

**Equity in access to HIV/AIDS services in Zambia:
The role of social cohesion in HIV prevention and
care**

Inauguraldissertation

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Basel, den 17 September 2013

Prof. Dr. Jörg Schibler

Dekan

Ubuntu

***‘I am, because we are, and
since we are, therefore I am’***

In the African context, Ubuntu is the philosophy that an individual only exist in relation to a community. This philosophy is based on values of mutuality and shared humanity.

Where there is Ubuntu there is social cohesion.



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Outline of publications

This thesis is based on the following papers:

As first author:

1. **Gari S.**, Doig-Acuna C., Smail T., Musheke M., Malungo RS J., Martin Hilber A. Ntalasha H, Merten S. *A systematic review of socio-cultural barriers to access HIV/AIDS services.* BMC Health Services Research 2013, 13:198
2. **Gari S.**, Musheke M., Malungo RS J., Martin Hilber A., Schindler C., Merten S. *Tolerance to gender based violence and HIV testing: a cross-sectional study in Zambia.* PLoS One. 2013; 8(8): e71922.
3. **Gari S.**, Musheke M., Malungo RS J., Martin Hilber A., Schindler C., Merten S. *Sex differential in the uptake of ART in Zambia.* AIDS Care. 2013; (in press).
4. **Gari S.**, Musheke M., Malungo RS J., Martin Hilber A., Schindler C., Merten S. *Risk of non-adherence and disengagement from ART programmes: findings from Zambia.* Journal of Int. AIDS Society. 2013; Manuscript submitted for publication

As co-author:

1. Musheke M, Ntalasha H, **Gari S**, Mckenzie O, Bond V, Martin-Hilber A, Merten S: A systematic review of qualitative findings on factors enabling and deterring uptake of HIV testing in sub-Saharan Africa. BMC Public Health. 2013; 13: 220.

Summary

Zambia has for many years experienced a generalised HIV epidemic. Large-scale antiretroviral programmes have been successfully introduced (Egger et al. 2005; Stringer et al. 2006). Despite progress in controlling both new infections and access to treatment, the scale and impact of the epidemic remain major concerns. Persistent social inequalities and discrimination continues to create significant barriers to access HIV/AIDS services. It has been argued that social cohesion, understood as collective networks of solidarity and trust in a society, could reduce susceptibility and vulnerability to HIV (Meyer-Weitz, 2005; Loewenson, 2007) and generate social action (Kawachi et al., 1997).

This thesis aimed to investigate the influence of social cohesion along the continuum of HIV care in Zambia (uptake of testing; uptake of ART; adherence to ART and retention in care). I was particularly interested in assessing the effect of specific combinations of social cohesion (couple, household and neighbours), economic and individual factors on the decision making related to access to HIV services.

To do so, a community-based cross-sectional survey methodology (N = 3,000) was implemented in four sites in the Southern and Central provinces of Zambia: two rural (Namwala and Monze district), one commercial centre (Mazabuka) and one urban area (Lusaka). The rationale behind the sites' choice was to have a comparative setting with varying health system, socio-economic and socio-cultural conditions (urban, periurban and rural). The study population consisted of

adults, women and men, over the age of 18, who were residents of one of the four sites.

This survey was the quantitative part of a larger mixed-method research study entitled “Improving equity of access to care and treatment in Zambia” financed by the Swiss National Science Foundation (SNSF, project nr: IZ 70ZO-123907). The development of the questionnaire was informed by the results of an ethnographic research carried out within the overall project and a systematic review of previously validated questionnaires that I personally carried out. In order to investigate the potential associations between social, economic and individual factors and access to HIV/AIDS services, the data was primarily analysed using multilevel and multinomial logistic regression models adjusting for potential confounders.

The main conclusions of this thesis are based on the results of four studies conducted to explore the effect of social cohesion along the HIV care continuum. The box below presents an overview of what this thesis adds to the existing evidence on the influence of socio-structural determinants on access to HIV/AIDS services.

What is already known?
<ul style="list-style-type: none">▪ Social cohesion plays a positive role in both reducing susceptibility to HIV and dealing with vulnerability to AIDS.▪ Gender-based violence and gender inequalities increase vulnerability to HIV infection and deter uptake of HIV testing in women.▪ HIV/AIDS-related stigma is a major barrier to HIV prevention efforts hampering uptake of HIV testing, adherence to ART and delaying general health seeking among people with HIV.▪ The existing quantitative studies on the link between poverty and HIV/AIDS present conflicting evidence.

What does this thesis add?
<ul style="list-style-type: none"> ▪ In Zambia, social cohesion - measured by networks of action, trust and reciprocity either at the level of the couple, the family and the community - plays a significant role in access to HIV/AIDS services even when factors such as stigma, socio-economic status, gender and other individual factors are taken into account. ▪ Not all levels of social cohesion (couple, family and community) exert their effect in the same way along the continuum of HIV care. ▪ Not only enacted violence but tolerance to gender-based violence within households hampers the uptake of HIV testing. This is often a reflection of prevailing social norms with respect to gender and power relations in a community. High levels of tolerance to gender-based violence are more common in dis cohesive environments. ▪ HIV/AIDS-related stigma strongly hinders uptake of testing and retention in care. High levels of stigma are more common in dis cohesive environments. ▪ Livelihoods insecurity deters uptake of treatment and adherence especially in women. However, increasing social ties can help balance this negative effect. ▪ Promoting social cohesion among men, especially through increasing men’s participation in community activities, could have harmful effects unless underlying gender norms of masculinity are mainstreamed in the design of the intervention.
What do these findings lead to?
<ul style="list-style-type: none"> ▪ Social dis cohesion and disempowering conditions (discriminatory gender norms, high levels of stigma and livelihoods insecurity) are the recurrent obstacles of access along the HIV continuum of care in Zambia. The strategy to scale up access to HIV/AIDS services in Zambia needs to prioritize interventions aimed at promoting social cohesion and reducing disempowering conditions which are especially present in dis cohesive environments. ▪ Social cohesion primarily deals with creating environments that enable couples, families and/or communities to overcome (inevitable) social tensions and conflicts. These enabling environments can be achieved through facility-, community- and policy/institutional- level interventions promoting non-violence and gender-equitable norms as well as mobilizing communities to enforce laws preventing discrimination based on gender and/or HIV status.

The detailed results are presented in four scientific papers that have been included as chapters in this thesis (Chapter 6 to Chapter 9).

Chapter 6 investigates, through a systematic review and meta-analysis, the evidence-based on social and cultural barriers to access HIV/AIDS services. The results revealed that there is a tendency, in quantitative studies, to study the same factors survey after survey. Furthermore, this trend varies with the economic level of the country. In low-income countries, surveys tend to examine socio-economic factors and health education, whereas in high-income countries more attention is paid to clinical and psychosocial factors such as depression, anxiety, self-efficacy and/or sexual identity. The effect of family and social relationships, including interpersonal violence, received, comparatively, little attention in both rich and poor countries. These results were instrumental in focusing my research on the influence of social cohesion in access to services for prevention and treatment of HIV/AIDS.

Chapter 7 investigates the influence of social cohesion factors on uptake of HIV testing through multilevel logistic regression analysis. This study shows that not only enacted violence is a burden for HIV prevention but that tolerance to gender-based violence is strongly associated with non-uptake of HIV testing. It further reports that cohesive couples (those with less conflicts and more trust) report lower levels of tolerance to gender-violence and are more likely to test. Promoting couple cohesion may help to reduce power imbalances in the couple.

Chapter 8 investigates the factors influencing uptake of ART and the gender differences in these associations through a case control analysis. It reports that gender differences in the way men and women perceived their health and anticipated the experience of taking ARVs which ultimately determined their

decision to accept or not ART treatment. In Zambia, decisions about ARV treatment for men may be influenced more significantly by social factors and therefore may be more susceptible to external influences, while for women, this is a more personal (individualistic) decision provided they have the necessary support to cover the material and social costs associated with the treatment.

Chapter 9 investigates which socio-structural factors play a role in adherence and retention in HIV care through a multinomial logistic regression analysis. This study shows that non-adherence to treatment appears to be strongly affected by external factors such as financial and livelihoods constraints while retention in care is more affected by internal factors such as gender, stigma and self-efficacy. Some factors which are largely established as barriers to adherence in the literature (e.g. side effects, lack of transport to go to the clinic, alcohol abuse or traditional medicine beliefs) were significant in bivariate analyses but not in the adjusted ones. Food insecurity, stigma problems, marital conflicts and self-efficacy issues outweighed their effect in this study.

In conclusion, this thesis shows that social cohesion influence access to HIV/AIDS services in Zambia. Promoting greater social cohesion in local communities in Zambia has the potential to reduce social inequalities that deters access to HIV/AIDS services. It may also facilitate collective action, for reducing tolerance to violence, reducing stigma and discrimination and compensating economic burden. However, the mobilisation of social cohesion in local communities requires an awareness of the risk of rising inequality, especially for men unless “masculine” gender norms are changed.

Zusammenfassung

Sambia erlebt seit vielen Jahren eine allgemeine HIV-Epidemie. Umfangreiche antiretrovirale Therapie-Programme sind erfolgreich eingeführt worden (Egger et al. 2005; Stringer et al. 2006). Ungeachtet der Fortschritte hinsichtlich der Kontrolle von neuen Infektionen und dem Zugang zu medizinischer Versorgung sind sowohl das Ausmaß als auch die Auswirkungen der Epidemie nach wie vor von großer Relevanz. Anhaltende soziale Ungleichheiten und Diskriminierung erschweren bzw. verhindern immer wieder den Zugang zu HIV/AIDS-Diensten. Es wurde behauptet, dass soziale Kohäsion - also gemeinsame solidarische Netzwerke und Vertrauen in die Gesellschaft - die Anfälligkeit und Verletzlichkeit bezüglich HIV reduziert (Meyer-Weitz, 2005; Loewenson, 2007) und ein soziales Handeln erzeugen kann (Kawachi et al., 1997).

Das Ziel dieser Dissertation war es, den Einfluss sozialer Kohäsion auf die HIV-Versorgung in Sambia zu untersuchen (Durchführung von Tests; Durchführung von ART; Einhaltung von ART und Verbleib in der Versorgung). Mein besonderer Fokus lag in der Abschätzung des Effektes zwischen spezifischen Kombinationen sozialen Zusammenhaltes (Partnerschaft, Haushalt und Nachbarschaft), wirtschaftlichen und individuellen Faktoren, die die Entscheidungsfindung bezüglich des Zugangs zu HIV-Diensten beeinflussen.

Dazu wurde an vier Orten in den südlichen und zentralen Provinzen Sambias eine gemeindebasierte Querschnittsstudie (N = 3,000) durchgeführt: zwei ländliche Orte (Namwala- und Monze-Distrikt), ein Handelszentrum (Mazabuka) und eine städtische Gegend (Lusaka). Die Orte wurden aufgrund vergleichbarer

Hintergründe mit variierenden Gesundheitssystemen, sozioökonomischen und soziokulturellen Bedingungen (urban, suburban, ländlich) ausgewählt. Die Studienpopulation umfasste erwachsene Frauen und Männer, mindestens 18 Jahre alt, die an einem der vier Orte ansässig waren.

Diese Datenerhebung war der quantitative Teil einer größeren, von der Swiss National Science Foundation (SNSF, project nr: IZ 70ZO-123907) finanzierten Mixed-Methoden Forschungsstudie mit dem Namen “Improving equity of access to care and treatment in Zambia”.

Der Fragebogen wurde mit Hilfe der Resultate einer ethnographischen Untersuchung, die innerhalb des gesamten Projekts ausgeführt wurde, und eines systematischen Reviews von vorausgehend validierten Fragebögen, die ich persönlich durchgeführt habe, entwickelt. Um die potenziellen Zusammenhänge zwischen sozialen, wirtschaftlichen und persönlichen Faktoren und dem Zugang zu HIV/AIDS-Diensten zu ermitteln, wurden die Daten zunächst mittels multilevel und multinomialer logistischen Regressionsmodellen analysiert, welche hinsichtlich möglicher Störfaktoren angepasst wurden.

Die wichtigsten Schlussfolgerungen dieser Arbeit basieren auf den Resultaten von vier Studien zur Erforschung der Effekte sozialer Kohäsion auf die HIV-Versorgung.

Die Ergebnisse werden ausführlich in vier wissenschaftlichen Artikeln dargestellt, die jeweils als ein Kapitel in dieser Dissertation beinhaltet sind (Kapitel 6 bis Kapitel 9).

In Kapitel 6 werden mittels eines systematischen Reviews und einer Meta-Analyse die sozialen und kulturellen evidenz-basierten Hindernisse analysiert, die den Zugang zu HIV/AIDS-Diensten erschweren. Die Ergebnisse zeigen, dass in quantitativen Studien eine Tendenz existiert, dieselben Faktoren zu untersuchen. Des Weiteren variiert dieser Trend mit dem wirtschaftlichen Stand des jeweiligen Landes. In einkommensschwachen Ländern werden eher Umfragen zu sozioökonomischen Faktoren und gesundheitlicher Aufklärung durchgeführt, während in einkommensstarken Ländern klinische und psychosoziale Faktoren wie Depressionen, Ängste, Selbstwirksamkeit und/oder sexuelle Identität die Schwerpunkte der Umfragen sind. Die Einflüsse von familiären und sozialen Beziehungen, was auch zwischenmenschliche Gewalt beinhaltet, fanden in den armen wie auch in den reichen Ländern vergleichsweise wenig Beachtung. Diese Resultate spielten eine wichtige Rolle dabei, meine Forschungsarbeit auf die soziale Kohäsion bezüglich dem Zugang zu Dienstleistungen für die Prävention und die Behandlung von HIV/AIDS zu fokussieren.

Kapitel 7 untersucht den Einfluss von sozialer Kohäsion auf die Durchführung von HIV-Tests mittels multilevel logistischer Regressionsanalyse. Diese Studie zeigt, dass nicht nur ausgeführte Gewalt eine Belastung für HIV-Prävention ist, sondern dass auch die Toleranz bezüglich geschlechtsspezifischer Gewalt stark mit der Nicht-Durchführung von HIV-Tests zusammenhängt. Weiterhin wird gezeigt, dass kohäsive Paare (mit weniger Konflikten und mehr Vertrauen) geschlechtsspezifischer Gewalt gegenüber weniger Toleranz zeigen und eher bereit sind, sich auf HIV testen zu lassen. Förderung von Zusammenhalt in einer

Partnerschaft kann helfen, Machtungleichgewichte zwischen Partnern zu reduzieren.

Kapitel 8 untersucht die Faktoren, die die Durchführung der ART beeinflussen, und die Geschlechtsunterschiede innerhalb dieser Zusammenhänge mittels einer Fall-Kontroll-Analyse. Es wird festgestellt, dass die Geschlechter sich bei der Gesundheitswahrnehmung und der Erwartung gegenüber der Erfahrung, ARV's zu nehmen, unterscheiden, was sie schließlich veranlasst, die ART-Behandlung zu akzeptieren oder nicht zu akzeptieren. In Sambia können Entscheidungen bezüglich ARV-Behandlung bei Männern erheblich von sozialen Faktoren beeinflusst werden und sind deshalb wahrscheinlich empfänglicher für externe Einflüsse, während es für Frauen eine persönliche (individuelle) Entscheidung ist, vorausgesetzt, dass sie die nötige Unterstützung haben, um die mit der Behandlung verbundenen materiellen und sozialen Kosten zu decken.

In Kapitel 9 wird anhand einer multinomialen logistischen Regressionsanalyse untersucht, welche soziostrukturellen Faktoren eine Rolle hinsichtlich Einhaltung und Verbleib der HIV-Versorgung spielen. Diese Studie zeigt, dass die Nichteinhaltung der Behandlung stark von externen Faktoren wie finanziellen und existentiellen Nöten betroffen zu sein scheint, während der Verbleib eher von internen Faktoren wie Geschlecht, Symptomen/Stigma und Selbstwirksamkeit betroffen sind. Manche Faktoren, die sich in der Literatur in hohem Masse als Hindernisse für die Einhaltung etabliert haben (z.B. Nebenwirkungen, fehlende Transportmittel zur Klinik, Alkoholmissbrauch oder der Glaube an die traditionelle Medizin), waren signifikant in den bivariaten Analysen, dies galt

jedoch nicht für die angepassten. Ernährungsgefährdung, Stigma-Probleme, Ehekonflikte und Selbstwirksamkeits-probleme überwogen ihren Effekt in dieser Studie.

Zusammenfassend zeigt diese Arbeit, dass soziale Kohäsion den Zugang zu HIV/AIDS-Hilfe in Sambia beeinflusst. Die Förderung von mehr sozialer Kohäsion in lokalen Gemeinschaften in Sambia hat das Potential, soziale Ungleichheiten zu reduzieren, die vom Zugang zu HIV/AIDS-Hilfe abhalten. Sie kann auch das kollektive Handeln erleichtern, was die Gewalt-Toleranz, Stigma und Diskriminierung reduziert und wirtschaftliche Belastungen kompensiert. Wie dem auch sei, die Mobilisierung der sozialen Kohäsion in den einheimischen Gemeinschaften erfordert ein Bewusstsein für die Risiken der zunehmenden Ungleichheit, insbesondere für Männer es sei denn „männliche“ Geschlechternormen werden verändert.

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Acronyms and abbreviations

AIDS	Acquired Immuno Deficiency Syndrome
ANC	Ante Natal Clinic/Care
ARV	Anti Retro Viral (drugs)
CHW	Community Health Worker
CI	Confidence Interval
CSO	Central Statistical Office
DHS	Demographic and Health Survey
FBO	Faith-based organizations
FGD	Focus groups discussion
HIV	Human Immunodeficiency Virus
IAG	Inter-Agency Group
MCH	Mother and Child Health care/clinic
MoH	Ministry of Health
NGO	Non Governmental Organisation
OR	Odds Ratio
PHC	Primary Health Care
PhD	Philosophers Degree
TB	Tuberculosis
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNIP	United National Independence Party
USD	United States Dollar
UNZA	University of Zambia
VCT	Voluntary, counselling and treatment services
WB	World Bank
WHO	World Health Organisation

Chapter 1 - Introduction

This thesis has been carried out in the framework of the three-year research project “Improving equity of access to care and treatment in Zambia” funded by the Swiss National Science Foundation (SNSF, project nr: IZ 70ZO-123907). The overall research project has been implemented in collaboration with the Swiss Institute of Tropical Medicine and Public Health, the University of Zambia and the Zambia AIDS Related Tuberculosis Project (ZAMBART). It aims at exploring the factors that influence access to HIV/AIDS services and health-seeking behaviour in Zambia based on a mixed methods approach. Dr. Sonja Merten (my main supervisor) and Dr. Jacob Malungo (co-supervisor at the University of Zambia) have been the principal investigators.

I became a member of this wider project in 2010 as a PhD student in the Swiss Tropical and Public Health Institute associated with the University of Basel. My first task was to prepare my own (PhD) research proposal. To do so, I carried out several comprehensive reviews of the literature, covering both qualitative and quantitative studies. This allowed me to broaden my knowledge of theories explaining social cohesion and health behaviour. As a health psychologist working in public health programmes my interest was to explore how the local social conditions in Zambia shape access to services (testing, uptake of ART, adherence and retention in care). Through the literature review I identified a wide array of individual, cognitive, social, cultural, and economic factors that hinder access to HIV/AIDS services and I also identified some gaps in research.

Most quantitative studies used facility-based samples, thus little was known about the distribution of the problem in the general population (compared to those

accessing and adhering). Moreover, the majority of studies assessed determinants of access using individual-level factors. There was a need to investigate how these factors interact with other potential factors at the community and household levels. Furthermore, little attention was paid to the socio-relational dynamics within the family and communities, although this was identified as a main influence on treatment seeking in a range of qualitative studies (Merten, 2010). If HIV prevention programmes are to reach more people, it is crucial to comprehensively examine the factors that are constraining access to the HIV/AIDS services at all levels.

This thesis and the scientific publications that it provides, contributes to progressing in the understanding of the socio-relational processes that interact with structural conditions, such as gender inequities and poverty, and that ultimately impact the ability of people to access HIV care. It also provides evidence of which factors influence every step of the HIV continuum of care thus advising on how to prioritize efforts to eliminate barriers to testing and uptake of treatment. The results are relevant for policy and practice to improve HIV prevention strategies in Zambia.

Chapter 2 - Global epidemiology of HIV

2.1 Status of the HIV epidemic

In the thirty years, since the first cases of AIDS were recognised, HIV/AIDS has affected the lives of millions of people all over the world.

Globally, about 34.0 million people were living with HIV at the end of 2011. The overall prevalence of infection among adults aged 15-49 years worldwide is 0.8%.

However, this overall figure is misleading as

Table 1 Global HIV/AIDS Epidemic	
Number of people living with HIV in 2009	
Total	33.3 million (31.4 -35.3 million)
Adults	30.8 million (29.2-32.6 million)
Women	15.9 million (14.8-17.2 million)
Children under 15 years	2.5 million (1.6-3.4 million)
People newly infected with HIV in 2009	
Total	2.6 million (2.3-2.8 million)
Adults	2.2 million (2.0-2.4 million)
Children under 15 years	370,000 (230,000-510,000)
AIDS deaths in 2009	
Total	1.8 million (1.6-2.1 million)
Adults	1.6 million (1.4-1.8 million)
Children under 15 years	260,000 (150,000-360,000)
Source: UNAIDS, 2010 .	

prevalence of infection varies dramatically across the world. According to the last estimates (UNAIDS, 2010) the burden of the epidemic continues to vary considerably between countries and regions.

The proportion of individuals infected is highest in sub-Saharan Africa, with nearly 1 in every 20 adults (4.9%) living with HIV and accounting for 69% of the world's HIV infected population.

Prevalence is highest in southern and eastern Africa, with one in four adults infected in Swaziland, and a prevalence of over 15% among adults in six other countries (Lesotho, Namibia, South Africa, Botswana, Zambia and Zimbabwe).

In West and Central Africa, the HIV prevalence remains comparatively low, with prevalence among adults estimated at 2% in 12 countries (Benin, Burkina Faso, Democratic Republic of the Congo, Gambia, Ghana, Guinea, Liberia, Mali,

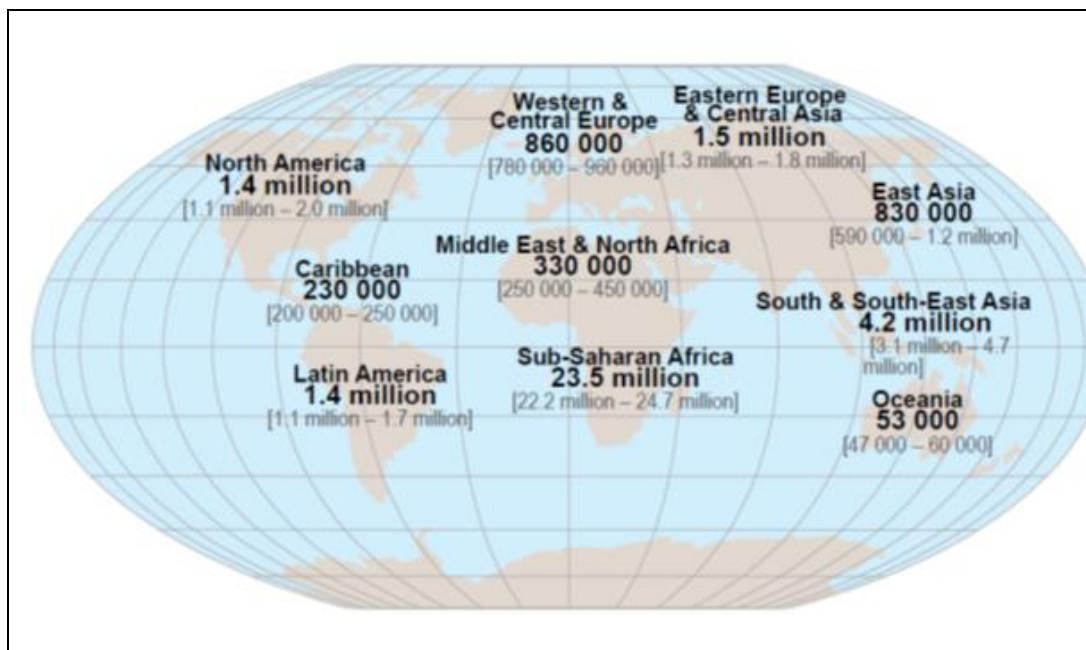
Mauritania, Niger, Senegal, and Sierra Leone). The highest prevalence of HIV has been reported in Cameroon at 5.3%, Central African Republic 4.7%, Côte d'Ivoire 3.4%, Gabon 5.2%, and Nigeria 3.6%. Programme data and research provide strong evidence that, in most West African countries high, rates of male circumcision, compared to other parts of sub-Saharan Africa, have helped to contain the spread of HIV and other sexually transmitted infections (STIs). But there is no evidence that male circumcision directly reduces transmission to women, or among men who have sex with men. Another feature of HIV epidemics in West Africa is the presence of the HIV-2 strain which is less transmissible and shows lower progression to disease. However, in most countries, the relative importance of HIV-1 has increased and is continuing to do so (Jenkins & Robalino, 2003).

No other region has similar HIV prevalence to those reported in sub-Saharan Africa. However, prevalence are relatively high in some countries in Latin America and the Caribbean (Bahamas 3.1%, Belize 2.3%, Haiti 1.9%, Guyana 1.2%), some countries in Eastern Europe and Central Asia (Ukraine 1.1%, Russian Federation 1.0%) and in South-East Asia (Thailand 1.3%, Myanmar 0.6%, Cambodia 0.5%). (UNAIDS, 2010)

In contrast, HIV prevalence remains at less than 0.2% in many countries in North Africa and the Middle East. Yet, "low prevalence does not equate to low risks" (the World Bank, 2003). UNAIDS estimates that 75,000 (61,000-92,000) people from the Middle East and North Africa were newly infected with HIV/AIDS in 2009 alone, more than double from 2001 (36, 000). Furthermore 24,000 (20,000-

27,000) adults and children died from the disease in the same year which is more than 3 times than in 2001 (8,300). (UNAIDS, 2010)

Figure 2.1 Adults and children estimated to be living with HIV (WHO 2011)



Note: Adapted from Hankins (2013)

Current scientific knowledge about HIV/AIDS transmission shows that once infection rates exceed “*a certain threshold, the virus spreads very fast, sometimes increasing by as much as tenfold in five years as has been the case in several southern African countries*” (the World Bank, 2005). This is technically described by the concept of reproductive rate (R_0), which is the average number of persons infected by a single disease source.¹ If governments delay action, scholars believe the trend witnessed in other regions will likely recur in the Middle East and North Africa.

¹ In other words, this is the number of expected secondary infections resulting from a single current infection. The threshold is exceeded when the reproductive rate exceeds one. This means that, if infected individuals, on average, infect more than one additional person in their lifetime, the disease will continue to spread within a population and the epidemic will be sustained and grow. At base, the threshold is usually designated as, and equal to, a 5 percent infection rate in most countries. (UNAIDS & WHO, 2003)

2.2 Key drivers of the HIV/AIDS epidemic

An understanding of the factors influencing the prevalence of HIV in the population is essential to control the epidemic. After nearly three decades of AIDS, the heterogeneity of the epidemic is well known. There are many factors that drive the epidemic and contribute not only to its regional variation but to intra-national differences. Early studies of HIV/AIDS focused on individual characteristics and behaviours in determining HIV risk, an approach that is known as “*biomedical individualism*” (Fee & Krieger, 1993). Biomedical individualism is the basis of risk factor epidemiology and focuses on risk manifested at individual level (Poundstone, 2004). Interventions based on this approach focus on individual behaviour change to prevent HIV transmission and promote access to clinical AIDS care.

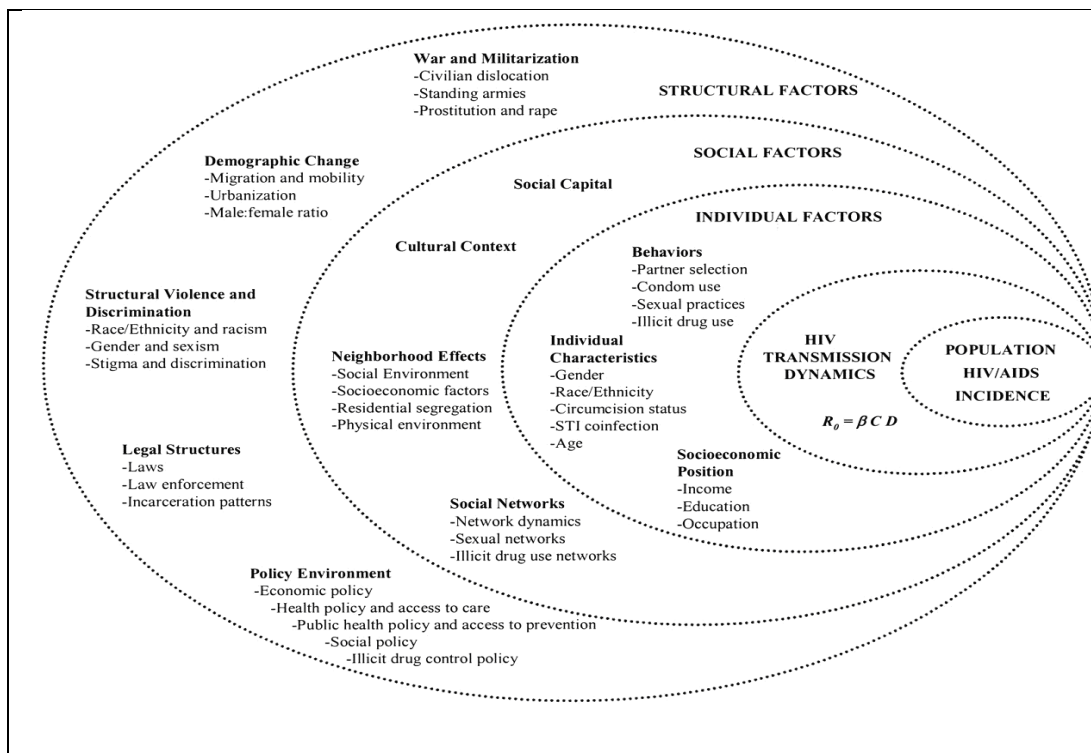
While this approach has improved our understanding of individuals with or at risk of AIDS, public health interventions focusing narrowly on individual risk behaviour has proved insufficient to address the many challenges of the HIV epidemic. One of the main criticisms is that biomedical individualist approaches neglect the social context in which individuals are embedded which can put them at risk by increasing their vulnerability to acquire or transmit HIV infection.

Social epidemiology emphasizes the social conditions as fundamental causes of disease and focus explicitly on the factors and pathways by which societal conditions (socio-relational, economic and political environments) affect health (Link & Phelan, 1995). Interventions based on this approach foster individual agency to allow people to act in their own and their community’s best interests (including taking up targeted behavioural and biomedical technologies), create and support AIDS-competent communities (Campbell, 2009), and build health-

enabling environments. They seek to modify social conditions by addressing the key drivers of HIV vulnerability (i.e. the ability of individuals to protect themselves and others from acquiring or transmitting HIV infection).

Currently, there is enough scientific evidence showing that the determinants of HIV/AIDS vulnerability must be conceptualized at multiple levels: individual, social and structural levels. Individual-level factors include biologic, demographic and behavioural risk factors that may influence the risk of HIV acquisition and disease progression. Social-level factors include critical pathways by which community and network structures link persons to society. These factors are central to understanding the diffusion and differential distribution of HIV/AIDS in population subgroups. Structural-level factors are contextual conditions outside the control of individuals which influence their perceptions, their behaviour and their health. This broad view of structural factors may include features of the social, cultural, economic, political and physical environment.

Figure 2.2 Different levels of determinants of the HIV/AIDS epidemic



Note: The dotted lines separating the levels illustrate the porous nature of the distinctions made between levels of analysis. In reality, there are extensive linkages between determinants at all levels that give rise to observed epidemic patterns.

Source: Poundstone et al., 2004

2.2.1 Biomedical factors

Biological mediators of infectivity. The probability of HIV transmission is influenced by the type of the virus involved, the part of the body it enters and the integrity of the skin or mucosal barrier. For example, the lower infectivity of HIV-2 compared to HIV-1 implies that fewer of those exposed to HIV-2 will be infected per exposure. Because of its relatively poor capacity for transmission, HIV-2 is largely confined to West Africa (Reeves & Doms, 2002). The estimated risk of transmission of HIV per single sexual contact is 0.04% for women-to-men and 0.08% for men-to-women. (Holmes et al., 2008; Boily et al., 2009) The integrity of the skin and mucous membranes of the body also influences the susceptibility of infection. Ulcerations and lesions of the skin due to co-infection with sexually transmitted infections (STIs) increase the risk of sexual HIV

transmission. (Mbopi et al., 1999; Hook et al., 1992) A host of epidemiological studies suggest that STIs are co-factors for HIV acquisitions or transmission. (Gray et al., 2001)

Vaginal infections are also emerging as important risk factors for HIV (Buve, 2002; Gregson et al., 2001). Brakes and abrasions of the mucous membranes of the body can be caused by behavioural factors such as vaginal practices which have been associated with an increased risk of infection. (Martin-Hilber et al., 2007)

Male circumcision is one of the most striking pieces of evidence that emerged in recent years as a protective factor for HIV infection. However, its protection is only partial. Randomized control trials have shown to reduce infection in men but no clear decrease in transmission from men to women and there is no information on transmission between men who have sex with men. (Weiss et al., 2010)

Exposure to infected blood or blood products through injection drug use and blood transfusion are two mechanisms of HIV exposure to infected blood. Because of the efficiency of HIV transmission through needle sharing, the introduction of HIV into an urban network of injecting drugs users can quickly raise the HIV prevalence in this population (Chaisson et al., 1989). The probability of becoming infected through an HIV-contaminated transfusion is estimated at more than 90 % (UNAIDS, 1997), and the amount of HIV in a single contaminated blood transfusion is so large that individuals infected in this manner may rapidly develop AIDS.

Perinatal HIV transmission provides evidence of the significance of viral load and transmission risk. In a randomized clinical trial in Kenya, maternal viral loads higher than 43,000 copies per millilitre increased four times vertical transmission

(John et al., 2001). Transmission through breastfeeding is likely associated with an elevated viral load in the breast milk, which in turn is associated with maternal plasma viral load and CD4 T cell levels (Read 2003; Coutsoydis et al, 2001).

2.2.2 Behavioural factors

The *types of sexual contacts* and the presence of certain co-factors in the setting will determine the transmission risk per sexual contact. For example, HIV is more easily transmitted through anal than vaginal sex, possibly because anal mucous is more susceptible than vaginal mucosa and it is rarely acquired through oral sex (Holmes et al., 2008).

(Un) Protected sex. Studies with cohorts of discordant couples have shown that consistent condom can reduce HIV transmission by 80-95% (Holmes et al., 2008). Other studies show that condoms are less used in poorer countries, a problem which has been largely attributed to problems of access and service provision (Wellings et al., 2006). The capacity of female barriers to halt the spread of HIV is unclear (Myer et al., 2005). Some studies found an increased risk of acquiring HIV, possibly due to irritation of the genital membranes providing an entry point to the virus (Wilkinson et al., 2002). Yet, a recent trial found that a vaginal gel reduced the risk of HIV (Abdool Karim et al., 2010).

Multiple sexual partners have proved to increase the risk of STIs and HIV in both men and women (Gouveia-Oliveria & Pedersen, 2009). Women risk is also significantly increased if her partner has multiple partners (Canchichuaman et al., 2010). Multiple partnerships can occur serially (i.e. one begins after another has

ended) or concurrently (i.e. people has other sexual partners while continuing sexual activity with the original partner). Concurrent partnerships have been widely believed to play a role in accelerating the spread of HIV, especially in sub-Saharan Africa. However, emerging evidence refutes this idea concluding that the risk is not affected by whether those partnerships overlap in time (Tanser et al., 2011; Sawers et al., 2011; Sawers & Stillwaggon, 2010).

Sexual networks and sexual mixing patterns also play an important role in the transmission of HIV and in understanding disparities of HIV infection across social groups. Sexual networks are structural and temporal representations of the way in which individuals are linked through sexual relationships, and provide pathways through which infection can be transmitted (Day et al., 1998). Partnership and network formation, and the chance of acquiring and transmitting an infection sexually are not random; they are determined by individual factors, cultural values, geography, demography, economics, health service, and political and legal structures (Doherty et al., 2005). As a result, there are individuals whose sexual behaviour patterns, and social and health-seeking behaviours within networks, contribute disproportionately to the transmission of infection. Sexual mixing patterns are especially important in the transmission of HIV. Assortative mixing refers to sexual partnerships among people with similar risk for HIV and disassortative mixing occurs when partnerships form between higher and lower risk people (Laumann & Youm, 1999; Aral et al., 1999). Usually, HIV spreads into the wider population when disassortative sexual mixing occurs. For example, a man may acquire HIV infection from a commercial sex worker (CSW) and then transmit the infection to his regular partner. In many countries, sex workers have been considered a core group for the transmission of HIV and other sexually

transmitted diseases (STDs) due to high infection rates and large number of sexual partners (Plummer et al., 1991). In addition, men who have both commercial and non-commercial sex partners play a major role in bringing HIV infection into the general population. These “bridge” populations are increasingly recognized as much important as core groups in HIV prevention programmes (Morris et al., 1996). The regular partners, or non-commercial partners of sex workers, are another important core group (Bloem et al., 1998). Several studies have observed a high prevalence of HIV infection and other STIs in African truck drivers, who are highly mobile both within countries and across borders (Ramjee et al., 2002, Lankoande et al., 1998; Hudson, 1996). Partnerships between individuals who do not use illicit drugs and those who inject illicit drugs is another example of disassortative mixing associated with HIV infection (Adimora et al., 2006; Kerr et al., 2006; Panda et al., 2005; Ellerbrock et al., 2004). Furthermore, evidence suggests that age-mixing (age differences between partners) in sexual relationships can be an important factor in explaining the spread of STIs and HIV in a population (Hurt et al., 2010; Leclerc-Madlala, 2008; Hellinginger & Kohler, 2007; Doherty et al., 2005). Sexual relationships between older men and younger women increase the risk of acquiring infection among females (Ford et al., 2004; Kelly et al., 2003; Gregson et al., 2002;). When a young woman enters into a sexual relationship with a man older than her, she is at a higher risk of contracting HIV than if she entered a relationship with a man of her own age (Ott et al., 2011).

2.2.3 Social and structural factors

For the purpose of this thesis, socio-structural factors are contextual conditions outside the control of individuals which influence their perceptions, their behavior and their health. This broad view of socio-structural factors may include features of the social, cultural, economic, political and physical environment.

Gender power inequities. Hierarchical relations of power between women and men tend to put women in disadvantage preventing gender equality and increasing the risk of infection in women. Women often experience the impact of HIV more severely than men. About 40% of all adult women with HIV live in southern Africa. In the Caribbean, as in sub-Saharan Africa, women and girls outnumber men and boys among people living with HIV. In Asia, women account for a growing proportion of HIV infections: from 21% in 1990 to 35% in 2009. In 2009, women comprised about 26% of the people living with HIV in North America and 29% of those in Western and Central Europe (UNAIDS, 2010). Women are both biologically and socially more vulnerable to HIV infection. Most prevention interventions have focused on sex workers or mother to child transmission (Carovano 1991). However, most women contract HIV from their primary partners (Exner et al., 1997; Allen et al., 1992.). Thus, to reduce HIV infection in women it is essential to focus on reducing the spread of HIV among men (Konde-Lule et al., 1997; Serwada et al., 1995). Relationship power inequity and intimate partner violence increases incidence of HIV infection in women (Jewkes, 2010) and power inequities in decision making and fear of abandonment

and violence hinders women's access to HIV testing (Musheke, 2013; Jürgensen et al., 2012; Edin & Hurtig, 2010; Theuring et al., 2009; Tolhurst et al., 2008).

Stigma and discrimination is considered one of the greatest obstacles to control the HIV epidemic. It has been consistently associated with rejection to uptake HIV testing (Jürgensen et al., 2012; Dye, Apondi & Lugada, 2011; Skovdal et al., 2011; Larsson et al., 2010; Simpson, 2010; Njizing, Edin & Hurtig, 2010; Roura et al., 2009). Despite the importance of stigma on the spread of the epidemic, there remains much controversy on how to define such construct. Stigma has often been examined from an individual perspective in studies of perceptions and interpersonal interactions (Link and Phelan, 2001). Some of the best known conceptualizations are: Herek et al. (1998 p.36) as "*the prejudice, discounting, discrediting, and discrimination that are directed at people perceived to have AIDS or HIV and at the individuals, groups, and communities with which these individuals are associated*"; Link & Phelan, (2001 p. 367) "*when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold*"; Parker & Aggleton (2003, p.16) who call for a new conceptual framework "*to reframe our understandings of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to broader notions of power and domination*".

