

London School of Economics and Political Science

**A new lease of life: sexual and reproductive behaviour  
among PLWHA in the ART era in Nairobi slums**

**Eliud Wekesa**

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## Declaration of Authorship

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## Abstract

The availability of antiretroviral treatment (ART) is enabling people living with HIV or AIDS (PLWHA) to reconsider their sexual and reproductive lives. The sexual and reproductive health (SRH) decisions that PLWHA make have implications for HIV transmission and prevention. Yet very little is known about SRH of PLWHA in sub-Saharan Africa, as studies as well as prevention strategies have historically neglected them and SRH matters are often not part of HIV/AIDS treatment and care services. This study looks at how HIV-positive men and women negotiate their sexual and reproductive lives and the barriers to the realisation of SRH needs in Nairobi slums.

This study employs a mixed methods study design involving both quantitative (survey n=513) and qualitative (in-depth interviews n=41 and key informant interviews n=14). Respondents were systematically recruited from the community in two slums in Nairobi for quantitative interviews, a subset of which was followed on for in-depth interviewing. Quantitative analyses include univariate, bivariate and multivariate logistic regression modelling. Qualitative data were transcribed, and coded and thematically analysed. SRH outcomes of the study include sexual activity/inactivity, condom use, multiple sexual partnerships, fertility intentions, contraceptive use and unmet need for family planning. Quantitative and qualitative components of the entire study are integrated throughout both analysis and interpretation.

The findings show that the SRH outcomes of PLWHA are somewhat different from the general population, but similar with other PLWHA in similar settings. Condom use at last sex is high although consistent use is an issue. PLWHA exhibit fertility desires and contraceptive behaviour that is more geared towards limiting fertility, but face barriers, and hence the high unmet need for contraception. The SRH outcomes are shaped by demographic (e.g. age, parity), socio-cultural (gender, societal norms) relationship (disclosure, intimacy, pleasure) and health factors (ART use, duration of HIV and side-effects and health concerns). Their SRH outcomes are reflective of their efforts for social approval. However, there is a conflict between social validation and moral pressures for HIV prevention presenting a dilemma to many about “proper” SRH behaviour in the ART era. There is need to include SRH counselling and services as part of the standard HIV treatment and care services for PLWHA.

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## **List of Acronyms**

- AIDS: Acquired immunodeficiency syndrome
- APHRC: African Population and Health Research Centre
- ART: Anti-retroviral treatment
- CHW: Community health worker
- DSS: Demographic surveillance system
- DSA: Demographic surveillance area
- FAO: Food and Agriculture organisation
- HIV: Human immunodeficiency virus
- IEC: Information, education and communication
- KAIS: Kenya AIDS indicator survey
- KEMRI: Kenya Medical Research Institute
- KNBS: Kenya National Bureau of Statistics
- KNASP: Kenya national AIDS strategic plan
- MDG: Millennium development goals
- MOH: Ministry of Health
- MSM: Men who have sex with men
- NACC: Nations AIDS Control Council
- NASCOP: National AIDS-STI Control Programme
- NGO: Non-governmental organisations
- NUHDSS: Nairobi Urban Demographic Surveillance System
- PLWHA: People living with HIV/AIDS
- PMTCT: Prevention of mother to child transmission of HIV
- RDS: Respondent driven sampling
- SRH: Sexual and reproductive health
- STI: Sexually transmitted infections
- SSA: Sub-Saharan Africa
- TS: Targeted sampling
- TMDS: Targeted mobiliser driven sampling
- UNAIDS: The Joint United Nations Programme on HIV/AIDS
- UNHABITAT: The United Nations Human Settlements Programme
- VCT: Voluntary counselling and testing
- WHO: World Health Organisation

## Chapter 1: Introduction

### 1.1. Problem statement and research question

Since the first case was discovered three decades ago, HIV/AIDS remains a major public health and development concern. Recent estimates indicate that about 34 million people were living with HIV at the end of 2010 (UNAIDS 2011). Sub-Saharan Africa (SSA) continues to be the most affected region – accounting for over 68% of the total HIV burden and 70% of new infections (UNAIDS 2011). The adult HIV prevalence in Kenya peaked at 14% in the 1990s, but has levelled at around 7.4%, with about 1.5 million people currently living with HIV (NACC 2009; UNAIDS 2010). The Kenyan HIV prevalence rate is higher than both the SSA regional rate (5%) and the global rate (1.2%) (WHO/UNAIDS 2008). The social and economic consequences of HIV and AIDS continue to be felt widely, not only in the health sector, but also in education, industry, agriculture, transport, human resources and the economy in SSA. In effect, the AIDS epidemic in SSA has had a devastating effect, rolling back years of development and life expectancy progress (Barnett and Whiteside 2006; Buvé, Bishikwabo-Nsarhaza, and Mutangadura 2002; UNAIDS 2008, 2010).

The discovery of anti-retroviral therapy (ART) more than a decade ago has, however, greatly improved the prognosis of HIV, with the potential to transform it from an imminent death sentence to a chronic condition. Access to ART, especially in the most affected regions in low and middle income countries has expanded rapidly in recent years. Current estimates show that 6.6 million people are now receiving treatment in low- and middle-income countries: nearly half of those eligible for treatment (UNAIDS 2011). The greatest increase in the number of people on treatment has been in SSA, which accounted for 72% of the total number of people on treatment by end of 2007 (UNAIDS 2008), and a further 20% increase in enrolment between 2009 and 2010 alone (UNAIDS 2011). At the end of 2009, 37% of adults and children eligible for ART were receiving it in SSA and 60% in Kenya (UNAIDS 2010).

The use of ART around the globe has reduced HIV/AIDS-related morbidity and mortality, reduced new infections, and substantially improved the quality of life of people living with AIDS (PLWHA) (Auerbach 2004; Coetzee et al. 2004; Mocroft et

al. 2003). It is estimated that 2.5 million deaths have been averted in low- and middle-income countries since 1995 due to ART (UNAIDS 2011).

The unprecedented increase in ART access creates new possibilities, challenges and potential problems. The primary aim of ART is to reduce HIV-related morbidity and mortality and to extend the survival of PLWHA (Cooper et al. 2007; Mocroft et al. 2003). There are, however, emergent public health and demographic consequences of ART that may not have been fully considered. In particular, as PLWHA realise that with treatment, HIV infection is no longer a death sentence, they endeavour to actualise their normal life obligations and prospects, which may include resumption of sexual relations and future fertility intentions (Smith and Mbakwem 2007; Smith and Mbakwem 2010). An important aspect of PLWHA's lives, as for any human being, is sexuality – a complex human expression that includes feelings of arousal, pleasure, intimacy, social meanings attached to sexual behaviour and reproduction (Birungi, Undie, and Aggleton 2009) – and PLWHA have a right to a satisfying and safe sex and reproductive life (Segurado and Paiva 2007; WHO 2006). However, very little is known about either the sexuality or the reproductive health and intentions of PLWHA in the context of ART in SSA settings. Most research has focused on the increase of ART access to those who need it and how to achieve optimal adherence to ART for treatment effectiveness (Bartlett 2002; Hardon 2006; Orrell et al. 2003).

As a consequence, the sexual and reproductive health rights and needs of PLWHA are under-researched (Cooper et al. 2009; Segurado and Paiva 2007; GNP+ 2009). In the absence of treatment, a positive HIV test was taken to mean an imminent death and the end of a person's sex life (Schiltz and Sandfort 2000). In reality a sexual life does not stop with an HIV positive diagnosis for most PLWHA. While some PLWHA may decide to stop sexual activities after their HIV diagnosis, others continue to have sex. Studies in the developed world show that over 70% of PLWHA remain sexually active (Crepaz and Marks 2002; Niccolai et al. 2006), therefore policy makers and health-care providers have a responsibility to support them and their partners in protecting their sexual and reproductive health (Cooper et al. 2009; Segurado and Paiva 2007). In the absence of a cure for HIV, sexual behaviour change remains one of the potentially effective available means of HIV prevention (Cleland and Sinding 2005), especially for those are potentially infectious.

Studies and prevention strategies have mainly focused on people at risk or the general population, who in most cases are either HIV- negative or do not know their status (Bunnell, Mermin, and De Cock 2006; Kennedy et al. 2010). While this is crucial in prevention strategies in the context of low HIV testing and status knowledge – where more than 60% of people living with HIV are unaware of their HIV status (UNAIDS 2011) – they have largely ignored both the needs and important role of people who are HIV-positive. Initially PLWHA were deliberately avoided in studies and prevention strategies as result of concerns of exposing them to stigma in the context of either the unavailability of or limited access to ART and HIV testing (Kennedy et al. 2010). Widespread ART access, dramatic scale up of HIV testing and stigma reduction efforts have helped alleviate some of these concerns (Bunnell, Mermin, and De Cock 2006; Kennedy et al. 2010).

Recent evidence suggests that in many SSA settings most cases of HIV infections occur in HIV-discordant couples, and hence the urgent need for prevention strategies targeting PLWHA (Bunnell, Mermin, and De Cock 2006). The prevention strategy for PLWHA is commonly known as positive prevention, which generally means a set of strategies that helps PLWHA live longer and healthier lives by protecting their sexual health and reducing the risk of HIV transmission (Auerbach 2004). A number of approaches have been used to respond to the prevention needs of HIV-positive people, but most of them have focused solely on the need to reduce HIV transmission and contain the epidemic among those who know their HIV status (Kennedy et al. 2010; Kalichman and Simbayi 2010). Crucial as this approach is, a broader approach that goes beyond safe sex practices for disease prevention to include other issues of sexuality such as pleasure, satisfaction, and functioning, sexual negotiation and partner disclosure within a human rights approach is more desirable (GNP+ 2009). This can contribute to the full enjoyment of sexual and reproductive health and rights as envisaged by the 1994 Cairo conference declaration (Gruskin, Ferguson, and O'Malley 2007).

Positive prevention has spurred a recent interest in studying the sexual behaviour of PLWHA (Kalichman and Simbayi 2010). There are concerns that there could be an

increase in “risky” sexual behaviour as people, both infected and uninfected, become aware that HIV/AIDS is a manageable condition and that people on treatment are less infectious (Luchters et al. 2008; Remien et al. 2007). This phenomenon is referred to as “treatment optimism” (Crepaz, Hart, and Marks 2004; Kennedy et al. 2007). The consequences of unsafe sexual behaviour amongst PLWHA include the possibility of: infecting their sexual partners with the virus; re-infection with multiple strains of HIV; and, transmission of drug resistant strains (Courtenay-Quirk et al. 2008; Maclachlan 2007; Kalichman et al. 2006). Studies report conflicting findings on whether PLWHA as a group generally, in the era of treatment, engage in less safe sex than their HIV negative counterparts. Some studies have reported substantial declines in unsafe sexual behaviour upon self-awareness of HIV status (Brooks et al. 2008; CDC 2004). On the other hand, others have reported elevated unsafe sexual behaviour of PLWHA when their health improves (Chen et al. 2002; Katz et al. 2002). The growth of recent interest in ART and sex behaviour in SSA notwithstanding, there are limited data on sexual behaviour of PLWHA, especially when comparing those on ART and those not yet on treatment in urban areas of resource poor settings (Eisele et al. 2009). The implications of ART for sexual behaviour in SSA settings are not well documented (Osinde, Kaye, and Kakaire 2011).

The second, unanticipated, consequence of ART is its potential effect on fertility desires. Most women and men living with HIV are of childbearing age (UNAIDS 2008) and in common with those not infected are expected to bear and raise children. This is especially so in the SSA context where a high premium continues to be placed on fertility and parenthood for social approval (Cooper et al. 2007). However, evidence relating to fertility and reproductive intentions among PLWHA are rare (Delvaux and Nöstlinger 2007). Studies on reproduction and fertility of PLWHA have tended to be clinical, focusing on the negative effect of HIV infection on the ability to conceive or carry a pregnancy to term (Kanniappan, Jeyapaul, and Kalyanwala 2008). Several studies have reported declines in fertility rates of women living with HIV/AIDS in SSA (Glynn et al. 2000; Lewis et al. 2004). HIV/AIDS infection can affect fertility directly by causing spontaneous abortion (Glynn et al. 2000; Segurado and Paiva 2007) or indirectly through decreased sexual desire, marital disruption and use of condoms (Glynn et al. 2000; Lewis et al. 2004).

Recent evidence suggests that availability of ART and prevention of mother-to-child transmissions (PMTCT) programmes, which dramatically reduce the risk of vertical transmission might allow PLWHA to develop previously suppressed child-bearing intentions (McCarragher et al. 2008). In SSA in particular, socio-cultural and economic factors influence reproductive preferences and choices of men and women regardless of sero-status (Cooper et al. 2007). Among PLWHA – as the case is with the general population – the pleasure, happiness and a sense of social fulfilment associated with parenthood (Boonstra 2006), familial and societal pressure (Cooper et al. 2009), the need to carry the family name and perpetuate the lineage (Agadjanian 2005; Smith and Mbakwem 2007) and the need for securing a marriage or relationship (Wagner et al. 2011) – are some of the reasons for their fertility intentions.

Emerging identity literature suggests that, since HIV infection leads to “spoilt identity” – mainly because of its association with moral transgressions – parenthood can be understood in terms of a quest to resume a “normal” identity (Smith and Mbakwem 2007). By pursuing “normative life projects” such as childbearing, PLWHA show that they are morally legitimate, despite their HIV status (Smith and Mbakwem 2010). Having children is, therefore, a mark of one’s contribution to family, community, and society, as well as potentially mitigating the stigma associated with HIV/AIDS.

However, unlike the general population, PLWHA face the dilemma of balancing their fertility desires with the need to protect themselves from reinfections and their partners and yet to be born children from HIV infections (Beyeza-Kashesya et al. 2009). For some PLWHA in SSA where parenthood is highly valued, meeting family and social obligations concerning reproduction, may be more important than the risk of HIV transmission (Smee et al. 2011). For others, however, their health status and risk of HIV transmission might dissuade them from desiring fertility and underline the need to avoid pregnancy (King et al. 2011; Laher et al. 2009). A number of assisted conception technologies for discordant and concordant couples to reduce the risk of infection such as artificial intrauterine insemination and sperm washing do exist, but are not easily accessible especially in resource-constrained settings such as SSA (Kaida et al. 2009).

Men and women living with HIV have a well-established right to fertility including in making decisions on such issues as the number, spacing and timing of pregnancies and



use of contraceptive methods (Paiva et al. 2007; Wilcher and Cates 2010; Segurado and Paiva 2007). Evidence from SSA studies suggests that most PLWHA also wish to protect themselves and their partners from unwanted pregnancies. For example, Cooper et al. (2009), in their study among PLWHA in South Africa found that 11% of female respondents who were not on ART had been pregnant since their HIV diagnosis and all of them reported the pregnancies as unintended. An unintended pregnancy can result from lack of contraceptive use or contraceptive failure. With a few exceptions, the family planning methods generally available globally can be used by HIV positive women as well (Delvaux and Nöstlinger 2007; WHO 2006). Most hormonal contraceptives can be used without any adverse outcomes, although WHO guidelines provide options in specific cases where drug interactions may reduce the effectiveness of certain oral contraceptives (WHO 2006). Lack of access to family planning commodities, spousal opposition, side effects and health concerns over ART interactions with some hormonal family planning methods have been cited as important factors constraining contraceptive uptake (Laher et al. 2009) and contributing to unmet need for family planning.

Unmet need for contraception will still put a PLWHA at risk of an unwanted pregnancy if they do not want to have a child in the future or want to postpone their next birth. While some studies show relatively higher contraceptive use among PLWHA compared to the general population, others do not find any consistent significant difference compared to their HIV – negative counterparts (Rutenberg and Baek 2005; Wanyenze et al. 2011). Emerging evidence shows that the level of unmet need for family planning among women living with HIV/AIDS in SSA is higher than the general population (Wilcher and Cates 2010). In the context of higher unmet need for contraception, access to safe and legal abortion (where laws allow) and post-abortion care services becomes critical for HIV positive women considering termination of an unintended pregnancy. The need for access to safe and legal abortion services has been regularly highlighted as essential in meeting the sexual and reproductive health needs and rights of PLWHA (WHO 2006).

The majority of studies on these two inter-connected issues of sexual behaviour and reproductive preferences use an individual risk behaviour approach. Individual risk is a

byword in HIV prevention and discourse (Rhodes 1997). Individual risk discourse is usually characterised by knowledge and attitudes about HIV prevention modes and practises that facilitate HIV transmission (Munro et al. 2007). The strategy to reduce individual risk has led to a plethora of studies and interventions to halt the spread of HIV targeting individual knowledge, attitudes and behaviour of the HIV risky groups such as commercial sexual workers, long distance truck drivers, injecting drug users or the general population (Barnett and Whiteside 2006). Indeed these studies and interventions have been crucial in behaviour change and reversing the HIV prevalence rates in the most affected regions of the world (UNAIDS 2008, 2010, 2011).

