationship between poor adherence and perceived HIV stigma, but also between an increased number of missed medication doses and higher levels of perceived HIV stigma. In addition, the 52-study meta-analysis on ART adherence in North America and Africa investigated stigma as one of a number of factors related to varying ART adherence (Mills, Nachega, Buchan et al., 2006). However, there have been relatively few longitudinal studies investigating the association between ART adherence and stigma. Pearson et al. (2009) found that one year after initiating ART in Mozambique, ART clients reported no change in stigma and no association between ART adherence and stigma.

There have been divergent findings in studies investigating adherence and depression. Previous cross-sectional studies (Amberbir, Woldemichael, Getachew, Girma, & Deribe, 2008; Ammassari et al., 2004; Byakika-Tusiime et al., 2009; Peltzer, Friend-du Preez, Ramlagan, & Anderson, 2010; Rao et al., 2011) and longitudinal studies (Carrieri et al., 2003; Kacanek et al., 2010; Spire et al., 2002) have found associations between depression and poor adherence. In Italy, clients receiving ART who exhibited depressive symptoms were up to 3 times more likely to be non-adherent to their medication regimens than their non-depressed counterparts (Ammassari et al., 2004). Structural equation modeling revealed that depression had a direct effect on adherence, and poorer adherence was associated with higher levels of depressive

symptoms in a study in the United States (Rao et al., 2011). In studies in Ethiopia, Uganda and South Africa, clients who were depressed were more likely to have poor adherence than those who were not depressed, based on multivariate analyses (Amberbir et al., 2008; Byakika-Tusiime et al., 2009; Peltzer et al., 2010). As for results of longitudinal studies, a change in the Center for Epidemiological Studies Depression Scale (CES-D) scores over a 4-month period was associated with non-adherence over the same time period in France (Spire et al., 2002). Carrieri et al. (2003) found that baseline depression was associated with an inability to maintain adherence at 18-month follow-up in a cohort of injection drug users initially adherent to ART in France. A study in the United States extended the findings of these previous longitudinal studies by demonstrating that onset of depressive symptoms was associated with increasing rates of suboptimal adherence (Kacanek et al., 2010). The odds ratios for the association between depressive symptoms and adherence to ART ranged from 0.01 to 0.88 in a systematic review of peer reviewed studies from Sub-Saharan Africa, although a few found that individuals with significant depressive symptoms were less likely to adhere to ART than were individuals without such symptoms (Nakimuli-Mpungu et al., 2011). In contrast to these results, others did not find an association (Garvie et al., 2011; Kleeberger et al., 2004; Ramadhani et al., 2007; Stone et al., 2001). In a study of males in a multicenter cohort study, the absence of depression was not associated with improved adherence

(Kleeberger et al., 2004). In addition, depression was not associated with suboptimal adherence in studies in Tanzania (Ramadhani et al., 2007) or in a survey of females in the HIV Epidemiological Research Study in the United States (Stone et al., 2001). Garvie et al. (2011) showed that higher depression scores at baseline predicted better community-based directly observed therapy (DOT) adherence in adolescents on ART in the United States. The causal pathways relating depression and non-adherence or adherence remain unclear, underlining the need for further study.

1-4. Stigma and depression among ART clients

Stigma is universally present. It is defined as 'an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society' (Goffman, 1963). It is a labeling of an individual or group as different or deviant. Stigma results when discriminatory behavior, such as social exclusion, restriction of expression, marginalization or prevention from access to services is experienced and initiated because of the undesired condition (Pearson et al., 2009). It is also a powerful means of social control applied by marginalizing, excluding and exercising power over individuals who display certain traits (UNAIDS, 2000). Individuals with an undesirable condition become aware of their differences (perceived stigma), eventually internalizing prejudices and stereotypes, resulting in self-stigma

(Parker & Aggleton, 2003).

Concern with HIV/AIDS related stigma has been widespread since the epidemic began in the 1980s. Self-stigma among PLWH may evoke feelings of shame, blame, hopelessness, guilt, unworthiness, perceptions of being discredited, fear of discrimination and behavioral intentions to conceal HIV status (Mak et al., 2007).

HIV/AIDS related stigma can interfere with HIV/AIDS prevention, testing and care including diminishing ART adherence (Corrigan, 1998; Parker & Aggleton, 2003), and ultimately increase morbidity and mortality (Holzemer et al., 2007). Stigma also has negative consequences for mental health outcomes, such as depression, lowered self-esteem, anxiety and disclosure of HIV status (Logie & Gadalla, 2009; Simbayi et al., 2007; Vanable, Carey, Blair, & Littlewood, 2006; Wagner et al., 2010; Wingood et al., 2007). Stigma and such mental health outcomes influence one another in a complex web of interactions that are difficult to disentangle. Self-stigma is especially likely to make an individual more sensitive to both actual and anticipated rejection and stigmatization by others, which negatively affects disclosure (Chesney & Smith, 1999; Pearson et al., 2009).

Depression is the most commonly observed mental health problem among PLWH (Olisah, Baiyewu, & Sheikh, 2010; Olley, Seedat, Reuter, & Stein, 2003; Sherr, Clucas, Harding, Sibley, & Catalan, 2011). Depression is defined as a mental illness that presents with sadness, loss of

interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy and poor concentration (WHO).The prevalence rate of depression in HIV positive clinic populations is about 3 to 5 times higher than that in the general population (Ciesla & Roberts, 2001; Olisah et al., 2010). Given that stigma and depression can have a tremendous negative impact on PLWH, investigators must take both into account to fully understand barriers to ART adherence.

Though the availability of ART and subsequent changes in perception of HIV/AIDS as a manageable chronic disease have led to reduced perceived HIV stigma (Genberg et al., 2009; Herek, Capitanio, & Widaman, 2002; Wolfe et al., 2008), PLWH in Sub-Saharan Africa still report high stigma and discrimination experiences because ART has only recently become available, and for a large number of PLWH, ART services remain inaccessible (Genberg et al., 2009; Gilbert & Walker, 2010; Maman et al., 2009; Simbayi et al., 2007). To make matters worse, this can lead to depression among ART clients. However, one study in South Africa showed that stigma increased despite the scale-up of ART services (Maughan-Brown, 2010).

1-5. Factors related to ART adherence in Zambia

Previous studies showed that 62.9% and 59.2% of clients adhered to ART in Lusaka, the capital of Zambia and Zambia's southern province, respectively (Birbeck et al., 2009; Chi et

al., 2009). Some reports have revealed factors associated with adherence in both urban and rural settings (Birbeck et al., 2009; Cantrell et al., 2008; Carlucci et al., 2008; Grant, Logie, Masura, Gorman, & Murray, 2008; Murray et al., 2009; Nozaki et al., 2011; Sanjobo, Frich, & Fretheim, 2008; Stringer et al., 2006). The common reasons raised by ART clients for poor adherence in qualitative studies included demographic and physical health factors (e.g. insufficient food and side effects) as well as interpersonal factors (e.g. lack of support) (Grant et al., 2008; Murray et al., 2009; Sanjobo et al., 2008). Other barriers included clients' mental health factors (e.g. fear of stigma/disclosure and presence of depression/ hopelessness) (Murray et al., 2009; Sanjobo et al., 2008).

Such qualitative studies in Zambia generate information from the respondent's perspective that may facilitate culturally appropriate and effective interventions. However, few quantitative studies have investigated associations between ART adherence and factors identified in these qualitative studies. In addition, to the best of my knowledge, no studies have investigated factors related to ART adherence focusing on clients' mental health factors at the early months of treatment.

1-6. Objectives of the present study

Concerted efforts have increased the availability of ART services at district and community

levels in Zambia. Expanding ART services in the community, however, may not automatically lead to optimal adherence to ART if factors related to adherence are not understood. From this point of view, identifying these factors can contribute to the development of practical strategies in policy and practice to improve the quality of ART services, and to sustain long-term treatment benefits.

Thus, the objectives of this study were to 1) identify factors associated with ART adherence, and 2) examine the relationship between ART adherence, self-stigma and depressive symptoms at the early months of treatment in rural Zambia.

Chapter 2: Methods

2-1. Study design and study site

This is a field based observational longitudinal study in Mumbwa district, which is located 150 km west of Lusaka in Zambia (Appendix 1). According to the Health Management Information System (HMIS) data in Zambia, the population in Mumbwa was over 220,000 in 2010. There was one district hospital (DH), one mission hospital and 27 RHCs in Mumbwa during the study period. Among the health facilities, ART services were available only at the DH, the mission hospital and at eight RHCs.

2-2. Study population

During the study period, all ART clients that came to the DH or to one of the eight RHCs where ART services were offered were asked to participate in the study. There were no seasonal variation in the numbers of clients who visited clinics in Mumbwa in 2009 according to the HMIS data, and no previous reports showing that seasonal variation affected ART adherence, as far as the researcher could find.

The eligible population was ART clients who 1) were aged 16 and over; 2) were ART-naïve and newly registered for ART services based on the Zambia HIV National Guidelines (Appendix 2) from September to November 2010; and 3) agreed to give an

informed consent. The exclusion criteria included the clients who were too ill to be interviewed.

Clients were interviewed at the initiation of treatment as well as six weeks later (Figure 1). We focused on the early months of treatment because the initial response to ART has long-term prognostic significance, and optimizing adherence in the early months is important for ensuring long-term immunological and virological success (Brinkhof, et al., 2008; Carrieri, Raffi, et al., 2003). In addition, earlier diagnosis and treatment are significant since most mortality occurs in the early months of treatment, as shown in a previous study (Stringer, et al., 2006).

2-3. Sample size calculation

Based on a 10% significance level using a two-sided test, with 80% statistical power and 15% self-stigma and depressive symptoms among clients who adhered to ART, the estimated sample size was 216 samples (Kihara & Kihara, 2004).

2-4. Study tools

Structured questionnaires for both at baseline and follow-up interviews were developed (Appendix 3), following the generic tools developed by WHO (WHO, 2009) and the AIDS

clinical trial group (ACTG) adherence follow-up questionnaires (Chesney et al., 2000). The questionnaires were first developed in English. After being translated into Nyanja (dominant regional language), these were back-translated to English to ensure clarity and consistency. The questionnaires covered respondents' sociodemographic characteristics, ART adherence, disclosing status, physical and mental health related characteristics, and sexual activities of the respondents. WHO HIV/AIDS stage (WHO, 2007), weight, CD4 lymphocyte count, TB status were extracted from individual medical record. The CD4 lymphocyte count was measured using flow cytometry at a laboratory in the DH.

2-4-1. Measurements

The accurate measurement of adherence to ART is a challenge. To date, there is no gold standard tool that has been developed to measure adherence to ART. That said, there are a number of tools that have been employed to assess levels of adherence. They include self-reports, pill counts, pharmacy refill tracking, therapeutic drug monitoring, medication event monitoring system (MEMS), a pill-cap that contains an electronic microchip that records date and time of each bottle-opening and biological markers (Lyimo et al., 2011). In this study, ART adherence was measured by using a self-report, because it is a simple, cheap, and quick tool in a field research and resource poor setting. In this study, full adherence to ART was

defined as when a client had never skipped prescribed drugs and had followed time restrictions during the previous four days before the interview.

Scores for internalized AIDS-related stigma and cognitive/affective depression were measured using scales developed and validated by Kalichman. He showed data from PLWH in Cape Town, South Africa (n=1068), Swaziland (n=1090), and Atlanta, United States (n=239) (Kalichman et al., 2009). The Internalized AIDS-related stigma (self-stigma) scale consists of six questions which focus on self-blame and concealment of HIV status and it was internally consistent. It had Cronbach's coefficient alpha (α) greater than 0.7 in Cape Town (α=0.73), Swaziland (α=0.74), and Atlanta (α=0.76) (Kalichman, et al., 2009). High α was also confirmed in this study (α=0.71 at a baseline survey and α=0.79 at a follow-up survey). To simplify administration, the items were responded to dichotomously, 1=Agree and 0=Disagree; scale scores represent the sum total of endorsed stigma items, range 0-6. The cognitive/affective depression subscale is an 11-item measure that assesses symptoms of depression over the previous seven days, 0=No days, 1=1-2 days, 2=3-4 days, and 3= 5-7 days. The scale ranges from 0 to 33. It was evidently internally consistent; α coefficients included Cape Town 0.79, Swaziland 0.73, and Atlanta 0.78 (Kalichman, et al., 2009). Cronbach's coefficient α was 0.80 at both baseline and follow-up surveys in this study. The median of each scale score was used as the cutoff point between clients who had self-stigma or

depressive symptoms and who did not.

Food insufficiency was measured by using one closed-ended question (Appendix 3) following the Sociodemographic Module of the Client Instrument developed by WHO as a generic tool for operational research on HIV testing, treatment and prevention (WHO, 2009). Clients were asked to recall the frequency with which there was not enough food in the month prior to interview: never, sometimes, often or almost always. A similar single question assessment of food insufficiency has been validated in previous studies (Alaimo, Briefel, Frongillo, & Olson, 1998; Franke, et al., 2010).

2-5. Data collection

After instruction and discussion on this study with the district medical office (DMO) in Mumbwa, official letters issued by the DMO were sent to the authorities in the DH and eight RHCs to explain the purposes and schedules of the survey. One focal person per site was selected. The focal person referred newly registered ART clients to one private room for interview after the clients' medical examination by a physician, clinical officer or nurse. At the interview room, the assigned interviewer confirmed that the participation was voluntary and gave assurance that they could withdraw from this study at any time. Then, a written informed consent (Appendix 4) was obtained from all participants before interviews for data collection.

Information on refusals to participate was not retained. The fee for the medical examination and laboratory tests were free of charge regardless of whether clients refused to participate in this study or not.

Before the commencement of the actual study, a three-day training course on research protocols, administration of questionnaires, and ethics was conducted for eight interviewers using instructions for interviewers (Appendix 5). They were recruited after oral examination. The selection criteria included the following: 1) at least a high school degree; 2) skills for writing, speaking, reading, and listening in English and Nyanja; 3) at least 20 years old; 4) a residence in Mumbwa. A small pilot study was carried out before the actual survey for face validity. During the pilot study, the interviewers ensured sequence, flow and clarity of the study. After the feedback from the interviewers, a baseline questionnaire and a six weeks follow-up questionnaire were revised accordingly. Field surveys were carried out from September 2010 to March 2011.

2-6. Data analysis

Data obtained from the questionnaire surveys were analyzed with SPSS version 19 statistical software. Baseline characteristics of participants were compared between clients who adhered to ART six weeks after starting ART and who did not by Pearson's chi-square test and

Fisher's exact test. Multiple logistic regression analysis was performed to identify the factors associated with ART adherence. Mental health related variables and the other variables of which the associated p value level was less than 0.1 were entered into a multiple logistic regression model. If the variable was highly correlated with the other variable, one of them was removed from the model. An adjusted odds ratio (AOR) was calculated for the levels of the other factors included in the model. The AOR for continuous variables represented changes in the estimated odds of the outcome when the continuous variable increased by one unit.

Clients' characteristics were also compared between those who had self-stigma or depressive symptoms at the initiation of ART and who did not by Pearson's chi-square test and Fisher's exact test. In addition, association between self-stigma and depressive symptoms at the initiation of ART and six weeks later was investigated using Spearman rank correlation coefficient.

2-7. Ethical considerations

This study was approved by the Research Ethics Committee of the University of Tokyo, the Biomedical Research Ethics Committee of the University of Zambia, and the Institutional Ethics Committee of the International Medical Center of Japan (Appendix 6, 7 & 8). Written informed consents were obtained from respondents at the beginning of interview after the

study was explained to them (Appendix 4). They were informed that participation in the study was voluntary. The participants were randomly assigned by one of the eight interviewers, and the name of the interviewer who would interview them was informed before interview. If a participant knew the name, the other interviewer was assigned. Data were recorded in anonymous form to protect the confidential information of all participants.

Chapter 3: Results

3-1. Description of study sample

During a field research, 241 ART clients who were newly registered for ART services were approached (Figure 1). Six clients who passed away and two clients who were trans-outs during the study period were excluded. After the baseline survey, 76 were excluded because the interview was incomplete or the clients did not appear on the appointment date and we could not reach their contact address. The sociodemographic and health characteristics of these clients did not differ from the clients included in the analysis except for the required time for coming to the health facilities (Table 1 & 2). Data from the remaining 157 were used for statistical analysis.

3-2. Status of ART adherence

Among the 157 ART clients who were included in this study, 94 (59.9%) were fully adherent and 63 (40.1%) were non-adherent to their drug regimens six weeks after starting ART, respectively.

3-3. Sociodemographic and economic characteristics

Seventy-four (47.1%) visited the DH for ART services (Table 3). The median age was 35

years old (range: 18-68), 94 (59.9%) were female, and 105 (66.9%) were married with the median number of three adults [Interquartile range (IQR), 2-4] and three children (IQR, 2-5) living together. The proportion of clients who were adherent to ART was significantly higher among females than males (p=0.01). Around half of the clients (n=77, 49.4%) had not completed the standard primary education of seven years and 107 (68.2%) were farmers. Sixty-one (38.9%) reported experiences of food insufficiency in the previous 30 days. The proportion of those who were adherent to ART was significantly lower among farmers than the others (p=0.038), but higher among clients who had experienced food insufficiency in the previous 30 days (p<0.001).

Regarding transportation, 127 (80.9%) did not need to pay the transportation access fee to the DH or RHCs. Over half of clients (n=80, 51%) came there on foot and 85 (54.8%) required more than one hour for it.

Except for sex, occupation and experiences of food insufficiency in the previous 30 days, all of the above baseline characteristics did not differ between clients who were adherent and non-adherent to ART by univariate analysis (Table 3).

