

ANTIRETROVIRAL TREATMENT
IN
SUB-SAHARAN AFRICA
CHALLENGES AND PROSPECTS



**Organisation for Social Science Research in
Eastern and Southern Africa (OSSREA)**

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OSSREA acknowledges the support of Swedish International Development Co-operation Agency (Sida), Norwegian Agency for Development Co-operation (NORAD), The Netherlands Ministry of European Affairs and International Cooperation, International Development Research Centre (IDRC), and Danish Development Agency (DANIDA).

Printed in Ethiopia

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ISBN: 978-99944-55-70-6

Edited by: *Getnet Tizazu* and *Rahel Mesfin*
Copy-edited at *OSSREA*
Text layout: *Alemtsehay Zewde*

Organisation for Social Science Research in Eastern and Southern Africa

P.O. Box 31971, Addis Ababa, Ethiopia

Fax: 251-11-1223921

Tel: 251-11-1239484

E-mail: ossrea@ethionet.et

Website: www.ossrea.net

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AMR	Adaptive Multi-Rate
ART	Antiretroviral therapy
ART	Antiretroviral Treatment
ARV	Antiretroviral
BCC	Behavioural Change Communication
BHPs	Biomedical Health Practitioners
BMPs	Biomedical Practitioners
CBOs	Community-based Organizations
CET	Cardio-respiratory Exercise Training
CORPs	Community-owned Resource Persons
CSA	Central Statistical Agency
CSOs	Civil Society Organizations
DCA	Danish Church Aid
EECMY	Ethiopian Evangelical Church Mekane Yesus
EIASC	Ethiopian Islamic Affairs Supreme Council
EIFDDA	Ethiopian Inter-faith Forum for Development, Dialogue and Action
EOC	Ethiopian Orthodox Church
ETNEREL A+	Ethiopian Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
EWB	Existential Well-being
FBOs	Faith-based Organizations
FHAPCO	Federal HIV/AIDS Prevention and Control Office
FMOH	Federal Ministry of Health
HAART	Highly Active Antiretroviral Therapy
HAPCO	HIV/AIDS Prevention & Control Office
HAPCSO	HIV/AIDS Prevention, Care and Support Organization
HBV	Hepatitis B
HC	Health Centre
HCV	Hepatitis C
HCT	HIV Counselling and Testing
HIV	Human Immuno-deficiency Virus
HRQL	Health-related quality of life

Acronyms

HSS	HIV Symptom Scale
IAS	International AIDS Society
IEC	Information Education and Communication
IGA	Income generation activity
IPA	Interpretative Phenomenological Analysis
KAP	Knowledge, attitude and practice
KS	Kaposi sarcoma
MEMS	Medication Event Monitoring Systems
MHS	Mental Health Summary
MOH	Ministry of Health
MOS	Medical Outcomes Study
MOS-HIV	Medical Outcomes Study HIV Health Survey
MVQOLI	Missoula Vitas Quality of Life Index
NAC	National AIDS Council
NCDs	Non-communicable diseases
NCS	Nutrition care and support
NGOs	Non-governmental organizations
OIs	Opportunistic infections
OLS	Ordinary Least Square
OVC	Orphan and Vulnerable Children
PHS	Physical Health Summary
PLHIV	People Living with HIV and AIDS
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
PSD	Psychosocial distress
QOL	Quality of life
RWB	Religious well-being
SDD	Stigma, denial and discrimination
SNNPR	Southern Nations, Nationalities and Peoples Region
SSDDIM	Stigma, shame, discrimination, denial, inaction and mis-action
STIs	Sexually transmitted infections
TASO	The AIDS Support Organisation
TAWG	Tanga AIDS Working Group
TB	Tuberculosis

TBA	Traditional birth attendants
THPs	Traditional health practitioners
TMPC	Traditional Medical Practitioners Council
TMPs	Traditional medical practitioners
ToT	Training of trainers
UAC	Uganda AIDS Commission
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations International Children's and Educational Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
ZINATHA	Zimbabwe National Traditional Healers Association

CHAPTER ONE

Introduction

Getnet Tizazu Fetene

The introduction of antiretroviral therapy (ART) in middle- and low-income countries is arguably one of the most meaningful outcomes recorded in the fight against HIV and AIDS. Thanks to the expansion of the therapy in these countries, fewer and fewer people are dying as a result of HIV and AIDS related causes. In other words, despite apparent expansion of ART that enabled eight million people worldwide to receive the treatment, it is reported that it is in the Sub-Saharan Africa, the region hit hardest, that the most dramatic progress has been observed (UNAIDS 2012). A record number of some 6.2 million people living with HIV and AIDS are reported to be benefiting from the treatment, which is reported to have risen by 19 per cent between 2010 and 2011 (*Ibid.* 19). As a result of this, the region has also enjoyed a significant decline in AIDS mortality. The number of AIDS-related deaths, which was frighteningly 1.8 million in the year 2005, has dropped to 1.2 million in 2011 (UNAIDS 2012). So has morbidity. All this is good news, and the success stories are largely attributable to the rapid expansion of ART.

Irrespective of these encouraging trends, a number of challenges/problems have been encountered following the introduction of ART and in relation to its expansion. The need to maintain/achieve equitable access, failure to reach those who haven't known their sero-status, and difficulty of convincing people living with HIV and AIDS (PLWHA), who are reluctant to receive the therapy until they see AIDS-related illness, are some of the challenges observed along the expansion of ART. Poor adherence (often leading to drug resistance), complete discontinuation of the treatment, some long-term and short-term side-effects resulting from ART management, are other key problems occurring following ARV (antiretroviral) therapy. The issue of maintaining the pace at which HIV treatment is currently expanding is also another related challenge (Ivers, Kendrick, and Doucett 2005; UNAIDS 2012).

Mostly inspired by the need to find ways of tackling these challenges, researchers and scholars in the developed and the developing world have been conducting various studies on ART-related issues. Even though there appears to be a consensus among them regarding the obvious benefits of ARV therapy, they disagree on a number of other issues, for example on measuring level of adherence among patients, on reasons for poor adherence, on the role of traditional medicine in HIV treatment, and on relevant methods of conducting related studies (Ivers, Kendrick, and Doucett 2005). The debates on these issues are ongoing and they are likely to continue.

At this juncture, it is perhaps worth citing some specific areas of ARV treatment that attracted scholars' and researchers' attention. Mostly because of the negative repercussions poor adherence can bring about at societal and individual levels, it could be argued that the issue of adherence is perhaps one of the areas that have been widely researched and debated. Many researchers such as (see Coetzee, Kagee, and Vermeulen 2011; Kalichman, Catz, and Ramachandran 1999; Tam *et al.* 2011 and Watta *et al.* 2010) have, for example, conducted studies examining the possible barriers (personal, structural or institutional) responsible for poor adherence. The different studies have come up with different findings and at times with conflicting results. Regarding the methods of assessing levels of adherence, some use indirect methods (e.g. Blacher *et al.* 2010); some others use direct methods (e.g. Liechty and Bangsberg 2003) and still others employ a combination of both direct and indirect methods. Thus, there doesn't seem to be a consensus on the perfect method for measuring adherence. While researchers who favour the direct method say the method is reliable, some question its applicability in resource-constrained settings, like the sub-Saharan Africa. Similarly, those who object to indirect methods argue that data gathered through these methods are questionable because of social desirability bias (Blacher *et al.* 2010). The studies included in this volume could be considered a continuation of and contributions to this ongoing debate on a number of ART- related issues.

This volume, titled "*Antiretroviral Treatment in sub-Saharan Africa: Challenges and Prospects*", is the outcome of the 'call for abstracts' put out by OSSREA in 2011 for senior researchers, social scientists and practitioners to write scientific articles on issues surrounding ARVs. Recognising the intricacies of numerous but often linked concerns surrounding ARVs, OSSREA invited interested authors to write book chapters, focusing on the following issues:

- Quality of life of patients under ARV treatment; social support systems to PLWHA in ARV treatment; role of gender, age, class, and ethnicity in determining patients' access to ARVs of life; and effectiveness of policies and programmes which attempt to ensure equitable and non-discriminatory access to ARVs;
- The link between the formal and informal HIV and AIDS treatment services, particularly on the role of informal health providers, including traditional and faith-based healers, in influencing patients' decision to receive and adhere to or refrain from ARVs treatment;
- The supportive role of community-based organizations (CBOs), non-governmental organisations (NGOs), and the private sector, especially in enhancing confidential, equitable and non-discriminatory provision of ARV treatment;
- Scaling up ARV and government budgetary allocations, support programmes for increasing access to patients, and roles of

international, continental and regional organizations in sub-Saharan Africa in ensuring sustained provision and use of ARV treatments.

This volume contains eight chapters organized into four sections. The chapters are contributed by Academics and researchers from three different African countries: four from Ethiopia, two from Uganda and two from Zimbabwe. The chapters put into the four sections have four themes: 1) ART and quality of life, 2) Adherence to ART, 3) Traditional medicine and ART, and 4) Sexual behaviour of ART attendants. While Sections I and III consist of two chapters each, Section II contains three chapters. Included in Section IV is just a chapter. Whereas two of the chapters incorporated in the first section are review works, the other six chapters presented under the three sections are results of original empirical studies. Four of the six empirical studies included in the volume employed qualitative methods while the other two are more of quantitative studies. Chapter Six, a study by Wasswa-Matovu is purely quantitative and it employs sophisticated statistics like logistic regression. The fifth chapter by Woinishet and Abiy is the only chapter that employed mixed methods (i.e. quantitative and qualitative). It could thus be said that the book contains chapters that are the result of studies that employed quite a variety of methods, and is apparently balanced in terms of methodology.

The two review articles, “*Adherence to Antiretroviral Therapy in sub-Saharan Africa: Challenges and Prospects*” and “*Quality of Life among Patients Living with HIV and AIDS in sub-Saharan Africa*” are intentionally included in the first section of the volume for two reasons. In the first place, in their comprehensive review of empirical works and theoretical issues, the two articles have attempted to offer the major debates raised on the subject in the region in particular and in the world as a whole. Secondly, the articles are complementary and foreshadow the kind of empirical works that need to be carried out.

Driven by the paucity of comprehensive review studies on ART in sub-Saharan African region, in the second chapter titled “*Adherence to Antiretroviral Therapy in sub-Saharan Africa: Challenges and prospects*”, Sibhatu Biadgilign and Ayalu Aklilu critically assess works that evidence challenges in and prospects of ART adherence in the region. To that effect, the authors make a thorough search of the literature from six online bibliographic sources and big databases of conference abstracts using some nine different relevant search items. The search has resulted in over 100 articles and abstracts written in English, which in turn led to analyses of works reviewed under three thematic headings: 1) adherence estimates, 2) adherence barriers, and 3) suggested solutions for mitigating the problem.

With respect to an overall adherence estimates, contrary to expectations, Sibhatu and Ayalu report a high degree of adherence ranging from 75 per cent to 77 per cent, a much higher level of adherence than the one reported in North American studies (55 per cent). The finding is in agreement with Ivers, Kendrick and Doucett’s (2005) meta-analyses. On a negative note,

the chapter reveals that, albeit the overall encouraging ART coverage/adherence among the adult PLWHA, the adherence among children and young adolescents is not that encouraging. The review has shown a number of challenges and problems resulting from poor adherence; and they are categorized under: patient and family-related challenges, socio-economic and environmental challenges, medication-related challenges, health care- and systems-related challenges, and patient- and family-related challenges. More specifically, regarding paediatric patients, the review has indicated that age, treatment refusal, knowledge about HIV status and treatment process, and depressive symptoms affect ART adherence. Denial and fear of HIV status, misinformation and misconceptions about HIV, low availability of ART, accessibility and acceptance of therapy are identified as some of the problems preventing HIV-infected adolescents from benefiting from ART. The administration of complex regimens also compounded the problems.

Lack of the will to disclose one's own sero-status to friends and family members is also reported as a predictor to poor adherence among adults. In relation to socio-economic and environmental challenges, poverty-related factors, for example, financial troubles, and distance or lack of transportation to the ART clinic are identified as some of the reasons for poor adherence.

With respect to solutions to mitigating adherence problems, the third major theme, the authors generally underlie the need to maintain regulated access to ART and avoid individual's treatment failure. Failure to do so, the author's caution, would lead to "rapid emergence of drug-resistant viral strain" and "the transmission of drug-resistant strains of HIV" that would seriously hamper future treatment efforts. The authors further call for rigorous evaluative and operational research on ART service provision. The chapter winds up by offering a conceptual framework that sums up factors that determine adherence to ART, with implications for possible intervention.

The overall objective of the third chapter by Bajunirwe is to provide aggregate evidence and research on quality of life (QOL) among HIV-infected patients in sub Saharan Africa. In this chapter, the author argues for the need to provide such a comprehensive review since the literature on QOL is dominated by empirical studies from the West, where ART has been available for a much longer period of time. In Africa, where free ART is a recent phenomenon—a little more than five years old— works that offer a review of studies on factors that affect the quality of life of PLWHA is, according to the author, scanty. Unlike related reviews such as Beard, Feeley, and Rosen (2009) which were dominantly on the impact of ART on quality of life (QOL), Bajunirwe's review is more comprehensive. It first chronicles factors that influence QOL of PLWHA prior to the initiation of ART. It then examines factors (variables) that positively or negatively affect the quality of life of people who are on ART.

Prior to dealing with factors associated with QOL, the author opens the chapter by acknowledging the difficulty of measuring quality of life in sub-Saharan Africa in the context of HIV and AIDS mainly because most of the tools used to measure it are developed in the West and are not always appropriate for the region. Additionally, it has several dimensions that cannot be accommodated by a single tool.

Regarding factors affecting QOL before the initiation of ART, the review reveals mixed results. While greater CD4 counts are generally reported to be indicative of positive QOL, high viral load is marker of low scores in QOL. Similarly, factors that affect socio-economic status (e.g., education, employment, and income) were reported to have meaningful association with QOL. For example, the higher the education level of a PLWHA, the better his/her quality of life and vice-versa. At the same time, the association of QOL with demographic variables such as age and gender is reported to be not as predictive.

On the other hand, the review showed that the initiation of ART in sub-Saharan Africa has improved the quality of life of people infected with HIV. At the same time, along with the author of Chapter one, Bajunirwe cautions that the gains made in QOL may be offset by the emergence of long-term side effects, for example body fat redistribution, rash, toxicity of some regimen, that arise following prolonged ART. What the author calls modifiable factors that follow the initiation of ART are reported to impact QOL positively. These include factors such as social support, disclosure, stigma support, nutrition, religiosity, use of less toxic and less pill burden regimens, exercise, support with income-generating activities, and treatment of co-morbidities such as malignancies and tuberculosis that are common among AIDS patients.

With regard to interventions to improve the quality of life to PLWHA, among other things, the author recommended the following: the introduction of simple regimens such as “one pill a day regimens”; maintaining the spiritual/religious wellbeing of PLWHA; empowering PLWHA through income-generating activities; and treatment of depression using different mechanisms. The chapter sums up its review by indicating possible research areas along with suggestions/recommendation of appropriate research designs.

As pointed out earlier, the subject of Section II, consisting of three chapters, is PLWHA’s adherence to ART. Chapter Four by Bereket Tarekegn is based on a qualitative case study that involved 52 research participants chosen from associations formed by religious leaders (Moslems as well Christians) who live with HIV as well as organizations that partner with these associations. In this chapter, Bereket critically examines the interplay of religion, stigma and adherence to ART. More specifically, the author seeks to empirically show the contribution of religious leaders and their fellowship/associations in helping themselves

and other believers live a positive life with HIV and AIDS, taking ARV treatment and withstanding stigma.

Before presenting the empirical findings of his actual work, Bereket makes a couple of interesting observations from the literature. The first key observation is the mixed reports about the influence of the availability of ART on PLWHA's ability to withstand stigma or their failure to cope with it. Some of the empirical works he reviewed (e.g., Castro and Farmer 2005) show that the availability of ART embolden PLWHA to come out and seek treatment, thereby anticipating a pursuit of an optimistic life style. At the same time, other works reviewed (e.g., Weiser *et al.* 2003), albeit acknowledging its role in reducing stigma, indicate that PLWHA have a long way to go in eliminating fear of stigma and discrimination. His second key observation has to do with the way religious leaders are depicted in relation to the HIV and AIDS pandemic. In the literature, the author argues, religious leaders are often blamed for equating HIV with sin and people infected with the virus as sinners; religious leaders are thus rarely depicted as accomplice in the fight against HIV and AIDS. Partly because of this stereotypical depiction of religious leaders, the author further argues, empirical studies investigating their positive role are rare. In doing so, the author carves a research space for his study.

From a unique set of participants, i.e. religious leaders living with HIV, it can be argued that Bereket, among other things, found two important related findings. The first finding — echoing the results of previous studies (e.g., Castro and Farmer 2005) — indicates that treatment availability has enabled people infected with HIV to break their silence about their HIV positive status. Linked with that is the contribution of the PLHIV fellowship and religious institutions (church and mosque) to other believers infected with the virus by way of providing strength and moral courage to reveal their status and thereby benefit from ART. The second finding, one could argue a contribution to the literature, is the exemplary contribution of religious leaders living with HIV to other members of the fellowship. The coming of the religious leaders in the open to declaring their status has been found to be instilling a feeling of confidence in withstanding stigma.

In Chapter Five, Woinishet and Abiy examine factors that determine adherence to ART drugs in sub-Saharan Africa by taking Ethiopia as their focus of study. Unlike some previous studies that mostly considered non-adherence to mean missing pills, the present study from the outset operationalises non-adherence both as missing pills and failure to observe intervals between doses— in a way addressing one of the limitations observable in related studies. Despite acknowledging the availability of a few related studies on the subject, the authors note that previous studies are limited in number and their findings are inconsistent. According to the authors, this inconsistency could partly be attributed to the dynamic nature

of adherence itself and to some measurement problems (e.g., focusing on certain health institutes, say hospitals).

In order to meet their objectives, Woinishet and Abiy have employed quantitatively slanted mixed methods (questionnaire, focus group discussions, and in-depth interviews). For gathering its quantitative data, the study has targeted some 510 HIV and AIDS patients (aged 18 years and above) who have been on ART for a minimum of one month. Data for the qualitative segment of the study was also collected from 10 patients who participated in focus group discussions and from in-depth interviews conducted with 12 health professionals chosen from different health institutes.

As a whole, the study reported that 63 per cent of the participants adhered to ART, an amount which could be described as sub-optimal. And the overall adherence was found to be 92 per cent. Of the many factors hypothesized to determine people's adherence to ART, demographic characteristics were found to have no statistical significance. In spite of that, patients' family size was reported to have positive and significant effect in increasing their adherence— those with larger family members enjoying better social support and exhibiting stronger adherence. The study further revealed that patients with prior history of hospitalization exhibited better adherence than their counterparts did. With respect to type of treatment institutes, those treated in hospitals showed higher adherence than those treated in clinics. The study also indicates that having mobile phone, owning TV, and not being under the influence of substance abuse were the other variables that are likely to increase rate of adherence to ART.

Maintaining intervals between doses, another form of adherence, was found to be affected by patients' sex and religion. More specifically, the study indicated that more males than females tended to be consistent in terms of keeping dose intervals for the former did not have to shift intervals between doses due to fasting. Similarly, religious people, particularly those who fast, exhibited higher probability of failing to maintain consistent intervals between doses. It is, however, worth noting that it is the Orthodox Christians (followed by Moslems and Protestants) that demonstrated the highest probability of failing to keep consistency of dose intervals.

Among those who reported to have missed medication, the study revealed that forgetfulness was reported to be the most common reason with 31 per cent of the non-adherents citing it as their major reason. That was followed by fear of stigma and discrimination (cited by 9 per cent of adherents) and due to side effects (with unspecified percentage). While most, i.e. 68 per cent, of those who reported to have adhered to medication attribute their adherence to their personal commitment, 38 per cent and 31 per cent of them owe their success to supports they received from health institutes and friends/support groups respectively.

As opposed to the other two chapters included in Section II of the book, the sixth chapter by Wasswa-Matovu conceptualises HIV and AIDS service treatment beyond ARV treatment. For him, the treatment service is more comprehensive and embraces different forms of counselling for HIV and AIDS including voluntary counselling and testing (VCT); prevention of mother-to-child transmission (PMTCT); and clinical management of patients under ART— ranging from the antiretroviral prescription to monitoring to community-based treatment, care and support. It could even include the diagnosis and management of opportunistic infections such as tuberculosis (TB). It should thus be noted that the author has operationalised treatment keeping these features/services in mind. The author opens the chapter by briefly outlining the phased approach that Uganda has followed in responding to the HIV and AIDS epidemic ranging from first phase experiential learning and social mobilization to the current phase identified as a socio-medico approach of HIV and AIDS treatment service, including ART as a key component— which in a way is indicative of the global trend.

Despite the commitment of the government of Uganda to provide a multi-faceted service delivery, the author argues, the service delivery is characterized by a number of problems: discriminatory practice, poor management system, inadequate supplies, failure to provide proper funding by bodies/ stakeholders concerned. On the other hand, at least according to government report, Uganda is reported to have done well in the provision of HIV and AIDS preventive spheres. Still, the author argues, the service is uneven.

Outlining the success of UGANDA in other HIV related activities, the author contends that treatment access to HIV and AIDS is rather uneven. In this chapter, the author seeks to explore factors that influence patients' choice for HIV and AIDS treatment. The study has also attempted to examine the efficacy of the service delivery in meeting their treatment needs. To meet these objectives, the study administered questionnaires to 208 AIDS patients seeking treatment services at various health centres/facilities.

The study reports some key findings. Not surprisingly, it documents that patients have easy access to HIV and AIDS-related information and free access to condoms. Though not to a high degree, evident in the report are also the availability of services such as: family planning, CD4 count test, antiretroviral medicines and PMTCT. On the other hand, services of limited provision include services like: Routine Counselling and Testing (RCT), TB medication, nutritional support, and more importantly, follow-up care plan services.

As indicated earlier, the role of traditional Medicine in HIV treatment is a thematic issue treated in Chapters Seven and Eight that form Section III. In Chapter Seven, Enock Mandizadza and Gordon Chavunduka basically explore the reasons (historical, legal, and political) that have hindered the

possible integration of traditional and modern medications in Zimbabwe. To meet these objectives, the authors draw their empirical data from archives and policy documents such as Zimbabwe National Traditional Medicine Policy 2007, Traditional Medical Practitioners Act. They also conducted in-depth interviews with seven key informants, i.e. officials working in relevant organizations (e.g., Traditional Medical Practitioners Council, Department of Traditional Medicine in the Ministry of Health, Zimbabwe Medical Association).

They begin with the proposition that sole reliance on western medicine in the fight against the HIV and AIDS pandemic in African region would not yield fruitful results. Given that approximately 80 per cent of the region has the culture of utilizing traditional medicine, at least by WHO admission, the authors argue, the exclusion of traditional medicine from HIV and AIDS treatment is detrimental to say the least. They go on to the extent of arguing that the practice of marginalizing cultural medicine is attributable to the colonial legacy of killing indigenous knowledge in Africa and other developing regions that had to undergo the brunt of colonialism. The enactment of the Witchcraft Suppression Act of 1899 during colonial Zimbabwe that indiscriminately criminalized the legitimacy and malpractices of traditional medicine, according to the author, is a proof for their derisory treatment of traditional healing.

Albeit admitting the difficulty of forging partnership between biomedical practice and traditional healing, Mandizadza and Chavunduka's work highlights the possibility of integrating the two in connection with ART. Evidences from key informants in particular reveal that while the administration of treatment regimens should obviously be left to modern medicine, the task of care and promoting adherence to ART, which is equally important, be entrusted to traditional practitioners, or be carried out in partnership. Extending the role of the traditional medicine practitioners, the study underlies that they could also be involved as social mobilisers of PLWHA to access ART. Owing to their social skills, the authors claim, they are well-paced in exhibiting success in these areas. In spite of that, they caution that there could be mistrust between the two as the traditional medicine practitioners' air concern that "their hard-earned knowledge on herbal medicine" could be stolen. The objection of herbal/traditional medicine by the proponents of biomedicine is obvious. Generally labelling their counterparts as unscientific, they critique the traditional practice on issues of improper dosage, poor diagnosis and unhygienic procedures. In spite of this mutual mistrust and suspicion, the authors are as a whole optimistic about meaningful collaboration between the two sides and appreciate the efforts that are underway in Zimbabwe.

In Section III, Shastry Njeru commences Chapter Eight by reporting on the wide practice of herbal medicines in African countries including Zimbabwe. Unlike Mandizadza and Chavunduka's work, Njeru, nevertheless, emphasizes the concomitant use of herbal medicines and ART

by PLWHA in Zimbabwe in managing HIV and AIDS. The author offers various reasons for this: Number one, like their fellow Africans, he notes that Zimbabweans use “herbs as their primary drugs to treat minor ailments.” Secondly, patients are sceptical about the efficacy of biomedical treatment because of its observable side-effects and its failure to cure. People’s belief of the disease as a “social and spiritual dysfunction” is also attributable to their reliance on traditional medicine.

The author, however, criticises that these reasons are rather inferential and not based on empirical studies on the concomitant use of ART and herbal medicines by HIV and AIDS patients. More specifically, despite sharing the view that there is some kind of ambivalence exhibited by patients towards ART and herbal medicine in the management of HIV and AIDS, the author contends that empirical studies on the subject are lacking. And the primary objective of the study is to empirically demonstrate this ambivalence from the horse’s mouth: the patients.

To that effect, guided by what he calls Interpretative Phenomenological Analysis (IPA), the author collects empirical data from three participants receiving ARV Treatment. Rigorous data gathered through semi-structured interview conducted with the three participants chosen through snowballing reveals four emerging themes: desperation as a cause of ambivalence; medical methods as threats to life; traditional/spiritual methods as comforters; and the HIV and AIDS health message. Partly because of their desperate need to obtain help or treatment, the author argues, patients involved in the study, exhibited ambivalence to conventional medicine and traditional healing. More specifically, as long as they get remedy for their sickness, they don’t show particular preference to either the biomedical or traditional medicine. A desperate question by Monica, one of the key informants of the study, if the researcher were there to give her counselling from the outset of the interview (despite her repeated earlier attempts to seek remedies from traditional healers), is indicative of patients’ desperate situation and their ambivalent stance. The desperation is in fact further compounded by abject poverty that the patients find themselves in. With regard to the second theme, considering biomedical methods as life threatening, the study revealed that patients regard them as menacing to them at two levels. On one level, as is the case with Monica, they think the CD4 count that precedes the introduction of ARV, indicates the physical state of their health with a sense of precision and that makes them rather anxious. At another level, equating lower numbers of CD4 counts with deteriorating health condition, they develop a sense of frustration. Contrary to that, when they resort to traditional healers, they see their problems externalized to evil spirits and all that. They find that comforting with the belief that they will feel better once the evil spirits are exonerated and in a way that is psychologically relieving. On the other hand, sufferers turn to ARTs when seeking a remedy for their deteriorating physiological state.

The ninth chapter in Section IV, the Sexual Behaviour of PLWHA, further deals with ART— treating the issue from the perspective of the sexual behaviour of the youth who are on ART. The overall objective of Nathan Negussie’s chapter is exploring the sexual behaviour of youth who are attending ART in Addis Ababa, Ethiopia. The chapter seeks to examine the youth’s understanding of risks once they begin attending ART and identifying issues influencing their sexual experiences.

The author begins the chapter by briefly acknowledging how the introduction of ART has dramatically changed people’s conception of HIV and AIDS from a killer disease to chronic ailment, thereby regenerating a sense of optimism for PLWHA. At the same time, the author underlies the short-term and long-term side-effects associated with taking the treatment as well as unsafe sexual behaviours demonstrated by some attendants— a theme shared by almost all the authors that contributed to this volume. The author then rightly justifies the need to explore the sexual behaviour of this group out of concern that unprotected sex could result in negative repercussions to themselves and to society at large. These risks include: the contracting of other STIs and another trait or HIV virus, transmission of drug resistant HIV to healthy people, unintended pregnancy as well as HIV positive births.

The study targeted the youth with the belief that it is the largest group consisting of the age group living with the virus. More specifically, the author has garnered the required data through in-depth interviews conducted with six heterosexual male youth (aged 25 to 29) living with HIV. Among other things, the study found that participants were all aware about the possible risks of having sex without condoms, including unplanned pregnancy, contracting STIs and the possibility of contracting drug resistant viral type. Despite this awareness, the study also found that condom use among the research participants was not uniform. Those who have had sex without condom after being on ART, the study reveals, attribute their practice of non-condom use to feelings of despair, substance abuse and pursuit of sexual pleasure. In some cases, the feeling of helplessness resulting in failure to use condom would extend to inconsistent use of the ART medication. For some, the desperate need to have children (fear of dying childless) would embolden them to have unsafe sex. Interestingly, complete abstinence was a behaviour reported by one of the participants who said he was too angry at himself to ever think of having sex or resuming sexual partnership.

The practice of having multiple sexual partners was, however, reported to be less severe among the participants. Though a couple of the respondents of the study reported to have had sex with a number of women, mainly out of hopelessness, right after commencing ART, they said they hadn’t sustained the malpractice. The practice of disclosing one’s sero-status exhibited lack of uniformity among the participants. Three of the participants who had no difficulty disclosing their sero-status were those

who met their partners while attending ART. On the other hand, those who refrained from disclosing their status were the ones who had intimate relations with women who they thought had not contracted the virus. Despite confessing to have involved in such immoral relations, they at the same time narrate to have pursued the relation for fear of losing their partners. The sexual lives of PLWHA appear to be influenced by their state of mind like that of healthy people. When they are emotionally distressed, they tend to be disinterested in sex. Conversely, their sexual interests are aroused when their body relaxes following good meal and sleep. Unlike healthy people, though, their stigma and discrimination negatively affect “their desire and hope of ever forming sexual partnerships.” Encouragingly, almost all the participants are reported as saying they resort to their spirituality to cope with their emotional distress. Participants spiritual engagement rekindles their hope to live longer, form sexual relation and even have children.

As a whole, though inconclusive, Nahatan’s study indicated that PLWHA have a tendency to avoid risky sexual behaviour after they are on ART, a finding in line with the findings of earlier studies conducted in Ethiopia and in other African countries.

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CHAPTER TWO

Adherence to Antiretroviral Therapy in sub-Saharan Africa: Challenges and Prospects

Sibhatu Biadgilign and Ayalu Aklilu

Abstract

There are no conclusive and exhaustive studies of ART adherence and its challenges in the sub-Saharan Africa region which has the largest number of HIV infections in the world. This chapter aims to assess the evidence on the challenges and prospects of ART adherence in sub-Saharan Africa. We conducted a systematic review of the evidence on selected original and review articles involving HIV-positive individuals that measured ART adherence level and factors associated to it in the past decade. Contrary to expectations, patients in sub-Saharan Africa have similar, if not higher, adherence levels compared to patients in developed countries. The barriers/challenges to ART adherence include factors related to patients and their families, socioeconomic factors, medication, health providers and healthcare systems among others. Prospects and challenges for the programme include possibilities of funding decline. There are substantial areas for improvement of ART programmes in sub-Saharan African countries.

2.1. Introduction

Acquired immune-deficiency syndrome (AIDS) is one of the most destructive epidemics the world has ever faced. By the end of 2011, an estimated 34 million people were living with HIV worldwide. Sub-Saharan Africa is the worst affected region where more than two thirds (69 per cent) of the HIV infected persons in the world live (UNAIDS 2012). Since the first Antiretroviral drug was approved 25 years ago, improvements in the potency, tolerability, simplicity, and availability of antiretroviral therapy (ART) have resulted in dramatically reduced numbers of opportunistic diseases and deaths where ART is accessible (Thompson *et al.* 2012). It has also reduced morbidities by delaying progression to AIDS (Mills *et al.* 2011; Thompson *et al.* 2012). This was achieved via greater and more sustained viral suppression and improved immunologic response (Chi *et al.* 2009).

In sub-Saharan Africa, there has been a dramatic increase in the number of HIV/AIDS patients on anti-retroviral treatment (UNAIDS 2012). There were 8 million people on treatment in 2011 from just 100,000 persons in 2003 – a twentyfold increase. The UNAIDS has called this progress one of the greatest public health achievements in recent history. Due to this massive expansion of access to treatment, close to 40 per cent of those in need of the treatment are now taking it (WHO 2010; UNAIDS 2012). Similarly, slightly more than 56 per cent of Africans with

advanced AIDS are on ART (WHO 2010; UNAIDS 2012). While three sub-Saharan African countries, namely Zambia, Botswana and Rwanda have achieved universal access target (with treatment coverage of 80 per cent or more of patients in need) at the end of 2009, countries such as Ethiopia, Namibia and Senegal are moving closer to the same target, having covered between 50 and 80 per cent of patients in need of treatment (WHO 2010; UNAIDS 2012). Due to these successes, hundreds of thousands of deaths have been averted. In sub-Saharan Africa, 9 million life-years have been added to patients since 1995 as a result of ART access (UNAIDS 2012). Sustaining the momentum of expansion of ART access to patients in developing countries will depend on the available infrastructure and resources. These are decisive in providing ART and for monitoring adherence to treatment, which is among the most important predictors of treatment effectiveness (Nachega *et al.* 2010).

Good adherence to ART treatment increases better clinical outcomes. It has been reported that the stepping-stones towards the achievement of long-term virus control among patients in developing countries are simplification of therapy, improvement of patient adherence and minimization of drug resistance (Kumari and Singh 2012). According to studies, ART regimens require 70–90 per cent adherence in order to be effective (Nachega *et al.* 2010). Sustaining adherence to antiretroviral therapy (ART) over the long-term requires accurate and consistent monitoring and follow up of HIV/AIDS patients. This is a challenge particularly for countries in the sub-Saharan Africa region (Nachega *et al.* 2010).

In many settings, maintaining high treatment adherence for a lifelong condition is a considerable challenge (Nachega *et al.* 2010). The HIV/ART management is further challenged by various social and clinical obstacles (Nachega *et al.* 2010; Coetzee and Kagee 2012) where inadequate suppression of viral replication by ART is resulting due to poor adherence to therapy, losses to follow up, low potency of the antiretroviral regimens, viral resistance to antiretroviral medications, and pharmacokinetic interactions (Friedland and Andrews 2001), causing inadequate drug delivery, and other system-wise problems (Lucas *et al.* 1999; Nachega *et al.* 2010).

The transmissibility of the antiretroviral resistant viruses from person to person further compounds the problem as a clinical and public health challenge (Truong *et al.* 2006; SPREAD programme 2008). Some of these major challenges are developing novel anti-HIV drugs with new mechanisms of action, tolerable toxicity and resistance properties (Kumari and Singh 2012).

Adherence to treatment is defined as the extent to which a patient correctly takes prescribed medication (Friedland 2006). However, the measurement of medication adherence is a difficult process in clinical care as well as research settings (Talam *et al.* 2010). Quantifying the

different methods for measuring adherence and the levels of adherence is specific not only to places and patient groups but also to the method of adherence measurement used (Landovitz 2011).

As there is no gold standard with which to measure adherence, there are several strategies that have been used to assess adherence which include direct methods such as biologic markers and body fluid assays (that involve laboratory test of the drug's extracts or related markers in the body); or indirect methods like self-report, interview, pill counts, pharmacy records, computerized medication caps, and viral load monitoring. While a combination of these methods may also be employed and are actually recommended, patient self-report is the most widely used (Vreeman *et al.* 2008). In developing countries, pharmacy refill reports and self-reports are commonly implemented for adults (Chesney 2006; Nachega *et al.* 2010), while caregiver reports are employed for children (Simoni *et al.* 2007; Vreeman *et al.* 2008; Biadgilign *et al.* 2011).

It is, however, worth noting that the impact of reduced adherence to ART particularly in countries that lack the capacity for indirect adherence measures such as regular viral load testing to detect drug resistance are very expensive or simply not available (Cohen 2007). There is a paucity of studies that address the matter of adherence to ART in sub-Saharan Africa. The aim of this review is to assess the challenges of adherence to ART, identify factors contributing to poor adherence and assess the prospects of the programme in this region.

2.2. Methods

We conducted a literature search of online bibliographic databases and major conference abstract databases (inclusion dates: from 2000–2013) for all English-language articles and abstracts. The databases searched include: EBSCO, PUBMED, EMBASE, ISI Web of Knowledge, CINAHL, Cochrane Database of Systematic Reviews, AIDSLINE, Google Scholar and conference abstract databases. The following terms were used in the search strategy: infection, adherence, follow up, follow-up, monitoring, Africa, sub-Saharan Africa, HIV, AIDS, patients, antiretroviral, therapy, treatment, medication, living with HIV, ART, highly active anti-retroviral treatment, and HAART using Boolean and/or combinations. The authors reviewed both original and review papers involving HIV-positive individuals of all ages that measured ART adherence and its predictors. Data on adherence monitoring, adherence estimates, adherence barriers and suggested solutions for mitigating the problem were looked for. Furthermore, we reviewed the references of the selected articles for identifying literatures not obtained through the electronic search.

2.3. Findings

2.3.1. Estimates of Adherence

Early in the course of the AIDS pandemic, there was widespread scepticism that initiating ART treatment to African patients would lead to extensive drug resistance due to poor adherence to treatment and lack of adequate infrastructure to combat the problem. Various studies (e.g., Friedland and Andrews 2001; Harries *et al.* 2001) indicate that despite earlier fears of poor medication adherence behaviour, patients in developing countries are able to achieve adherence levels similar to or higher than those of patients in developed countries (Orrel *et al.* 2003). Similarly, the majority of reports in developing countries report paediatric adherence levels of more than 75 per cent (range 45–100 per cent) (*et al.* 2008), while in developed countries, the majority report less than 75 per cent adherence (range 20–100 per cent) (Simoni *et al.* 2007). This is possibly due to improved efforts on supporting patients and community acceptance of adherence behaviours and the ART treatment (Nachega *et al.* 2010).

Again, contrary to expectations, a review by Mills and colleagues obtained a pooled estimate of adequate adherence by sub-Saharan Africa patients of 77 per cent (95 per cent confidence interval, 68–85 per cent; whereas the figure for North American patients was 55 per cent (95 per cent confidence interval; 49–62 per cent; (Mills *et al.* 2006). The same study concluded that adherence is a concern in North America (Skovdal *et al.* 2011). However, some researchers have questioned the long-term sustainability of these encouraging findings, citing threats such as loss to follow up (Nachega *et al.* 2010). Retention to treatment seems to be an urgent problem facing African countries. According to the recent UNAIDS report released in November 2012, about half of the patients who started antiretroviral treatment at a centre in Malawi are no longer following treatment after five years. This figure is close to 40 per cent in Kenya (UNAIDS 2012). The problem may be serious than this (UNAIDS 2012) - we just do not have systematic and adequate reporting mechanisms for retention to treatment to understand the true extent of the problem.

2.3.2. Patient and Family-associated Barriers

Despite the overall encouraging ART use adherence among the adult PLWHA, the adherence among children and adolescents is not that positive. With regard to children, if the caregiver himself/herself is infected, then he/she is likely to struggle with his/her own illness, psychosocial issues, medication regimens, and, most often, financial burdens due to expenses incurred on his/her own therapy, the child's therapy and associated costs of medical treatment (Mellins *et al.* 2004; Ivers *et al.* 2005). All of these have been reported to result in negative impacts on adherence. Likewise, empirical data support that increasing the user fees in some centres for antiretroviral therapy (ART) and HIV/AIDS care decrease adherence (Lanièce *et al.* 2003; Byakika-

Tusiime *et al.* 2005). These factors on top of the caregivers and patients' experience, knowledge, and beliefs on ART reduce (Crane *et al.* 2006) the caregiver's ability to provide proper care to the child, thereby affecting the necessary adherence over time (Chesney 2000; Lwin and Melin 2001; Byrne *et al.* 2002; Ferris and Kline 2002; Gavin and Yogev 2002; Gibb *et al.* 2003).

Interestingly, factors such as age, especially infancy and adolescence, have been reported a negative effect in some studies (e.g. Orrel *et al.* 2003). Refusal of treatment, knowledge about HIV status (negatively), and the treatment process, clinical stage, and depressive symptoms, meals and changes in health status were also identified as important factors associated with adherence to ART in paediatric patients (Chesney 2000; Lwin and Melin 2001; Wedekind and Pugatch 2001; Byrne *et al.* 2002; Ferris and Kline 2002; Mellins *et al.* 2004).

A couple of studies (Weiser *et al.* 2003; Eholié *et al.* 2007) in Africa reported that higher levels of education were associated with poor adherence. Denial and fear of HIV status, misinformation and misconceptions about HIV (for instance beliefs that ART cures HIV (Biadgilign *et al.* 2011), low availability, accessibility and acceptance of therapy have also been reported as some of the obstacles leading to non-adherence among HIV infected adolescents. On top of that, administration of complex regimens at a time when adolescents do not want to be different from their peers can act as a significant barrier for adherence in this age group. In study conducted in South Africa, Reddi (2007). shows that only 7.9 per cent of children had been made aware of their own HIV infection status in their study. However, children's psychosocial features also affect adherence. Adherence rates were significantly lower in children who were aware of their infection status than in those who were not (Wiener *et al.* 2007). It is known that mothers tend to hide HIV infection status from their children and disclosure is often delayed until adolescence (Armistead *et al.* 2001). Disclosure of HIV infection status is a critical step and has obvious implications for adherence. Starting the disclosure process as early as 8–9 years of age and combining it with specific support, as suggested in some works (e.g., <http://www.hivatis.org>) may result in increased adherence among children. There are similar reports implicating lack of disclosure as a predictor of poor adherence in adults (Bajunirwe *et al.* 2009). Self-perceived family support and/or the family's and the household's knowledge of the patient's HIV infection status are considered important predictors of adherence (Sellier *et al.* 2006).

Social or familial stigmatization and fear of the consequences of revealing HIV infection status to sexual partners, in particular, are closely related to poor adherence (Nachega *et al.* 2004). Good levels of social support have been found to improve adherence to HIV medication and are linked to an improved quality of life for HIV infected patients (Peltzer

et al. 2010). On the other hand, low social support was found to predict poor adherence according to a study in Ivory Coast (Diabaté *et al.* 2007).

As indicated in a number of studies, family plays a crucial role in any kind of treatment in children (Pontali 2005) or adults (Skovdal *et al.* 2011). And major issues related to family or caregiver that influence adherence include: presence of anxiety, depression (Amberbir *et al.* 2008; Byakika-Tusiime *et al.* 2009; Nash *et al.* 2011); active substance abuse (Nash *et al.* 2011); the presence of HIV infection in another family member; fear of disclosure of HIV-positivity to the family; family disruptions, and belonging to racial minorities or other vulnerable groups of the population. One of the unfortunate realities is that the majority of children and adults with HIV also have a family member with HIV. This has serious implications for the patients' care and the health of the sexual partners of adults with HIV (Steele and Grauer 2003). This is because family and community members could both play a positive and negative role in ART treatment initiation and adherence as already stated above (Skovdal *et al.* 2011). For instance, the stigma associated with HIV infection or AIDS may be more severe than that of other illnesses, creating barriers to treatment initiation and support for adherence that might otherwise be available (Kip *et al.* 2009; Skovdal *et al.* 2011). On a positive note, family members and friends could play the role of treatment partners and provide much needed support (Birbeck *et al.* 2009; Watt *et al.* 2009; Skovdal *et al.* 2011).

Drug abuse and alcohol consumption are factors that further threaten proper adherence; a number of studies have shown that active alcohol or substance abuse makes it more difficult for patients to adhere to treatment (Weiser *et al.* 2006). In a study conducted in Botswana, nearly 40 per cent of patients surveyed, for example, admitted that they had missed a dose because of alcohol consumption (Kip *et al.* 2009).

2.3.3. Socio-economic Barriers

Social and economic conditions of the country and the individuals affected have significant roles as social determinant of the spread of the HIV virus, access, and adherence to ART treatment (Domek 2006; Skovdal *et al.* 2011). Despite the commendable initial scramble to distribute scarce and expensive medications to the world's poor, several social and economic problems like stigma and hunger hinder access to these medications even when they are now available relatively widely in many poor settings.

Common reasons reported for missing doses include financial trouble (Rachlis *et al.* 2010; Ramadhani *et al.* 2007) that prevented caregivers of children or adult patients from collecting medication on time (Skovdal *et al.* 2011); distance or lack of transportation to the ART clinic (Kip *et al.* 2009; Nash *et al.* 2011); difficulty affording transportation to the clinic; vomiting of medication without re-dosing; incorrect dosing by a

caregiver; missed clinic appointments and pharmacy collections; confusion between multiple caregivers; and self-discontinuation or refusal by children (Weiser *et al.* 2003; Hardon *et al.* 2007; Reddi 2007). Furthermore, beliefs by patients that medications need to be taken with food could interfere with adherence whenever food is unavailable (Nachega *et al.* 2006; Skovdal *et al.* 2011). Sometimes, patients are forced to choose between paying for transportation to the ART facility and using the money for food (Rachlis *et al.* 2010; Sanjobo *et al.* 2008; Skovdal *et al.* 2011).

Determinants of ART adherence for HIV-infected persons in sub-Saharan Africa were examined through ethnographic research methods at HIV treatment sites in Jos, Nigeria; Dar es Salaam, Tanzania; and Mbarara, Uganda. In addition to revealing factors that impede adherence, the findings of this study also indicated the mechanisms individuals taking ART routinely use to overcome economic obstacles to ART adherence. These mechanisms include a number of deliberate ways aimed at prioritizing adherence: borrowing and “begging” transport funds, making “impossible choices” to allocate resources in favour of treatment, and “doing without”. Prioritization of adherence is accomplished through resources and help made available by treatment partners, by other family members and friends, and by health care providers (Ware *et al.* 2009).

In addition to the general knowledge of the population about HIV/AIDS and ART treatment, stigma is an important systematic determinant of adherence in sub-Saharan African countries according to studies conducted recently (Ramadhani *et al.* 2007; Simoni *et al.* 2007; Birbeck *et al.* 2009; Nash *et al.* 2011). As a result, patients need to be encouraged by health care workers to disclose their status.

Disclosure of infection status has been linked with better adherence (Weiser *et al.* 2003). However, studies of interventions to facilitate disclosure are lacking. Social institutions like the religious institutions, Non-Governmental Organizations (NGOs), and food aid services play a crucial role in issues such as creating awareness about the illness, mobilizing support, facilitating treatment and promoting adherence (Cantrell *et al.* 2008; Biadgilign *et al.* 2011; Skovdal *et al.* 2011). In a programme evaluation about the impact of family nutritional support during the first year of antiretroviral treatment in the West Africa region, family nutritional support for persons living with HIV showed a positive impact in initiating antiretroviral treatment after six months (Serrano *et al.* 2010).

2.3.4. Medication-associated Barriers

Characteristics of the commercially available drug formulations such as taste, palatability, size of pills, availability of liquid formulations, and adverse effects (e.g. metabolic complications, lipodystrophy) can significantly affect adherence. Furthermore, the complicated regimen

(Mukhtar-Yola *et al.* 2006) to be followed such as a need for daily administration, dietary restriction, drug interactions, frequency of dosing, dosage and therefore pill burden or amount of liquid, also influence a child's adherence to therapy (Wedekind and Pugatch 2001; Byrne *et al.* 2002; Gavin and Yogev 2002; Gibb *et al.* 2003; Domek 2006). The afore-mentioned medication-related factors are particularly crucial in determining children's adherence to HAART.

