Factors influencing uptake of HIV testing and non-initiation of and attrition from antiretroviral therapy care in Lusaka, Zambia

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Prof. Dr. Jörg Schibler
Dekan

If there were only one truth, you couldn’t paint a hundred canvases on the same theme.

--Pablo Picasso (1881-1973)

PREFACE

My interest in AIDS research dates back to 2005 when I did my Master of Public Health (MPH) research on 'work-related stress amongst home-based caregivers of people living with HIV (PLHIV) affiliated to Kara Counselling and Training Trust,' a local HIV service non-governmental organisation. While my study was exclusively quantitative and focused on assessing the prevalence and determinants of stress amongst the caregivers, field observations to understand the work of home-based care givers and more informal discussions with them gave me in-depth insights into the social milieu of HIV. Two recurring themes emerged during these discussions and observations. First was the observed tendency by some individuals to not seek HIV testing despite knowing the HIV-positive status of their marital partners. Second, and conversely, some PLHIV were not disclosing their HIV status to their marital partners. My life experiences outside work and living in a high HIV prevalence setting also reinforced these patterns of response to HIV and how these HIV aspects were so critical to investigate.

In 2007, I was thrust into the foray of HIV research when I joined ZAMBART, a local research-focused non-governmental organisation that focuses on generating epidemiological and social science oriented evidence to inform policy and practice on addressing the dual HIV-TB epidemic. At ZAMBART, I was recruited as a Social Scientist on the Evidence for Action (EFA) research consortium, a 5-year (2006-2011) research project funded by the British government through the Department for International Development (DfID). The aim of the research consortium was to contribute to knowledge on how best to design, manage and deliver comprehensive HIV treatment and care in resource-limited settings. Herein, my interest in HIV research was reignited and I was involved in two research studies that would later lay the foundation for my current PhD research: First, in 2007-2008, I worked with Johanna Hanefeld, then a PhD student at the London School of Hygiene and Tropical Medicine (LSHTM), on a north-south 'twinning project' supported by EFA. Through supporting her PhD field work on the policy implementation processes of antiretroviral therapy (ART) roll-out in Zambia, I gained insights into how HIV treatment was financed and delivered, including the challenges associated with treatment roll-out. Second, in 2008, together with Karina Kielmann (then of LSHTM) and Fabian Cataldo (then of International AIDS Alliance (UK), I was part of a research team which conducted a one-year EFA funded study on the ‘shifts in home-based care for PLHIV in an era of antiretroviral therapy in Zambia.’ As a co-investigator and research coordinator, interactions and interviews with home-based caregivers, ART providers and PLHIV further highlighted the complexity of the ‘social ecology’ of HIV treatment. Patient uptake of and retention into treatment and care were salient challenges of the treatment roll-out and yet there was still a dearth of evidence on these bottlenecks: Why were some PLHIV reluctant to start treatment despite being eligible for it? Why were some PLHIV discontinuing their medication despite its proven efficacy in prolonging life? These became central questions for future investigation.

In 2009, ZAMBART entered into tripartite research partnership with the now Swiss Tropical and Public Health Institute and the University of Zambia. Funded by the Swiss National Science Foundation (SNSF), the 3-year ARTACCESS research project involved exploring factors influencing HIV testing and treatment-seeking behaviour in Zambia. Sonja Merten (my PhD supervisor) and Jacob Malungo (University of Zambia) were the principal investigators. I was brought on board, inter alia, as a PhD student as part of capacity building component of the research project. This meant developing my PhD research protocol within the framework of the project. This provided me with the opportunity to explore PLHIV non-uptake of and attrition from ART care.

The PhD thesis tackles three broad themes. First, through a synthesis of qualitative research findings, it explores the factors influencing uptake of HIV testing in Sub-Saharan Africa, the sub-continent worst hit by HIV. These findings are complemented by additional research in Zambia, in particular, the reasons why individuals aware of the HIV-positive status of their marital partners opt not to seek HIV testing and how provider-initiated couple HIV testing is undertaken in antenatal clinic. Second, in view of the increasingly wider availability of free of cost life-saving antiretroviral therapy, some treatment-eligible people living with HIV (PLHIV) still opt not to initiate treatment. The thesis examines why this is the case. Third, the wider roll-out of treatment has, paradoxically, been accompanied by patient attrition from ART care, thus undermining the achievements scored thus far in reducing AIDS-related mortality and morbidity amongst PLHIV. The PhD thesis provides insights on why this is the case, too. So, how do PLHIV not on treatment manage their health condition? As a corollary, the thesis encapsulates the self-care practices of PLHIV not receiving treatment and examines their implications for

successful delivery of HIV treatment. In the light of the findings, the thesis discusses the implications for HIV policy and practice. Thus, this PhD thesis holds significance for better delivery of HIV testing, treatment and care in Zambia and other similar settings grappling with optimising uptake of these services.

DEDICATION

To my wife Mable and my son Lumba who had to endure long spells of my absence from home and limited time with them whilst I was studying for my PhD.

SUMMARY

Background: The Human Immunodeficiency Virus (HIV) still remains a global public health burden with an estimated 34 million people living with HIV; 69% of these residing in sub-Saharan Africa (SSA). Although many countries have made steady progress in reducing HIV prevalence, the burden of HIV still remains high and new infections are still occurring. HIV testing has long been touted as an important strategy for the prevention, control and management of HIV infection. Similarly, in recent years and arising from increased funding and reduction in the cost of antiretroviral therapy (ART), there has been considerable progress in expanding the coverage of antiretroviral treatment. For instance at the end of 2009, about 36% of the 15 million people with HIV in low and middle-income countries in need of treatment were receiving it. Consequently, the annual AIDS-related deaths have declined from an estimated peak of 2.1 million in 2004 to an estimated 1.8 million in 2009; and since 1996, 14.4 million life-years have been gained. However, not everyone knows his or her HIV status, and not all HIV-infected individuals who need treatment are receiving it. Attrition from ART care has also been reported. The aim of this PhD thesis was to explore factors influencing uptake of HIV testing and non-initiation of and attrition from antiretroviral therapy in Lusaka, Zambia.

Objectives: This PhD thesis had 4 objectives:

1. To synthesise qualitative research findings on factors influencing uptake of HIV testing in sub-Saharan Africa (Chapter 3);
2. To find out why marital partners of individuals living with HIV did not seek HIV testing despite knowing the HIV-positive status of their partners (Chapter 4);
3. To explore factors influencing uptake of provider-initiated couple HIV testing and its effect on marital relationships (Chapter 5);
4. To investigate the reasons people living with HIV and eligible for treatment either opted not to start treatment or dropped out of treatment (Chapters 6, 7 & 8).

Methods: The study was conducted in Lusaka's Jack compound residential area and nearby communities. The surrounding communities were *Chawama*, *Kuku*, *Misisi*, *Kuomboka*, John Howard, *Kamwala* south and *Lilayi*. The study settings are predominantly low-income, high-

density urban residential areas located about 10 km south of Lusaka city centre, the capital city of Zambia.

The PhD thesis used qualitative research methods. To achieve the first objective, a meta-ethnographic approach (first put forward by Noblit and Hare 1988), was used to synthesise published qualitative research findings of factors influencing uptake of HIV testing in sub-Saharan Africa (SSA). Meta-ethnography involves re-interpretation and synthesis of qualitative research findings across multiple studies in order to gain in-depth understanding of phenomenon. 5,686 citations were identified out of which 56 were selected for full-text review and synthesised 42 papers from 13 countries using Malpass' notion of first-, second-, and third-order constructs. To attain objective 2, in-depth interviews were conducted with individuals who knew the HIV-positive status of their marital partners but had opted not to test (n=30). Objective 3 was achieved by interviewing couples who had undergone couple HIV testing (n=10). To attain objective 4, interviews were held with PLHIV who had dropped out of ART care (n=25) and those that opted not to initiate treatment despite it being recommended to them by health care providers (n=37). Data collection was conducted between March 2010 and September 2011.

For the systematic review using meta-ethnography, to establish how the concepts from different papers were related to one another, we created a grid and entered the concepts from each paper. We used Malpass's notion of first-, second-and third-order constructs to generate the concepts. First-order constructs represent the views of research participants while second order-constructs are authors' interpretation of research participants' views. Second-order constructs were identified, cross-compared and used to develop third-order constructs - our interpretations of the researchers' interpretation of research participants' views. Using the process of translation, comparisons of the concepts of the papers was undertaken i.e. paper 1 with paper 2 and the synthesised concepts of the two papers with paper 3 and so on until all studies had been translated into each other. The translation process was iterative to ensure that third-order constructs reflected concepts of the individual papers.

For the other qualitative PhD thesis studies, all interviews conducted in the local language (*Nyanja*) were translated and all interviews were transcribed verbatim. Focus group discussions (FGDs) and observational field notes were typed in as much detail as possible. Latent content analysis was used to analyse and interpret the data. All interview and focus group discussion transcripts and observational field notes constituted unit of analysis. These were read several times to create a sense of the emergent themes. Atlas ti version 6 was used to organise and manage the data. Meaning units were abstracted and coded and the codes compared for similarities and differences, and then grouped into categories on a manifest level. Themes were then generated by interpreting the categories for their underlying meaning. In line with the social ecological analytical framework, the themes for non-uptake of treatment are presented as individual-level, interpersonal, health-system and structural-level factors.

Findings:

Factors influencing uptake of HIV testing: The predominant factors enabling uptake of HIV testing are deterioration of physical health and/or death of sexual partner or child. The roll-out of various HIV testing initiatives such as ‘opt-out’ provider-initiated HIV testing and mobile HIV testing has improved uptake of HIV testing by being conveniently available and attenuating fear of HIV-related stigma and financial costs. Other enabling factors are availability of treatment and social network influence and support. Major barriers to uptake of HIV testing comprise perceived low risk of HIV infection, perceived health workers’ inability to maintain confidentiality and fear of HIV-related stigma. While the increasingly wider availability of life-saving treatment in SSA is an incentive to test, the perceived psychological burden of living with HIV inhibits uptake of HIV testing. Other barriers are direct and indirect financial costs of accessing HIV testing, and gender inequality, which undermines women’s decision making autonomy about HIV testing. Despite differences across SSA, the findings suggest comparable factors influencing HIV testing.

Non-uptake of treatment & patient attrition from ART care: Lack of self-efficacy, negative perceptions of medication, desire to avoid stigma and maintain social identity and relationships and fear of treatment-induced physical body changes, all modulated by feeling healthy, undermined uptake of treatment. Social relationships generated and perpetuated these health and treatment beliefs. Long waiting times at ART clinics, concerns about long-term availability of treatment and taking strong medication amidst livelihood insecurity also dissuaded PLHIV from initiating treatment. PLHIV opted for herbal remedies and faith healing as alternatives to ART, with the former being regarded as effective as ART while the latter contributed to restoring

normalcy through the promise of being healed. A complex and dynamic interplay of personal, social, health system and structural-level factors coalesce to influence uptake of ART care.

Conclusions: Improving uptake of HIV testing requires addressing perception of low risk of HIV infection and perceived psychological burden of living with an incurable condition. Building confidence in the health system through improving delivery of health care and scaling up HIV testing strategies that attenuate social and economic costs of seeking HIV testing could also contribute towards increasing uptake of HIV testing in SSA. Ensuring patients initiate ART requires interventions at different levels, addressing in particular, people's health and treatment beliefs, changing perceptions about effectiveness of herbal remedies and faith healing, improving ART delivery to attenuate social and economic costs and allaying concerns about future non-availability of treatment. Linked to uptake of HIV testing and treatment is the need to promote disclosure of HIV status to social network members – family members, friends and peers.

ZUSAMMENFASSUNG

Hintergrund: Infektionen mit dem Human Immunodeficiency Virus (HIV) stellen nach wie vor ein globales Gesundheitsproblem dar. Es wird geschätzt, dass 34 Millionen Menschen mit HIV leben, davon 69% in Subsahara-Afrika (SSA). Obwohl viele Länder stetige Fortschritte bei der Verringerung der HIV-Prävalenz gemacht haben, ist das Problem unvermindert hoch, und neue Infektionen treten nach wie vor auf. Das Anbieten von HIV-Tests ist seit langem eine zentrale Strategie für die Prävention, Kontrolle und Behandlung von HIV-Infektionen. In den letzten Jahren, in denen in den Ländern mit tieferen Einkommen die Finanzierung der HIV Therapie verbessert werden konnte und in denen zudem die Kosten der antiretroviralen Therapie (ART) immer mehr gesenkt wurden, gab es erhebliche Fortschritte bei der Abdeckung der HIV positiven Bevölkerung mit antiretroviraler Therapie. Zum Beispiel hatten in Ländern mit niedrigen und mittleren Einkommen Ende 2009 bereits rund 36% der 15 Millionen Menschen mit HIV Zugang zu einer Behandlung. In der Folge sind die jährlichen AIDS-Todesfälle von rund 2,1 Millionen im Jahr 2004 auf rund 1,8 Millionen im Jahr 2009 zurückgegangen, und es wurde geschätzt, dass seit 1996 etwa 14,4 Millionen Lebensjahre gewonnen werden konnten. Doch nach wie vor kennen zu wenige Betroffene ihren HIV-Status, und nicht alle HIV-Infizierten, die eine Behandlung benötigen, erhalten diese. Zudem beendet eine beträchtliche Anzahl Personen ihre antiretrovirale Therapie. Das Ziel dieser Doktorarbeit war es, Einflussfaktoren auf die Inanspruchnahme von HIV-Test-Angeboten und von antiretroviralen Therapieangeboten in Lusaka, Sambia, zu untersuchen.

Ziele: Diese Doktorarbeit verfolgte 4 Ziele:

1. Erstellen einer Synthese bereits vorhandener qualitativer Forschungsergebnisse zu Einflussfaktoren auf die Nutzung von HIV-Tests in Afrika südlich der Sahara zu erstellen (Kapitel 3);
2. Zu untersuchen, warum Ehegatten von HIV-infiszierten Personen, selber keinen HIV-Test durchführten wollten (Kapitel 4);
3. Einflussfaktoren der Inanspruchnahme von HIV-Tests für (Ehe-)Paare und die Auswirkungen solcher Tests auf eheliche Beziehungen zu untersuchen (Kapitel 5);

4. Die Gründe zu untersuchen, warum HIV-positive Personen sich entscheiden, keine antiretrovirale Therapie zu beginnen, oder warum sie diese wieder abbrechen (Kapitel 6, 7 und 8).

Methoden: Die Studie wurde in Lusaka, der Hauptstadt von Sambia durchgeführt. Die meisten Interviews fanden in der Siedlung Jack statt, sowie vereinzelt in den umliegenden Gemeinden wie Chawama, Kuku, Misisi, Kuomboka, John Howard, Kamwala Süd und Lilayi. Diese Siedlungen sind dicht bevölkert und charakerisiert durch ein eher niedriges Einkommen ihrer Bewohner. Sie liegen ca. 10 km südlich von Lusakas Innenstadt.

Die Doktorarbeit verwendet qualitative Forschungsmethoden. Für das erste Ziel, eine Literaturübersicht über qualitative Forschungsergebnisse der Einflussfaktoren auf die Aufnahme von HIV-Tests in Subsahara-Afrika (SSA) zu erstellen, wurde ein Meta-ethnographischer Ansatz verwendet. Meta-Ethnographie beinhaltet Re-Interpretation und Synthese von qualitativen Forschungsergebnissen über mehrere Studien. 5,686 Zitate wurden identifiziert, von denen 56 für die Volltext-Bewertung ausgewählt wurden. Schliesslich wurden 42 Arbeiten aus 13 Ländern berücksichtigt.

Für die systematische Meta-Ethnographie entwickelten wir ein konzeptuelles Raster, um zu untersuchen, wie die Konzepte der verschiedenen Publikationen miteinander in Bezug gesetzt werden können. Wir verwendeten dazu Malpass' Begriff der ersten, zweiten und dritten Ordnung. Konstrukte erster Ordnung sind Meinungen der Studienteilnehmer selber, während zweite-Ordnung-Konstrukte Interpretationen der Autoren darstellen. Second-order-Konstrukte wurden identifiziert, verglichen, und zu dritte-Ordnung-Konstrukten entwickelt - unsere eigenen Interpretationen. In diesem Prozess wurden Konzepte, die in den Publikationen identifiziert wurden, verglichen und zwar Papier 1 mit Papier 2, dann wurde die abgeleitete Interpretation der beiden Publikationen mit Publikation 3 verglichen, und so weiter, bis alle durchgeführten Studien miteinander verglichen worden waren. Dieser iterative Prozess stellte sicher, dass Konstrukte dritter Ordnung alle Konzepte der einzelnen Papiere reflektierte.

Für die Fragestellung des zweiten Forschungsziels wurden vertiefende Interviews mit Personen, die mit HIV-positiven Ehepartnern lebten, aber selber keinen HIV Test durchführen wollten (n = 30). Im Bezug auf das dritte Forschungsziel wurden Paare befragt, die sich gemeinsam testen liessen (n = 10), und im Bezug auf das vierte Forschungsziel wurden Interviews mit HIV positiven Personen durchgeführt, die eine antiretrovirale Therapie abgebrochen haben (n = 25) oder mit der medikamentösen Therapie gar nicht erst begonnen hatten (n = 37).

Alle Interviews wurden in der Landessprache (Nyanja) durchgeführt, danach ins Englische übersetzt und wörtlich transkribiert. Fokusgruppendiskussionen (FGD) und Feldnotizen wurden typologisiert. Latent-Content-Analyse wurde verwendet, um die Daten zu analysieren und zu interpretieren. Dafür wurden die Transkripte sämtlicher Interviews und Fokusgruppen-Diskussion sowie die Feldnotizen, welche Beobachtungen verschiedener Art enthielten, in die Analyse einbezogen. Texte wurden mehrmals gelesen, um ein Gefühl für die Themen zu erhalten. Atlas-ti Version 6 wurde verwendet, um die Daten zu organisieren und zu verwalten. Bedeutungseinheiten wurden abstrahiert und codiert, und die Codes auf Gemeinsamkeiten und Unterschiede verglichen, und dann in Kategorien gruppiert. Anschliessend wurden Themen anhand ihrer zugrunde liegenden Bedeutung generiert. Im Einklang mit dem sozial-ökologischen analytischen Rahmen werden die Themen für Nicht-Aufnahme der antiretroviralen Behandlung auf individueller Ebene, zwischenmenschlicher, Gesundheits-System-Ebene und struktureller Ebene dargestellt.

Resultate:

Einflussfaktoren auf die Inanspruchnahme von HIV-Tests: Die wichtigsten Gründe für die Inanspruchnahme von HIV-Tests sind eine Verschlechterung der körperlichen Gesundheit und / oder Tod des Partners oder eines Kindes. Die Verbreitung der verschiedenen HIV-Testangebote, wie zum Beispiel ins Gesundheitssystem integrierte "opt-out"-Angebote, sowie mobile HIV-Testangebote, wirkte sich positiv aus, indem Tests vielerorts günstig erhältlich waren und dadurch zudem die Angst vor HIV-Stigmatisierung gedämpft wurde. Andere Faktoren sind Verfügbarkeit von antiretroviraler Behandlung und Einflüsse und Unterstützung durch soziale Netzwerke. Wesentliche Hindernisse für die Aufnahme von HIV-Tests umfassen ein geringes Risiko für eine HIV-Infektion, Angst, dass das Gesundheitspersonal keine Vertraulichkeit gewährleistet und die Angst vor HIV-Stigma. Während die zunehmend breitere Verfügbarkeit der antiretroviralen Behandlung in SSA ein Anreiz zu testen ist, hemmt die wahrgenommene psychische Belastung durch ein Leben mit HIV die Nutzung von HIV-Tests. Andere Hindernisse sind direkte und indirekte finanzielle Kosten für den HIV-Test, und die Ungleichheit der

Geschlechter, welche die Entscheidungsfindung und Autonomie der Frauen im Bezug auf HIV-Tests untergräbt.

Nicht-Aufnahme der Behandlung und schlechte Teilnahme an HIV Therapie: Mangel an Selbstwirksamkeit, die negative Wahrnehmung der Medikation, der Wunsch, Stigmatisierung zu vermeiden, Verlust der sozialen Identität und Beziehungen, und die Angst vor behandlungsinduzierten Veränderungen des physischen Körpers, besonders solange sich eine Person gesund fühlt, untergraben die Aufnahme der Behandlung. Lange Wartezeiten bei ART Kliniken, Bedenken über die langfristige Verfügbarkeit von Medikamenten und Unsicherheit über die eigene materielle Situation haben PLHIV vom Beginn der Behandlung abgebracht. Ein Teil der Menschen mit HIV hat sich für pflanzliche Heilmittel und Geistheilung als Alternative zu ART entschieden, wobei ersteres als genauso effektiv wie ART betrachtet wurde, während letzteres dazu beitrug, die Normalität durch das Versprechen geheilt zu sein wiederherzustellen. Ein komplexes und dynamisches Zusammenspiel von persönlichen, sozialen, gesundheitlichen und strukturellen Faktoren beeinflussen gemeinsam die Aufnahme von antiretroviraler Therapie.

Schlussfolgerungen: Um eine Verbesserung der Inanspruchnahme von HIV-Tests zu erreichen, müssen falsche Einschätzungen der eigenen Gesundheit und des Infektionsrisikos angegangen werden. Zudem braucht es bessere Information und Unterstützung darin, mit einer chronischen Krankheit zu leben. Eine Verbesserung des Vertrauens in das Gesundheitssystem kann durch bessere Qualität der Betreuung sowie eine Ausweitung der HIV-Teststrategien erreicht werden, indem die sozialen und wirtschaftlichen Kosten der Inanspruchnahme eines HIV-Tests reduziert würden, was zu einer besseren Akzeptanz von HIV-Tests beitragen würde. Um die Aufnahme einer antiretroviralen Therapie zu verbessern, sind Interventionen auf verschiedenen Ebenen erforderlich. Insbesondere die Risikowahrnehmung, die Überzeugung von der Wirksamkeit der antiretroviralen Therapie im Gegensatz zu den überall angepriesenen pflanzlichen Heilmitteln und Geistheilung angesprochen werden. Versorgungsengpässe mit antiretroviralen Medikamenten müssen überwunden werden, um Befürchtungen darüber zu zerstreuen, dass in Zukunft Medikamente nicht immer verfügbar sein könnten. Verbunden mit der Inanspruchnahme von HIV-Tests und antiretroviraler Behandlung ist die Notwendigkeit, seinen HIV-Status offenzulegen, um die Unterstützung durch das eigene soziale Netzwerk zu fördern - Familienmitglieder, Freunde und Kollegen.

LIST OF PUBLICATIONS

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

2. **Musheke, M.**, Bond, V. & Merten, S. (2013) Couple experiences of provider-initiated couple HIV testing in an antenatal clinic in Lusaka, Zambia: Lessons for policy and practice. *BMC Health Services Research*, 13, 97.

3. **Musheke, M.**, Merten, S. & Bond, V. (2013) Why do marital partners of people living with HIV decline HIV testing? Insights from a qualitative study in urban Lusaka, Zambia. Prepared for submission to BMC Infectious Diseases.

4. **Musheke, M.**, Bond, V. & Merten, S. (2013) Deterrents to HIV-patient initiation of antiretroviral therapy in urban Lusaka, Zambia: A qualitative study. *AIDS Patient Care & STDs*, 27(4), 231-241.

5. **Musheke, M.,** Bond, V. & Merten, S. (2012) Individual and contextual factors influencing patient attrition from antiretroviral therapy care in an urban community of Lusaka Zambia. *Journal of the International AIDS Society*, 15(Suppl 1), 17366.

6. **Musheke, M.**, Bond, V. & Merten, S. (2013) Self-care practices and experiences of people living with HIV not receiving antiretroviral therapy in urban Zambia: Implications for HIV treatment programmes. *AIDS Research & Therapy*, 10, 12.

7. Merten, S., Kenter, E., McKenzie, O., **Musheke, M.,** Ntalasha, H. & Martin-Hilber, A. (2010) Patient-reported barriers and drivers of adherence to antiretrovirals in sub-Saharan Africa: a meta-ethnography. *Tropical Medicine and International Health*, 15 (Suppl. 1), 1-18.

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
AZT	Zidovudine
CBO	Community-based organisation
CIDRZ	Centre for Infection Disease Research in Zambia
CSO	Central Statistics Office
DFID	Department for International Development
EFA	Evidence for action on HIV treatment and care systems
EFV	Efavirenz
FGD	Focus group discussion
FTC	Emtricitabine
3TC	Lamivudine
GFTAM	Global fund to fight AIDS, Tuberculosis and Malaria
GRZ	Government of the Republic of Zambia
HBC	Home-based care
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
LPV/r	Lopinavir/Ritonavir
LTFU	Lost-to-follow up
MoH	Ministry of Health
NAC	National AIDS Council
NGO	Non-governmental organisation
NVP	Nevirapine
PEPFAR	Presidential Emergency Plan for AIDS Relief
PLHIV	People Living with HIV and AIDS

PMTCT	Prevention of mother-to-child transmission of HIV
SDA	Seventh-Day Adventist Church
SNSF	Swiss National Science Foundation
SSA	Sub-Saharan Africa
STI	Sexually transmitted infections
TB	Tuberculosis
TDF	Tenofovir
UNAIDS	Joint United Nations Programme on AIDS
UCZ	United Church of Zambia
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
USA	United States of America
UTH	University Teaching Hospital
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation
ZAMBART	Zambia AIDS related TB Research Project
ZDHS	Zambia Demographic and Health Survey
ZEBS	Zambia Exclusive Breastfeeding Study

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CHAPTER 1

1.0 Background

1.1 Global burden of HIV and roll-out of antiretroviral therapy

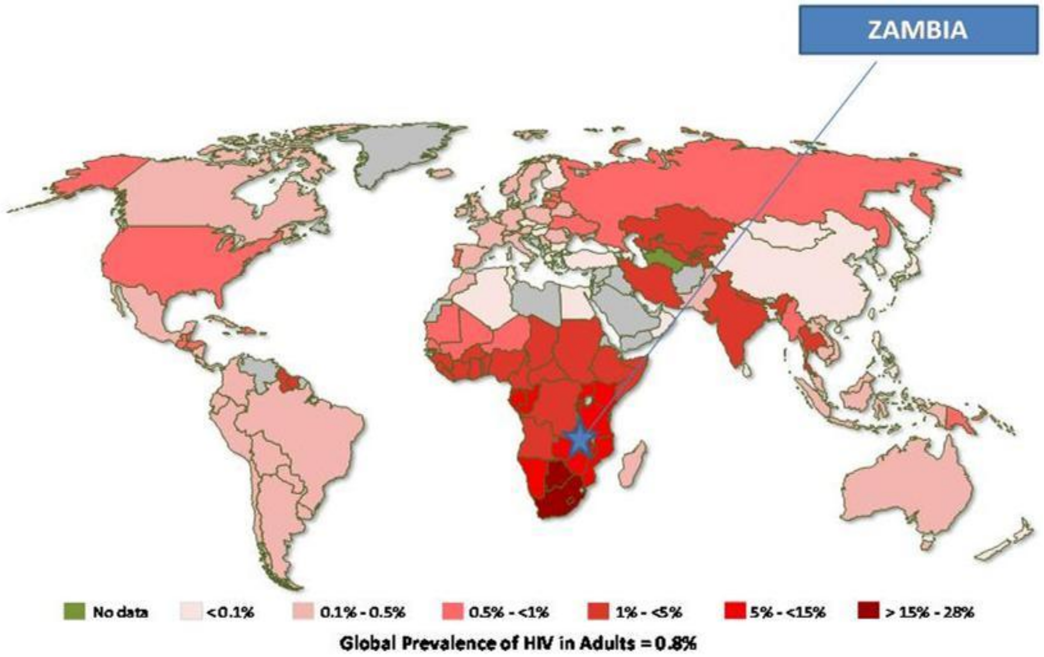
HIV continues to be a global public health problem and sub-Saharan Africa (SSA) remains the epicenter of the epidemic. Globally, an estimated 34 million people were living with HIV at the end of 2011, 69% of these in SSA (UNAIDS 2012); and an estimated 2.5 million adults and children became newly infected in 2011. This was despite the fall of new infections by more than 25% between 2001 and 2011 in 39 countries (UNAIDS 2012). Despite the low number of people getting infected, sub-Saharan Africa accounted for 71% of new infections in adults and children (UNAIDS 2012).

To address this public health problem, many countries in SSA have in recent years scaled-up HIV testing services. For instance, health facilities providing HIV testing services in 37 countries of SSA increased by 50% from 11,000 in 2007 to 16,500 in 2008 (WHO/UNAIDS/UNICEF 2009). More so, antiretroviral treatment has also become increasingly available, thus contributing to the reduction in AIDS-related mortality and morbidity. For instance at the end of 2009, about 36% of the 15 million people with HIV in low and middle-income countries in need of treatment were receiving it (UNAIDS 2010a). Consequently, the annual AIDS-related deaths have declined from an estimated peak of 2.1 million in 2004 to an estimated 1.8 million in 2009; and since 1996, 14.4 million life-years have been gained by providing antiretroviral therapy (UNAIDS 2010a). In SSA, 37% of those in need of HIV treatment were accessing it and the effects of wider availability of ART were even more salient in SSA where AIDS-related deaths declined by 320, 000 (or 20%) in 2009 compared to 2004 (UNAIDS 2010a).

1.2 HIV and HIV testing in Zambia

Zambia is one of the countries in sub-Saharan Africa worst hit by the HIV pandemic. According to the 2007 Zambia Demographic and Health Survey, 14.3% of the Zambian population (aged 15-49 years) is estimated to be living with HIV (CSO 2009). The incidence of HIV is estimated at 1.6% (NAC/MoH 2010). The first case of HIV was reported in 1984 and the prevalence picked in the 1990s before declining to current rate (NAC/MoH 2010). The drivers of HIV include multiple and concurrent sexual partnerships, low and inconsistent condom use, low rates of male circumcision, mobility and labour migrations, social vulnerability and marginalisation and vertical mother-to-child transmission (NAC/MoH 2010).

Figure 1-1 Global burden of HIV



Notes: Data are estimates. Prevalence rate is for those aged 15-49.
Source: UNAIDS, *Report on the Global AIDS Epidemic*, 2010.

To continue addressing the HIV pandemic, Zambia is currently implementing a multi-sectoral and decentralised national AIDS strategic framework (2011-2015) in which two of the four priorities are "to accelerate and intensify prevention in order to reduce the annual rate of new HIV infections" and "to accelerate the provision of universal access to comprehensive and quality treatment, care and support" (NAC 2010, p.3). At the end of 2010, there were 1,690 health facilities providing HIV services of which 1,471 were public health facilities (NAC 2012). HIV testing is mainly provided through 'opt-in' stand-alone or mobile HIV testing services, mainly run by non-governmental organisations. Provider-initiated 'opt-out' HIV testing is provided in health facilities as part of routine provision of health care. 'Opt-out' HIV testing is used at different health facility screening points such as STI clinics, antenatal clinics and Tuberculosis (TB) clinic (NAC/MoH 2010). In Zambia, more than 90% of women attending antenatal care are tested for HIV (MoH 2010). The Determine^{TM} HIV-1/2 for initial HIV screening, Uni-Gold Recombigen test (for confirmation of results) and the Bioline HIV-1/2 test (as a "tie breaker") are rapid HIV diagnostic test tools used in Zambia (MoH 2010a).

Despite the high prevalence of HIV in Zambia, and the increasing wider availability of HIV testing and treatment services, the uptake of HIV testing still remained sub-optimal at the time of this research study. Estimates at the time showed that 35% of women had tested and received their results, 4% had tested but never received their results and 60% had never tested for HIV. For men, only 20% had tested for HIV and received their results; 2% had tested but did not receive their results while 78% had never tested for HIV (CSO 2009). It was also estimated that 57% of HIV-positive people (49% of HIV positive women and 69% of HIV positive men) did not know that they were infected with HIV (CSO 2009). Therefore current efforts to halt the spread of HIV and increase the uptake of HIV treatment in Zambia needed to increase the number of people seeking HIV testing.

1.2 Scale-up of antiretroviral therapy in Zambia

Up until 2003, there were no public sector clinics providing antiretroviral treatment in Zambia. However, to curb the burden of AIDS-related mortality and morbidity, in late 2002, The Zambian government through the late President Levy Mwanawasa announced government's aim to provide treatment to 10,000 people through public sector health facilities by 2005 (Schumaker & Bond 2008). At the time, antiretroviral treatment was only privately acquired, in private clinics in Zambia and outside the country, albeit at high financial cost. A pilot treatment programme was initiated at two tertiary hospitals in the country – Lusaka's University Teaching Hospital (UTH) and Ndola central hospital. Treatment was also being provided as part of prevention of mother-to-child transmission of HIV (PMTCT). Despite the good policy intentions to ensure access to treatment, patients had to pay a user fee of ZMK40,000 (about US$10 at the time). In the face of widespread poverty levels, the user fee was a hindrance to patient uptake of treatment. In 2004, HIV treatment was rolled-out to the nine provincial hospitals and by mid 2004, treatment was rolled-out to selected primary health care facilities in Lusaka, the capital city of Zambia, which also happened to be the epicentre of the epidemic (Schumaker & Bond 2008). Due to the progressive roll-out of treatment, there was an exponential increase in the number of people with HIV receiving antiretroviral therapy – from 3,000 at the end of 2003 to an estimated 24,000 at the end of 2004 (Schumaker & Bond 2008). In 2005, user charges for HIV treatment and related medical investigations were scrapped to further increase uptake of HIV treatment.

During the treatment roll-out period, policy changes were also happening at global level. The World Health Organisation (WHO) initiated the 3 x 5 initiative aimed at putting 3 million people in low and middle-income countries on HIV treatment by end of 2005. In 2002, the Global fund to fight AIDS, Tuberculosis and Malaria (GFTAM) was formed to serve as a financial mechanism for global mobilisation and distribution of funds to fight the three diseases. In 2003, the former President of the United States of America (USA), George W. Bush launched a 5-year Presidential Emergency Plan for AIDS Relief (PEPFAR) to support countries worst hit by the HIV pandemic to provide HIV treatment, care and support and prevent the further spread of HIV. Zambia was one of the 14 focus countries of the PEPFAR programme. His successor, President Barack Obama renewed PEPFAR for another 5 years.

Increased funding for HIV provided additional impetus for delivery of HIV treatment in Zambia. Consequently at the end of 2009, Zambia had 447 public sector and non-public sector health facilities providing or prescribing antiretroviral treatment – 29% of the total health facilities in the country (NAC/MoH 2010). The number of people on treatment had also dramatically increased – from 30,103 at the end of 2005 to 283,863 at the end of 2009, representing 68% of those in need of treatment (NAC/MoH 2010).

In line with the revised WHO treatment guidelines (WHO 2010), people with HIV with CD4 cell count of <350 cell/mm^3 are initiated on treatment while those with CD4 cell count of 350-500 are subjected to clinical observations every 3 months; those with CD4 cell count of >500 undergo clinical follow-up every 6 months (MoH 2010a). First-line drug regimens in Zambia comprise two nucleoside reverse transcriptase inhibitors - tenofovir (TDF) with either emtricitabine (FTC) or lamivudine (3TC) and one non-nucleoside reverse-transcriptase inhibitor – efavirenz (EFV) or nevirapine (NVP) (MoH 2010a). The first-line and second-line treatment combinations are outlined in Table 1-1.

Since 2009 when WHO recommended phasing out of stavudine due to long term, cumulative and non-reversible toxicities such as peripheral neuropathy - disorder of peripheral nerves characterized by numbness, weakness and burning pain of hands and feet, and lipoatrophy - the loss of fat from specific parts of the body (WHO 2009a), the Zambian governmental has recommended a gradual withdrawal of the drug.

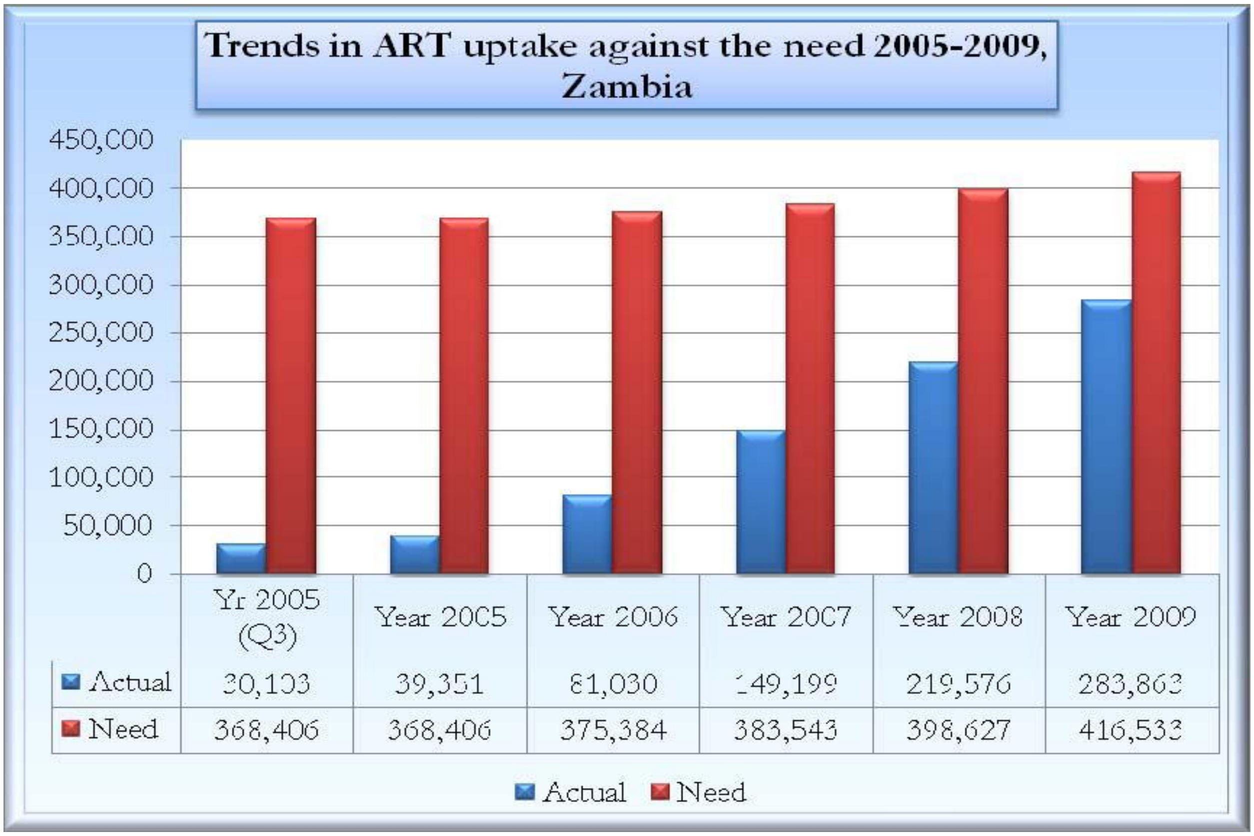


Figure 1-2. Source: NAC/MoH. (2010) UNGASS biennial report for 2008-2009. Lusaka, NAC/MoH.

Table 1-1 Recommended first- and second-line HIV treatment combinations in Zambia

First-line regimen		**Second-line regimen**		
TDF/FTC or 3TC	EFV or NVP	AZT	3TC or TDF/FTC or 3TC	LPV/r
		D4T/3TC		

Source: MoH (2010). Adult and adolescent antiretroviral therapy protocols. Lusaka, MoH.
(TDF=tenofovir, FTC=emtricitabine, 3TC= lamivudine, EFV=efavirenz, NVP=nevirapine, AZT=zidovudine, d4T=stavudine, LPV/r=lopinavir/ritonavir)

1.3 Barriers to uptake of HIV testing and treatment: An overview of literature

1.3.1 Barriers to uptake of HIV testing

Despite the increasingly wider availability of HIV testing services, uptake of HIV testing in HIV endemic countries of SSA, including Zambia, is still relatively low (WHO/UNAIDS/UNICEF 2010). Personal-level, social-relational, health system and wider structural-level factors inhibit uptake of HIV testing. At individual level, barriers to HIV testing include perceived psychological burden of living with HIV (MacPhail et al. 2008; Angotti et al. 2009; Råssjö et al. 2009; Obermeyer et al. 2009; Simpson, 2010), perception of already being infected (Bwambale et al. 2008; Jürgensen et al. 2012) and self-perception of being at low risk of infection (de Paoli, Manongi & Klepp 2004; Bhagwanjee et al. 2008; Chirawu et al. 2010). Individuals planned to test after their health had deteriorated (Oshi et al. 2007; Grant et al. 2008; Chirawu et al. 2010; Namakhoma et al. 2010; Simpson, 2010).

Interpersonal-level factors that inhibit uptake of HIV testing include fear of stigma and discrimination (Kalichman & Simbayi 2003; Grant et al. 2008; Jürgensen et al. 2012). Others include the fear of losing social support networks (Oshi et al. 2007; Denison et al. 2008; Meiberg et al. 2008; Råssjö et al. 2007) which also includes marital partners (Izugbara et al. 2009; Grant et al. 2008; Skovdal et al. 2011a), and even facing the consequences fear of straining marital relationships, including possibilities of abandonment, divorce, or even violence (Mlay et al. 2008; Chirawu et al. 2010; Njozing, Edin & Hurtig 2010; Jürgensen et al. 2012). In highly socially-centred but poor-resource settings characterised by weak formal institutional safety nets, social capital assets are central to survival and therefore families and other network members are critical making (Roura et al. 2009). In patriarchal societies, gender inequality also limits women’s decision making about accessing HIV testing (Urassa et al. 2005; Taegtmeyer et al. 2006; Mabunda 2006).

Health system-level factors that affect uptake of HIV testing include perceived poor location of testing facilities (Taegtmeyer et al. 2006; McPhail et al. 2008; Bwambale et al. 2008; Jürgensen et al. 2012) and perceived lack of confidentiality by health service providers (Pool, Nyanzi & Whitworth 2001; Mabunda 2006; Meiberg et al. 2008; Chirawu et al. 2010; Namakhoma et al. 2010). Fylkesnes and Siziya (2004) reported a nearly fivefold increase in VCT uptake when patients were given the choice of an "optional location" for testing rather than the routine clinical setting. Gilson has also noted that health systems are social institutions, and therefore, people's experiences with the health care sector influence service utilisation. She points out that the attitude of the staff can cause dissatisfaction with services, which even good technical care may not offset (Gilson 2003). In a study on HIV testing among antenatal attendees in Lusaka, Zambia, Thiermann et al. (2006) found that perceived anonymity of HIV testing also affected the uptake of HIV testing. Women who met their counsellors for the first time were more likely to test for HIV, while those who refused to be tested were more likely to support HIV testing outside the regular clinical setting (Thiermann et.al. 2006). Van Dyke et al. (2003) also found that 33% of surveyed patients would prefer to undergo HIV testing in a setting where no one would know them. In the context of fragile livelihoods, the direct financial costs of accessing testing services also inhibit uptake of testing (Råssjö et al. 2007; Angotti et al. 2009). Where user fees were charged, individuals weighed the benefits of testing against other competing human needs (Oshi et al. 2007; Råssjö et al. 2007; Mlay et al. 2008; Angotti et al. 2009). More so, the opportunity costs of suspending income generating activities and time-off work (Råssjö et al. 2007; Skovdal et al. 2011a) discouraged uptake of HIV testing.

1.3.2 Barriers to uptake of antiretroviral therapy

Despite the proven efficacy of ART in reducing mortality among PLHIV (Egger et al. 2002; Coetzee et al. 2004; Hammond & Harry 2008), some PLHIV still drop out of treatment. An analysis of 33 patient cohort studies from 13 Africa countries revealed that on average, 60% of patients were retained in ART care after two years of initiation (Rosen, Fox & Gill 2007); another study has reported retention rates of 75% at 12 months and 67% at 24 months (Tassie et al. 2010). The reasons for reluctance to start treatment and patient attrition from ART care are varied and include financial costs associated with accessing treatment (Zachariah et al. 2006; Miller et al. 2010;), fear of side effects (Beer et al. 2009; Miller et al. 2010), fear of toxicity and long-term harm to the body (Siegel & Gorey 1997; Gold & Ridge 2001) and feeling healthy (Gold & Ridge 2001; Beer et al. 2009; Katz et al. 2011). Other barriers are stigma (Beer et al. 2009; Miller et al. 2010), belief in faith healing (Wanyama et al. 2007; Wringe et al. 2009; Roura et al. 2010; Unge et al. 2011), use of traditional medicine (Babb et al. 2007; Wringe et al. 2009;

Unge et al. 2011;) and perceived burden of being on life-long treatment (Stevens & Hilderbrandt 2009).

1.3.3 Disclosure of HIV status

Successful prevention, control and management of HIV infection in part depends on disclosure of HIV status to family members, friends and most importantly sexual partners (WHO 2003). For instance, women who disclose their HIV status to their partners are more likely to participate in prevention of mother-to-child transmission of HIV (PMTCT) programmes (Medley et al. 2004; WHO 2003); and people who disclose their HIV status have better adherence to antiretroviral therapy (Waddell & Messeri 2006). Various studies have revealed different effects of disclosing one's HIV positive status. The negative outcomes have included blaming the PLHIV for 'loose morals' because of the association of HIV infection with sexual promiscuity (Greeff et al. 2008), being disowned, abandoned and rejected or deterioration in relationship with social network members and partners (Greeff et al. 2008) and verbal and physical abuse (Kilewo et al. 2001; Greeff et al. 2008).