3-4. Medication, physical health and interpersonal characteristics

The majority of clients reported that HIV testing was voluntary (n=118, 77.1%) and 65

(41.7%) knew their positive result within 30 days (Table 4).

Only four of the clients (2.6%) did not use anything to remind oneself to take ARV drugs (Table 4). One hundred-five (67.7%) used watches or clocks; 51 (32.9%) had mobile phones; 15 (9.7%) used the position of the sun; and 15 (9.7%) used radios.

Median CD4 lymphocyte count was 154.5 cells/μl (IQR, 91-237.3), and half of clients were in WHO stage one or two (n=78, 50%) (Table 4). One hundred thirty-eight (87.9%) were in the functional status of being able to work and 11 (7.1%) were with smear-positive TB.

Fifty-eight (44.6%) of the participants' spouses were HIV positive (Table 5-1). In addition, 36 (29.3%) spouses were on ART.

Regarding disclosure, 89 (85.6%) disclosed one's HIV status to their spouse, and many disclosed it to others such as their sibling (n=85, 57%) and mother (n=59, 37.8%) (Table 5-2). The proportion of those who were adherent to ART was significantly higher among clients who disclosed it to one's spouse than those who did not (p=0.048).

As for sexual behavior, 28 (22.4%) stopped sexual intercourse and 36 (33%) did not have sexual intercourse without condoms after knowing their own HIV status (Table 5-3). Most female clients (n=85, 93.4%) were not pregnant.

Most of clients were satisfied with health services in the DH or RHCs (n=150, 96.8%). In addition, they trusted in clinical officers (n=152, 97.4%), nurses (n=152, 98.1%), and

treatment supporters or adherence counselors (n=149, 96.1%) (Table 5-4).

Apart from HIV status disclosure to one's spouse, these characteristics did not differ between clients who were adherent and non-adherent to ART by univariate analysis. Moreover, there were no differences in the above baseline characteristics between female clients and male clients except for the proportion of those who disclosed one's HIV status to their sibling or mother: female clients were more likely to disclose it to them [65.1% versus (vs) 44.3%, p=0.022 for sibling; 45.2% vs 27%, p=0.009 for mother].

3-5. Mental health characteristics

Over half of clients had self-stigma and were depressed (n=87, 56.5%; n=92, 58.6%) (Table 6). These characteristics did not differ between clients who were adherent and non-adherent to ART by univariate analysis.

3-6. Factors associated with full ART adherence

To identify the factors associated with full ART adherence, multiple logistic regression analysis was performed. Full adherence was associated with being female [AOR, 6.4; 95% Confidence interval (CI), 1.7-23.5], experience of food insufficiency in the previous 30 days (AOR, 5.7; 95% CI, 1.6-21.2), spouse undergoing ART (AOR, 5.4; 95% CI,1.4-19.9),

self-stigma at the initiation of ART (AOR, 0.1; 95% CI, 0.02-0.6), being more depressed (AOR, 1.1; 95% CI, 1.0-1.3) and having less self-stigma (AOR, 0.6; 95% CI, 0.5-0.9) after six weeks compared with at the initiation of ART (Table 7).

3-7. Reasons for missed doses

Some of the most common reasons for missed doses were being away from home (n=21, 53.8%), food insufficiency (n=20, 51.3%), being busy with other things like work (n=15, 38.5%), being depressed (n=5, 12.8%), and forgetfulness (n=4, 10.3%) (Table 8).

3-8. Comparison of clients' characteristics between clients who had self-stigma or depressive symptoms and who did not have such at the initiation of ART

The clients' characteristics did not statistically differ between those who had and who did not have self-stigma in all the dimensions except for time required for coming to health facilities: the proportion of the clients who needed to take more than one hour was significantly higher among clients who had self-stigma than those who did not have (63.2% vs 43.1%, p=0.014) (Table 3).

Regarding depressive symptoms, the proportions of male and married clients were significantly lower among the clients who had depressive symptoms than those who did not

(32.6% vs 50.8%, p=0.022; 59.8% vs 76.9%, p=0.025) (Table 3). The other characteristics did not differ between the two groups.

3-9. Association between self-stigma and depressive symptoms

Association between self-stigma and depressive symptoms was investigated. Self-stigma was positively associated with depressive symptoms at the initiation of ART (r=0.18, p=0.029) (Table 9). The result was also found six weeks after starting ART (r=0.2, p=0.015).

Chapter 4: Discussion

This study described the status of ART adherence by PLWH who started ART and identified factors associated with ART adherence at the early months of treatment, focusing on mental health issues in a rural setting in Zambia. Factors positively associated with ART adherence were being female, experiencing food insufficiency in the previous 30 days, spouse undergoing ART, having no self-stigma at the initiation of ART, being more depressed and having less self-stigma after six weeks compared with at the initiation of ART.

4-1. Status of ART adherence in the Mumbwa district

In this study, 59.9% were considered fully adherent to ART six weeks after starting ART, defined as full adherence for the four days prior to data collection. This result was similar to results in previous studies in Zambia, which assessed adherence based on a combination of clinic attendance, client report, staff assessment and pharmacy-based measures (Birbeck et al., 2009; Chi et al., 2009). However, the percentage was lower than that found in studies conducted in other countries in Sub-Saharan Africa, which have shown a full medication adherence of 76% (Mills, Nachega, Buchan et al., 2006).

This difference in results could be related to the criteria for measuring ART adherence. Because long-term viral suppression requires consistent and high percent dose adherence

accompanied by optimal inter-dose intervals (Liu et al., 2006), not only adherence to dose, but also adherence to schedule was considered in this study. Those who never skipped prescribed drugs and followed time restrictions during the previous four days were considered fully adherent. In contrast, most other studies that have measured ART adherence using clients' self-report only have shown adherence to dose instructions (Mills, Nachega, Buchan et al., 2006).

In addition, African studies in previous analyses were conducted in areas with a low availability of ART. During this study period, the availability of ART was nearly 70% and had become generalizable to the larger HIV epidemic in Zambia. The relatively high levels of adherence in previous studies may decline as treatment access expands in the areas (Mills, Nachega, Buchan, et al., 2006).

The relatively high availability of ART in Zambia is explained by the rapid scale-up of ART delivery through decentralized primary health care (PHC) programs such as mobile ART services in rural areas, including Mumbwa. Dube et al. (2010) showed that mobile ART services can increase the number of ART clients by reducing the need to travel long distances to reach health facilities. These services enable clients to start ART at an earlier stage in their disease when voluntary counseling and testing (VCT) is located at the same site, although the mortality of clients served at the mobile sites has been higher than that for those visiting the

DH (Dube et al., 2010). A possible reason for this may be not only the weaker ascertainment of deaths among clients lost to follow-up at the hospital level, but also the human resource capacity and quality of ART delivery at RHCs, which have been identified as the main constraint in Sub-Saharan Africa (Boyer et al., 2011; Fredlund & Nash, 2007). Decentralization of ART services is necessary to increase the coverage and improve service quality by maximizing utilization of limited space, infrastructure and the health workforce through task shifting, better service integrations into existing RHC's services, and service linkages such as referral and follow-up systems between facility levels.

4-2. Factors related to full adherence to ART

Gender remained significant after adjusting for potential confounders in a multivariate model. It is commonly thought that female clients have better ART adherence because they have more opportunities to access care and start treatment at less advanced stages of HIV, likely through their participation in prevention of mother-to-child transmission (PMTCT) programs (Alibhai et al., 2010). Zambia's PMTCT initiative was launched in 1999, beginning with a three-year pilot program in Copperbelt province. It has expanded so that an estimated 69% of pregnant women living with HIV had received ARV drugs for PMTCT by the end of 2009 (WHO/UNAIDS/UNICEF, 2010). Scaling-up national PMTCT services in Zambia may

contribute to earlier ART for a larger group of HIV-positive females. In this study, however, there were no differences in baseline physical health status such as disease stage, functional status and TB comorbidity between male and female clients.

Although not determined in this study, sex differences in ARV drug metabolism, distribution and side effects could have contributed to the outcome observed. Higher ART adherence demonstrated among female clients in this study might have been linked to better treatment response compared with that of male clients, as shown in a previous study (Ofotokun, Chuck, & Hitti, 2007). That study also showed that side effects related to ARV drugs were more frequently observed in male clients than in female clients. In this study, nearly 70% were married, and the median number of children living in the home was three. Therefore, female clients may have had a greater reason to stay alive and be motivated to adhere to ART since children are known to be a facilitating factor in adherence, primarily among female clients (Wood, Tobias, & McCree, 2004).

On the other hand, previous research has shown that HIV-positive females often experience gender-related barriers to accessing health services, thus affecting ART adherence (Eckman, Blakley, & Anita, 2004; ICW, 2004). The International Community of Women Living with HIV/AIDS (ICW) found that gender inequality within families is a barrier to female's access to treatment and other health services (ICW, 2004). For example, many

females have to obtain permission from a male spouse or a relative to seek HIV care, which is difficult when females have to ask for money and take time away from household chores. In addition, where costs for treatment are involved, families may prioritize paying for male's treatment (Eckman, Blakley, & Anita, 2004). Gender-based violence has also affected female's access and ART adherence (Watch, 2007). Females report a range of abuses from beatings and rape to loss of property upon divorce or death of a spouse. These abuses influence female's behavior related to ART adherence (Watch, 2007). Although these barriers were not found in this study, the issue demands further exploration, particularly given the different social influences on males and females (Watt et al., 2009).

A number of qualitative studies have reported that food insufficiency is an important barrier to ART adherence (Au et al., 2006; Grant et al., 2008; Hardon et al., 2007; Murray et al., 2009). However, quantitative evidence to support this hypothesis is limited. In urban Peru, Franke et al. (2010) found that individuals who reported food insufficiency in the month prior to interview were more likely to experience suboptimal adherence than those who did not. In Atlanta, Georgia in the United States, there was a consistent association between ART adherence and markers of food insecurity such as running out of food, cutting back meals and going hungry (Kalichman & Grebler, 2010). Other indirect quantitative evidence comes from a pilot study in Zambia, which found that individuals with food insecurity who received

nutritional support demonstrated significantly better ART adherence compared with a group who did not receive this support (Cantrell et al., 2008).

Contrary to previous findings (Franke et al., 2010; Kalichman & Grebler, 2010), this study found that the experience of food insufficiency in the previous 30 days from the baseline interview date was positively associated with ART adherence. More studies are needed to better understand the association between ART adherence and food issues. A single question was used to assess food insufficiency in this study, which is only one aspect of food insecurity. However, results may be explained by enhanced social support among people living in such extreme poverty that they cannot afford to buy food, which has been indirectly explained as good adherence (Cantrell et al., 2008). The World Food Program (WFP) has been implemented in Zambia since 1967 and is committed to providing food assistance to approximately 2.3 million people in Zambia in 2011(WFP, 2011). The ART clients who suffer from insufficient food might easily receive such assistance.

Regarding HIV disclosures, over 80% disclosed to their spouse. This was positively associated with ART adherence in bivariate analysis, although it was not seen in the final model. The spousal disclosure rate was relatively higher than in a previous study conducted in another part of rural Zambia in 2005–2006 (Birbeck et al., 2009). The higher rate of disclosure in this study may be attributed to the establishment of peer counselors or treatment supporters

during the past few years in Zambia, which encourages disclosure and ART adherence in the DH and RHCs. Such programmatic actions and expansion of ART services which might make HIV less stigmatized could increase spousal disclosure rates.

However, disclosure can still have both positive and negative consequences. Disclosure has the potential to yield much-needed social support. Alternatively, it may also lead to stigmatization, discrimination or abandonment (Birbeck et al., 2009). Some of these concerns may be particularly important for female clients, who depend on the support of male partners for their livelihood as well as their children's. Results in this study showed that disclosure to siblings and mothers was more common among female clients than male clients. In addition to the perceived stability of family relationships relative to marital/sexual relationships, female clients may be more likely to need economic and emotional support from their family because of negative events that could possibly occur after disclosing their HIV status to their male spouse or partners. This result was congruent with previously published research (Birbeck et al., 2009).

Spousal use of ART was found to be positively associated with ART adherence in this study. To the best of my knowledge, no studies have found any association between ART adherence and spousal use of ART, although associations between ART adherence and spousal disclosure or spousal HIV status were previously investigated (Birbeck et al., 2009;

Unge et al., 2010; Weiser et al., 2003). Having a treatment partner such as a spouse, family member, friend or peer counselor is reportedly positively associated with ART adherence (Stubbs, Micek, Pfeiffer, Montoya, & Gloyd, 2009). Treatment partners are defined as the people who follow clients taking ART over time, with the goal of providing social support and encouraging clients to take their medications as prescribed (Stubbs et al., 2009). Spouses on ART might play a role as a treatment partner more spontaneously than spouses not on ART because they have a better understanding of ART adherence for their partners and themselves. Given that married clients were less likely to be depressed in this study, spouses might also contribute to decreasing their partners' depression level. While it could not be determined from the results whether spouses were supportive, ART programs should consider the potential benefit of providing treatment support from surroundings, especially from those on ART. In addition, counseling for HIV positive couples should be strengthened with regular sessions on prevention and treatment because HIV positive couples are known to have more unprotected sex and run the risk of re-infection, with one partner infecting the other with a different and potentially more virulent strain of HIV that might worsen their condition (Smith, 1998; Venkatesh et al., 2011).

The pathways through which self-stigma and depressive symptoms influence ART adherence remain understudied in Zambia. To enhance understanding of self-stigma and

depressive symptoms among ART clients, these associations were assessed.

Having self-stigma at the initiation of ART was negatively associated, and a decrease in self-stigma six weeks after starting ART was positively associated with ART adherence. Although the mechanisms linking self-stigma to poor adherence are not well known, a possible explanation for this association is that clients who have self-stigma at the initiation of ART are less enthusiastic about seeking regular medical care, filling their prescriptions and taking their medications because of concern about being inadvertently 'outed' as HIV positive (Vanable et al., 2006). They internalize shame, blame, hopelessness, guilt and fear of discrimination associated with being HIV positive, which are symptoms of self-stigma.

However, access to health facilities and ART might reduce self-stigma, as shown in a previous study (Kaai et al., 2007). This association may have been reflected in the present study result showing that clients who needed more than one hour to get to health facilities were significantly more likely to have self-stigma. Moreover, being on ART might improve clients' physical health, contributing to improvements in self-image and self-worth and leading to reductions in fears of disclosure and negative public attitudes. Long-term HIV care must include assessment and treatment of self-stigma, and more work is needed to determine what factors may either mitigate or heighten the self-stigma that HIV positive people feel (Lee, Kochman, & Sikkema, 2002). It is also important to continue ongoing stigma-reduction efforts

with expanding ART in rural areas in Zambia, such as providing information, fostering community involvement in ART, providing treatment support and carrying out activities to reduce stigma and discrimination.

Although depression has been identified as a factor associated with poor adherence in multiple studies, no association was found between depressive symptoms at the initiation of ART and ART adherence. The limited numbers of subjects with poor adherence may have prevented the identification of potential associations (Ramadhani et al., 2007).

However, an increase in depressive symptoms six weeks after starting ART was positively associated with ART adherence in this study. While most previous studies investigated whether ART clients were depressed at a given point in time, changes in cognitive/affective depression scale scores six weeks after starting ART were compared with depressive symptoms at baseline in this study. Some level of depression may function as a motivator for ART adherence, with self-protective alertness about following the medication regimen related to post-traumatic stress disorder (PTSD) symptoms and ART adherence, as shown in a Swedish study (Nilsson et al., 2007).

On the other hand, the results might also be explained by the concept of ART adherence proposed by Jones et al. (2002). That study described ART adherence as being ‘constantly tethered’, echoing the ‘life in a pill bottle’ metaphor and reflecting the central focus of HIV

medications in clients' lives as they attempt to incorporate the new behavior of scheduled medication taking into their daily lives. Those results showed that integrating daily pill taking was a constant battle, especially for female clients, because they already tended to have more complicated daily lives with money worries. ART adherence as 'perseverance' was a daily struggle taken 'one day at a time'. In the present study, the 'life in a pill bottle' metaphor likely applied to the lives of the ART clients, contributing to depression even when they adhered to their medication regimen.

The results that full ART adherence was predicted by gender (females), and female clients were more likely to be depressed were also supported by previous findings that female clients were more likely to feel the 'life in a pill bottle' metaphor (Jones, 2002).

Moreover, clients on ART might feel pressure and experience increased depressive symptoms because incomplete adherence can quickly lead to viral mutation and drug resistance once ART is initiated, although they must deal with the rigors of adhering to a difficult medicine regimen and its side effects (Jones, 2002). Taking medicines is also time consuming, a constant reminder of HIV positive status for life and conflicts with confidentiality. These factors might worsen depressive symptoms after ART initiation. Assessment and treatment of depressive symptoms should be incorporated into ongoing HIV care even after starting ART.

Additionally, this study found an association between self-stigma and depressive symptoms. This finding is consistent with previous studies showing that poor psychological health of PLWH was associated with higher levels of self-stigma (Lee et al., 2002; Vanable et al., 2006).

There is growing evidence that treatment of mental distress likely increases ART adherence (Dalessandro et al., 2007; Himelhoch et al., 2009; Yun, Maravi, Kobayashi, Barton, & Davidson, 2005). For example, Himelhoch et al. (2009) found that clients who attended six or more mental health sessions per year were less likely to discontinue ART compared with those who attended less than six, among a sample of 4,989 ART users with serious mental disorders. Results of both previous studies and this study suggest that interventions for improving ART adherence must take into account therapeutic techniques and strategies used in the treatment of self-stigma and depressive symptoms for ART clients.