Conversely, good adherence (more than 95 per cent) was associated with beliefs regarding the positive impact of the medications on participants' quality of life. According to a report by van Dyke and colleagues (2002), the main reasons mentioned by patients for non-adherence were taste or flavour (16 per cent) and child refusal (16 per cent) for ritonavir and taste (9 per cent) and interference of medication schedule with lifestyle (10 per cent) for drugs such as nelfinavir (van Dyke *et al.* 2002). Side-effects are also usually associated with irregular medication intake or stopping medication altogether.

2.3.5. Health Care Systems-associated Barriers

Structural factors not directly related to patients or medications can also influence adherence. Some researchers have even contended that these could be the most important barriers to ART adherence in resource-limited settings in the form of frequent treatment interruptions (Nachega *et al.* 2010).

Limited availability and accessibility of ARVs and healthcare facilities for diagnosis and treatment of HIV, especially in developing countries, high cost of ART and other health services, presence of healthcare providers experienced in ART provision, patient-provider relationships, health care providers' beliefs, waiting time and opening hours (Biadgilign *et al.* 2011; Skovdal *et al.* 2011), availability of counselling services and social, economic or psychological support for people living in both developing as well as developed countries can influence adherence positively or negatively (Byrne *et al.* 2002).

The flip side of the positive improvement in access to treatment will be that the quality of patient-provider interactions will become more important – and probably more challenging. This is because as the number of patients that enrol in ART programmes increases the shortage of health care workers throughout sub-Saharan Africa will be felt acutely (Barnighausen, Bloom and Humair 2007; Kumar 2007). If the access is on top of this done on a partial or co-pay bases the cost of medication will be a significant contributor to poor adherence. According to a study conducted in Botswana, patients who reported cost of ART as a problem were more likely to have poor adherence and subsequent reduction of the price of ART resulted in better adherence by patients (Lanièce *et al.* 2003; Weiser *et al.* 2003).

Researchers thus underlined the need to ensure the privacy of ART clinics and waiting areas (Biadgilign *et al.* 2011; Skovdal *et al.* 2011). For instance, Skovdal and colleagues report patients who refuse to leave consultations rooms citing to nurses as “Mr. so and so is outside” (Skovdal *et al.* 2011). Furthermore, patients need to be encouraged to disclose their infections so that they will feel less stress going to centres for medication refills (Reda *et al.* 2012). In our work in hospitals we have come across patients seeking treatment far from home to increase their level of privacy and avoid the risk of being seen by family members.

Adherence support and clinic policies have been reported to be important predictors of adherence (Nash *et al.* 2011). Also lack of adherence monitoring mechanisms is an important factor determining the outcome of treatment (Landovitz 2011). A recent study from South Africa indicates that improving adherence helps to reduce health care costs, especially those of hospital care (Nachega *et al.* 2010).

2.3.6. Interventions to Improve Adherence

Reports indicate that in the context of HIV/AIDS illness, addressing issues related to adherence and medication regimens before therapy are beneficial. This proactive process helps to identify the readiness for treatment and other patient characteristics that might hamper or promote treatment and adherence thereof and act up on the negative indicators (Zachariah, *et al.* 2007). Continuous monitoring of both adherence and correlating it with clinical outcomes will create an interactive feedback mechanism that could lead to optimal clinical states and improved quality of life for patients. All this entails the need for further research and development in the areas of ART adherence, adherence support and patient behaviour. Different intervention modalities are customised to improve adherence levels among patients on ART. These include behavioural interventions, reminders, pre-treatment and continuous counselling and education, house to house treatment provision and nutritional support among others.

Diagnosing and treating health problems such as depression, reducing substance abuse, improving patient and provider relationship, counselling and enhancing family and community support mechanisms are shown to improve adherence, as well as intervening on modifiable barriers to adherence before starting ART (Castro 2005; Bangsberg 2008; Simoni, *et al.* 2008).

A meta-analysis indicated that adherence interventions may be efficacious when targeted at individuals who are identified- or anticipated to have poor adherence (Amico, Harman and Johnson 2006). A few research carried out in the area of the interventional applicability that indicate electronic reminders, pill organizers, medication event monitoring systems (MEMS) to record dosing behaviour, use of internet, education services, use of phones (Collier *et al.* 2005), and the like could

also enhance adherence. Nevertheless, most of these technologies have not had thorough scientific evaluation and their efficacy and cost-effectiveness may not be as high as expected (McDonald *et al.* 2002; Bangsberg 2008; Nachega *et al.* 2010). For instance, cell phone message reminders and web-based interventions require patient resources and literacy which could create obstacles to their applicability in sub-Saharan Africa. A Cochrane Database of Systematic Reviews reached similar conclusions. It cited diverse methodological problems, issues of study quality, among others as problems underlying the scant evidence on adherence improvement interventions and called for standardized and methodologically rigorous trials of interventions to improve and measure adherence to anti-retroviral treatment (Rueda *et al.* 2006).

Recent reports indicate that mobile phone text messages and other reminder services, treatment support, non-physician treatment providers, alternative modes of ART provision, teaching and educational programmes, directly observed treatment (DOT), food supplementation, could improve adherence in sub-Saharan Africa (Barnighausen *et al.* 2011).

2.3.7. Into the Future of ART in Sub-Saharan Africa

Impressive achievements have been made in increasing access to ART in sub-Saharan Africa through commendable commitments of development partners, international organizations and NGOs working with the governments of the region. In some low-income countries, up to 79 per cent of the spending on HIV/AIDS care and treatment comes from donors (UNAIDS 2012). However, it may not be realistic to expect that this aid could continue. As a result, prospects for the programme include possibilities of funding decline and reduced donor commitments. In fact, recently the Global Fund, set up to fight HIV/AIDS, malaria and tuberculosis, has declared that it is closing some of its programmes due to failure of donors to meet their financial pledges following the economic crisis (Roehr 2010; Moszynski 2011). And the whole programmes would have been endangered if benefactors like Bill Gates and other country level donors had not mobilized funds to meet the required targets. Furthermore, there is a need for stringent efforts to control drug resistance (Wainberg *et al.* 2011) as this would increase funding required to provide second line drugs (costing about twice that of first line drugs) which could worsen funding needs. The foremost step needed in combating drug resistance includes reducing losses to follow up and increasing retention treatment. Considering these scenarios, there is a need for countries to take an active and increasing role in ART programmes; monitoring and financing; and locally applicable research and best practice experimentation toward improving service delivery.

The fact that adherence to ART also reduces transmission of the virus is good news for preventing the spread of the HIV infection and anti-retroviral resistance both at the individual and population levels (Hammer

2011). At individual levels, discordant couples and mothers reduce the chance of transmission through early medication initiation and good adherence (Cooper *et al.* 2002; Donnell *et al.* 2010; Romero *et al.* 2010) as it reduces viral load in body fluids (Vernazza *et al.* 2000). Cohen, (*et al.* 2011) indicated that there was a 96 per cent reduction in virologically linked transmissions among early starters of ART due to reduced viral replication. This has the potential to reduce the need for ART medications, and hence freeing up much needed funds and service capacity for other health problems.

Devising a mechanism of providing, increasing and maintaining treatment access and securing adherence to ART for special groups such as children and during situations such as disasters are also important challenges. For instance, ART access and adherence by children is negatively impacted by issues such as limited availability of paediatric drug formulations, lack of early diagnosis of HIV status and monitoring facilities and dependence on caregivers among others in the context of competing priorities of sub-Saharan Africa health systems (Painstil E 2010). Due to this, it has been reported that children and adolescents are reported to have consistently suboptimal adherence levels (Steele and Grauer 2003) and reduced coverage by ART treatment (WHO 2010). In fact, their problems have been cited as neglected diseases by some authors (Lallemant *et al.* 2011) who call for more research and service focus for these special groups.

The other topic that seems to be missing from the research literature is long-term adherence. Given that ART is a lifelong treatment, few studies or programmes have assessed longitudinally its level or clinical impact on patients (Steele and Grauer 2003; Simoni *et al.* 2008). In addition to this, the current model of ART delivery adopted from Western countries may need to be carefully evaluated for effectiveness and improved upon. As it stands, donors and sub-Saharan African countries are devoting very little resource and priority for operational research into improving the programme (Jaffar *et al.* 2005; Painstil 2010). Areas of potential improvement and emphasis include bridging the gaps in current levels of access and adherence with their respective targets. These may include methods of health systems, potential involvement of non-clinical staff, use of lower tier health system establishments, issues of cost-effectiveness, development of locally applicable cost-effective service provision and monitoring of clinical progress and adherence indicators (Steele and Grauer 2003; Jaffar *et al.* 2005; Painstil 2010). As Gill and colleagues indicate there is no room for complacency; adherence rates tend to deteriorate over time (Gill *et al.* 2005).

2.3.8. HIV/AIDS and Directly Observed Treatment Programmes

Directly Observed Therapy (DOT) antiretroviral treatment has been documented to improve adherence according to studies conducted in low and middle income countries in both clinic and community levels

(Farmer, *et al.* 2001; Pearson *et al.* 2007). A study in Cape Town, South Africa (Nachega *et al.* 2010) compared partial DOT-ART by patient-nominated treatment supporter versus self-administration. It found that patients on DOT-ART had better early CD4 responses even though it was not sustained beyond 6 months. Another study from Mombasa, Kenya (Sarna *et al.* 2005) reported that a DOTS programme in addition to a health facility based patient monitoring and follow up programme helped achieve better adherence levels. Similarly, other studies (Harman and Johnson 2006; Nachega *et al.* 2010) have shown that targeting groups with poor to ART adherence had more positive effects than those targeting groups with mixed levels of adherence.

2.4. Discussion

This review identified findings that are contrary to general expectations: sub-Saharan Africa patients have similar or higher adherence levels as compared to patients in developed countries. The barriers and challenges to ART adherence identified include factors related to patients and their families, socioeconomic factors, medication, and health providers and systems as summarized under the conceptual framework in Box 1 below. This has implications for interventions to improve ART adherence and therefore programmes need to address these inter-related and multi-dimensional factors (Gusdal *et al.* 2011; Skovdal *et al.* 2011). Ensuring and maintaining adherence to treatment and retention requires an understanding of the multiple barriers that patients face and developing interventions that overcome these barriers. Furthermore, long-term maintenance of adherence requires the integration of these interventions into sustainable programmes that ensure a reliable supply of drugs, patient education, and on-going support (Rosen *et al.* 2007). Prospects for the programme include possibilities of funding decline and rooms for further improvement of ART delivery and adherence.

It is clear that those adherence problems would constitute a perceived significant barrier to ART programmes in sub-Saharan Africa or elsewhere. Without regulated access to ART, rapid emergence of drug-resistant viral strains and individual treatment failure is a potential threat and could curtail future treatment options, leading to the transmission of drug resistant strains of HIV (Harries *et al.* 2001). The present review has identified that in order to increase adherence to the appropriate level, there needs to be concerted efforts to evaluate and conduct operational research on ART service provision. These include use of new monitoring mechanisms, infrastructure, staffing, training of counsellors, community support systems and drug formulations (Gusdal *et al.* 2011). But currently there are several research gaps such as lack of capacity to survey the level of drug resistance in sub-Saharan Africa and testing of new tools for monitoring adherence. Low adherence to treatment has been associated with higher hospitalization rates, productivity loss, disease progression,

and death in both high-income and resource-limited settings (Bajunirwe *et al.* 2009).

This review mainly focused on studies conducted on sub-Saharan Africa HIV/AIDS patients. As a result, the potential weaknesses and strengths of ART adherence identified in the review may not necessarily be applicable to countries outside this region. Furthermore, currently there is no gold standard for measuring adherence. Because of this, most of the studies included used the most common forms of adherence assessment— patient recall and pill count— which have recognized biases in their use, such as over reporting, recall and social desirability bias (Wagner and Miller 2004; Berg and Arnsten 2006).

Health system barriers, especially absence of a regular and timely supply of medication to patients, affect adherence. An unreliable supply of medications can severely reduce patient adherence rates. In that majority of the sub-Saharan African countries, they are manifested by weak procurement and supply management systems that lead to frequent shortages of ART and other essential inputs. In 2008, of the 91 low- and middle-income countries surveyed, 34 per cent had experienced at least one stock out of a required ART medication (WHO 2010).

Looking into the future, it is possible that the encouraging trend of increased access to ART access may be further scaled up if governments and donors continue their commitment to the programme. However, it is important that national governments play a prominent role to ensure sustainability. This includes channelling of funds and policy commitments toward evaluation and improvement of the programme. This also calls for further activities to prevent the virus. In addition, efforts to improve the socio-economic status and empowerment of their citizens in general are very important.

2.5. Conclusion

Despite highly encouraging achievements in expanding access to HIV/AIDS treatment, there is substantial room for improvement of ART programmes in sub-Saharan African countries. Antiretroviral treatment is challenged by a range of hierarchical and intricately related factors that are amenable for interventions. Children, adolescents, poor, conflict-affected and displaced populations and minorities need special attention by health workers and policy makers. National governments may need to play a major role in the programme especially in designing effective programmes that systematically expand access to treatment and, increase care and support to patients. Counselling patients on adherence, retention and encouraging them to disclose their infection are also important goals. There is also a need for adherence indicators and interventions that are applicable in the setting of developing countries and focusing on those identified factors will guarantee on the sustainability of ART programme, hence for adherence.

Box 1. Conceptual Framework on Determinants of Adherence to Antiretroviral Therapy in sub-Saharan Africa

Inter-related factors that influence ART adherence	
<p>PATIENT AND FAMILY/CAREGIVER RELATED FACTORS</p> <ul style="list-style-type: none"> ➤ Disclosure of HIV status ➤ Sex of the patient ➤ Age of the patient ➤ Active drug and alcohol use by patient or caregiver ➤ Substance use ➤ Perceptions to the medication ➤ Presence of anxiety, depression ➤ The presence of HIV infection in another family member ➤ Family disruptions ➤ Education ➤ Cognitive impairment ➤ His/her own knowledge about the disease 	<p>MEDICATION RELATED FACTORS</p> <ul style="list-style-type: none"> ➤ Too many pills ➤ Side effect of the drugs ➤ Scheduling problem ➤ Access to medication ➤ Access to medical care ➤ Frequency of daily doses ➤ Length of the treatment ➤ Administration of the drug ➤ Child refusal/vomiting ➤ Self discontinuations ➤ Need for daily administration ➤ Dietary restriction, ➤ Drug interactions,
<p>MEDICATION RELATED FACTORS</p> <ul style="list-style-type: none"> ➤ Too many pills ➤ Side effect of the drugs ➤ Scheduling problem ➤ Access to medication ➤ Access to medical care ➤ Frequency of daily doses ➤ Length of the treatment ➤ Administration of the drug ➤ Child refusal/vomiting ➤ Need for daily administration ➤ Dietary restriction, ➤ Drug interactions, 	<p>HEALTH CARE DELIVERY SYSTEMS RELATED FACTORS</p> <ul style="list-style-type: none"> ➤ Limited availability and accessibility of ARVs ➤ Healthcare facilities for diagnosis and treatment of HIV ➤ Healthcare providers experienced in HIV treatment, ➤ Patient-provider relationship, availability of counselling services ➤ Health education/information
<p>OTHERS</p> <ul style="list-style-type: none"> ➤ Cultural views of health and illness ➤ Psychological state and mental health ➤ Motivation and self-esteem 	

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CHAPTER THREE

Quality of Life among Patients Living with HIV AIDS in Sub-Saharan Africa

Francis Bajunirwe

Abstract

Quality of life (QOL) among patients infected with HIV is significantly reduced by the illness. The aim of this paper is to provide a comprehensive review of literature to show the impact of antiretroviral therapy (ART) on quality of life and to identify other factors that influence QOL for patients receiving ART in sub Saharan Africa. The review showed that QOL improves after initiation of ART but starts to suffer as side-effects such as body fat redistribution occur. The other factors that influence QOL include age, gender, socio-economic status, stage of AIDS, CD4 count and viral load. Provision of food supplements, social support, financial independence, good adherence, religiosity and provision of decentralized services improve QOL but is reduced by comorbid conditions such as TB, diabetes and malignancies. QOL improves after initiation of ART. Interventions such as income generating activities, exercise and micronutrients may improve QOL.

3.1. Introduction

3.1.1. Background

Antiretroviral treatment is now widely available in Africa where previously a diagnosis of HIV and AIDS was a death sentence. With antiretroviral therapy (ART) use, the survival of patients with HIV and AIDS is expected to improve and life expectancy has been predicted to reach near normal (Mills *et al.* 2011). HIV disease has been controlled with ART that the condition is already being referred to as a chronic disease (Justice 2010) and programmes should start to brace themselves up to deal with the effects of long-term ART. As patients stay and live longer on ART, quality of life (QOL) becomes an issue of major importance.

Currently, there are limited studies on QOL in sub Saharan Africa. There has been few attempts to review and aggregate the literature on quality of life among HIV patients in this region of the world (Beard *et al.* 2009). Majority of the publications on QOL are from the West where antiretroviral therapy has been available for a much longer period of time. According to the Dictionary of Epidemiology (Last 2001), QOL is defined as “The degree to which persons perceive themselves able to function physically, emotionally, and socially.” The definition includes a number of domains and this is reflected in the tools that are being used to measure QOL.

3.1.2. Purpose of the Review

The purpose of this review is to aggregate evidence and research on QOL among HIV-infected patients in sub-Saharan Africa. The review collected publications on the impact of ART on quality of life, both in the short- and long-term, and identify the correlates of QOL. It focused on the modifiable factors that influence QOL so as to propose a broad spectrum of potential interventions to enhance the same. Equally emphasized in the review are interventions (both successful and unsuccessful) that have been tested in Africa with the aim of improving QOL. Included in the review are also tools that have been used to measure QOL.

3.1.3. Measurement of QOL in Africa

Most of the tools used to measure QOL have been developed in the West and therefore may not be appropriate for application to a population in an African setting. However, before we conduct a comprehensive discussion on QOL, it is important to understand that measurement of this domain is quite complex. Quality of life has several domains and hence cannot be measured in one dimension only. The other complexity is that there are indeed many tools that have been developed to measure QOL and while many of them share similarities, they also have some differences. And because there are a number of tools to measure QOL, it may, to some extent, become difficult to make comparisons between cohorts in different African countries when different tools have been used. In the next section, the author reviews some of the tools that have been used to measure QOL among African populations.

3.1.4. Medical Outcomes Study (MOS)

Despite the multiplicity of tools used to measure QOL and complexity of the task of measuring it, MOS is the most commonly used tool to measure QOL in Africa. The tool is designed to use a number of items to measure a number of domains related to QOL (Ware and Sherbourne 1992). MOS is one of the few QOL tools that have been culturally adapted and widely applied in Africa. It has, for example, been culturally adapted in rural Uganda (Mast, Kigozi *et al.* 2004) and has also been tested among tuberculosis patients in urban Uganda (Babikako, Neuhauser *et al.* 2010) and was shown to be highly reliable and valid.

Several other tools for measuring QOL have been used in Africa. These include the EQ 5D, the World Health Or WHOQOL, the ACTG Sf 21 (Safren *et al.* 2011), and the Missoula Vitas Quality of Life Index (MVQOLI). MVQOLI has also been applied in Africa among palliative patients in Uganda and South Africa and has been found to be highly reliable (Selman *et al.* 2011) "HIV Symptom Scale" (HSS) and the "Quality Of Life Scale" (QOLS) have, however, been reported as the lesser used tools (Ogbuji and Oke 2010).

3.2. Methods

We searched PubMed, Google Scholar, and Cochrane databases for literature published on QOL in Africa using the search terms “Quality of life, Africa”, and HIV. We also searched conference proceedings of the International AIDS Society (IAS) and looked out for other grey sources like dissertations. The articles were sorted according to the subheadings such as measurement of QOL, impact of antiretroviral therapy, impact of other factors, and interventions for QOL.

3.3. Results

3.2.1. Impact of Antiretroviral Therapy on Quality of Life

In the absence of treatment, HIV-infected patients experience the onset of symptoms such as weight loss, fever and night sweats, deterioration in their immune function and general wellbeing and all aspects of quality of life (O'Keefe and Wood 1996a and b). Initiation of ART among these severely immune-- suppressed AIDS patients results in the restoration of CD4 count, suppression of viral load (Akileswaran *et al.* 2005; Fairall *et al.* 2008) and improvement in quality of life and restoration of activities of daily living (Kakinami *et al.* 2011). Data from several treatment cohorts in sub Saharan Africa shows significant increases in several dimensions of QOL following initiation of ART (Jelsma *et al.* 2005; Booysen *et al.* 2007; Louwagie *et al.* 2007; Stangl *et al.* 2007; Wouters *et al.* 2007; Rosen *et al.* 2008; Wouters *et al.* 2009; Alibhai *et al.* 2010). The majority of the improvement in the PHS and MHS scores is seen in the first three months (Stangl *et al.* 2007) and continues to rise through up to twelve months but the rise is less steep (Figure 1).

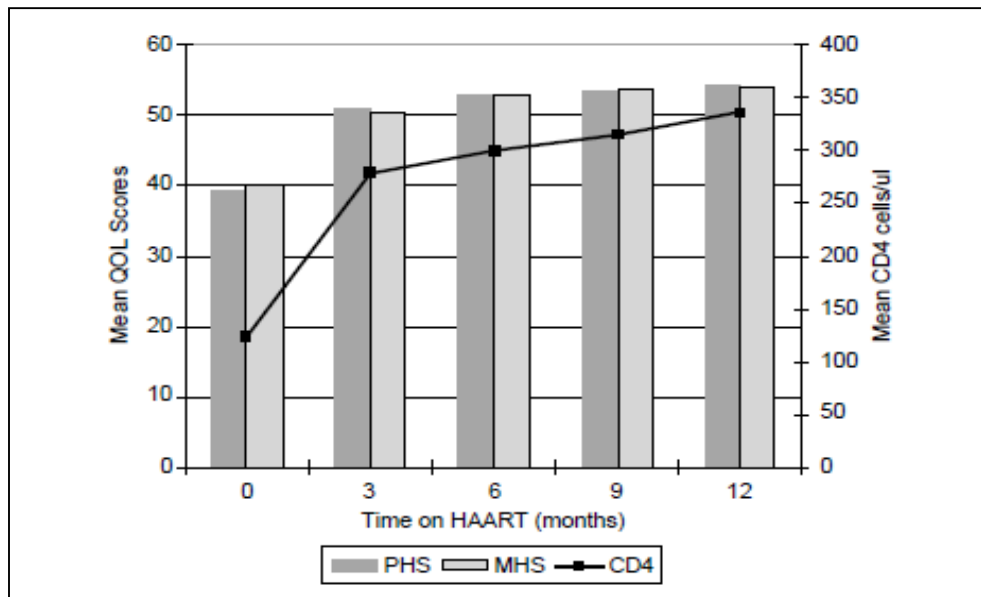


Figure 1. Changes in Quality of Life and CD4 Count in the First 12 Months Following Initiation of ART in a Cohort in Rural Uganda

SOURCE: Adapted from Stangl *et al.* (2007).

Studies also show that even before the patients receive treatment, qualification for treatment and the resultant anticipation and expectation that antiretroviral therapy was soon to be initiated resulted in an improvement in self-perception of physical health (Booyesen *et al.* 2007).

3.2.2. Long-term Impact of ART on QOL

There is clear evidence that ART improves QOL functioning in the short-term. There is concern that gains made in QOL may be cancelled out by the emergence of side-effects to ART that emerge after prolonged ART. In a Kenyan cohort, Fox *et al.* (2010) followed up over two years, the number of days of poor health reported declined from seven during the first month on ART to three days in the 24th month period ($p=0.043$), a significant reduction. Pain and fatigue also declined significantly over time.

A sizeable proportion of patients reported skin rash as a side-effect in the long-term follow. Although it was not significant, the occurrence of skin rash raises concern about the potential emergence of side-effects following long-term treatment. Self-reported side-effects have been associated with lower scores on the physical and mental health scales (Boyer *et al.* 2011), and though the side-effects may happen in the short term, they are more likely to become apparent in the long-term.

Duration of time on ART has been positively correlated with QOL with patients who had been on ART for a longer period of time having better physical functioning (McInerney *et al.* 2008). The analysis in this paper used linear regression which assumes a linear relationship between a predictor and outcome and assumes this relationship remains valid even with extreme values such as those observed for patients that have been on ART for long periods of time. Instead, a curvilinear relationship may predict the relationship better, allowing for the flattening in the QOL as time on ART progresses. A study in the same setting in KwaZulu Natal showed that the duration of time of taking ART medications significantly predicted the improvement in QOL with a correlation coefficient of 0.55 ($p=0.001$) (Bhengu *et al.* 2011).

3.2.3. Impact of ART on the Different Dimensions of QOL

Duration of time on ART was positively correlated to physical functioning scores, with the patients who had been on ART for longer period of time having higher scores in physical functioning (correlation coefficient =0.42 and $p<0.05$) (McInerney *et al.* 2008). Antiretroviral therapy improves function in all dimensions of physical, mental and emotional or social functioning.

3.2.4. Body Fat Redistribution and Other Side-effects

Side effects to ART negatively impact on physical and emotional quality of life (Wouters *et al.* 2009). Body fat redistribution is one of the long-term side-effects of treatment with antiretrovirals and is fairly common among African patients with a prevalence of almost 70 per cent among patients that have received Highly Active Antiretroviral Therapy (HAART) for at least 72 weeks (Mutimura *et al.* 2007a). Body fat redistribution involves an abnormal gain in body fat on the trunk including the abdomen, breast, neck (buffalo hump) with fat loss on the face, limbs and buttocks (Reynolds *et al.* 2006). This results in an apparent dissatisfaction on people exhibiting these features. A study conducted in Rwanda, for example, revealed that Rwandan women with HIV and body fat redistribution were more likely to be less satisfied with their body image, self-esteem and social life (Mutimura *et al.* 2007b) compared to HIV-positive women without the redistribution. Drug toxicities such as skin rash and neuropathy were also reported to have negatively impacted QOL. In a South African study, presence of toxicities severely affected physical functioning on the QOL scale (Pitt *et al.* 2009).

3.2.5. Traditional and Complementary Medicine

The use of herbal medicine in sub Saharan Africa is very common. In one empirical study, at least 50 per cent of patients at a clinic in South Africa were reported to be using herbs before initiating antiretroviral therapy (Peltzer, *et al.* 2008). Though in a lesser degree, in another related research, up to 32 per cent of patients in a Ugandan clinic were found to be using traditional medicines and ART concurrently (Langlois-Klassen *et al.* 2007).

The major reason for using these medicines was the perception that ART alone had failed to relieve all their illnesses and traditional medicines would increase the efficacy of the antiretroviral therapy and improve the quality of life.

However, a study conducted in Zimbabwe (Bepe *et al.* 2011) shows that herbal medicines may actually have adverse effects that impact negatively on the QOL of HIV patients who are using the herbs together with ART. Patients who were using herbs were more likely to report occurrence of abdominal pain and rash compared to the patients who were not using these herbs. Some of these herbs, such as *Moringa*, are known to interfere with the drug metabolism (Monera *et al.* 2008)—resulting in higher than normal blood drug levels potentially giving rise to the side-effects of abdominal pain and rash.

Garlic supplements may cause negative interaction by reducing blood drug levels of protease inhibitors such as Saquinavir (Piscitelli *et al.* 2002; Sussman 2002; Berginc *et al.* 2010) by inhibiting the metabolism of the enzyme that breaks down the drug (Ho *et al.* 2010), leading to lower plasma drug levels and resulting in a reduction in the QOL.

As opposed to that, a study in Thailand (Sugimoto *et al.* 2005) found that herbal medicine use was associated with better mental health function among AIDS patients who were socially disadvantaged. In a similar setting in South Africa (Tshibangu *et al.* 2004) and Zimbabwe (Taylor *et al.* 2008), use of herbal medicine was associated with better physical well-being and improvement in objective measures such as viral load and CD4 count. The question of traditional medicine has attracted significant interest that a systematic review (Littlewood and Vanable 2008) found that use of complementary medicines is very common with up to 60 per cent of patients using the methods and are used mostly to alleviate symptoms and improve QOL function.

3.2.6. Factors Associated with QOL Prior to the Initiation of ART

3.2.6.1. CD4 Count and Viral Load and AIDS Disease Stage

In a population of severely ill patients initiating ART, CD4 count greater than 50 was the strongest predictor of better QOL (Stangl *et al.* 2007). Other studies have shown that patients with a higher CD4 count generally have higher QOL scores (Schroecksnadel *et al.* 2008; Bhargava and Booysen Fle 2010). Increasing viral load is a marker of disease progression and has also been associated with QOL among HIV-infected patients. In a Ugandan cohort, high viral load at the start of ART was associated with lower scores of PHS and MHS (Stangl *et al.* 2007). Other studies have also shown the association between viral load and QOL (Schroecksnadel *et al.* 2008).

Progression from HIV infection to AIDS is associated with increasing viral load and decline in CD4 count, all of which are associated with declining

QOL scores (Schroeksnadel *et al.* 2008). Patients in stages 3 and 4 of AIDS have severely impaired QOL scores on the domain for mobility, usual activities, pain and anxiety or depression as measured using the EQ-5D (Hughes *et al.* 2004). Initiation of ART among AIDS patients restores CD4 cells and suppresses viral replication.

3.2.6.2. Role of Symptoms

A cross-sectional study in KwaZulu Natal (Bhengu *et al.* 2011) explored the role of symptom intensity on their physical functioning. There was a negative correlation between level of intensity of symptoms and physical activity (correlation coefficient = -0.71 and $p < 0.001$) with patients reporting more symptoms having less activity. These symptoms may be related to the disease itself or may be a result of the treatment side-effects. The cross-sectional nature of the study makes it difficult to tease apart the source of the symptoms.

3.2.6.3. Baseline QOL

Patients with lower PHS scores were associated with gains in PHS scores compared to those with higher baseline PHS scores ($p < 0.01$) (Alibhai *et al.* 2010). Similarly, patients with lower baseline MHS scores were associated with significant increases in MHS ($p < 0.01$) after one year of follow up on ART. As expected, patients that have more severely deranged QOL functioning are also more likely to experience significant recovery.

3.2.6.4. Age

Few studies examine the association between age and QOL. A west African study in Ibadan, Nigeria (Ogbuji and Oke 2010) showed no relationship between age and QOL. In rural western Uganda (Alibhai *et al.* 2010), younger age was, however, associated with an increase in both PHS ($p < 0.01$) and MHS ($p = 0.03$) scores compared to the older age group after one year of ART. In a multi country study among patients starting antiretroviral therapy, physical functioning differed by age (Safren *et al.* 2011).

3.2.6.5. Gender

Like that of age, studies that investigated the impact of gender difference on QOL revealed mixed results. In a multi-country study among patients initiating ART in resource-limited settings (Safren *et al.* 2011), QOL scores were, for example, similar among men and women except for the social functioning subscale where men had poorer scores compared to women. Another study in rural Uganda (Stangl *et al.* 2007) showed no significant differences between men and women at the start of ART. Peltzer *et al.* (2008) also found no significant differences in QOL scores among men and women initiating ART in South Africa. Interestingly, the same study showed lower QOL scores among patients who were married and cohabiting compared to those who were single, divorced or widowed.

Contrary to these studies, research carried out in Sweden and the US have shown that women have a lower QOL compared to men (Cederfjall *et al.* 2001; Mannheimer *et al.* 2005). In Africa, a study in Niger found that QOL among HIV-infected patients was worse among women compared to men (Abasiubong *et al.* 2010).

3.2.6.6. Socioeconomic Status

Socio-economic variables whose effects on QOL have been studied include: educational level, employment and income (financial resources). A study in Nigeria showed that lower educational level was associated with lower scores on all domains of QOL except that of social functioning (Adewuya *et al.* 2008). In other studies, patients with a post primary level of education enjoyed higher scores of QOL compared to those with primary school or lower level of education (Stangl *et al.* 2007; Peltzer *et al.* 2008). With regard to income, patients who were economically dependent had lower QOL than those in gainful employment (Stangl *et al.* 2007). Data from South Africa (Peltzer *et al.* 2008) showed that patients who did not have enough money to meet their basic needs were more likely to report lower QOL. Also, patients who face financial barriers to access HIV care had lower scores on the physical and mental health scales of QOL (Boyer *et al.* 2011).

3.2.6.7. Depression

Mental health conditions are common among persons infected with HIV and depression is the commonest condition seen among these patients (Olley *et al.* 2006; Myer *et al.* 2008; Owe-Larsson, Sall *et al.* 2009; Nakasujja *et al.* 2010). In one Ugandan study, the prevalence of any form of depression in an HIV cohort was almost 47 per cent (Nakimuli-Mpungu *et al.* 2011). HIV infected patients with depression present with lower scores of QOL than patients without depression (Schroecksnadel *et al.* 2008; Vyavaharkar *et al.* 2011). In another study, patients with depression were also found to have lower scores on all the Medical Outcomes Study HIV Health Survey (MOS-HIV) general domains and in the Physical Health Summary score (PHS) and Mental Health Summary score (MHS) (Briongos-Figuero *et al.* 2011). Depression seriously affects activities of daily living among HIV patients including their ability to swallow medications (Lawler *et al.* 2011).

Initiation of antiretroviral therapy reduces the occurrence of symptoms of depression. In the Ugandan cohorts (Jelsma *et al.* 2005; Sacktor *et al.* 2006; Stangl *et al.* 2007), the symptoms of depression and cognitive impairment decreased over time. In another Ugandan cohort, prevalence of depression decreased from 46 per cent to 8 per cent after 12 months of antiretroviral therapy (Bock 2008). Kaharuza *et al.* (2006) propose that treating depression at the initiation of ART may have a role in mediating positive outcomes.

3.2.7 Factors Associated with QOL during Antiretroviral Therapy

Majority of patients who start ART experience improvement in QOL functioning. However, some patients do not, and in fact some experience declines in their overall wellbeing. This may happen even in circumstances where patients have achieved complete virological suppression (Alibhai *et al.* 2010). The review that follows looks into factors that enhance gains in QOL for patients continuing with antiretroviral therapy.

3.2.7.1 Social Support

Social support has been shown to positively influence QOL by mitigating the effects of depression (Jia *et al.* 2004). This report is also in agreement with data from South Africa showing that HIV patients with greater social support had better physical functioning (McInerney 2008) and higher QOL scores (Bhargava and Booysen Fle 2010). Several other studies have shown the importance of social support on quality of life (Bajunirwe *et al.* 2009; Vyavaharkar 2011).

3.2.7.2. Community-Based Support

The burden of HIV in sub Saharan Africa is extremely huge that the health facilities are likely to be overwhelmed by the cumulative number of patients seeking treatment. Programmes are likely to devise other mechanisms to deliver medicines such as community-based services or outreaches which use a public health approach of use of simplified tools and approaches to clinical decision making, monitoring and improved access which have been recommended by the World Health Organization (Gilks *et al.* 2006). Community-based services work to bring the services nearer to the patients and hence might serve to achieve higher quality of life compared to the facility-based services. Data from four Southern Africa countries (Kabore *et al.* 2010) showed that patients exposed to community-based supportive services experienced higher QOL than those that did not receive it, probably because of the higher adherence levels and social support that patients among the home-based care programmes achieve compared to those in hospital-based antiretroviral programmes.

3.2.7.3. Stigma

Stigma still persists in Africa many years after availability of ART, and patients that have been on ART longer experience even more stigma (Nattabi *et al.* 2011). A qualitative data collected in Nigeria (Ogbuji and Oke 2010), for instance, shows that patients who experienced discrimination from family and friends reported negative effects on their quality of life. Data from several African studies (Holzemer *et al.* 2009; Greeff *et al.* 2010; Peltzer and Ramlagan 2011; Vyavaharkar *et al.* 2011) revealed that patients with internalized AIDS stigma scored significantly low on QOL scales compared to the patients that do not have stigma. Stigma may also result from body fat changes and redistribution (Martinez *et al.* 2001) leading to poor quality of life.

3.2.7.4. Disclosure

Disclosure of HIV positive sero-status has been associated with a variety of positive outcomes including safer sexual practices (Luchters *et al.* 2008; Loubiere *et al.* 2009) and adherence to antiretroviral therapy (O'Laughlin *et al.* 2011; Watt *et al.* 2011). For this reason, one might expect that disclosure is also associated with better QOL outcomes. A Zimbabwean study among HIV-positive women (Patel *et al.* 2011) showed that disclosure was significantly associated with lower perceived stigma, higher self-esteem and fewer depressive symptoms. These outcomes may not necessarily be on the QOL scales described above, but are indeed correlated with QOL. Community support promotes disclosure (Wouters *et al.* 2009) and has been associated with positive outcomes on quality of life, showing the connection between disclosure, community support and quality of life.

3.2.7.5. Alcohol and Substance Abuse

Alcohol use has been associated with lower quality of life scores among patients receiving antiretroviral therapy (Rosenbloom *et al.* 2007; Korthuis *et al.* 2008; Bajunirwe *et al.* 2009). Alcohol abuse is very common among HIV infected patients, and it is associated with non-adherence (Martinez *et al.* 2008; Jaquet *et al.* 2010) and hence poses a significant threat to the benefits in QOL gained from use of ART.

3.2.7.6. Nutrition

Adequate and proper nutrition is critical among HIV-infected patients, because certain vitamins play a role as antioxidants which support the immune system and enhance suppression of viral replication (Suttajit 2007). For HIV-infected persons, food insecurity and nutritional vulnerability may be a bigger problem because many of them have lost their jobs due to illness or are simply too weak to continue working at their gardens to ensure adequate harvest (Lemke 2005). A recent paper from Uganda has, for instance, shown that ART patients who suffered food insecurity had poorer quality of life scores in the PHS scale compared to the patients that had enough food (Weiser *et al.* 2011). It is therefore reasonable to hypothesize that patients with adequate nutrition to accompany their antiretroviral therapy will have better QOL outcomes compared to patients without adequate nutrition. In an observational community-based study in four southern African countries, patients who received food support services had greater improvements (Kabore *et al.* 2010) in selected QOL functionings compared to patients that did not have the food. The patients who received the food support also experienced high CD4 count improvements ($p=0.016$) which may explain the improvement in QOL.

Another nutrition study in South Africa showed that household food insecurity and lack of dietary diversity impaired QOL (Oketch *et al.* 2011). Overall, there was no significant difference in QOL impairment among

patients receiving Nutrition care and support services (NCS) compared to those who were not receiving the support— hence, the study does not provide conclusive evidence. There are very few interventional studies that have compared different nutritional approaches and another such study was conducted in Malawi (Ndekha *et al.* 2009). The study compared patients who received ready-to-use fortified spread and those that used corn/soy-blended flour. There were significant improvements in body mass index and quality of life in both groups at three months when the intervention stopped, but no differences between the two groups. Similarly, there were no differences at nine months of follow up, six months after the intervention had stopped.

3.2.7.7. Religiosity

Many HIV-infected persons turn to religiosity to cope with the stressors associated with the demands of living with HIV-associated illnesses (Bosworth 2006). The focus for clinicians is often on medical problems and rarely does the care extend to handle the spirituality and religiosity of these patients. A study in Uganda and South Africa (Selman *et al.* 2011) among patients receiving palliative care, and majority of who were HIV-infected, showed that spiritual wellbeing was highly correlated with QOL. It also showed that spiritual elements such as feeling at peace and having a sense of meaning in life were more important than obvious elements of good health such as being active or being physically comfortable. Another study in South Africa showed that patients who had used prayer in the last six months were more likely to report higher scores on QOL functioning than those who had not used prayer, despite having more symptoms (Peltzer *et al.* 2008).

3.2.7.8. Patient Satisfaction

A study done in Europe shows that patient-provider relationships matter and satisfaction with information and explanation provided by health worker is associated with higher QOL scores (Preau *et al.* 2004). Whereas, there are very few African studies that have explored this relationship between patient satisfaction and QOL. In Africa, a study conducted in Cameroon showed that patients who rated the services and staff at the treatment sites favourably also had higher quality of life indices (Bhargava and Booyesen Fle 2010) compared to those who rated the services lower.

3.2.7.9. Type of Service Provider

In a Cameroon study, patients followed-up at central and district level facilities had similar physical QOL scores, but the patients followed up at the more decentralized district level facilities had significantly better mental QOL scores (Boyer *et al.* 2011), signifying better functioning at the lower level health facilities. The explanation for the better mental health functioning at the district level may be that patients at the district level enjoyed better relationship with their caregivers, had easier access to consultations and more reliable drug supply. More evidence to support

service provider is seen among an urban clinic population receiving tuberculosis treatment in Uganda (Babikako *et al.* 2010) where patients enrolled at public facilities had lower scores on perceived health compared to those at private facilities. The findings of this study should, however, be interpreted with caution since its subjects at private health facilities tend to be well off and hence do not provide an equal comparison with patients at public facilities.

3.2.7.10 Adherence to Antiretroviral Medications and Type of Medication

Adherence to antiretroviral medications is necessary for the success of HIV treatment (Bangsberg *et al.* 2007). It is therefore likely that adherence may also directly impact quality of life among patients receiving HIV treatment. In a cross sectional study in KwaZulu Natal (Bhengu, Ncama *et al.* 2011), the patients who reported higher adherence were 50 per cent more likely to report higher physical health compared to those who reported low adherence ($p=0.04$). The patients with higher adherence were also more likely to have greater psychological health than patients with lower adherence ($p=0.03$).

The simplification of treatment regimens not only improves adherence and quality of life but also prevents toxicity and reduces the costs of health care (Nachega *et al.* 2011). In a related study, patients who were switched to a one-pill per day regimen of ART from a multiple pill regimen (Airoldi *et al.* 2010), resulted in improved adherence ($p<0.001$) and quality of life ($p<0.041$) and these patients simultaneously maintained viral load suppression and immunologic efficacy. In a Nigerian study, emotional quality of life deteriorated among patients with a high pill burden (Erhabor. 2006).

3.2.8. Impact of Comorbid Conditions

Chronic diseases other than HIV are generally expected to have a negative impact on the QOL of patients that suffer these conditions. The situation may be even worsened when HIV combines with other chronic diseases as is likely to happen because of the association of HIV with several other comorbid conditions. Chronic disease co-morbidity has been associated with negative physical functioning among patients receiving antiretroviral therapy (Magafu *et al.* 2009). In this section, we review the common comorbid conditions that affect HIV-infected patients and examine the impact of these co-morbidities on quality of health functioning.

3.2.8.1 Symptoms and AIDS Diagnosis

HIV-infected patients without an AIDS diagnosis are more likely to report higher QOL scores compared to patients with AIDS diagnosis, higher symptom intensity or other co-morbid conditions (Phaladze *et al.* 2005). A study from South Africa also showed that patients with fewer comorbid health problems had better physical functioning (McInerney *et al.* 2008). In a similar study area among patients receiving antiretroviral therapy, the

presence of comorbid health problems reduced scores on physical functioning, but TB alone was not a significant predictor ($r = .66$, p value = 0.001). The inverse relationship between symptoms, comorbid health problems and QOL is also seen in the west (Mannheimer *et al.* 2008).

3.2.8.2. Tuberculosis

Tuberculosis is a common infection among HIV-infected patients and because it is a debilitating disease by itself, it may worsen the QOL of HIV-infected patients.

In an Ethiopian study, TB and HIV co-infected patients scored lower on all domains of QOL compared to their HIV-positive counterparts that did not have active TB (Deribew *et al.* 2009). As opposed to that trend, a comparison between those who were HIV-negative and those who were HIV-positive showed no significant difference among them in terms of QOL measures (Babikako *et al.* 2010). However, since the study was cross-sectional and the sample size was quite small, it might have lacked the power to detect the expected differences.

3.2.8.3. Hepatitis B and C Infection

The prevalence of Hepatitis B and C was recently found to be 9.9 per cent and 1.2 per cent respectively among patients initiating antiretroviral therapy in Zambia (Kapembwa *et al.* 2011). The prevalence of Hepatitis B and C among HIV-positive women attending a hospital in Nigeria was 8.9 per cent and 1.9 per cent respectively (Adesina *et al.* 2010), very similar to those of Zambian patients. However, the burden of liver fibrosis, a sequel of hepatitis B infection or antiretroviral therapy, has been shown to be high at 17 per cent among patients infected with HIV (Stabinski *et al.* 2011). Even though studies that have explored the role these co-infections may have on the QOL of the HIV-infected patients are non-existent, it can be hypothesized that the additional burden of hepatitis infection is likely to worsen the quality of life of these patients. Self-reported fatigue and depression have been shown to be frequent and the best indicators of QOL among patients infected with hepatitis C (Marcellin *et al.* 2007). In a Canadian study, HIV-infected people co-infected with hepatitis C were more likely to report symptoms of depression, fatigue and poorer quality of life compared to the HIV-infected patients that did not have the co-infection (Braitstein *et al.* 2005).

3.2.8.4. Malignancies

Kaposi sarcoma (KS) is the commonest malignancy among HIV-infected patients and its incidence may also be on the increase (Mosam *et al.* 2010). Kaposi Sarcoma has been associated with extremely poor quality of life scores (Harris *et al.* 2002). Patients with KS report an improvement of QOL after initiation of ART (Krown 2011) and the treatment is specifically associated with improved social and cognitive function (Hoosen *et al.* 2006) among these patients.

3.2.8.5. *Cardiovascular and Metabolic Disorders*

The incidence of non-communicable diseases (NCDs) such as diabetes, hypertension, and cancers is on the rise in sub-Saharan Africa (Mufunda *et al.* 2006; Dalal *et al.* 2011) and HIV-infected patients have not been spared. In situations where ART is widely available, HIV is fast becoming a chronic treatable illness (Henry *et al.* 2011). The population of patients living with HIV infection is growing, aging, and experiencing a widening spectrum of non-AIDS diseases including non-communicable diseases. One of the common NCD that is a sequel of HIV and HIV treatment is diabetes (Gupta *et al.* 2011; Hall *et al.* 2011; Paik and Kotler 2011). There is no study that compared QOL among patients with HIV and diabetes with those that have HIV only. A recent study in South Africa compared emotional distress among patients with HIV and AIDS, hypertension, diabetes, and those with both hypertension and diabetes and found no significant difference among all the four groups (Kagee 2010). In the era of ART, the results may come as no surprise and the authors of the paper also attribute this partly to the high prevalence of HIV and mental health conditions in South Africa, causing the boundaries between the different conditions to blur.

3.2.9. *Quality of Life among Children Infected with or Affected by HIV*

Mother-to-child transmission (MTCT) of HIV remains the main route of infection for paediatric HIV. A large number of the infected children have been initiated on antiretroviral treatment and have shown good response to treatment (Musoke *et al.* 2009; Ahoua, Guenther *et al.* 2011; Purchase *et al.* 2011). All of these studies document the improvement in CD4 count and virological suppression, but our review yielded no studies that have measured QOL among these children. For this reason, we present no evidence to show the correlation between the improved biological markers of disease and activities of daily living. Previous reviews (Medina *et al.* 2008) have similarly yielded no results—signifying the dearth of literature on paediatric QOL, except for one study from China (Xu *et al.* 2010). Quality of life among children infected with HIV may be difficult to measure because of the absence of validated tools to make the assessment among children until recently (Xu *et al.* 2010). Psychosocial distress (PSD) may be used as one of the measures of QOL and indeed there are studies that have shown significant PSD among HIV orphans compared to non-orphanded children (Atwine *et al.* 2005; Nyamukapa *et al.* 2008).