Despite the fear to disclose one's HIV status, various studies have revealed that disclosure also brings positive elements. These positive aspects include a sense of self-understanding, healing and authenticity in social relationships, relief from the burdens of secrecy and rumours, serving as role models in helping others to go for testing and as an important pre-requisite for timely and adequate social support (Greeff et al. 2008).

1.4 Rationale of the PhD thesis

First, despite the volume of empirical evidence on factors influencing uptake of HIV testing in SSA, no study has drawn together all the existing evidence to provide comprehensive insights into factors influencing uptake of HIV testing. This was one of the objectives of the PhD study. This also provided an opportunity to identify where paucity of data still existed, namely why individuals who knew the HIV positive status of their marital partners opted not to seek HIV testing. In Zambia, notwithstanding the scale-up of HIV testing and treatment services, uptake is not yet optimal. For instance the last held Zambia Demographic and Health Survey (ZDHS) conducted in 2007 reports that while awareness of HIV was high (above 90%) and knowledge of testing sites and desire to be tested was also high (83% and 73% respectively), only an estimated 30% of Zambians had tested for HIV and knew their HIV status (CSO 2009). The uptake of HIV testing and treatment is also hampered by reported non-disclosure of HIV status (Human Rights Watch 2007).

Second, despite the increasingly wider availability and free provision of life-saving treatment in Zambia, not all people living with HIV and in need of treatment are receiving it. At the end of 2010, out of an estimated 503,284 adults and children in need of ART, 68.4% were receiving it (NAC 2012). This puts such PLHIV not on treatment at risk of AIDS-related morbidity and mortality. Critically, not all PLHIV initiated on treatment are retained in ART care. Statistics from a local public sector clinic located in the study setting showed that by mid-2011, about 7.5% of patients initiated on ART had been classified as lost-to-follow up (LTFU) because they were late for pharmacy pick up by at least 180 days. The revised Zambian ART treatment guidelines have reduced the LTFU threshold to at least 60 days (MoH 2010a). Therefore, successful delivery of HIV treatment requires understanding and addressing the different factors that undermine patient initiation of treatment as well as patient retention in ART care.

Against this backdrop, this PhD thesis therefore aimed at generating insights into factors influencing uptake of HIV testing and treatment in SSA and Zambia in order to contribute towards the development of appropriate measures to improve uptake of HIV testing and treatment and retain PLHIV in antiretroviral therapy care.

The PhD study was nested within a 3-year (2009-2012) Swiss National Science Foundation (SNSF) funded collaborative, multi-disciplinary research project to explore policy and practice-relevant insights into factors influencing health-seeking behaviour related to HIV testing, treatment and care in Zambia. The research project was undertaken in four (4) districts of Zambia - two rural districts (Namwala and Monze), one commercial/industrial district (Mazabuka), and one urban setting (Lusaka). A mixed-method study, combining qualitative research with cross-sectional survey, was carried out. This PhD thesis draws on qualitative data collected in Lusaka, Zambia.

1.5 Analytical framework: The Social ecological framework

Over the years, various theories and models have been developed to help understand health-seeking behaviour (UNAIDS 1999; Mackian, Bedri & Lovel 2004). The social ecological model is one of them. The social ecological model provides a comprehensive approach for exploring and encapsulating the wide ranging individual and non-individual factors that influence health-seeking behaviour. It positions health-seeking behaviour in a 'social ecology' (Roura et al. 2009) in which health-seeking is influenced by an array of personal, interpersonal, health-system and structural-level factors, all embedded in a 'social ecology.' (Figure 1-3). Individual-level factors comprise personal characteristics such as perceived disease severity, illness and wellness interpretations and knowledge and attitudes towards treatment (Roura et al. 2009).

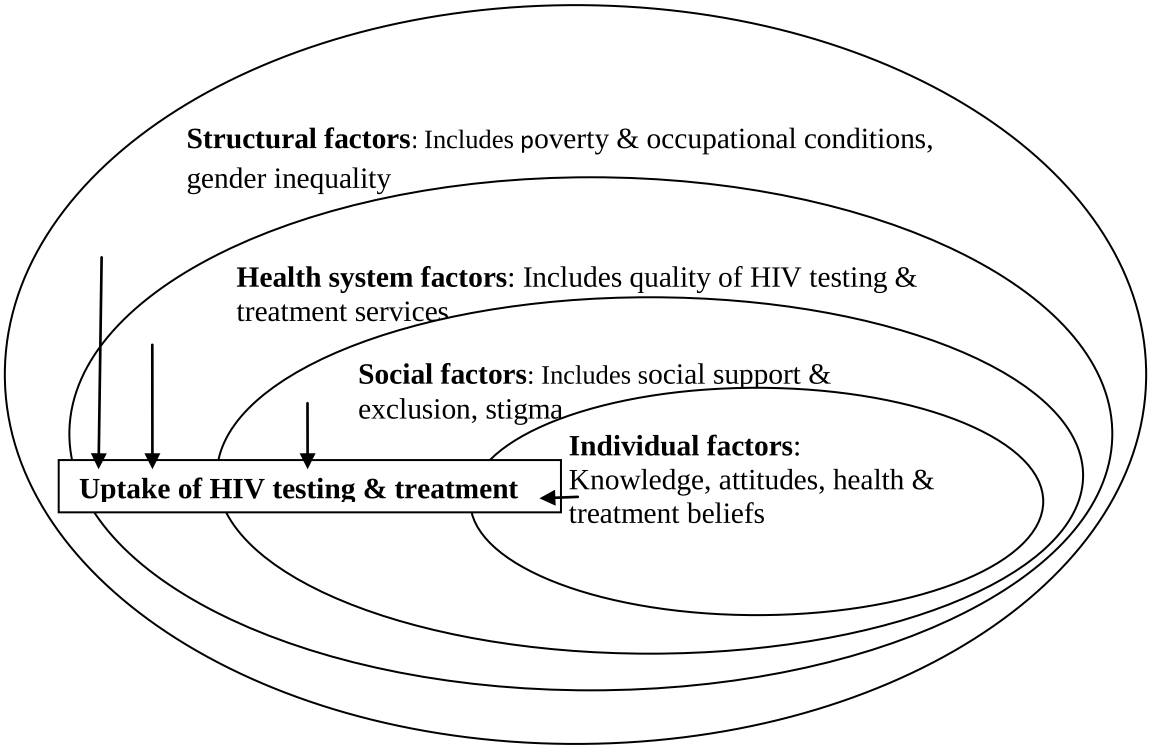


Figure 1-3 Schema of the social-ecological framework

Social factors include interpersonal relationships with marital partners, family members and peers that in turn affect individual behaviour and action (Roura et al. 2009). Social factors also include relationships with, and influence of, social institutions like the church and traditional health care systems which are deeply embedded in people’s socio-cultural systems. Social exclusion, discrimination and stigmatization are located on this level too. Health system factors relate to the way health services are organized and delivered (Munro et al. 2007). These include availability and accountability of services, attitude of providers, waiting time and distance to health facilities (Munro et al. 2007; Roura et al. 2009) while structural factors are those external to the control of the individual (Parker, Easton & Klein 2000; Munro et al. 2007). These include endemic poverty, livelihood circumstances, health policies, laws and regulations, and the financing of the healthcare system, which is linked to the national economy (Sumartojo 2000). Sometimes a combination of different level-factors may influence health-seeking behaviour. For instance, stigma (social factor) and long waiting times at ART clinic (health system factor) may coalesce resulting in non-uptake of HIV services.

The social ecological framework thus bridges the divide between “individualist” and “structuralist” models of health-seeking behaviour by treating both paradigms as complementary and lying on the same continuum (Roura et al. 2009). Health-seeking behaviour is therefore construed not as something that exclusively resides in the individual but also a reflection of wider interactive dynamic processes in the social environment (Latkin & Knowlton 2005; Roura et al. 2009; Musheke, Bond & Merten 2012).

The thesis uses the social ecological framework to explore the reasons for HIV-patient non-uptake of treatment and patient attrition from antiretroviral therapy care. Data collection and analysis was guided by these different multi-level categorizations that underpin the framework.

CHAPTER 2

2.0 STUDY AIM, OBJECTIVES AND METHODS

2.1 Aim

The aim of the PhD thesis was to explore factors influencing uptake of HIV testing in sub-Saharan Africa and HIV-patient non-initiation of and attrition from ART care in an urban community of Lusaka, Zambia.

2.2 Objectives

1. To synthesise qualitative research findings on factors influencing uptake of HIV testing in sub-Saharan Africa (Chapter 3);
2. To find out why marital partners of individuals living with HIV did not seek HIV testing despite knowing the HIV-positive status of their partners (Chapter 4);
3. To explore factors influencing uptake of provider-initiated couple HIV testing and its effect on marital relationships (Chapter 5);
4. To investigate the reasons people living with HIV and eligible for treatment either opted not to start treatment or dropped out of treatment (Chapters 6, 7 & 8).

2.3 Study Setting

The study was conducted in Jack compound and nearby and surrounding communities. The surrounding communities are *Chawama*, *Kuku*, *Misisi*, *Kuomboka,* John Howard, *Kamwala* south and *Lilayi*. The study setting is predominantly a low-income, high-density urban residential area located about 10 km south of Lusaka city centre, the capital city of Zambia. The setting comprises multilingual ethnic groups, with *Bemba* and *Nyanja* the most widely spoken local languages. There are also strong kin and non-kin social network relationships. Some individuals were born and have grown up together in the area. However, in and out mobility and migrations in the area are high. Most of the families are large, in part due to the ravages of HIV with some individuals have grown up as orphans under the care of extended family members. Although not all family members lived together, they still maintained reciprocal social and economic support ties. Other social network relationships are a product of similar religious affiliations, occupational and social lifestyle activities. Due to lack of public social amenities, social lifestyle activities mostly revolve around patronising the ubiquitous bars and drinking places, which are also a prime source of sexual network relationships.

The livelihood conditions of the local people are mixed, but predominantly poor. A few people are employed in low-paid jobs in the public and private sectors of the formal economy. However, the majority eke out a living in the informal economic sector as cross-border traders and local market traders mainly selling fruits, vegetables, meat products, charcoal and second-hand clothes either in the city centre markets or in the open - air local markets. Small makeshift shops, locally called *'tuntemba'* are ubiquitous in the area. Unemployment is also endemic in the area, among the lowly educated youth but also among the old, some of whom travelled from the mining towns on the Copperbelt province to Lusaka in search of job opportunities following the structural economic reforms of the 1990s which resulted in the collapse of the mining sector in Zambia at the time. The unemployment situation is further exacerbated by rural-urban migration as people move into the city in search of job opportunities and a better life as well as, unlike in the past, reluctance by people to return to rural areas upon retirement.

Health services in the area are mainly provided by an easily accessible public sector clinic called *Chawama* health centre which provides both in-patient and out-patient health services. At the end of 2012, *Chawama* clinic had approximately 11,930 people on ART and about 2,470 people on pre-ART. The clinic started providing ART in March 2006 following the Zambian government's decision to start providing free ART services in public health facilities. However, before 2006, there was a program which started in 2001 called Zambia Exclusive Breastfeeding Study (ZEBS) which used to provide ART services to pregnant women to reduce mother-to-child transmission of HIV. This program phased out around 2004. At the end of 2012, the clinic has about 97% of its clients on first-line treatment, 3% on second-line and has no client on third-line treatment. The clinic also provides HIV testing, PMTCT, family planning and reproductive health services; houses a couple HIV testing research project and a non-governmental organisation that provides sexual education, nutritional counselling and psychosocial support to women and new mothers living with HIV.

Figure 2-1 Traditional medicine and faith healing as alternative health care services

Christianity is the dominant religion in the area, with a myriad of charismatic evangelical Pentecostal churches, some of which provide healing sessions for people with different ailments, including HIV.

2.4 Study Population

The study population comprised women and men living with HIV (both on treatment and not on treatment) aged ≥18 years old and residents of the study area; lay and professional health care workers of the local public sector clinic; herbal medicine providers; marital partners of PLHIV who had not tested for HIV (and did not know their HIV status). The sample sizes, study methods and research participant characteristics are summarised in Table 2-1 and described in the respective study chapters of the PhD thesis.

2.5 Study Design and Sampling Methods: An overview

2.5.1 Meta-ethnography: Meta-ethnography first put forward by Noblit and Hare (1988) was used to synthesise published qualitative research findings of factors influencing uptake of HIV testing in SSA. Meta-ethnography involves re-interpretation and synthesis of qualitative research findings across multiple studies in order to gain in-depth understanding of phenomena (Britten et al. 2002; Campbell et al. 2003; Pound et al. 2005; Merten et al. 2010). This involves the ‘juxtaposition of studies and the connections between them’ (Harvey 2007) in order to achieve greater conceptual development and insight than would be obtained from individual studies (Campbell et al. 2003). Emphasis is on developing new interpretations and concepts rather than accumulation of information (Walsh & Downe 2005). CINAHL, CSA, EMBASE, JSTOR, Medline and Web of Science were searched for published articles. The first search was done on 30th June 2010 and repeated on 26th February 2011. Additional searches were periodically undertaken until end of February 2012 to ensure that no new publications were omitted. The searches yielded 5,684 citations of which 4,464 were subject to title and abstract review. 1,220 were duplicate papers and 42 papers were included in the synthesis. The PhD student took the lead in conceptualizing the study, doing the literature search, conducting title, abstract and full-text review and drafting the systematic review paper.

2.5.2 Qualitative studies: The rest of the qualitative sub-studies drew on classic ethnographic data collection methods. The PhD student was embedded (lived) in the study setting for 18 months and conducted all the interviews and observations. This helped develop rapport with and win the trust of research participants and also facilitated collection of in-depth insights into the social context within which people lived and made decisions about their actions and behaviours (Hammersley 1990; Van Maanen 1996; Cresswell 1998). In-depth, semi-structured interviews, FGDs and observations were used to collect data. Participants were sampled purposefully to ensure diversity of study participants such as age, sex, marital status, livelihoods and time on and off treatment.

2.6 Data management and analysis

For the systematic review using meta-ethnography, to establish how the concepts from different papers were related to one another, we created a grid and entered the concepts from each paper. We used Malpass’s notion of first-, second-and third-order constructs to generate the concepts (Malpass et al. 2009). First-order constructs represent the views of research participants while second order-constructs are authors’ interpretation of research participants’ views (Britten et al. 2002; Atkins et al. 2008). Second-order constructs were identified, cross-compared and used to develop third-order constructs - our interpretations of the researchers’ interpretation of research participants’ views (Atkins et al. 2008; Malpass et al. 2009).

Table 2-1 Methods used in the PhD thesis studies

Study /Chapter	**Study Design**	**Methods**	**Sample size**	**Data analysis method**
Chapter 3	Systematic review	Systematic review	5,686 citations reviewed; 42 papers synthesized.	Meta-ethnography
Chapter 4	Qualitative	In-depth interviews; Focus Group Discussions; Observations	Partners of PLHIV (n=30); antenatal clinic staff (n=10); FGD VCT counsellors (n=8)	Latent content analysis.
Chapter 5	Narrative approach	In-depth interviews; Observations	Couples (n=10); VCT counselors (n=5); antenatal nurses (n=2)	Narrative approach.
Chapter 6	Qualitative	In-depth interviews; Observations	PLHIV who declined ART (n=37); ART staff (n=5); faith healers (n=5); herbal medicine providers (n=5); home-based caregivers (n=5)	Latent content analysis.
Chapter 7	Qualitative	In-depth interviews; Observations	PLHIV dropped out of ART (n=25); ART staff (n=5); faith healers (n=5); herbal medicine providers (n=5); Home-based caregivers (n=5)	Latent content analysis.
Chapter 8	Qualitative	In-depth interviews	PLHIV dropped out of ART (n=25); PLHIV who declined ART (n=37)	Latent content analysis.

Using the process of translation (Britten et al. 2002), we compared the concepts of the papers i.e. paper 1 with paper 2 and the synthesised concepts of the two papers with paper 3 and so on, until all studies had been translated into each other (Pound et al. 2005; Atkins et al. 2008). The translation process was iterative to ensure that third-order constructs reflected concepts of the individual papers.

For the other qualitative PhD thesis studies, data coding and analysis was conducted by the PhD student. All interviews conducted in the local language (*Nyanja*) were translated and all interviews were transcribed verbatim. A research assistant helped with translating and transcribing the interviews. These were cross-checked by the PhD student for quality control. FGDs and observational field notes were typed by the PhD student in as much detail as possible. Latent content analysis approach (Graneheim & Lundman 2004) was used to analyse and interpret the data. Qualitative content analysis entails "interpretation of text data through the systematic classification process of coding and identifying themes or patterns (Hsieh & Shannon

2005, p. 1278). It also involves “data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings” (Patton 2002, p.453). All interview and focus group discussion transcripts and observational field notes constituted unit of analysis (Graneheim & Lundman 2004). These were read several times to create a sense of the emergent themes (Graneheim & Lundman, 2004) ATLAS.ti version 6 - a qualitative software for organising and managing textual data - was used to organise, manage and code the data. Coding took place in multiple stages. The initial coding process was an open coding process during which the interview transcripts and field notes were read and annotated. During this process, the concepts were identified and labelled. Subsequent coding involved comparing codes for similarities and differences and additional codes were identified. An example of a coding schema is provided in the methods section of Chapter 8 of the PhD thesis. Similar codes were grouped into categories on a manifest level. Themes were then generated by interpreting the categories for their underlying meaning (Graneheim & Lundman, 2004). In line with the analytical framework, the themes for non-uptake of treatment are presented as individual-level, interpersonal, health-system and structural-level factors.

The data collection, data analysis and write up were all conducted by the PhD student. The student was also the lead author of all the articles that make up the chapters of this PhD thesis.

2.7 Ethical Considerations

2.7.1 Ethical Review of Research Protocol

Nested within a bigger project ‘Improving equity of access to care and treatment in Zambia’, the PhD research was locally approved by the Humanities and Social Sciences Research Ethics Committee of the University of Zambia and the Ethik Kommission Beider Basel, Switzerland. Administrative clearance was also obtained from the Zambian Ministry of health (MoH) at national and district levels. The PhD research proposal was approved by the Research Commission (*Forschungskommission*) of the Swiss Tropical and Public Health Institute.

2.7.2 Informed Consent and Confidentiality

The right to informed consent was observed, giving respondents as much information about the purpose and outcomes of the research. Written informed consent was obtained from all research participants who were given an opportunity to ask questions until they fully understood the study and the implications of their participation. Participants were also informed about voluntary withdraw from the study for any reason at any time. However, challenges were encountered when administering consent. Some study participants that had dropped out of and those that had not initiated treatment were initially suspicious of providing written consent as well as having the interviews recorded. They feared that the study was an attempt by the health system to 'spy' on them for non-uptake of treatment. These fears were reinforced by the study's use of clinic staff to make initial contact with the potential study participants. These fears were allayed by living in the study setting for an extended period of time and explaining to them that the research was a school project conducted independent of the health system and not a health facility 'spy' project.

All participant information and records that contained names or other personal identifiers, such as informed consent forms, were stored securely in areas with access limited to the researcher (PhD student) and his supervisors. No identifying information was used in the transcripts in order to protect research participants' identity. More so, data from personal narratives was not linked to any type of personal clinical data.

2.7.3 Risks to Research Participants

Risks to research participants were minimised. Therefore, research participants were interviewed either within their households or outside their households, depending on their preferences and desire for privacy and confidentiality.

2.7.4 Incentives for Research Participants

No financial incentives were given to study participants. However, lunch was provided whenever interviews took place at neutral locations during lunch time. While attempts were made to ensure that data collection was conducted within the locality and convenience of the research participants, where participants moved to convenient distant places to be interviewed, they were given transport reimbursements.

RESULTS

Chapter 3

A systematic review of qualitative findings on factors enabling and deterring uptake of HIV testing in Sub-Saharan Africa*

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Abstract

Background: Despite Sub-Saharan Africa (SSA) being the epicenter of the HIV epidemic, uptake of HIV testing is not optimal. While qualitative studies have been undertaken to investigate factors influencing uptake of HIV testing, systematic reviews to provide a more comprehensive understanding are lacking.

Methods: Using Noblit and Hare's meta-ethnography method, we synthesised published qualitative research to understand factors enabling and deterring uptake of HIV testing in SSA. We identified 5,686 citations out of which 56 were selected for full text review and synthesised 42 papers from 13 countries using Malpass' notion of first-, second-, and third-order constructs.

Results: The predominant factors enabling uptake of HIV testing are deterioration of physical health and/or death of sexual partner or child. The roll-out of various HIV testing initiatives such as 'opt-out' provider-initiated HIV testing and mobile HIV testing has improved uptake of HIV testing by being conveniently available and attenuating fear of HIV-related stigma and financial costs. Other enabling factors are availability of treatment and social network influence and support. Major barriers to uptake of HIV testing comprise perceived low risk of HIV infection, perceived health workers' inability to maintain confidentiality and fear of HIV-related stigma. While the increasingly wider availability of life-saving treatment in SSA is an incentive to test, the perceived psychological burden of living with HIV inhibits uptake of HIV testing. Other barriers are direct and indirect financial costs of accessing HIV testing, and gender inequality which undermines women's decision making autonomy about HIV testing. Despite differences across SSA, the findings suggest comparable factors influencing HIV testing.

Conclusions: Improving uptake of HIV testing requires addressing perception of low risk of HIV infection and perceived inability to live with HIV. There is also a need to continue addressing HIV-related stigma, which is intricately linked to individual economic support. Building confidence in the health system through improving delivery of health care and scaling up HIV testing strategies that attenuate social and economic costs of seeking HIV testing can also contribute towards increasing uptake of HIV testing in SSA.

3.0 Background

HIV continues to be a public health burden in Sub-Saharan Africa (SSA). Out of an estimated 34 million people living with HIV worldwide at the end of 2010, 68% resided in SSA (UNAIDS 2011) and an estimated 1.9 million people became newly infected in 2010 (WHO, UNAIDS & UNICEF 2011). Efforts to achieve zero new infections and zero AIDS-related deaths (UNAIDS 2010b) require increased uptake of HIV testing as a gateway to HIV prevention, treatment and care. To address this health problem, coupled with increasingly wider availability of antiretroviral therapy (ART), many countries in SSA have in recent years dramatically scaled up HIV testing services. For instance, health facilities providing HIV testing services in 37 countries of SSA increased by 50% from 11,000 in 2007 to 16,500 in 2008 (WHO, UNAIDS & UNICEF 2009).

Despite the increasingly wider provision of HIV testing services, ten population-based surveys estimate that the median percentage of people living with HIV who know their status is below 40% (WHO, UNAIDS & UNICEF 2010). Quantitative studies have identified stigma and discrimination (Kalichmam & Simbayi 2003); perceived low risk of HIV infection (Nakanjako et al. 2006); perceived lack of confidentiality (Van Dyke & Van Dyke 2003); and distance to testing sites (Marum, Taegtmeyer & Chebet 2006) as barriers to uptake of HIV testing. Enabling factors include perceived anonymity of testing (Fylkesness & Siziya 2004); convenience of home-based HIV testing (Mutale et al. 2010) and availability of ART (Warwick 2006). Qualitative studies have also been conducted in SSA that additionally highlighted social dynamics influencing uptake of HIV testing. Despite the volume of this evidence and the contribution it can make towards a better understanding of factors influencing uptake of HIV testing in SSA, systematic reviews are lacking.

3.1 Methods

We used the meta-ethnographic approach first put forward by Noblit and Hare (1988) to synthesise published qualitative research findings. Meta-ethnography has increasingly been used to re-interpret and synthesise qualitative research findings across multiple studies in order to gain in-depth understanding of a phenomena (Britten et al. 2002; Campbell et al. 2003; Pound et al. 2005; Merten et al. 2010). This involves the 'juxtaposition of studies and the connections between them' (Harvey 2005) in order to achieve greater conceptual development and insight than would be obtained from individual studies (Campbell et al. 2003). Emphasis is on developing new interpretations and concepts rather than accumulation of information (Walsh & Downe 2005).

3.1.1 Search strategy and identification of papers

CINAHL, CSA, EMBASE, JSTOR, Medline and Web of Science were searched for published qualitative research findings up to end of February 2012. The first search was done on 30th June 2010 and repeated on 26th February 2011. Repeated searches using the same search strategy were undertaken until end of February 2012 to ensure that no new publications were omitted. The searches yielded 5,686 citations of which 4,466 were subject to title and abstract review. 1,220 were duplicate papers. An over-inclusive search strategy was used to ensure that no papers were missed. The key search words used were: "HIV OR "Acquired Immuno-deficiency Syndrome" OR "AIDS" OR "HIV infection" or "HIV/AIDS"; "VCT" OR "voluntary counselling and testing" OR "HIV test"; "Africa" OR "sub-Saharan Africa" OR "SSA". We also reviewed references of the selected papers to ensure that no papers were missed. Two researchers (MM and HN) reviewed titles and abstract in duplicate to exclude ineligible articles. Papers that met the inclusion criteria were subject to full-text review (Figure 3-1).

3.1.2 Quality assessment and inclusion criteria

Quality appraisal of qualitative research still remains contested (Mays & Pope 2000; Smith, Pope & Botha 2005; Munro et al. 2007; Atkins et al. 2008) because 'there is no unified body of theory, methodology or method that can collectively be described as qualitative research' (Rolfe 2006). Previous meta-ethnography studies have not used any formal appraisal checklist (Smith, Pope &Botha 2005; Merten et al. 2010) or did not exclude any paper on the basis of pre-specified quality assessment criteria (Munro et al. 2007; Briggs & Flemming 2007; Malpass et al. 2009). Barbour (2001) has pointed out that while checklists are useful in improving qualitative research, such 'technical procedures' can affect the contributions of systematic qualitative research. With this contestation in mind, but to ensure inclusion of relevant 'quality' papers, our inclusion criteria comprised: peer-reviewed publications only; published in English; conducted in SSA;

focused on access to HIV testing; and reported qualitative findings - including mixed-methods papers. Forty-two (42) publications from thirteen (13) SSA met the inclusion criteria (Table 3-1).

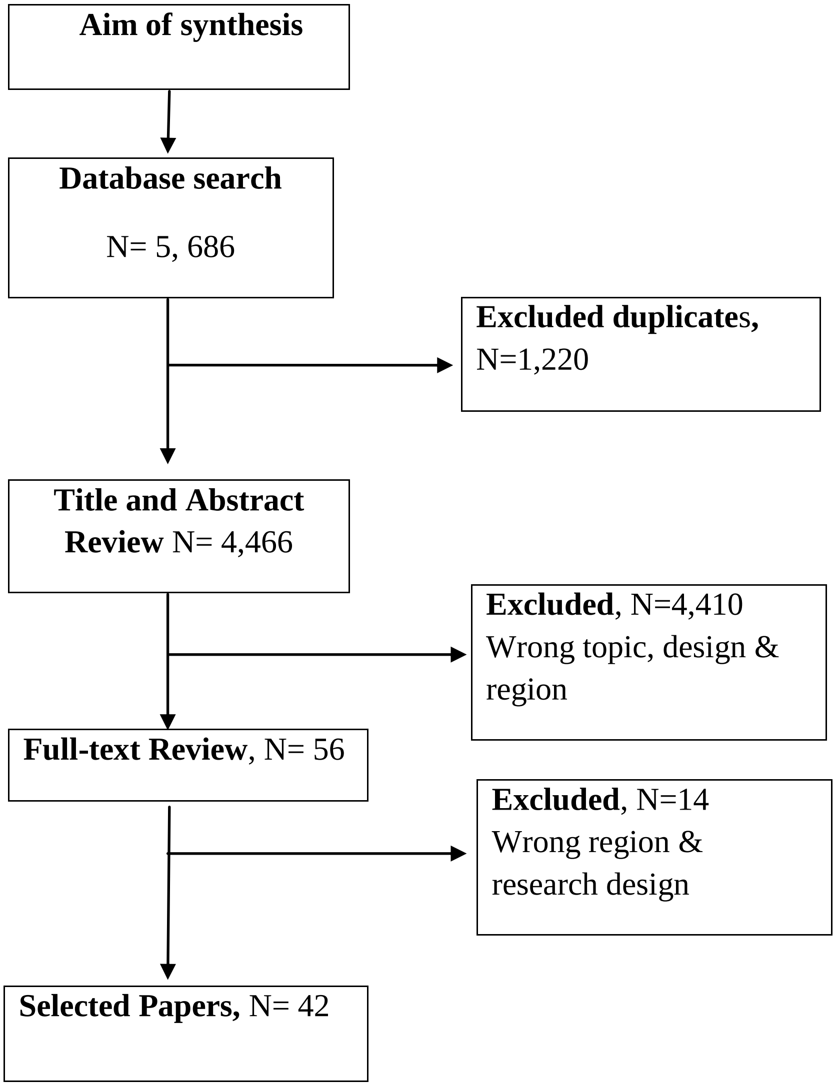


Figure 3-1 Search strategy and paper selection flowchart

3.1.3 Analysis and synthesis process

To establish how the concepts from different papers were related to one another, we created a grid and entered the concepts from each paper (see Table 3-2). We used Malpass et al. (2009) notion of first-, second-and third-order constructs to generate the concepts. First-order constructs represent the views of research participants while second order-constructs are authors' interpretation of research participants' views (Britten et al. 2002; Atkins et al. 2008). Second-order constructs were identified, cross-compared and used to develop third-order constructs - our interpretations of the researchers’ interpretation of research participants’ views (Atkins et al. 2008; Malpass et al. 2009).

Table 3-1 Characteristics of selected papers

1st Author/Year [Citations]	Country	Settings Urban/Rural	Sample (sub-group)	Study type	Aim
Castle 2003 [28]	Mali	Urban	Men & women 20-34 yrs; Young people 17-24 yrs	Qualitative	To assess attitude towards HIV with a view to setting up VCT services.
Pool 2001 [29]	Uganda	Rural	Women antenatal care attendees	Qualitative	To explore attitudes to VCT among women attending antenatal care.
Daftary 2007 [30]	South Africa	Urban	In-patient with TB	Qualitative	To explore decision making processes for HIV testing and disclosure by TB patients.
Maman 2001 [31]	Tanzania	Urban	Men, women, Couples	Qualitative	To explore individual, relational and environmental factors influencing HIV testing decision & disclosure of status to partners.
Mabunda 2006 [32]	South Africa	Rural	Men and women ≥ 18yrs	Qualitative	To identify themes related to VCT services in rural South Africa.
Angotti 2009 [33]	Malawi	Rural	Married women & men 15-49 yrs; Married & unmarried adolescents 15-24 yrs	Qualitative	To examine the acceptability of HIV testing in 3 rural districts.
MacPhail 2008 [34]	South Africa	Urban	Adolescents 12-24 yrs; parent	Qualitative	To establish the perceptions of and needs for VCT among young people.
Mlay 2008 [35]	Tanzania	Urban	Women 18-49 yrs; Men 20-75 yrs;	Qualitative	To gain insight into the views of counsellors men and women on VCT for couples.
Izugbara 2009 [36]	Malawi & Uganda	Rural/Urban	Male youths 14-19 yrs	Qualitative	To offer youth-centred perspectives & masculinity as they relate to HIV services, including VCT.
Grant 2008 [37]	Zambia	Urban	People living with HIV	Qualitative	To examine what factors affect a person's decision to seek testing and then start and stop treatment.
Denison 2008 [38]	Zambia	Urban	Adolescents 16-19 yrs	Qualitative	Explore how adolescents involve their families, friends, sex partner about VCT & disclosure of status.

Table3-1 Characteristics of selected papers (cont'd).

1st Author/Year [Citations]	Country	Settings Urban/Rural	Sample (sub-group)	Study type	Aim
Oshi 2007 [39]	Nigeria	Urban	University Students	Qualitative	To investigate if self-perception of risk of HIV infection causes Nigeria youths to reduce risky sexual behaviour & seek VCT.
Meilberg 2008 [40]	South Africa	Urban	University Student	Qualitative	To identify psychosocial correlates of HIV voluntary counselling & testing.
Groves 2010 [41]	South Africa	Urban	Women at antenatal clinic	Qualitative	To explore women's experiences with HIV testing & the consent process in a public antenatal clinic.
Rassjo 2009 [42]	Uganda	Urban	Young men & women	Qualitative	Attitude to VCT among young men & women in a slum area of Kampala, Uganda.
Chirawu 2010 [43]	Zimbabwe	Rural	Men and women ≥ 18yrs	Mixed methods	To examine the acceptability & feasibility of providing client-initiated VCT in health facilities & research-initiated VCT in a non-clinic setting.
De Paoli 2004 [44]	Tanzania	Rural	Women at antenatal clinic	Mixed methods	To identify factors associated with pregnant women's willingness to accept VCT.
Ayenew 2010 [45]	Ethopia	Not stated	Patient with TB; Nurse counselors	Mixed methods	To assess predictors of HIV testing among TB patients.
Namakhoma 2010 [46]	Malawi	Urban & Rural	Health Workers	Mixed methods	To explore the enablers and access barriers to HIV-VCT & ART by health workers in Malawi.
Urassa, 2005 [47]	Tanzania	Not Stated	Women 15-45 yrs old	Mixed methods	To identify risk factors for preferring to avoid HIV testing among women attending antenatal care.
Obermeyer2009 [48]	Burkina Faso	Urban & rural	Men & women	Mixed methods	To investigate the utilization of services around HIV testing.

Table3-1 Characteristics of Selected papers (cont'd)

1st Author/Year [Citations]	Country	Settings Urban/Rural	Sample (sub-group)	Study type	Aim
Bhagwanjee 2008 [49]	South Africa	Not stated	Mine employees	Qualitative	To understand users' perceptions of VCT & HIV treatment services offered by a mining company.
Luginaah 2005 [50]	Ghana	Not stated	Pastors, Marriage counsellors, men & women	Qualitative	To examine efforts by some men & women churches in Ghana to reduce the spread of HIV through HIV-VCT.
Taegtmeyer 2006 [51]	Kenya	Urban & rural	Men & women	Mixed methods	To better understand the reasons behind gender differences in Kenyan VCT sites.
Larson, 2010 [52]	Uganda	Urban	Men	Qualitative	To explore men's views on, and experiences of couple HIV testing during antenatal care.
Varga, 2008 [53]	South Africa	Urban & rural	adolescent mothers 15-19 yrs old	Qualitative	To examine barriers to HIV testing uptake & participation in PMTCT services.
Sherr 2003 [54]	South Africa	Urban & rural	Health staff & women	Qualitative	To establish the attitude of clinic staff & pregnant women to routine HIV testing & counselling.
Simpson 2010 [55]	Zambia	Urban & rural	Cohort of school boys	Qualitative	To describe masculinity, religious ideas & response to VCT among a cohort of catholic boys.
Nuwaha 2002 [56]	Tanzania	Urban & rural	Men & women	Mixed methods	To understand factors influencing choice of VCT.
Theuring 2009 [57]	Tanzania	Rural	Men of reproductive age	Mixed methods	To assess male attitude regarding partner involvement in ANC and PMTCT services.
Mbonye 2010 [58]	Uganda	Rural	Women, Men & adolescents Local leaders & health workers	Mixed methods	To understand care-seeking practices and barriers to PMCT services.

Table 3-1 Characteristics of selected papers (cont'd)

1st Author/Year [Citations]	Country	Settings Urban/Rural	Sample (sub-group)	Study type	Aim
Levy 2009 [59]	Malawi	Urban	HIV-positive women; PMTCT programme managers; policy makers; health workers	Qualitative	To examine women's decisions about HIV testing & experiences of PMTCT & HIV-related care.
Bwambale 2008 [60]	Uganda	Rural	Men & women aged ≥18 years; CHWs; NGO health workers	Mixed methods	To determine the prevalence and factors associated with VCT use amongst men.
Frank, 2009 [61]	Zambia	Rural	Women and men with HIV; village leaders; health workers	Qualitative	To determine if community structures and livelihood strategies were changing to mitigate the impact of the HIV epidemic.
Larson, 2012 [62]	Uganda	Rural	Pregnant women at ANC	Qualitative	To explore pregnant women experiences of opt-out HIV testing.
Dye, 2011 [63]	Kenya	Rural	Men & women in the community	Qualitative	To ascertain motivational & experiential dimensions of participation in rapid integrated prevention campaigns.
Roura, 2009 [64]	Tanzania	Rural	Community leaders, ART users, Health workers	Qualitative	To investigate the effects of ART scale up on stigma & HIV testing in rural Tanzania.
Day, 2003 [65]	South Africa	Urban & rural	Mine workers	Mixed methods	To identify the attitude influencing uptake of VCT among Gold mine workers in South Africa.
Phakathi, 2011 [66]	South Africa	Rural	Community members	Qualitative	To examine the influence of ART on willingness to test for HIV in a rural community.
Skovdal, 2011 [67]	Zimbabwe	Rural	ART users, Health workers, care givers of children on ART	Qualitative	To examine how local construction of masculinity impact on men's use of HIV services.
Njozing, 2010 [68]	Cameroon	Not stated	TB Patients	Qualitative	To explore the barriers and barriers to HIV testing among TB patients.
Jürgensen 2012 [69]	Zambia	Urban & rural	Community members & VCT counsellors	Qualitative	To explore local meaning attached client initiated HIV testing in rural & urban setting of Zambia.

Using the process of translation – transfer of ideas, concepts and metaphors across different studies (Britten et al. 2002), we compared the concepts of the papers i.e. paper 1 with paper 2 and the synthesised concepts of the two papers with paper 3 and so on, until all studies had been translated into each other (Pound et al. 2005; Atkins et al. 2008). The translation process was iterative to ensure that third-order constructs reflected concepts of the individual papers. New concepts were also identified through the process. Thus, we were able to re-interpret and re-conceptualise the findings to develop deeper meaning across the individual papers. The third-order constructs were transposed into a conceptual model showing the relationships between the different factors influencing uptake of HIV testing in SSA.

3.2 Results

Forty-two (42) peer-reviewed qualitative and mixed-method papers published between 2001 and 2012 from thirteen (13) SSA countries were included in the synthesis (Table 3-1). Thirty (30) were exclusively qualitative studies and twelve (12) were mixed-methods papers. While SSA is not a heterogeneous setting, some common characteristics could be deciphered: generalised HIV epidemic (HIV prevalence of more than 1% in the general population), and predominantly low-income countries with generally weak health systems and where HIV is mostly heterosexually transmitted. Twenty-three (23) second-order constructs were generated and summarised into eight (8) third-order constructs (Table 3-2). The findings are derived from second-order constructs and are categorised into enabling and deterring factors.

Table 3-2. Translation table of factors influencing uptake of HIV testing (See details of source papers at the end of this chapter)

3rd Order constructs	2nd Order constructs	Summary definition (translation) of 1st & 2nd order constructs	Source Papers
Lay construction of risk of infection & health.	Low self-perception of risk of infection.	Perception of being at less risk of infection and carrying on with life as normal sometimes based on HIV status of sexual partner.	36,38,43,44,45, 49,50,56,60,67
	Chastity/sexual inactivity	The lack of a sexual partner or abstinence from sex creates perception of being at less risk of infection.	38,50
	Ill-health &/or death of child/sexual partner.	Experience of sexually transmitted infection, physical deterioration of one's health or poor health/death of sexual partner/child creates a sense of susceptibility to HIV infection.	30,31,32,33,37, 39,40,42,43,48, 49,55,56,59,60, 65,67,68,69
	Social contact with person with HIV.	Personal contact/knowing someone with HIV or who had died of AIDS raise concern about its existence & susceptibility thus creating a sense of vulnerability. In settings with low prevalence creating a sense of vulnerability. In settings with low prevalence HIV raises doubts about its existence, and creates social distance from HIV.	28,40,49
	Risky sexual lifestyle.	Experience of multiple sexual partners, including past sexual life or perceived partner infidelity either creates a sense of susceptibility or creates assumption of already being infected.	32,34,36,39,40, 42,44,48,59,60, 69
Mental burden of living with HIV.	HIV+ status as imminent death & psychological burden.	In the absence of a cure, despite the availability of ART, HIV positive status perceived as hastening death. Thus, imminent death is avoided by shunning HIV testing.	29,33,34,37,38, 40,42,44,47,48, 53,55,57,60,65, 68,69
		Perceived incapacity to psychologically cope with a positive HIV result & associated lack of will to live with HIV.	32,34,36,40,43, 45,46,48,53,54, 56,61,69

Table 3.2 Continued

3rd Order constructs	2nd Order constructs	Summary definition (translation) of 1st & 2nd order constructs	Source Papers
Social support & exclusion.	Family & peer network influence & support.	Social influence and green light from family and friends influence decision making (not) to test.	36,37,38,40,42, 47, 56, 57, 58, 67
		The fears of losing social/economic (support) networks, including sexual partners discourage HIV testing.	38,39,40,42,64, 67
	(Mis-) trust in marital relationships.	In marital relationships with perceived mutual trust & fidelity, HIV testing seen as unnecessary. Where there is mistrust, testing is done to allay concerns of infidelity.	33,34,35,44,45, 50,51,52,54,65
	Blame & partner reaction.	Fear of partner reaction, blame and straining relationships, which sometimes can lead to abandonment, divorce or even violence. Those who decide to test, especially without partner consent fear being held responsible for infidelity. Testing is therefore seen as a spoiler of harmony & trust in relationships.	31,35,37,43,47, 57,68
	Fear of anticipated stigma & discrimination.	Fear of isolation, rejection & blame (for immoral behaviour) discouraging uptake of HIV testing.	28,29,30,31,34, 36,37,39,40,45, 46,48,49,51,52, 53,54,55,56,60, 61,63,65,66,68, 69
		Being on ART also creates stigma-“responsible for spreading” HIV	64
Gender inequality & influence.	Gendered power relationships.	Female lack of negotiating power in marital relationship, including their lack of control over their health affects uptake of HIV testing. On the other hand, male domination of decision making, and their control over household resources enables them easily access testing.	30,31,32,35,42, 43,47,51,52,55, 57,59,68
	Maintaining masculine identity.	Men also exhibit reluctance to test to preserve their masculine identity as strong and resilient. Others test in order to start treatment in order to maintain their status as breadwinners	30,36,37,67,68

Table 3-2 Continued

3rd Order constructs	2nd Order constructs	Summary definition (translation) of 1st & 2nd order constructs	Source Papers
Reproductive health aspirations.	Procreation & marital aspirations.	Larger social & reproductive health aspirations motivation for HIV testing. For women, testing invokes maternal duty the unborn child.	29,34,40,41,42, 43,44,46,47,52, 54,58,59
		Desire to marry also prioritized; testing and being found HIV positive perceived as reducing chances of finding marital partner unless potential partner is also infected; others fear that sexual partners will shun then if they are HIV positive.	34,36,61,67,69
	Testing as marital requirement.	In some churches, it is a requirement for Christians to test before marriage could be sanctioned by the church. Individuals also wait till it is time to get married before seeking HIV testing.	31,39,40,42,46 50,58,61
Organisation/delivery of HIV services.	Opt-out HIV testing.	Routine offer of HIV testing to pregnant women & TB patients has shifted provider-service user power relationships in the testing process. Clients may fear being denied access to health care if they refused to test; sometimes women at antenatal care directed to bring their spouses for testing.	29,30,35,41,53, 54,57,58,62
	Location of HIV testing facilities.	Isolated testing centers within health facilities creates a barrier as people fear being seen seeking HIV testing as this may imply being sexually activity and/or already being infected.	34,51,52,60,61, 69
	Feminisation of health care settings.	Health care facilities, particularly antenatal clinics perceived by men as female domains, out of bounds for men.	35,52,57,67
	HIV testing as package of health care.	Providing HIV testing with non-HIV related interventions provides an incentive to test as this helps mask HIV testing as primary objective in settings characterized by stigma. Provision of material benefits (i.e. food aid) to those found HIV positive also encourage uptake of HIV testing.	43,63

Table 3-2 Continued

3rd Order constructs	2nd Order constructs	Summary definition (translation) of 1st & 2nd order constructs	Source Papers
	Availability & efficacy of ART.	The availability of antiretroviral therapy & transformation of HIV into a manageable chronic condition has served as an incentive to test.	30,55,59,65,66,69
		However, the absence of/limited access to ART and the continued absence of a cure still inhibits uptake of testing.	32,40,48,54,55,65,66,68
	Burden of treatment for HIV-TB co-morbidity.	Patients with TB are subjected to (opt-out) HIV testing as part of care. However, dealing with the treatment burden of dual infections & double stigma forces them to deal with TB & HIV in succession rather than in concurrence, thus delaying uptake of testing.	30,45,68
Trust in the health system.	Quality of health care.	Perceived lack of confidentiality & privacy; perceived poor attitude of health staff affect health seeking behaviour. The use of non-familiar health personnel allays fears of breach of confidentiality, thus improving uptake of testing.	28,29,33,34,40,43,46,49,52,53,55,56,60,68
	Distrust of testing process & technology	Perceived unreliability of test results, notions of testing instruments as sources of infection & association of drawing of blood with rituals inhibit uptake of HIV testing. Confidence in test technology, including encouraging clients read test results creates credibility of test results.	33,36,42,61
	Conspiratorial beliefs.	HIV seen as a ‘plot’ by western countries to control/dominate SSA population & promote western interests.	28,61
Financial costs of HIV testing.	Indirect financial costs of HIV testing.	Long distance to testing sites & associated transport costs & travelling time discourage uptake of testing. Opportunity costs of travelling time, suspending livelihood activities & time of work inhibits HIV testing.	33,36,42,50,5256,57,63,67
	Direct financial costs.	Convenience of testing i.e. home/workplace-based testing at attenuates associated costs and travel time.	33,34,35,42,49
		Where user charges are non-existent, this encourages testing; paying for services competes with other human needs.	33,35,39,42,47,50,56,57,64

3.2.1 Enabling factors for HIV testing

Poor health or death of sexual partner or child. Physical deterioration of health (Mabunda 2006; Daftary, Padayatchi & Padilla 2007; Oshi et al. 2007; Meiberg et al. 2008; Grant et al. 2008; Obermeyer et al. 2009; Chirawu et al. 2010; Namakhoma et al. 2010; Simpson 2010; Skovdal et al. 2011; Jürgensen et al. 2012) and poor health/death of sexual partner or child (Maman et al. 2001; Obermeyer et al. 2009; Levy 2009; Chirawu et al. 2010; Njozing, Edin & Hurtig 2010) elevated the perceived risk of infection and a decision to test:

> *"My husband passed away two years ago, he had TB [tuberculosis]. I also looked after my daughter who was sick for a long time before she passed away and so my mind was not settled as I was suspecting that I could have acquired the deadly virus. When I heard that VCT was taking place today, I decided to put my mind at rest by being tested."* (Female Tester, Zimbabwe) (Chirawu et al. 2010)

Experience of a sexually transmitted infection sometimes heightened risk perception (Råssjö et al. 2007; Levy 2009) as did personal contact with or knowing someone who had died of AIDS (Castle 2003; Meilberg et al. 2008; Bhagwanjee et al. 2008), thus increasing the willingness to test. Experiences of multiple sexual partners and perceived partner unfaithfulness also created as sense of vulnerability and therefore encouraged uptake of HIV testing (Mabunda 2006; Bwambale et al. 2008; Obermeyer et al. 2009; Levy 2009).