Social capital (individual and collective). Several studies have examined social capital in the context of HIV/AIDS. In South Africa, Campbell et al. (2002) examined one dimension of social cohesion, civic participation, in order to assess

community influences on HIV infection. They found that participation in certain types of organizations (e.g. churches, sports clubs, and youth groups) was protective, while membership in other social groups (e.g. groups with high levels of social drinking) increased HIV risk. Studies using a social network approach have demonstrated that patterns in the structure of relationships (social network)-rather than differences in individual risk behaviours alone-explain observed HIV patterns (Poundstone, 2004; Friedman et al., 2000). Specific network characteristics that have been associated with HIV/AIDS include: (i) social network size (Friedman et al., 1997), (ii) the centrality of HIV-positive persons within networks (Rothenberg et al., 1995), (iii) patterns of partner selection (Zaric, 2002; Laumann et al., 1999). Network-related social and normative influences have also been associated with individual HIV risks such as the use of illicit drug (Lovell, 2002) and condom use behaviour (Latkin et al., 2003; Sherman & Latkin, 2001). More recently, it has been explored how neighbourhood factors shape population HIV/ AIDS patterns. Length of survival after an AIDS diagnosis, both before and after the introduction of ART has been associated with neighbourhood measures of income (Wallace, 2003; McFarland et al., 2003; Rapiti et al., 2000). According to Poundstone (2004), other neighbourhoods factors that may play a role in shaping HIV/AIDS patterns are income inequality (Kawachi, 2000) and residential segregation by race/ethnicity (Acevedo-Garcia, 2000).

Legal structures refer to laws that, according to Burris et al. (2002), can affect health in two ways: 1) influencing social determinants that affect health (direct effect) such as legal restrictions on access to sterile injection equipment, which

have been associated with higher HIV incidence (Friedman et al., 2001); and 2) shaping social conditions associated with health outcomes (indirect effect) such as tax laws on income inequality, that may worsen social conditions and increase HIV vulnerability. According to laws underlie many key social determinants of HIV/AIDS, including housing, poverty and income inequality, racism and community social organization (Poundstone et al. 2004; Lazzarini et al., 2002).

Demographic change also affects HIV/AIDS patterns through migration, urbanization and the age and gender structures of subpopulations (Poundstone, 2004). It is now well accepted that HIV/AIDS greatly spread in environments of social vulnerability and exclusion. Migrants and mobile populations often live in such environments, hence increasing their vulnerability to HIV. Some migrants are most vulnerable at their destination – for example, men who work far from home, such as mine workers, farm workers and military personnel who live in men-only camps or barracks (IOM, 2003; John Snow, 2001). For others, the greatest risk occurs in transit, when female informal traders or farm workers might have to trade sex in order to survive or complete their journeys. (Legget 2001; IOM, 2003)

2.3 Global action to control HIV

“Getting to Zero” is the new UNAIDS strategy for the period 2011-2015. It provides the

*Zero discrimination.
Zero new HIV infections.
Zero aids-related deaths*

framework for the global response towards HIV which calls for a global transformation. The strategy puts HIV prevention efforts at the forefront of the most effective development practice by supporting a renewal of HIV prevention in synergy with expanding treatment access, focus and rigour in programme implementation and country ownership that enables HIV responses to set the pace in creating resilient, equitable and inclusive societies.

The ultimate goal is to stop new infections, discrimination and AIDS-related deaths by achieving universal access to effective HIV prevention, treatment, care and support.

2.3.1 HIV/AIDS prevention strategies

The UNAIDS 2010 report on the global AIDS epidemic confirmed the link between declining new HIV infections and changes in behaviour and social norms together with increase knowledge of HIV. However, despite the availability of a number of prevention tools which have proven cost-effective (Bertozzi, 2006) many existing national prevention strategies are still made up of a collection of disconnected interventions which lack clear objectives and integrated approaches (UNAIDS, 2009; Bertozzi et al., 2008). Too often prevention efforts focus on reducing individual risk with fewer efforts to address structural factors - socio-cultural, economic, political, legal and other contextual factors— that increase vulnerability to HIV (Gupta et al., 2008). Recent analytical studies have identified a number of weaknesses in existing prevention efforts (The Lancet Series on HIV Prevention, 2008).

To overcome these weaknesses, HIV research and programme experts, civil society and policy makers began in recent years to unite behind the broad concept of “combination prevention.” This is not a new approach but evidence has shown that despite being widely endorsed in the AIDS policy discourse, it was rarely implemented. “Combination Prevention” is now pushed forward as the best approach for generating significant, sustained reductions in HIV incidence in diverse settings and ensure that every country moves closer to UNAIDS’ global vision – Zero new HIV infections, Zero discrimination and Zero HIV related deaths (UNAIDS, 2010).

The goal of “combination prevention” strategy is to reduce the transmission of HIV by implementing a combination of behavioural, biological, and structural interventions that are carefully selected to meet the needs of a population. Combination prevention programmes operate on different levels (e.g., individual, relationship, community, societal) to address the specific, but diverse needs of the populations at risk of HIV.

Box 1 Definition of Combination Prevention (adapted from UNAIDS 2009)

The UNAIDS Prevention Reference Group agreed in December, 2009 that combination prevention programmes are:

... rights-based, evidence-informed, and community-owned programmes that use a mix of biomedical, behavioural, and structural interventions, prioritized to meet the current HIV prevention needs of particular individuals and communities, so as to have the greatest sustained impact on reducing new infections. Well-designed combination prevention programmes are carefully tailored to national and local needs and conditions; focus resources on the mix of programmatic and policy actions required to address both immediate risks and underlying vulnerability; and they are thoughtfully planned and managed to operate synergistically and consistently on multiple levels (e.g. individual, relationship, community, society) and over an adequate period of time. They mobilize community, private sector, government and global resources in a collective undertaking; require and benefit from enhanced partnership and coordination; and they incorporate mechanisms for learning, capacity building and flexibility to permit continual improvement and adaptation to the changing environment...

Nearly 20 years of evidence strongly suggests that prevention strategies are most effective when they are tailored to the nature and stage of the epidemic in a specific country or community (Bertozzi et al., 2006). Thus the starting point for “combination prevention” programming is a timely, thorough and evidence-informed understanding of one’s HIV epidemic and the response. This approach is often referred to as “Know Your Epidemic/Know Your Response” (UNAIDS, 2007).

2.3.2 HIV/AIDS treatment, care and support strategies

The main goal of the treatment, care and support strategy is achieving universal access to treatment for all eligible individuals.

Africa, especially the southern and eastern regions, has been and remains disproportionately affected by the HIV epidemic. Until quite recently, the international response to HIV in Africa has focused upon prevention of sexual transmission, with little emphasis upon providing equitable access to effective HIV prevention and care services. This emphasis on prevention of sexual risk behaviours over equitable care has shifted in recent years.

In 2003, the World Health Organisation (WHO) proposed an ambitious initiative to deliver antiretroviral therapy to 3 million persons living with HIV infection in resource poor areas by 2005 (the '3 by 5' initiative). This target was not achieved although some progress was made. In 2006, the international community set up another target that aimed for universal access to HIV prevention, treatment and care by 2010. This target was neither achieved and, in 2011, the goal of universal access was recommitted in the new 2011-2015 global health strategy (WHO 2011).

To achieve universal access there are two main strategies. One focuses on renovating approaches such as (i) developing easier, more affordable and effective treatment regimens; (ii) adopting innovative service delivery models that reduce costs and empower communities to demand and deliver more quality equitable care services and (iii) joining efforts between health and community services. The other focuses in the strengthening of national and community systems to

decentralise and integrate services. As the majority of care and support is provided by families and communities, strengthening community systems is the main focus. (Haregy 2003)

It is important to stress that HIV prevention and treatment are interdependent and mutually reinforcing (UNAIDS, 2006b). There is increasing evidence showing that treatment scale-up play a vibrant role in HIV prevention (Granich et al., 2009; Montaner et al., 2006; Wawer et al., 2005). Recently a study from Vietnam has provided evidence that the “combination prevention” strategy with targeted HIV testing and early antiretroviral therapy has the potential to virtually eliminate new HIV transmissions in Vietnam (Kato et al, 2013).

2.3.3 HIV/AIDS social structural strategies

“Universal access means more than ensuring that those who need treatment or prevention services receive them. It implies an extra effort to reach those who are marginalized, criminalized or disenfranchised.”

Secretary-General Ban Ki-moon

“Combination Prevention” put more attention on social and structural factors that may increase HIV vulnerability or reduce the reach and impact of prevention programmes. In addition to documenting trends and patterns in incident HIV infections and identifying determinants “combination prevention” also requires the analysis of available research concerning the social, cultural, economic and political forces and conditions that contribute to HIV transmission (Boerma & Weir 2005). At the heart of social structural perspective is the recognition that behaviour is more than merely a personal choice. Social structures, institutions

and norms provide potential for and impose limitations on human agency and action.

Structural interventions are activities designed to alter specific environmental features – such as inequitable gender norms, or HIV-related stigma– so as to create a more enabling environment for HIV prevention, treatment and care and support. For reviews of the extensive literature and perspectives on the importance of environmental conditions for HIV programmes (see Auerbach et al. 2009).

Structural interventions differ from many public health interventions in that they locate the cause of public health problems in contextual or environmental factors that influence risk behaviour and other determinants of infection or morbidity, rather than in characteristics of individuals who engage in risk (Blankenship et al, 2006). Example of these interventions include community mobilization to support human rights, or policy dialog and action to increase food security which benefit the overall access to HIV prevention, treatment, care and support (WFP 2008, Save the Children, 2004). Other means of ending the HIV-related stigma and discrimination and gender inequality are enforcing laws, policies and programs against discrimination. Other examples are creating legal access to free sterile injecting equipment without fear of arrest, making contraception available free of charge and ensuring that they can be accessed discretely to reduce fears of social disapproval. To do so country capacities to create protective social and legal environments, and to include gender issues in the design, delivery and monitoring of health services need to be strengthened (Haregy 2003).

2.4 Main challenges in HIV control

Advances toward universal access to treatment, care and support services have reached significant success in 2009, especially given the considerable challenges that accompanied the flattening of global funding for HIV programmes in low and middle-income countries. By the end of 2011, ten low- and middle-income countries², including Zambia, achieved universal access (UNAIDS 2012).

2.4.1 Integrating prevention and treatment

The practicability of rolling out successful large-scale treatment programmes is threaten by cost-related problems, health system constraints, ethical considerations and social cultural barriers involved. Increased treatment coverage is not a substitute for other preventative measures that have been proven to work in reducing new HIV infections (Van Damme, 2006). Prevention programmes must be expanded alongside treatment programmes.

2.4.2 Financing HIV treatment

In 2010, WHO launched revised treatment guidelines (2) recommending earlier initiation of antiretroviral therapy, at a CD4 count of <350 cells/mm³. These new criteria increased the total number of people medically eligible for antiretroviral therapy by roughly 50%—from 10 million to 15 million in 2009 (UNAIDS 2010). In some lower-income countries, governments decide whether to follow old guidelines, which recommend starting treatment at 200 cells/mm³ (WHO 2009). At the end of 2011, 88 of 93 countries reporting to WHO adopted the new guidelines, including Zambia, Tanzania Zimbabwe, Kenya, Lesotho, Malawi,

² Botswana, Cambodia, Cuba, Dominican Republic, Guyana, Mexico, Namibia, Rwanda, Swaziland and Zambia.

China and some countries in Eastern Europe such as Romania and Ukraine (WHO 2011).

Scaling up “Universal access to treatment” inevitably requires greater initial spending. Overall costs of providing HIV treatment will increase as countries scale up treatment, adopt the new WHO guidelines on earlier initiation of antiretroviral therapy, provide safer but more expensive regimens and respond to the growing need for second- and third-line treatment (WHO 2010). Additionally the non-drug costs of delivering antiretroviral therapy remain high, accounting for up to 60% of the overall costs of treatment (UNAIDS 2010). The main challenge lies in increasing the availability of treatment in resource-limited countries which usually have a weak infrastructure, limited human and financial resources, and poor integration of HIV-specific interventions within broader maternal and child health services.

Also of concern is the cost implication of the longer treatment, although this increase may in part be offset by the reduction in morbidity following initiation of ART. However in resource-limited countries many ART regimens still include thymidine analogue NRTI known as not too well tolerated (Renaud-Thery, 2007; Sungkanuparph 2007; Boyd 2007). Scientific evidence has shown that it is difficult to maintain optimal adherence to drugs that cause unpleasant side effects so some patients are likely to develop resistance and require a change in their regime. Recent studies in resource-limited settings suggest there will be an ongoing need for expanded ART options in third-line therapy. The proportion of patients on second-line ART in resource-limited settings is estimated between ~1-5% (Renaud Thery 2007; Egger 2009; Pujades-Rodriguez 2008). Estimates of

failure on first-line NNRTI-based regimens range between 18-32% (Ramadhani 2007; Keiser 2008;

Bartlett 2009). Since many of the resource constrained settings, which usually are the most affected by the HIV epidemic, are not yet able to offer third line regimens, outside the private sector, for some non-adherent patients this could mean the exhaustion of all available therapeutic options and could have the effect of accelerating mortality rather than delaying it..

2.4.3 Improving Human rights and gender equality

Expansion of testing also has prompted debates within the bioethics and human rights literature (Bayer & Edington 2009; Obermeyer 2013). The main concerns are related to threats of the fundamental rights to counseling, voluntary informed consent and confidentiality. Questions raised are whether confidentiality would be protected in overstretched health facilities, whether clinical settings would provide adequate post-test counseling and linkages to treatment and whether benefits would outweigh the risks of adverse consequences such as stigma, rejection and spousal abuse such as domestic violence (Kippax 2006; Monjok et al., 2010). Recent research and experience in programme implementation emphasizes the importance of actively engaging men in addressing negative male behaviour and changing harmful gender norms such as early marriage, male domination of decision-making, intergenerational sex and widow inheritance (Ringheim & Jacobs, 2009; Barker, 2007). In sub-Saharan Africa, 60% of the people living with HIV are women and girls (Garcia-Calleja et al., 2006; UNAIDS 2008), but most funding dedicated to women provides antiretroviral therapy to prevent vertical transmission. It is essential to combine HIV-related funding with other resources to address the full range of women's vulnerabilities, such as programmes for

discordant couples, young women and female sex workers and for changing harmful gender norms and economic disempowerment.

Other hot topics discussed are how to balance HIV-positive persons' right to confidentiality with the need to prevent transmission to others and to diagnose partners living with HIV (Obermeyer et al, 2010), and how to ensure equitable access to testing and treatment for those who face barriers to testing and care in sub-Saharan Africa, particularly most at risk groups (Mitchell et al., 2010). Protective social and legal environments are essential to reach universal access to HIV prevention, treatment, care and support. However, in 2008, too many countries still did not have laws prohibiting discrimination against people living with HIV. Nearly two thirds of countries reported policies or laws that impede access to HIV services by certain populations, such men who has sex with men, injection-drug users and sex workers including minors (UNAIDS 2010).

2.4.4 Linking persons to treatment

Before people can be treated they need to know they are infected. Encouraging more people to test for HIV before having symptoms has proved extremely challenging. Recent data shows that many HIV-positive people wait too long to seek treatment, usually with CD4 count below 200 cells/mm³ (ART-LINC 2010). This limits the overall impact of HIV treatment programmes (UNAIDS 2010). Furthermore, adherence and retention in treatment, remains a big challenge in many settings. A recent study from South Africa reported that among persons who receive a HIV positive result, one-third to two-thirds never return for follow-up care (Basset et al., 2008; Basset et al., 2009). Furthermore a recent systematic

review reported that many clinics record high rates of loss to follow-up (LTFU) - 4% to 39% (even after accounting for mortality following ART initiation) (Rosen et al., 2007). These factors are increasingly recognized as central barriers to scale-up of ART programs in sub-Saharan Africa.

Some of the most important difficulties in linking persons living with HIV to testing and treatment and retaining them in care are related to quality of the health system services and to organizational problems. The most commonly reported are the lack of health services near to the population who need them, inadequate organization and management of the health service, limited number of qualified health staff, restricted budget, unreliable supplies of antiretroviral and other materials, badly organized referral systems and wrong administrative procedures such as record keeping that is not confidential. Other barriers mentioned are lack of clear and transparent policies and limited involvement of the community in the program planning process (for a global overview, see: UNAIDS 2003). Several studies have found that the perceived quality of the healthcare system play an important role on the decision making to access HIV/AIDS services (Mohseni 2007; Gilson 2003). In Zambia, for example, a major issue is the failure of many healthcare providers to guarantee confidentiality. Many people do not access HIV/AIDS services or travel long distances to other centres located in other communities (making it difficult to maintain long-term adherence) because they don't trust the health workers in their community clinic. Fear of involuntary disclosure is a serious concern since it could raise marital conflicts and divorce – with all its implications for the material survival of an individual and his or her family (Merten et al., 2010; Bond & Nyblade 2006).

Other widely reported barriers are more related to physical factors. Long travel distances to the clinics without adequate vehicles in terrains that may be difficult to cross due to rainy season or hilly geography and/or unsafe journeys due to warfare or criminal activities make difficult, sometimes impossible, for the population to physically access the HIV/AIDS services (UNAIDS 2003). In Zambia, most of the clinics with adequate equipment to provide HIV testing and ART are primarily found in the urban areas. This builds a clear barrier for those living in remote rural areas who do not have an adequate vehicle and/or who cannot easily afford the related transport costs (Asante 2007; Egger 2005). Financial barriers also compromise access. People living with HIV/AIDS and their families, especially those living in very poor conditions, very often face difficult choices about the costs of treatment. For instance, they may have to decide between paying for treatment and buying food or paying school fees for children. On the one hand, research has shown that, in these situations, treatment seeking in general (not specific for HIV/AIDS) with the formal health sector is often not the priority for people who make the decisions (Obrist, Iteba et al. 2007). Allegedly that could also be the case for HIV/AIDS services. On the other hand, differentials in socio-economic status have not shown yet a clear association with HIV testing as opposed to the finding that poverty is generally associated with a lower health status in the study area (Merten et al., 2007).

Finally, socio-cultural barriers also play an important role on access to HIV/AIDS-related treatment. Individual decisions (such as going for HIV testing) are not taken in isolation but influenced by the socio-cultural context (family, communities and broader society levels) where the individuals are embedded. At a broader social level, the policy, legal and institutional context (schools,

workplace, health care systems, HIV/AIDS programs and religious institutions) can have a direct or indirect impact on the access to HIV/AIDS-related treatment through laws, policies and administrative procedures. Some examples are policies that promote compulsory testing or laws that protect the rights of people living with HIV/AIDS (PLHA) (UNAIDS 2003). At community level, the local healing traditions and the local cultural beliefs about HIV/AIDS and its cause may also influence the way that communities and families respond to HIV/AIDS and manifest HIV/AIDS related stigma and discrimination (S&D). For instance, in communities where HIV/AIDS is associated to being the result of "immoral" or "improper" behaviours, HIV/AIDS reinforces pre-existing stigma of those whose behaviour is considered to be "deviant" (Warwick et al. 1998). In the same direction, Merten and Haller (Merten & Haller, 2007) have shown that, in the Zambian context, being suspected of an HIV infection may signify for an individual being associated with an already marginalized group, such as prostitutes, influencing the decision making related to HIV: "maintaining a good reputation in order to be retained within a social support network was more important than protecting one's own health". Where there is neither formal social security nor medical insurances, the social network of an individual provides the material support in times of crises (Chileshe 2008; Benda-Beckmann & Kirsch 1999) and therefore becomes essential for his survival. Several studies on HIV/AIDS-related S&D have confirmed these findings in other settings (Scambler 2008; Campbell et al. 2007; Crawford et al. 2006). Gender roles and power relationships at family level can also have an important effect on individual treatment decision making. Several studies have showed that gender roles and power imbalances within the family determine how the intra-household resources

are allocated and that this influences the decision of treatment seeking (Tolhurst, Amekudzi et al. 2008; Merten et al., 2006; Hausmann Muela et al. 2003; Tanner & Vlassoff 1998). In addition, the way that family members function is partly determined by socially prescribed roles. These roles may change when a family member becomes infected with HIV/AIDS. For example, women who usually have the role of "caregivers" may need to adopt a socially prescribed male role as "bread-winner" in order to financially sustain the family when the husband is sick. Similarly, children may need to adopt the role of caregiver when they have to attend their sick parents. This type of shift or disruption of family functioning has been found to lead to emotional distress (Thompson & Bolger 1999; Larson & Almeida 1999; Larson & Gillman 1999) in individuals suffering from other chronic diseases (Compas et al., 1991; Forehand et al., 1986). High levels of emotional distress have also been documented as one of the reasons for non-adherence to ART (Sarna et al. 2008; Cook et al. 2004; Kagee et al. 2004; Catz 2000; Kalichman et al. 1999; Sullivan 1995). HIV positive people with relatively high levels of depression and low sense of social support were less likely to follow medication and health advice and to keep appointments than people with a high sense of social support (García & Côte 2003).

Chapter 3 - Zambia at a glance

3.1 Country Background

Zambia is a landlocked country in southern Africa, bordering with the Democratic Republic of Congo, Angola, Namibia, Botswana, Zimbabwe, Mozambique, Malawi and Tanzania.

Zambia, formerly known as Northern Rhodesia, was a territory administered by the South Africa Company from 1891 until the takeover by the UK in 1923. During the 1920s and 1930s, advances in mining spurred development and immigration. The name was changed to Zambia upon independence in 1964 (CIA - the World Factbook, 2012).

Zambia became a republic immediately upon attaining independence in October 1964. Its legal system is based on English common law and customary law with judicial review of legislative acts in an ad hoc constitutional council. The country became a multi-party democracy in the early 1990s after 27 years of one party rule.

The country is divided into nine provinces and 72 districts each administered by an appointed deputy minister. Each province is subdivided into several districts with a grand total of 72 districts. Within the districts, the administrative units were Chiefdoms and Constituencies. Constituencies were made up of Wards. The political system is openly democratic with multi-party elections for the Presidency, Constituencies and Wards held simultaneously every five years. (NAC/MOH 2011) The last of these elections were in 2011. Chiefs are selected

through clan and family lineages within the ethnic groups. Zambia's current president is H.E. Michael C. Sata.

Figure 3.1 Administrative Map of Zambia



The population of Zambia has rapidly grown from about 3 million people in 1964, to approximately 13.3, whereof just over 1.4 million live in Lusaka, the capital. With about 39 % living in urban areas (CSO 2011), Zambia is one of the most urbanized countries in sub-Saharan Africa. Overall, the population of Zambia is young with 66.3 % under the age of 25. The annual population growth is 2.8 % .The average life expectancy at birth has also increased from 40.5 years in 1998 to 51.3 years in 2008 (WHO 2008). This rapid population growth places an increasing burden on the national economy, particularly the country's capacity to keep pace with the health needs of a rapidly increasing population.

The official language is English, but there are about 73 ethnic groups in Zambia (Posthumus 1997) and about 20 distinct languages, many with several dialects. The distribution of the languages roughly coincides with the distribution of the ethnic groups. Main groups and languages include Bemba (north and centre), Tonga and Ila (south), Nyanja (east) and Lozi (west). (Else, 2002)

As a result of the activities of the first missionaries who arrived in the 19th century, most people in Zambia are Christian (50-75%). Officially Zambia is a Christian nation (1996 Zambia Constitution). A wide variety of Christian denominations exist: Roman Catholic, Anglican, Pentecostal, New Apostolic Church, Lutheran, Jehovah's Witnesses, Seventh-day Adventist, The Church of Jesus Christ of Latter-day Saints, and a variety of Evangelical denominations. They spread from the original missionary settlements (Portuguese and Catholicism in the east from Mozambique) and Anglicanism (British influences) from the south. Pentecostal congregations expanded considerably after President Chiluba (a Pentecostal Christian) was elected in 1991 (Steel, 2005). Zambia has one of the largest percentages of Seventh-day Adventist per head in the world, about 1 in 18 Zambians (Zambia Union Conference, 2012).

There are also small congregations of Muslims and Hindus in the cities (24-49%), most of who are of Asian origin. At the same time, however, Zambians still adhere to indigenous African beliefs (1%). (CIA - the World Factbook, 2012)

Estimates of adult literacy rates (age 15 and over who can read and write English) in the country is about 80.6% with almost 75% of women and 87% of men.

Zambia is the largest copper producer in Africa, which makes the economy highly vulnerable to fluctuations in world market prices of copper. Since 2004, the increase in global demand for copper and related foreign investments, have enabled significant annual economic growth of around 6 % in the past five years (NAC/MOH 2011). In addition, the 2010 Zambia had a bumper crop of corn, which helped the country avoid large extent the effects of the global economic crisis. However, despite this recent economic growth, poverty rates in Zambia have remained virtually unchanged, with about 60 % of the population living below the poverty line (WB, 2012).

3.2 Zambia Health Sector

In Zambia health services are provided by the Government, NGOs and the private sector which includes the Churches Health Association of Zambia (CHAZ), mining companies, private clinics and hospitals and traditional healers. The government supplies essential public health services through five types of standard services: health post, health centre, and the first, second and third level referral Hospitals (NHSP 2009).

A number of factors have limited the provision of high quality healthcare in Zambia, in particular, the concentration of health infrastructure in urban areas, the lack of funding for medicines and medical supplies such as laboratory equipment, weak supply systems and poor working conditions that have resulted in exodus of much needed human resources from the sector (USAID 2008). In Zambia, the staff-to-population ratios are 1:17,589 and 1:8,064 for doctors and nurses, respectively (WHO recommend 1:5,000 and 1:700). (USAID 2008) With more

than 250,000 people eligible for treatment, there is a great need for increasing human resources and improving infrastructure in the health sector.

To improve equitable access to quality health services the government launched, in 2006, a reform plan of services focused on the decentralization of health services and the provision in the 72 districts of Zambia. This reform placed special emphasis on prevention, not only curative care. As a first step toward health reform, the government launched a package of essential health care and encouraged community participation in health sector planning. The main objective is to support and strengthen delivery of primary care services. Another focus was to strengthen the referral system and improve control emerging priority diseases, such as non-communicable diseases (PHR, 2009). International cooperating partners continue to support the government's efforts through a sectoral approach (SWAP) in health, after a temporary suspension of support in response to the mismanagement of the resources in the health sector (UNFPA, 2012).

3.3 Overview of HIV/AIDS epidemics in Zambia

The first case of HIV/AIDS in Zambia was reported in 1984, followed by a rapid rise in HIV prevalence. By the early 1990s, the HIV prevalence was already one of the highest in Sub-Saharan Africa but it has remained quite stable for many years.

In 2007, 14.3% of the Zambian population (aged 15-49 years) was infected with HIV (DHS 2007). The MDG 6 target for Zambia, which is to keep prevalence below 15.6%, has been met. The challenge is now to reduce new HIV infections.

The primary modes of **HIV transmission** are heterosexual sex and mother-to-child transmission during pregnancy, at birth and through breastfeeding. Other drivers of the epidemic include multiple sexual partnerships, low and inconsistent condom use, low rates of male circumcision, mobility and labour migrations, social vulnerability and marginalisation (NAC/MoH 2010). The majority of new adult infections occur in people whose partner has casual sex (37 percent), followed by persons reporting casual heterosexual sex (34 percent), low-risk individuals, i.e. monogamy mutual (21 percent), and clients of sex workers (4 percent) (NHSP 2009). The last report indicated that only one percent of new infections are estimated to occur among men who have sex with men.

With regards mother-to-child transmission, about 10 percent of babies born to HIV infected mothers became infected with HIV (NHSP 2009). Other means of infection contributed less than 0.5 per cent to the transmission of HIV among adults and children. Other less prevalent forms of transmission include medical injections (0.2 per cent) and contaminated blood transfusions (estimated at 0.02 percent).

The population size of injecting drug use (IDU) in Zambia is not known, nor the frequency of injecting drugs or sharing injecting equipment.

The HIV epidemic is characterized by a wide **geographic variation** with higher prevalence rate in urban areas than rural (23.1 and 10.8 respectively). The highest rates is found in the most densely populated urban area, Lusaka (20.8 per cent) and the lowest in one of the least urbanized province, Northern Province (6.8 per cent). (NAC/MoH 2012). The reason for the lower level of HIV in the Northern

Province has been attributed to aspects of the matrilineal culture that dominates this area. Matrilineal culture differs from the patrilineal line, predominant in other provinces translating in a less dominant male society in which men and women seem to be less likely to engage in extra-marital sex. Gender inequalities with male domination and other forms of inequality have been identified as a structural factor driving the HIV epidemic in Zambia (Kimuna et al., 2005; Fenton 2004; Gillespie et al., 2007).

The age-sex distribution of the epidemic reflects gender inequalities. Despite an decline in the overall prevalence rate since 2002 this reduction is not equitable between women and men. Zambian women have a higher prevalence rate of 16.1% compared to men at 12.3%. (CSO 2009) Young women are especially vulnerable. They are taught from a young age to never refuse their husband sex regardless of the extra sexual partners he may have or his non-willingness to use condoms (NHASF, 2006). This perpetual dominance of male interests puts both women and men at greater risk for HIV infection. Age-mixing patterns are characterized by older men having sex with younger women and are reported by 4.5 per cent of women aged 15-19 years (with a non-marital, non-cohabiting man who was more than 10 years her senior) (CSO 2009).

Young people comprise over 50% of Zambia's population and it is estimated that those aged 15-24 years account for 17.5% of HIV positive population between ages 15-49. In the young population, HIV infection increases among young men in urban areas but appears to be declining in young women. The latest data also indicate a reduction among young pregnant women aged 15-19 and 20-24 in

urban areas, yet in women of 30-39 years there is an increase in both urban and rural areas (NAC/MoH 2012). Among **children** aged 1-4 years, the estimated number of new infections has dropped dramatically to 5,520 (est. 2009) (compared with its highest peak of 27,978 in 2000). This is a combined effect of the decrease in women's incidence and the introduction of the PMTCT program. The estimated numbers of new infections in infants and children 1-4 years are 9726 and 2946, respectively, in 2011(NAC/MoH 2012).

3.4 National Response against the HIV Epidemic

In 2003, the Government launched its national policy to provide free and universal access to antiretroviral therapy, which was expanded in 2005 to include all related services. Since then, the Government of Zambia has proved very committed to control the HIV/AIDS epidemic. The national policy rightly recognizes that the HIV epidemic is deeply influenced by the social, economic and political environments and put in place measures to address some of the socio-structural factors that feed the epidemic. At present the national response to the epidemic is guided by the 2011-2015 National AIDS Strategic Framework (NASF 2011-2015) that recognizes HIV/AIDS and gender as the two main cross-cutting themes that should be integrated in all social, economic and political programmes.

The NASF 2011-2015 vision is "a nation free from the threat of HIV and AIDS." This plan was developed through a consultative process that included civil society, people living with HIV, government institutions, development institutions, the private sector and development partners. Consultation with groups

such as sex workers, traditional leaders and others became through representative organizations.

(NAC/MoH 2012).

The NASF establish four priorities: (i) to reduce annual rate of new infections through preventing sexual transmission of HIV and STIs, preventing mother-to-child transmission; improving counselling and testing and integrating HIV prevention services in the primary health care; (ii) to accelerate provision of universal access; (iii) to mitigate socio-economic impacts of HIV, especially among the most vulnerable and (iv) to strengthen a multi-sectorial response to control HIV.

3.5 Access to HIV/AIDS services: future challenges

The starting point in improving access was to integrate HIV and AIDS services in the comprehensive health care package that is provided, consummate with the level of the health care facility. In this regard, the number of health facilities that were providing HIV and AIDS services to various degrees was increased between 2008 and 2010 by 8.1 per cent. At the end of 2010, there were 1,690 health facilities providing HIV and AIDS services of which 1,471 were public and 240 were private. The total increased to 1,769 in 2011.

Antiretroviral therapy (ART) was introduced to the general public in 2004 on the provincial level. Treatments were not for free at that time. Clients had to pay US\$10 per month towards the cost of HIV treatment, in addition to the costs of clinical baseline investigations. Only in 2005 free ART was introduced and scaled

up to include more health centres, which could provide ART nation-wide. In 2007 332 health centres provided ART in the country. In addition, the number of health facilities providing HIV testing and counselling services had been increased to 1,563 in 2008 from the 1,083 in September 2007. Health facilities providing PMTCT services reached 936 at the end of 2008. (NAC/MoH 2012)

Nonetheless, in 2009 still only a fraction of the adult Zambians knew their serostatus. Last estimates point that as much as 60% and 78% of women and men respectively have never tested for HIV (CSO 2009). About 60% of people newly infected through heterosexual transmission are infected within marriage or cohabitation, compared with more than half (50%–65%) in Swaziland, 35%–62% in Lesotho and an estimated 44% in Kenya. (UNAIDS 2010) Prevention strategies, however, often do not adequately address the patterns of HIV transmission. Couples testing and other prevention services for serodiscordant couples receive inadequate support. (UNAIDS 2010)

Thanks to an increased national political commitment and international funding the number of people on treatment had also dramatically increased – from 30,103 at the end of 2005 to 344,407 at the end of 2010, representing 68.4% of those in need of treatment (NAC/MoH 2012). For those included in antiretroviral therapy programs, still too many had difficulties to consequently adhere to the therapeutic scheme (9-11). Treatment adherence continues to be a significant challenge in both urban and rural Zambia. Studies showed that 59.5% of patients in Zambia's southern province throughout a period of 15–723 days (a median follow-up of 275 days) and 62.9% of patients in Lusaka over the first 12 months (a median follow-

up of 15.7 months from 12 months onwards) were adherent to ART. (Sasaki et al. 2012 ; Chi et al. 2009, Birbeck et al. 2009; Carlucci et al. 2008; Krebs et al. 2008)

Furthermore, recent studies have showed that about one third of patients who were lost to follow up and who fully stop the ART program were still alive. Some participants gave a wrong address or a wrong name because they didn't want to be found. This 'deliberate' being lost to follow up was estimated about 15% of all persons in an ART program (Chi et al., 2007). Little information is available on this group of people who are not found in loss to follow up studies. A similar situation has been described for other Southern African countries (Weisser et a., 2003 Ferradini & Jeannin 2006; Mills & Nachega 2006). This group creates an additional challenge for the control of the HIV epidemic since in addition to the possible ineffectiveness of only partial adherence to treatment for the individual, the risk of antiretroviral resistance in general increases. (Oyugi & Byakika-Tusiime 2007; Bangsberg 2008)

This relatively low uptake of HIV testing as well as the issues of adherence and retention in ART care are also evident in many other Southern African countries (Namakhoma et al. 2009; Visser et al. 2009; Dunkle et al, 2008; Ferradini et al. 2006; Weiser et al. 2003).

While recognising progress made in addressing HIV, Zambia still a long way to go to control its HIV epidemic. These figures suggest that other than health system barriers continue preventing people from accessing HIV/AIDS services. Deep social inequalities based on gender and age contributes to increase vulnerability to HIV.

Chapter 4 - Aims and objectives

Aim

This thesis aimed to investigate the influence of social cohesion along the continuum of HIV Care in Zambia (uptake of testing; uptake of ART; adherence to ART and retention in care) and to assess the effect of specific combinations of social cohesion, economic and individual factors on individual decision making related to access HIV/AIDS services.

Objective 1

To systematically review previous quantitative studies examining socio-cultural barriers to access and adherence to HIV/AIDS services and treatment in developed and developing countries, and to conduct a meta-analysis

It was hypothesized that:

In prior research, the socio-cultural barriers to HIV testing and compliance with HIV related services identified in low- and high-income countries were different.

Objectives 2

To investigate the influence of social cohesion on:

- the uptake of HIV testing,
- the uptake of ART,
- the adherence to ART programs

in the general population and in a highly HIV vulnerable population in Zambia.

Social cohesion was measured on the level of the couple, family and neighbours.

It was hypothesized that:

Low levels of social cohesion make people less likely to test for HIV

Low levels of social cohesion make people less likely to start ART

Low levels of social cohesion make people less likely to adhere to ART

Objectives 3

To examine whether the influence of social cohesion varies by gender, especially in the context of livelihood insecurity

It was hypothesized that:

The influence of social cohesion, in the context of livelihood insecurity, is stronger in women than in men.

Chapter 5 - Conceptual framework

5.1 Health seeking behaviour and access to healthcare

Over the years, a wide variety of theoretical approaches have been developed to investigate health seeking behaviour and access to healthcare. Two major frameworks have however emerged. The first emphasizes the utilisation of the formal system describing the steps of the health seeking process from recognition of symptoms to the use of a particular health facility. The second emphasizes the determinants associated with the choice of different kinds of health services (for a complete overview, see MacKian, 2004 and Hausmann-Muela, 2003).

Most commonly used models are the behaviour-oriented health belief model (Sheeran, 1996) and/or the Penchansky access models (Penchansky, 1981) which addresses the so called "four A": availability, affordability, accessibility and acceptability of healthcare. These models have been employed in numerous epidemiological studies as a framework to study the barriers to healthcare from a user or health service perspective. One of the major critiques of these studies is the strong focus they have on cognitive aspects and the fact that they rely on the assumption that individual behaviour is built upon rational decision making based on knowledge, without reflecting that individuals are embedded in social contexts that affect the way they process and act on information.

During the last decade, the focus of the research in health seeking behaviour has started to move from the individual into the reality of interaction in the social world. One way in which researchers have attempted to do so is through the lens of livelihoods. Several studies have shown that, in low income countries, resource constraints in an insecure socio-economic context (Merten, 2008; Obrist, 2007; Merten, 2006; Hausmann Muela, 2000) have a negative effect on access to

healthcare. Lack of trust in the health sector can also hamper access to HIV/AIDS related treatment (Mohseni, 2007; Gilson, 2003). A widespread interest has arisen in using social capital theories (which central idea is that social networks are a valuable asset) to understand the social processes behind health inequalities (Szreter, 2004). This trend has begun to enter the health seeking behaviour literature (Adam, 2000; Campbell, 2001). Where there is no formal social security and/or healthcare insurance, social networks may become crucial in order to obtain support during illness and other crises. Several studies examining the role of social support and trusting relationships found that these relationships have a positive effect on health outcomes (Mansyur 2008; Chandola 2007). However, these effects are different between countries, pointing at the need to address contextual factors (Poortinga 2006).

5.2 What is social cohesion?

One of the great challenges of conducting a literature review on social cohesion is the vast amount of publications on the topic and the lack of consensus on a definition and appropriate measure. The conceptual debate among social scientists is still on-going. The notion of social cohesion has been developed alongside with social capital. In the literature, it is difficult to separate the two concepts as social capital is often used as an indicator of social cohesion (Chidester et al., 2003). In general, it is understood that high levels of social capital is a characteristic of cohesive societies (Fukuyama, 1999).

It is important to note that this chapter of my thesis does not aim at conducting a comprehensive review of the literature on social cohesion, but it rather aims at

summarising some of the most important theories that attempt to define the concept as well as the mechanisms to explain how social cohesion affects health. For a complete review of the theories on social capital, I recommend reading the thesis of Malin Eriksson (2010) which I have relied upon for this summary.

5.2.1 Difference between social capital and social cohesion

The first sociological study on this subject was made by Emile Durkheim who studied the association between social integration and suicide. One conclusion from this study was that people less integrated in society were more likely to commit suicide compared to those who were more socially integrated (Durkheim, 1951). He postulated that social integration acts as a “buffer” against stress. Other two of the most influential authors in the area of social capital are Pierre Bourdieu and Robert Putnam whose work was initially one of the most used in the field of public health. Both proposed a different approach to understand social capital.

Bourdieu (1986) postulates social capital as an individual asset. This is known as the *social network approach*. Putnam (1993) proposes social capital as a collective attribute of social networks which is known as the *social cohesion approach*. Whether social capital is an individual or collective feature is still in debate. In the field of public health, it is often studied from both perspectives and each requires different considerations and methods. (Eriksson, 2010)

The social network approach

The individual approach understands social capital as the resources available to individuals through involvement in social networks. This approach is, mainly,

grounded on the work of Pierre Bourdieu (1986), James Coleman (1988) and Alejandro Portes (1998; 2000).

Bourdieu defines social capital as *“the aggregate of the actual or potential resources which are linked to possessions of durable network of more or less institutionalized relationships of mutual acquaintance and recognition—or in other words, to membership in a group—which provides each of its members with the backing of the collectivity-owned capital, a credential which entitles them to credit, in the various senses of the word”* (Bourdieu, 1986, pp. 248-249).

According to Bourdieu, each person who is a member of a network accumulates resources such as information, knowledge, material goods and social contacts. These resources are available to all members of the network. However, inclusion in social networks is not a natural process but a consequence of "investment strategies" (Eriksson, 2010). Without investing resources, it is difficult to establish meaningful relationships with others (Portes, 2000). In Bourdieu's vision, capital (in all forms) is equivalent to power and its distribution determines the social structure. The dominant groups in a society have more power to decide which networks are valuable and to include or exclude people from these networks. (Bourdieu, 1986)

Coleman (1988) sees social capital as a resource for action. Social capital is a public good in the sense that its benefits can reach people who are not members of the social network. Coleman defines social capital as *“a variety of entities with two elements in common: They all consist of some aspects of social structures,*

and they facilitate certain action of actors whether persons or corporate actors - within the structure. Like other forms of capital, social capital is productive, making possible the achievement of certain ends that in its absence would not be possible” (Coleman, 1988, p. S98).