The three most frequently cited reasons for missing doses by this study population were 1) being away from home; 2) food insufficiency; and 3) being busy with other things like work. This observation is consistent with findings in previous studies (Bhat et al., 2010; Byakika-Tusiime et al., 2009; Garang et al., 2009; Hardon et al., 2007; Krebs et al., 2008; Mills, Nachega, Bangsberg et al., 2006; Mills, Nachega, Buchan et al., 2006; Mugusi et al., 2009; Murray et al., 2009; Muyingo et al., 2008; Nachega et al., 2004; Olowookere, Fatiregun,

Akinyemi, Bamgboye, & Osagbemi, 2008; Sanjobo et al., 2008; Shah et al., 2007; Wang & Wu, 2007).

Clients in Mumbwa probably needed more time to get to treatment facilities than clients living in urban areas. This is supported by the result that it took over half the clients in this study more than one hour to get to the DH or RHCs. Because of this regional situation, clients who miss doses might report that the distance from home to the DH or RHCs caused the disruption in ART adherence. This might represent an increased risk for missing doses, although time required for transportation to the DH or RHCs and transportation fees were not significantly associated with ART adherence.

Food insufficiency is an added concern for poor clients not covered by food support. The body needs extra nutrition as it regains strength and weight in the initial treatment phase. As shown in previous studies, some medicines have to be taken with food, and some clients took their medicines only once a day (instead of twice daily) because that is the only time they had food (Hardon et al., 2007; Weiser et al., 2010). Food insufficiency also affects ART adherence due to side effects and access to health facilities. It potentiates drug toxicity (Casey, 1997; Salomon, De, & Melchior, 2002) and deprives clients of the energy to travel to health facilities to collect medicines (Marston & De Cock, 2004).

On the other hand, experiencing food insufficiency in the previous 30 days from the

baseline interview date was positively associated with ART adherence in this study. This might be understood by considering the timing of the interviews. The question about reasons for missing doses was asked six weeks after starting ART, while the question regarding food insufficiency was also asked at the initiation of ART. Therefore, clients who experienced food insufficiency in the 30 days previous to ART initiation might easily have gotten food supplementation or counseling afterward. On the contrary, clients who were not so poor that they ever experienced food insufficiency might have received less support. In addition, some clients might have needed financial assistance for transportation and could have lost wages due to long waiting times for a check-up. They might eventually fall into poverty even if the ART services are provided free of charge in Zambia. Thus, individuals who missed ART doses might consider food insufficiency the reason.

Although it was not significant in multivariable logistic regression analysis, clients whose occupation was agriculture were more likely to have poor adherence. It is possible that clients who worked in agriculture had difficulty coming for medicines because of their work's seasonal nature. This might be corroborated by the study finding that being busy with other things like work was the major reason for missing ART doses.

4-3. Implications

As far as the researcher could find, this was the first study to broadly identify and quantitatively examine factors related to ART adherence, focusing on associations between ART adherence and mental health issues at the early months of treatment in a rural setting in Zambia.

There are several implications of these findings. Full adherence to ART was relatively lower than in other Sub-Saharan countries. Self-report adherence measurements should include not only adherence to dose instructions, but also adherence to dosing schedule to increase validity and avoid overestimation.

In addition, decentralization of ART services through mobile facilities is necessary to strengthen and improve the quality of services by effective use of infrastructure, financing, and human resources. For example, integration of programs is needed, especially prevention activities related to HIV/AIDS, viral hepatitis, other STDs and TB. In addition, a referral network between health facilities and different organizations for comprehensive HIV care and treatment services as well as continued contact with clients and families who need ongoing care and support is important. There is also a need for training of nurse and non-clinical personnel such as community health workers and peer counselors.

Given that gender differences in ART adherence emerged and spousal use of ART were

predictors of ART adherence in this study, interpersonal factors, including gender-related issues, should be further explored, focusing on different social influences on males and females in rural Zambia.

Food insufficiency was also associated with ART adherence. Because illness and death can disrupt the farming cycle and reduce the ability of households to produce and buy food, it is necessary for poverty reduction strategies to mitigate the influence of HIV infection and reduce future vulnerability. Food supplementation by support programs might be beneficial, although it might be necessary to reexamine the criteria for such support.

However, there are potential risks of such support programs, such as fueling discrimination and decreasing clients' motivation in life. Policies should direct resources in a more sustainable manner, such as promoting early HIV testing to reduce the risk of severe illnesses as well as ensuring employment and working opportunities for the poor and those who fall into poverty after HIV infection.

This study revealed the necessity of mental health care for clients who have self-stigma at the initiation of ART. In addition, assessment, follow-up and continuing management of mental illness are necessary even after the initiation of ART. It is important to examine and strengthen mental health care services as part of the overall HIV care program.

4-4. Limitations

This study has several limitations. First, assessment of ART adherence based on self-report may be subject to recall and social desirability bias that may result in under-reporting of missed pill intakes. Thus, an under-estimation of non-adherence is possible, although there is evidence that a simple self-report adherence questionnaire provides a sensitive measure of non-adherence that predicts viral rebound and is almost always reliable (Chesney, 2000; Glass et al., 2008; Shi et al., 2010).

Second, a comparison of the main characteristics of clients who were included or excluded in this study showed that the latter required less time to get to the health facilities. However, this influence on the study results may be relatively limited, with no other significant difference in basic sociodemographic or health characteristics between clients who were included or excluded.

Third, this study had a relatively small sample size. For this reason, findings cannot be generalized to the broader community. In addition, a limited number of variables were entered into the multiple logistic regression model to avoid unreliable results, although we did identify some significant factors related to adherence.

Fourth, we only asked one question about food insufficiency during the past one month both at baseline and follow-up interviews because interview time was limited so as to decrease

the clients' burden. Therefore, we could not investigate the broader construct of food issues at the time of the interviews.

Fifth, recent changes such as the adoption of free access to ART in Zambia may have some implications for the study results. While it is expected that this policy will reduce financial constraints, the high level of other health expenditures still experienced by clients suggests that the detrimental influence of out-of-pocket payments will certainly not be fully eliminated. Further studies are needed to assess this policy for ART adherence and treatment interruptions.

Finally, related to recent changes in Zambia, this study was conducted in a rural area where mobile ART services have been initiated. Therefore, it is difficult to generalize the study findings to the population in areas where mobile ART services are not yet available, although there were no differences in clients' characteristics between clients who visited the DH and RHCs.

Chapter 5: Conclusions and Recommendations

ART adherence continues to be a significant behavioral challenge in HIV medical care. Based on adherence to dose and schedule, there was a relatively low level of ART adherence in this rural area where ART services have become widespread. Scaling-up ART services should entail implementing and improving a broad range of HIV services. Regarding the feasibility of expanding mobile ART services, more human resources and an increased budget may be needed. Community members such as well-trained peer counselors and treatment partners should be more involved in the services than at present to address skilled personnel shortages. In addition, a database system with clinical information is also imperative for improvements in clinical care using mobile ART services in rural Zambia. Therefore, individuals who are well-trained in data capture are also essential.

The study showed that female gender, food insufficiency in the previous 30 days and a spouse on ART were associated with full ART adherence. Related to mental health issues, no self-stigma at the initiation of ART, being more depressed and having less self-stigma after six weeks compared with at the initiation of ART were also associated. These are likely the issues that ART services will need to focus on in the future beyond current efforts such as increasing accessibility by expanding mobile ART services in rural areas in Zambia.

In particular, adherence issues associated with mental health challenges should be

addressed through a comprehensive approach to HIV care. Self-stigma reduction interventions should be the priority in this population to enhance adherence to ART. HIV counseling and support services should include clients' self-stigma concerns prior to and during the early months of treatment, providing a better understanding of gender differences in treatment and food security situations among ART clients.

This study investigated clients' adherence to ART over a short period of time, because the initial response to ART has long-term prognostic significance, and optimizing adherence in the early months is important for ensuring long-term immunological and virological success (Carrieri, Raffi et al., 2003; Chene et al., 2003). However, the information at follow-up after six weeks on ART was limited, and long-term analyses are clearly needed to fully assess factors related to ART adherence and to allow some generalizability of the results. Future studies should examine ART adherence over longer time scales, or even lifetime adherence.

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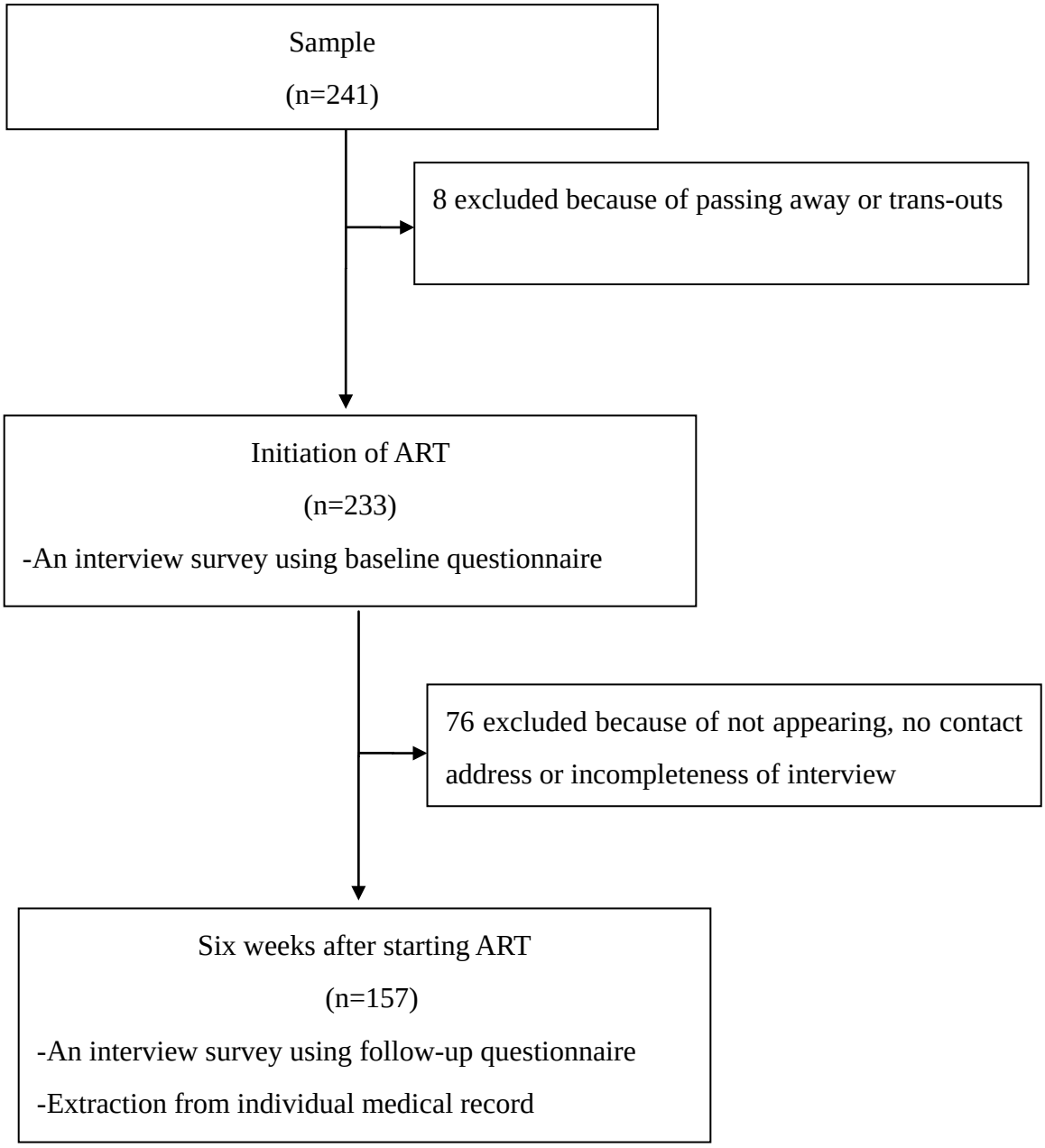

Figure 1. Description of study sample

Table 1. Sociodemodraphic and economic characteristics of clients who were excluded compared with those included in the study

	Excluded (n=84) n	(%)	Included (n=157) n	(%)	p-value
Site					
Mumbwa District Hospital	42	(50.0)	74	(47.1)	0.671
Rural Health Centers	42	(50.0)	83	(52.9)	
Age					
<35 years old	40	(47.6)	70	(46.1)	0.817
≥35 years old	44	(52.4)	82	(53.9)	
Sex					
Female	43	(51.2)	94	(59.9)	0.195
Male	41	(48.8)	63	(40.1)	
Education					
No or primary incomplete	39	(46.4)	77	(49.4)	0.665
Primary complete or more	45	(53.6)	79	(50.6)	
Marital status					
Married	46	(55.4)	105	(66.9)	0.080
Not married	37	(44.6)	52	(33.1)	
Occupation					
Agriculture	49	(58.3)	107	(68.2)	0.128
Others	35	(41.7)	50	(31.8)	
Transportation					
On foot	50	(59.5)	80	(51.0)	0.204
Others	34	(40.5)	77	(49.0)	
Time required for transportation to health facilities by above method					
Within one hour	51	(61.4)	70	(45.2)	0.017*
More than one hour	32	(38.6)	85	(54.8)	
Transportation cost					
Zero	72	(85.7)	127	(80.9)	0.347
More than zero	12	(14.3)	30	(19.1)	
Lack of food during the past 30 days					
Yes	27	(32.5)	61	(38.9)	0.334
No	56	(67.5)	96	(61.1)	

Pearson's chi-square test; *$p<0.05$.

Table 2. Physical health, self-stigma and depressive symptoms of clients who were excluded compared with those included in the study

	Excluded (n=84) n	(%)	Included (n=157) n	(%)	p-value
Knowing HIV status					
Within 30 days	34	(40.5)	65	(41.7)	0.858
More than 30 days	50	(59.5)	91	(58.3)	
Test was					
Voluntary	50	(71.4)	118	(77.1)	0.360
Others	20	(28.6)	35	(22.9)	
CD4					
<154	43	(51.2)	77	(50.0)	0.861
≥154	41	(48.8)	77	(50.0)	
Disease stage at one month and a half					
Ⅰor Ⅱ	40	(50.0)	78	(50.0)	1.000
Ⅲor Ⅳ	40	(50.0)	78	(50.0)	
Functional status					
Working	69	(85.2)	138	(87.9)	0.556
Ambulant or bed lid	12	(14.8)	19	(12.1)	
Tuberculosis					
Positive	9	(11.1)	11	(7.1)	0.286
Negative or not sure	72	(88.9)	145	(92.9)	
Self-stigma at baseline					
Yes (Score:2-6)	52	(62.7)	87	(56.5)	0.359
No (Score:0-1)	31	(37.3)	67	(43.5)	
Depressive symptoms at baseline					
Yes (Score:13-33)	50	(62.5)	92	(58.6)	0.562
No (Score:0-12)	30	(37.5)	65	(41.4)	
Pearson's chi-square test.					

Table 3. Sociodemographic and economic characteristics

	Total (n=157) n	(%)	Not full adherence (n=63) n	(%)	Full adherence (n=94) n	(%)	p-value		No Self-stigma (Score:0-1) (n=67) n	(%)	Self-stigma (Score:2-6) (n=87) n	(%)	p-value		No Depressve symptoms (Score: 0-12) (n=65) n	(%)	Depressive symptoms (Score:13-33) (n=92) n	(%)	p-value	
Site																				
Mumbwa District Hospital	74	(47.1)	32	(50.8)	42	(44.7)	0.452		27	(40.3)	44	(50.6)	0.205		26	(40.0)	48	(52.2)	0.132	
Rural Health Centers	83	(52.9)	31	(49.2)	52	(55.3)			40	(59.7)	43	(49.4)			39	(60.0)	44	(47.8)		
Age																				
<35 years old	70	(46.1)	25	(41.7)	45	(48.9)	0.381		26	(39.4)	43	(51.8)	0.131		24	(38.1)	46	(51.7)	0.098	
≥35 years old	82	(53.9)	35	(58.3)	47	(51.1)			40	(60.6)	40	(48.2)			39	(61.9)	43	(48.3)		
Sex																				
Female	94	(59.9)	30	(47.6)	64	(68.1)	0.010	*	37	(55.2)	56	(64.4)	0.250		32	(49.2)	62	(67.4)	0.022	*
Male	63	(40.1)	33	(52.4)	30	(31.9)			30	(44.8)	31	(35.6)			33	(50.8)	30	(32.6)		
Education																				
No or primary incomplete	77	(49.4)	30	(48.4)	47	(50.0)	0.844		37	(55.2)	40	(46.5)	0.285		36	(55.4)	41	(45.1)	0.203	
Primary complete or more	79	(50.6)	32	(51.6)	47	(50.0)			30	(44.8)	46	(53.5)			29	(44.6)	50	(54.9)		
Marital status																				
Married	105	(66.9)	45	(71.4)	60	(63.8)	0.321		47	(70.1)	55	(63.2)	0.367		50	(76.9)	55	(59.8)	0.025	*
Not married	52	(33.1)	18	(28.6)	34	(36.2)			20	(29.9)	32	(36.8)			15	(23.1)	37	(40.2)		
Occupation																				
Agriculture	107	(68.2)	26	(41.3)	24	(25.5)	0.038	*	41	(61.2)	65	(74.7)	0.073		42	(64.6)	65	(70.7)	0.055	
Others	50	(31.8)	37	(58.7)	70	(74.5)			26	(38.8)	22	(25.3)			23	(35.4)	27	(29.3)		
Number of adults(18 years or more) living together																				
<3	65	(42.8)	24	(38.7)	41	(45.6)	0.402		34	(50.7)	29	(35.4)	0.059		29	(46.0)	36	(40.4)	0.493	
≥3	87	(57.2)	38	(61.3)	49	(54.4)			33	(49.3)	53	(64.6)			34	(54.0)	53	(59.6)		
Number of children (less than 18 years)																				
<3	36	(26.5)	16	(29.1)	20	(24.7)	0.568		14	(21.9)	21	(30.0)	0.285		16	(26.7)	20	(26.3)	0.963	
≥3	100	(73.5)	39	(70.9)	61	(75.3)			50	(78.1)	49	(70.0)			44	(73.3)	56	(73.7)		
Transportation																				
On foot	80	(51.0)	36	(57.1)	44	(46.8)	0.204		33	(49.3)	49	(51.7)	0.761		30	(46.2)	50	(54.3)	0.312	
Others	77	(49.0)	27	(42.9)	50	(53.2)			34	(50.7)	31	(48.3)			35	(53.8)	42	(45.7)		
Time required for transportation to health facilities by above method																				
Within one hour	70	(45.2)	29	(46.8)	41	(44.1)	0.742		37	(56.9)	32	(36.8)	0.014	*	29	(46.0)	41	(44.6)	0.857	
More than one hour	85	(54.8)	33	(53.2)	52	(55.9)			28	(43.1)	55	(63.2)			34	(54.0)	51	(55.4)		
Transportation cost																				
Zero	127	(80.9)	50	(79.4)	77	(81.9)	0.690		54	(80.6)	70	(80.5)	0.983		55	(84.6)	53	(78.3)	0.319	
More than zero	30	(19.1)	13	(20.6)	17	(18.1)			13	(19.4)	17	(19.5)			10	(15.4)	16	(21.7)		
Lack of food during the past 30 days																				
Yes	61	(38.9)	14	(22.2)	47	(50.0)	<0.001	***	36	(53.7)	60	(69.0)	0.053		34	(52.3)	62	(67.4)	0.056	
No	96	(61.1)	49	(77.8)	47	(50.0)			31	(46.3)	27	(31.0)			31	(47.7)	30	(32.6)		

Pearson's chi-square test; *p<0.05; ***p<0.001.