While heightened risk of HIV infection triggered uptake of HIV testing, sometimes it dissuaded people from testing as some assumed that they were already infected (Meiberg et al. 2008; Izugbara et al. 2009; Simpson 2010; Larsson et al. 2012).

Availability of life-prolonging antiretroviral therapy. While HIV was previously perceived as a 'death sentence', the increasingly wider availability of life-saving medication in many countries of SSA has shifted this notion. In some countries of SSA, this was found to be an incentive to test (Day et al. 2003; Daftary, Padayatchi & Padilla 2007; Simpson 2010; Levy 2009; Roura et al. 2009; Phakathi et al. 2011; Jürgensen et al. 2012). Therefore, testing and knowing one's HIV status was no longer associated with death, but as a path to start treatment and prolong one's life. For pregnant women, and despite the reported existence of gender inequality in health seeking decision making, testing was often undertaken as maternal obligation to protect the unborn child from HIV infection (Pool, Nyanzi & Whitworth 2001; Sherr et al. 2003; de Paoli, Manongi & Klepp 2004; Urassa et al. 2005; Råssjö et al. 2007; Meiberg et al. 2008; McPhail et al. 2008; Groves et al. 2010; Larsson et al. 2010; Mbonye et al. 2010).

> *"I tested the time I was pregnant. I wanted to know if I was negative or positive, and I didn't want to put my baby at risk…" (Woman respondent,* South Africa*)* (McPhail et al. 2008).

HIV testing as preparation for marriage. In other instances, HIV testing was undertaken as an essential part of preparation for marriage (Maman et al. 2001; Luginaah Yiridoe & Taabazuing 2005; Oshi et al. 2007; Råssjö et al. 2007; Meiberg et al. 2008; Frank 2009; Namakhoma et al. 2010; Mbonye et al. 2010). For instance, a study in Ghana (Luginaah Yiridoe & Taabazuing 2005) encapsulates the role that the church was playing in increasing the uptake of HIV testing as an integral part of marriage preparation and counselling. As part of marital rituals, the church required prospective couples to seek HIV testing before the church could sanction such marriages. Explaining how this 'mandatory' strategy came about, one study participant noted that:

> *"We had an HIV/AIDS awareness programme in our church…After an expert delivered a lecture, we were shocked at the numbers… we decided all those who are planning to marry must be tested for HIV/AIDS… We wanted to protect our future generations…"* (Respondent, Ghana) (Luginaah Yiridoe & Taabazuing 2005).

Organisation and delivery of HIV testing. The roll-out of diverse HIV testing initiatives has contributed towards uptake of HIV testing. The implementation of 'opt-out' provider-initiated HIV testing - HIV testing and counselling which is recommended by health care providers to persons seeking health care services as a standard component of medical care - has contributed to increased uptake of HIV testing. For instance, service users reported being tested at antenatal care (Groves et al. 2010; Sherr et al. 2003; Theuring et al. 2009; Mbonye et al. 2010; Larsson et al. 2012) or as TB patients (Daftary, Padayatchi & Padilla 2007; Njozing Edin & Hurtig 2010; Ayenew et al. 2010) as an integral part of health care. This strategy was sometimes regarded as non-voluntary. Individuals sometimes acquiesced to the pressure by service providers to test:

> *"Although they say its voluntary, but they put pressure on you to test for it….If you don't want to do it then, they must say 'Okay, tell us when you feel comfortable for an HIV test.'''* (23-year old female tester, South Africa*)* (Daftary, Padayatchi & Padilla 2007).

Similarly, bringing testing services closer to the people through outreach mobile HIV testing attenuated (opportunity) costs of travelling and waiting times (McPhail et al. 2008; Mlay, Lugina & Becker 2008; Angotti et al. 2009) and provision of free testing services in Kenya (Dye, Apondi & Lugada 2011) and expectations/provision of material benefits (i.e. food relief) encouraged uptake of HIV testing (Chirawu et al. 2010; Dye, Apondi & Lugada 2011; Skovdal et al. 2011). The use of non-familiar counsellors through mobile VCT was viewed as enhancing confidentiality, thus improving uptake of HIV testing (Angotti et al. 2009; Chirawu et al. 2010; Bwambale et al. 2008).

Social network influence and support. Decision making about HIV testing were inextricably linked to social network influence (Nuwaha et al. 2002; Råssjö et al. 2007; Grant et al. 2008; Denison et al. 2008; Meiberg et al. 2008; Bhagwanjee et al. 2008; Izugbara et al. 2009; Theuring et al. 2009; Levy 2009; Skovdal et al. 2011a). A study in Zambia (Denison et al. 2008) poignantly describes how individuals sought the views and support of their peers and family members during the decision making process about seeking HIV testing. In part, this was because friends and family members were crucial sources of psychosocial support and for family members a critical source of economic support:

> *"In the first place I never wanted to go there [for an HIV test], but I consulted my sister. She said no and I also said no. But afterwards I asked my brother who said… you should go for VCT, so that is when I went."* (Male tester, Zambia) (Denison et al. 2008).

3.2.2 Deterrents to HIV testing

Perceived low risk of infection. One recurring theme was that across SSA, individuals self-assessed their risk of infection. Lay interpretations of being at low risk of infection (Chirawu et al. 2010; de Paoli, Manongi & Klepp 2004; Bhagwanjee et al. 2008), sometimes because of abstaining from sex or lacking a sexual partner (Taegtmeyer et al. 2006; Mabunda 2006; Råssjö et al. 2007; Angotti et al. 2009) negatively affected uptake of HIV testing. Proxy testing - adopting the status of sexual partner - was sometimes used as a risk estimate and a representation of one's own HIV status (Denison et al. 2008; Bwambale et al. 2008). Some people felt they were at low risk of infection because they trusted their partner (Day et al. 2003; de Paoli, Manongi & Klepp 2004; Taegtmeyer et al. 2006; Luginaah Yiridoe & Taabazuing 2005; Larsson et al. 2010; Ayenew et al. 2010) or because HIV was mainly perceived as a problem for sex workers (Oshi et al. 2007; Meiberg et al. 2008; Groves et al. 2010). A lack of physical symptoms or deterioration of health was also perceived as a sign of not being infected (Day et al. 2003; McPhail et al. 2008; Angotti et al. 2009; Jürgensen et al. 2012). In low prevalence settings like Mali (Castle 2003), not knowing someone with HIV or who had died of AIDS created a perception of being at low risk of infection, thus undermining uptake of HIV testing.

Stigma, social exclusion and gendered relationships. Fear of stigma was another dominant theme for the low uptake of HIV testing in many settings of SSA (Pool, Nyanzi & Whitworth 2001; Maman et al. 2001; Castle 2003; Sherr et al. 2003; Mabunda 2006; Taegtmeyer et al. 2006; Daftary, Padayatchi & Padilla 2007; Oshi et al. 2007; McPhail et al. 2008; Bhagwanjee et al. 2008; Varga & Brooks 2008; Bwambale et al. 2008; Grant et al. 2008; Denison et al. 2008; Meiberg et al. 2008; Izugbara et al. 2009; Frank 2009; Ayenew et al. 2010; Namakhoma et al. 2010; Larsson et al. 2010; Simpson 2010; Dye, Apondi & Lugada 2011; Skovdal et al. 2011; Njozing, Edin & Hurtig 2010; Jürgensen et al. 2012). Particularly because HIV transmission is predominantly heterosexual across SSA, being seen at a testing centre was synonymous with sexual promiscuity and assumed HIV-positive status (Taegtmeyer et al. 2006; McPhail et al. 2008; Bwambale et al. 2008; Frank 2009; Larsson et al. 2010). For TB patients in South Africa, Ethiopia and Cameroon (Daftary, Padayatchi & Padilla 2007; Ayenew et al. 2010; Njozing, Edin & Hurtig 2010), the prospects of dealing with potential 'double' TB/HIV stigma acted as disincentive to test. The fear of HIV-related stigma is reflected in the following:

> *'Even if I am already infected, nobody knows and it causes me no problems, at least for now. Imagine I go and do the testing and I find out I am positive, for how long will I hide it? Once people get to know I will be finished. My family will shun me. My friends will desert me. I will not be able to get a decent job. That is dying even before the infection kills me.'* (25-year old female non-tester, Nigeria) (Oshi et al. 2007).

A study in Tanzania (Roura et al. 2009) found that while the effect of ART on improving corporeal health had motivated uptake of HIV testing, a new form of stigma had emerged in which individuals on ART were stigmatised as they were viewed as being responsible for the continued spread of HIV on account of them living longer with HIV. This in turn undermined uptake of HIV testing.

Across the sub-regions of SSA, fear of social exclusion also negatively influenced uptake of HIV testing (Nuwaha et al. 2002; Råssjö et al. 2007; Grant et al. 2008; Denison et al. 2008; Bhagwanjee et al. 2008; Roura et al. 2009; Mbonye et al. 2010; Skovdal et al. 2011). The fear of losing social support (Råssjö et al. 2007; Oshi et al. 2007; Denison et al. 2008; Meiberg et al. 2008; Roura et al. 2009) and sexual partners (Grant et al. 2008; Izugbara et al. 2009; Roura et al. 2009; Skovdal et al. 2011) and the fear of straining marital relationships, including possibilities of abandonment, divorce, or even violence (Mlay et al. 2009; Chirawu et al. 2010; Njozing, Edin & Hurtig 2010; Jürgensen et al. 2012) inhibited uptake of HIV testing. The desire to marry also weighed heavily on people's mind and a positive sero-status was viewed as threatening the chances of finding a marriage partner (McPhail 2008; Frank 2009; Skovdal et al. 2011a; Jürgensen et al. 2012). In Uganda, there was fear that where discordance arose, test results could be used as confirmation of infidelity which could strain marital relationships (Larsson et al. 2010; Larson et al. 2012).

Within marital relationships, gender inequality affected women's uptake of HIV testing. Studies in South Africa, Uganda and Tanzania found that men enjoyed decision-making autonomy on HIV testing (Daftary, Padayatchi & Padilla 2007; Råssjö et al. 2007; Theuring et al. 2009). Most studies reported women lacking control over their health; decisions about seeking HIV testing had to be discussed with, and permission obtained from, spouses (Maman et al. 2001; de Paoli, Manongi & Klepp 2004; Urassa et al. 2005; Mabunda 2006; Taegtmeyer et al. 2006; Daftary, Padayatchi & Padilla 2007; Mlay, Lugina & Becker 2008; Theuring et al. 2009; Chirawu et al. 2010; Larsson et al. 2010; Njozing, Edin & Hurtig 2010; Simpson 2010; Larsson et al. 2012). In Tanzania and Zimbabwe, obtaining consent still raised suspicions of possible infidelity (Maman et al. 2001; Chirawu et al. 2010) and those found HIV positive risked being blamed for contracting HIV (Urassa et al. 2005; Grant et al. 2008; Theuring et al. 2009; Njozing, Edin & Hurtig 2010). Thus HIV testing was shunned to avoid straining marital relationships. In Malawi, Uganda and Zimbabwe, men refused to test since this was at odds with masculine identity of self-confidence, resilience and stoicism (Izugbara et al. 2009; Skovdal et al. 2011a). In Zambia, one study found that if the wife suggested testing, this was viewed by men as undermining their role as decision makers (Grant et al. 2008).

Quality of HIV testing services. Across sub-regional settings of SSA, individual perceptions of and experiences with the health care system undermined uptake of HIV testing. Perceived lack of confidentiality by health staff (Pool et al. 2001; Mabunda 2006; Meiberg et al. 2008; Bhagwanjee et al. 2008; Bwambale et al. 2008; Chirawu et al. 2010; Namakhoma et al. 2010; Simpson 2010; Njozing, Edin & Hurtig 2010); perceived lack of confidence in the competence of health personnel (Pool et al. 2001; Castle 2003; Meilberg et al. 2008); and perceived poor attitude of health staff (Varga & Brookes 2008; Larsson et al. 2010) dissuaded people from testing. Perceived unreliability of test results in Malawi and Uganda (Råssjö et al. 2007; Angotti et al. 2009; Izugbara et al. 2009) and distrust of HIV testing technologies in Uganda and Zambia (Råssjö et al. 2007; Frank 2009) discouraged uptake of HIV testing. Describing his concerns about confidentiality, one respondent in Malawi said:

> *''It's because if I can be tested at Mhojo Health Centre, VCT counsellors there know me and if that counselor at the VCT [centre] finds me with the virus then he can start spreading the messages to friends of mine, and if I know about that then it becomes very bad to my life, that's why to be tested with someone else whom you never know it's good''* (Male, 48 years old, Malawi) (Angotti et al. 2009).

Similarly, at health facilities, perceived poor location of testing facilities undermined uptake of HIV testing (Taegtmeyer et al. 2006; McPhail et al. 2008; Frank 2009; Larsson et al. 2010; Bwambale et al. 2008; Jürgensen et al. 2012). Secluded testing facilities or use of VCT-specific clinic cards created social visibility of seeking HIV testing and assumption of being sexually active and/or already being infected. Where couple counselling was conducted at antenatal clinics, men perceived the testing sites as feminised settings, and therefore out of bounds (Daftary, Padayatchi & Padilla 2007; Mlay, Lugina & Becker 2008; Theuring et al. 2009; Larsson et al. 2010; Skovdal et al. 2011a).

Trust in the health care system and conspiratorial beliefs. Although not universally held across SSA, conspiratorial beliefs about HIV being a 'western plot' to dominate SSA were reported in Mali and Zambia (Castle 2003; Frank 2009). This inhibited uptake of HIV testing. These conspiracy views were nested within historical discourse about "colonial projects [which] turned African patients into objects to be studied and scrutinised, categorised and measured" (Frank 2009). In Mali (Castle 2003), HIV was viewed as an invention to halt the growth of the African population or to sell western bio-medical products. Promotion of HIV testing by western countries as a gateway to accessing treatment and living a longer, healthy life was therefore viewed as a ploy to expand western countries' interests:

> "*In reality, AIDS is an invention to sell condoms. The West created the idea of AIDS to put a stop to sexual relations or even better it's a policy to put a brake on the growth of the African population*."(23-year old male non-tester, Mali*)* (Castle 2003).

While HIV testing services were increasingly provided free of charge in many settings of SSA, this 'gift' by western countries and agencies or their local affiliates was viewed as attempts to further subjugate the weak African populations and to benefit western countries. As one old man in Zambia put it:

> *"Look around you, who is making money off of this disease? It is not Zambians. It is you [white Westerners]. This is why people are suspicious of this disease. This is why they think it [AIDS] was brought in from the outside."* (Male respondent, Zambia) (Frank 2009).

Where religious discourse was dominant, a study in a rural setting of Zambia found that distrust of drawing blood for Satanic motives (synonymous with vampires), and perception of western medical technologies as instruments of the 'devil' created apprehension about HIV testing. HIV testing was viewed as plunging an individual into "spiritual darkness, pain, loneliness and death" (Frank 2009, p.519).

Financial costs of accessing HIV testing. In the context of fragile livelihoods, the direct and indirect financial costs of accessing testing services inhibited uptake of testing (Nuwaha et al. 2002; Luginaah, Yiridoe & Taabazuing 2005; Råssjö et al. 2007; Angotti et al. 2009; Izugbara et al. 2009; Larsson et al. 2010; Dye, Apondi & Lugada 2011). Although HIV testing had become increasingly free in many settings of SSA in order to improve access levels, where user fees were charged, individuals weighed the benefits of testing against other competing human needs (Luginaah, Yiridoe & Taabazuing 2005; Urassa et al. 2005; Oshi et al. 2007; Råssjö et al. 2007; Mlay et al. 2008; Angotti et al. 2009). More so, the indirect opportunity costs of suspending income generating activities and time-off work discouraged uptake of HIV testing (Luginaah, Yiridoe & Taabazuing 2005; Råssjö et al. 2007; Theuring et al. 2009; Skovdal et al. 2011a). One respondent in Nigeria said:

> *"It costs 1000 Naira (approximately 8 US Dollars) to do blood test for HIV in the laboratories in Enugu. That is the minimum you can get it. I even heard that it costs more than that in some laboratories. So, why would I spend that amount of money to find out if I am HIV positive or not?"* (24-year old non-tester, Nigeria) (Oshi et al. 2007).

Perceived psychological burden of living with HIV. The motivation to test also depended on a person's perceived ability to manage HIV. Even with availability of life-prolonging treatment, in many settings of SSA, a positive-HIV test result was still associated with death (Pool et al. 2001; Sherr et al. 2003; Urassa et al. 2005; Råssjö et al. 2007; McPhail et al. 2008; Denison et al. 2008; Meiberg et al. 2008; Bwambale et al. 2008; Angotti et al. 2009; Chirawu et al. 2010; Obermeyer et al. 2009; Simpson 2010; Jürgensen et al. 2012) and mental distress was anticipated (Mabunda 2006; McPhail et al. 2008; Izugbara et al. 2009; Frank 2009; Jürgensen et al. 2012) with an HIV positive test causing an individual to 'begin to think too much.' This was perceived as hastening physical deterioration of health:

> *"Why look for troubles; I will never do a test. I cannot look for my death. I am afraid of dying. Haven't you seen those who go for counselling? They are the ones who die very soon.*"(Male non-tester, Tanzania) (Urassa et al. 2005).

The reported absence of, or limited access to, treatment in some settings was a disincentive to test (Sherr et al. 2003; Day et al. 2003; Mabunda 2006; Meiberg et al. 2008; Obermeyer et al. 2009; Simpson 2010; Njozing, Edin & Hurtig 2010; Phakathi et al. 2011). Similarly, given the prevalence of HIV-TB co-infection, TB patients in Cameroon and South Africa avoided HIV testing to avoid the burden of being on dual strong treatment regimens for two diseases (Daftary, Padayatchi & Padilla 2007; Njozing, Edin & Hurtig 2010).

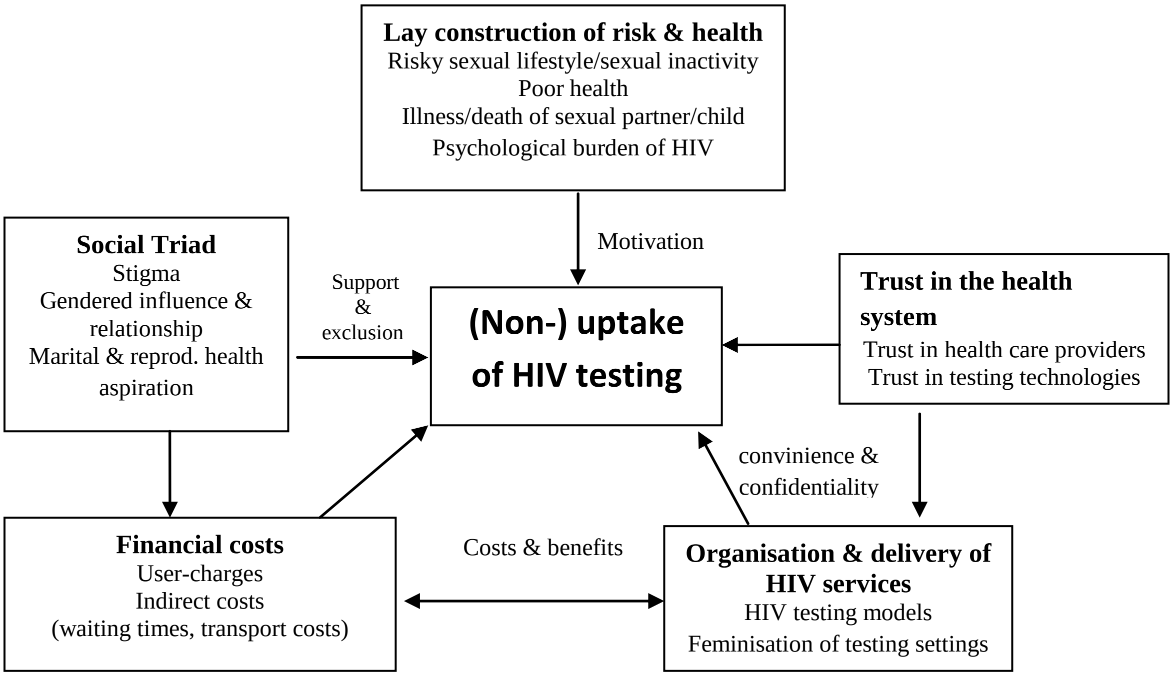
3.3 Discussion: synthesis and line-of-argument

This synthesis shows that uptake of HIV testing in SSA is influenced by an array of individual, relational and contextual-based factors. While SSA is not a homogeneous setting, our synthesis suggests that the barriers and facilitators are comparable across SSA. It is worth pointing out that the factors influencing uptake of HIV testing are not mutually exclusive. As depicted by our conceptual model (Figure 3-2), they are inextricably linked and may coalesce or reinforce one another to influence uptake of HIV testing. Based on the analysis and interpretation of second-order constructs, high-level third-order constructs were developed (Table 3-2) to form a 'line of argument' about factors influencing uptake of HIV testing in SSA. These are condensed into four themes (Figure 3-2) and discussed as below:

3.3.1 Lay construction of risk of infection and health

First, one dominant factor that influences uptake of HIV testing is lay construction of risk and health. Individuals engage in intense activity of experience-sorting and interpretation as they situate themselves in terms of danger (Warwick, Aggleton & Homans 1988). This lay assessment is informed by individuals' knowledge of own and partner's sexual behaviour and observations and experiences of their health (Paicheler 1999). This lay analysis influences behaviour in two different ways. While heightened risk of infection provides impetus to test, there is also a disjunction between perceived risk of HIV infection and uptake of testing, as those who perceive themselves as being infected already do not see the value of knowing their HIV status. Thus, HIV testing is more often undertaken when there is clear decline in health status which necessitates access to health care.

Figure 3-2 Conceptual model of nested relationships of factors influencing uptake of HIV testing.



3.3.2 Trust in the health system and conspiratorial beliefs

Second, even when individuals view themselves at risk of HIV infection and/or are willing to seek HIV testing, uptake of testing is influenced by people's trust in the health care system and providers (Figure 3-2). The lack of trust manifests itself in lack of confidence in individual health workers and trust in the health institution as a whole (Cunning et al. 2007). Perceived poor quality of health services as characterised by inability by health workers to maintain confidentiality, perceived poor calibre of health workers and lack of trust in testing technologies inhibit uptake of testing. As Gilson (2003) has noted, health systems are social institutions and therefore people's perceptions of and experiences with the health care system is crucial in influencing service utilisation which even good technical care may not remedy.

Studies on trust conducted in the United States of America have reported how distrust of health providers and health system as a whole affect utilisation of HIV services (Altice, Mostashari & Friendland 2001; Bogart & Thornburn 2005; Whetten et al. 2006). For instance, one study reported that trust in physicians was associated with acceptance of ART and a minority of individuals that felt mistreated by health care providers were resistant to accepting ART (Altice, Mostashari & Friendland 2001). Narratives from the synthesis indicate that lack of trust in health care providers was attenuated by the provision of HIV testing through non-facility based HIV testing by non-familiar providers, thus improving uptake of HIV testing (Figure 3-2).

Another dimension of lack of trust in the health system relates to conspiracy narratives (Figure 3-2). In a few settings of SSA, HIV and HIV testing were viewed as western countries' insidious ways of dominating SSA. HIV testing was viewed as being used to benefit western countries through creation of market for bio-medical products (Castle 2003) and job opportunities for its citizens (Frank 2009). These geo-political conspiratorial beliefs sometimes coalesce with religious discourse. In Zambia for instance, blood drawn for HIV testing was viewed as being used for satanic rituals (Frank 1999; Schumaker & Bond 2008). These findings corroborate previous medical research conducted in Gambia and Zambia where local people were highly suspicious of and shunned medical tests which involved the drawing of blood (Fairhead, Leach & Small 2006; Kingori et al. 2010).

3.3.3 Social triad: Stigma, gendered influence and reproductive health aspirations

Third, HIV testing behaviour is strongly socially delineated. Social relationships play a significant role in influencing HIV testing behaviour through social influence and perceived (lack of) social support (Figure 3-2). For instance, in the absence of strong formal safety nets, social capital is central to survival. Therefore, the desire to preserve social relationships and identity inhibit uptake of HIV testing. This is because while individuals may acknowledge the importance of knowing their HIV status and even show willingness to seek testing in response to (perceived) decline in health or because of previous sexual risk behaviour, ultimate decision making and attitude towards testing is influenced by concerns about anticipated stigma, which is sometimes inextricably linked to possible loss of economic support. Thus, being found HIV positive represents an undesirable characteristic, a ‘spoiled identity’ (Goffman 1963) from which individuals try to distance themselves.

Paradoxically, while the availability of treatment has become an incentive to test, a new form of stigma has emerged. A study in Tanzania (Roura et al. 2009) found that while ART roll-out had led to the ‘normalisation’ of HIV and thus stimulated uptake of testing, the stigmatisation of people on treatment that they ‘spread the disease’ also undermined uptake of HIV testing.

Gendered power relationships also undermine uptake of HIV testing (Figure 3-2). In most parts of SSA, ultimate authority on health care seeking lies with men (Tolhurst et al. 2002; Tolhurst et al. 2008) and communication with, and support from, partners improves uptake of HIV testing by women (Bajunire & Muzoora 2005; Sarker et al. 2007). This was a common narrative amongst women in some of the synthesised papers. Their lack of access to and control over financial resources affected their access to and utilisation of HIV testing services. Conversely as primary caregivers, their subordinate role in decision making about HIV testing was mitigated by their regular contact with reproductive and child health services, thus being able to utilise HIV testing services. The onset of provider-initiated HIV testing also absolved women from blame for testing without their partners’ consent by shifting attention to testing as part of routine health care.

Similarly, the uptake of HIV testing is inextricably linked to individuals’ marital and reproductive health aspirations. Thus, marriage and parenthood represent social duties, expectations and individual aspirations (Smith & Mbakwem 2007) and a connection with one’s community (Fortes 1978; Hollos & Larsen 2008). This affects uptake of HIV testing behaviour in two opposing ways. As an enabler, both men and women sought HIV testing as preparation for marriage or achieving reproductive health aspirations. Those that had never tested claimed willingness to seek HIV testing when it was time to get married. For women, as Fortes has put it, "the achievement of parenthood is regarded as a *sine qua non* for the attainment of the full development as a complete person to which all aspire...and a woman becomes a woman when she becomes able to bear children and continued child bearing is irrefutable evidence of continued femininity" (Fortes 1978, p.125).

Narratives from the synthesised papers suggest that HIV testing was accepted during antenatal care primarily because it was essential for achieving reproductive health aspirations and as a moral and social obligation to give birth to a healthy child. On the other hand, both men and women declined HIV testing for fear of straining marital relationship or undermining chances of finding a marriage partner.

3.3.4 Organisation and delivery of HIV testing: mitigating the financial and social costs

Lastly, the synthesis shows that uptake of HIV testing is influenced by the way HIV services are delivered. Where user-fees are charged or services are far away, investment in health (HIV testing) competes with, and is ranked low in relation to, other immediate human needs. This is because, for people in precarious living conditions, access to, and utilisation of, health care imposes inordinate opportunity costs (Tolhurst et al. 2002). However, the roll-out of different HIV testing initiatives such as mobile HIV testing services, provider-initiated HIV testing, home-based HIV testing (Matovu & Makumbi 2007) has mitigated these barriers such as distance, financial costs, long waiting times, inconvenient testing hours, and allayed fears of perceived lack of confidentiality (Fylkesness & Siziya 2004; CDC 2004; Ostermann et al. 2011). When individuals are in contact with the health system for other health conditions, provider-initiated HIV testing ensures uptake of testing not only because it is necessary and is conveniently available at the time of seeking medical attention, but also because it helps preserve service users' sense of moral worth by not making assumptions about their behaviour which could lead to stigmatisation (Obermeyer & Osborn 2007).The drawback is that men shunned testing services even if they were readily available if they viewed them as being provided in settings perceived as 'female spaces' such as antenatal clinics (Barker & Ricardo 2005).

3.3.5 Strengths and limitations

The strength of this synthesis lies in the extensive search of literature. The inclusion of papers utilising different methodological approaches, including mixed-methods papers provided in-depth insights into factors that influence uptake of HIV testing. Also, like previous studies that have used the meta-ethnography approach (Smith, Pope & Botha 2005; Munro et al. 2007; Briggs & Flemming 2007; Malpass et al. 2009; Merten et al. 2010), not using pre-determined quality assessment criteria or excluding papers on the basis of pre-specified quality assessment criteria enabled us to draw on the 'richness' of these papers. Using a multi-disciplinary team also enriched the synthesis by enabling us to draw and collate team members' interpretations of the findings. However, an inherent weakness of this synthesis is the possibility of having missed some publications. We tried to mitigate this by scouring references of selected papers and manually searching the databases. Another limitation of this synthesis is that due to language constraints, we only included papers published in English. Similarly, due to publication restrictions, the context of the synthesised studies were not extensively described thereby limiting detailed contextualisation of the synthesised findings and comparing the findings across different settings.

3.3.6 Conclusions

Uptake of HIV testing in SSA is influenced by an array of often inter-linked factors. Despite the heterogeneity of SSA, our findings suggest that there is a strong similarity in the barriers to and facilitators of HIV testing across SSA. Lay interpretation of risk of infection either encourages or discourages uptake of HIV testing. Depending on past sexual lifestyles and the state of individual, marital partner and child's corporeal health, individuals construct own probabilities of being infected. While direct and indirect financial costs inhibit uptake of HIV testing, access to HIV testing is also deeply engendered, and individuals also have to balance the social benefits and costs of seeking HIV testing. Although the wider availability of HIV testing and treatment services and roll-out of various HIV testing strategies has contributed towards increased uptake of HIV testing, lack of confidence in the health system and conspiratorial beliefs undermine testing uptake. Even though the enablers and barriers to uptake of HIV testing cut across many settings of SSA, interventions aimed at increasing uptake still need to be context specific, sustaining the enabling factors and concurrently addressing the barriers.

3.4 Policy and practical implications

The synthesis suggests that the policy of provider-initiated HIV testing coupled with increased wider availability of life-saving HIV medication is crucial in scaling up uptake of HIV testing in SSA. Due to fear associated with seeking HIV testing, availability and convenience of provider-initiated HIV testing provides that extra ‘push’ that enables individuals to overcome barriers and effect their intentions to test and at the same time assuage fear of stigma and attenuate costs. This, therefore, calls for stepping up provider-initiated HIV testing when individuals come into contact with the health system.

At practical level, our synthesis suggests the need for scaling up and sustaining the roll-out of different and locality-specific HIV testing models i.e. mobile HIV testing to respond to the peculiarities of each setting, even within the same country. Improving quality of HIV service delivery, particularly ensuring confidentiality - which many studies identified as a barrier - is also vital. Interventions such as home-based HIV testing that focus on social network relationships (i.e. couples and households) rather than individual-focused interventions are also critical given inequitable power dynamics and the significance of social networks in decision-making processes about HIV testing. Such strategies could also help assuage fears of confidentiality as reported in many studies as well as attenuate direct and indirect financial costs of seeking HIV testing. Given the reported persistence of stigma, continued sensitization campaigns are need. Also, provision of HIV testing interventions particularly in non-clinical settings need to be combined with screening for other less stigmatizing health conditions to avoid stigma associated with being seen accessing HIV testing. Most crucially too, through sensitization campaigns, there is need to focus on addressing socially constructed individual risk assessments, especially in low HIV prevalence settings where HIV may be viewed as unreal and a far-off threat. In settings where mistrust and conspiratorial beliefs about HIV and HIV testing exist, these need to be addressed through sensitization campaigns.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

MM, VB and SM conceptualized the study. MM, SG and OM did the literature search. MM and HN did the title and abstract review and all authors were involved in full-text review. MM drafted the first manuscript into which co-authors contributed input. All authors have given final approval of the version to be published.

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Chapter 4

Why do marital partners of people living with HIV decline HIV testing? Insights from a qualitative study in urban Lusaka, Zambia*

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Abstract

Background: In view of the scale-up of HIV testing services alongside increased availability of free life-prolonging antiretroviral therapy (ART), why do marital partners of people living with HIV (PLHIV) decline HIV testing?

Methods: An exploratory qualitative study was undertaken in urban Lusaka, Zambia. Between March 2010 and September 2011, in-depth interviews were held with marital partners of PLHIV (n=30) and antenatal care and ART staff (n=10) of a public-sector clinic. One focus group discussion with voluntary counselling and testing (VCT) staff (n=8) was also conducted. Data was transcribed and coded using Atlas ti and analysed using latent content analysis.

Results: Marital partners of PLHIV classified themselves as already infected on account of the HIV-positive status of their spouses thus viewing HIV testing as unnecessary. Despite availability of life-prolonging treatment, perceived psychological burden of living with an incurable health condition and association of knowledge of HIV-positive status with rapid physical deterioration of health dissuaded individuals from seeking HIV testing. Lack of self-efficacy, negative treatment beliefs modulated by treatment experiences of HIV-positive spouses further undermined uptake of HIV testing. Alternatively, to 'sustain' physical health, spouses of PLHIV opted for herbal remedies and conventional non-HIV medication to mitigate possible HIV-related symptoms while faith healing was sought with the hope of getting complete healing from perceived HIV infection. A desire to maintain high moral credibility within marriage and avoiding legitimising partner behaviour suspected to have to HIV infection modulated by masculinity and gender inequality also inhibited uptake of HIV testing. Fear of enacted stigma was not reported to be a barrier to HIV testing. The overarching barrier to HIV testing was respondents' perception of their corporeal health with participants indicating willingness to test if they noticed a decline in their health.

Conclusions: These findings call for efforts to address lay risk perceptions, treatment and health beliefs, perceived inability to live with an incurable infection and a need to promote the benefits of early initiation of testing and treatment. Strengthening the promotion of couple HIV testing, including for de-escalating conflictive situations would ensure joint knowledge, acceptance and management of HIV status in marital relationships.

4.0 Introduction

Heterosexual exposure remains the primary mode of HIV transmission in sub-Saharan Africa, and accounts for 80% of new infections globally (UNAIDS 2010b). Despite the roll-out of different HIV testing initiatives in many settings of sub-Saharan Africa as a crucial HIV prevention strategy (Makumbi & Matovu, 2007), less than 40% of people know their HIV status (WHO/UNICEF/UNAIDS, 2010). Barriers to HIV testing have included stigma and discrimination (Kalichman & Simbayi, 2003; Grant et al., 2008; Jürgensen et al., 2012), self-perception of being at less risk of infection (de Paoli, Manongi, & Klepp 2004; Bhagwanjee et al., 2008; Chirawu et al., 2010), perceived inability by service providers to maintain confidentiality (Fylkesness & Siziya 2004; Bhagwanjee et al., 2008; Namakhoma et al., 2010), lack of symptoms or deterioration of health (MacPhail et al., 2008; Angotti et al., 2009; Day et al. 2003) and women's lack of control over access to HIV testing (Urassa et al., 2005; Taegtmeyer et al., 2006; Mabunda, 2006).

Zambia has an estimated HIV prevalence of 14.3% in the adult population aged 15-49 years (CSO, 2009). The HIV prevalence peaked in the late 1990s before levelling off and declining to current rates (NAC/MoH, 2010). The 2007 Zambia Demographic Health Survey (ZDHS) reports that for individuals that had previously not tested, 69% of HIV-positive men and 49% of HIV-positive women may not have been aware that they were infected (CSO, 2009). For marital partners, the need to test as an HIV prevention and control measure is even more critical. Empirical data on urban Zambia shows that at least 60% of new heterosexual HIV infections occur within marriages or cohabiting relationships (Dunkle et al., 2008), and among married/cohabiting partners, discordance rate is about 11% (NAC/MoH, 2010). Therefore, HIV testing is critical for adoption of risk reduction sexual behaviour (Roth et al., 2001; Allen et al., 2003) and for women, uptake of treatment for prevention of mother-to-child transmission of HIV (Farquhar et al., 2004; Conkling et al., 2010).

While a recent systematic review has reported factors hindering uptake of HIV testing (Musheke et al. 2013), there is still a dearth of information on specifically why individuals aware of the HIV-positive status of their marital partners do not seek HIV testing. As a result, it is not clear whether the reasons for not testing by this 'at-risk' sub-group are unique to this group or generally reflect the barriers to HIV testing. To add to the body of knowledge, this study explored why marital partners of HIV-positive individuals did not seek HIV testing.

4.1 Methods

4.1.1 Study setting

The study was conducted in a low-income, high-density urban residential area of Lusaka, Zambia. The living conditions of the local people are generally poor. The majority of the people eke out a living in the informal sector of the economy, mostly as traders mostly selling fruits, vegetables, meat products, fish, charcoal and second-hand clothes either in the city centre markets or in the open-air local markets in the area. Health services in the area are mainly provided by a public sector clinic. The health facility has an ‘opt-in’ VCT centre. HIV testing is also provided at the antenatal clinic and the tuberculosis clinic. In addition, mobile VCT services in the area are periodically provided by non-governmental organisations.

4.1.2 Methods

This was an exploratory qualitative study. This study design was suitable for identifying and eliciting in-depth insights into factors hindering uptake of HIV testing by individuals who knew the HIV-positive status of their marital partners. Study participants were identified, contacted and recruited through their marital partners seeking ART care at a local public sector clinic. ART clinic staff identified HIV patients who disclosed their status to their spouses but whose spouses had opted not to seek HIV testing. These patients were then asked to go and find out if their spouses could be contacted for interviews. Only those participants who agreed to participate were contacted by the researchers through their spouses for interviews.

Data was collected between March 2010 and September 2011. Opened-ended, face-to-face in-depth interviews were held with marital partners of people living with HIV (n=30), antenatal clinic and ART clinic staff (n=10). In addition, one focus group discussion (FGD) was conducted with VCT counsellors (n=8). The main research question asked was: “what are the reasons for not seeking HIV testing despite knowing the HIV-positive status of your/their spouses?” Interviews with clinic staff were conducted in English while interviews with respondents who had not tested for HIV were conducted in the local language mainly spoken in the area, *Nyanja*. In-depth interviews lasted between 30 and 45 minutes and because of the busy schedule of the VCT staff, the FGD only lasted about an hour.

Data collection and preliminary data analysis was a cyclical process: interview data informed ensuing interviews and data collection was ended when emerging data became repetitive.All interviews conducted in local language were translated and all interviews were transcribed verbatim. Qualitative latent content analysis (Graneheim & Lundman, 2004) was used to analyse and interpret the data. All interview and focus group discussion transcripts constituted our unit of analysis. Unit of analysis refers to all words and phrases of the interview transcripts and group discussion (Graneheim & Lundman, 2004). They were read several times to create a sense of the whole data (Burnard, 1991; Graneheim & Lundman, 2004).

The transcripts were then entered into and organised and managed using Atlas ti version 6. The data was then coded inductively. Within-case and across-case analysis (Ayres, Kavanaugh & Knafl 2003) of the interview and group discussion transcripts was undertaken to inductively generate concepts across the individual interviews. For each interview transcript, we conducted within-case analysis and retrieved and coded reasons for not seeking HIV testing despite knowing the HIV-positive status of a marital partner. Thereafter, we conducted across-case analysis by comparing and contrasting participants' reasons. Similar codes were then put together to form categories. Themes were then developed by interpreting categories for their underlining meaning (Graneheim & Lundman, 2004). These themes are described in the discussion section of the paper. Three reference points were used to identify emergent themes: recurrence, repetition and forcefulness of ideas within the interview data (Overcash 2004). Through this analytical strategy, we were able to identify themes that cut across study participants but were still grounded in individual perspectives (Ayres, Kavanaugh & Knafl 2003). Lastly, we selected interview and group discussion excerpts that best illustrated these themes.

4.1.3 Ethical considerations

The study was approved by the ethics committee in Basel (Ethik-Kommission beider Basel) and the University of Zambia School of Humanities and Social Sciences Research Ethics Committee as part of the research project 'Improving equity of access to HIV care and treatment in Zambia'. Written informed consent was obtained from all research participants. To ensure confidentiality, interviews and FGD with clinic staff took place in private spaces within the clinic premises whilst interviews with marital partners of people living with HIV took place at locations of their choice. Some preferred to be interviewed at home albeit in the absence of their spouses, others preferred to be interviewed at neutral locations such private spaces at the local clinic and homes of respondents' friends.

To protect the identity of respondents, all identifying information was excluded from the interview transcripts. No financial incentives were given to study participants but where interviews were conducted outside the home setting of the study participants, a transport reimbursement of US$10 was provided.

4.2 Results

Half of the respondents were women; more than half of the respondents were aged more ≥ 35 years with the oldest being a 51-year old man; and two-thirds had known the HIV-positive status of their spouses for at least 2 years. All the marital partners of the respondents were on ART (Table 4-1).