From his perspective, social capital is a resource embedded within people themselves and within the structure of relations between people (social network). Thus social capital is both, collective and individual. Furthermore this author identifies three forms of social capital: 1) obligations, expectations and confidence in social structure, 2) information channels, and 3) norms and effective sanctions. According to him, these three forms of social capital are the basis of human actions. Doing things for others establishes an “obligation” that they do something back. These obligations act as debts to be paid when needed. Consequently members of the network that generate more obligations have more social capital (Eriksson, 2010). The information embedded in social relations is a valuable form of social capital because information is essential for action. Belonging to the social network facilitates access to information that otherwise would be difficult to obtain. Prevailing norms also influence on the actions through expectation of rewards (such as reputation) if people adheres to the rules or sanctions (such as social exclusion) if they do not follow the rules (Eriksson, 2010).

Portes (1998) adds an important perspective to the individual approach of social capital, as he distinguishes between the causes (sources) and the effects of social capital. In his view, social capital is the resources people can access based on their social ties. These resources are not inherent to the individual (intrapersonal) but embedded within the structure of the social network. Portes defines social capital

as “*the ability of actors to secure benefits by virtue of membership in social networks and other social structures*” (Portes, 1998, p. 6). Therefore, to access capital, a person must be related to others (Eriksson, 2010).

This author argues that social capital theories often do not distinguish between its causes (sources) and effects resulting in a circular argument as if social capital (information, trust and norms) were caused by its own effects. He intends to bring clarity by identifying the characteristics of the networks themselves as the causes (sources) of capital. Leaning on classic sociological theories by Marx, Simmel and Durkheim (Eriksson, 2010), Portes postulates that people may be willing to contribute with their available resources due to: (i) internalized norms to behave in an appropriate manner, (ii) solidarity with whom people identify, (iii) norms of reciprocity, due to expectations of payment, either directly from the receiver or from the whole community through social status or reputation. For Portes (1998) the information, support and opportunities are the effects generated by capital sources.

Another contribution of Portes (1998) is the potential negative effects of social capital. According to the author, the same strong ties that are beneficial for some network members can also generate restrictions and exclusion for others. Strong support networks can result in an overload of demands for some members of the group, especially if they have more resources available. And as participation in the group necessarily requires a certain level of conformity it may generate strong social control and restrictions of individual freedom (Eriksson, 2010).

The social cohesion approach

The social cohesion approach understands social capital as a collective attribute that characterizes structures of social relations, such as communities. The theoretical approach is grounded on the work of Robert Putnam who describes social capital as: “*Whereas physical capital refers to physical objects and human capital refers to properties of individuals, social capital refers to connections among people—social networks and the norms of reciprocity and trustworthiness that arise from them*” (Putnam, 2000, p. 19). Putnam suggests that social capital has both individual and group characteristics. Besides of being a "private good" is also a "collective good" (Putnam, 2000, p. 20). Thus social capital can be beneficial even for people with few social connections because of the benefits of living in highly cohesive communities (Putnam, 2000; Eriksson, 2010).

Putnam (1993, 2000) separates three essential forms of social capital: *networks of civic engagement, norms of reciprocity and social trust*. These three elements influence and reinforce each other. *Reciprocity* is generated by the obligations derived from being a member of a social network (Putnam, 2000). How these obligations arise or remain is unclear but they may be associated with sanction capacity of networks (excluding people who do not follow the rules) (Eriksson, 2010). The norms implied in reciprocity, personal and generalized, generate trust. For example, generalized reciprocity occurs when an individual do something for someone without expecting this person to do something back but the network (Eriksson, 2010). This, according to Putnam, builds trust between people. The more people trust each other the greater the possibility of mutual interest to collaborate. This reasoning has been criticized by Portes (2000) for being

“circular” as he says that being part of the network generates trust which in turn facilitates collaboration (Eriksson, 2010).

According to Putnam (1993, 2000), cohesive communities are characterized by the existence of associations between citizens who actively participate in public affairs and are capable of putting the public good before private good. This type of communities grants the same rights and obligations for all and horizontal relations of reciprocity and cooperation are common (Eriksson, 2010). Finally, levels of interpersonal and generalized trust are high, which encourages people to cooperate on the basis of expected reciprocity. According to Putnam, a community with these characteristics is more efficient than others in regards to democracy, economic prosperity, health and happiness (Eriksson, 2010).

Michael Woolcock is another author who theorizes about social cohesion. He defines social capital as “*norms and networks that facilitates collective action*” (Woolcock, 2001, p. 13). As Portes (1998), Woolcock (2001) stresses the importance of the separation between the causes (sources) and effects of social capital. In the view of this author trust is a consequence of capital, not a part of it (Eriksson, 2010). Szreter and Woolcock (2004) identify the requisites for trust to develop: (i) an understanding between the members of a social network; (ii) shared objectives and purposes (work together towards a common goal). In turn this requires a shared sense of justice and respect (Eriksson, 2010).

The author also recognizes not only the importance of social ties within and between community members, but also between community members and the

different political institutions in a society. With this it emphasizes the role of state-society relations for public health outcomes (Eriksson, 2010).

5.2.2 Individual social capital: linking health and social networks

The links between individual social capital and health has been widely documented in studies with adults. A recent systematic review (Kim et al., 2008) shows that the strongest associations are found between the cognitive component of social capital and health. For example, trusting the neighbours (access to personal trust) is a form of cognitive social capital which is associated with better self-rated health (Erikson, 2010).

Summarizing, within the individual approach, the link between social capital and health is said to happen through: (i) various forms of social support that act as “buffering factors” for stress (Bartley 2004) and can provide access to resources and services (Eriksson 2010); (ii) social influence (Merzel & D’Afflitti, 2003); (iii) social participation either through direct activation of cognitive systems, or indirectly, giving a sense of coherence and belonging to the community (Berkman & Glass, 2000). Recently a new via has been debated related to status in the social hierarchy of the social network. According to Marmot (Marmot, 2005), having more opportunities than others within the same environment gives “status syndrome” which could influence health through positive emotions generated due to the privileged status as well as having a life less daily tensions (Eriksson, 2010).

5.2.3 Social cohesion: linking health and social inequalities

Studies investigating the relationship between social cohesion (collective social capital) and health are less numerous and the results are rather inconclusive (Islam et al., 2006). As for the individual approach, there are several paths through which social cohesion can affect health.

Wilkinson (1996) has theorised on the relationship between social cohesion, income inequality and health. According to his work, social cohesion is a mediator in the association between income inequality and health. He found that populations with low levels of income inequality have better health and that equal societies are more cohesive than less equal societies (Eriksson, 2010). Therefore, the author concluded that the equitable distribution of income leads to cohesive social environments, which ultimately enable better health (Wilkinson, 1996).

Kawachi and Berkman (2000) argue that social cohesion influences health by influencing health-related behaviours, access to health services, and psychosocial processes. As Eriksson (2010) points out this reasoning is *a priori* confusing since the effect of social cohesion, is expected to occur on a collective level (as it is a collective attribute) and not on the individual level (health behaviour). But, in her thesis Erikson argues that Woolcock (2001) and Grootaert & van Bastelaer (2002) provide the theoretical basis to solve this conflict by identifying “collective action” as the mechanism through which social cohesion exerts its effect. Thus, while individual social capital can influence health through the support obtained by participating in social networks, social cohesion may influence health through

collective action. Similar effect but different mechanism of action (Eriksson, 2010).

Collective action is broadly defined as any action taken by a group (either directly or on its behalf through an organization) in pursuit of members' perceived shared interests (Marshall, 1998). It occurs when individuals voluntarily cooperate as a group to coordinate their behaviour to solve shared problems. According to Kawachi (1999) high levels of social cohesion in a community, characterized by trust between citizens, norms of reciprocity, and group membership, facilitates collective action. Kawachi, Kennedy and Glass (1999) found that cohesive communities are more successful to come together and get to influence local political decisions to improve their neighbourhoods. Communities with high social cohesion may have a greater ability to influence local government decisions for example on availability of health services in their communities.

Another route by which social cohesion exerts its influence is facilitating the process of "*community empowerment*" that enables health behaviour change (Campbell & Jovchelovitch, 2000). Community empowerment refers to "*the process of enabling communities to increase control over their lives*" (WHO 2009) In this definition community means that groups of people who may or may not be spatially connected, but share common interests, concerns or identities. "*Empowerment*" refers to the process by which people gain control over the factors and decisions that shape their lives (WHO, 2009). It is the process by which they increase their assets and attributes to build capacity to access partners, networks and / or speak with one voice in order to gain control. "*Enabling*"

implies that *“people cannot be empowered by others; they can only empower themselves by acquiring more of power's different forms”* (Laverack, 2008). Environments characterized by trust, participation and mutual support (i.e. cohesive environments) are more effective to bring change and to support health enhancing behaviours. (Campbell & Jovchelovitch, 2000)

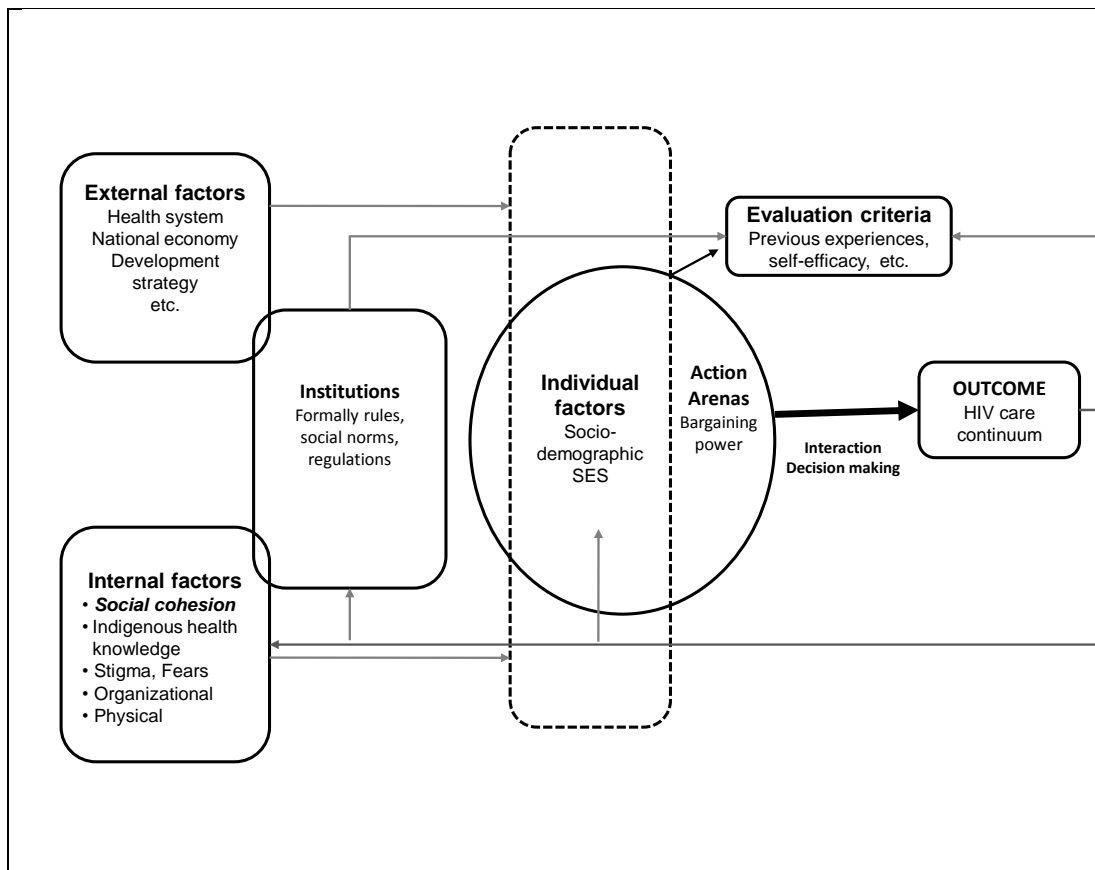
Finally, social cohesion may facilitate the process of diffusion (Rogers, 1995) that postulates the possibility to influence health by creating healthy social norms that promote desirable behaviours and limit other less desirable in the community (Kawachi et al., 1999). Social cohesion could boost the rapid and widespread dissemination of (health) information and knowledge (Kim et al., 2008). In cohesive community neighbours trust each other and have more interactions, disseminating information more effectively.

5.3 Suggested analytical framework

In order to investigate the factors influencing the decision-making process related to access HIV/AIDS-related treatment in specific situations, a comparative study setting with varying health systems, socio-economic and socio-cultural conditions (urban/rural) have been chosen for the study. This study is based on the premise that individuals do not take decisions in isolation but are influenced by the whole socio-cultural context where they are embedded. In this regard, the study needs a framework that accommodates all these elements. Ostrom's Institutional Analysis and Development framework (Ostrom, 2005) conceptualizes that perceived options on actions (e.g. HIV testing) are modulated by a variety of external (e.g. health system) and internal factors (e.g. community, family) as well as by

norms/values (underlying factors that could be institutional, political, economic or cultural) and implicit or explicit expectations about outcomes (evaluation criteria), that, ultimately, influence decision making. The difference to usual treatment seeking frameworks is the consideration of shared rules, norms and values for decision making and their possible modification by external factors, which may alter legitimacy (Merten & Malungo, 2008). Another advantage of this framework is the introduction of evaluation criteria (implicit or explicit) of expected outcomes based on prior experiences as influencing decision making. In addition, it accommodates power relations that might influence the bargaining power of individuals in decision making process. Figure 5.1 shows an adaptation of this framework.

Figure 5.1 Factors influencing access to HIV/AIDS services



Framework adapted from Ostrom 2005 and Merten 2009.

Chapter 6 - Methods

6.1 Systematic review of the literature

6.1.1 Search strategy for identification of literature

I used a key word approach including terms describing HIV/AIDS, social cohesion and health seeking behaviours. The scope of the review was narrowed down by using Boolean operators "AND" and "OR". In addition I limited the searches to those published from 1995. Literature older than 20 years was deemed as no longer relevant, and time constraints dictate that only the most recent materials can be reviewed. More details of this method are described in Paper 1 of this thesis.

The specific search terms (key words) have been built around the following themes: "social networks", "social cohesion", "social capital", "social support", "social determinants", "health seeking behaviour", "self-rated health", "socio-economic status", "poverty", "HIV/AIDS", "access to health services", "Sub-Saharan Africa" and "Zambia". The terms of social capital, social cohesion, and social support, although related are not the same but were included in the search in order to have a wider coverage of the literature related to the influence of the social context on health and access to health services.

The search strategy included a review of seven electronic databases Medline, Embase, CINAHL, JSTOR, CSA databases, including Sociological Abstracts and ERIC.

6.1.2 Exclusion/inclusion criteria

Literature was included in the review in accord with inclusion and exclusion criteria.

Inclusion criteria included:

Design: The review included quantitative studies using a survey methodology.

Population and setting: The review included studies focusing on general adult population (over 18 years old), who were in need of HIV/AIDS care and treatment and living in high and low income countries.

Outcome measures: The studies investigated determinants associated with HIV testing, initiation of ART, adherence to ART and retention in ART programmes.

Exclusion criteria included:

Studies focusing on children and/or adolescents; studies investigating determinants associated with other non-related HIV continuum of care outcomes and qualitative studies.

6.1.3 Review methods

Titles, abstracts and full texts found in the search were reviewed and assessed for eligibility against inclusion criteria. To reduce selection bias, each step of the search and the review were done in duplicate by two independent reviewers.

Disagreements were discussed to reach consensus. Full text papers were retrieved for the studies that meet all the inclusion criteria. Reference lists of all studies which meet the inclusion criteria were hand searched to confirm that all relevant studies were included in the review. The selected articles were carefully read to assess methodological and content quality using a critical appraisal framework.

Reported effects, settings, study population, sample size and other background variables were extracted onto a data extraction form. A list of finally included

studies was created. A description of this comparative evidence was prepared to inform the construction of the survey tool. The results are reported in Chapter 6 of this thesis.

6.2 Cross sectional community based survey

6.2.1 Study design

A survey methodology has been applied in order to document distribution patterns of treatment seeking behaviours related to HIV/AIDS and to measure the association between access to HIV/AIDS-related treatment (access to VCT, initiation to ART and adherence to ART) and socio-structural factors. Results from previous qualitative research, conducted in the framework of the same overall study, guided the choice of the themes to be investigated in the questionnaire. These themes were: socio-demographic and socio-economic factors, livelihoods and social (in-)security (social cohesion at the level of that couple, family and neighbours), health literacy and culturally shaped beliefs about HIV/AIDS, stigma and discrimination and treatment related factors such as side effects, quality of care and distance to clinics.

A review of previous quantitative studies provided the basis for developing the questions and identifying relevant indicators to accommodate the themes adequately.

When needed existing scales, especially if they had been validated in a resource poor setting were adapted to the Zambian context to be used in our questionnaire.

The questionnaire was pilot tested with a small purposive sample. It was translated into Nyanja, Tonga and Ila which are the main local languages of the

study sites (Lusaka, Mazabuka, Chivuna and Mbeza). The interviews were conducted by experienced local interviewers that were contracted for each site and trained during three weeks on the use of the questionnaire and on the ethical principles that should be taking into account during and after the interviews. The interviewers spoke at least one of the required local languages since all interviews were conducted in the mother tongue of the respondents.

6.2.2 Study site and study population

The survey study was conducted in two rural (Namwala and Monze district), one commercial centre (Mazabuka), and one urban area (Lusaka) from the Southern and Central provinces of Zambia. The rationale behind the sites' choice was to have a comparative setting with varying health system socio-economic and socio-cultural conditions (urban, periurban and rural). The study population consisted of adults, women and men, who were residents of one of the four sites.

Inclusion Criteria

- residents of the study site;
- aged ≥ 18 years;
- tested for HIV (HIV positive and HIV negative);
- living with HIV (both on treatment and not on treatment);
- never tested for HIV (and do not know their HIV status).

Exclusion Criteria

- Non-residents of study site;
- Age below 18 years old.

6.2.3 Sampling strategy

A random community-based sample was combined with a clinic based sample of people on ART, or who were lost to follow up. In order to compare the characteristics of people with HIV who were not accessing services with those who were accessing HIV related programs, we needed to randomly sample 540 persons per site (Lusaka, Mazabuka, Chivuna, Mbeza) and 210 persons per site in the clinics (N=3,000). An additional purposive sample was necessary to recruit a sufficient number of people at high-risk of HIV. Therefore the total sample for this study was derived using three different sampling methods:

a. Random household sample

We used 3-stage sampling design (Primary sampling units (PSUs)-Households-Individuals) to derive our sample. First, we randomly selected PSU's (chiefdoms or municipalities) in the four study areas from a list of enumeration areas obtained from the last census conducted in Zambia in 2010. We calculated the number of households using a probability proportional to size (PPS) sampling strategy. Households were randomly selected from household lists with the exception of Lusaka where a random walk scheme was used. In each household our interviewers selected one permanent resident >18 years using the Kish within-household respondent selection method (Kish, 1949). With this method we ensured equiprobability of selection among individuals who fall within the scope of the survey (thus every eligible individual in the household – in our case, all those aged 18 and over – had the same chance of being selected). If the selected individual was not present, an appointment was made. Only if this appointment was missed, a new household was selected. In Lusaka we additionally applied a

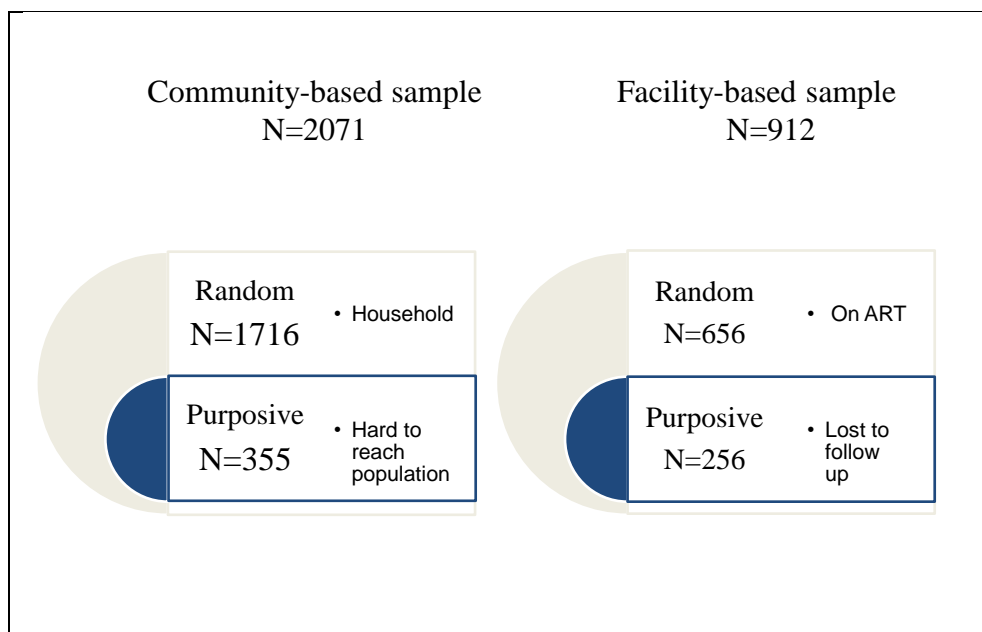
weighted sampling strategy to build a representative sample of the population living in high, medium and low density areas.

b. Facility-based sample

This sample was derived from all health facilities located within the boundaries of each PSU selected for the household survey as well as the health facilities in the next outer ring of the PSU. Interviews in health facilities were conducted over a defined period of days, where all clients consulting ART services or TB corners were approached. An additional over-sampling (N=60) was necessary to identify individuals who were not retained in care. We asked the health staff of the facilities' sampled to identify patients, from their lists, who were lost-to-follow-up (LTFU) and to ask them for participation in our study. Upon agreement of these patients, our research assistants contacted them to schedule a time for the interview either at an office in the facility and/or in their homes. They were administered the same questionnaire.

c. Purposive sample (hard-to-reach population)

To derive this sample we approached community traditional healers / herbalists and STI clinics and asked them to collaborate with us by contacting people who were HIV positive but not on ART and informed them about the opportunity to participate in the study.

Figure 6.1 Sampling strategy

6.2.4 Measures and data collection

6.2.4.1 Measures and questionnaire development

The questionnaire has two parts (Appendix 2). The first part contained questions about socio-demographic, socio-economic and social relationship factors, stigma and discrimination, health related knowledge and beliefs and health seeking behaviour. These questions were asked to all study participants. The second part contained specific questions about HIV testing, uptake of ART and adherence to antiretroviral programmes.

The selection of the themes for the questionnaire was guided by the results of an ethnographic study on health seeking behaviour and perceived barriers to HIV treatment conducted in the same areas over the previous year. Additionally a literature review, that I personally conducted, before the development of the questionnaire helped to identify questionnaires and scales that were used by other

studies to measure similar themes. A panel of national and international experts reviewed these instruments and scales and selected pertinent questions and indicators to measure each theme. All questions and indicators were adapted to the Zambian context. The questionnaire was checked translated from the original language (English) into the languages of the target population [Tonga, Ila and Nyanja]. Two translators fluent in the languages of the target population with a good understanding of the original language produced the initial translations independently. The translated versions were synthesized into one version by a third independent translator. Thereafter the synthesized version was back-translated independently by two different translators. The back-translators were fluent in the original language and had a good understanding of the languages in the target population. The translated version and the back-translated version were reviewed by the expert committee to assess if a word or several words reflect the same ideas or subjects in both the original and adapted versions of the questionnaire. The experts committee also assessed the operational validity of the final questionnaires checking that the format, instructions, mode and administration and measurement methods were appropriate to the Zambian context. Once consensus was reached the instrument was pilot tested twice before final validation. In each pilot study 60 respondents were probed for their understanding, acceptability and emotional impact of the items in order to detect confusing or misleading items.

6.2.4.2 Data collection

A team of 30 experienced Zambian surveyors were trained in survey techniques and the use of the questionnaire for a period of 4 days. They worked in teams of 10 in the four sites and conducted the interviews in the respondents' mother

tongue which were Tonga and Ila (in Namwala, Monze and Mazabuka) and Nyanja (in Lusaka).

Interviews took place between September 2010 and February 2011. They obtained signed informed consents from (Appendix 1) the participants prior to start the interview (further details in the next section – Ethical considerations). Participants who requested it were offered psychosocial counselling by qualified professionals and obtained referral information for local HIV/AIDS voluntary counselling and testing (VCT) services.

The interviews took place in safe, quiet and private surroundings of the respondents' households where interview and interviewee were left alone and participants felt comfortable to talk and could not be overheard. In order to reduce interviewer-interviewee bias the interviewers were selected to match the characteristics of the respondents in terms of ethnic group and gender. Female respondents were interviewed by women and when men were to be interviewed they were given the choice of a male or female interviewer. Additionally all the interviewers were trained in interviewing skills (i.e. appropriate questioning skills, including an ability to use non-judgemental language and tone and to generally present a non-judgemental manner and attitude) and in communication skills (i.e. listening skills, coupled with appropriate non-verbal (facial expressions, body language) and verbal responses). We also made sure that all interviewers were familiar with, and abide by, the ethical and safety recommendations included in the WHO guide: Putting women first: Ethical and safety recommendations for research on domestic violence against women (WHO 2003), when carrying out survey research. To reduce social desirability bias we used indirect questioning methods which have proved to provide a better estimate than direct questioning of

the respondent's true feelings on a socially-sensitive subject (Fisher & Robert 1993). For example the interviewee asked the respondent to specify their level of agreement to this statement by indicating a position along a continuous line between two end-points using a visual analogue scale (VAS): In my household if a wife comes home late without the permission of the husband she will be beaten (instead of direct questioning the wife: "In my household if I come home late without the permission of my husband I will be beaten). There is evidence showing that visual analogue scales have superior metrical characteristics than discrete scales (Reips & Funke 2008). In practice, the computer-analysed VAS responses were measured using discrete values (1 to 5 Liker scale) due to the discrete nature of the computer displays.

6.3 Data management and analysis

I have personally entered the data in Stata 12.1 and clean it. For the processing of the data I used Teleform® Software. Before the data collection, I prepared the questionnaire template using the programme Designer of Teleform software. This questionnaire was printed out in paper format and distributed per site for collecting the data. In each site, a supervisor from the core study team supervised the fieldwork. As described before, the data collection took place between September 2010 and February 2011. After the data was collected but before processing and entering the data, two quality data-checks were performed by two independent research assistants. The first quality check was conducted in the field. The team supervisors reviewed the questionnaires administered at the end of each day so that we were able to address inconsistencies and data missing while the team was still in the study-site. Once the questionnaire was approved by the

supervisor, it was scanned and converted into a PDF. The hard copies were classified and stored in the office of one of the main researchers in the University of Zambia. The PDFs were sent to Switzerland where I personally conducted a second quality-check using the program Verifier of the Teleform software. Once the data was verified, it was electronically read using Teleform Reader and automatically imported into a Stata database. Both hard and soft copies of the questionnaires had codes to protect the identity of the participants. In addition, access to the electronic questionnaires (PDFs) is password-protected to guarantee confidentiality.

The core quantitative data was analysed using STATA. Scales were validated using appropriate psychometric analyses. Descriptive statistics were used to calculate the distribution of the barriers to access HIV/AIDS service (factors above mentioned) in the general population and in highly HIV vulnerable population. I also compared the accessing and adhering population (facility-based samples) with the general population (community based samples).

Multilevel and multinomial logistic regression analyses, adjusting for confounding, have been used to measure the associations between the outcomes and the explanatory variables. Odds ratios and Relative Risk Ratios (RRR) have been calculated as the measure of the strength of the associations. Paper 1 to Paper 4 of this thesis describes in detail the statistical analyses conducted and the results obtained.

Three outcomes:

- access to HIV testing (yes/no)
- uptake of ART(yes/no)
- adhering to ART (yes/no) and retention in care (yes/no)

Explanatory variables:

- individual-level factors such as: demographic characteristics, perceived health, perceived care system quality and medical trust, health literacy and culturally shaped beliefs
- socio-structural factors such as social cohesion (couple, family and neighbours); social network size; community stigma, livelihood (in)-security.

6.4 Ethical considerations

6.4.1 Ethical review of the research protocol

This PhD research proposal is nested within the main research proposal "improving equity of access to care and treatment in Zambia" and focuses on one particular aspect (the quantitative part) of the overall proposal. The main research proposal was submitted and approved by the EKBB Ethical Committee (*Ethik-Kommission beider Basel*) in Switzerland and by the Humanities and Social Sciences Research Ethics Committee of the University of Zambia in 2009. Clearance has been obtained from the Zambian Ministry of Health. The research Ethics Committees in Zambia will be notified of any fundamental changes to the research protocol or instruments.

6.4.2 Informed consent and confidentiality

The right for informed consent was observed, giving to the respondents information about the purpose and outcomes of the research. Signed informed consent was obtained from each research participant prior to the interview (Appendix 1). In the case the research participant was illiterate an impartial witness was asked to be present during the entire informed consent discussion.

Both the respondent and the witness signed the consent form attesting that the information in the consent form was accurately explained to and understood by the participant and that the participant freely agreed to participate. Participants could voluntarily withdraw from the interviews for any reason at any time. In such instances and depending on their wishes, any data held about them was deleted. All participant information and records that contain names or other personal identifiers, such as informed consent forms, were stored securely in areas with access limited only to the main researchers. Identity codes were used to protect participants' real identity. Data from the interviews were not linked to any type of personal clinical data.

6.4.3 Risks to research participants

Special efforts have been made to identify and minimize any potential emotional or physical risks on individuals as a result of the research. First, some participants felt uncomfortable or even experience emotional breakdown while talking about their experience of being found HIV positive and living with the HIV virus. Under such circumstances, the researcher stopped the interview depending on the wishes of the research participant. Depending upon their wishes, HIV positive participants or participants at high risk of being HIV positive were referred (through provision of information) to appropriate HIV-service organisations and support groups for on-ward psycho-social support. We also acknowledged that disclosure in the context of HIV was a sensitive issue within families and communities given the stigmatising nature of HIV infection. Therefore, research participants were interviewed either within their households or outside their households, depending on their preferences and desire for privacy and confidentiality.

Incentives for Research Participants:

No incentives have been provided to the respondents. However, when participants moved to convenient distant places to be interviewed, they received transport reimbursements.

Chapter 7 - Socio-cultural determinants of access to HIV/AIDS care

Access to HIV/AIDS care: a systematic review of socio-cultural determinants in low and high income countries

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Access to HIV/AIDS care: a systematic review of socio-cultural determinants in low and high income countries

7.1 Abstract

Background: The role of socio-cultural factors in influencing access to HIV/AIDS treatment, care and support is increasingly recognized by researchers, international donors and policy makers. Although many of them have been identified through qualitative studies, the evidence gathered by quantitative studies has not been systematically analysed. To fill this knowledge gap, we did a systematic review of quantitative studies comparing surveys done in high and low income countries to assess the extent to which socio-cultural determinants of access, identified through qualitative studies, have been addressed in epidemiological survey studies.

Methods: Ten electronic databases were searched (Cinahl, EMBASE, ISI Web of Science, IBSS, JSTOR, MedLine, Psycinfo, Psycindex and Cochrane). Two independent reviewers selected eligible publications based on the inclusion/exclusion criteria. Meta-analysis was used to synthesize data comparing studies between low and high income countries.

Results: Thirty-four studies were included in the final review, 21 (62%) done in high income countries and 13 (38%) in low income countries. In low income settings, epidemiological research on access to HIV/AIDS services focused on socio-economic and health system factors while in high income countries the focus was on medical and psychosocial factors. These differences depict the perceived different barriers in the two regions. Common factors between the two regions were also found to affect HIV testing, including stigma, high risk sexual

behaviours such as multiple sexual partners and not using condoms, and alcohol abuse. On the other hand, having experienced previous illness or other health conditions and good family communication was associated with adherence to ART uptake. Due to insufficient consistent data, a meta-analysis was only possible on adherence to treatment.

Conclusions: This review offers evidence of the current challenges for interdisciplinary work in epidemiology and public health. Quantitative studies did not systematically address in their surveys important factors identified in qualitative studies as playing a critical role on the access to HIV/AIDS services. The evidences suggest that the problem lies in the exclusion of the qualitative information during the questionnaire design. With the changing face of the epidemic, we need a new and improved research strategy that integrates the results of qualitative studies into quantitative surveys.

Keywords: Socio-cultural barriers; Access; Adherence; HIV/AIDS; Antiretroviral therapy; survey study; Systematic review.

7.2 Background

Socio-cultural diversity needs to be considered during the design of HIV/AIDS policies and programmes. Social attitudes and prejudices towards people living with HIV/AIDS, sexual taboos and gender inequality are some of the most important challenges for prevention and treatment of HIV/AIDS [1-6]. Despite an improved performance of health and community services, people living with HIV/AIDS continue to face persistent, deeply rooted, social and cultural barriers. International donors, public health experts, programme planners and policy makers need to begin to recognize the need to take into account this socio-cultural diversity in program planning. Hence it is essential to gather the scientific evidence generated so far on this topic. Much of this evidence has been generated from qualitative studies. The most important and frequently reported socio-cultural barriers in both low income and high income countries include fear of disclosure, anticipation of stigma, limited social support, interpersonal violence and alcohol abuse [2-7]. To better understand the distribution, frequency, and potential impact that these factors may have on the population, quantitative epidemiological surveys should ideally incorporate similar questions. It is currently unclear to what extent socio-cultural determinants of access, identified by qualitative studies, are addressed in survey studies. To our knowledge there is no systematic review of epidemiological literature available to clarify this question. Therefore, this article seeks to answer three questions: What socio-cultural factors have been measured in epidemiologic studies to assess access to HIV/AIDS services? What are the differences between factors measured in low and high income countries? And what are the associations and effect sizes of these factors?

7.3 Methods

A systematic search of quantitative studies addressing factors that influence access to HIV testing, uptake of antiretroviral therapy (ART) and adherence to antiretroviral (ARV) regimens was performed. In order to determine the differences between the factors studied in low and high income and test whether these differences were consistent with the findings of qualitative studies for each context we scrutinized studies from low and low-middle income countries and from upper-middle and high-income countries as defined by the World Bank Classification [8].

To facilitate the comparative analysis and the description of the results the countries belonging to these four income groups were reclassified into two broader categories: low and high income countries. The category low-income countries included low income countries and low-middle income countries and the high-income category included upper-middle and high-income countries.

Search Strategy

The search was restricted to studies with sample population over 18 years old and in English, French, German, Spanish, Portuguese and Italian. No other limitations were applied. The systematic search lasted one day with date 07th October 2011. The search terms were: ‘HIV OR AIDS’, ‘voluntary counselling and testing’ ‘HAART OR antiretroviral*’, ‘compliance OR adherence’, ‘factors OR determinant* OR barriers’ and ‘motivat* OR facilitat*’. The search included Cinahl, EMBASE, CSA databases, IBSS, ISI Web of Science, JSTOR, MedLine, Psycinfo and Psycindex and the Cochrane Database of Systematic Reviews. Conference abstracts from the International AIDS Society conferences web site

were also searched. We complemented the search by reviewing the bibliographies of key papers. The detailed search strategy is available upon request.

Inclusion and Exclusion Criteria

To be eligible, articles needed to: report an original research study; measure one of these three outcomes: HIV testing, initiation of ART and adherence to antiretroviral therapy; study associations (of one of the three outcomes) with socio-cultural factors; target adult participants over 18 years old; apply a survey methodology for data collection; estimate risk effects as an outcome; and control for confounding in the analysis. Studies that reported socio-demographic or socio-economic factors but not any of the other categories of socio-cultural variables were excluded.

Study Selection and quality appraisal

The study selection followed a four-step process: title review; abstract review; full text review and quality appraisal. First, two of the authors independently reviewed all identified study titles. Duplicates and titles that did not meet the inclusion criteria were removed. The same authors then independently assessed the abstracts, and then the full papers of those abstracts that met the eligibility criteria. Finally, a quality appraisal was done on all full texts using consolidated criteria of the STROBE guidelines [9]. STROBE is a checklist of 22 items that must be addressed in the report of observational studies. This list is not really a tool to assess the quality of observational research but provides valuable guidance on the quality of reporting the studies.

In addition, a modified version of the Newcastle–Ottawa Scale (NOS) for observational studies (e.g. cross-sectional and cohort studies) was used to assess the methodological quality [10]. NOS is a tool to assess the quality of non randomized studies to be used in a systematic review. Each study is judged with a 'star system' on three points: the selection of the study groups, the comparability of the groups, and the ascertainment of the exposure or outcome. In our review, only studies in which five of nine items on the NOS were deemed satisfactory and in which appropriate statistical analysis (e.g. multivariate controlling for confounders) was conducted were considered to be of high methodological quality (maximum score of 9). At each stage of the quality assessment the reviewers discussed together until a consensus on which studies to include was reached. Finally, the reviewers manually searched the reference lists of the included articles for further key studies that could potentially be included in the analysis.

Data Extraction and classification

The following data was extracted and summarized in evidence tables: citation; year of publication; country; study design and sampling; characteristics of the study population; community versus facility based; sample; outcomes (HIV testing, uptake of ART, adherence and dropout); and factors that facilitated and/or hindered access to HIV care such as: socio-demographic; socioeconomic; medical; health system; knowledge and beliefs; risky health behaviours; psychosocial; stigma and discrimination; family and interpersonal violence; communication about HIV/AIDS; community prevalence. An overview of data extraction is provided in Table 7.1 and 7.2.

Table 7.1 Characteristics of the study

Source	Year	Country	Design	Population	Setting	N	Outcome
Aloisis	2002	Italy	Longitudinal	HIV + adults	Clinic	366	Adherence
Bardford	2005	Denmark	Cross sectional	HIV + adults	Clinic	887	Adherence
Boyer	2011	Cameroon	Cross sectional	HIV + adults	Clinic	2,381	Adherence
Carlucci	2008	Zambia	Cross sectional	HIV + adults	clinic	424	Adherence
Charurat	2010	Nigeria	Longitudinal	HIV + adults	Clinic	4,529	Adherence
Cunningham	1999	USA	Longitudinal	HIV + adults	Clinic	2,864	Initiation
de Castilho	2006	Brazil	Longitudinal	HIV + adults	Clinic	498	Adherence
Franke	2011	Peru	Longitudinal	HIV + adults	Clinic	132	Adherence
Gebo	2003	USA	Cross sectional	HIV + adults	Clinic	196	Adherence
Giday	2010	Ethiopia	Cross sectional	HIV + adults	Clinic	510	Adherence
Grierson	2011	Australia	Cross sectional	HIV + adults	Clinic	1,106	Adherence
Holmes	2007	USA	Longitudinal	HIV + adults	Clinic	116	Adherence
Karcher	2007	Kenya	Longitudinal	HIV + adults	Clinic	159	Initiation
Koku	2011	Ghana	Cross sectional	Female 15-49	Community	3,766	HIV testing
Kranzer	2010	South Africa	Longitudinal	HIV + adults	Clinic	1,154	Defaulting
Kranzer_b	2008	Malawi	Cross sectional	People 18-59	Community	2,047	HIV testing
Li	2010	Thailand	Cross sectional	HIV + adults	Clinic	386	Adherence
MacPhail	2009	South Africa	Cross sectional	People 15-24	Community	7,655	HIV testing
Martinez	2008	Uganda	Cross sectional	HIV + adults	Clinic	421	Initiation
Mugavero	2006	USA	Cross sectional	HIV + adults	Clinic	611	Adherence
Nam	2010	Vietnam	Cross sectional	HIV + adults	Clinic	353	Initiation
Okonsy	2011	USA	Cross sectional	HIV + adults	Clinic	558	Adherence
Peltzer	2011	South Africa	Cross sectional	HIV + adults	Clinic	735	Adherence
Pettifor	2010	South Africa	Cross sectional	People over 15 years old	Community	198	HIV testing
Pinheiro	2002	Brazil	Cross sectional	HIV + adults	Clinic	195	Adherence
Remien	2007	Brazil	Cross sectional	HIV + adults	Clinic	200	Adherence
Rintamaki	2006	USA	Cross sectional	HIV + adults	Clinic	204	Adherence
Sambisa	2010	Zimbabwe	Cross sectional	People over 15 years old	Community	12,254	HIV testing
Sarna	2008	India	Cross sectional	HIV + adults	Clinic	310	Adherence
Sayles	2006	USA	Longitudinal	HIV + adults	Clinic	1,910	Adherence
Sayles	2009	USA	Cross sectional	HIV + adults	Clinic	202	Adherence
Van Servellen	2005	USA	Cross sectional	HIV + adults	Clinic	85	Adherence
Wang	2007	China	Cross sectional	HIV + adults	Clinic	181	Adherence
Watt	2009	Tanzania	Cross sectional	HIV + adults	Clinic	340	Adherence

The data was extracted and reviewed in duplicate from identified studies. Common indicators were grouped into bigger categories (factors) in duplicate by independent reviewers. Disagreements in the categorization of the factors were discussed until consensus was reached. Countries of the study were classified as high or low income countries as defined by the World Bank [8]. Odds ratio (OR) or similar estimates (e.g. relative risk, hazard ratio) and their respective confidence intervals for every unique risk estimate involving a specific indicator

and the uptake of testing, initiating ART and adhering to ART were extracted when available.