3.2.10. *Quality of Life among Caregivers of Persons Living with HIV*

In many resource-limited settings, family care giving is the most common and sometimes the only form of care that AIDS patients receive. That is because clinic-based care is often not available close to home or is not affordable (Kipp *et al.* 2007). The roles of the caregivers include administration of HIV medications, preparing meals and taking the children or accompanying the adults to the hospital for review. In most of Africa,

the role of caregiver often falls to the elderly and the stress resulting from the additional responsibilities of taking care of a chronically ill patient may take its toll on their quality of life. In rural Uganda, elderly caregivers of orphans and vulnerable children face severe disruption of their living arrangement and extended travel away from home as they care for the sick (Ssengonzi 2009).

The work demands from the elderly have been shown to affect the emotional and physical health and nutrition of the elderly, all of which impact their QOL (Ssengonzi 2007). Most of the elderly in this study reported anxiety about their future health and wellbeing. Another study found that the high burden of care giving puts family caregivers at risk for decreased health status and increased social isolation and depression (Kipp *et al.* 2007). In Nigeria, a study measured stress usually manifesting as anxiety and depression among caregivers of persons living with HIV at an urban hospital (Abasiubong *et al.* 2011) and found high levels of stress among 67 per cent of the caregivers. Home-based care programmes are convenient for patients because they don't have to be away from home and they can receive care in a familiar environment. One such example is a South African home-based programme (Singh *et al.* 2011). At least 47 per cent of them marked one or more items on the HIV stigma scale but 88 per cent had low to moderate levels of caregiver burden, much lower than the levels of burden among the Nigerian caregivers. Among the caregivers of HIV-infected children, the levels of stress seem to be even higher as evidenced from a longitudinal study among caregivers of children in South Africa (Potterton *et al.* 2007) who were mostly the mothers.

3.3. Interventions to Improve QOL

3.3.1. Micronutrients

Selenium has been shown to inhibit the replication of HIV through the inhibition of reverse transcriptase (Schrauzer and Sacher 1994). In a randomized controlled trial, a combination of selenium and aspirin did not significantly increase CD4 count but was associated with an increase in mean body weight and QOL (Durosinmi *et al.* 2008). There is a need to conduct more studies to generate evidence on the efficacy of micronutrient supplementation in the improvement of QOL. The potential study design would be a comparison of a combination of ART with selenium as adjuvant therapy compared to standard ART alone in the improvement of QOL.

3.3.2. Nutrition

The review has shown that food insecurity is associated with poorer QOL and the patients who received nutritional support had better quality of life scores than those that did not receive the support. Nutritional supplementation needs to be tested in properly designed randomized trials to determine which nutritional supplementation is most effective. One of the few trials that have compared nutritional supplementations used

historical controls (Manary *et al.* 2010) and did not have clear randomization for the intervention arms.

3.3.3. Impact of ART Treatment Adherence on QOL

Interventions designed to motivate patients to adhere to their medications are expected to improve the QOL of HIV-infected patients. The interventions designed to improve adherence should include simple regimens such as “one pill a day regimens” since these regimens are easier to adhere.

3.3.4 Socio Behavioural Interventions

Studies aimed at testing ways of improving patient-provider relationships should also be conducted (Preau *et al.* 2004). The interventions might include developing training sessions for health workers on how to handle their clients especially in the increasingly busy ART centres where patient-provider relationships are likely to suffer because of the work burden.

3.3.5. Income Generating Activities

Economic dependence has been cited as one of the factors associated with low QOL scores (Stangl *et al.* 2007) in a cohort study in western Uganda and many other cohorts reviewed in this paper. Indeed, the authors in the Ugandan study have proposed that further research is needed to determine whether programmatic interventions such as income-generating activities or job training integrated within HAART programmes, will maximize the potential gains in QOL. This can be achieved by conducting randomized trials using step-wedged designs to ensure that all participants eventually receive the interventions.

3.3.6. Spiritual and Psychological Well-being

Spiritual well-being might be tackled by the involvement of lay counsellor and religious persons such as pastors, reverends and imams from the churches and mosques and other faiths to provide a holistic approach to care. Potentially, a randomized trial might be proposed and conducted to compare clinics that have religious leaders involved in the counselling with those that do not (Dalmida *et al.* 2009).

3.3.7. Depression

The review has shown that depression is the commonest mental health disorder among patients infected with HIV (Myer *et al.* 2008) and not only seriously impacts on the quality of life but is also associated with non-adherence (Adewuya *et al.* 2010; Do *et al.* 2010; Etienne *et al.* 2010; Farley *et al.* 2010; Lawler *et al.* 2011). Depression can be treated with antidepressants but other specific interventions may be necessary to ensure adequate benefit for the patients. A work that has reviewed the scope and effectiveness of different interventions for depression among HIV-infected patients found that interventions were diverse and impacts were not

conclusive (Sherr *et al.* 2011). More studies need to be done in Africa to evaluate the impact of treatment for depression on QOL.

3.3.8. Exercise Training

Treatment with HIV may result in fat redistribution and body disfigurement, which may impact negatively on quality of life (Blanch *et al.* 2002; Blanch *et al.* 2004; Reynolds *et al.* 2006). Exercise may be used to mitigate the effects of such disfigurement. Several studies conducted in the western world have shown positive benefits of exercise among HIV-infected patients (Roubenoff and Wilson 2001; Smith *et al.* 2001; Ciccolo *et al.* 2004). These studies have shown positive improvements in outcomes such as depression, anxiety and quality of life (Wagner *et al.* 1998). An aerobic exercise intervention among women infected with HIV resulted in a reduction in depressive symptoms and improved the general well-being of the patients compared to the controls (Neidig *et al.* 2003). One of very few studies, if not the only one, in Africa to examine the role of exercise on quality of life among HIV-infected patients with body fat redistribution was a randomized trial conducted in Rwanda (Mutimura *et al.* 2008a). In the exercise group, women improved more than the men in all three domains of psychological, social and HIV-HAART. The study provides evidence that exercise training results in improvement in QOL. Six months of Cardio-respiratory exercise training (CET) also resulted in a reduction in waist circumference, skin fold thickness and body fat among patients with body fat redistribution (Mutimura *et al.* 2008b).

3.4. Discussion

The paper has reviewed the literature on measurement of QOL and the factors that influence QOL among HIV-infected patients in sub Saharan Africa. This review differs from previous reviews (Beard *et al.* 2009) which focused on impact of ART; the current review is more comprehensive and explores other factors that influence QOL and the possible mechanism and also proposes interventions to improve QOL— It has explored evidence on the potential interventions to improve QOL that have been tested in both observational and experimental studies.

The review has shown that a number of factors interplay to influence quality of life. The focus of ART programmes must shift from a narrow interest in CD4 counts, HIV-RNA, and AIDS-defining illnesses to determining the optimal management of HIV infection as a complex chronic disease in which the causes of morbidity and mortality are multiple and overlapping. These programmes need to adopt a new paradigm of care with which to maximize functional status, minimize frailty, and prolong life expectancy (Justice 2010).

The Chapter reviewed several studies that show a significant increase in QOL with the initiation of ART (Louwagie *et al.* 2007). However, we note that the most significant increases are made in the first three months after initiation of ART and thereafter the gains slow down. Many of the papers

have performed analyses using linear regression, which obviously assumes a linear relationship between two variables. However, this may not be the case since the majority of patients have been on ART for a limited length of time and this relationship may cease to be linear in the long-term. ART programmes need to continue to monitor patients' QOL routinely as part of their treatment plans so as to document the changes. This is critical since we expect that once the long-term side-effect start to appear, it is likely that QOL will start to drop.

A study in Kenya (Fox *et al.* 2010) showed that gains made in the first two years are sustained but there is concern about the blips seen in the QOL functioning at the end of the two year follow up and the emergence of skin rash as a potential side-effect. In order to sustain the gains in QOL, treatment programmes will need to use regimens that have lesser pill burden and are free from potential toxicities that may deter patients from maintaining adherence.

It is a well-established fact that medication adherence is a prerequisite for antiretroviral treatment success. This review has shown that medication adherence is also associated with quality of life. The double-edged success of treatment adherence necessitates that research should also focus on adherence motivation to ensure long-term adherence, which may slacken after symptoms subside significantly.

Further research should also be done to understand the role of traditional and complementary medicine in modifying QOL. Clearly, the association will be influenced by the nature of the traditional medicines used. Some of these medicines are known to interfere with the pharmacokinetics and pharmacodynamics of antiretroviral drugs but, for some of them, the mechanism is not known. Social scientists and basic scientists need to work together to understand the common herbal medicines that are being used and their mechanism of interaction with antiretroviral drugs. In the absence of a scientific explanation for the higher QOL among patients using herbal medicine, it is likely that the use of these medicines serves the patients' conscience that they are using something effective or something that will get them better faster.

Monitoring quality of services and patient satisfaction with services provided may be critical for ART programmes. The review has shown that patient satisfaction with a service has an impact on their QOL (Bhargava and Booyesen Fle 2010). The process of continuous monitoring of health care programmes may inform the necessary interventions for the programmes as part of a continuous quality improvement. Programmes can intervene in real time to ensure that patients are satisfied with the services. The attributes to monitor include patient waiting time, availability of medications and the courteousness of the service providers among other variables.

There are no studies in Africa that have been done to compare the QOL among HIV and AIDS patients that suffer diabetes with those that do not have diabetes. One would expect that the added burden of diabetes or cardiovascular diseases will cause more psychological distress and lead to poorer quality of life among HIV patients suffering from diabetes. Apart from the disease itself being a threat, diabetes would lay an additional pill burden on these patients leading to more distress.

There are also no studies in sub Saharan Africa done specifically to explore the role of Hepatitis co-infection on quality of life among HIV patients. Hepatitis B and C are thought to be rare in Africa but data is emerging to show these infections are fairly common (Barth *et al.* 2010). Hepatitis B is associated with progressive liver disease and may develop into liver cancer. Routine screening for Hepatitis B and C should be initiated among patients initiating ART and is also recommended for HIV positive pregnant women. Detection of hepatitis will assist the health workers to administer social support and appropriate medical care because certain antiretroviral drugs may cause liver damage (Puoti *et al.* 2009), hence worsening the quality of life and prognosis of patients co-infected with hepatitis infection.

Community-based ART programmes work to relieve the hospitals of congestion from patients seeking chronic HIV care. However, this review has shown that these programmes may also function to improve QOL. Home-based programmes have been studied extensively in Africa and have been found to be associated with high adherence to ART (Ndekha *et al.* 2005; Weidle *et al.* 2006; Abaasa *et al.* 2008). Home-based care programmes are also associated with other positive social outcomes such as community support, family support and relationship strengthening (Apondi *et al.* 2007), all of which may impact on quality of life of these patients. However, the cost-effectiveness of community-based compared to facility-based programmes has yielded conflicting results (Babigumira *et al.* 2009; Marseille *et al.* 2009) and hence needs further evaluation before concrete recommendations can be made.

3.5. Limitations

This review has some limitations, one being that attrition rates for ART programmes are very high in Africa and may be as high as 40 per cent (Rosen *et al.* 2007). The ART programmes may be selectively losing patients that are experiencing side-effects, which may inadvertently underestimate the proportion of patients experiencing declines in QOL functionings. Programmes that evaluate QOL should take losses to follow up into account because the losses to follow up may be informative (Brinkhof *et al.* 2008; Geng *et al.* 2010; Nglazi *et al.* 2010). Second is that the most of African studies on QOL are from South Africa and may not necessarily represent all of Africa. Thirdly, most of the studies in this review are quantitative studies, though this review made attempts to include qualitative studies as well. Lastly, a lot of literature in Africa is not published and hence may have been left out of this review. The gray

literature includes dissertations by students, reports of conferences, projects and workshops, all of which may contain important information on quality of life in Africa. We made attempts to search conference reports and found some useful references.

3.6. Conclusions and Recommendations

Data on quality of life among HIV-infected patients in Africa is limited. This literature review showed that antiretroviral therapy improves QOL among HIV-infected patients. However, the gains in QOL start to slacken as side-effects emerge. Several factors interplay to influence the quality of life and these include CD4 count, viral load, age, socio-economic status, gender and presence of depression. The modifiable factors that may positively impact QOL include social support, disclosure, stigma support, nutrition, religiosity, use of less toxic and less pill-burden regimens, exercise, support with income-generating activities and treatment of co-morbidities such as malignancies and tuberculosis that are common among AIDS patients. A few interventions such as exercise and nutrition have been tested. Interventions targeting more of these modifiable factors should be designed and tested using ethically sound study designs before large scale implementation can be recommended.

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CHAPTER FOUR

Religion, Stigma and ART Adherence in Ethiopia: The Experience of Ethiopian Religious Associations of People Living with HIV and AIDS

Bereket Tarekegn

Abstract

Stigma is one of the major factors why people are reluctant to be tested, to disclose their HIV status and to take antiretroviral drugs in Ethiopia. The study, using qualitative case studies, explored the role of Religious People Living with HIV and AIDS (PLHIV) associations and HIV-positive religious leaders in averting stigma and creating a supportive environment for care and treatment. The findings revealed that religious PLHIV associations have indeed played a key role in promoting positive living among PLHIV believers, which is central to their adherence to ART. The role of religious leaders living with HIV was also found to be instrumental in breaking stigma and creating supportive environment for PLHIV in religious institutions. It is recommended that ongoing efforts to eliminate HIV and AIDS related stigma and improve ART adherence in Ethiopia include, among others, increased and strategic involvement of religious PLHIV associations and HIV-positive religious leaders.

4.1. Introduction

4.1.1. Background

Stigma has been identified as a primary barrier to the provision of care and support to PLHIV¹. Disclosure of HIV-positive status is an important public health strategy as it offers a number of benefits to the infected and to the general public. However, this has continued to be difficult due to existing stigma and discrimination. As a result, PLHIV miss out on the spiritual, social, emotional and medical care and support they need.

4.1.2. Statement of the Problem

Stigma in Ethiopia is much rooted in the religious tradition that relates HIV to sin and infidelity. Religious institutions have also been blamed for long for their role in spreading stigma. Beyond blaming religious institutions on commonsensical basis, to the researcher's knowledge, no systematic study has been conducted in Ethiopia on whether religious institutions adhere to their stereotypical roles or they are reversing this conception by providing the social space for positive living through associations and fellowships of PLHIV as has been reported in other

settings. In addition, the study hypothesizes that PLHIV find it easier to identify with and disclose their status, and get spiritual and emotional support from religious leaders living with HIV and AIDS.

4.1.3. Research Objective

The main objective of the study is to explore the role of HIV-positive religious leaders and religious PLHIV fellowships/associations in alleviating HIV-related stigma within religious institutions in Ethiopia. The specific objectives of the study are to:

- Explore the role of HIV-positive religious leaders in promoting positive living and contribute to ART adherence in religious communities,
- Assess the significance of religious PLHIV associations in breaking stigma, promoting disclosure, and creating a conducive environment for ART adherence.

4.1.4. Methodology

Case study is the main research strategy adopted to conduct the study. The study relied on qualitative data collected through key informant interviews and a review of relevant documents. A total of 52 informants from Muslim and Christian religious PLHIV associations, Ethiopian Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (ETNERELA+) board, and partner organizations participated in the study. With regard to relevant documents, periodic progress reports, workshop proceedings, and strategic plan documents have been used as sources of empirical materials.

In order to select the participants involved, purposive sampling technique was used, i.e. HIV- positive religious leaders who are members of ETNERELA+ and key informants from organizations that worked with ETNERELA+ project in the last three years took part in the study. To reach potentials participants, snowball sampling technique was also used.

Ethical clearance was obtained from Ethiopian Inter-faith Forum (EIFDDA), which implemented ETNERELA+ project from 2007 to 2010. All interview participants gave their consent individually. An interview guide with open-ended questions was used by the principal investigator. The interviews were conducted in Amharic language in a setting that was convenient for key informants. Tape recordings at the conclusion of each interview were transcribed in English for data analysis. All transcripts were reviewed, and subsequently emerging themes were derived and presented.

4.2. Literature Review

Goffman (1963, 3) defines stigma as “an attribute that is deeply discrediting”. Stigma occurs within a social context that defines an attribute as devaluing (Yang *et al.* 2007, 1525).

Some authors associate stigma with social identities. Social identities are heavily determined by the ways we are viewed by others (Mead 1934). Parker and Aggleton (2003, 19) theorize “changing constructions of identity” in relation to the experience of stigma and in “resistance to it”. A vital precondition for human well-being is that people are recognized as having value by those around them (Honneth 1995). Stigma arises when people are denied such recognition (Campbell *et al.* 2010).

Brimlow *et al.* (2007) define HIV-related stigma as all unfavourable attitudes, beliefs, and policies directed toward people perceived to have HIV and AIDS. People living with HIV and AIDS feel stigma because of “their interactions with others or actual experiences with public attitudes through which AIDS-related social standards are manifested” (Zhou 2007, 285–6). Stigmatizing beliefs and actions may also be imposed by people living with HIV themselves (AVERT 2010).

ATLIS (2010) indicated that 79 per cent of PLHIV who participated in a global study feared social discrimination following their status disclosure. Also WHO cites fear of stigma and discrimination as the main factor for people’s reluctance to be tested, to disclose their HIV status or to take antiretroviral drugs (WHO 2008). A study found out that people who reported high levels of stigma were more than four times more likely to report poor access to care (Sayles *et al.* 2009).

4.2.1. Stigma and ART

Actively disclosing HIV status is believed to facilitate adherence to ART as people around the patients support them. Many PLHIV, however, feel stigmatized and fear being recognized as an AIDS patient and that prevents them from seeking ART services (Skovdal *et al.* 2011). Many of the people tested positive for HIV do not enrolled in treatment services; one of the main underlying reasons for the weak linkage between testing for HIV and enrolling in treatment services, according to both clients and providers, is stigma and discrimination (FMOH 2009: 2–3).

Findings on the relationship between increased access to HIV treatment and a reduction in stigma are quite mixed (Makoae *et al.* 2009). Castro and Farmer (2005) argue that access to ART enables PLHIV to reclaim potential value as economically and socially competent citizens, and that as ART becomes universally accessible, stigma will gradually disappear. A study on 1,268 adults in Botswana, on the other hand, concluded that although improving access to antiretroviral treatment may be a factor in reducing stigma, it does not eliminate stigma altogether and does not lessen the fear of stigma amongst HIV-positive people (Weiser *et al.* 2003).

Studies also pointed out that the availability of treatment may reduce some types of stigma and not others as there are many types of stigma. For example, a study in Tanzania found out that stigma caused by the perception of PLHIV as weak and therefore a feeling of being 'burden' on the community had decreased with the uptake of treatment (Evidence for

Action 2011). The tendency of PLHIV to 'self-stigmatize' had also decreased, as contact with other PLHIV helped them see that they were not alone. On the other hand, 'fear-based stigma' was found to have increased as it is now difficult to differentiate between people infected with HIV and those who are not (*Ibid.*).

The fact that stigma remains in developed countries such as America, where treatment has been widely available for over a decade, also indicates that the relationship between HIV treatment and stigma is not straightforward. An estimated 27 per cent of Americans would prefer not to work closely with a woman living with HIV (UNAIDS 2008).

4.2.2. HIV and AIDS and Sin

Stigma towards PLHIV is much related to the notion and understanding of sex and sexuality, which is entrenched within religious beliefs and institutions (Campbell Skovdal and Gibbs 2010). Faith communities respond to HIV and AIDS from a standpoint of judgment born from negative images of sex and sexuality, which drives stigma that renders treatment, care and support significantly less effective (Mokgethi 2010: 78). HIV and AIDS is perceived to be 'part of God's judgment in a wicked world' (Senkima 2010). A national stigma survey of 2010 conducted in Ethiopia also revealed that doctrines, moral and ethical positions have contributed to the perception that those infected have sinned and deserve "punishment" (Tsegazeab *et al.* 2010).

On a positive note, the national stigma survey found out that PLHIV have a relatively better level of confidence on health personnel (88 per cent) than any other group in disclosing their status (*ibid.*, 46). The decision by PLHIV to keep their HIV-status secret to religious and community leaders may be because of the perceived fear of rejection/discrimination or fear of being viewed as promiscuous (*ibid.*, 70). A study conducted in South Africa (Campbell *et al.* 2005, 3) is also in agreement with this trend. Reported in the study is that while ART contributed to 'normalization' of AIDS-affected people, AIDS has continued to be stigmatized as a 'moral disease'.

4.2.3. Social Groups and Their Role in Reducing Stigma

Social support theory puts forward that social support protects individuals against the negative effects of stressors, such as discrimination (Galvan *et al.* 2008, 423). People are able to resist stigma to the extent that they have access to social identity/group memberships to which they can ascribe positive value and meaning (Goudge *et al.* 2009).

Some empirical studies (Campbell and Deacon 2006; Tadios and Davey 2006) provide preliminary evidence that membership in certain grassroots social groupings can play a role in shaping how members respond to the HIV and AIDS epidemic. Social spaces in community groups help to identify, challenge and reformulate disempowering social representations (Campbell and Deacon 2006). An empirical study conducted in Ethiopia

also indicated that social support could enhance adherence through encouragement, reassurance, reinforcement, and motivation, or by masking the effect of stress, anxiety, and depression (Tadios and Davey 2006).

Investing in social support systems helps to provide social environments that are effective to promote more general mental and physical well-being for PLHIV (UNAIDS 2010). PLHIV can optimize ART adherence by drawing on support from community members and friends (Skovdal *et al.* 2011).

Creating communities where PLHIV are treated with love, care and compassion is seen as a key element of stigma reduction, and to this extent faith-based institutions are considered to play crucial roles. Agadjanian (2001) states that church groups in Africa are key to creating social spaces that nurture social interaction and exposure to social issues. However, he says, the extent to which these social spaces facilitate or hinder support for PLHIV, and promote or challenge stigmatizing attitudes remains unexplored.

A research conducted by Christian Aid and Life in Abundance on PLHIV in FBOs in Addis Ababa in 2006 indicated that PLHIV have not been considered as central agenda of Faith-Based Organizations (FBOs) in Ethiopia. The research put forward controversial issues such as ARV drug versus divine healing and economic status and HIV AIDS, i.e. depicting PLHIV fellowship as a fellowship of the needy. Apart from that, the study didn't critically assess the merits and challenges of PLHIV fellowships in FBO contexts and their role in the fight against stigma, denial and discrimination.

4.3. Case Study: ETNERELA+ and Religious PLHIV Associations in Ethiopia

4.3.1. The Research Setting

Religious institutions and their leaders have been key actors in the HIV and AIDS response. They have been instrumental in raising awareness and mobilizing communities for care and support for Orphan and Vulnerable Children (OVC) and PLHIV. Religious institutions are noted to be significant in generating demand for ART and PMTCT services. The appreciative inquiry research conducted by EIFDDA in 2007 identified exemplary relationships of religious leaders with PLHIV throughout Ethiopia, and highlighted their role in tackling SDD in Ethiopia.

Though there are achievements and success stories in the effort to curb the spread of HIV and mitigate its impacts in Ethiopia, Stigma, Shame, Discrimination, Denial, Inaction and Mis-action (SSDDIM) have been major impediments for effective response at all levels. These barriers are worse within some segments of the society, particularly the religious communities (ETNERELA+ 2010).

Religious leaders living with or personally affected by the pandemic face severe stigma and discrimination, more than any other members of the community, since religious leaders are regarded as “Bastions of good religion.”²

The role of HIV positive religious leaders in the overall HIV and AIDS response has not been investigated and clear. Key questions that still linger in the minds of many include, what value that HIV positive religious leaders bring to these efforts; what do they accomplish differently compared to other religious leaders, and what are the risks and opportunities for religious leaders who disclosed their positive HIV status.

4.3.2. Institutional Background

The African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (ANERELA+) was established in Uganda in 2003. ANERELA+ made efforts to overcome stigma and discrimination by demonstrating in practice that perceptions, such as 'AIDS is God's punishment for sin', 'nobody in our Faith community has AIDS', 'HIV relates to immorality', and 'Religious leaders are “Bastions of perfect religious living” so they deserve greater stigma', are wrong. It engaged in providing accurate information about the pandemic, searching for emotional, economic social and political solutions with respect to HIV-related problems, and breaking the silence about the disease within faith based institutions.

ANERELA+ operates by identifying one person in a country to work with, broadening membership, and developing in country strategy. It works towards empowering, equipping and engaging religious leaders living with or personally affected by HIV and AIDS to live positively and openly in the community by breaking the silence, bringing hope and transformation.

ETNERELA+ was introduced in Ethiopia by Reverend Ayano Chule, who is an ordained priest from Nigeria and also member of ANERELA+. Originally from Konso, South Ethiopia, he lost his wife and son due to AIDS. Ethiopian Evangelical Church Mekane Yesus (EECMY) has accepted Reverend Ayano as a religious leader.

ETNERELA+ has been hosted within EIFDDA- Christian Aid-EU-funded Programme on SDD as a project for the past three years in Ethiopia. The mission of the programme is to mobilize and empower religious leaders of all faiths in Ethiopia to become more compassionate and supportive in their relationships with HIV+ people, and fight against stigma, discrimination and denial within their communities. Establishing fellowships, support groups and networks of HIV+ believers and religious leaders within religious communities and congregations; and among religious leaders of the various faiths is one of the five strategic objectives of the programme.

Organizing HIV+ religious leaders in an institution in Ethiopia has been a tough challenge. After long and tedious efforts, the association has received

legal recognition in July 2010. ETNERELA+ has brought together about 185 HIV positive religious leaders from different religions. Its membership also includes fellowships and associations of HIV positive religious followers of different faiths.

ETNERELA+ has undergone key institutional building processes in this period. These include setting up a governing board and a General Assembly, and so far it held two annual General Assembly meetings in the last two years. Currently, efforts are underway to strengthen the institutional capacity of ETNERELA+ through establishing and strengthening governance systems, building constituency, safeguarding the well-being of key HIV+ Religious Leaders, who are founders of ETNERELA+ and who disclosed their HIV status, and promoting networking and partnership with key stakeholders.

Donor partner organizations, such as Dan Church Aid, have expressed their continued interest and commitment to build the capacity of ETNERELA+ through faith-based organizations, namely, Ethiopian Orthodox Church (EOC) and EECMY so that it can grow into a network. In other words, this means that ETNERELA+ fellowships should be established and strengthened within the major religious institutions, and these fellowships will form the Network of Fellowships of Religious Leaders Living with or personally affected by HIV and AIDS (ETNERELA+ 2010).

4.3.3. Strategies: SAVE Prevention Model

ETNERELA+ uses the 'SAVE' approach to HIV, a response originally formulated by ANERELA+ as a reaction to the shortcomings of the 'ABC' comprehensive HIV prevention approach. ABC stands for 'Abstinence; Be faithful; Use Condoms.' Unfortunately, the way in which it has been presented in the past was like: 'Abstain. If you can't abstain, be faithful. And if you can't be faithful, use a condom'. Proponents of 'SAVE' claim that the implication that the use of a condom automatically marks a person as unable to be faithful fuels stigma and acts as a disincentive to evidence-based prevention. Furthermore, they say ABC fails to consider a person's HIV status (INERELA+ 2011).

The SAVE approach provides a more holistic way of preventing HIV by incorporating the principles of ABC as well as providing additional information about HIV transmission and prevention, providing support and care for those already infected and actively challenging denial, stigma and discrimination associated with HIV. The letter A in SAVE, for instance, refers to available medications, not just ART, but treatment for HIV-related infections and provision of good nutrition (particularly to help to ensure adherence to ART) and clean water (*ibid.*).

4.3.4. Key Findings

Clarity of Mission and Operation: The mission of ETNERELA+ is noted to be creating the right environment for PLHIV within religious institutions

and communities. According to the majority of informants, the success of ETNERELA+ lies in creating space for HIV-positive believers including religious leaders to restore their identity, confront stigma, and find the social sphere for hope, care, and support. During a key informants discussion held with ETNERELA+ members, they said that they wanted to become members of ETNERELA+ because the mission of fighting stigma within faith communities has united them around the cause of ETNERELA+.

In the beginning, there was an impression that the mission of ETNERELA+ seems to be geared towards improving the quality of life of HIV-positive religious leaders rather than using or involving them in the HIV and AIDS response. Respondents mentioned that it seemed as if FBOs have been working with Reverend Ayano out of pure sympathy and there has been lack of clarity and understanding on the vision of ETNERELA+, and its strategies of involving Religious leaders living with HIV and AIDS. Nonetheless, it was learnt that the integral values of compassion and support towards PLHIV and recognition of their contribution in the HIV and AIDS response has opened doors for Reverend Ayano to start his activities at Ethiopian Evangelical Church Mekane Yesus (EECMY).

One of the challenges faced by ETNERELA+ since it started operation has been finding a universal definition across faith communities in Ethiopia for what refers to 'religious leader'. In the Muslims context, for instance, the participants have identified Imam and Dai (Preacher), who qualify as a religious leader. It was learnt that Imams can be ordered by the Supreme body namely Ethiopian Islamic Affairs Supreme Council at various levels or others can assume the role informally with de facto support from their congregation. Imams lead the daily prayer and oversee the spiritual activities of their congregation, thus have significant opinion and moral leadership over their constituency. As can be seen from the Muslims case, ordination is not as centralized as the Ethiopian Orthodox Church, and it varies from mosque to mosque.

Partly due to this, there has been lack of clear eligibility criteria of membership in ETNERELA+. For the purpose of this article, and taking into consideration the majority of members at present in ETNERELA+, a religious leader (lay or ordained) is defined as a person with spiritual education and/or leadership status at different levels, who can dictate a certain level of influence among followers within his/her places of worship.

The informants mentioned for many PLHIV in Ethiopia at the grassroots community level, their religious leaders (their priest, pastor or imam) are their main sources of pastoral support. They commented that religious leaders therefore are facing the daily challenge of how best to offer pastoral support to PLHIV members of their congregation. Hence, it was suggested that concerted efforts should be made to help religious leaders particularly those that are positively living with the virus or are personally affected by it

to develop qualities, attitudes, knowledge and skills to adequately communicate theological messages responding to the needs of PLHIV.

Acceptance and Integration: Almost all informants share the difficulty of perceiving HIV positive religious leader. It brings suspicion especially in Faith-based institutions that have stringent doctrine of deaconship. Many therefore die hiding their status because of fear.

Some informants mentioned that 'Religious people' are vulnerable to HIV as it is difficult for them to access prevention methods such as condom in public, and if such acts ever happen, they take place in a rushed and hidden environment and thus are short of measures for safe sexual practices. There are also informants who said that religious leaders at various levels are vulnerable to sexual fall as they encounter different kinds of people in their day-to-day lives.

HIV-positive Religious leaders' involvement in spiritual ministry is not yet recognized formally by major faith institutions in Ethiopia. According to some informants, the reservation of some FBOs in this regard should not be perceived as an act of stigma and it is not directed to the individual PLHIV. Sin and righteousness are usually tied to individual's wilful act and there is a tendency to consider HIV as a result of a sinful act. Thus, a religious institution that aligns itself with this sinful behaviour will be considered sinful and that plays against the age-old reputation of the institution.

Some informants on the other hand believe that some FBOs are not totally free from stigmatizing attitudes towards people living with HIV/AIDS. They fear that leaders of Faith in Ethiopia exhibit a professional stigma fighting approach as compared to a compassionate one. They are dismayed by the position of some senior religious leaders that 'those sacred and holy can't be HIV positive'.

The study noted, however, that there are variations in the understanding of HIV and AIDS among religious leaders of the same faith. It was also mentioned that there has not been yet a clear theologically consistent and profound teaching presented to religious authorities that integrates sex, sexuality, sin and HIV.

There is consensus among key informants from every religious group on the issue that being positive shouldn't prevent one from carrying out his spiritual duties, and either there was no experience of a religious leader openly denounced by the church or mosque from carrying out his duties as a result of HIV and AIDS. Muslim informants on the other hand emphasized the need to raise awareness among some Mosque leaders to accept PLHIV Muslim brothers to be assigned and serve in the spiritual services of the Mosque.

The study revealed that religious institutions such as EOC and Ethiopian Islamic Affairs Supreme Council (EIASC) showed relatively slow response to the cause of ETNERELA+ in the last three years. The study noted that it

still creates amusement among some priests to think of HIV and AIDS-positive religious leader, particularly a leader who made a life time commitment to abstain from marriage. They directly relate being HIV-positive to promiscuity, which is a sinful act according to Holy Scriptures. Their main reason is the fact that more than 90 per cent of HIV/AIDS cases are transmitted through sexual intercourse³.

ETNERELA+ won relatively higher support from Evangelical Christians, compared to Orthodox Christians and Muslims. The fact that the nature of the project needed constant engagement and recognition of the spiritual wings of participating FBOs and the fact that EIFDDA Secretariat has been constituted mainly by the development wings of these FBOs and works with these organizations on a regular basis, may have created a gap in bringing on board senior religious leaders during the project implementation. ETNERELA+ is believed to bring impact related to stigma within religious institutions if it gets endorsement from higher level leadership of the respective institutions.

There were also problems in the beginning related to the fact that the founding members see themselves as branches of the international, and found it difficult to operate according to the existing culture and norms of the country. It was underlined by the majority of the key informants that ETNERELA+, as an independent quasi-secular organization, should work in partnership with fellowships, which operate under recognized religious institutions in Ethiopia.

Almost all members of ETNERELA+ have become members as individuals. Efforts are now underway to integrate them back to their institutions by establishing and strengthening fellowships of PLHIV within churches and mosques.

Today, ETNERELA+ is getting increasing recognition from religious and government authorities. The Patriarch of the Ethiopian Orthodox Church, His Holiness Abune Paulos, has given ETNERELA+ office space within the Addis Ababa Diocese of the Orthodox Church. The founder is also currently board member of the National Network of People Living With HIV and AIDS (NEP+). His life testimonies are being used by the government and the media as part of their HIV and AIDS response strategies.

Disclosure and HIV-Positive Religious Leaders: Informants stated that if religious leaders are accepted as PLHIV they can be role models for more people to take VCT. There is belief among the respondents that if more HIV-positive religious leaders disclose their status, more other people will openly declare their status. The issue of disclosure, however, was challenged by some informants and it was stressed that it should be clearly known for what purpose, for whom and when a person should disclose his/her HIV status. Reverend Ayano's public disclosure of his status was noted to have helped many to defeat self-stigma, to disclose their status,

and to see hope for their future. However, a lot remains to be done, according to an anonymous informant.

The law was enacted by the Ethiopian Orthodox Church for positive priests and deacons to continue to serve on their ministries. However, a lot has to be done on stigma. The silence is not yet broken. Many still fear of stigma and discrimination if they are tested positive and begin taking ART. They fear their deaconship will be threatened if they disclose their status so they chose to live covered. We believe if they disclose their status and begin teaching in public the issues of stigma and discrimination will ease. Now many are coming out openly about their status not voluntarily but because of economic reasons particularly in need of food as adequate diet is mandatory while taking ART. The example of Reverend Ayano shows how one can live positively taking ARV drug. (Anonymous informant).

According to informants, most of the religious institutions are not yet opened up to issues related to HIV, and change can be attained if HIV-positive religious leaders keep their position and continue to serve as a religious leader. Informants said that disclosing their status is more helpful to other PLHIV in their congregation than the religious leaders themselves. Informants said once the religious leaders disclose their status or they are known to live with HIV, they are pushed systematically from mainline prayer, in mosques for instance, using pretexts such as: “It is not good for your health to lead prayer for it is cold during morning and night prayers (*Subahi* and *Ishah*)”. Such acts hurt the morale of HIV-positive leaders and erode their self-esteem.

Responding to the question on the fate of a religious leader living with HIV and AIDS upon disclosing his HIV positive status, almost all respondents noted that it would be difficult for a religious leader, who can be Archbishop, priest, or deacon with all possible connotation of the term, to be declared HIV-positive and resume on his duty as a spiritual leader.

Informants from EOC said that priests who do not marry by virtue of their deaconship will not be in a position to continue as a religious leader once they declare their HIV-positive status. It is assumed that they contracted the infection through sexual misconduct, and it is difficult for them to prove otherwise. However, they won't be openly ostracized or labelled sinful.

They said that it is understandable that priests do not want to be tested and reveal their HIV status where there is no experience on the fate of one who did the same before in the church, and where they have no guarantee to continue on their spiritual and moral leadership. They also said that priests who disclosed their HIV-positive status may exhibit low morale and confidence in their future ministries.

The key informants affirmed that ETNERELA+'s teaching on positive living has great potential to change the course of stigma related to HIV and AIDS. They underlined that Reverend Ayano's testimony of positive living has given hope and spiritual rebirth to many. They mentioned that as a result of ETNERELA+ sensitization on positive living, a sheik has revived his hope and decided to conceive a child with his wife, and an evangelist living with HIV has reconciled with his wife after four years of separation because of HIV.

Many warned however on the risk of mobilizing religious leaders to openly disclose their status without having alternative strategy to sustain their livelihood. That is because, informants cautioned, most of them are at the risk of being expelled from their spiritual duties in their respective religious institutions. Economic support for HIV-positive religious leaders was recommended to enable them to boldly challenge stigma among their followers. Many of the key informants agreed that religious leaders take risk in disclosing their status to be part of ETNERELA+.

However, it is shared by many of the informants that it doesn't make sense if religious leaders, who are social mobilization agents, are given economic support after they lose their position as a religious leader. The informants also agree on the fact that religious leaders are public figures and they are not ordinary people and have different identity and challenges so they need special attention, and they deserve to get economic support.

Other informants believe that religious leaders who disclosed their status should be supported out of fairness and responsibility. HIV-positive religious leader from Nur Association of Ethiopian Muslims living with HIV said, "Religious institutions give food to our spirit, and not to our flesh" and stressed the need to support PLHIV with adequate food and income-generating opportunities.

Stigma and ART Adherence: The informants unanimously agreed that ART has brought about normalization of HIV in the public. There are now increasingly less bedridden patients and they can work and support their families. Naming of PLHIV related to their physical appearance is also no longer observed. The way HIV and AIDS is being communicated is also mentioned to have contributed to the progress made in response to stigma.

Some informants mentioned that ARV medicine has improved the moral and emotional wellbeing of PLHIV as they are able to work and support their families. However, this does not necessarily mean that stigma no longer exists. Many still noted to take their ARV pills outside of working hours to avoid stigma at the workplace.

According to Melake Tsehay Sebhat, senior priest of the Hawassa Tikur Weha Debre Tsehay Kedest Mariam Church⁴, there used to be stigma during Holy Communion and other believers were not comfortable to stand in queue with PLHIV. The priests usually identify PLHIV during teaching and spiritual counselling sessions, and give them encouragement and

support to enrol and adhere to ARV medicine. Now, the PLHIV no longer refuse to take the ARV medicine with the Holy Water, and they take the medicine openly. The ARV treatment has boosted their morale and confidence and many of them now pass the day in town working. Some are also working as cleaners and storekeepers in the Church.

There are different conceptions of ART in the various religious institutions. Among the evangelicals, the issues of divine healing and the use of ART was raised as a controversial issue. Informants recommended for dialogues to be held at each institution so that they take a clear position on ART in relation to divine healing. There is consensus in the Orthodox Church on the use of ARV medicine with Holy Water as declared by the Patriarch, His Holiness Abune Paulos. There is, however, some gap in implementing this national consensus at local level.

Muslim religious leaders have played a key role through their teachings in resolving a problem in Muslim communities of taking ARV medicine during the fasting season of Ramadan. Many Muslim PLHIV were reported to distort their normal daily schedule and take the drug all at once at night (fast breaking hours) despite the fact that those who take ARV drug between 12 hours interval (not 24 hours) were advised not to participate in fasting. Regular uptake of the ARV medicine is one of the indicators of measuring successful adherence to ARV treatment.

It was stressed that HIV-positive religious leaders should work more on sensitizing their followers on ART adherence. As they are role models to their followers, they can educate and mobilize PLHIV to adhere to ART. The informants also mentioned that once their health improves after taking ARV medicine more and more female members of the religious PLHIV associations are becoming pregnant. Therefore, more sensitization has to be done on PMTCT in these associations.

The national stigma survey (2010) indicated the decrease in the level of stigma at national level. Some informants relate the decrease in stigma to the recent changes in local religious institutions' attitude towards PLHIV. They said church leaders, for instance in Hawassa and Bahir Dar, are taking the lead in supporting PLHIV. The role of PLHIV associations in religious institutions such as Tsion Mengedegnoch PLHIV Choir was also mentioned to have contributed to stigma reduction.

Some informants, however, disagree and attribute the decrease in stigma to the introduction of ARV treatment and not to the acceptance or creation of a supportive environment within religious communities for PLHIV. Some key informants also attributed the decrease in stigma to the impact of IEC and improved awareness of the public on HIV and AIDS. It was observed that many of the religious institutions claim stigma is low in general terms, but, when measured against various indicators of stigma, they still exhibit some forms of stigma.

Stigma and Religious PLHIV Associations: Establishing Fellowships of HIV positive laities within religious institutions has been one of the strategic objectives of ETNERELA+. There are two religious PLHIV associations, which are members of ETNERELA+. These are Ye Tsion Mengedegnoch⁵ and Nur PLHIV Muslims Association⁶ PLHIV Association.

So far, ETNERELA+ has initiated seven fellowships in Gambella Region, eight fellowships in Bahir Dar, and three fellowships in Bati in Amhara Regional State, and one fellowship in Hawassa, SNNPR. Almost all informants agreed that fellowships help PLHIV not to feel isolated because of their status and help them to integrate easily with their respective community of believers.

Kamil Tayeb, Director of the Nur Muslim PLHIV-Association, said the main goal of the Association is to alleviate isolation and provide psychosocial support to Muslim PLHIV. He said that close to 50 Muslim PLHIV couples are now married as a result of the teachings of the association. According to him, only one out of five Muslim PLHIV find their partners through the media, which is currently a common medium for PLHIV couples to find their partners.

HIV-positive religious leader informant from Tsion Mengedegnoch PLHIV Association indicated that many PLHIV bring clearance from other PLHIV associations to join this association saying that they can't experience the same love, fellowship, prayer, and spiritual peace elsewhere. It also gives them greater feeling of satisfaction when they get acceptance from their church and mosque leadership and communities, and they feel the worst emotional downfall when they feel marginalized by their church or mosque communities compared to other sects of the society.

The head of Tsion Mengedegnoch also noted that the members prefer talking to him than to their pastors since he is HIV-positive and personally share the challenges they encounter. Because living with HIV is often linked with sin, they say, they are in fear of condemnation when they discuss the issue with their pastors.

Membership in these religious associations seems to correlate with gender, age, level of education and economic status of the PLHIV. As indicated earlier, it was, for example, noted that the fellowship enjoy a very high proportion of women members. That, according to respondents, is mainly because women first visit these associations in need of economic support. Others also said women prefer disclosing their HIV status in these fellowships. That is in fact contrary to findings of a recent stigma survey in Ethiopia in which it was reported that as compared to their male counterparts, fewer women disclose their HIV status to their husbands.

Almost all informants agree that PLHIV with low economic status tend to join the associations than those who have better income. In terms of age, the majority of members are adults. That in fact is contrary to what is

reported by Charles (2005) in which older age is associated with increased HIV stigma and less disclosure of HIV status. Older adults are less likely to disclose their being tested HIV-positive to relatives, partners, mental health workers, neighbours and church members than those in 20–39 years of age brackets (*ibid*).

It has been also observed across the fellowships and associations covered in the study that PLHIV with lower level education constitute the majority of the membership. Informants said PLHIV with higher level of education tend not to disclose their status, but they adhere better to ART as they also have the capacity to access other resources such as the internet, and inform themselves.

According to informants from Nur PLHIV Association, there has been a strong taboo that says “Muslims do not contract HIV/AIDS”, and this has made it challenging in particular for Muslim PLHIV associations to partner with mosque leaders in the fight against HIV and AIDS-related stigma and discrimination. Muslim informants stated that there was distress and loneliness among Muslim PLHIV for long period of time as they are unable to get the needed social support within their religious communities.

According to informants, there is still a challenge in speaking about HIV in mosques. Nur Muslims Association has mobilized many of its members during the one time opportunity it has got to speak on HIV at one mosque in Addis Ababa. That implies the need to sensitize mosque leadership on positive living, as only when they are convinced that PLHIV Imams and others can use prayer gatherings to convey messages on HIV and AIDS.

Though it is difficult to assert from the findings of the case studies that social support groups such as religious fellowships have directly contributed to increase in ART adherence, they have indeed played a key role in promoting positive living among PLHIV followers, which is one key factor in ART adherence. Before they join the associations, the life of many PLHIV was under question let alone their adherence to ART.

Informants underlined the support and the counselling they have got from their fellowship and church/mosque leadership helped them to adhere to ART. They also agreed that enrolment in ART helped them to defeat self-stigma as it gives them healthy physical attributes, and raised their confidence to live a normal life within their community.

Informants from Tsion Mengedegnoch PLHIV Association mentioned that ART adherence has increased and drop out decreased among members as they watch over and encourage each other to adhere to drug schedules. Almost half of the members are also enrolled in ART after they joined the association.

4.5. Conclusions and Recommendations

As reported in the case study, HIV-positive religious leaders have the capacity to create enabling environment for disclosure as HIV-positive

believers tend to confide in them without fear of being viewed as promiscuous. The support structures of religious fellowships and associations are also found to be valuable to improve the spiritual and emotional well-being of PLHIV, which directly influences their ability to fight stigma and adhere to ART.

Religious leaders are highly respected in any society; so, the testimony they give that they are HIV positive promotes voluntary counselling and testing. There is also almost a unanimous belief among informants that HIV-related stigma will decrease in religious communities if HIV-positive religious leaders disclose their status and if they teach and advocate holding on to their offices.

It appears that organizing HIV-positive religious leaders as an independent institution is a pragmatic approach at this stage as it gives them institutional support until enabling conditions are in place within their respective religious institutions. Once the right environment is created within their respective religious institutions, efforts should be made to integrate them back to their institutions, and enable them to take a leading role in the PLHIV fellowships within the religious institutions. They will be instrumental in creating the support environment within church and mosque structures for PLHIV.

It is recommended that advocacy and awareness raising works should target senior religious leaders and make use of documentation of the various ways religious leaders and believers can be exposed to HIV. There were also suggestions from some key informants that ETNERELA+ should aggressively sensitize and mobilize local faith communities, and, in such a way, create enabling environment for its operation.

The noted variability in the ordination and conception of a religious leader especially among the major religious groups signifies that ETNERELA+ cannot follow a homogenous approach across all faith groups, and it should rather pilot contextual projects in PLHIV fellowships of different religious congregations. It would be necessary that each fellowship may follow its own approach in involving senior religious leaders in its operations.

If equipped, empowered and engaged, religious leaders, especially those living with and those personally affected by HIV and AIDS have the personal experience and the potential to make an impactful contribution in ending HIV and AIDS-related ignorance, fear and prejudice and promoting social values and policies that enhance prevention, care and treatment.