Table 4-1 Characteristics of respondents who have not tested for HIV

Characteristic	Number of Respondents
Age (Years)	
18-24	4
25-34	9
35-44	10
>44	7
Sex	
Male	15
Female	15
Source of livelihood	
Formal employment	5
Informal employment	18
Not working/dependant	7
Duration since known HIV status of partner	
6-<12 months	4
1-<2 years	6
2-<3 years	9
3-<4 years	9
≥ 4 years	2
Treatment status of HIV+ marital partner	
On ART	30
Not on ART	0

Perception of risk of HIV infection. The majority of our respondents regarded themselves as already infected on account of the HIV-positive status of their spouses. Despite the existence of discordance, the majority of them felt this was a mystery and almost impossible given the long duration of their marital relationship, length of time since knowing their partners' HIV status and that unprotected sex - the predominant way in which HIV was transmitted - was an integral part of their marital relationships. Two respondents explained:

> *"I was sure that I was also going to get the same results. So there was no need for me to go for the test. You know we have had unprotected sex and one can get HIV through unprotected sex. Since my husband is HIV positive, I am also HIV positive." (20-year old woman)*

> *"I also believe that I am HIV-positive because my wife has already tested HIV-positive. So, I just take precaution to maintain my health by drinking herbal medication. When I develop fever, I just take coartem*." (47-year old man)

State of physical health. Even when individuals suspected to be already infected, individuals' perception of their corporeal health influenced HIV testing behaviour. Poor health was viewed as *sine qua non* for seeking HIV testing. Asked when she would consider going for HIV testing, one respondent bluntly said: *"[I will test] when I get sick, I mean as in being bed-ridden. Not when I am still strong, I do not see any need to test and I pray that I will not get to that stage."* (30-year old woman). Another respondent said: *"She (wife) went to the clinic; she tested and was given her results. I saw the results as well.... But me, I am just ok....Because I rarely get sick, I do not see any need to go and test. So it is very difficult to just go and test when you feel that there is nothing wrong in your body."* (47-year old man)

These sentiments were echoed by health care providers. One of the ART staff noted:

> *"I think from what I have observed, somebody might know their HIV status, but because they still have energy to run around and do their work, they would not care about coming for HIV testing. Most of them wait until they have serious opportunistic infections. That is when we see them rushing here to the clinic."*

Perceived psychological burden of living with HIV. While acknowledging the possibility of being infected, the psychological burden of living with HIV was also found to undermine uptake of HIV testing. Drawing on the experiences of their spouses, some respondents perceived knowing one's HIV status as having deleterious physical and mental health effects, which in turn was perceived as hastening deterioration of health. Some respondents gave vivid accounts of how their HIV-positive spouses had exhibited "despair", become "irritable", "non-sociable" and "fatalistic" on account of their HIV-positive status. They worried that this could trigger adoption of similar behaviour if they sought HIV testing. These fears were put in the following way:

> *"When you are just feeling ok, to go and test and be found HIV-positive would just bring psychological problems. You start thinking too much about your health and your life and how your new status will alter your outlook to life."(47-year old man)*

> *It's the fear of being told your results. You cannot be safe; you will die quickly if you know your results because all the time you will be thinking about your status. That creates worries about your future. You cannot live a normal happy life like that."* (42-year old woman)

Fear of blame and maintaining moral credibility in marital relationship. Non-uptake of HIV testing was also used to fend off blame or accusations of being responsible for HIV infection, thus being able to maintain moral standing in the eyes of the partner. Instead, the HIV-positive spouse bore the responsibility for HIV infection. Some respondents went as far as blaming their marital partners for knowing but deliberately hiding their HIV-positive status from them. Seeking HIV testing was seen as condoning and legitimising the perceived behaviour of marital partner which allegedly led to HIV infection:

> *"Sometimes there is a problem of blaming each other as to who could have been responsible for bringing HIV in the marriage. So when I get upset sometimes I hit back as well to say between you and I, whose health is ok? Who has tested HIV-positive?"* (31-year old man)

Moral credibility was found to be inextricably linked to gender inequality. For women, seeking HIV testing meant their spouses could easily shift the blame on them for bringing HIV infection in the matrimonial home, as one woman and a health worker succinctly explained:

> *"Sometimes we women fear that if went for testing, men would take advantage of the situation and shift the blame on us. So, to avoid being blamed, some women opt not to go and test.* (45-year old woman)

> *"Usually the ones that behave badly are men; when the wife is positive or even when both are positive, they (men) deny it or claim that they are not responsible for the infection. So women become reluctant to test for HIV for fear of being blamed.*" (VCT counsellor, FGD)

On the other hand, men acknowledged having extra-marital relationships and feared that seeking HIV testing and being found HIV-positive would confirm their partners' suspicions – marital infidelity:

> *"If my wife knows that I am HIV-positive, she would say 'yes, it is because you had other sexual partners'. Sometimes the best way to avoid problems with women is not to test. They cannot blame you for HIV because you have not tested even if deep down your heart, you know that you are HIV-positive and you are the one who infected your wife."* (32-year old man)

Lack of self-efficacy and negative attitude towards antiretroviral treatment. Since HIV testing was a pre-requisite for initiating HIV treatment, the prospects of starting medication dissuaded individuals from HIV testing. This negative attitude towards treatment happened in two ways: lack of self-efficacy to be on life-long treatment and fear of treatment-related side effects and complications. For many respondents, observing the struggles of their spouses as they experienced and confronted treatment-related side effects did little to bolster their interest in and embolden them to seek HIV testing:

> *"Sometimes people worry about taking drugs for the rest of their lives. So, they fear to test because they are not ready to start treatment in case they are found HIV-positive.*"(VCT counsellor, FGD)

> *"Those [side effects] also contribute. You see the person that has tested and started treatment, when the drugs react. So even when you have intentions to test, when you see the reactions of the drugs, the side effects, it scares you from even going for testing because you start imagining the reactions on your body."* (38-year old man)

For others, the perceived stringent treatment requirements accounted for the uneasiness to test:

> *"Sometimes people worry about taking the drugs for the rest of their lives. So they fear to test because they are not ready to start treatment in case they are found HIV-positive."* (VCT counsellor, FGD)

In other instances, some respondents were concerned about the perceived harmful and toxic nature of HIV medication. This made them question the value of testing if they would not start treatment in the first place. These fears were based on rumours in the community about the negative long-term effects of treatment:

> *"Taking the medication? Most people in the compounds say when you start taking these drugs, the liver would start bulging in size; maybe you would have a problem of the heart. There is a friend whose husband went blind after starting treatment*." (30-year old woman)

> *"There are a lot of stories. Others say that people on ARVs, they look healthy but you just discover that one develops headache and then dies. That scares people. That means that the drugs have destroyed that person, saying 'akufa oyina' [dying whilst healthy]."* (42-year old man)

Opting for herbal remedies and non-HIV medication to mitigate HIV-related symptoms. Due to the perception of already being infected and the dislike and distrust of HIV medication, all the respondents reported seeking recourse to alternative care - herbal remedies and conventional non-HIV medication to mitigate HIV-related symptoms. *Aloe vera gel,* Chinese herbs generally known as "immune boosters" and a local herbal plant called *tembusha* were the mostly widely used herbs. Some participants also reported treating opportunistic infections using conventional non-HIV medication used by their spouses. This in turn undermined uptake of HIV testing. Two research participants poignantly narrated this self-care practice:

> *"I saw that people that have HIV but have not yet qualified to start ARVs take septrin. So, because I suspect that I have HIV, I just take septrin....Sometime back, when he (husband) was on septrin, we used to share the medication. So when he stopped taking septrin that is when I started organizing it on my own."(45-year old woman)*

> *"Even if I have not tested to confirm my HIV status, at least I take herbal medication in order to boost my immune system. At the moment, I am using tembusha. I make a 2.5 litre herbal solution and I take a glass in the morning, in the afternoon and in the evening*." (23-year old woman)

Opting for faith healing instead of seeking HIV testing was also reportedly a common practice. Some local Pentecostal religious leaders reportedly offered healing prayers for those with different health conditions, including HIV:

> *"Yes, and it depends on your faith, like there is this friend of mine who went to [Dr...], she went there and she was prayed for....So people in the community would prefer going for churches to be prayed for than to come to the clinic... for HIV testing."* (28-year old woman)

> *"There is one woman who came with a pastor. He claims that he is a man of God and that God is using him, and he has been healing people through prayers and they have been coming out negative. And he brought a young girl here aged between 22-26 years. He said that personally 'I am from praying for this person and God has told me that this person is healed. Test her and you will prove it.' We tested her and it came out reactive."* (VCT counsellor, FGD)

Self-stigma. Fear of enacted stigma – 'othering', social isolation, gossip, labelling and public shaming – was not reported as a barrier to HIV testing. This was attributed to the low level of stigma in the community and the experiences of their HIV-positive partners. Instead, self-stigma – feeling of guilt and shame of having a stigmatising condition – was described as undermining HIV testing:

> *"In the community there, stigma is no longer there. People would just sympathise with you. What is just remaining is self-stigma. You just feel guilty and ashamed that you have HIV. I avoid this feeling by not going to testing."* (31-year old man)

> *"No, stigma is very low…. You know some of our clients when they come here for treatment, at times their phones will ring and they would say 'my friend, I am at the clinic, I am getting my ARVs.' You know such statements and openness can give you an impression that people have now taken it to be normal….What is killing people is the self-stigma that they have."* (Health worker, ART clinic)

4.3 Discussion

This study sought to explore why individuals who knew the HIV-positive status of their marital partners did not seek HIV testing. We report new insights whilst corroborating previous findings, and discuss the implications of the findings for scaling up HIV testing, a critical strategy for achieving UNAIDS vision of zero new HIV infections (UNAIDS 2010b).

Maintaining high moral standing and de-legitimising partner behaviour: One new insight not reported in previous studies was the impact of deeply felt but not openly expressed resentment towards the HIV-positive spouse on uptake of HIV testing. Some respondents, both men and women, expressed deep feelings of betrayal by their HIV-positive spouses. Therefore, seeking HIV testing was viewed as legitimising partner's behaviour that could have led to HIV infection. Second, non-uptake of HIV testing was done in order to maintain high moral standing within marital relationships. These findings corroborate those of Larsson et al. (2010) who reported that unstable and distrustful nature of marital relationships undermined couple HIV testing. These insights have implications for HIV prevention in marital relationships. Strengthening the promotion of couple HIV testing remains the most viable option to help mediate blaming attitude and may improve couples' ability to manage HIV in marital relationships. This is especially so given the reported high rate of new infections in steady, long-term partnerships (UNAIDS 2010a).

These findings also suggest that non-uptake of HIV testing may signify masculinity – male notion of power, influence and being in control (Izugbara et al. 2009; Skovdal et al. 2011a), and gender inequality – subordination of women in male-female relationships. For men, non-uptake of HIV testing may therefore be used as a social practice to maintain social status and power within marital relationship as seeking HIV testing may be perceived as a sign of weakness, acknowledgement of mistake that could have led to HIV infection and consequently diminish influence, control and power in marital relationship. Studies in Malawi and Uganda (Izugbara et al. 2009) and Zimbabwe (Skovdal et al. 2011a) encapsulate how masculinity acts as a barrier to men's use of HIV services. We also found that masculinity undermined women's uptake of HIV testing. This may signify gender inequality in marital relationships as exemplified by women's fear that seeking HIV testing would lead to men shifting blame on them for HIV infection. A previous study in Uganda also reached this conclusion (Pool et al. 2001). Similarly, our findings also corroborate those of Skovdal and colleagues (2011b) in which masculinity was found to interfere with women's uptake of HIV treatment. Further studies on impact of masculinity on uptake of HIV testing are warranted.

Shame and burden of living with HIV undermine HIV testing. The impact of stigma on uptake of HIV testing has been previously reported (Kalichman & Simbayi, 2003; Mabunda, 2006; Izugbara et al., 2009; Namakhoma et al., 2010; Simpson, 2010; Jürgensen et al., 2012). It is important to distinguish two forms of stigma – enacted stigma and self-stigma. Enacted stigma entails experiences of being disadvantaged or unfairly treated on account of one's HIV-positive status while self-stigma entails personalised feelings of shame or blame derived from having an infection or disease socially constructed as degrading and shameful (Roura et al. 2009). Fear of enacted stigma was not found to be a barrier in our study, even after probing for its influence. This was attributed to the experiences of respondents' spouses who were described as not having reported experiencing stigmatising conditions. Instead, HIV testing was shunned in order to avoid carrying the burden of shame associated with having brought HIV infection in the marital relationship. This finding should however be interpreted with caution. It might be limited to this particular group of spouses of infected persons. Couple HIV counselling and testing is therefore critical to create openness, understanding and promote social acceptance of HIV infection in marital relationships. Despite the potential benefits, couple HIV testing and counselling has not been widely implemented (WHO 2012). This should however be done with caution taking into account marital 'lived' experiences as couple HIV counselling and testing could aggravate already fragile marital relationships as has been reported in a recent study in Zambia (Musheke, Bond & Merten 2013a).

Perceptions of risk of infection undermine HIV testing. The use of HIV-positive status of marital partners as a marker for HIV infection is consistent with evidence reported elsewhere (Bwambale et al., 2008; Jürgensen et al., 2012). Our findings suggest that while having an HIV-infected partner elevates the risk of infection, this does not *ipso facto* lead to initiation of HIV testing as those at risk assume that they are already infected despite the existence of HIV discordance. For individuals not already infected, the use of partner HIV-positive status as a proxy for own HIV status may undermine chances of practicing protective sexual behaviour, thus raising the risk of contracting HIV from partners. This underscores a need for more HIV awareness campaigns on existence and possibility of HIV discordance in marital relationships. Successful HIV prevention also requires addressing the disjunction between perceived and actual risk of HIV infection as previously reported in Zambia (Stringer et al., 2004), Malawi (Bignami-Van et al., 2006; Anglewicz & Kohler 2009) and Nigeria (Fagbamigbe et al., 2011).

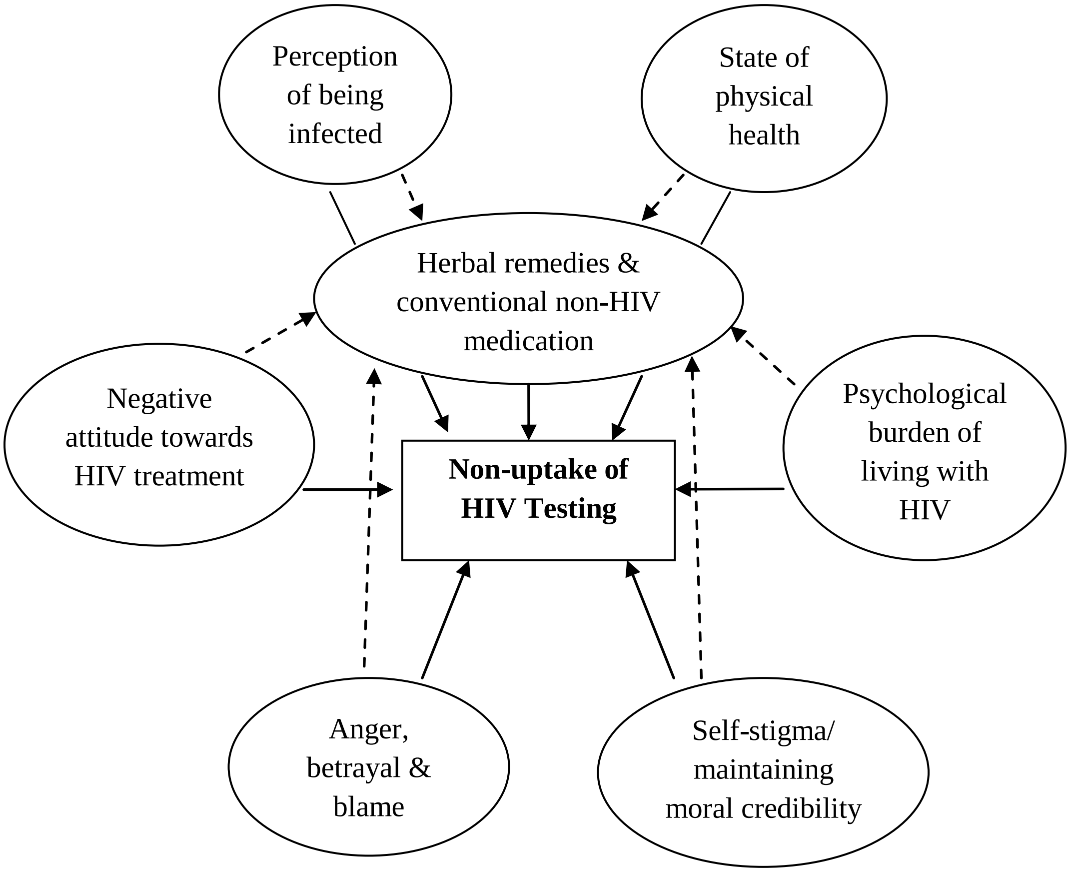
Negative HIV treatment beliefs inhibit uptake of HIV testing. Previous studies have reported how fear of ART undermines initiation of treatment by those living with HIV (Gold, Hinchy & Batrouney, 2000; Gold & Ridge, 2001; Gellaitry et al., 2005; Alfonso et al., 2006; Fox et al., 2010; Musheke, Bond & Merten 2013b). Our findings suggest that this fear of medication applies to those who do not know their HIV status, thus inhibiting uptake of HIV testing. This is despite the reported positive impact of availability of ART on uptake of HIV testing (Day et al., 2003; Warwick 2006; Simpson, 2010; Phakathi et al., 2010; Jürgensen et al., 2012). Alternatively, individuals sought herbal remedies to mitigate possible HIV-related symptoms and 'sustain' physical health. This suggests that improving uptake of HIV testing also requires addressing lack of self-efficacy and negative HIV treatment and health-related beliefs.

Wellness and illness beliefs undermine HIV testing. The overarching barrier to uptake of HIV testing was individuals' perception of their corporeal health. Perceived good physical health dissuaded individuals from testing despite being at heightened risk of HIV infection. These findings are consistent with previous studies (Oshi et al., 2007; Grant et al., 2008; Chirawu et al., 2010; Namakhoma et al., 2010, Simpson, 2010). Instead, HIV testing was deferred until health had deteriorated. This suggests that HIV testing is perceived as a gateway into treatment and care and not a critical strategy for HIV prevention. These findings support the observation by Jürgensen et al., 2012 that HIV testing is used as a diagnostic tool to access health care and not as an HIV prevention mechanism. Risk of declining health was however counter-balanced by uptake of herbal remedies and conventional non-HIV medication to "boost" the immune system and to deal with episodic non-severe HIV-related symptoms. This undermined access to HIV testing and possible entry into ART care. Sensitisation efforts are therefore warranted on the benefits of testing and early initiation of treatment.

As a corollary, fear of psychological burden associated with knowing one's HIV status and its perceived negative impact on physical health dissuaded individuals from seeking HIV testing. This is consistent with previous studies (MacPhail et al., 2008; Angotti et al., 2009; Råssjö et al., 2009; Obermeyer et al., 2009; Simpson, 2010; Jürgensen et al. 2012). Our findings suggest that not seeking HIV testing despite acknowledging possibility of being infected is used as a psychological buffer against the perceived mental burden of living with an incurable infection. This suggests that despite the wider availability of life-saving antiretrovirals, HIV still exudes fear of death in view of its incurable nature and this fear is exacerbated by the memories of suffering and death of people infected with HIV, including those on treatment. Being found HIV-positive therefore makes death a certainty. Thus, sensitization activities on the benefits of HIV testing regardless of physical health continue to be important. Misconception that knowledge of one's HIV-positive status leads to rapid deterioration of health point to a need for continuous post-test counselling and support, especially that psychological distress associated with knowledge of HIV-positive status is in part based on observing the experiences of those living with HIV.

Faith healing and herbal remedies to mitigate HIV-symptoms undermine HIV testing. Our findings suggest that the perception that treatment was insidiously harmful and had deleterious effects in the long-term resulted in the use of alternative care – faith healing and herbal remedies, with the latter being reported as effective as antiretrovirals while hoping to get cured through the former. What these findings indicate is that negative attitude towards treatment does not only result in HIV-patient non-initiation of and attrition from antiretroviral treatment (Musheke, Bond & Merten 2013b & 2012), it also undermines uptake of HIV testing – the first step in ART care. Therefore, sensitisations on the benefits of HIV testing as opposed to seeking faith healing and scientifically unproven herbal remedies are warranted.

Figure 4-1 Nested relationships of barriers touptake of HIV testing



Our study suggests that barriers to HIV testing despite knowledge of marital partner's HIV-positive status are not mutually exclusive. They are interrelated and some may intersect and coalesce to undermine HIV testing behaviour (Figure 4-1). For instance, while perception of being infected reduces motivation to test, feeling healthy, sometimes due to the use of herbal remedies and non-HIV conventional medication to mitigate HIV-related symptoms, inhibit uptake of HIV testing. Similarly, although negative attitude towards HIV-medication, concerns about psychological burden of living with HIV and need to maintain moral credibility reduces motivation to seek HIV testing, these barriers may be modulated by the state of physical health with participants showing willingness to test and initiate treatment if their health deteriorated and herbal remedies and conventional non-HIV medication were no longer effective in sustaining physical health.

Possible limitations of the study

The study participants were recruited through their spouses receiving ART care at a local public sector clinic. The findings may therefore not be representative of other individuals whose spouses were not receiving ART care. However, because the focus of the study was on testing behaviour of individuals who knew the HIV-positive status of their spouses, treatment status of their spouses could have played little effect on their testing behaviour. Interviewing the HIV-positive spouses could have provided more insights on non-testing behaviour through comparability of marital partners' perspectives. Future studies should explore this further. Notwithstanding the limitations, the strength of this study was the equal representation of men and women in our study sample thereby being able to elicit the perspectives of both men and women. The use of different data collection methods with different type of study participants was useful for gathering in-depth insights and for triangulation of data.

A more general limitation concerns the generalisability of the findings. This study was conducted in a low-income setting with a small sample of respondents and aimed at in-depth insights into factors undermining uptake of HIV testing rather than getting a representative sample. Similar studies are therefore warranted in other settings for comparability of findings. However, our findings are probably generalisable to similar settings in urban areas in the country and provide useful insights that can inform policy and practice to improve uptake of HIV testing for prevention of HIV transmission.

4.4 Conclusions

Decision making about HIV testing is influenced by a wide range of factors that interact and coalesce. Individuals reach lay conclusions of already being infected on account of the HIV-positive status of their spouses, thus viewing HIV testing as unnecessary. However, testing is also not done to avoid legitimizing the perceived betrayal and subsequent HIV infection of HIV-positive partners and to maintain moral credibility within marital relationship. Not knowing one's HIV status is also aimed at creating a distance from HIV, thus acting as a buffer against the perceived psychological burden of living with HIV. While free HIV treatment has become widely available, the perceived negative effects of treatment coupled with use of herbal remedies to mitigate HIV-related symptoms still hamper uptake of testing. All these barriers appear to be modulated by the state of corporeal health, with individuals planning to test only after their health had deteriorated. Therefore, HIV prevention efforts should aim at addressing lay interpretations of risk of HIV infection, health and treatment beliefs and promote the preventive and treatment benefits of early diagnosis of HIV. The reluctance by individuals to test despite knowing the HIV-positive status of their marital partners also calls for stepping up couple HIV counselling and testing.

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Authors' contributions

MM conceptualized the study, conducted data collection and analysis and wrote the draft manuscript. **VB** and **SM** contributed towards the conceptualization of the study, provided input in the analysis, interpretation of the findings and drafting of the manuscript. All authors have given final approval of the version to be published.

Chapter 5

Couple experiences of provider-initiated couple HIV testing in an antenatal clinic in Lusaka, Zambia: Lessons for policy and practice*

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Abstract

Background: Couple HIV testing has been recognized as critical to increase uptake of HIV testing, facilitate disclosure of HIV status to marital partner, improve access to treatment, care and support, and promote safe sex. The Zambia national protocol on integrated prevention of mother-to-child transmission of HIV (PMTCT) allows for the provision of couple testing in antenatal clinics. This paper examines couple experiences of provider-initiated couple HIV testing at a public antenatal clinic and discusses policy and practical lessons.

Methods: Using a narrative approach, open-ended in-depth interviews were held with couples (n=10) who underwent couple HIV testing; women (n=5) and men (n=2) who had undergone couple HIV testing but were later abandoned by their spouses; and key informant interviews with lay counsellors (n=5) and nurses (n=2). On-site observations were also conducted at the antenatal clinic and HIV support group meetings. Data collection was conducted between March 2010 and September 2011. Data was organised and managed using Atlas ti, and analysed and interpreted thematically using content analysis approach.

Results: Health workers sometimes used coercive and subtle strategies to enlist women's spouses for couple HIV testing resulting in some men feeling 'trapped' or 'forced' to test as part of their paternal responsibility. Couple testing had some positive outcomes, notably disclosure of HIV status to marital partner, renewed commitment to marital relationship, uptake of and adherence to treatment and formation of new social networks. However, there were also negative repercussions including abandonment, verbal abuse and cessation of sexual relations. Its promotion also did not always lead to safe sex as this was undermined by gendered power relationships and the desires for procreation and sexual intimacy.

Conclusions: Couple HIV testing provides enormous bio-medical and social benefits and should be encouraged. However, testing strategies need to be non-coercive. Providers of couple HIV testing also need to be mindful of the intimate context of partner relationships including couples' childbearing aspirations and lived experiences. There is also need to make antenatal clinics more male-friendly and responsive to men's health needs, as well as being attentive and responsive to gender inequality during couselling sessions.

5.0 Introduction

A growing body of evidence shows that a large proportion of HIV infection occurs in marital or cohabiting relationships (Carpenter et al. 1999; Hugonnet et al. 2002; Malamba et al. 2005, UNAIDS 2010a), for instance, 50-65% in Swaziland; 35-62% in Lesotho; and 44% in Kenya (UNAIDS 2010a) and a high prevalence of discordant couples has been reported in some 12 sites of Eastern and Southern Africa (UNAIDS 2010a). Therefore, couple HIV testing has long been touted as essential for facilitating disclosure of HIV status in marital relationships (Painter 2001; Kairania 2010); adoption of risk reduction sexual behaviour (Kamenga et al. 1991; Allen et al. 1992; Van der Straten et al. 1995; Skurnick et al. 1998; Roth et al. 2001; Allen et al. 2003); uptake of treatment for prevention of mother-to-child transmission of HIV (PMTCT) (Farguhar et al. 2004; Conkling et al. 2010); and reduction in loss-to-follow up of women on treatment (Conkling et al. 2010).

With a population of slightly over 13 million people, an estimated 14.3% of Zambians (aged 15-49 years) are living with HIV (CSO 2009); 69% of HIV-positive men and 49% of HIV-positive women may not be aware that they are infected (CSO 2009). Urban data on Zambia suggests that more than 60% of new infections occur within marriage or cohabiting relationships (Dunkle 2008; UNAIDS 2010a) and discordance rate is estimated at 11% (NAC/MoH 2010). Whilst more than 90% of women attending antenatal care services are tested for HIV - under an ‘opt-out’ strategy - only 10% of couples in Zambia have tested together for HIV (MoH 2010b).

The Zambian PMTCT protocol recommends the provision of couple HIV testing in antenatal clinics as part of HIV prevention, treatment and care (MoH 2010b). However, there is little empirical evidence about how this is actually achieved and couples’ experiences of this testing strategy. As the World Health Organisation (WHO) has recently noted about couple HIV testing, “there are very few data… on adverse social and psychological outcomes such as those affecting quality of life, marital relationships or the risk of violence, including emotional abuse and gender-based violence (WHO 2012, p. 56). Additionally, most studies on couple HIV testing in sub-Saharan Africa (SSA) have largely consisted of quantitative studies (Allen et al. 2003; Chomba et al. 2008; Katz et al. 2009; Conkling et al. 2010; Byamungisha et al. 2011; Mohlala, Boily & Gregson 2011; Lambdin et al. 2011; Wall et al. 2012) and there have been calls for more studies to better understand issues related to its provision (Painter 2001; Mohlala, Boily & Gregson 2011; WHO 2012).

In view of this gap, this study explored couple experiences of couple HIV testing with a specific focus on the impact on treatment uptake, social support and adoption of risk-reduction sexual behaviour. The paper begins by giving an overview of couple HIV testing pathway in an antenatal clinic followed by an encapsulation of the strategies used by health care providers to promote it. Drawing on couple and provider experiences, we then present the effects of couple HIV testing on marital relationships and discuss policy and practical lessons.

5.1 Methods

5.1.1 Research location and context

The study was conducted in a high-density urban residential area of Lusaka, the capital city of Zambia. As a result of rural-urban migration that Zambia has witnessed particularly in the last three decades as people moved to the city in search of economic opportunities, the study setting comprises people from different ethnic groupings although two vernacular languages (namely *Bemba* and *Nyanja)* are the most widely spoken. While living conditions of the local people are mixed, the majority of residents are poor, mostly making a living within the informal sector of the economy.

Despite the diversity of ethnic groups, there are strong similarities in Zambian marriage practices (Chondoka 1988) and inter-ethnic marriages are common. Payment of bride-price by the man’s family, locally called *lobola*, is common. There is a pattern of marriage taking place when a woman falls pregnant in casual relationships, partly to avoid a financial penalty charged by the woman’s family (locally called ‘damage’). This pattern of early pregnancies and subsequent marriages is reflected in the national fertility trend - 61% of women become mothers by the time they are 20 years old (CSO 2009). Since some of these marriages are often a ‘forced’ option and couples (particularly women) are young, in these unions, conflict, lack of intimacy and lack of social support are more evident. Although the majority of the marital relationships are supposedly monogamous, extra marital relationships and multiple concurrent non-spousal sexual partnerships are reported, often linked with hanging out in beer drinking places.

Health services in the area are mainly provided by a public sector clinic. The clinic has an estimated catchment population of over 150,000 and provides out-patient and in-patient health services. The clinic also provides HIV testing, PMTCT, family planning and reproductive health services; houses a couple HIV testing research project and a non-governmental organization that provides sexual education, nutritional counselling and psychosocial support to women and new mothers living with HIV.

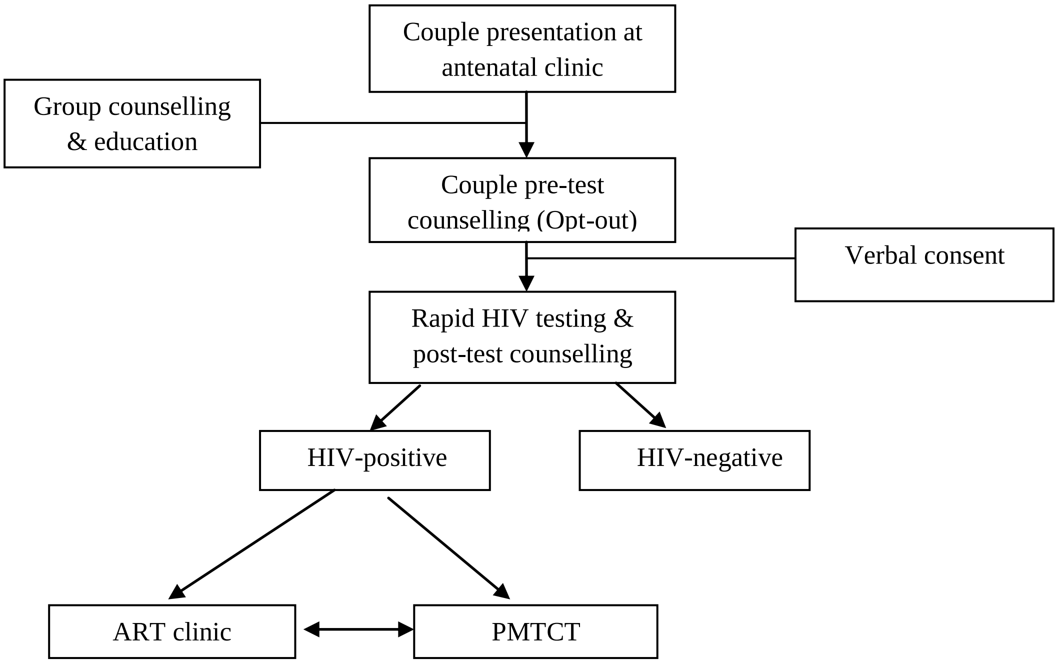
HIV testing pathway in the antenatal clinic

When women present pregnant, they are booked for antenatal care. At the booking stage, married women are sometimes asked to go back home to bring their spouses for couple HIV counselling and testing. Group counselling and education is then provided focusing on inter alia, HIV transmission and prevention measures; the benefits of HIV testing including PMTCT; and implications of a positive HIV test result including the availability and provision of antiretroviral therapy (ART). To ensure that men - most of who are breadwinners for their families - do not stay long at the often congested antenatal clinic, couples are given preferential treatment. Group counselling and education is followed by individual and couple pre-test and post-test counselling. The men found HIV-positive are referred to the ART clinic (not based at the antenatal clinic) for further clinical assessments and enrolment into ART care while HIV-positive women continue to receive, inter alia, PMTCT care within the antenatal clinic (Figure 5-1).

5.2 Research design

A qualitative study utilising narrative analysis (Sandelowski 1991; McCance, McKenna & Boore 2001) was used. Ten (10) couples aged ≥ 18 years old who underwent couple HIV testing at a public sector antenatal clinic were interviewed. The marital partners were interviewed separately. Maximum-variation sampling (Patton 2001) was used to select the study participants. This sampling strategy allows for selection of participants with a wide variety of ‘lived’ experiences (and not representative sample) in order to elicit a range of experiences, views and interpretation about a subject matter (in this case couple HIV testing). The women were identified and recruited through an HIV support group based at the antenatal clinic. Since men did not attend HIV support group meetings at the antenatal clinic, initial contact to recruit them was made through their spouses who attended these HIV support group meetings. In addition, five women and two men who had undergone couple HIV testing but were later abandoned by their spouses were also interviewed; their spouses could not be traced. In addition, key informant interviews were held with lay HIV counsellors (n=5) and antenatal clinic nurses (n=2) to gain in-depth understanding of the couple HIV testing process and their experiences of providing couple HIV testing.

Figure 5-1 Couple HIV testing and treatment pathway at antenatal clinic



Face-to-face, open-ended, in-depth interviews were conducted by the lead author. The interviews were conducted between March 2010 and September 2011. Interviews with the counsellors and nurses were conducted in English while interviews with the women and men were conducted in *Nyanja,* the local language widely spoken in the area. The interviews were framed as a narrative production. Research participants were asked to describe their HIV testing experiences as stories, recounting how they came to get tested as couples, what happened inside the antenatal clinic and their 'lived' experiences after couple HIV testing. All interviews with clinic staff were conducted at the antenatal clinic while the interviews with couples were conducted outside the clinic setting to ensure that the respondents were not inhibited by the clinic surrounding to share their experiences. All interviews were audio-recorded and usually lasted about 30 minutes. In addition to the interviews, the first author conducted sit-in observations at the antenatal clinic and attended HIV support group meetings based at the antenatal clinic.

All interviews were transcribed verbatim and field observational notes typed. These were imported into, and organised and managed using, Atlas ti version 6. The transcripts and field notes were read several times to develop a deep sense of the data. For interview transcripts, within-case and across-case analysis (Ayles, Kavanaugh & Knalf 2003) and 'paradigmatic analysis' of narrative (Polkinghorne 1995) were undertaken to inductively generate themes and concepts across the individual narratives (McCance, McKenna & Boore 2001). Three reference points were used to identify emergent themes: recurrence, repetition and forcefulness of ideas within the narrative data (Overcash 2004). For each narrative, we conducted within-case analysis and retrieved and coded each participant's HIV testing experience. Thereafter, we conducted across-case analysis by comparing and contrasting participants' experiences. This enabled us to construct storylines across study participants' testing experiences. By using this analytical strategy, we were able to generate experiences across study participants that were still grounded in individual experiences (Ayles, Kavanaugh & Knalf 2003). Lastly, we selected interview excerpts that best illustrated the storylines.

5.2.1 Ethical approval

The study was approved by the Ethics Committee of the State of Basel (Ethik-Kommission beider Basel) and the University of Zambia Humanities and Social Sciences Research Ethics Committee within the framework of a bigger research project - 'Improving equity in access to HIV care and treatment in Zambia.' Administrative approval was obtained from the Ministry of Health at national and district levels. Written informed consent was obtained from all research participants. To maintain confidentiality, no identifying information is mentioned in the narrative transcripts.

5.3 Results

Characteristics of Study participants

Out of the 10 couples, three (3) were in discordant marital relationships in which the women were HIV-negative (Table 5-1). In total, ten of the fifteen women and eight of the twelve men were on ART while the rest were not yet clinically eligible for treatment. The respondents were relatively young couples: the majority of the women were in their twenties while the men were in their thirties. The main outcomes of couple HIV testing are summarized in Table 5-1.

Table 5-1 Characteristics of marital partners & outcomes of couple HIV testing

Age of marital partners (in year)	**Length of marriage (in years/months)**	**Couple-HIV Status**	**Main outcome of CVCT**
Couple 1: Man 32 yrs; woman 28 yrs	4 yrs	Concordant couple	Supportive marriage; protective sex; woman assertive on condoms; Man provides treatment support.
Couple 2: Man 32 yrs; Woman 27 years	4.6 yrs	Concordant couple	CVCT strengthened marital bond; man now 'sticks' to his wife; alternate use of condoms.
Couple 3: Man 36 yrs; Woman 29 years	8 yrs	Concordant couple	Man refuses to use condoms; threatens wife with divorce; wife economically dependent on spouse.
Couple 4: Man 26 yrs; Woman 22 years	3.8 yrs	Concordant couple	Man felt "trapped" to test; CVCT empowered wife to form new treatment support social networks.
Couple 5: Man 34 yrs; Woman 26 years	2.6 yrs	Concordant couple	Initial cessation of sex after CVCT. Safe sex still a challenge. However, CVCT enabled woman create supportive social support networks.
Couple 6: Man 23 yrs; Woman 20 years	2.1 yrs	Concordant couple	Supportive couple; young couple struggling to balance between protection & procreation.
Couple 7: Man 34 yrs; Woman 26 years	4.9 yrs	Concordant couple	Man felt "trapped" to test; but encourages wife to attend support group meetings.
Couple 8: Man 26 yrs; Woman 22 years	4 yrs	Discordant couple (woman HIV-)	Supportive couple; reproductive aspirations undermine safe sex.
Couple 9: Man 28 yrs; Woman 23 years	2.6 yrs	Discordant couple (woman HIV-)	Strong bond but man's desire for sexual intimacy & child bearing affect safe sex practice.
Couple 10: Man 46 yrs; Woman 29 years	5.7 yrs	Discordant couple (woman HIV-)	Man refuses safe sex; he wants male child; HIV-negative woman fears infection & threatens divorce.

Note: In all the discordant couples, women were HIV negative. Three women and two men not listed as couples experienced marital dissolution after testing.

Strategies of promoting couple HIV testing in antenatal clinic

Pregnant women directed to bring spouses. Aware of low participation of men and often confronted by fears that some married women faced to test and later disclose their HIV status to their spouses, one strategy, although infrequently and unsuccessfully used by antenatal clinic staff, was to instruct women to bring their spouses for HIV testing. One female lay counsellor explained this process:

> *"Every day, we test about 30 pregnant women but because men rarely come here, we have adopted a deliberate strategy where half the women are asked to bring their spouses. So for instance, we count 1, 2, 3, 4, 5 up to 15, then the rest, we tell them to go back and come with their spouses."*

Sometimes men were summoned under the pretext of discussing pregnancy and the well-being of the unborn child. Two antenatal clinic staff narrated:

> *"There is another option we use. We tell the women that 'go and tell your husband, there is something that we want to discuss about the baby with him.' You know when men hear anything to do with the baby, they come….We use that as a chance to counsel them for HIV, test them and tell them their results together."* (Female nurse, antenatal clinic)

> *"He just thinks that may be it has to do with the woman's pregnancy. When they come here, they are educated about the pregnancy, family planning, STIs, and then they are tested. Normally, when the man is already here, he fails to say I do not want to test."* (Female lay counsellor, antenatal clinic)

To beguile the men and to motivate the women to bring their spouses for couple HIV testing, women who brought or came with their spouses for HIV testing were given preferential treatment so that the men as breadwinners did not spend a lot of time at the clinic. In the light of congestion at public sector antenatal clinics, women found this strategy of being given preferential treatment appealing and often encouraged their spouses to come for couple HIV testing.

Coercing men to test. In some cases, women themselves reportedly used coercive strategies, sometimes threatening not to go for antenatal care and ultimately holding their spouses responsible for any pregnancy-related complications if they refused to accompany them to the antenatal clinic. As one woman explained:

> *"I told my husband that if we do not go to the clinic together, I will never go for antenatal care....If anything happens to my pregnancy and my life, my family will hold you responsible.*

> *When I said this, he agreed to come with me to the clinic*." (32-year old woman, living with HIV)

Inside the clinic, 'opt-out' HIV testing not fully articulated. During group counselling, observations revealed that the opt-out requirement was not explicitly articulated. Antenatal clinic staff often emphasised the bio-medical benefits of testing, including access to treatment and prevention of mother-to-child transmission (PMTCT) of HIV. Sometimes moral obligations were used to encourage uptake of HIV testing. As one lay counsellor said during one group HIV counselling meeting: *"You have to test to protect the child….It is the right of the baby to be born negative, to live a normal and healthy life."*

By simply evoking maternal/paternal responsibility to encourage uptake of HIV testing, couples were deprived of the right to consent and time and opportunity to reflect on the implications of HIV testing. While women interviewed acknowledged the bio-medical benefits of testing, including for prevention of mother-to-child transmission of HIV, they also expressed concerns about the possible negative impact of testing on their marital relationships. As one woman illustrated:

> *"At the clinic, you have little chance of refusing to test. They tell you that you have to do it to protect the child, meanwhile you; you are thinking about what will happen at home. You know a lot of things happen in these marriages."* (24-year old woman, living with HIV)

Some men reported feeling 'trapped' in the antenatal clinic and only acquiesced to test for fear that their partners could be denied antenatal care services. Even though some men reported knowing beforehand that they might end up getting tested, others were oblivious of this possibility. One man elucidated his experience:

> *"I really felt trapped when I was told that I needed to test because I did not go to the clinic in order to test. My wife told me that I was wanted so that they can tell us about the pregnancy and how to look after the unborn child."* (34-year old man, living with HIV)

Effects of couple HIV testing on marital relationships

Couple emotional and social support. For some couples, joint knowledge of their HIV status became a platform to renew their commitment to marriage and family life in the face of HIV, enabling them to be sensitive and responsive to the treatment, emotional and social needs of each other:

> *"Me, that is when my marriage became sweet; what can I compare it to? It is as if we have just started our relationship….My husband begun to love me more than before. I don't know whether he felt guilty, and was a way of compensating for his misdeeds."* (27-year old woman, living with HIV).

Development of supportive social relationships and networks. Outside the household setting, couple HIV testing enabled some women to develop new social network relationships and receive additional social support outside marital relationships. However, this was not found to be the case amongst men as most of them preferred to conceal their HIV status and did not attend HIV support group meetings. One woman narrated her experience:

> *"Since both my husband and I tested, I feel free to come for support group meetings, to go to the clinic for my drugs. I now have friends who are also HIV positive. We encourage each other."* (26 year old woman, living with HIV)

Access to and retention in antiretroviral therapy care. Couple HIV testing also helped legitimise access to treatment on account of disclosure of HIV status to marital partner. Couples on HIV treatment gave accounts of how testing as a couple had made it easier for them to access and remain on treatment. For instance, as 'treatment supporters', sometimes men collected HIV medication on behalf of their wives or encouraged them not to miss taking their medication. One woman explained:

> *"My husband is very supportive. He always reminds me to take my medication. He sets his alarm clock and even when he is not at home, he calls to make sure that I have not forgotten to drink my medicine."* (28-year-old woman, living with HIV)

Another woman echoed these sentiments:

> *"When it is my appointment day at the ART clinic, my husband works up early in the morning, at 04 hours and comes to line up here on my behalf, and I follow later. When it is the time to bring my child for under-five, he even sets the alarm clock to wake me up."* (26-year old woman, living with HIV)

Negotiating safe sex in marital relationships. In the light of HIV-positive test results, negotiating adoption of safe sex was also a recurrent theme among some couples. Our findings revealed that although couples did not always practice safe sex, for some women, being counselled and tested together as a couple had empowered and legitimised their quest to negotiate and demand, or sometimes secretly adopt, safe sexual practices to avoid contracting HIV or re-infecting one another. As one woman poignantly put it:

> *"We agreed that we use condoms so that 'you keep your HIV virus which is used to the medication and I keep my HIV virus which is not yet used to the medication.'"* (27-year old woman, living with HIV)

Our respondents' narratives further indicate that even for couples that struggled to agree on safe sex, women's access to female condoms during antenatal care and at support group meetings empowered them to *'secretly'* protect themselves that "*he [husband] would not even know that I am using the female condom."* (26-year old woman, living with HIV)

Despite these bio-medical and social benefits, our study also revealed that couple HIV testing had negative effects on marital relationships:

Testing space still reproduced entrenched gender inequalities. Although women felt comfortable, even empowered in the public antenatal clinic space, in more intimate spaces, either within counselling sessions or at home, entrenched power relations which sometimes gave rise to strained marital relationships arose. Men were reportedly more assertive during counselling sessions than women, and at home, asserted their authority over women on sexual and reproductive health decisions. One counsellor illuminated her experience:

> *"Although during counselling session you are not supposed to concentrate on one person, the problem is that men tend to dominate discussions; women feel intimidated…. Most women say 'I agree with whatever my husband has said.' It has to do with our culture."*

Safe sex or safe marriage? For both concordant and discordant couples, couple HIV testing did not always lead to practicing safe sex. This was undermined by tension between protection on one hand and the desire for sexual intimacy and procreation on the other hand, sometimes modulated by gendered power relationships. For some couples, having unprotected sex was construed as *sine qua non* for consummating marital relationships while condom use was synonymous with having sex with a non-regular sexual partner - with no emotional intimacy attached. Consequently for some couples, the desire for sexual intimacy, and particularly for women to preserve their marriages, compelled them to engage in unprotected sex, even at the expense of their own health.

Modulated by gendered power relationships in marital relationships as well as economic dependence on their spouses, some women acquiesced to the demands of their spouses in order to preserve their marital relationships. One 29-year old woman in an HIV concordant marriage recounted her experience:

> *"He told me that if you do not want sex without a condom, then you will go back to your parents and I will find another woman to marry. So since I am scared of losing my marriage, I just give him 'live' sex. What can I do because when I tell him about using condoms, he refuses, so what can I do, apart from re-infecting him? Me, I want to help him, and also help myself from getting re-infected, but he threatens to divorce me. How am I going to look after myself and my children?"*

Failure to practice safe sex sometimes led to previously HIV-negative partners particularly women getting infected. An ART nurse explained:

> *"You know when a couple comes, they are discordant, you find that the man is positive and the woman is negative, the woman would support the husband, she will always be with him, and come to the clinic together and what do you discover further, 3-4 months? The wife is also positive. But if a man is negative and the woman is positive, you would find the woman losing weight, the woman coming alone, and the man would never get the virus."*

For discordant couples, negotiating this intricate balance between HIV prevention and preserving one's marriage was acutely complex and sensitive. A case study illuminates this dilemma: A 46-year old man and his 29-year old wife had been married for almost 6 years. The man had HIV while the woman was not infected. The man insisted on unprotected sex because he wanted another child, a son, while the woman wanted the couple to practice protective sex to avoid getting infected. While she valued her marriage, she threatened to break up with the husband to preserve her HIV-negative status unless the spouse acquiesced to the use of condoms.