Recent reviews of positive prevention strategies among PLWHA have revealed the continued focus on individual risk prevention (ABC - Abstinence, Be faithful and Condomise) model commonly applied to the general population (Crepaz et al. 2006; Kennedy et al. 2010). Critics of such individualised strategies observe that they are bound to be less successful as they do not take into account the socio-economic and structural context that shapes individual risk behaviour (Barnett and Whiteside 2006; Campbell and Cornish 2003; Coast 2007). Indeed the success of interventions and HIV preventive strategies increase substantially if they incorporate the broader context that shape individual sexual behaviour such as gender, power and poverty (Coates, Richter, and Caceres 2008). This study focuses on three contextual aspects, which influence sexual and reproductive behaviour, but have received less research attention: self-identity, gender and poverty.

Firstly, most HIV studies and interventions fail to consider the lived experience, self-identity and meaning that PLWHA give to their status of being HIV+ and how this is being reshaped in the era of ART (Bartos and McDonald 2000). Studies show that PLWHA undergo a transition to a new sense of self-identity as they incorporate HIV/AIDS and possibly also ART into their lives and as they interact with others (Russell and Seeley 2010; Seeley and Russell 2010). Infection with HIV/AIDS is a disruptive event and PLWHA strive to return to normalcy after a period of initial turmoil (Baumgartner 2007; Carricaburu and Pierret 1995; Kralik 2002). Resumption of sexual and reproductive lives by PLWHA is reflective of their quest for normalcy after disruption to their identity (Smith and Mbakwem 2010). Considering how the meanings of being a person with HIV/AIDS are being reshaped in the context of

treatment will help us understand how PLWHA, together with their families and social networks, manage their illness and lives in general and sexual and reproductive lives in particular.

Secondly, the HIV risk behavioural change approach does not sufficiently take into account the effect of gender on sexual and reproductive behaviour. The importance of gender in shaping sexual and reproductive behaviour cannot be gainsaid, not least because in heterosexual relationships, sex and reproduction is a dual undertaking between men and women, with differential power relations that tend to favour men. Extant literature indicates that gender makes women in SSA vulnerable to “risky” sexual behaviour and HIV infection (Kalipeni et al. 2004; Kalipeni, Oppong, and Zerai 2007; Mill and Anarfi 2002). Patriarchal structures in SSA have ensured that sexual and reproductive decisions tend to be controlled by males (Mantell et al. 2009; Mbizvo and Bassett 1996; Varga 2003). Not only are women at elevated risk of sexual violence and exploitation compared to men (Akeroyd 2004), but also economic situations force women to engage in transactional sex relations (Moore and Oppong 2007; Dunkle et al. 2007; Luke 2006). However, little is known about the sexual and reproductive lives and experiences of heterosexual men (Doyal, Anderson, and Papparini 2009). The gender discourse that portrays men as promiscuous, violent and irresponsible ignores men’s responsibilities and care in romantic relationships and protection of women partners against HIV and pregnancy (Long 2009). Some evidence contradicts the depiction of women as passionless and powerless who only seek extra-marital relations for financial gain (Tawfik and Watkins 2007).

Thirdly, the role of poverty in HIV transmission is under-specified in many studies and interventions (Stillwaggon 2006; Stillwaggon 2009; Nattrass 2009). The relationships between poverty and HIV are far from simple and direct, and the relationship is generally described as a vicious circle with one causing and/or exacerbating the other (Piot, Greener, and Russell 2007). On the one hand poor individuals and households generally lack resources (financial and human) for HIV prevention (Krishnan et al. 2008; Madise, Zulu, and Ciera 2007). The poor are also more likely to adopt behaviours such as transactional or survival sex, which expose them to HIV infection (Kalipeni, Flynn, and Pope 2009; Wojcicki 2002; Zulu, Dodoo, and Ezeh 2002; Campbell 2000; Wamoyi et al. 2011). Poverty is also associated with inability to

acquire food and maintaining optimal nutrition (Faye et al. 2010). Malnutrition weakens the immune system, thereby increasing susceptibility to HIV infection when exposed (Gillespie and Kadiyala 2005; Stillwaggon 2006), hastens the progression from HIV to AIDS (de Waal and Whiteside 2003; Gillespie and Kadiyala 2005) and increases chances of death upon ART initiation (UNAIDS 2011). On the other hand individuals, families and communities are impoverished by their experience of HIV and AIDS. The experience of HIV diminishes individual and household resources as a result of morbidity and death of family members and breadwinners and generally reduces their capacity to cope with its socio-economic consequences (Barnett and Whiteside 2002; Fox et al. 2004; Linnemayr et al. 2011).

The main argument for this study is that the dominant “risk behaviour” framework in which research on sexual and reproductive behaviour tends to be conducted is inadequate and that due consideration to the “risk environment” is necessary. The risk behaviour approach is based on individual-based-models of behaviour that assume autonomous and rational decision-making based on individual beliefs and risk perception (e.g. Health Belief Model) or knowledge, intentions, skills and personal control (e.g. Theory of Planned Behaviour and Information-Motivation-Behavioural Skills Model (Munro et al. 2007; Noar 2007)). There is a growing understanding that individual sexual and reproductive behaviour and decisions are not always autonomous, but are affected by other social actors and networks and embedded in the social milieu. For example, not using a condom during sex may signify emotional intimacy, trust and fidelity. Under such circumstances, insistence of condom use may be interpreted as lack of love and respect from partners or suggestive of unfaithfulness (Varga 2003), not least because condoms are associated with disease and promiscuity (Askew and Berer 2003). That is why condom use is more likely in casual sexual relationships or those in which trust is yet to be established; and is stopped if the relationship became long-term (Allen et al. 2011; Undie et al. 2009). Similarly, fertility preferences and contraceptive use are influenced through social interactions and partner influences (Agadjanian 2005; Montgomery and Casterline 1996; Cleland et al. 2006).

Increasingly, calls have been made to shift the focus away from risky individual behaviour in isolation, towards recognising and addressing environmental and social

factors that create vulnerability to HIV (Barnett and Whiteside 2006; Evans and Lambert 2007; Stillwaggon 2002, 2006). This study responds to this challenge and takes as its departure point the need to integrate broader socio-economic and cultural contexts, namely, poverty, gender and identity as part of the “risk environment” alongside individual-level factors. The risk environment is the physical or social space in which factors exogenous to the individual operate to increase vulnerability to harm (Rhodes 2002) or facilitate risk behaviour (Barnett and Whiteside 2006). By setting this study in a poor slum settlement environment, a particular risk environment is identified, with socio-economic and cultural conditions interacting to impact on sexual behaviour, fertility desires and demand for contraceptives among PLWHA.

This study is guided by the following research questions:

***Overall research question:***

- How do men and women living with HIV/AIDS consider, and manage, their sexual and reproductive lives?

***Specific research questions:***

- How do men and women living with HIV/AIDS perceive their own sense of self and life prospects as related to sexual and reproductive outcomes in the current era of treatment?
- What factors contribute to an explanation of sexual and reproductive intentions and behaviour of men and women living with HIV and AIDS?
  - In what ways does the use of ART affect sexual and reproductive behaviour and intentions of men and women living with HIV/ AIDS?
  - What are the barriers to achieving sexual and reproductive intentions of men and women living with HIV/AIDS?

**1.2. Rationale**

Despite sub-Saharan Africa being the epicentre of the HIV pandemic and having the largest absolute number of PLWHA on ART (UNAIDS 2008, 2010, 2011), studies on sexual and reproductive behaviour of PLWHA in the region are limited (Sarna et al. 2008; Bunnell et al. 2006; Cooper et al. 2007). Specifically, few attempts have been made to examine the interrelated issues of sexuality, fertility desires and contraceptive use and demand in one study. What explains the dearth of research on these related issues in this setting? The paucity of research on sexuality and reproduction of

PLWHA is a result of the fact that infection with HIV, until recently, meant a death sentence (Schiltz and Sandfort 2000). The focus has, essentially been on either establishing a case for ART access (Orrell et al. 2003) or highlighting challenges in order to prevent improper use of ART (Bartlett 2002; Hardon et al. 2007; Harries et al. 2001). Scant consideration was given to the fact that PLWHA might be sexually active<sup>1</sup>, or consider reproduction. With recent widespread availability of ART, a treatment that restores people's health and quality of life (Moatti and Souteyrand 2000) an assumption of PLWHA remaining sexually abstinent is no longer tenable. Studies suggest that the majority of PLWHA are sexually active with some desiring fertility and others wishing to limit or regulate their fertility (Chama, Morrumpa, and Gashau 2007; Chen et al. 2001; Cooper et al. 2009; Myer, Morroni, and Rebe 2007). This study will add to the emergent body of evidence on sexual and reproductive behaviour of PLWHA in a SSA setting.

The majority of evidence dealing with sexual and reproductive behaviour in the context of ART is based on studies set in the global North. Studies from the global North (mainly on men who have sex with men - MSM) suggest that PLWHA engage in sexual unions involving "risky" sexual behaviour, including multiple sexual partnerships and non-use of condoms (Katz et al. 2002; Olley 2008), and important factors implicated for this include treatment optimism, depression and drug use and internalised stigma (Brooks et al. 2008; Courtenay-Quirk et al. 2008; Crepaz, Hart, and Marks 2004). This raises questions about the applicability of this individual-level evidence to resource-poor settings in general and sub-Saharan Africa in particular. Individualised models of health behaviour have been shown to be inadequate in a variety of settings in the global South (Airhihenbuwa and Oregon 2000). Moreover, studies on sexual behaviour of PLWHA have been done principally on MSM in the global North (Courtenay-Quirk et al. 2008). There are, therefore, gaps in our knowledge of sexual behaviour among heterosexual PLWHA in the global South. This study helps fill these gaps.

In order to design effective policies and interventions that will protect PLWHA and their sexual partners, and unborn children, knowledge of patterns of sexual and

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<sup>1</sup> the issue of HIV-positive CSWs notwithstanding

reproductive behaviour amongst PLWHA is crucial. Evidence on desires and intentions related to reproduction are absent, as extant studies on PLWHA mainly consider the impact of HIV on clinical perinatal outcomes such as miscarriage (Glynn et al. 2000) or the effect of HIV on population fertility rates (Magadi and Agwanda 2010). PLWHA who want or intend to have (more) children need information on how to prevent vertical transmission; PLWHA who are sexually active, but do not want to have children need information and services on appropriate contraception. However, PMTCT programmes in SSA miss out on providing family planning counselling and services (Rutenberg and Baek 2005), yet contraception has been showed to be more cost-effective than provision of ART prophylaxis (Reynolds et al. 2008). Health services for PLWHA in SSA have, understandably, focused on providing ART and care for opportunistic infections, but there is also a need for appropriate reproductive health services for PLWHA (Cooper et al. 2009; Elul et al. 2009).

This study adopted a mixed methods design to explore sexual behaviour, fertility desires and demand for contraception and identify factors that influence these decisions among PLWHA in poor Nairobi slum settlements. It is expected that findings generated from the study will contribute to the understanding of the level and factors influencing sexual activity, fertility desire and contraceptive demand and aid programme designing and practice to address counselling and SRH service needs of PLWHA. Given that the majority of PLWHA are of reproductive age and the main modes of HIV transmission in Kenya are heterosexual and mother-to-child transmission, a nuanced understanding of sexual behaviour and reproductive decisions of PLWHA is crucial for HIV prevention and their quality of life. Understanding sexual activity, desire for children and demand for contraceptives among PLWHA is necessary to help them enjoy their sexual lives and achieve reproductive goals without sacrificing the health of their partners, their children and their own health.

### **1.3. Structure and contents of the thesis**

The thesis consists of two main parts. Chapters 1 to 3 provide background and theoretical and methodological bases for the study. Following a statement of the problem, research questions and rationale of the study in chapter 1, chapter 2 covers a review of global and local epidemiological, demographic, sociological and anthropological literature on sexual and reproductive behaviour, examining the main

theoretical approaches, their pros and cons and implications and applications to the study. A review of the literature discusses the relevance of these theories and develops the theoretical framework that guides the methodology of the study and empirical analysis of sexual behaviour, fertility desires and contraceptive demand and use. The methods used to collect and analyse data for study are discussed in chapter 3.

Chapters 4-9 cover the empirical side of the study. The research questions provided the chronological order of empirical chapters. Chapter 4 presents the empirical analysis of lived experience of life in a slum setting, which sets out the context for the analysis of sexual and reproductive health outcomes in the proceeding chapters. Chapter 5 presents analysis of empirical data on self-identity and how this is reshaped in the course of HIV and its implication for sexual and reproductive health behaviour of PLWHA in the study sites. Chapter 6 explores one aspect of sexual life, focusing on sexual activity/ inactivity, pleasure, functioning and satisfaction. Chapter 7 extends the analysis of sexual behaviour by concentrating on HIV prevention or transmission behaviour such as condom use and multiple sexual partnerships and sexual abstinence and barriers to safer sex. Fertility desires, contraceptive use and unmet need for contraception and barriers to the realisation of reproductive health are explored in chapter 8. Chapter 9 concludes, drawing together results of the theoretical and empirical analysis, discussing the limitations of the study and implications for policy.



## **Chapter 2: Literature review: Sexual and reproductive behaviour among PLWHA**

### **2.1. Introduction**

This chapter examines existing studies on sexual and reproductive lives of PLWHA in relation to the study's research questions (chapter 1). The purpose of this chapter is threefold. One, it seeks to demonstrate the rationale of the research questions. Two, it provides a theoretical framework and informs the design for the study. Finally, the chapter identifies the gaps in the literature that the study sets out to fill.

This chapter is divided into four main sections. The first section begins with an overview and inadequacies of behavioural change theories – the mainstream approaches and models to HIV studies – to set the stage for the focus on the risk environment. The second section describes the risk environment that people live in, which is likely to shape the sexual and reproductive behaviour among PLWHA in a slum settlement. This review focuses on poverty and gender inequalities, and how they operate cyclically to increase vulnerabilities to poor SRH outcomes. It also considers self-identity as another contextual factor likely to influence the sexual and reproductive behaviour of PLWHA. This is followed by an examination of the literature on the sexual behaviour of PLWHA and its determinants in the third section. The fourth and final section looks at the extant literature on the reproductive preferences of PLWHA and barriers to the realisation of their reproductive goals.

### **2.2. Behavioural change theories**

The majority of socio-behavioural studies on sexual and reproductive behaviour in the general population as well as among PLWHA use biomedical and behavioural models that rely on individual behaviour change (Bartos and McDonald 2000; Coates, Richter, and Caceres 2008; Kennedy et al. 2010). HIV/AIDS prevention interventions, namely; Abstinence- Being faithful and Condom use (ABC) tend to have an individual behaviour focus, with strategies to changing “risky” sexual behaviour (Evans and Lambert 2007; Kennedy et al. 2010). Of course riskier sexual behaviour exposes individuals to the risk of HIV infection. But the fact that differences in “risky” behaviour – early sexual debut, unprotected sex and multiple sexual partnerships – between rich nations and SSA is not matched with differences in their HIV/AIDS

prevalence rates (Stillwaggon 2009), demonstrates that behaviour alone is not the end of the story. Sexual behaviour – in terms of frequency of sex and number of sexual partners in a life-time – show no significant variation by countries, even though reported multiple (without distinguishing between concurrent and sequential) sex partnership is slightly higher in developed countries (Wellings et al. 2006), where, incidentally, HIV prevalence is lower. In common with behaviour change models used in the general population, studies on PLWHA largely endeavour to profile PLWHA who exhibit certain characteristics such as unprotected sex, multiple sexual partnership, non-adherence to ART and pregnancies that make them “risky” groups or entities (Bartos and McDonald 2000).

The most common behavioural models used in HIV/AIDS related behaviour change interventions are the Health Belief Model (HBM) (Janz and Becker 1984), Theory of Planned Behaviour (TPB) (Ajzen and Madden 1986) and Information-Motivation-Behavioural Skills Model (IBM) (Fisher and Fisher 1992; Fisher et al. 2006). These models have certain constructs in common, including, perceived threat and severity of the disease, personal susceptibility and behavioural control (Noar 2007; Crepaz and Marks 2002) as determinants of preventive behaviour. At the heart of the behavioural models is the notion of a rational appraisal of the cost (barriers) and benefit analysis in adopting behaviour (Munro et al. 2007). Individuals who expose themselves to risk, do so by acting irrationally on the basis of (mis-) information and failing to evaluate the risk correctly, or so the argument goes (Bajos and Marquet 2000). The HBM underscores the importance of risk perception in terms of perceived threat of and susceptibility to HIV/AIDS infection as drivers of safer sexual behaviour. TBP and IBM include perceived ability to execute safer sexual practices (self-efficacy) by possessing requisite knowledge, skills and personal control (Molla, Nordrehaug Åström, and Brehane 2007; Fisher et al. 2006). These behavioural theories all take an individual level approach to understanding HIV/AIDS preventive behaviour (for extensive reviews see Munro et al. 2007; Noar 2007).