As much of the HIV and AIDS-related stigma is quite often due to the religious and societal association of HIV and AIDS with sexual immorality, irresponsibility, impurity and looseness, religious leaders especially those living with HIV and AIDS are uniquely placed to break this negative and inaccurate mentality. Sex and sexuality issues should be vigorously addressed at church and mosque level. Theological reflection is needed on

these issues and FBOs should be challenged to create openness on the subject.

The National Strategy (2009) on referral and linkage emphasized the role of PLHIV alongside Health Extension Workers as a support group and adherence supporters. The role of PLHIV fellowships within religious institutions in particular also need to be given due emphasis as they give tremendous emotional and spiritual support to PLHIV to adhere to ART and defeat the challenges of self- and social-stigma. They are also strategically placed to reach people with old age, lower level of education, low economic status, and women PLHIV, who have low self-esteem, economic challenges, and who often find it difficult to disclose their status to their husbands and families.

Notes

1. According to MOH/FHAPCO (2007), there were 1.2 million PLHIV in Ethiopia in the year 2010. Currently, there are 397, 818 PLHIV who need ART drugs.
2. Rev. Ayano Chule personal experience in Ethiopia, “I will never die of ADIS...” positive living
3. The Ethiopian Strategic Plan for Multi-Sectoral HIV / AIDS Response (2004–2008) reported that the major mode of HIV transmission in Ethiopia is heterosexual—accounting for 87 per cent of all infections.
4. There are 29 PLHIV currently living in the church premises. Many of them come to the church from far places for Holy water and most of them choose to flee away from their communities after they are aware of their HIV status. Many groups of people take refuge in the church at different times of the year for personal spiritual reflection (*'Subae'*). Their numbers range from 160 to 560. The church is giving them spiritual education, and food as much as possible, but they still lack blankets, water, mattress and warm clothes. The church is discussing the situation with donors and individuals to mobilize resources to construct shops within the church as income generating activity for the PLHIV'.
5. *Ye Tsion Mengedegnoch* is an association of PLHIV established in 2007. It has 424 members and 80 per cent of its members are female. It is one of the associations which constitute the Network of Ethiopian Evangelical Believers HIV Positive Association's Desk (NEEBPAD). *Ye Tsion Mengedgnoch* has 18 support groups in churches across Addis Ababa. Each support group consists of 18–30 members. Each support group has also ART Adherence Promoters, who took training on ART Adherence Literacy. They get comprehensive teaching on issues such as balanced diet and stigma. They also pray for one another and encourage one another. The groups organize social gatherings such as coffee and tea ceremonies. This has contributed to increase their intimacy and they now consider themselves as one family.
6. Nur is Association of Ethiopian Muslims Living with HIV. It has now membership of 450 Muslim PLHIV from Addis Ababa and surrounding areas. One third of the members are women. The members were hopeless and many of them neither had

married nor had children when they joined the association. There are now nine married couples in the association who have children. The members gather together every two weeks for spiritual reinforcement. Since its establishment four years ago, it has not given any financial or material support to its members. The members, however, said they highly value the benefit of the fellowship as it has given them the opportunity to share their challenges and experiences with their fellow PLHIV brothers and sisters, and it gives them emotional and spiritual strength and healing.

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CHAPTER FIVE

Determinants of Adherence to Antiretroviral Therapy Drugs in the Phase of Rapid Scale-up of Antiretroviral Treatment in sub-Saharan Africa: The Case of Ethiopia

Woinishet Asnake Sisay and Abiy Ayalew Alemayehu

Abstract

For ART to be effective, high level of adherence is required. In spite of this, there is limited available information on adherence to ART and its predictors in Ethiopia. This study examined adherence levels and explored factors associated with adherence among PLHA receiving ART in Ethiopia. Using cross-sectional study design, 508 HIV+ patients receiving ART were interviewed from 9 districts. A focus group discussion with 10 persons receiving ART was conducted and discussions with 12 key-informants working in ART clinic were employed. The median age of the respondents was 37. The data were analysed. It was found that 35 per cent of the respondents were on ART for more than 5 years, 47 per cent for 1 to 5 years, and 18 per cent for less than a year. Overall adherence level was 92 per cent of which 63 per cent (n=320) of them adhered to ARV therapy while 37 per cent (n=187) of them did not adhere to therapy based on reported number of missed doses. About 37 per cent had a treatment interruption for more than 7 days; 18 per cent shift interval of doses; and 36 per cent take pills without eating food for fasting purpose. Forgetting (31 per cent) was the most common reason for missing doses. Probability of adhering to doses was higher among individuals that have large family sizes, that are hospitalized, that are hospital users, that had been on ART for more than five years, that took lower number of pills per day, that do not use substances of abuse, and that live near treatment centre. Moreover, females and religious have higher probability of shifting drug schedule. The study also revealed that there are HIV patients that discontinue ART and resorted to using traditional medicine and Holly water. Individuals that have mobile phone, that do not use substance of abuse and that live near treatment centre have the highest adherence rate. Level of adherence was sub-optimal, 92 per cent based on self-reported method, but comparable to the level of adherence in other developing countries. Both missing doses and not observing the interval between doses were the forms of non-adherence. The study recommends that care and support provision should extend beyond antiretroviral drug prescription: it should include psychological support, food and shelter support, reimbursement of transport costs, and various manual skill trainings for those who are genuinely in need.

Keywords: Adherence, ART, ARV, HIV/AIDS, SSA, Ethiopia

5.1. Introduction

Investment in health areas makes it possible to change the nature of the non-curable HIV and AIDS into treatable through the introduction of antiretroviral therapy (ART). The advent of Highly Active Antiretroviral Therapy (HAART) has substantially changed the clinical course and management of HIV and AIDS, leading to comparable virologic and immunologic outcomes among HIV-infected patients in high- and low-income countries. However, medication discontinuation becomes a major problem. For example, in Ethiopia, more than a quarter of clients who started ART are not on treatment as of 2009 due to various reasons among which death and loose follow-up take the highest share (FHAPCO 2009). HAART discontinuation could give way to the emergence of drug-resistant strains of the virus and could negate much of the benefit sought by ART treatment. Another critical issue is that drug-resistant strains of the virus can be transmitted to others whereby the new infections turn resistant to treatment¹. As a result, adherence to treatment remains an important factor for effective management of the treatment.

Understanding the level of adherence and factors that affect adherence could assist policy makers to take corrective actions and to reduce the burden of chronic illness (WHO 2003). However, the available information on the determinants of adherence in Africa remains inconsistent and limited. The possible reasons could be the dynamic nature of adherence and different social, environmental and institutional setups. The other possible reason could be due to methods and measurements used in assessing. In addition, factors affecting level of adherence are less studied in SSA. Adherence is expected to be linked to a patient's belief and little is known on how personal belief affects adherence in SSA. Noting this gap, the study aims at first, identifying the levels of adherence; second, examining factors that determine adherence to the therapy; third, finding out factor that affect levels of adherence, and fourth, assessing the association among health institutions, health professionals and adherence to ARV therapy.

5.2. Methodology

This study was conducted in Addis Ababa, the capital city of Ethiopia. The target population was all HIV and AIDS patients and the study population was AIDS patients on ART attending health institutions in Addis Ababa. Primary data was collected by interviewing study participants, key informants (health care providers) and by conducting focus group discussion. Sample size of nearly to 500 was computed using one-sample population formula by assuming adherence prevalence rate of 50 per cent with 5 per cent marginal error and 95 per cent confidence interval and 30 per cent non-response rate. Therefore, the study sample targeted 510 patients who have been on ARV for a minimum of one month, greater than 18 years old, able to give their consent for participation and not seriously sick. We have selected 3 sub-cities: Lideta, Kirkos and Bole considering variation in economic condition as a representative of 10 sub-cities in Addis Ababa. Nine woredas

(districts) were selected from the 3 sub-cities using simple random sampling techniques. Most individuals living with HIV and AIDS are members of support centres. These are associations that provide supports like capacity building, counselling and training to people living with HIV and AIDS. The personal profile and address of individuals under ARV treatment is found from the support centres and this information has been used to find potential respondents. The 510 individuals living with HIV and AIDS were selected by means of systematic random sampling technique using the name list from the support centres. They were selected to fill a questionnaire having 36 closed-ended questions. The questionnaire was translated into Amharic and pre-tested before it was used for the final data collection process. Coordinators from support group were assigned to interview, coordinate and control the process. Conducting the interview by a coordinator who is also HIV positive has an advantage to maintain the privacy of participants and to encourage participants to respond openly.

The assessment also involved a focus group discussion that was conducted to get in-depth understanding of the factors behind the estimated results and to fill the limitation of the quantitative data analysis method. Besides, 72 studies (35 qualitative) conducted in developed nations and 12 studies (two qualitative) conducted in developing nations were systematically reviewed. The results of the review showed the presence of a tremendous paucity of qualitative research in developing countries (Mills *et al.* 2006). The meta-analysis by Mills and colleagues indicated that many barriers to adherence could better be addressed through direct discussion with patients and suggested the superiority of qualitative studies in identifying patient-important barriers and facilitators of ART adherence (*ibid.*). Mindful of this suggestion, the focus group discussion for the present study was conducted in a place where the participants would feel free and could express their feelings without hesitation. Methods of the discussion and profile of the 10 focus group participants are attached as Annex 2. In addition, data has been collected from key informants. Twelve health professionals from health institutions in Addis Ababa and that are working on ARV treatment were asked to answer a series of questions that mainly focused on patient-provider relationships and health facility. The 508 records were entered and analyzed using STATA version 11; 2 records were excluded for incompleteness. The study specifies two empirical models. The first model empirically examined the characteristics of an individual who is adhering to ARV therapy and the second model analyzed factors that determine the rate of adherence to ART. Accordingly, the basic econometric equation of the study is specified as follows:

$$y_i = \beta_1 + \varphi \sum ED_i + \phi \sum PS_i + \gamma \sum MD + \alpha \sum PD + \eta \sum x_i + \varepsilon_i$$

Where, y_i is outcome variables related to i^{th} patient's adherence to antiretroviral therapy. In the first model, this key variable (y_i) is specified as a dummy variable for adherence status of an individual (=1 if adhered, =0 otherwise). Two key dependent variables were used separately to examine

determinants of adherence to ART. The first one is a dummy variable showing if an individual adhered or not on a weekly basis measuring adherence based on the number of prescribed pills taken. The second one is a dummy variable showing if individuals were maintaining the interval between doses. As explained, moving the time of pills can be considered as non-adherence.

In the second model, the dependent variable was measured as a continuous variable for the rate of self-reported adherence on the preceding week. The outcome variables of the studies were regressed across a vector of factors that related to the socio-economic and demographic factors (ED), psychosocial factors (PS), medication factors (MD), patient-provider relationship and disease characteristics (PD) and other important factors like location. Finally, ε_i is error term and β_1 , ϕ 's, φ 's, γ 's, α 's, and η 's are coefficients to be estimated. Noting the binary nature of the dependent variable in the first case, the study used logistic regression model to estimate the probability of adherence to ARV for patients with specific conditions and circumstances. On the other hand, the rate of adherence was estimated using ordinary least square (OLS) method. We had controlled for many important factors that could explain variations in adherence to ARV. However, it should be noted that there could still be potential bias from unobservable factors in the error term which may have correlation with the explanatory variable controlled in the model and which may affect the dependent variables. Unfortunately, the cross-sectional nature of the data could not help us to address such endogeneity issue substantially. The availability of qualitative information in this study is quite important in such case in order to understand the factors determining adherence and to reduce estimation bias. Finally, regarding ethical consideration, permission to carry out the research study was sought from the support group. Informed consent was sought from all the study participants. Confidentiality and privacy were fully guaranteed through the data collection process.

5.3. Literature Review

HIV and AIDS continues to be one of the main causes of morbidity and mortality throughout the world, especially in lower income countries. UNAIDS estimates that there are 33.4 million people in the world living with HIV, with 2.7 million new infections and 2 million AIDS-related deaths (UNAIDS 2010 and WHO 2009). Sub-Saharan Africa bears an inordinate share of the global HIV burden. About 22 million HIV-infected people are living in SSA countries. Currently, there are 1.2 million people living with HIV and more than 800,000 orphans in Ethiopia with significant health, economic and social impacts due to HIV/AIDS. Universal efforts have been implemented towards fighting HIV/AIDS, for example, through targeting 80 per cent of the population in need to access ARV treatment by 2010. Strong evidence of progress towards achieving this target has been registered; some countries like Botswana and Rwanda from Africa already attained the target; countries, partners and communities

succeeded in scaling up access to HIV prevention, treatment and care in 2009 (WHO 2010). SSA had the greatest increase in the absolute number of people receiving ARV treatment in 2009, from 2,950,000 in December 2008 to 3,911,000 a year later (WHO 2010). The goal of HAART is to suppress viral load in the blood to undetectable level and adherence to treatment is critical to get full benefits of HARRT. Further to this, recent results from United States National Institute of Health shows that adherence to an effective antiretroviral therapy regimen is found to act as a preventive mechanism to reduce the risk of transmitting the virus to their uninfected sexual partner by 96 per cent (<http://www.unaids.org> accessed 23/05/2011).

Adherence to ARV therapy in this paper is conceptualized as the patients' ability to stick to or be devoted to ARV therapy that involves taking medications in the correct amount, at the correct time, and in the way they are prescribed (FHAPCO 2009).

According to WHO, accurate assessment of adherence to ARV therapy is required for effectiveness of the therapy and efficient treatment planning (WHO 2003). There are various methods used to measure ART adherence rate. According to Steel, Nwokike and Joshi (2007), the first method used to measure ART is direct observation. This method requires health care professionals to observe and report the level of adherence. It is costly, erodes the patients' privacy and is difficult to implement for a lifelong treatment, especially among patients that are not hospitalized. The second method is called therapeutic drug monitoring which is done by measuring the level of drug in the blood. Also this method is expensive and difficult to implement in resource-limited settings. There is also an electronic tools fitted to pill containers which records the removal of the cap. It measures the number of pills removed from the package. This method forced to consider the removal of pills as pills taken and also this one is difficult to apply in resource-limited settings. Pharmacy records, self-report, pill count, visual analogue scale and pill identification test are commonly used. Further to their applicability, each method has its own pros and cons that are stated by many scholars and there is no single measurement strategy deemed optimal (WHO 2003).

In resource-limited settings, self-reported measure of adherence is found to be the most feasible method for assessing ART (Sethi *et al.* 2003). This method is also found to be useful in clinical management of individual patients and in monitoring adherence (Ross-Degnan 2010). In many settings, it agrees well with actual medication intake and is found to correlate with other objective measures of adherence like viral load (Simoni *et al.* 2006). In addition, this method is expected to reinforce the central role which individuals under therapy themselves have in managing their adherence (Poppa *et al.* 2004). A review of 36 studies indicated that self-report appeared to be the most informative measure of adherence (Henry 2011). Hence, in this study, patient self-report method was employed to

measure adherence rate. Adherence to therapy was then calculated using the formula of the number of doses taken divided by the number prescribed over seven days (Paterson *et al.* 2000). A study estimated that the required level of adherence for sustained virological suppression is 95 per cent (Steel, Nwokike and Joshi 2007). A 95 per cent level of adherence is also considered as good level of adherence according to Ethiopian ART guidelines. Following Steel, Nwokike and Joshi (2007) and Ethiopian ART guidelines (FHAPCO 2007), an individual under study was considered as having adhered to ARV therapy if the adherence level is 95 per cent or greater.

The available data on adherence to ART in Africa remain limited and heterogeneous (Hegazi *et al.* 2010). In Ethiopia, it was mean adherence level has been reported as 74.2 per cent by Markos, Worku and Davey (2008), 94.3 per cent by Amberbir *et al.* (2008) and 87 per cent by Tessema *et al.* (2010) different levels of adherence are also registered in countries from other continents. For example, it was found to be 84 per cent in Nepal (Bam *et al.* 2011), 93 per cent in India (Sarna *et al.* 2008). The possible reasons for this variation could be due to the dynamic nature of adherence. That is, the levels of adherence could change over time even though the level is measured correctly. Another reason for the variation could be due to difference in setup, method of measurements, or addressing only specific situations without controlling possible factors that affect level of adherence. For example, there are studies that assessed adherence level focusing only on specific health institutions which might limit controlling the effect of health institutions on ARV.

Earlier studies in SSA mostly focused on pill counts by using different ways ranging from self-report to electronic supported methods. However, adherence level could not only be measured by focusing only on proportion of dose taken. The forms of non-adherence could be explained as missing one or more of the prescribed doses, not observing instructions regarding dietary or fluid intake, or not taking medication at the prescribed time interval. The person under therapy may simply fail to follow the prescription, may incorrectly time the medication, might take the wrong dose, and/or may self-adjust the regimen (WHO 2003). This suggests that attention should be given to dose timing as it was given to the number of pills taken. But the contribution of dose timing is less studied (WHO 2003). Taking this into consideration, in this study, failure to maintain dose interval has been incorporated in assessing adherence level using self-report method.

Factors that influence adherence are categorized as patient factors, treatment regimen, disease characteristics, patient-provider relationship and clinical setting (WHO 2003, cited in Horizons/Population Council 2010). Similarly, Steel, Nwokike and Joshi (2007) explained that patient behaviour, health system, socioeconomic factors, disease-related and drug-related factors affected adherence. In this study, factors that affect

adherence to ARV therapy referred from the recommendation of WHO (2003) and Steel, Nwokike and Joshi (2007) because of their applicability in the resource limited settings are considered. Socio-economic and socio-demographic factors constitute a number of factors such as social and economic factors; demographic characteristics (age, sex, ethnicity, marital status, employment, income, education and literacy); psychosocial factors (drug or alcohol use, degree of social support, social stability, depression, patient knowledge on medication, belief and confidence in ART); medication factors (pill burden, doses per day, duration of treatment, side-effect); patient-provider relationships and disease characteristics.

As indicated in WHO (2006), the success of any adherence strategy mainly depends on positive patient-provider interactions. The health care providers working at ART clinic should be efficient in giving education to patients before initiation of ART; an assessment of their understanding of the therapy and their readiness for treatment is thus important. Adherence counselling includes giving basic information on HIV and its manifestations, the benefits and side-effects of ARV medications, how the medications should be taken and the importance of not missing any doses. After therapy has begun, it is essential to continue with support for adherence. This should involve adherence assessments during every treatment centre visit, the need to emphasize adherence principles to the patient, and continuous involvement of relatives, friends and/or community support personnel. At the programmatic level, ensuring adequate stocks and storage of ARVs and is vital to provide necessary resources for culturally appropriate adherence counselling. Privacy should be respected during consultations, at the pharmacy where they wait for drugs and at the laboratory where they test and wait for results (WHO 2006).

In Ethiopian setup, nurse counsellors and ART physicians are expected to see patients who receive antiretroviral treatment at each clinic visit, often at an interval of 4–6 weeks. The longest appointment is every 3 months. Patients are asked questions regarding their knowledge about their drug regimens, drug-taking behaviours, and the barriers to adherence. They also receive counselling on the issues raised. The health facilities register and provide free ART services for those who fulfil the standard eligibility criteria to start ART at a separate unit for the ART programme. There is a well-organized intra-facility referral system to send all diagnosed HIV-positive individuals from Voluntary Counselling and Testing (VCT), Prevention of Mother-to-Child Transmission (PMTCT) or inpatient services to the ART centre for registration. Most AIDS cases are being treated on ambulatory basis, with the exception of a few patients who require admission for medical reasons. Health officers are responsible to provide care in most health centres whereas physicians are the ones who deliver services to patients at the hospital settings. Those patients with either difficult diagnosis or serious illnesses requiring further investigation are transferred from health centres to hospital for better management and follow up.

In general, a stronger commitment and coordinated action from health professionals, researchers, health planners and policy-makers are needed for the success of ARV therapy (WHO 2003).

5.4. Results and Discussion

5.4.1. Background Characteristics

About 58 per cent (n=295) of patients were women and average age was 27 years (SD=10.4). The respondents' age ranged from 18 to 90 years with the peak age group from 25 to 45 years. Forty one per cent of the study participants were engaged in private activities, about 26 per cent were government employed, and 3 per cent were students. Fifteen per cent of them never started formal education and majority of them (41 per cent) enrolled in primary school. About 44 per cent of the respondents were married, 16 per cent were widowed, 24 per cent were single, and 16 per cent were divorced. Thirty five per cent (n=179) were more than 5 years on ART, 47 per cent of them are between 1 to 5 years on ARV treatment, and 18 per cent were on ART for less than one year. Monthly mean income is ETB507 (US\$30) with 95 per cent CI between 461 and 552. Individuals that fall under the upper last income quintile have a mean monthly income of ETB1348 whereas those under the median quintile have a mean monthly income of ETB390. Mean (95 per cent CI) CD4 cell count at the start of ART was 138 (130–145) and the current mean (95 per cent CI) CD4 count was 386 (371–400). The demographic and other HIV-related behaviour and characteristics of individuals under study are presented in Table 1.

Table 1- Summary of variables

Variable Name	Type	Frequency	Percentage
Religion	Orthodox	318	62.6
	Muslim	97	19.09
	Catholic	22	4.33
	Protestant	69	13.58
Sub city	Others	2	0.39
	Lideta	147	28.94
	Kirkos	147	28.94
	Bole	214	42.13
Marital Status	Married	223	43.9
	Unmarried	121	23.82
	Divorced	81	15.94
Sex	Widowed	82	16.14
	Female	295	58.07
	Male	213	41.93
Employment	Government employee	130	25.59
	Private employee	210	41.34
	Unemployed	98	19.29
	Others	54	10.63

	Student	16	3.15		
	Not in formal education	78	15.35		
Education	Primary	206	40.55		
	Secondary	166	32.68		
	Higher level	58	11.42		
	More than 5	179	35.24		
Starting Date of ART	1 to 5 years	236	46.46		
	Less than 1 year	93	18.31		
	Clinic	87	17.13		
Type of Health Service	Health centre	235	46.26		
	Hospital	167	32.87		
	Others	19	3.75		
	Near	98	19.29		
Distance to ART centre	Medium	244	48.03		
	Far	166	32.68		
	Chat	56	11.02		
	Cigarette	30	5.91		
Substance of abuse	Alcohol	52	10.24		
	Nothing	370	72.83		
	Mean	SD	min	max	
Age	37.09055	10.42696	18	90	
Income	506.6102	21.13	0	4500	
household size	3.683071	1.772001	1	11	
Having mobile Phone	.7165354	.4511242	0	1	

SOURCE: Authors Computation Based on the Data Collected

5.4.2. Level of Adherence to ARV Therapy

Following Steel, Nwokike and Joshi (2007), we categorized an individual as having adhered to ARV therapy if the adherence level of that person is greater than 95 per cent. Missing one dose of ARV drugs in a week translates to only 92.8 per cent adherence, which is sub optimal level (Paterson *et al.* 2000). Accordingly, from the 508 individuals that participated in the survey, 63 per cent (n=320) of them are categorized as having adhered to ARV therapy while 37 per cent (n=187) of them are categorized as not having adhered to therapy. Individuals under study were grouped into five to determine their adherence level based on the number of pills missed (see Table2). Level of adherence was 100 per cent for those who never missed a dose (n=320), 87 per cent for those who missed from 1 to 3 doses per week (n=136), 67 per cent for those who missed from 4 to 7 doses per week (n=38), and 38 per cent for those who missed from 8 to 12 doses (n=8). Overall adherence level was found to be 92 per cent.

Table 2. Level of adherence to ART based on number of pills taken

Group	No. of Patients	Pills missed per week	Adherence level (%)
A	320	0	100
B	136	missed 1 to 3	87
C	38	missed 4 to 7	67
D	8	missed 8 to 12	38
E	6	all doses	0
Total	508		

SOURCE: Authors computation based on the data from the respondents

Adherence was also assessed qualitatively using a focus group discussion. A remark by a 31 year old respondent could be indicative of the overall trend: “Most of us [people living with HIV/AIDS]” said women, “were reluctant to start the ART drug. That is because we believe that once we started taking it, any interruption could result in death”. This perception, which seems to be shared by most of the ART users under study, may have contributed for the sub-optimal level of adherence. However, this observation is solely based on the number of pills taken as the measure of adherence.

Secondly, we assessed adherence level by observing the interval between doses in relation with religious issues. In Ethiopia, where religion has tremendous influence on life style in a society, it is expected that the influence of religion, specifically fasting, has a possibility to affect meeting time requirements of ARV therapy. We tried to capture this effect by analysing the fasting behaviour of individuals under study. Hence, respondents were asked about their experiences during fasting seasons. We found that a significant number of them were complying with religious requirements by shifting their drug schedule, which led to dose time error.

The most dominant religions in Ethiopia are Orthodox Tewahido, Muslim, Catholic and Protestant. Orthodox Tewahido followers, who exercise fasting, abstain from food and drink at least up to noon and do not consume animal products during fasting days. Muslims fast up to dusk without taking any food or drink. Under Protestant religion, though the date and length of fasting period varies across individual, it was found that those fasting abstain from all types of foods and drinks. Although there is a confirmation from religious authorities that individuals under therapy are not obliged to fast, the findings show that a significant number of individuals under study are fasting either by taking the pills without food or by shifting the time to take the prescribed pills. It was found that 18 per cent (n=93) of the individuals were shifting drug schedule to evening doses while fasting. Out of the individuals who indicated their shifting the prescribed time, 59 per cent of them are Orthodox, 28 per cent Muslim, 10 per cent Protestant and 3 per cent Catholic religion followers. Also results

of the focus group discussion revealed that individuals under study were trying to take the prescribed pills; however, the effectiveness of the drug is under question as most of them are not fulfilling time requirements. Faith-based organizations and community leaders are involved in HIV and AIDS case management in Ethiopia (FHAPCO 2009). It is to be noted that people living with HIV and AIDS need not only medical services but also have social, psychological, legal, and economic needs which can serve as psychosocial indicators for adherence to treatment and care (*Ibid.*). Hence, effective management of treatment calls for a better coordination among health management unit, faith-based organizations and community leaders such as religious and traditional leaders.

5.4.3. Reasons for Non-adherence

This section summarizes the response provided by participants of the survey as a reason for missing prescribed pills. Forgetfulness was the most common reason for missing medication in 31 per cent of the cases (see Table 3).

Table 3. Justification given by respondents for missing prescribed pills

Reason provided for missing pills	Percentage	Frequency
Forgetting	31.50	160
Side-effect	10.24	52
Feels discrimination	8.86	45
Taking alcohol	7.48	38
Feels ill	7.28	37
Food shortage	4.13	21
Feels depression	2.76	14
Religious	2.17	11
Pills out of stock	1.77	9
Feels healthy	1.38	7

SOURCE: Authors' computation based on survey data

This finding is consistent with similar studies such as Markos, Worku and Davey (2008), Weiser *et al.* (2003), and Sellier *et al.* (2006). Most of the focus group participants replied that they used mobile phones to remember the pill time and the statistics shows that 71 per cent of individuals under study have mobile phones. It is expected that disclosing HIV-positive status reduces the probability of forgetting to take pills. Our finding shows that HIV-positive status disclosure rate was as high as 75 per cent, but (53 per cent) of the respondents disclosed their status to their family members and close relatives only due to fear of stigma and discrimination. More specifically, we found that about 9 per cent of the respondents missed the prescribed pills for fear of stigma and discrimination. This finding is in line with earlier findings such as Assefa *et al.* (2010), Weiser *et al.* (2003), Sellier *et al.* (2006) and Tessema *et al.* (2010). Similarly, participants of the

focus group discussion confirmed that they disclosed their HIV status to their close relatives, close friends or family members only. They explained that their limited disclosure has made it difficult for them to follow their dose as prescribed. Most of them reported that they had hidden their status from their own housemaids and landlords for fear that these people might stigmatise or discriminate against them once they discover their HIV-positive status. What a 30 year old female has observed in one of the FGDs conducted is quite telling:

One day, I forgot to hide the drugs in the locker after receiving a 3 months dose from the health centre. The housemaid identified this. She immediately informed the landlord about my sero-status. When I returned home, all were staring at me. I immediately recognized that they had identified about my HIV status. I was depressed and my health situation totally got worsened. They even started urging me to leave the house. I then changed to a new location.

Contrary to that, a 37 year old cheerful female had this to say, “I disclosed my HIV status to everybody; I even take drugs in the presence of others and I have benefited a lot from that. They even remind me to take my pill on time.”

A thorough discussion with other respondents, however, revealed that most of them do not feel comfortable disclosing their sero-status to the public at large. Disclosing even to friends and relatives, they noted, could have a negative repercussion on their day-to-day activities as stigma and discrimination still exist within the society. More needs to be done on training and counselling services. Key informants stressed on the need for pre-counselling, counselling and handing out written information to patients, as well as to the public at large.

The findings also show that a side-effect of the treatment is one of the reasons for missing the prescribed doses. It was also found that patients missed doses when they become ill and unable to take the drug. Similar results were found by Tessema *et al.* (2010). This is also in line with what was observed during the focus group discussion. A 31 years old female participant explained “these medicines make me feel exhausted especially when I shift my schedule to evening during the fasting period”. In relation to this, another male participant, aged 36, said that he would miss his dose when taking the pills results in dizziness and nausea.

Other reasons given for missing doses include sharing pills with other PLWHA, losing pills, and being away from home.

Respondents were also asked about measures they take when pill side-effects aggravate. While 72 per cent of them said that they would visit health institutions, 23 per cent reported that they keep on taking the pills without reporting to a health professional. On the other hand, a very small proportion (5 per cent) reported that they had stopped ART.

Shortage of food and uses of substance of abuse were also reasons cited for missing prescribed pills. Respondents explained shortage of food as the most prevalent problem among patients which highly affects proper adherence. A remark by a 28 years old male patient is reflective of that trend. "If I have not had meal, I can hardly take this medicine; nutrition is very important to withstand these drugs". Key-informants suggested the usefulness of linking patients at the hospital to the community or community-based organizations so that they can receive the needed support which includes food, reimbursement of transport costs, as well as clothing and shelter. Depression was also mentioned as a reason for missing pill. In this regard, a 32 years old female respondent said: "Sometimes I feel worthless because I am HIV-positive; that is why I do not take the medications properly."

Fear of stigma, forgetfulness, high pill burden, concomitant substance abuse, and drug side-effects were also indicated as major barriers of adherence by key informants. On the other hand, key informants noted that work load of health professionals due to high staff turnover and lack of motivation of health professionals were also among reasons for non-adherence.

We finally asked individuals under study to whom they give credit for their current level of adherence (more than one response was given). While 38 per cent of the respondents expressed their indebtedness to health institutions, a slightly lesser proportion (31 per cent) of them gave credits to their family member. A much lesser proportion, but equal percentage of respondents (8 per cent each), owe their adherence to friends and support groups. Interestingly, about 67 per cent (n=340) of them replied that adherence is more of personal commitment. That is quite encouraging in the sense that presence of such confidence among persons under therapy, in resource-limited settings, is a motivating factor for all who work on HIV treatment. As Poppa *et al.* (2004) indicated the role of patients themselves is fundamental in maintaining high adherence level.

5. 4.4 Determinants of Adherence to ARV Therapy

This section explains determinants of adherence to ARV therapy. We employed two models using logistic regression and the marginal effects of selected independent variables on dependent variables (see Table 4 columns 2 and 3).

Table 4. Summary of quantitative model estimations

Dependent Variables	Adherence to pill regimen dummy (Logit)	Adherence to the time and food requirement Dummy (Logit)	Rate of weekly adherence
Sex	0.0268 (0.0599)	0.119** (0.0580)	-0.00943 (0.0154)
Age	0.000864 (0.00300)	-0.00425 (0.00289)	0.000336 (0.000869)
Income	9.63e-05 (8.35e-05)	-3.27e-05 (7.40e-05)	-1.11e-06 (1.89e-05)
Radio	-0.0388 (0.0593)	-0.0172 (0.0602)	-0.0274* (0.0162)
TV	-0.00632 (0.0621)	0.195*** (0.0594)	0.0273* (0.0160)
Mobile phone	0.100 (0.0663)	0.00694 (0.0644)	0.0381** (0.0177)
Family size	0.0363** (0.0162)	-0.0209 (0.0150)	0.000640 (0.00490)
Disclosed HIV	0.0263 (0.0587)	-0.0384 (0.0607)	-0.0104 (0.0150)
Hospital Admitted	0.111** (0.0525)	0.0371 (0.0572)	0.0232 (0.0149)
Lideta	0.207*** (0.0576)	-0.0838 (0.0740)	-0.0197 (0.0202)
Kirkos	0.273*** (0.0552)	-0.0604 (0.0721)	0.0218 (0.0196)
Orthodox	0.0225 (0.375)	-0.998*** (0.00158)	-0.0558 (0.0745)
Muslim	-0.0862 (0.399)	-0.964*** (0.00749)	-0.0575 (0.0716)
Catholic	0.0809 (0.344)	-0.653*** (0.0239)	-0.0689 (0.0748)
Protestant	0.0626 (0.347)	-0.891*** (0.0163)	-0.0554 (0.0753)
Government employed	-0.101 (0.0918)	-0.0527 (0.0861)	-0.0391 (0.0253)
Private employed	-0.0509 (0.0760)	-0.0200 (0.0723)	-0.0188 (0.0204)
Student	-0.164 (0.109)	0.0681 (0.104)	-0.00657 (0.0195)
Other type of works	-0.231 (0.209)	0.00825 (0.174)	-0.0206 (0.0320)
Primary education	-0.0387 (0.0774)	-0.0255 (0.0816)	-0.0183 (0.0225)
Secondary education	0.0224 (0.0882)	-0.0375 (0.0939)	0.00115 (0.0278)
Higher education	0.0151 (0.129)	-0.0743 (0.142)	0.0136 (0.0384)

Dependent Variables	Adherence to pill regimen dummy (Logit)	Adherence to the time and food requirement Dummy (Logit)	Rate of weekly adherence
Married	0.0293 (0.0736)	-0.0420 (0.0757)	0.0220 (0.0172)
Divorced	-0.00769 (0.0888)	-0.142* (0.0838)	-0.00102 (0.0293)
Widowed	-0.0983 (0.0975)	-0.0460 (0.0898)	-0.0275 (0.0274)
Clinic	-0.207** (0.0942)	-0.122 (0.0762)	-0.0119 (0.0165)
Health centre	-0.0885 (0.0596)	-0.0526 (0.0612)	-0.0202 (0.0157)
Other centre	-0.104 (0.157)	-0.164 (0.139)	0.00354 (0.0328)
Five year On ART	-0.227*** (0.0837)	-0.0327 (0.0794)	-0.0367 (0.0259)
FourTotoTwoOnART	-0.0831 (0.0740)	-0.0222 (0.0723)	0.000686 (0.0218)
Twopill	-0.378*** (0.0836)	0.000919 (0.172)	-0.0435 (0.0394)
Threepill	-0.452** (0.230)	-0.197 (0.166)	-0.000146 (0.0451)
One day council	-0.0843 (0.0943)	-0.138 (0.0902)	-0.0209 (0.0227)
One-two week council	-0.0502 (0.0873)	-0.0742 (0.0845)	-0.000571 (0.0183)
Chat user	-0.342*** (0.0950)	-0.0787 (0.0870)	-0.0894*** (0.0282)
Cigarette user	-0.307*** (0.119)	-0.0777 (0.115)	-0.0779* (0.0442)
Alcohol user	-0.382*** (0.0923)	-0.0210 (0.0862)	-0.0720*** (0.0253)
Near Distance	0.142** (0.0583)	0.116 (0.0771)	0.0304* (0.0182)
Medium Distance	0.197*** (0.0616)	0.0118 (0.0623)	0.0394*** (0.0143)
Constant			1.029*** (0.105)
Observations	508	508	508
R-squared			0.158

Robust standard errors in parentheses *** p<0.01, ** p<0.05, * p<0.1

5.4.4.1. Factors that Determine Adherence to the Prescribed Doses

Some earlier studies found that demographic characteristics significantly affect adherence to ART (Hegazi *et al.* 2010; Orrell *et al.* 2003; Bose, Varanasi and Mo 2009). However, some found no systematic association between these characteristics and adherence. For example, the average retention rate in low and middle income countries in 2009 was found to be approximately the same among men and women (WHO 2010). Our finding also shows that demographic characteristics were not statistically significant to determine the characteristics of individuals to take pills regularly. It is to be noted that adherence rates vary not just between individuals but within the same individual over time (Carrieri, Cailleton, and le Moing 2002).

The finding also shows that family size has positive and statistically significant effect on increasing the probability of the patient to take the prescribed pills. Family size might reflect the potential help the individual patient has in order to take the prescribed pills and it might also show the magnitude of social support that the individual patient has. Hence, the result could be interpreted as large family size provides better social support, which is expected to lead to good adherence to ART. The result shows that 75 per cent of the informants disclosed their HIV-positive status, and among them, 53 per cent disclosed their status to their family member. This could be an evidence for considering family members as a possible social support to improve adherence, especially if the individual under therapy disclosed the HIV status. There is substantial evidence that social support can improve adherence to therapy (WHO 2003). The experience of a 33 year old female participant is supportive of this. "I have large family size and disclosed my status to all family members. All of them play major roles in reminding me to take my pill on time. Even my youngest son uses some gestures to remind me the time of pill when there are visitors at home." On the other hand, family size could also be a potential breach to privacy to sustain stigma. It is advisable to strengthen the health education in the community to eradicate stigma and discrimination.

We have included a dummy variable showing prior history of hospitalization before starting ART in order to find out the association between recognizing the severity of illness and adherence. This variable was found to be positive and highly statistically significant. It could be interpreted as those who have prior history of hospitalization had a higher probability of taking the prescribed pills than their counterparts had. As explained, the perception of the severity of the illness might motivate patients to take the prescribed pills. But, it is worth noting that findings contrary to this are reported in some studies (Sarna *et al.* 2008).

We also included a variable showing the type of treatment institutions that the study participants were attending to find out if level of adherence has association with health institution set up. We included a dummy variable

showing if the individual had follow-up at hospital, clinic, health centre or other institutions. We found a significant difference only among individuals that had follow-up at hospital and clinic, showing that individuals treated in hospital have higher adherence rate.

Respondents were also asked about the quality of services in health facilities. The majority (79 per cent) of them had a positive impression: While 41 per cent rated the services as excellent, 38 per cent indicated that it was very good. Whereas, 21 per cent of the respondents noted that the services required some improvement. This finding, should, however, be interpreted with caution for it contradicts what has observed during the focus group discussion. In the FGDs conducted, most of the participants they were not happy with the service provided by health institutions. In a remark that might be regarded as representative of the FGD participants, a 35 years old female participant complains, "Most of the time, the care providers do not give us warmly welcome; instead they rush to prescribing the drugs the moment we are in the ART clinic. Most of the physicians working in the ART clinics are not motivated enough to provide optimal clinical care." That is contrary to a key informant health professional's observation about the quality of service expected of health facilities. According to the key informant,

Regular supportive medical supervision is recommended as a way of improving the quality of health care services. Facilities should reinforce skills of staff to monitor adherence and to improve defaulter tracing. Provider motivation through performance-based recognition and financial incentives and an increase in the number of health care staff are also suggested as an important factor in adherence promotion for ART. Each health facility should have a comprehensive clinic with fully equipped laboratory and pharmacy to provide free treatment services. Documentation should be computerized to reduce paper work so that professionals might have ample time for discussion with the patients.

A meta-analysis by Mills *et al.* (2006) that reviewed 31 studies from North America and 27 studies from SSA observed a relatively higher level of adherence in SSA than in Latin America. One of the possible reasons given was that in African studies patients during early therapy were included in the study and it was hypothesized that the relatively high level of adherence in SSA may decline when patients develop long-term adverse effects of the therapy and when treatment access expands in the region. We, therefore, included a variable showing duration of treatment on ART to find out if duration determines the characteristics of individuals on taking pills. Similarly, we found that the probability of missing pills is higher among those who are more than five years on ART as hypothesized by Mills *et al.* (2006). Adherence decreases over time as learned behaviours change over time and long-term adverse effects can lead to non-adherence (Steel, Nwokike and Joshi 2007).

To date, ARV is a lifelong therapy and it requires taking several doses per day, including restriction on food and fluid. Normally, patients prefer small number of doses per day and it is, therefore, expected that the number of doses taken inversely associates to the likelihood of adherence. Keeping that in mind, the present study has included a variable showing the number of pills per day that individuals are supposed to take in order to capture the association between number of pills and adherence. It was found that the probability of missing pills was lower among individuals that were taking one pill per day than among those taking two or three pills per day. Our findings is in agreement with that of the previous studies, such as Paterson *et al.*(2000); Sarna *et al.* (2008); Heyer and Ogunbanjo (2006); Mills *et al.* (2006); Orrell *et al.*(2003). Attention has to be given by policy makers and scientists to focus on reducing the number of doses taken per day to enhance adherence to therapy. In July 2010, UNAIDS and WHO launched Treatment 2.0 platform, which aims at accelerating access to more effective and less toxic drug combinations, reducing pill burden by developing ‘one pill a day’ (or less often) fixed-dose combinations (UNAIDS 2010). All the focus group participants agreed on the positive effect of a minimum number of pills per day on the level of adherence. They are eager to see the day that the treatment could be taken in the form of injection on a biannual or yearly basis.

We have also included a variable showing the effect of proximity to treatment centre on the level of adherence. Data was collected by a self-report measure of distance to treatment centre as near, medium and far. The logistic regression shows that distance to ART centre predicts the probability of adherence. Hence, those living near to a treatment centre have the highest probability of taking prescribed pills than those living far from a treatment centre. Similar results have been reported in Ethiopia in earlier studies (Markos, Worku and Davey 2008; Assefa *et al.* 2010). The key-informants also emphasized the positive effect of accessibility of the health institutions on patient’s capability to follow-up the therapy.

It was hypothesized that taking substance of abuse like ‘chat’, cigarette and alcohol reduces the probability of taking pills. We included three dummy variables showing if the study participants were taking substance of abuse. All the three variables were found to be highly statistically significant in determining the probability of missing the prescribed pills. Hence, those who are taking stimulating substances such as *chat*, cigarette and alcohol have higher probability of missing the prescribed pills than those who are not taking those substances. Earlier studies also found similar results (Heyer and Ogunbanjo 2006; Mills *et al.* 2006; and Bam *et al.* 2011).

5.4.4.2. Factors that Determine Adherence to Interval(s) between Doses

We also assessed the characteristics of individuals who failed to observe the interval between doses by quantitative research method. As explained, we captured this effect by analyzing the fasting behaviour of the study participants. One of the significant variables that was found to affect the

probability of maintaining intervals between doses while taking pills is sex. The finding shows that more males than females take pills without affecting dose interval. This shows that among the participants, as compared with their male counterparts, it was female patients who are found to be fasting more by shifting intervals between doses.

As expected, it is found that religious individuals have the highest probability of affecting intervals between doses. Moreover, the probability of failing to maintain intervals varies among religions. It was found that followers of Orthodox Tewahido have the highest probability of failing to meet interval between doses. The level of probability of failing to meet intervals between doses decreases from Muslims to Protestants and then to Catholics. So far, we haven't seen a research that incorporates such issues; however, in Ethiopia, Assefa *et al.* (2010) and Deribe *et al.* (2008) also found association between use of Holy water with poor adherence and poor retention. In addition, during the focus group discussion, we observed that there are HIV patients using traditional medicine and Holy water after discontinuing ART. A 28 year old male participant explained the situation as follows: "I remember one of my friends who had discontinued his medication for Holy water. His condition deteriorated much; as a result he resumed his medication and showed significant improvement."

5.4.5. Factors that Determine the Level of Adherence to ART

This section presents factors that determine the level of adherence to ART. The dependent variable under this model is a variable showing the level of self-reported adherence on the preceding week and the results are presented in Table 4 Column 3.

A variable showing availability of mobile phones was found to be statistically significant. This might explain that individuals that use mobile phone to remember the pill-taking time have had a higher rate of adherence than those who did not use mobile phones to that purpose. This may also explain a direct association between better access for communication and higher level of adherence. We also included a variable showing if the individual under study had information communication technologies such as radio and television set in order to capture the association of access to information to adherence and also to examine economic situation of an individual with adherence. It was found that individuals that had television have higher adherence rate than television have-nots. Again this might explain the positive association between better access to information and level of adherence. In addition, those who are not under the influence of substance of abuse (chat, alcohol and cigarette) have a greater adherence rate (Mills *et al.* 2006; Bam *et al.* 2011). Moreover, those that are living far from a treatment centre have also lower adherence rate— showing a positive association between better access to health institutions and higher adherence rate.

5.5. Conclusions

The study set out to establish the factors that influence adherence to antiretroviral therapy among HIV and AIDS patients. It revealed that both missing pills and failure to notice interval between doses were the forms of non-adherence in this particular study. The findings also indicated that 63 per cent of the participants adhered to ART, which could be described as sub optimal. Overall adherence level was found to be 92 per cent. Of which 100 per cent level of adherence was witnessed among those who never missed a dose (n=320); 87 per cent for those who missed from 1 to 3 doses per week (n=136); 67 per cent for those who missed from 4 to 7 doses per week (n=38); and 38 per cent for those who missed from 8 to 12 doses (n=8).

When assessing adherence level by observing the interval between doses among study participants, we found that 34 per cent (n=93) of them were shifting their drug schedule to evening doses for fasting. Moreover, female participants had a higher probability of shifting drug schedule for fasting. There are HIV patients who still use traditional medicine and Holly water after discontinuing ART.

Individuals that have relatively better social support, those who are not taking substance of abuse, those who have better access to treatment institutions, and those who use mobile phone to remember the time of pills have a higher probability of taking the prescribed pills. In addition, individuals who have prior history of hospitalization and feel the severity of the diseases are likely to be taking the pills regularly. Besides, the probability of taking the prescribed pills was found to diminish as duration on treatment increases. Lack of food support, stigma and discrimination, preference to traditional medicine, religious commitment like fasting profoundly contributed to non-adherence to ART. Antiretroviral regimen, that is number of drug regimens per day and drug side-effects influenced adherence to ART.

Individuals under therapy that have mobile phone and having a better communication/ information opportunity, those who are not taking substance of abuse and those living near the treatment centre have a higher adherence rate. Regarding belief and awareness of the study participants as to the efficacy of ARV treatment, the majority of the participants (94 per cent) had a positive attitude toward ART and they all approved ART for management of AIDS (Tables 5 and 6).

Table 5. Summary of responses on effect of ARV therapy

ART effects	Frequency	Percentage
ART makes me healthy	480	94.49
It improves my work attendance	443	87.20
It helps me to improve work performance	460	90.55
It helps me to gain weight	362	71.26
It doesn't have any effect on me	24	4.72
It deteriorates my health condition	8	2

SOURCE: Authors computation based on sample response

Table 6 - Perception of respondents on ARV therapy

Perception	Frequency	Percentage
ART heals HIV	95	18.70
It is good to be under therapy	343	67.52
The drugs should be taken hidden	230	45.28
ART should be taken lifelong	390	76.77

SOURCE: Authors computation based on sample response

Based on the descriptive analysis, forgetfulness was the most common reason for missing doses followed by fear of discrimination, drug side-effects, and lack of family and community support. Even if stigma was still high in the study area, respondents who revealed their HIV-status to close relatives and family members were supported during ARV treatment.

As a whole, the findings of the study show that patient-healthcare provider relationship was not at a level to maintain good level of adherence at least across all health institutions. Health care infrastructure and quality of relationship with health care providers determined whether patients adhered to ART or not. Patients lacked economic power to consistently meet their basic needs. Lack of motivation among health care providers due to workload or recognition; lack of capacity building and poor infrastructure made it difficult for health care providers to address the challenges of ART adherence.