Strained marital relationships: cessation of sex, mental abuse and abandonment. Another downside of couple HIV testing was the reported cessation of sexual relationships (sometimes intermittent, in some cases permanent), and experiences of mental abuse and abandonment. This was not limited to discordant relationships. One woman whose husband was also HIV-positive explained:

> *"What happened was that after testing, my husband shifted from the bedroom and started sleeping in the sitting room. From January - June, my husband slept in the sitting room…."* (34 year-old woman, living with HIV)

> Cases of mental abuse, although infrequent, were noted. A counsellor recounted:
> *"Such cases arise from time to time. I had such an experience before where the man was torturing, ill-treating the wife. The man was negative and the wife was positive. Each time the man came from work, he would tell the wife, 'come out of the bedroom, you are a sick woman. I have come with another woman.' Then the woman would sleep in the sitting room, and the man would go into the bedroom with another woman. I felt very bad. I tried to talk to the man but he was a drunkard. He was so sarcastic. So I referred him to another counsellor for further counselling. So I do not know what happened from there."*

Our findings show that separation or divorce took place, often triggered by knowledge of HIV status. This was not restricted to discordant couples only. Three women and two men living with HIV also reported being abandoned by their HIV-positive spouses after couple HIV testing. Two respondents narrated their experiences:

> *"We were both tested and found HIV positive but to my surprise, my husband decided to desert me. He just left without saying a word. I later just heard that he was living in […….] (another town). He left me when I was 8 months pregnant. He does not even know the child, he has never seen her, and he has never called me."* (24-year old woman, living with HIV)

> *"It (couple testing) affected our relationship. Her friends started pressurising her to leave our marriage. My wife and her friends opened a saloon at local market, and in no time, she stopped coming home. She started living in […] compound….I looked for my wife and pleaded with her to come back but she refused."* (46-year old man, living with HIV)

Due to our inability to interview individuals who had abandoned their spouses after testing, we were unable to establish the reasons for their actions. However, two interviews with two men abandoned by their spouses pointed to blaming attitude as one of the reasons for marriage dissolution.

5.4 Discussion

Our study explored how couple HIV testing was undertaken and its impact on marital relationships. Low male partner participation in antenatal HIV counselling has been reported in other studies (Semrau et al. 2005; Msuya et al. 2008; Byamugisha et al. 2011). This was also the case in our study. As a result, our findings suggest that antenatal clinic staff used subtle and sometimes coercive strategies to promote couple HIV testing. This deprived couples not only of voluntary informed consent but also the time and opportunity to weigh the implications of HIV testing. Our findings are consistent with previous studies that have expressed concerns about the impact of 'opt-out' provider-initiated HIV testing on voluntary informed consent (Gruskin Ahmed & Ferguson 2008; Maman & King 2008; Ujiji et al. 2011; Njeru et al. 2011; Larsson et al. 2012) because of the inherent skewed power relationships between health staff and service users. As WHO/UNAIDS (2007, p.17) have cautioned, "endorsement of provider-initiated HIV testing and counselling is not an endorsement of coercive or mandatory HIV testing."

From the way couple HIV testing was being promoted, our findings suggest that the aim of couple HIV testing was primarily to improve maternal and child health outcomes and not to improve the health status of couples. This explains why some men reported feeling "trapped*"* in the antenatal clinic. Larson and colleagues reached similar conclusions (Larsson et al. 2010).

Contrary to our findings where subtle means were used, previous studies have found that a good proportion of men willingly came for couple HIV testing if sent invitations and were fully counselled on the benefits of testing (Mohlala, Boily & Gregson 2011; Lambdin et al. 2011; Wall et al. 2012). On the balance, what these findings indicate is that appropriate non-coercive strategies can successfully be implemented and need to be adopted, including adoption of community sensitization campaigns about the value of couple HIV testing.

One notable benefit of couple HIV testing was its positive impact on access to treatment, garnering partner support, adoption of risk reduction sexual behaviour in some instances and the ability by women to form new social network relationships. These findings suggest that being diagnosed with HIV and the uncertainty of living with an incurable infection creates marital cohesion and solidarity. As Rolland (1994) has pointed out, a diagnosis of a serious condition (in this case HIV) heightens feelings of loss which can prompt couples either to pull apart or to cling together. Clinging together happens in order to ensure “partnership security” and “relational survival” (Rhodes & Cusick 2000) in the face of HIV. Our study revealed that partner cohesion and solidarity were achieved because some couples accepted the diagnosis, avoided apportioning blame and viewed HIV as a conjoint problem. In terms of adoption of safe sexual practices, we noted that women’s exposure to support group meetings enabled them to be more assertive in marital relationships, including the need for adoption of safe sex to avoid (re-)infection. These findings mirror other studies that have reported increased adoption of safe sex among marital partners that have accessed couple HIV testing (Roth et al. 2001; Allen et al. 2003; Becker et al. 2010).

Given that couple HIV testing facilitated disclosure of HIV status to marital partner, this helped legitimise access and adherence to treatment and access to social support. Women reported being reminded, encouraged and supported by their spouses about taking their medication. Outside the household setting, couple HIV testing provided women with opportunity to develop new social network relationships and receive social support beyond household level. Our findings corroborate other studies which have shown that couple HIV testing increased uptake of ART (Farquhar et al. 2004; Becker et al. 2010). These benefits clearly demonstrate the value of its promotion.

As a caveat, couple HIV testing needs to be promoted while being sensitive to individuals’ or couples’ ‘lived’ experiences given the social context and dynamics of marital relationships. This is especially so given the physical, mental and sexual violence that women are subjected to. For instance, the Zambia Demographic and Health Survey 2007 report indicates that almost half (47%) of women aged 15-49 years interviewed had experienced physical violence in their life time and one-third of women had experienced physical violence in the 12 months preceding the survey; one in five women had experienced sexual violence at some point in their lives (CSO 2009). Although experiences of physical violence after couple HIV testing were not reported in our study, however, intermittent and permanent cases of strained marital relationships, including abandonment by spouses after undergoing couple HIV testing were reported. Our findings corroborate previous findings (Becker et al. 2010). Larson and colleagues have reported that men found couple testing unappealing because of the unstable and distrustful nature of their marriages (Larsson et al. 2010). These findings demonstrate the fragility of marital relationships.

The findings also suggest that the effects of couple HIV testing on marital relationships may be modulated by inequitable, gendered power relationships. For instance in their familial relationships, women are confronted with patriarchal power dynamics and even those that assert their position in public spaces on HIV seem to have little control over their health when dealing with men in their private lives (Susser 2009). In our study, men were reported to be generally more assertive during counselling sessions than women, and at home, asserted their authority over women on sexual and reproductive health decisions. Our findings therefore echo previous calls for gender-sensitive HIV control activities (Vlassoff & Moreno 2002; WHO 2009b; Ujiji et al. 2011) to avoid adverse social effects.

Couple knowledge of HIV status did not always lead to adoption of risk reduction sexual behaviour. This was linked to socially constructed views of sexual intimacy and the difficulties of balancing between HIV prevention and child bearing aspirations. Men often declined the use of condoms and the subordinate position of women compelled them to acquiesce. Previous studies have reported the challenges of reconciling protection on one hand with childbearing aspirations (Nakayiwa et al. 2006; Beyeza-Kashesya et al. 2009; Rispel et al. 2011; Kelly et al. 2011) and sexual intimacy (Bond & Dover 1997) on the other hand, thus leading to unprotected sexual behaviour.

The study has both strength and limitations. The findings are based on a relatively small, purposively chosen sample, with a relatively young group of couples who accessed couple HIV testing in one public sector clinic. The findings may therefore not reflect what was going on in other clinics or the experiences of couples in different settings. Further research is needed to encapsulate the experiences of diverse couples receiving provider-initiated couple HIV testing in other settings. More so, interviewing men and women who abandoned their spouses after testing would have provided more insight into factors underlying partner abandonment.

Despite these possible limitations, the findings could still be generalisable to similar settings and clinics that have adopted similar provider-initiated couple HIV testing strategies. What we have attempted to do is to draw on the deep, rich narratives of a small set of couples in order to elicit rich lived experiences of undergoing provider-initiated couple HIV testing to provide insights which can help policies and practices aimed at improving couple HIV testing.

5.5 Lessons for policy and practice

Our findings have implications for better delivery of couple HIV testing services. At policy level, couple HIV testing in antenatal clinics as part of PMTCT needs to be clearly and explicitly articulated within PMTCT protocol, and operational guidelines on how to implement it developed.This will ensure that at service delivery level, couple HIV testing is not conducted simply to meet PMTCT targets but to respond to the health needs of both men and women.

At service delivery level, while efforts to encourage couple HIV testing should be promoted, the 'opt-out' requirement needs to be well articulated to ensure that individuals' rights are respected and couples are given time and opportunity to reflect on the implications of HIV testing. Similarly, non-coercive strategies need to be adopted. Previous couple HIV testing programmes have shown than non-coercive strategies can successfully be implemented Mohlala, Boily & Gregson 2011; Lambdin et al. 2011; Wall et al. 2012). Second, even when couple HIV testing is promoted, during counselling sessions, service providers need to be sensitive to the experiences and fragility of marital relationships, including paying close attention to and addressing gendered power relationships. This is because couple HIV testing may be achieved at the expense of harmony in and stability of marital relationships. Third, since one of the primary aims of promoting couple HIV testing in antenatal clinics is to facilitate adoption of protective sexual behaviour (MoH 2010), counsellors should focus on improving the image of condoms within marriages during counselling sessions to facilitate their use. Fourth, couple participation in support groups should be encouraged and sustained. Efforts should also be made to encourage men to attend support group meetings including scheduling these meetings during weekends when men have time-off from their respective livelihood activities. Fifth, there is a need to make antenatal clinics more male-friendly, including recruiting and using male lay counsellors and nurses and possibly integrating some male health care services in antenatal clinics. This could make men feel comfortable and part of maternal and child health care services. Lastly, given the availability of antiretroviral therapy that significantly reduces the viral load and subsequent transmission of HIV (Castilla et al. 2005; Barreiro et al. 2006), closer professional support should be provided to concordant and discordant couples with childbearing ambitions.

5.6 Conclusions

While couple HIV testing is an important HIV prevention strategy, the way it is undertaken needs to be needs-based and beneficiary-responsive. Our study indicates that in its current form, couple HIV testing in antenatal clinic is coercive and subtle, thus undermining informed consent. Couple HIV testing also has negative effects including abandonment, mental abuse and cessation of sexual relationships in some cases. This was despite the enormous bio-medical and social benefits that included access and adherence to treatment and social support, and in some cases adoption of protective sexual behaviour. To build on these benefits, there is need to make couple HIV testing in antenatal settings less coercive, more male-friendly as well as being sensitive and responsive to gendered power relationships and fragility of marital relationships. The tension associated with balancing between HIV prevention and sexual intimacy and procreation amongst concordant and discordant couples needs to be mitigated by improving the image and use of condoms in marital relationships and providing continuous close medical support to HIV concordant or discordant couples with reproductive health aspirations.

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Authors’ contributions

MM conceptualized the study, did the data collection and analysis and drafted the manuscript. VB and SM contributed towards the conceptualization of the study, the analysis and interpretation of the findings and provided input in the drafting of the manuscript. All authors have given final approval of the version to be published.

Chapter 6

Deterrents to HIV-patient initiation of antiretroviral therapy in urban Lusaka, Zambia: A qualitative study[*]

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Abstract

Some people living with HIV (PLHIV) refuse to initiate antiretroviral therapy (ART) despite availability. Between March 2010 and September 2011, using a social ecological framework, we investigated barriers to ART initiation in Lusaka, Zambia. In-depth interviews were conducted with PLHIV who were offered treatment but declined (n=37), ART staff (n=5), faith healers (n=5), herbal medicine providers (n=5) and home-based care providers (n=5). One focus group discussion with lay HIV counselors and observations in the community and at an ART clinic were conducted. Interviews were audio-recorded, transcribed and translated, coded using Atlas ti and analyzed using latent content analysis. Lack of self-efficacy, negative perceptions of medication, desire for normalcy and fear of treatment-induced physical body changes, all modulated by feeling healthy, undermined treatment initiation. Social relationships generated and perpetuated these health and treatment beliefs. Long waiting times at ART clinics, concerns about long-term availability of treatment and taking strong medication amidst livelihood insecurity also dissuaded PLHIV from initiating treatment. PLHIV opted for herbal remedies and faith healing as alternatives to ART, with the former being regarded as effective as ART while the latter contributed to restoring normalcy through the promise of being healed. Barriers to treatment initiation were not mutually exclusive. Some coalesced to undermine treatment initiation. Ensuring patients initiate ART requires interventions at different levels, addressing in particular, people's health and treatment beliefs, changing perceptions about effectiveness of herbal remedies and faith healing, improving ART delivery to attenuate social and economic costs and allaying concerns about future non-availability of treatment.

6.0 Introduction

Despite the increasingly wider availability of antiretroviral therapy (ART), only an estimated 37% of people in sub-Saharan Africa (SSA) eligible for treatment were receiving it by end of 2009 (UNAIDS 2010a). One reason given for the low uptake of treatment has been low and inequitable coverage (UNAIDS 2010a). However, even where treatment is readily available, some people living with HIV (PLHIV) and eligible for medication have opted not to initiate treatment. Previous studies have attributed non-uptake of treatment to personal-level factors such as feeling healthy (Murphy 2010; Katz et al. 2011), low self-efficacy to be on life-long treatment (Maisels, Steinberg & Tobias 2001) and avoidance of being reminded of having HIV (Gold, Hinchy & Batrouney 2000; Beer et al. 2009). Interpersonal-level factors such as fear of stigma (Beer et al. 2009), treatment-related concerns such as drug toxicity (Gold & Ridge 2001) and side effects (Gold, Hinchy & Batrouney 2000; Gellaitry et al. 2005; Alfonso et al. 2006) also undermine treatment uptake. Health-system-related factors such as financial costs of accessing treatment (Zachariah et al. 2010), dissatisfaction with medical care (Beer et al. 2009; Garland et al. 2011) and beliefs about the effectiveness of faith healing (Beer et al. 2009; Wringe et al. 2009) and traditional medicine (Wringe et al. 2009; Murphy et al. 2010) also dissuade individuals from seeking treatment.

With HIV prevalence estimated at 14.3% in the Zambian population aged 15-49 years (CSO 2009) and an estimated HIV incidence of 1.6% (MoH 2010) Zambia is one of the countries in SSA worst hit by the pandemic. Since 2005, free ART services have been progressively rolled-out in public sector clinics resulting in a steady increase in the number of people on ART. However, not everyone eligible for treatment is receiving it. At the end of 2010, out of an estimated 503,284 adults and children in need of ART, only 68.4% were receiving it (NAC 2012).

While many studies have been conducted on barriers to patient initiation of ART, most of these studies have been conducted outside sub-Saharan Africa (SSA), the sub-continent worst hit by the HIV pandemic. In Zambia, these studies have comprised: a quantitative study (Fox et al. 2010); a sub-study of a clinic-based HIV prevention programme (Murray et al. 2009; and a qualitative study conducted during the early years of ART roll-out (Grant et al. 2008). The reported barriers to patient-initiation of ART have included financial and logistical costs (Fox et al. 2010; Grant et al. 2008), negative perceptions of medication (Fox et al. 2010; Murray et al.

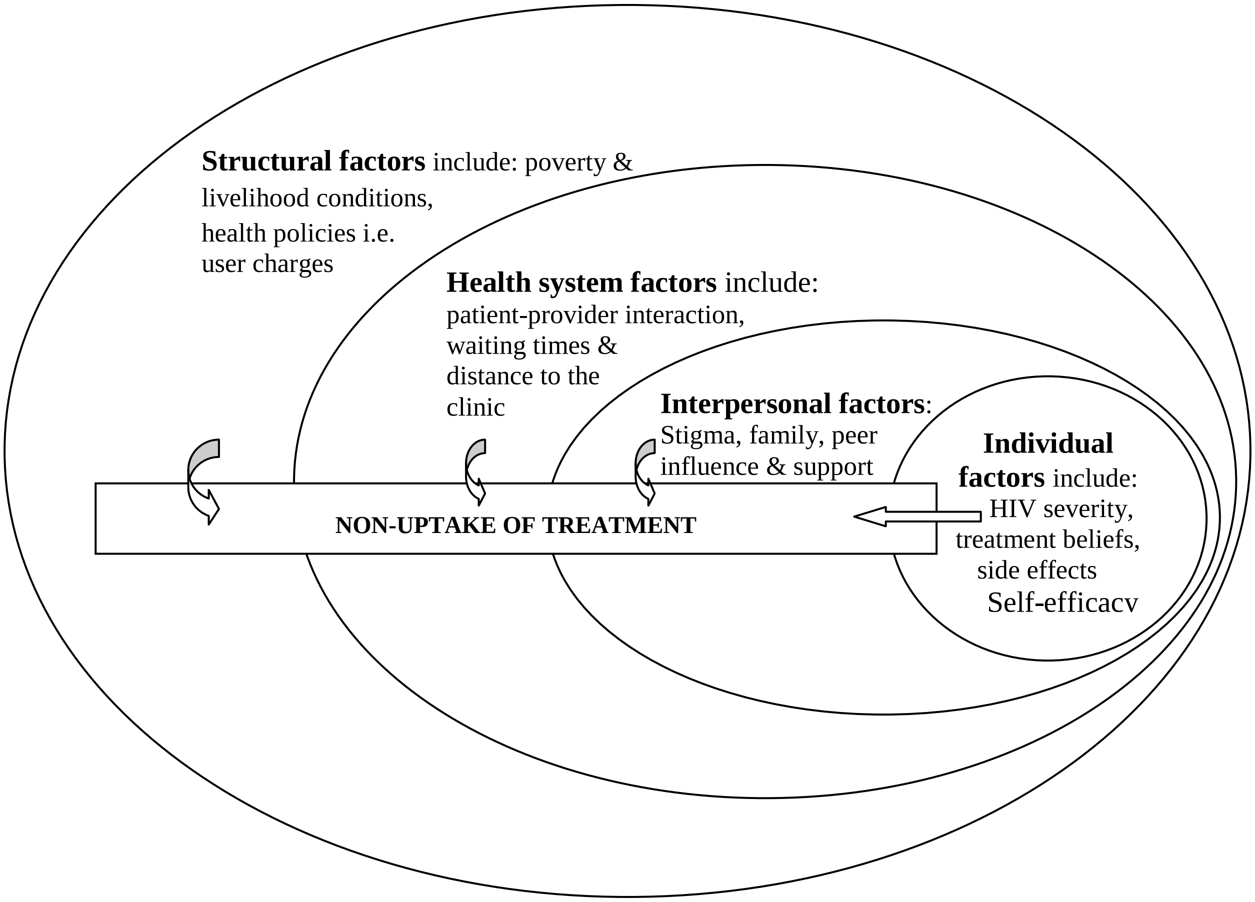
2009), fear of stigma (Murray et al. 2009; Simpson 2009) and fear of involuntary disclosure and straining marital relationships (Murray et al. 2009). In view of the steady roll-out of free life-saving antiretroviral medication in many countries and the drive towards universal access, more studies on non-uptake of treatment have become more critical to inform successful delivery of ART services. To corroborate previous evidence and to add to the body of evidence, we used the social-ecological framework (Latkin & Knowlton 2005; Roura et al. 2009; Musheke, Bond & Merten 2012) to investigate the different-level factors hindering HIV-patient initiation of HIV treatment.

6.1 Analytical framework: Social ecological framework

The social ecological framework provides a comprehensive approach for exploring and encapsulating the wide ranging individual and non-individual level factors that dissuade individuals from initiating treatment, including how they are linked. The social ecological framework positions health-seeking behaviour in a ‘social ecology’ (Roura et al. 2009) in which treatment-seeking behaviour is influenced not only by personal factors but also by interpersonal, health system and structural-level factors, all embedded in this ‘social ecology’ (Figure 6-1). The framework bridges the divide between “individualist” and “structuralist” models of health-seeking behaviour by treating both paradigms as complementary and lying on the same continuum (Roura et al. 2009). Human behaviour is therefore construed not as something that exclusively resides in the individual but also a reflection of wider interactive dynamic processes in the social environment (Latkin & Knowlton 2005; Roura et al. 2009; Musheke, Bond & Merten 2012).

Based on previous studies on non-uptake of treatment (Gold, Hinchy & Batrouney 2000; Gold & Ridge 2001; Maisels et al. 2001; Unge et al. 2008; Murray et al. 2009; Roura et al. 2009; Beer et al. 2009; Wringe et al. 2009; Zachariah et al. 2010; Duff et al. 2010; Fox et al. 2010; Skovdal et al. 2011; Unge et al. 2011), we developed a schema of the social-ecological framework that depicts the different-level factors that undermine patient uptake of treatment (Figure 6-1). At individual level, personal characteristics such as perceived disease severity, illness and wellness interpretations and treatment beliefs inhibit uptake of treatment (Musheke, Bond & Merten 2012). The social ecological framework also shows that treatment-seeking behaviour is generated and perpetuated through socially structured interactions (Latkin & Knowlton 2005), which are sometimes deeply engendered (Skovdal et al. 2011b). These social relationships serve as a source of information, influence, experience (Musheke, Bond & Merten 2012) and social and economic support (Van Servellen & Lombardi 2005; Roura et al. 2009; Merten et al. 2010), which in turn impacts on treatment-seeking behaviour.

Figure 6-1 Social ecological framework of non-uptake of HIV treatment



Treatment-seeking behaviour is also influenced by the way health services are provided (Musheke, Bond & Merten 2012). Even when individuals are motivated to seek treatment, studies have shown that health system constraints like long waiting times (Roura et al. 2009; Musheke, Bond & Merten 2012), costs of accessing treatment due to distance to the treatment centres (Roura et al. 2009; Zachariah et al. 2010) and poor patient-provider interactions (Duff et al. 2010; Musheke, Bond & Merten 2012) dissuade individuals from seeking treatment. At the wider society level, structural-level factors - barriers that lie outside the direct control and influence of the individual (Roura et al. 2009; Musheke, Bond & Merten 2012) also undermine uptake of treatment. These include health policies such as charging user fees (Grant et al. 2008) and poverty and livelihood circumstances (Unge et al. 2008; Fox et al. 2010). As a result, based on their health and treatment beliefs as well as social influences, some individuals opt for herbal medication and faith healing (Unge et al. 2011).

The data collection and analysis was therefore guided by these different multi-level categorizations that underpin the social-ecological framework in order to gain in-depth insights into the different factors that undermine patient uptake of antiretroviral treatment.

6.2 Methods

6.2.1 Study setting

The study was conducted in a low-income, high-density residential area of Lusaka, Zambia. The majority of the residents are poor, eking out a living in the informal sector, mainly selling fruits, vegetables, meat products, charcoal and second-hand clothes in the city centre markets or in the open-air local markets. Small makeshift shops, locally called *'tuntemba'*, are ubiquitous – scattered along the dusty roads, in the local markets or next to homes. A few residents are in formal employment in the public and private sectors of the economy. Some youth earn their income by doing daily piece-works as construction workers in the neighbouring communities. Others work as taxi, bus and truck drivers. Most days, many of these informal sector workers set off for livelihood activities early morning and return home late in the evening. Unemployment is endemic, not only amongst youth but also amongst the old, many of whom lost their jobs during the economic reforms of the 1990s. Some of the unemployed, more especially the youth, have had little formal education and spend time patronizing the bars and drinking places. These places provide opportunities for girls and young women to engage in transactional sexual relationships.

Christianity is the predominant religion. The United Church of Zambia (UCZ), Roman Catholic Church, New Apostolic Church and the Seventh-Day Adventist Church (SDA) are the mainstream churches. Since the official declaration of Zambia as a Christian in the 1990s, there has been an exponential increase in the number of Pentecostal churches in Zambia, some of which profess faith healing for health problems, including HIV.

Since 2006, a public sector clinic based in the study area has been providing free ART services. The clinic services a catchment population of over 150,000 people. By mid-2010, the clinic had more than 5,000 people on ART and more than 5,000 on pre-ART. The ART clinic attends to more than 100 patients (old and new) per day. Other HIV-related services in the area such as

HIV testing, male circumcision and reproductive health services are complemented by local and international non-governmental organisations. In parallel with the formal health system, traditional healers and herbalists abound, some claiming to provide herbal remedies that 'boost' the immune system of PLHIV. Home-based care providers either affiliated to local non-governmental organisations or churches provide psychosocial, treatment and spiritual support to PLHIV and their families.

6.2.3 Study procedures

This was an exploratory, community-based qualitative study. This study design was suitable for identifying and eliciting in-depth insights into factors hindering uptake of treatment. Due to the difficulties of identifying PLHIV eligible for but not on ART, a three-pronged purposive sampling strategy was employed. Some PLHIV who had been initiated on but opted not to start ART were identified, contacted and recruited through ART staff of a public-sector clinic located in the study area. Others were contacted and recruited through their lay home-based care providers. Also, because some of the PLHIV had formed social networks, using snowball sampling, each PLHIV interviewed was asked to nominate and contact on behalf of the researchers individuals they knew were eligible for ART but had opted not to start treatment. In all instances, only PLHIV that agreed to be interviewed were later contacted and appointments made for interviews. Living in the study area for an extended period of time (18 months), helped the researcher (first author) to win the trust and confidence of these PLHIV thereby enabling them to open up and share their perspectives for not starting treatment.

6.2.4 Data collection and analysis

Data was collected between March 2010 and September 2011. Three data collection methods were employed. In-depth, audio-recorded, open-ended interviews were held with PLHIV (n=37); ART staff (n=5); religious leaders (n=5); home-based caregivers (n=5) and herbal medicine providers (n=5). Some PLHIV were contacted again and re-interviewed during the study period. The main initial question asked to PLHIV was: 'would you explain why you decided not to start treatment?' Data on the demographic characteristics and livelihood conditions of the PLHIV was also collected. Key informants were asked: 'why do PLHIV eligible for treatment opt not to start medication?' Interviews with clinic staff and religious leaders were conducted in English while interviews with PLHIV, herbal medicine providers and home-based caregivers were mostly conducted in the local language, *Nyanja*. One focus group discussion was conducted with voluntary counselling and testing (VCT) staff (n=10) of the local public sector clinic to elicit their perspectives on PLHIV reluctance to initiate treatment.

Structured observations were conducted at the local ART clinic and in the community. Sit-in observations at the ART clinic aimed at gaining insights into inter alia, patient-provider relationships, waiting times and patient beliefs about and experiences of being on treatment. Observations in the community included conducting transect walks, attending social events and religious/church meetings. They were aimed at understanding social relationships and ties, lifestyle activities, livelihood activities of the people, identifying health care providers located in the community and gaining insights into 'lay talks' about HIV treatment and informal health care services.

The use of different data collection methods helped gather in-depth data as well as triangulate the data collected. Data collection and preliminary data analysis were cyclical: preliminary data analysis informed ensuing interviews and data collection was ended when no new insight emerged from the interviews.

The interviews conducted in the local language (*Nyanja*) were translated, and all interviews were transcribed verbatim. Latent content analysis[29] was used to analyse and interpret the data. All interview and focus group discussion transcripts and observational field notes constituted our unit of analysis. Unit of analysis refers to all words and phrases of the interview transcripts and written field notes.[29] These were read several times to create a sense of the whole data.[29,30] Atlas ti version 6 was used to organise, manage and code the data. The interview transcripts and field notes were coded, and the codes compared for similarities and differences, and then grouped into categories on a manifest level. Themes were then generated by interpreting the categories for their underlying meaning. In line with the analytical framework, the themes for non-uptake of treatment are presented as individual-level, interpersonal, health-system and structural-level factors. For instance, codes such as feeling healthy, lack of self-efficacy, fear of treatment-induced body changes and perceptions of HIV medication as poisonous and harmful were categorised as individual-level factors. Collectively, these were thematically interpreted as perceptions and experiences of health and treatment.

6.2.5 Protection of research participants

Ethical approval was granted by the Ethics Committee in Basel (Ethik-Kommission beider Basel) and the University of Zambia Humanities and Social Sciences Research Ethics Committee as part of the research study ‘Improving equity of access to HIV care and treatment in Zambia.’ Administrative clearance was also obtained from the Ministry of Health at national and district levels. Written informed consent was obtained from all research participants. To ensure confidentiality and avoid involuntary disclosure of their HIV status, most of the PLHIV were interviewed at neutral locations such as at the local health facility, homes of respondents’ friends and at respondents’ local churches. Some PLHIV preferred to be interviewed at home. To protect the identity of respondents, all identifying information was excluded from the interview transcripts.

6.3 Results

Characteristics of PLHIV not on ART

The majority of the respondents (n=24) were women, almost half (n=18) were aged between 25-34 years old and the oldest was a married woman aged 51 years old. More than two-thirds (n=27) made a living in the informal sector. Almost two-thirds (n=21) had known their HIV status for at least two years and more than two-thirds (n=27) had not been on ART for between six months and two years (Table 6-1).

Reasons for declining ART

Using the social ecological conceptualisation, factors inhibiting patient uptake of HIV treatment are subsumed as individual, interpersonal, health system and structural factors.

Table 6-1 Characteristics of PLHIV not on ART

Characteristic	No. of PLHIV (n=37)
Age (Years)	
18-24	4
25-34	18
35-44	14
>44	1
Sex	
Male	13
Female	24
Marital status	
Single	5
Married	22
Divorced/separated	6
Widowed	4
Source of livelihood	
Formal employment	5
Informal employment	27
Not working/dependant	5
Duration of knowing HIV status	
6-<12 months	5
1-<2 years	11
2-<3 years	6
3-<4 years	4
4-<5 years	2
≥ 5 years	9
Length of time not on ART	
6-<12 months	17
1-<2 years	10
2-<3 years	6
≥ 3 years	4

Individual-level factors: Perceptions and experiences of health and treatment

Feeling healthy

Individual experience of health was found to heavily influence uptake of treatment. Despite acknowledging being infected, some PLHIV nonetheless assessed their eligibility for treatment not in terms of their immune system as clinically defined through CD4 cell count and viral load but in terms of their subjective experiences of their corporeal health. The absence of severe physical symptoms and the lack of negative impact of HIV infection on their productive and social lives dissuaded them from starting treatment. Normalcy was maintained as long as possible, as one PLHIV explained:

> "*For me, I am living a normal life; I am not experiencing any problems. My life is just normal, not until it hits in, you know what I mean, not until it really becomes worse. So, I do not think the medicine will make any difference right now*." (23-year old man)

Feeling healthy also made a few PHIV express doubt about their HIV status. For a few women, lack of symptoms and giving birth to an HIV-negative child without taking medication for prevention of mother-to-child transmission of HIV (PMTCT) fed into doubts about the validity of the HIV test results.

Lack of self-efficacy

Perceived inability to be on life-long treatment discouraged some PLHIV from starting medication. They felt that they would not manage to adhere to life-long treatment. Others expressed reluctance to adjust their social lifestyles particularly stopping alcohol consumption as advised by treatment counsellors. As one lay ART support worker explained:

> "*Some, it is because of beer, especially men, what I have seen is that it is common. You find that when they are told that you cannot mix beer and medication, they really find it hard because they think they cannot do away with beer. So they do not want to start medication."* (37-year old ART adherence counsellor)

Fear of treatment-induced body changes

While some PLHIV acknowledged the value of treatment, side effects including treatment-induced body changes inhibited its uptake. Most PLHIV, especially women, gave accounts of how ART had irreversibly made the body shapes of their spouses, friends and relatives "structure-less" or "deformed" and these experiences dissuaded them from initiating treatment. Some were fearful that this could ignite stigma, alter their social relationships or reducing their chances of finding marital partners. The commonly mentioned bodily changes were breast enlargement, abdominal fat accumulation, skin pigmentation, and muscle wasting in the face, arms and legs. As one PLHIV illustrated:

> "*Like my husband when he started, he was taking Triomune 30. He was slimming and slimming, and even this time when you look at him, his legs are very thin, not the way he was at first. Even my sister-in- law, she had a very nice body but when she just started treatment,*

> *her breast grew big, her stomach bulged.... It changes the structure of the body, you become structure-less.*" (32-year old woman)

Perception of HIV medication as poisonous and harmful

Related to concerns about side effects and treatment-induced body changes, some PLHIV perceived ART as poisonous and harmful. While they acknowledged witnessing a trajectory of improved health in other PLHIV after starting treatment, they also viewed HIV medication as harmful and insidiously inflicting bodily harm, sometimes leading to death in unexplained circumstances. While some PLHIV may have died on account of starting treatment late, some PLHIV attributed their death to the treatment itself. Two excerpts below illustrate these concerns:

> "*The ARVs kill very slowly. Your body looks healthy, but inside, the ARVs are eating, eating up your body. Then next, you just develop small sickness and then die. Can't you say it is the ARVs that have killed that person? The problem is that with ARVs, you look very healthy, but you do not know what the ARVs are doing in your body*." (30-year old man)

> "*You know what happened is that I had my late sister, second born in our family. Up to now, I still believe that it is the ARVs that killed her because before she started treatment, yes she used to complain about her health here and there, but when she just started treatment, a week never elapsed and she died, only after 3 or 4 days of starting treatment*." (27-year old man)

Interpersonal-level factors: Social exclusion and social network influence and experience

Treatment-induced stigma

At social relational level, fear of stigma either within the family or at community level dominated the thoughts of some PLHIV. They feared that being seen at the ART clinic or experiencing treatment-induced body changes would creating visibility of their HIV status and consequently attract stigma:

> "*Like me, my relatives do not know that I am HIV positive. My fear is that if I start treatment, they will know. You know even in the families, not everyone has knowledge about HIV and treatment. Stigma is there in the homes."* (39-year old married woman)

> “*For a kind of body like mine, if you gain weight, people would start suspecting. So to avoid people talking, to avoid people discriminating against you, I think it is better to live without the medicine.”* (24-year old man)

Family influence

Non-uptake of treatment was further modulated by family influence. Family members and friends not only served as sources of information about ART but also imposed their health beliefs and wielded influence, and sometimes power, on treatment-seeking behavior. Many of our research participants gave accounts of how friends and family members had encouraged them to take herbal remedies or go for faith healing instead of ART. One young woman explained her experience:

> “*My mother told me that I should just be going to church for prayers. So that is how I started going for prayers…. So, when I was prayed for, I went to the clinic to re-test to find out if truly I had been healed. So when I was tested, I was told that I was still HIV positive. I never believed this and my mother was very cross with me. She accused me of lacking faith and explained that, that was also the reason why I was not getting healed*.” (24-year old woman)

The family influence could also be directed from the children to the parents. An elderly PLHIV died on account of having declined to start treatment following the wish of his children. A lay home-based care provider narrated the experience of his deceased client:

> “*There is one man in the area, one of my clients. We approached him and counseled him and he was ready to start treatment. When he told his children about it, the children followed us up and told us to keep away. They said that they go for prayers and there is no need for their father to go to the clinic and start medication. So that is how we gave up and a few months later, we just heard that the man had passed away…. If the man had started treatment, he could have been alive up to this day*.”

Peer influence

Similarly, for some PLHIV, observing friends continue living ‘healthy’ and ‘normal’ lives without recourse to treatment further convinced them not to start treatment. Within friendship circles, PLHIV reportedly discussed ART and these discussions often centered on the negative effects of treatment, including being a drug ‘addict’. As one man succinctly put it:

> "*You find that sometimes in social gatherings, you talk about some of these things. Others would say the drugs are not good for your health, others would say once you start treatment, you become like an addict; you cannot stop the medication, and if you do, you die. Some people would say the drugs have very, very bad side effects; very difficult to deal with. That you see a person becoming fat, not that normal way of gaining weight*." (27-year old man)

Structural-level Factors: Livelihood constraints and sustainability of HIV treatment

Food insecurity – "...the drugs will just kill me"

Most of the PLHIV interviewed reported lacking an adequate and steady income and came from food insecure households. This dissuaded them from starting treatment. Some respondents reported more than one household member and sometimes multiple generations of family members on treatment or diagnosed with HIV. Given the food and nutritional demands associated with being on antiretroviral treatment, some PLHIV suspended initiating treatment until their livelihood conditions had improved. Two respondents who suspended starting treatment narrated their exasperating situation:

> "*I was wondering how I was going to manage to take the medication; I do not have a good job and steady income; I do not have a good diet; so how am I going to manage those drugs? My husband is on treatment and he is not working; the little money that we make have to be spent on him to improve his nutritional status. So, I said I will not start now."* (51-year old married woman)

> "*The other problem is that once you start treatment, you need to have good nutritional foods to accompany the medication and for the medication to work well in the body. But for us, we do not have good jobs, and sometimes the whole day goes without selling anything [earning an income] and that creates problems in terms of having enough food to eat*." (30-year old man)

Future availability of treatment

A few PLHIV expressed doubts about long-term availability of treatment. These fears were reinforced by reported intermittent shortages and rationing of drugs in public sector clinics and reported pronouncements by Zambian government officials about challenges of keeping people on long-term treatment. Aware that HIV drug supplies were heavily funded by external support and harboring doubts about government's ability to fund treatment with local resources, some PLHIV opted not to take the risk of starting treatment. One PLHIV illuminated this concern:

> "*Even these days when you are listening to the news, the Minister of Health was saying that the way HIV is going, in future, the government might even fail to provide these ARVs....These drugs, we are told that if you stop for some time, it is a problem. Imagine the government just tells us that there is a shortage of ARVs, then what happens?"* (42-year old woman)

Programme-level factors: Health system constraints and availability of alternative therapy

Quality of ART care

Even for those eager to start ART, the way treatment services were being delivered dissuaded PLHIV from initiating treatment. Health facilities had to cope with an enormous number of patients and lacked the resources and time to adequately attend to patients. For PLHIV not on ART, congestion and long waiting times at ART clinics were seen as imposing inordinate social and opportunity costs. The social costs included involuntary disclosure of HIV status while seeking care meant suspending livelihood activities. Therefore, the incentive to start treatment especially when PLHIV still felt 'healthy' diminished:

> "*Truly speaking, it is not because of ignorance; it is not that we do not know the good things that the ARVs can do to us. The problem is because of the services....The process is so long*." (27-year old man)

> "*The thing they are also complaining about is that they come here at 05 hours but leave at 16 hours. That day when they are coming to get their ARVs, their day's programmes are all shattered. Right now, if you have to look at the defaulter rate, it is also growing. There are people who even say that 'if I had money, I would go and look for alternative treatment instead of spending time at the clinic.*'"(ART support worker)

In view of the perceived disadvantages of initiating treatment, there are also alternatives to ART that may seem more attractive. These serve as pull-factors from seeking ART care:

Herbal treatment

In the quest to maintain their health in the absence of ART, all the PLHIV interviewed reported using herbal remedies, sometimes at great financial cost. The most commonly used herbal remedies were *moringa*, *aloe vera* gel (also locally available in plant form called *tembusha*), ginger, garlic and Chinese herbal remedies. While some of the herbs were bought from the drug stores and mobile herbal medicine traders, some PLHIV reported locally growing some of these herbs (particularly *tembusha*) thus ensuring easy and unfettered access to 'treatment'. A local herbal medicine provider sold aloe vera gel for ZMK150 (US$30) for one litre container. Some PLHIV reported being financially supported by other family members to purchase these herbal remedies. Ironically, some ART staff with HIV also reported opting for herbal remedies instead of ART:

> "*When they told me that my CD4 count was low, I just started using herbs like moringa, mojic and after that, my CD4 count improved a bit up to 460 something*." (32-year old woman - PMTCT support worker, not on ART)

Faith healing

Some PLHIV also opted for faith healing. Some church Pastors either from within or outside the study area conducted healing sessions. One local church held healing sessions every Wednesday and Thursday afternoon while another church conducted healing sessions every Saturday. Sometimes open-air inter-denominational prayer sessions for 'healing and deliverance' were conducted and people moved across Christian denominations for healing. Observations in selected churches revealed some Pastors openly preaching about God's power to cure any disease, including AIDS, and some PLHIV gave testimonies of how God had 'cured' them of HIV. One old woman challenged her fellow church members to always look up to God for help. In our ensuing interview, she explained:

> "*God heals, if you just have faith in Him....It is by faith; God can do anything, the miracles are there, so it is up to you as an individual*." (50-year old woman)

Some PLHIV with financial means reported travelling outside Zambia, to South Africa or Nigeria, at great financial cost for healing sessions while others bought 'anointing water' (spiritual water purported to have healing properties) from their respective churches. One respondent who had travelled to Nigeria for prayers bought a 100 mls bottle of ‘anointing water’ for US$100. Droplets of this anointing water were either added to drinking water, sprinkled on food or swallowed in the mouth. Ironically, even some ART support workers with HIV opted for faith healing instead of initiating ART. One PLHIV explained:

> “*They told me to start treatment but then I was about to go to South Africa for prayers with my husband....There, we were taught how to receive healing. We were learning about how to have faith, and how to receive healing....When I came back, I went to the clinic to check my CD4 cell count and it had been boosted; from 165 to 365. So that is it.”* (37-year old female ART support worker)

While some PLHIV who went for faith healing never re-tested to confirm their ‘new’ status, a few did. However, re-testing and still being found HIV positive did not lead to uptake of treatment:

> “*There is this woman also who after testing HIV positive, she decided to go and consult a Pastor. The Pastor took her into the mountains for some days for prayers and fasting for healing. After that, the woman came back here and said she had tested positive but had gone for prayers….We re-tested her and even told her how to read the results. The results still came out positive. She left without saying a word.”* (FGD, VCT lay counsellors)

Although patient-reported benefits of ART appeared to contradict their reasons for not initiating treatment, these conflicting viewpoints intersected. For instance, while reluctance to start treatment was due to fear of side effects and perceived deleterious effects and concerns about future availability of treatment, PLHIV still reported willingness to start treatment if their health deteriorated. However, the use of herbal remedies and conventional non-HIV medication to mitigate HIV-related symptoms reduced the motivation to initiate treatment. One PLHIV explained:

> “*Yes, I have seen that some people that were very sick are now doing fine but those drugs, ARVs, are also bad for the body. That is why at the clinic, people do laboratory tests to find out how the drugs are destroying their bodies, like the liver. Me, I will only start when I feel that the sickness is more problematic now. For now, I just take herbs*.” (29-year old man)

6.4 Discussion

In our study of reasons for non-uptake of ART in an urban area of Lusaka, Zambia, several factors that undermined PLHIV uptake of ART were identified: subjective perceptions and experiences of health and treatment; stigma, peer and family influence and experience; livelihood constraints and concerns about future availability of treatment; and ART delivery constraints and availability of alternative care. While the majority of the respondents were women, our findings suggest that the barriers to patient uptake of treatment were similar across men and women. From these findings, the following insights can be deciphered:

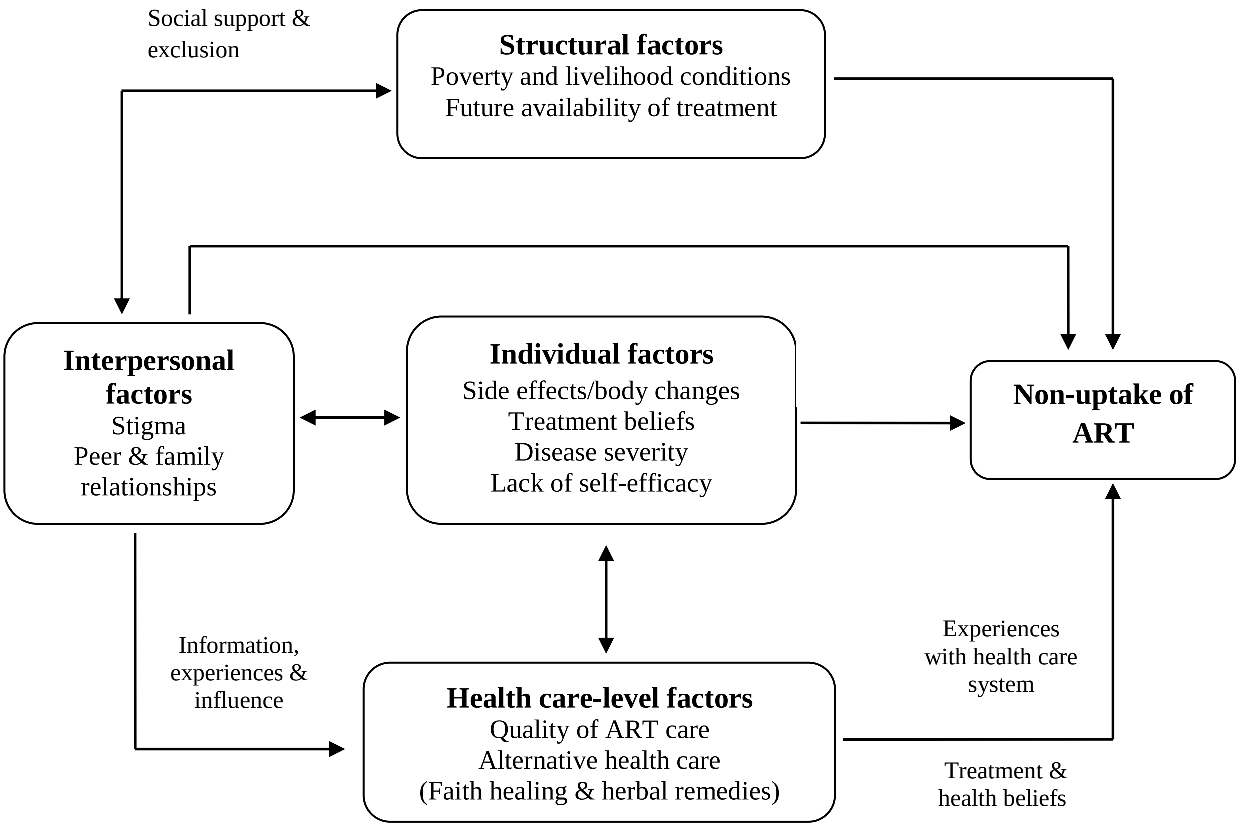
PLHIV measure their health in terms of functional ability and not clinical condition

Our study found that lay experience of health and treatment negatively affect treatment-seeking behavior. Individuals assess and perceive their health not only in terms of their clinical health condition as reported by their health care providers; rather, in terms of their corporeal health and functional ability (McKague & Verhoef 2003) - being able to live 'normal' and 'healthy' lives and engage in productive activities and social lifestyles without recourse to treatment. The findings are consistent with other studies which showed that individuals understood illness in terms of feeling sick and therefore never sought treatment when asymptomatic (Siegel & Gorey 1997; Beer et al. 2009). These findings suggest that PLHIV are not passive recipients of ART care. They act as 'naïve scientists' (Sigel, Schrimshaw & Dean 1999) and use 'lay logic and reasoning' (Lumme-Sandt, Hervonen & Jylha 2000) as a basis of deciding whether to initiate treatment or not. These lay assessments lead to delays to initiate ART and undermine recent HIV treatment policy changes which stipulate treatment initiation at higher CD4 cell count (from <200 cells/mm^3 to ≤350 cells/mm^3) to reduce AIDS-related mortality and morbidity (MoH 2010; WHO 2010). They also cast doubt about the viability of universal testing and immediate treatment as a way of reducing HIV incidence (Granich et al. 2009).