Table 4. Medication and physical health characteristics

	Total (n=157) n	(%)	Not full adherence (n=63) n	(%)	Full adherence (n=94) n	(%)	p-value		No Self-stigma (Score:0-1) (n=67) n	(%)	Self-stigma (Score:2-6) (n=87) n	(%)	p-value		No Depressve symptoms (Score: 0-12) (n=65) n	(%)	Depressive symptoms (Score:13-33) (n=92) n	(%)	p-value	
Knowing HIV status																				
Within 30 days	65	(41.7)	37	(39.8)	28	(44.4)	0.562	a	29	(43.3)	34	(39.5)	0.640	a	26	(40.6)	39	(42.4)	0.826	a
More than 30 days	91	(58.3)	56	(60.2)	35	(55.6)			38	(56.7)	52	(60.5)			38	(59.4)	53	(57.6)		
Test was																				
Voluntary	118	(77.1)	43	(71.7)	75	(80.6)	0.197	a	54	(80.6)	61	(73.5)	0.307	a	48	(75.0)	70	(78.7)	0.596	a
Others	35	(22.9)	17	(28.3)	18	(19.4)			13	(19.4)	22	(26.5)			16	(25.0)	19	(21.3)		
Remind yourself of the time to take ART by (Multiple answers)	n=155																			
Use watch or clock	105	(67.7)																		
Use mobile phone	51	(32.9)																		
Position of the sun	15	(9.7)																		
Use radio	15	(9.7)																		
Use television	2	(1.3)																		
Nothing	4	(2.6)																		
CD4 count																				
<154	77	(50.0)	29	(47.5)	48	(51.6)	0.621	a	28	(41.8)	47	(56.0)	0.084	a	32	(50.8)	45	(49.5)	0.870	a
≥154	77	(50.0)	32	(52.5)	45	(48.4)			39	(58.2)	37	(44.0)			31	(49.2)	46	(50.5)		
Disease stage																				
Ⅰor Ⅱ	78	(50.0)	28	(44.4)	50	(53.8)	0.253	a	34	(50.7)	41	(47.7)	0.706	a	35	(54.7)	43	(46.7)	0.329	a
ⅢorⅣ	78	(50.0)	35	(55.6)	43	(46.2)			33	(49.3)	45	(52.3)			29	(45.3)	49	(53.3)		
Functional status																				
Working	138	(87.9)	58	(92.1)	80	(85.1)	0.190	a	61	(91.0)	74	(85.1)	0.263	a	60	(92.3)	78	(84.8)	0.154	a
Ambulant or bed lid	19	(12.1)	5	(7.9)	14	(14.9)			6	(9.0)	13	(14.9)			5	(7.7)	14	(15.2)		
Tuberculosis																				
Positive	11	(7.1)	5	(7.9)	6	(6.5)	0.722	a	4	(6.1)	6	(6.9)	0.836	a	4	(6.3)	7	(7.6)	1.000	b
Negative or not sure	145	(92.9)	58	(92.1)	87	(93.5)			62	(93.9)	81	(93.1)			60	(93.8)	85	(92.4)		

a: Pearson's chi-square test; b: Fisher's exact test.

Table 5-1. Interpersonal characteristics

	Total		Not full adherence		Full adherence			No Self-stigma (Score:0-1)		Self-stigma (Score:2-6)			No Depressve symptoms (Score: 0-12)		Depressive symptoms (Score:13-33)		
	(n=157) n	(%)	(n=63) n	(%)	(n=94) n	(%)	p-value	(n=67) n	(%)	(n=87) n	(%)	p-value	(n=65) n	(%)	(n=92) n	(%)	p-value
People in community know that my HIV status even though I did not tell them																	
Yes	48	(33.6)	21	(37.5)	27	(31.0)	0.424 [a]	25	(40.3)	23	(29.5)	0.180 [a]	21	(36.2)	27	(31.8)	0.581 [a]
No or unsure	95	(66.4)	35	(62.5)	60	(69.0)		37	(59.7)	55	(70.5)		37	(63.8)	58	(68.2)	
First wife/husband's HIV status if married (including divorced, separated, widow/widower)																	
Positive	58	(44.6)	20	(37.7)	38	(49.4)	0.190 [a]	27	(45.8)	29	(42.6)	0.724 [a]	29	(48.3)	29	(41.4)	0.430 [a]
Negative or unsure	72	(55.4)	33	(62.3)	39	(50.6)		32	(54.2)	39	(57.4)		31	(51.7)	41	(58.6)	
First wife/husband is (was) on ART(including divorced, separated, widow/widower)																	
Yes	36	(29.3)	10	(20.0)	26	(35.6)	0.062 [a]	17	(30.4)	17	(26.6)	0.645 [a]	16	(29.1)	20	(29.4)	0.969 [a]
No or unsure	87	(70.7)	40	(80.0)	47	(64.4)		39	(69.6)	47	(73.4)		39	(70.9)	48	(70.6)	
First sexual partner's HIV status excluding wife/husband																	
Positive	0	0.0	0	0.0	0	0.0		0	0.0	0	0.0		0	0.0	0	0.0	
Negative or unsure	21	(100.0)	10	(100.0)	11	(100.0)		11	(100.0)	10	(100.0)		9	(100.0)	12	(100.0)	
First sexual partner excluding wife/husband is on ART																	
Yes	0	0.0	0	0.0	0	0.0		0	0.0	0	0.0		0	0.0	0	0.0	
No or unsure	18	(100.0)	9	(100.0)	9	(100.0)		10	(100.0)	8	(100.0)		8	(100.0)	10	100.0	
I think HIV infection is a manageable condition																	
Yes	98	(73.7)	39	(75.0)	59	(72.8)	0.782 [a]	37	(72.5)	60	(75.9)	0.664 [a]	39	(70.9)	59	(75.6)	0.542 [a]
No or unsure	35	(26.3)	13	(25.0)	22	(27.2)		14	(27.5)	19	(24.1)		16	(29.1)	19	(24.4)	

a: Pearson's chi-square test; b: Fisher's exact test.

Table 5-2. Interpersonal characteristics (related to disclosure)

Disclose to	Total (n=157) n	(%)	Not full adherence (n=63) n	(%)	Full adherence (n=94) n	(%)	p-value		No Self-stigma (Score:0-1) (n=67) n	(%)	Self-stigma (Score:2-6) (n=87) n	(%)	p-value		No Depressve symptoms (Score: 0-12) (n=65) n	(%)	Depressive symptoms (Score:13-33) (n=92) n	(%)	p-value	
First wife/husband if married																				
Yes	89	(85.6)	35	(77.8)	54	(91.5)	0.048	a*	43	(91.5)	44	(77.2)	0.064	b	45	(90.0)	45	(78.9)	0.119	a
No	15	(14.4)	10	(22.2)	5	(8.5)			4	(8.5)	13	(22.8)			5	(10.0)	12	(21.1)		
First extra sexual partner																				
Yes	13	(59.1)	7	(63.6)	6	(54.5)	1.000	b	7	(63.6)	6	(54.5)	1.000	b	3	(42.9)	10	(66.7)	0.376	b
No	9	(40.9)	4	(36.4)	5	(45.5)			4	(36.4)	5	(45.5)			4	(57.1)	5	(33.3)		
Daughter/Son																				
Yes	47	(33.3)	18	(30.5)	29	(35.4)	0.546	a	25	(40.3)	21	(27.3)	0.104	a	21	(33.9)	26	(32.9)	0.905	a
No	94	(66.7)	41	(69.5)	53	(64.6)			37	(59.7)	56	(72.7)			41	(66.1)	53	(67.1)		
Sibling																				
Yes	85	(57.0)	31	(50.8)	54	(61.4)	0.201	a	23	(35.9)	39	(47.6)	0.159	a	29	(47.5)	56	(63.6)	0.051	a
No	64	(43.0)	30	(49.2)	34	(38.6)			41	(64.1)	43	(52.4)			32	(52.5)	32	(36.4)		
Mother																				
Yes	59	(37.8)	20	(31.7)	39	(41.9)	0.198	a	24	(35.8)	34	(39.5)	0.639	a	19	(29.7)	40	(43.5)	0.081	a
No	97	(62.2)	43	(68.3)	54	(58.1)			43	(64.2)	52	(60.5)			45	(70.3)	52	(56.5)		
Father																				
Yes	49	(31.4)	19	(30.2)	30	(32.3)	0.782	a	21	(31.3)	27	(31.4)	0.995	a	15	(23.4)	34	(37.0)	0.074	a
No	107	(68.6)	44	(69.8)	63	(67.7)			46	(68.7)	59	(68.6)			49	(76.6)	58	(63.0)		
Mother-in-law																				
Yes	34	(23.9)	15	(25.9)	19	(22.6)	0.656	a	17	(27.4)	16	(20.8)	0.360	a	11	(17.5)	23	(29.1)	0.106	a
No	108	(76.1)	43	(74.1)	65	(77.4)			45	(72.6)	61	(79.2)			52	(82.5)	56	(70.9)		
Father-in-law																				
Yes	28	(19.7)	12	(20.7)	16	(19.0)	0.809	a	16	(25.8)	11	(14.3)	0.088	a	8	(12.7)	20	(25.3)	0.060	a
No	114	(80.3)	46	(79.3)	68	(81.0)			46	(74.2)	66	(85.7)			55	(87.3)	59	(74.7)		
Other relatives																				
Yes	73	(46.5)	32	(50.8)	41	(43.6)	0.377	a	33	(49.3)	39	(44.8)	0.585	a	28	(43.1)	45	(48.9)	0.470	a
No	84	(53.5)	31	(49.2)	53	(56.4)			34	(50.7)	48	(55.2)			37	(56.9)	47	(51.1)		
Friend																				
Yes	52	(33.1)	23	(36.5)	29	(30.9)	0.460	a	25	(37.3)	26	(29.9)	0.332	a	19	(29.2)	33	(35.9)	0.384	a
No	105	(66.9)	40	(63.5)	65	(69.1)			42	(62.7)	61	(70.1)			46	(70.8)	59	(64.1)		
Support group member																				
Yes	16	(10.2)	7	(11.1)	9	(9.6)	0.755	a	10	(14.9)	5	(5.7)	0.057	a	6	(9.2)	10	(10.9)	0.738	a
No	141	(89.8)	56	(88.9)	85	(90.4)			57	(85.1)	82	(94.3)			59	(90.8)	82	(89.1)		
Others																				
Yes	4	(2.5)	1	(1.6)	3	(3.2)	0.650	b	2	(3.0)	1	(1.1)	0.580	b	3	(4.6)	1	(1.1)	0.307	b
No	153	(97.5)	62	(98.4)	91	(96.8)			65	(97.0)	86	(98.9)			62	(95.4)	91	(98.9)		
Total number of persons disclosed outside DH/HC																				
<4	68	(44.7)	31	(50.8)	37	(40.7)	0.217	a	23	(35.4)	44	(52.4)	0.039	a*	35	(55.6)	33	(37.1)	0.024	a*
≥4	84	(55.3)	30	(49.2)	54	(59.3)			42	(64.6)	40	(47.6)			28	(44.4)	56	(62.9)		

a: Pearson's chi-square test; b: Fisher's exact test; *p<0.05.

Table 5-3. Interpersonal characteristics (related to sexual behavior)

	Total		Not full adherence		Full adherence			No Self-stigma (Score:0-1)		Self-stigma (Score:2-6)			No Depressve symptoms (Score: 0-12)		Depressive symptoms (Score:13-33)		
	(n=157) n	(%)	(n=63) n	(%)	(n=94) n	(%)	p-value	(n=67) n	(%)	(n=87) n	(%)	p-value	(n=65) n	(%)	(n=92) n	(%)	p-value
Extra sexual partner																	
Zero	130	(82.8)	50	(79.4)	80	(85.1)	0.350 [a]	54	(80.6)	73	(83.9)	0.592 [a]	55	(84.6)	75	(81.5)	0.613 [a]
More than zero	27	(17.2)	13	(20.6)	14	(14.9)		13	(19.4)	14	(16.1)		10	(15.4)	17	(18.5)	
Frequency of sexual intercourse after knowing your HIV status																	
Stopped	28	(22.4)	10	(20.0)	18	(24.0)	0.599 [a]	14	(24.1)	14	(20.9)	0.665 [a]	8	(15.4)	20	(27.4)	0.112 [a]
Continues	97	(77.6)	40	(80.0)	57	(76.0)		44	(75.9)	53	(79.1)		44	(84.6)	53	(72.6)	
Sexual intercourse without condom after knowing your HIV status																	
Yes	36	(33.0)	19	(41.3)	17	(27.0)	0.116 [a]	21	(42.0)	15	(25.9)	0.076 [a]	17	(34.7)	19	(31.7)	0.738 [a]
No	73	(67.0)	27	(58.7)	46	(73.0)		29	(58.0)	43	(74.1)		32	(65.3)	41	(68.3)	
Current use of contraceptive device																	
Use	67	(74.4)	30	(73.2)	37	(75.5)	0.800 [a]	30	(73.2)	37	(75.5)	0.800 [a]	30	(71.4)	11	(22.9)	0.539 [a]
No use	23	(25.6)	11	(26.8)	12	(24.5)		11	(26.8)	12	(24.5)		12	(28.6)	37	(77.1)	
Pregnant(for women)																	
Yes	6	(6.6)	2	(7.1)	4	(6.3)	1.000 [b]	3	(8.1)	3	(5.7)	0.687 [b]	2	(6.5)	4	(6.7)	1.000 [b]
No	85	(93.4)	26	(92.9)	59	(93.7)		34	(91.9)	50	(94.3)		29	(93.5)	56	(93.3)	
Plan a(another) child																	
Yes	52	(36.9)	23	(41.1)	29	(34.1)	0.402 [a]	20	(33.3)	32	(39.5)	0.453 [a]	26	(45.6)	26	(31.0)	0.077 [a]
No	89	(63.1)	33	(58.9)	56	(65.9)		40	(66.7)	49	(60.5)		31	(54.4)	58	(69.0)	
Regular sexual partner wants to have a child																	
Yes	55	(49.1)	25	(51.0)	30	(47.6)	0.721 [a]	27	(50.9)	28	(47.5)	0.713 [a]	24	(45.3)	31	(52.5)	0.443 [a]
No or unsure	57	(50.9)	24	(49.0)	33	(52.4)		26	(49.1)	31	(52.5)		29	(54.7)	28	(47.5)	

a: Pearson's chi-square test; b: Fisher's exact test.

Table 5-4. Interpersonal characteristics (related to satisfaction with health services)

	Total		Not full adherence		Full adherence			No Self-stigma (Score:0-1)		Self-stigma (Score:2-6)			No Depressve symptoms (Score: 0-12)		Depressive symptoms (Score:13-33)		
	(n=157) n	(%)	(n=63) n	(%)	(n=94) n	(%)	p-value	(n=67) n	(%)	(n=87) n	(%)	p-value	(n=65) n	(%)	(n=92) n	(%)	p-value
Trust in clinical officer																	
Yes or soso	152	(97.4)	62	(98.4)	90	(96.8)	0.648	66	(98.5)	84	(97.7)	1.000	62	(95.4)	90	(98.9)	0.309
No	4	(2.6)	1	(1.6)	3	(3.2)		1	(1.5)	2	(2.3)		3	(4.6)	1	(1.1)	
Trust in nurse																	
Yes or soso	152	(98.1)	61	(98.4)	91	(97.8)	1.000	66	(98.5)	83	(97.6)	1.000	62	(96.9)	90	(98.9)	0.569
No	3	(1.9)	1	(1.6)	2	(2.2)		1	(1.5)	2	(2.4)		2	(3.1)	1	(1.1)	
Trust in treatment supporter or adherence counselor																	
Yes or soso	149	(96.1)	59	(95.2)	90	(96.8)	0.684	64	(95.5)	82	(96.5)	1.000	62	(96.9)	87	(95.6)	1.000
No	6	(3.9)	3	(4.8)	3	(3.2)		3	(4.5)	3	(3.5)		2	(3.1)	4	(4.4)	
Satisified with health services in DH or HC																	
Yes or soso	150	(96.8)	60	(96.8)	90	(96.8)	1.000	66	(98.5)	81	(95.3)	0.270	62	(96.9)	88	(96.7)	1.000
No	5	(3.2)	2	(3.2)	3	(3.2)		1	(1.5)	4	(4.7)		2	(3.1)	3	(3.3)	

Fisher's exact test.