Patients recommended that: the government should provide food and transport for those genuinely in need and provide income-generating activities for AIDS patients. They also requested the government to arrange HIV-related trainings for care and support providers to update their knowledge and to improve their communication skill. Furthermore, they also asked for stakeholders to make the treatment available in the form of injection at least on semi-annual basis.

Care and support provision should extend beyond Antiretroviral drug prescription to include psychological support, food and shelter support, reimbursement of transport costs and various manual skill trainings for those who are genuinely in need. Support from the community and local partners might be important to implement these interventions locally to enhance adherence to ART.

Appropriate interventions and policies are needed to respond to the concerns identified from the study regarding inability to attend to the problems of patients because, on the one hand, medical staff are occupied, and due to respondents' perception that staff do not treat patients with enough respect, on the other hand. Capacity building measures should be taken through inter-sectoral collaboration so that all health facilities have a functioning laboratory and adequate personnel to ensure free laboratory and treatment services. Knowledge building measures like seminars, workshops, refresher trainings, performance-based recognition and financial incentives should be undertaken to bring about provider motivation, which is an important factor in adherence promotion for ART.

We need to intensify health education campaigns against stigma and promote family and community support for people living with HIV and AIDS. Youth-friendly programmes should be set up to continue educating patients and community to eradicate stigma and discrimination which is still a huge obstacle to success of treatments. Moreover, we need to sensitise further and demand religious leaders to harmonize religious requirements with service delivery in order to promote adherence. In addition, regular supportive medical supervision for monitoring and reinforcement of patients' adherence to therapy is a crucial element for the success of HIV management.

A longitudinal study is needed to better understand the predictors of short- and long-term adherence and in order to explore ways to better assess the relevance, content and quality of support services being utilized by ART patients at facility and community levels, and to improve medical care and quality of life of persons living with HIV and AIDS. It is essential that partners and countries step up efforts to strengthen patient and cohort monitoring systems to capture, process and to allow using longitudinal retention data (WHO 2010).

Note

1. Adherence to Antiretroviral Therapy in Adults a guide for trainees 2004, Horizons/Population Council, International Centre for Reproductive Health and Coast provinces General Hospital, Mombasa. 2004 Population Council.

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CHAPTER SIX

Determinants of Access to Treatments by AIDS Patients in Uganda

Joseph Wasswa-Matovu

Abstract

In Uganda, the availability of HIV and AIDS treatment services has in recent years followed a phased approach, whose pace has been dictated by the financing mechanisms for ARVs, the cost of treatment to users, efforts to strengthen the health system, partnerships involving all stakeholders (including the community and development partners) and the adopted model of delivery of HIV and AIDS services. In particular, the service delivery model for AIDS regimens has come to outline a primary and community home-based care model that extends services to the community in the context of Uganda's decentralized health system. However, there is evidence that the service delivery model for AIDS-related treatments in Uganda is fraught with failures in relationships of accountability, which engender patterns of social differentiation and exclusion in access to treatment services. Thus, PMTCT programmes provide no options for poor mothers to access treatment services post-delivery; weaknesses in management systems manifest as frequent drug stock-outs and corruption when ARV drugs are diverted to the black-market and private clinics; many health facilities are inadequately supplied with STIs drugs, condoms, equipment and clinical expendables; there is a minimal rolling out of voluntary counselling and testing (VCT) services, with communities poorly mobilized for ART; and there is a paucity of community-owned resource persons (CORPs) and care mechanisms, and skilled health workers equipped to support the rational use of ARV therapies at community-level. Using primary data recently collected from 208 HIV and AIDS patients accessing different HIV and AIDS-related treatment services at selected treatment centres in two districts in central Uganda, logistic choice models in two themes, i.e., (a) patient's choice of access to a given HIV/AIDS treatment service, and (b) patient's perceptions of the efficacy of a given treatment service at a given point in the HIV and AIDS treatment services' delivery channel, are to be estimated. The objective was to examine factors that are most significant in determining patients' choice of access to a given HIV and AIDS treatment service, where *a priori*, an assumption is made that all the different services are available to all patients who may need them at the relevant points in the HIV and AIDS treatment services delivery channel.

6.1. Introduction

Uganda was one of the first African countries to respond aggressively to the HIV and AIDS epidemic, moving rapidly to introduce measures to prevent HIV transmission. Uganda's experience with HIV and AIDS can be

coalesced into a number of phases that include: the experiential learning and social mobilization phase (1982 to 1989), the multi-sectoral structuring phase (1990 to 2000), the research and community engagement phase (2001 to 2005), and the current phase of the socio-medico approach to the epidemic. In the current phase, focus has shifted to research into vaccines, herbal medicines, condom distribution, circumcision, partner reduction, discordant couple follow-up, and strategies built around counselling and testing, which eventually graduate into patients being placed on antiretroviral (ARV) drugs.

In Uganda, the availability of HIV and AIDS treatment services¹ has in recent years followed a phased approach, whose pace has been dictated by the financing mechanisms for ARVs, the cost of treatment to users, efforts to strengthen the health system, partnerships involving all stakeholders (including the community and development partners) and the adopted model of service delivery for HIV and AIDS services. In particular, the service delivery model for AIDS regimens has come to outline a primary and community home-based care model, which seeks to extend services to the community level in the context of Uganda's decentralized health system (see Figure 1).

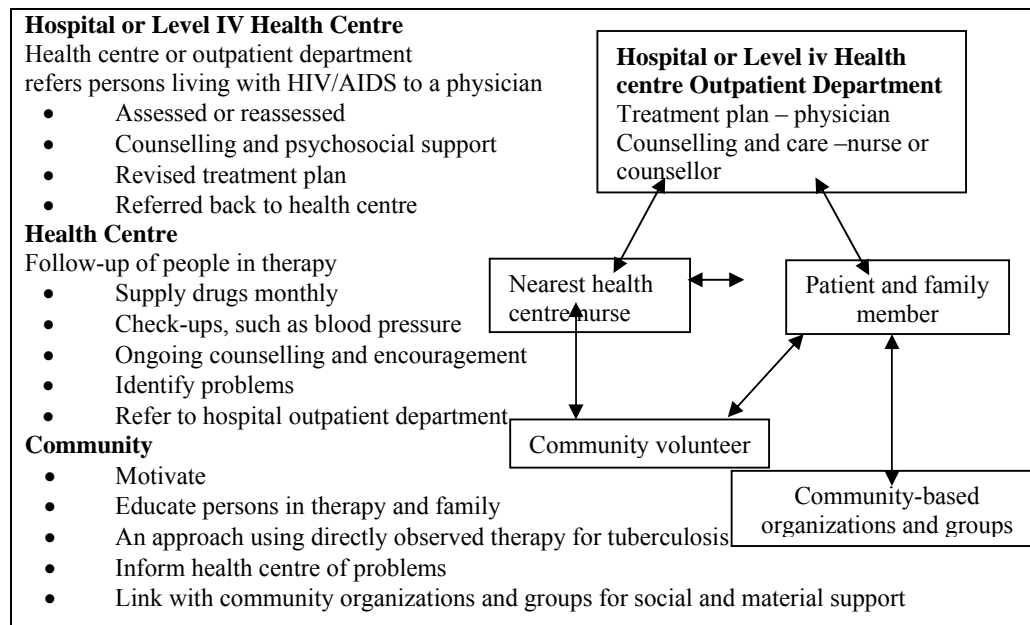


Figure 1. Model of Service Delivery

SOURCE: Implementation guidelines for ART in Uganda

For example, the service delivery model for antiretroviral treatment (ART) in Uganda called for all hospitals and higher level health centres to provide key ART services by the end of 2006. The model proposed to extend services to the most remotely located people living with HIV and AIDS (PLWHA) by focusing on the diagnosis and management of opportunistic infections. Community health workers and other key stakeholders in this model (e.g., nongovernmental organizations (NGOs), community-based organizations (CBOs), community volunteers, family members and friends) were expected to identify clients and refer them to more comprehensive services at higher level health centres; with services linked to communities through home-based care, including palliative care.

6.2. Problem Justification

However, there is evidence that the service delivery model for AIDS-related treatments in Uganda is fraught with failures in relationships of accountability. These failures are shown to engender patterns of social differentiation and exclusion concerning access to treatment. For example, Whyte *et al.* (2004) show cases where patients have needed to pass a 'blanket sign' test to access certain services². Equally, prevention of mother-to-child transmission (PMTCT) programmes that provide free nevirapine to HIV+ mothers to prevent the risk of infection to the unborn are shown to provide no options for poor mothers to access further HIV and AIDS treatment services post-delivery (*ibid*).

Noted as well are weaknesses in management systems along services delivery channels, which manifest as frequent drug stock-outs and corruption, which respectively, lead to delays in HIV and AIDS treatment programme roll-out and to the diversion of ARV drugs to the black-market and private clinics (WHO 2008; DFID 2008). Many health facilities are also inadequately supplied with sexually transmitted infections (STIs) drugs, condoms, equipment and clinical expendables (Eliot *et al.* 2003). Also along services delivery channels, Okero *et al.* (2003) have observed minimal rolling out of voluntary counselling and testing (VCT) services, communities that are poorly mobilized for ART, and a paucity of community-owned resource persons (CORPs) and care mechanisms, and skilled health workers equipped to support the rational use of ARV therapies at community-level.

Government and donors have also been blamed for not guaranteeing the proper funding of HIV and AIDS programmes. Thus, unanticipated shortfalls in funding have been cited as leading to stoppages in enrolment of new patients, and/or to the enrolment of patients with very low CD4 cell counts, and to under-dosage (The East African 2009). In some cases, Government has been shown to divert funds earmarked for ART programmes to cover recurrent health system costs (health workers' salaries) or to undertake key investments³. The lack of appropriate pediatric ARV formulations also means that the treatment needs of HIV and AIDS-afflicted children remain largely unmet (Barigye and Luyirika 2003).

Also Richey and Haakonsson (2004) have identified poor coordination between treatments⁴ and their providers⁵ with the expansion of treatment options; and the difficulties that arise when wedding decentralized service provision with improved access to HIV and AIDS treatment services. The private sector has also been shown to be slow to buy into national procedures of accreditation and quality assurance, leading to problems of quality in the delivery of private clinical HIV and AIDS-related services (Okero *et al.* 2003:5). To this end, the preponderance of more than one service delivery channel for treatments in the health system has been identified as detrimental to wider access to treatment services by PLWHA (Larsson and Okong 2009).

At the household level, the decision to engage with HIV and AIDS regimens involves painful prioritizing as family members are usually economically dependent on one another. Consequently, for households, supporting treatment for one person means not helping some other household member with money for school fees or some other important life project. Thus, when resources are scarce, people must decide which individual to help, which means not only weighing needs but also a patient's ability to stick to regimens (Whyte *et al.* 2004).

According to a recent report by the Uganda AIDS Commission (UAC) (2009), on the whole, Uganda has performed relatively well in the provision of preventive HIV and AIDS services to patients, mainly providing and supporting Information Education and Communication (IEC) activities⁶, condoms⁷ HIV Counselling and Testing (HCT)⁸ services, STI⁹ and (PMTCT) services¹⁰. The agencies providing these services are also shown to be fairly well distributed throughout the country although poor distribution for child counselling services and HIV and AIDS training is evident¹¹. This is also the case for school-based interventions and blood transfusion services¹².

Also, few agencies are involved in the provision of income-generating activities (IGAs)¹³ and care and support for orphans and other vulnerable children (OVCs)¹⁴, and/or those providing palliative¹⁵ and psychosocial support services¹⁶ to PLWHA. Finally, the distribution and number of agencies providing ARVs throughout the country is poor and low, respectively¹⁷.

Thus, despite or because of the aforementioned picture, one can expect uneven access to HIV and AIDS treatment services among PLWHA in Uganda. The question of interest here, therefore, relates to an examination of how the service delivery model for HIV and AIDS treatment services in Uganda conditions patients' choices of services and the efficacy patients attach to the different points in this service delivery model in meeting their treatment needs.

6.3. Study Objectives

This study sought to tease out factors that influence patients' choices of HIV and AIDS treatment services. Specifically, it aimed to:

- examine factors that underpin PLWHA's choice of HIV and AIDS treatment services.
- assess PLWHA's perceptions about the efficacy of the HIV and AIDS treatments service delivery model in meeting their treatment needs.

6.4. Research Questions

In light of the above objectives, key study research questions include:

- What factors condition PLWHA's propensity to access different ART services in Uganda's ART service delivery channels?
- To what extent is PLWHA's access to ART services determined exogeneously by factors outside their personal or family members' control?
- What can be learnt about the factors that condition PLWHA's access to different ART services, which afford the charting of a way forward for PLWHA's improved access to regimens?
- What factors influence PLWHA's valuations about the effectiveness with which different points in the HIV and AIDS treatments service delivery channels meet their access needs for different services?
- What can we learn about these factors, which help us chart a way forward for PLWHA's improved access to different regimens?

6.5. Significance of the Study

Lack of or unequal access to HIV and AIDS treatment services by PLWHA poses questions of social justice in countries such as Uganda, where most people may not afford the cost of services, where access to services is limited, and where social and cultural factors denied many of them from accessing the services. It poses dilemma for health workers and households who have to make tough decisions on when patients should begin treatment and adhere to regimens that last months and years in the face of many other needs.

It is the author's view, therefore, that an inquiry, albeit exploratory, into factors most critical to explaining PLWHA's choice of access to treatment services and the effectiveness the PLWHA attach to various service points in meeting their access needs for treatment services, is necessary for moral, humanitarian and public health reasons.

Moreover, unless attention is paid to those factors that hinder PLWHA's increased access to treatment services, Uganda runs the risk of failing to achieve the Millennium Development Goals and the targets for PLWHA's increased access to regimens. Thus, by contributing to a better

understanding of factors that promote or hinder PLWHA's access to treatment services, the study should inform policy agendas that seek to ensure such services are equitably accessible to all who need them.

6.6. Research Methodology

Primary data was collected from 208 AIDS patients seeking treatment services at different health centres/facilities (see Table 1)

On obtaining their informed consent, patients were requested to fill a simple questionnaire that consisted of questions on how well HIV and AIDS was addressed at the interface level for a person seeking treatment, and the facility providing such treatment services in the HIV and AIDS treatment services delivery model.

Table 1. Sample patients characteristics and health centres/facilities where accessed

Patient characteristics	Health Centre/Facility								Total
	<i>Baylor</i>		<i>Kisubi</i>		<i>MildMay</i>		<i>Mulago</i>		
	<i>AIC</i>	<i>College</i>	<i>JCRC</i>	<i>Hospital</i>	<i>Centre</i>	<i>MJAP</i>	<i>Hospital</i>	<i>Service Centre</i>	
<i>Adults on ARVs</i>	10	1	10	3	19	9	12	4	68
<i>Patients on TB Medication</i>	5	2	6	5	12	3	8	10	51
<i>Patients receiving RCT New patient (last 6 months)</i>	5	1	4		8	2	4	11	35
	10	2	10	2	12	5	8	5	54
Total (%)	30(14)	6(3)	30(14)	10(5)	51(25)	19(9)	32(15)	30(15)	208(100)

Notes: RCT = Routine Counselling and Testing; AIC=AIDS Information Centre; JCRC= Joint Clinical Research Centre; MJAP= Mulago/Mbarara Joint AIDS Programme; TASO=The AIDS Support Organization

The choice of treatment centres/facilities covered a wide range of national referral and faith-based hospitals, and national and international NGO treatment service providers. The hope was that in sourcing respondents from these treatment centres, insights would be obtained on how different patients are facilitated to access treatment services in the HIV and AIDS treatments service delivery model. Finally, documentary reviews¹⁸ and direct observation methods were also employed to establish the types of health services expected to be available to patients and their quality (availability of medicines, attitudes and behaviours of health workers and the state of health facilities).

6.6.1. The Models

Data analysis methods involved the estimation of logistic models in two themes using Stata. The themes related to:

1. AIDS patients' choice of treatment services;
2. AIDS patients' perceptions of the effectiveness of the HIV and AIDS treatments service delivery channels in meeting their treatment needs.

Specifically, the baseline logistic models were multinomial ones, and assumed that all patients in the sample faced the same range of treatment options. The models sought to ascertain which patient characteristics and treatment service delivery attributes had the greatest effects on a patient's choice of access for a given treatment service once a decision had been made (by the patient) to seek treatment.

The assumption is that along the HIV and AIDS treatment service delivery model is a set of treatment services that can be accessed by the patient, and which comprise a bundle of characteristics. Thus, a utility maximizing patient i , is assumed to have preference over these characteristics as specified by his/her individual utility function:

$$U_{ij} = X_i\beta_j + \alpha_j + \varepsilon_i$$

U_{ij} represents the utility valuation that the patient i ($i=1, \dots, n$) attaches to accessing treatment service j , where j could be VCT, TB medication, ARV treatment therapies, community-based treatment, care and support at the various health facility along the HIV and AIDS treatment services delivery model; and X is a vector of the patient's observable demographic characteristics. In addition, access to a treatment service is conditional on the service's attributes, with the result that a patient's utility function following from McFadden (1974) can be extended as:

$$U_{ij} = x_i\beta_j + z_j\alpha_j + \varepsilon_i$$

Such that U_{ij} represents the utility valuation that patient i ($i=1 \dots n$) attaches to accessing a service j . Again, X is a vector of the patient's observable demographic characteristics, and Z is a vector of observable characteristics

of the treatment service. The general expressions of the multinomial logistic models that were estimated are presented as Themes 1 and 2.

6.6.2. Theme 1: Treatment Services Access Models

$$\text{Prob}(\text{TRE}_{ij} = 1) = f(C_i, K_{ij}, H_{ij}, X_{ij}, V_{ij})$$

Where,

TRE_{ij} is the treatment service j accessed by patient i ;

C_i is a set of patient i 's demographic characteristics;

K_{ij} are the service delivery channel attributes of the facility patient i accesses treatment service j ;

H_{ij} is patient i 's valuations about the effectiveness of treatment service j ;

X_{ij} is patient i 's valuations about the ease with which treatment service j can be accessed; and

V_{ij} is a dummy of whether patient i expects to shoulder part or all of the cost of treatment service j .

6.6.3. Theme 2: Treatment Services Delivery Effectiveness Models

$\text{Prob}(\text{TREF}_{ic}=1) = f(C_i, \text{CS}_i)$...Service delivery model for treatment services at community level;

$\text{Prob}(\text{TREF}_{if}=1) = f(C_i, \text{HCS}_i)$...Service delivery model at health centre level; and

$\text{Prob}(\text{TREF}_{ip}=1) = f(C_i, \text{HOS}_i)$...Service delivery model at the hospital level.

Where:

TREF_{ic} is individual i 's rating of the effectiveness of the treatment service delivery model in meeting his/her treatment needs at the community level;

TREF_{if} is individual i 's rating of the effectiveness of the treatment service delivery model in meeting his/her treatment needs at the health centre level;

TREF_{ip} is individual i 's rating of the effectiveness of the treatment service delivery model in meeting his/her treatment needs at the hospital level;

C_i is a set of individual i 's demographic characteristics;

CS_i is a set of variables capturing the effectiveness of ART service delivery at the community level for individual i ;

HCS_{ij} is a set of variables capturing the effectiveness of the ART service delivery at health centre level for individual i ; and

HOS_i is a set of variables capturing the effectiveness of ART service delivery at the hospital level for individual i .

6.7. Results

6.7.1. Sample Characteristics

In the sample, males and females accounted for 82 (39.4 per cent) and 126 (60.6 per cent) of the respondents, respectively. Of the patients, 97 (46.6 per cent) claimed to be heads of households, of which 57 and 40 were male and female, respectively. Patients' average age was 33.6 years; on average, patients claimed to have 12 years of formal schooling. Patients also claimed to come from households that had on average 4.1 persons, and an average monthly income of Uganda shillings 383,188 (US\$ 174). Of the patients, 42 per cent were married, 39 per cent were unmarried/separated and 19 per cent were widowed. Concerning employment, 37 per cent were self-employed, 18 per cent were civil servants (government employees), 15 were private sector employees, and 30 per cent unemployed, respectively.

6.7.2. Access to Treatment Services and the HIV and AIDS Treatment Service Delivery Model

There is a range of treatment services that were available, and accessed by patients at varying levels (see Table 2). Overall, almost all patients had had some access to HIV and AIDS-related information, and for men, almost universal access to free condoms. Heavy access to family planning services, CD4 count test services, antiretroviral medicines and PMTCT (for women) was also evident. However, there was less access to services such as RCT, TB medication, nutritional support, and more importantly, follow-up care plan services.

As pertains patients' socio-economic attributes and access to key treatment services, head of household status was significantly related to access to TB test and family planning services; gender to VCT, RCT and PMTCT; marital status and age to all services except antiretroviral services; education to TB medication and family planning services; household size to all services except PMTCT, and surprisingly family planning; occupation to condom and HIV-AIDS information, PMTCT and family planning services; and income to VCT and condom and HIV/AIDS-related information.

Table 2. Number and proportion (per cent) of patients who had accessed different ART services

ART Services	Number of Patients	Percentage
Condoms/HIV-AIDS info	205	99
VCT	139	67
RCT	94	45
TB Tests	131	63
TB Medication	85	41
PMTCT	94	75
Family Planning Services	151	73
CD4 Count Test	165	79
Antiretroviral Medicines	179	86
Follow-up Care Plans	66	31
Nutritional Support	98	47
Care and Support Services	116	56

In terms of where those patients accessed different services along the services delivery model, disproportionately more patients sought condoms and HIV/AIDS-related information, VCT, PMTCT (for women) and family planning services at government-run health centres, and in particular, Health Centre Level IV (hospitals), which, in Uganda's decentralized health system constitute the hub of health services delivery at local level. International NGOs including HIV/AIDS-related research institutions had a dis-proportionally more elevated role in the provision of RCT, TB test, CD4 count tests services, follow-up care services and antiretroviral therapies. National NGOs also played an important role in the provision of CD4 count test services. Finally, community level institutions appeared to play a dis-proportionally important role in the provision of nutritional support and care and support services.

Patients in the sample also viewed their decision to access a given service as significantly related to the ease with which the service was accessible, the usefulness of the service as a component in their regimens, and whether or not all of a service's protocols were available at the point of service access. It was only with respect to ARV therapies that statistical significance was not established with respect to ease of service access. However, this appears self-evident, since ARV therapy services are more regimented where they are dispensed, which in this case was predominately done at international NGO and HIV and AIDS-related research institutions and facilities.

6.7.3. Patients' Choice of HIV and AIDS Treatment Services

Using a parsimonious process, the results from models with the best fit are presented momentarily. It should be noted that congruent and robust logistic models on patients' choice of access for condom and HIV and

AIDS information-related services, and CD4 count test services were untenable. It is clearly plausible that, given the efforts all stakeholders in the HIV and AIDS arena have undertaken over the last two decades in HIV and AIDS prevention, condoms and HIV and AIDS information services are so easily and widely available, that modelling patients' choice of access as contingent on their socio-economic and other service delivery model attributes would be spurious.

On the other hand, CD4 count test services still remain largely unavailable to many HIV and AIDS patients because of cost. So, while close to 80 per cent of sampled patients claimed to have had access to CD4 count test services, they did so within donor-funded programmes in international NGO and HIV and AIDS research-related institutions. This made an examination of choice of access statistically redundant on the variables of interest in this study.

For VCT services, household headship, patients' valuations about the usefulness of service, service access time, patients' valuations of service delivery modalities, and expectations of the availability of protocols at the point of service access were statistically significant factors explaining patients' choice to access the services. The result shows that except for service access time, all the other coefficients on the marginal effects have positive signs. The results suggest that the probability of a patient accessing VCT services is 18 per cent if they are household heads; 40 per cent if they regard the service useful; 33 per cent if the service is effectively provided at the point of access; and 56 per cent if the patient expects all its protocols to exist where the service is accessed. On the other hand, the probability is 9 per cent that a patient may wish not to access the service for every hour he/she spends waiting to access it.

As with VCT, how patients value RCT's usefulness as part of their regimen is a significant factor in their choice of access; the probability being 66 per cent. The health facility where RCT services are accessed is also important to patients' choices to access the service. Results show that patients' choice to access RCT services is about 11 per cent when household size increases by one person. This finding indicates that within households, individuals appear to monitor the health status of HIV and AIDS-afflicted family members and as such to encourage them to access RCT services.

Further, gender had some effect on the choice of access to RCT services. In particular, women more than men were apt to adopt self-care practices in the management of HIV and AIDS if one assumes that RCT services encapsulate those self-initiated efforts by patients to monitor their health status, maintain healthy lifestyles (avoiding multiple sexual partners and adhering to regimens). Thus, the probability was about 24 per cent that a patient would not seek to access RCT services if they were male. In fact, a statistically significant relation was found between gender and patients' choice of access to RCT services ($\text{Chi}^2(1) = 5.2771$, $\text{Pr} = 0.022$), and that disproportionately more women accessed RCT services.

The number of household members appears to have an effect on the choice patients make to access TB test services. Thus, the probability that a patient would seek to access TB test services for every one person increase in household size was 5 per cent. Here again, the chances that households with more members may be more disposed to identifying members with TB symptoms and advising them to seek treatment is implied. A patient's occupation also appears to play a role in their decision to seek TB test services, with the chances of this happening being 4 per cent as the patient moves up the occupational ladder. How well patients value how useful TB test services are to their regimen and the ease with which such service can be accessed; increase a patient's chances of accessing the services by 60 and 23 per cent, respectively.

For patients, the value attached to TB medication as useful to one's regimen increases patients' chances of adhering to a strict regime of TB medication by 74 per cent. Also the expectation of the existence of TB medication protocols has a similarly large and positive effect (74 per cent). However, improvements in service delivery at the point of access lower by 11 per cent the probability that patients will seek medication— a perverse outcome. A plausible explanation is that TB medication intake involves an element of self-discipline, which outside the precincts of health centres/facilities, imposes an imperative on the patient to follow an unsupervised regime of adherence.

On the question of pregnant women's choice of access to PMTCT services, marital status, age and levels of education were the significant factors. The data shows that there is a 15 per cent chance that an unmarried woman will seek not to access PMTCT services. In fact, of the 75 per cent of women in the sample who accessed PMTCT services, 43 per cent were married, 16 per cent unmarried/separated, and 14 per cent widowed. Also, one additional year to one's age and time in formal education increase the chances of a pregnant HIV+ woman accessing PMTCT services by 12 and 27 per cent, respectively.

For family planning services, patients' status as household head increases the chance of services access by 11 per cent. Also, the chances that male and unmarried patients are not likely to access family planning services are 19 and 13 per cent, respectively. On the other hand, one additional year to a patient's age and years in formal schooling increase a patient's chance of accessing family planning services by 1 and 2 per cent, respectively. Finally, the more favourably family planning services are viewed by patients as useful to their treatment regime, the higher the chance that they increases the patients' chances of accessing the services by 25 per cent.

For antiretroviral medicines, significant factors that underpin a patients' choice of service access were: number of persons in the household, the usefulness patients attach to the ARV to their regimen; and patients' expectations about the existence of ARV protocols at points of service delivery. Thus, adding one person to a household induces a 2 per cent

probability that a patient in that household will not wish to access antiretroviral medicines— suggesting that larger household may face an economic dilemma committing sick members to a costly regime of ARVs in the face of other family livelihood demands. On the other hand, the expectation that those antiretroviral medications will be available at treatment centres and are useful to one's treatment regime increase the chance that patients will seek such medication by 12 and 28 per cent, respectively.

Regarding follow-up care plans, key significant variables for patients included: gender, number of persons in household, and patients' valuations of the effectiveness of service delivery for the services at health facilities. The probability that a patient would wish not to engage with follow-up care plan services if a male, was about 8 per cent. However, as household size increases by one person, the probability that a patient will engage with these services increases by about 6 per cent— suggesting that in larger households, the role of monitoring and encouraging HIV and AIDS-affected members may be more pronounced than in smaller sized households. Also, patients' valuations of how well health facilities handle follow-up care plan services induces a 38 per cent probability that patients will choose to engage with the services.

Age, education, number of persons in household, patients' valuations of service usefulness to treatment needs, and expectation of existence of such support; were all significant factors for patients seeking to access nutritional services. It is plausible that these services were more important for older patients, with data suggesting that every additional year to one's age induces a probability of about 2 per cent that a patient will seek to access nutritional support services. Education, on the other hand, had the opposite effect; with every additional year of formal education inducing a probability of 2 per cent that a patient will not wish to access nutritional support services. However, the relation with education was not significant. Adding one person to the household induced a probability of 12 per cent that a patient will seek to access nutritional support services; while patients' knowledge of the importance of these services to their treatment needs and their expectations of the existence of such support raised the probabilities that a patient will seek to access nutritional support services by 95 and 68 per cent, respectively.

Key significant explanatory variables for care and support services included household head status, marital status, age, persons in household, ease of service access and expectation of existence of service protocols. There was a 26 per cent probability that household heads will not wish to access care and support services, which may be linked to patriarchal sentiments given that a statistically significant relationship existed between gender and household headship ($\text{Chi}^2 = 28.468$ $p=.000$). Also, the probability that an unmarried patient will seek care and support services is 14 per cent, although the relation was significant at 15 per cent. Not surprisingly, the

probability rises by 2 per cent for every additional year added to a patient's age that such a patient will seek to access care and support services. A rise by one person in household size raises by 4, 33 and 36 per cent respectively the chances that a patient will seek to access the services, the patient's favourable valuations of ease of service access, and the patient's expectation of the existence of care and support service protocols.

6.7.4. Patients' Evaluations of the Efficacy of HIV and AIDS Service Delivery Channels

Logistic models were run for patient evaluations of the efficacy of HIV and AIDS treatment services channels at the community, health centre (HC), and hospital levels. At all the three levels, the question was how patients rated HIV and AIDS treatment services' delivery in meeting their treatment needs. At the community level, specific questions revolved around the effectiveness with which community level institutions such as family, friends, CBOs, local NGOs, community volunteers, and CORPs,

- provided patients with social and material support;
- informed health centres of any clinical problems patients faced;
- observed and monitored patients' regimens such as with respect to ARV and TB medication adherence, and maintenance of good nutritional habits;
- educated patients and their family members about therapy regimes; and
- motivated and encouraged patients to cope with the disease.

At the HC level, questions revolved around frequency of referrals for patients across the HIV and AIDS treatment services delivery channel; the frequency with which HCs were able to identify new health problems facing patients; and the frequencies with which HCs provided counselling and encouragement sessions for patients, took blood pressure check-ups, and filled patients' prescriptions. Finally, at the hospital level, key questions revolved around the frequencies with which patients were referred back to HCs for less complicated health problems, were provided with counselling and psychosocial support services, were reassessed for disease progression, and put on revised treatment plans.

For community level service delivery efficacy, patients' marital status, access to social and material support and community-mediated efforts to inform health centres of any clinical problems patients faced were significant factors for patients in assessing the efficacy of HIV/AIDS treatment services delivery at the community level (see Table 3). Results revealed that there was a 10 per cent probability that unmarried patients will view the efficacy of community level HIV and AIDS treatment services delivery channels unfavourably. The probability that a patient will favourably regard services delivery at the community level was 32 per cent

when the community level service delivery institutions provide patients with access to social and material support and 19 per cent the institutions have in place a mechanism to inform HCs about clinical problems patients might face.

Table 3. Logistic estimates for community level service delivery Efficacy

Variable	Odds		Marginal Effects	
	Ratio	Significance	Ratio	Significance
Marital status	.634	.051	-.102	.049
Married				
Unmarried/separated				
widowed				
Access social and material support	4.234	.001	.317	.000
No				
Yes				
Inform HCs of patients' clinical problems.	2.338	.080	.190	.076
No				
Yes				
Observe/monitor patients' adherence to treatment regimes	1.537	.372	.096	.371
No				
Yes				
Educate patients and family members about treatment regimes	.609	.365	-.111	.366
No				
Yes				
Motivate/encourage patients to cope with HIV/AIDS	1.432	.444	.081	.443
No				
Yes				
Logistic Regression	Number of Obs = 206			
	LR Chi2(6) = 48.36			
	Pro > Chi2 = .0000			
Log Likelihood = -111.97531	Pseudo R2 = 0.1776			

At the HC level, it was only the ability of lower level HCs to refer patients to higher level HCs (i.e., HC IV and FBHs), which appeared significant in engendering a favourable view among patients about the efficacy of lower level HCs in meeting patients' treatment needs. Thus, a probability of 9 per cent existed that a patient will view the efficacy of service delivery at the HC level favourably, if the frequency of HIV and AIDS patients referrals to

higher level HCs increases in any given six month period. Though not statistically significant, the frequency with which patients were availed blood pressure check-up at lower level HCs also appeared important in engendering a favourable outcome on the part of patients as regards service delivery efficacy at the HC level.

On the other hand, the patients' socioeconomic attributes did not seem to feature prominent in their assessment of the efficacy of service delivery at lower HC levels (Table 4). Age was the only statistically significant variable; the older a patient, a probability of 5 per cent existed that he/she might regard the efficacy of service delivery at HC level favourably. Though not significant in a statistical sense, gender appeared to be an important variable in this regard as well. Thus, a 10 per cent probability existed that male patients were likely to regard service delivery at lower level HCs unfavourably.

Table 4. Logistic estimates for the efficacy of service delivery by Level II and III HCs .

Variable	Odds		Marginal Effects	
	Ratio	Significance	Ratio	Significance
Marital status	1.231	.327	.049	.326
Married				
Unmarried/separated				
widowed				
Sex	.653	.173	-.103	.173
Female				
Male				
Age	1.022	.104	.005	.103
Education	1.029	.472	.007	.472
Frequency of patient referrals to higher level HCs (HC IV & FBHs)	1.415	.092	.083	.092
Frequency of patients' access to blood pressure checkups	1.588	.182	.111	.181
Logistic Regression	Number of Obs = 208 LR Chi2(6) = 21.04 Pro > Chi2 = .002 Pseudo R2 =0.0746			
Log Likelihood =-130.5244				

At the hospital and/or HCs IV level, the frequency with which patients were availed counselling and psychosocial support in the last six months preceding the interview was a significant variable explaining patients' assessment of the efficacy of hospital level facilities in meeting the patients' treatment needs. The probability that a patient would be of this view was 6 per cent. Also household headship engendered a similar outcome, with the probability that hospital level health service delivery to HIV/AIDS patients was likely to be seen favourably if a patient was the household head (see Table 5).

Table 5. Logistic estimates for hospital and/or HC IV service delivery efficacy

Variable	Odds		Marginal Effects	
	Ratio	Significance	Ratio	Significance
Household Head	2.884	0.102	0.061	0.09
No				
Yes				
Sex	0.477	0.194	-0.046	0.228
Female				
Male				
Marital Status	0.639	0.263	-0.026	0.258
Married				
Unmarried/separated				
widowed				
Occupation	1.323	0.227	0.016	0.220
Self employed				
Government employee				
Private sector employee				
Unemployed				
Frequency of referrals back to lower level HCs (No in last 6 months)	0.731	0.370	-0.018	0.365
Frequency of assess to counselling and psychosocial support services (No in last 6 months).	1.898	0.079	0.037	0.061
Logistic Regression	Number of Obs = 208			
	LR Chi2(6) = 8.33			
	Pro > Chi2 = .2148			
Log Likelihood =-	Pseudo R2 =0.0739			
52.241296				

6.8. Conclusions and Policy Implications

Overall, patients appeared to have some leeway over choice of access to treatment services in the HIV and AIDS treatment services delivery channels. Some like condoms and HIV/AIDS related information were widely available at treatment facilities and offered free, making choice of access easy. However, access to some higher level services such as TB test services, TB medication, CD4 count test services, PMTCT for women, follow-up care plans, and antiretroviral therapies, while desirable as a complete package of treatment for patients, depended on decisions made by qualified medical personnel.

However, because patients in the sample accessed higher level services at facilities where they were provided free, cost of services was not an issue as might be the case for AIDS patients outside the study sample. Nevertheless, an exploratory assessment from this sample of patients reveals that even with these specialized treatment services, key patient socioeconomic and treatment service delivery attributes play an important role in conditioning the patients' choice of access to particular HIV/AIDS treatment services.

Thus, features such as: the size of a patient's household (for TB test services, follow-up care plan services and antiretroviral therapies); patients' valuation of the usefulness of the service (for TB test services, TB medication and antiretroviral therapies); and marital status (PMTCT), age (follow-up care plans and PMTCT) and education (for PMTCT) play an important role in patients' choices to access services. Also, for these specialized services, service delivery attributes such as patients' expectations of the existence of a full range of service protocols (for TB medication and antiretroviral therapies), ease of access to services (for TB test services), and patients' valuation of efficacy of service's delivery at point of service's access (follow-up care plans) are important in the patients' choice of access to services.

For routine services such as VCT, RCT and family planning; these have a bearing on the patients' self-initiated efforts to monitor their health status, and as such, choice of access is endogenous to the patients' decision map with respect to whether or not to access these routine services. This is particularly true given the mass HIV and AIDS prevention campaigns targeted at people to undertake VCT to establish their HIV status, RCT to maintain their health status and access treatment (antiretroviral therapies), and family planning services as an entry point for women to access PMTCT services.

It was not surprising, therefore, that for these routine HIV and AIDS-related treatment services, factors particular to patients' socioeconomic characteristics were most significant in determining choice of access to services. Thus, household headship status was critical in patients' choices to access VCT and family planning services; gender, marital status, age,

and years of formal education in their choices to access family planning services; and household size (RCT) and patient's valuations of the usefulness of the service to treatment needs (VCT, RCT, and family planning services) were critical in patients' choices to access services.

Even where service delivery attributes mattered, they appear to reinforce patients' personal attributes as they relate to choice to access these supposedly routine services. Specifically, service access time, valuation of services' delivery, and patients' expectations of the existence of protocol at services access point appear to dampen or downplay the usefulness patients might attach to VCT services. Similarly, point of services' access in the service delivery channel would appear to dampen or downplay the usefulness patients might attach to RCT services. Accordingly, given that the appearance of these service delivery attributes appears less clinical to patients, they have to weigh the opportunity cost of access they face in terms of cost and time.

With respect to services with a mostly community-based component of service delivery, namely nutritional support and care and support services, a key conclusion is that for these services expectation of the existence of service protocols, ease of access to services, and the usefulness patients attach to the services, as in the case of nutritional support, may adduce patients to choose to access these services if the patients are older, come from big-size households, are unmarried (care and support services) or are heads of their households (care and support services).

Pertaining to the efficacy patients' attach to service delivery channels for HIV and AIDS-related treatment services in meeting their treatment needs, patients were most satisfied at the local level where local institutions in the HIV/AIDS arena are well positioned to provide social and material support, and where they are able to link patients to the formal health system, where they may face clinical problem; especially if unmarried. This finding also appears to reinforce the finding that the expectations on the part of patients that service protocols exist for nutritional and care and support services, increase the propensity for patients to access the services.

At the HC level, patients would appear to regard the efficacy of HIV and AIDS treatment services' delivery favourable where HC II and III are better positioned to refer patients to higher level HC, most probably HC IV and hospitals. Given that lower level HCs are in all probability likely to be dispensing routine HIV and AIDS treatment services (VCT, RCT, family planning services), it is logical to suggest that HIV and AIDS patients with more serious clinical problems may regard them more favourable in the HIV and AIDS services' delivery channel the more they were able to address their referral needs for more specialized treatment services.

At the hospital level, a designation that may include HC IV, faith-based and other hospitals, and HIV and AIDS-related research institutions and international NGOs that are engaged in dispensing treatments, efficacy of

service delivery in patients' eyes hinges on facilities being able to effectively provide counselling and psychosocial support services. A conclusion which might be drawn from this is that having come to the end of the service delivery model for HIV and AIDS treatment services, especially the more specialized services such as antiretroviral therapies, chronically ill patients may be in need of better psychosocial support services to deal with living with HIV and AIDS.

The findings and conclusions drawn have the following policy implications. First, since household size is shown to have positive implications on patients' choices to access specialized HIV and AIDS treatment services such as TB test services, follow-up care plan services and antiretroviral therapies, and routine ones like RCT, interventions that seek to ensure patients access treatment and adhere to regimens, ought to include patients' family members as key treatment facilitators. Such interventions may cover the gamut of information dissemination on regimens to patients and/or their family members, to requirements restricting patients' access to services, unless accompanied by family members.

Second, the weaknesses in the management systems along the services delivery channels for HIV and AIDS treatment services need to be addressed, given the great importance, the role patients' expectations about the existence of treatment protocols at health facilities play in influencing their choices to access a range of services, from the routine (e.g., VCT and RCT) to specialized (e.g., ARVs) and community-based treatment services (e.g., care and support services). In this regard, government agencies such as the National Medical Stores, and other internationally-driven programmes such as, PEPFAR, The Global Fund to Fight AIDS, Tuberculosis and Malaria will need to work closely with HC IV and hospitals, which are the hub of health service delivery at the local level, to streamline the drugs logistics cycle and avoid ARV drug stock-outs.

The finding that household headship plays an important role in determining patients' choice to access VCT and family planning services (services that are key to maintaining household members' health status (knowledge of one's HIV status) and in the prevention of MTCT) will need to elevate the role men play in HIV and AIDS prevention and treatment. This is because one can expect to find a disproportionate prevalence of men as household heads in contemporary Uganda. To this end, information on VCT and family planning services should strive to target men, which traditionally has not been the case.

Results also pointed to marital status being critical to patients' decisions to access nutritional support, and care and support services. This, together with the fact that patients had a propensity to rate services delivery at community level highly, based on the ability of local institutions to provide social and material support to patients, highlights the need for local level HIV and AIDS service providers to focus on the needs of the most

vulnerable in communities. These may include single mothers, the youth, the homeless and children. To this end, there may be a need for local level HIV and AIDS service providers to design programmes, which specifically address the nutritional, and care and support services needs of particular disadvantaged patients in communities.

Finally, referral mechanisms at lower level HCs will need to be strengthened to ensure patients who require more specialized clinical services can be quickly facilitated to access them at higher level health centres, hospitals and other treatment facilities. This will require building up more efficient referral mechanisms at lower level health centres, which link them to hospitals. In the context of health services decentralization in Uganda, HCs IV that act as heads of the Health Sub-District concept could play a pivotal role in the design and implementation of these referral mechanisms. At the hospital level, where service delivery graduates into the dispensing of ARVs, and where patients value service delivery highly based on service providers' being able to offer counselling and psychosocial support services to patients, the need for efforts at this level to design effective end-of-life counselling programmes for patients is implied.

Notes

1. In this study, HIV/AIDS treatment services go far beyond the provision of ARV therapies to different subgroups. Thus, in line with the National Strategic Framework for Expansion of HIV/AIDS Care and Support in Uganda, it also includes counselling for HIV/AIDS including VCT, prevention of MTCT, and clinical management of patients under ART— ranging from the antiretroviral prescription to monitoring to community-based treatment, care and support.
2. For example, health workers in hospital settings decided on whom to inform about ART services, and thus who deserves to be served, on the basis of which in-patients brought nice bedding and were visited by well-dressed family members, as indications of who was able to afford services such as ARVs.
3. For example, government recently diverted US\$15 million, which was earmarked for purchasing ARV drugs, to purchase shares in a local drugs manufacturing firm (African Press International 2009).
4. Types of care for AIDS-related-illnesses.
5. Both vertical and horizontal referrals.
6. The country has a national average performance rate of 82 per cent measured by proportion of agencies supporting IEC and number of beneficiaries reached by the agencies' IEC activities. For example, a total of 9,013,423 HIV/AIDS IEC-targeted beneficiaries were registered in the entire country during 2008.
7. The majority (80 per cent) of ART service providers support condom services (i.e., condom distribution and condom education). Government is the leading source of

condoms distributed by the different service providers, about 90 per cent are distributed free.

8. About two thirds of service providers are involved in HCT services, nearly all at no cost. The country has a national average of 72 per cent across all regions, measured considering the number of agencies providing HCT services in a district. However, child counselling is low at 43 per cent.
9. A large proportion (71 per cent) of service providers support/provide STI services, mainly syndromic management, lab testing, HIV testing, syphilis screening, education and counselling, partner notification, condoms and prophylaxis. Countrywide, the distribution is also relatively high at 66 per cent. In 2008, a total of 4,073,568 STI service beneficiaries were registered. Kampala registered the highest number of STI service beneficiaries, with over a million clients targeted.
10. A relatively big proportion (60 per cent) of service providers support PMTCT services in the country, especially sensitization. This is also true in terms of geographical distribution.
11. A little more than half of the stakeholders carry out HIV/AIDS training. Majority of the agencies have trained people in life skills development, peer education, VCT, PMTCT and counselling, and few in OIs, ART, STIs, IGAs, home-based care (HBC), counselling/psychosocial support, palliative care, and trainings relating to culture, gender and HIV/AIDS.
12. Nearly half of service providers provide school-based interventions, mostly life skills training in primary schools. Very few service providers support/provide blood donation/transfusion services, and the country's blood/blood products are mostly from the Blood Bank.
13. Very few (29 per cent) HIV/AIDS agencies are providing IGAs, with glaring gaps in the geographical distribution of service providers for these services in the country.
14. A small proportion of service providers support and care for OVCs, mainly material, education, nutrition, and psychosocial support. Overall, the national mean is 25 per cent in relation to the distribution of agencies providing OVC support.
15. Very few service providers provide palliative care in the country (national average is as low as 19 per cent) and most districts lie below this mean.
16. Slightly more than half of service providers provide some kind of psychosocial support (national distribution is 50 per cent).
17. It is evident that the country is performing poorly in this service area. Very few agencies are involved in the provision and support of ARVs. Nearly three quarters of the districts fall below the national mean of 27 per cent in relation to support and provision of ARVs.
18. Documents and reports in the public domain on the workings of the HIV/AIDS services delivery model.
19. Service access applies to women alone.

20. This has implications for the role family members play in the decision HIV/AIDS patients take to access specialized HIV/AIDS-related treatment services.

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CHAPTER SEVEN

Traditional Medicine and HIV and AIDS Treatment: Challenges, Prospects and Lessons for Zimbabwe

Enock Mandizadza and Gordon Chavunduka

Abstract

This paper discusses the historical backdrop against the evolvement of traditional medicine in Zimbabwe, the pursuant challenges in recognising traditional medicine in national policy for the purpose of integrating it into the national health delivery system and prospects for collaboration with biomedicine in running HIV and AIDS treatment programmes. Drawing on existing literature and review of policy guidelines and interviews with selected key informants, this paper offers some policy implications on prospects for such collaboration. Foucaudian Sociology is enlisted as analytical lens from which to comprehend and elucidate findings. The key findings are that the historical forces of colonisation which shaped the views of the generality of people have filtered into the current policy arena to the detriment of any collaborative efforts. In light of the unacceptable high HIV and AIDS rates of mortality and morbidity in Zimbabwe, it is a paradox that the pandemic offers a ‘window of hope’ a rare opportunity for collaboration between traditional and conventional medical practitioners. Collaboration between traditional health practitioners and biomedical practitioners is possible in areas of minimum or no dispute with the government (policy makers) playing an instrumental and decisive role.