Quest to protect normalcy and social identity undermine uptake of treatment

While ART is crucial for long-term survival and its efficacy is indisputable, the assumption that individuals would prioritise treatment because of the associated bio-medical benefits is not always the case. This is because, as our findings show, taking medication is a 'meaning-filled subjective expression' (Wong & Ussher 2008) and individuals conduct 'cost-benefit analyses' (Rier & Indyk 2006) of medicine-taking and treatment can be shunned if perceived to have negative impact on social image, social relationships and social aspirations. Therefore, PLHIV avoid actions that would expose them as having HIV especially if uptake of treatment threatens their social and economic networks or alters their lifestyles and aspirations. This explains why despite treatment being available, some PLHIV opted not to take it. Our findings mirror previous studies that have reported that some PLHIV did not initiate treatment because they did not want to be identified as having HIV (Barton et al. 2000; Skovdal et al. 2011).

Figure 6-2 Nested relationships of factors influencing non-uptake of treatment



Perceived long-term negative effects of treatment inhibits its uptake

The findings also suggest that uptake of treatment is undermined by perceived impact of medication on physical and physiological wellbeing. In our study, PLHIV did not want to start treatment because of the perceived toxicity of treatment. Interestingly, some PLHIV were concerned about the effects of treatment on their body shape. They were fearful of their bodies being ‘structure-less’, ‘deformed’ or ‘disfigured’ due to ART. For some PLHIV, physical changes to their bodies could limit their chances of finding marital partners. Also, there was a strong perception that despite improving corporeal health, the medication did more harm to the body in the long term. Previous studies have also found that PLHIV opted not to start treatment because side effects and drug toxicity were perceived as a threat to their physical and psychological wellbeing (Gold, Hinchy & Batrouney 2000; Maisels, Steinberg & Tobias 2001; Gold & Ridge 2001). In our study, PLHIV drew on the negative experiences of close family members or friends and their death or declining health led them to conclude that treatment had deleterious effects and was insidiously harmful.

PLHIV regard food security as pre-requisite for treatment uptake

Even when individuals are willing to start treatment, the findings suggest that its uptake requires navigating and overcoming broader structural-level factors. Structural factors are those non-individual based circumstances present in the environment that influence health-seeking behavior but over which the individual has no direct control (Parker, Easton & Klein 2000; Munro et al. 2007). These comprise the economic, social, policy, organisational or other aspects of the environment (Surmatojo 2000). Although health system-level factors may be subsumed under structural-level factors, we have separated wider-level structural factors from health system-level factors in order to facilitate analysis and identify interventions that could specifically be aimed at addressing health system-level constraints (Munro et al. 2007).

Previous studies have implicated economic-related barriers as influencing patient uptake of treatment (Hardon et al. 2007; Roura et al. 2009; Zachariah et al. 2010; Fox et al. 2010; Duff et al. 2010; Chileshe & Bond 2010; Tuller et al. 2010). In our study, it was neither the transport costs of accessing treatment nor the cost of medication that inhibited uptake of treatment because ART services were free and the health facility was conveniently located within the study area. Instead, inadequate income and household food insecurity dissuaded PLHIV from starting treatment due to the nutritional demands of being on treatment. Consistent with the findings of Unge and colleagues (2008), due to livelihood constraints, some PLHIV were often scared of taking strong HIV medication on an empty stomach as this was viewed as inimical to the effectiveness of treatment and their long-term health. They opted to postpone starting treatment until their livelihood conditions had improved.

Lack of trust in government and health system also undermine access to treatment

Structural conditions also entail national health policies related to funding and delivery of ART care. While ART has become widely available in many resource-limited settings like Zambia, our study found that the downside was the lack of trust in government's ability to sustain provision of treatment in the long-term in the absence of external support. Interestingly, for some of our research participants, the heavy reliance on donor support created anxiety about future availability of treatment.

These concerns need to be contextualised. Zambia is heavily reliant on external funding for HIV services (NAC 2010). About 85% of HIV interventions are funded by external support agencies with the Presidential Emergency Plan for AIDS Relief (PEPFAR) of the United States of America being the major contributor (NAC 2012). Therefore, any disruptions in the funding and supply of medication undermine people's confidence in government's ability to provide HIV treatment and care. For instance, the alleged embezzlement of donor funds at the Zambian Ministry of Health and the subsequent freezing of donor support by Global Fund to fight AIDS, Tuberculosis and Malaria (GAFTM) and other bilateral donors in 2010 which in turn led to periodic stock-outs and rationing of drugs (IRIN Plus News, 14th March 2010) exposed the fragility of the HIV treatment programme in Zambia. As UNAIDS Executive Director Michel Sidibe recently warned, the heavy reliance on external funding by countries heavily affected by HIV was "a source of great risk and potential instability. The status quo cannot be sustained." (Post Newspaper, 30th January 2012)." For some PLHIV, this unpredictability and fragility of treatment supply casts serious aspersions about future availability of treatment. Therefore, not starting treatment was construed as a rational individual strategy to avoid future negative health outcomes associated with discontinuation of treatment on account of its possible non-availability.

Faith healing and herbal remedies also reflect dissatisfaction with formal health care

Various studies have described the impact of faith healing (Berhanu 2010; Tocco 2010; Togarasei 2010; Balogun 2010) and herbal remedies (Morris 2001; Banda et al. 2007; Unge et al. 2011) on uptake of ART. Consistent with these findings and unlike previous studies conducted in Zambia (Grant et al. 2008; Murray et al. 2009; Fox et al. 2010), the use of faith healing and herbal remedies were found to be prevalent in our study. Our findings suggest that opting for faith healing and herbal remedies was not based on ignorance of the benefits of antiretroviral treatment. Neither was it solely a reflection of individual health beliefs. Rather, it was also a response to dissatisfaction with the formal health care and perceived shortcomings of ART. Concerns about treatment side effects and toxicity, worries about sustainability of treatment in addition to perceived low self-efficacy to be on life-long treatment resulted in individuals opting for herbal remedies and faith healing.

Interestingly and unlike previous studies, our findings suggest that factors undermining uptake of HIV treatment are inextricably linked and sometimes coalesce to affect treatment-seeking behavior (Figure 6-2). For instance, while livelihood constraints such as food insecurity (structural factor) dissuades individuals from starting treatment, long waiting times at ART clinics (health system factor) also create opportunity costs which exacerbate already fragile livelihood conditions thus reducing the motivation to initiate treatment. Similarly, opting for alternative care (herbal remedies and faith healing) is as much a result of concerns about future availability of treatment (structural factor) as much as it is about fear of side effects and lack of self-efficacy (individual-level factors).We may also subsume the plethora of alternative treatments in view of a weak health system, but its use is shaped by individual treatment beliefs, which are perpetuated in social relationships with peers, family members, faith healers and traditional medicine providers who not only exert influence but also provide information and share experiences (Figure 6-2).

Implications for policy and practice

At policy level, there is need for increased funding for HIV treatment from local resources rather than heavy reliance on external support. This would help build confidence in local capacity to deliver HIV treatment and assuage fears about future non-availability of treatment. Pronouncements by Zambian government officials to establish a national health fund to help hedge against unpredictable external financial support particularly for HIV treatment are a step in the right direction. Additionally, at global and national levels, efforts should be made to assess the therapeutic benefits of herbal medication and authorise and regulate those found to have therapeutic value without undermining access to and effectiveness of ART. As the World Health Organisation (WHO) noted more than two decades ago, there is need "...to evaluate those elements of traditional medicine, particularly medicinal plants and other natural products, that might yield effective and affordable therapeutic agents" (WHO 1989, p.613). Such efforts to identify and promote certain herbal remedies should be counter-balanced by strong regulatory measures to avert proliferation of fake herbal medication.

The fragile food security situation of some PLHIV clearly demonstrates the impact of poverty on access to health care. As previously noted elsewhere (Fox et al. 2010), while provision of food aid to vulnerable PLHIV may enable them initiate treatment, this could be difficult to sustain in the long-term due to the costs of providing such support in a poverty-endemic setting where access to formal social welfare programmes is very limited. Instead, funding for HIV should also prioritise livelihood empowerment programmes for economically disadvantaged people living with HIV.

At service delivery level, efforts to improve uptake of ART should comprise close, open rapport between HIV testing/ART service providers and service users, and general sensitisation campaigns, to ensure that (potential) HIV service users' negative health and treatment beliefs are identified, understood and addressed. This also entails treating (potential) service users not merely as passive recipients of HIV information and services; rather as active agents and co-producers of good health outcomes. Attention should also focus on building confidence, self-esteem and positive body image of PLHIV in the face of treatment-related side effects. Equally, focus should be placed on sensitisation campaigns on the benefits of early initiation of treatment and dispel beliefs about perceived effectiveness of herbal remedies in the absence of scientific proof. Individuals that have sought faith healing should be encouraged to re-test for HIV. Additionally, sensitisation campaigns should also target faith healers and herbalists about the benefits of ART and the dangers of unproven healing practices. As many people get onto treatment, there is also need for increased manpower in the ART clinics and adoption of longer, flexible clinic hours to avoid congestions and long waiting hours to help attenuate possible opportunity costs associated with seeking ART care. This has policy implications as it requires increased funding for additional health workers.

Possible limitations of the study

Some PLHIV were recruited in the community through their caregivers or snowball sampling and their eligibility for the study was based on self-reports of being eligible for treatment. Consequently, this recruitment strategy could have led to some clustering of shared ideas and views. However, more than three-quarters of our study participants were identified, contacted and recruited through the ART clinic. The clinic staff were aware of which individuals had declined ART despite it being recommended to them suggesting that our sample largely comprised treatment-eligible PLHIV who were independent from each other. Also, more women than men were recruited due to the difficulties of recruiting men for the study. The reasons included: some men refused to be interviewed; many were mobile due to their livelihood activities; and others were no longer in contact with the health system in the area and not attached to home-based care providers. However, as the findings suggest, the reasons for non-uptake of treatment were similar between men and women. Future studies should aim to explore this further.

A more general limitation concerns the generalisability of the findings. This study was conducted in a low-income setting with a small sample of respondents and aimed at identifying a wide range of themes rather than getting a representative sample. Similar studies are therefore needed in other settings, especially targeting people in higher socio-economic strata. Despite these possible limitations, our study is probably generalisable to similar settings in urban areas in the country and provides useful insight that can inform policy and practice to improve ART uptake.

In conclusion, using the social ecological framework, our findings suggest that patient non-uptake of treatment is complex and dynamic, and is influenced by interplay of individual-level and contextual factors outside the direct control of the individual. Individual health and treatment beliefs undermine treatment initiation and these are generated and perpetuated through close social network influence and experiences. Even for those willing to start treatment, the necessity and utility of treatment is counter-balanced by concerns about future supply of treatment, perceived opportunity costs of seeking treatment and by attempts to preserve physical, mental and social wellbeing. This balancing act is mediated by the state of corporeal health, faith healing and availability of herbal remedies which are perceived as effective as ART but with perceived less side effects and less arduous treatment requirements. Thus, ensuring that PLHIV initiate treatment requires addressing individual health and treatment beliefs through close patient-provider rapport and sensitization campaigns targeting faith healers, herbalists and wider community members. Efforts should also be made to assess the therapeutic value of herbal remedies and enforce pharmaceutical measures to regulate their supply and use. There is also need for improved resource allocation for HIV treatment to ensure sustainability of care and for efficient delivery of ART services. Strong inter-sectoral collaboration is also needed to support economically vulnerable individuals who cannot access treatment due to income/food insecurity concerns.

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Chapter 7

Individual and contextual factors influencing patient attrition from antiretroviral therapy care in an urban community of Lusaka, Zambia*

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Abstract

Introduction: Despite the relatively effective roll-out of free life-prolonging antiretroviral therapy (ART) in public sector clinics in Zambia since 2005, and the proven efficacy of ART, some people living with HIV (PLHIV) are abandoning the treatment. Drawing on a wider ethnographic study in a predominantly low-income, high-density residential area of Lusaka, this paper reports the reasons why PLHIV opted to discontinue their HIV treatment.

Methods: Opened-ended, in-depth interviews were held with PLHIV who had stopped ART (n=25), ART clinic staff (n=5), religious leaders (n=5), herbal medicine providers (n=5) and lay home-based caregivers (n=5). In addition, participant observations were conducted in the study setting for 18 months. Interview data were analysed using open coding first, and then interpreted using latent content analysis. The presentation of the results is guided by a social-ecological framework.

Findings: Patient attrition from ART care is influenced by an interplay of personal, social, health system and structural-level factors. While improved corporeal health, side effects and need for normalcy diminished motivation to continue with treatment, individuals also weighed the social and economic costs of continued uptake of treatment. Long waiting times for medical care and placing ‘‘defaulters’’ on intensive adherence counselling in the context of insecure labour conditions and livelihood constraints not only imposed opportunity costs which patients were not willing to forego, but also forced individuals to balance physical health with social integrity, which sometimes forced them to opt for faith healing and traditional medicine.

Conclusions: Complex and dynamic interplay of personal, social, health system and structural-level factors coalesces to influence patient attrition from ART care. Consequently, while patient-centred interventions are required, efforts should be made to improve ART care by extending and establishing flexible ART clinic hours, improving patient-provider dialogue about treatment experiences and being mindful of the way intensive adherence counselling is being enforced. In the context of insecure labour conditions and fragile livelihoods, this would enable individuals to more easily balance time for treatment and their livelihoods. As a corollary, the perceived efficacy of alternative treatment and faith healing needs to be challenged through sensitizations targeting patients, religious leaders/faith healers and herbal medicine providers.

7.0 Background

Even though the benefits of ART in reducing mortality among people living with HIV (PLHIV) are well documented (Egger et al. 2002; Coetzee et al. 2004; Ivers, Kendrick & Doucette 2005; Laurent et al. 2005; Hammond & Harry 2008; UNAIDS 2010a), some PLHIV still drop out of treatment programmes (UNAIDS 2010a; Fox et al. 2010). An analysis of 33 patient cohort studies from 13 Africa countries revealed that on average, 60% of patients were retained in ART care after two years of initiation (Rosen, Fox & Gill 2007); another study has reported retention rates of 75% at 12 months and 67% at 24 months (Tassie et al. 2010). Reasons for patient attrition from ART care have included the use of traditional medicine (Babb, Pemba & Seatlanye 2007; Dahab, Charalambous & Hamilton 2008; Unge et al. 2011), costs, side effects and stigma (Miller, Ketlhapile & Rybasack-Smith 2010), and belief in faith healing (Wanyama et al. 2007; Roura et al. 2010; Unge et al. 2011).

Zambia is one of the countries in sub-Saharan Africa (SSA) worst hit by the HIV pandemic. Since 1984 when the first case of HIV was detected, the country recorded a steady increase in HIV prevalence, peaking at around 16% in the 1990s before levelling off and marginally declining to current rates (NAC/MoH 2010). Recent estimates indicate that 14.3% of the Zambian population (aged 15-49 years) is living with HIV (CSO 2009). In 2005, the Zambian Government introduced free ART services in public sector health facilities. This resulted in a rapid increase in the number of PLHIV on treatment, from 30,103 at the end of 2005, to an estimated 283, 863 (adults and children) at the end of 2009 (NAC/MoH 2010).

Despite the provision of free treatment, some PLHIV still drop-out of ART care, running the risk of developing drug resistance and negative health outcomes. Three case studies in Lusaka, Zambia identified the use of herbal remedies and opting for faith healing as reasons for discontinuation of ART (Reid, Mulenga & Folk 2008) while two other studies (Grant et al. 2008; Murray et al. 2009) reported concerns about side effects, food insecurity and mistrust of medication as some of the factors influencing patient attrition from ART care. While previous studies have provided insight into the various reasons for non-uptake of ART, there is dearth of evidence on how different factors interact to influence health-seeking behaviour, and how they are reflected by the healthcare providers. In this study, we explored the reasons for patient attrition from ART care in an urban community of Lusaka, Zambia in order to understand how

PLHIV balance their decisions based on the underlying framework of socio-economic, cultural, and health-system-related factors.

7.1 Methods

7.1.1 Theoretical framework: Social-ecological framework

Over the years, various theories and models have been developed to help understand health seeking behaviour (UNAIDS 1999; Mackian, Bedri & Lovel 2004). We adapted the social-ecological framework by Roura et al. (2009) to explore the factors that influenced patient attrition from ART care (Figure 7-1). The theoretical framework provides a comprehensive approach to understanding health-seeking behaviour. It frames human behaviour as a function of personal and environmental (social, economic, political, health system) factors (Stokols 1996; Choi, Yep & Kumekawa 1998; UNAIDS 1999; Roura et al. 2009).

The approach avoids exclusive focus on either individual or environmental factors as separate analytical factors, but pays attention to the dynamic interaction of both personal and non-personal factors in understanding health-seeking behaviour (Choi, Yep & Kumekawa 1998; Roura et al. 2009). The premise of the framework is that individuals' health-seeking behaviour is located in social, institutional and physical environments, and consequently, behaviour shapes and is shaped by, the social environment (Roura et al. 2009; Ulin, Robinson & Tolley 2005). Health-seeking behaviour is therefore construed not as something that exclusively resides in the individual, but rather as a reflection of wider interactive situational processes (Mackian, Bedri & Lovel 2004; Latkin & Knowlton 2005; Roura et al. 2009).

The social-ecological framework categorises factors influencing health-seeking behaviour into individual, social, health system and structural factors (Roura et al. 2009). Individual-level factors comprise personal characteristics such as perceived disease severity, illness and wellness interpretations, and knowledge and attitudes towards treatment, as well as somatic response to medication (Roura et al. 2009; Duff et al. 2010).

Social factors include interpersonal relationships with marital partners, family members, and peers that in turn affect individual behaviour and action (Roura et al. 2009). Social factors also include relationships with, and influence of, social institutions like the church and traditional health care systems which are deeply embedded in people's socio-cultural systems. Morality, norms and values reflect and shape social processes. Social exclusion, discrimination and stigmatization are located on this level, too. Similarly, the relationship between health professionals and clients is structured by social order: social distance and poor relationship between health workers and patients affect access to treatment (Duff et al. 2010).

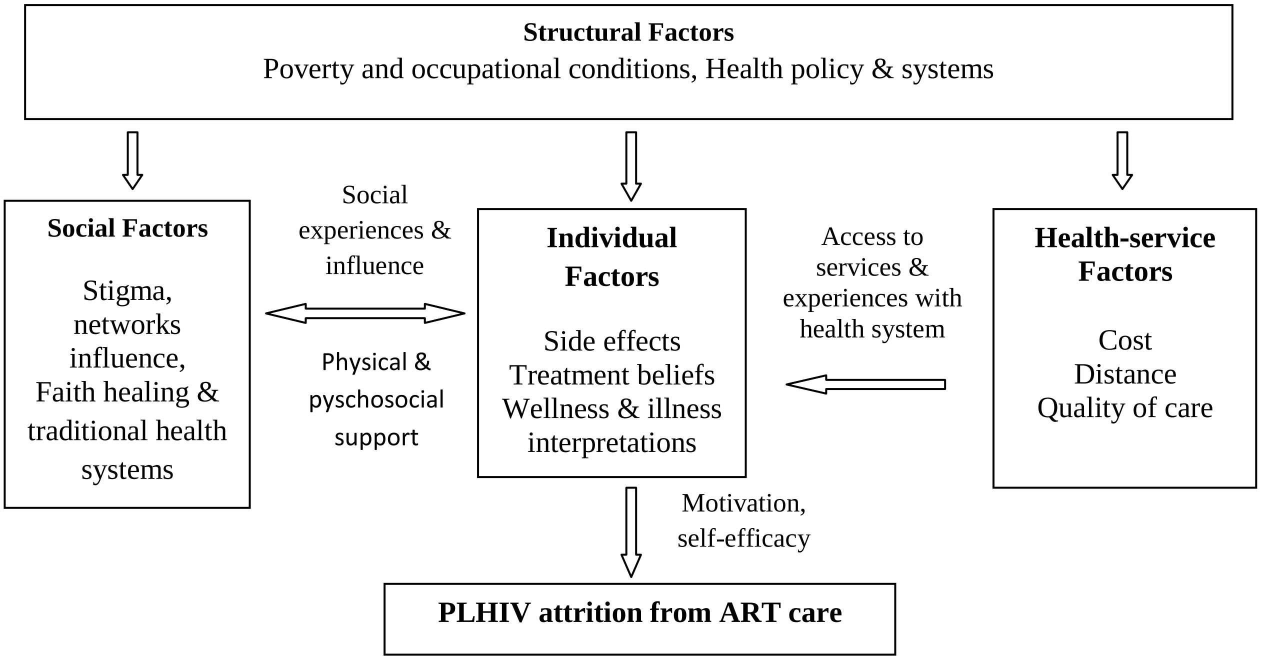

Figure 7-1 Social-ecological framework of PLHIV attrition from ART: Adapted from Roura et al. 2009

Note:

⟺ Suggests a bi-directional relationship. For instance, failure to cope with side effects (individual level factor) may force PLHIV to opt for faith healing (social factor). Similarly, lack of social network support (social factor) can affect attitude towards treatment leading to low self-efficacy.

Structural factors are those external to the control of the individual (Parker, Easton & Klein 2000; Munro et al. 2007). These include endemic poverty, livelihood circumstances, health policies, laws and regulations, and the financing of the healthcare system, which is linked to the economic conditions (McLeroy et al. 1988; Sumartojo 2000). Health system factors relate to the way health services are organized and delivered (Munro et al. 2007). These include availability and accountability of services, attitude of providers, waiting time, and distance to health facilities (Munro et al. 2007; Roura et al. 2009).

Due to its comprehensive and multi-faceted approach, the social-ecological framework avoids the theoretical divide between “individualist” and “structuralist” models by treating both paradigms as complementary and lying on the same continuum (Roura et al. 2009). Individual, social, health system and structural-level factors are viewed not as mutually exclusive, but inextricably linked and in some cases mutually reinforcing. For instance, health service interventions such as reduced waiting times (health system factor) may improve patient adherence behaviour through motivation to seek treatment (individual factor); patients' contact with the health system are likely to be influenced by their attitude and beliefs about treatment, and their lay interpretation of illness and wellness (Munro et al. 2007). Sometimes a combination of different level-factors may influence non-uptake of treatment. For instance, pervasive stigma (social factor) and long waiting time at ART clinic (health system factor) may coalesce leading to lack of self-efficacy (individual factor) resulting in patient attrition from ART care.

7.1.2 Research setting

The study was conducted in a predominantly low-income, high-density urban residential setting of Lusaka, Zambia. The setting comprises of multilingual ethnic groups, with *Bemba* and *Nyanja* the most widely spoken local languages. The socio-economic status and housing conditions of the residents are mixed, but predominantly poor. The majority of the residents are either in the informal sector of the economy or in lowly-paid jobs of the public and private sectors. A lot more other people are not in any form of employment.

Health services in the area are mainly provided by a public sector clinic which provides both in-patient and out-patient health services. The clinic serves an estimated catchment population of more than 150, 000 people. The clinic has been providing ART since 2006 and by mid-2010, the clinic had over 5,000 people on ART, and over 5,000 registered for pre-ART. In addition to the requirement for every patient to have a treatment supporter, called 'buddy', the ART clinic runs a treatment support group, and employs paid lay treatment supporters that follow-up and trace treatment defaulters. A community-based home-based care (HBC) programme also provides physical, psychosocial and treatment support to PLHIV.

There are also a myriad of traditional healers in the area; some of them advertise their health services, including treatment for sexually transmitted diseases (STIs) and 'immune boosters' for HIV. Religion, particularly Christianity, also plays a pivotal role in the lives of many people, providing spiritual, material and social support. The major Christian churches in the area are the United Church of Zambia (UCZ), Roman Catholic Church, New Apostolic Church and the Seventh-Day Adventist Church (SDA). There is also a growing movement of evangelical charismatic Pentecostal churches, some of which claim to provide faith healing for different health problems, including HIV.

7.2 Research design and study participants

A descriptive qualitative study nested within a wider ethnographic study was conducted. The study sample comprised of PLHIV (≥18 years old and residents of the study setting) and classified as lost-to-follow up (LTFU)/defaulters by a local public sector clinic for missing their scheduled pharmacy pick up for at least 6 months (180 days).The revised Zambian ART treatment guidelines have reduced the LTFU threshold to at least 60 days (MoH 2010). Our sample also comprised ART staff of the local public sector clinic, home-based care providers, herbal medicine providers, and religious leaders (Pastors) based in the study setting.

7.2.1 Participant recruitment strategy

All participants were recruited through a purposive sampling strategy. This approach was used in order to identify appropriate key informants (i.e. clinic staff involved in the delivery of ART; religious leaders involved in faith healing and herbal medicine providers). The sampling strategy also helped identify PLHIV with unique and diverse experiences related to discontinuation of treatment. PLHIV who had discontinued ART were first contacted and recruited through ART staff. From patient records, patient locator information was extracted by ART staff to identify eligible participants. Other research participants were identified and recruited through their home-based care providers. The ART staff and home-based care givers explained the purpose of the research.

7.2.2 Data collection and analysis

Data was collected between September 2010 and March 2011. Open-ended in-depth interviews were held with PLHIV who had stopped ART (n=25); VCT/ART staff (n=5); religious leaders (n=5); herbal medicine providers (n=5); and lay home-based care givers (n=5). The main research question posed to PLHIV was: ‘What made you decide to discontinue taking your HIV medication?’ Key informants were asked the question: ‘Why do PLHIV started on treatment later discontinue their medication?’ The majority of the interviews were recorded using a digital audio recorder. Where digital recording was not possible due to respondent refusal or malfunctioning of the digital recorder, the interviewer took detailed handwritten notes. Some of the interviews were conducted in the local language, *Nyanja*, and others in English. The interviews usually lasted between 30-45 minutes.

Structured observations were also conducted at the local public sector ART clinic, at religious gatherings, including church services. Social contact with residents, social institutions and the local health system provided more in-depth perspectives which helped situate PLHIV health-seeking behaviour into their lives and experiences. The observations also helped triangulate the data collected through in-depth interviews. All interviews and observations were conducted by the first author.

The interviews conducted in the local language were translated, and all interviews were transcribed verbatim. The interview transcripts were entered into, and managed using Atlas ti version 6. We used latent content analysis as described by Graneheim & Lundman (Graneheim & Lundman 2004). The transcripts were read several times to develop a sense of the whole, and then conducted open coding of the data. The codes were then compared for similarities and differences, and then grouped into categories on a manifest level. Themes were then generated by interpreting the categories for their underlying meaning.

Observational notes were manually analysed to develop broad themes that best captured and typologised the study setting, and described the livelihood and treatment experiences of PLHIV. In our study, the framework was not used for thematic coding but served as a guide to present the results in a structured way.

7.2.3 Protection of research participants

As a component of a bigger research project, ‘improving equity of access to HIV care and treatment in Zambia’, the study was approved by the ethics committee of the state of Basel (EKBB) and the University of Zambia Humanities and Social Sciences Research Ethics Committee. Clearance was also obtained from the Ministry of Health, at national and district levels. Only PLHIV that had been contacted by ART staff and home-based caregivers and agreed to be interviewed were recruited for interviews. To ensure privacy and confidentiality, the interviews took place in different settings, mainly neutral locations depending on the preferences of the respondents. Where appropriate, PLHIV were given lunch and/or transport reimbursements (of up to US$10). All research participants provided written informed consent.

7.3 Results

We first present individual-level, social and structural-level factors emphasised by PLHIV in order to give an overview of their main concerns. This is followed by findings that specifically relate to patient-healthcare provider interaction, in which individual, social, and structural factors are mirrored as well.

7.3.1 Profile of PLHAs who had discontinued ART

A total of twenty-five (25) PLHIV who had discontinued their treatment were included in the analysis. The majority of the respondents (n=17) were women, and nearly half (n=11) were aged between 25-34 years old. The oldest respondent was a widow aged 48 years old. More than half (n=15) of the PLHIV were in informal employment. In terms of treatment history, eight (8) of the 25 PLHIV had been on treatment for up to a year; and less than half (n=10) abandoned medication within a year of starting treatment (Table 7-1).

7.3.2 Reasons for patient attrition from ART Care

Individual-level factors:

Side effects and treatment beliefs: Treatment-related side effects were a recurrent theme for discontinuing treatment. The frequently mentioned side effects were severe stomach pains and diarrhoea, severe leg pains and headache, body rash, fatigue and vomiting. While PLHIV acknowledged that side effects were inevitable, they felt that the side effects were inimical to their health and comfort and interfered with their engagement in livelihood activities. An unemployed 33-year old woman narrated how side effects sapped her energies and made her incapable of engaging in livelihood activities:

"The time I was on treatment, I used to feel weak all the time. I used to feel dizzy. I used to fail to carry even a 10 litres container of water. I could not do any piece works to make money. Although I still cough, it is much, much better now than when I was on treatment."

Table 7-1 Characteristics of PLHIV who have dropped out of ART

Characteristic	**No. of PLHIV (n=25)**
Age (Years)	
18-24	5
25-34	11
35-44	3
>44	6
Sex	
Male	8
Female	17
Marital status	
Single	4
Married	12
Divorced/separated	7
Widowed	2
Source of livelihood	
Formal employment	4
Informal employment	15
Not working/dependant	6
Time on treatment	
<12 months	8
1-<2 years	6
2-<3 years	6
3-≤4 years	2
>4 years	3
Duration not on treatment (up to time of interview)	
6-<12 months	10
1-<2 years	8
2-<3 years	5
3-<4 years	2

Some PLHIV expressed concerns about the dangers of treatment to their lives and long-term health. One respondent narrated: "*Those drugs almost killed me. I almost went mad. Today, if I was still taking those drugs, I would either be mad or I would have died by now."* (28-year old woman). Although not explicitly expressed by others, one PLHIV felt that while the drugs generally improved health, they also inflicted debilitating effects in the long term:

> *"The problem with ARVs is that you become fat first before you die, that you look healthy outwardly, but inside your body, you are rotten, being eaten up by the drugs*." (48-year old woman)

Treatment fatigue and low self-efficacy: While side effects were a reason for abandoning treatment, improving wellbeing decreased motivation to continue on treatment too. Often triggered by physical improvements of corporeal health, some PLHIV saw no need to continue with treatment. One participant said: *"To tell you the truth, I have consumed those drugs, I am now tired….Now that I feel better, I decided to stop."* (48-year old woman)

Change of identity: A few PLHIV emphasized their desire to feel 'normal': continued uptake of treatment often reminded them of being 'sick', having an incurable and fatal condition, and dependent on medication. Therefore to construct a positive and 'healthy' image of themselves, they opted to discontinue their medication. As one PLHIV explained:

> *"Taking ARVs always reminds you of HIV. Sometimes you just want to forget about it, to be like others who are not infected. So when you feel ok, you want to stop taking the drugs so that you also feel that you are also a normal person."* (34-year old man)

Social-level factors:

Fear of losing social and emotional support due to anticipated stigma: Some PLHIV were fearful of involuntary disclosure of their status, either to their marital partners or other social network members and facing the prospects of social exclusion. Especially women, social support was crucial because of their subordinate socio-economic status. Some women were full-time housewives and/or small traders operating small makeshift shops locally called *tutembas.* Consequently, to avoid involuntary disclosure of their HIV status, they opted to stop treatment in order to preserve social support systems. One woman narrated her dilemma:

> *"I feared that my husband would know, and if he knew, he was going to divorce me. Where can I go if I got divorced? Who will look after my children? I just said to myself that it is better I stop medication so that I can protect my marriage, and so that my children can have a future." (32*- year old woman living with HIV)

Social network influence and experiences: In some cases, PLHIV stopped treatment altogether or opted for faith healing and herbal remedies after being influenced by, and drawing on the health experiences of, other PLHIV who had stopped treatment. This was confirmed by ART staff, home-based caregivers and a few PLHIV. As an ART staff explained:

> *"Some people boast [among their friends] that 'here I am, I stopped medication but I am just fine'. So when other people see that, they also think that you can stop treatment and nothing would happen to you."*

Faith in God: Personal relationship with, and trust in, a surpernatural being (God) also led to patient attrition from ART care. The majority of the respondents interviewed professed being Christians and some narrated how being 'born-again' and their 'personal relationship' with God dissuaded them from continuing with treatment. A 47-year old widow who underwent some healing sessions explained:

> *"I give praise to God that He healed me. I never thought that I would be healed because I was HIV positive. I used to take my medication every day, in the mornings and in the evenings. And at the clinic, they told me that if you stop taking your medication, you will die. But me, I stopped treatment and I have not died, I am still alive. God is great. Glory be to God.*"

Observations revealed that some local Pentecostal churches hosted healing sessions for people suffering from different ailments, including HIV. One Pentecostal church conducted healing prayer sessions every Saturday; on the wall of the local church read the banner: *"Come for counselling, deliverance and healing from all sickness and disease*". Another Pentecostal church conducted 'deliverance and healing' sessions every Wednesday and Thursday afternoon. During one of the church services, a middle-aged woman testified about how she was found HIV-positive at a local public sector clinic and put on medication but opted to put her faith in God. She testified in church:

> *"I embarked on prayer and fasting…. I told the devil that you are a liar. I asked God, can you show your power, and thank God, I am cured. Our living God is a God of wonders."*

The practice of faith healing was confirmed by evangelical Pastors, ART staff and home-based care providers. People moved across Christian denominations in search of healing. An ART staff recounted an incident where ARVs were dumped at the ART clinic during the same week that a visiting Pastor conducted a series of 'deliverance and healing' sermons in the area.

One of the local Pastors interviewed explained:

> *"We pray for them and never lose hope even at the point of death. We still stand by the word of God, that God is able to cure or heal you. If God does not cure you, it is because of His personal reasons."* Another Pastor proclaimed: *"The Bible teaches us that the things which are impossible with men are possible with God."*

Opting for alternative treatment: In the study setting, alternative forms of treatment co-existed with ART care. PLHIV accessed herbal remedies either from traditional healers or from herbal medicine traders. Some of these remedies were being used either as purported cures or as 'immune boosters'. These remedies included crocodile fats, *moringa oleifera* and *aloe vera* gel (also locally available in plant form called *tembusha*). While some PLHIV initially used herbal medicines concurrently with ART, overtime, they reported exclusively opting for herbal remedies. For some, opting for alternative treatment was triggered by ART-induced side effects, dissatisfaction with ART care and inability to stick to the stringent ART regimen. For other PLHIV, the quest to get cured attracted them to use herbal remedies. One PLHIV explained:

> *"I never had any problem with the health workers. But I just decided on my own when I heard that crocodile fats cure, so I decided to start taking crocodile fats in the hope of being healed."* (46-year old man)

A herbal medicine trader supplying herbal medication to PLHIV claimed that her herbal remedies were as effective as ART in boosting the immune system:

> "*I have different types of herbs which improves the health of people who have HIV. Some of the herbs boost the immune system. I also have other herbs that cleanse the body of toxins. Some of my customers were not recovering when they were taking ARVs, but when they started taking my herbs, their health improved."*

Structural-level Factors:

Insecure labour conditions: For some PLHIV, the fear of losing their jobs on account of their HIV status, anticipating stigma, hindered them from accessing treatment. Most people, even when employed, did not have proper contracts which would protect them in case of illness as foreseen by the law. People with job insecurity who also reported earning meager income did not want to lose their livelihoods on account of disclosure of their HIV status. The lack of both formal and strong informal social safety nets reinforced the need to preserves sources of socio-economic support. One woman said:

> *"I lost my marriage when I told my husband my status....So I did not tell my boss that I was HIV positive, so I feared that if I told her, she was going to fire me. So I decided to keep quiet*

> *so that I keep my job.....Instead, I decided to stop going to the clinic so that she does not know my status." (30-year old divorced woman)*

Poor labour conditions that did not respect employee right of access to health care also made it difficult for PLHIV to reconcile time for treatment and their livelihoods. The majority of our respondents were engaged in informal, low-income livelihoods (i.e. bus drivers, house maids, construction workers, petty traders) and getting time off-work presented enormous opportunity costs. Some PLHIV experienced worse dilemmas. A Zambian truck driver working for a South African-based transport company narrated his harrowing experience:

> *"My drugs got finished when I was in South Africa. The problem was that when I told my boss that I want to go to Zambia for treatment, he told me that 'if you decide to go, you should never come back for work.' So you know how hard jobs are to find. So I just decided to hang around so that I do not lose my job."* (32-year old truck driver)

Sometimes PLHIV 'cooked-up' stories that would generate compassion from employers such as a child, wife or husband being sick at home or the need to attend a funeral of a close relative. Even where permission was obtained, PLHIV had to tread a thin line between accessing treatment and securing their jobs. The frequency of getting permission had to be minimal to avoid being misconstrued by employers as not being committed to work. One 30 years old PLHIV who lost his job twice, first as a plumber and then as a minibus conductor, after frequently getting permission from work to seek treatment narrated his ordeal:

> *"Your health is your health, and what they [employers] care about is their business, doing their work. Sometimes if you ask for permission frequently, they think that you are just giving excuses. So, they fire you and replace you with someone else. That is how I lost my jobs."*

Health system-level Factors:

Competing priorities and dissatisfaction with ART care: When livelihood problems and low perceived quality of care coalesced, incentives to stay on treatment diminished. For some PLHIV, long waiting time and frequent trips to the clinic presented enormous opportunity costs which they were not willing to forego. This was especially the case for those who reported living 'hand-to-mouth' livelihoods or were in insecure employment and therefore frequent trips to the clinic 'forced' them to choose between treatment and their livelihoods. Relatedly, the long clinic appointments often lasting almost a whole day, non-availability of some drugs and laboratory test results, and perceived rudeness of some clinic staff frustrated and dissuaded other PLHIV from seeking ART care. A woman in an HIV concordant marriage narrated their disillusionment with ART care:

> *"Sometimes, you go there, they collect your blood, but the next time you go to the clinic, they tell you that your results got lost and you should give fresh blood and come again after two weeks. That frustrates a lot of people.…One time, my husband's results and my results got lost twice."* (33-year old)

Dissatisfaction with the way clinic staff responded to patients' concerns included the problem of side effects, too. Several PLHIV reported not going back to the clinic to report side effects; others indicated that whenever they did, ART staff often dismissively told them that "*you will be fine once your body gets used to the medication"* (32-year old man). The unresolved concerns about side effects often triggered PLHIV to opt for faith healing and herbal remedies.

Paradoxical impact of intensive adherence counselling: In order to reduce non-adherence, clinic staff included so-called 'defaulters' in special counselling programs. The compulsory participation in intensive adherence counselling offered by the ART clinic involved reverting 'defaulters' to weekly doses of treatment in which they were asked to report to the clinic weekly for adherence counselling for at least a month. This exasperated the balancing act between treatment and livelihoods. Several PLHIV described this approach as insensitive and a threat to their livelihoods. Looking livid, one 30-year old woman complained:

> *"Do we only live to go to the clinic or we also have other things to do in life? If I keep on spending time at the clinic, then, how I am going to look after myself and my family? What will we be eating with my family? What time would I have to go and do my work to earn a living? This really annoyed me and I got fed up with the clinic and decided to stop my medication."*

Another PLHIV, a second-hand clothes trader, opted to stop treatment after being put on intensive adherence counselling. She reportedly attended her mother's funeral outside Lusaka and missed her clinical appointment by four days because she stayed longer for the funeral than anticipated. When she returned to the clinic, she was classified as a 'defaulter' and immediately put on intensive adherence counselling despite not intentionally missing her clinical appointment. She complained:

> *"I went with my medication but because I stayed there [at the funeral] for a week, my medication got finished. But then they [ART staff] just said that we will give you drugs for one week and put you on intensive adherence counselling. The counsellor just said you patients are a problem, you just want to come to the clinic whenever you feel like. This put me off. It was like I was being punished for attending my mother's funeral."*(21-year old woman)

7.4 Discussion

The results illustrate how individual, social, and structural-level factors influencing why patients discontinued ART care in an urban community of Lusaka are equally characterizing the patient-provider interaction. Every person who stopped ART did this knowing that this was against the recommendations of the health system.

When looking at individual-level reasons given by PLHIV, treatment was often interrupted when side effects became too severe or were perceived as compromising quality of life, a finding reported in many other studies, too (Siegel & Gorey 1997; Siegel, Schrimshaw & Dean 1999; Lumme-Sandt, Hervonen & Jylha 2000;; Stevens & Hilderbrandt 2009; Wong & Ussher 2008). The health system's response that side effects will disappear after some time was not convincing to many PLHIV. Our findings suggest that the conception of being healthy is subjectively experiential rather than shaped by laboratory test results that cannot be felt (Wong & Ussher 2008; Stevens & Hilderbrandt 2009). Patient's perceptions of the impact of treatment on physical, physiological and psychological wellbeing influenced their decisions. For instance, lack of motivation to continue with treatment was influenced by perceived improvement of corporeal health. In this case, good health and wellbeing are not only about improved CD4 cell count and lower viral load as measured in bio-medical discourse, but also in terms of comfort and unfettered ability to participate in day-to-day life activities (Wong & Ussher 2008). Indirectly, this shows that the expert opinions of the ART providers are not trusted enough to legitimate a continuation of treatment.

Individual health-seeking behaviour is also strongly influenced by, and responds to, factors in the immediate social environment (Roura et al. 2009). Social exclusion and discrimination is anticipated in case of disclosure of one's positive status. PLHIV fear the breakdown of their marriages, families, and loss of employment. In the absence of institutional social safety net, individuals rely exclusively on social network support to cope with unforeseen events. However, when social support is threatened by involuntary disclosure of HIV status, individuals abandon treatment as a protective mechanism.

Public identity transformation was avoided by all means especially if PLHIV were dependent on their social support networks. A strong urge to be ‘normal’ was characterized by a variety of strategies of PLHIV. One example are the religious coping strategies of PLHIV, which cannot be discussed separately from the stigma associated with the condition of being HIV positive.

Despite the availability of antiretrovirals and the good health of many PLHIV, the moral dimension of HIV has not diminished, at least in this community. Coupled with livelihood insecurity, disclosure of a positive HIV status breeds tremendous social insecurity and loss of material and emotional support by spouses, families and friends. PLHIV coping strategies, such as re-establishing normalcy through being healed, unfortunately often implies abandonment of antiretroviral therapy.

Structural factors influence patient attrition as well. Our findings further suggest that livelihood constraints characterised by low-income, labour condition constraints and absence of strong formal and informal socio-economic safety nets affected patient continuation with treatment. While previous studies have found no correlation between poverty and adherence to treatment (Orrell et al. 2003; Mills et al. 2006), other findings have reported the negative impact of livelihood constraints on treatment adherence (Merten et al. 2010; Reda & Biadgilign 2012). Our findings suggest that in settings with endemic poverty levels and weak social safety net, individuals are inclined to avoid actions that would expose them to further socio-economic vulnerability.