Behavioural models have been able to identify particular individual characteristics such as HIV-related knowledge, risk perception, self-efficacy, attitudes, and beliefs (Crepaz and Marks 2002) that predict certain HIV/AIDS prevention behaviour such as safer sex and HIV testing. People with a higher of level of knowledge are more likely

to avoid risk sexual behaviours and to consistently use a condom (Wiener, Battles, and Wood 2007). Risk perception also affects adoption of HIV risk reduction strategies (Kohler, Behrman, and Watkins 2007). A study in Kenya found a strong relationship between perceived risk of HIV/AIDS and risky sexual behaviour in both men and women (Akwara, Madise, and Hinde 2003). Similarly, a study in Nairobi slums found that perceived risk of HIV infection motivated HIV testing among youth (Kabiru et al. 2011). Studies in Kenya (Kabiru et al. 2010) and elsewhere in SSA (Scott-Sheldon et al. 2011) have demonstrated that people who were tested for HIV were more likely than those who did not to change their sexual behaviour.

Such findings have informed the centrality of information, education and behavioural change (IEC/BCC) interventions in HIV prevention programmes. These interventions have been geared towards disseminating correct information and reducing of misinformation on HIV/AIDS transmission. In Kenya awareness of HIV/AIDS is now almost universal and levels of knowledge about HIV transmission and prevention are very high, a factor that has been attributed to declines in HIV prevalence (NASCO 2007; NACC 2009).

Individual level characteristics represent just one aspect of SRH behaviour. The complexity of sexual and reproductive behaviour cannot, therefore, simply be understood in terms individual level factors and autonomous individual decisions. The gap between HIV related knowledge and sexual behaviour is one of the best documented conundrums in HIV/AIDS research. Widespread awareness of HIV/AIDS has not been accompanied by changes in sexual behaviour in Kenya (Bauni and Jarabi 2000; Dadoo and Ampofo 2001; Njogu and Martin 2005) and elsewhere in SSA (Mwale 2008; Odu and Akanle 2008), indicating that having knowledge does not necessarily translate into changed, less risky, behaviour (Campbell and Cornish 2003). The evidence regarding the relationship between risk perception and safer sexual behaviour is at best mixed (Mwale 2008). Moreover risk perception is not only a function of individual perception, but also an outcome of social interaction (Kohler, Behrman, and Watkins 2007).

Behavioural models that focus on individual behaviour at the expense of the social, cultural, political and economic setting do not capture the entire picture (Barnett and

Whiteside 2006; Kalipeni et al. 2004) and hence the need to focus on the broader risk environment. The success of strategies to reduce individual risk increases substantially if they address the broader context that shape or constrain individual behaviour such as poverty, gender and power (Coates, Richter, and Caceres (2008). The next section examines this broader risk environment.

### **2.3. The risk environment framework**

The risk environment refers to the physical or social space in which factors exogenous to the individual interact to facilitate (or reduce) individual risk or vulnerability (Barnett and Whiteside 2006; Rhodes 2002). The risk environment comprises the physical, socio-cultural, economic, political and policy contexts that shape individual behaviour (Rhodes 2009). This can be at the micro-level – individual and community level practices and norms or the macro-level – structural factors (economic conditions, poverty, cultural beliefs and practises, legal framework) (Rhodes and Simic 2005). At the micro-level risk behaviour and perception is a product of local social norms and values that shape identity, local social relations and networks, and community health and social care services. At the macro-level risk behaviour is shaped by, for example, the public and legal context; economic, gender, stigma and cultural beliefs (Rhodes 2002, 2009; Rhodes and Simic 2005). People's embeddedness within particular social, cultural and economic contexts shape their risky behaviour (Barnett and Whiteside 2006; Campbell 2000; Coast 2007; Kalipeni et al. 2004). It certainly requires close linkage and even cross fertilization between epidemiology and social science to understand the risk environment (Rhodes and Simic 2005), not least because HIV/AIDS is a biological condition influenced by socio-economic forces.

The risk environment is without doubt a broad and multifaceted framework to be exhaustively analysed in a single study such as this. This study deliberately focuses on selected aspects of the risk environment: Poverty, gender relations, socio-cultural norms and values, which shape the identities and experiences of PLWHA in Nairobi slums, and consequent sexual behaviour and reproductive preferences.

### *2.3.1. The relation between Poverty and HIV/AIDS*

This section examines poverty as the first aspect of the risk environment that is likely to shape sexual and reproductive behaviour of PLWHA in slums (Amuyunzu-Nyamongo et al. 2007; Montgomery 2009). Poverty is a complex and contested term in terms of definition and measurement. General consensus in the literature centre around the ability of the individual or household to meet its basic needs (Coudouel, Hentschel, and Wodon 2002). Poverty can be described in absolute or relative terms. For example, the World Bank defines absolute poverty using a monetary household income of less than 1 US dollar per person per day (Marais et al. 2008). Relative poverty can be measured using wealth quintiles (Madise, Zulu, and Ciera 2007). This study will mostly utilize wealth quintiles although absolute poverty is used when setting the context (chapter 4). Poverty is thought to create fertile grounds for HIV infection while HIV infection further impoverishes individuals and households (Marais et al. 2008). This section will briefly outline some of the effects that HIV/AIDS and poverty have on each other in reference to SSA and the study site. This will attempt to show that HIV/AIDS and poverty have a mutually reinforcing relationship.

Evidence of the relationship between poverty and spread of HIV/AIDS in SSA is growing (Barnett and Whiteside 2002; Gillespie, Kadiyala, and Greener 2007; Natrass 2009; Whiteside 2002). As the number of studies on poverty and HIV/AIDS has grown so has the debate among scholars. Some studies have shown that there is no consistent relationship between poverty (or rather measures of economic deprivation) and HIV/AIDS at the aggregate level (Natrass 2009). Others show that it is inequality that is associated with HIV prevalence (Holmqvist 2009). The fact that some of the economic giants of the continent such as South Africa and Botswana have the highest HIV prevalence (Whiteside 2002) may suggest that wealth and HIV/AIDS are positively associated. Some studies in Kenya and Tanzania found a positive association between household wealth and individual HIV prevalence (Shelton, Cassell, and Adetunji 2005).

Explanations for the positive relationship between wealth and HIV prevalence has been that relatively wealthier individuals can afford to maintain concurrent multiple

sexual partners and are more mobile (Nattrass 2009; Shelton, Cassell, and Adetunji 2005). Conversely, a study among adolescents in Kenya, Uganda, Ghana and Malawi did not document any significant association between wealth and multiple sex partnerships (Madise, Zulu, and Ciera 2007). The positive relationship between inequality and HIV prevalence may be due to the fact that high inequality increases transactional sex, mobility and gender violence, which are risk factors for HIV infection (Durevall and Lindskog 2009).

However, the relationships between poverty and HIV/AIDS are very complex, with feedback loops, that cannot simply be reduced to a simple correlation between measures of wealth (for example material possessions e.g.: household possession) and HIV prevalence rates. Measures of wealth using material possessions favour urban residence and studies show that HIV prevalence rate in urban areas is higher (Dyson 2003). Secondly, HIV prevalence is a function of survival and the wealthier have the means (for example, nutrition, access to ART) to live longer with HIV than their poorer counterparts (Kongnyuy et al. 2006).

Poverty and HIV/AIDS have been described as a vicious cycle: one either causes and/or exacerbates the other (Piot, Greener, and Russell 2007). For example increased poverty and inequality fuel the spread of the epidemic. In turn, infection with HIV can worsen the economic situation of the household or individual leading to increased poverty and/or inequality (Masanjala 2007). I examine these pathways in turn.

#### Effect of poverty on HIV/AIDS and PLWHA

Poverty is thought to influence HIV infection through three main pathways: lack of food and attendant malnutrition; the practice of survival sex; and, rural-urban migration.

The role of malnutrition in susceptibility to disease, whether sexually transmitted or not, has long been recognised (Stillwaggon 2006). Malnutrition weakens the immune system and hence the risk of contracting HIV is higher for malnourished individuals (Gillespie and Kadiyala 2005; Stillwaggon 2006). Malnutrition among PLWHA also hastens disease progression from HIV to AIDS (de Waal and Whiteside 2003; Gillespie and Kadiyala 2005). Malnutrition also affects survival as PLWHA are 2 to 6

times more likely to die soon after initiating ART if they are malnourished (UNAIDS 2011). HIV leads to malnutrition among PLWHA by impairing their nutrient uptake, absorption and use (Fawzi 2003; Piwoz and Preble 2000; Friis 2005).

Malnutrition is very common in many SSA settings. In Nairobi slums, only 1 in 5 households is defined as food secure (Faye et al. 2010). Yet, good nutrition is necessary for ART effectiveness (de Waal and Whiteside 2003) and hence is an important component of ART treatment and adherence. However, a study in Nairobi slums found that many PLWHA are unable to follow optimal food and nutrition recommendations for ART use due to poverty and an inability to buy food (Izugbara and Wekesa 2011). Food insecurity may also increase HIV risk, especially among poor women who may engage in transactional or survival sex to obtain food for themselves and their family (Gillespie, Kadiyala, and Greener 2007). A study in Botswana found that food insufficiency was associated with increased HIV risk behaviour among women (Weiser et al. 2007).

The second way through which poverty operates to increase HIV risk is survival or transactional sex, which refers to sexual relationships that are motivated by financial or material rewards (Dunkle et al. 2007). In conditions of poverty, people without any source of income can sometimes have no other option, but to exchange sex for material resources even though they may not consider themselves as sex workers (Luke 2003; Wojcicki 2002). Much as some transactional sex is motivated by survival, recent studies show that transactional sex may also help in acquisition of education, employment or higher status (Dunkle et al. 2007). A distinction between transactional gifts and other normal courtship gifts to show affection needs to be made, as the former underpin the existence of the sexual relationship (Dunkle et al. 2007). Most transactional sex studies focus on young women with older men (Luke 2003), and so there is little information on other types of participants in transactional sex relationships.

In urban settings, money is crucial for survival, and lack of alternative sources of income forces some women to use sex as a means of survival in the general population (Dodoo, Zulu, and Ezeh 2007; Zulu, Dodoo, and Chika-Ezeh 2002) and among HIV infected women (Amuyunzu-Nyamongo et al. 2007). Unprotected transactional sex is

a risk for HIV infection (and re-infection) because of the multiple partners involved. A study in South Africa showed that self-reported participation in transactional sex was associated with HIV sero-status (Dunkle et al. 2004a). A study in four African countries showed that poverty was associated with early sexual debut for female adolescents and non-use of condoms (Madise, Zulu, and Ciera 2007). Women involved in transactional sex lack the ability to negotiate for safer sex since condom use is at the discretion of the paying client (Campbell 2000; Wojcicki 2002). Condom use in transactional sexual relationships can decline over time as a result of increased material and financial gifts. A study in Kenyan found that the likelihood of condom use at last sex in transactional partnership was lower when the value of a man's financial and material contributions over the last month was higher (Luke 2006).

Poverty and lack of economic opportunities in rural areas is one factor influencing rural-urban migration. In many parts of SSA paid employment opportunities in rural areas are rare, and individuals migrate to urban areas in search of higher wages (Krishnan et al. 2008). The link between migration and HIV transmission patterns has been documented (Brockhoff and Biddlecom 1999; Lurie et al. 2003). The movement of young adults from traditional rural African settings to urban areas that are more sexually permissive with lower levels of social control has been cited as one of the causes of high urban HIV rates (Brockhoff and Biddlecom 1999; Mberu and White 2011). Migration can also increase HIV infection risk due to the formation of new sexual relationships in areas of origin and destination due to spousal separation. Studies in South Africa show that migrant workers and their wives form new sexual relationships during periods of their separation and this transmits HIV to their wives or returning husbands (Lurie et al. 2003). However, a study in urban Tanzania, counter-intuitively, challenges the circular urban-rural migration HIV transmission link (Coast 2006). This study found that Maasai migrants regulate their sexual behaviour to reflect their local understanding of HIV –that it is an urban disease – and so avoid engaging in sex in urban areas. HIV/AIDS may also trigger migration, both rural-urban and return migration (Krishnan et al. 2008).

#### Effects of HIV/AIDS on poverty

Infection with HIV/AIDS has been shown to impoverish households and individuals through loss of property, increased expenditure and reduced capacity to earn income



(Fox et al. 2004). A study in Uganda found that almost half of PLWHA who did not work in the last 7 days, cited illness as the major reason (Linnemayr et al. 2011). Loss of earning potential also results from diversion of productive labour to take care of sick family members (Barnett and Whiteside 2002; Whiteside 2002) or loss of job due to HIV status (Linnemayr et al. 2011). A study in Kenya among tea workers found their productivity decreased due to HIV infection (Fox et al. 2004).

The other economic effect of HIV/AIDS is loss of property through the sale of assets and erosion of savings in order to meet medical care and funeral expenses and also cope with diminished income earning potential and unemployment (Barnett and Whiteside 2002). One consequence of impoverishment is a reduced ability to get HIV/AIDS related care and needs. Even if ART drugs are free in public health facilities, poor families may have insufficient resources to meet the costs of travel to health facilities for care and the requisite nutritional needs (Hardon 2006; Izugbara and Wekesa 2011).

Household composition and roles may change with HIV-related death or illness of adults. For example, marriage dissolution and instability are associated with HIV-related stigma or suspicion of infidelity (Porter et al. 2004). This can result in child headed, single parent and grandparent headed household (Barnett and Whiteside 2002). Children who take on caring roles or are raised in single parent households are more likely to drop out of school (Case, Paxson, and Ableidinger 2003), with long-term implications for poverty. Secondly, HIV has caused an increasing number of orphans in SSA, estimated to be 12 million children (UNAIDS 2008). This has overwhelmed the capacity of traditional extended family care (Heymann and Kidman 2009; Nyambedha, Wandibba, and Aagaard-Hansen 2003) and intergenerational dependency and knowledge transmission, creating a generation that is less well educated, socialised and cared for (Barnett and Whiteside 2006).

Notwithstanding the recent growth of interest in the poverty- HIV/AIDS nexus, there exists, in SSA, a paucity of research on how they interact to influence sexual and reproductive behaviour in general and PLWHA in particular. Stillwaggon (see Stillwaggon 2006; Stillwaggon 2009) has lamented the tendency of HIV/AIDS research and policy to over-emphasise risky sexual behaviour and neglecting

underlying causes such as poverty, in contrast to work on other epidemics and infectious diseases. Sexual behaviour is, of course, important because the majority of HIV/AIDS in SSA is through heterosexual intercourse. But in the absence of co-factors, the heterosexual route is a relatively inefficient mode of transmission – estimated probability of about 1 per 1,000 contacts (Stillwaggon 2006; Gray et al. 2001). Sexual intercourse with an infected person is thus a necessary, but not a sufficient condition for HIV infection (Stillwaggon 2009). The second route is vertical transmission from mother to child. Vertical transmission before ART prophylaxis ranged from 14% in Europe to 40% in SSA, and thus, being born to an HIV positive mother does not always lead to infection of the infant (Stillwaggon 2009). Therefore, other structural factors play a role in influencing vulnerability to HIV infection in addition to individual sexual behaviour. The next section looks at gender as a social factor that plays a role in HIV spread.

### 2.3.2. *Gender and HIV/AIDS*

Gender refers to the socially constructed roles, activities and behaviour that are considered as appropriate for men and women, as opposed to sex, which refers to biological differences between men and women (Mane and Aggleton 2001). Therefore, "male" and "female" are sex categories, while "masculine" and "feminine" are gender categories. As a social construct, gender has the potential to confer on men and women differential roles, social norms and expectations regarding appropriate conduct in society. Gender norms and ideals about masculinity and femininity govern behaviour that affect the sexual and reproductive experiences of men and women (Varga 2003).

Studies have shown how gender shapes sexual and reproductive behaviour of men and women that exposes them to differential risk of HIV infection. In SSA, women constitute 60% of people living with HIV (UNAIDS 2008) and gender is identified as being at the heart of the feminisation of the African HIV/AIDS epidemic (Gupta 2002; Jewkes, Levin, and Penn-Kekana 2003; Kalipeni, Flynn, and Pope 2009; Kalipeni, Oppong, and Zerai 2007; Mill and Anarfi 2002; UNAIDS 2008; Varga 2003). The contemporary gender discourse propagates the idea of vulnerability to describe women's social susceptibility to HIV/AIDS (Persson and Richards 2008), in addition to their physiological susceptibility. There are three pathways through which gender

relations foster women's vulnerability to HIV/AIDS infection: social norms governing women's acceptable behaviour and responsibilities; economic dependency on men; and, gender related violence from their male counterparts (Jewkes, Levin, and Penn-Kekana 2003).