Table 6. Mental health characteristics

	Total (n=157) n	(%)	Not full adherence (n=63) n	(%)	Full adherence (n=94) n	(%)	p-value
Self-stigma at baseline							
Yes (Score:2-6)	87	(56.5)	39	(61.9)	48	(52.7)	0.260
No (Score:0-1)	67	(43.5)	24	(38.1)	43	(47.3)	
Depressive symptoms at baseline							
Yes (Score:13-33)	92	(58.6)	38	(60.3)	54	(57.4)	0.720
No (Score:0-12)	65	(41.4)	25	(39.7)	40	(42.6)	

Pearson's chi-square test.

Table 7. Multiple logistic regression analysis of factors affecting adherence to ART (n=91)

Variable	B	SE	β	p		AOR	95% CI
Gender (Females)	0.24	0.09	0.24	0.006	**	6.35	1.71–23.52
Food problems during the last one month	0.24	0.10	0.24	0.009	**	5.73	1.55–21.18
Disclose HIV status to spouse	0.15	0.12	0.11	0.276		2.25	0.52–9.66
Spouse on ART	0.24	0.09	0.23	0.012	*	5.36	1.44–19.90
Having self-stigma (B)	−0.30	0.12	−0.30	0.010	*	0.12	0.02–0.60
Having depressive symptoms (B)	0.08	0.11	0.08	0.413		1.83	0.43–7.70
Self-stigma score(6w)−Self-stigma score(B)†	−0.07	0.02	−0.33	0.004	**	0.63	0.45–0.86
Depression score (6w)−Depression score(B)†	0.02	0.01	0.25	0.020	*	1.13	1.02–1.26
R^2	0.37						

B: Unstandardized coefficient; SE: Standard error; β :Standardized coefficient;p value significant at <0.05;
AOR: Adjusted odds ratio; CI: Confidence interval;R^2: Coefficient of determination; (B): Baseline; (6w): 6 weeks after the initiation of ART.

*p<0.05; **p<0.01;†Continuous variables; The AOR for continuous variables represented changes in the estimated odds of the outcome when the continuous variable increased by one unit.

Table 8. Reasons for missed doses (multiple answers) (n=39)

	n	(%)
Were away from home	21	(53.8)
Not enough food	20	(51.3)
Were busy with other things like work etc	15	(38.5)
Felt depressed, overwhelmed, hoplelessness	5	(12.8)
Forgot	4	(10.3)
Felt sick or ill	3	(7.7)
Ran out of pills	2	(5.1)
Traditional prohibition	2	(5.1)
Felt asleep or slept through dose time	1	(2.6)
Had a change in daily routine	1	(2.6)
Had problem taking pills at specific times with meals	1	(2.6)
Sold out the pills	1	(2.6)

Table 9. Association between self-stigma and depressive symptoms

	Self-stigma at baseline	Depressive symptoms at baseline	Self-stigma at follow-up
Self-stigma at baseline			
r			
p-value			
n=			
Depressive symptoms at baseline			
r	0.176		
p-value	0.029*		
n=	154		
Self-stigma at follow-up			
r	0.070	0.100	
p-value	0.392	0.218	
n=	150	153	
Depressive symptoms at follow-up			
r	-0.106	0.126	0.198
p-value	0.189	0.118	0.015*
n=	154	156	152

Spearman rank correlation coefficient; r: Correlation coefficient; *$p<0.05$.

Appendix1. Map of Zambia

Appendix 2. Timing of initiation of ART based on Zambia HIV National Guidelines

	WHO stage I*	**WHO stage II**	**WHO Stage III**	**WHO Stage IV**
CD4 <200 cells/µl	Treat	Treat	Treat	Treat
CD4 200-350 cells/µl	-Pregnant: Treat -Others: monitor and consider ART based on clinical or immunologic deterioration	-Pregnant: Treat -Others: monitor and consider ART based on clinical or immunologic deterioration	Treat	Treat
CD4 >350 cells/µl	-Do not treat -Monitor and consider ART based on clinical or immunologic deterioration	Monitor and consider ART based on clinical or immunologic deterioration	Treat	Treat
CD4 not available	-Do not treat -Monitor and consider ART based on clinical or immunologic deterioration	-Treat if total lymphocyte count <1200 -Monitor and consider ART based on clinical or immunologic deterioration	Treat	Treat

***** WHO (2007): WHO case definitions of HIV for surveillance and revised WHO clinical staging and immunological classification of HIV and case definition of HIV for surveillance.

Appendix 3. Questionnaires (Baseline questionnaire and Follow-up questionnaire)

Baseline questionnaire

Date:_____/_____/_____(day/month/year)	Research ID: _____
1☐Mumbwa D.Hos	ART No: _____
2☐Lungobe RHC	
3☐Keezwa RHC	
4☐Mwembezhi RHC	
5☐Kaindu RHC	
6☐Nalubanda RHC	
7☐Sichobo RHC	
8☐Nampundwe RHC	
9☐Mpusu RHC	

Don't read the sentence in italics and underlining. it is instructions for interviewer.

Socio-demographics&Disclosure (Generic tools for operational research)

S1.1 Just to confirm, is this a first time to take ART to manage your HIV infection?	1☐Yes 2☐No→*Go to the end.* *If the client was the serious condition in the first visit and could not be interviewed at the first visit, but he/she is in condition to be interviewed at the second visit (2 weeks later from his/her first visit), include the client.*
S1.2 Sex of the respondent	1☐ Female 2☐ Male
S1.3 How old are you? *In years*	( )Years old
S1.4 What is your religion?	1☐Christian 2☐Muslim 3☐Other, please specify:_____ 4☐Declined to answer
S1.5 What was the last level of schooling that you completed?	1☐No formal education 2☐Primary incomplete 3☐Primary complete 4☐Secondary/vocational incomplete 5☐Secondary/vocational complete 6☐Post secondary or more 7☐Other, please specify:_____ 8☐Declined to answer

Now I have some questions about the type of work you do and your access to food and health facility.

S2.1 What kind of work do you do? By that I mean, what kind of activities keep you busy during an average day, whether you earn money from them or not? *It is unnecessary to read all items of 1-12. Check all items that clients raised as their job.*	1☐Agriculture 2☐Fishing 3☐Commerce 4☐Clerical/employee 5☐Professional 6☐Skilled/semi-skilled labor 7☐Unskilled labor 8☐Student 9☐Apprentice 10☐Homemaker/housewife 11☐None (Probe: No agriculture or housework?) 12☐Other, please specify:_____
S2.2 During the past month, how often have you had problems getting the food you need? *Read all items of 1-4.*	1☐Never 2☐Sometimes 3☐Often 4☐Always
S2.3 How did you come here? *It is unnecessary to read all items of 1-7.Check the item that the client raised.*	1☐On foot 2☐Bicycle 3☐Scooter/motorcycle 4☐Mini Bus 5☐Vehicle/Car 6☐Ban 7☐Coachcut 8☐Others_____
S2.4 How long does it take from here to your home by means mentioned above? (One-way)	1☐Within 1 hours 2☐1-2 hours 3☐2-3 hours 4☐3-6 hours 5☐More than 6 hours
S2.5 How much does it cost for coming here? (One-way)	_____ZMK

Now I would like to ask you some question about your home and living conditions.

S3.1 How many members do you live with (including yourself) ? *Include children who are not own of the clients*	Adult ☐☐ Child (18>)☐☐

S3.2 Do you [or anyone cohabiting with you] own any of the following: *Read all items of a-k.*	Yes	No	Declined to answer
a. Drinking water from a tap/borehole?	1☐	2☐	3☐
b. Toilet?	1☐	2☐	3☐
c. Electricity?	1☐	2☐	3☐
d. Television?	1☐	2☐	3☐
e. Radio?	1☐	2☐	3☐
f. Electric or gas kitchen stove?	1☐	2☐	3☐
g. Landline?	1☐	2☐	3☐
h. Mobile phone?	1☐	2☐	3☐
i. Land?	1☐	2☐	3☐
j. Livestock/animals that are raised?	1☐	2☐	3☐
k. Bank/savings account?	1☐	2☐	3☐
S3.3 If you [or anyone cohabiting with you] own animals, what kind of animals and how many do you own? *If clients own 'Cattle','Goat','Chicken',or 'Pig', ask them the numbers of the domestic animals. (If the clients do not know the exact number, the rough number is acceptable)*	Do not own	Own	Numbers of animals
a. Cattle	☐	☐→	☐☐☐
b. Goat	☐	☐→	☐☐☐
c. Chicken	☐	☐→	☐☐☐
d. Pig	☐	☐→	☐☐☐

Treatment Module (Generic tools for operational research)

I would like to ask you about your experiences with taking ART and understanding your surroundings related to your HIV status.

Antiretroviral therapy

A4.1 When did you know your HIV positive status?	1☐0-7 days ago 2☐8-14 days ago 3☐15-30 days ago	4☐1-2 months ago 5☐3-4 months ago 6☐5-6 months ago	7☐More than 6 months ago

Dis5.1 Present marital status *Ask present marital status. If clients say 'Single', 'Divorced', 'Separated', 'Disappeared', or 'Widow/widower', skip Dis5.2-Dis5.5, and go to Dis5.6.*	1□Single (Never married)→Go to Dis5.6 2□Married→Go to Dis5.2 3□Divorced/separated/disappeared→Go to Dis5.6 4□Widow/widower→Go to Dis5.6	
Dis5.2 If you are married, how many wives/husbands do you have?	( )	
---Dis5.3 Have you ever told your HIV status to your first wife/husband? If yes, how soon did you tell it? If no, why you have not told your HIV status? *-If the client answered 'No', ask the reason of not having told his/her status to his/her first wife/husband.*	Yes 1□→ No 2□→	How soon? _____days after learning my HIV status Why you have not told your HIV status? Reasons: _____ _____
---Dis5.4 Have you ever told your HIV status to your second wife/husband? If yes, how soon? *-Even if the client answered 'No', it is unnecessary to ask the reason of not having told his/her status to his/her second wife/husband.*	Yes 1□→ No 2□	_____days after learning my HIV status
---Dis5.5 Have you ever told your HIV status to your third wife/husband? If yes, how soon? *-Even if the client answered 'No', it is unnecessary to ask the reason of not having told his/her status to his/her second wife/husband.*	Yes 1□→ No 2□	_____days after learning my HIV status
Dis5.6 How many extra sexual partners do you have?(eg. Boy/girl friend) *Extra sexual partner means sexual partners other than husbands or wives like boy/girl friends.*	0□No extra sexual partners Number of extra sexual partners ( )	
---Dis5.7 Have you ever told your HIV status to your first extra sexual partner? If yes, how soon did you tell it? If no, why you have not told your HIV status to your first extra sexual partner? *-if the client answered 'No', ask the reason of not having told his/her status to his/her first extra sexual partner.*	Yes 1□→ No 2□→	How soon? _____days after learning my HIV status Why you have not told your HIV status? Reasons: _____ _____
--Dis5.8 Have you ever told your HIV status to your second extra sexual partner? *-Even if the client answered 'No', it is unnecessary to ask the reason of not having told his/her status to his/her second extra sexual partner.*	Yes 1□→ No 2□	_____days after learning my HIV status

---Dis5.9 Have you ever told your HIV status to your third extra sexual partner? *-Even if the client answered 'No', it is unnecessary to ask the reason of not having told his/her status to his/her third extra sexual partner.*	Yes 1□→ No 2□	_____days after learning my HIV status
Dis5.10 Have you ever told your HIV status results to the following persons? If yes, how soon did you tell your status to these people after learning your status? *-Read all items of a-m, check all items that the clients answered 'Yes'.* *-Check the answer of Dis5.3-Dis5.5& Dis5.7-Dis5.9.* *-If clients never told the result with anyone outside the HC, choose 'Yes' in 'a', ask the reasons of not having told HIV status and check '0' in Dis5.11.* *-If clients told their HIV status only to their present husbands/wives or extra sexual partners, don't check 'Yes' in 'a' In that case, go to Dis5.11, and count the number of person that the clients told their HIV status to.* *Example: A client only told his/her HIV status to husband/wife, write '1' in Dis5.11.* a. I never told the results with anyone outside the HC including spouse and extra sexual partners.	□→	Why you have not told the result with anyone outside the HC including your spouse(s) or extra sexual partner(s)? Reasons: _____ _____
b. Divorced/separated/disappeared sexual partner before divorced/separated/his or her disappeared	□→	How soon? ___days after learning my HIV status
c. Deceased spouse before his/her death	□→	___days after learning my HIV status
d. Daughter/son *Ask total number of daughter/son and total number of dauters/sons he/she told his/her HIV status.* Total no of daughters/sons ( ) Total no of daughters/sons you disclosed ( )	□→	___days after learning my HIV status
e. Sibling *Ask total number of siblings and total number of siblings he/she told his/her HIV status.* Total no of siblings ( )	□→	___days after learning my HIV status

Total no of siblings you disclosed ( )			
f. Mother	☐→	___days after learning my HIV status	
g. Father	☐	___days after learning my HIV status	
h. Mother-in-law/Step mother	☐→	___days after learning my HIV status	
i. Father-in-law/Step father	☐→	___days after learning my HIV status	
j. Other relative	☐→	___days after learning my HIV status	
k. Friend *Ask total number of friend that he/she told his/her HIV status.* Total no of friends you told your HIV status( )	☐→	___days after learning my HIV status	
l. Self-support group members	☐	___days after learning my HIV status	
m. Others: please specify_____	☐→	___days after learning my HIV status	
Dis5.11 How many persons outside the HC, have you told your HIV status in total?	Total numbers (_____)		
Dis5.12 Do any other people in your community know that you are HIV-positive even though you did not tell them?	1☐Yes 2☐No 3☐Don't know		
Dis5.13 If you are married, what is your spouses' HIV status? (If you divorced, separated, or your spouse was dead, what was his/her HIV status?) *-If clients have only one wife/husband, get the information in the part of 1st wife/husband, and check 'Not applicable' in the part of 2nd &3rd wife/husband.* *-If clients have never been married, but have extra sexual partner such as boy/girl friend, check 'Not applicable' in Dis5.13 and Dis 5.14, and go to Dis 5.15.* *-If clients are divorced/separated/widow/widower, ask the clients to answer about past husband/wife in Dis5.13 and Dis5,14.* *-If clients have both marital partner(s)& extra sexual partner(s), ask the clients to answer about both marital partner(s)& extra sexual partner(s) in Dis5.13-Dis5.16.*	1st wife/husband 1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable	2nd wife/husband 1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable	3rdwife/husband 1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable
Dis5.14 If your spouse is HIV positive, is your spouse on ART? (If your deceased/separated spouse was HIV positive, was your spouse on ART?)	1st wife/husband 1☐Yes 2☐No 3☐Don't know 4☐Not applicable	2nd wife/husband 1☐Yes 2☐No 3☐Don't know 4☐Not applicable	3rdwife/husband 1☐Yes 2☐No 3☐Don't know 4☐Not

			applicable
Dis5.15 If you have extra sexual partner like boy/girl friend, what is his/her HIV status? (If your extra sexual partner like boy/girl friend was dead, what was his/her HIV status?)	1st extra partner 1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable	2nd extra partner 1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable	3rd extra partner 1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable
Dis5.16 If your extra sexual partner is HIV positive, is your extra sexual partner on ART? (If your extra sexual partner was HIV positive, was your extra sexual partner on ART before he/she died?)	1st extra partner 1☐Yes 2☐No 3☐Don't know 4☐Not applicable	2nd extra partner 1☐Yes 2☐No 3☐Don't know 4☐Not applicable	3rd extra partner 1☐Yes 2☐No 3☐Don't know 4☐Not applicable
Dis5.17 What was the reason for your having a test?(multiple answers) *It is unnecessary to read all of the items of a-g. Check all items that clients raised as the reasons for having HIV test.*	a☐I wanted to know serostatus b☐Sexual partner's past sexual behaviour(Including spouse) c☐Sexual partner told you to get tested(Including spouse) d☐Sexual partner ill or died(Including spouse) e☐My child ill or died f☐Your own past sexual behaviour g☐Blood transfusion h☐Taking care of people living with HIV/AIDS i☐Contaminated instrument j☐Syringe exchange k☐Symptoms that made you or a health provider think you might have HIV l☐Hospitalization for another reason m☐Giving Blood n☐PMTCT o☐Health provider said it was a routine part of care p☐Future plans・・・Marriage q☐Future plans・・・Having children r☐Future plans・・・Planning for future s☐Offered test at home t☐Others_____ u☐Don't know v☐Declined to answer		

Dis5.18 Was the test voluntary or compulsory?	1☐Voluntary 2☐Compulsory 3☐Don't know 4☐Declined to answer