7.1. Introduction

7.1.1. Background

It is an axiom that there is no known cure for AIDS yet. This allows for all health systems to exude their ‘best practices’ in treatment and care, with governments nurturing cut-in-the-edge research, till a breakthrough is realised. Globally, there is an observed increase in popularity and use of traditional medicine and ‘alternative’ therapies, such that collaboration between traditional and conventional medicine is inevitable and vital. African traditional medicine and traditional healing has been in existence since well before the advent of Western medicine. This includes plant, mineral and animal remedies, and spiritual therapies including participation in ritual ceremonies. Initial attempts to foster collaborative work between allopathic medicine and traditional medicine in light of the AIDS epidemic began in the early 1990’s when WHO recommended that traditional medicine be roped in, in national responses to HIV (UNAIDS 2006).

The estimates by WHO (2010) that 80 per cent of people in developing countries and the African region utilise traditional medicine for their

primary health care, has provided a rallying point and rationale for recognition of Traditional Health Practitioners (THPs) and traditional medicine in national health policy. The omnipresence of THPs in most developing countries, the exorbitant health fees which are beyond the reach of many, and the shortage of health personnel coupled with the cultural acceptability of traditional medicine make a strong case for ‘integrating’ traditional medicine in the national response against HIV and AIDS and in the national health delivery system in general.

7.1.2. The Research Setting

In Zimbabwe, the story of traditional medicine entails a panorama of colonial imprints, alienation, hypocrisy, politics of identity, individual idiosyncrasy, and discourse aggrandisement. Despite firing ‘early shots’, soon after political independence in 1980, with the enactment of the Traditional Medical Practitioners Council Act in 1981, for a long time, the issue of traditional medicine has continued to lie in dormancy. Implementation of policy to do with traditional medicine has been lethargic. This is despite the fact that long before some medicine has been found to ameliorate the debilitating impacts of the scourge, THPs in Zimbabwe had come up with some medicine to engulf some symptomatic elements of the epidemic and reduce the viral load. In the 1990s, a conglomeration of ZINATHA, WHO, UNESCO and scientists from the University of Zimbabwe were involved in the trials of gundamiti, a herbal concoction claimed to reduce the viral load and cure opportunistic infections. Though the promotion of gundamiti drew criticism from many sceptics owing to lack of efficacy tests, there are two points to note from this case: THPs under the banner of ZINATHA were at the fore-front of searching for medicine which could treat HIV before similar attempts by Biomedical Health Practitioners (BHPs); and this case illustrates, early experiences of collaboration between THPs and BHPs, though in a rudimentary form. It is hard to comprehend 20 years or so down the line, there is no formal role of THPs in HIV and AIDS prevention, treatment, support and care in Zimbabwe.

Even though the HIV prevalence rate in Zimbabwe plummeted from the peak of 26 per cent in 1997 to the current 13.7 per cent, the figures are still unacceptably high. It is a paradox that the latest WHO guidelines on ART in developing countries have at best put the problem in a sharper focus and at worst have imprinted desperation and dire need of PLWHA. WHO guidelines recommended the initiation of clients on ART at a CD4 count of 350 up from 200. As a result, according to the Ministry of Health, Zimbabwe now has nearly 600, 000 people who urgently require ARV treatment—a figure which is up from 350 000 in 2009. Little has been said and done to consider prospects for collaboration in the provision of ART between modern medicine and traditional medicine. This is as well against a backdrop of weak health infrastructure (after a decade of a comatose economy) and shortage of critical health staff. It is pertinent to establish the

possible role of traditional medicine in supplementing, complimenting or providing an alternative to ART. Equally instructive is to reveal challenges, which are anathema to such collaboration and to recommend some policy shifts.

7.1.3. Statement of the Problem

Despite the shared knowledge and compelling evidence of the co-existence of various health systems and rampant use of traditional medicine in African countries, there exist glaring gaps between policy and practice. In Zimbabwe, the issue is brought into sharper focus, where steps to regularise use of traditional medicine were taken soon after political independence in 1980, and now 32 years down the line, the ‘final trigger for takeoff is yet to be pulled’. It is a paradox that the severity of HIV and AIDS has created fertile ground for meaningful integration and collaboration between traditional and modern medicine, as no single health system can cope with morbidity and mortality rates from the epidemic. Most studies have proffered pragmatic and moral justifications for the inclusion of traditional medicine in the national health delivery system, at the same time over estimating possibilities for such collaborations. There is thin body of problem-solving research that emphasizes hitches to such collaboration. Few researches which embody such a thrust do not employ in-depth historical analysis, which suggest a preponderance of more continuities than discontinuities of the apathy of the colonial state to the post-colonial state. Such a research thrust, holistic in scope, allows for a deeper insight into challenges, prospects and lessons that are country-specific and situation-based. In addition, such a focus puts power relations at the centre of analysis. This enables a scrutiny of all actors involved which include the Ministry of Health, Traditional Medical Practitioners Council, unions of traditional health practitioners, faith healers, herbalists, and unions of modern health practitioners to engender an interface. This study seeks to narrow such gaps. Eventually, such an approach is likely to harvest some pragmatic and effective policy actions.

Neither is situating and defining the ‘problem’ in scholarly debate such a straightforward neat pack. Indeed, there is a panorama of diverging and competing viewpoints in conceptualising the nature of the uneasy relationship between modern medicine and traditional medicine with the ‘impartial’ ‘benevolent’ state in Machiavellian gloves mediating. For some, it is more prudent to locate the ‘problem’ from the colonial imprints. Murray and Chavunduka (1986, 29) observe that before colonisation, western education and Christianity, traditional healers used to enjoy a lot of prestige. Taking a historical perspective, Doyal and Pennell draw an analogy between imperialism and western medicine and observe, “throughout much of human history, health care has been, in one way or the other, an organic part of community life” (1979, 37). However, with the development of capitalism, traditional healers gradually became less important and health care was predominantly offered in hospitalised

technologised set ups. Wahlberg (2006: 127) concurs with this view as can be evidenced with this excerpt:

Crucially, the professionalization of bio-medicine that started in most industrial countries in the 1800s, quickly spreading to the colonies, is seen to have led to a good century's worth of self-interest, bio-medical 'monopoly' 'hegemony' 'domination' that the bio-medical profession continues to actively try to protect in the face of challenges stemming from the increasing popularity of traditional medicine.

Thus, any talk on 'integration' 'mainstreaming' and/or 'collaboration', no matter how well-intentioned it is meant to be, is viewed as a covert attempt at undermining the very principles fortifying the exploits and professional stature of medical orthodoxy.

Another way of looking at the issue is whether it is an epistemological question. Rukangaira (2000) cited in Homsy *et al.* (2004, 906) observes that "one of the main limitations in the use of traditional medicine is the lack of scientific evidence regarding their effectiveness." Most of what constitutes traditional medicine generally falls under what Mararike (2011) termed "intangible assets", something that has been passed from generation to generation by experience and observation and does not necessarily satisfy western benchmarks of scientific rigour. It becomes a question of 'according to whose standards?' 'Whose reality counts?' 'Whose evidence?' It can be argued that the epistemological question best encapsulates this seemingly perennial rivalry between modern medicine and traditional medicine.

Could it be the question of funding? In line with Foucauldian Sociology, the idea that knowledge is supported with centres of power, the voices of those who fund health interventions in Africa holds sway. They prescribe and proscribe the nature of such interventions which predominantly will be western modern medicine in form and substance. Naturally, traditional medicine is relegated to the periphery. Currently, Zimbabwe relies heavy on the Global Fund and international partners in the procurement of ARV treatment.

Another over romanticised viewpoint is 'lack of political will' (or its presence). Most scholars and lobbyists are quick to lay the blame squarely on reluctance on the part of Ministers of Health and governments to promulgate and implement policies on traditional medicine. It is an axiom that, in most (African) nation states now, there is the heavy presence of the state in regulating the lives of its citizens. One such area is governance of individual people's health. The arm of the government, the legislature has formulated laws which govern activities of all health systems. Could it be that the existing laws undermine traditional medicine or traditional medicine has been too 'professionalised' and 'rationalised' to the extent of compromising it? Or is it lack of political will per se, or what we have is a

deep entrenchment of western modern medicine in the health infrastructure (including the mindset of ministers of health, medical practitioners themselves, medical students and the general public as well) which is irresistible so to say and therefore difficult to disentangle? A recurring argument in this paper is that any policy proposition should reflect these milieus. Regrettably, the issue of traditional medicine in relation to health policy in general and HIV and AIDS treatment and care in particular has been reduced into an advocacy and lobby issue, just like human rights demands. Success of such an approach will then hinge upon individual whims and caprices in the figures of Ministers of health, who choose whether to give a sympathetic ear or show diffidence.

7.1.4. Objectives and Research Questions

The overall objective of the present study was to explore why it has remained a challenge to integrate traditional medicine to the modern medicine. To that effect, the study was guided by the following more specific research questions:

1. What is the historical backdrop against the evolvement of traditional medicine in Zimbabwe?
2. What are the legal and political challenges that hinder integration of traditional medicine in the western dominated health delivery system in Zimbabwe?
3. What are the opportunities and prospects for integration of tradition medicine in the national HIV and AIDS treatment and care, including running of ARV programmes?

7.2. Methodology and Data Analysis

This study was carried out from June to August 2011. The study used both primary and secondary sources of data. The researcher also conducted a desk review of policy papers, international guidelines, conference resolutions, case studies, Acts and Reports namely Zimbabwe National Traditional Medicine Policy 2007, Traditional Medical Practitioners Act Chapter 27:14 and the National AIDS Council 2009 Report. This suits well with the overall objective of the study which attempts to seek an answer to the question: “Why, despite well-written and well-intentioned policy papers on traditional medicine, implementation has remained a challenge?” This brings into sharper focus what ought to be done and what then gets done. This is augmented by key informant interviews which take the form of ‘interviews as conversations’ to discuss policy documents, Acts and Reports and ‘what has been the missing link if any’.

Key informant interviews conducted involved seven participants: the Chairperson of the Traditional Medical Practitioners Council and the Acting Chairperson of the Department of Traditional Medicine in the Ministry of Health, an official with the Zimbabwe Medical Association, an official of ZNNP+ a network of PLWHA in charge of overseeing faith-

based organisations, the information and communication officer of the National AIDS Council, an academic and former Chairperson of the TMPC, Professor C.G Mararike, and Professor Chavunduka as the incumbent President of ZINATHA. The research design fits well the overall objectives of this study. The institutions and key informants were selected on the basis that they are better placed to articulate policy issues. This also justifies the selection of umbrella bodies like ZINATHA, which is an association of traditional healers including bone setters, herbalists and spirit mediums and ZNNP+ which is the umbrella body for PLWHA in Zimbabwe (there are other similar bodies). The thrust is on getting the overall institutional and organisational perspective. We also conducted semi-structured interviews with five traditional healers who treat HIV-related illnesses. (These were snowballed from contacts with Professor Chavunduka).

Data is analysed thematically with the framework of Foucaudian Sociology and reviewed literature, in line with the study objectives and research methodology. The study also employed secondary analysis and content analysis of documents, quantitative indicators from statistical tables.

7.3. Theoretical and Conceptual Frameworks

This study harnesses the revealing works of Michel Foucault on the concepts of power, medicine and discourse. Though not without flaws, there is a common thread which interlaces these three concepts, which in turn offers a framework for a critical appraisal of matters arising in this study. In his work, *The archaeology of knowledge*, Foucault transcended the over-romanticised view of power as a property inherent in something out there, by emphasising the capillary nature of power. In other words, as noted by Pylypa, “Power is dispersed throughout society, inherent in social relationships, embedded in a network of practices, institutions and technologies operating on all of the micro-level of everyday life” (1998, 21). It is pertinent to unravel how medical power manifests, how certain medical knowledge comes to assume hegemony over other medical knowledge to the point of articulating them.

Foucault coined the term “bio-power”, a kind of power that “...operates on our very bodies, regulating them through self-disciplinary practices which we adopt, thereby subjugating ourselves” (Pylypa 1998, 21). The end result is a discourse emanating from the production of scientific knowledge, to define what is normality and abnormality to which individuals feel obliged to conform. According to Gelfand (1981) discourse is about production of knowledge through language but itself it is produced by social practice. Gelfand (1981:170) notes that “a discourse draws elements in other discourses binding them into its own network of meanings”. Foucault traces the emergence of modern medicine and its institutions through the evolution of disciplinary institutions in the eighteenth century. Through the “clinical gaze” the [human] body becomes an object of inquiry with the individual being the case (Henderson 1994). It is illuminating to establish

why the discourse of traditional medicine sits at the periphery of hierarchalised medical knowledge.

Such conceptual apparatus in the foregoing permit a rigorous appreciation of the current position or role of traditional medicine and biomedicine, a practical assessment of any prospects for collaboration between BHPs and THPs as well, challenges to those prospects in light of HIV and AIDS.

7.3.1. Conceptualising Traditional Medicine and Collaboration

The Fiftieth Session of the WHO Regional Committee for Africa (2000:1), in its Resolution on Promoting the Role of Traditional Medicine in Health Systems, defines traditional medicine as: “The total combination of knowledge and practices, whether explicable or not, used in diagnosing, preventing or eliminating physical, mental or social diseases and which may rely exclusively on past experience and observation handed down from generation to generation, verbally or in writings.” The practitioners include traditional healers (n’anga) herbalists, bone setters, faith healers and spirit mediums. This study adopts this definition. Mhame, Peter and Kofi (2010: 41) define integration as “increase of health care coverage through collaboration, communication, harmonisation and partnership-building between conventional and traditional systems of medicine, while ensuring the protection of intellectual property rights and indigenous knowledge”. This conceptualisation, offers invaluable insights to this paper. This study uses ‘integration’ and ‘collaboration’ interchangeably and we rather see these in a continuum and not absolute terms.

7.4. Review of Related Literature

Kanyombo *et al.* (2007) reviewed empirical evidence of initiation of collaboration between traditional healers and the Institute of Traditional Medicine in Arusha and Dar-es-Salaam municipalities. Key findings were that colonial imprints characterised by undermining of traditional healers informed the general reservations, and that collaboration is not easy as it appears to be from literature. This study as well puts the colonial experience at the centre of the analysis which, in essence, is country-specific. Nyika (2006) discusses the regulatory ethical guidelines surrounding use of traditional medicine in light of HIV and AIDS and notes that it is the magical branch of traditional medicine that complicates the application of ethical guidelines. Taylor *et al.* (2008) examined changes resulting from traditional African care and Western medical care over one month in the rural community of Chipinge in Zimbabwe. The study reveals the potential benefit of integrating traditional African care sites in ART rollout programmes in resource-poor settings, which may well go beyond cultural sensitivity to impact on health itself and ART adherence. The study, though of limited generalisability, appears to be among the first to provide evidence on the cultural dynamics that are missing from the current policies of ART roll out for Africa (*ibid.*). Bunnett *et al.* (1999) undertook a study of traditional healers and formal health workers in Zambia to

determine their knowledge and practices in the field of HIV and AIDS and examined their training needs and attitudes to collaboration in preparation for joint training workshops. The study revealed willingness to collaborate between the two sides. Peltzer, Mngqundaniso and Petros (2006) assessed 233 traditional healers in 4 selected communities in Kwa-Zulu Natal province, either on experimental intervention or intervention control condition. The study found a high level of preparedness among traditional healers to work with and refer patients to biomedical practitioners after training and not vice versa. This study mainly tackles policy issues surrounding traditional medicine in AIDS treatment and care. Wreford (2005) discusses problems and potential for collaborative efforts between biomedicine and traditional healers in South Africa in the times of AIDS. Supported by ethnographic evidence from ongoing research with THPs mainly in the Western Cape Province, the study discusses witchcraft as the prominent factor which poses a challenge to any prospects for collaboration. This is instructive to our study.

There are several examples of projects initiated on collaboration between MMPs and THPs in HIV and AIDS prevention, treatment, support and care from which lessons can be drawn. According to Madiba (2010), there is dearth of documentation of such attempts in most sub Saharan African countries. Kaboru *et al.* (2006) bemoans lack of a systematic description of experiences of and attitudes towards collaboration. Such efforts will act as vital texts from which to draw lessons and compare notes between and within countries. In the Uganda case, the Traditional and Modern Practitioners against HIV and AIDS (THETA), initiated in 1992 a partnership between The AIDS Support Organisation (TASO) Uganda Limited and Medicines Sans Frontiers. THPs were involved in evaluating effectiveness of local herbs in treating selected AIDS-related illnesses. Hills, Finch and Eunice (2006: 224) notes several innovative responses to HIV and AIDS of THPs and BMPs which include Tanga AIDS Working Group (TAWG) in Tanzania; a traditional medicine experimental centre for PROMETRA (CEMETERA) in Senegal and Buyijja Traditional Healing Institute associated with PROMETRA (BUTHI-PROMETRA) in Uganda are providing care to people in HIV and AIDS using traditional medicine. These have joined hands in the management of opportunistic infection, providing counselling services, treatment of pain as well as offering spiritual care. South African experiences include a controlled study of an HIV /AIDS/STI/TB intervention with traditional healers in two rural and two urban areas in Kwa Zulu-Natal. The idea was on assessing whether training traditional healers can reduce the risks of the practices and encourage them to provide appropriate information and referrals for TB and HIV (Mhame, Peter and Kofi 2010). Commenting on the Botswana experience, Madiba (2010) observes that patient-referral was the preferred approach. Nonetheless, despite not being familiar with traditional practices, BHPs were reluctant to learn anything from THPs, but were favourable towards exchange of information and bio-medical skills (*ibid*).

Thus, BHPs were not ready for collaboration. We argue that such findings are instructive in that they point to possible areas of collaboration. It will be inaccurate to declare any collaboration prospects untenable.

Kaboru *et al.* (2005) gathered communities' views for collaboration in HIV and AIDS care in Zambia where people were supportive of collaboration given the chronicity of AIDS and multiplicity of opportunistic infections that can be treated by traditional medicine. There was a need for research on plant parts like African potato which are touted for treating AIDS-related illnesses as well as gundamiti. Nevertheless, a common thread that seems to knit these integration endeavours is the asymmetrical relationship, the preponderance of BHPs 'discourse' over their THPs counterparts. Mhame, Peter and Kofi (2010, 42) raises two pertinent issues: it is imperative for health personnel to have an understanding of all health services accessible to their patients and all health personnel (including THPs) act as repositories of information to patients in all health and health-related matters. Thus, collaboration works to the vantage point of all concerned parties. According to King (2005), dialogue, unswerving exchange of information and keenness to learn from each other will build the much needed mutual trust and respect between BHPs and THPs. According to Homsy *et al.* (2004, 906), a regional consultation that took place in May 2003 in Kampala, Uganda defined standards of practice around themes regarding involvement of traditional healers and traditional medicine in HIV and AIDS prevention, care and treatment. The recommendations were made in accordance with the WHO guidelines. The first one had to do with evaluation of traditional medicine. It was observed that "standard clinical trial methodology was deemed inappropriate and too costly for evaluating the numerous preparations already in use by millions of people including persons living with HIV and AIDS throughout Africa" (*ibid*: 906). Spiritual healing was noted as something discrete from witchcraft.

7.5. Findings and Discussions

7.5.1. Overview of Traditional Medicine in Zimbabwe: A Historical Perspective

As with many African states, once under the colonial rule of Anglo-Saxon countries, the story of traditional medicine is one of 'subjugated knowledges' and a field treated with derision. In colonial Zimbabwe, traditional medicine was at best treated with disdain and at worst outlawed. The enactment of the Witchcraft Suppression Act of 1899 was a tacit interdiction to a belief in traditional medicine and its practice. According to Waite, the Act: "criminalised both malpractice and legitimate practice since it subsumed most materials used by healers under the rubric of "witchcraft" even though many of their charm have nothing to do with witchcraft" (2000, 238).

Waite (2000) also gives interesting insights of parliamentary debates of the 1970's and 1980's where colonial doctors and politicians alike showed disinterest in indigenous medicine. Inevitably, the African elites which include politicians and health personnel trained in western medicine also embodied this apathy. Mbwambo, Mahunnah and Kayombo (2007, 15) posit that "Colonial masters equipped with education and religious beliefs, brainwashed the African elites, which later led them to despise traditional medicine and the role of traditional health care systems that was embedded in the African traditional culture". It is an analysis of that general apathy which informs the same ambivalent feelings in the post-independence period, and hence forms the linchpin of our argument.

An overview of traditional medicine in Zimbabwe will not be decorated enough if one does not discuss the activities of Zimbabwe National Traditional Healers Association (ZINATHA). Formed barely three months after independence, and being national in outlook, it became the most organised association of traditional healers amongst many (smaller) others, with Chavunduka as the interim president. ZINATHA held its first congress in September 1980, and Chavunduka was retained as chair of ZINATHA till the early 1990s, when he was appointed University of Zimbabwe Vice Chancellor. All these fora saw the then Minister of Health, Hebert Ushewokunze and his Deputy Simon Mazorodze in attendance. Waite (2000), citing the *Herald* of May 31 1980, notes that immediately Chavunduka charged the white-dominated Medical Council and its members with trying to undermine ZINATHA, in an effort, he was convinced, to retain "full control of the field of medicine". Waite (2000) citing Chavunduka (1986a) attests that after gaining government recognition, ZINATHA went on open a research centre, a department of education and two medical colleges which taught uses of traditional medicine and account keeping but not spirit possession. In addition, ZINATHA operated four clinics in Harare and one in Bulawayo for training and treatment. With time, all these projects were aborted owing to lack of funding.

In spite of this, as rightly argued by Waite, "...still witchcraft, witch-finding and traditional doctors were associated in the public mind, and would continue to haunt the issue in a new Zimbabwe" (2000, 250). Prospects for collaboration between BMPs and TMPs may be possible on one condition from BMPs that 'TMPs do away with their religious-magico elements, something which is immeasurable and hard to prove'. Such research, health and educational institutions would need to be revitalised, if there can be some collaboration between MMPs and THPs in the provision of ART.

7.5.2. Zimbabwe National Traditional Medicine Policy of 2007: An Appraisal

With the promulgation of the Traditional Medical Practitioners Council (TMPC) through an Act of Parliament in 1981 (revised in 1996, 2000, 2001, 2002), traditional medicine was eventually put under spotlight.

Prospects of integrating traditional medicine into the mainstream health delivery system could at least be pondered on, with the former, hitherto, having existed in the periphery, unofficial and unrecognised. The Code of Conduct for Traditional Medical Practitioners was established as a statutory instrument 245 of 1997 and practicing without a license is a statutory offence. The mandate of TMPC is to supervise, regulate and control traditional medical practitioners' activities in Zimbabwe, which are all African Spiritism Medicine and Christian Faith Healing including traditional birth attendants (TBA). In other words, the TMPC is the ultimate body in the regulation of traditional medicine in Zimbabwe involved in the registration and licensing of all Traditional Medical Practitioners (TMPs).

It took the Zimbabwean government 25 years to formulate a policy on traditional medicine with the TMPs' Act having been ratified in 1981. In his foreword, in the Zimbabwe National Traditional Medicine Policy of 2007, the incumbent Minister of Health and Child Welfare, Dr. Henry Madzorera, observes that the establishment of the TMPA (1981)... "was not followed up by establishment of requisite institutional framework and mechanisms that would ensure sustained development of the sector". Thus, the 2007 policy document heralded such a watershed. It can be posited that such a lapse in time not only points to the hesitancy on the part of the government, but the tumultuous and anaemic road to implementation. Many would recall the Ushewokunze-Chavunduka era, with the former being the Minister of Health and Child Welfare then, who had to bear the brunt of an scathing criticism from his cabinet counterparts upon the reading of the Traditional Medical Practitioners Bill in parliament, attacks amounting to personal ridicule (this is well captured by Waite 2000 who scrutinised parliamentary debates and the press of the time). The point is not that such personal ridiculing is something uncommon or unwarranted; it is that such episodes tended to predict how the issue of traditional medicine was going to be personalised, such that the implementation (or lack of it) of a country's policy document was to hinge upon an individual (such as a minister) and not to the best of 'national interests'. Based on observations from key informant interviews (the Chairperson of the TMPC and Professor Mararike), one can actually draw a typology of the reign of a particular minister, whether he/she is 'sympathetic' to traditional medicine or not and the implementation thereof.

The Zimbabwe National Traditional Medicine Policy of 2007 is a comprehensive document which is sound in most respects that can be envisaged from a policy blue print of that nature. Nonetheless, the document seems to have suffered the same fate with most policy blue prints—non implementation. The vacillating stance of the government becomes apparent where no funding from the national budget has been availed and researching on traditional medicine has not been made a priority (key informant interview with the Chairperson of the Department of traditional medicine in the Ministry of Health). It would seem a pipe dream, realising some collaborative work between THPs and BMPs in

provision of ARVs to PLWHA when institutions and structures are weak. According to a key informant interview with the Chairperson of the TMPC, funds from the government available to them are not enough to meet even the administrative costs of the Council. Another challenge seems to be too much power retained by the Minister of Health in terms of the Public Health Act. For instance, it is the Minister who appoints the Chairperson of the TMPC. One would envisage a different scenario when the Chairperson of the TMPC comes from associations in traditional medicine. It is a mammoth task for traditional medicine to be recognised when the incumbent minister is not sympathetic to the cause. We are persuaded to go along with Foucault's notion of discourse which has a tendency to draw elements in other discourses binding them into its own network of meanings. Here, we see the usurping powers of biomedicine in conjunction with laws, with biomedicine being the dominant discourse which defines minimum standards. Any prospects for collaboration between BMPs and TMPs in running HIV and AIDS treatment will have to be engendered in legal instruments which support the cause.

7.5.3. Traditional Medical Practitioners Code of Ethics: A Review

There continues to be preponderance of western medicine which emphasize strict streamlining and specialisation in both form and substance of the medical practice. Traditional medicine engenders a holistic approach to illness, which in most cases involves a combination of various diagnostic measures relating herbalism, spiritual therapy and/or 'bone throwing'. A strict and rigid definition of medical practice in western medicine does not fit to traditional medicine. Significant clauses of the Code of Ethics have a whole list of 'don'ts' on the part of TMPs. TMPs are outlawed from employing the title "doctor" "...either directly or indirectly, in a way likely to suggest that they are registered conventional/orthodox medical practitioners, except if that is the case". They are prohibited from using equipment normally used by 'qualified conventional medical practitioners as well as administering an anaesthetic. It is interesting to note that in this section of the code of conduct, emphasis is put on 'don'ts' and no attempts are made to include 'do's'. Could it be that, there was no enough consultation to outline how TMPs administer medicine or diagnose their patients. Why should use of the title 'doctor' be so important in relation to the public (after all it is synonymous with practitioner or specialist) than maybe to the medical fraternity itself.

7.5.4. Zimbabwe National Strategic Plan 2006–2010: The Case of Research and Development

In its five-year strategic plan, there was no explicit mention of traditional medicine whatsoever in treatment, care or psycho-social support by the National AIDS Council in Zimbabwe, which is the umbrella body tasked with leading and coordinating a multi-sectoral national response to HIV and AIDS. Twelve years down the line since its formation in 1999, NAC still planned to embark on "research and development initiatives which will

include expanding studies into the effectiveness of alternative therapies, what they offer and how they can be utilised ...” The Zimbabwe National Traditional Medicine Policy emphasizes the need for funding research and development of traditional medicine in light of HIV and AIDS. To date, no serious work has been done to that effect. As noted by Patwardhan, Vaidya and Chorghade (2004: 789), “Traditional knowledge will serve as a powerful search engine and most importantly, will greatly facilitate intentional, focused and safe natural products research to rediscover the drug discovery process.”

According to Amon (2008), in Zimbabwe, the herbal remedy '*guandamiti*' — developed with support from the United Nations Educational, Scientific and Cultural Organization (UNESCO), Kellogg Foundation, the US National Cancer Institute and the World Health Organization — has been promoted as significantly reducing viral load (variously reported as 60–76 per cent or 90 per cent) and opportunistic infections. The story of '*guandamiti*' died a natural death with results of its efficacy and safety still shrouded in mystery. Scholars such as Amon (2008) writing in a Western tradition, launch unscathing criticism on what has been pigeonholed as traditional medicine in light of HIV and AIDS as nothing but 'fraudulent and counterfeit drugs which should be urgently outlawed' by WHO and governments. Though there is nothing wrong with drawing attention to such 'counterfeit AIDS drugs' in rampant use in the African townships and cities, it is such scholarship which does not acknowledge some opportunities in traditional medicine in AIDS treatment which underlies the general apathy shown by governments to fund research in traditional medicine. Another reason for the general apathy is purely an economic one. Modern medicine means lucrative business for large pharmaceutical industries of American and Western origin. Any such attempts at undermining their businesses will be met with equal resistance. Foucault emphasizes on how what counts as knowledge is supported with centres of power. UN agencies including WHO will inadvertently emphasize biomedicine in the form of ART, giving a cosmic attention to African traditional medicine.

Given that a 2010 target of universal access to ARV treatment has already been missed and in light of the fact that the number of people who are on ARV treatment falls short of the total number of people requiring such treatment, it calls for a long-term and pragmatic approach in AIDS treatment which should consider the significant role of traditional medicine. We argue that given the deep entrenchment of modern medicine in HIV and AIDS treatment and the national health delivery system in general, one of the most feasible areas of collaboration with traditional medicine is in research and development. Therefore, in light of new infections and high morbidity rates, long-term strategies are required and one such is investment in research and development of traditional medicine.

7.5.5. Political Will and Policy Implementation: The Place of Politics

When one traces the trajectory towards professionalization of traditional medicine (getting traditional medicine formally recognised by the government in Zimbabwe), the Ushewokunze-Chavunduka provided the watershed towards that goal. Then Minister of Health, Hebert Ushewokunze did not give a cosmic attention to traditional medicine. He embraced it and energetically advocated its use and its incorporation into law and mainstreaming into the national health delivery system. One may be tempted then, to pose a hypothetical question: Had Hebert Ushewokunze continued to be the Minister of Health to date, what would be the status of traditional medicine in light of HIV and AIDS treatment, support and care?

After the Hebert Ushewokunze era (we have ignored the reign of his predecessors who came in-between with brief stints) came Timothy Stamps who had the longest period as Minister of Health than his precursors. Being white in race and having been schooled in Europe, it was hard to conceive his zeal and passion for traditional medicine. His era was a fascinating scene of politicking and bickering. During a key informant interview, Gordon Chavunduka, the President of ZINATHA, confided that though government was supportive of traditional medicine, 'politics was starting to cripple in. The then ZANU PF government started to portray neo-patrimonialism and cronyism whereby they expected all bearers of offices in institutions to be sympathetic to the party. At one point, Stamps confided to Chavunduka that the latter was the subject matter in a cabinet meeting and Stamps was tasked with removing him because "his politics was wrong". After failing to remove Chavunduka, the government then began to support other splinter groups. The point here is that well-intentioned policies may fail to be implemented because of individual idiosyncrasies and incompatible personalities. We argue that any prospects for collaboration between BHPs and THPs in HIV and AIDS work will have to deal with these seemingly individualistic matters, in case they arise. During the reign of David Parirenyatwa as Minister of Health and Child Welfare (a student of Timothy Stamps), emphasis was put on a strong regulatory framework for traditional medicine. The focus was not so much on advocating and justifying the integration of traditional medicine into the national health delivery system but on regulating and 'policing' traditional medicine so that it operates within the confines of law and international guidelines. The zeal of championing the cause of traditional medicine reminiscent of the Ushewokunze era had waned. Parirenyatwa was very sceptical and, for a long time, declined to register apostolic sects under the TMPC.

Under the current government of national unity, one can safely pronounce a policy vacuum. Again traditional medicine is likely to be pushed to the periphery in a period when the ministry depended on the Global Fund and foreign donors to procure HIV medicines. These funders emphasise on ART as opposed to traditional medicine. Thus, it will be long before we see

a huge investment in traditional medicine per se. The best that can be harvested in the near future in light of the HIV and AIDS pandemic is development and strengthening of rudimentary forms of referral system between modern medicine and traditional medicine, especially in treatment, support and care. We argue that the challenge is not with the policy. The challenge lies with bearers of offices who choose to either give a sympathetic ear or show diffidence in implementing policy. This state of affairs only goes to substantiate our argument that most well-intentioned policies have failed to achieve intended targets owing to individual idiosyncrasies, whims and caprices.

7.5.6. Possible Collaborative Work in the Provision of Antiretroviral Treatment

Given the uneasy relationship that exists between TMPs and MMPs, it may seem hard to conceive of any common ground in offering HIV and AIDS treatment in Southern Africa. Taking into account ‘windmills of stigma’, characterising traditional medicine, it would seem impossible for traditional medicine to form an alliance with modern medicine. Given the severity of HIV and AIDS in resource-constrained settings and where moral belief on the pandemic is still rife, it takes a nation to harness all its resources, be it medicines, human resources and the emotional intelligence to offer hope for access to universal treatment and prolong lives.

Generally, BHPs are sceptical and downplay any role by THPs in the provision of ART. An official from ZIMA and Chairperson of the TMPC showed a lot of scepticism and the latter sarcastically retorted: “*You now want us to talk theory*”. This portrays the uneasy relationship between the two systems. Himself a pharmacist by qualification and by profession, who has received years of tutelage in orthodox medicine, and now heading the TMPC, he seems to be in an intercalary position. However, he declared his passion for TM which has been stigmatised since colonial rule. He stated his vision as one of rebranding TM in the country so that we can tap into its richness and efficacy in preventive remedies. However, some common ground can be found in provision of treatment in general and ARV treatment in particular. The study revealed that some common areas between traditional medicine and modern medicine can be found in running ARV programme. All the key informants concurred and marvelled at the ‘emotional intelligence’, the charisma in social mobilisation, embodied by most TMPs. Thus, we rather think of roping TMPs in adherence counselling in running ARV programmes. It is well-documented that accessing ARV treatment is one thing and adherence to the treatment is another. In essence, it is problematic to separate treatment and care (as is easily done in HIV and AIDS discourse). The two are mutually exclusive. Treatment regimens are administered and care and adherence is equally as important as the treatment itself.

Related to the foregoing, TMPs come in handy as part of the human resources for social mobilisation as well as being a conduit in accessing

ART by PLWHA. According to one key informant, we rather think of basic training of TMPs in subjects like safety and hygiene, ethics and rolling out ARV prescriptions. Thus, TMPs, because of their social skills which most medical doctors lack, become conduits for accessing of ARV treatment by their communities. However, there are always sticking points. According to Chavunduka and Murray (1986: 259), the challenges can be stated in the form of questions: “How will they be remunerated? Will they sign medical certificates? Will professional association defend their rights? What will be the degree of their formal subordination?” These questions would need answers. The encouraging thing is that something can be worked out to the best of ‘national interests’. Nonetheless, it will require commitment on both parties (BHPs and TMPs) and the government. Foucault notes that knowledge is an expression of power and itself a manifestation of power. Modern doctors are quick to dismiss TMPs as unschooled and uneducated, at least according to formal schooling standards. It takes five years for someone to complete a degree in medicine and become a medical doctor. Thus, what then will be the degree of formal subordination with someone who did not take that route? TMPs themselves may be unwilling to enter into a partnership where they are looked down upon and scoffed at. However, it can be argued that with a committed minister of health, the medical fraternity, some unity of purpose can be realised.

Given the burden of disease and a depleted trained health personnel in resource constrained countries like Zimbabwe, there are immense benefits that can be harvested from a joint running of ARV programmes. Notably, Homsy *et al.* posits of “Maximum benefits that can be reaped from antiretroviral therapy hinge on sustained drug supply, the adoption of practical treatment regimens and sustained follow up and support before, during and after enrolment into treatment programmes” (2004, 1723). In other words, given how chronic the AIDS epidemic is, coupled with the fact that despite the dominance of the biomedicine discourse, moral beliefs on the pandemic are still rife; it calls for a concerted effort by all stakeholders in the health system to monitor and evaluate progress. It is one thing to give AIDS patients antiretroviral therapy and another thing to ensure it has been utilised. We argue that despite burgeoning messages and information on AIDS epidemiology, native people in farm compounds, mine compounds, ‘secret societies’, religious sects, and ethnic groups have their own ‘moral geography’ ‘own world views’ and cultural practices with own moral entrepreneurs and gatekeepers. It follows that a nationally government-run ARV programme ‘a one size fits all’ approach may record varying levels of effectiveness, because people may be utilising traditional medicine, which is culturally appropriate and relevant. THPs, familiar with ancestral community roots and their lived experiences of poverty, inequality and diseases, AIDS included, have earned great social honour which makes them better placed to promote behaviour change, to support and refer PLWHIV (*Ibid.* 2004). A triple role of complementary caregivers, treatment adherence counselling and referral advisors could thus be

fulfilled by THPs (*Ibid.* 2004). The foregoing concurs with views from a key informant interview that: “In Zimbabwe, traditional healers from ZINATHA were among the first to come up with some form of medicine to treat AIDS-related illness in the form of *gundamiti*. Why, then, are they not involved in the rolling out of ARV programmes today? Why are they not trained to administer even ARVs?”

One of the major sentiments revealed from the study is that indisputable areas form the basis for collaboration between TMPs and BMPS. Some areas of traditional medicine seem less problematic and can readily be integrated with mainstream medicine. Herbal medicine is one such area. According to Chavunduka and Murray (1986, 264) herbalists have been pushed by University Departments of Pharmacology, Pharmacognosy and Chemistry seeking collaboration and local expertise. The Director of TMPC noted in an interview that the Department of Pharmacy at the University of Zimbabwe is ready to partner in projects on medicinal plants and animal parts that are of medicinal value. Plans are already under way to single out specialists in medicinal plants who can recruit ‘students’ under their tutelage for grooming over a specified period of time. Some courses will be offered in code of ethics, safety/hygiene, and basic accounting. Minimum entry qualifications of five passes in ordinary level will be demanded and then ‘continuous professional improvement’. Such a project is similar to the one started by Chavunduka in the early 1980s. However, standards of “do no harm” (safety), efficacy and quality seem not to be negotiable. There are some herbs which help deal with symptomatic issues, some on immune boosting (for instance, *Moringa*) and which can be taken concurrently with ARVs.

In view of the foregoing, such lines of less resistance again are not without problems. Chavunduka and Murray (1986, 267) observe that “Technical herbal expertise will be recognised for its empirical pharmacognosy, without reference to the symbolic and ritual matrix within which it is used—till less, the social matrix in which those rituals and symbols have meaning at any particular time or place”. This corroborates with the sentiments from a key informant that read: “we can’t teach someone to be a spirit medium”. UNAIDS (2000, 10) envisages some consensus for collaboration and support if TMPs divorce the metaphysical from their physical elements in their profession and this is met by BHPs jettisoning their rigid dogma and disparagement. Thus, there is some acceptable work from traditional medicine but some which cannot be compatible with biomedicine. This stance only goes to show how modern medicine has become a discourse in the Foucaudian sense, something deeply ingrained in the national health delivery system such that any attempts to introduce something alien, is complete upset of the very basis of social order. It is more prudent to take that which can be married with the mainstream than to declare such collaboration impossible and unworkable at all.

Commenting on the possible collaboration with traditional medicine in HIV and AIDS prevention and care in SSA, UNAIDS (2000, 10) notes that, “Traditional healers provide client-centred, personalised health care that is culturally appropriate, holistic and tailored to meet the needs and expectations of the patient”. This again buttresses the point that traditional healers can be roped in treatment and ARV adherence counselling because of their skills in social engineering with a high social standing in their communities. Sentiments from the key informants aver that THPs can mobilise communities to HIV testing— promoting adherence to drug regimens, monitoring side-effects, sharing their experiences in disease progression (or lack of it) with BHPs and vice-versa. It is also worthwhile to train TMPs on the prevention, treatment and care though Ritcher (2003, 20) is quick to caution that such training will not involve them using ART but “guidelines on HIV-related care”. The major objective is to “incorporate traditional medicine into the pharmacovigilance process which will include the development of a national database on phytovigilance and their interactions between ART and traditional medicine”. Again, the much cherished virtue here, on the part of TMPs, is their supposed ‘emotional intelligence’, their ability to hold sway over communitarians, which have earned them social honour as gatekeepers, family counsellors and even as religio-political leaders (key informant, Professor Mararike).

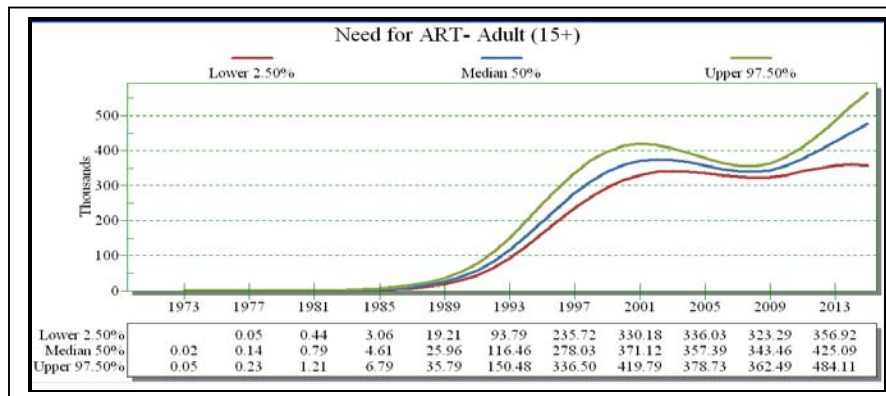


Figure 1. ART Trends¹ in Adults

SOURCE: National AIDS Council Annual Report (2009)

Figure 1 shows trends in the increasing gap between the number of people who can be accommodated on the public ART rollout programme. WHO (July 2010) guidelines which recommend initiation on ART at 350 CD4 count has increased the number of adults who require ART in Zimbabwe up from 350,000 to 600,000, which creates a dire situation. In light of this, traditional medicine can act as a ‘bridge’ for those on the ‘waiting list’ who will ultimately enrol on ART treatment (key informant ZNNP + FBO). Private institutions are out of question for many people who cannot afford

exorbitant costs of ART. The activities of faith-based organisations, traditional healers and herbalists have opened avenues and rays of hope for such people. It can be argued that religion is one of the major pillars of human life which engenders psychosocial support in times of uncertainty and where an ailment does not have a cure. The point is not whether the activities of faith healers are authentic and are effective in treating HIV and AIDS or not. The point is what people believe to be true can actually be true in its consequences. In this scenario, both TMPs and MMPs can establish a ‘working relationship’— a referral system where people who cannot be accommodated on ART treatment at a particular time can be catered for by either party.

However, in view of the foregoing, such arrangements are not without problems. It is interesting to note that under the membership of TMPC of Zimbabwe, we find both ZINATHA and FBOs. There is a ‘struggle within a struggle’ where traditional healers, herbalists, and spirit mediums on one end and FBOs on the other, at best are not premised on the same basis on disease aetiology and diagnosis and at worst undermine each other. The uneasy relationship between Christian organisations and traditional medicine dates back to missionary work during colonial times when traditional medicine was dismissed as heathen and fake. One wonders if the very institutions are pigeonholed under the same banner of traditional medicine, some positive output could be realised. A case in point, trivial though instructive, is what kind of ‘prayer’ should herald the start of a council meeting (interview with Chair of the TMPC). We argue that it is very problematic to house FBOs and traditional programmes to faith healers to ‘pray for the HIV-positive persons and refer the person to the hospital. The consistent argument here is that TMPs, be they traditional healers, faith-healers and/or herbalists, cannot be entrusted with the actual administering of treatment of ART. TMPs are essential for social mobilisation, referral system, and adherence counselling. In view of the foregoing sentiments, two issues become apparent. The incidences of charlatans who go on to fake use of herbs and fake healing of PLWHIV of the virus is not uncommon. However, in line with Foucauldian analysis, it can also be argued that the strong detest shown in the foregoing, embodies a discourse, which has been generated, propagated and sustained by proponents of western medicine in the medical field, educational institutions and government. This has percolated into society and ‘there is no treatment which equals ART when treating HIV! This discourse has been made possible by studies in epidemiology and aetiology (during the earlier years when the pandemic was discovered) which came from the West. This discourse is sustained by funding which specifically promotes ART treatment. One may be persuaded to concur with Marxist view on medicine that monopolies and oligopolies of pharmaceutical companies supplying ART are part of the wider capitalist system with an insatiable desire to make profit. Traditional medicine is viewed as a threat to this drive!

7.5.7. *The Bone of Contention*

The issue of intellectual property rights with regards to traditional medicine remains a sticking point shrouded in great mystery and controversy. According to Tshibangu *et al.* (2004) “Traditional health practitioners are reluctant to collaborating with modern doctors for fear of giving away their hard-earned knowledge on herbal medicine”. In a key informant interview, the President of ZINATHA revealed that there is a lot of mistrust and suspicion between BHPs and TMPs. The argument by THP is that “*tinobirwa mishonga yedu*” (our medicines are stolen). One of the key informants, Professor Mararike, observed that Pharmacists trained in modern medicine go on to making a lot of financial gains at the expense of TMPs and their communities and worse still, BHPs do not even acknowledge TMPs as a source of discovery. The issue of intellectual property and its compensation has been one of the contentious issues with regard to traditional medicine. Hillenbrand (2006) attests that traditional healers reflect on the bumpy road they would travel— to master their art, they are unwilling to handover to an uninitiated researcher even if such sharing stands to benefit themselves or the communities. The issue of how to compensate THPs of their medical and botanical knowledge has proved to be a moot and sensitive one. Thus, as revealed from a key informant interview with the Information and Communication Officer with NAC, it is hard to conceive collaboration as TMPs then prefer remaining secretive. Thus, most of the medicines cannot be tested. On the other hand, BHPs are convinced that it is out of question to think or view BHPs to be at par with TMPs or to insinuate something of that idea. BHPs are quick to point to several years needed to obtain a degree in medicine, let alone several years of secondary and advanced level education. Nonetheless, the premier of ZINATHA alleges that for a *makumbi*, someone under the tutelage of a seasoned traditional healer take even more years learning the practice. Any prospect for collaboration between BHPs and TMPs in HIV and AIDS will have to take this into account.

There are a lot of issues which underlie the discordant relationship between BMPs and THPs, the lack of confidence in each other, mistrust and suspicion. Hillenbrand (2006) notes that proponents of biomedicine attest that traditional medicine is fraught with problems of imprecise dosage, poor diagnosis, charlatanism, inadequate knowledge of anatomy, hygiene and disease transmission which endanger lives. The predicament of TMPs was summed up well by the OAU:

The main contributing factor [for the poor cooperation between traditional and conventional medical practitioners] has been lack of confidence, since they [traditional medical practitioners] are seldom legally protected. There are very few if any, that address the issue of traditional medical systems in totality. Merely recognising the existence of MTPs is not sufficient. Laws and regulations to empower and protect them have been enacted. These legal rights

would allow the TMPs to benefit from adequate compensation for their knowledge. (OAU 1997, 8).

The foregoing argument is supported by the case of ZIMA which is one of the most powerful institutions which influence medical policy and enjoys the support of government, unlike ZINATHA which has been reduced to a pressure group (Interviews with Professor Mararike and Chavunduka). Thus, any mulling of the idea of some collaborative work in running ARV programmes between BMPs and TMPs has to be cognisant of these challenges, and at least try to address them. These challenges should not be insurmountable to the point of declaring any collaboration null and void.