Social norms and societal ideas about masculinity and femininity have been shown to expose women to risk of HIV risk infection. Masculinity ideologies can encourage males to have multiple female sexual partners (MacPhail and Campbell 2001). With an emphasis on male prowess and invincibility, masculinity is often thought to be expressed by having multiple girlfriends and sometimes wives in SSA (Long 2009). However, having multiple sexual partners is, conversely, is not an expected feminine attribute. Women are taught to be passive in matters sexual and assent to man's sexual needs (Varga 2003). Double standards one would say.

The second aspect of social norms is the system of patriarchy in many SSA contexts, where men wield power in all spheres of life including domination of sexual and reproductive lives of women. This system ensures that men play a leading role in sexual matters, while women are expected to be coy and resistant to sexual advances (Varga 2003) or give priority to the sexual needs of men (Jewkes, Levin, and Penn-Kekana 2003). As such women are unable to insist on condom use for fear of appearing promiscuous or their concern about men's sexual pleasure (Jewkes, Levin, and Penn-Kekana 2003). Moreover, motherhood is crucial to many women's social status and HIV positive women will proceed with childbearing despite the risks in order to fulfil societal expectations (Cooper et al. 2007; Mill and Anarfi 2002).

Economic dependency of women on men contributes to women's poorer sexual health outcomes. Women's unequal access to economic resources leads to situations of dependency on men, making it difficult for them to exercise control over their bodies and sexuality (Mill and Anarfi 2002). Economic vulnerability can force women into sexual relationships with wealthier older men (Luke 2003). This intergenerational sex contributes to higher infection rates among young women (15-24 years) compared to young men (UNAIDS 2008). Many women, especially those living with HIV, lose their homes, inheritance, possessions, livelihoods and even their children when their partners die. This forces many women to adopt survival sexual relationships that

further increase their chances of contracting and spreading HIV. Women in such relationships are less likely to succeed in negotiating protective sex and to leave risky and abusive relationships (Jewkes, Levin, and Penn-Kekana 2003).

Gender-based violence is the third factor that the literature attributes to women's vulnerability. Violence against women increases their vulnerability to HIV/AIDS in two ways. One, forced sexual intercourse with an infected partner increases the chances of infection because of possible tears in their genitalia due to force, and their inability to determine conditions under which to have sex, such as ask for use of condoms (Jewkes, Levin, and Penn-Kekana 2003). Secondly, women who have experienced prior gender-based violence may fear that suggesting condom use might result in more violence, as doing so may imply infidelity, since condoms are associated with promiscuity (Jewkes, Levin, and Penn-Kekana 2003), disease and lack of trust (Visser and Smith 2001; Westercamp et al. 2010; Askew and Berer 2003). Women may fear to question the infidelity of their husbands to avoid experiencing another round of domestic violence (Kalipeni, Flynn, and Pope 2009). Experience of intimate partner violence in South Africa was associated with being HIV positive (Dunkle et al. 2004b). Finally, fear of violence can prevent women from learning and/or sharing their HIV status with their partners and/ or accessing treatment.

Gender discourse on HIV risk exposes how women's capacity to control their bodies and sexuality is hampered by gender inequalities. However, there are some problems and weaknesses with the dominant gender discourse. First, it has made gender analysis almost an exclusively female issue (Dowsett 2003; Dworkin 2005). When men are mentioned, it is invariably about the risk they pose to women. In the words of Dudgeon and Inhorn (2004, 1381): "They [men] have been seen primarily as impregnators of women, or as the cause of women's poor reproductive health outcomes through STI exposure, sexual violence, and physical abuse... and as barriers to women's decision making about fertility, [and] contraceptive use...". Vulnerability is certainly not confirmed to women alone. The same gender norms and masculinity ideologies that make women vulnerable can also make men vulnerable. In a heterosexual transmission, women can only contract HIV from a man who might have been vulnerable and at risk himself (Dworkin 2005). The feminisation of gender has created a substantial literature examining women's vulnerability to HIV, but there is an

absence of literature on heterosexual men (Persson and Richards 2008; Doyal, Anderson, and Papparini 2009).

The second critique of the dominant gender vulnerability discourse is that it relies on relatively simplistic and stereotypical ideas of gender. It tends to depict all heterosexual women as categorically powerless and oppressed and all heterosexual men as aggressors, vile, evil and irresponsible. The discourse typically suggests that power is categorically owned by men and its *raison d'être* is to oppress and dominate women (Dworkin 2005). What essentially come out of the predominant discourse are preconceived gender roles. Power asymmetries between men and women in SSA are not in dispute. However, not all women are homogeneously powerless and all men categorically powerful and all controlling in matters sexuality. Tawfik and Watkins' (2007) study in Malawi challenges the stereotypical depiction of women as powerless, poor, passionless and only used to satisfy men's sexual desire in the gender discourse. Contrary to typical presentations of women as powerless who only engage in extra marital sex for survival, some women in rural Malawi actively sought extra-marital affairs for other reasons including: desire for consumer goods; passion; and, revenge for a husband's infidelity.

Secondly, the vulnerability gender discourse is a static and rigid representation of gender, which gives little cognizance to changes in gender attitudes and behaviour. Gender norms are not static; they change in response to changing social-economic circumstances (Mantell et al. 2009). Some women and men question and resist dominant masculine and feminine roles. Evidence of women's resistance to gender norms that pose risk to HIV and some men challenging dominant gender norms has been documented in studies in Namibia (Brown, Sorrell, and Raffaelli 2005), and South Africa (MacPhail 2003; MacPhail and Campbell 2001). Gender relations are becoming more "egalitarian", with young women and men welcoming and supporting women's initiation of sexual activity and condom use (Mantell et al. 2009). It becomes crucial to examine, not just how dominant gender roles pose HIV risk, but also how the HIV/AIDS pandemic is effecting changes in gender roles and attitudes around hegemonic masculinity, especially from accounts of PLWHA themselves.

The stereotypical gender discourse, as a consequence misses out at least two issues in relation to HIV prevention and sexual and reproductive outcomes of individuals whether HIV infected or not. One, the discourse leaves out men's responsibility and care in their sexual relationships with women, and places all this on women's shoulders. This is apparent in what is referred to as the "paradox of power and responsibility": women have responsibility for safer sex and yet have no power to do so in the gendered relationship (Strebel 1997 cited in Long 2009). The discourse fails to countenance that men might protect women from HIV or pregnancy in a romantic relationship. It allows men to escape responsibility by portraying them as violent, dangerous and irresponsible. However, beliefs and attitudes of PLWHA about their own responsibility for HIV/AIDS prevention are poorly understood (Wolitski et al. 2007).

Secondly, the discourse fails to appreciate the reproductive health needs and rights of men as partners of women. Sex and reproduction in heterosexual relationships involves men and women. Women's as well as men's intentions affect achieved fertility and contraceptive use (Dudgeon and Inhorn 2004). Some studies, for example, suggest that estimates of unmet need for contraception in SSA may be invalid when focussed on women data alone (Bankole and Ezeh 1999). Despite calls to include men in the measure of unmet for contraception, only very few studies (eg Ngom 1997) have made this attempt.

For gender discourse to be meaningful it needs to consider gender not purely in terms of power between men and women, but also include love, intimacy, and even sero-status in heterosexual relations (Persson and Richards 2008). Presenting women as oppressed and men as oppressors glosses over a nuanced understanding of vulnerabilities to adverse sexual and reproductive health outcomes of both men and women. In any case it tends to be the elites and men and women of a high class in society that wield political and economic power (Mane and Aggleton 2001). There is need to pay attention to women's and men's privileges and inequalities, as no individual or even gender has singular experiences (Dworkin 2005). Therefore, we need to understand how gender and socio-economic factors create vulnerability in women as well as men. Ultimately, the tone of blame in the gender discourse is hardly conducive for building partnerships between men and women and male involvement in

sexual and reproductive health matters (Mane and Aggleton 2001). The rigid gender stereo-types found in SSA make it difficult for men and women to talk to each other or narrate their HIV experiences (Long 2009) as well sexual and reproductive health experiences and intentions.

The following section considers self-identity as another contextual factor likely to affect PLWHA's SRH outcomes. Emerging evidence shows that perceptions of self-identity and lived experience have a bearing on the sexual and reproductive behaviours of PLWHA (Bartos and McDonald 2000; Smith and Mbakwem 2010).

### *2.3.3. Self-identity, HIV/AIDS, sexual and reproductive behaviour*

Living with a chronic illness can lead to a biographical disruption of the self (Bury 1982) and the need for reconstruction mechanisms to return to a more normal state (Carricaburu and Pierret 1995; Kralik 2002). The concept of biographical disruption has been applied to HIV/AIDS by scholars in the North (e.g Carricaburu and Pierret 1995; Ciambone 2001) and recently in SSA (Russell and Seeley 2010; Seeley and Russell 2010). This body of research has described how people manage the incorporation of HIV into their self-identity – a sense of who one is – in response to a positive diagnosis. These studies show that PLWHA undergo a transition to a new sense of self-identity as they incorporate HIV/AIDS into their lives and as they interact with others (Russell and Seeley 2010). This process is iterative – from initial turmoil to order, and sometimes back – all the way from a positive diagnosis, self and others' responses to the diagnosis and seeking care to manage their HIV/AIDS condition and achieve some normalcy (Kralik 2002; Baumgartner 2007). Most studies on self-identity focus primarily on how self-identity is shaped by living conditions and socio-cultural context and overlook other structural factors such as medical developments (Pierret 2007). Medical interventions and attendant “medicalisation” of HIV bring changes in people's daily lives (Seckinelgin 2008). The effect of ART on PLWHA's construction of self-identity is deserving of research attention, in addition to the socio-cultural context, not least because PLWHA need to incorporate both the HIV condition and treatment in their lives (Russell and Seeley 2010; Seeley and Russell 2010).

There is limited evidence to show that perceptions of self-identity have a bearing on sexual and reproductive behaviour of PLWHA (Bartos and McDonald 2000). For

example, the way PLWHA in Australia perceived their HIV status affected their sexual behaviour – whether to disclose their status to a sexual partner, use of condom or have a negotiated long term regular sexual partnership (Bartos and McDonald 2000). Another study in Brazil found that the search for ways of “social validation” such as expression of intimacy with sexual partners and having (more) children affected condom use among PLWHA. In the same study there was an indication that lack of self-acceptance combined with denial and anger was associated with unsafe sex in a bid to intentionally infect others (Kerrigan et al. 2006).

Sexual activity and reproductive desires among PLWHA are reflective of their quest for normalcy after disruption to their identity (Smith and Mbakwem 2010). Parenthood is one of the most important aspects in the hierarchy of expectations for many people and is central to social life in SSA (Cooper et al. 2007; Hosegood 2009; Smith and Mbakwem 2010; Kisakye, Akena, and Kaye 2010). The quest to adhere to societal expectations with regard to reproduction is, arguably, even more urgent among PLWHA. This is because infection with HIV/AIDS, is not only disruptive of one’s biography, but is associated with moral failures such as sexual promiscuity and a breach of societal norms and taboos, and damaged self-identity (Lekas, Siegel, and Leider 2011; Smith and Mbakwem 2010). The moralising of the HIV condition contributes to stigma and discrimination towards PLWHA (Parker and Aggleton 2003; Visser, Kershaw, et al. 2008). Stigma can, among other things, prevent HIV testing, seeking of treatment and care services, undermine adherence to treatment and reduce likelihood of disclosure to sexual partners (Kalichman and Rompa 2003; Simbayi et al. 2007b; Kaler and Watkins 2010). Resuming sex and having children not only provides an opportunity for PLWHA to lead normal lives, but is also as a way to mitigate stigma and social disapproval and discrimination (Smith and Mbakwem 2010).

In the next two sections, I review the socio-behavioural literature on the sexual and reproductive outcomes of PLWHA. This shows how aspects of the risk environment interact to influence the sexual and reproductive health outcomes of PLWHA, with specific reference to resource-poor SSA settings.



#### **2.4. Sexual behaviour and experiences of PLWHA**

In general there has been little attention paid to the sexual behaviour of PLWHA by both social and behavioural science researchers (Moatti and Souteyrand 2000; Kennedy et al. 2007). This is paradoxical as HIV/AIDS, especially in SSA, is primarily spread through unprotected heterosexual intercourse. Schilitz and Sandfort (2000) examine why the sexual behaviour of PLWHA has received insufficient attention from the research community. First, they argue, that until quite recently infection with HIV implied a death sentence. The main focus was on interventions that provided medical, financial and moral support to PLWHA, and their sex lives were a minor issue. Secondly, they contend that studies focussing on PLWHA were avoided for the fear of exposing them to stigma. As a result specific prevention challenges as well as overall sexual health and wellbeing of PLWHA have been ignored.

The introduction of ART has altered the scope of knowledge needed to inform the research agenda related to PLWHA. ART use increases the quality of life and life expectancy of PLWHA (Jahn et al. 2008). ART reduces AIDS-related mortality, morbidity and transmission of HIV and improves the health of PLWHA, (Crepaz, Marks, and Hart 2004; Harries et al. 2001) as well as the general population (Egger and Boulle 2008). Improvements in health and quality of life among PLWHA may enable them to engage in sexual activity (Kennedy et al. 2007; Luchters et al. 2008; Niccolai et al. 2006; Remien et al. 2007). Evidence from the global North shows that over 70% of PLWHA are sexually active (Crepaz and Marks 2002; Niccolai et al. 2006). The consequences of unsafe sexual behaviour amongst PLWHA include the possibility of: infecting their sexual partners with the virus; re-infection with multiple strains of HIV; and, transmission of drug resistant strains (Courtenay-Quirk et al. 2008; Maclachlan 2007). PLWHA infected with multiple strains of HIV progress to AIDS and death much faster in comparison with people infected with a single strain (Maclachlan 2007; Moore and Oppong 2007).

The need to prevent HIV/AIDS transmission among PLWHA has led to development of the concept of “Positive Prevention” (Auerbach 2004). There is no single definition of positive prevention, but it generally refers to activities centred on the ability of PLWHA to protect their own health and avoid transmitting HIV to others (Kennedy et al. 2010). Studies on sexual behaviour among PLWHA have begun to emerge, in part

to inform positive prevention strategies. In common with studies on sexuality in the era of HIV/AIDs, the focus on PLWHA is skewed in favour of disease prevention while neglecting other aspects of sexual experience. Evidence focuses on risky sexual behaviour and transmission rather than the quality of sexual experience (Keegan, Lambert, and Petrak 2005). Yet sexual satisfaction is an important aspect of sexual health and overall quality of life of PLWHA (De Ryck et al. 2011).

Studies have examined the sexual functioning, pleasure and satisfaction of PLWHA in America (Keegan, Lambert, and Petrak 2005; Siegel, Schrimshaw, and Lekas 2006) and SSA (Sarna et al. 2009; Allen et al. 2011). What this literature shows is that HIV infection affects sexual functioning negatively, resulting in reduced sexual desire, libido and satisfaction; and, diminished sexual frequency or abstinence. Reduced sexual desire, interest and satisfaction have been attributed to the emotional distress of living with HIV and fears and worries around infections and reinfections (Keegan, Lambert, and Petrak 2005; Rispel et al. 2011; Siegel, Schrimshaw, and Lekas 2006) and perceived negative effect of ART use (Sarna et al. 2009).

#### *2.4.1. ART and sexual behaviour among PLWHA*

There has been growing concern that ART will make people eschew protective sexual behaviour (Crepaz, Marks, and Hart 2004; Kennedy et al. 2007). So far, evidence of the extent to which PLWHA on ART engage in unsafe sexual behaviour is mixed. Some studies suggest that there is a substantial increase in sexual risk-taking amongst PLWHA (Crepaz, Marks, and Hart 2004; Olley 2008). For example, one study done on MSM in San Francisco reported an increased frequency of unprotected sex (Chen et al. 2002). Another study showed that HIV+ MSM on ART in San Francisco were more likely to develop an STI than those that were not on treatment, implying an increased unprotected sex amongst those on ART (Katz et al. 2002). The rise in “risky” sexual behaviour amongst ART users has been attributed to the phenomenon referred to as “treatment optimism” or “disinhibition” (Kennedy et al. 2007). This refers to a situation where PLWHA believe that since ART reduces their viral load to undetectable levels, they are well and no longer infectious (Kennedy et al. 2007; Kerrigan et al. 2006; Kalichman et al. 2006). Recent evidence suggests that reduced viral load lowers the level of infectiousness of ART users (Attia et al. 2009; De Cock et al. 2009). As this information filters into the public arena, it becomes vital to

examine its effect on peoples' beliefs about treatment, including treatment optimism, and sexual behaviour. Studies among MSMs in developed countries show that PLWHA who believed that receiving ART or having an undetectable viral load protects against transmission had higher levels of unprotected sex (Brennan et al. 2010; Crepaz, Hart, and Marks 2004; Kalichman et al. 2006). The extent to which this applies to SSA African setting is unclear.