Tra6.1 What is (are) the most likely way(s) that you became infected with HIV? *It is unnecessary to read all items of 1-6. Check the items that the client raised.*
1☐Sex with a person who was HIV+ 2☐Shared needles/sharps with a person who was HIV+ 3☐Blood transfusion or other medical procedure 4☐Mother to child transmission 5☐Don't know 6☐Other (needle stick at work.) Please specify: _____

	Yes	No	I do not know
Ma7.1 Do you think HIV infection is a manageable condition?	1☐	2☐	3☐

Depression (Measuring AIDS stigmas in people living with HIV/AIDS: the Internalized AIDS-Related Stigma Scale. AIDS Care 2009, 21(1) 87-93)

Dep8.1 How often you have thought the following things in the past 7days? *No=Rarely or none of the time,* *1-2days=Some or a little of the time,* *3-4days=Occasionally or a moderate amount,* *5-7days=Most or all of the time* *Don't miss the answers from a-k as possible as.*	No	1-2 days	3-4 days	5-7days
a. You were bothered by things that usually don't bother you	0☐	1☐	2☐	3☐
b. You felt you were just as good as other people *(reversed)*	0☐	1☐	2☐	3☐
c. You felt depressed	0☐	1☐	2☐	3☐
d. You thought your life had been a failure	0☐	1☐	2☐	3☐
e. You felt fearful	0☐	1☐	2☐	3☐
f. You were happy *(reversed)*	0☐	1☐	2☐	3☐
g. You talked less than usual	0☐	1☐	2☐	3☐
h. You felt sad	0☐	1☐	2☐	3☐
i. You felt lonely	0☐	1☐	2☐	3☐
j. You had crying spells	0☐	1☐	2☐	3☐
k. You felt that people disliked you	0☐	1☐	2☐	3☐

Fear and experience with stigma and discrimination (Generic tools for operational research)

FE9.1 Have you personally ever made to feel bad because of things people did or said to you on account of your HIV status?	1☐Yes 2☐No

FE9.2 Have you ever experienced any of the following by your spouse or extra sexual partner like boy/girl friend when you thought it was because of your HIV status? Have you ever been: *Read all items of a-g and check 'Yes', 'No' or 'Unsure' each by each.*	Yes	No	Unsure
a. Physically assaulted?	1☐	2☐	3☐
b. Told that it is your fault you have HIV?	1☐	2☐	3☐
c. Verbally abused or ridiculed?	1☐	2☐	3☐
d. Divorced/Left?	1☐	2☐	3☐
e. Ignored/Avoid?	1☐	2☐	3☐
f. Abandoned?	1☐	2☐	3☐
g. He/she had sexual intercourse with others?	1☐	2☐	3☐
FE9.3 Have you ever experienced any of the following by others than your spouse or extra sexual partner when you thought it was because of your HIV status? Have you ever been: *Read all items of a-j and check 'Yes' 'No' or 'Unsure' each by each.*	Yes	No	Unsure
a. Physically assaulted?	1☐	2☐	3☐
b Told that it is your fault you have HIV?.	1☐	2☐	3☐
c Verbally abused or ridiculed?	1☐	2☐	3☐
d. Abandoned by the family members other than your spouse?	1☐	2☐	3☐
e. Excluded from social events?	1☐	2☐	3☐
f. Fired from work or lost your job?	1☐	2☐	3☐
g. Expelled from home?	1☐	2☐	3☐
h. Had property taken away?	1☐	2☐	3☐
i. Denied health services?	1☐	2☐	3☐
j. Heard your gossip?	1☐	2☐	3☐

Stigma Scale (the Internalized AIDS-Related Stigma Scale: IA-RSS).

FE9.4 Please tell me whether you agree or disagree with each statement? *Don't miss the answers from a-f as possible as.*	Agree	Disagree
a. It is difficult to tell people about your HIV infection	1☐	2☐
b. Being HIV positive makes you feel dirty	1☐	2☐
c. You feel guilty that you are HIV positive	1☐	2☐
d. You are ashamed that you are HIV positive	1☐	2☐
e. You sometimes feel worthless because you are HIV positive	1☐	2☐
f. You hide your HIV status from others	1☐	2☐

Condom use (Towards an understanding of barriers to condom use in rural Benin using the Health Belief Model: A cross sectional survey. BMC Public Health 2005, 5 (8))

Please tell me about your condom use.	Yes	No	Never had sexual intercourse in my life	Not applicable
Con10.1 Did you use condom during the last sexual intercourse?	1☐	2☐	3☐	4☐
Con10.2 How many sexual partners did you have during the last one month and a half? *If the clients do not have sexual partners during last one month and a half, write '0' person(s).*	☐☐ persons			

	Stopped sexual intercourse	Less than before	Similar	More than before	Not applicable
Con10.3 Did you change your frequency of sexual intercourse by knowing you were HIV positive? *-If clients have never sexual intercourse in their lives, check 'Not applicable.* *-If clients say 'Stopped sexual intercourse', skip 'Con10.4' and go to Fam11.1.*	1☐→go to Fam11.1	2☐	3☐	4☐	5☐
Con10.4 Did you have sexual intercourse without condom after knowing your HIV status?	Yes 1☐	No 2☐	Declined to answer 3☐		

Family Planning(Generic tools for operational research)

	Yes	No	Unsure	Not applicable
Fam11.1 Are you currently pregnant? *-If a client is male, check 'Not applicable'*	1☐	2☐	3☐	4☐
Fam11.2 Do you have a plan to have a/another child? *-If a client is pregnant, check 'Yes'.*	1☐	2☐→go to Fam11.4	3☐→go to Fam11.4	4☐→go to Fam11.4
Fam11.3 In what time frame do you plan to have a/another child? *-If a client is pregnant, check 'Within 1 year'*	1☐Within 1 year 2☐In 2-3 years 3☐After more than 3 years 4☐Don't know			

	Yes	No	Don't know	Not applicable
Fam11.4 Does your regular sexual partner want to have a/another child? *If clients have no regular sexual partner at present, check 'Not applicable'and go to Ss12.1*	1☐	2☐	3☐	4☐→go to Ss12.1
Fam11.5 Which method(s) are you or your regular sexual partner currently using? *If the answer is 'No method', check 'a' and check 'No' from b-n. Unless the answer is 'No method', read all items and check 'Yes', 'No', or ''Don't know' each by each from b-n.*				
a. No method ☐				
	Yes	No	Don't know	
b. Pill---women can take a pill every day	1☐	2☐	3☐	
c. Injections---women can have injections that prevent pregnancy for several months	1☐	2☐	3☐	
d. Male condom---men can use a rubber sheath on their penis during sexual intercourse	1☐	2☐	3☐	
e. Female condom	1☐	2☐	3☐	
f. Male sterilization---men can have a operation to avoid having any more children	1☐	2☐	3☐	
g. Female sterilization---women can have an operation to avoid having any more children	1☐	2☐	3☐	
h. Natural method---every month women can avoid having intercourse in the days of the month she is most likely to get pregnant	1☐	2☐	3☐	
i. Withdrawal---men can be careful and pull out before the fluids come out	1☐	2☐	3☐	
j. Others---_____	1☐	2☐	3☐	

Social Support (Measuring AIDS stigmas in people living with HIV/AIDS: the Internalized AIDS-Related Stigma Scale. AIDS Care 2009, 21(1) 87-93)

Ss12.1 Please tell me whether it is completely true, relatively true, relatively false, or completely false? *-Don' t miss the answers from a-c as possible as.* *-Show the sheet which indicates the four options: 'Completely true', 'Relatively true', 'Relatively false', 'Completely false'*	Completely true	Relatively true	Relatively false	Completely false	
a. If you were sick and needed someone to take you to a doctor you would have trouble finding someone (reversed);	1☐	2☐	3☐	4☐	
b. You feel that there is no one you can share my most private concerns and fears (reversed);	1☐	2☐	3☐	4☐	
c. You feel a strong emotional bond with at least one other person	1☐	2☐	3☐	4☐	
Ss12.2 I would like to know your satisfaction for the health services in HIV treatment. Please answer 'Yes', 'So-so' or 'No'. *-Ask clients of preset feeling/impression to the following persons. Even if the clients contact with the following health staff only once, ask their feeling/impression whether the following persons seems to be trustworthy or not.*	Yes	So-so	No	Don't know	Not applicable
d. Do you trust in clinical officer?	1☐	2☐	3☐	4☐	5☐
e. Do you trust in nurse?	1☐	2☐	3☐	4☐	5☐
f. Do you trust in treatment supporter/adherence counsellor?	1☐	2☐	3☐	4☐	5☐
g. Are you satisfied with health services in DH or HC?	1☐	2☐	3☐	4☐	5☐

Thank you very much. This is the end of interview.

Please be assured again that the information you provided will not be communicated to anyone.

We would like you to interview after 1 month and half later.

From Medical Record

Check Medical Record after finishing interview

M13.1 Date of HIV test	_____/_____/_____(day/month/year)
M13.2CD4 count at the last test	_____cells/mm^3
M13.3 Disease stage at registration	1☐ Ⅰ 2☐ Ⅱ 3☐ Ⅲ 4☐ Ⅳ
M13.4 Functional status	1☐Working 2☐Ambulant 3☐Bed lid
M13.5 Weight at registration	_____ kg
M13.6 Tuberculosis	1☐Positive 2☐Negative 3☐Not sure

Follow-up questionnaire Research ID:_____

Date: ___/_____/_____(day/month/year) Information of Interview date 1☐Appointment date 2☐Within 15 days of an appointment date 3☐defaulter 4☐Referred to the other health facility 5☐Dead	ART No: _____

First, I have some questions about the type of work you do and your access to food.

S1.1 What kind of work do you do? By that I mean, what kind of activities keep you busy during an average day, whether you earn money from them or not? *It is unnecessary to read all items of 1-12. Check all items that clients raised as their job.*	1☐Agriculture 2☐Fishing 3☐Commerce 4☐Clerical/employee 5☐Professional 6☐Skilled/semi-skilled labor 7☐Unskilled labor 8☐Student 9☐Apprentice 10☐Homemaker/housewife 11☐None (Probe: No agriculture or housework?) 12☐Other, please specify:_____ 13☐Declined to answer
S1.2 During the past month, how often have you had problems getting the food you need? *Read all items of 1-4.*	1☐Never 2☐Sometimes 3☐Often 4☐Always
S1.3 How many members do you live with (including yourself)? *Include children who are not own of the clients.*	Adult ☐☐ Child (18>)☐☐

(ACTG Adherence Follow Up Questionnaire)

If you took only a portion of a dose on one or more of these days, please report the dose(s) as being missed.

A2.1 During the past 4 days, on how many days have you missed taking all your doses?	
1☐	None
2☐	One day
3☐	Two days
4☐	Three days
5☐	Four days

A2.2 Most anti-HIV medications need to be taken on a schedule, such as "2 times a day" or "3 times a day" or "every 8 hours." How closely did you follow your specific schedule over the last four days?				
Never	Some of the time	About half of the time	Most of the time	All of the time
1☐	2☐	3☐	4☐	5☐

A2.3 Do any of your anti-HIV medications have special instructions, such as "take with food" or "on an empty stomach" or "with plenty of fluids?" *If clients say 'No', skip A2.4 and go to A2.5.*	
Yes	No
1☐	2☐→Go to A2.5

A2.4 How often did you follow those special instructions over the last **four** days?				
Never	Some of the time	About half of the time	Most of the time	All of the time
1☐	2☐	3☐	4☐	5☐

A2.5 Some people find that they forget to take their pills on the weekend days. Did you miss any of your anti-HIV medications last weekend— last Saturday or Sunday?	
Yes	No
1☐	2☐

A2.6 When was the last time you missed any of your medications? *Check one.*					
Within the past week	1-2 weeks ago	2-4 weeks ago	1-3 months ago	More than 3 months ago	**Never** skip medications or **not applicable**
1☐	2☐	3☐	4☐	5☐	6☐

A2.7 At any point during the past 4 days, did you take a double dose of ART medications after missing a dose? (or your daily doses of medication in one intake?)	1☐No, never 2☐Yes, once 3☐Yes, sometimes 4☐Yes, frequently

	5☐Declined to answer

Treatment interruption

A2.8 During the past one month, did you ever stop taking your ART for 48 hours or longer? *If clients say 'No', skip A2.9*	☐Yes ☐No→Go to A2.10 ☐Declined to answer
A2.9 How long did you stop taking your antiretroviral therapy? *Probe for a guess if respondent does not remember very clearly.*	☐For more than 48 hours and less than a week ☐From one to two weeks ☐For more than two weeks and less than one month ☐For more than one month ☐Declined to answer

A2.10 *Only ask this question of respondent: missed one or more doses during the past four days; missed one or more dose on the weekend, took a double dose of ART medication during the past four days; stop taking ART for 48 hours or longer. Check the answers of A2.1, A2.5, A2.7 & A2.8.*
Read all items of a-B and check 'Yes' or 'No' each by each.
What are the reasons for missed doses or double dose within the four days, on the weekend or stop taking ART for 48 hours or longer during the past one month? Please circle one response for each question.

	Yes	No
a. Were away from home	1☐	2☐
b. Were busy with other things	1☐	2☐
c. Simply forgot	1☐	2☐
d. Had too many pills to take	1☐	2☐
e. Wanted to avoid side effects	1☐	2☐
f. Did not want others to notice you taking medication	1☐	2☐
g. Had a change in daily routine	1☐	2☐
h. Felt like the drug was toxic/harmful/skeptical/doubt	1☐	2☐
i. Felt asleep/slept through dose time	1☐	2☐
j. Felt sick or ill	1☐	2☐
k. Felt good	1☐	2☐
l. Felt depressed/overwhelmed	1☐	2☐
m. Had problem taking pills at specified times (with meals, on empty stomach, etc.)	1☐	2☐
n. Clinic ran out of pills	1☐	2☐
o. You ran out of pills	1☐	2☐
p. Hard to swallow	1☐	2☐
q. Sold of the drugs	1☐	2☐

r. Too far to the treatment site where I can get the drugs	1☐	2☐
s. Cost a lot for adhering ART	1☐	2☐
t. Not enough food	1☐	2☐
u. Fasting or attending ceremony such as a wedding and a funeral	1☐	2☐
v. Health staff attitude was bad	1☐	2☐
w. Treatment being a reminder of HIV status	1☐	2☐
x. Hopelessness	1☐	2☐
y. Problem leaving work to take drugs or make clinic appointment	1☐	2☐
z. Traditional prohibition	1☐	2☐
A. Lack of information	1☐	2☐
B. Others:_____		

	Yes	No	I do not know
Ma3.1 Do you think HIV infection is a manageable condition?	1☐	2☐	3☐

Socio-demographics&Disclosure (Generic tools for operational research)

Dis4.1 Present marital status *Ask present marital status. If clients say 'Single', 'Divorced', 'Separated', 'Disappeared', or 'Widow/widower', skip Dis4.2-Dis4.5, and go to Dis4.6.*	☐Single (Never married)→Go to Dis4.6 ☐Married→Go to Dis4.2 ☐Divorced/separated/disappeared→Go to Dis4.6 ☐Widow/widower→Go to Dis4.6	
Dis4.2 If you are married, how many wives/husbands do you have?	Number of wife/husband ( )	
---Dis4.3 Have you ever told your HIV status to your first wife/husband? If yes, how soon did you tell it? If no, why you have not told your HIV status? *-If the client answered 'No', ask the reason of not having told his/her status to his/her first wife/husband.*	Yes 1☐→ No 2☐→	How soon? _____days after learning my HIV status Why you have not told your HIV status? Reasons: _____ _____
---Dis4.4 Have you ever told your HIV status to your second wife/husband? If yes, how soon? *-Even if the client answered 'No', it is unnecessary to ask the reason of not having told his/her status to his/her second wife/husband.*	Yes 1☐→ No 2☐	_____days after learning my HIV status
---Dis4.5 Have you ever told your HIV status to	Yes	

your third wife/husband? If yes, how soon? *-Even if the client answered 'No', it is unnecessary to ask the reason of not having told his/her status to his/her second wife/husband.*	1□→ No 2□	_____days after learning my HIV status
Dis 4.6 How many extra sexual partners do you have?(eg. Boy/girl friend) *Extra sexual partner means sexual partners other than husbands or wives like boy/girl friends.*	0□No extra sexual partners Number of extra sexual partners ( )	
---Dis4.7 Have you ever told your HIV status to your first extra sexual partner? If yes, how soon did you tell it? If no, why you have not told your HIV status to your first extra sexual partner? *-if the client answered 'No', ask the reason of not having told his/her status to his/her first extra sexual partner.*	Yes 1□→ No 2□→	How soon? _____days after learning my HIV status Why you have not told your HIV status? Reasons: _____ _____
--Dis4.8 Have you ever told your HIV status to your second extra sexual partner? *-Even if the client answered 'No', it is unnecessary to ask the reason of not having told his/her status to his/her second extra sexual partner.*	Yes 1□→ No 2□	_____days after learning my HIV status
---Dis4.9 Have you ever told your HIV status to your third extra sexual partner? *-Even if the client answered 'No', it is unnecessary to ask the reason of not having told his/her status to his/her third extra sexual partner.*	Yes 1□→ No 2□	_____days after learning my HIV status
Dis4.10 Have you ever told your HIV status results to the following persons? If yes, how soon did you tell your status to these people after learning your status? *-Read all items of a-m, check all items that the clients answered 'Yes'.* *-Check the answer of Dis4.3-Dis4.5& Dis4.7-Dis4.9.* *-If clients never told the result with anyone outside the HC, choose 'Yes' in 'a', ask the*		

reasons of not having told HIV status and check '0' in Dis4.11. *-If clients told their HIV status only to their present husbands/wives or extra sexual partners, don't check 'Yes' in 'a' In that case, go to Dis4.11, and count the number of person that the clients told their HIV status to.* *Example: A client only told his/her HIV status to husband/wife, write '1' in Dis4.11.* a. I never told the results with anyone outside the HC including spouse and extra sexual partners.	□→	Why you have not told the result with anyone outside the HC including your spouse(s) or extra sexual partner(s)? Reasons: _____ _____
b. Divorced/separated/disappeared sexual partner before divorced/separated/his or her disappeared	□→	How soon? ___days after learning my HIV status
c. Deceased spouse before his/her death	□→	___days after learning my HIV status
d. Daughter/son *Ask total number of daughter/son and total number of dauters/sons he/she told his/her HIV status.* Total no of daughters/sons ( ) Total no of daughters/sons you disclosed ( )	□→	___days after learning my HIV status
e. Sibling *Ask total number of siblings and total number of siblings he/she told his/her HIV status.* Total no of siblings ( ) Total no of siblings you disclosed ( )	□→	___days after learning my HIV status
f. Mother	□→	___days after learning my HIV status
g. Father	□→	___days after learning my HIV status
h. Mother-in-law/Step mother	□→	___days after learning my HIV status
i. Father-in-law/Step father	□→	___days after learning my HIV status
j. Other relative	□→	___days after learning my HIV status
k. Friend *Ask total number of friend that he/she told*	□→	___days after learning my HIV status

his/her HIV status. Total no of friends you told your HIV status( )		
l. Self-support group members	□→	___days after learning my HIV status
m. Others: please specify_____	□→	___days after learning my HIV status
Dis4.11 How many persons outside the HC, have you told your HIV status in total?	Total numbers (_____)	
Dis4.12 Do any other people in your community know that you are HIV-positive even though you did not tell them?	1□Yes 2□No 3□Don't know	