These findings need to be contextualised. Zambia ranks poorly (164 out of 187 countries) on the human development index (HDI) (UNDP 2011); 68% of its population falls below the national poverty line (GRZ 2006); and 90% of the labour force is in informal sector employment (GRZ 2011). Consequently, even where PLHIV are motivated to continue accessing treatment, health-seeking behaviour is undermined by coalesced effect of non-individual level factors such as fragile livelihoods, health system factors like long waiting times for medical care, which in turn compels PLHIV to prioritise their livelihoods over their health. Thus, to still maintain ‘good’ health, some PLHIV opt for alternative forms of health care, like herbal remedies because they are easily accessible and do not impose inordinate opportunity costs.

Since the beginning of ART care, the health sector has tried many support strategies to improve adherence. Nonetheless, there are shortcomings of ART delivery, which are partly due to resource constraints. Similar to findings from previous studies (Muchedzi et al. 2010; Mutale & Bond 2010) long waiting times at health facilities affected patient access to treatment. In contrast however, neither the costs of treatment nor distance to the medical facilities were influencing patient attrition from ART care because ART services were free and within reach in this urban community.

Unexpectedly however, specific interventions aimed at improving adherenc to ART seemed counter-productive. This was the case for putting 'defaulters' on intensive adherence counselling. What was striking in our study, which previous studies in Zambia have not reported (Grant et al. 2008; Murray et al. 2009), was the negative impact of intensive adherence counselling on patient retention in ART care. For patients, this was interpreted as being 'punished' for circumstances beyond their control. Consequently, while aimed at achieving positive 'quantitative aspects of HIV management and monitoring' (Wong & Ussher 2008), intensive adherence counselling was also achieving the opposite. Our findings corroborate the findings of Tugenberg et al. (2006) who found that heavy insistence on adherence by clinicians forced some PLHIV to abandon medical visits to avoid confrontations with their doctors for non-adherence. Thus, perceived unresponsiveness of the health system pushes patients to seek alternative forms of health care, such as faith healing (Wanyama et al. 2007; Tocco 2010; Berhanu 2010) and traditional medicine (Banda et al. 2007; Reid, Mulenga & Folk 2008; Unge et al. 2011).

Possible limitations of the study

This study was conducted in a high density, generally poor urban setting, with a small purposively chosen sample of PLHIV. The findings may not be fully generalisable to other settings. Each setting may have unique characteristics that may influence health-seeking behaviour. However, our study has generated new insight about patient-provider interactions, role of faith healing and traditional medicine, which may be generalisable beyond our setting and which contributes to the body of evidence on factors influencing patient retention in ART care.

7.5 Conclusions

Patient attrition from ART care is not exclusively an individual choice, but affected by a complex and dynamic interplay of personal, social, health system and structural-level factors. Even for the most motivated patient, being on life-long treatment is not easy. Patients have to balance the exigencies of treatment with the effects of accessing treatment on their social, physical, mental and economic well-being. Therefore, while patient-centred interventions are critical to promote adherence, there is need to be mindful of, and address the influence of, non-personal-level factors which interact to influence health-seeking behaviour. This is crucial to achieve needs-based, demand-driven and beneficiary responsive ART care and ultimately retain patients in treatment programmes.

Authors’ contributions

MM conceptualized the study, did the data collection and analysis, and wrote the first draft of the manuscript. VB and SM contributed towards the conceptualization of the study, participated in the analysis and interpretation of the findings, and writing of the manuscript. All authors have given final approval of the version to be published.

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Chapter 8

Self-care practices and experiences of people living with HIV not receiving antiretroviral therapy in an urban community of Lusaka, Zambia: implications for HIV treatment programmes*

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Abstract

Background: Despite the increasingly wider availability of antiretroviral therapy (ART), some people living with HIV (PLHIV) and eligible for treatment have opted to adopt self-care practices thereby risking early AIDS-related mortality.

Methods: A qualitative study was conducted in urban Zambia to gain insights into PLHIV self-care practices and experiences and explore the implications for successful delivery of ART care. Between March 2010 and September 2011, in-depth interviews were conducted with PLHIV who had dropped out of treatment (n=25) and those that had opted not to initiate medication (n=37). Data was entered into and managed using Atlas ti, and analysed inductively using latent content analysis.

Results: PHIV used therapeutic and physical health maintenance, psychological well-being and healthy lifestyle self-care practices to maintain physical health and mitigate HIV-related symptoms. Herbal remedies, faith healing and self-prescription of antibiotics and other conventional medicines to treat HIV-related ailments were used for therapeutic and physical health maintenance purposes. Psychological well-being self-care practices used were religiosity/spirituality and positive attitudes towards HIV infection. These practices were modulated by close social network relationships with other PLHIV, family members and peers, who acted as sources of emotional, material and financial support. Cessations of sexual relationships, adoption of safe sex to avoid re-infections and uptake of nutritional supplements were the commonly used sexual and healthy lifestyle practices.

Conclusions: While these self-care practices may promote physical and psychosocial well-being and mitigate AIDS-related symptoms, at least in the short term, they however undermine PLHIV access to ART care thereby putting PLHIV at risk of early AIDS-related mortality. The use of scientifically unproven herbal remedies raises health and safety concerns; faith healing may create fatalism and resignation with death while the reported self-prescription of antibiotics to treat HIV-related infections raises concerns about future development of microbial drug resistance amongst PLHIV. Collectively, these self-care practices undermine efforts to effectively abate the spread and burden of HIV and reduce AIDS-related mortality. Therefore, there is need for sensitization campaigns on the benefits of ART and the risks associated with widespread self-prescription of antibiotics and use of scientifically unproven herbal remedies.

8.0 Background

While an estimated 5.9 million people in low and middle-income countries were on antiretroviral therapy (ART) by end of 2009, saving 14.4 million life-years since 1996 (UNAIDS 2010), this only represented half the estimated people eligible for treatment (WHO, UNAIDS, UNICEF 2011). Previous studies indicate that patient retention in ART care is problematic. For instance, in sub-Saharan Africa (SSA), only an estimated 60% of patients were retained in ART programmes after 2 years of starting treatment (Rosen, Fox & Gill 2007; Harries et al. 2010). This is despite the proven efficacy of ART in reducing AIDS-related deaths (Egger et al. 2002; Coetzee et al. 2004; Ivers, Kendrick & Doucette 2005; Hammond & Harry 2008).

The reasons for patient attrition from ART care and failure to initiate treatment are varied and include financial costs associated with accessing treatment (Miller, Ketlhapile & Rybasack-Smith 2010; Zachariah et al. 2010), fear of side effects (Gold & Ridge 2001; Gellaitry et al. 2005; Alfonso et al. 2006; Beer et al. 2009; Miller, Ketlhapile & Rybasack-Smith 2010), fear of drug toxicity and long-term harm to the body (Gold & Ridge 2001; Musheke, Bond & Merten 2010) and feeling healthy (Gold & Ridge 2001; Beer et al. 2009; Musheke, Bond & Merten 2010; Murphy et al. 2010; Katz et al. 2011). Other barriers are stigma (Beer et al. 2009; Miller, Ketlhapile & Rybasack-Smith 2010), belief in faith healing (Wanyama et al. 2007; Beer et al. 2009; Wringe et al. 2009; Roura et al. 2010; Unge et al. 2011), use of traditional medicine (Babb et al.2007; Wringe et al. 2009; Murphy et al. 2010; Unge et al. 2011) and perceived burden of being on life-long treatment (Gold & Ridge 2001; Alfonso et al. 2006; Stevens & Hilderbrandt 2009).

Zambia is one of the countries in SSA worst hit by the HIV pandemic, with an estimated HIV prevalence of 14.3% in the Zambian population aged 15-49 years (CSO 2009). The national HIV prevalence peaked at around 16% in the 1990s before levelling off and marginally declining to current rates (NAC 2012). Since 2005 when Zambia started providing free ART services in public sector health facilities, there has been a steady increase in the number of PLHIV accessing treatment, from 57,164 in 2005 to an estimated 344, 407 (adults and children) at the end of 2010, representing 68.4% of those in need of treatment (NAC 2012). Similar to studies elsewhere, barriers to accessing ART in Zambia include financial and logistical costs (Grant et al. 2008; Fox et al. 2010), concerns about side effects (Grant et al. 2008; Murray et al. 2009; Fox et al. 2010), negative perceptions of medication (Murray et al. 2009; Musheke, Bond & Merten 2010; Fox et al. 2010) and overcrowded health facilities (Grant et al. 2008; Musheke, Bond & Merten 2010). Other barriers are stigma and fear of straining interpersonal relationships (Grant et al. 2008; Murray et al. 2009), fear of being on life-long treatment and inadequate/lack of food and nutritional support (Murray et al. 2009).

While the reasons for non-uptake of ART are known, there is paucity of evidence on how PLHIV eligible for but not on treatment manage their health condition; how PLHIV perceive and experience their health on account of any self-care practices; and the implications of self-care practices for successful delivery of ART care. Therefore, within a wider ethnographic study, this study explored the self-care practices and health experiences of PLHIV not receiving ART care in an urban community of Lusaka, Zambia. Self-care in this paper is defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition [in this case HIV]...ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain satisfactory quality of life" (Barlow et al. 2002).

8.1 Methods

8.1.1 Research setting

The study was conducted in a predominantly low-income, high-density urban residential area of Lusaka, Zambia. Observations and interviews with study participants indicate that the area comprises multilingual ethnic groups with *Bemba* and *Nyanja* the most widely spoken local languages. Most residents are embedded in strong kin and non-kin social network relationships. Most of the families are large, in part due to the affect of HIV with some individuals growing up as orphans under the care of extended family members. Although not all family members lived together, they still maintained reciprocal social and economic support ties. Other social network relationships are a product of similar religious affiliations and occupational and social lifestyle activities. Due to lack of public social amenities, social lifestyle activities mostly revolve around patronising the ubiquitous bars and drinking places, often a prime source of sexual network relationships.

Most of the residents are poor. A few people are employed in low-paid jobs in the public and private sectors of the formal economy. The majority earned their living in the informal economic sector: as cross-border traders and local market traders mainly selling fruits, vegetables, meat products, charcoal and second-hand clothes either in the city centre markets or in the open-air local markets. Small makeshift shops, locally called *'tuntemba'* are ubiquitous in the area - along the dusty and seasonally muddy roads and in the local open-air markets or next to homes. Unemployment is also endemic in the area especially among the lowly educated youth. The unemployment situation is further exacerbated by rural-urban migration as people move into the city in search of job opportunities and better life.

Health services are mainly provided by a public sector clinic which provides both in-patient and out-patient health services. The clinic also provides ART services. By mid-2010, the health centre had an estimated catchment population of over 150,000 with over 5,000 people on ART and over 5,000 registered for pre-ART care. Alongside the formal health system are traditional healers and herbalist who also provide 'health' care services, including for HIV. There is also a plethora of drug stores, some unlicensed, which provide over-the-counter medication.

Christianity is the dominant religion with a myriad of charismatic evangelical Pentecostal churches, some of which provide healing sessions for people with different ailments, including HIV.

8.1.2 Research design and study participants

The paper draws on data from two exploratory qualitative lines of enquiry nested within a wider 18-month ethnographic study: namely patient attrition from ART care and barriers to patient initiation of ART. For the former, participants were PLHIV who had not reported for pharmacy pick up for at least 6 months hence being classified by the local ART clinic as lost-to-follow up (LTFU). The revised Zambian ART treatment guidelines have reduced the LTFU threshold to at least 60 days from the previous 180 days (MoH 2010). In the latter, participants comprised PLHIV recommended to start treatment by ART providers but declined. Only participants aged ≥18 years old constituted our respondents.

8.1.3 Sampling strategy and recruitment of study participants

Purposive sampling using maximum variation sampling procedure was used to select study participants. The sampling technique allows for selection of participants with unique and diverse characteristics in order to generate in-depth unique insights and shared patterns that cut across cases. In this study, the diverse characteristics used to select study participants were demographic characteristics and length of time on and off HIV treatment. The sampling strategy facilitated collection of wide ranging, in-depth insights into self-care behavioural practices and experiences of PLHIV associated with not being on ART.

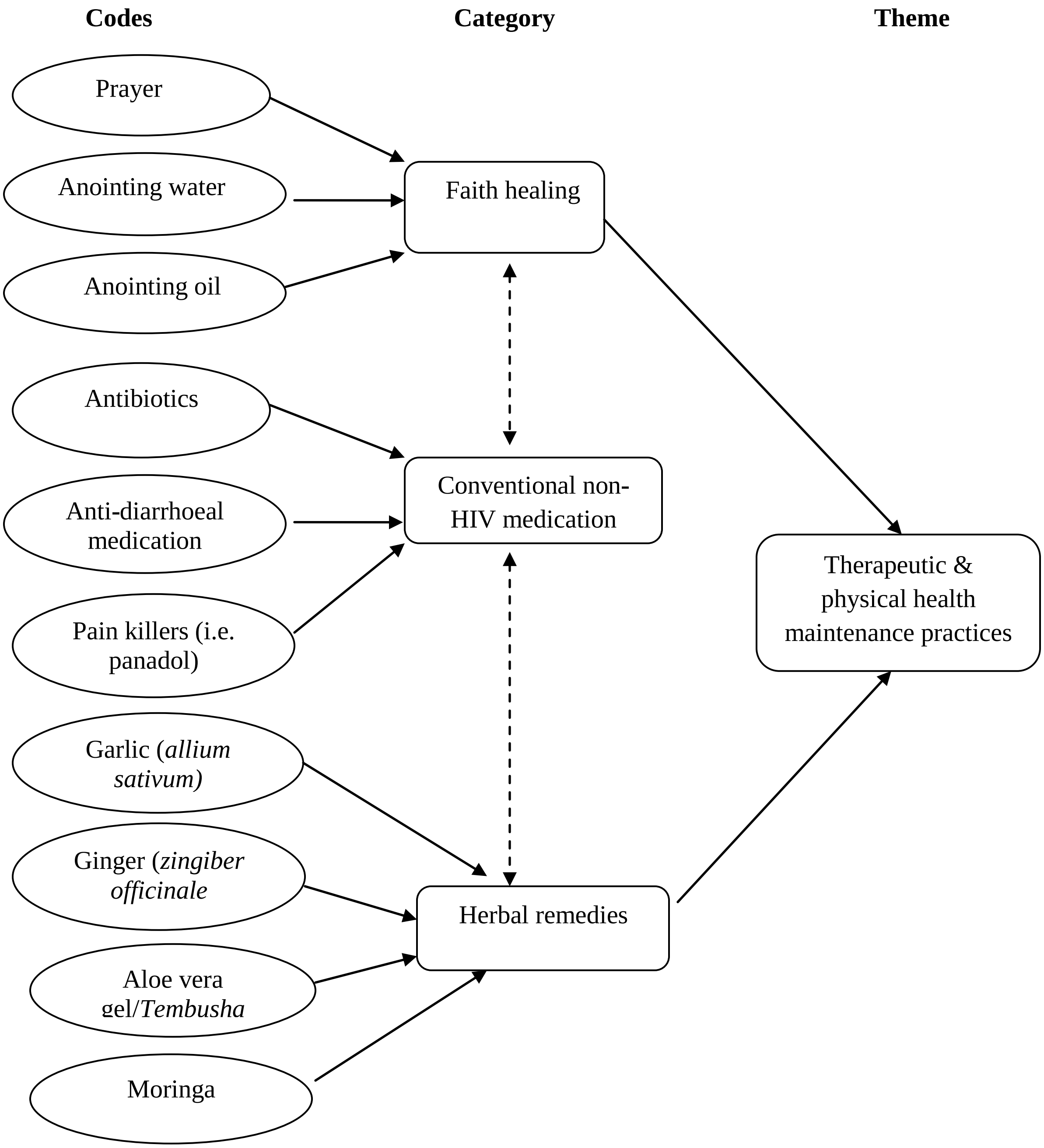
Due to the difficulties of identifying PLHIV who had dropped out of ART and those who had refused to initiate treatment, some PLHIV not on ART were first contacted and recruited through ART staff. They were contacted by mobile phone and/or physically followed up using locator information (physical address and mobile phone details) they had provided to ART providers at the time of enrolment for treatment. Other research participants were identified and recruited through community-based lay home-based care providers. Given that PLHIV had formed or belonged to social networks, a few study participants were recruited through snowball sampling in which PLHIV interviewed nominated and contacted on behalf of the researchers, friends and family members that they knew had discontinued HIV treatment or had opted not to start treatment despite it being recommended to them by ART providers. For both categories of PLHIV, only those that agreed to be interviewed were later contacted and followed up for interviews by the researchers.

8.1.4 Data collection and analysis

Face-to-face, one-on-one, open ended in-depth interviews were conducted between March 2010 and September 2011. The main research question asked was: “how do you manage your HIV condition in the absence of ART?’ Follow-up interviews were conducted during the study period. The initial interviews usually lasted between 30-45 minutes and for those re-interviewed, follow-up interviews lasted between 15-20 minutes. All the interviews were recorded using a digital audio recorder. The majority of the interviews were conducted in the local language, *Nyanja,* and a few in English.

All interviews were transcribed verbatim. Data collection and preliminary data analysis was cyclical with some participants being re-interviewed and analysis continuously informing ensuing interviews. At the completion of data collection and transcription, all interview transcripts were entered into and organised and managed using Atlas ti version 6. Latent content analysis as described by Graneheim and Lundman (Graneheim & Lundman 2004) was undertaken. The transcripts were read several times to develop a sense of the whole data followed by open coding of the transcripts. The codes were compared for similarities and differences and then grouped into categories on a manifest level. Themes were generated by interpreting the categories for their underlying meaning (Figure 8-1).

Figure 8-1 Example of coding framework of PLHIV self-care practices



For instance, codes such prayer, anointing oil, anointing water were categorized as faith healing. Similarly, codes such as antibiotics, anti-diarrheal medication and pain killers were categorized as conventional non-HIV medication while garlic (*allium sativum*), ginger (*zingiber officinale*) aloe vera and *moringa* were categorized as herbal remedies. As a theme, the categories were collectively interpreted as therapeutic and physical health maintenance practices.

8.1.5 Protection of research participants

Ethical approval was granted by the Ethics Committee of the State of Basel (Ethik-Kommission beider Basel) and the University of Zambia Humanities and Social Sciences Research Ethics Committee as part of a bigger research study, 'Improving equity of access to HIV care and treatment in Zambia.' The Ministry of health at national and district levels provided administrative clearance.

To ensure confidentiality and prevent involuntary disclosure of research participants' HIV status, locations for interviews were based on the preferences of the respondents. Some interviews were conducted at the local public sector clinic and private spaces within the homes of respondents' friends. A few PLHIV preferred being interviewed at home. This was done in the absence of family members to ensure privacy. Written informed consent was obtained from all research participants, including for quotes to be used anonymously in published reports.

8.2 Results

A total of thirty-seven (37) PLHIV who declined to be enrolled into ART care and twenty-five (25) PLHIV who had abandoned ART care were interviewed. The majority of the respondents (n=41) were women and almost half (n=29) were aged between 25-34 years old. More than two-thirds (n=42) of the PLHIV were in informal employment. For the PLHIV who had stopped ART, eight (8) of the 25 PLHIV had been on treatment for less than a year; and less than half (n=10) abandoned medication in less than a year of being initiated on treatment. For PLHIV who had never been on ART, almost half (17 out of 37) were recommended ART within the year preceding the interviews (Table 8-1).

Self-care behavioural practices of PLHIV not on ART

Seven (7) self-care practices were identified subsumed under four (4) main themes: Therapeutic and physical health maintenance; psychological well-being practices; healthy lifestyle and risk reduction practices.

Table 8-1 Characteristics of PLHIV not on ART

Characteristic	No. of PLHIV who dropped out of ART	No. of PLHIV never on ART
Age (Years)		
18-24	5	4
25-34	11	18
35-44	3	14
>44	6	1
Sex		
Male	8	13
Female	17	24
Marital status		
Single	4	5
Married	12	22
Divorced/separated	7	6
Widowed	2	4
Source of livelihood		
Formal employment	4	5
Informal employment	15	27
Not working/dependant	6	5
Time on treatment		
<12 months	8	-
1-<2 years	6	-
2-<3 years	6	-
3-<4 years	2	-
≥4 years	3	-
Duration not on treatment (up to time of interview)		
6-<12 months	10	17
1-<2 years	8	10
2-<3 years	5	6
3-<4 years	2	4
4-<5 years	-	-
≥5 years	-	-

Therapeutic and physical health maintenance practices

Taking herbal therapies

Sustaining physical health involved taking herbal remedies to treat opportunistic infections and mitigate HIV symptoms, 'wash toxins' from the body, replace nutrients and improve appetite levels. Garlic (*allium sativum)*, ginger (*zingiber officinale*), aloe vera (also locally called *tembusha*), *moringa oleifera*, Ngetwa from Tanzania, crocodile fats, Chinese herbal remedies, stametta (aloe mixed with vitamins and herbs) and some herbs simply labeled '*Back to Eden'* were the most commonly used herbal remedies. Two PLHIV elucidated their experiences of herbal remedies:

> *"I take some moringa. It is a tree with small leaves; we have it in the backyard of our house.... I just put it in tea or even in vegetables; we cook and mix it with other vegetables. Sometimes we "sashila" (add pounded groundnuts] to moringa and cook it as relish. Or you can even add the moringa to porridge."* (50-year old woman; never been on ART)

> *"You know with herbs, if you are coughing, you get guava leaves, lemon leaves, boil and drink them and then you are done. Even now, when my daughter is coughing, I would just take garlic, I mix with lemons, honey and make cough syrup and it is done."* (42-year old woman; never been on ART)

For many PLHIV, herbal remedies were taken as a routine part of life regardless of whether they were experiencing illness-related symptoms or not. Some herbal remedies were cheap while others like aloe vera gel were expensive, fetching as high as US$30 per one liter container. Those with financial means were able to buy these herbal remedies from drug stores, pharmacies, herbal medicine traders and herbal medicine shops. Some PLHIV periodically relied on financial support of relatives to procure these herbal remedies. Some herbal remedies like moringa and ginger, comparatively cheap, were routinely added to food or tea or juice to treat or prevent illnesses such as cold and flu, diarrhoea or generally to allegedly 'boost' the immune system and reinvigorate the body.

Some PLHIV reported planting these 'health-enhancing' herbs, particularly *moringa* and aloe vera (*tembusha)* at home to ensure easy and unfettered access. While ART required high levels of adherence, this was reportedly not the case with herbal remedies. PLHIV reported taking them if and when they wanted. The flexibility of herbal treatment requirements was in part the reason why some PLHIV found herbal remedies attractive compared to conventional HIV medication which required strict adherence. One woman proudly expressed her affection for these herbal remedies:

> *"For me, I take tembusha (aloe vera), and my CD4 cell count is high; that explains that the herbal medication is working. So, why should I start ART?"* (32-year old woman; never been on ART)

One of the recurring themes was that while the study participants acknowledged the efficacy of ART, the burden of taking treatment for life, stringent adherence requirements and concerns about treatment side effects attracted them to use herbal remedies. One woman said:

> *"Even if the ARVs work, people say they are for life and that they have side effect. So when people hear that, they decide to go for herbs because no one wants to experience the side effects or to take the medication for life. They say that herbs have no side effects.*" (23-year old woman; never been on ART)

Faith healing as HIV cure

Faith healing was also sought for curative purposes. Some PLHIV reported travelling outside Zambia in search of healing while others relied on their faith in God to secure healing:

> "*When I went [to Nigeria] for healing, I was never the same person again…No one can deceive me that the power of God cannot work or does not work. I saw blind people gaining back their sight; I saw people in wheelchair walk; I saw people who could not hear start hearing. What more evidence does one need to believe that God performs miracles?* (48-year old man; stopped ART)

> *"The thing is that when I pray, God tells me what to do. So God told me in a vision that you are healed and from the time that I prayed and stopped treatment, I have never been sick and have never taken any form of medication. The only secret which is there is to pray, and to believe in God, to have faith in Him."* (45-year old man; stopped ART)

Ironically, some health workers with HIV, including those working in the ART clinic and eligible for ART also opted for faith healing and/or herbal remedies:

> *"I have also taken anointing water from [....]. They say it cures if you have faith because it is prayed for by the man of God."* (27-year old woman; pharmacy technologist)

Using conventional medicine, but only to treat HIV-related infections

Acutely aware of their fledgling health and limitations of other self care strategies, some PLHIV did not completely cut-off ties with the formal health system. In the absence of herbal medication or whenever symptoms did not abate, some PLHIV sought formal health care, but only to use conventional medicine to treat opportunistic infections. Skin infections, respiratory infections and gastrointestinal tract infections were the most commonly reported HIV-related ailments. In other instances, PLHIV got over-the-counter medication, from a plethora of drug outlets in the area and the city centre. Antibiotics such as septrin (cotrimoxazole prophylaxis), flagyl, amoxicillin, anti-diarrhoeal medication were the most reported conventional drugs used. Some PLHIV reportedly used antibiotics used by their spouses on ART. Two PLHIV narrated:

> *"I just go to the clinic, they give me amoxil, and at times I go to the drug store and buy panadol or septrin or drugs for diarrhoea.... At the clinic, I just pretend as if I was never on ARVs because if I tell them, they [nurses] will just tell me to go to the ART clinic and get ARVs."* (43 years old woman; stopped ART)

> *"I take two tablets of septrin in the morning every day. When the drugs get finished, I go and buy…. Like today, I took my last drugs and I am planning to go and get some drugs from my friend on credit. She runs a drug store. She gives me on credit each time I do not have money to buy.*" (31-year old woman; stopped ART)

Periodic monitoring of CD4 cell count

Coupled with uptake of herbal remedies, faith healing and conventional non-HIV medication, some PLHIV also monitored their immune system through periodically seeking CD4 cell count testing. Those with the financial means went to private clinics while others made private arrangements with public sector clinic staff to access CD4 cell count testing. At private clinics, charges for CD4 count testing ranged between ZMK50, 000 (US$10) and ZMK 150,000 (US$30) per test. Financial support from family members enabled some PLHIV to meet the costs. One PLHIV explained this strategy:

> *"I do my tests at a private clinic, there at Dr [.....]'s clinic. He tests for CD4 count. The last time I tested my CD4 count, it was in 2009 but time has elapsed since I last did my CD4 count."* (43-year old woman; never been on ART)

Healthy lifestyle practices

Dietary improvements

Good nutrition was a recurring theme as a self-care practice. While many PLHIV found this hard to sustain due to fragile livelihoods characterised by lack of job opportunities and steady and 'adequate' income, this problem was attenuated by improvising local food menus, for instance adding pounded groundnuts to vegetables like rape, cabbage, pumpkin leaves, locally called *"kusashila"* to nourish their bodies and improve their health condition. Other PLHIV heavily relied on nutritional supplements, sometimes supplied by relatives outside the country – in Europe, South Africa and United States of America:

> *"I usually depend on a food supplement called 'Shake herbal life'. It comes from America. It is in powder form. When you want, you can add it to milk or you can add even fruit juice. It is like powdered milk. What I do is, in the morning, I just take a glass of water and put two full tea spoons of the same 'Shake' and then I mix it and then I drink. If I have money, instead of water, I put milk, I mix it with milk and then I drink. If I have money and I have bananas, I blend and add it to my water and milk and then I drink. Those are my ARVs."* (38-year old woman; never been on ART)

Risk reduction practices

Safe sex and cessation of sexual relationships

To avoid re-infections particularly through unprotected sex, some PLHIV, especially those not married - either widowed or divorced/separated - reported either practicing safe sex or ceasing sexual relationships altogether. Some PLHIV drew lessons from the experiences of other PLHIV who had reportedly continued to live 'healthy' and 'normal' lives without ART partly because they had reportedly avoided re-infections. Two PLHIV explained:

> *"From the time my husband died, I have vowed to abstain from sex. This has helped me because I learnt it from my HIV positive sister who has not been on any form of treatment*

> *since 1995 but is still alive and healthy today. Her secret is good diet and no sex.”* (42-year old woman; never been on ART)

> *“Then we developed a culture in the house to say that let us start using condoms. In the house, it is condomising now. Then I think sometimes God comes in, you know. I have been praying to ensure that he would be agreeing to it, you know and for sure, he was not like, no what, what, and so we have been on condoms like that. He has been comfortable with it and we have been living like that.”* (38-year old woman; never been on ART)

Psychological wellbeing self-care practices

“I rely on Jesus Christ”- Religiosity and spirituality

Religiosity, particularly Christianity, was found to be woven into the day-to-day lives of some PLHIV, thus becoming a powerful self-care practice. Despite anticipation of stigma in religious circles due to the perceived association of HIV infection with improper sexual behaviour and a sinful lifestyle, through self-identification as Christians, some PLHIV, mostly women, drew on the biblical assurances of healing as a source of comfort and hope. Through organized religion, some PLHIV belonged to Christian denominations that were more accepting to PLHIV, particularly churches whose leaders or pastors professed to offer healing for people with HIV. While hoping for healing, some PLHIV reportedly put ‘everything in the hands of God’. They reported conducting private individual prayers with their pastors, going for collective intercessory prayers in which they opened up to one another and religious leaders about their HIV condition. One PLHIV who disclosed her status to her pastor described her unflinching belief in God:

> “*As for me, I rely on Jesus Christ…. I just told myself that it is better I face Jesus Christ, God himself since He is the one that gave me life, not a human being. In John 14:1 [Bible], Jesus says ‘I am the way, the truth, and the Life.’ You know if God wants to take my life now, He can do it, whether I am on ARVs or not. I have a lot of friends who were on ARVs but have since died. Why? It is because man cannot preserve life; only God can.”* (48 year old HIV positive woman; stopped ART)

Another PLHIV explained her prayer life:

> *"Even if you take the medicine, if you do not look to God for healing, you cannot get cured. So everything only works if you also involve God. So I also pray to God for me to be cured. I go for prayers every morning. There are inter-denominational prayer meetings here in Chawama, there at Pentecostal holiness in Kuku compound. Prayers are held every morning, everyday, Monday to Saturday. The prayers start at 06 hours up to 7 hours*." (21-year old young woman; stopped ART)

To complement their prayer lives, some PLHIV reported using 'anointing water' - water believed to have healing properties after being prayed for by a Pastor believed to have spiritual healing powers - in order to ward off illnesses. They bought it from their churches that sold it or ordered it from Nigeria where a renowned Pentecostal tele-evangelist was reported to have spiritual healing powers. It cost at least US$100 for a 100 mls bottle. At a time when ART was free in public sector clinics, some PLHIV still opted for faith healing despite the associated financial costs. One PLHIV who went to Nigeria for prayers and bought the 'anointing water' explained:

> *"It is called anointing water. I have got it right with me in the car. What happens is that he [Pastor] does not heal you, you heal yourself. The belief that you have got yourself that God can heal you is what heals you. The belief that tomorrow I will walk, that tomorrow my immunity will rise, it will. It is you and God, and I believe it. Belief is not medicine, but it also heals. You do not just need medicine to get healed. You also need belief."* (48-year old man; stopped ART)

'I avoid thinking about it too much': Positive attitudes towards HIV infection

Some PLHIV acknowledged the relationship between psychological well-being and their immune system. Therefore, developing and maintaining positive attitude towards their HIV condition was viewed as another pre-condition for improved physical well-being. This meant reconstructing their lives to attain a sense of normalcy. PLHIV avoided 'thinking too much' about HIV and treated HIV as any other infection: "*I just try by all means to ignore it; I just pretend as if it does not exist. I tend to live a normal life",* said *a* 23-year old man, who had never been on ART. *"I do exercises; and I keep my mind very free. I avoid thinking about it too much,*" said another 24-year old man who has never been on ART. This enabled them to treat

HIV not as a fatal condition; rather as something that they could live with and manage while acknowledging episodic periods of good and poor health.

The role of social network relationships

The self-care practices were modulated by kin and non-kin social network relationships. PLHIV treatment seeking behaviour was influenced by relationships with friends/family members and some formal health care providers. For instance, limited disclosure of HIV status to close and trusted friends and family members as well as formation of or belonging to informal networks of PLHIV facilitated coping and self-management of HIV. The social support received could be delineated into two: illness-specific support such as provision of financial resources to access herbal remedies and over-the-counter conventional medication to mitigate the HIV-related symptoms and obtain nutritional supplements. This type of support was mainly provided by family members:

> *"So me, I just use herbal remedy called 'palibe kantu' (there is no problem) which my mother organises for me.... from the farm in Mumbwa (another district). This herb grows and spreads on the ground like sweet potatoes. So you peel it and boil it and start drinking the water. So she brings that for me from time to time."* (32-year old woman; never been on ART)

The second form of social support mainly provided through religious groupings and networks with other people living with HIV involved psychosocial support. In addition, PLHIV also provided informational support to each other on illness management including which herbal remedies to use for what symptoms or ailments. They also shared information about sources of herbal remedies. As one PLHIV explained:

> *"You know, you come to know each other when you start treatment because in a day, they enrol may be 10 people which means these ten people will be coming to the clinic on the say day plus those that have already started treatment. So, even when you stop taking ARVs, you reach a stage where you know each other, support each other, and even encourage one another."* (39-year old woman; stopped ART)

In some cases, driven in part by their own treatment and health beliefs, it appeared that some health workers encouraged PLHIV to use faith healing and herbal remedies either in combination with or to the exclusion of ART care. Asked how she reconciled her non-uptake of treatment and counselling PLHIV to start and adhere to ART, one lay ART support worker explained:

> *"You know, me even when I am at the ART clinic, I also encourage those people to say that it is not only ARVs, even herbs, because sometimes you find that somebody is taking ARVs, but still more the CD4 count keeps on dropping. You see, I would also advise them that can you also try this, try herbs."* (42-year old ART support worker; never been on ART)

For better and for worse: PLHIV perceptions and experiences of self-care practices

Some PLHIV reported a rebound in their CD4 cell count or improved physical health due to the use of herbal remedies or after going through prayer sessions and therefore believed that it was possible to live a normal and healthy life if one used herbal medication and/or 'surrendered' his life to God for care. One lay health worker who has never been on ART explained her experience:

> *"When they told me that 'your CD4 count is low', I just started using herbs like moringa, and after that, my CD4 count improved a bit up to 460 something."* (32-year old Treatment support worker; never been on ART)

Another PLHIV - an ART support worker - who went to South Africa for prayers instead of seeking ART care also reported a rebound in her CD4 cell count. She recounted:

> *"We were taught how to receive healing. We were learning about how to have faith, and how to receive healing. And when we [with the husband] came back from there, I was just ok. When I came back, I went to the clinic to check my CD4 count and it had been boosted from 165 to 365. So that is it.*" (37-year old woman; never been on ART)

For some PLHIV, a rebound in physical health was not associated with previous use of ART. Instead, they attributed 'good' health to the effectiveness of their non-ART related self-care practices. One PLHIV who had gone to Nigeria for healing prayers explained his experience:

> *"When I went there, I was not walking. Other people were assisting me to walk. But when I came from there, I was walking. He never gave me any herbs; he never gave me any medicine. He just gave me water and prayer."* (48-year old man; stopped ART)

Notwithstanding the perceived effectiveness of these self-care strategies, some PLHIV reported noticeable decline in their health and all PLHIV contemplated starting ART if all other efforts failed. For others, a decline in health status was attributed to either lifestyle behaviour deemed incompatible with their condition or due to psychosocial distress. These included beer drinking, smoking, challenges of maintaining a nutritious diet, pregnancy and psychological distress due to strained family relationships. As two PLHIV explained:

> *"The only problem why I develop these health problems, I look sick, is that I started drinking again. After two years of stopping treatment, I was ok. But that habit of drinking came back….The only mistake I made was that I started excessive drinking. Again I realized that this beer will kill me. So I stopped. I do not drink beer anymore."* (48-year old man; stopped ART)

> *"I used to monitor my CD4 count, and it was high... until 2008 when I was pregnant that is when my CD4 count came down.... But I think my CD4 count is also low because most of the time, we are quarrelling with my husband, so I think my mind is often disturbed."* (32-year old woman; never been on ART)

Despite reporting a decline in health status, some PLHIV still remained upbeat, viewing their poor health as temporal - a period which every individual, regardless of their HIV status went through - and not an indication that they needed to start treatment. HIV treatment was viewed as not a guarantor of good health and their lives. To them, the death of PLHIV despite being on ART was emblematic of the shortcomings of ART:

> *"It happens in life. Sometimes you can have good days and sometimes you can have bad days. So, if my health is not good today, it does not mean that it will be like that forever. Things change; starting treatment does not guarantee that you will become healthy forever. What about those people who have died despite taking ARVs?"* (24-year old man; stopped ART)

8.3 Discussion

Our study explored the different self-care practices that PLHIV used as alternatives to ART care. We found that PLHIV used - often concurrently - herbal remedies, over-the-counter conventional medicine and faith healing, augmented by adoption of healthy lifestyle practices to promote physical and psychosocial well-being. If PLHIV opting for self care alternatives subsequently accessed health services, they never mentioned to non-ART prescribing health workers that they had opted to discontinue accessing ART or that they had opted not to start treatment. Neither did health workers inquire about the health and treatment history of these PLHIV. Thus, health workers missed the opportunity to bring these PLHIV back into ART care and treat them for the underlying cause of their ill-health. These self-care practices were modulated by availability of social support (Figure 8-2). These findings have implications for successful delivery of ART care.

Herbal remedies may mitigation HIV symptoms but undermine access to ART care

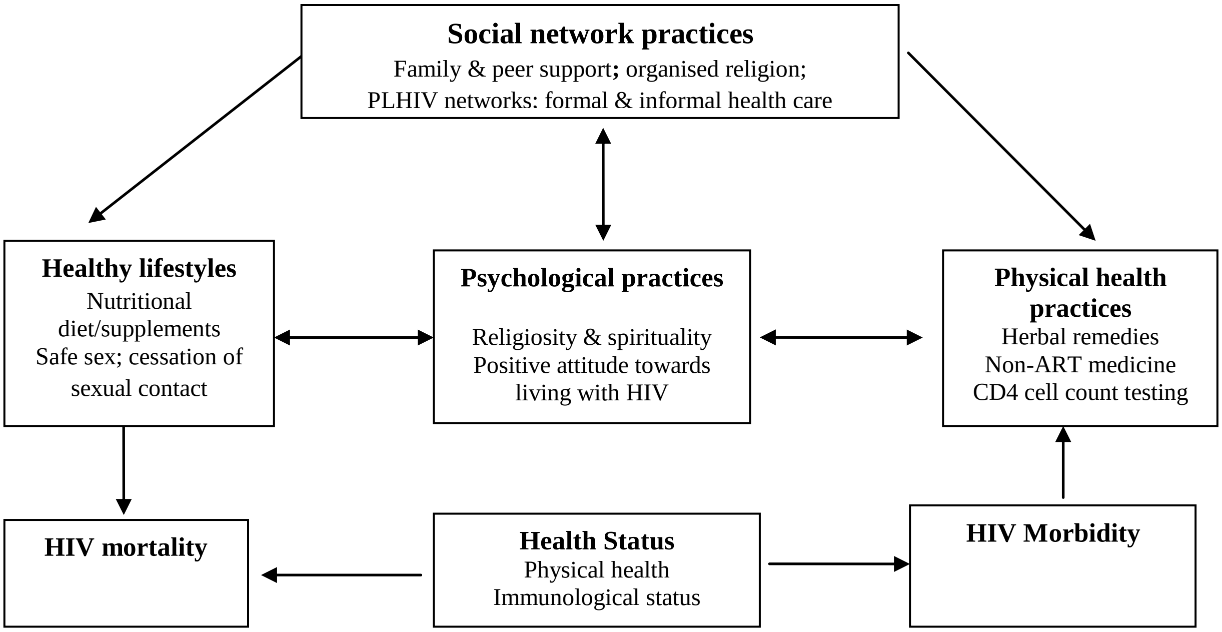
Our findings show that herbal remedies were widely used as a self-care practice. The herbs were reportedly used to ‘cleanse’ the body of toxins, to treatment opportunistic infections, ‘boost’ the immune system and enhance physical functioning. The pressure associated with adhering to ART compared with herbal remedies that were taken on “if and when they want” basis motivated PLHIV to opt for herbal remedies. These herbs were perceived to be as effective as ART, albeit with perceived fewer side effects and no strict dosage and adherence requirements. Our findings are consistent with previous studies that have reported wide use of herbal medication as a self-care strategy (Ernst 2000; Duggan et al. 2001; Thorne et al. 2002; Hsiao et al. 2003; Marie Modeste & Majeke 2010; Monera & Maponga 2010).

Worryingly, the growth of the market for herbal remedies, their popularity and perceived effectiveness without scientific proof, risks undermining the success of ART care and consequently increasing the burden of HIV care in the long term. This could happen in three ways: first, by inhibiting patient (re-) entry into ART care and second, by ‘pulling’ out of ART care PLHIV already receiving medication due to the perception that herbal remedies were effective. Consequently, delayed initiation of ART may create additional therapeutic costs when PLHIV eventually return for ART care, albeit in poor health. The reported decline in health by some PLHIV clearly suggests that it is just a matter of time before PLHIV seek ART care.

Third, the perceived effectiveness of herbal remedies could also attract even those already in ART care to use them. For these PLHIV, combining herbal remedies and antiretrovirals could affect the pharmacokinetics of antiretrovirals. This could either lead to higher antiretroviral plasma levels thus putting PLHIV at greater risk of developing serious side effects or lower the optimal therapeutic level of antiretrovirals thereby leading to treatment failure and an enhanced risk of developing drug resistance (Van den Bout-van den Beukel 2006). For instance, garlic, which is widely used as herbal therapy or nutritional supplement, has been reported to affect the pharmacokinetic concentration of HIV medication (Piscitelli et al. 2002; Borrelli, Capasso & Izzo 2007). Bepe and colleagues (2011) found that concomitantly using herbal remedies with antiretrovirals elevates some adverse events. Other studies have also reported reduced adherence to ART by those using herbal remedies and other alternative forms of care (Owen-Smith, Diclemente & Wingood 2007; Peltzer et al. 2011).

Importantly too, with growing demand for these herbal remedies and drawing on the desperation and naiveté of PLHIV, scientifically unproven herbal remedies could pose a health-risk to PLHIV. There have been reports about bogus HIV 'cures' or 'immune boosters' in Zambia and the dangers they presented to the lives and health of PLHIV. For instance in 2007, one of the purported AIDS 'cure' or 'immune booster' was found to be a pesticide, tetrasil, used for cleaning swimming pools (Amon 2008). Therefore, to ensure successful delivery of ART care, there is need for HIV care providers to step up sensitisation campaigns during ART counselling sessions and more widely about the health risks associated with use of unproven herbal remedies. This is critical not only to improve uptake of and adherence to treatment, avert possible negative interaction effects with antiretroviral treatment, but also to protect the health and lives of PLHIV and ensure patient retention in ART care.

Figure 8-2 Nested relationships of self-care practices of PLHIV not on ART



Religiosity and spirituality may simulate counselling but undermine uptake of ART

Our study also found that some PLHIV sought recourse to religiosity and spirituality as a self-care practice. This is consistent with previous studies that have reported use of religiosity and spirituality as coping strategies by those with chronic health conditions, including HIV (Woods & Ironson 1999; Ridge et al. 2007). Religiosity has been associated with less psychological distress (Simoni, Martone & Kerwin 2002) and less depression (Simoni & Ortiz 2003), suggesting that it provides beneficial psychological outcomes. This is despite the reported stigmatizing influence of religious beliefs due to the association of HIV infection with improper sexual relationships (Genrich & Brathwaite 2005; Zou et al. 2009).

In our study, religion and Christianity in particular was not only used to secure complete healing, but also to provide hope, comfort and assurances in the face of an incurable disease. While PLHIV were exposed to stigmatizing attitudes within religious settings, they often navigated their spiritual lives by moving to churches that preached healing and deliverance and whose leadership was perceived as open and receptive to PLHIV. Some PLHIV that were not publicly open about their HIV status only confided in and sought healing from their religious leaders. Two lessons can be drawn which have implications for successful delivery of ART care: On a positive note, these findings suggest that prayer simulates aspects of counselling (Ridge et al. 2007) and can therefore be a useful coping mechanism for living with HIV. However, there is a thin line between faith healing as a psychosocial coping strategy and faith healing as a cure, with the latter posing a threat to patient access to and retention in ART care. More so, religious beliefs can trigger a fatalistic attitude and passive resignation with death, thus hindering uptake of treatment. Therefore, during group sensitisation and individual counselling sessions at ART clinics, health workers should tap into PLHIV belief systems to identify and harness those beliefs that promote psychosocial well-being without hindering PLHIV uptake of treatment. At community level, sensitisation efforts are required to encourage PLHIV claiming to have experienced healing through prayers to undergo formal medical tests to substantiate these claims. This is critical to ensure that PLHIV get (back) into ART care.