Conversely, several studies do not find any increase in unsafe sexual behaviour as a result of ART use. A meta-analysis of studies done in the North on the association between ART use and "risky" sexual behaviour failed to find any positive relationship between the two (Crepaz, Marks, and Hart 2004). A similar meta-analysis of studies in developing countries also concluded that ART is not associated with "risky" sexual behaviour (Kennedy et al. 2007). It is, however, difficult to draw any meaningful conclusions from the latter study given that its evidence-base is just three studies.

A number of studies done in SSA suggest decreased sexual "risky" behaviour amongst ART users. A prospective cohort study in Mombasa, Kenya found a substantial reduction in unprotected (uncondomised) sex among ART users after 12 months (Luchters et al. 2008). The study did not, however, consider other forms of risky sexual behaviour such as multiple and casual sexual partnerships. Similar prospective studies reported a decrease in unprotected sex following ART initiation in South Africa (Eisele et al. 2009) and Uganda (Bunnell et al. 2006). A recent prospective study in Mozambique found an increase in consistent condom use after 12 months of ART, although concurrent partnerships also increased (Pearson et al. 2011).

The explanation for the decline in risky sexual behaviour seems to follow along the lines that contact with the health system to receive ART and related counselling encourages protective sexual behaviour (Kennedy et al. 2007). For example, ART initiation is usually accompanied by counselling on protective sexual behaviour, in addition to adherence counselling (Allen et al. 2011). The different effect of ART on sexual behaviour in resource-poor settings may also be due to less familiarity with treatment benefits such as diminished infectivity (Venkatesh et al. 2011). Knowledge regarding levels of viral loads and transmissibility risks may not have achieved wide circulation to influence PLWHA's sexual behaviour towards disinhibition.

#### 2.4.2. *Other factors that affect sexual behaviour among PLWHA*

Studies based in the North, mainly on MSM, have identified a number of factors that are associated with unsafe sex behaviour such lack of condom use and multiple sexual partnerships among PLWHA. The most reported factors in these settings include use of drugs and alcohol (Brooks et al. 2008; Marks, Bingman, and Duval 1998; Theall et al. 2007); stigma and non-disclosure of status (Courtenay-Quirk et al. 2008; Parsons et al. 2005); psychological distress (including depression) (Courtenay-Quirk et al. 2008; Stall et al. 2003); partnership characteristics i.e partner HIV status and partnership type (Niccolai et al. 2006); perceived responsibility to protect sexual partner (altruism) (Parsons et al. 2005; O’Dell et al. 2008; O’Leary and Wolitski 2009) and self-rated health status (Golin et al. 2009).

Recent studies in SSA have identified a number of factors that affect sexual behaviour of PLWHA, some of which are similar to those found in other settings. The first factor that is similar is disclosure of HIV status to sexual partners. A recent study among clinic attendees in 3 sites in Kenya found that those who knew the HIV status of their partners were 6 times more likely to use a condom at last sex than those who do not (Benki-Nugent et al. 2011). In a prospective cohort study in Mombasa (Kenya), Luchters et al. (2008) found that unsafe sexual behaviour was associated with non-disclosure of HIV status to sexual partners. The second similar factor, which is related to disclosure, is stigma. Stigma, especially internalised stigma – the “shame” associated with and/or “fear” of encountering stigma (Lekas, Siegel, and Leider 2011) – contributes to risk behaviour through non-disclosure of status (Simbayi et al. 2007b). The third similar factor is psychological distress, including depression. For example, Olley’s (2008) study in Nigeria suggests that elevated “risky” sexual behaviour among PLWHA is one of the coping mechanisms for stress and negative life events associated with their positive status. PLWHA who reported more negative life events in the preceding six months were more likely to report “risky” sexual behaviour than those who reported fewer negative events.

Other factors reported in SSA that affect unsafe sexual behaviour among PLWHA include those that apply to the general population such as transactional sex for survival (Moore and Oppong 2007; Amuyunzu-Nyamongo et al. 2007); gender–power relations

where women are inhibited to negotiate for safe sex (Moore and Oppong 2007) and reported multiple sex partners among men PLWHA (Luchters et al. 2008) because it is more acceptable for males than females to have multiple sexual partners; a sign of intimacy, love and affection in marital or committed relationships (Allen et al. 2011; Undie et al. 2009); alcohol use (Kiene et al. 2006) and the desire to have children (Moore and Oppong 2007). The following section examines fertility desires and intentions among PLWHA.

### **2.5. Reproductive preferences among people living with HIV/AIDS**

The effects of HIV/AIDS on fertility and the reproductive preferences among PLWHA are poorly understood (Cooper et al. 2009; Myer, Morroni, and Rebe 2007). Most demographic and public health research has tended to focus on the impact of HIV/AIDS on mortality and life expectancy. Studies that have attempted to link HIV/AIDS and fertility have shown inconclusive results and there is a lack of consensus on the extent and direction of the effect on fertility (Magadi and Agwanda 2010). Studies on reproduction and fertility have been mainly biological, focusing on the negative effect of HIV infection on the ability to conceive or carry a pregnancy to term (Darak, Janssen, and Hutter 2011) and fertility rates among PLWHA and general population (Lewis et al. 2004; Magadi and Agwanda 2010). Several studies have reported declines in fertility rates of women living with HIV/AIDS in SSA (Glynn et al. 2000; Lewis et al. 2004). HIV/AIDS infection can affect fertility directly by reducing fecundity and causing spontaneous abortion (Glynn et al. 2000; Segurado and Paiva 2007; van Leeuwen et al. 2007). HIV may also work indirectly through decreased sexual desire and activity, marital disruption and instability, and use of condoms to prevent HIV transmission (Glynn et al. 2000; Lewis et al. 2004; Hosegood 2009).

The possibility of PLWHA having fertility and parenthood desires is an issue that is beginning to elicit some debate. For a long time, there has been a pervasive anti-natality stance towards PLWHA, from both societies and health professionals (Lusti-Narasimhan, Cottingham, and Berer 2007; Nattabi et al. 2009). This school of thought contends that child-bearing by PLWHA is detrimental to their health and wellbeing and risks horizontal and vertical transmission of HIV (Boonstra 2006; Courtenay-Quirk et al. 2008). There is, however, a growing discourse that is in favour of PLWHA

being allowed to choose child bearing. This alternative view holds that the ability of PLWHA to express themselves sexually and experience parenthood is a human right. Thus, any pressure or coercion for PLWHA to terminate pregnancies and undergo sterilisation is considered a violation of their human rights (Segurado and Paiva 2007).

What is the evidence concerning the underlying assumptions of the different sides of this debate? The anti-natalists hold that since HIV infection compromises a woman's immune system, being pregnant can only worsen their health status. Unprotected sex (in order to conceive) might expose PLWHA to the risk of re-infection with other strains of HIV, including drug resistant ones (Courtenay-Quirk et al. 2008; Maclachlan 2007). Infection with HIV also risks vertical transmission (Cooper et al. 2007). Being HIV-positive is associated with adverse perinatal outcomes such as miscarriages, still birth, perinatal mortality, and low birth weight-preterm delivery (Segurado and Paiva 2007). The alternative perspective contests that these issues no longer hold in the era of ART, and available evidence seems to back their case. Evidence indicates that pregnancy is neither associated with accelerated HIV/AIDS disease progression nor obstetric complications (Boonstra 2006; Segurado and Paiva 2007). The use of ART substantially reduces transmission not only between sexual partners (Crepaz, Marks, and Hart 2004) but also the probability of perinatal transmission to below 2% (Boonstra 2006).

ART and prevention of mother to child transmission (PMTCT) programmes have the potential to influence fertility desires. This is because these medical interventions will allow PLWHA to have more normal sexual lives and potentially HIV-free children (Bharat and Mahendra 2007; Cooper et al. 2007).

#### *2.5.1. Fertility intentions and HIV/AIDS*

Fertility “desires” and “intentions” are, strictly speaking, used to refer to different things in demography. Desires are wishes, which may be based on emotions rather than reality, whereas intentions denote a commitment to implementing fertility desires. Therefore, intention comprises both desire and planning aspects (Chen et al. 2001; Kodzi, Johnson, and Casterline 2010). However, the questions in international surveys such as the Demographic and Health Surveys (DHS) on fertility preference, which are

translated in local languages, may not adequately distinguish between the two, perhaps explaining why the two terms are sometimes used interchangeably (Kodzi, Johnson, and Casterline 2010). The relationship between fertility intentions and consequent reproductive behaviour has elicited a substantial amount of debate in the demographic literature. The debate has centred on the extent to which fertility intentions predict future fertility and fertility regulation behaviour. Fertility intentions have been shown, in a majority of studies, to be a consistent predictor of future fertility (Bankole and Westoff 1998; Kodzi, Johnson, and Casterline 2010; Lewis et al. 2004; Pritchett 1994) and contraceptive use to regulate fertility (Bongaarts 1992; Casterline and Sinding 2000).

There are various ways of measuring fertility preferences in household surveys, which can be grouped into two: retrospective and prospective questioning (Pritchett 1994). Retrospective questioning asks about the “desired or ideal” family size, that is, the number of children people would freely choose to have based on their assessment of costs and benefits of child bearing, and the wanted status of the most recent birth or pregnancy (Bongaarts 1990). Prospective questioning asks about fertility “intentions” that is, the desire to continue (or start) childbearing (Bongaarts 1990; Pritchett 1994). Fertility intentions derived from prospective reporting has been found to be less biased, not least because it is immune to “post facto rationalisation”. Post facto rationalisation refers to a situation where individuals adjust upwards their stated desired family to be close to the actual number of children they have, thereby “rationalising unwanted” children (Bongaarts 1990; Pritchett 1994). This is primarily caused by understandable reluctance on the part of women or couples to classify their births and children as unwanted (Bongaarts 1992).

Evidence relating to fertility and reproductive intentions among PLWHA is rare (Yeatman 2009), despite the fact that more than 80% of PLWHA are of reproductive age (Delvaux and Nöstlinger 2007). Emerging studies on fertility intentions among PLWHA have mainly been conducted by public health practitioners in clinic settings (eg Heys et al. 2009; Kakaire, Osinde, and Kaye 2010; Myer, Morroni, and Rebe 2007; Nobrega et al. 2007) –with the aim of identifying service needs for PMTCT, rather than demand for fertility-related services. Comparative studies show that HIV-positive women who know their status are less likely to want another child in future than HIV

negative women. Demographers have attempted to look at fertility intentions or contraceptive need among those infected or affected by HIV using DHS data. Since it is not possible to identify people who are infected with HIV and who know of their infection using DHS data, these scholars have relied on proxies of HIV status or knowledge of HIV. For example, Ezeh's (2003) study, which examined the association between experience of HIV and fertility intentions using DHS data for 12 SSA countries, did not deal specifically with PLWHA, but rather used proxies of HIV experience such as perceived risk of infection, knowledge of someone who suffers/died from the disease and presence of an orphaned child in the household. The study did not find any consistent relationship between HIV experience and fertility intentions.

With HIV testing being implemented in subsequent DHS, two demographic studies have used HIV status biomarkers to assess differential fertility intentions between the infected and non-infected in a number of countries in SSA. A study on women (Johnson et al. 2009) and the other one on men and women (Bankole, Biddlecom, and Dzekedzeke 2011) observed a negative association between HIV status and fertility desires using DHS data. Despite providing crucial population-based evidence on fertility desire and HIV status relationship, in SSA contexts where only about 10%-20% of those infected know their status (Anand et al. 2009), it is possible that most of those defined as HIV positive, by the proxies of probable knowledge, do not actually know that they are.

### *2.5.2. ART and fertility desires and intentions among PLWHA*

Evidence on the effect of ART on fertility intentions is very mixed. Most studies have documented a positive relationship between ART use and desire for future fertility. A study in Brazil found that ART use was positively associated with a woman's desire to have a child (Nobrega et al. 2007). Similar positive associations between ART and fertility desire have been reported in studies in South Africa (Cooper et al. 2009; Myer, Morroni, and Rebe 2007); Uganda (Maier et al. 2009), and India (Kanniappan, Jeyapaul, and Kalyanwala 2008). The availability of PMTCT programmes has also been found to motivate fertility desire (Cooper et al. 2007; Peltzer, Chao, and Dana 2009). The explanation for the positive association between ART use and fertility



desire – from a limited number of qualitative studies – is that improvement in physical and emotional health as a result of ART leads to increased sexual desire and also ability to take care of children and plan for the future (Kisakye, Akena, and Kaye 2010).

Conversely, some studies do not find any association between ART use and fertility desires. A recent study in Soweto slums of South Africa found a lack of association between ART use and childbearing intentions (Kaida et al. 2011). No association between ART use and fertility desires have been documented in studies in Uganda (Homsy et al. 2009; Kipp et al. 2011; Kakaire, Osinde, and Kaye 2010), and Nigeria (Iliyasu et al. 2009). Interestingly one study documented a significant negative association between ART use and fertility desires in Nigeria (Olufemi et al. 2005). The lack of association between ART use and fertility desires has been attributed to the fact that with rapidly increasing access to ART, those not yet enrolled are confident enough to enrol once they become eligible, thereby minimizing the differences between the groups (Kaida et al. 2011).

There are two main limitations of studies on the effect of ART on fertility desires. One is that they focus almost exclusively on women without a corresponding comparison of men. Secondly, the studies are predominantly quantitative and explanations for the changing relationship between ART use and fertility desires in specific contexts are largely unclear (Nattabi et al. 2009).

### *2.5.3. Other factors that affect fertility desires and intentions among PLWHA*

PLWHA, just like the general population, desire to have children after learning of their HIV status (Awiti Ujiji et al. 2010; Chen et al. 2001; Cooper et al. 2009; Nã³brega et al. 2007). Unlike the general population, however, people who know they are HIV infected have additional issues to consider, including potential health risks for (re)infections, vertical transmission of HIV and orphaning. Despite these concerns, studies show that some PLWHA still wish to have children for a range of reasons (Cooper et al. 2007; Nattabi et al. 2009).

Demographic factors that influence fertility desire among PLWHA include age, gender and number of living children. In several studies across a range of countries younger

age was significantly associated desire for more children. Studies in Brazil (Nobrega et al. 2007), United States (Chen et al. 2001), South Africa (Myer, Morroni, and Rebe 2007) , Uganda (Kipp et al. 2011; Nakayiwa et al. 2006) and Nigeria (Olufemi et al. 2005) have shown that younger PLWHA are more likely to desire (more) children than older PLWHA. Gender has been reported to influence fertility desires, with men being more likely than women to desire children in Uganda (Nakayiwa et al. 2006), Malawi (Yeatman 2009), South Africa (Cooper et al. 2009) and Brazil (Paiva et al. 2007). However, one study in Nigeria (Iliyasu et al. 2009) did not find any association between gender and fertility intentions among PLWHA. The number of surviving children has been shown to be a consistent predictor of fertility desires across a variety of contexts. Fertility desire has been reported to be negatively associated with number of living children among PLWHA in the United States (Chen et al. 2001), Brazil (Nobrega et al. 2007); South Africa (Kaida et al. 2011; Myer, Morroni, and Rebe 2007), Uganda (Heys et al. 2009; Nakayiwa et al. 2006), Nigeria (Iliyasu et al. 2009) and Malawi (Yeatman 2009). However, one study among PLWHA in the United States did not document an independent significant association between desire for children and age and parity of women (Finocchario-Kessler et al. 2010).

Health-related factors that affect future fertility among PLWHA apart from ART use include subjective health status (Nattabi et al. 2009). A limited number of studies shows that PLWHA who felt healthier were more likely to be in favour of having more children in the United States (Chen et al. 2001), India (Kanniappan, Jeyapaul, and Kalyanwala 2008) and Nigeria (Smith and Mbakwem 2007).

Socio-cultural factors that affect fertility desire among PLWHA include cultural norms and values about parenthood, social support, and disclosure of status. Although it is well known that cultural factors contribute to high fertility rates in the general population in SSA (Caldwell and Caldwell 1987; Isiugo-Abanihe 1994), extant studies on PLWHA rarely consider cultural factors, as most of them are quantitative, while qualitative and mixed methods studies are few and far between (Nattabi et al. 2009). In many societies and especially in SSA, a high premium is placed on motherhood, with those who are childless receiving negative social disapproval. Men's social status in SSA is also enhanced through having children (Cooper et al. 2007). Children are valued for their household or farm labour and economic contribution, insurance for old

age support, lineage perpetuation and posterity and securing a marriage (Agadjanian 2005; Isiugo-Abanihe 1994). The value of children in the identity and social status of men and women applies to PLWHA as well, and so they are under intense pressure from family, spouses and friends to reproduce (Agadjanian and Hayford 2009; Cooper et al. 2007; Wagner et al. 2011). Moreover, having children may re-establish the PLWHA with higher self-esteem, may help them restore a sense of normalcy in family life and health, and mitigate the potentially dehumanising effects of living with HIV/AIDS (Boonstra 2006; Smith and Mbakwem 2010).