Table 7.2 Outline of the factors identified per study

Country group	Source	Clinical	Disclosure	Location	Violence	Risk behaviour	Health system	Health Beliefs	Psychosocial	Social support	SES	Stigma
Low and low middle income countries	Boyer	x	.	.	.	x	x	.	.	x	x	x
	Carlucci	x	x	x
	Charurat	x	x	.	.	.	x	.	.	.	x	.
	Franke	x	.	.	.	x	.	.	x	x	x	x
	Giday	x	.	.	.	x	.	.	.	x	x	.
	Karcher	x
	Koku	x	.	x	x	.	x	x
	Martinez	x	.	.	.	x	.	.	x	.	.	.
	Nam	x	x	.	.	x	x	.	.	x	x	.
	Sarna	x	x	.	x	.	x	.
	Watt	x	.	x	.	.	.
	Kranzer_b	.	.	x	x	.
	Sambisa	x	.	x	.	.	x	x
	Aloisis	x	.	.	.	x
	Bardford	x	.	.	.	x	x	.	x	x	.	.
	Cunningham	x	.	x	.
	High and upper middle income countries	De Castilho	x	.	.	.	x	.	.	x	.	.
Gebo		x	.	x	.	x	x	.
Grierson		x	.	.	.	x	x	x	x	.	.	x
Holmes		x	x	.
Kranzer		x
Li		x	x	.	.	.	x	.	x	x	x	x
Mugavero		x	.	.	x	.	x	.
Okonsy		x	x	.	.
Peltzer		x	.	.	.	x	.	.	x	x	x	x
Pettifor		x	x	.	.	.	x	x	.	.	.	x
Pinheiro		x	x	.
Remien		x	x	.	.	.
Rintamaki		x	x
Sayles_a		x	.	.	x
Sayles_b		x	.	.	x	x	.	.	x	.	x	.
Vanservellen		x	x	x	x	x	.	.
Wang		x	x
Mc Phail	x	x	.	.	x	.	x	x

Statistical analysis

Descriptive statistics were used to examine patterns across countries with respect to: proportion (%) of factors studied in relation to access to HIV/AIDS care, estimated effect sizes (adjusted odd ratios) identified (protective *vs* risk) for each factor and the precision around the estimates (95% confidence intervals). Additionally meta-analysis was done for nine specific socio-cultural factors identified by the studies as statistically significantly associated with adherence to antiretroviral therapy. Despite the expected heterogeneity within the review (great variability of the measures used to study socio-cultural factors) we assessed the comparability of the results from individual studies using the I^2 statistic for quantifying inconsistency. An overall I^2 test-value greater than 60% was considered as indicative of a high level of heterogeneity for which statistical pooling was not appropriate. Further analyses included sensitivity analysis performed by removing the studies that contributed to the heterogeneity in the meta-analysis and subgroup analyses to compare high-income countries with low-income countries. A p-value of less than 0.05 was considered statistically significant. Analyses were performed in STATA 12.1.

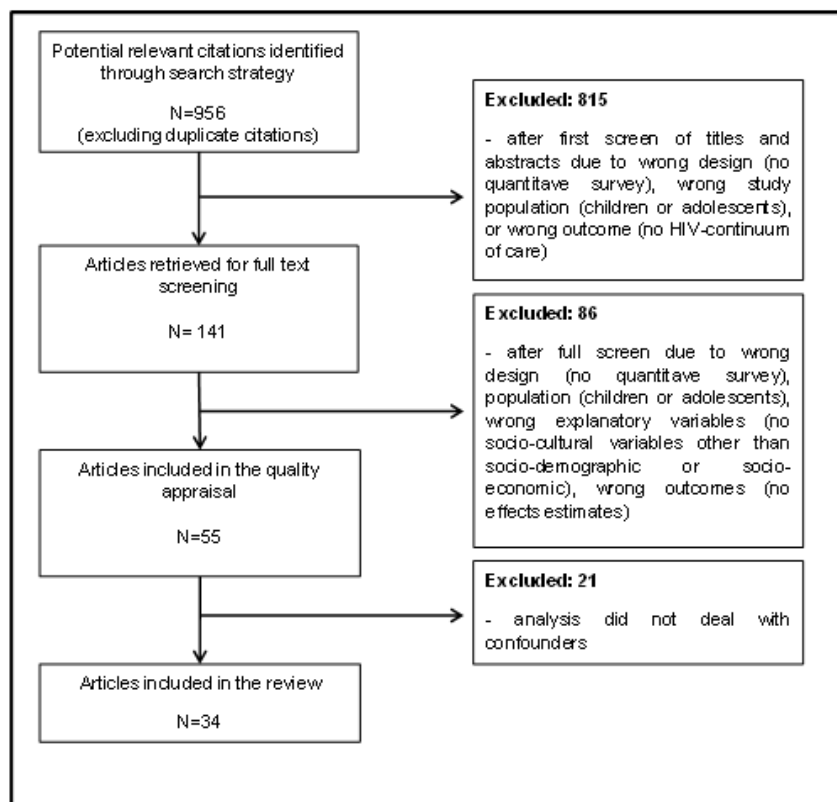
7.4 Results

Study selection

The primary search strategy identified 1,671 potentially relevant citations. After searching for duplicates 715 citations were discarded. Initial title and abstract screening excluded 815 manuscripts based on the inclusion - exclusion criteria. The remaining 141 were then retrieved for full text review. A further 86 manuscripts were excluded as not meeting the inclusion criteria. The remaining 55 manuscripts were quality appraised and 21 were excluded as they did not deal

with confounding in their analysis. Thirty-four articles were included in our analysis. Figure 7.1 displays the flow chart of the selection process.

Figure 7.1 Flow chart describing the process for the systematic review



Study characteristics

All 34 included studies employed a quantitative methodology (surveys) and used structured questionnaires to determine potential factors. 13 studies (38%) were conducted in low income countries [11-23] and 21 (62%) in high income countries [24-44]. The studies conducted in low income countries included one from Cameroon [11], Zambia [12], Nigeria [13], Peru [14], Ethiopia [15], Kenya [16], Ghana [17], Uganda [18], Vietnam [19], India [20], Tanzania [21], Zimbabwe [22] and Malawi [23]. From high income countries, nine studies were from USA [26, 28, 30, 33-34, 39-42], four from South Africa [31, 35-36, 44], three

from Brazil [27, 37-38] and one each from Italy [24], Denmark [25], Australia [29], Thailand [32] and China[43].

29 studies (85%) were clinic based [11-16, 18-21, 24-35, 37-40, 42] and five (15%) were situated at community level [17, 22-23, 36, 44]. Twenty-four studies (70%) focused on adherence to ART [11-15, 20-21, 24-25, 27-30, 26-29, 32-39, 41-43], five studies (15%) focused on uptake of voluntary and counselling testing (VCT) [17, 22-23, 36, 44], four (11%) on ART initiation [16, 18-19, 26] and one (3%) on attrition [31]. Table 7.1 displays the characteristics of the studies.

Factors measured by quantitative surveys to study access to HIV/AIDS-care in high- and low-income countries

12 factors were identified as measured by the studies to assess access to HIV care: (i) socio-demographic, (ii) socioeconomic, (iii) medical, (iv) health system, (v) knowledge and beliefs, (vi) risky health behaviours, (vii) psychosocial, (viii) stigma and discrimination, (ix) family (x) interpersonal violence, (xi) communication about HIV/AIDS and (xii) community prevalence. Table 7.2 shows an outline of the factors identified per study.

Comparative analysis showed important divergences across countries. Surveys in low income countries tended to focus on the study of socio-demographic, socio-economic and health system factors in relation to access to HIV/AIDS services [24-25, 27, 29, 31-32, 34-40, 42-44] while in high income countries the emphasis was on medical and psychosocial conditions [25-27, 29, 32-33, 35, 38, 40-42]. Figure 7.2 graphically displays the distribution of factors by country. Socio-demographic, economic, clinical and sexual behavioural factors were considerably measured in all surveys conducted in low and high income countries while

interpersonal relationships, communication and interpersonal violence factors remained highly understudied in both low and high economic countries.

Figure 7.2 Proportion of factors (%) in studies carried out in high vs. low income countries

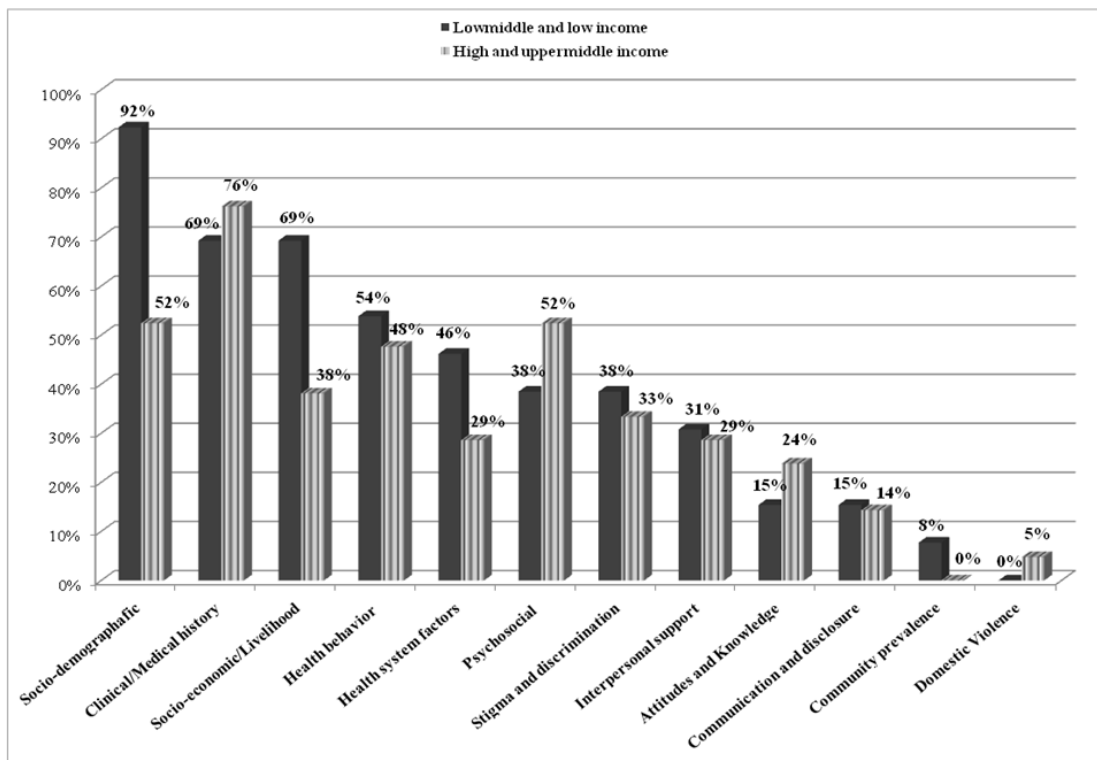


Table 7.3 displays the ranking of factors by the proportion of studies where they were included.

Table 7.3 Ranking of proportion (%) of factors studied in low and high income countries

Low income countries			High income countries		
Rank		%	Rank		%
1	Socio-demographic factors	92%	1	Clinical factors	76%
2	Clinical factors	69%	2	Socio-demographic factors	52%
3	Socio-economic factors	69%	3	Psychosocial factors	52%
4	Health behavior factors	54%	4	Health behavior factors	48%
5	Health system factors	46%	5	Socio-economic factors	38%
6	Psychosocial factors	38%	6	Stigma and discrimination	33%
7	Stigma and discrimination	38%	7	Health system factors	29%
8	Social and family support	31%	8	Social and family support	29%
9	Knowledge and beliefs	15%	9	Knowledge and beliefs	24%
10	Communication and disclosure	15%	10	Communication and disclosure	14%
11	Community characteristics	8%	11	Domestic Violence	5%
12	Domestic Violence	0%	12	Community characteristics	0%

Reported risk factors significantly associated with access to HIV/AIDS services across countries

Non-uptake of HIV testing in high income countries was associated with socio-demographic constructs such as being black [44], being between 25 to 34 years old, and living in a community with high HIV testing refusal rates [23]. Other barriers included high risk sexual behaviours [36] such as multiple sexual partners and not using condoms and enacted stigma [39]. In low income countries, the barriers associated to HIV testing included belonging to the age group from 25 to over 45 [17, 22], having unprotected sex and having sex with a non-spousal or non-cohabiting partner [17] and anticipated stigma [17, 22].

Non-uptake of ART in high income countries was only statistically significantly associated with having other competing subsistence needs [26]. In low income countries, the barriers to initiate ART included indirect costs of health care, not

having a known HIV-positive family member, non-disclosure of HIV status and having additional pregnancies [11, 19-20].

In high income countries, **low adherence to ART** was associated with being black [41, 44], being between 25-34 years old [27, 41] and having less than primary education [27]. Other barriers were clinical and treatment factors such as protease inhibitor ART regimens [34], frequent doses of ART [29, 37], experience of side effects [34, 38], feeling unhappy with the treatment [25], initiating the treatment with a CD4 count over 200 Cells/mL³ [31]. Alcohol and/or substance abuse [24, 27-29, 33] and anticipated and internalized stigma were associated with low levels of adherence [29, 33, 35, 39].

In low income countries, age groups associated with low adherence to ART were 19-30 years and over 50 years [21]. The latter deviate from the risk age reported from high income countries where being over 50 was found to be protective. Other risk factors included having a main couple but not living together [11], being Muslim [13], being female [14], food insufficiency [14] and household financial problems [11, 15]. Alcohol abuse and experienced discrimination were associated with low adherence also in low income countries [11]. With respect to clinical and treatment factors in low income countries initiation of ART with CD4 over 200 cells/ml³, being on ART less than 15 months [13, 15] and having switched ART regimen [11] were associated with low adherence. Health system barriers included ARV stock outs, inadequate communication with health staff [11, 13, 21] and health care indirect costs [11, 19-20]. One study reported an inverse association between free cost of ARV and adherence [20]. Concerning interpersonal and psychosocial factors, perceived lack of family support [11], not

having disclosed to the family members [19] and feeling depressed [20] were negatively associated with adherence.

Reported protective factors significantly associated with access to HIV/AIDS services across countries

In high income countries, protective factors for **uptake of HIV testing** were being female [36, 44], having a history of previous illnesses [31, 34, 41, 44], having disclosed and/or having conversations about HIV/AIDS with parents [44] and believe that most people do not want to get tested for HIV or do it only if they are sick [36, 44]. In low income countries, being educated beyond primary school [17], single [22], affiliated to non Christian religions [17], living in a high prevalence community [22], knowing someone infected with HIV/AIDS [22], practicing safer sexual behaviours such as using condoms and being exposed to media [17, 22] were positively associated with uptake of testing.

In low income countries, belonging to the age group 30 to 40 years of age and having greater than a primary school education facilitated **initiation of ART** [18]. Not drinking alcohol in the past year was also a protective factor [22]. No protective effects were reported from high income countries.

In high income countries, being older than 50 years of age [29] and on ART treatment for more than two years were positively associated with **adherence to ART** [35]. Previous illnesses or having other health conditions were positively associated with good adherence [31, 34, 41, 44]. Self-perception of good health status [35, 38] and no consumption of alcohol in the past year [30] were also

protective. Good family communication [32, 42], higher levels of treatment information [35] and believing in the benefits of ARVs [28] were facilitators of adherence. In low income countries, good social support and self-efficacy were positively associated with adherence as well as having disclosed to at least one family member about one's positive HIV status [13-14]. Experiencing other health conditions was also associated with a protective effect on adherence [31, 35, 41, 44].

No studies reported significant risk effects for defaulting.

Combined effect sizes associated with adherence.

The pool estimates of the 34 studies which included socio-cultural factors are shown for a) general socio-demographic factors, and b) specific socio-cultural factors. Due to an insufficient number of studies for other outcomes, only adherence could be included in the model.

The meta-analysis showed that being male was associated with optimal adherence in low income countries (OR= 0.16, 95%CI= 0.04-0.66) while the association with being female was not statistically significant. Conversely, in high income countries low adherence was associated with females (OR= 1.29, 95%CI: 1.06-1.58) while the association with male was not statistically significant. Being single (OR= 2.72, 95%CI= 1.58-4.69), and younger than 30 (OR= 1.04, 95%CI= 1.01-1.07) was significantly associated with lower adherence in low income countries. Being older than 50 years of age was associated with optimal adherence (OR= 0.80, 95%CI= 0.59-1.07) and was statistically significant in both settings; having no education was significantly associated with suboptimal adherence (OR= 1.76, 95%CI= 1.18-2.60) in both settings.

Table 7.4 Meta-estimates: effect of socio-demographic factors on adherence to ART

Socio-demographic	Pool ES	CI 95%	p value*	Pool studies	I ²
Male	0.77	0.48-1.24	0.28	7	61.3%
High income countries	0.94	0.57-1.55	0.81	4	54.6%
Low income countries	0.16	0.04-0.66	0.01	3	0.0%
Female	1.05	0.97-1.13	0.27	7	49.1%
High income countries	1.29	1.06-1.58	0.01	4	34.6%
Low income countries	0.99	0.91-1.08	0.85	3	0.0%
Married	1.10	0.85-1.42	0.46	2	0.0%
High income countries	1.10	0.84-1.45	0.49	1	-
Low income countries	1.10	0.56-2.16	0.78	1	-
Single	2.49	1.51-4.12	0.000	3	0.0%
High income countries	1.53	0.42-5.56	0.52	1	-
Low income countries	2.72	1.58-4.69	0.00	2	-
Separated/divorced	-	-	-	-	-
High income countries	-	-	-	-	-
Low income countries	1.07	0.42-2.73	0.89	2	0.0%
Age less than 20	1.14	0.96-1.37	0.14	2	60.1%
High income countries	0.47	0.96-1.37	0.13	1	-
Low income countries	1.18	0.98-1.42	0.08	1	-
Age less than 30	1.04	1.01-1.07	0.01	2	0.0%
High income countries	-	-	-	-	-
Low income countries	1.04	1.01-1.07	0.01	2	0.0%
Age 20-30	1.38	1.21-1.58	-	5	60.2%
High income countries	1.30	0.86-1.94	0.21	3	20.2%
Low income countries	1.39	1.21-1.60	-	2	74.0%
Age 30-50	1.08	0.97-1.19	0.16	6	0.0%
High income countries	1.06	0.77-1.46	0.72	4	0.2%
Low income countries	1.08	0.97-1.20	0.17	2	0.0%
Age over 50 years	0.80	0.59-1.08	0.14	5	59.4%
High income countries	0.55	0.41-0.75	0.00	4	0.0%
Low income countries	6.68	3.15-14.15	0.00	1	-
No education	1.76	1.19-2.60	0.01	3	0.0%
High income countries	1.69	0.82-3.48	0.16	1	-
Low income countries	1.78	1.12-2.85	0.02	2	0.0%
Primary education	0.98	0.85-1.13	0.80	4	9.3%
High income countries	0.99	0.86-1.15	0.91	3	0.0%
Low income countries	0.30	0.06-1.49	0.14	1	-
Secondary education	1.04	0.95-1.14	0.43	10	60.4%
High income countries	1.03	0.95-1.28	0.75	6	73.7%
Low income countries	1.04	0.94-1.15	0.47	4	19.8%

Tertiary education	0.85	0.58-1.24	0.39	3	60.9%
High income countries	0.69	0.45-1.07	0.10	2	44.8%
Low income countries	1.56	0.73-3.34	0.25	1	-
Socio-cultural	Pool ES	CI 95%	p value*	Pool studies	I2
Low self-efficacy	1.025	0.57-1.85	0.94	3	63.1%
High income countries	2.13	1.03-4.41	0.01	2	0.0%
Low income countries	1.75	1.91-1.31	0.04	1	-
Lack of social support			0.02	2	0.0%
High income countries	1.04	1.01-1.08	0.02	2	0.0%
Low income countries	-	-	-	-	-
No depression	0.89	0.83-0.96	0.00	2	0.0%
High income countries	0.92	0.82-1.04	0.17	1	-
Low income countries	0.88	0.80-0.96	0.01	1	-
Stigma	2.17	1.52-3.09	0.00	2	62.1%
High income countries	3.70	1.92-7.42	0.00	1	-
Low income countries	1.74	1.14-2.65	0.01	1	-
Abuse of alcohol	1.75	1.41-2.18	0.00	6	59.8%
High income countries	1.43	1.09-1.86	0.01	4	24.0%
Low income countries	2.72	1.84-1.69	0.00	2	32.7%
Abuse of drugs	1.86	1.48-2.33	0.01	9	1.1%
High income countries	1.89	1.49-2.41	0.00	6	23.2%
Low income countries	1.58	0.78-3.22	0.21	3	0.0%

Socio-cultural factors associated with lower adherence included perceived lack of social support although sufficient data were available only in high income countries (OR= 1.04, 95%CI: 1.01-1.07). Perceived social stigma had an overall risk factor (OR= 2.17, 95%CI= 1.52-3.09) in both settings. High risk health behaviours such as alcohol abuse (OR= 1.75, 95%CI= 1.41-2.18) and abuse drugs (OR= 1.86, 95%CI= 1.48-2.33) were also significant in both settings, while low levels of self-efficacy were negatively associated with adherence in both settings. This effect was stronger in high income countries (OR=2.13 95%CI=1.03-4.41) than in low income countries (OR= 1.75 95%CI=1.91-1.31). Absence of symptoms of depression was positively associated with optimal adherence in both settings (OR= 0.89, 95%CI= 0.83-0.96). Tables 7.4 and 7.5 summarize the meta estimates of the socio-demographic and socio-cultural factors respectively.

Table 7.5 Meta-estimates: effect of socio-cultural factors on adherence to ART

Socio-cultural	Pool ES	CI 95%	p value*	Pool studies	I ²
Low self-efficacy	1.025	0.57-1.85	0.94	3	63.1%
High income countries	2.13	1.03-4.41	0.01	2	0.0%
Low income countries	1.75	1.91-1.31	0.04	1	-
Lack of social support			0.02	2	0.0%
High income countries	1.04	1.01-1.08	0.02	2	0.0%
Low income countries	-	-	-	-	-
No depression	0.89	0.83-0.96	0.00	2	0.0%
High income countries	0.92	0.82-1.04	0.17	1	-
Low income countries	0.88	0.80-0.96	0.01	1	-
Stigma	2.17	1.52-3.09	0.00	2	62.1%
High income countries	3.70	1.92-7.42	0.00	1	-
Low income countries	1.74	1.14-2.65	0.01	1	-
Abuse of alcohol	1.75	1.41-2.18	0.00	6	59.8%
High income countries	1.43	1.09-1.86	0.01	4	24.0%
Low income countries	2.72	1.84-1.69	0.00	2	32.7%
Abuse of drugs	1.86	1.48-2.33	0.01	9	1.1%
High income countries	1.89	1.49-2.41	0.00	6	23.2%
Low income countries	1.58	0.78-3.22	0.21	3	0.0%

7.5 Discussion

This review revealed a trend in quantitative survey studies to explore the same kinds of factors in relation to access to HIV/AIDS services. Overall the most studied factors in all regions, including Africa, Asia, Latin America and some groups and communities in North America, were socio-economic, medical and health risk behaviour. In low-income countries the research focus was on socio-economic and health system factors while in high-income more attention was given to clinical and psychosocial factors such as depression, anxiety, self-efficacy and/or sexual identity. Socio-cultural factors including social and family support, interpersonal violence, and disclosure about HIV/AIDS received, in comparison, very little attention in both rich and poor countries.

These results should call the attention of survey researchers and systematic reviewers. The aforementioned socio-cultural factors have been widely published in qualitative studies [2-6] as critical factors that influence access to HIV/AIDS services, both in high and in low income countries. However most of the quantitative studies included in our review, from both high and low income countries, omitted them in their surveys or explored them very superficially. This is not justified as these factors are key issues for survey research. Our results suggest that the problem lied in the exclusion of qualitative information in the questionnaire design. Of the 34 studies included in this review, 27 [12-18,20,22-24,27-28,30-36,38-44] used validated measures from previous quantitative studies to derive their questionnaires and only seven studies, three, in low income countries [11,19,21] and four in high income countries [25-26,29,37], conducted an informative phase, using qualitative methods, to inform the questionnaire development.

The exclusion of qualitative information during the questionnaire design in the rest of the studies could have led to over-emphasis in the research of the same kind of easily measured variables.

This compromises the interpretation and generalization of the evidence and its application to inform health policies and programs. Indeed, this review showed that according to the quantitative evidence the factors studied to assess the barriers to access HIV/AIDS services inexplicably differ between richer and poorer countries contrary to the evidence from qualitative studies.

Additionally, due to an insufficient number of consistent studies for other outcomes, only adherence outcomes could be meta-analysed. The meta-analysis of the other outcomes proved untenable as the wide range of instruments and

indicators used to assess socio-cultural variables such as social support, stigma, depression, and self-efficacy, introduced too much heterogeneity in the studies and impeded the pooling and synthesis of the results. Table 7.6 shows the variability of the instruments used to assess the same indicator. Risk factors of low-adherence, in both rich and poor countries, were stigma and discrimination, alcohol and drug abuse, depression and low self-efficacy. Social support was the only factor that showed a protective effect. Yet, it is unclear whether this effect occurred equally in rich and poor countries as enough data were available only from high income countries. The comparative approach between high and low income countries of this systematic review and meta-analysis has several advantages over pooling all countries included in the review. This comparative nature yielded valuable information about the differences and similarities of social and cultural processes that affect access to treatment in each context. The comparison also reveals a potential bias in the factors studied in the different regions that may be motivated by cultural stereotypes and has also facilitated the detection of trends and the identification of gaps in the surveys conducted which otherwise would have remained in the shadows. Thus this comparative approach has helped to produce a more detailed description of these gaps which can be beneficial for the preparation of future surveys in this field.

Table 7.6 Overview of measurement tools used to evaluate same socio-cultural constructs in different studies

Source	Year	Country	Outcome	Measurement instrument
Family support				
Boyer	2011	LIC	Adherence	Self-reported
Bardford	2005	HIC	Non adherence	Self-reported
Li	2010	HIC	Adherence	Adapted from FAD
Social support				
Vanservellen	2005	HIC	Adherence	MOS scale

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Li	2010	HIC	Adherence	Adapted from MOS Scale
Franke	2011	LIC	Adherence	Duke-UNC Functional Social Support Questionnaire
Peltzer	2010	HIC	Adherence	Adapted Social Support Questionnaire
Okonsy	2011	HIC	Adherence	Rates social support 1 to 10
Giday	2010	LIC	Adherence	Own questions
Self-efficacy				
Franke	2011	LIC	Adherence	ACTG
Remien	2007	HIC	Adherence	ACTG
Vanservellen	2005	HIC	Adherence	ACTG
Watt	2009	LIC	Adherence	10 item scale adapted
Depression				
Martinez	2008	LIC	Initiation ART	Hopkins Symptoms Checklist
Franke	2011	LIC	Adherence	Hopkins Symptoms Checklist
Peltzer	2010	HIC	Adherence	CES-D
Vanservellen	2005	HIC	Adherence	CES-D
Mugavero	2006	HIC	Adherence	BSI
Sarna	2008	LIC	Adherence	BDI
Bardford	2005	HIC	Non adherence	ACTG
Li	2010	HIC	Adherence	Thai Department of Mental Health
Patient-provider relationship				
Bardford	2005	HIC	Non adherence	Self-reported
Vanservellen	2005	HIC	Adherence	Satisfaction survey
Watt	2009	LIC	Adherence	9 item scale adapted from Panpanich 2004
Quality of life				
Franke	2011	LIC	Adherence	Medical Outcomes Study HIV Health Survey
Peltzer	2010	HIC	Adherence	WHOQOL-HIVBREF
Stigma				
Rintamaki	2006	HIC	Adherence	3 items from PMAQ
Franke	2011	LIC	Adherence	Berger Scale
Carlucci	2011	LIC	Adherence	Own scale
Pettifor	2004	HIC	HIV testing	Genberg scale
Li	2010	HIC	Adherence	Adapted from Herek and Capitanio
Sayles_a	2009	HIC	Adherence	Own scale
Koku	2011	LIC	HIV testing	2003-GDHS
Discrimination				
Boyer	2011	LIC	Adherence	Self reported
Grierson	2011	HIC	Adherence	Self reported
Peltzer	2010	HIC	Adherence	Own 7it scale_ yes/no
Pettifor	2004	HIC	HIV testing	Genberg scale

There are several limitations to our study. Publication bias may be limiting our systematic review of quantitative studies. Another limitation is the difference between the timing of the preparation of the surveys and the one of the publications of qualitative studies. We would not expect a survey published in the early 90s to be aware of the problems identified in qualitative studies published

later. But our analysis indicates that in general the quantitative studies have not systematically addressed important issues identified in qualitative studies that were published at least two years before the implementation of their surveys.

7.6 Conclusions

This review has highlighted a number of issues requiring further research and demonstrated the need to improve the research strategy in epidemiological survey studies. Improvement of this strategy requires better integration of the findings of qualitative studies in quantitative surveys and more consistency between survey studies. This review also offered evidence of the lack of consistency in the measurement of socio-cultural factors which hinders comparisons between studies.

We recommend that, prior to developing a questionnaire, literature reviews should be systematically carried out including qualitative studies. This would help to identify appropriate themes for the context avoiding the tendency to focus on the same topics.

We further recommend using validated instruments giving priority to cultural adaptations over the development of new measures. We also call for a generalization of some variables without limiting the specificity of the various contexts. For example, it would be useful to report the effects of different types of stigma, as defined by subscales of validated tools, rather than global scores which cannot be disentangled and are less informative. Another example is the social support measure which could also be broken down by subtypes, material, emotional, etc.

Further quantitative research is needed on socio-cultural determinants of HIV testing, initiation of antiretroviral therapy and defaulting in both low- and high-income countries. More consistency between qualitative and quantitative research and between quantitative measures of socio-cultural factors will help to increase the quality of the data collected, to enhance comparability which is a prerequisite for meta-analyses, to avoid duplication and in general to produce better scientific evidence to inform managers and policy-makers working on HIV/AIDS.

Competing interests

The author(s) declare that they have no competing interests

Authors' contributions

Conceived and designed the study: SG, SM, JM, AMH. Performed the systematic searches and abstracted data: SG, CD, TS. Analyzed the data: SG, TS. Wrote the paper: SG, SM, AMH, JM, TS, CD. All authors have read and approved the final manuscript.

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Chapter 8 - HIV testing and tolerance to gender based violence

HIV testing and tolerance to gender based violence: a cross-sectional study in Zambia

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HIV testing and tolerance to gender based violence: a cross-sectional study in Zambia

8.1 Abstract

This paper explores the effect of social relations and gender-based conflicts on the uptake of HIV testing in the South and Central provinces of Zambia. We conducted a community-based cross-sectional study of 1716 randomly selected individuals. Associations were examined using mixed-effect multivariable logistic regression. A total of 264 men (64%) and 268 women (56%) had never tested for HIV. The strongest determinants for not being tested were disruptive couple relationships (OR= 2.48 95% CI=1.00-6.19); tolerance to gender-based violence (OR= 2.10 95% CI=1.05-4.32) and fear of social rejection (OR= 1.48 95% CI=1.23 – 1.80). In the Zambian context, unequal power relationships within the couple and the community seem to play a pivotal role in the decision to test which until now have been largely underestimated. Policies, programs and interventions to rapidly increase HIV testing need to urgently address gender-power inequity in relationships and prevent gender-based violence to reduce the negative impact on the lives of couples and families.

Keywords: Counselling and voluntary HIV testing; Family relationships; Gender based violence; Community gossip; Zambia.

8.2 Introduction

Gender inequity is intimately linked to HIV/AIDS. Without addressing gender inequity AIDS will remain a substantial problem. There is evidence showing that gender-power inequity in relationships and gender-based violence (GBV) increases vulnerability to HIV infection (1-4). In Zambia, the HIV prevalence among young women aged 15-24 is more than twice that of men in the same age category (5-6). A number of factors resulting from gender inequity contribute to this higher prevalence. In Zambia, women have practically no ability to refuse sex or to demand the use of condom, a demonstration of their limited agency in sexual relationships. Age-mixing sexual patterns between young girls and older men also play an important role on their greater susceptibility to HIV. (7)

Recent strategies to improve testing rates in Zambia have included the strengthening of provider-initiated HIV testing and counselling (9), and home-based HIV counselling and testing (HBCT) (10, 11). These strategies however have not yet achieved a sufficient increase in the uptake of testing (12). In 2009 only 23% of the Zambian population voluntarily requested an HIV test and this percentage was slightly higher among women (25%) than men (21%) (12). Although this figure indicates remarkable progress (7% in 2005), the overall testing rate remains low. Common barriers to HIV testing are low levels of education (13-16), accessibility issues (13, 14 17-19), concerns about confidentiality and privacy (9, 10, 10, 21), discrimination from health workers and stigmatizing attitudes towards HIV/AIDS in the community (22-24). Recent studies have shown that fear of being rejected by family or abandoned by one's partner is an important reason why people delay or refuse HIV testing (25). There is evidence showing that a positive HIV diagnosis can lead to a variety of negative

effects such as gender-based violence and loss of social and family support (26, 27).

While most studies on gender inequity and AIDS have focused on examining the relationship between vulnerability to HIV and gender-based violence (27, 28), few have considered the effect on access to HIV care. Some recent studies from Zambia show that women who have suffered gender-based violence often are more likely to choose not to receive treatment because they are afraid of violent behaviour and abandonment by family (29, 30). These studies are based on clinical practice and focused on women who were victims of gender-based violence. There is no published research of large community based studies that examine the relationship between social relationships, tolerance of gender-based violence and HIV testing. We hypothesized that the relational dynamics of one's social relationships; the level of tolerance of gender-based violence and the fear of such abuses determine decisions about HIV testing. This study tested this hypothesis using social cohesion indicators measured at three different socio-relational levels: the couple, the family and the neighbourhood.

8.3 Methods

We conducted a community based cross-sectional study of 1716 randomly selected individuals in South and central provinces of Zambia (Chivuna, Mbeza, Mazabuka and Lusaka). We used three-stage sampling design (Primary sampling units (PSUs)-Households-Individuals) to derive our sample. First, we randomly selected PSU's (chiefdoms or municipalities) in the four study areas from a list of enumeration areas obtained from the last census conducted in Zambia in 2010. We calculated the number of households using a probability proportional to size

(PPS) sampling strategy. Households were randomly selected from household lists with the exception of Lusaka where a random walk scheme was used. In each household our interviewers selected one permanent resident >18 years using the Kish within-household respondent selection method (31). With this method we ensured equiprobability of selection among individuals who fall within the scope of the survey (thus every eligible individual in the household – in our case, all those aged 18 and over – had the same chance of being selected). If the selected individual was not present, an appointment was made. Only if this appointment was missed, a new household was selected. In Lusaka we additionally applied a weighted sampling strategy to build a representative sample of the population living in high, medium and low density areas. A team of 30 experienced Zambian surveyors, who were trained in survey techniques and sexual and reproductive health (SRH) issues, conducted the interviews in the respondents' mother tongue. They obtained signed informed consents from the participants prior to start the interview. Interviews were done between September 2010 and February 2011. Participants who requested it were offered psychosocial counseling by qualified professionals and obtained referral information for local HIV/AIDS voluntary counseling and testing (VCT) services.

The questionnaire included questions on demographic and socioeconomic characteristics, food insecurity, health risk behaviours, social cohesion, anticipated stigma and fear of social rejection and HIV/AIDS-related beliefs. The selection of these themes was guided by the results of an ethnographic study of barriers to HIV treatment conducted in the same areas over the previous year. Additionally we systematically reviewed the literature to identify instruments and

scales used by other studies to measure similar themes. A panel of national and international experts reviewed these instruments and scales and selected pertinent questions and items to measure each theme. When necessary we reformulated and adapted questions and items to the Zambian context. We originally created the questionnaire in English and translated it into Nyanja, Ila and Tonga. It was pilot tested twice before final validation. To ensure the confidentiality of the participants' information we anonymised the questionnaires using numerical codes.

Ethical statement

This study was approved by the EKBB Ethical Committee (Ethik-Kommission beider Basel) and by the Humanities and Social Sciences Research Ethics Committee of the University of Zambia. Clearance was obtained from the Zambian Ministry of Health.

Measures

Socio-demographic questions were adapted from the Zambian Sexual Behavior Survey (32).

Cohesion of social relationships was assessed at three levels. We adapted partner and family relationships items from the Family Assessment Device (FAD) (33). We asked the respondents to score their agreement on eight statements (items) using a five point visual scale that we previously piloted on 50 respondents with similar characteristics. Participants with higher scores were considered to have more social (dis)-cohesion and vice versa. To evaluate whether the eight items formed a one-dimensional homogenous scale we performed

Mokken Scale analysis for polytomous items (34), using the STATA 12.1 command MSP (35). Mokken models belong to the class of statistical models called non-parametric item response theory (NIRT). The crucial aspect of the Mokken scale analysis is its ability to establish hierarchies of items ordered by 'difficulty' (facility) such that any individual who endorses a particular item should endorse one with a lower difficulty. Mokken scales require three basic assumptions: (1) unidimensionality (one latent variable summarizes the variation in the item score in the questionnaire), (2) local independence (item score are statistically independent conditional on the value of the latent trait), and (3) monotonicity (for all items the probability of a positive response increases monotonically with increasing values of the latent trait). Scale homogeneity is based on Loevinger's index of homogeneity H (36). As a rule of thumb Loevinger's coefficient $H < 0.30$ indicates poor scalability properties, for $0.30 < H < 0.40$ the scale is weak; for $0.40 < H < 0.50$ the scale is medium, and for $H > 0.50$ the scale is strong. The reliability of Mokken scales is estimated using Rho which is a test-retest reliability coefficient with $Rho > 0.7$ considered to indicate a reliable scale (37). The items that satisfied the three assumptions of the Mokken analysis can be added up and individual scores are then computed as the rank of the highest endorsed item in this hierarchy, i.e. it is a simple total score (sum of positive responses). This total score is used as an estimate of the level of the latent construct, in our case relationships' cohesion in each subject. Of the initial eight statements Mokken analysis generated three scales. The first one contained four items measuring couple (dis)-cohesion: *In times of crises I cannot turn to my spouse for support; my partner and I do not get along well; I do not trust my partner; I do not feel supported by my spouse/partner* with $H = 0.43$. Reliability as

measured by $Rho = 0.96$. A second scale with two items measuring family (dis)-cohesion: *people in this household only help you if they can get something out of it; people in this household do not get along well* with $H= 0.43$ and $Rho = 0.98$. A third scale was also created with also two items measuring individual perception to the use of domestic violence in their households: *If someone in the household misuses money it is acceptable to beat him/her; In my household if a wife comes home late without the permission of the husband she will be beaten* with $H=0.40$ and $Rho =0.73$. Thus, a family and a couple (dis)-cohesion as well as a perceived tolerance to violence scale score were computed as the averaged sum of valid answers 1 to 5. Neighbourhood (dis)-cohesion was assessed with two items adapted from the work of Sampson et al. (38). A neighbourhood cohesion scaled score with two items was built using the same method: *People in this neighbourhood don't get along well with each other; People around here are not willing to help their neighbours* with $H=0.40$ and $Rho =0.73$.

Perception and beliefs about antiretrovirals (ARVs) and traditional medicine items were adapted from previous validated questionnaires used in similar contexts (39, 40). Three separated scales were defined using MSP. The first included five items on knowledge about ARVs: *ARVs can make me sick; ARVs are not good for children; ARVs can make me impotent; ARVs can kill* ($H= 0.36$, $Rho=0.99$), the second contained four items about traditional medicines: *TM can cure HIV/AIDS; TM are easier to take; TM are easier to access* ($H= 0.53$, $Rho=0.98$); And the third contained two items measuring conspiracy beliefs: *HIV/AIDS was released to eradicate the black race; People who take ARVs are guinea pigs for the government and other*

organizations (H=0.59 and Rho=0.97). Three scaled scores were computed as the averaged sum of valid answers 1 to 5.

Health risk behaviours were measured with two items assessing alcohol use and sexual risk behaviour. Both items were included as individual variables in the regression models.

Stigma and discrimination were conceptualized according to the instrumental-symbolic framework (41- 42). Respondents' experiences of internal and enacted stigma were investigated. Internal stigma integrated indicators of anticipated (expected) and self-stigma (internalized). For this paper only anticipated stigma indicators have been analysed. Self-stigma and enacted stigma are necessarily linked to a positive test result thus they are outside of the scope of this work. Anticipated stigma was measured using 4 items collected from previous validated scales (43, 44) and adapted to the *Zambian context: People with HIV fully participate in the social events in this community; People infected with HIV loose respect in this community; HIV positive children are bullied by other children in this community; People here believe that children should not play with infected children.* Response categories ranged from 1 (strongly disagree) to 5 (strongly agree). Using MSP command a scale with the three last items was defined (H=0.41 and Rho=0.97). A scaled score was computed as the averaged sum of valid answers, 1 to 5.

Fear of social rejection items were adapted from previously validated questionnaires used in similar contexts (39, 40). Two scales were defined using the same method. One included five items expressing fear of social rejection: *Fear of divorce; Fear of losing friends; Fear of damaging the family reputation; Fear of not being able to get married; Fear of being rejected by sexual partners*

(H= 0.74, Rho=0.99). The second scale included three items about self-efficacy: *Fear of having to take medication forever; Fear of side effects; Fear of not being able to handle a life as an HIV positive person* (H= 0.71, Rho=0.98). Two scaled scores were computed as the averaged sum of valid answers, 1 to 5.