7.6. Conclusions and Recommendations

7.6.1. Conclusions

In view of the foregoing, a number of conclusions can be drawn. Collaboration between biomedical health practitioners and traditional medical practitioners in running ARV programmes is readily applicable in referral system, adherence counselling, social mobilisation and management of opportunistic infection. In other words, biomedical health practitioners embrace collaboration with traditional health practitioners, where the latter are not involved in actual administering of treatment. In ARV programmes THPs can only play a complementary role given that most traditional medicines are still undergoing trial on safety, equality and efficacy. THPs are vital health personnel who are readily available and can be considered in scaling up ARV treatment, support and care. Another key conclusion is that collaboration in running ARV programmes by both BHPs and THPs would require a lot of consultative work to cultivate mutual trust and respect. Areas for collaboration would require clear elaboration, the work of which will require to be operationalised by statutory instruments. Experiences from other country projects are vital texts from which to compare notes and consider replicating. For instance, in 1992, the Traditional and Modern Practitioners against HIV and AIDS (THETA) initiated a partnership between TASO Uganda Limited and Medicines Sans Frontiers. In light of the uneasy relationship between traditional medicine and modern medicine, which dates back to colonial times, the challenge cannot be solved any time soon to the satisfaction of either party. The most judicious decision to make in light of a life threatening pandemic like HIV and AIDS is to look for areas where the two can partner to the best of 'national interests' (referral system and minimal integration). It is apparent that the whole national health delivery system in Zimbabwe is premised on modern medicine, and any future work should focus more on rebranding and professionalising traditional medicine to meet the standards of mainstream medicine. The other policy option is to take traditional medicine as a science on its own and everything will hinge serious political commitment of the government, WHO and other funding agencies to heavily invest in research and development (parallelism). Full integration is neither possible nor desirable. Traditional medical institutions indeed have

a role to play in the running of ARV programmes. Given that access by all to ARV treatment may not be realised any time soon, and noting that adherence is a separate important issue alone, Africa including Zimbabwe needs to harness its readily available resources to achieve universal access to treatment and care. The major bone of contention between traditional medicine and modern medicine is the magico-spiritual component of the former. Research has revealed that a person's belief system is so intimate and so sacrosanct to one's identity, hence it can go a long way in offering psycho-social support, itself an important ingredient which impacts on treatment. The question now should not be on whether collaboration is feasible or desirable but on how such collaboration can be realised.

7.6.2. Recommendations

In light of issues from the foregoing study, the following policy lessons and recommendations can be drawn. There is need for strengthening of the referral systems between traditional medicine and biomedicine; collaboration should be provided for and defined by statutory instruments; there is need for extensive consultation between THPs and BHPs to minimise differences and define the nature of collaboration; heavy investment in research and development of traditional medicine as an entity on its own should be prioritised; there is need for mobilisation of local financial resources as outside assistance comes with strings attached to it; there is need for rebranding of Traditional Medicine in light of ingrained stigma; mainstreaming of studies in Traditional Medicine in educational curricula especially at tertiary level so that it becomes a discourse on its own is pertinent and separating policy from individual idiosyncrasies (Ministers of Health) for improved policy implementation is vital as well as clarifying of intellectual property rights on the part of TMPs.

Notes

1. The estimated number of adults (age 15–49 years) needing antiretroviral therapy (ART) first peaked at 366,550 in 2004 and it dropped to a low of 338,947 in 2008. The number in need of ART is estimated to increase to 343,460 in 2009. Thereafter, the increase is estimated to continue throughout the projection period. Approximately 150,000 people received ART in 2008 through the public sector programme which started in 2004.

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CHAPTER EIGHT

The Ambivalent Patient: A Study of Patients' Attitudes and Perceptions Towards ARVs and Traditional Medicines or Faith Healing for Managing HIV and AIDS Illness in Rural Harare, Zimbabwe

Shastry Njeru

Abstract

The packaged weakness of antiretrovirals (ARVs) is that they do not promise a cure for HIV and AIDS problem. ARVs are actively encouraged among patients in order to delay full-blown AIDS. Yet, for pharmaceutical companies, for generic ARV drugs and their distribution chain, alternative treatment (from traditional and faith healers) is a barrier to universal access to ARV treatment for people suffering from AIDS. The patients seem to understand this paradox and some have become ambivalent in their uptake of ARVs. It can take months for a person diagnosed with HIV to be on the ARV treatment plan in Zimbabwe, because of clinical challenges and shortages of drugs. This lengthens the ARV demand queue to the point of tiring. As a result, very few people are on the ARV treatment scheme compared to those already diagnosed with HIV. In Zimbabwe, sickness representation is not so simple. It is both a medical issue and a spiritual misadventure. In the process of consulting hospitals for medical advice and treatment, patients often consult traditional or faith healers, just in case. Ardent believers of traditional or faith healing find it hard to accept the opinions from the medical practitioners. It is no wonder why the practice of referring seriously ill patients to the traditional healers or faith healers during their terminal days is so rife in Zimbabwe. This chapter looks at the crosshairs of treatment decisions from a view point of patients suspected of suffering from HIV and AIDS on what should be done to reduce the suffering in the context where options to disease treatment are a collective responsibility. Disease treatment options therefore resonate a powerful social response to what has already been said of ARV drugs (that they do not cure); the general stigma suffered by the infected patient, lack of information, level of illness, family beliefs and the treatment costs that wreak havoc in psyche of the patient. It is not a weakness often seen as ambivalence by biomedical practitioners.

Keywords: ARVs, traditional medicines, faith healing, therapy, ambivalent

8.1. Introduction

Reducing the spread of HIV and AIDS among the people is any government's critical health priority. Reflective of that trend, in Zimbabwe, resources that have been provided toward the measures that ensure this pandemic do not reach unprecedented levels. The Ministry of Health and Child Welfare reports an encouraging declining trend in HIV and AIDS

prevalence in Zimbabwe (UN 2010). This has been attributed to the effects of concerted efforts in the fight against HIV and AIDS through spirited awareness programmes and making ARVs accessible to the patients. The reduction is also attributable to the World Health Organisation's "3 by 5" initiative and expanded efforts toward universal access by 2010 of the antiretroviral therapy in sub-Saharan Africa where 65 per cent of the people live with HIV and AIDS (Birbeck *et al.* 2009). But, it will be incomplete to attribute this development to the success of biomedical intervention alone and information availability. Oftentimes the traditional/faith healing and biomedical traditions have played vital roles by providing medical solutions to many Zimbabweans. In the bazaar of medical solutions, sick people have chosen one medical trajectory or they have eclectically mixed different medical solutions in an attempt to cure debilitating sickness like HIV and AIDS. Obviously, this is discouraged in modern medical practice. However, it is fascinating to note that the greatest response to the impact of the AIDS pandemic has been the patient's ability to use the allopathic and traditional medicines concomitantly. As put across by Ross, 8 out of every 10 black South Africans are believed to rely on traditional medicine alone, or in combination with Western medicine (Ross 2010).

AIDS patients have been noted for their "medical plurality" as a result of their search for proximate, lasting, affordable and effective healing. Medical plurality is viewed as a normal response to illness in Africa. "Medical plurality" here should be understood as the capacity to have different representation of illness, health and therapeutic acts co-existing (Ribera 2007). Many have visited healers and medical practitioners concurrently in search of medicines that heal. It is estimated that 80 per cent of the populations in the SSA use traditional healers as their first line of contact (Mutinta 2007) for medical support. In South Africa, it is also estimated that 80 per cent of black people regularly consult traditional healers for the majority of their health care. Traditional healers claim a big market niche since they "can be consulted before, during or after seeking medical treatment, as they tend to provide patient-oriented and culturally appropriate care" (Shuster *et al.* 2009).

In the developed world, too, concomitant use of drugs is not uncommon. The multivitamin and mineral dietary supplements are mostly used as complementary and alternative medicines (Kiguba *et al.* 2007). Most patients argue that the pharmaceutical drugs fail to treat symptoms adequately when rapid symptom relief is required (*ibid*). Some complain of dangerous side-effects from antiretroviral therapies (ART). As a result, some stop using the ART and resort to the use of local herbs (*ibid*). Moreover, the uncertainty of the chronic character of the HIV and AIDS and its lifelong treatment is worsened by the paradox of the HIV medications: they are both life-saving and toxic. This causes worries in patients leading to the development of ambivalence that leads to non-adherence (Vervoort *et al.* 2007, 275).

The traditional medicines are considered as dietary supplements, safe, and effective without side-effects as well. This inoffensive image of the herbal medicines encourages self-medication (Sales *et al.* 2008). In some cases, upon the advice of their traditional healers, patients combine the ARVs and herbs, thus making some form of modification of the drug regimen. As in some cases, the traditional healers have not supported biomedical treatment interventions in the long run, which they blame for not addressing the reason for illness. According to them, biomedical interventions cannot provide the complete healing for the patients affected by HIV and AIDS (Shuster *et al.* 2009).

In an era when the coverage and access to free highly active antiretroviral therapy has doubled in Africa (UNAIDS 2006) and exponentially in Zimbabwe by 29 per cent (Government of Zimbabwe 2009), there are many people who still cannot completely rely on the biomedical therapies. Using a western Ugandan study, Bepe *et al.* (2011) have demonstrated that HIV-positive patients combine the traditional herbs and ARV drugs at the same time for the management of HIV infection. The major reason for this behaviour is that traditional medicines are considered capable of giving additional efficacy, improved quality of life, and a feeling of control over the disease (*ibid.*). In Zimbabwe, the commonly used herbal medicine is *Moringa oleifera* (Fahley-Jed 2005) and the African potato (*Hypoxis hemerocallidea*) (*Ibid. op cit*). Besides making herbs more visible during the HIV and AIDS era, many Zimbabweans have always used herbs as their primary drugs to treat minor ailments like common flu, diarrhoea, and headaches with varied success.

The other drive for resorting to traditional medicines even where ARVs are freely provided has to do with disease representation and healing beliefs. In most Zimbabwean traditional systems, sickness and healing are often “cast as holistic, personal and social” (Morgan, Williams and Wright 1997). Success in disease treatment becomes a “meaningful explanation for illness and response to personal, family and community issues surrounding illness” (Davanesen 1985). Illness, therefore, is “social and spiritual dysfunction” (Saethre 2007). Conversely, the biomedical approach casts a disease as a result of physical and environmental factors. For example, cholera outbreak is clearly a result of sanitation problems, but death as a result of contracting cholera could be spiritual mishap. This has resulted in “poor compatibility” (Mahaer 1999) of traditional and biomedical disease representation and a “clash” or barriers to effective clinical treatment has often resulted in some cases.

The major goal of antiretroviral therapy is to reduce the incidence of opportunistic infections and delaying the progression of AIDS (Bepe *et al.* 2011). Strict adherence to ARVs is regarded as effective in reducing the incidence of such infections (Birbeck *et al.* 2009). Many patients have failed to adhere strictly as required in those taking ARVs while taking traditional medicines as well. But, in countries like Thailand, the use of

herbal medicines has been associated with better mental health outcomes (Langlois-Klassen *et al.* 2007). However, research in Zimbabwe has shown that concomitant use of ARVs and herbal medicines causes pharmacokinetic problems. Monera *et al.* (2008) found that *M. oleifera*, popular in Zimbabwe as immune boosting foliage as well as a dietary supplement often taken concomitantly with ARVs, has inhibitory effects on the way Nevirapine and Efavirenz are metabolised or transported (*Ibid.*). Toxicity, pathogen resistance and treatment failure are said to be the negative results (Bepe *et al.* 2011) of taking *M. oleifera* concomitantly with either Nevirapine or Efavirenz. Even the eating of garlic as herbal remedy or nutritional supplement is reported to have ramifications as well.

Despite the known problems for using the traditional herbs as sole treatment regimen for AIDS and/or concomitant use of ARVs and herbs or discontinuation of ARV therapies, many rural Zimbabweans continue to fall back on the herbs. In a research conducted by Stein, Gora and Macheke (1989) in rural and urban areas in Zimbabwe, a conclusion was arrived that even when drugs could be as cheap by 52 per cent, people tend to self-medicate in rural areas. In similar studies conducted in rural Uganda, it was found that 63.5 per cent of AIDS patients had used herbal medicine after HIV diagnosis. Same-day herbal medicine and pharmaceutical drugs use was reported by 32.8 per cent of AIDS patients. Patterns of traditional herbal medicine use were quite similar between those on antiretroviral therapy and those who received supportive therapy only. The primary conclusion is that AIDS outpatients commonly use herbal medicine for the treatment of HIV and AIDS (Langlois-Klassen *et al.* 2007). However, studies have shown that viral suppression and improvement in immune status can be achieved among patients with near-perfect adherence to antiretroviral therapy (Kiguba *et al.* 2007). In spite of these findings, patients continue to take ARVs and herbal drugs as already shown. The literature available seems to point to the fact that there are very few ART adherence researches conducted in rural Africa (Birbeck *et al.* 2009: 672). Most conclusions about concomitant use of ARVs and traditional medicines are based on inferences. Literature on Zimbabwe on this problem does not exist. This chapter seeks to demonstrate that there is some level of ambivalence among HIV and AIDS patients caused by underlying factors that are based on preponderant “social construction and world views of health, illness, disability and healing” (Ross 2010). These shape the changing perceptions and attitudes of the patient to ARVs in rural Zimbabwe even when they are offered free of charge.

8.2. Literature Review

Medicines constitute a meeting point of almost any imaginable human interest: material, social, political, and emotional... They are indeed emblems of concern but also commodities in a hard and merciless market. They are political weapons in the hands of the powerful. They play their many roles at different levels of social and political organization: in

international policy and funding, in national politics, in local health institutions, in consulting rooms and shops, on the street corner, in households and, ultimately, in the private lives of individual patients. They are merchandise in formal and informal, public and secret, legal and illegal transactions (Sjaak van der 2006).

Compounding the foregoing medical cliché, HIV and AIDS problem has a crippling metaphor (Sontag 1989). This metaphor prompts fear, revulsion, paranoia and stigmas among the infected, affected and the onlookers. Caught up in between medical vortex is the poor rural sufferer of HIV and AIDS seeking nothing else but lasting solutions to his/her problems. As illustrated in the cliché the *homo sacri* is the patient affected by medical politics and initial lack of understanding of the disease by the modern medical practice. This lack of knowledge has led the medical community and the lay people to think that the disease is a “veritable plague” (Comaroff 2007), an end time apocalyptic vengeance of God.

HIV and AIDS has not only rewritten the “geopolitical coordinates” where people think in and act on, but also challenged the etiological underpinnings of disease, illness and responses. With this view, Comaroff concludes that AIDS and HIV have crystallised the “latent contradictions and anxieties” in the disease’s aetiology already in the body politic of the therapeutic trajectories available to reduce suffering (*ibid.* 198). As an iconic social pathology of all time, the response to the disease had been medical, religious and political, thus creating what Simon Watney called “politics of intense moral purity” (Watney 1990) among the practices claiming capability in addressing the extent of human suffering. This lack of consensus on what constitutes a proper representation of the HIV and AIDS and crisis of “contradictions and anxieties” have bred “desperate forms of inventiveness, representation and enterprise” (*Ibid.*, 203), even across all cultures. There is, however, a knowledge gap on how rural people in Zimbabwe have responded to problems of HIV and AIDS at a time when the economy is imploded and there are many fake and extremely dangerous drugs for HIV and AIDS on the market. The available scholarship, which is urban-centred, is equally scanty.

The biomedical industries and their supply chain have viewed the “creative” response to the cataclysmic pathology by the ordinary people as unwarranted attitudinal change against ARVs by people infected and affected by HIV and AIDS. A lack of faith in biomedical solutions at a time when more and more cheap drugs deemed to have some capacity to contain the problem are getting accessible to all is perplexing. A widespread error perpetuated by the “biomedical tradition is that their medical product is superior to that of traditional medicine. They fail to take into account local criteria for acceptability and efficacy or the real condition in which biomedicine is practiced including the structural, political and economic framework within which it operates (Ribera 2007).” The suppliers of biomedical solutions would not want to share this practical blame. The

problem which sets the sufferers and their families adrift from strict adherence to ARVs is always a sense of condemnation by the biomedical tradition to callous exclusion through being left exposed to often-cheap imitations or untreated in an “era of pharmacological salvation” (Biehl 2001).

In spite of the pharmacological findings in ARVs and the promised relief they bring, many people in Africa “stubbornly” continue to trust their traditional medicines. WHO (2012, 1) has reported that 80 per cent of the population used traditional medicines in Africa. In Uganda, there is evidence of the increased usage of traditional herbs among patients such that “funding agencies, the government and NGOs have supported research in herbal medicines through a collaborative effort between practitioners in herbal and modern treatment methods” (Nalugwa undated). In Zimbabwe, many people know one or two drugs that can be prepared for making a strong concoction to treat everyday ailments. Thus, as discussed earlier, interaction with herbal medicines is not strange in all African communities.

But the dealers in biomedical materials and funders of the ART projects in Africa have been worried by what they think as interference by the African herbs in the “access” chain to ARVs by the ordinary people. Monera *et al.*'s (2008) finding on the effects of *M. oleifera* on the metabolism of Nevirapine drug for HIV and AIDS therapy seem to confirm the competition feared by the pharmaceutical industries and drug dealers from readily available herbs. The massive funding towards researching on the side-effects of popular alternative medicines preferred by rural people in Zimbabwe and the rest of Africa demonstrates the rivalry instead of collaboration that has developed between modern medicines and alternative medicines meant for curing or controlling AIDS in Zimbabwe.

As the intense competition, intransigence and backstabbing between modern medicines and traditional medicines continue, the patient reacts by making conscious decision informed by various etiological and economic factors in the management of HIV and AIDS and medicine up take. The AIDS patient has gained support from the African intellectual who has become disenchanted by modernist's claim on the efficacy of everything that is western. Like forms of subaltern activism against the preponderance of the modern medicines, rural people have resorted to the drugs that “offer holistic treatment of the afflicted-treatment that is also sensitive to psychological and spiritual parts of the human animal” (Xaba 1998). It appears that taking up traditional herbs is akin to maintaining spaces for “counter-hegemonies” and medical sovereignty.

8.2.1. Ambivalence?

Ambivalence reflects the co-existence of positive and negative evaluations of an attitude object (Nordgren, van Herrveld and van der Pligt 2004). It is when people feel a pattern of negative and positive effect at the same time (Larsen 2007). Attitudes can be weak or strong. Weak attitudes, considered

ambivalent, do not resonate the four dimensions discovered by Petty and Krosnick, which are resistant to persuasion and predictive behaviour, are stable and affect information processing (Petty and Krosnick 1995). In fact, ambivalence is a reflection of where there is a conflict in an attitude. This dynamics is present in most HIV patients, but cannot be taken fully as an ideal descriptor of all HIV patients seeking to access both biomedicines and traditional medicines concomitantly. This could be a manifest of medical pluralism, which is “a rule than exception” in Zimbabwe. People tend to use the various medical traditions to which they have access in ways that may be exclusive, sequential or complementary (Ribera 2007).

The availability of free ARV drugs and their vaunted promises has not persuaded many African patients to have total adherence to ARVs. To be HIV sero-positive is a struggle one has to overcome and one longs for the day when total victory against suffering will be achieved. It is accepted that concomitant use of ARVs and local herbs is not only a sign of desperation for a quick solution, but an assertion that there is a plurality to addressing illness in Africa. This plurality has been explained by pharmaceutical industry and distribution chain as unexplainable ambivalence or victimhood of the patient to the whims of the charlatans. Despite these negative descriptors of the sick and the healers who attend to them, there are those who view that sick people cannot be “passive acceptors” (Stimson 1974) of doctors’ instructions. Medicines and their uptake are as well discussed in families, friends and neighbours and drug taking decisions are made on the basis of this, even contrary to a doctor’s advice. The neighbour who had bad reaction to the medicine may have more influence than the doctor.

The characteristics of the medical traditions are critical to the role they play in understating “both their acceptability and their real use in the community” (Ribera 2007). The comparative costs of treatment, waiting time, distance, specialist charisma and trust or efficacy are important in assessing continued uptake of ARVs in most patients.

The lack of trust for the doctor or the medicines can cause the patient not to follow the drug regimen as prescribed by the biomedical practitioner. Altice, Mostashari and Friedland (2001) found that low adherence to drugs by AIDS patients were because they did not trust the doctors. Some patients did not simply believe in the effectiveness of the drugs (Andreo *et al.* 2001). Spire *et al.* (2002) say that the non-adherents mentioned as their reasons that drugs were toxic or ineffective. In South Africa, there were fears among patients that anti-AIDS drugs accelerate deaths and this was compounded by a doubtful government on whether the drugs should be used at all (Schuklenk and Ashcroft 2002). Providers of ART have done little to dispel these fears. After all, ART drugs have not promised any cure.

In some cases, the problem of not trusting ARVs is caused by the patient refusing objective medical explanation or diagnosis on face value as a result of personal beliefs held by the patient. Becker (1995) outlines three kinds of beliefs that undermine the belief about medical diagnosis as: a

patient's powerful health beliefs that conflict with doctor's assessments; 2) a patient's feeling the doctor is "not hearing him" or paying attention to presenting symptoms; and 3) that the diagnosis may be too painful to accept. The most overriding problem is the barrier between the doctor and the patient caused by poor communication or relationship (Bour, Blanchard, and Segal 1993). Schoni, Horak, and Nikolaizik (1995) concluded that it is the efficacy of the drug itself and the attitude of the doctor that motivated compliance. Most doctors have been accused of lacking warmth; of being unable to explain the diagnosis; and of failing to convey the significance of the regimen to the patient— and thus of having been the causes of patient ambivalence (Francis, Korsch and Morris 1969).

The ambivalence of the patients has been explained by their psychiatric conditions. It is argued that patients with psychiatric disorders are often non-committal to bio-medical drugs. Anxiety has been considered as a good predictor for drug non-compliance. Patients with higher symptom scores of depression have also challenges of compliance to one drug regimen whether it is traditional or biomedical medicines.

The desire by the patients to control their lives could be one cause of their ambivalence. Once HIV-positive people enter the world of medication, it seems that they often become captives of the medical world and lose some say over themselves. Their lives appear to become dependent on the opinions of medical professionals as well as test results (Hall 2003). Patients with external locus of control tend to be fatalistic and sometimes feel hopeless as they think the events in their lives are under some external force. The search for more than one medical tradition in managing HIV and AIDS is a manifestation in patients for the quest of liberation and power to control events surrounding their illness.

The ART-seeking behaviour has also been affected by other shortcomings such as "lack of confidentiality, lack of bed space, lack of transport to the hospitals, shortages of qualified staff, long queues, and side-effects" (Chinsebu 2009). Side-effects are detrimental to the wellbeing of the patient as they cause secondary stigmatisation. Lipoatrophy and central fat accumulation resulting in thin facial pads, thin arms and legs, potbellies and "buffalo humps" (Chinsebu and Hedimbi 2010) are signs that a patient is on ARVs and can lead to stigmatisation. These shortcomings have motivated new vistas in the use of traditional medicines.

8.2.2. The Preponderance of Traditional and Faith Therapies

Mitchell *et al.* (2007) in their study of communities undergoing ART in the Eastern Cape Province of South Africa found that in areas where ART has been introduced, the patients have "enthusiasm for traditional medicines and dietary supplements than for ART. The subjects viewed ART as just a variation of those treatments" (Mitchell *et al.* 2007: 76–84). The popularity of traditional therapies is that they may have posted a positive image. This is, traditional "medical system shares social values, beliefs and a world

view with the patients. Traditional medicines are also regarded as having concerns with and treat illness or the emotional component of the disease” (Ribera 2007). They are also viewed as holistic as they target the mind, body and soul of patients within their family, community and religious contexts (Ross 2010). Contrary to that, biomedical professionals are seen as “socially and culturally distant from their patients, focused on the organic pathology” (Velimirovic 1990).

The prevalence of the traditional healers in the everyday lives of many Africans explains why the preference of traditional medicines cannot be wished away. In South Africa alone, there are three classes of healers integral to the traditional medical systems, namely, the Inyanga, Sangoma and the faith healer. Many South Africans consult these healers as the first effort to remedy ailments (Peltzer, Mngqundaniso and Petros 2006). Traditional healers seem to be consulted for the treatment of sexually transmitted infections as well “because they (are deemed to) provide client-centred and personalised health care that is tailored to meet the needs and expectations of their patients, paying special respect to social and spiritual matters” (King and Homsey 1997). More so, traditional healers and faith healers are well known in their communities for treating various ailments. The traditional healers may be more physically and geographically accessible to populations residing far from centres that dispense Western medicine and their services are also usually more affordable, particularly for poor rural families or for those who live in the poorest parts of developed countries. They are also readily available after hours (Ross 2010).

There are views that biomedical system fails to recognise the “spiritual” element about illness. As such, biomedical regimens are only restricted to natural factors, but if spiritual forces cause illness, then the sick people would approach the healers for the spiritual illness. In this case, “diagnosis and aetiological beliefs become two important issues in determining treatment” (Saethre 2007). Belief in the “double causality” of illness causes patients to seek alternative medicines. For instance, susceptibility to infection can be explained by behaviour (e.g. promiscuity), but also in terms of strength or weakness of blood, as well as other factors that contribute to strengthening or weakening it (e.g. food or emotional states). In addition to this aspect in seeking medical treatment, individual knowledge of the herbal medicines is important. It is important to note that just as in many rural African countries (Prince *et al.* 2001), every adult and many children in rural Zimbabwe have some knowledge of bush medicines (Chigora, Masocha and Mutenheri 2007).

A belief that illness is caused by some spiritual forces may delay or preclude the patient from approaching biomedical treatment. If the foregoing assessment is true, belief dictates action of those seeking medical treatment for any illness. Sickness in some parts of the country reflects the violated social norms, realities and tensions. When a patient approaches the

faith or traditional healers, this should be considered an attack on the disease and addressing social dysfunctionality caused by his/her actions or omissions.

Experience with illness is one other aspect that has led to patients dabbling in both traditional/faith therapies and biomedical ones. "Illness episodes, not the access to medication, can influence the way in which pharmaceuticals are consumed. Despite having symptoms, patients may take any bush medicines during their illness episodes" (Prince *et al.* 2001:105). Therefore, in the case where there is "infrequent use of bush medicines, this can be attributed to convenience rather than a distrust of the efficacy of these therapies" (*Ibid.*, op cit.). Just as in many parts of the world (Ross 2010), those who use traditional medicines want to make a statement that the cause and cure of an "illness need not necessarily act only as a road map to treatment, but may also be a social tool or method through which events can be meaningfully interpreted" (*Ibid.*). As a result, clinical treatment may not necessarily result in the rejection of traditional causes of illness or traditional medicines. The traditional/faith therapies, however, can be credited with precipitating healing even though the biomedical facilities can be used.

The treatment-seeking behaviour, therefore, cannot solely be attributed to the diagnosis offered by the biomedical system, but to the powerful influence of social concerns, familiarity, experience and convenience, as well. In addition, local aetiological beliefs are central to whether or not biomedical therapies are adopted alone or concomitantly with traditional or faith healing therapies. The effects of health messages on local models of illness and treatment impact on the treatment-seeking behaviour of patients. ARVs clearly do not provide cure for HIV and AIDS. People absorb and dynamically interpret this biomedical information working from their own cultural models of illness representation and practice (Ribera 2007). Biomedical concepts may be known, but not believed or they may be misinterpreted or reinterpreted. Also, desperate search for solution and pragmatism¹ may cause the existence of multiple therapeutic itineraries.

Traditionally, ethno-medicines have for centuries been used for treating ailments. The same drugs have been used for treating opportunistic infections and even for offsetting side-effects of ARVs. In the case of rural communities, the biomedicines are hardly accessible. Thus, whilst the majority of HIV and AIDS patients rely on ART, some still have faith in the use of traditional medicines (Chinsebu and Hedimbi 2010). Africans are also exposed to over 3000 known plant species used as medicines (van Wyk and Gericke 2000). It is therefore understandable that "HIV/AIDS patients are vulnerable in their choice of treatments, some of them do vacillate from conventional ART programmes to traditional medicines and vice versa; they want the best of both worlds" (Chinsebu and Hedimbi 2010, 75).

8.3. Methodology

8.3.1. Research Design

This was a qualitative research based on interpretative phenomenological analysis (IPA). IPA assisted in exploring in detail how the infected participants perceive and react to ARVs and traditional medicines or faith healing for managing HIV and AIDS illness. IPA is an experiential qualitative approach to research in psychology and the human, health and social sciences. IPA has a 'phenomenological requirement to understand and 'give voice' to the concerns of the participants; and the interpretative requirement to contextualize and 'make sense' of these claims and concerns from a psychological perspective' (Larkin, Watts and Clifton 2006: 102). IPA was used to explore how infected participants make sense of their world. The researcher achieved this by engaging with the meanings that experiences, events and actions hold for participants. These subjective meanings were gathered through the use of semi-structured interviews (Smith and Osborn 2003). While engaging with the subjective meanings, from HIV-positive participant, the researcher also engaged in an interpretative activity using own conceptions which were largely middle position between a hermeneutics of empathy and a hermeneutics of suspicion (Smith, Flowers and Larkin 2009). The simultaneous combination of subjective meanings from a participant and the researcher's conception gave a deeper understanding of the personal world of the HIV-positive participant.

8.3.2. Sampling Participants

Purposive sampling was used to recruit participants for semi-structured interviews. Purposive sampling involves using the researcher's verdict in choosing the right participants for the purpose of the study (Patton 1990). Referrals from gatekeepers, opportunities as a result of the researcher's own contacts and snowballing, as in referral by participants (Smith, Flowers and Larkin 2009), were the purposive sampling methods used for the selection of participants. Preferred participants were those who were HIV-positive and were already taking any conventionally acceptable medication such as ARVs, and living in rural Harare.

Three participants were recruited for the interviews. This figure appears not representative in statistical sense; however, it provides useful illustrative accounts of how the infected participants perceived and reacted to ARVs and traditional medicines or faith healing. Participants in this study 'represented' a perspective rather than a population (*Ibid.*). This is mainly because they grant access to a particular personal world of the participants—a subjective phenomenon. Typically, IPA studies use small sample sizes that enable a detailed analysis of each case (*Ibid.*). The primary concern of IPA is with a detailed account of individual experience, thereby benefiting from intensive focus on a small number of participants. Historically, qualitative researchers opted for quite large samples; however,

contemporary qualitative proponents are increasingly supporting and using smaller samples (*Ibid.*).

The use of small sample is further justified by the rigorous and time-consuming process involved in data preparation and analysis. The raw data were transcribed and transcripts were subjected to a detailed systematic qualitative analysis, case by case (Willig 2001). The first transcript was read and examined a number of times and, with each reading, the researcher annotated the text with initial comments (Smith and Osborn 2003). The next stage involved transforming these comments into emergent themes that captured succinctly the essential features of the initial readings. Subsequently, connections were methodically forged between themes until a coherent and organised super-ordinate thematic account of the case was produced (Larkin, Watts and Clifton 2006). Connections across cases were made to produce a set of master super-ordinate themes. Each super-ordinate theme is connected to the underlying themes which, in turn, are connected to the original annotations and extracts from the participant's verbal responses. Finally, the table of master super-ordinate themes was translated into a narrative account, where the themes were outlined, exemplified and illustrated with verbatim extracts from the participants (Smith 2003). Surely, such a rigorous analysis required a small sample in order to avoid being overwhelmed by the data.

The researcher's starting point was at Monica's place. Monica was known through the researcher's personal contacts. Monica referred the researcher to Gogo, who became the second participant. These names and any other names are pseudonyms and fictitious; they were used for illustrative purposes only. Any resemblance to actual persons is coincidental and unintentional.

8.3.3. Data Collection

Semi-structured interviews were used. Smith and Osborn suggested that IPA requires a flexible data collection instrument such as semi-structured interviews which he noted as the best. Data was collected within participant's familial (residential) setting. Collecting data in a residential setting made it easy to establish rapport with the participants. All interviews were audio-taped and transcribed verbatim.

Semi-structured interviews were conducted with a fairly open framework which allowed for focused, conversational, two-way communication. Unlike the questionnaire and guided interview framework, where detailed questions are formulated ahead of time, semi-structured interviewing starts with more general questions or topics. Relevant topics were initially identified and the possible relationships between these topics became the basis for more specific questions, which did not need to be prepared in advance. Not all questions were designed and phrased ahead of time. The majority of questions were created during the interview, allowing both the interviewer and the person being interviewed the flexibility to probe for

details or discuss issues (Smith 2003). Semi-structured interviewing was guided only in the sense that some form of interview guide was prepared beforehand, and provided a framework for the interview (Smith, Flowers and Larkin 2009).

8.1.4. Instrument

A schedule for interviewing HIV-positive participants was constructed. The schedule sought to only guide the interviewer into asking the key issues, but not limiting to those key issues. The guide instructed to start with introducing the researcher to the participant and explaining the purpose of research. It then asks for the consent to proceed with the interview. It also instructs to ask for a pseudonym from the participant. The schedule's key issues concerned the general history from the realization of HIV-positive status to present. The idea was to make the participant to freely talk as much as possible about how they have reacted and sought support and treatment. The schedule also had a section for whether the participant visited a prophet or traditional healer, and the evaluation of faith/traditional healing and ARVs.

8.2.5. Data Preparation and Transformation

The audio files were recorded using a cell phone (Samsung Champ (GT-C330)) and the recorded files were in Adaptive Multi-Rate (.amr) format. Adaptive Multi-Rate (AMR) is used in speech coding and involves audio data compression (AMR to MP3 Website (<http://www.amrtomp3converter.com/>)). Audio data compression allows for more storage on voice files. ".amr" is a popular filename extension for AMR.

Transcription was done with the help of software called Express Scribe version 5.13 (Express Scribe Transcription Software accessed at <http://www.nch.com.au/scribe/index.html>). Express Scribe is a free professional audio player software for PC or Mac designed to assist the transcription of audio recordings. The researcher downloaded and installed Express Scribe on the computer and controlled audio playback using keyboard (with 'hot' keys). This transcribing software also offers valuable features such as variable speed playback, multi-channel control, file management, and more. It has a noting space at the bottom that was used to type the verbal responses.

8.3.6. Data Analysis

Interpretative Phenomenological Analysis (IPA) was used for data analysis. This analysis was concerned with the participants' personal perceptions and attitudes towards ARVs and traditional medicines or faith healing for managing HIV and AIDS illness. After transcription, data analysis started by reading the transcripts a number of times, making initial comments and identifying themes that were emerging. The participant's lived responses were analytically interpreted to give transformed meaning in the form of

super-ordinate (higher-level) themes from which subordinate (lower level) themes were derived. Each super-ordinate theme was analyzed using a single ‘results and discussion’ section. This involves discussing the links to the literature as the researcher presents each super-ordinate theme.

8.3.7. Validity and Reliability

Respondent validation (member checking) was used as part of error reduction. Respondent validation involves reporting to the participant an account of the data, allowing them to verify their views. Issues of validity, reliability and generalisability were relatively inapplicable in the current study since the gist of the study is to explore the subjective experiences. The results obtained might not be representative to the general population albeit they can be inferred to the individuals studied.

In this study, participants’ rights and dignity were upheld through the respect of their privacy, confidentiality, and self-determination (Rivera *et al.* 2001). The researcher was aware of and respected familial, cultural, individual, and role differences, including those based on age, gender, gender identity, race, ethnicity, culture, religion, sexual orientation, disability, language, and socioeconomic status and considered these factors when working with participants of such groups. Therefore, during this research, the researcher did not knowingly overlook and encourage discrimination of others based upon familial, cultural, individual, and role differences.

The researcher took it mandatory to protect confidential information obtained from participants. The participants were asked to provide pseudonyms to protect them from personalization. In order to minimize intrusions on privacy, the researcher restricted the research to information perceived relevant to the purpose for which the research was made.

The purpose of the study was unveiled to participants. Informed consent was solicited from all participants. Participants were free to withdraw from the study if they so wished at any juncture throughout the study.

8.4 Results

8.4.1. Introduction

This section presents the findings of the study. As pointed out earlier, the data were collected through semi-structured interviews and analysed following the guidelines of Interpretative Phenomenological Analysis (IPA). All interviewees regarded their illness as so serious and needing urgent attention. However, they disagreed on the method of therapy that is efficacious. There was also consensus that biomedical support does not provide the cure but can prolong life. Some interviewees had faith in the traditional or faith healing and believed that modern medicine can fail due to intervention of evil spirits. Therefore, they regarded medicines to be as effective as the protection one receives from the attacks by evil spirits. However, in some cases, confusion and desperation caused by terminal

illness push people to take desperate measures. Themes related to the patients' ambivalence resulting from desperation, medical methods, traditional/faith healing beliefs, and the health messages were identified.

8.4.2. Unit of Analysis

The main question that the study sought to address itself to was to investigate the patient's attitudes and perceptions towards ARVs and traditional medicines or faith healing for managing HIV and AIDS illness. The units of analysis in this study were the verbal responses from the participants. IPA assumes a connection between verbal responses and a psychological state. Verbal responses were collected from three participants: Monica, Gogo and Tawengwa. These names used in the text are fictitious. Any resemblance to actual persons or companies is purely coincidental and unintentional.

8.4.3. Themes

Themes were obtained deductively. Four main themes emerged: 1) desperation as a cause of ambivalence, 2) medical methods as threats to life, 3) traditional/spiritual methods as comforters and 4) the HIV and AIDS health messages.

8.4.3.1. Desperation as a Cause of Ambivalence

Ambivalence of the PLWHA is partly due to desperation. Desperation is a form of extreme anxiety that makes the HIV positive person open and non-selective to potential sources of help. As a result, this desperation propels the HIV-positive person to mix both conventional medicine and traditional/faith healing. Monica gave away her identity during the interview.

Interviewer: We are researching on how HIV-positive people are coping....

Monica: Do you provide counselling support or other things?

Interviewer: If needed, we will make recommendations for counselling. As for this interview, we would like to talk about how HIV-positive people use ARVs and other methods of coping with their HIV status and medication.

Monica: Thank you. I am going to disclose my name. I am Monica ***

Monica's surname has been withheld for the sake of protection of confidentiality. Her decision to voluntarily disclose her name seemed to have been in anticipation of help. Giving up her identity without duress shows some level of desperation in her and also shows that she can take in any help from any one if it promises a cure for her ailment. She did also ask whether the interviewer was to give help when she said, 'Do you provide counselling support or other things?' This showed that she was open to receive any 'other things' related to reducing the effect of HIV. HIV does not have a cure but incessant efforts are being made to mitigate the

problem. Many people live in anticipation of a cure of the disease. This creates anxiety that makes them vulnerable to trial and error. Monica opened to the interviewer because she is living her life open to meeting with any potential help. However, it is important to understand that not all HIV sero-positive are desperate. Some cope with their conditions with hope and gallantly.

Poverty can also cause desperation that will propel ambivalence. Low wages, unemployment and poor living conditions make some HIV-positive persons open to any potential help.

Monica: I am always sick and this has affected my employment routine and the general upkeep of my family. Apart from that, I get a low wage for a sick woman with a large family.

Monica is worried about her family. Being 'always sick' has caused her to fail to adequately provide for her 'large family'. As a result, she is open to 'other things' that she thinks can help to lessen or remove the HIV effect. Similarly, Gogo indicated that she is no longer working for her family and is now living in poverty:

Interviewer: When did you know that you are HIV-positive?

Gogo: Last year, when I fell sick, I had chest pains. I was put on *cotrimoxazole*. I reacted and it swelled my body. I tried everything and even went to Nyadire clinic and it helped a little. It's a long story of sickness. Right now I no longer work at the market due to the sickness.

Gogo had a 'long story of sickness' that has brought poverty in her house. The idea that she 'tried everything', insinuated that she was not selective in her endeavours to seek help over her condition. Her situation was exacerbated by poverty brought about by her incapacity to work at her market. She became open to any type of help as a result of this desperation.

8.4.3.2. *Bio-medical Methods as Threats to Life*

Conventional medical methods cause anxiety to the sufferers. Medical methods describe and explain the disease in a way that is psychologically threatening. Biomedical methods are too personal and to some extent make sufferers feel uncomfortable and guilty. They state the condition of a disease with a certain level of precision that may cause anxiety. Monica spoke of numbers (CD4 counts) that are used to show the state of HIV:

Monica: I was diagnosed HIV-positive five years ago. I received my CD4 count for the first time which was 471. I went for the second, third, and the sixth with CD4 count ranging from as low as 300 to as high as 500.

These numbers offer a threatening reality. If the number decreases, then the patient would have to know for herself that she is getting worse. Making the probability of life known to the sufferer can evoke more anxiety than limiting it to the 'eyes of prophets and *sangomas*.' The numbers seem to stand as transparent numerations of the sufferer's chances of survival. Gogo also shared her experience with the biomedical method:

Gogo: I had aches all over and went to the clinic and was told my blood was not fine. My husband had died and I wanted to find out in case. My daughter who was almost a teenager was also sick and tested positive. She died because she could not be put on ARV in spite of the doctor's recommendations... She was prescribed cotrimoxazole... My friend had a contact at Mashambanzou Hospital who facilitated for my testing for HIV. I tested positive. I was referred to Nazareth Infectious Disease Hospital. There, they prescribed for me antibiotic cotrimoxazole.

Monica and Gogo showed that some patients prefer biomedical solutions when their health deteriorates. The physicians use precise tools to gauge the extent of deterioration like the CD4 counts. Such information can be more threatening to the sufferer than going to the spiritual method that usually points to external influence of evil spirits. Therefore, sufferers go for ARVs only to cater for their deteriorating physiological state but turn to spiritual method for their psychological well-being. A sufferer hopes that when a condition is expressed in medical terms like low CD4 counts, then one automatically will qualify for the ART. A sense of trepidation is activated when one is prescribed anti-biotic, cotrimoxazole. This drug is used in the treatment and prophylaxis of several opportunistic infections. In patients with HIV and AIDS, cotrimoxazole use can cause a higher rate of adverse drug reactions than in the general population. Compared to traditional or faith healing where the disease is fought at the mental ground, the biomedical therapies address more the physiological state than the psychological wellbeing.

Tavengwa also believed that ARVs create poisons in the body that have a potential to kill. As a result, he mixed the ARVs with herbs and 'African medicines' because he believed that these herbs and 'African medicines' can reverse the poisons caused by ARVs.

Tavengwa: I eat a lot of those traditional medicines (herbs) to boost my immunity. Before the herbs I used to take ARVs alone and it was very difficult. ARVs can be difficult to take just like TB drugs.

Interviewer: Isn't that when you are taking ARVs you do not need to take any other stuff or alternative drugs? Why do you mix?

Tavengwa: *Kunyeperwa* (They lie to you). *Chokwadi ndechekuti* (The truth is) ARVs do not cure. I was told that some of them are

poisonous. But herbs and other African medicines can reverse poisons created by ARVs, even though they also do not cure the disease. Look I never had side effects the moment I started eating herbs and partaking ARVs concurrently.

8.4.3.3. *The Traditional/Spiritual Methods as Comforters*

The anxiety caused by the biomedical approaches to the individual wellbeing often pushes out the patient who finds refuge in the traditional or faith healing method. As already shown, the biomedical professionals are seen as socially and culturally distant from their patients, focused on the organic pathology. Patients interviewed held a belief that the vulnerability of a person to any disease or a mishap is a result of unfortunate visitation by evil spirits. This notion that the evil spirits are involved at every stage forms the basic ingredient for the patient's ambivalence. The patients were of the strong view that evil spirits may cause wrong diagnosis, delay a diagnosis or inhibit effectiveness of a drug regimen. The case of Monica is illustrative:

Monica: At Wilkins Hospital, I was tested three times for tuberculosis (TB) and the results came negative even when I had all the symptoms of the disease. It was at Hatcliffe Clinic that I finally tested positive for TB. The elusiveness of the bacteria is nothing but *Mweya yetsvina!* (Evil spirits!).

Interviewer: Did you try other help outside the hospitals?

Monica: Yes, I consulted faith healers, *vaindishandira* (they prophesied and exorcised the evil spirits). I needed prayers to cast the evil spirits. Sometimes I need both of the biomedicines and spiritual things to work together. But counselling can assist better.

Monica also gave an example of another person she knew:

Interviewer: Do you think that this evil spirits can accelerate one's vulnerability to HIV/AIDS?

Monica: Yes. It's possible. I have an example of a woman-case who was ignored by the medical officials as a result of bad spirits. It was later discovered that it was bad spirit causing problems for the woman. This was addressed and now she is on ARVs.

Monica believed that the confounding of the biomedical approach was possible with evil spirits. Similarly, Gogo echoed the same sentiments:

Gogo: I was helped at the church with prayers. But they encouraged going to the hospitals.

Interviewer: Do you think churches make drugs effective?

Gogo: Yes.

Interviewer: Do you think bad spirits affect the effectiveness of drugs?

Gogo: Yes. They cast darkness. This may cause wrong diagnosis and delays.

Interviewer: Do you think prayers help there?

Gogo: I encourage people to go to church and then go to hospital. This helps the drugs uptake.

Monica and Gogo believed that fighting against evil spirits should be a concomitant of the use of biomedical remedies. Sufferers believe that spiritual perception should monitor medical progress if medical method is to be successful. Spiritual methods offer soothing explanations. They ascribe the cause to evil spirits and offer a way in which one can be 'free' from suffering. As a result, after being relieved of the spiritual burden, the sufferer feels relatively progressing well.

Spiritual method also gives sufferers less guilt by giving them an opportunity to externalize the disease.

Interviewer: do you think that this evil spirit can accelerate vulnerability to AIDS?

Monica: Yes. It is possible. I have an example of a woman-case who was ignored by the medical officials as a result of bad spirits. It was later discovered that it was bad spirit causing problems for the woman. This was addressed and now she is on ARVs.

The spiritual method would point to spiritual reasons that seem to be beyond the sufferer's control; in a way the spiritual method shifts the blame (if any) from the sufferer to the spiritual realm. By shifting the source of the disease or cause of the infection, the sufferer feels less responsible or just feels like an unwitting victim. Generally, the spiritual method offers more hope and comfort because it focuses on a spiritual level. Gogo also illustrates this below:

Interviewer: Do you think churches make drugs effective?

Gogo: Yes. They chase away the evil spirits.

Interviewer: Do you think evil spirits affect the effectiveness of drugs?

Gogo: Yes. They cast darkness. This may cause wrong diagnoses and delays...I encourage people to go to church and then go to hospital. This helps the drugs uptake.

Interviewer: Can the *n'angas* help as much as churches?

Gogo: Yes some may help. But it depends on one's faith. While I encourage biomedicine, they can as well visit traditional healers or churches, depending on one's pocket. They do help since they encourage restful mind.

Interviewer: Do you think bad spirits can expose someone to disease?

Gogo: Maybe. Our jealousy relatives can cause others to suffer mishaps.

By blaming the ‘evil spirits’ and ‘jealousy relatives’ the sufferers externalise the disease. They feel irresponsible for contracting HIV because the ‘evil spirits’ and ‘jealousy relatives’ were behind this ‘mishap’. Therefore, the sufferer uses the spiritual methods to develop a ‘restful mind’ through telling himself or herself that all will be fine as long as evil spirits are cast away. In a way, the spiritual methods locate other causes that are not as permanent as ‘bad blood’ or ‘low CD4 count’ but rather removable disease causing agents such as the “*mweya yetsvinda*” (evil spirits).