Social support and disclosure and stigma are some of the related social factors that affect fertility desire among PLWHA. Studies show that stigma and social support can affect fertility intentions in both directions (Nattabi et al. 2009). Social support, both emotional and financial, may help PLWHA to mitigate distress and cope better with HIV (Lam, Naar-King, and Wright 2007) and hence feel more comfortable pursuing their reproductive intentions. PLWHA with greater internalised stigma find it difficult to disclose their status in order to obtain social support (Kalichman et al. 2003; Lam, Naar-King, and Wright 2007). Those with perceived low self-stigma are more likely to disclose their status (Visser, Neufeld, et al. 2008; Kalichman et al. 2003), discuss their fertility intentions with partners and health care providers (Wagner et al. 2011) – factors that may foster positive feelings towards childbearing. However, stigma and social support can also have a reverse effect. For example, a study in Uganda found that those PLWHA with higher scores on social support and internalised stigma were less likely to desire children. This may suggest that perhaps PLWHA may want to have children to avoid stigma and conceal their status (Cooper et al. 2007; Smith and Mbakwem 2010) and social support may help them overcome the pressure from society to have children (Wagner et al. 2011).

There are, nevertheless, PLWHA who do not wish to have any (more) children, social pressure and improvements in their health by virtue of being on ART notwithstanding (Delvaux and Nöstlinger 2007). The subsequent section looks at the need and demand for contraception among PLWHA.

#### 2.5.4. *Contraceptive use and unmet need for family planning among PLWHA*

The use of and demand for contraception by PLWHA is poorly understood (Rutenberg and Baek 2005; Whiteman et al. 2009). As a consequence family planning needs of PLWHA are seldom met by health systems, which tend to focus on their access to VCT and ART services (Boonstra 2006; Lusti-Narasimhan, Cottingham, and Berer 2007). Family planning use among PLWHA has considerable population and public health benefits. In addition to reducing unwanted pregnancies, family planning can help PLWHA to prevent the transmission of HIV to sexual partners and children. There is evidence that provision of contraception is a more cost-effective approach than use of antiretroviral prophylaxis in preventing vertical transmission (Halperin, Stover, and Reynolds 2009), and so should be an important component of PMTCT (Elul et al. 2009). Family planning serves to improve maternal and child health, reduces HIV infected infants and orphans, and reduces fertility (Cleland et al. 2006; Kaida et al. 2009; Smith et al. 2009). Despite their apparent link, family planning and HIV have “remained strange bedfellows” (Wilcher, Cates, and Gregson 2009), not least because their integration has rarely been achieved (Wilcher and Cates 2010).

The effect of HIV on contraceptive use and need reported in a small, but growing body of literature is mixed. Some studies show a positive relationship between HIV infection and contraceptive use. For example, studies show that women who know that they are HIV positive are more likely than HIV negative women to be using contraception in Zimbabwe (Johnson et al. 2009) and Rwanda (Elul et al. 2009). Conversely, studies in Kenya and Zambia showed that HIV- positive women and HIV- negative women had similar contraceptive use rates (Rutenberg and Baek 2005). A study in three SSA countries found that the demand for contraceptives was similar for both HIV-positive and negative women in Kenya and Zambia, but higher for HIV-positive women in Rwanda (Delvaux and Nöstlinger 2007).

Unmet need for family planning – a condition of being sexually active and wanting to avoid pregnancy but not using any family planning method (see chapter 8 for definition) – among PLWHA is poorly understood. Emerging evidence shows that the level of unmet need for family planning among women living with HIV/AIDS in SSA is higher than the general population. Analysis of DHS data from Kenya and Malawi found that of nearly three-quarters of HIV- infected women with a need for family

planning, who reported not wanting a child or not wanting a child in the next two years, only 32% and 20% were currently using contraception in Kenya and Malawi respectively (Anand et al. 2009). Other studies in Uganda have found high levels of unwanted pregnancies among PLWHA (Homsy et al. 2009).

#### *2.5.5. Factors that affect contraceptive use*

In the midst of mixed evidence of the effect of HIV infection on contraceptive demand and use, it is plausible to assume that factors that affect contraceptive uptake among PLWHA apply to the general population as well, while others may only be relevant to PLWHA. These can be grouped broadly into demand- and supply- level factors.

Demand factors that affect contraceptive use in the general population, and which may apply to PLWHA include demographic factors such as age, parity and educational status. Age and/or parity of the women have been shown to be positively associated with contraceptive use in the general population in Kenya (Magadi and Curtis 2003), Pakistan (Saleem and Bobak 2005) and among PLWHA in Russia (Whiteman et al. 2009). Age and parity affect contraceptive use because they are positively associated with desired family size. Education of women has been positively associated with contraception in the general population in Pakistan (Saleem and Bobak 2005), Kenya (Magadi and Curtis 2003) and among PLWHA in Uganda (Nattabi et al. 2011). Education is believed to influence contraceptive use through enhancement of female autonomy (Dyson and Moore 1983; Jejeebhoy and Sathar 2001; Moursund and Kravdal 2003) and knowledge about contraception.

Health-related factors are another group of demand-side factors that affect contraceptive use among PLWHA. Fears of infecting the partner and unborn child or infant (Cooper et al. 2007; Laher et al. 2009) and the negative effect of pregnancy on the health of the mother (illness, immunity and blood loss) (Laher et al. 2009) influence contraceptive use. Common side effects that influence contraceptive use include heavy bleeding, vaginal wetness and raised blood pressure (Campbell, Sahin-Hodoglugil, and Potts 2006). Fear of side effects may come from previous use or hearsay and rumours from others' experiences. Health concerns among PLWHA include the perception that hormonal methods might exacerbate their HIV condition or make their ART ineffective (Laher et al. 2009). Among the most common

(mis)conceptions are that family planning reduces libido and that condoms may be laced with the HIV virus (Thomsen, Stalker, and Toroitich-Ruto 2004).

Another demand factor that influences contraceptive use among PLWHA is disclosure of HIV status to a partner. A study in Uganda found that women living with HIV who had not disclosed their status to their sexual partners were less likely to use a modern method of contraception (Wanyenze et al. 2011).

Other studies show that contraceptive use in the general population in SSA is enhanced by spousal discussion, self or spousal approval family planning (Bankole, Rodríguez, and Westoff 1996; Kayembe et al. 2006; Magadi and Curtis 2003). Spousal resistance or self-opposition of contraception may stem from personal reasons such as perceived reduced sexual sensation and pleasure or on religious grounds (Nagase et al. 2003; Nattabi et al. 2011). Spousal resistance or perceived husband resistance (Cleland et al. 2006) may lead to fear of reprisals due to the power of the husband in reproductive decision making in SSA (Bankole and Ezeh 1999). A study among PLWHA in South Africa found that partner influence was an important factor in adoption of family planning (Laher et al. 2009).

Supply-side factors that affect contraceptive use in the literature include availability and cost of contraceptive commodities, user fees and transport and health system capacity (Campbell, Sahin-Hodoglugil, and Potts 2006; Cleland et al. 2006; Bongaarts and Sinding 2009). Supply level barriers to access contraception abound in poor settings in the developing world. A study in India found that health care providers face various challenges in meeting reproductive health needs of PLWHA, including health system capacity and lack of knowledge and skills for meeting them (Bharat and Mahendra 2007). A recent study in a rural setting in Uganda found that use of family planning among PLWHA was associated with discussion of family planning with a health provider (Nattabi et al. 2011).

Moreover, lack of systematic integration of HIV and family planning services means that most PLWHA are missed out (Nattabi et al. 2011). The cost of contraception may prevent some PLWHA from accessing them. Even in cases where subsidies are provided by the government, provider fees and transport to faraway health facilities

can be prohibitive (Bongaarts and Sinding 2009). Frequent stock-outs of family planning commodities and their insecurity were found to influence contraceptive use among female PLWHA in Ethiopia (Bradley et al. 2010).

A major weakness of previous studies on family planning use and need, whether in general population or among PLWHA is that they focus on women alone. Whilst it is women who bear the brunt of childbearing and unwanted pregnancies; information of females alone is insufficient. In patrilineal contexts such as SSA, fertility control decisions are very much influenced by male spouses and partners (Bankole and Ezeh 1999). A fuller picture can only be captured when men's family planning use, need, perceptions, experiences are also documented. Evidence on reproductive health needs of both men and women is still lacking, a few studies in this direction (e.g Bankole, Biddlecom, and Dzekedzeke 2011; Nattabi et al. 2011), notwithstanding.

PLWHA who want to limit or space their childbearing can be advised to use condoms, with or without other contraceptive methods. Most existing contraceptive methods are safe and effective for HIV-positive men and women. However, a consideration of the potential drug interaction between hormonal contraception and certain types of ART needs to be done before use (Delvaux and Nöstlinger 2007). It is, therefore, imperative to investigate how these reproductive health needs for PLWHA are being met in SSA where studies are limited.

## **2.6. Conclusion**

This literature review has revealed a small and relatively recent set of studies on sexual and reproductive behaviour of PLWHA in SSA. An understanding of the sexual and reproductive health needs is of great public health importance. Ensuring that PLWHA have safer sexual lives and bear children safely, is key to maintaining their own health and the health of others in the general population. Despite the contributions of socio-behavioural studies on HIV and safer sex, they mostly focus on individual risk behaviour and pay little attention to the broader risk environment – socio-cultural and economic context – of sexual behaviour. Little attention has been given to the effects of poverty on sexual and reproductive behaviour in the rapidly growing poor urban population in the developing world. Setting this study in an urban slum settlement

provides an appropriate context to investigate the risk environment of poverty and gender social relations on sexual and reproductive behaviour among PLWHA.

Sexual and reproductive experiences are also governed by gender norms. However, the dominant gender discourse and approaches have been criticised for being narrow, looking at women as passive and dominated by men in the patriarchal systems. The gender discourse is based on western liberal feminist ideologies and often has a stereotypical view of SSA women as a powerless homogenous group sharing similar status, experiences and concerns in the face of male domination. Calls have been made for women in SSA to be reconceptualised as active agents in social life who can and do influence their sexual and reproductive choices. There is also need to recognise that ideals of masculinity that may be associated with risk taking and sexual conquest also create vulnerability in men. Understanding women's as well as men's sexual and reproductive health outcomes and experiences is thus vital.

Previous demographic studies have mostly focused on socio-demographic factors that affect reproductive preferences and contraceptive use. The most common socio-demographics identified are parity, maternal age and educational status. Although individual socio-demographics may shape individual reproductive desires and preferences, the socio-cultural environment in which an individual lives also has a great influence. A few studies indicate that issues of the importance of children, their role in marriage stability, old age support and lineage posterity are still pertinent among PLWHA as well. There are also health concerns regarding HIV transmission concerns and disease progression that affect reproductive desires and contraceptive use among PLWHA. Studies also point to the importance of the supply environment and health system capacity to meet the reproductive health needs of women as well men living with HIV.



## **Chapter 3: Methodology**

### **3.1. Introduction**

This chapter describes the whole process of conducting the research from planning, to collecting and analysing data. To put the chosen methodology into perspective, I will first discuss the research design –mixed methods – presenting an overview, a working definition, rationale and the strategy of mixed methods research. I will then follow it up with description of the study site, the study population and sample selection strategy for respondents. This will be followed with an account of how data was collected, managed and analysed. These are discussed in the context of integration of quantitative and qualitative research techniques in the entire research process. Reflecting on my own personal experience of the research process I will close with a section on the ethics, reflexivity and positionality.

### **3.2. Research Design: Mixed Methods**

Mixed methods research has grown in popularity and visibility in the last decade in the social and behavioural sciences. This can be seen in the sheer volume of mixed methods publications; its main theorizers (e.g Bryman 2006a, 2006b, 2008; Creswell 2003, 2009; Tashakkori and Teddlie 2003); and of course, its own dedicated journals – Journal of Mixed Methods Research, Quality and Quantity and International Journal of Multiple Research. So much has been its popularity that it has attracted a view in some quarters that we are in the new era of mixed methods (Bryman 2006a). The use of mixed methods designs, if not by name, but certainly by practice, has a long history in social and behavioural sciences. Some authors (eg Creswell 2009; Johnson, Onwuegbuzie, and Turner 2007) trace its origins to psychology following the 1959 multi-methods study of Campbell and Frisk. Nonetheless, what is new is the emerging recognition of mixed methods as a distinct methodology in its own right.

The growth of the mixed methods as a separate entity from Qualitative and Quantitative methodologies has not been without its share of controversy. There have been long- drawn “paradigm wars” between qualitative and quantitative practitioners especially in the 1980s, with emerging “purists” at both ends of the methodological divide (Johnson and Onwuegbuzie 2004, 117). The schism has mainly been

epistemologically-driven, revolving around what has variously been referred to as the “incompatibility thesis”. The incompatibility thesis posits that quantitative and qualitative research paradigms are based on different and irreconcilable principles – deduction (positivism) and induction (interpretivism) respectively – a position which has been discounted by some authors (Bryman 2006a; Johnson and Onwuegbuzie 2004). The incompatibility thesis has been discounted (see Bryman 2008; Gilbert 2008), not least because it oversimplifies and exaggerates the qualitative/quantitative divide. This has paved the way for some truce of sorts between the two paradigm combatants, allowing the mixed methods research to grow and harness the strengths of two.

Quantitative approaches have strength in quantifying the phenomena and the capacity to examine the strength of association between categories or variables. However, one of their major weaknesses is that they detach the information from their original context. On their part qualitative approaches examine the context, meanings and provide breadth and depth of the phenomenon, but lack the capacity to assess the strength of the relationship among categories or constructs (Castro et al. 2010). The phenomena addressed by social and behavioural scientists are so complex that the use of either quantitative or qualitative approaches can sometimes be inadequate, and a combination of the two methods can help to gain a broader understanding (Creswell 2009).

It is imperative to point out from the outset that a lot of ink has been poured in defining the mixed methods approach. Despite plenty of convergence in the definitions, I found these two to be the most comprehensive, at least for informing this study:

“Mixed methods research is a type of research in which the researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration”(Johnson, Onwuegbuzie, and Turner 2007, 123).

“Mixed methods research is an approach to inquiry that combines or associates both qualitative and quantitative forms. It involves philosophical assumptions, the use of qualitative and quantitative approaches, and the mixing of both approaches in a study. Thus, it is more than simply collecting and

analysing both kinds of data; it involves the use of both approaches in tandem so that the overall strength of a study is greater than either qualitative or quantitative research” (Creswell 2009, 4).

The most critical thing from the definition and practice of mixed methodology is the ability to combine the two methods so that the end product is more than the sum of individual methods (Bryman 2007; Woolley 2009). This is because the essence of the mixed approach is to enhance the understanding of the phenomenon by looking at it from different viewpoints, exploiting the strengths and minimising the weaknesses of both methods (Johnson and Onwuegbuzie 2004; Miller and Gatta 2006). How to blend and mesh the two data streams has received considerable attention, with different authors offering tips and practical guides to practitioners. This growing body of literature shows that the mixed methods practitioners use the two methods of inquiry either sequentially or concurrently. A recent review revealed that the majority (66.1%) of studies employed a concurrent design while (33.9%) used a sequential one (Collins, Onwuegbuzie, and Jiao 2007). Concurrent designs are typically used for triangulation or corroboration while sequential designs are used to help explain and interpret relationships (Creswell 2003, 2009).

What is critical, however, is the extent to which to these studies - whether sequential or concurrent in their design – are able to integrate the two strands of data into a holistic whole (Bazeley 2009; Woolley 2009). Yet evidence shows that integration of qualitative and quantitative approaches is not easy and there are very few exemplars of integration (Bryman 2007; Laub and Sampson 2004). It is on this basis that Yin (2006) and Wolley (2009) have proposed a scheme of integration in mixed methods research. Drawing on the works of Bryman (2007) and Yin (2006), Wolley (2009, 7) defined integration as: “ Quantitative and qualitative components can be said to be integrated to the extent that these components are explicitly related to each other within a single study and in such a way as to be mutually illuminating”.

Yin (2006) proposed a framework, elaborated by Wolley (2009), to include the following five stages: the research questions being studied, the definitions of the units of analyses, the structure of samples being studied, the instrumentation and data collected, and the analytic strategies. In short, the framework calls for full integration of the two methods in all the stages of the study, right from conception, to data

analysis, interpretation and write-up. Thus: “ the more that a single study integrates mixed methods across these five procedures, the more that mixed methods research, as opposed to multiple studies, is taking place” (Yin 2006, 42). This study adopted this framework of integration, which is the only framework of integration to-date. What follows now is how the integrative strategy was achieved in all the stages of the research process.