Dis4.13 If you are married, what is your spouses' HIV status? (If you divorced, separated, or your spouse was dead, what was his/her HIV status?) *-If clients have only one wife/husband, get the information in the part of 1st wife/husband, and check 'Not applicable' in the part of 2nd &3rd wife/husband.* *-If clients have never been married, but have extra sexual partner such as boy/girl friend, check 'Not applicable' in Dis4.13 and Dis 4.14, and go to Dis 4.15.* *-If clients are divorced/separated/widow/widower, ask the clients to answer about past husband/wife in Dis4.13 and Dis4,14.* *-If clients have both marital partner(s)& extra sexual partner(s), ask the clients to answer about both marital partner(s)& extra sexual partner(s) in Dis4.13-Dis4.16.*	1st wife/husband 1□Positive 2□Negative 3□Don't know 4□Not applicable	2nd wife/husband 1□Positive 2□Negative 3□Don't know 4□Not applicable	3rdwife/husband 1□Positive 2□Negative 3□Don't know 4□Not applicable
Dis4.14 If your spouse is HIV positive, is your spouse on ART? (If your deceased/separated spouse was HIV positive, was your spouse on ART?)	1st wife/husband 1□Yes 2□No 3□Don't know 4□Not applicable	2nd wife/husband 1□Yes 2□No 3□Don't know 4□Not applicable	3rdwife/husband 1□Yes 2□No 3□Don't know 4□Not applicable
Dis4.15 If you have extra sexual partner like	1st extra partner	2nd extra partner	3rd extra partner

boy/girl friend, what is his/her HIV status? (If your extra sexual partner like boy/girl friend was dead, what was his/her HIV status?)	1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable	1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable	1☐Positive 2☐Negative 3☐Don't know 4☐Not applicable
Dis4.16 If your extra sexual partner is HIV positive, is your extra sexual partner on ART? (If your extra sexual partner was HIV positive, was your extra sexual partner on ART before he/she died?)	1st extra partner 1☐Yes 2☐No 3☐Don't know 4☐Not applicable	2nd extra partner 1☐Yes 2☐No 3☐Don't know 4☐Not applicable	3rd extra partner 1☐Yes 2☐No 3☐Don't know 4☐Not applicable

The next questions are about those people around you who do or do not know you are taking ART, and how these people may make it easier or harder to take your medications.

Taking ART(Generic tools for operational research)

	1st wife/husband	2nd wife/husband	3rd wife/husband
Ar5.1 If you are married, does your spouse know that you are taking ART? (If you divorced, separated or spouse was dead, did your spouse know that you were taking ART before he/she was dead?) *-If clients have never been married but have extra sexual partner such as boy/girl friend, check 'Not applicable in Ar5.1.* *-If clients have more than one husband/husband, get the answers in Part of 2nd wife/husband and 3rd wife/husband.* *-If clients are divorced/separated/widow/widower, ask the clients to answer about their past husband/wife.*	1☐Yes 2☐No 3☐Don't know 4☐Not applicable	1☐Yes 2☐No 3☐Don't know 4☐Not applicable	1☐Yes 2☐No 3☐Don't know 4☐Not applicable
Ar5.2 *If respondent lives with other people:* Do all the other adults living in your household know that you are taking ART? *Check 'Yes' if all the other adults know that the clients are taking ART.*	1☐Yes 2☐No 3☐Don't know 4☐No other adults live in the household 5☐Declined to answer		
Ar5.3 Is it ever difficult for you to take your ART when someone from your family can see you?	1☐Yes 2☐No 3☐Don't know 4☐Not applicable		
	1st extra partner	2nd extra partner	3rd extra partner

Ar5.4 If you have extra sexual partners like boy or girl friend, do your extra sexual partners know that you are taking ART? (If your extra sexual partners was dead, did your extra sexual partners know that you were taking ART before he/she was dead?) *-If clients do not have any extra sexual partners, check 'Not applicable'.* *-If clients have more than one extra sexual partners, get the answer in part of 2nd and 3rd extra sexual partners.* *-If his/her extra sexual partner was already dead, ask the clients to answer about their past extra sexual partner.*	1☐Yes 2☐No 3☐Don't know 4☐Not applicable	1☐Yes 2☐No 3☐Don't know 4☐Not applicable	1☐Yes 2☐No 3☐Don't know 4☐Not applicable
Ar5.5 Is it ever difficult for you to take your ART when someone from your community or your workplace can see you?	1☐Yes 2☐No 3☐Declined to answer		
Ar5.6 Is there anyone who regularly reminds you to take your ART?	1☐Yes 2☐No 3☐Declined to answer		
Ar5.7 How do you remind yourself of the time to take your medicines? (Multiple answers) *Read all items of a-j.*	a☐Nothing particular to do b☐Use watch or clock c☐Use mobile phone d☐Use TV e☐Use Radio f☐Position of the sun g☐Reminded by cohabiting h☐Reminded by others i☐Others_____ j☐Declined to answer		
Ar5.8 Have you ever experienced that someone asked you to share your ARVs?	1☐Yes 2☐No 3☐Declined to answer		
Ar5.9 Have you ever shared your ARVs with others?	1☐Yes 2☐No 3☐Declined to answer		
Ar5.10 From the initiation of ART, have you ever not taken your ART because you did not want someone to find out?	1☐Yes 2☐No 3☐Declined to answer		

Ar5.11 In general, do you find it easy, not very easy or difficult to take your ART?	1☐Easy 2☐Not very easy 3☐Difficult 4☐It depends 5☐Declined to answer

The next questions concern any possible problems you may have had getting your ART.

Access

Ar6.1 Have you ever had problems getting your ART on time because you were not able to reach the clinic since starting ART?	1☐Yes 2☐No 3☐Declined to answer
Ar6.2 Has the cost of medication or the cost of clinic care ever interfered with your ability to get your ART and take your medication on time since starting ART?	1☐Yes 2☐No 3☐Declined to answer
Ar6.3 Has the cost of transportation ever interfered with your ability to get your ART and take your medication on time since starting ART?	1☐Yes 2☐No 3☐Declined to answer

Food security

Ar6.4 Have you ever missed a dose of your ART because you did not have enough food since starting ART?	1☐Yes 2☐No 3☐Declined to answer

Now I would like to ask you some questions about your health before and after starting your ART, and then I will ask about side-effects or body changes you experienced after starting ART.

Health status

Ar6.5 How would you rate your health before starting ART? Would you say it was: *Read all options for expressing client's health condition from 1-6.*	1☐Excellent 2☐Very good 3☐Good 4☐Fair 5☐Poor 6☐Declined to answer
Ar6.6 Now that you are taking ART, how is your health? Would you say it is: *Read all options for expressing client's health condition from 1-6.*	1☐Excellent 2☐Very good 3☐Good 4☐Fair 5☐Poor 6☐Declined to answer

Some people experience side-effects when they take ART. This varies a great deal. Some people have a few, while others have more.

Perceived side-effects

Ar6.7 Have you experienced any side-effects since you started taking ART?	1☐Yes→Specify( ) 2☐No 3☐Don't know 4☐Declined to answer

Depression (Measuring AIDS stigmas in people living with HIV/AIDS: the Internalized AIDS-Related Stigma Scale. AIDS Care 2009, 21(1) 87-93)

Dep7.1 How often you have thought the following things in the past 7days? *No=Rarely or none of the time,* *1-2days=Some or a little of the time,* *3-4days=Occasionally or a moderate amount,* *5-7days=Most or all of the time* *Don't miss the answers from a-k as possible as.*	No	1-2 days	3-4 days	5-7days
a. You were bothered by things that usually don't bother you	0☐	1☐	2☐	3☐
b. You felt you were just as good as other people *(reversed)*	0☐	1☐	2☐	3☐
c. You felt depressed	0☐	1☐	2☐	3☐
d. You thought your life had been a failure	0☐	1☐	2☐	3☐
e. You felt fearful	0☐	1☐	2☐	3☐
f. You were happy *(reversed)*	0☐	1☐	2☐	3☐
g. You talked less than usual	0☐	1☐	2☐	3☐
h. You felt sad	0☐	1☐	2☐	3☐
i. You felt lonely	0☐	1☐	2☐	3☐
j. You had crying spells	0☐	1☐	2☐	3☐
k. You felt that people disliked you	0☐	1☐	2☐	3☐

Fear and experience with stigma and discrimination (Generic tools for operational research)

FE8.1 Have you personally ever made to feel bad because of things people did or said to you on account of your HIV status?	1☐Yes 2☐No

FE8.2 Have you ever experienced any of the following by your spouse or extra sexual partner like boy/girl friend when you thought it was because of your HIV status? Have you ever been: *Read all items of a-g and check 'Yes', 'No' or 'Unsure' each by each.*	Yes	No	Unsure
a. Physically assaulted?	1☐	2☐	3☐
b. Told that it is your fault you have HIV?	1☐	2☐	3☐
c. Verbally abused or ridiculed?	1☐	2☐	3☐
d. Divorced/Left?	1☐	2☐	3☐

e. Ignored/Avoid?	1☐	2☐	3☐
f. Abandoned?	1☐	2☐	3☐
g. He/she had sexual intercourse with others?	1☐	2☐	3☐
FE8.3 Have you ever experienced any of the following by others than your spouse or extra sexual partner when you thought it was because of your HIV status? Have you ever been: *Read all items of a-j and check 'Yes' 'No' or 'Unsure' each by each.*	Yes	No	Unsure
a. Physically assaulted?	1☐	2☐	3☐
b Told that it is your fault you have HIV?.	1☐	2☐	3☐
c Verbally abused or ridiculed?	1☐	2☐	3☐
d. Abandoned by the family members other than your spouse?	1☐	2☐	3☐
e. Excluded from social events?	1☐	2☐	3☐
f. Fired from work or lost your job?	1☐	2☐	3☐
g. Expelled from home?	1☐	2☐	3☐
h. Had property taken away?	1☐	2☐	3☐
i. Denied health services?	1☐	2☐	3☐
j. Heard your gossip?	1☐	2☐	3☐

Stigma Scale (the Internalized AIDS-Related Stigma Scale: IA-RSS).

FE8.4 Please tell me whether you agree or disagree with each statement? *Don't miss the answers from a-f as possible as.*	Agree	Disagree
a. It is difficult to tell people about your HIV infection	1☐	2☐
b. Being HIV positive makes you feel dirty	1☐	2☐
c. You feel guilty that you are HIV positive	1☐	2☐
d. You are ashamed that you are HIV positive	1☐	2☐
e. You sometimes feel worthless because you are HIV positive	1☐	2☐
f. You hide your HIV status from others	1☐	2☐

Condom use (Towards an understanding of barriers to condom use in rural Benin using the Health Belief Model: A cross sectional survey. BMC Public Health 2005, 5 (8))

Please tell me about your condom use.	Yes	No	Never had sexual intercourse in my life	Not applicable
Con9.1 Did you use condom during the last sexual intercourse?	1☐	2☐	3☐	4☐
Con9.2 How many sexual partners did you have during the last one month and a half? *If the clients do not have sexual partners during the last one month and a half, write '0' person(s).*	☐☐ persons			

	Stopped sexual intercourse	Less than before	Similar	More than before	Not applicable
Con9.3 Did you change your frequency of sexual intercourse **by** knowing you were HIV positive? *-If clients have never sexual intercourse in their lives, check 'Not applicable.* *-If clients say 'Stopped sexual intercourse', skip 'Con9.4' and go to Fam10.1.*	1□→go to Fam10.1	2□	3□	4□	5□
Con9.4 Did you have sexual intercourse without condom after knowing your HIV status?	Yes 1□	No 2□	Declined to answer 3□		

Family Planning(Generic tools for operational research)

	Yes	No	Unsure	Not applicable
Fam10.1 Are you currently pregnant? *-If a client is male, check 'Not applicable'*	1□	2□	3□	4□
Fam10.2 Do you have a plan to have a/another child? *-If a client is pregnant, check 'Yes'.*	1□	2□→go to Fam10.4	3□→go to Fam10.4	4□→go to Fam10.4
Fam10.3 In what time frame do you plan to have a/another child? *-If a client is pregnant, check 'Within 1 year'*	1□Within 1 year 2□In 2-3 years 3□After more than 3 years 4□Don't know			
	Yes	No	Don't know	Not applicable
Fam10.4 Does your regular sexual partner want to have a/another child? *If clients have no regular sexual partner at present, check 'Not applicable'and go to Ss11.1*	1□	2□	3□	4□→go to Ss11.1

Fam10.5 Which method(s) are you or your regular sexual partner currently using? *If the answer is 'No method', check 'a' and check 'No' from b-n.* *Unless the answer is 'No method', read all items and check 'Yes', 'No', or ''Don't know' each by each from b-n.*			
a. No method ☐			
	Yes	No	Don't know
b. Pill---women can take a pill every day	1☐	2☐	3☐
c. Injections---women can have injections that prevent pregnancy for several months	1☐	2☐	3☐
d. Male condom---men can use a rubber sheath on their penis during sexual intercourse	1☐	2☐	3☐
e. Female condom	1☐	2☐	3☐
f. Male sterilization---men can have a operation to avoid having any more children	1☐	2☐	3☐
g. Female sterilization---women can have an operation to avoid having any more children	1☐	2☐	3☐
h. Natural method---every month women can avoid having intercourse in the days of the month she is most likely to get pregnant	1☐	2☐	3☐
i. Withdrawal---men can be careful and pull out before the fluids come out	1☐	2☐	3☐
j. Others---_____	1☐	2☐	3☐

Social Support (Measuring AIDS stigmas in people living with HIV/AIDS: the Internalized AIDS-Related Stigma Scale. AIDS Care 2009, 21(1) 87-93)

Ss11.1 Please tell me whether it is completely true, relatively true, relatively false, or completely false? *-Don' t miss the answers from a-c as possible as.* *-Show the sheet which indicates the four options: 'Completely true', 'Relatively true', 'Relatively false', 'Completely false'*	Completely true	Relatively true	Relatively false	Completely false
a. If you were sick and needed someone to take you to a doctor you would have trouble finding someone (reversed);	1☐	2☐	3☐	4☐
b. You feel that there is no one you can share my most private concerns and fears (reversed);	1☐	2☐	3☐	4☐
c. You feel a strong emotional bond with at least one other person	1☐	2☐	3☐	4☐

Ss11.2 I would like to know your satisfaction for the health services in HIV treatment. Please answer 'Yes', 'So-so' or 'No'. *-Ask clients of preset feeling/impression to the following persons. Even if the clients contact with the following health staff only once, ask their feeling/impression whether the following persons seems to be trustworthy or not.*	Yes	So-so	No	Don't know	Not applicable
d. Do you trust in clinical officer?	1☐	2☐	3☐	4☐	5☐
e. Do you trust in nurse?	1☐	2☐	3☐	4☐	5☐
f. Do you trust in treatment supporter/adherence counsellor?	1☐	2☐	3☐	4☐	5☐
g. Are you satisfied with health services in DH or HC?	1☐	2☐	3☐	4☐	5☐

Thank you very much. The information that you provided will help with the development of better drug regimens for all patients with HIV.

From Medical Record

M12.1 Disease stage at 1month and a half from initiation of ART.	1☐ Ⅰ 2☐ Ⅱ 3☐ Ⅲ 4☐ Ⅳ
M12.2 Functional stage at 1month and a half from initiation of ART.	1☐Working 2☐Ambulant 3☐Bed lid
M12.3 Weight at 1 month and a half from initiation of ART	_____ kg
M12.4 Tuberculosis	1☐Positive 2☐Negative 3☐Not sure

Appendix 4. Informed consent for the study

Study Information Form (A)

Please visit here in the following date:

Your next interview date (one and a half month later): ____/____/_____(dd/mm/yyyy)

MoH Zambia – JICA SHIMA project

ART Cohort Study (SHIMA Mumbwa Cohort 2010)

Provision of ART and related services and its outcomes in Mumbwa district

The purpose of this study is to assess overall situation on ART and related services including the quality of the services and to determine factors associated with access to the services, ART outcomes and ART adherence, in order to improve the quality of ART and related services in Mumbwa district.