8.4.3.4. *The HIV and AIDS Health Messages*

The health messages also have had an impact on the extent the patients adhere to the ART. Powerful challenges including side-effects, drug toxicities, drug resistance, and realities in the access to ART for most of the infected, affect the commitment to the ARV regimens. Some patients who were interviewed found it imprudent to be on a system that is not only demanding, but would eventually kill them. Side-effects such as nausea, vomiting, headaches and diarrhoea were classified as difficulties related to the use of medication. Side-effects are detrimental to the wellbeing of the patient as they cause secondary stigmatisation. Lipoatrophy and central fat accumulation resulting in thin facial pads, thin arms and legs, potbellies and “buffalo humps” are signs that a patient is on ARVs and can lead to stigmatisation.

In addition, the patients claimed that prescribed regimens are complicated and challenging to everyday life as HIV therapies. Moreover, the realities that the regimens do not provide any cure but some form of life prolongation, therapies which promise definite cure are attractive. Traditional healers, while capable of reversing optimistic infections such as fevers, diarrhoea, respiratory diseases, and sexually transmitted infections (STIs), they were caring for before the arrival of HIV. Their drugs have not been blamed for causing side-effects or toxicities. In most cases, the drugs have dietary and medicinal properties. In other cases, traditional medicine has been shown to relieve or successfully treat HIV-associated symptoms or minor opportunistic infections.

Interviewer: Who planted this herbal garden and who needs it?

Tavengwa: That’s my drugstore. I-pharmacy *yangu* (it’s my dispensary). I eat a lot of those drugs to boost my immunity. Before the herbs, I used to take ARVs alone and it was very difficult. ARVs can be difficult to take just like TB drugs.

Interviewer: Isn’t that when you are taking ARVs you do not need to take any other stuff or alternative drugs? Why do you mix?

Tavengwa: *Kunyeperwa* (They lie to you). *Chokwadi ndechekuti* (The truth is) ARVs do not cure. I was told that some of them are

poisonous. But, herbs and other African medicines can reverse poisons created by ARVs, even though they also do not cure the disease. Look, I never had side effects the moment I started eating herbs and partaking ARVs.

Interviewer: What would you advise others who are in your condition on how to manage the disease?

Tawengwa: Herbs are good for health, but you need to know your herbs as well. A good traditional herbalist will provide a list of herbs that you can manage on your own. Even the Chinese have good herbs too. Try them, but do not forget your ARVs.

8.5. Conclusions

Patients interviewed (that is those who claimed that they were diagnosed HIV sero-positive) double their biomedical therapeutic approaches with faith and traditional healing. However, there is some level of secrecy in this process and very few of the patients would make it public that they are receiving traditional and biomedical therapies concomitantly. In poor communities, adherence to ARVs among patients is complex and multi-causal phenomenon, creating anxiety and desperation. The routineness of the ARVs is also a challenge. The negative beliefs about the ARVs such as “the medicine is what kills”, “too much medicine is bad for health”, “medicine makes you drowsy and slow”, “you need to take a break from the medicine” affect the strict adherence expected of the ART and motivate ambivalence.

Four reasons observed in this research appear to be fuelling ambivalence in patients. These are desperation, medical methods, comforting nature of traditional/spiritual methods and the HIV and AIDS health messages. Desperation is a form of extreme anxiety, coupled with high levels of poverty among the HIV and AIDS patients; it can make the HIV positive person open and non-selective to potential sources of help. As a result, this desperation propels the HIV positive person to mix both conventional medicine and traditional/faith healing in order to survive.

The conventional medical practice is equally scary for the patients. The way disease and its causal agents are described to the sufferer may threaten patients who do not want to know more about the disease; yet their conditions demand that such information be made known to them. Biomedical methods describe and explain the disease in a way that is psychologically threatening. Biomedical methods are too personal and to some extent make sufferers feel uncomfortable and guilty. They state the condition of a disease with a certain level of precision that may cause anxiety. Some patients may not want to know this; yet taking ARVs may be a continual reminder of their capture by an incurable disease. Such patients would interrupt their adherence to ARVs with traditional herbs.

Traditional medicines arguably provide solutions beyond what biomedical products can give. This is because illness is framed differently in traditional medical practice. This view was shared by all the patients interviewed in this study. Therefore, taking up traditional medicines in addition to biomedicines was believed to have the potential to strengthen the patients from attacks by the evil spirits and deterioration of the physical body as a result of the virus. There was general agreement among patients interviewed that the virus that causes AIDS exists but can only be managed when the spiritual realm is taken care of through traditional or faith healing.

The health messages also have had an impact on the extent the patients adhere to the ART. Powerful challenges including side-effects, drug toxicities, drug resistance and realities in the access to ART for most of the infected, affect the commitment to the ARV regimens. Some patients who were interviewed found it imprudent to be on a system that they perceived to be not only demanding but also killing. Conversely, the traditional medicines and herbs such as garlic, which are normally prescribed to the patients, have no known side-effects. Paradoxically, the ARVs have the life elongation and toxic properties, factors which have not made them attractive among patients who have known alternative medicines throughout their lives.

This chapter recommends the policymakers, public health officials, international donors, and others to recognize that the conventional biomedical healthcare system alone has not and will not be in a position to fulfil the ultimate goal of every national HIV and AIDS strategic plan—namely, to curb the spread of HIV— without engaging the help of all relevant therapies and stakeholders, including traditional healers (King *et al.* 2009).

The governments can reduce the sense of desperation in the patients by increasing medical convenience and choices to the ailing patients. “Illness episodes, not the access to medication, can influence the way in which pharmaceuticals are consumed” (King *et al.* 2009:105).

The chapter further recommends that medical institutions with authority to prescribe the ART should create strong therapeutic alliance between themselves and the traditional/faith healers in which the goals of dealing with HIV and AIDS problems are mutually affirmed. Lack of goal articulation and agreement between two often antagonistic practices often leads to non-adherence of the ARV regimens.

Notes

1. There are two types of pragmatism: (1) use of biomedicines and traditional medicines to treat different aspects of illness “because they work”; and (2) changing from one medical tradition to another for “practical reasons” either for material nature (costs) or emotional nature (the way one is treated).

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CHAPTER NINE

Sexual Behaviour of People Attending Anti-retroviral Therapy in Addis Ababa

Nathan Negussie

Abstract

This study illuminates the sexual feelings and experiences of heterosexual male anti-retroviral therapy attendants in Addis Ababa, Ethiopia who were between the ages 25 and 29. Qualitative case study approach was used to undertake this research, employing in-depth interviews with six purposely selected participants. The data from these interviews were analyzed using Open Code software package. Thematic analysis was used as an approach to the data analysis. The study indicated that participants knew from hospital sources the risk unprotected sex and multiple sexual partnerships entailed for their health. Their sexual desire and experience as well as likelihood of involvement in unprotected sex were influenced by emotional distress, stigma and discrimination, alcohol, spiritual devotion and physical body conditions. Addressing the psychological, social and economic needs and problems of people living with HIV/AIDS is essential in the preventive and treatment efforts.

Keywords: Sexual behaviour, ART attendants, sexual feelings, risks.

9.1. Introduction

9.1.1. Background

The introduction of ART has changed HIV and AIDS from being a terminal disease to a chronic one. Upon taking the treatment, people who were once bed ridden can regain the strength to lead a normal life with less possibility of recognition of their sero-status. However, this resumption of normal life is sometimes accompanied by a renewed desire for sex and bearing child (Tun *et al.* 2004 cited in Seeley *et al.* 2009). As many as one in three HIV-positive people are reported to continue unprotected sexual practices after learning that they are HIV-infected (Kalichman *et al.* 2001).

People living with HIV and AIDS (PLWHA) who engage in unprotected sex place their sex partners as well as themselves at substantial risk for Sexually Transmitted Infections (STIs). Unprotected sex even for people who already are living with the virus may entail contracting other kinds of STIs, including another trait of the HIV virus. It may also result in the transmission of drug-resistant HIV virus, which may require even more expensive second or third line regimens of anti-retroviral drug (Bunel *et al.* 2006).

Risky sexual behaviour among ART attendants may eventually lead to pregnancy and HIV-positive births. There is a strong association between maternal mortality in the developing world and the HIV epidemic (Parisaei, Hemelaar and Govind 2010). This would invariably increase the number of children who are being orphaned in sub Saharan Africa.

Despite the various risks associated with it, the sexual behaviour of ART attendants remains largely unexplored in Ethiopia. Two unpublished works (Yadeta 2009 and Kekebo 2008¹) have tried to see the sexual behaviour of such people in Addis Ababa and Southern Ethiopia. Both of these studies, however, focus on the numeration of the frequencies of condom use and number of sexual partners. While such survey-based researches can indicate the degree of risky sexual practices, they do not usually provide detailed accounts of issues ART attendants think affect their sexuality. Consequently, both of these researches have indicated the need for further researches.

This study sought to explore the contexts and influences underlying sexual behaviour of male youth ART attendants living in Addis Ababa. It focused on youth because people in this age group, according to Central Statistical Authority (CSA2006), are engaged in higher risky sexual behaviours. Ethiopia's Ministry of Youth, Sports and Culture (2011) defines youth as people who fall between the ages of 15 and 29. This study, however, looked at men PLWHA who were between the ages of 25 and 29 because, among the youth who have the virus in their blood, the majority falls in this age group (Federal HIV/AIDS Prevention and Control Office (HAPCO) 2006). This has made their sexual behaviour worth giving prior attention to study.

This study is hoped to inform concerned policy-makers, practitioners and scholars about the sexual experiences of people in Ethiopia who have the virus in their blood. Ethiopia's Ministry of Health (MOH) and (HAPCO) have indicated the need to integrate prevention efforts with provision of care and treatment (MOH - HAPCO 2007). Such integration efforts are more likely to be effective when supported with empirical studies.

9.1.2. Objectives of the Study

The general objective of the research was to explore the contexts underlying the sexual behaviour of heterosexual male youth attending ART in Addis Ababa. The specific objectives are:

- to describe how male youth ART attendants living in Addis Ababa understand risks associated with sex;
- to identify the issues male youth ART attendants living in Addis Ababa feel influence their sexual experiences; and
- to explain the interplay between the sexual experiences of male youth ART attendants living in Addis Ababa and issues that influence such experiences.

9.2. Literature Review

9.2.1. ART Commencement and Sexual Behaviour

Anti-retroviral therapy (ART), also known as HIV-treatment, aims at suppressing the viral replication sufficient to prevent selection of drug resistance mutations (Volberding *et al.* 2008). Antiretroviral are drugs that fight infections caused by retroviruses, the family of viruses to which HIV belongs (Kane 2008). Kane explains these drugs could be associated with short-term side-effects such as fatigue, skin rashes, diarrhoea occurring within days or weeks of starting a new drug, and, possibly, long-term complications like heart diseases and diabetes.

Since the advent of ART in 1996, studies have been conducted to assess the impact of improved HIV treatments on preventive attitudes and behaviour (Demmer 2003). Demmer notes that most of these studies have focused on gay men. According to Demmer, this is because the AIDS epidemic has affected gay men more than other groups in society in the Western world. Usually, after recuperation through the ART, people regain their strength to resume normal lives. Researches carried out among the homosexual living in the United States and Netherlands showed that this resumption of normal lives could be accompanied by increase in risky sexual behaviour and incidence of STIs (Boily *et al.* 2004; Dukers *et al.* 2001).

The vast majority of PLWHA in sub-Saharan Africa, where 22.5 million of the 33.3 million worldwide reside, usually acquire the virus through heterosexual contact and vertical transmissions from mother to child (UNAIDS 2010). With the ever expanding ART service in this region, the UNAIDS report signifies the potential for further transmission of HIV arising from the sexual behaviour of those who already know their status. However, it has been reported that the introduction of ART in Kenya (Sarna *et al.* 2008) and Uganda (Bateganya *et al.* 2005) among heterosexuals was not followed by a rise in unprotected sex and STIs. Bunnell *et al.* (2006) also found that risky sexual practices reduced by 70 per cent six months after initiating ART among 926 HIV-infected heterosexual adults in rural Uganda. Risky sexual practices were defined as inconsistent or no condom use with partners of HIV-negative or unknown sero-status in the previous three months.

Two unpublished works (Yadeta 2009; Kekebo 2008) carried out in Ethiopia echo research findings from other African societies. In a cross sectional survey among 461 heterosexual patients receiving ART in five hospitals of Ethiopia's Southern Nations, Nationalities and Peoples Region (SNNPR), Kekebo(2008), for example, found that 42.1 per cent of his subjects reported abstinence from sex after starting the treatment. A similar study among heterosexual ART attendants in Addis Ababa public hospitals also indicated that 63 per cent of the respondents use condoms consistently (Yadeta 2009). While this can be taken as an encouraging sign for the success of integrating prevention with treatment, there is still no room for

complacency as 36.9 per cent of the respondents in Yadeta's research admitted having had unprotected sex three months prior to the study.

Involvement in risky sexual practices after starting the HIV treatment has been found to be associated with non-adherence to and beliefs related with ART (Kalichman *et al.* 2010; Kalichman and Rompa 2003). But there has been conflicting findings regarding the interplay of these associations. For instance, Kalichman *et al.* (2010) interviewed 226 men receiving ART in Atlanta, Georgia and found that, in the 23 per cent of the cases, non-adherence to ART was associated with risky sexual behaviour which included having unprotected sex and multiple sexual partners. The researchers also found that belief that having an undetectable viral load leads to lower infectiousness was associated with greater number of partners, including non-positive partners, and less condom use. However, Luchters *et al.* (2008) interviewed 234 adult men in Mombasa, Kenya and found that ART beliefs, adherence, and viral suppression were not associated with unsafe sex.

Kalichman *et al.* (2006) gave explanation as to how ART beliefs might be associated with sexual behaviour. In a sample of 158 HIV-positive men and women who were receiving HIV treatments, they examined the association between HIV treatment beliefs, HIV transmission risk perceptions, medication adherence, viral load and engaging in unprotected intercourse with any sex partners and specifically with sex partners who were not HIV-positive (non-concordant). In the study, multivariate models showed that only treatment beliefs were significantly associated with engaging in unprotected intercourse with non-concordant partners. They concluded that HIV treatment beliefs are often associated with sexual practices among PLWHA but these associations may depend on the HIV status of sex partners.

The aforementioned studies are helpful in identifying and examining the issues that influence ART attendants' sexual behaviours. Nevertheless, they have come up with differing findings with regards to the factors that influence the sexual behaviour of ART attendants. Furthermore, they have not also clearly shown how these identified factors influence the sexual feelings and experiences of ART attendants. This shows the need for a study that details the contexts underling the sexual behaviour of people attending ART. This calls for an in-depth qualitative research inquiry as qualitative research is appropriate when a detailed understanding of an issue is needed (Creswell 2007). Yin (2003) also adds that case study is good when the researcher wants to explore why or how behavioural event takes place.

9.2.2. Anti-Retroviral Therapy in Ethiopia

Policy on Anti-Retroviral Drugs Supply and Use was issued by the Government of Ethiopia in 2002. The policy defines HIV and AIDS as an epidemic that blurs the development vision, exerts strong negative impact

on socio-economic, peace and stability, and psychosocial life of a nation. The three goals of the policy are “to reduce transmission of HIV from mother to child; prolong and improve the quality of lives of PLWHA;... and reduce the accidental HIV infection within health care institutions” (2002: 16).

The implementation of this policy went on in the following year after the ratification of this policy. Hence, ART first started in Ethiopia in 2003 (MOH- HAPCO 2007). Later in 2005, the free ART initiative was launched to increase its accessibility. In 2010, about 397,818 of an estimated 1,216,908 PLWHA which were said to be in need of ART (HAPCO 2007). Yet, only 176, 632 had access to ART by 2010 (UNAIDS 2010).

In Addis Ababa, there were 210,306 PLWHA by 2010 of which 70,097 were said to be in need of ART. Yet, there were only 45,193 people using the ART service in all the 56 public and private hospitals and clinics offering the treatment across the city (HAPCO 2010). As indicated earlier, qualitative research regarding the sexual behaviour, experience and beliefs of people attending ART has been scarce.

9.3. Research Method

This study employed descriptive case study approach to understand the sexual experiences of people after starting ART in Addis Ababa. Accordingly, six in-depth interviews with ART attendants living in Addis Ababa were carried out. The School of Social Work at Addis Ababa University approved the study.

9.3.1. Recruiting Participants

The study participants were heterosexual male youth clients of Hiwot HIV and AIDS Prevention, Care and Support Organization (HAPCSO) who had been attending ART in Addis Ababa. Community workers and nurses who work in the organization had helped in recruiting suitable participants. Participants were recruited on the following criteria: (1) heterosexual male aged between 25 and 29; (2) those being able to give consent to discuss the issues the study raises, (3) those already attending the ART for at least 12 months; and (4) those having never been married. For case study research, it is suggested that four or five cases “provide ample opportunity to identify themes of the case as well as conduct across-case theme analysis” (Creswell 2007, 128).

9.3.2. Data Collection and Analysis

Upon gaining participants’ consent, in depth interviews were conducted for a maximum of one hour with each participant. The place of the interview was arranged by HAPCSO. Participants were assured that their participation was confidential and they could refuse to answer questions that would make them feel uncomfortable. Each participant was given 50 Ethiopian Birr to compensate for the time they spent with me. They were also informed that they would still receive the money should they choose to

leave before completing the interview. Interviews were recorded with digital voice-recorder. They were transcribed verbatim to enable thorough reading and coding. Codes were developed by the lines and paragraphs while reading. A total of 229 codes finally emerged. The 229 codes were then transformed into 23 categorical labels or themes. The transcribed data were then analyzed using a through thematic analysis looking for meaningful patterns and processes. This task of data analysis was facilitated by the use of Open Code software. I have used Pseudonyms while presenting participants' account both to give human characters to participants and maintain their anonymity.

9.4. Results and Discussions

9.4.1. Participants' Background

Table 1. Participants' basic information

Name	Age	Ethnicity	Education	Employment
Bezabeh	29	Amhara	Literate	Cloth Sewer
Dawit	26	Amhara	Grade 9 th	Business broker
Meberatu	26	Amhara	Grade 10 th	Unemployed
Meteku	29	Tegerie	12+2	Assistant Librarian
Zacharias	26	Amhara	12	Unemployed
Zenebe	29	Amhara	Grade 6 th	Guard

As indicated in Table 1, Meberatu, Dawit and Zacharias were 26 while Bezabeh, Meteku and Zenebe were 29. All but Meteku were from Amhara Ethnic group. Participants were all followers of Orthodox Christianity. Dawit and Meberatu had reached high school before they stopped their studies because of their sickness with AIDS. Meteku had a "12+2" certificate. Zacharias was a freshman Accounting student in the Addis Ababa University Commercial College before he dropped his education upon HIV diagnosis. He never went back to resume his studies. Bezabeh learned reading and writing while he was in Gojjam, his birth place, but did not get the chance to have a formal education. Zenebe stopped at sixth grade. His interruption of education was not, however, related with his HIV diagnosis. Zacharias and Meberatu did not have any employment. They depend on their family for their living. Bezabeh, Dawit, Zenebe and Meteku were engaged in cloth sewing, brokering business deals, guarding and library work, respectively. Participants' age and medical information has been presented in Table 2.

Table 2. Participants' medical information

Name	Age at starting ART	Time gap between HIV diagnosis & starting the ART	Time duration since starting ART	Current CD4 level
Bezabeh	26	15 days	2½ years	136
Dawit	23	1 year	2 years	240
Meberatu	23	No gap	3½ years	448
Meteku	25	4 years	5 years	216
Zacharias	23	4 years	3 years	258
Zenebe	24	1 month	5 years	460

Dawit, Meberatu and Zacharias started the treatment when they were 23 years of age. Zenebe was 24, Meteku 25 and Bezabeh 26 when they started the ART (see Table 2). The mean ART starting age was 24. While Bezabeh, Meberatu and Zenebe started the treatment in a month or less than time, Meteku and Zacharias had to wait four years. Dawit waited for one year before starting the ART. All of the participants had been taking the ART for at least two and half years. The mean duration since starting the ART was three years. The lowest CD4 count was 136 while the highest was 460.

9.4.2. What Do ART Attendants Feel about Risks Associated with Sex?

9.4.2.1. Condom Use

All of the participants said that sex without condom use could still be risky for them. They mentioned their health providers as the major source of information. All of the participants talked about the risk of contracting another strain of HIV and other STIs as well as unplanned pregnancy. Zacharias, Meberatu, Zenebe mentioned that condom non-use could subsequently lead to contracting drug resistant viral type. Even Bezabeh who did not have any formal education knows about this. Here is how he explained the risks:

In the hospital, they tell us that the shape of the virus differs from person to person. And we have been told that viral transmission even amongst ourselves is harmful. If this happens, they tell us that, we will not have the chance of having a prolonged life. I had better treat my own problem rather than add another. And it is not only HIV; there are other sexually transmitted infections that could be contracted. In my case, HIV did not cause skin rash, bulging or other infections. There are even people who cannot control their urine. If I do sex, then I too may contract the virus type that causes such complications.

Meteku and Dawit said they regularly used condoms. "This has never been subject to negotiation" Meteku stressed. On the other hand, Zacharias and Zenebe confessed that they had practiced sex without using condoms after

commencing the ART. In fact, Zacharias even said he rarely used condom with his ex-girlfriend who he recently broke up with. He said that feeling of hopelessness, alcohol abuse and 'limited sexual pleasure during condom use' made him reluctant to use condom regularly. Here is how he shared his experience:

We rarely used condom. Yet, we knew about the risk of viral transmission between people who already have the virus. We are both educated. Despite our knowledge of the apparent risks, we simply did not use condom. We did not want to see anything worse coming. We both knew the risk because we were educated. But we were frustrated. We saw no hope in our lives. We were heartbroken...I would think about my past and get angry at how things turned out. I had deeper frustrations in life. To escape this feeling, I had to drink. You could not process things very well at such times and so you do not care to use condoms. There is something that just makes you so careless about condom use in such times. I don't know. When you are sober, you can clearly see the advantage of condom and so you use it. But, if you take substances, you don't. It is only in the mornings that you regret your acts... Besides, I used to feel better satisfaction when I had sex without condom. Condoms limit sexual satisfactions. So, we were not happy to use condom. There is some unique pleasure that you feel when you have sex without condom. Since we felt the damage had been done already, we did not see anything left that was worth giving up the pleasure. Besides, it is when you have vision and hope for the future that you care to use condoms. At times when everything around you looks dark, you simply don't care about condoms at all. They say '*Yebelese zenabe ayeferame*' [an Amharic idiom which, which literally means: the wet no longer fears the rain]. I feel it was just like that.

Zacharias's engagement in unsafe sex was related with the feeling of hopelessness and despair. Conversely, a cross-sectional survey among men and women living with HIV indicated that emotional distress and maladaptive coping were not related to risky sexual practices (Kalichman 1999). Hence, this association needs further investigations. On the other hand, this same feeling of hopelessness, Zacharias noted, also made him reluctant to take the medication properly. Results of researches indicate that non-adherence is related with increased risky behaviour (Kalichman *et al.* 2010; Kalichman and Rompa 2003). In Zacharias' case, this interplay seems to be linked with the feelings of hopelessness and despair. Whereas, Zenebe said his hope to have his own child led him do the same. Zenebe said he had a strong desire to have a child. Most of his agemates in the community already have children and he often felt he was left behind. Thus, he avoided condom use. This is consistent with the findings of several other researches (e.g., Yadeta 2009; Kekebo 2008; Wossenyelesh 2006) that have also shown that the desire for a child can push ART attendants and other PLWHA to engaging in unprotected sex.

Bezabeh maintained he was better off abstaining from sex altogether. He said he had never used condoms. He did not intend to use in the future either because he did not trust its protection. He did not want to risk losing his health once again. Here is what he made of condom and the risks of non-use:

Oh, that is like requesting your execution! Death comes in different ways to us. Sometimes, it is instantaneous. But if you have sex without a condom, you are asking for a painful death that would come through long misery. Let alone without condom, there is nothing in me to have sex altogether. Sorry to say that but I don't have confidence in condom, by the way. So, I don't want to have sex. I don't want sex altogether.

9.4.2.2 Multiple Sexual Partnerships

When asked about their feeling about having more than one sexual partner at a time, participants expressed it in words like “risky”, “meaningless”, “unnecessary” and “worthless”. Bezabeh indicated that it was “sinful” to have multiple partners. Participants mentioned the risk of transmitting the virus to others and contracting other kind of STIs including another type of HIV traits. They also maintained that it was morally wrong to transmit the virus to others. Encouragingly, none of the participants said they were currently seeing more than one sexual partner. None of them also expressed a favourable attitude towards having more than one sexual partner.

Despite their present disinterest in having sex with more than one partner, Zacharias, Dawit, and Meteku admitted that they had practiced it for a while after they had started the treatment. Zacharias said that he frequently went out with different girls each week without bothering to know their sero-status. “They were like Guest of the Week.” However, these participants were quick to add that they were no longer involved in the practice. When asked about how he came to stop the practice, Zacharias said he no longer wanted to date or have sex at all because these things had negatively affected his health. Meteku and Dawit said they had their ‘own’ partners who they wanted to be faithful to. They maintained that they were too satisfied with their partners to think of going to other girls.

9.4.2.3. HIV Sero-status Disclosure to Partners

Meteku, Dawit and Zenebe said that they had sexual partners. They said their HIV-positive status is known by their partners. They added that their partners also had the virus. In fact, Meteku and Dawit said that they met their partners at the hospital where they attended ART. All of the participants stressed that in the future, they did not want to have a date or mate with who did not have the virus. This openness is beneficial as Stirratt *et al.* (2006) indicate that people who disclose their positive sero-status to others demonstrate higher rates of adherence. Since adherence brings down the viral load, it subsequently decreases the risk of transmission (Volberding *et al.* 2008).

However, Dawit and Zacharias admitted that they had been sexually intimate without disclosing their status after starting the ART. In fact, Dawit said he knew the girl was not having the virus. He shared with me his struggle to tell the girl about his status like this:

There was this girl that I dated after I started the ART. She was black and beautiful. I used to love her. Oh no, she used to love me rather. I was always worried whenever I had sex with her. I was always worried that I would destroy her life even though I was using condom. I did not tell her but later I wanted to. I felt like my mind was going to explode. I was filled with remorse and guilt. I was very worried. I could not take it anymore. Then, I told her.

Researches carried out in America suggest that the belief that having an undetectable viral load leads to lower infectiousness was associated with greater number of partners, including non-positive partners, and less condom use (Kalichman *et al.* 2010; Kalichman *et al.* 2006; Kalichman and Rompa 2003). But participants in this study indicated to have neither this belief nor the awareness about such association between the medication and risk of transmission. The absence of such beliefs is further demonstrated by the worry of Dawit about infecting his girlfriend even though he was using condoms properly. Hence, it can be said the findings of this study are inconsistent with findings of previous researches done elsewhere in this regard.

9.4.3. What Issues do ART Attendants Feel Influence Their Sexual Life?

Participants indicated that emotional distress, discrimination, alcohol use, spiritual devotion and physical conditions affected their sexual and dating experiences. Most of these issues appear to also influence the sexual experience of any other individual who is free from HIV. Kekebo(2008) also notes that HIV-positive status does not affect the sexual preferences and needs of people.

9.4.3.1. Emotional Distress

Meteku, Zacharias, and Meberatu indicated that they became disinterested in sex when they experience emotional distress such as feelings of despair, inferiority and frustration. They noted that they had to constantly battle with these sorts of feelings. They said these feelings were invoked when they thought of the educational and career opportunities they had missed due to their sickness. However, they also indicated that such emotional distress could also be triggered by circumstances they considered trivial. For Meteku, for example, “getting common cold” could be a reason enough to bring emotional strain.

Meteku and Zacharias said that feelings of despair, inferiority and frustration affected not only their sexual lives but also their social relationships, work and health. Both indicated that they preferred to disassociate themselves from others when they had these feelings. These in

turn influenced their sexual lives as well. Meteku said that this had been a reason why he found dating difficult for so long before meeting his present girlfriend. He said:

There are times I get frustrated and depressed with little things. I guess this is something we who live with the virus cannot get over with forever. I just don't feel like having sex during such times. I don't even want to talk to people. I want to be alone. I always see myself different from others despite my unawareness about their status. I feel inferior. How can I relate with girls or date under such circumstances then? I could not. I felt like I have already taken my share of the bread. After eating, you no longer feel hungry. That is how I felt about sex. I felt that the pleasure of sex was no more for me. Sex wouldn't just come to my mind at all. When nights come, I no longer think of sex but about the drugs I must take before I go to bed. The drug makes me dizzy, forgetful and delusional. Taking the drugs takes much of your attention that you don't think of sex as such.

Meteku and Meberatu said that anger and regrets also affected the quality of their lives, sexual feelings and experiences. Both said that they had felt anger towards themselves for catching the virus. Meteku thought that he was “*arada*” (smart guy). He confessed that he later realised and often regretted that he was not “smart enough” to take care of himself from HIV. Meberatu mentioned that his sexual desires had literally “vanished” after commencing the ART. He thought his anger at himself might have caused this.

Depression and low self-esteem may play an important role in the development and maintenance of risky sexual behaviours (Shrier, *et al.* 2005). Participants' disinterest to have sex when they were emotionally distressed contradicts the assertion of Bancroft *et al.* (2003) who writes that when one is depressed, sex can serve needs for intimacy and self-validation as well as sexual pleasure.

9.4.3.2. Stigma and Discrimination

Meberatu, Meteku and Zacharias mentioned that the stigma and discrimination they face brought them despair and frustration besides limiting their social network. Stigma and discrimination challenges their desire and hope of ever forming sexual partnerships. They preferred to dissociate themselves from their friends, community members, and colleagues; and this, they said, limited their prospect of dating.

The three participants also indicated self-stigma as a serious influence on their prospect of dating. All of them said that they always struggled with the feeling of inferiority. Commenting on how his feelings of inferiority had prevented him from dating, Meberatu had, for example, this to say:

Whenever I stand to talk to a girl, I always imagine people gossip that I am going to infect her. They may not be thinking and talking

about me; but I feel they do. I have not actually heard anyone saying such things. They may or may not say that. Only the Creator knows that. But, because I am hurt inside, I feel that they think of me that way and talk behind my back.

Despite the many efforts aimed at reducing stigma and discrimination, PLWHA still had to struggle with the fallouts. In fact, it has been reported that stigma and discrimination still remained high in Ethiopia with only slight decline over the years (CSA 2006). Once provoked, stigma contributes to the creation of a new social role that can perpetuate itself (Leff and Vaughn 1985). In addition to directly limiting participants' social network and consequently their ability to form sexual partnerships, discrimination also caused low self-esteem, frustration and symptoms of depression. These in turn influenced their sexual experiences and feelings.

9.4.3.3. Alcohol

With the exception of Dawit, all of the participants said that they were “drunk” while having the sex they suspect led to their contracting HIV. Alcohol still influenced their sexual experience after they started the ART and resumed normal lives. Zenebe said that he took alcohol because he wanted to have sex, while Zacharias and Meteku said they had sex because they were drunk. Zenebe indicated that he still took alcohol when he wanted to have sex with his girlfriend. On the other hand, Meteku and Zacharias said that they used to get “heavily drunk” and engage in unsafe sex whenever they were emotionally distressed till recently. This is consistent with literature in which drinking is found strongly related to the decision to have sex and to indiscriminate forms of risky sex (e.g., having multiple or casual sex partners) (Cooper 2010).

9.4.3.4. Spiritual Devotion

In their attempt to cope with the emotional distress, stigma and discrimination, Dawit, Bezabeh, Zacharias and Meteku, resorted to increased church attendance and devotion to “spiritual matters”. For instance, Dawit and Bezabeh indicated that this devotion to spiritual matters had influenced their sexual practices. Dawit became a “serious” churchgoer for one year after starting the ART. “I did not have the interest to have sex during that time” he recalled. On the other hand, Zacharias had never gone to church before his diagnosis. After resorting to alcohol and “*chat*”, he finally went to church one day which he said brought a major relief to his soul. He became a committed churchgoer. He also said he had come to be less interested in sex since then.

9.4.3.5. Physical Condition

All of the participants except Meberatu said that they wished they had sex when their body relaxed after a good meal and sleep. This appears to be the case with people who do not have the virus in their blood also. Conversely, the participants also indicated that they did not want to have sex when they

were physically and mentally exhausted. They said they would think of sex when they felt healthy. Meteku said:

I want to have sex when I feel healthy and clean. My sexual feelings come after I have rested well from work. I like to have sex during the weekends when I have long and free hours. I take her out for a dinner. In such instance, we did not even have to talk about having sex. We just knew it and did it.

Despite his commitment to abstinence, Bezabeh also admitted that there were times he wished he had sex. He described such moments like this:

I think of having sex when I have money in my pocket, eaten good food, and had enough rest. I like to have it when my body relaxes. Early in the morning after sleeping through the nights, I think of sex. We are humans so we think of sex.

9. 5. Conclusions and Implications

9.5.1 Conclusions

This research has shown that the introduction of ART did not result in increase in risky sexual behaviour among the participants. They said that they used condoms regularly or have abstained since starting the treatment. This finding is in agreement with findings of other studies conducted in Ethiopia (Kekebo 2008; Yadeta 2009) and some other countries in Africa (Bateganya *et al.* 2005; Bunnell *et al.* 2006; Sarna *et al.* 2008). These studies indicated considerable decline of risky sexual behaviour after ART commencement.

Participants' knowledge of the risk of unprotected sex among PLWHA was high and helped them avoid risky behaviour. All participants knew the risks unprotected sex entails for their health. The major sources of information were doctors and other health professionals. Participants indicated the risk of contracting another kind of HIV trait, possibly drug resistant, other STIs, and unplanned pregnancies. Of the four participants who had been sexually active after starting the treatment, two of them said they regularly used condoms. The other two admitted that they had sex without condom. This indicates that risk knowledge alone does not determine safe sexual behaviour. The findings of the study also indicated that frustration in life, alcohol abuse and the desire for having a child influence participants to avoid condom use. On the other hand, those who used condoms regularly said that their desire to live longer and healthier as well as understanding of the risks of non-use contributed for regular condom use.

All of the participants who currently had partners said their HIV status was known by their partners. In fact, another commonality among the participants was their interest in exclusively dating females who also have the virus in their blood. They said this had helped them to share their life experiences and support each other freely with regard to various life challenges including adherence to the medication.

The sexual experience of participants after they started the treatment is influenced by stigma and discrimination, emotional distress, alcohol, spirituality, and physical body conditions. Stigma and discrimination restricted participants' capacity to form sexual partnerships. Additionally, stigma and discrimination also caused depressive symptoms which in turn negatively affected participants' sexual experiences. Participants noted that they usually felt despair, frustration, inferiority, anger and self-blame because of their HIV status.

Future researches should continue to explore the association of mental health problems with the sexual experiences of people who have the virus in their blood. Moreover, the sexual experience of female ART attendants in Ethiopia still remains largely unexplored. Females may probably have different sexual experience from males because their sexuality is influenced by different psychosocial, biological and economical influences.

9.5.2. Implications

This research has attempted to point out the issues that underlie the sexual feelings and experiences of ART attendants. Participants' lives and sexual experiences are different from one another. While some appear to be leading emotionally stable lives, the others were emotionally distressed, this negatively affected their sexual behaviour. Intervention strategies should therefore consider the diverse experiences and needs of ART attendants in designing their strategies. A single and overarching intervention strategy therefore does not appear to be the best option.

This study has indicated that risk knowledge alone does not determine safe sexual behaviour. It has shown the vulnerability of the participants to mental health problems. These problems have been found associated with participants' sexual experiences including involvement in risky practices. Hence, this association deserves more investigations as it could add valuable insights for the integration of ART with prevention efforts.

Stigma and discrimination have continued to negatively affect the lives of the participants. The mental health problems participants encountered were found associated with the stigma and discrimination they faced. Hence, the fight against discrimination should be strengthened and continued. This should ultimately lead to the promotion of the deprived status of PLWHA with the delicate task of recognizing and respecting the sexual needs and rights of PLWHA.

One of the mechanisms participants used to cope with stigma and discrimination and the various mental health problems was devotion to spirituality. Participants indicated that they gained emotional comfort and strength by going to church and attending some events there. Their disinterest to engage in multiple sexual partnerships was also associated with their conviction of the practice as morally wrong and sinful. These indicate that religious organizations could be valuable partners in both the prevention and treatment efforts. Hence, intervention programmes should

recognize and capitalize on the spiritual dimension of ART attendants' behaviour to achieve their goal of improving these people's lives.

Notes

- ¹ In accordance with Ethiopian custom, the first name or given name is substituted for the surname and the father's name and grandfather's name is spelled out in full. Thus, Ethiopian names are spelled out in full and the citation format is: Given/first name, Father's name (Grandfather's name is added if used) followed by date.

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CHAPTER TEN

Concluding Remarks

Getnet Tizazu Fetene and Rahel Mesfin

As pointed out earlier, antiretroviral treatment (ART) has significantly reduced mortality, minimized morbidity, and by and large, sparked some sense of optimism among PLWHA who have had access to the treatment (UNAIDS 2012). ART involves taking drugs which prolong the life of HIV or AIDS patients. Due to the encouraging results of ARVs and the need to reach HIV and AIDS patients widely, the “Treat 3 million by 2005 Initiative” (“3 by 5” initiative) was launched by WHO and UNAIDS, compelling governments to increase access and distribution of ARVs to HIV and AIDS patients (WHO and UNAIDS 2006). Even if most countries were not successful in achieving the target of the initiative, the number of people on ARV more than doubled. In addition to the ‘3 by 5 initiative’ and universal access to ARV by 2010, access to ARVs has also been considered one of the major health indicators of the Millennium Development Goals, thus invigorating and, to a certain extent, assuring the allegiance of governments to sustain efforts in addressing HIV and AIDS as their prime concern. It seems apparent that due emphasis has been alluded to scaling up of ARVs. Though increasing the coverage or distribution, ARVs have had tremendous impacts; consequently, the increasing statistics by itself may not yield the anticipated results. More and more evidence shows the importance of recognising social inequality, poverty, stigma and discrimination among other factors in HIV prevention, treatment and care programmes.

The eight chapters in this volume convey some similarities and differences over the challenges and prospects of ARV treatment in eastern and southern Africa. Almost all authors, however, convey the need to conduct more empirical studies on the various aspects of the epidemic. In brief, it can be argued that issues treated in the eight major chapters can be summed up in the following key themes: Choice of treatment, exposure to HIV and AIDS, the role of traditional medicine in HIV and AIDS treatment services, exposure to HIV and AIDS, and future course for the sustainability of ART programmes.

Choice of Treatment and Adherence to ARV: The issue of choice and treatment is a theme dealt with in depth in Matovu’s work as well as by Woineshet and Abiy’s study. Having identified three key HIV and AIDS treatment services categorized as: specialized, routine (VCT, RCT, family planning services) and community-based (nutritional support, care and support services), Matovu’s work reflected on factors which influence patients’ choice of treatment services. The study indicated the role of socio-economic conditions such as age, gender, marital status, education, household headship and size as well as the manner of service delivery, and

opportunity cost of access by and large influenced patients' choice of a particular type (routine, specialized community based) service. Among these services, access to high level resource-laden services such as TB medication, PMTCC for women, follow up care plan often rely on the evaluation of competent medical personnel. Contrary to that, the decision to access routine services mostly rests on patients' own-initiated efforts.

Woineshet and Abiy's study on factors influencing ART adherence in Ethiopia revealed that the participants' adherence was found to be suboptimal— only 63 per cent of the participants reported to be adhering to the ARV treatment. This level of adherence is, however, quite lower when compared to the average rate of adherence reported by Sibhatu Biadgiligne and Ayalu Aklilu's study (i.e. 75 per cent to 77 per cent). Notwithstanding the need for more research for a more conclusive evidence, the rate of adherence reported in the study is in fact a cause for concern. Among other things, the study revealed that forgetfulness and reluctance to stick to their treatment over a period of time are the major negative factors reported in the study. Equally worrisome is patients' failure to observe dose intervals. More than a-third of the participants exhibited a habit of shifting drug schedule due to religious fasting which is quite apparent among women, making them a vulnerable group. On a positive note, factors such as better social support, refraining from substance abuse, owning cellular phones were reported to increase rate of adherence.

Exposure to HIV and AIDS: This theme was the focus of two of the works by Bereket Tarekegn and Nathan Negussie. Focusing on religious leaders who, at least according to conventional wisdom, are considered to be immune from contracting HIV and AIDS, Bereket shows that these groups could catch the virus and they, too, could seek some antiretroviral treatment. It also implies that religious leaders as a group can carve safe religious space different from the mainstream religious institutions. It indicates that they could also serve as sources of inspiration to ordinary believers by way of mitigating stigma as people notice that religious leaders could contract HIV, it would allow them to acknowledge the fact that the disease is not necessarily associated “with sexual immorality, irresponsibility, impurity, and looseness” (a belief held by mainstream religious leaders). They would thus tend to be less critical of their status. This also has implication with a potential for the involvement of mainstream faith institutions as adherence supporters and VCT promoters.

On another note, Nathan Negussie's study brings out the issue of the sexual behaviours of HIV and AIDS patients on ART. The study highlights that HIV and AIDS patients do not seem to exhibit irresponsible sexual behaviour. Most use condoms. They avoid multiple sexual partnerships and tend to disclose their sero-status to their sexual partners. Though this is the overall trend, it does not mean that they lead their sexual life easily and freely. Instead, their sexual performances are compromised/affected by factors such as stigma and discrimination, emotional distress, alcohol,

spirituality, and physical body conditions. Albeit depending on rather limited number of subjects (i.e. three subject), the study has important implications on the excuse of some youth living with HIV and AIDS for having sex without condoms—the desire to have children. More in-depth research on the sexuality of people on ART and particularly females is prerequisite prior to designing interventions.

The role of traditional medicine in HIV and AIDS treatment services:

This issue has received extensive treatment in Mandizadza and Chavunduka as well in Njeru's studies both of were set in Zimbabwe. Both studies were carried out on the backdrop that a significant portion of the people in Africa (about 80 per cent) uses traditional medicine to deal with their ailments. Njeru, focusing on patients' attitude and perception of traditional medicine, points out that individuals' decision on treatment options may not be entirely in response to the health predicament (health response). He argues that it is also 'social response' which draws on individuals' own and family beliefs, ability to access information, level of illness, and cost of treatment. Hence, such ambivalence leads patients to confidentially opt for both biomedical therapeutic with faith and traditional healing. Patients receive traditional medicine and biomedical therapies concomitantly. Disclosed along with this concomitant use is a sense of secrecy about the double use. For fear that their concomitant use would be disapproved, informants appear to manifest a feeling of shame and some sense of discomfort while talking about the practice. Their use of ART also appears to be characterized by poor adherence resulting from their negative beliefs about the therapy (e.g., too much medicine is harmful; taking a break from medication is necessary; strict adherence to ART is too demanding). According to the study, despite a general consensus among patients about the existence of HIV and AIDS, they seem not to be entirely convinced that it can be dealt with single-handedly by ART. They, for example, believe that the evil spirit, one characteristic feature of the disease, can be exonerated through traditional medicine or faith healing.

Patients' desperation, and the strict regimen administration of the medication coupled with the callous/direct factual health messages surrounding HIV and AIDS on the one hand and the seemingly consoling traditional/spiritual methods on the other hand seem to cause anxiety and hesitation to patients when selecting treatment options. Hence, the study exudes the impression that informal health care to certain extent fills the gap that modern biomedicine fails to address in terms of patients' psychological needs and assurances.

In brief, it might be argued that the two studies intersect in the sense that both see a room for the TPM to fill in this area that seems to be neglected by modern medicine. Both emphatically note that sole reliance on biomedical practice to curb the spread of HIV or promote HIV/AIDS treatment is unlikely to work. Whilst Njeru points out the scepticism expressed by biomedical health practitioners towards the medicine, and to a

degree by traditional medical practitioners, Mandizadza and Chavunduka note a sense of optimism and envisage meaningful collaboration about the possible partnership/collaboration between biomedical and traditional medicine practitioners. They further argue for the need to redefine the health system, which solely relies on modern medicine by disparaging the traditional medicine. Mandizadza and Chavunduka are explicit and identify possible areas that traditional medicine practitioners can be involved in. They argue that policy makers, public health officials and other stakeholders need to revise the scare discourse surrounding biomedicine and medical inconvenience characterizing the management of ART (e.g., side-effects, medical toxicities) which eventually arm-twist patients to look for some sanctuary in traditional healing that promises to offer what is lacking (i.e. mainly psychological comfort) in the former. Added to that, both works decry that enough has not been done by way of integrating the two practices.

The role of traditional medicine is subject, albeit not on an equal degree, treated by almost all the contributors. Most see little contribution from TMP in the fight against HIV/AIDS. Instead, they tend to see one of the factors that interfere with the healthy administration of the ART in many ways: concomitant use and replacing ART by traditional medicine. Whether or not to involve TMP in the HIV/AIDS treatment is probably one of the most thorny issues in the ART literature. Indicative of this fierce debate, the role of traditional medicine is a subject, though not with equal depth, that has been dealt with by almost all the contributors of this volume. Most see little contribution from TMP in the fight against HIV/AIDS. Instead, they tend to see traditional medicine as one of the factors that interfere with the healthy administration of the ART in many ways.

Future course for the sustainability of ART programmes: It could be said that the future fate of ART programmes was the concern of almost all the contributors to this volume. Acknowledging the success of ART programmes launched in sub-Saharan African countries, particularly in relation to the adult population taking the treatment, the decisive role of governments' in running ART programmes is, for example, emphasised in Sibhatu and Ayalu's study. Even though there is room for partnership between government and other stakeholders, there is some scepticism about the sustained commitment of donor organizations in funding ART programmes, hence calling for home grown-initiatives which engage and empower communities.

By the same token, despite airing methodological concerns and expressing some reservation about the sustainability of the therapy, Bajunirwe acknowledges an increase in the quality of life (QOL) of people who are on ARV. Wary of maintaining the positive momentum and fear that the treatment may drop when long side-effects surface, Bajunirwe emphasizes the need to regularly monitor patients' QOL and document the changes observed. It is further noted that the literature in QOL is quantitatively

slanted and dominantly employs linear regression which precludes the possibility of curvilinear relation between study variables. The fact that the bulk of the research comes from Southern African countries is another concern of the author and rightly recommends more research from other African countries of the region.

One key policy direction advocated is that anti-retroviral treatment should go beyond drug prescription and include different forms of support (psychological, food and shelter, community). The authors also underlined the need to intensify health education campaigns to stigma and promote family and community support. The need to conduct longitudinal studies to entirely understand variables predicting adherence is an intervention forwarded in terms of research (see the work by Woinshet and Abiye). In this regard, Matovu stresses the role of patients' family members and recommends that programmes which aim to ameliorate treatment and adherence ought to strive and include patients' family members as key treatment facilitators.

On another note, the recognition of traditional medical practice in the fight against HIV and AIDS is presented as policy direction which ought to be explored by most of Africa countries. The collaboration between the formal and informal health care providers including traditional faith-based healers is called for/should be explored and enhanced. Understanding how the disease is framed in traditional and faith-based healing practices is imperative to defining frameworks for collaborative initiatives and policies on HIV and AIDS prevention, treatment and care (see Mandizadza and Chavunduka, and Njeru).

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