Fear of community gossip was assessed with a 5 point Likert scale (1: very afraid of community gossip; 5: not afraid of community gossip).

Household food insecurity was assessed with a shortened version of the 10-item Radimer/Cornell hunger scale (45). A scaled score with four items was created with MSP: *I worry whether my food will run out before get money to buy more; I eat less than I think I should because I don't have enough money for food; I know my child(ren) is/are hungry sometimes, but just can't afford more food; I can't feed my child(ren) with a balanced meal because I can't afford it* (H=0.65 and Rho=0.97).

Data analysis

We used Stata 12.1 software to perform the statistical analysis. First we ran univariable logistic regression models to assess associations between uptake of HIV testing and each individual item related to couple, family, and neighbour relationships and anticipated stigma. We repeated this analysis using the scored scales. Other associations assessed included health risk behaviors, beliefs related to ARVs and traditional medicines (individual items and score), socio-demographic and socio-economic variables. We also tested interactions with sex. Our initial multivariable mixed model included all variables with $p < 0.2$ and interaction terms with $p < 0.1$ in the univariable analysis. In this paper we wanted to focus on individual factors influencing the decision of undergoing HIV-testing.

Therefore we chose to model influences at the primary sampling unit level by random effects. The initial multivariable model was then reduced using backward selection. We dropped the least significant variables, as long as they were not significant according to our chosen critical level. In our case $p < 0.2$ for variables and $p < 0.1$ for interactions. We continued by successively re-fitting reduced models and applying the same rule until all remaining variables were statistically significant.

We also carried out sensitivity checks through subgroup analyses that excluded HIV positive respondents who disclosed their status and respondents who reported a change in the relationship with the partner after being tested.

8.4 Results

The surveyors visited a total of 1750 households in which eligible individuals were randomly identified. A total of 1716 participants (98.6%) responded to the interview questions. In Table 8.1 & 8.2, we summarize the characteristics and proportions of persons ever tested for HIV.

Table 8.1 Descriptive characteristics of respondents by gender and testing status

	Men				Women			
	Ever tested	Never tested	P	Total	Ever tested	Never tested	P	Total
	444 (35.8)	264(64.2)		708	740 (45.1)	268 (54.9)		1008
Age (years)								
18–24	60 (8.5)	67 (9.5)	*	127 (17.9)	149 (14.8)	63 (6.3)	*	212 (21.0)
25–34	125 (17.7)	77 (10.9)	*	202 (28.5)	250 (24.8)	57 (5.7)	*	307 (30.5)
35–44	150 (21.2)	55 (7.8)	*	205 (29.0)	184 (18.3)	56 (5.6)	*	240 (23.8)
45–54	60 (8.5)	25 (3.5)	*	85 (12.0)	82 (8.1)	36 (3.6)	*	118 (11.7)
>55	46 (6.5)	36 (5.1)	*	82 (11.6)	69 (6.8)	55 (5.5)	*	124 (12.3)
Education								
None	15 (2.1)	15 (2.1)	*	30 (4.2)	49 (4.9)	20 (2.0)		69 (6.8)
Primary	210 (29.7)	90 (12.7)	*	300 (42.4)	374 (37.1)	109 (10.8)		483 (47.9)
Secondary	172 (24.3)	117 (16.5)	*	289 (40.8)	254 (25.2)	109 (10.8)		363 (36.0)
Tertiary	36 (5.1)	34 (4.8)	*	70 (9.9)	56 (5.6)	21 (2.1)		77 (7.6)
Marital status								
Widowed	10 (1.4)	12 (1.7)	*	22 (3.1)	78 (7.7)	44 (4.4)	*	122 (12.1)
Married	327 (46.2)	138 (19.5)	*	465 (65.7)	474 (47.0)	103 (10.2)	*	577 (57.2)
Polygamy	87 (12.3)	27 (3.8)		114 (16.1)	114 (11.3)	13 (1.3)	*	127 (12.6)
Monogamy	239 (33.8)	109 (15.4)		348 (49.2)	347 (34.4)	88 (8.7)	*	435 (43.2)
Single	85 (12.0)	96 (13.6)	*	181 (25.6)	134 (13.3)	93 (9.2)	*	227 (22.5)
Separated/ divorced	12 (1.7)	10 (1.4)	*	22 (3.1)	38 (3.8)	23 (2.3)	*	61 (6.1)
SES								
Self-perception of wealth - Poor	297 (41.9)	177 (25.0)		474 (66.9)	504 (50.0)	176 (17.5)		680 (67.5)
Self-perception of wealth - Rich	132 (18.6)	76 (10.7)		208 (29.4)	197 (19.5)	74 (7.3)		271 (26.9)
Employed	119 (16.8)	73 (10.3)		192 (27.1)	126 (12.5)	65 (6.4)	*	191 (18.9)
Urban/Rural								
Urban – low/medium density	82 (11.6)	71 (10.0)	*	153 (21.6)	173 (17.2)	84 (8.3)	*	257 (25.5)
Urban - high density	68 (9.6)	80 (11.3)	*	148 (20.9)	153 (15.2)	91 (9.0)	*	244 (24.2)
Rural	293 (41.4)	113(16)	*	406 (57.3)	413 (41.0)	93 (9.2)	*	506 (50.2)

* p<0.05

A total of 532 (31%) respondents had never been tested. Of those 264 (49.6%) were men and 268 (50.5%) women. Most people tested did it only once (27%) or twice (23%). Half of them (52%) were tested less than 6 months before the survey. Surprisingly, more people living in cities (39%) reported to not have been tested as compared to rural areas (27%). Unmarried people and those who

perceived their households poorer than other households in the community were also less likely to be tested.

Table 8.2 Testing characteristics of respondents by gender and testing status

	Men	Women
Number of HIV tests		
One	142 (32.0)	172 (23.2)
Two	105 (23.6)	168 (22.7)
Three	52 (11.7)	119 (16.1)
Four or more	66 (14.9)	126 (17.0)
Time since last test		
Less than 6 months	236 (53.2)	372 (50.3)
6 to 12 months	109 (24.5)	156 (21.1)
1-2 years	26 (5.9)	63 (8.5)
2-3 years	24 (5.4)	51 (6.9)
More than 3 years	15 (3.4)	33 (4.5)

In Table 8.3 we displayed the top 10 reasons for not testing. The reasons most often reported were: "Fear that people gossip about me" (37%), "Fear that I'd be rejected by sexual partners" (36%); "No-one would marry me" (35%) and "Fear that my family's reputation would be damaged" (32%). Other reasons were related to perceptions of self-efficacy: "I would not be able to handle life as HIV positive person" (29%) and "I'm afraid to take medication forever" (29%). Other reasons related to social support were "I'm afraid of being abandoned by my partner" (26%) and "I'm afraid to lose my friends" (25%). Only one reason was directly related to treatment with ARVs: "I'm worried about side effects" (19%).

Table 8.3 Top 10 reasons for non-uptake of HIV testing among non-tested participants

	N	%
Fear of gossip and finger point in the community	199/532	37%
Fear of being rejected by sexual partners to have sexual intercourse	194/532	36%
Fear of being rejected by potential partners to get married	188/532	35%
Fear of damaging the family reputation	168/532	32%
Fear of not being able to handle a life as an HIV positive person	153/532	29%
Fear of taking medication forever	153/532	29%
Fear of losing the main partner	140/532	26%
Fear of losing friends	135/532	25%
Fear of ARVs' side effects	103/532	19%
Fear of not being able to have children	100/532	19%

In Tables 8.4-8.6 we show the crude odds ratios associated with non-uptake of HIV testing. Living in urban areas (OR= 2.40 95% CI= 1.94-2.96), and being educated (OR= 1.12 95% CI= 1.05-1.21) increased the odds of not being tested while being female (OR= 0.61 95% CI= 0.50-0.75), married (OR= 0.40 95% CI= 0.32-0.49), very religious (OR= 0.83 95% CI= 0.73-0.94) and involved in community activities (OR= 0.55 95% CI= 0.45-0.68) were positively associated with testing. Limited knowledge of ARVs (OR= 1.62 95% CI=1.09-2.41) and reliance on traditional medicines (OR=1.29 95% CI=1.10-1.51) increased the odds of not being tested. Being unemployed (OR= 1.34 95% CI= 1.06-1.71), not owning household assets (OR= 1.74 95% CI= 1.41-2.14), having no power to decide over household resources (OR= 1.31 95% CI= 1.13-1.52) and food insecurity (OR= 1.17 95% CI= 1.02-1.33) increased the risk of non-uptake of testing.

Table 8.4 Crude odds ratios for socio-demographic and socio-economic factors

	N (%)	OR	P value	95% CI	
Socio-demographic factors					
Age*		1.01	0.060	1.00	1.01
Urban*	782 (45.6)	2.40	0.000	1.94	2.96
Women*	1008 (58.7)	0.61	0.000	0.50	0.75
Education level					
None vs. any education	99 (5.8)	1.25	0.299	0.82	1.92
Primary education	783 (45.6)	0.62	0.036	0.40	0.97
Secondary education*	652 (38.0)	0.97	0.893	0.62	1.51
Tertiary education*	147 (8.6)	1.09	0.004	0.64	1.85
Religious feeling (the more)*	1395 (81.3)	0.83	0.004	0.73	0.94
Do not attend religious services*	394 (23.0)	1.25	0.000	1.10	1.41
Participates in community activities*	864 (50.3)	0.55	0.000	0.45	0.68
Married*	1042 (60.7)	0.40	0.000	0.32	0.49
Widow or divorce	227 (13.2)	1.53	0.004	1.15	2.04
Socio-economic factors					
Employment (any)*	741 (43.2)	1.34	0.016	1.06	1.71
Does not own any household assets*	201 (11.7)	1.74	0.000	1.41	2.14
Cannot decide on household resources*	309 (18.0)	1.31	0.000	1.13	1.52
Often ate less than wanted due to lack of money to buy food*	782 (45.6)	1.17	0.020	1.02	1.33

*statistical significance $p < 0.05$

Being unaware of where to go for testing was the greatest risk factor (OR= 39.11 95% CI=14.14-108.20) for not testing but only about 4% of the respondents said they did not know where to go.

Table 8.5 Crude odds ratios beliefs about HIV and ARVs

	N (%)	OR	P value	95% CI	
Does not know any place to go for testing*	65 (3.8)	39.11	0.000	14.14	108.20
ARVs can make sick*	246 (14.3)	1.34	0.050	1.00	1.80
ARVs are not good for children*	276 (16.1)	1.39	0.023	1.05	1.84
Health literacy (ARVs) score* ₁	131 (7.6)	1.62	0.017	1.09	2.41
Traditional medicine (TM) can cure HIV/AIDS#	36 (2.1)	0.97	0.698	0.83	1.14
TM are easier to take	81 (4.7)	1.09	0.195	0.96	1.23
TM are easier to access	89 (5.2)	1.09	0.169	0.96	1.23
TM belief score* ₂	108 (6.3)	1.29	0.002	1.10	1.51

*statistical significance $p < 0.05$ ₁ score included: ARVs can make sick; ARVs are not good for children; ARVs can make impotent; ARVs can kill₂ score included: TM can cure HIV/AIDS; TM are easier to take; TM are easier to access

With regard to social cohesion/discohesion, feeling supported within the household (OR= 0.79 95% CI=0.70-0.89), which was the case for only 7% of the respondents, increased the likelihood of being tested. Conversely, not getting along well with the spouse (OR=1.19 95% CI=1.06-1.35), not feeling supported by the spouse (OR=1.14 95% CI=1.02-1.27) and fear of being abandoned by the spouse (OR=1.13 95% CI=1.05-1.21) increased the odds of not being tested. Not getting along well with the neighbours (OR=1.18 95% CI=1.06-1.32), high levels of perceived stigma in the community (OR=1.21 95% CI=1.09-1.35) and fear of community gossip (OR= 1.12 95% CI=1.05-1.19) also increased the risk of not being tested. In stratified analysis by location and gender, the fear of community gossip was positively associated with uptake of testing in women living in rural areas (OR=0.56 95% CI=0.32-0.99) while for men it remained a non-statistically significant risk (OR=1.41 95% CI=0.89-2.22). In urban areas the fear of community gossip was a risk factor for both women (OR=1.52 95% CI=1.02-2.27) and men (OR=2.00 95% CI=1.23-3.26). Being afraid of social rejection (OR= 1.25 95% CI=1.16-1.35) also increased the odds of not being tested. The odd ratios reported in this section referred to a one unit increase in the respective 5-level score (score 1-5).

Table 8.6 Crude odds ratios of social support factors

	N (%)	OR	P value	95% CI	
Social support					
Lack of household support*	113(6.59)	0.79	0.000	0.70	0.89
Lack of support from partner*	1027 (59.8)	1.14	0.019	1.02	1.27
Does not get along well with partner/spouses*	1065 (62.1)	1.19	0.005	1.06	1.35
Tolerance of interpersonal violence	1346 (78.4)	0.95	0.318	0.86	1.05
Tolerance of gender based violence	208 (12.1)	0.98	0.626	0.89	1.08
Domestic violence score₁					
People in this neighbourhood don't get along well with each other	255 (14.9)	0.98	0.699	0.89	1.08
People around here are not willing to help their neighbours*	275 (16.0)	1.28	0.000	1.17	1.40
Community cohesion score*₂					
Fear of divorce*	428 (24.9)	1.13	0.001	1.05	1.21
Fear of losing friends*	375 (21.9)	1.13	0.001	1.05	1.21
Fear of damaging the family reputation*	412 (24.0)	1.23	0.000	1.14	1.31
Fear of not being able to get married*	467 (27.2)	1.23	0.000	1.15	1.31
Fear of being rejected by sexual partners*	496 (28.9)	1.22	0.000	1.14	1.31
Fear of social rejection score*₃					
Fear of having to take medication forever*	467 (27.2)	1.08	0.023	1.01	1.16
Fear of side effects	342 (19.9)	1.03	0.467	0.95	1.11
Fear of not being able to handle a life as an HIV positive person	478 (27.9)	1.06	0.082	0.99	1.14
Self-efficacy score₄					
People with HIV loose respect in this community*	405 (23.6)	1.18	0.002	1.06	1.31
HIV positive children are bullied by other children in this community	182 (10.6)	1.02	0.777	0.91	1.13
People here believe that children should not play with children infected	154 (9.0)	1.09	0.099	0.98	1.22
Stigma score*₅					
Fear of community gossip (social control)*	259 (15.1)	1.12	0.001	1.05	1.19

*statistical significance $p < 0.05$

₁ score included: If someone in the household misuses money it is acceptable to beat him/her; In my household if a wife comes home late without the permission of the husband she will be beaten

₂ score included: People in this neighbourhood don't get along well with each other; People around here are not willing to help their neighbours

₃ score included: Fear of divorce; Fear of losing friends; Fear of damaging the family reputation; Fear of not being able to get married; Fear of being rejected by sexual partners

₄ score included: Fear of having to take medication forever; Fear of side effects; Fear of not being able to handle a life as an HIV positive person

₅ score included: People infected with HIV loose respect in this community; HIV positive children are bullied by other children in this community; People here believe that children should not play with children infected

In Table 8.7 we display the results of the multivariable logistic regression model controlling for the random effect of location (PSUs). On the individual level being male, older (every five year increase in age), living in urban areas and having no education were all associated with non-uptake of testing. People married (OR=

0.57 95% CI=0.37-0.88) had a lower risk of refusing the HIV test yet those who perceived a high tolerance of gender-based violence in their households (OR= 2.10 95% CI=1.05-4.32) and did not get along well with the spouse (OR= 2.48 95% CI=1.00-6.19) were twice more likely of not being tested. These effects were consistent with the unadjusted analysis and did not change when we conducted sensitivity analysis excluding from the analysis HIV positive participants who disclosed their status to a family member and who reported a change in the relationship in their couple after being tested. About 29% of married individuals reported conflicts within the couple of whom less than half (43.5%) were tested for HIV. Among couples who didn't have marital conflicts the testing prevalence was about 74.1%. Similarly 20.2% of all married participants perceived a high tolerance to gender-based violence in their households. Furthermore being afraid of social rejection (OR= 1.48 95% CI=1.23-1.80) also increased the odds of not being tested and this effect was strongly modified by the level of fear of community gossip.

Table 8.7 Adjusted odds ratios associated with non-uptake of HIV testing

Risks determinants for not testing	AOR	P	95% CI
Urban*	2.31	0.000	1.45 - 3.69
Men*	1.64	0.000	1.34 - 2.02
Age*	1.12	0.001	1.05 - 1.19
No education*	2.00	0.041	1.03 - 3.88
Community participation	0.72	0.073	0.50 - 1.03
Married*	0.57	0.012	0.37 - 0.88
Respondent does not get along well with spouse/partner _# *	2.48	0.045	1.00 - 6.19
Tolerance of gender based violence in the household _# *	2.10	0.041	1.05 - 4.32
Alcohol abuse	1.12	0.093	0.98 - 1.27
Fear of social rejection score* ₁	1.48	0.000	1.23 - 1.80
Fear of community gossip*(social control)	0.81	0.014	0.68 - 0.96
Random-effect: District/Village	0.43	0.186	0.18 - 1.01

*statistical significance p<0.05

_# reported per five unit increase

₁ score included: Fear of divorce; Fear of losing friends; Fear of damaging the family reputation; Fear of not being able to get married; Fear of being rejected by sexual partners

We tested the interaction between these two variables but it was not statistically significant. Further analysis suggested that community gossip would rather be a mediator of the association between fear of social rejection and uptake of HIV testing. To test this mediating effect, we ran a multinomial regression analysis using first the following categorical outcome: reference category (being tested), category 1 (being not tested but have no fear of community gossip) and category 2 (being not tested but have fear of community gossip). We computed the relative risk ratios (RRR) of each predictor associated with each outcome's category and then computed the RRR of the contrast between outcome's category 2 and 1 using the command LINCOM in Stata 12 (which works like changing the outcome's reference category and running again the multinomial regression). The results of this analysis offered evidence in favour of our mediating effect hypothesis as the risk for not testing due to fear of social rejection (RRR=3.44; 95% CI= 2.78 - 4.25) tripled when respondents were afraid of community gossip as compared to those who had no fear of gossip. This analysis also showed how gossip in the community can mediate access to HIV testing in men. A high level of community gossip doubled the risk that men were never tested. Alcohol abuse was also a risk factor for HIV testing, especially in the absence of community gossip, probably to avoid the stigma associated with a positive result and be blamed for having acquired the virus because of the drinking behavior. These results are presented in Table 8.8 in an online supplement.

Table 8.8 Multinomial regression: community gossip as a mediator of the association between social rejection and HIV testing

	Category 1 Not tested & No fear of gossip <i>against</i> being tested			Category 2 Not tested & Fear Gossip <i>against</i> being tested			Category 1 <i>against</i> Category 2		
	RRR	P>z	95% CI	RRR	P>z	95% CI	RRR	P>z	95% CI
Urban	2.12	0.006	1.24 - 3.64	3.25	0.000	1.81 - 5.85	1.54	0.240	0.75-3.14
Men	1.73	0.009	0.38 - 2.60	4.65	0.000	2.57 - 8.41	2.69	0.002	1.46 - 4.97
Age	1.02	0.000	1.01 - 1.04	1.01	0.460	0.99 - 1.03	0.99	0.249	0.96-1.01
No education	2.41	0.011	1.22 - 4.77	0.45	0.468	0.05 - 3.83	0.19	0.104	0.25-1.41
Community participation	0.80	0.260	0.53 - 1.18	0.51	0.018	0.29 - 0.89	0.64	0.217	0.32-1.29
Married	0.55	0.027	0.32 - 0.93	0.66	0.195	0.35 - 1.24	1.20	0.673	0.51 - 2.81
Alcohol abuse	1.19	0.012	1.04 - 1.36	0.95	0.624	0.79 - 1.15	0.80	0.035	0.65-0.98
Couple's conflict _# *	1.84	0.290	0.59 - 5.37	3.05	0.098	0.81 - 11.50	1.69	0.530	0.32-8.38
Domestic Violence _# *	2.19	0.019	1.16 - 4.16	1.76	0.284	0.62 - 5.00	0.82	0.733	0.25-2.59
Fear of social rejection score* ₁	0.77	0.006	0.63 - 0.93	2.77	0.000	2.29 - 3.35	3.44	0.000	2.78 - 4.25

* statistical significance p<0.05

effect reported per five unit increase

₁ score included: Fear of divorce; Fear of losing friend ; Fear of damaging the family reputation; Fear of not being able to get married; Fear of being rejected by sexual partners

8.5 Discussion

Our findings show that marital conflicts, individual perceptions of high tolerance to gender-based violence within the household and the fear of social ostracism put people at greater risk of not being tested. In addition fear of social rejection was a strong risk for not getting tested but only if people were also afraid of gossip in the community. All these fears and conflicts are a likely result of prevailing social norms in the community. Acceptance of these norms especially those related to marriage rules may promote gender power inequality which can lead to violence and social abuses. There is significant evidence that gender inequity and gender-based violence increase vulnerability to HIV infection (27, 28) and that gender-based violence and sexual risk may be linked through alcohol consumption (46). Our study expands on this evidence by showing that not only enacted gender-based violence adds to the burden of HIV, but tolerance of gender-based violence

within families per se jeopardizes uptake of HIV care. The provision of couple counselling within the intervention package for VCT programs offer an opportunity to address these problems but those that do not test will nevertheless not benefit from such efforts.

Fear of gossip (about oneself) in the community was the most reported reason to have not been tested for HIV. Sociological and psychological evidence has long established that gossip is not simply trivial chat but an efficient means of social control and moral instruction (47-54). A recent study from South Africa showed that in communities with high HIV prevalence gossip is used to spread information considered relevant to the prevention of HIV/AIDS at the local level and also to instruct people about socially (un-) acceptable behaviours in the community. In the words of the author "*Gossip about AIDS does not only describe, but is prescriptive. It creates moral readings of behaviour, linking AIDS to discourses of tradition, gender, and generational relationships*". (55)

The problem of gossip further shows that community based strategies are urgently needed, in complement to individual and family-based interventions. Interventions research on how to influence social norms and mobilize community support and how to enforce the statutory family and criminal law are needed in order to mitigate the negative effects of marital conflicts on women in Zambia. The last report on Human Rights in Zambia (2007) concluded that the lack of enforcement and the culture of impunity for perpetrators of violence against women were key challenges for the country. This report argued that although the government had established special units to respond to violence against women, discriminatory

attitudes within the system (police and judiciary) prevented women from reporting violence and that women were often pressured by law enforcement officials to withdraw the allegations of violence or for reconciliation with abusive husbands.

(56)

Other than individual- and marriage-centered approaches such as couples counselling we suggest studying the potential value (capacity and authority) that traditional authorities of the clan / kinship system (57) or of the various churches could have for mobilizing the community and influencing negotiation within family networks on how marital conflicts and violence can be mitigated. The potentially effective leadership role of traditional leaders in Zambia for changing marital norms, such as to abolish informal marriage rules like levirate marriage (marriage with a brother's widow or inheritance of the brother's wife), has been previously highlighted (58) but less is known about the influence of religious leadership.

To our knowledge this is the first study providing quantitative evidence on the association between unequal power relations within couples, tolerance of gender-based violence within families and HIV care seeking behaviour in Southern Africa. It is consistent with recent findings from Zambia, Zimbabwe and Kenya showing that a low tolerance for domestic violence is positively associated with greater acceptance of HIV testing among women although, in this study, the effect was statistically significant only in Kenya (59). Our results also confirm those of other studies conducted in the United States (60), China (61) and recently in Zambia (62) reporting that family and couple relationships are instrumental in the

prevention and treatment of HIV/AIDS, that gender-based abuses increases the risk of not getting tested (63) and that social and family capital have the potential to influence vulnerability to HIV in Sub-Saharan Africa (64, 65).

We are aware that the interpretation of our results is limited by the cross-sectional design of the study which does not allow establishing a causal relationship between couple conflicts, tolerance to gender based violence, fear of social rejection and uptake of HIV testing. However, the fact that we found similar associations in persons having disclosed their HIV-positivity or having reported a change in their relationship argues against inverse causality. We cannot rule out the possibility of hidden confounding factors that could explain these effects. However, in our models we consider a large set of variables that were selected based both on our previous knowledge of the topic and the context and on a comprehensive literature search. We further assessed whether the association between couple dis cohesion and HIV-testing was modified by age, sex and perceived stigma in the community but found no evidence of such interactions. Nonetheless longitudinal research is needed to clarify these potential causal relationships. Another limitation is that our analysis was based on self-reported prevalence of HIV testing. Yet, our results were similar to those of another study, which actually tested the respondents, (66) and was conducted in the same areas and during the same period. Thus we are confident that our data reflects the reality of the communities we studied. Finally, although our study had a limited geographical scope the sample in Lusaka was representative of a large urban environment in Zambia and, as the country has a high degree of urbanization, we assume that our results are nationally relevant. Likewise both rural areas and the

peri-urban town that we surveyed offered three different rural environments increasing the likelihood that the study is generalizable to the Southern Zambian rural context as well.

8.6 Conclusion

In Zambia, as in other parts of Sub-Saharan Africa, programmes to increase access to HIV care services have strongly relied on stigma reduction campaigns and the promotion of couple VCT. Although these interventions were correctly targeted and contributed to improve uptake (67-69) they did not aim to reduce power imbalances between men and women. Couple-testing may be most beneficial to couples with a mutually supportive relationship but it is unlikely that it adequately accommodates couples in conflict especially because, as our study shows, these couples have a higher risk of not being tested.

Even if services are enhanced and stigma is reduced prevailing gender inequality and tolerance of gender-based violence will continue to pose a significant barrier to uptake of testing unless there is real commitment to engage in social processes to reduce gender inequality. Not being able to freely decide whether to get tested due to fear of violence or social exclusion is a moral and human rights violation that can and must be urgently addressed. Programs to prevent AIDS and increase access to HIV care must be planned and designed using frames to protect and promote equal rights thus improving the participation of those who are most vulnerable. Addressing gender issues is not just a matter of including a focus on women and girls as a crosscutting issue in HIV/AIDS programming. Ending

gender inequality requires political will and a comprehensive rights-based approach to HIV/AIDS.

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Author Contributions

Conceptualized and designed the experiments: SM, AMH. Contributed to the conceptualization of the study: JRSM, MM, CS. Performed the data collection: SG, MM. Analysed and interpreted the data: SG. Contributed to analysis of the data: CS. All authors contributed to the final publication. Wrote the paper: SG. Principle investigator: SM.

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Chapter 9 - Uptake of antiretroviral therapy: sex differentials

Sex differentials in the uptake of antiretroviral treatment in Zambia

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Sex differentials in the uptake of antiretroviral treatment in Zambia

9.1 Abstract

This study explores socio-structural factors that influence uptake of antiretroviral treatment (ART) in Zambia and assess differences between men and women. We conducted a case-control study nested in a community- and health facility-based survey, between September 2010 and February 2011. Cases were defined as HIV positive individuals who, while eligible, never started ART and controls were HIV positive individuals who were on ART. Cases and controls were matched by place of residence. We performed a conditional logistic regression analysis using a discrete logistic model stratified by sex. Overall a significantly larger proportion of men (32.7%) than women (25.6%) did not uptake ART (Pearson $\chi^2 = 5.9135$; $p = 0.015$). In the crude analysis, poor health status and low self-efficacy were common factors associated with non-uptake in both sexes. After adjusting for covariates men were more likely than women to refuse ART even though men's self-rated health was lower than women's. In general, the adjusted analysis suggest that HIV status disclosure affects uptake in both sexes but women's uptake of ART is largely hampered by poverty-related factors while for men, side effects and social pressure, probably associated with masculinity, are more important barriers. Alarmingly men's health seems to deteriorate until they start treatment, in contrast to women. Understanding gender differences in uptake and attitudes to ART is a crucial component to providing effective and appropriate health care to both men and women living with HIV/AIDS in Zambia.

Keywords: HIV/AIDS; Antiretroviral therapy; Gender; Masculinity; Social cohesion

9.2 Background

Early uptake of antiretroviral treatment (ART) is critical to control the HIV epidemic (Granich et al., 2009; UNAIDS, 2012). In many Southern Africa countries, uptake of treatment remains below estimated needs (WHO, 2011). Contrary to expectations, ART coverage is higher among women

than men. In Zambia, 42% of ART patients are men compared to 57% women (Zambia NAC, 2012). A WHO report (2007) suggests that women are over-represented in ART programmes because they are better linked to community networks and thus have more information about the availability of services and how to access them (WHO 2007). Other studies suggest that men might be less likely to access ART due to norms circumscribing male behavior by stigmatising weakness and discouraging treatment seeking (Braitsen et al., 2007; Hawkes & Buse, 2013; Msellati et al., 2003; Natrass, 2008; Shisana et al., 2005).

In this paper, we explore factors associated with uptake of ART in Zambia and assess differences in uptake between men and women. We assume that health-seeking behaviour is not necessarily based on logical-rational decision-making but rather comprises a set of social acts and practices that simultaneously demonstrate and construct gender and the associated normative behaviours (Hausmann-Muela et al., 2003; MacKian & Bedri, 2004). Through this study, we contribute to understanding the challenges and implications of scaling-up HIV treatment and overcoming gender barriers in HIV/AIDS programmes in Zambia.

9.3 Methods

Study design, participants and setting

We conducted a case-control study nested in a community- and health facility-based survey, between September 2010 and February 2011, in the central and southern provinces of Zambia. The study included urban (Lusaka, Mazabuka) and rural sites (Chivuna, Mbeza). Persons living with HIV infection (PLWHA), over 18 years old and living in the study area were included. PLWHA on ART and not yet on ART were selected from the random community and health facility samples. An additional purposive sample of those lost-to-follow-up from local clinics was obtained to identify a sufficient number of PLWHA not yet on ART. Health professionals from ART, TB, and STI clinics, community health workers, and community-based traditional healers

were invited to contact PLWHA not on ART and inform them about the opportunity to participate in the study. Upon agreement of these individuals, they were informed about the nature of the study, guaranteed confidentiality and informed about their voluntary participation. Informed consent was obtained prior to the interviews. All participants were further informed about the services offered by health centres and offered professional counselling if requested. The Ethical Committee of the University of Basel (EKBB), and the University of Zambia review boards approved the consent and recruitment procedures.

Measure

Participants were administered a pre-tested and structured questionnaire which was translated into the local languages (Nyanja, Ila and Tonga). It gathered information on socio-demographic and economic characteristics; conspiracy beliefs; trust in traditional medicines; ART knowledge; social support; social cohesion; HIV-stigma and self-perceived health status. This instrument has been described in a previous publication (Gari et al, 2013). Data was cleaned and analysed using STATA 12.1 statistical software.

Analysis

The case-control study compared PLWHA on ART (controls) and PLWHA who, though currently eligible, reported to have never taken ART (cases). We also assessed differences between men and women, using a conditional logistic regression analysis with a discreet logistic model stratified by sex. Each case identified was matched to one control on place of residence.

9.4 Results

Of the 1209 PLWHA identified, a total of 1140 (94.3%) responded to the questionnaire. Among those, 401 reported to have never been on ART and 112 reported a CD4 count above 350 and were thus not eligible for ART in Zambia at the time of the interview. A total of 1024 participants were ultimately included in the analysis. Among them 735 were on ART while 289 were not despite

being eligible for treatment. The proportion of men (32.7%) not on ART was significantly higher than women (25.6%) (Pearson $\chi^2 = 5.9135$; $p = 0.015$) (**Table 9.1**).

Table 9.1 Socio-demographic characteristics of the respondents

	Non-uptake		Uptake	
	Men (%) 123	Women (%) 166	Men (%) 253	Women (%) 482
Age group				
18-24	12 (9.8)	44 (26.5)	12 (4.7)	39 (8.1)
25-34	42 (34.1)	59 (35.5)	62 (24.5)	139 (28.8)
35-44	51 (41.5)	43 (25.9)	106 (41.9)	186 (38.6)
45-54	13 (10.6)	12 (7.2)	44 (17.4)	83 (17.2)
Older 55	5 (4.1)	8 (4.8)	29 (11.5)	35 (7.3)
Education level				
No education	5 (4.1)	17 (10.2)	10 (4)	45 (9.3)
Primary	73 (59.3)	101 (60.8)	117 (46.2)	270 (56)
Secondary	42 (34.1)	47 (28.3)	113 (44.7)	155 (32.2)
Tertiary	3 (2.4)	1 (0.6)	13 (5.1)	12 (2.5)
Marital situation				
Single (never married)	26 (21.1)	30 (18.1)	27 (10.7)	59 (12.2)
Married	87 (70.7)	84 (50.6)	189 (74.7)	235 (48.8)
Monogamist	74 (60.2)	57 (34.3)	161 (63.6)	181 (37.6)
Polygamist	13 (10.6)	27 (16.3)	28 (11.1)	53 (11)
Separated	4 (3.3)	25 (15.1)	20 (7.9)	68 (14.1)
Widowed	6 (4.9)	27 (16.3)	17 (6.7)	120 (24.9)
Urban	48 (39)	74 (44.6)	131 (51.8)	248 (51.5)
Low density	9 (7.3)	14 (8.4)	20 (7.9)	56 (11.6)
Medium density	6 (4.9)	13 (7.8)	43 (17)	76 (15.8)
High density	33 (26.8)	47 (28.3)	68 (26.9)	116 (24.1)
Rural	75 (61)	92 (55.4)	122 (48.2)	234 (48.5)

Table 9.2 and Table 9.3 show the results of the unadjusted and adjusted models respectively. Non-disclosure of one's HIV status was strongly associated with non-uptake of ART in men (AOR: 4.14 95%CI: 1.11-15.48) and even more so in women (AOR: 6.14 95%CI: 2.20-17.10). Participating in community activities was associated with a decreased risk for non-uptake of ART in women (AOR: 0.37 95%CI: 0.18-0.79). For men, living in dis cohesive neighbourhoods (AOR: 1.88 95%CI: 1.18-3.00) was associated with an increased risk for non-uptake. Not owning household assets (AOR: 2.68 95%CI: 1.14-6.29) and living in food-insecure households (AOR: 1.64 95%CI: 1.02-2.65) were also associated with non-uptake in women while anticipation of side effects (AOR: 1.56 95%CI: 1.11-2.17) and poor health status (AOR: 1.97 95%CI: 1.14-3.40) were associated with non-uptake in men.

Table 9.2 Crude odd ratios associated with non-uptake of ART stratified by sex

Explanatory variables	Men			Women		
	OR	p	95% CI	OR	p	95% CI
Age	0.78	0.011	0.64- 0.95	0.75	0.000	0.65- 0.87
Participate in community activities	1.04	0.934	0.45- 2.38	0.41	0.004	0.22- 0.75
Do not own household assets	1.31	0.531	0.56- 3.10	2.36	0.010	1.23- 4.50
Food insecurity ^a	0.99	0.967	0.64- 1.53	1.46	0.049	1.00- 2.13
Poor health ^b	1.97	0.003	1.26- 3.08	1.57	0.005	1.15- 2.16
Dis cohesive neighbourhood ^c	1.39	0.049	1.00- 1.93	1.17	0.191	0.92- 1.49
No disclosure	4.46	0.003	1.66- 11.99	5.92	0.000	2.58- 13.61
Fear of side effects	1.10	0.602	0.77- 1.56	1.09	0.497	0.85- 1.41

* Statistical significance $p < 0.05$

^a Defined by: I know my children are hungry but I do not have enough money to buy food 2 Defined by: In times of crisis I can turn to my spouse/partner for support

^b Self-rated health in a Likert scale from 1 to 5 recoded as binary

^c Defined by: Neighbours don't get along well with each other

Table 9.3 Adjusted odd ratios associated with non-uptake of ART stratified by sex

Explanatory variables	Men			Women		
	AOR	p	95% CI	OR	p	95% CI
Age	0.69	0.003	0.54 - 0.88	0.68	0.000	0.57 - 0.82
Participate in community activities	2.70	0.064	0.94 - 7.71	0.37	0.011	0.18 - 0.79
Do not own household assets	0.62	0.363	0.22 - 1.74	2.68	0.024	1.14 - 6.29
Food insecurity ^a	0.98	0.938	0.58 - 1.65	1.64	0.043	1.02 - 2.65
Poor health ^b	1.97	0.015	1.14 - 3.40	1.16	0.460	0.78 - 1.72
Discohesive neighbourhood ^c	1.88	0.008	1.18 - 3.00	1.07	0.709	0.76 - 1.50
No disclosure	4.14	0.035	1.11 - 15.48	6.14	0.001	2.20 - 17.10
Fear of side effects	1.56	0.009	1.11 - 2.17	1.30	0.057	0.99 - 1.70

* Statistical significance $p < 0.05$

^a Defined by: I know my children are hungry but I do not have enough money to buy food 2 Defined by: In times of crisis I can turn to my spouse/partner for support

^b Self-rated health in a Likert scale from 1 to 5 recoded as binary

^c Defined by: Neighbours don't get along well with each other

9.5 Discussion

Determinants of ART uptake differed between men and women except when related to disclosure of HIV status. Non-disclosure of HIV status was the strongest determinant for non-uptake of ART in both men and women. Presumably however, people who do not uptake ART are less inclined to disclose their HIV status, and thus, do not get the support needed to start treatment, which might explain the strength of this association. Gendered factors affecting uptake were less intuitive. Men who rated their health as poor were more likely to not have started ART as compared to women who assessed themselves in poor health. This effect may be due to reverse causality, with poor health being a result of non-treatment. Nonetheless, the data suggests that men not only uptake less but may also let their health deteriorate more, than women, before they seek help. This is consistent with previous findings that show that HIV infection is detected later in men and that men have lower CD4 counts than women upon initiation of ART (Chen, 2008; Hawkins, 2011; Johannessen, 2008; May 2010). Fear of side effects was also an important determinant of non-uptake of ART in men but not so in women. Recent similar findings from South Africa (Beck, 2004; Harrison et al., 2006; Hunter, 2005), Namibia (Brown, Sorrel & Rafaelli 2005) and Zambia

(Simpson, 2005) suggest that acknowledgement of health problems and treatment seeking is seen as a sign of weakness by men. Starting ART could mean having to care more for their health (diet, medication, clinic visits, etc.) which could interfere with their perception of "masculinity" and maleness. As more women go to ART clinics men's access may be further limited by a public perception that clinics are female spaces. Accessing care in such clinics may be further rejected by men in an attempt to affirm their masculinity (Natrass, 2008).

Women's uptake of ART was largely hampered by poverty-related factors while being involved in community activities was associated with increased uptake of ART. These findings may indicate that the existence of strong social ties, especially in a context of livelihood insecurity, may empower women to take up treatment as a means of overcoming structural and economic barriers. Interestingly, it had the opposite effect on men probably due to social pressures associated with masculinity that hinder the uptake of ART.

These differences between men and women suggest that while it remains important to continue working on women's empowerment, in a context of a feminised epidemic, there is an emerging need to reach out to men who are increasingly limited by socially confining norms that discourage their health seeking behaviours. Interventions in places frequented by men should be expanded to provide opportunities for men to relate to other men in discussion groups led by peers. These interactions may generate new knowledge and conceptions of masculinity that are more conducive to health management (UNAIDS, 2006). Mass media campaigns could also play a role in challenging prevailing gender constructs.

The results above should be interpreted with caution taking into account the limitations inherent in this study. Firstly, our data is based on self-reported statements which can be affected by recall and social desirability bias. This limitation is however minimized by the use of validated questions from other studies that addressed similar issues and contexts. Another limitation is that part of our sample was not randomly selected limiting the generalizability of the results. Nevertheless, researcher and selection bias was minimized by specifying clear inclusion criteria for the

population at risk of being HIV positive with no treatment, based on expert elicitation and/or accepted criteria to assess high risk population. Finally, the cross-sectional design does not allow causal attributions of the effects which could be identified, in the future, in a longitudinal study.

9.6 Conclusion

In Zambia, HIV positive men are likely at a higher risk for late or non-uptake of ART as compared to women. The wish to protect their "masculinity" seems to shape treatment-seeking decisions. In recent years, Zambia launched large programmes specifically targeting women's health. Both men and women should be actively addressed in programmes and policies to provide effective and appropriate health care to all people living with HIV/AIDS in Zambia.

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Additional tables

The additional tables show the detailed results of the bivariate analysis.