We would like you to participate in the interview, in which you will be asked about your age, sex, marital status, family members, resident places, education, occupation, religious, distance from medical facilities, medical cost, social support, health condition, side effects, stigma and discrimination, disclosure of HIV status to family members or community members, negative reactions from family members or community members, concern about confidentiality, sexual activities, condom use, reasons for continuation of the treatment (or cessation of the treatment), quality of services, issues and remedies for the services. In addition, information about your clinical condition, such as CD4 cell counts, regimen, clinical stage and weight as well as the access to related services will be collated with medical records.

We would like to interview you (i.e. newly enrolled ART clients) at the beginning of the treatment, after 1 month and a half and thereafter as needs arises. You will be followed for the period of 5years (2010~2014).

The result of this study will be used to understand the situation of the services and plan future interventions to improve these services in the district.

It is to inform you that your response will be kept confidential. None of the information you give will not be communicated to anyone except the research team.

You will be interviewed privately at your comfort.
Although your participation is much appreciated, your participation is voluntary and you are free to withdraw from the study at any time and all of the data will be deleted if you withdraw.
Your participation and response will not affect the quality of care you receive at the care facility.

Please read next page and if you agree then sign the document. If you feel comfortable and allow us, I can start the interview. It will take about 40-50 minutes.

We will highly appreciate your support.
Thank you for your cooperation.

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Informed Consent (B)

I acknowledge that:

- I have been given all the information regarding the research
- I have been told that confidentiality and privacy will be maintained and my name and information given will not be disclosed by any means
- I am not under any pressure to contribute to the research
- I clearly know that I can quit answering questions at any stage and no action will be taken against me
- I am satisfied with the information given
- I will now sign this paper formally, so that they can start their study

Name: _____ Signature: _____

Name (Interviewer): _____

Date(dd/mm/yyyy): _____

Facility name:

- ☐ Mumbwa DH
- ☐ Lungobe RHC
- ☐ Keezwa RHC
- ☐ Mwembezhi RHC
- ☐ Kaindu RHC
- ☐ Nalubanda RHC
- ☐ Sichobo RHC
- ☐ Nampundwe RHC
- ☐ Mpusu RHC

Appendix 5. Instructions for interviewers

Instructions for Interviewers

-Step 1. Introduce yourself and this study following **a Study Information "A".**

-Step 2. Explain that **respondents can use their most understandable language** for the interview.

-Step 3. Answer the respondent's questions briefly.

-Step 4. Give **the Study Information "A"** to clients

-Step 5. If you can get agreement from clients, ask them to write their name and signature in **an Informed Consent "B"**.

-Step 6. Get **an Information Form "C"** that clients are given from health care provider.

-Step 7. Check the information form whether **Schedule date, Research ID Number,** ART Number, **Name of Client, Date of Interview,** Cell Phone Number of Client, and **Site of Interview** are filled in or not.

-Step 8. After you have finished asking all the questions, thank clients and give them a boom for our thanks to participate in the interview.

-Step 9. Put the completed questionnaire in the file. Then you should sign your name on the **Informed Consent "B".**

A. Ethical Consideration

1. Keep confidentiality of all information that respondents give.

2. Don't disturb **the respondents' privacy.**

3. Don't be communicated to anyone about all information that respondents give except the research team.

4. Don't put pressure on the participation for the interview.

5. Explain that the respondents **are free to withdraw from the interview.**

6. Don't be surprised at any answers that respondents give. **(Don' t be judgmental and be neutral** at any answers.)

* If you cannot keep the above, you will lose your qualification as an interviewer.

B. How to Read Questions

1. All questions should be read in **a natural conversational rhythm in a normal tone of voice.** We tried to write the questions in the everyday language that people use in conversation, you must learn to read them exactly as written but should as though you are **talking rather than reading.** Do not read a question too fast. Clients may not feel free to ask you to repeat it and may guess at what the question was. If the clients do not

understand a question, repeat it exactly as written.

2. **Be careful for your tone of voice and facial expressions& don't put pressure on clients.** How you ask a question or probe can be just as important as the wording of the question. Also your face may give you away. The best way is to remember that your job is not to get clients to agree with you, but to try **to understand howclients feel and think and what they do.**

3. **Ask the questions exactly as they are worded and in the same order as in questionnaire.** Even minor changes in the questionnaire wording can completely change the meaning of a question. So every interviewer must ask the questions just as worded or the responses are meaningless. Also you must follow the order of the questions and never ask questions out of order.

C. How to Get Adequate Answer

1. **Learn the purpose of each question.** In order to do a good job of interviewing, you must understand the kind of information we are trying to get by asking a question. Unless you understand its purpose, you will not be able to judge when a response is adequate and you must probe for clarity or for more information.

2. **Don't try to explain the question.** Be neutral. As mentioned before, if clients do not understand a question, repeat the question slowly and clearly. Give the respondent time to think about the question. **Never explain the meaning or purpose of a question .**

3. **Don't leave a question as possible as you can** until you have an adequate answer or find that clients can't give a clearer answer.

4. **Don't accept a 'don't know' as possible as you can.** When you ask a question, people often say 'I don't know' just to give themselves time to collect their thoughts. If anyone says 'don't know', then probe by saying **'Well, what do you think?'** or **'I just want your opinion'** (if the question asks for opinions rather than facts). Or, if the question asks for facts, we prefer if you probe further by saying **'What's your best guess?'**

D. Instruction for Each by Each Question (Baseline Questionnaire)

Instructions to interviewers are *in italics*. **Do not read the sentence in italics.**

Page1.

-If clients say 'Yes' in A1.5, go to A1.6 and ask his/her cell counts.

-It is unnecessary to fill in A1.7-A1.10.

Page2.

-S1.1

If clients say ‘No’, he/she is not applicable for this study, so finish the interview and thank the client.

-S1.6

We ask **present** marital status. If clients say ‘Single’, ‘Divorced’, ‘Separated’, ‘Disappeared’, or ‘Widow/Widower’, **skip S1.7-S1.10, and go to S1.11.**

-S1.11

Extra sexual partner means sexual partners other than husbands or wives like boy/girl friends.

Page3.

-S1.15

①If clients never told the results with anyone outside the HC, **choose S1.15a, skip S1.16 and go to S1.17.**

②If clients told their HIV status only to their present husbands/wives or extra sexual partners, **don’t check S1.15a.** In that case, go to S1.16, and count the number of person that the clients disclosed.

Example 1: A client only disclosed her HIV status to her husband, you can just check ‘No’ from S1.15b-S1.15m and write ‘1’ in S1.16.

③If clients told their HIV status to the one who was already dead, don’t count it in S1.16

Example 2. A client disclosed his HIV status to his wife who was dead and his brother who was also dead, check ‘No’ from S1.15b-S1.15m and write ‘0’ in S1.16.

Page 3-4

-S1.19-S1.22

①If clients have only one wife/husband, get the information in the part of 1st wife/husband, and **check ‘Not applicable’ in the part of 2nd &3rd wife/husband.**

②If clients have never been married but have extra sexual partner such as boy/girl friend, check **‘Not applicable’ in S1.19&S1.20and go to S1.21.**

③If clients are married, ask the clients to answer about their present marital partner. If

the clients have more than one marital partner, get the information in the part of 2nd wife/husband, and 3rd wife/husband in S1.19&S1.20.

④If clients are divorced/separated/widow/widower, ask the clients to answer about **their past husband/wife in S1.19&S1.20.**

⑤If clients have both marital partner(s) & extra sexual partner(s), ask the clients to answer about **both from S1.19-S1.22.**

-S1.23
It is unnecessary to read all of the items of 1-22. **Check all items that clients raised as reasons for having HIV test.**

Page 5.
-S2.1
Check all items that clients raised as their job.

Page 6.
-S3.1
Include children **who are not own of the clients.**
-S3.3
If clients own 'Cattle', 'Goat', 'Chicken' or 'Pig', ask them to answer the number of the domestic animals. (If the clients do not know the exact number, **the rough number is acceptable)**

Page 6-7
-S3.2
It is necessary to read all items of S3.2.1-S3.2.11.
-Tra1
It is unnecessary to read all items from Tra1a-Tra1f, but **check 'Yes' or 'No' for each question.**

Page 7
-Dep1.
Don't miss the answers from Dep1a-Dep1k.
0=No=Rarely or none of the time

1=1-2 days=Some or a little of the time
2=3-4 days=Occasionally or a moderate amount
3=5-7 days=Most or all of the time

Page 7-8
-FE.2
It is necessary to read all items of FE.2 a-FE.2k.

Page 8
-FE.3
Don't miss the answers from FE.3a-FE.3f.

-Ss. 1a-Ss.1c
Don't miss the answers from Ss.1a-Ss.1c and tell clients exactly that they have four options to answer: Completely true; Relatively true; Relatively false; Completely false.

-Ss. 1d-Ss. 1g
①Ask clients of present feeling to the health staff. **Even if the clients contact with the health staff only once, ask their impression whether the health staffs seem to be trustworthy or not.**

②If clients have never contacted with health staff such as adherence counsellor, check 'Not applicable'

Page 9
-Con.1 b.
If clients do not have sexual partners during last 3 months, **write '0' person(s).**

-Con. 1 c.
①If clients have never sexual intercourse in their lives, check 'Not applicable'.

②**If clients say 'Stop sexual intercourse', skip Con.1c and go to Fam 1.**

③**If clients are divorced/separated/widower/widow, and they have no sexual partner at present, check 'Stop sexual intercourse'.**

Page9-10
-Fam 1-4
①If clients answered **‘No’ in Fam 1., skip Fam 2. and go to Fam 3.**

②If clients answered **both ‘No’ in Fam 1. & Fam 3, skip Fam 4 and go to the V.1.**

③It is unnecessary to read all methods of Fam 4.a-Fam 4.m. Check all methods that the clients raised.

④If clients answered **‘Yes’ in either Fam1 or Fam3, go to the Fam 4.**

⑤If clients answered ‘Yes’ in either Fam1 or Fam3, but **they do not use any methods, check ‘Yes’ in Fam 4.n.**

Page10
-V.1-2
①If clients do not have spouse(s) and extra sexual partner(s), check ‘Not applicable’.

②**If clients are divorced/separated because of their HIV status, check ‘Yes’ in V.1 and check ‘3. Divorced/Left’ in V.2.**

E. Instruction for Each by Each Question (Follow-up Questionnaire)

Page 1
-A1.1-A1.4
It is unnecessary to fill in.

Page 2
-A1.7
If clients say ‘No’, skip A1.8 and go to A1.9.

Page 3
-A1.12
If clients say ‘No’, skip A1.13.

-A1.14
Only ask this question of clients: missed one or more during the past four days; missed

one or more dose on the weekend, took a double dose of ART medication during the past four days; stop taking ART for 48 hours or longer. **Check the answers of A1.5, A1.9, A1.11,&A1.12.**

Page 4

We ask **present** marital status. If clients say 'Single', 'Divorced', 'Separated', 'Disappeared', or 'Widow/Widower', **skip S1.2-S1.5, and go to S1.6.**

-S1.6

Extra sexual partner means sexual partners other than husbands or wives like boy/girl friends.

Page 5

-S1.10

①If clients never told the results with anyone outside the HC, **choose S1.10a, skip S1.11 and go to S1.12.**

②If clients told their HIV status only to their present husbands/wives or extra sexual partners, **don't check S1.10a.** In that case, go to S1.11, and count the number of person that the clients disclosed.

Example 1: A client only disclosed her HIV status to her husband, you can just check 'No' from S1.10b-S1.10m and write '1' in S1.11.

③If clients told their HIV status to the one who was already dead, don't count it in S1.11.

Example 2. A client disclosed his HIV status to his wife who was dead and his brother who was also dead, check 'No' from S1.10b-S1.10m and write '0' in S1.11.

Page 5-6

-S1.14-17

①If clients have only one wife/husband, get the information in the part of 1st wife/husband, and **check 'Not applicable' in the part of 2nd &3rd wife/husband.**

②If clients have never been married but have extra sexual partner such as boy/girl friend, check **'Not applicable' in S1.14&S1.15and go to S1.16.**

③If clients are married, ask the clients to answer about their present marital partner. If

the clients have more than one marital partner, get the information in the part of 2nd wife/husband, and 3rd wife/husband in S1.14&S1.15.

④If clients are divorced/separated/widow/widower, ask the clients to answer about **their past husband/wife in S1.14&S1.15.**

⑤If clients have both marital partner(s) & extra sexual partner(s), ask the clients to answer about **both in S1.14-S1.17.**

Page 6
-S2.1
Check all items that clients raised as their job.

-S2.3
Include children **who are not own of the clients.**

Page 7
-Ar1.1
①If clients have never been married but have extra sexual partner such as boy/girl friend, check **'Not applicable' in Ar1.1and go to Ar1.2.**

②If clients have more than one wife/husband, get the answer in part of 2nd wife/husband and 3rd wife/husband.

③If clients are divorced/separated/widow/widower, ask the clients to answer about **their past husband/wife.**

-Ar1.2
Check 'Yes' if **all** the other adults know that the clients are taking ART.

-Ar1.4
①If clients do not have any extra sexual partners, check **'Not applicable'.**

②If clients have more than one extra sexual partners, get the answer in part of 2nd and 3rd extra sexual partners.

③If his/her extra sexual partner was already dead, ask the clients to answer about **their past extra sexual partner.**

Page 7
-Ar1.7
It is necessary to **read each item from 1-9.**

Page 8-9
-Ar1.16-17
It is necessary to **read all options for expressing clients' health condition.**

Page 9
-Dep1
Don't miss the answers from Dep1a-Dep1k.
0=No=Rarely or none of the time
1=1-2 days=Some or a little of the time
2=3-4 days=Occasionally or a moderate amount
3=5-7 days=Most or all of the time

Page 10
-FE.3
Don't miss the answers from FE.3a-FE.3f.

-Ss. 1a-Ss.1c
Don't miss the answers from Ss.1a-Ss.1c and tell clients exactly that they have four options to answer: Completely true; Relatively true; Relatively false; Completely false.

-Ss. 1d-Ss. 1g
①Ask clients of present feeling to the health staff. **Even if the clients contact with the health staff only once, ask their impression whether the health staffs seem to be trustworthy or not.**

②If clients have never contacted with health staff such as adherence counsellor, check 'Not applicable'

Page 11

-Con.1 b.
If clients do not have sexual partners during last 3 months, **write '0' person(s).**

-Con. 1 c.
①If clients have never sexual intercourse in their lives, check 'Not applicable'.

②**If clients say 'Stop sexual intercourse', skip Con.1c and go to Fam 1.**

③ **If clients are divorced/separated/widower/widow, and they have no sexual partner at present, check 'Stop sexual intercourse'.**

Page 11
-Fam 1-4
①If clients answered **'No' in Fam 1., skip Fam 2. and go to Fam 3.**

②If clients answered **both 'No' in Fam 1. & Fam 3, skip Fam 4 and go to the V.1.**

③It is unnecessary to read all methods of Fam 4.a-Fam 4.m. Check all methods that the clients raised.

④If clients answered **'Yes' in either Fam1 or Fam3, go to the Fam 4.**

⑤If clients answered 'Yes' in either Fam1 or Fam3, but **they do not use any methods, check 'Yes' in Fam 4.n.**

Appendix 6. Ethical approval by the Research Ethics Committee of the University of Tokyo

様式第２号

倫　理　委　員　会
審 査 結 果 報 告 書

平成２２年６月１４日

申請者
健康学習・教育学
教授
甲斐　一郎　殿

東京大学大学院医学系研究科長・医学部長
清水　孝雄　　印

審査番号　3036
研究課題　ザンビアのヘルスセンターにおける抗レトロウイルス療法（Antiretroviral Therapy:ART）継続要因、HIV　status の開示要因、ART 患者の self-stigma 要因の検討

上記研究計画を平成２２年６月１４日の委員会で審査し下記のとおり判定しました。
ここに通知します。

判　定	
○承認する。	承認しない。
条件付きで承認する。	該当しない。
変更を勧告する。	

条件あるいは変更勧告の理由（細則第３条第２項）

Appendix 7. Ethical approval by the Biomedical Research Ethics Committee of the University of Zambia

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm or unzarec@zamtel.zm

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Assurance No. FWA00000338
IRB00001131 of IORG0000774

11 December, 2009
Ref.: 022-11-09

Dr Ikuma Nozaki, MD
JICA, HIV/AIDS Care Project Expert
C/O JICA Zambia Office
P.O. Box 30027
10101 Lusaka, Zambia

Dear Dr Nozaki,

RE: SUBMITTED RESEARCH PROPOSAL: **"EFFICACY AND IMPACTS OF ANTIRETROVIRAL THERAPY (ART) IN RURAL AREAS, ZAMBIA"**

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 23 October, 2009 where changes were recommended. We acknowledge receipt of the revised proposal with corrections/clarifications. The proposal is approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a copy of final results of the study is submitted to this Committee.**

Yours sincerely,

Dr James Munthali
A/CHAIRPERSON

Appendix 8. Ethical approval by the Institutional Ethics Committee of the International Medical Center of Japan

国立国際医療センター倫理委員会審査判定通知書

平成２１年　９月３日

申　請　者
　垣本　和宏　　殿

国立国際医療センター総長

受付番号　６９０

課　題　名　ＨＩＶサービスへのアクセス改善とサービスの質に関する研究

代　表　者　垣本　和宏

上記課題を平成２１年　９月３日の倫理委員会で審査し、下記のとおり判定したので通知する。

記

判定	「　承　認　」
理由	附記 略語を使用する際は、初回使用時にフルスペルで解説して下さい。