### **3.3. Stage One: Planning for the mixed methods study**

Authors have pointed out that conducting a mixed methods study is not as easy as it appears (see Molina-Azorín 2011). Several challenges associated with mixed methods studies have been identified. First, mixed method studies require more time and resources to implement both the qualitative and quantitative aspects of the study. Second, mixed methods research requires that the researcher acquires skills in both qualitative and quantitative methods (Molina-Azorín 2011; Tashakkori and Teddlie 2003). This makes planning for the execution of a mixed methods study a very important element of the research process. Key stages of the study comprised of three major phases, each lasting approximately one year (appendix 4). Planning and preparation for this study, therefore, involved conceptualising the study and getting equipped with the requisite skills and enterprise to adequately execute a mixed methods study. The following section explains how this was accomplished.

#### *3.3.1. Resource Preparation: Time and skills*

Part of my resource preparation was the acquisition of the skills that span the quantitative and qualitative fields. In addition to my two masters’ degrees – Anthropology and Population and Development – I undertook methodological courses in both qualitative and quantitative approaches. These skills were complemented with my experience of quantitative and qualitative interviewing techniques, having worked as a research assistant for a research organisation – African Population and Health Research Centre (APHRC) – between 2000 and 2006.

#### *3.3.2. Conceptual preparation: The research question*

The research question can be regarded as the engine and the driving force of the research design and methods. The decisions about the appropriate techniques of data collection and analysis are ultimately guided by the research question. This is because

decisions about research design and methods should be made with the primary purpose of answering the study's research questions (Bryman 2007; Gilbert 2008). It is, therefore, vital that the methods so selected for a study provide the best possible chances of answering your research questions, both general and specific, as unambiguously as much as possible.

The research questions for this study (Chapter one) invited the use of both qualitative and quantitative methods to answer them. The purpose of having an integrated research question was to ensure that the two methods played a complementary role, each addressing a particular subsidiary research question or an aspect of the same research question (Creswell 2003; Woolley 2009). For example, it required qualitative methods to answer my subsidiary question 1 - How do men and women living with HIV/AIDS perceive their own sense of self and life prospects as related to sexual and reproductive outcomes in the current treatment era? On the other hand it required a blend of qualitative and quantitative methods to answer my subsidiary question 2 – What factors contribute to an explanation of sexual and reproductive intentions and behaviour of men and women living with HIV and AIDS? The quantitative and qualitative methods dealt with magnitude (e.g levels of sexual and reproductive practices and unmet need for contraception) and context (e.g socio-cultural institutions and conditions) ends of the broad research question respectively.

### **3.4. Stage two: Units of analysis:**

The integrative framework suggests that the units of analysis should have the same “points of reference” (Woolley 2009; Yin 2006).

#### *3.4.1. Study population: PLWHA*

The primary units of analysis, that is, the research subjects for the survey and in-depth interviews for this study were the same broad group – men and women living with HIV/AIDS, resident in a geographically delineated slum setting. The choice of this study population was done deliberately in respect of the study's framework of the risk environment. By setting this study in slums, a particular risk environment is identified, with its own set of socio-cultural, economic and environmental conditions likely to have an impact on SRH outcomes of PLWHA. Previous research in the study sites has documented poor SRH outcomes such as early sexual debut, multiple sexual

partnerships, unprotected sex, and high HIV prevalence rates compared to other settlements (Dodoo, Zulu, and Ezeh 2007; Zulu, Dodoo, and Ezeh 2002).

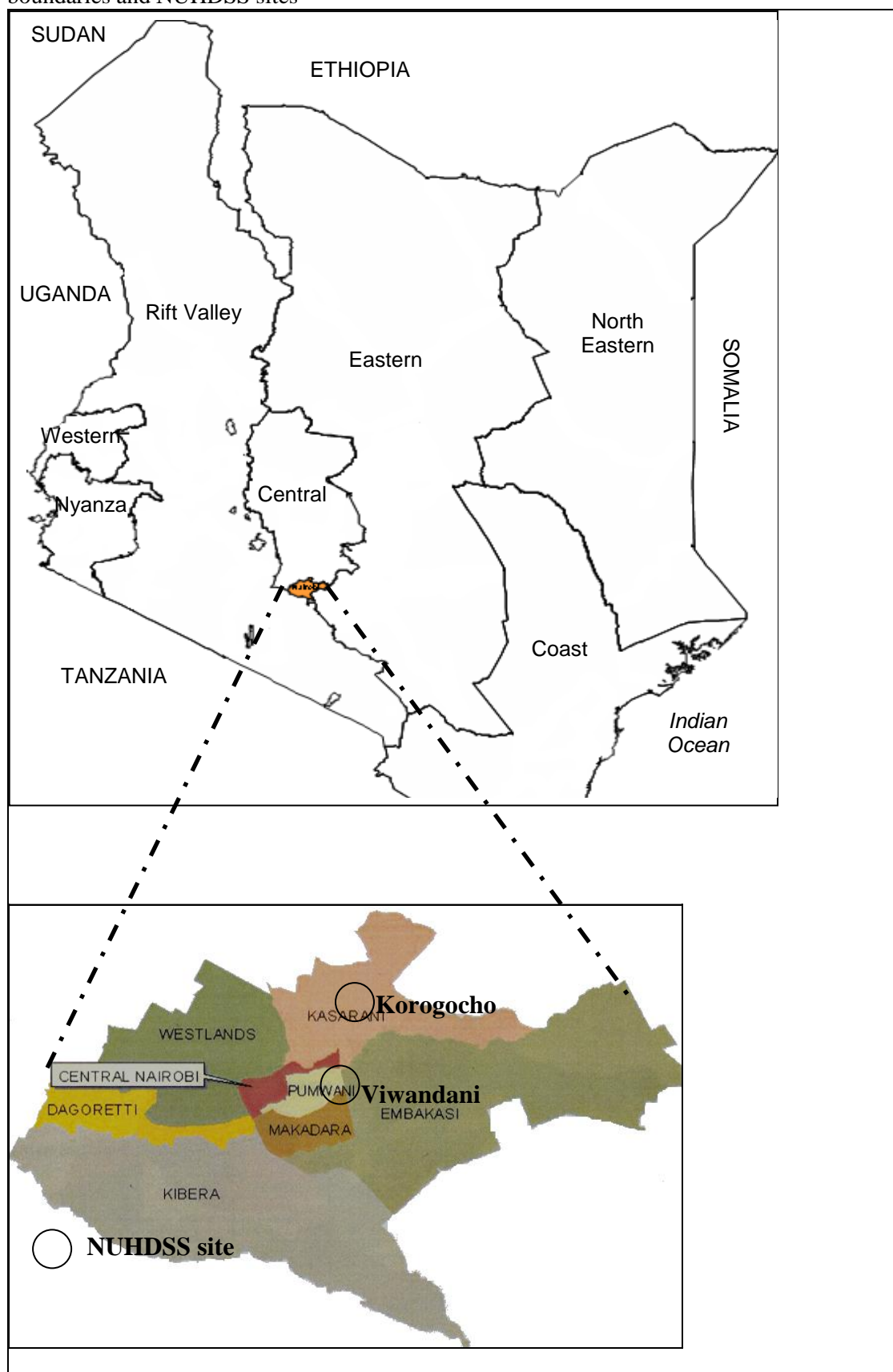
### *3.4.2. Study sites: Viwandani and Korogocho*

The study was carried out in the two slums of Viwandani and Korogocho in Nairobi city where APHRC<sup>2</sup> carries out a longitudinal study, the Nairobi Urban Health and Demographic Surveillance System (NUHDSS). The two slums are located on the eastern side of Nairobi City, about 5 km from each other. Viwandani is located in Nairobi's Industrial area about 5 km from the city centre. Korogocho is located about 10 kilometres from the city centre (Figure 3.0.1). The NUHDSS follows approximately 56,000 residents in the two sites (Viwandani approx. 29,000, Korogocho approx. 27,000). The core function of the NUHDSS is to monitor population dynamics, that is, fertility, mortality and migration of the population under surveillance by recording all the births, death and movements occurring in this population every 4 months. The NUHDSS also acts as platform for conducting other panel and cross-sectional surveys within the defined geographical setting, known as Demographic Surveillance Area (DSA). The study population was PLWHA who are resident members of the NUHDSS. The NUHDSS members and their residential units are assigned unique identification numbers (IDs).

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<sup>2</sup> APHRC is an international research organisation based in Nairobi. They are my former employers whom I paid to use their office space and study sites for my PhD fieldwork.

Figure 3.0.1: Map showing Kenya's province boundaries and (inset) Nairobi's division boundaries and NUHDSS sites



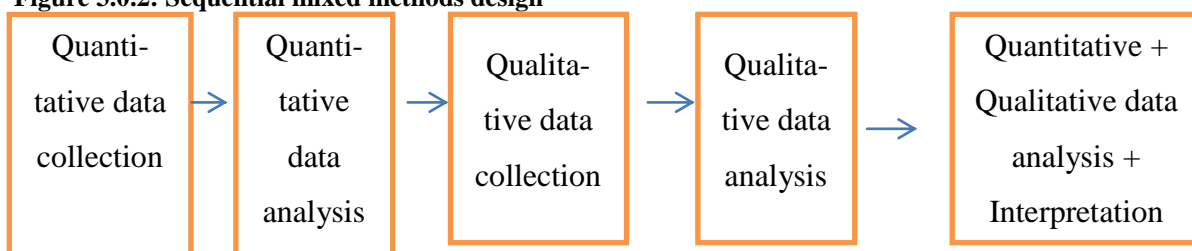
Source: [inset map](CBS 2003)

### 3.5. Stage Three: Sampling

Yin's integrative framework calls for the sample respondents of each method to be "nested within the other" (Woolley 2009; Yin 2006). The case selection strategy for the study was designed in a way that ensured these conditions were met in order to have an integrated process of respondent sampling. The nested arrangement was facilitated by using sequential mixed methods design. Creswell (2009) distinguishes between two strategies of this design: sequential explanatory and sequential exploratory. In the former, quantitative data collection and analysis is done in the first phase and is followed by a second phase of qualitative data collection and analysis. The qualitative builds on the results of the quantitative, but the weight is usually placed on the quantitative, although equal priority can be given to both. In the latter the reverse is true: quantitative data collection and analysis is preceded by the qualitative and the weight is normally placed on the qualitative phase.

This study employed a sequential mixed methods design (Figure 3.0.2) where the quantitative phase preceded and informed its qualitative counterpart, but equal weight was placed on the two. In the first phase, the quantitative data was collected, using a questionnaire based survey (Appendix 1). Qualitative data, using in-depth interviews (Appendix 2) was collected in the second phase. The purpose of the quantitative phase was to identify the general numeric picture and magnitude of SRH outcomes of PLWHA and to provide a sampling frame for selecting participants for the second qualitative phase. The qualitative phase helped to explain and interpret these statistical results by exploring respondents' views in more depth. In the main, integration was accomplished at this stage when selecting respondents for in-depth interviews and developing the interview guide based on the results of the statistical analysis. The following section describes the case selection strategy for study participants for each phase.

**Figure 3.0.2: Sequential mixed methods design**





### 3.5.1. Case selection for Phase one: Survey respondents

For pragmatic reasons the majority of cross-sectional studies on PLWHA rely on convenience samples from accessible health facilities, HIV-based organisations and/or snowballing through peer referrals (Chesney et al. 2000; Halkitis, Palamar, and Mukherjee 2008; Honghong et al. 2008; Remien et al. 2007; Weiser et al. 2003). This can be explained in part by confidentiality (as a result of stigma) concerns associated with HIV/AIDS. In this respect, PLWHA are a hard-to-reach population. It is virtually impossible to obtain a sampling frame of all HIV+ people for any given study site in order to draw a probabilistic sample. Non-probabilistic sampling approaches are the only viable way of accessing this sort of population.

One approach is to use convenience samples at care institutions. The main criticism levelled against convenience sampling is that it inherently carries an “institutional bias”(Heckathorn 1997) that is, only recruiting from a selected group who attend particular facilities and institutions. It was decided not to use this approach for the current study because of the nature of the study settings (informal settlements) which lack government health facilities. Residents of slums tend to seek HIV care at a range of different health facilities across Nairobi, most of which are located outside the slums or even outside Nairobi. Another non-probabilistic approach, snowballing was rejected for this study on the grounds of being likely to produce a “network bias” (Heckathorn 1997). This study adopted a systematic recruitment procedure which tried to circumvent potential “institutional bias” and “network bias” problems. This procedure, which I call Targeted Mobilizer Driven Sampling, is described below.

#### Targeted Mobilizer-Driven Sampling

This recruitment procedure borrows heavily from two established recruitment strategies for hard to reach populations, namely: Targeted Sampling and Respondent Driven Sampling.

Targeted Sampling (TS) is defined as “a purposeful, systematic method by which controlled lists of specified populations within geographical districts are developed and detailed plans are designed to recruit adequate numbers of cases within each of the targets” (Watters and Biernacki 1989, 420). Targeted sampling, therefore, involves mapping of the geographical area and use of secondary analysis of existing data to gain

knowledge of the distribution of the phenomenon in the study population. Targeted recruitment plans (usually quotas) from each geographical area and demographic characteristic are developed (Kral et al. 2010; Watters and Biernacki 1989) in order to allow for the drawing of quota samples from different segments of the study population to gain some degree of representativeness.

Respondent Driven Sampling (RDS), a modified form of snowball sampling, is a procedure that relies on respondents recruiting their own peers through incentives (Kral et al. 2010). There are two typical features of RDS. Firstly, it limits the number of peers that a respondent can recruit, usually 3-4, to avoid over-reliance on one chain of networks. Secondly, it uses an incentive system (monetary or non-monetary) in which respondents are given a “primary” incentive for participating in the study and a “secondary” one for recruiting their peers for the study (Heckathorn 1997). The approach involves recording the recruiter-recruit chains and networks, which can be used for statistical adjustment to the results to account for differential probabilities of inclusion (Heckathorn 1997; Kral et al. 2010).

This study developed a modification of these two approaches, Targeted Mobilizer-Driven Sampling (TMDS), a hybrid procedure that seeks to utilize the strengths of Targeted Sampling and Respondent Driven Sampling. This strategy was chosen because it was better suited to yield a representative sample in the context of the study sites. TMDS is a recruitment procedure that used existing information about HIV prevalence in the study sites to systematically recruit respondents to represent a range of socio-demographic characteristics in the DSA by using “mobilisers” (community health workers and respondents) who were given incentives for recruitment. It, therefore, adapts the idea of mapping and use of existing secondary information from Targeted Sampling, and the use of incentives from Respondent Driven Sampling.

Mapping of the study sites benefitted from the presence of the NUHDSS run by APHRC (see 3.4.2). The NUHDSS mapped a delineated geographical area (DSA) and numbered every residential unit within it. Existing HIV prevalence data for the DSA were obtained from a sero-prevalence study carried out in 2006/7 (Madise et al., in press; APHRC unpublished) . The study showed that the following characteristics are associated with HIV prevalence in the study population: Sex (gender), marital status,

ethnicity, age, education (appendix 8). The current study therefore ensured that these characteristics were well represented in the final sample (Table 3.0.1). We believe that the sample is fairly representative enough to draw valid inferences from, hence the use of p-values and confidence intervals when reporting quantitative results in subsequent chapters. The recruitment process for the survey interviews is described next.

#### Recruitment strategy

In order to identify mobilizers the study first had to identify community health care workers (CHWs) active in the study settings who provide support care to PLWHA. Each CHW takes care of PLWHA in a specific region- a “village” (*kijiji*) within the slum. CHW are the frontline resource persons, who act as a link between communities and health facilities, especially to the urban poor. They must be respected literate members of the community and willing to volunteer their services (MOH 2006). CHWs provide a range of extension health care services to PLWHA, including: referring clients to health facilities for services, adherence follow-up, home visits, identification of PLWHA in potential need for treatment, and identification of individuals that might be in need of HIV testing. Each CHW is attached to, and serves people from, different health facilities. CHWs were used as primary mobilizers in the identification of potential respondents for this study. Previous experience of the author showed that it is not appropriate to use nearby health facilities to obtain a representative sample of PLWHA within the study site. This is because PLWHA tend to choose not to attend local facilities, primarily for reasons of stigma and fear of identification. By using TMDS rather than convenience sampling at facilities, this study was able to include respondents who obtain health care from a range of facilities, including facilities at some distance from the slums where they lived.

I identified ten (five from each site) CHWs to act as primary mobilizers in order to identify potential respondents. Each mobiliser was asked to recruit respondents with particular socio-demographic characteristics as earlier explained. Mobilisers identified clients with these attributes and asked them whether they would be willing to participate in our research. CHWs were given a monetary incentive (£2) for each respondent that they recruited. Those clients who agreed to participate in our research had interview appointment dates scheduled. The response rates of individuals approached by the CHWs cannot be calculated as the mobilisers were not asked to

keep a record of all of the people they approached. This was an oversight in study design.