Table 9.1(additional) Self-reported reasons for non-uptake of ART among people living with HIV eligible for treatment

	Women		Men	
	N= 166		N= 123	
ARVs' effect -related fears	133	80%	97	79%
Fear of long-life treatment	73	44%	54	44%
Fear of side effects	60	36%	43	35%
Distrust in western bio-medicine	124	75%	89	72%
I don't believe the results of the HIV test	44	27%	29	24%
I have seen many people on ART dying	44	27%	32	26%
I don't believe ART works	36	22%	28	23%
Preference for traditional treatments	103	62%	64	52%
I take traditional medicines	54	33%	30	24%
I go for prayers	49	30%	34	28%
I feel healthy	91	55%	65	53%
Health system constraints	74	45%	48	39%
I am worried about the sustainability of ARVs	33	20%	24	20%
I do not have the money to go to the clinic	25	15%	16	13%
ART centre is too far	11	7%	6	5%
ARVs are not available in my area	5	3%	2	2%
Family support issues	38	23%	18	15%
My spouse does not want me to take ARVs	22	13%	10	8%
My family do not support me to take ARVs	16	10%	8	7%

Table 9.2 (additional) Crude odds ratios associated with ART refusal: Socio-demographic and SES factors

Explanatory variables	Men			Women		
	OR	p	95% CI	OR	p	95% CI
Age	0.78	0.011	0.64- 0.95	0.75	0.000	0.65- 0.87
No education	0.59	0.621	0.07- 4.78	2.72	0.048	1.01- 7.32
Primary education	2.04	0.508	0.25- 16.97	0.38	0.060	0.14- 1.04
Secondary education	1.57	0.679	0.19- 13.09	0.34	0.052	0.11- 1.01
Tertiary education	0.77	0.851	0.05- 12.10	0.16	0.134	0.01- 1.77
Religious feeling (the more)	0.50	0.002	0.33- 0.78	0.95	0.796	0.67- 1.36
Does not attend religious services	1.60	0.010	1.12- 2.30	1.19	0.312	0.85- 1.69
Participate in community activities	1.04	0.934	0.45- 2.38	0.41	0.004	0.22- 0.75
Employment	0.51	0.141	0.20- 1.25	1.57	0.206	0.78- 3.14
Wealth perception: poor ^a	0.92	0.672	0.63- 1.35	1.45	0.022	1.06- 1.99
Do not own household assets	1.31	0.531	0.56- 3.10	2.36	0.010	1.23- 4.50
Do not own household amenities	3.59	0.175	0.57- 22.80	4.04	0.018	1.27- 12.80
No power to decide over household resources	1.62	0.189	0.79- 3.30	1.68	0.023	1.08- 2.63
Food insecurity ^b	0.99	0.967	0.64- 1.53	1.46	0.049	1.00- 2.13

* Statistical significance $p < 0.05$

^a Self-perception of wealth as compared to other households in the community (score 1 to 5 in a Likert scale)

^b Defined by: I know my children are hungry but I do not have enough money to buy food 2 Defined by: In times of crisis I can turn to my spouse/partner for support

Table 9.3 (additional) Crude odds ratios associated with ART refusal: Health and treatment related factors

Explanatory variables	Men			Women		
	OR	p	95% CI	OR	p	95% CI
Poor health status	1.97	0.003	1.26- 3.08	1.57	0.005	1.15- 2.16
No disclosure	4.46	0.003	1.66- 11.99	5.92	0.000	2.58- 13.61
Low Self efficacy score a	1.39	0.025	1.04- 1.84	1.31	0.023	1.04- 1.65
Fear of medication forever	1.12	0.462	0.83- 1.50	0.93	0.554	0.73- 1.18
Fear of side effects	1.10	0.602	0.77- 1.56	1.09	0.497	0.85- 1.41
Fear of not being able to face a life as a HIV+ person	0.83	0.422	0.53- 1.30	1.29	0.094	0.96- 1.73
Traditional medicine trust score b	1.34	0.510	0.56- 3.18	1.76	0.053	0.99- 3.10
TM relief symptoms of HIV	1.26	0.366	0.76- 2.09	1.47	0.083	0.95- 2.29
TM can cure HIV/AIDS	1.18	0.501	0.72- 1.94	1.07	0.716	0.74- 1.56
TM are easier to take	1.02	0.912	0.67- 1.58	1.19	0.313	0.85- 1.67
TM are easier to access	1.13	0.552	0.76- 1.67	1.33	0.119	0.93- 1.91
ARVs misbeliefs score c	0.83	0.845	0.13- 5.40	5.72	0.033	1.15- 28.50
ARVs can make sick	1.34	0.686	0.32- 5.53	1.23	0.732	0.38- 3.96
Arvs are not good for children	0.55	0.464	0.11- 2.72	3.44	0.010	1.34- 8.83
ARVs can make impotent	0.40	0.471	0.03- 4.88	3.25	0.101	0.80- 13.32
ARVs can kill	1.39	0.630	0.37- 5.24	1.71	0.418	0.47- 6.27
Conspiracy beliefs score d	1.04	0.853	0.66- 1.64	1.46	0.032	1.03- 2.07
Genocide	1.15	0.514	0.75- 1.77	1.29	0.182	0.89- 1.87
Guinea pigs	0.90	0.627	0.58- 1.38	1.34	0.068	0.98- 1.83

* Statistical significance $p < 0.05$ ^a score included: Fear of having to take medication forever; Fear of side effects; Fear of not being able to handle a life as an HIV positive person^b score included: TM can cure HIV/AIDS; TM are easier to take; TM are easier to access^c score included: ARVs can make sick; ARVs are not good for children; ARVs can make impotent; ARVs can kill^d score included: HIV/AIDS was release to eradicate the black race; People who take ARVs are guinea pigs for the government

Table 9.4 (additional) Crude odds ratios associated with ART refusal: Social support factors

Explanatory variables	Men			Women		
	OR	p	95% CI	OR	p	95% CI
Nb trusted contacts	1.06	0.229	0.97- 1.15	1.03	0.393	0.96- 1.11
Nb family contacts	0.89	0.142	0.77- 1.04	0.94	0.476	0.80- 1.11
Couple discohension score^a	2.18	0.001	1.35- 3.51	1.02	0.875	0.77- 1.37
Couple do not get along well	1.53	0.034	1.03- 2.27	0.64	0.019	0.44- 0.93
I do not trust my partner	1.80	0.022	1.09- 2.96	1.03	0.838	0.75- 1.43
I do not feel very supported in my relationship	1.70	0.009	1.14- 2.53	1.21	0.148	0.93- 1.58
Family discohension score^b	0.95	0.770	0.65- 1.38	0.94	0.729	0.68- 1.31
Lack of support from family members	0.98	0.874	0.72- 1.33	0.93	0.583	0.71- 1.21
Family members do not get along well	0.93	0.704	0.66- 1.33	0.99	0.951	0.73- 1.35
Community discohension score^c	1.31	0.171	0.89- 1.92	1.20	0.224	0.90- 1.60
Neighbours don't get along well with each other	1.39	0.049	1.00- 1.93	1.17	0.191	0.92- 1.49
People around here are not willing to help their neighbours	1.18	0.381	0.81- 1.73	1.21	0.178	0.92- 1.59
Domestic violence score^d	1.76	0.030	1.06- 2.93	1.20	0.260	0.87- 1.64
Tolerance of interpersonal violence	0.65	0.079	0.41- 1.05	0.84	0.205	0.64- 1.10
Tolerance of gender based violence	1.51	0.059	0.98- 2.32	1.18	0.281	0.87- 1.61

* Statistical significance $p < 0.05$

^a *score included:* In times of crisis I cannot count on my spouse/partner for support; I do not get along well with my spouse/partner; I do not trust my spouse/partner; I do not feel supported at home

^b *score included:* In my household people support you only if they can gain something out of it; In my household people do not get along well with each other

^c *score included:* In my community neighbours do not get along well with each other; People in my community are not willing to help their neighbours

^d *score included:* If someone in the household misuses money it is acceptable to beat him/her; In my household if a wife comes home late without the permission of the husband she will be beaten.

Table 9.5 (additional) Crude odds ratios associated with ART refusal: Stigma and discrimination

Explanatory variables	Men			Women		
	OR	p	95% CI	OR	p	95% CI
Fear of community gossip	1.20	0.126	0.95- 1.51	1.18	0.089	0.97- 1.44
Perceived community stigma score^a	1.17	0.423	0.79- 1.74	1.05	0.766	0.76- 1.45
People with HIV lose respect in this community	1.12	0.462	0.83- 1.50	0.93	0.554	0.73- 1.18
Children who are HIV + are bullied by other children	1.10	0.602	0.77- 1.56	1.09	0.497	0.85- 1.41
No mother would let their children play with HIV + children	0.83	0.422	0.53- 1.30	1.29	0.094	0.96- 1.73
Fear of Social rejection score^b	1.25	0.151	0.92- 1.69	1.24	0.075	0.98- 1.58
Fear of divorce	1.00	0.991	0.79- 1.27	1.12	0.266	0.92- 1.36
Fear of losing friends	1.18	0.212	0.91- 1.54	1.25	0.038	1.01- 1.56
Fear of damaging the family reputation	1.22	0.136	0.94- 1.59	1.24	0.048	1.00- 1.54
Fear of not being able to get married	1.16	0.229	0.91- 1.49	1.19	0.097	0.97- 1.47
Fear of being rejected by sexual partners	1.22	0.116	0.95- 1.56	1.10	0.358	0.90- 1.34
Discrimination score^c	0.14	0.132	0.01- 1.83	0.50	0.486	0.07- 3.52
I was called bad names	0.00	1.000	0.00- 0.00	0.27	0.226	0.03- 2.24
I was told that I would die anytime	0.35	0.434	0.03- 4.81	0.35	0.302	0.05- 2.58
I was blamed for my HIV status	0.76	0.673	0.21- 2.71	0.57	0.377	0.16- 1.98
People avoided me	0.68	0.557	0.19- 2.44	0.93	0.888	0.34- 2.55
I was asked not to touch someone's child	0.26	0.105	0.05- 1.33	1.49	0.377	0.62- 3.58
I was asked to leave because I was coughing	0.00	1.000	0.00- 0.00	0.52	0.153	2.58-
Self-stigma score^d	1.53	0.352	0.62- 3.78	1.91	0.068	0.95- 3.85
I'm ashamed of having the disease	1.63	0.230	0.74- 3.60	1.69	0.082	0.94- 3.05
I embarrassed my family because of my HIV+ status	1.61	0.289	0.67- 3.87	1.61	0.127	0.87- 2.97
I isolate myself from friends and family because I am HIV+ .	0.99	0.986	0.23- 4.32	1.08	0.894	0.36- 3.21

* Statistical significance $p < 0.05$

^a *score included:* People infected with HIV lose respect in this community; HIV positive children are bullied by other children in this community; People here believe that children should not play with children infected

^b *score included:* Fear of divorce; Fear of losing friends; Fear of damaging the family reputation; Fear of not being able to get married; Fear of being rejected by sexual partners

^c *score included:* I was called bad names; I was told that I would die anytime; I was blamed for my HIV status; People avoided me; I was asked not to touch someone's child; I was asked to leave because I was coughing; I was made to eat alone.

^d *score included:* I'm ashamed of having the disease; I brought a lot of embarrassment to my family because of my HIV+ status

Chapter 10 - Adherence to treatment and retention in care

Determinants of non-adherence and disengagement from ART programmes: findings from Zambia

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Determinants of non-adherence and disengagement from ART programmes: findings from Zambia

10.1 Abstract

Introduction: Retaining HIV-infected patients in care and sustaining high levels of adherence to antiretroviral treatment remains a challenge in most resource-limited settings. Common barriers for adherence are insufficient food, medication side effects, limited social support, fear of stigma and of involuntary disclosure, feelings of depression/hopelessness and wishing to "return to a normal life". But are these the reasons to disengage from ART programmes? Little is known about why people disengage from care. This study compares the effect of behavioural and structural factors on three different levels of compliance (i.e., adherence, non-adherence and full disengagement from care).

Methods: These effects were analysed using multinomial logistic regression models applied to a community and clinical sample in rural and urban areas of Zambia.

Results: Men were more likely to disengage from ART [RRR: 6.26, 95% CI 2.49-15.76], as well as people with low self-efficacy [RRR: 2.00, 95% CI: 1, 44-2.77], self-stigmatization [RRR: 3.53, 95% CI: 1.38 to 9.06] and those with family conflicts [RRR: 2.09, 95% CI 1.28-3.43], and living in highly stigmatizing communities [RRR: 2.03, 95% CI 1.13-3.65]. Risk factors for non-adherence were food insecurity [RRR: 3.26, 95% CI 1.28-8.31], marital conflicts [RRR: 2.01, 95% CI 1.28-3.15] and social pressure [RRR: 2.17, 95% CI 1.23-3.84].

Conclusions: Non-adherence to ART and disengagement from ART programmes are not equally determined and therefore require separate interventions.

10.2 Introduction

Retaining HIV-infected patients in care and sustaining high levels of adherence to antiretroviral treatment (ART) remains a challenge in most resource-limited settings [1-7]. As a consequence, the priorities of the global response to HIV/AIDS have begun to shift from increasing access to HIV treatment to enhancing retention in care.

In Zambia, in 2009, 70% of persons living with HIV/AIDS (PLHA), eligible for treatment, were on ART as compared to 32.9% in 2006 [8]. This remarkable success, however, is threatened by large numbers of people who have problems to adhere and/or who disengage from ART programmes [9, 10]. Common barriers for adherence are insufficient food, side effects, limited social support, fear of stigma and of involuntary disclosure, feelings of depression/hopelessness and wishing to "return to a normal life" [11-18]. But, are these the reasons to disengage from ART programmes? Little is known about why people stop ART and do not return to treatment (disengagement from ART).

To clarify this question, we compared PLHA, eligible for ART, with three different levels of compliance: patients on ART and adherent; patients on ART but non-adherent; and patients who stopped taking ART and did not return to the treatment (disengaged from ART). The results of this study may inform programmes and policies in Zambia which aim to promote optimal compliance and minimize disengagement from ART programmes.

10.3 Methods

Study population and sampling

We recruited 701 HIV positive patients on ART from a health-facility sample. We first applied a probability proportionate to size sampling strategy to primary sampling units (PSU, n=182), that were randomly selected from administrative data in two rural (Mbeza

and Chivuna) and two urban sites (Lusaka and Mazabuka), in the Central and Southern provinces of Zambia. The health-facility sample was derived from all health facilities located within the boundaries of each PSU. Interviews, in the health facilities, were conducted over a predefined period of days, where all clients consulting ART services or Tuberculosis clinics were approached. An additional over-sampling was necessary to identify individuals who disengaged from the ART programmes. To do so, we invited the health clinic staff to contact patients who were lost-to-follow-up (LTFU) and inform them about the opportunity to participate in our study. Patients who agreed to participate were contacted by our research assistants to schedule a time for an interview. They were administered the same questionnaire. The inclusion criteria were to be at least 18 years old, HIV positive eligible for treatment on ART and HIV positive eligible for treatment not on ART who had ever initiated ART.

Measures

The development of the survey instrument has been described in a previous publication [24]. In brief, the questionnaire consisted of closed-ended questions exploring socio-demographic, socio-economic and socio-cultural factors including social cohesion indicators on the community level (within the neighbourhood), on the family level (within the household) and on the couple level.

Adherence was assessed by asking patients three simple questions: In the last month... (i) how long have you been missing your medication?; (ii) how often have you mistaken the doses?; (iii) how often have you mistaken the time to take the medication?. Response categories ranged from: Never, one day, 2-3 days, 1 week, and more than one week. Adherence was considered optimal if patients reported 'never' to all three questions, and suboptimal if they answered otherwise. The use of such a strict definition of adherence was necessary to minimize self-reporting bias.

Disengagement from ART was defined by asking the LTFU participants whether they had restarted ART in another clinic. Those who had not restarted ART were classified as disengaged from care.

Data collection

We conducted the survey between September 2010 and January 2011. A team of 30 trained research assistants administered the questionnaire in the mother tongue of the respondents. Participants who were identified as LTFU were given the choice of being interviewed either at the clinic or in their homes. Reimbursements of transportation costs were given directly to the participants who came to the offices in the clinics. All participants were provided explanations about the study, assured confidentiality, and informed that their participation was voluntary. Written informed consent was obtained prior to conducting the interviews.

Ethical approval was obtained by the Ethikkommission beider Basel (EKBB), Switzerland, and the University of Zambia Humanities and Social Sciences Research Ethics Committee. Permission was also obtained from the Zambian Ministry of Health.

Data analysis

Our goal was to determine whether the factors associated with non-adherence were different from the factors associated with disengagement from care and to ascertain whether treating these two groups as one may lead to misleading statistical results and thus to inaccurate targeting of the population truly at-risk for dropping out of the HIV care system.

In particular, we identified three groups: HIV patients who were enrolled on ART programmes and adherent to the treatment; HIV patients enrolled on ART programmes but not adherent; HIV patients who were disengaged from care. We use a multinomial logit specification to model the likelihood of these three outcomes.

Mathematically, a multinomial logit model is a set of binary logit models, all compared against a base alternative (in our analysis – patients enrolled on ART and adherent). The advantage to fit the model simultaneously, instead of performing three separate logistic regression analyses, is that it provides a more accurate and efficient picture of the data. (25). Each independent variable was simultaneously assessed for association with three outcome categories (adherence, non-adherence and disengaged from care) and for interactions with gender. Variables and interaction terms with significance level at $p < 0.2$ and $p < 0.1$, respectively, associated with at least one of the outcome's categories were retained in a multivariable model. Thereafter we used backward model selection to eliminate non-significant variables. Relative risk ratios (RRR) were computed for each predictor. They should be understood as the ratio of the probability of belonging to the category of interest over the probability of belonging the baseline category (in our case, adherence).

The analysis was conducted in Stata 12 using the `mlogit` command. We also obtained the RRR for the difference between the outcome categories "non-adherent" and "disengaged from care" using the post-estimation command `LINCOM` available in Stata 12 [26]. This command works just like doing a re-estimation of the model with a different reference outcome category.

Ethical considerations

Ethical approval was obtained by the Ethikkommission beider Basel (EKBB), Switzerland, and the University of Zambia Humanities and Social Sciences Research Ethics Committee.. Permission was also obtained from the Zambian Ministry of Health.

10.4 Results

Of the 701 HIV-infected adults who ever initiated ART, 185 (26%) were non-adherent. A total of 256 (37%) individuals who were lost to follow up were recruited. Among them 58 individuals (22.6%) fully disengaged from the treatment programme while the others were on ART in other clinics. Both, 76% among the non-adherent and 79% among the disengaged initiated antiretroviral therapy at least 1 year before the interview. More women (64%) than men (36%) were non-adherent but this difference was minor (53% women and 47% men) for those disengaged from care. Overall, most participants in both outcome categories were in the age group 25 to 44, had completed at least primary education and were in a monogamist marriage. A large percentage (73% of non-adherent and 83% of disengaged) perceived themselves poorer than the others living in the same community and in both categories this perception was higher in women than in men. Unemployment rates were 78% among the non-adherent and 60% among disengaged. This trend was also higher in women than men. Characteristics of the sample can be found in Table 10.1.

Table 10.1 Characteristics of non adherent respondents as compared to fully disengaged from HIV care

Characteristics	Non Adherent N= 185		Disengaged from care N=58	
	Men	Women	Men	Women
Sex	67	118	27	31
Rural	33 (49.3)	65 (55.1)	12 (44.4)	12 (38.7)
Urban	34 (50.7)	53 (44.9)	15 (55.6)	19 (61.3)
Age group				
18-24	2 (3)	13 (11)	2 (7.4)	3 (9.7)
25-34	19 (28.4)	32 (27.1)	8 (29.6)	12 (38.7)
35-44	31 (46.3)	47 (39.8)	9 (33.3)	11 (35.5)
45-54	12 (17.9)	19 (16.1)	4 (14.8)	5 (16.1)
>55	3 (4.5)	6 (5.1)	4 (14.8)	0 (0)
Education level				
None	2 (3)	12 (10.2)	1 (3.7)	3 (9.7)
Primary	28 (41.8)	65 (55.1)	12 (44.4)	13 (41.9)
Secondary	31 (46.3)	38 (32.2)	13 (48.1)	14 (45.2)
Tertiary	5 (7.5)	3 (2.5)	1 (3.7)	0 (0)
Marital status				
Married	48 (71.6)	61 (51.7)	19 (70.4)	12 (38.7)
Polygamist	6 (9)	13 (11)	2 (7.4)	3 (9.7)
Monogamist	40 (59.7)	45 (38.1)	17 (63)	9 (29)
Divorced/Separated	9 (13.4)	15 (12.7)	3 (11.1)	6 (19.4)
Single	6 (9)	16 (13.6)	4 (14.8)	8 (25.8)
Widow	2 (3)	22 (18.6)	1 (3.7)	5 (16.1)
Socio-economic				
Poorer ^a				
Wealthier ^b	47 (70.1)	88 (74.6)	20 (74.1)	28 (90.3)
Unemployed	20 (29.9)	26 (22)	7 (25.9)	2 (6.5)
Employed skilled and unskilled	46 (68.7)	98 (83.1)	15 (55.6)	20 (64.5)
Time on treatment	19 (28.4)	20 (16.9)	12 (44.4)	11 (35.5)
1 to 3 weeks				
1 month	3 (4.5)	2 (1.7)	0 (0)	0 (0)
3 to 6 months	6 (9)	4 (3.4)	2 (7.4)	0 (0)
6 to 11 months	6 (9)	5 (4.2)	1 (3.7)	2 (6.5)
1 year or more	8 (11.9)	7 (5.9)	2 (7.4)	3 (9.7)

Unadjusted multinomial logistic regression analyses

Socio-demographic, socio-economic and structural factors

Being a man (RRR: 1.85; 95%CI: 1.06 - 3.22), employed (RRR: 2.34 95%CI: 1.32-4.15), not owning household amenities (RRR: 2.42; 95%CI: 1.37-4.29) or lacking power to decide on household resources (RRR: 1.58; 95%CI: 1.05-2.38) significantly increased the risk of disengaging from care but had no significant effect on adherence. Factors that increased the risk of non-adherence were lacking food to take with the medicines (RRR: 3.56; 95%CI: 1.74 – 7.29) and not having the money to afford accessing treatment (RRR:

3.94; 95%CI: 0.97 – 16.00). In contrast being older (RRR: 0.98; 95%CI: 0.98-1.00) and living in poor households (RRR: 0.83; 95%CI: 0.70 – 0.98) significantly decreased the risk for non-adherence. A common barrier was having no transport to go to the clinic which considerably increased the risk of non-adherence (RRR: 4.31; 95%CI: 1.96 – 9.46) and disengagement from care (RRR: 3.76; 95%CI: 1.30-10.85). Table 10.2 summarizes these results in more detail.

Table 10.2 Unadjusted relative risk ratios (RRR) for socio-demographic and socio-economic factors

OUTCOME	<i>Category 1</i> Non-adherent			<i>Category 2</i> Disengaged from care		
	RRR	P	95% CI	RRR	P	95% CI
Socio-demographic and socio-economic predictors						
Urban	0.88	0.464	0.63-1.24	1.40	0.229	0.81-2.44
Men	1.20	0.316	0.84-1.72	1.85	0.030	1.06-3.22
Age	0.98	0.044	0.97-1.00	0.98	0.118	0.95-1.01
Tertiary education	1.11	0.563	0.78-1.58	1.68	0.067	0.96-2.93
Employment	0.97	0.872	0.64-1.47	2.34	0.004	1.32-4.15
My household is poorer as compared to neighbours ^a	0.83	0.025	0.70-0.98	1.17	0.249	0.89-1.54
I do not own any household amenities	1.11	0.560	0.78-1.57	2.42	0.002	1.37-4.29
Decision making power over household resources	1.27	0.086	0.97-1.66	1.58	0.028	1.05-2.38
Food insecurity	0.86	0.174	0.69-1.07	1.09	0.616	0.77-1.56
I do not have the food to take with the medicines	3.56	0.001	1.74-7.29	1.81	0.318	0.57-5.78
I do not have the money to afford the treatment	3.94	0.055	0.97-16.00	4.20	0.122	0.68-25.92
I do not have the transport to go to the clinic for refill	4.31	0.000	1.96-9.46	3.76	0.014	1.30-10.85

^a Self-perception of wealth as compared to other households in the community (score 1 to 5 in a Likert scale)

Social relationships and cohesion

The RRR reported in this section refer to a one-level increase on the respective 5-level Likert scale.

Having the support of family (RRR: 0.39; 95%CI: 0.20 – 0.75) and friends (RRR: 0.27; 95%CI: 0.14 – 0.52) to be on treatment decreased the risk of disengaging from care. Instrumental support such as being reminded by someone to take medication decreased the risk of both, non-adherence (RRR: 0.62; 95%CI: 0.43 – 0.91) and disengagement (RRR: 0.47; 0.25-0.83). Being discouraged to take ARVs by close colleagues doubled the risk of both, non-adherence (RRR: 2.71; 95%CI: 1.66 - 4.42) and disengagement from care (RRR: 2.60; 95%CI: 1.24-5.44). On the household level, marital conflicts increased the risk of disengaging from care (RRR: 1.48; 95%CI: 1.14-1.91) while conflicts within the family (with other household members than the husband/wife) increased the risk for non-adherence (RRR: 1.40; 95%CI: 1.18 - 1.66). High tolerance of domestic violence increased the risk of both, non-adherence (RRR: 1.30; 95%CI: 1.07 - 1.59) and disengagement (RRR: 1.39; 95%CI: 1.04 - 1.86). At community level, conflictive relationships between neighbours (RRR: 1.24; 95%CI: 1.05 - 1.46) and not attending religious services (RRR: 1.26; 95%CI: 1.01 - 1.58) increased the risk of non-adherence. In contrast regular participation in community activities (RRR: 0.64; 95%CI: 0.45 - 0.91) decreased the risk for non-adherence. Table 10.3 displays the RRR of these bivariate analyses.

Table 10.3 Unadjusted relative risk ratios (RRR) for interpersonal and social support factors

OUTCOME	<i>Category 1</i> Non-adherence			<i>Category 2</i> Disengaged from care		
	RRR	P	95%CI	RRR	P	95%CI
Interpersonal and social support predictors						
<i>Individual level</i>						

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Number of family contacts	1.01	0.823	0.96-1.05	1.07	0.042	1.00-1.14
Number of trusted friends	1.00	0.951	0.93-1.07	0.88	0.097	0.75-1.02
Being reminded by someone to take the treatment	0.62	0.013	0.43 - 0.91	0.47	0.009	0.25 - 0.83
Being discouraged by close persons to take the treatment	2.71	0.000	1.67-4.42	2.60	0.011	1.24-5.44
Having the support of my spouse/partner to take the treatment	0.92	0.767	0.53 - 1.59	0.39	0.005	0.20 - 0.75
Having the support of my family and friends to take the treatment	0.94	0.836	0.53 - 1.68	0.27	0.000	0.14 - 0.52
Household (Family/ Couple) level						
Couple conflicts score ^a	1.06	0.515	0.88-1.28	1.48	0.003	1.14-1.91
Lack of couple support in times of crisis	1.00	0.959	0.84-1.18	1.14	0.267	0.90-1.45
Couple do not get along well	1.12	0.262	0.92-1.35	1.65	0.000	1.29-2.10
I do not trust my partner	1.13	0.137	0.96-1.34	1.15	0.273	0.89-1.48
I do not feel very supported in my relationship	1.13	0.139	0.96-1.33	1.34	0.014	1.06-1.70
Family conflicts score ^b	1.40	0.000	1.18-1.66	1.32	0.039	1.01-1.72
Lack of support from family members	1.23	0.012	1.04-1.43	1.21	0.121	0.95-1.55
Family members do not get along well	1.29	0.000	1.12-1.48	1.19	0.113	0.95-1.48
Domestic violence score ^c	1.30	0.008	1.07-1.59	1.39	0.028	1.04-1.86
Tolerance to interpersonal violence	0.84	0.061	0.70-1.00	0.75	0.028	0.58-0.97
Tolerance to gender based violence	1.29	0.006	1.07-1.55	1.30	0.070	0.98-1.72
Community level						
Does not attend religious services	1.26	0.039	1.01-1.58	1.33	0.094	0.95-1.86
Participate in community activities	0.64	0.014	0.45-0.91	0.82	0.477	0.47-1.42
Tolerance of drunkenness in neighbourhood	0.87	0.039	0.76-0.99	1.07	0.568	0.84-1.36
Bad relationship with neighbours	1.24	0.011	1.05-1.46	1.25	0.078	0.97-1.61

^a score included: In times of crisis I cannot count on my spouse/partner for support; I do not get along well with my spouse/partner; I do not trust my spouse/partner; I do not feel supported at home

^b score included: In my household people support you only if they can gain something out of it; In my household people do not get along well with each other

^c score included: If someone in the household misuses money it is acceptable to beat him/her; In my household if a wife comes home late without the permission of the husband she will be beaten.

Knowledge and practices related to HIV and ARVs

Limited knowledge about HIV/AIDS and ARVs considerably increased the risk of both, non-adherence (RRR: 3.66; 95%CI: 1.39 - 9.69) and disengagement from care (RRR: 5.93; 95%CI: 1.61 – 21.76). Alcohol abuse, increased the risk of disengaging from care (RRR: 1.41; 95%CI: 1.13 - 1.72) but was not related to adherence. Reliance on traditional medicines increased the risk of both, non-adherence (RRR: 1.55; 95%CI: 1.07 - 2.24) and disengagement (RRR: 1.82; 95%CI: 1.07 – 3.08) while conspiracy beliefs (RRR: 1.22; 95%CI: 1.02 - 1.46) was only associated with non-adherence. Table 10.4 summarizes the results of these bivariate analyses.

Table 10.4 Unadjusted relative risk ratios (RRR) for Health behavior, literacy and beliefs determinants factors

OUTCOME	Category 1 Non-adherent			Category 2 Disengaged from care		
	RRR	P	95%CI	RRR	P	95%CI
Health behavior, literacy and beliefs predictors						
Alcohol abuse (own problem)	1.11	0.174	0.95-1.30	1.40	0.002	1.13-1.72
Having many sexual affairs	1.08	0.253	0.95-1.24	1.12	0.124	0.97-1.30
The drug makes me sick	2.49	0.023	1.13-5.47	0.93	0.926	0.20-4.28
ARVs literacy score ^a	3.66	0.009	1.39-9.69	5.93	0.007	1.61-21.76
ARVs can make sick	2.06	0.021	1.12-3.80	2.61	0.026	1.12-6.07
ARVs are not good for children	1.27	0.527	0.60-2.69	3.21	0.008	1.35-7.63
ARVs can make impotent	0.84	0.798	0.22-3.15	1.87	0.432	0.39-8.91
ARVs can kill	2.30	0.011	1.21-4.37	1.84	0.238	0.67-5.07
Traditional medicine reliance score ^b	1.55	0.020	1.07-2.24	1.82	0.027	1.07-3.08
TM relief symptoms of HIV	1.35	0.009	1.08-1.69	0.88	0.527	0.58-1.32
TM can cure HIV/AIDS	1.18	0.233	0.90-1.56	0.67	0.120	0.41-1.11
TM are easier to take	1.12	0.328	0.89-1.42	0.98	0.940	0.66-1.46
TM are easier to access	1.31	0.017	1.05-1.64	1.66	0.001	1.24-2.23
Being told to stop by traditional healers	3.35	0.005	1.43-7.83	0.62	0.658	0.08-5.04
Have ever been discouraged to take ARVs	2.71	0.000	1.66-4.42	2.60	0.011	1.24-5.44
Conspiracy beliefs score ^c	1.22	0.026	1.02-1.46	0.93	0.720	0.65-1.35
Genocide	1.10	0.308	0.91-1.33	1.16	0.33	0.86-1.57
Guinea pigs	1.16	0.072	0.99-1.38	0.63	0.082	0.37-1.06

^a score included: ARVs can make sick; ARVs are not good for children; ARVs can make impotent; ARVs can kill

^b score included: TM can cure HIV/AIDS; TM are easier to take; TM are easier to access

^c score included: HIV/AIDS was release to eradicate the black race; People who take ARVs are guinea pigs for the government

Treatment-related and psychological factors

Respondents who were on treatment for more than a year were at higher risk of being non-adherent (RRR: 1.21; 95%CI: 1.02 - 1.43) and also of disengaging from care (RRR: 1.52; 95%CI: 1.07 - 2.15). Not participating in HIV support groups almost doubles the risk of disengagement (RRR: 1.92; 95%CI: 1.00 - 3.68) but was not associated with adherence. Participants who experienced treatment side effects were at higher risk of not adhering (RRR: 2.49; 95%CI: 1.13-5.47) but no association was observed with disengagement from care. The effect of low self-efficacy differed by sex. Men who perceived themselves as having low self-efficacy were at increased risk of both non-adherence (RRR: 1.17; 95%CI: 1.02-1.35) and disengagement (RRR: 1.52; 95%CI: 1.27-1.82). Yet women with low self-efficacy were at an increased the risk of disengaging (RRR: 1.26; 95%CI: 1.06 – 1.50).

Seeing someone on ART who recovered decreased the risk of disengaging from care (RRR: 0.49; 95%CI: 0.24-0.99). In contrast seeing people on ART who died doubled the risk for non-adherence (RRR: 2.35; 95%CI: 1.02 – 5.41). We display these results in Table 10.5.

Table 10.5 Unadjusted relative risk ratios (RRR) for Treatment-related and psychological factors

OUTCOME	<i>Category 1</i> No adherent			<i>Category 2</i> Disengaged from care		
	RRR	P	95% CI	RRR	P	95% CI
Treatment-related predictors						
Time on treatment	1.21	0.025	1.02-1.43	1.52	0.019	1.07-2.15
Time receiving food supplement (the longest)	0.80	0.230	0.56-1.15	1.31	0.454	0.65-2.67
Food supplement length men	0.90	0.445	0.70-1.17	1.06	0.768	0.71-1.58
Food supplement length women	0.99	0.911	0.81-1.20	0.70	0.085	0.46-1.05
Do not participate in HIV support groups	1.10	0.632	0.75-1.61	1.92	0.051	1.00-3.68
Low Self efficacy _sc ^a	1.14	0.068	0.99-1.31	2.26	0.000	1.82-2.80
Fear of medication forever	1.10	0.109	0.98-1.24	1.72	0.000	1.45-2.04
Fear of side effects	1.08	0.256	0.95-1.23	2.09	0.000	1.73-2.52
Fear of not being able to face a life as a HIV+ person	1.13	0.049	1.00-1.27	1.96	0.000	1.64-2.35
Low Self efficacy's men	1.17	0.030	1.02-1.35	1.52	0.000	1.27-1.82
Low Self efficacy's women	0.96	0.577	0.85-1.09	1.26	0.009	1.06-1.50
Seeing someone on ART who recovers	0.76	0.276	0.46-1.24	0.49	0.048	0.24-0.99
I saw someone on ART who die	2.35	0.044	1.02-5.41	2.36	0.158	0.72-7.81

^a score included: Fear of having to take medication forever; Fear of side effects; Fear of not being able to handle a life as an HIV positive person

Stigma and discrimination factors.

People who are afraid of involuntary disclosure of their HIV positive status had almost five times the risk of not being adherent (RRR: 4.54; 95%CI: 2.21 - 9.32) and more than eight times the risk of disengaging from care (RRR: 8.57; 95%CI: 3.69 - 19.89) than those who did not fear that others knew about their HIV status. The effect of experienced discrimination also have a strong effect increasing five fold the likelihood of disengaging from care (RRR: 5.85; 95%CI: 1.83 - 18.68) yet with no effect on adherence. The indicator of discrimination that accounted for most of this effect was "I was asked to leave because I was coughing" (RRR: 6.80; 95%CI: 3.39 - 13.66) which related to instrumental stigma (fear of contagion) rather than to symbolic stigma (moral judgements of HIV positive people). With regards to internal stigma, self-stigma increased the risk of non-adherence (RRR: 1.82; 95%CI: 1.18 - 1.83) and moreover disengagement from care (RRR: 5.96; 95%CI: 3.11-11.43). Expected community stigma also increased the risk of both, non-adherence (RRR: 1.24; 95%CI: 1.03 - 1.49) and disengagement (RRR: 2.25; 95%CI: 1.74 - 2.91). Fear of community gossip had a similar effect on non-adherence (RRR: 1.12; 95%CI: 1.00 - 1.26) and disengagement (RRR: 1.58; 95%CI: 1.33-1.88). Similar to self-stigma, expected stigma was linked to a greater risk for disengagement from care. Being afraid of social rejection, defined as a composite score of fear of divorce, of losing friends, of damaging the family reputation, of not being able to get married and of being rejected by sexual partners increased the risk of both, non-adherence (RRR: 1.23 ;95%CI: 1.07 - 1.41) and LTFU(RRR: 1.62 ;95%CI: 1.33 - 1.98). Table 10.6 shows the results of these bivariate analyses.

Table 10.6 Unadjusted relative risk ratios (RRR) for Stigma and discrimination factors

OUTCOME	Category 1	Category 2
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Stigma and Discrimination	No adherent			Disengaged from care		
	RRR	P	95% CI	RRR	P	95% CI
Fear of community gossip	1.12	0.051	1.00-1.26	1.58	0.000	1.33-1.88
I do not want others to notice	4.54	0.000	2.21-9.32	8.57	0.000	3.69-19.89
Fear of Social rejection score ^a	1.23	0.004	1.07-1.41	1.62	0.000	1.33-1.98
Fear of divorce	1.19	0.004	1.06-1.33	1.37	0.000	1.15-1.62
Fear of losing friends	1.11	0.110	0.98-1.27	1.46	0.000	1.22-1.75
Fear of damaging the family reputation	1.13	0.083	0.98-1.29	1.69	0.000	1.41-2.01
Fear of not being able to get married	1.15	0.020	1.02-1.30	1.48	0.000	1.25-1.76
Fear of being rejected by sexual partners	1.15	0.016	1.02-1.29	1.37	0.000	1.16-1.61
Expected stigma score ^b	1.24	0.021	1.03-1.49	2.25	0.000	1.74-2.91
People with HIV lose respect in this community	1.14	0.055	1.00-1.30	1.43	0.000	1.17-1.74
Children bullied	1.20	0.019	1.03-1.41	2.08	0.000	1.68-2.58
Children should not play with children infected	1.08	0.418	0.90-1.28	1.88	0.000	1.51-2.35
Self-stigma score ^c	1.82	0.007	1.18-2.83	5.96	0.000	3.11-11.43
I'm ashamed of having the disease	1.74	0.004	1.19-2.53	3.63	0.000	2.05-6.43
I brought a lot of embarrassment to my family because of my HIV+ status	1.47	0.059	0.99-2.18	5.06	0.000	2.82-9.09
I isolate myself from friends and family because of my HIV+ status.	0.31	0.000	0.17-0.58	0.25	0.002	0.10-0.61
Discrimination score ^d	2.04	0.129	0.81-5.14	5.85	0.003	1.83-18.68
I was called bad names	1.14	0.765	0.48-2.69	0.95	0.945	0.21-4.23
I was told that I would die anytime	0.88	0.781	0.36-2.14	1.77	0.318	0.58-5.42
I was blamed for my HIV status	1.19	0.583	0.65-2.18	1.17	0.758	0.44-3.13
People avoided me	1.80	0.038	1.03-3.14	3.42	0.001	1.64-7.14
I was asked not to touch someone's child	1.54	0.299	0.68-3.46	1.55	0.500	0.43-5.50
I was asked to leave because I was coughing	2.25	0.006	1.26-4.01	6.80	0.000	3.39-13.66
I was made to eat alone	1.28	0.493	0.64-2.56	3.55	0.003	1.55-8.15

^a score included: Fear of divorce; Fear of losing friends; Fear of damaging the family reputation; Fear of not being able to get married; Fear of being rejected by sexual partners

^b score included: People infected with HIV loose respect in this community; HIV positive children are bullied by other children in this community; People here believe that children should not play with children infected

^c score included: I'm ashamed of having the disease; I brought a lot of embarrassment to my family because of my HIV+ status

^d score included: I was called bad names; I was told that I would die anytime; I was blamed for my HIV status; People avoided me; I was asked not to touch someone's child; I was asked to leave because I was coughing; I was made to eat alone.

Adjusted multinomial logistic regression analyses

Determinants of non-adherence compared to adherence

Living in a poor household [RRR: 1.53; 95% CI 0.95 to 2.45] and not having enough food to take with ART [RRR: 3.29; 95% CI 1.30 to 8.36] were associated with an increased likelihood of non-adherence. Receiving food supplements was associated with a decreased risk of non-adherence [RRR: 0.58, 95% CI 0.37-0.89]. Participants, who were longer enrolled on ART programme, for at least one year, were more likely to be non-adherent [RRR: 1.28; 95% CI: 1.04-1.57]. The feeling of low self-efficacy was not associated with adherence but those who reported feeling under intense peer pressure to stop ART [RRR: 2.17; 95% CI: 1.23-3.84] were more likely to be non-adherent. We found an interaction between the level of stigma in the community and marital conflicts. In communities with high levels of stigma, marital conflicts did not show any significant association with non-adherence; however in communities where stigma was lower, marital conflicts were strongly associated with an increased likelihood of non-adherence [RRR: 2.01, 95% CI: 1.23 to 2.28].

Determinants of disengagement from care:

Compared to adherence

Men were more likely than women to disengage from ART programmes [RRR: 6.26; 95% CI 2.49 to 15.76] as compared to the adherent group. Factors that increased the likelihood of being disengaged from care, as compared to being adherent, were taking ART for at least for one year [RRR: 2.27; 95% CI: 1.28-4.02], low levels of self-efficacy [RRR: 2.15; 95% CI: 1.56-2.97] and high levels of self-stigma [RRR: 3.53, 95% CI: 1.38 to 9.06] and community stigma [RRR: 2.03; 95%CI: 1.13-3.65]. Marital conflicts were strongly

associated with an increased likelihood of being disengaged from care [RRR: 2.09, 95% CI: 1.28 to 3.43] especially in communities with high levels of stigma. Poverty related factors were not significantly associated with disengagement from care.