PLHIV self-prescription of antibiotics raises concerns about development of microbial resistant strains

Due to the experiential limitations of faith healing and herbal remedies in addressing HIV-related ailments, we found that the use of conventional medicine, particularly antibiotics as a self-care strategy was common amongst PLHIV. Since the onset of ART roll-out, western medicines like co-trimoxazole prophylaxis (trimethoprim-sulfamethoxazole) have become widely available in low-income countries to treat microbial infections in PLHIV. The World Health Organisation (WHO) guidelines recommend provision of co-trimoxazole prophylaxis to all HIV symptomatic adults with CD4 count lower than 350 cells per μL in resource-limited settings (WHO 2006). Co-trimoxazole prophylaxis has been found to reduce mortality and morbidity amongst PLHIV through prevention and control of opportunistic infections (Walker et al. 2007; 2010). Based on their knowledge of these conventional medicines and experiences with the formal health system and social network ties, PLHIV opted to obtain antibiotics in order to manage AIDS-related ailments. Our findings suggest that there was widespread use of antibiotics obtained either privately from the public sector clinics or purchased from a plethora of drug stores and pharmacies. The self-prescription of antibiotics raises great concern about future development of microbial resistance to antibiotics amongst PLHIV which could undermine future efforts to deal with HIV-related opportunistic infections. In the past, the World Health Organisation (WHO) has raised concerns about bacterial resistance to antibiotics due to their inappropriate use (WHO 2000). The reported widespread self-prescription and use of antibiotics by PLHIV therefore calls for sensitization measures about the dangers of self-prescription of antibiotics, especially amongst PLHIV. There is also need for enforcement of pharmaceutical regulations to control self-prescription and use of antibiotics, including clamping down on unregistered drug stores. This is even more critical for effective care of patients in ART care.

Social support may also undermine uptake of ART care

As a corollary, self-care practices were found to be socially delineated and modulated by social support mechanisms. Social support “entails the structure of an individual’s social life (i.e. group memberships, existence of familial ties) and the explicit functions they serve such as emotional support” (Uchino 2006). Previous studies have reported that social support was a strong predictor of utilization of formal HIV care services (Uphold & Mkanta 2005) and improved the odds of entry into and use of ART care (Waddell & Messeri 2006). Our findings suggest that while social support may serve as a stress-buffer and enables individuals through their social support networks to easily come to terms with their condition and develop a more positive outlook to life in the face of an incurable condition, social support is also a key self-care input factor that undermines access to ART care (Figure 8-2). For instance, social pressure and influence existed at family and interpersonal level to shun ART. Conversely, social support in the form of material, financial and moral support was provided to access herbal remedies, over-the-counter conventional medication to treat AIDS-related symptoms, and faith healing as cure for HIV. This places PLHIV at risk of AIDS-related morbidity and early mortality (Figure 8-2).

While the physical and psychological self-care practices complemented by adoption of healthy lifestyles such as practicing safe sex/cessations of sexual relationships to avoid re-infections are vital in the overall management of HIV, these behavioural practices in the absence of ART care are not sufficient to effectively prevent disease progression. The long-term benefits, therefore, reside in encouraging PLHIV to get back into ART care.

Study limitations

Caution has to be taken when generalising the study findings. Some PLHIV were recruited in the community through their caregivers or snowball sampling and their eligibility for the study was based on self-reports of being eligible for treatment. Snowball sampling may have led to clustering of shared ideas and views. However, over two thirds of the study participants were identified, contacted and recruited through the ART clinic staff who were aware of which individuals had dropped out of ART or declined ART despite being eligible, suggesting that our sample largely comprised of treatment-eligible PLHIV who were independent from each other. Also, this study was descriptive and exploratory, aimed at providing wide ranging insights into how PLHIV managed their health in the absence of ART and how these self-care practices impacted uptake of ART. Thus, the purpose of the study was neither to establish causal relationships (i.e. effect of herbal remedies on immune system) nor to assess the effectiveness of these self-care strategies.

The paucity of data on PLHIV self-care practices meant that the study had to focus on identifying a wide range of themes rather than securing a representative sample of non-uptakers of treatment. To mitigate the potential for bias in the selection of study participants, we endeavoured to ensure that our study sample was diverse in terms of demographic, length of time since diagnosis and treatment-related characteristics. Therefore, similar studies are needed in other settings for comparability of findings. Despite these possible limitations, our findings could be generalised to similar settings in urban areas in the country and provide useful insight to inform policy and practice to improve ART uptake.

8.4 Conclusions

This study explored the self-care practices of PLHIV not receiving ART. These PLHIV comprised those to whom ART was recommended by ART providers but for other reasons opted not to initiate treatment and PLHIV who had completely discontinued their medication. Our findings show that the use of herbal remedies and faith healing were dominant self-care practices. In addition, PLHIV used conventional medicines, but only to deal with AIDS-related ailments. It was also common for PLHIV to concomitantly use these different self-care practices. While these self-care practices were perceived by PLHIV to be effective, some PLHIV still reported slow and intermittent decline in health status, an indication that these self-care strategies were not as effective as reported and experienced. For PLHIV that had dropped out of ART, the perceived effectiveness of self-care practices could be attributed to previous use of antiretrovirals. These self-care practices undermine patient uptake of treatment and risk compromising future effectiveness of medical therapies and increase likelihood of microbial resistance and HIV resistant strains amongst PLHIV. In turn, this could increase the costs of ART care and family and community resources. Therefore, to ensure effective delivery of ART care, there is need to compile and include evidence of complementary HIV care practices into counselling guidelines and encourage those self-care practices that do not affect the effectiveness of antiretrovirals and do not put the health of PLHIV at risk. On the other hand, some of the self-care practices like self-prescription and indiscriminate use of antibiotics and use of scientifically unproven herbal remedies may cause long-term harm to PLHIV hence the need for sensitization campaigns and enforcement of pharmaceutical regulations to address them.

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Authors' contributions

MM conceptualized the study, conducted data collection and analysis and wrote the draft manuscript. **VB** and **SM** contributed towards the conceptualization of the study, provided input in the analysis, interpretation of the findings and drafting of the manuscript. All authors have given final approval of the version to be published.

Chapter 9

Discussion, Conclusions and Implications for Policy and Practice

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9.0 Discussion of the thesis

From a public health perspective, effective control and management of HIV requires ensuring increased uptake of HIV testing to facilitate entry into care by those infected and ensure adoption of risk reduction behaviour by those not yet infected. It also entails ensuring that those living with HIV access and remain in ART care. This is critical to realize UNAIDS vision of achieving new zero infections and zero AIDS-related deaths (UNAIDS 2011). This PhD thesis therefore makes a contribution towards generating evidence to inform policy and practice for better delivery of HIV testing and treatment services in Zambia and SSA.

9.1 Methodological considerations: Justification, reflections & limitations

To understand factors influencing uptake of HIV testing in sub-Saharan Africa (SSA), a systematic review using meta-ethnography was undertaken. In recent years, systematic reviews have been conducted on, for instance, provider-initiated HIV testing linked to antenatal and delivery services (Ferguson et al. 2012; Hensen et al. 2012) and amongst non-pregnant adults in SSA (Roura et al. 2013). A review of different models of HIV testing in SSA has also been conducted (Matovu & Makumbi 2007). However, systematic reviews of qualitative studies have been lacking. The only study that has synthesised qualitative studies was undertaken by Obermeyer & Osborn (2007). However, this synthesis used a literature review approach - summarising the main findings of the studies - and was not specifically restricted to SSA. On the other hand, meta-ethnography was used in this PhD thesis to synthesise qualitative research findings on SSA. For meta-ethnography, emphasis is on developing new interpretations and concepts across multiple studies rather than accumulation of information (Walsh & Downe 2005). This led to the development of a conceptual model to depict the nested relationships of these factors (Figure 3-2). This approach also helped identify research gaps, in this case why individuals who knew the HIV status of their marital partners never sought HIV testing. This became a focus of the PhD thesis too.

Using a multi-disciplinary team ensured rigour of the synthesis and enriched it by drawing on research team members' diverse disciplinary orientations which informed their interpretations of the findings. An inherent weakness of the meta-ethnography was the possibility of having missed some publications. This was however mitigated by scouring references of selected papers and manually searching the databases. Not using a pre-determined quality assessment criteria or excluding papers on the basis of pre-specified quality assessment criteria ensured that papers were included on the basis of the 'richness' of the findings and not methodological weaknesses. Another limitation of this synthesis was that due to language constraints, we only included papers published in English.

To explore factors influencing uptake of HIV testing and HIV-patient non-initiation of and attrition from antiretroviral therapy (ART) care, qualitative studies were conducted. Qualitative research is the most useful approach for exploring an under-researched area and providing explanatory power about a given phenomenon. In Zambia, it was evident that there was paucity of data on why individuals dropped out of ART or never initiated treatment despite availability (Reid, Mulenga & Folk 2008). Given the 'hard-to-reach' nature of people living with HIV (PLHIV) who had either dropped out of ART or were unwilling to initiate treatment by virtue of their non-contact with the health system, qualitative purposive sampling methods were more appropriate for identifying and interviewing them. Living in the study area helped developed rapport with the study participants and facilitated the contextualization of the meanings and interpretations that informed research participants' health-seeking actions. By using the social ecological framework, the study was able to use a holistic approach that bridges the divide between "individualist" and "structuralist" models of understanding health-seeking behaviour (Roura et al. 2009). Interestingly, the PhD findings suggest that the multiple-level factors influencing non-uptake of treatment are not mutually exclusive, confirming Bronfenbrenner's assertion that: "In ecological research, the principal main effects are likely to be interactions" (Bronfenbrenner 1977, p. 518).

Since different research methods reveal different aspects of empirical evidence, different methods of data collection and analysis were employed (Patton 1999). The use of triangulation –

different methods of data collection on the same subject such as in-depth interviews, focus group discussions, key informant interviews and observations ensured in-depth collection and triangulation of the findings.

Despite the aforementioned, two limitations of the qualitative studies could still be deciphered. A more general limitation concerns the generalisability of the findings. The qualitative studies were based on small-purposively chosen samples aimed at identifying a wide range of themes rather than getting a representative sample. For studies 6 and 7 (Chapter 6 and 7), some PLHIV were recruited in the community through their caregivers or snowball sampling and their eligibility for the study was based on self-reports of being eligible for treatment. Consequently, this recruitment strategy could have led to some clustering of shared ideas and views. However, more than three-quarters of the study participants were identified, contacted and recruited through the ART clinic. The clinic staff were aware of which individuals had declined or dropped out of ART care suggesting that our sample largely comprised treatment-eligible PLHIV who were independent from each other. Maximum variation sampling was used to ensure that research participants were of diverse key characteristics including age, sex, marital status, duration on and off treatment to ensure transferability of study findings to similar settings. Also, more women than men were recruited due to the difficulties of recruiting men for the study. The reasons included: some men refused to be interviewed; many were mobile due to their livelihood activities; and others were no longer in contact with the health system in the area and not attached to home-based care providers. However, as the findings suggest, the reasons for non-uptake of treatment were similar between men and women. Future studies should aim to explore this further including targeting rural and higher socio-economic strata populations for comparability of findings.

9.2 Factors influencing uptake of HIV testing

Based on the meta-ethnography and additional qualitative research on factors influencing uptake of HIV testing in Zambia and sub-Saharan Africa, the following insights were generated:

9.2.1 Lay perceptions of risk of HIV infection and health promote & undermine HIV testing. In Chapter 3 and 4, this PhD thesis has shown that one recurring theme for non-uptake of HIV testing is that individuals conduct their own lay assessments of their health and engage in intense activity of experience-sorting and interpretation as they situate themselves in terms of risk of HIV infection (Warwick et al. 1988). This lay assessment is based on individuals' assessment of their own and partner's sexual behaviour - a proxy for risk of infection - and observations and experiences of their physical health or that of their partners or children (Paicheler 1999). Consequently, heightened risk of infection provides impetus either to test to confirm HIV status or leads to perception that one is already infected thereby undermining uptake of HIV testing. In chapter 4, the PhD thesis illuminates how research participants did not seek HIV testing because they assumed that they were already infected on account of the HIV-positive status of their spouses. The findings point to the need for sensitization measures specifically focusing on addressing the disjunction between perceived and actual risk of HIV infection. Previous studies in Malawi (Anglewicz & Kohler 2009; Bignami-Van et al. 2006), Nigeria (Fagbamigbe et al. 2011) and Zambia (Stringer et al. 2004) have reached similar conclusions.

In both Chapter 3 and 4 of the thesis, the psychological burden of living with an incurable disease was also found to undermine uptake of HIV testing. Having HIV was associated with imminent death despite the increasingly wider availability of life-prolonging antiretroviral therapy in Zambia and most parts of SSA. Given its incurable nature, the findings suggest that HIV still exudes fear and not knowing one's HIV status was used as a powerful psychological buffer. In particular, psychological distress of knowing one's HIV-status was viewed as leading to rapid deterioration of health. Thus, individuals would only seek HIV testing when it necessitated access to health care. What the findings therefore mean is that HIV testing is still largely undertaken to facilitate access to health care and not as an HIV preventive strategy pointing to the need for continued sensitisation especially if UNAIDS vision of new zero infections is to be attained.

9.2.2 Trust & confidence in the health system critical for utilisation of HIV testing services: In chapter 3 of the PhD thesis, the findings suggest that even when individuals view themselves at risk of HIV infection and/or are willing to seek HIV testing, uptake of HIV testing is influenced by their perception of and trust in individual health workers and the health care system as a whole (Cunning et al. 2007). Perceived inability by health workers to maintain confidentiality, perceived poor calibre of health workers and lack of trust in testing technologies which are sometimes couched in religious discourse inhibit uptake of testing. For instance in a study in Zambia (Frank, 2009), the health system was viewed as a place for HIV sero-conversion. Studies in the United States of

America have reached similar conclusions (Altice, Mostashari & Friendland, 2001; Bogart & Thornburn, 2005; Whetten et al. 2006). Narratives from Chapter 3 (systematic review) indicate that lack of trust in health care providers was attenuated by the provision of HIV testing through non-facility based HIV testing by non-familiar providers, thus improving uptake of HIV testing. Therefore, since health institutions are social institutions (Gilson, 2003), improving utilisation of HIV testing services requires improving the quality of health care delivery particularly ensuring health worker professionalism.

In a few settings of SSA, lack of trust in the health care system also took the form of conspiracy beliefs. HIV testing was viewed as a western ploy to benefit western countries through creation of market for bio-medical products (Castle, 2003) and job opportunities for its citizens (Frank, 2009). These geo-political conspiratorial beliefs sometimes coalesced with religious discourse. In Zambia for instance, blood drawn for HIV testing was viewed as being used for satanic rituals (Frank 2009). These findings are corroborated by previous research conducted in Gambia (Fairhead, Leach & Small 2006) and Zambia (Schumaker & Bond 2008; Kingori et al. 2010). These conspiracy beliefs were not found in the PhD research. On balance, these findings suggest that political and religious beliefs are potent forces that undermine uptake of HIV testing and therefore need to be addressed.

9.2.3 Social support and exclusion: HIV testing requires navigating social dilemmas: In Chapter 3, the PhD thesis clearly demonstrates that HIV testing behaviour is strongly socially delineated. Social relationships and aspirations play a significant role in influencing HIV testing behaviour. For instance, in the absence of strong formal safety nets, the desire to preserve social relationships and identity inhibit uptake of HIV testing. This is because while individuals may acknowledge the importance of knowing their HIV status and even show willingness to seek testing in response to (perceived) decline in health or because of previous sexual risk behaviour, ultimate decision making and attitude towards testing is influenced by concerns about anticipated stigma, which is sometimes inextricably linked to possible loss of economic support. Similarly, in most parts of SSA, gendered power relationships undermine uptake of HIV testing as ultimate authority on health care seeking lies with men (Tolhurst et al. 2002; Tolhurst et al. 2008) and communication with and support from partners improves uptake of HIV testing by women (Bajunire & Muzoora 2005; Sarker et al. 2007). Failure to access HIV testing by women due to gendered decision making power was a recurring narrative in Chapter 3 of the thesis.

Even though ART roll-out had reduced AIDS-related mortality and morbidity and thus stimulated uptake of testing, the stigmatisation of people on treatment that they ‘spread the disease’ however undermines uptake of HIV testing. This was reported in a study in Tanzania (Roura et al. 2009). What the findings in this research suggest is that despite the benefits of life-prolonging and physical transformative effects of ART, uptake of HIV testing could only be optimised if stigma is reduced. Sensitisation efforts to address stigma are therefore still warranted.

Chapter 3 encapsulates the crucial role that individuals’ marital and reproductive health aspirations play in either facilitating or undermining uptake of HIV testing. In the synthesised papers, both men and women sought or planned to seek HIV testing as preparation for marriage or achieving reproductive health aspirations. Others reported getting or planning to get tested because it was a church requirement for sanctioning of marriage. These findings suggest that marital and reproductive health aspirations present an opportunity to facilitate uptake of HIV testing. This is even more relevant given the growing body of evidence that shows that a large proportion of HIV infection occurs in marital or cohabiting relationships (Carpenter et al. 1999; Hugonnet et al. 2002; UNAIDS, 2010a) and high prevalence of discordant couples (UNAIDS, 2010a).

9.2.4 Mitigating financial and social costs: The role of routine, mobile & home-based HIV testing services: Early advocates of provider-initiated HIV testing have pointed out that HIV ‘exceptionalism’ is no longer adequate to deal with the HIV pandemic in SSA (De Cock et al. 2002). In June 2007, UNAIDS and WHO issued guidance recommendations on provider-initiated HIV testing (WHO/UNAIDS 2007) and 42 Africa countries have since adopted this HIV testing strategy (Baggaley et al. 2012). In Chapter 3, the PhD thesis shows that many innovative HIV testing initiatives have been undertaken in order to scale-up coverage of HIV testing in SSA (Matovu & Makumbi 2007). For instance, in Chapter 3 and 5, the thesis reports that the implementation of diverse testing initiatives has resulted in increased uptake of HIV testing. Individuals got tested through provider-initiated HIV testing in TB, antenatal clinic; ‘opt-in’ mobile HIV testing and home-based HIV testing. Mobile and home-based HIV testing initiatives have mitigated barriers to HIV testing (Mutale et al. 2010; Ostermann et al. 2011) such as distance, financial costs, long waiting times, inconvenient testing hours and allayed fears of perceived lack of confidentiality by health facility staff. When individuals are in contact with service providers either through mobile and home-based HIV testing or through routine HIV testing in clinical settings, HIV testing is undertaken not only because it is conveniently available but also because it helps preserve service users' sense of moral worth and subsequent stigmatisation associated with having specifically sought HIV testing (Obermeyer & Osborn 2007). In their systematic review of HIV testing approaches, Matovu and Makumbi (2007) have reported high rates of uptake of HIV testing through mobile and home-based HIV testing.

Similarly, in view of pervasive gender inequality in many part of SSA as reported in Chapter 3, routine offer of HIV testing in medical settings absolved women from blame for testing without their partners' consent. However in both Chapter 3 and 4, our findings suggest that uptake of HIV testing was also due to coercive and subtle strategies that are used by health care workers to promote uptake of HIV testing. In Chapter 4, study participants narrated how they were directed to bring their spouses for testing to facilitate disclosure of their HIV status and that informed consent was not explicitly mentioned during the HIV testing process. What the findings suggest is that while adoption of diverse HIV testing strategies is a step in the right direction and is critical to optimise uptake of HIV testing, informed consent especially during provider-initiated HIV testing in clinical settings should not be undermined.

It must also be pointed out that these diverse HIV testing initiatives need to be context-specific given the variations in HIV prevalence in different settings of SSA. This is so because costs per HIV-positive individual identified will be inversely related to the HIV prevalence in those tested (Roura et al. 2013). Therefore, initiative such as mobile and home-based HIV testing may only be cost-effective for high and not low HIV prevalence settings, and the resources needed to achieve this could be substantial.

9.3 Non-initiation of and attrition from ART care

In Chapter 6-8, the PhD thesis encapsulates factors influencing PLHIV non-uptake of and attrition from ART care. The following insights can be deciphered:

9.3.1 *Functional ability and not clinical condition determine uptake of treatment:* In Chapter 6, lay experience of health and treatment negatively affect treatment-seeking behaviour. The findings suggest that individuals assess and perceive their health not only in terms of their clinical health condition as reported by their health care providers; rather, in terms of their corporeal health and functional ability (McKague & Verhoef 2003). The ability to live 'normal' and ‘healthy’ lives and engage in productive activities and social lifestyles without recourse to treatment undermine treatment-seeking. The findings are consistent with other studies (Siegel & Gorey 1997; Beer et al. 2009). These findings suggest that PLHIV are not passive recipients of ART care. Instead, they are active agents and act as ‘naïve scientists’ (Sigel, Schrimshaw & Dean, 1999) and use ‘lay logic and reasoning’ (Lumme-Sandt, Hervonen & Jylha, 2000) as a basis of deciding whether to be on treatment or not. Therefore, ensuring patient initiation of and retention into ART care requires addressing patient health and treatment beliefs. While global (WHO 2010) and national (MoH 2010) HIV treatment policy changes (treatment initiation at higher CD4 cell count of $\leq$350 cells/mm^3) are essential to reduce AIDS-related mortality and morbidity, success will also largely depend on addressing these lay health and treatment beliefs that undermine enrolment or retention in ART care.

9.3.2 *Uptake of treatment competes with desire to preserve social identity and relationships:* In Chapter 6 and 7, the PhD thesis demonstrates that while ART is crucial for long-term survival, uptake of treatment competes with desire to preserve social image, social relationships and social aspirations. The findings imply that the moral dimension of HIV has not diminished. In addition to livelihood insecurity, disclosure of a positive HIV status breeds tremendous social insecurity and loss of material, emotional and social support. Being known as having HIV is therefore avoided by all means especially if PLHIV are dependent on their social support networks. PLHIV coping strategies to preserve social identity through being faith healed, which unfortunately cannot be discussed separately from the stigma associated with being HIV-positive, often meant abandonment or non-initiation of treatment These findings mirror previous studies that have reported that some PLHIV did not initiate treatment because they did not want to be identified as having HIV (Barton et al. 2000; Skovdal et al. 2011c). Thus ensuring patient initiation of and retention in ART care requires addressing HIV-related stigma.

9.3.3 *Accessing treatment requires navigating livelihood and other structural constraints*. Even when individuals are willing to be on treatment, Chapter 6 and 7 show that its uptake requires navigating and overcoming broader structural-level factors. Structural factors are those non-individual based circumstances present in the environment that influence health-seeking behaviour but over which the individual has no direct control (Surmatojo 2000; Parker, Easton & Klein, 2000; Munro et al. 2007). Previous studies have implicated economic-related barriers as influencing patient uptake of treatment (Hardon et al. 2007; Zachariah et al. 2010; Fox et al.

2010; Duff et al. 2010; Tuller et al. 2010). Our findings suggest that livelihood constraints characterised by low-income, insecure labour conditions and difficulties of balancing uptake of treatment and livelihood activities undermined uptake of treatment. Chapter 6 and 7 are replete with evidence of how individuals failed to access treatment either because their employers could not allow them or because they feared losing their jobs if they sought permission to access treatment.

While previous studies have found no correlation between poverty and adherence to treatment (Orrell et al. 2003; Mills et al. 2006), other findings have reported the negative impact of livelihood constraints on treatment adherence (Merten et al. 2010; Reda & Biadgilign 2012). In Chapter 6 and 7, the thesis indicates that it was neither the transport costs of accessing treatment nor the cost of medication that inhibited uptake of treatment because ART services were free and the health facility was conveniently located within the study area. Instead inadequate income and household food insecurity and the challenges of balancing time to access treatment and engagement in livelihood activities dissuaded PLHIV from starting treatment or forced them to drop out of ART care. On balance, these findings suggest that in settings with endemic poverty levels and weak social safety net, individuals are inclined to avoid actions that would expose them to further socio-economic vulnerability. Therefore HIV treatment programmes should be accompanied by livelihood empowerment programmes for PLHIV.

Health system-level factors are also subsumed under structural-level factors. In Chapter 6 and 7, long waiting times were described as undermining patient initiation of and retention in ART care. Interestingly but unexpectedly, specific interventions aimed at improving adherence to ART seemed to push PLHIV out of ART care. Putting ‘defaulters’ on intensive adherence counselling - reverting PLHIV who missed their clinical or pharmacy appointments to weekly doses of treatment and asked to report to the clinic weekly for adherence counselling for at least a month was a case in point. This exasperated the balancing act between treatment and livelihoods as clearly encapsulated in Chapter 7. This finding has not been reported in previous studies conducted in Zambia (Grant et al. 2008; Murray et al. 2009). For patients, this was interpreted as being ‘punished’ for circumstances beyond their control. This and other treatment-related constraints attracted patients to adopt self-care practices such as faith healing, herbal remedies and uptake of conventional non-HIV medication to mitigate HIV-related symptoms as described in Chapter 8. Our findings corroborate the findings of Tugenberg et al. (2006) who found that heavy insistence on adherence by clinicians forced some PLHIV to abandon medical visits. Thus, formal health care system measures – while aimed at achieving positive clinical outcomes - also achieve the opposite. Therefore, while patient-centred interventions are critical to promote adherence, there is need to be mindful of circumstances that make patient unable to fulfil their clinical appointments. Open and close rapport between patients and providers is therefore warranted to establish flexible, patient-friendly treatment plans.

9.3.4 *Use of faith healing and herbal remedies both a reflection of individual health beliefs and dissatisfaction with formal health care.* Various studies have described the impact of faith healing (Berhanu 2010; Tocco 2010; Togarasei 2010; Balogun 2010) and herbal remedies (Banda et al. 2007; Unge et al. 2011) on uptake of ART. Consistent with these findings and unlike previous studies conducted in Zambia (Grant et al. 2008; Murray et al. 2009; Fox et al. 2010), the use of faith healing and herbal remedies were found to be prevalent as encapsulated in Chapter 6-8. This was attributed to concerns about the negative effects of treatment and dissatisfaction with the way ART care was being delivered. When looking at individual-level reasons given by PLHIV, treatment was often abandoned or not accepted when side effects became too severe or were perceived as compromising quality of life, a finding reported in many other studies (Siegel & Gorey 1997; Siegel, Schrimshaw & Dean, 1999; Lumme-Sandt, Hervonen & Jylha, 2000). The health system's response that side effects will disappear after some time was not convincing to some PLHIV. The negative effects of treatment run contrary to patients' perception of the role of medicine, that it should improve quality of life and physical wellbeing and not the opposite. Therefore, while non-uptake of treatment may appear at odds with bio-medical logic, Siegel, Schrimshaw & Dean (1999, p.256), have pointed out that failure to adhere to treatment requirements "is not engaged in capriciously. It is not a reflection of a lack of concern about one's health; rather it is often an attempt to maintain it, gain control over it, or maintain an acceptable quality of life."

Similarly, there is also a perception that treatment is insidiously harmful and has deleterious effects on health and long-term wellbeing. In Zambia, concerns about HIV medication are not without foundation. In 2007, the pharmaceutical company Roche announced that some batches of viracept (an ARV used in second-line treatment) had been accidentally contaminated with mesylate (which can cause cancer and genetic mutation); the drug was immediately discontinued (Schumaker & Bond 2008). More generally, in November 2009, WHO recommended a gradual phase-out of stavudine (d4T) because of its long-term, irreversible side-effects such as neurological problems and muscle wasting and recommended zidovudine (AZT) or tenofovir (TDF) as less toxic and equally effective alternatives (WHO 2009). While newer drugs with better safety profiles are increasingly available in Zambia, lingering beliefs about HIV medication being harmful have continued to undermine patient initiation of ART and have negatively affected patient retention in ART care. Thus stringent quality controls of ART and treatment literacy campaigns are warranted.

9.4 Conclusions

Uptake of HIV testing is influenced by an array of individual and non-individual level factors. These factors may intersect and coalesce to influence uptake of HIV testing. Ensuring uptake of HIV testing requires particularly addressing perception of low risk of HIV infection and perceived inability to live with HIV. There is also a need to continue addressing stigma, which is intricately linked to individual social and economic support. Building confidence in the health system through improving delivery of health care and scaling-up HIV testing strategies that attenuate social and economic costs of seeking HIV testing is critical in ensuring uptake of HIV testing. No single intervention is likely to address these barriers. Therefore context-tailored combinations of interventions are warranted.

Similarly, HIV-patient non-initiation of and attrition from ART care is not exclusively an individual choice, but affected by a complex and dynamic interplay of personal, social, health system and structural-level factors. Individual health and treatment beliefs undermine treatment initiation but these are generated and perpetuated through close social network influence and experiences. Even for those willing to be on treatment, the necessity and utility of treatment is countered-balanced by concerns about future supply of treatment, perceived opportunity costs of seeking treatment and by attempts to preserve physical, mental and social wellbeing. This balancing act is mediated by the state of corporeal health, faith healing and availability of herbal remedies which are perceived as effective as ART but with perceived less side effects and less arduous treatment requirements.

9.5 Implications for policy and practice

The findings in this PhD thesis have implications for policy and practice to ensure uptake of HIV testing and treatment services:

9.5.1 Promoting uptake of HIV testing

At policy level:

- *Promote scaling-up of diverse models of HIV testing*. Scaling up of provider-initiated, mobile and home-based HIV testing coupled with increased wider availability of life-saving HIV medication is crucial in improving uptake of HIV testing in SSA. Such strategies could help assuage fears of stigma and lack of confidentiality as reported in many studies as well as attenuate direct and indirect financial costs of seeking HIV testing. However, these HIV testing strategies need to be context-specific to ensure cost-effectiveness given the variations in HIV prevalence levels in different settings of SSA. The costs associated with each strategy should also not be under-estimated.

- *Integrate HIV testing into out-patient unit.* Screening for HIV needs to be integrated into out-patient unit instead of referring patients to a stand-alone centre for HIV testing. This will help assuage fear of involuntary disclosure of HIV status as being seen seeking HIV testing could be misconstrued as already infected.

- *Remove user fees*. Where user charges still exist for accessing HIV testing, these need to be removed to ensure increased access to HIV testing. This is because in poverty endemic settings of SSA, paying for health services competes with other human needs such as food, shelter and education and paying for HIV testing may rank low in relation to other needs.

At service delivery level:

- *Focus on social network relationships*. Interventions such as home-based HIV testing that focus on social network relationships (i.e. couples and households) rather than individual-focused interventions are critical given inequitable power dynamics and the significance of social networks in decision-making processes about HIV testing. However, couple and home-based HIV testing need to be implemented while being mindful of couple and household lived experiences including paying close attention to and addressing gendered power relationships. This is because uptake of HIV testing could be achieved at the expense of harmony in and stability of marital and household relationships or even precipitate stigma and discrimination or even violence.

- *Fully articulate the 'opt-out' strategy to HIV testing*. In health facility settings, while efforts to encourage couple HIV testing should be promoted to mitigate gender inequality in accessing HIV testing and ensure disclosure of HIV status, the 'opt-out' requirement needs to be well articulated to ensure that individuals' rights are respected and couples are given the social time and space to reflect on the implications of HIV testing. Similarly, coercive strategies particularly in health facility settings need not be adopted.

- *Participatory awareness campaigns on stigma & lay perceptions of risk of infection.* Given the reported persistence of stigma, continued sensitization campaigns are needed. There is a need to focus on addressing socially constructed individual risk assessments especially in low HIV prevalence settings where HIV may be viewed as unreal and a far-off threat. In doing this, target individuals should not be merely viewed as passive recipients of health information or services. Instead, they need to be engaged as active agents and co-producers of positive health outcomes.

- *Combine HIV testing interventions with screening for other health conditions*. Provision of HIV testing interventions particularly in non-clinical settings need to be combined with screening for other less stigmatizing health conditions to avoid stigma associated with being seen accessing HIV testing.

- *Improving quality of HIV service delivery*, particularly ensuring confidentiality - which many studies identified as a barrier - is also vital.

9.5.2 Improving patient initiation of and retention in ART care

At policy level:

- *Increased funding for HIV treatment from local resources* rather than heavy reliance on external support is needed. This could help build confidence in local capacity to deliver HIV treatment and assuage fears about future non-availability of treatment. Establishing a national health fund to help hedge against unpredictable external financial support particularly for HIV treatment is critical.

- *Current trends of providing newer patient-tolerant drugs with better safety profiles should continue.* This will ensure patient retention in ART care and attract PLHIV with misgivings about availability of safe and patient-friendly drugs to initiate treatment.

- At global and national levels, efforts should be stepped up to *assess and promote the therapeutic benefits of complementary and alternative medicine* (CAM). This is in line with the World Health Assembly resolution 62.13, passed in May 2009 by WHO Member States which urged national governments "to respect, preserve and widely communicate traditional medicine knowledge while formulating national policies and regulations to promote their appropriate, safe and effective use; to further develop traditional medicine based on research and innovation, and to consider the inclusion of traditional medicine into their national health systems" (WHO 2011, p.7). For PLHIV, this could help provide symptomatic relief, manage opportunistic infections and mitigate side effects of antiretrovirals without undermining the optimal performance of antiretrovirals. In the long-term, this could help retain patients in ART care and encourage initiation of treatment.

- *Strict enforcement of pharmaceutical regulations*. The reported diversity of herbal products on the market and their use raises public health concerns. Their strict monitoring is therefore critical. In addition, the reported widespread self-prescription and use of antibiotics by PLHIV calls for strict enforcement of pharmaceutical regulations to control self-prescription and use of antibiotics, including clamping down on unregistered drug stores.

- *Livelihood empowerment programmes for PLHIV*. The fragile food security situation of some PLHIV clearly demonstrates the impact of poverty and livelihood constraints on access to treatment. While provision of food aid to vulnerable PLHIV may enable them initiate treatment, this could be difficult to sustain in the long-term due to the costs of providing such support in a poverty-endemic setting where access to formal social welfare programmes is very limited. Instead, funding for HIV should also prioritise livelihood empowerment programmes for economically disadvantaged people living with HIV.

At service delivery level:

- *Rapport between service providers and service users*. Efforts to improve uptake of ART should comprise close, open rapport between HIV testing/ART service providers and service users, and general sensitisation campaigns, to ensure that (potential) HIV service users' negative health and treatment beliefs are identified, understood and addressed. This also entails treating (potential) service users not merely as passive recipients of HIV information and services; rather as active agents and co-producers of good health outcomes.

- *Dispel negative beliefs about HIV medication and perceived efficacy of herbal remedies.* With the onset of better, patient-friendly medication, there is need for sensitisation programmes to assist in patient acceptance and compliance of ART. In the same vein, sensitisation measures should aim at dispelling negative beliefs about HIV medication and perceived efficacy of scientifically unproven herbal remedies.

- *Promote benefits of early initiation of treatment*. Focus should also be placed on sensitisation campaigns on the benefits of early initiation and continuation of treatment and dispel beliefs about perceived effectiveness of herbal remedies in the absence of scientific proof. Individuals that have sought faith healing should be encouraged to re-test for HIV. Sensitisation campaigns should also target faith healers and herbalists.

- *Increase number of staff in ART clinic and longer ART clinic hours*. As many people get onto treatment, there is need for increased human resources in the ART clinics and adoption of longer, flexible clinic hours to avoid congestions and long waiting hours to help attenuate possible opportunity costs associated with seeking ART care. This has policy implications too as it requires increased funding for additional professional and lay health workers.

- *Encourage re-testing to ascertain faith healing claims*. For PLHIV that claim to have been healed through faith healing, sensitisation activities should focus on encouraging them to re-test to ascertain faith healing claims. This is because, due to people's deeply entrenched religious beliefs, simply telling them not to seek faith healing might not work as it may be at variance with their religious beliefs.

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APPENDICES

Appendix 1: Information Sheet for Research participants

Factors influencing uptake of HIV testing and non-initiation of and attrition from antiretroviral therapy care in Lusaka, Zambia

What the study is all about

My name is **Maurice Musheke.** I am a PhD student at the Swiss Tropical and Public Health Institute of the University of Basel, Switzerland. I also work for ZAMBART Project, University of Zambia, Ridgeway Campus. I am contacting you in relation to a study I am conducting to understand what discourages people from seeking HIV testing; why people who test HIV-positive do not want to start treatment or opt to abandon treatment. I also want to understand people's experiences of living with HIV and disclosure of their HIV status to their marital partners. Over the next 18 months, I will be interviewing people living with HIV, those that have not tested for HIV, health workers, church leaders (Pastors) and traditional healers about these issues. Due to your knowledge/expertise/involvement/experience *[depending on type of respondent]* about HIV testing and treatment, I am contacting you for your participation in this study.

Participation and Confidentiality

Your participation in this study is voluntary. You are free not to answer any questions that you are not comfortable with. You can also withdraw from the study at anytime without any consequences for doing so. The information you will provide will be strictly confidential and your identity will be protected.

Risks and Benefits

No risks are anticipated as a result of your participation in the study. To avoid involuntary disclosure of your HIV status to other people *[in the case of people living with HIV]*, the interview will be conducted in a confidential manner and setting. There will also be no direct and immediate material and financial benefits to you. However, where interviews are conducted during lunch time or outside your home setting, a small lunch allowance/transport reimbursement will be provided. In general, this study will help contribute towards the improvement of the way HIV testing and treatment services are being provided in Zambia.

Ethical Clearance

This study has been approved by the University of Basel Research Ethics Committee and the University of Zambia Humanities and Social Sciences Research Ethics Committee. Permission has also been obtained from the Ministry of Health. Should you have any questions or want clarification about the study, do not hesitate to get in touch directly with me or the Chairperson, University of Zambia Humanities and Social Sciences Research Ethics Committee on the address and contact details below.

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Appendix 2: Informed Consent Form

Factors influencing uptake of HIV testing and non-initiation of and attrition from antiretroviral therapy care in Lusaka, Zambia

Contact of Principal Investigator: **Maurice Musheke**
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[**PLEASE CROSS OUT AS APPROPRIATE]**

THE PURPOSE OF THIS STUDY HAS BEEN CLEARY EXPLAINED TO ME	YES/NO
I AGREE TO BE INTERVIEWED	YES/NO
I AGREE TO THE INTERVIEW BEING RECORDED	YES/NO

I DO/ DO NOT AGREE TO ANY QUOTATIONS OR ANY RESULTS ARISING FROM MY PARTICIPATON IN THE STUDY BEING INCLUDED ANONYMOUSLY IN ANY REPORT RESULTING FROM IT.

"I have understood the verbal explanation concerning this study and I understand what will be required of me and what will happen to me if i take part in it. My questions concerning this study have been answered by the researcher. I understand that at any time I may withdraw from this study without giving a reason. I agree to take part in this study."
My signature below says that I am willing to participate in this research:

Participant's name (Printed): ………………………………………..............…………….............

Participant's signature/thumb print ………………………................ Date: ………………………...

Witness's name (Printed):……………………………………..........Date:…………………………...

Witness's signature:……………………………………………………...

Name of Interviwer conducting informed consent (Printed)………………………….....................

Signature of Interviewer: ……………………………..............Date: ....

Appendix 3: In-depth Interview Guide (Adapt based on Respondent)

Sampling Criteria:

Inclusion criteria:

- Tested for HIV (regardless of their HIV status)
- Gender balance (Male Vs Female)
- Aged ≥18 years

Exclusion criteria:

- <18 years old
- Non residents of study sites

Part 1: Background data

Could you tell me more about yourself...………................

1. Could you tell me about yourself? [Ask about Age/Marital status/education levels/occupation; Household composition

Part 2: HIV Testing Trajectory

I would like us now to talk about your experience of going for an HIV test, and knowing your HIV status..........

2. When did you first go for HIV testing?
3. Where were you first tested for HIV? Was it your decision to test or were you referred for a test? If referred, by whom?
4. What made you decide to go for an HIV test? *(Probe for health experience before going for VCT; previous risk behaviour etc; probe for time lapse between wanting to get tested and actually getting tested)*
5. How was your decision to get tested arrived at? [*Probe about decision making processes and consultations before going for an HIV test; Probe about factors taken into account before deciding whether to go for a test or not*].
6. Can you describe to me your experience during the counselling and testing process? (*encourage description of preparedness for HIV results, implications of a positive test and disclosure of HIV results, support etc)*
7. Have you been for an HIV test again? [*Probe for reasons for/against going for HIV testing again]*

Part 3: Disclosure of HIV Status

Can we now talk about disclosing the results of your HIV test...

8. Could you kindly relay to me how it felt to be tested for HIV? *[Probe regardless of whether test was negative or positive]*.
9. Who was the first person you told about your HIV test results? How long did it take from the time you received your HIV test results and the time you told the first person about your HIV status? Why did it take you that period of time to disclose your status?
10. Would you explain to me how you went about disclosing your HIV status to (sexual partner?) What were his/her immediate reactions? What have been his/her reactions over time?
11. Would you explain to me the reasons for disclosing/concealing your HIV status?
12. What challenges did you face in disclosing your HIV status?
13. Were you counselled about disclosing your HIV status? What did the counselling involved?

Part 4: Uptake of HIV Treatment

We have talked about your experiences of being tested, disclosing your status and the impact of HIV testing and disclosure on your life, can we now talk about your experiences of being on treatment...........................

14. Did you start HIV treatment immediately you were found with the HIV virus?[*Probe about treatment pathway, treatment preparedness, use of alternative remedies and possible delays and reasons about starting treatment*]
15. What made you decide to stop treatment/not to initiate treatment? [*Probe about challenges of being on treatment, effects of HIV treatment on bodily changes, use of alternative forms of care etc).* Could you tell me your experiences of being on treatment?
16. What do you think needs to be done to encourage more people to initiate treatment or not to drop out of treatment?

Appendix 4: Key Informant Interview Guide for VCT/ART Staff

Part 1: Profile of VCT and ART services

Ask about the VCT/ART services here……………………………………………………………………….

1. When did the facility start providing HIV testing services?
2. On average how many clients do you counsel/test per day?
3. How are patients recruited for HIV testing? [*Probe about the different pathways; how VCT is linked to other health care units*]
4. Can you describe to me the nature of your clients who seek/are tested for HIV? (*Age, sex, socio-economic status? Stage of illness or illness symptoms they present*?)

Part 2: HIV Testing: Motivations and Barriers

M*otivating and deterring factors to uptake of HIV testing*..

5. What are the main reasons for seeking HIV testing? (*probe about personal, interpersonal and structural factors*)
6. Do all your clients that seek or are referred for HIV testing actually undergo the test? (*if not, probe reasons for refusal to undergo HIV testing*)
7. Do all your clients that undergo HIV testing actually get their HIV test results? (*if not probe reasons explain the reasons for failure to get/know their HIV test result*). What do you do with those that test positive but do not want to know their status?
8. What is your view about provider-initiated HIV testing? [*Probe about client acceptability, staff attitude, experiences of staff in delivering routine HIV testing*]
9. Ask about personal experience of testing people for HIV and telling them their results

Part 3: Disclosure of HIV status [Those that Tested HIV positive]

Can we now talk about disclosure of HIV status by your clients..

10. Do you counsel your clients on how to go about disclosing their HIV positive status? What does counselling on disclosure entail?
11. What do your clients say about disclosing their HIV status? [*Probe about client concerns, worries etc*]. From your experience, do all your clients disclose their status to sex partners? [*Probe about the reasons for disclosure/non disclosure of HIV status, including outcomes of disclosure*]
12. From your experiences with your clients, what reactions (positive and negative) have your clients faced resulting from HIV testing and disclosing their HIV status to sexual partners or close social network members?

Part 4: Uptake of Treatment after HIV Testing

13. What is the treatment pathway that those that test HIV positive go through? [*Probe for reasons for delays, refusal of patients to be initiated on ART etc*]

14. From your experiences with your clients what factors inhibit people who are HIV positive from starting HIV treatment?
15. What are the reasons why those started on treatment discontinue their medication?

Appendix 5: Observations Checklist

How to observe:

- Sit/stand/wander around at health facilities, VCT centres observing situation, people in the context
- Blend and socialise with community members as much as possible – language, clothing, attitudes, etc.
- Where possible ask questions, to community members & patients, to others around to know what is going on or what happened in a certain situation
- During observations, write up notes discretely....do not allow participants know that you are observing them;
- Note who said what (gender, age) and in what context? Take note of differences between what you see, the facts, and your interpretation of events
- Write up all notes at the end of each period of observation, provide as much detail as possible, describe literally what you saw happening.

Where to observe:

- Out-patient waiting rooms of health facilities, outside the health facility etc
- In the local courts i.e. following up HIV related cases being handles there
- HIV sensitisation meetings; ART sensitisation talks at health facility, social gatherings
- Churches

Length of time to observe

- At least 1 hour

What to observe

- At the health facility, whether individuals are accompanied or not for testing, ART, etc. if so, by whom, what role do they play, what do they say, etc.
- At the health facility, issues related to HIV testing and treatment that health workers discuss with their patients, including reactions, questions and fears of patients etc
- The attitudes of health staff towards patients, especially in relation to HIV testing and ART
- How do patients in the ART clinic freely interact with patients from other clinics at i.e. pharmacy?
- Check what people say, do, their reactions, interactions etc. after they leave the facility/have seen the health staff
- What HIV education messages are disseminated in the community, and by whom? What people say about the messages-their fears, reactions etc
- What people are saying about HIV testing and treatment in the community, and to who?
- Can also follow up some cases in the local court on HIV testing, being on treatment and HIV disclosure issues? What are the issues, what do local court justices say about this, reactions within the courts, outside etc?