Compared to non-adherence

The third column of the table 10.7 presents the factors by which the probability of belonging to the group disengaged from ART differs from the probability of belonging to the non-adherent group. Men were almost five times more likely (than women) to be disengaged from ART [RRR: 4.57; 95% CI: 1.75-11.92] as compared to the non-adherent group. Factors associated with an increased probability of belonging to the group of patients disengaged from care, as compared to the non-adherent group, were being on ART for at least one year [RRR: 1.71; 95% CI: 0.93-3.14], low levels of self-efficacy [RRR: 2.39; 95% CI: 1.68-3.40] and high levels of self-stigma [RRR: 2.24, 95% CI 0.82 to 6.08] and community stigma [RRR: 2.37, 95% CI 1.27 to 4.40] Family conflicts were associated with an increased risk for being disengaged from care in communities with high levels of stigma. However in communities with low levels of stigma this effect was the opposite and the same effect was found for marital conflicts. Living in poor households [RRR: 0.33, 95% CI: 0.11-0.98] and not having the food to take with ARVs [RRR: 0.03, 95% CI 0.00 to 0.38] were also associated with a decreased likelihood of being disengaged from care as compared of being non-adherent.

Table 100.7 Adjusted relative risk# ratios (RRR) between different levels of compliance

	Non-adherence			Disengaged from care					
	<i>against Adherence</i>			<i>against Adherence</i>			<i>against Non-adherence</i>		
	RRR	P	95%CI	RRR	P	95% CI	RRR	P	95% CI
Men	1.37	0.169	0.88-2.14	6.26	0.000	2.49-15.76	4.57	0.002	1.75-1.92
Self-perceived wealth	1.53	0.080	0.95-2.45	0.50	0.208	0.17-1.47	0.33	0.047	0.11-0.98
Community stigma score ^a	0.86	0.375	0.62-1.20	2.03	0.017	1.13-3.65	2.37	0.007	1.27-4.40
High com stigma × marital conflict ^b	0.93	0.765	0.57-1.50	1.29	0.463	0.66-2.52	1.38	0.366	0.68-2.80
Low com. stigma × marital conflict	2.01	0.002	1.28-3.15	0.71	0.313	0.37-1.38	0.35	0.002	0.18-0.68
High com. stigma × family conflict ^c	0.96	0.764	0.74-1.25	2.09	0.003	1.28-3.43	2.17	0.004	1.28-3.69
Low com. stigma × family conflict	1.27	0.064	0.99-1.62	0.55	0.041	0.31-0.98	0.44	0.006	0.24-0.79
Self-stigma score ^d	1.58	0.100	0.92-2.71	3.53	0.009	1.38-9.06	2.24	0.113	0.82-6.08
Low Self-efficacy score ^e	0.84	0.081	0.68-1.02	2.00	0.000	1.44-2.77	2.39	0.000	1.68-3.40
Time on ART	1.28	0.022	1.04-1.57	2.18	0.010	1.21-3.94	1.71	0.084	0.93-3.14
Being discouraged to take ART	2.17	0.008	1.23-3.84	2.30	0.111	0.83-6.41	1.07	0.913	0.37-3.03
Not having food to take ARVs	3.29	0.012	1.30-8.36	0.09	0.067	0.01-1.19	0.03	0.007	0.00-0.38
Receiving food packages	0.58	0.014	0.37-0.89	0.91	0.826	0.41-2.06	1.59	0.296	0.66-3.76

Relative risk refers to the factor by which the probability of belonging to the category of interest differs from the probability of belonging to the reference category.

^a *score included:* People infected with HIV loose respect in this community; HIV positive children are bullied by other children in this community; People here believe that children should not play with children infected

^b *score included:* In times of crisis I cannot count on my spouse/partner for support; I do not get along well with my spouse/partner; I do not trust my spouse/partner; I do not feel supported at home

^c *score included:* In my household people support you only if they can gain something out of it; In my household people do not get along well with each other

^d *score included:* I'm ashamed of having the disease; I brought a lot of embarrassment to my family because of my HIV+ status

^e *score included:* Fear of having to take medication forever; Fear of side effects; Fear of not being able to handle a life as an HIV positive person

10.5 Discussion

Non-adherence and disengagement from care are two different but interrelated phenomena with different influencing factors. In our study, time on ART, was the only factor associated with both, non-adherence and disengagement from care, which is consistent with previous research [30, 31]. Our research confirms the findings of other studies showing that the nature and characteristics of a patient's social support system greatly influence one's ability to adhere to ART [27-29]. The presence of intra-family conflicts was a strong risk factor for disengagement from ART, especially in highly stigmatizing communities. Marital conflicts, however, were a stronger risk for non-adherence, even when the levels of community stigma were low. Men were more likely to disengage from care as compared to women which is consistent with previous research [32-37]. The reason for this could be attributed to their non-participation in support groups and because of the difficulties to balance access to treatment and livelihood activities as reported in a previous study [18]. Unexpectedly patients with lower socio-economic status were less likely to disengage from care, possibly because they expected some kind of material support such as food packages. Our results confirm the findings of other studies showing that the provision of food rations enhanced medication adherence [11, 12] and additionally shows that food aid also has the potential to improve engagement in care.

Some factors were significant in bivariate analyses but not in the adjusted ones: side effects, lack of transport to go to the clinic, alcohol abuse and traditional medicine beliefs. All of these factors have been established as barriers to adherence [38-40] but, in our study, food insecurity, stigma problems, marital conflicts and self-efficacy issues outweighed their effect. We have confirmed the importance of social factors over financial limitations [41- 43] and it's worth noting that the fear of side effects was a trait included in

our self-efficacy score which indicates that the anticipation of this problem indeed hindered both, adherence and retention in care.

While ART adherence has been widely studied in both high- and low income countries [44-46], there are fewer studies that examine engagement in ART programmes [18, 42, 43, 47-49]. To our knowledge there is only one study from Kenya [50] which proposed a similar analysis distinguishing between adherence and retention in care. We additionally conducted a comparative assessment between non-adherence and disengagement from care to explore factors associated with the probability of belonging to one group or the other.

However the cross-sectional design limits our capacity to establish causal relationships between risk factors and outcome categories. Longitudinal studies are therefore needed to clarify potential causal relationships between livelihood insecurity, community stigma and marital conflicts with non-adherence and disengagement from ART. These studies urgently need to include a gender perspective to explore why men are at higher risk of disengaging from care.

Another limitation of our study stems from the assessment of non-adherence which was based on self-reports and it may be subject to recall and social desirability bias resulting in underestimation of non-adherence. However previous studies confirmed that using patient reports is a satisfactory way of measuring adherence [51-54] and our study reported similar rates to those of national surveys [55]. Thus we are confident that this bias was minimized. Social desirability bias was reduced by employing interviewers independent of the hospitals and clinics staff. The strengths of this study are clear definitions of non-adherence, LTFU and disengaged from care and the very high survey response rate.

10.6 Conclusion

Adherence to ART and retention in care, although related, are not the same phenomenon thus requiring interventions with different approaches. For example, food assistance may be essential to complement ART programs and improve adherence to treatment. Interventions aimed at improving patient retention in care might be more successful if they integrate a gender perspective [mainly focused on men]. In parallel, the use of a community-based approach is critical to address community stigma and resolve conflicts within the family and the couple, which are persistent barriers of adherence and engagement to ART. These barriers, however, are based on social institutions and norms, such as gender norms, social customs or even family law. To mitigate some of these effects there is a continued need to mobilize the community, with concomitant interventions in the policy and regulatory area that can help to create non-discriminatory contexts in which people living with HIV/AIDS are able to care for their health over the longer term without having to pay a high social price. The commitment of the Government of Zambia to strengthen its health system and the adoption of free access to ART has certainly had implications on the results of our study. In Zambia financial constraints related to the cost of treatment no longer seem to be major barriers to care. Rather food insecurity, social stigma and lack of social support, mostly related to marital conflicts, seem to be the primary impediments to adherence and engagement in Art programmes.

Reducing gender inequalities through interventions focused on individuals but also on families and communities, as well as continues providing food aid to vulnerable groups needs to be a central feature of any strategy for improving adherence and retaining patients in ART in Zambia.

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Author Contributions

Conceptualized and designed the experiments: SM, AMH. Contributed to the conceptualization of the study: JRSM, MM, CS. Performed the data collection: SG, MM. Analyzed and interpreted the data: SG. Contributed to analysis of the data: CS. All authors contributed to the final publication. Wrote the paper: SG. Principle investigator: SM.

Competing Interests The authors declared they have no competing interests

10.7 References

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Chapter 11 - Discussion and conclusions

11.1 Methodological issues

Strengths

The strength of this thesis is the use of robust data collection methods and tools adapted to the Zambian context. The carefully designed questionnaire yielded a very satisfactory response rate (98.6%). The development of the social cohesion indicators was guided by the results of an ethnographic study conducted in the same areas. This made possible the definition of complex measures of social cohesion at the level of the couple, the family and the community, which have enabled a relatively deep exploration of this construct in Zambia. As a consequence, the analyses carried out allowed to capture a broad picture of the complex interplay between the different levels of social cohesion and access to HIV/AIDS care.

Logistics and resources constraints were the largest difficulties to collect data, especially in remote rural areas. Close collaboration with community leaders and the employment of local people as field assistants have been crucial to overcome these challenges. In particular, field assistants were central to maximize the use of available resources and establish contact with hard-to-reach population as they knew the local social settings well.

Limitations

From a theoretical perspective, it is considered that cohesion within the couple, the family and the community can affect health and access to HIV/AIDS services. However, the actual causal direction can only be tested and verified through a prospective study. Following a cross-sectional analysis, this study faces the limitation of not allowing to draw causal relationships. There are some plans to overcome this in forthcoming studies based on longitudinal follow-up.

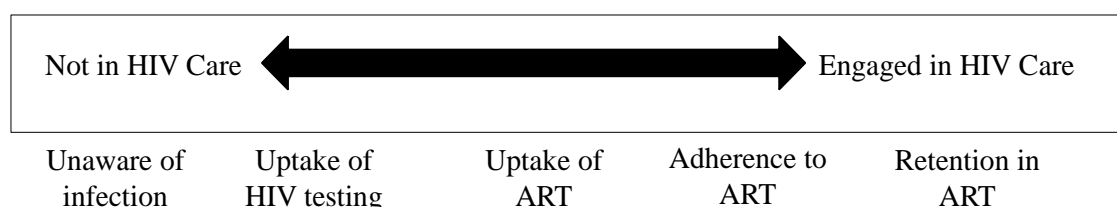
These study analyses determinants of access to HIV / AIDS services, therefore the indicators used to measure social cohesion represent proxies and do not provide a complete measure of the social cohesion construct. Nonetheless, the indicators are well adapted to the context in Zambia and can serve as a starting point for the development of a scale that captures all dimensions of social cohesion in Zambia.

11.2 Discussion of results and overall conclusions

This section discusses the contribution of the previous chapters to answer the main question of this thesis: In Zambia, does social cohesion have an influence on access to HIV/AIDS services?

In reading this chapter, it is important to keep in mind that the definition of social cohesion chosen for this thesis reflects “*the collective action networks of trust and solidarity of society, whether through regulated, authority driven systems or networks of trust and reciprocity*” (Lowenson, 2007; Barnett et al., 2002; Decosas, 1998, 2002). For the purpose of this study, relationships of trust, solidarity and reciprocity have been studied on three different levels: the couple, the family and the community³. As illustrated in the figure below, access to HIV/AIDS services has been understood as a continuum of successive stages in which individuals must balance many factors for making a choice.

Figure 11.1 Continuum of HIV care



Note: Adapted from Gardner et al. (2011).

³ I.e. relationships within the villages - rural - and neighbourhoods - urban.

The following sub-sections detail the complex interplay of social and structural factors that have been found to influence access to HIV/AIDS services. To facilitate understanding, the findings are presented along the continuum of HIV care (HIV testing, uptake of ART, adherence to ART and retention in care).

11.2.1 Key findings on factors influencing access to HIV testing

Chapter 7 of this thesis investigate factors that influence uptake of HIV testing. The analysis has led two major findings. Firstly, the study shows that **marital conflicts and high rates of tolerance to gender-based violence within the household are associated with non-uptake of HIV testing**. This effect persists even when people who reported changes in their couple's relationship after being tested are removed from the analysis. So, we can be confident that, in this study, marital conflicts are not a consequence of testing but a preceding characteristic of the relational dynamics of the couple. Secondly, the study shows that, **high levels of stigma are associated with non-uptake of testing and more common in dis cohesive communities**. The findings in Chapter 7 show that stigma, indicated by fear of social rejection, increases the probability of not getting tested; however fear of gossip, a powerful indicator of social control in a community, positively influences the uptake of testing. Furthermore fear of social rejection is higher in communities where neighbours have conflicts among them and do not trust each other.

Marital conflicts and tolerance to violence against women is often a reflection of prevailing social norms with respect to gender and power relations in a community. In Zambia, the last DHS (2007) shows that, up to 62% of women and 48% of men believe that "it is justified that a husband hits or beats his wife under certain circumstances".

Several studies in Africa have shown that power imbalances in a couple deter uptake of HIV testing in women (Tolhurst et al., 2002; Tolhurst et al., 2008; Musheke, 2013) and that partner support and communication improves uptake of testing (Bajunire and Muzoora 2005; Sarker et al 2007). There is also evidence showing that gender-based violence increases vulnerability to HIV infection and sexual risk, possibly linked through the abuse of alcohol (Jewkes et al., 2010). The results of this thesis are consistent with these findings and further enlarge the evidence showing that not only enacted violence adds to the burden of HIV but that tolerance of gender-based violence in the household can compromise the effectiveness of HIV prevention strategies.

This thesis argues that interventions to scale up testing through couple VCT are well oriented and should be strengthened as they provide an opportunity to address these problems. However, those who do not go for VCT cannot benefit from these efforts. Community outreach activities should also be encouraged and aimed at bringing social change especially in attitudes based on ideas of male superiority. Existing studies suggest that the most promising interventions to reduce tolerance to gender-based violence promote non-violence and gender-equitable norms among boys and men. Examples of initiatives that succeeded in bringing about norm change in this area are Stepping Stones in Gambia (Shaw & Jawo, 2000) and ReproSalud in Peru (Rogow & Bruce, 2000). They used peer-education approaches to mobilize communities and bring members together to discuss the issue of violence within more comprehensive peer workshops. A common feature of these programmes is that they are particularly careful not to focus on negative messages but encouraging cohesion among men for non-violence and the creation of spaces for dialogue in the community for women and men to discuss about their concerns.

In addition to the implementation of strategies to change social norms, it is crucial that, in Zambia, the relevant existing policy and legislative framework is correctly translated into practice. For instance, several reports prepared by human rights organizations (OMCT 2002, 2007) claim that, although the government has established special units to respond to violence against women, persistent discriminatory attitudes in the police and judiciary system prevent women from reporting violence and women are regularly pressured by officials to drop the charges and/or to reconcile with their abusive husbands.

In summary, the strategy to scale up HIV testing in Zambia needs to prioritize interventions aimed at promoting social cohesion to reduce tolerance to gender-based violence in the community and broader political efforts to enforce laws related to gender-based violence.

This thesis also shows that, despite increased availability of HIV/AIDS services, stigma in the community still undermine uptake of HIV testing. In Chapter 7, it is reported that fear of social rejection increases the probability of not getting tested. Surprisingly, fearing that “people gossip about me”, initially considered an indicator of stigma, showed a positive effect as it was associated with an increased uptake of HIV testing. Gossip, rather than trivial talking, is an effective means of social control and moral instruction in a community (Gluckman, 1963; Hannerz, 1967; Sabini, 1982; Andreasen, 1998; Dunbar, 1992; Besnier, 1994; White, 2000). In the context of HIV, it has been reported (Stadler, 2003) that in South-African communities with high prevalence of HIV, gossip is used to obtain/spread information deemed as relevant to protect from HIV infection, e.g. asking around to find out more about the sexual behaviour of a person before start dating. This information, indirectly, “educate” people about socially acceptable behaviours in a community.

The finding that stigma and social control (indicated by the level of gossip) have opposite effects suggests that they may represent different social processes yet intertwined. Gossip may be a mechanism by which stigma is operationalized in the community. Furthermore, it was found that high levels of stigma are more common in dis cohesive communities. This suggests that communities with high social cohesion and high social control may be more able to integrate rather than exclude people or groups whose behaviours have been "socially unacceptable". The theoretical basis for this can be found in diffusion theory (Rogers, 1995), a theory that explains how a new idea or behaviour is spread throughout a population using interventions such as social media, opinion leaders and change agents. Community-based interventions that promote social cohesion combined with diffusion-based interventions such as popular opinion leaders promises to be an effective strategy to overcome stigma and discrimination. Evidence shows that the most effective interventions are those in which the affected communities have mobilized to fight stigma and discrimination (Esu et al, 2006; Solorzano et al., 2008, Nyblade et al., 2008). Models based on popular opinion leaders have also proved effective in reducing the risk of HIV among men who have sex with men and women with low socio-economic status (Moreau et al., 2007; Young et al., 2011).

11.2.2 Key findings on factors influencing uptake of ART

Chapter 8 investigates factors that influence uptake of ART and shows that **the effect of social cohesion on uptake of ART is different for men and women**. While *dis cohesive communities* are strongly associated with uptake of ART in men, poverty and livelihood insecurities are the major obstacles to uptake of ART in women. It has also, been found that *participation in community activities* facilitates access to treatment in women and thus can compensate poverty and livelihood insecurities. In men, however, participation in

community activities, has an opposite effect which can be explained by men's concerns about the impact of poor health and side effects on their reputation (ill-health may be seen as reducing a man's status in the social hierarchy).

The finding of the different effect of social links in the community confirms results of previous studies such as Campbell, Williams and Gilgen (2002). These authors investigated the links between sexual health and social capital in South African mining communities and found that belonging to a number of networks could be positive or negative for sexual health and that these effects were different for men and women. This may be related to underlying concepts of masculinity. Evidence has showed that health seeking behaviour is associated with a set of social acts and practices that simultaneously demonstrates and construct gender (Hausmann-Muela Muela Ribera and Nyamongo, 2003; Mackian and Bedri, 2004). Studies from South Africa (Beck, 2004; Hunter, 2005; Harrison et al, 2006), Namibia (Brown, Sorrel and Raffaelli, 2005) and Zambia (Simpson, 2005) have reported that men tend to think about ill-health as a sign of weakness. This links to the finding of this thesis showing that fear of side effects is strongly associated with lower uptake of treatment only in men.

In women, poor livelihoods conditions outweighed this effect. In our study, women who did not own household assets, lack control over household resources and lived in food insecure households were at a higher risk of non-uptake of ART. Previous studies have found that poverty-related barriers influence uptake of treatment (Hardon et al., 2007; Zech et al., 2010; Fox et al., 2010; Duff et al., 2010; Tuller et al., 2010). Our findings further show that insecure livelihoods households make women particularly vulnerable in communities with low level of social cohesion.

This thesis suggests that, in Zambia, rejection of ART in men may reflect a strategy to safeguard male identity. Strengthening participation of men in community activities may increase social pressure to keep their man's status in the social hierarchy and interfering in the uptake of treatment. This seems to be especially risky in communities with more conflicts and less trust among neighbours. However, for women the existence of strong social ties may empower them to initiate treatment, as it may offer a way to overcome disempowering conditions, especially in contexts of livelihood insecurity.

This does not mean that interventions to promote social cohesion should be discarded. As noted above, trust and positive interactions among neighbours, are associated with better access to ART treatment. However, engaging men in social activities require awareness of this risk and programmes to increase ART uptake need to integrate activities to bring about change on gender norms related to masculinity and masculine attitudes towards health.

In summary, the thesis shows that gender differences should be carefully considered in order to maximize the effectiveness of interventions directed at increasing uptake of ART. Two types of gender-specific activities are recommended: (i) activities focusing on men such as community-based interventions to bring about change on social norms related to masculinity and health; (ii) activities focusing on women such as reducing livelihood insecurity.

Although social ties and food insecurity are discussed above as important factors influencing uptake of ART, the strongest determinant was, in fact, disclosure of the HIV positive result. Chapter 8 shows that people who do not disclose are five times more likely

to refuse ART. However, it has been assumed, that this effect is due to reverse causality. We consider that people who do not intend to start ART would also be less likely to disclose their HIV status. This, in contexts of economic insecurity, would further fuel the cycle of vulnerability because non-disclosure would impede getting support to start the treatment, which could explain that rejection of ART in women is largely determined by household poverty-related factors.

11.2.3 Key findings on factors influencing adherence and retention in care

Chapter 9 of this thesis investigates adherence and disengagement from ART, and shows that, although interrelated, these two stages of HIV care are determined by different factors. **While non-adherence to treatment appears to be strongly affected by social dis cohesion, livelihoods and financial insecurity, disengagement from ART is more affected by stigma and self-efficacy.**

Couple dis cohesion significantly undermines adherence to treatment in both men and women. This effect persists regardless of the level of community stigma. This finding helps to explain the significant harmful effect that poor livelihoods conditions have in women. Dis cohesive marital relationships may certainly add to the burden of poverty increasing women vulnerability and limiting their ability to adhere to the treatment.

Similar findings have been reported before (Merten et al. 2010; Reda & Biadgilign 2012). Congruently, in the analysis carried out in this thesis, receiving food packages as part of the ART programme has proved helpful to keep adherent. These findings confirm others that also found positive effects of food rations on adherence in Zambia (Cantrell et al., 2008; Tirivayi et al., 2012).

While couple cohesion and poverty-related factors play a key role in adherence to ART, stigma-related issues appears to be more important for retention in care. High levels of stigma in the community increase the likelihood of disengaging from ART programmes. An interesting finding is that, in highly stigmatizing contexts, family conflicts increase even more the risk of disengaging from ART. This suggests that interventions aimed at strengthening cohesion within families might have a potential to lessen the negative effect of stigma. This is consistent with other studies showing that strong family cohesion could be a platform from which to extend and strengthen trust and networks in the community to facilitate social support for people living with HIV and confronting AIDS stigma (Abdool Karim et al., 2008).

Treatment related factors pose additional challenges for adherence and retention in care. As for the uptake of ART (Chapter 8), side effects and fear of lifelong medication are detrimental for both, adherence and retention in care. Quite striking is the finding that men are five times more likely to disengage from care than women. Similar results have been reported in other studies (Lagarde et al., 2003; Makombe et al., 2007; Ochieng-Ooko et al., 2010; Zhang et al., 2010; Ekouevi et al., 2010). This higher risk in men may be attributed to difficulties balancing treatment care and safeguarding a masculine identity and/or to difficulties balancing treatment and subsistence activities (Musheke et al., 2012) which are also related to traditional male roles. Our study shows that non-adherent patients with low socio-economic status remain in care despite of not being able to adhere to ART, possibly because they expect some sort of material support, such as food packages. This finding provides further evidence supporting the provision of food packages as an

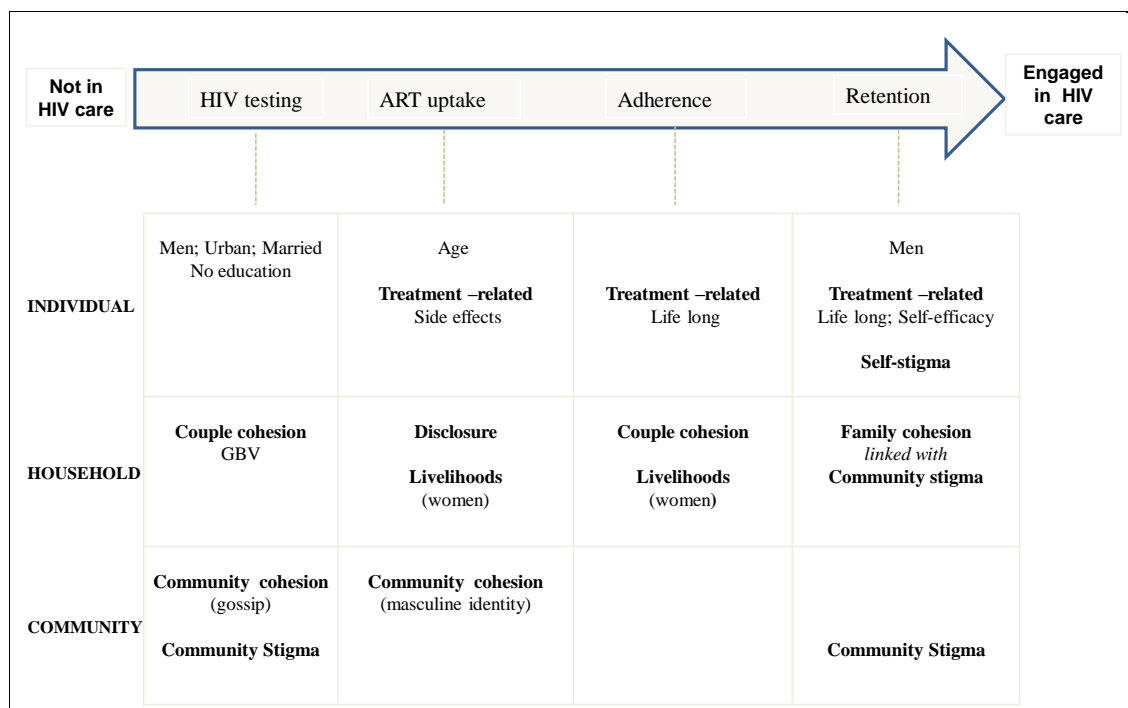
effective component of ART that not only improves adherence but has the potential to increase patient retention.

11.2.4 Conclusions

The findings of this thesis lead me to draw four main conclusions:

1. In Zambia, **social cohesion is strongly associated with access to HIV/AIDS services**. This thesis provides evidence that this association persists even after taking into account socio-demographic and economic conditions, stigma, and discrimination and treatment-related factors (e.g. quality of care, side effects or health-related beliefs).
2. Social cohesion - either at the level of the couple, the family or the community - plays a significant role in access to HIV/AIDS services but **not all levels of cohesion (couple, family and community) exert their effect in the same way along the continuum of HIV care**. The figure below summarises the key factors that influence access along the continuum of HIV care.

Figure 11.2 What influences access to HIV care



3. Promoting social cohesion among men, especially **through increasing men’s participation in community activities, could have harmful effects unless underlying gender norms of masculinity are mainstreamed** in the design of the interventions. Engaging men in HIV prevention activities requires being aware of this risk.

4. **Discohesive environments with disempowering gender norms and livelihoods constraints are the recurrent obstacle to access along the HIV continuum of care in Zambia.** The effectiveness of existing individual HIV prevention programmes (e.g. promotion of VCT, health education or stigma reduction) can be maximised if interventions adequately integrate strategies to improve these three components.

11.3 Recommendations for policy and practice

This thesis highlights a number of possible avenues to operationalize the above results. The key idea is to ensure that interventions aimed at reducing inequalities in access to HIV / AIDS services keep a focus on social relations (i.e. enhancing social cohesion).

Social cohesion means that members of a couple, family or community interrelate, commit to and trust each other. However, promoting social cohesion does not necessarily mean eradicating all tensions and conflicts between members of these groups. This thesis assumes that mistrust, tension and conflict are part of human social relations and that enhancing social cohesion primarily deals with creating environments that enable couples, families and/or communities to overcome (inevitable) social tensions and conflicts.

These enabling environments can be achieved through interventions at **facility, community and policy/institutional levels.**

At the **facility-level**, interventions to improve access to HIV/AIDS services should take into account the important role of the dynamics of power, conflict and violence within couple relationships. Based on the findings of this thesis, it is recommended keeping the focus of facility-based interventions on three major aspects.

- **Improving couple counselling in the VCT package through the integration of relationship-based HIV/STD prevention programmes.** These interventions should focus on teaching techniques and skills for couples to improve their communication skills and promote a shared commitment to safety and health. The intervention would imply a number of facilitated sessions aimed at redefining risk reduction from individual perspective “protecting me” to couple perspective “protecting us”. This includes discussing ideas about fidelity, gender stereotypes and power imbalances as

well as using modeling and role-play communications to teach and practice couple communication, negotiation and problem-solving skills. This type of interventions has proved to be effective in the context of HIV prevention among heterosexual couples (El-Bassel 2003).

- **Supporting positive livelihood strategies aimed at women** to reduce dependency of men and vulnerability to HIV. Providing food rations as part of the ART package may substantially improve uptake of ART and retention in care.
- **Providing psychosocial counselling in the ART package** as a way to improve adherence and retention in care. Currently non adherence and retention in care are mainly addressed by follow up activities. It is crucial to also provide psychosocial counselling as soon as problems to adhere are observed. The counselling should allow to better assess and address the root causes of non-adherence and disengaging from care, which, in this thesis, have been found to be linked to self-efficacy and self-stigma. A special attention should be given to men, who are more at risk of disengaging from care.

At the **community level**, the important role of family and neighbour relationships in the Zambian context should be considered when planning interventions to increase access to HIV/AIDS services. Communities with greater control and social cohesion may allow better health-related behaviour and may lessen the burden of stigma and discrimination. Two main types of community-based interventions can be identified.

- **Strengthening collective action interventions to enable people to bring about changes in the norms which are sustaining discrimination based on gender and HIV status (stigma).** Depending on the objectives pursued, these interventions should have different focuses. When aiming at scaling-up HIV testing, the

intervention should pay a special attention to reduce tolerance to gender-based violence in the community and gender-power imbalances within couples. When aiming at enhancing uptake of ART and adherence, interventions should target norms of masculinity among men. Ignoring this last dimension could backfire and further hinder the access of men to HIV / AIDS services. When aiming at improving retention in care, interventions should target stigma and discrimination of people living with HIV in the community. The most effective strategies to bring about change in social norms and discriminatory attitudes, either related to gender or HIV status, are those that engage people in thinking critically about these norms (e.g. gender inequality, gender roles, discrimination of people living with HIV, etc.) and bring them together to exchange about their concerns and possible solutions. Other promising interventions include mass media communication programmes to raise awareness and foster dialogue about social norms and discriminatory attitudes.

- **Promoting community-development programmes, especially interventions aimed at women, to address factors in the socio-economic environment that shape vulnerability to HIV.** Microfinance has proven to be a powerful tool to help impoverished women to create and build sustainable livelihoods. Such activities would reduce their dependence of men and vulnerability to HIV as well as enhance long term self-reliance. As shown in this thesis, these activities may greatly impact uptake of treatment and adherence. However, when planning them, careful attention should be put to the dynamics of power, conflict and violence within couple relationships. Increasing women's independence in households where men feel powerless (for example, in poorer households) may lead them into a vicious cycle of violence and abuse. Poverty-focused microfinance initiatives for women in poor

communities should be accompanied by community-based interventions addressing gender norms and gender inequity.

At a **broader policy/institutional level**, since the way a national epidemic spreads is closely associated with the underlying fabric of society, HIV control programmes cannot be the responsibility of the health sector alone. Social relations and gender inequalities are deeply influenced by the way in which they are reinforced (or denied) by public policies and practice. Two main recommendations can be identified.

- **Enforcing laws that prevent gender-based discrimination.** The Government of Zambia has developed and enacted specific laws and guidelines that prohibit discrimination based on gender and violence against women and criminalize domestic violence between spouses and among family members living in one home. But these laws have not been effectively enforced as women continue experiencing high levels of violence at home. The last report on Human Rights in Zambia (2007) concludes that the lack of enforcement and the culture of impunity for perpetrators of violence against women are key challenges for the country. The report also argues that although the government has established special units to respond to violence against women, discriminatory attitudes within the system (police and judiciary) prevent women from reporting violence and women are often pressured by law enforcement officials to withdraw the allegations of violence or for reconciliation with abusive husbands. Strong political will and sustained awareness efforts are required to change the culture of the institutions in charge of enforcing the law.
- **Continuing the development of an overarching framework to protect people vulnerable to HIV.** There remain a number of gaps in the Zambian legal framework that challenge HIV control. The penal code provisions that criminalize rape do not

extend to victims of rape by a spouse. In addition, despite constitutional and legal protections, customary law subordinates women with respect to property ownership, inheritance and marriage, and women continue face discrimination in inheritance and ownership of land or other property. Other gaps include the absence of anti-discrimination regulation expressly stating that HIV status is a matter of non-discrimination, the lack of protection for employees living with HIV/AIDS and the criminalization of same-sex relationships. For the everyday life of people affected by HIV, this means persistent social exclusion. Overcoming these obstacles and promoting the rights of Zambian people living with HIV/AIDS is essential both to prevent HIV transmission and to encourage appropriate levels of access to health care and support services.

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Appendices

Appendix 1: Research participant consent form

Appendix 2: Questionnaire

Appendix 3: Curriculum vitae

Appendix 1

Information sheet and consent form

General information

Greetings! I am _____ and I am *working/studying* at the University of *Zambia/Basel*. We are also collaborating with ZAMBART (Zambia AIDS Related TB Project), an organization, which is aiming at improving the quality of life of persons affected with TB or HIV.

We are conducting a research project aiming at improving the health care services. The study has two main objectives. First, we would like to explore what a person usually does when he or she is sick and needs treatment. Some people may face problems like a lack of money, or a lack of support in the family. Sometimes health care services may not be able to respond to particular health problems.

Second we are interested whether there are special concerns as regards HIV related health services. We would like to know how you have been informed about HIV testing and treatment options and whether you have ever made use of such services, or intend to in future. Today an HIV infection does no longer signify death. Medication has become available also in Zambia. If this medication is taken regularly it can improve survival and the wellbeing of a person with HIV. However, still many persons do not consult HIV related services. They may fear the reaction of their families and the community. There might be other reasons. Also, of those who are participating in an ART program, some stop going there. It is therefore important to know more about people's views on HIV related health services to improve health services. This interview is part of the second phase of the study. We plan to interview XX households in this village (name). We will also interview more households in other villages of Mbeza and in some districts of Monze, Namwala, and Mazabuka. Other members of the team are doing these interviews in Chivuna and Lusaka too. The purpose of this interview is to learn about households concerns with healthcare and treatment seeking.

Confidentiality

We will ask several persons the same questions. We will not tell any names to anyone. Everything you say will be treated highly confidential. The results of this research will be written down in a report where no names are mentioned.

Study team

This study is led by UNZA and the University of Basel, Switzerland, and their collaborating institution ZAMBART.

Responsible persons are Dr. Jacob Malungo, UNZA, and Dr. Sonja Merten, University of Basel, Switzerland.

The following persons are part of the Mbeza study team: *Dr. Sonja Merten, Mr. Cosmas Holo, Ms. Winnie Kazoka, Ms Sara Gari, Mr. Oran McKenzie, Mr. Defent Shikapande*

The interview will take no longer than 1 hour. Your participation in this interview is completely voluntary. Any question you feel uncomfortable about, please feel free not to answer it. Your names and other information that may identify your household will be kept confidential. The results of this research may be published but your identity will be protected.

There may be unexpected concerns arising during your participation in this study. Some questions may make you uncomfortable. If so, you are not obligated to answer them and we can move on or stop the interview.

We will not provide money for this survey. There are no direct benefits associated with participation in this survey but may be indirect benefits for your community in the future. The information gained in this study may help organizations design future interventions.

If you have further questions about this research, you may contact the following persons:

Dr. Jacob S. Malungo
The University of Zambia,
School of Humanities and Social Sciences
Social Development Studies Department
P.O.Box 32379, Lusaka, Zambia
Tel/Fax: 260-1-290320
Cell: 097805997
Email: shakumenzya@hotmail.com.

Dr. Sonja Merten
Swiss Tropical and Public Health
Institute, an associated institute of the
University of Basel, Switzerland
Socinstrasse 57A
4051 Basel
Tel: +41 270 22 22 / 0975 792714
Email: Sonja.merten@unibas.ch

If you have any questions about the ethics of this research, please contact the Chairperson of the Research Ethics Committee at UNZA, PO Box 50110, Lusaka. Telephone +260 1 256067.

We are asking you for written consent to take part in this discussion. Could you please read (or have read to you) this consent form and then sign it if you agree?

Date:

Signature PI:

Interviewer :

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Consent form

You understand that your participation in this study will not benefit you directly, but it may benefit others in the future.

You understand that your participation in this study is voluntary. You will be free to decline if you wish. If you agree to participate, you can decide not to answer certain questions and can stop the interview at any time.

You understand that you are free to ask questions before signing this form and that if you have further questions about my dissertation research, you may contact Dr. Jacob S. Malungo, The University of Zambia

Tel/Fax: 260-1-290320. If you have any questions about the ethics of this research, please contact the Chairperson of the Research Ethics Committee at UNZA, PO Box 50110, Lusaka. Telephone +260 1 256067.

You have been provided with this information in writing and/or had it read to you by a researcher from the study.

Consent statement for signature

YES, I have read this entire consent form, or had it read to me, and any questions have been answered to my satisfaction.

YES, I have been informed by the interviewer in oral or written form about the aims of this study, and about the ways how the information I will provide can be used. I've had enough time to take my decision. All questions I have regarding the study have been answered satisfactorily.

YES, I agree that the responsible researchers, and representatives of the ethical committee can obtain insight of the information I provide, however under strict confidentiality.

YES, I confirm to participate in this study out of my free will. I know that I can withdraw my consent at any time. I can keep a copy of this consent form.

Consent

I agree to participate in this study

no

yes

I need more time to decide, another contact time agreed:

Study participant:

Date: _____

Location: _____

Signature: _____

Interviewer:

I confirm that I have explained the participant the aims and contents of the study. I will comply with all the requirements of this study as mentioned above. In case I become aware of any potentially negative effects on the study participant I will inform him/her immediately and not influence him or her in his decision.

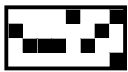
.....Date: _____

Location: _____

Signature: _____

Appendix 2

Questionnaire



Draft

I. IDENTIFICATION

Town/Chiefdom District/Village Community/Clinic

II. INTERVIEWER VISITS

FIRST VISIT

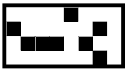
SECOND VISIT

DATE	<input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
INTERVIEWER NAME	-----	-----
INTERVIEWER CODE	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
RECORD THE TIME	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> HOUR : MINUTES	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> HOUR : MINUTES
RESULT OF THE VIST*	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>

*** CODES FOR "RESULT of the VISIT"**

- 01= COMPLETED
- 02= NOT AT HOME
- 03= POSTPONED
- 04= REFUSED
- 05= PARTLY COMPLETED
- 06= INCAPACITATED

SUPERVISED BY	EDITED BY
NAME _____	NAME _____
DATE _____	DATE _____



Draft

SECTION 1. DEMOGRAPHIC INFORMATION

Q.1 SEX OF THE RESPONDENT

1= MALE

2= FEMALE

Q.2 HOW OLD ARE YOU?

AGE IN COMPLETED YEARS

Q.3 WHAT IS YOUR NATIONALITY?

COUNTRY

TRIBE

Q.4 WHAT TRIBE DO YOU BELONG TO?

Q.5 WHAT IS THE HIGHEST LEVEL OF EDUCATION YOU HAVE COMPLETED?

1= NONE

2= PRIMARY INCOMPLETE

3= PRIMARY COMPLETED

4= SECONDARY (LOWER)

5= SECONDARY (UPPER)

6= POST SECONDARY

97= DON'T KNOW

98= REFUSED TO ANSWER

Q.6 WHAT IS YOUR RELIGION?

1= CHRISTIAN: ROMAN CATHOLIC

12= LUTHERAN CHURCH

2= SDA

13= BAPTIST

3= ECZ

14= ISLAM

4= RCZ

15= ANIMIST

5= APOSTOLIC FAITH

16= BUDDHISM

6= JEHOVA'S WITNESSES

17= HINDUISM

7= UCZ

18= JUDAISM

8= AFRICAN METHODIST

19= OTHER, SPECIFY: _____

9= EPISCOPAL CHURCH

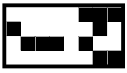
97= DON'T KNOW

10= ANGLICAN CHURCH

98= REFUSED TO ANSWER

11= SALVATION ARMY

99= NOT APPLICABLE (NOT RELIGIOUS)



Draft

Q.7 HOW RELIGIOUS DO YOU CONSIDER YOURSELF TO BE?

Read options: this is respondent's self assessment

- 1= NOT RELIGIOUS
- 2= NOT VERY RELIGIOUS
- 3= AVERAGE RELIGIOUS
- 4= VERY RELIGIOUS
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q.8 HOW REGULARLY DO YOU ATTEND RELIGIOUS SERVICES?

- 1= EVERY WEEK
- 2= ABOUT ONCE A MONTH
- 3= LESS THAN ONCE A MONTH
- 4= I DON'T ATTEND SERVICES
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q.9 DO YOU PARTICIPATE REGULARLY (AT LEAST ONCE A MONTH) IN OTHER COMMUNITY GROUP OR ACTIVITY?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.10 WHAT IS YOUR CIVIL STATUS?

<input type="checkbox"/> 1= MARRIED	Ask Q. 11 and Q.12 and skip to Q.14
<input type="checkbox"/> 2= SINGLE	
<input type="checkbox"/> 3= DIVORCED OR SEPARATED	Skip to Q. 13
<input type="checkbox"/> 4= WIDOWED	
<input type="checkbox"/> 98= REFUSED TO ANSWER	

Q.11 WHAT IS YOUR MARRIAGE TYPE?

- 1= POLYGAMIST
- 2= MONOGAMIST
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q.12 WHERE DID YOU SETTLE AFTER GETTING MARRIED?

- 1= WOMAN MOVED TO THE MAN'S HOMESTEAD
- 2= MAN MOVED TO THE WOMAN'S HOMESTEAD
- 3= WE SETTLED IN A NEW PLACE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER



Draft

Q.13 ARE YOU IN A STABLE UNION WITH A MAN/WOMAN?

- 1= YES
- 2= NO
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.14 DO YOU LIVE WITH YOUR HUSBAND/WIFE OR PRIMARY PARTNER?

- 1= YES
- 2= NO
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.15 FOR HOW LONG HAVE YOU BEEN IN A RELATIONSHIP WITH YOUR HUSBAND/WIFE OR PRIMARY PARTNER?

- 1= LESS THAN 1 YEAR
- 2= 1-5 YEARS
- 3= MORE THAN 5 YEARS
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

SECTION 2. HOUSEHOLD COMPOSITION AND LIVELIHOODS

I would like to continue to talk to you about your household. These include questions about people that live with you, the main income generating activities and how the decisions related to common issues are taken in the household. We need these information to understand the circumstances surrounding health seeking strategies.

Q.16 HOW MANY PEOPLE LIVE IN YOUR HOUSEHOLD?

Number

--	--

Q.17 HOW MANY CHILDREN BELOW 18 LIVE IN THIS HOUSEHOLD?

Number

--	--

Q.18 HOW MANY CHILDREN UNDER FIVE YEARS OLD?

Number

--	--

Q.19 HOW MANY OF THOSE CHILDREN HAVE YOU GIVEN BIRTH?

Number

--	--



Draft

Q.20 WHAT IS YOUR RELATIONSHIP WITH THE HEAD OF THE HOUSEHOLD?

- 1= PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= SIBLING
- 4= PARENT
- 5= FRIEND
- 6= COUSIN
- 7= PARENT IN LAW
- 8= SON IN LAW/DAUGHTER IN LAW
- 9= NIECE/NEPHEW
- 10= ADOPTED/FOSTER
- 11= STEPCHILD
- 12= GRANDPARENT
- 13= GRAND CHILD
- 14= OTHER RELATIVE
- 15= I AM THE HEAD OF THE HOUSEHOLD
- 97= I DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.21 WHAT IS YOUR MAIN ECONOMIC (INCOME GENERATING) ACTIVITY?

- 1= PERMANENT EMPLOYED, SKILLED
- 2= PERMANENT EMPLOYED, UNSKILLED
- 3= PIECEWORK, NON-PERMANENT WORK
- 4= FARMING, NO CATTLE
- 5= FARMING WITH CATTLE
- 6= FISHING
- 7= SELF-EMPLOYED (formal or informal)
- 8= UNEMPLOYED, LOOKING FOR WORK
- 9= HOUSEWORK (Unpaid)
- 10= STUDYING/ IN SCHOOL
- 11= RETIRED (ELDER)
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.22 WHAT IS THE MAIN ECONOMIC (INCOME GENERATING) ACTIVITY OF THE HEAD OF THE HOUSEHOLD?

Ask this question only if the respondent is NOT the head of the household.

- 1= PERMANENT EMPLOYED, SKILLED
- 2= PERMANENT EMPLOYED, UNSKILLED
- 3= PIECEWORK, NON-PERMANENT WORK
- 4= FARMING, NO CATTLE
- 5= FARMING WITH CATTLE
- 6= FISHING
- 7= SELF-EMPLOYED (formal or informal)
- 8= UNEMPLOYED, LOOKING FOR WORK
- 9= HOUSEWORK (Unpaid)
- 10= STUDYING / IN SCHOOL
- 11= RETIRED (ELDER)
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE



Draft

Q.23 COMPARED TO MOST HOUSEHOLDS IN YOUR COMMUNITY, DO YOU CONSIDER YOUR HOUSEHOLD...

- 1= MUCH WEALTHIER
- 2= A LITTLE BIT WEALTHIER
- 3= SAME
- 4= SLIGHTLY POORER
- 5= MUCH POORER
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.24 IN YOUR HOUSEHOLD, WHO PROVIDES MOST OF THE MONEY FOR FOOD?

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= SIBLING
- 4= PARENTS
- 5= FRIEND
- 6= PARENT IN LAW
- 7= OTHER RELATIVE
- 8= MYSELF
- 9= ME AND MY PARTNER/SPOUSE (JOINTLY)
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q.25 IN YOUR HOUSEHOLD, WHO PROVIDES MOST OF THE MONEY FOR HEALTH CARE?

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= SIBLING
- 4= PARENTS
- 5= FRIEND
- 6= PARENT IN LAW
- 7= OTHER RELATIVE
- 8= MYSELF
- 9= ME AND MY PARTNER/SPOUSE (JOINTLY)
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER



Draft

Q.26 DO YOU PERSONALLY OWN HOSEHOLD AMENITIES SUCH AS POTS, PLATES, BLANKETS OR FURNITURE?

- 1= YES
- 2= NO
- 98= REFUSED TO ANSWER

Q.27 DO YOU PERSONALLY OWN HOSEHOLD ASSETS SUCH AS HOUSE, ANIMALS OR FARMING EQUIPMENT?

- 1= YES
- 2= NO
- 98= REFUSED TO ANSWER

Q.28 WHO IN YOUR HOUSEHOLD USUALLY DECIDES ON EVERYDAY EXPENDITURES? (Clothing, transports, etc..)

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= SIBLING
- 4= PARENTS
- 5= FRIEND
- 6= PARENTS IN LAW
- 7= OTHER RELATIVE
- 8= MYSELF
- 9= ME AND MY PARTNER/SPOUSE (JOINTLY)
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q.29 WHO IN YOUR HOUSEHOLD USUALLY DECIDES ON SPECIAL EXPENDITURES? (Business investments, seeds, etc..)

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= SIBLING
- 4= PARENTS
- 5= FRIEND
- 6= PARENTS IN LAW
- 7= OTHER RELATIVE
- 8= MYSELF
- 9= ME AND MY PARTNER/SPOUSE (JOINTLY)
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q.30 DO YOU MAKE DECISIONS (HAVE AUTHORITY) ABOUT HOW THE HOUSEHOLD INCOME IS USED OR SPENT ON DAILY PURCHASES?

- 1= ALWAYS
- 2= SOMETIMES
- 3= NEVER
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Include expenditures for Food, routine activities, school fees, water, electricity and communication (talk-time)..



Draft

SECTION 3. FOOD SECURITY

Sometimes	Often	Never	Don't know	Refused	N/A
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Q.31. Do you worry that your family may run out of food before you have money to buy again?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

Q.32. Have you ever eaten less than you wanted because you don't have enough money to buy food?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

Q.33. Do you know that your children are hungry but you just do not have enough money to buy food?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

Q.34. Do you not have enough money to buy healthy and nutritious or balanced food for your children?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

SECTION 4. HEALTH SEEKING STRATEGIES

Now, I will ask you some questions about your health status and about what do you do when you are sick or concern about your own health.

Q.35 WHEN WAS THE LAST TIME YOU WERE ILL?

- 1= WITHIN THE PAST 6 MONTHS
- 2= 1 YEAR AGO
- 3= MORE THAN ONE YEAR AGO
- 4= NEVER
- 97= DON'T KNOW

Q.36 WHAT KIND OF ILLNESS, PROBLEMS OR CONCERN DID YOU HAVE?

Q.37 HOW WOULD YOU RATE THE SEVERITY OF THE ----- (illnes in Q. 36), FROM YOUR POINT OF VIEW?

- 1= VERY SEVERE
- 2= SEVERE
- 3= AVERAGE
- 4= LITTLE SEVERE
- 5= NOT SEVERE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.38 AT THE TIME YOU WERE SICK WITH ----- (name illness from Q.37), WHO DID YOU CONSULT FOR TREATMENT?

After the fist answer, ask if he/she consulted anyone else; read all the options and check all tha apply, up to 3 responses.

- 1= TRADITIONAL HEALER
- 2= PRIEST/FAITH HEALER
- 3= HERBALIST
- 4= CLINIC/HOSPITAL
- 5= PHARMACIST
- 6= RELATIVE OR FRIEND / HOME REMEDIES
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE



Draft

Q.39 WHEN YOU FELT ILL WITH -----
(illness from Q.36), HOW LONG DID YOU
WAIT UNTIL YOU CONSULTED SOMEONE FOR
TREATMENT?

- 1= SEVERAL DAYS
- 2= 1-2 DAYS
- 3= IMMEDIATELY
- 4= I NEVER CONSULTED SOMEONE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99=NOT APPLICABLE

Q.40 HOW WOULD YOU RATE YOUR PERSONAL
HEALTH NOW?

- 1= VERY GOOD
- 2= GOOD
- 3= AVERAGE
- 4= POOR
- 5= VERY POOR
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q. 41 IN GENERAL, WHEN YOU ARE SICK OR
HAVE CONCERNS ABOUT YOUR HEALTH, WHO
DO YOU FEEL MORE COMFORTABLE TO
CONSULT FOR TREATMENT?

*READ ALL THE OPTIONS. AFTER THE FIRST
ANSWER ASK IF HE/SHE CONSULTED ANYONE
ELSE. CHECK ALL THAT APPLY UP TO
THREE RESPONSES.*

- 1= TRADITIONAL HEALER
- 2= PRIEST/FAITH HEALER
- 3= HERBALIST
- 4= CLINIC/HOSPITAL
- 5= PHARMACIST
- 6= RELATIVE OR FRIEND / HOME REMEDIES
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.42 WHEN YOU ARE SICK, WHO DO USUALLY
DECIDES WHO SHOULD YOU CONSULT FOR
TREATMENT?

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= SIBLING
- 4= PARENTS
- 5= FRIEND
- 6= PARENTS IN LAW
- 7= OTHER RELATIVE
- 8= MYSELF
- 9= ME AND MY PARTNER/SPOUSE (JOINTLY)
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE



Draft

Q.43 WHEN YOU ARE SICK, WHO DO USUALLY PAY FOR THE RELATED HEALTH TREATMENT COSTS?

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= SIBLING
- 4= PARENTS
- 5= FRIEND
- 6= PARENTS IN LAW
- 7= OTHER RELATIVE
- 8= MYSELF
- 9= ME AND MY PARTNER/SPOUSE (JOINTLY)
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

SECTION 5. RELATIONSHIPS AND SOCIAL NETWORKS

I would like to continue talking with you about your social network. These can be your family but also your friends, church mates or professional colleagues. I will also ask you some questions about your family relationships, in order to know better where you can go for help when you need it. As for the questions before, answers to these questions will be kept confidential and will not be revealed to anybody.

Q.44 WITH HOW MANY OF YOUR RELATIVES, THAT LIVE OUTSIDE YOUR HOUSEHOLD, DO YOU KEEP REGULAR CONTACT, AT LEAST EVERY TWO WEEKS?

WRITE NUMBER : _____

--	--

DON'T KNOW = 97
REFUSED TO ANSWER = 98
NOT APPLICABLE= 99

Q.45 WITH HOW MANY OF YOUR COLLEAGUES, FROM THE CHURCH, WORK, SCHOOL, ETC. DO YOU KEEP REGULAR CONTACT, AT LEAST EVERY TWO WEEKS?

WRITE NUMBER : _____

--	--

DON'T KNOW = 97
REFUSED TO ANSWER = 98
NOT APPLICABLE= 99

Q.46 WITH HOW MANY OF YOUR MOST TRUSTED FRIENDS DO YOU KEEP REGULAR CONTACT, AT LEAST EVERY TWO WEEKS?

WRITE NUMBER : _____

--	--

DON'T KNOW = 97
REFUSED TO ANSWER = 98
NOT APPLICABLE= 99



Draft

Q.47 COULD YOU TELL ME TO WHOM YOU WOULD GO TO FOR HELP IN CASE OF MATERIAL AND FINANCIAL PROBLEMS?

SPONTANEOUS ANSWER.
AFTER THE FIRST ANSWER,
ASK: IS THERE ANYBODY ELSE? - CODE ALL THAT APPLY UP TO THREE

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= BROTHER/SISTER
- 4= MOTHER/FATHER
- 5= FRIEND
- 6= FAMILY IN LAW
- 7= UNCLE/ANTIE
- 8= NEIGHBOUR
- 9=TRADITIONAL HEALER
- 10= FAITH HEALER/PRIEST
- 11= TRADITIOANL COUNSELLORS
- 12= PROFESSIONAL COUNSELOR
- 13= MONEY LENDER
- 14= BANK
- 15= SOMEONE ELSE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.48 COULD YOU TELL ME TO WHOM YOU WOULD GO TO FOR HELP IN CASE YOU ARE WORRIED ABOUT SOMETHING?

SPONTANEOUS ANSWER.
AFTER THE FIRST ANSWER,
ASK: IS THERE ANYBODY ELSE? - CODE ALL THAT APPLY UP TO THREE

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= BROTHER/SISTER
- 4= MOTHER/FATHER
- 5= FRIEND
- 6= FAMILY IN LAW
- 7= UNCLE/ANTIE
- 8= NEIGHBOUR
- 9=TRADITIONAL HEALER
- 10= FAITH HEALER/PRIEST
- 11= TRADITIOANL COUNSELLORS
- 12= PROFESSIONAL COUNSELOR
- 15= SOMEONE ELSE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.49 COULD YOU TELL ME TO WHOM YOU WOULD GO TO CONFIDE YOUR SECRETS?

SPONTANEOUS ANSWER.
AFTER THE FIRST ANSWER,
ASK: IS THERE ANYBODY ELSE? - CODE ALL THAT APPLY UP TO THREE

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= BROTHER/SISTER
- 4= MOTHER/FATHER
- 5= FRIEND
- 6= FAMILY IN LAW
- 7= UNCLE/ANTIE
- 8= NEIGHBOUR
- 9=TRADITIONAL HEALER
- 10= FAITH HEALER/PRIEST
- 11= TRADITIOANL COUNSELLORS
- 12= PROFESSIONAL COUNSELOR
- 15= SOMEONE ELSE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE



Draft

Q.50 THE ORANGE CIRCLE REPRESENTS YOUR PERSON. I AM GOING TO ASK YOU HOW CLOSE DO YOU FEEL ARE OTHER PERSONS FROM YOU? CAN YOU LOCATE THEM ON THE TABLE?

USE PRISM

A.- PERSON YOU DISLIKE THE MOST

_____ cm

B.- PERSON YOU FEEL THE CLOSEST

_____ cm

C.- YOUR SPOUSE

_____ cm

D.- CLOSEST PERSON TO YOU IN YOUR HOUSEHOLD (DIFFERENT FROM YOUR SPOUSE)

_____ cm

Who is this person? _____

_____ cm

E.- CLOSEST PERSON TO YOU IN YOUR FAMILY

Who is this person? _____

_____ cm



Draft

Q.53 HOW STRONG ARE THE PROBLEMS MENTIONED BEFORE (Q.52), IN YOUR HOUSEHOLD? (If not yours because of the behaviour of another person...?)

USE PICTOGRAM 1

	Very strong	Quite strong	Somewhat strong	Little strong	Not strong	Don't know	Refused	N/A
A-Drinking Alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B- Having sexual affairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C- Misusing money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.54 HAVE YOU EVER BEEN SEPARATED FROM YOUR SOPUSE/PARTNER BECAUSE OF CONFLICTS WITHIN THE MARRIAGE?

- 1= YES
- 2= NO
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.55 HOW SUPPORTED DO YOU FEEL BY THE PEOPLE OF YOUR HOUSEHOLD?

- 1= VERY SUPPORTED
- 2= QUITE SUPPORTED
- 3= SOMEWHAT SUPPORTED
- 4= LITTLE SUPPORTED
- 5= NOT SUPPORTED AT ALL
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

SECTION 6. PERCEPTIONS AND BELIEFS

We have heard a lot about you and your family and about what do you do when you are ill. Now, I would like to continue talking to you about HIV and AIDS.

Q.56 HAVE YOU HEARD ABOUT ANTIRETROVIRALS (ARVs)?

<input type="checkbox"/> 1= YES	SKIP TO Q. 58
<input type="checkbox"/> 2= NO	
<input type="checkbox"/> 98= REFUSED TO ANSWER	
<input type="checkbox"/> 99= NOT APPLICABLE	



Draft

Now I would like to know more about the role that HIV/AIDS plays in your own life.

Q.59 DO YOU PERCEIVE THAT HIV/AIDS IS A PROBLEM IN YOUR LIFE?

USE PICTOGRAM 1

- 1= VERY BIG PROBLEM
- 2= RATHER A BIG PROBLEM
- 3= SOMEWHAT A PROBLEM
- 4= A MINOR PROBLEM
- 5= NOT A PROBLEM
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE





Q.60 HOW OFTEN DO YOU THINK ABOUT HIV/AIDS?

USE PICTOGRAM 1

- 1= ALWAYS/ EVERYDAY
- 2= OFTEN/EVERYWEEK
- 3= SOMETIMES/NOT EVERYWEEK
- 4= RARELY /NOT EVEN ONCE A MONTH
- 5= NEVER
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.61 THE ORANGE CIRCLE REPRESENTS YOUR PERSON. I AM GOING TO ASK YOU HOW CLOSE DO YOU FEEL ARE THESE SICKNESSES FROM YOU? CAN YOU LOCATE THEM ON THE TABLE?

USE PRISM

- A.- BRAIN TUMOUR  cm
- B.- SYPHILIS  cm
- C.- MALARIA  cm
- D.- HIV/AIDS  cm



SECTION 7. HIV VOLUNTARY COUNSELING AND TESTING

I would now like to continue to talk to you about some personal matters related to HIV and AIDS. These include questions about HIV testing and counseling. What we will discuss during the rest of the interview depends on whether you have been tested or not. Like all the other answers your answers to these questions will be kept confidential and will not be revealed to anybody. We need this information to understand the circumstances surrounding health seeking strategies.

Q.62 DO YOU KNOW ANY PLACE WHERE YOU CAN GO FOR HIV TESTING?

- 1= YES
- 2= NO
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.63 HAVE YOU EVER BEEN TESTED FOR HIV?

<input type="checkbox"/> 1= YES	
<input type="checkbox"/> 2= NO	SKIP TO Q.89
<input type="checkbox"/> 97= DON'T KNOW	
<input type="checkbox"/> 98= REFUSED TO ANSWER	
<input type="checkbox"/> 99= NOT APPLICABLE	

QUESTIONS APPLICABLE FOR RESPONDENTS WHO HAVE BEEN TESTED

Q.64 HOW DID YOU GET TESTED THE FIRST TIME?

- 1= I went for VCT
- 2= Antenatal
- 3= Testing of mothers during under five check up
- 4= Referred during another diagnosis process
- 5= TB corner
- 97= I don't know
- 98= Refused to answer
- 99= not applicable



Draft

Q.72 BEFORE TESTING, HOW STRONG DID YOU HAVE PROBLEMS WITH...?

USE PICTOGRAM 1

	Very strong	Quite strong	Somewhat strong	Little strong	Not strong	Don't know	Refused	N/A
A-Drinking Alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B- Having sexual affairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C- Misusing money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.73 BEFORE TESTING, HOW STRONG DID THOSE ISSUES MENTIONED IN Q.71 CAUSE PROBLEMS IN YOUR HOUSEHOLD?

USE PICTOGRAM 1

	Very strong	Quite strong	Somewhat strong	Little strong	Not strong	Don't know	Refused	N/A
A-Drinking Alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B- Having sexual affairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C- Misusing money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.74 THINK OF YOUR RELATIONSHIP BEFORE YOU WENT FOR TESTING.TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENTS?

USE PICTOGRAM 1

	Stronlgy agree	Agree	Somewhat agree	Disagree	Stronlgy disagree	Don't know	Refused	N/A
A-I could turn to my spouse/partner for support in times f crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B- My spouse/partner and I got along well together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-I trusted my spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.75 DO YOU STILL HAVE THE SAME SEXUAL PARTNER NOW THAN BEFORE GOING FOR TESTING?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE



Draft

Q.76 HOW DID YOUR RELATIONSHIP CHANGE AFTER YOU WENT FOR TESTING?

- 1= I was abandoned
- 2= It deriorated
- 3= It remained the same
- 4= It improved
- 97= Don't know
- 98= Refused to answer
- 99= Not applicable

Q.77 BEFORE TESTING, HAVE YOU EVER BEEN SEPARATED FROM YOUR SPOUSE BECAUSE OF CONFLICTS WITHIN THE MARRIAGE?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.78 HAVE YOUR CURRENT SEXUAL PARTNER BEEN TESTED IN THE LAST YEAR?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.79 DO YOU KNOW THE HIV STATUS OF YOUR CURRENT SEXUAL PARTNER?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.80 HOW MANY TIMES HAVE YOU BEEN TESTED FOR HIV?

--	--

WRITE NUMBER

Q.81 HOW LONG AGO DID YOU DO YOUR FIRST HIV TEST?

- 1= within the last year
- 2= 2-3 years ago
- 3= less than 10 years ago
- 4= more than 10 years ago
- 97= don't know
- 98= refused to answer
- 99= not applicable



Draft

Q.82 WHEN DID YOU DO YOUR LAST HIV TEST?

- 1= less than 6 months ago
- 2= 6-12 months ago
- 3= 1-2 years ago
- 4= 2-3 years ago
- 5= more than 3 years ago
- 97= don't know
- 98= refused to answer
- 99= not applicable

I would like to ask you to share your test results with me; You don't have to. If you do it, you can be sure that this information will be kept confidential and that they will not be revealed to anybody.

Q.83 WHAT IS YOUR HIV STATUS?

<input type="checkbox"/> 1= HIV POSITIVE	Continue next question
<input type="checkbox"/> 2= HIV NEGATIVE	SKIP TO Q.87
<input type="checkbox"/> 97= DON'T KNOW	
<input type="checkbox"/> 98= REFUSED TO ANSWER	
<input type="checkbox"/> 99= NOT APPLICABLE	



Draft

APPLICABLE FOR RESPONDENTS HIV POSITIVE

I would like to continue to talk to you about your reactions when you were told that your results were positive. As for the questions before, all your answers will be kept confidential and will not be revealed to anybody. It will help us to understand the circumstances surrounding health seeking strategies related to HIV/AIDS.

Q.84 I WILL NOW READ YOU SOME REACTIONS AND FEELINGS THAT PEOPLE MAY HAVE WHEN THEY ARE TOLD ARE HIV POSITIVE. HOW STRONGLY HAVE YOU FELT THEM?

USE PICTOGRAM 1	Very strong	Quite strong	Somewhat strong	Little strong	Not strong	Don't know	Refused	N/A
A-I felt very depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B-I felt ashamed of having the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-I felt I could continue having a normal life as planned and I could handle my positive status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D-I wanted to keep it secret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-I feared of a near death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F-I felt that I brought a lot of embarrassment to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G-I felt relieved because I could start the medication and avoid of being sick/weak during long time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H-I could plan realistically for the future of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I-I felt I brought a lot of financial problems to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.85 AFTER ALL THIS TIME, DO YOU THINK THERE ARE MORE ADVANTAGES OR DISADVANTAGES OF KNOWING YOUR HIV POSITIVE STATUS?

- 1= All advantages
- 2= More advantages than disadvantages
- 3= Some advantages and some disadvantages
- 4= More disadvantages than advantages
- 5= All disadvantages
- 97= Don't know
- 98= Refused to answer

Q.86 HOW COMFORTABLE DO YOU FEEL NOW AS A PERSON LIVING WITH HIV?

- 1= Very comfortable
- 2= Comfortable
- 3= Same as before of being diagnosed
- 4= Uncomfortable
- 5= Very uncomfortable
- 97= Don't know
- 98= Refused to answer

NOTE FOR THE INTERVIEWER:

SKIP TO Q. 97 to continue the interview



Draft

APPLICABLE FOR RESPONDENTS HIV NEGATIVE

I would like to continue to talk to you about how do you think people react when they are told that their test results are positive. What do you think about it will help us to better understand the circumstances surrounding health seeking strategies related to HIV/AIDS.

Q.87 I WILL NOW READ YOU SOME REACTIONS AND FEELINGS THAT PEOPLE MAY HAVE WHEN THEY ARE TOLD ARE HIV POSITIVE. TRY TO ASSUME THAT YOU HAD BEEN FOUND HIV POSITIVE, HOW WOULD YOU HAVE FELT?

USE PICTOGRAM 1	Very strong	Quite strong	Somewhat strong	Little strong	Not strong	Don't know	Refused	N/A
A-I would have felt very depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B-I would have felt ashamed of having the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-I would have felt I could continue having a normal life as planned and I could handle my positive status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D-I would have wanted to keep it secret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-I would have feared of a near death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F-I would have felt I brought a lot of embarrasment to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G-I would have felt relieved because I could start the medicationand avoid of being sick/weak during long time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H-I would have felt relieved because I could plan realistically for the future of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I-I would have felt I brough a lot of financial problems to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.88 DO YOU INTEND TO GO FOR TESTING AGAIN?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

NOTE FOR THE INTERVIEWER:

SKIP TO Q. 148 AND FINISH THE INTERVIEW



Draft

Q.91 HAVE YOU TALKED TO YOUR SPOUSE/PARTNER ABOUT GOING FOR HIV TESTING?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.92 SOME PEOPLE HAVE FEAR TO CONSULT THEIR PATNER(S) BEFORE GOING FOR HIV TESTING. HOW STRONGLY HAVE YOU EXPERIENCED THE FOLLOWING FEARS?

USE PICTOGRAM 1

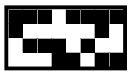
	Very strong	Quite strong	Somewhat strong	Little strong	Not strong	Don't know	Refused	N/A
A-Fear that she/he would not allow me to go for testing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-Fear of being accused of misbehavior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B-Fear of being abandoned	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D-Fear of violence (physical and/or verbal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.93 HAVE YOUR SPOUSE/PARTNER BEEN TESTED IN THE LAST YEAR?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.94 DO YOU KNOW THE HIV STATUS OF YOUR SPOUSE/PARTNER?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE



Draft

Q.95 I WILL NOW READ YOU SOME REACTIONS AND FEELINGS THAT PEOPLE MAY HAVE WHEN THEY ARE TOLD THEY ARE HIV POSITIVE. TRY TO ASSUME THAT YOU HAD BEEN TESTED AND FOUND HIV POSITIVE, HOW STRONGLY WOULD YOU FEEL THEM?

<i>USE PICTOGRAM 1</i>	Very strong	Quite strong	Somewhat strong	Little strong	Not strong	Don't know	Refused	N/A
A-I would feel very depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B-I would feel ashamed of having the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-I would feel I could continue having a normal life as planned and I could handle my positive status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D-I would want to keep it secret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-I would fear of a near death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F-I would feel I brought a lot of embarrassment to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G-I would feel relieved because I could start the medication and avoid of being sick/weak during long time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H-I would feel relieved because I could plan realistically for the future of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I-I would feel I brought a lot of financial problems to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.96 DO YOU INTEND TO GO FOR TESTING AGAIN?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

NOTE FOR THE INTERVIEWER:

SKIP TO Q. 148 AND FINISH THE INTERVIEW



SECTION 8. DISCLOSURE - (only for HIV +)

I would like to continue talking to you about DISCLOSURE. I would like to know whether you have talked to anybody about your HIV status and about the treatment with ARVs. This information will help us to understand the circumstances surrounding the access to the HIV/AIDS related services. As before, all your answers will be kept confidential and will not be revealed to anybody.

Q.97 HAVE YOU SHARED YOUR HIV POSITIVE TEST RESULTS WITH ANYONE OUTSIDE THE CLINIC?

<input type="checkbox"/> 1= YES	Continue with next question
<input type="checkbox"/> 2= NO	
<input type="checkbox"/> 97= DON'T KNOW	SKIP TO Q.116
<input type="checkbox"/> 98= REFUSED TO ANSWER	

APPLICABLE FOR RESPONDENTS WHO HAVE DISCLOSED

Q.98 WHO HAVE YOU SHARED YOUR HIV POSITIVE STATUS WITH?

READ ALL THE OPTIONS. AFTER THE FIRST ANSWER, ASK: IS THERE ANYBODY ELSE? - CODE ALL THAT APPLY UP TO THREE RESPONSES

- Spouse/partner
- Household relatives
- Close relatives (not living in my household)
- Co-wife (ves)
- My friend(s)
- Other sexual partners
- Someone else
- Don't know
- Refused to answer

Q.99 TO WHOM DID YOU DISCLOSE FIRST YOUR HIV POSITIVE STATUS?

READ ALL THE OPTIONS. CODE ONLY ONE RESPONSE

- Spouse/partner
- Household relatives
- Close relatives (not living in my household)
- Co-wife (ves)
- My friend(s)
- Other sexual partners
- Someone else
- Don't know
- Refused to answer



Draft

Q.112 IN THE LAST 12 MONTHS, HAVE YOU EVER FOUND YOURSELF AVOIDING OR ISOLATING FROM FRIENDS OR FAMILY BECAUSE OF YOUR HIV STATUS?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.113 HOW MUCH NEGATIVE REACTIONS FROM OTHERS DO YOU FEEL IN YOUR DAY-TO-DAY LIFE?

- 1= A LOT
- 2= RATHER
- 3= SOME
- 4= LITTLE
- 5= NONE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q.114 I WILL NOW READ YOU SOME NEGATIVE REACTIONS FROM OTHER THAT MANY PEOPLE LIVING WITH HIV EXPERIENCE. HAVE YOU EVER FELT THEM?

	YES	NO	DON'T KNOW	REFUSED TO ANSWER	N/A
A-I was asked not to touch someone's child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B-I was asked to leave because I was coughing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-I was called bad names	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D-I was told that I would die anytime	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-I was made to eat alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F-I was blamed for my HIV status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G-People avoided me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.115 HOW WOULD YOU RATE THE SEVERITY OF STIGMA, WHICH IS ANY NEGATIVE REACTIONS TOWARDS ANY HIV POSITIVE PERSON, IN THIS COMMUNITY?

- 1= VERY SEVERE
- 2= SEVERE
- 3= AVERAGE
- 4= LITTLE SEVERE
- 5= NOT SEVERE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

USE PICTOGRAM 1

NOTE FOR THE INTERVIEWER:

SKIP TO Q. 120 to continue the interview



Draft

APPLICABLE FOR RESPONDENTS WHO HAVE NOT DISCLOSED

Q.116 I WILL NOW READ SOME REASONS AND FEARS THAT PEOPLE HIV + MAY HAVE TO DO NOT DISCLOSE THEIR STATUS TO ANYONE. TELL ME HOW STRONGLY DO YOU FEEL THEM?

USE PICTOGRAM 1

	Very strong	Quite strong	Somewhat strong	Little strong	Not strong	Don't know	Refused	N/A
A- I am afraid of being abandoned by my spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B- I am afraid of being rejected by my family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-I am afraid of being blamed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D-I am afraid of violence (physical and/or verbal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.117 DO YOU INTEND TO DISCLOSE YOUR HIV POSITIVE STATUS TO ANYONE IN THE FUTURE?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.118 TO WHOM WOULD YOU DISCLOSE YOUR HIV POSITIVE STATUS?

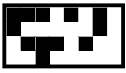
READ ALL THE OPTIONS. CODE ONLY ONE RESPONSE

- Spouse/partner
- Household relatives
- Close relatives (not living in my household)
- Co-wife (ves)
- My friend(s)
- Other sexual partners
- Someone else
- Don't know
- Refused to answer
- Not applicable

Q.119 HOW WOULD YOU RATE THE SEVERITY OF STIGMA, WHICH IS ANY NEGATIVE REACTIONS TOWARDS ANY HIV POSITIVE PERSON, IN THIS COMMUNITY?

USE PICTOGRAM 1

- 1= VERY SEVERE
- 2= SEVERE
- 3= AVERAGE
- 4= LITTLE SEVERE
- 5= NOT SEVERE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER



Draft

SECTION 9. TAKE UP OF HIV TREATMENT - (Applicable only for respondents HIV +)

I would like to continue talking to you about your experience with the HIV/AIDS related treatment. This information will help us to understand the circumstances surrounding the the access to the treatment and the difficulties that people have to take it up. As before, all your answers will be kept confidential and will not be revealed to anybody.

Q.120 ARE YOU CURRENTLY ON HIV/AIDS TREATMENT (ANTIRETROVIRALS THERAPY)?

<input type="checkbox"/> 1= YES	Continue with next question
<input type="checkbox"/> 2= NO	
<input type="checkbox"/> 97= DON'T KNOW	SKIP TO Q.127
<input type="checkbox"/> 98= REFUSED TO ANSWER	
<input type="checkbox"/> 99= NOT APPLICABLE	

QUESTIONS APPLICABLE FOR RESPONDENTS HIV + ON ART

Q.121 FOR HOW LONG HAVE YOU BEEN ON TREATMENT?

- 1= Less than 6 months
- 2= 6 - 12 months
- 3= Since 1 - 2 years
- 4= Since 2 - 3 years
- 5= Since more than 3 years
- 97= don't know
- 98= refused to answer

Q.122 WHEN DID YOU START TO TAKE ART?

- 1= Immediately after knowing my test result
- 2= Within the first 6 months
- 3= Within 1 year after
- 4= Within more than 1 year after
- 97= Don't know
- 98= Refused to answer



Draft

Q.123 I AM GOING TO READ SOME REASONS WHY PEOPLE DECIDE TO START TO TAKE ART. THINK ABOUT YOUR OWN REASONS AND TELL ME TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THEM.

USE PICTOGRAM 2

	Stronlgy agree	Agree	Somewhat agree	Disagree	Stronlgy disagree	Don't know	Refused	N/A
A-I had to do what I was told at the clinic/hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B-I just wanted to stay healthy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-I wanted to support my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D-I was encouraged by my spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-I was encouraged by my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G-I saw someone on ART recovered, that motivated me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Some people say that it is good to take other treatments, such as herbs. Others consult a priest or a faith healer. I would like to know whether you have ever made use of such treatments. It is important that you are open about this, even if you were told at the clinic that you should not use such treatments. All what you told to me will be kept confidential and it will not be revealed to anybody.

Q.124 AFTER KNOWING YOUR POSITIVE HIV TEST RESULTS, WHO DID YOU CONSULT FIRST FOR TREATMENT?

- 1= TRADITIONAL HEALER
- 2= PRIEST/FAITH HEALER
- 3= HERBALIST
- 4= ART CENTRE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q.125 HAVE YOU EVER CONSULTED FOR TREATMENT RELATED TO HIV/AIDS A.....?

	YES	NO	Don't know	Refused	N/A
A- Traditional healer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B- Priest/Faith healer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C- Herbalist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.126 HAVE YOU EVER COMBINED ARVs WITH?

	YES	NO	Don't know	Refused	N/A
A- Traditional medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B- Spiritual practices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C- Herbs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NOTE FOR THE INTERVIEWER:

SKIP TO Q. 130 to continue the interview



Draft

QUESTIONS APPLICABLE FOR RESPONDENTS HIV + NOT ON ART

Q.127 WHEN WAS THE LAST TIME THAT YOUR CD4 COUNTS WERE TAKEN?

- 1= Less than 6 months
- 2= 6 - 12 months
- 3= Since 1 - 2 years
- 4= Since 2 - 3 years
- 5= Since more than 3 years
- 6= CD4 counts never taken
- 97= don't know
- 98= refused to answer

Q.128 WHAT WAS THE RESULT OF YOUR CD4 COUNTS?

- 1= Below 200
- 2= Between 200-300
- 3= 350 and above
- 97= Don't know
- 98= Refused to answer
- 99= Not applicable (CD4 counts not taken)

Q.129 I AM GOING TO READ SOME REASONS THAT PEOPLE WHO ARE HIV + MAY HAVE TO DO NOT TAKE UP TREATMENT (ART). THINK ABOUT YOUR OWN REASONS AND TELL ME TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THEM.

USE PICTOGRAM 2

	Stronlgy agree	Agree	Somewhat agree	Disagree	Stronlgy disagree	Don't know	Refused	N/A
A-ARVs are not available in my area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B-I feel healthy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A-I don't believe the result	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C-I don't believe ARVs work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D-I am worried about the sustainability of ARV's supply	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-I take traditional medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A-I go for prayers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F-My family would not support me if I take ARVs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G- My spouse/partner does not want me to take ARVs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H- The ART centre is too far	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I- I do not have the money to go for treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J- I have seen many people on ART dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NOTE FOR THE INTERVIEWER:

SKIP TO Q.148 AND Finish the interview



Draft

SECTION 8. ADHERENCE TO ART; (only for HIV + ON ART)

I would like to continue talking to you about your experience with ARVs. I would like to know whether you have or have had difficulties to follow the prescriptions with ARVs. This information will help us to understand the circumstances surrounding the treatment. As before, all your answers will be kept confidential and will not be revealed to anybody.

Q.130 FOR HOW LONG HAVE YOU BEEN TAKEN YOUR MEDICATION?

- 1= 1-3 weeks
- 2= 1 month
- 3= More than 3 months
- 4= More than 6 months
- 5= 1 year or more
- 97= Don't know
- 98= Refused to answer

Q.131 HAVE YOU EVER RECEIVED ANY FOOD SUPPLEMENT BECAUSE YOU WERE ON ART?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.132 IF YES, FOR HOW LONG HAVE YOU RECEIVED THE FOOD SUPPLEMENT?

- 1= Up to 1 month
- 2= 2-3 months
- 3= More than 3 months
- 4= Since I started ART, it has not stopped
- 97= Don't know
- 98= Refused to answer
- 99= Not applicable

Q.133 DO YOU PARTICIPATE IN ANY SUPPORT GROUP FOR PEOPLE LIVING WITH HIV/AIDS OR DOING THINGS FOR HIV/AIDS RELATED ISSUES?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER



Draft

Q.134 HOW OFTEN DO YOU PARTICIPATE?

- 1= Once a week
- 2= More than once a week
- 3= Once or twice a month
- 97= Don't know
- 98= Refused to answer
- 99= not applicable

Q.135 DO YOU HAVE SOMEONE CLOSE TO YOU WHO ENCOURAGES/REMINDS YOU TO TAKE THE MEDICATION (ART)?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.136 IF YES, WHO?

- 1= MY PARTNER/SPOUSE
- 2= DAUGHTER/SON
- 3= BROTHER/SISTER
- 4= MOTHER/FATHER
- 5= FRIEND
- 6= FAMILY IN LAW
- 7= UNCLE/ANTIE
- 8= NEIGHBOUR
- 9= TRADITIONAL HEALER
- 10= FAITH HEALER/PRIEST
- 15= SOMEONE ELSE
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.137 HOW SATISFIED YOU ARE OF THE SUPPORT YOU RECEIVED FROM THEM?

- 1= VERY SATISFIED
- 2= RATHER SATISFIED
- 3= SOMEWHAT SATISFIED
- 4= LITTLE SATISFIED
- 5= NOT SATISFIED
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.138 HAVE SOMEONE EVER DISCOURAGED YOU TO TAKE THE HIV TREATMENT (ART)?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE



Draft

Many people find it difficult to take all their ART as prescribed. We would not be surprised if you have missed taking some of your medication over the last few days. We are trying to find out how difficult it is for patients to take their medication. Please answer these questions as honestly as you can. All the information that you provide us will be kept confidential and will not be revealed to anybody.

Q.142 IN THE LAST MONTH, HAVE YOU EVER TAKEN AN INCORRECT DOSIS OF YOUR MEDICATION?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.143 IN THE LAST MONTH, HAVE YOU EVER TAKEN YOUR MEDICATION AT THE WRONG TIME (ARVs)?

- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER
- 99= NOT APPLICABLE

Q.144 IN THE LAST MONTH, HAVE YOU EVER MISSED YOUR MEDICATION (ARVs)FOR MORE THAN ONE DAY?

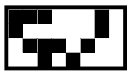
- 1= YES
- 2= NO
- 97= DON'T KNOW
- 98= REFUSED TO ANSWER

Q. 145 INCLUDING BEFORE THE LAST MONTH, WHAT IS THE LONGEST PERIOD OF TIME THAT YOU HAVE EVER MISSED OR STOPPED THE MEDICATION-ARVs?

<input type="checkbox"/> 1= 1-2 weeks	SKIP TO Q.148 Finish the interview
<input type="checkbox"/> 2= 2-8 weeks	
<input type="checkbox"/> 3= More than 2 months	
<input type="checkbox"/> 4= Never stopped/missed medication	
<input type="checkbox"/> 97= I don't know	
<input type="checkbox"/> 98= Refused to answer	

Q. 146 HAVE YOU RE-STARTED AGAIN?

- YES, I am still on treatment
- YES, but I stopped again
- NO, I didn't start ARVs again
- Don't know
- Refused to answer



Draft

END OF THE INTERVIEW

Q.148 WE HAVE COMPLETED THE QUESTIONNAIRE. BEFORE WE CONCLUDE THE INTERVIEW, DO YOU HAVE ANY QUESTIONS OR ADDITIONAL COMMENTS YOU WOULD LIKET O SHARE WITH ME?

WRITE COMMENTS

Q. 149 RECORD THE TIME OF COMPLETING THE INTERVIEW

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HOUR : MINUTES

THANK YOU VERY MUCH FOR YOUR COOPERATION