The recruitment process was iterative and regular meetings were held with my research assistants and mobilizers to evaluate and revise recruitment targets. After three weeks of recruitment, for example, it became clear that targets for female respondents were relatively easy to achieve whilst men were more difficult to recruit. In part this was attributed to the fact that men are more likely to be employed in paid casual jobs in factories and construction sites, making them less likely to be at home (chapter 4). It might also be attributable to men having greater problems with disclosure to CHWS and use of HIV services (chapter 5).

This meant that a more targeted strategy for recruiting men had to be devised. In our initial recruitment we had identified a respondent who was a member of the Men's group – Movement of Men with HIV/AIDs in Kenya (MOMWHIK). We recruited him as a mobilizer, and he was given a monetary incentive to recruit a further three men and a non-monetary incentive (food stuffs) for being interviewed himself. Two of these men that he recruited as respondents were aged less than 24 years, an age group that we had been struggling to recruit. These two younger men were also given monetary incentives to recruit two of their peers each. Meetings and revision of recruitment targets were done until a desirable sample size (n=513) was reached (Table 3.3), which was above the minimum sample size (n=385) required according to our sample calculation.

#### Socio-demographic characteristics of the survey sample

The majority (62%) of respondents were female, partly because of the differential gender prevalence rates, and their relatively easy access to CHWs (Table 3.0.1). The sample was almost evenly spread with regards to marital status, with just over half (55%) being in some marital union (married or living with a spouse). The proportion of women who were not in a marital union (divorced, widowed and never married) was significantly higher than that of men, perhaps suggesting that men separate or divorce their women or it is relatively easy for men to remarry. About two thirds (65%) of the respondents had attained primary level education and 28% had reached secondary level. The majority of study population comprised of four (Kikuyu, Luo,

Luyia and Kamba) of the five major ethnic groups in Kenya. The ethnic composition does not necessarily reflect the national composition because of unique slum ethnic composition and ethnic differences in HIV prevalence (APHRC 2002). The sample characteristics closely resemble the sero-prevalence study's sample (see appendix 8).

The average age of respondents was 38 years, ranging from 18-66 years, with female respondents on average (36 years) being significantly younger than men (42 years).

The length of time since testing HIV positive varied considerably for the survey respondents, with a mean duration of 3.2 years and a range of less than one year - to 22 years. The mean duration since diagnosis was significantly higher for women than men, and in part this is likely to be because women are more likely to be routinely tested as part of ANC (Chapter 5), supporting evidence from studies elsewhere show that women tend to get diagnosed earlier than men (Gersovitz 2011). The proportions of those on ART and not were almost evenly split. However, women were significantly more likely than men to be on ART. The mean duration of being on ART was also significantly longer for women than men, reflecting women's earlier testing.

**Table 3.0.1: Socio-demographic characteristics of respondents**

CHARACTERISTIC	FEMALE (N=318)	MALE (N=195)	TOTAL (N=513)
	%	%	%
<b>Slum of residence</b>			
Korogocho	49	54	51
Viwandani	51	46	49
<b>Ethnicity</b>			
Kikuyu	33	26	30
Luo	21	30	25
Luyia	21	19	20
Kamba	18	14	17
Other	7	10	8
<b>Education***</b>			
No Schooling	7	5	6
Primary	72	54	65
Secondary+	20	41	28
<b>Marital Status***</b>			
Married/Cohabiting	42	75	55
Divorced/separated	21	12	18
Widowed	27	9	20
Never Married	10	3	7
<b>Age</b>			
18-29	24	7	17
30-39	45	34	41
40-49	25	38	30
50+	7	21	12
<b>Treatment Status**</b>			
On ART	58	43	52
Not on ART	42	57	48
<b>HIV Duration (years)</b>			
Under 1	19	28	22
2-3	28	33	30
3-4	20	22	21
5+	33	17	27

Significance levels \*\*\* <0.001; \*\*<0.01, \*<0.05

### 3.5.2. Case selection for Phase Two

#### In-depth interviews with PLWHA

As an integrative strategy, this study selected subsamples of the survey respondents to participate in in-depth interviews (IDIs). IDIs were purposively selected from questionnaire respondents on the basis of their questionnaire answers. There are few guidelines as to how one should proceed in selecting cases for qualitative follow-up from quantitative studies, and for mixed methods sequential design include either selecting typical cases or outlier (extreme) cases for follow-up (Ivankova, Creswell, and Stick 2006). This study selected typical cases from the survey for follow-up in-depth interviews so that quantitative results can be better explained with qualitative analysis. Survey respondents were grouped into 3 typical case groups on the basis of responses and for labelling purposes categorized as: A (least risk); B (moderate risk) and C (most at risk).

Group A: Sexually abstinent in last 12 months

- **and**
- Do not want any (more) children.
- **or**
- Currently using contraception.
- **and**
- Adherent to ART

Group B:

- Had sex at least once in the last 12 months
- **and**
- Used condoms every time
- **and**
- Currently using contraception

Group C:

- Had sex at least once in the last 12 months
- **and**
- Inconsistent condoms use in last 12 months
- **and**
- Want (more) children in the future
- **and**
- Not currently using contraception
- **and**
- No intention to use contraception in the future
- **and**
- Non adherent to ART

This procedure resulted in a total of 148 (Viwandani=61 and Korogocho=87) typical cases identified from the survey sample grouped as follows: 67 cases in A, 37 cases in B and 44 cases in C (Table 3.0.2). Roughly a third of these cases were selected for IDIs: A (20); B (10); C (15) =45.

**Table 3.0.2: Distribution of cases for sampling of respondents for IDIs**

SLUM	FEMALE			MALE			TOTAL
	A	B	C	A	B	C	
VIWANDANI	18	8	10	7	7	11	<b>61</b>
KOROGOCHO	30	8	9	12	14	14	<b>87</b>
<b>TOTAL</b>	<b>48</b>	<b>16</b>	<b>19</b>	<b>19</b>	<b>21</b>	<b>25</b>	<b>148</b>

The final sample was selected from this number to ensure a diversity of the following characteristics: sex, treatment status, marital status and age. These factors were statistically associated with the sexual and reproductive health outcomes of interest during preliminary quantitative data analysis. Out of an initial sample of 45, we managed to interview 41. Two respondents had moved to unknown locations, one refused to be interviewed and one migrated to rural areas. The final sample (n=41) for in-depth interviews was distributed as follows (table 3.0.3): 19 cases in A, 9 cases in B, and 13 cases in C.

**Table 3.0.3: IDI sample distribution by sex, study site and grouping**

SLUM	FEMALE			MALE			TOTAL
	A	B	C	A	B	C	
VIWANDANI	5	2	3	2	2	3	17
KOROGOCHO	6	3	4	5	3	3	24
<b>TOTAL</b>	<b>11</b>	<b>5</b>	<b>7</b>	<b>7</b>	<b>5</b>	<b>6</b>	<b>41</b>

#### Interviews with KIIs (health care providers)

In addition to in-depth interviews with PLWHA, the study conducted Key informant interviews (KIIs) with providers of healthcare. This selection was done to include



providers that deal directly with PLWHA: Clinicians, Nurses, HIV counsellors and community health workers. These were selected based on their role in HIV/AIDS care programmes. In total 14 care providers were interviewed (Table 3.0.4). All KIIs approached accepted to be interviewed.

**Table 3.0.4: Health care workers for key informant interviews**

SLUM	TITLE / DESIGNATION				TOTAL
	CLINICAL OFFICER	NURSE	COUNSELLOR	CHW	
VIWANDANI	2	2	1	1	6
KOROGOCHO	2	3	2	1	8
<b>TOTAL</b>	<b>4</b>	<b>5</b>	<b>3</b>	<b>2</b>	<b>14</b>

### 3.6. Stage Four: Research instruments

Using an integrative framework for mixed methods requires the linkage of instrumentation and data collection methods in order to address the “same substantive issue” (Woolley 2009; Yin 2006). This linkage is crucial in order to understand how PLWHA consider, and manage their sexual and reproductive lives from multiple perspectives (Laub and Sampson 2004; Miller and Gatta 2006; Woolley 2009). The quantitative survey helped to elicit and quantify the magnitude of SRH behaviours among PLWHA. The qualitative IDIs help to unpack the meaning and lived experiences of reproductive health of PLWHA within their local contexts. The questionnaire and the PLWHA IDIs were also linked through the use of some dependent questions, based on survey responses, in the IDIs to checking validity of some survey responses.

All the research instruments were translated by the candidate together with research assistant into the local language (Kiswahili) and back translated by an independent Kenyan researcher working at APHRC into English for validity.

#### 3.6.1. Questionnaire based survey

Data in the first phase were collected using an interviewer-administered questionnaire with face-to-face structured retrospective interviews. In the study context of non-

existent postal listings and low literacy levels, an interviewer administered procedure is the only feasible form of data collection. Face- to-face interviews can also help to motivate respondents and provide instructions and explanations (Alasuutari, Bickman, and Brannen 2008).

The questions were structured and closed, that is, with pre-set questions and pre-set answers, in order to communicate the same frame of reference to all respondents and to provide direction for interviewers (Gilbert 2008). Where appropriate there were limited open-ended questions to elucidate explanations if the need arose. The questionnaire used and adapted questions from several different sources, including: Family Health International's (FHI) behavioural surveillance surveys (BSS); Demographic and Health Survey (DHS); and, Patient Medication Adherence Questionnaire (PMAQ)<sup>3</sup>. Appendix 5 gives a summary of all the sources of the questionnaire items for the study. Where appropriate, questions were modified in order to be relevant to PLWHA and their local context. This ensured that the questionnaire struck a balance between being sufficiently comparable with existing secondary data sources so that comparative analyses could be performed and sensitivity to the study's setting.

The questionnaire (Appendix 1) was organised in 5 sections. Section one asks questions about the respondents socio-demographic background information including, name, age, marital status, education, ethnicity and monthly income. The second section asks of medical and clinical information including treatment and adherence. The third section captures respondents' sexual behaviour. Section 4 captures fertility intentions and contraceptive use behaviour. Social factors constitute the fifth and final section of the questionnaire. A ten item scale is used to measure knowledge; six item scales to measure treatment optimism and social support; a 15 item scale to measure internalised stigma; and a ten point rating to measure psychological distress including depression.

### 3.6.2. *In-depth interviews (IDIs)*

An in-depth interview is a conversation with an individual done by a researcher or trained research assistant that usually collects detailed personal and sensitive

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<sup>3</sup> Self-report adherence instrument developed by Chesney et al. (2000)

information and experiences, which cannot be collected in a group or in closed questionnaire-type surveys (Sharp and Frechtling 1997). An IDI allows for the collection of rich and detailed information about peoples' experiences, actions and how their behaviour is embedded in their socio-cultural context (Bauer and Gaskell 2000). IDIs were done with a subsample of the survey interviewees (41) to help explain and interpret relationships in the survey findings. This study adopted a risk environment framework and IDIs were used to capture the risk environment, that is, ecological, socio-cultural and economic context that shapes SRH behaviour (Rhodes 2002, 2009; Rhodes and Simic 2005) (Chapter One).

Specifically, the IDIs elicited lived experience (and how it shapes identity), and gender relations and socio-cultural values of PLWHA as contextual elements of the risk environment that affect their SRH outcomes. By lived experience is meant how the social world or phenomenon is experienced and made sense of by people. It is not just what happens to people, but also how people make sense of what happens to them. Lived experience shapes who people are or become (identity), how this identity is understood, articulated and shared with others (Pickering 2008). To capture lived experience, PLWHA were asked to provide narratives of their experience using their own words.

The questions in the interview guide were semi-structured with pre-determined topics for discussion. The semi-structured nature of the interview helps the interviewer to cover the salient issues for all respondents as well as flexibility for the respondents to respond in a unique way. This way the interviewer is able to direct the interview, yet adapt the inquiry by probing interesting responses for clarifications and elaborations (Bauer and Gaskell 2000; Lee, Sullivan, and Lansbury 2006). The issues covered included general well-being, brief life history, HIV/AIDS history and experience, treatment history and experience, sexual and reproductive experience and behaviour, and contraceptive utilization and experience ( appendix 2). Three in-depth guides were developed for the different typical cases (A, B and C) in order to explore some of the issues particular to the group in-depth. There were, however, some questions that were same and relevant for all three groups.

### 3.6.3. *Key Informant Interviews*

Key informants are people who are knowledgeable about the topic of interest or local beliefs (Campbell et al. 1999). In contrast with the IDIs with “cases”, key informants are asked to report about the behaviour of the population of interest rather than their own behaviour. Key informants for this study were health care providers who were likely to substantially shape the health-related lived experiences of PLWHA. As service providers they were also able to provide a glimpse into the policy guidelines and how these operate on the ground. It was also expected that their views on ART use and sexual and reproductive behaviour might be different from those of PLWHA. The decision to include them in the study was in line with imperative of getting a wide range of perspectives from different information-rich “stakeholders” (Bauer and Gaskell 2000; Coyne 1997).

This study interviewed a total of 14 health care providers that comprised of nurses, clinicians, HIV counsellors and CHWs serving the study sites. The topic guide for the key informant interviews was also semi-structured and interviewer administered. The issues explored included: description of typical clinic consultation with ART clients, how ART use, and SRH issues are dealt with during the consultations and their perceptions of barriers to SRH faced by PLWHA (appendix 3).

### 3.6.4. *Recruitment and training of fieldworkers*

The study recruited research assistants (RAs) to help the principal researcher conduct the survey, in-depth interviews, transcribe and enter quantitative and qualitative data. The study was able to recruit from APHRC’s staff of male and female fieldworkers who have extensive experience in both quantitative and qualitative data collection in the two study sites, and experience with interviewing PLWHA. Eight RAs (four for each site) were recruited for the quantitative phase, half of which were retained for the qualitative phase. Four of them had university degrees while the other four had diploma qualifications in counselling and were trained as HIV/AIDS counsellors, and one RA was a PLWHA. They all had many years of experience of data collection in the study site and were familiar with the context. Their familiarity with the socio-cultural context and residents greatly encouraged, not only respondent participation, but also discussion of sensitive matters of sexual and reproductive behaviour.

RAs were trained for a week before each phase of data collection. The first session entailed a general overview of the study including research questions, sample selection procedures, the research process and research ethics. In addition to the study's research questions, interviewers were kept abreast with the current basic bio-medical information about HIV/AIDS. These included, HIV transmission modes, definition of viral loads and CD4 cell counts, ARV treatment and adherence issues and the effect of treatment on levels of infectiousness. Training was done specifically on probing, obtaining sufficient answers, being neutral throughout the interview and maintaining the wording and, whenever required, the sequence of questions. Special attention was dedicated to the ethical principles of researching human subjects. More specifically, the sensitive nature of the study on PLWHA with its attendant ethical implications was addressed, especially the confidentiality of the information obtained and the privacy of the research participants. As a matter of course, different aspects of ethical consideration were addressed, including obtaining informed consent (voluntary participation, right to withdraw), explaining the purpose of study, risks and benefits of the study, confidentiality (guaranteeing and preserving anonymity) and doing no harm.

The second session dealt with the technicalities of the research instruments and their implementation. For the questionnaire, the following were included: description of different sections and instructions; overview of individual questions and their response options; recommendation for editing questionnaires and clarity and removal of any ambiguity in the question. For qualitative interviewing, the emphasis was on the informal and conversational nature of the process with the aim of eliciting a narration, and concomitant probing techniques. Desirable interviewer attributes that can greatly help the interview process were emphasised, including courtesy, friendliness, accuracy, adaptability, patience, honesty and non-prejudice.

The third session was interview practice with mock as well as actual interviews with the respondent. During mock interviews, the trainees practised interviewing their colleagues, followed by a review of interviewers' performance and general tips and recommendations for improvement. Practice interviews with respondents for this session were done when pre-testing research instruments, during which the principal investigator conducted sit-in reviews. This was again followed by review of interviewers' performance and feedback in a class group meeting. Interviewers' filled

out questionnaires and taped transcripts were assessed, and feedback and recommendations for improvement made.

### *3.6.5. Data collection procedures*

All the data, both qualitative and quantitative, were collected through face to face interviews with respondents who met the inclusion criteria: being at least 18 years, having known HIV status by the time of interview, and a resident member of the Demographic Surveillance System. The exclusion criteria included, being too ill to participate in the interview, unable or unwilling to give informed consent and non-residence of the study sites. Before conducting interviews, the informed consent process (see section 3.8) was done. The consent form was translated into Kiswahili, and read to the respondents. They were asked to sign the consent form. The quantitative interviews lasted about 45 minutes while in-depth interviews last about 1 hour 15 minutes. Interviews were conducted in the homes of the respondents where possible. Some interviews were conducted in hired separate rooms or in a separate room at the clinic at the request of the respondents who were uncomfortable with interviews in their homes. This was deliberately done to protect the privacy and confidentiality of the research participants and the information collected.

During data collection interviewers were routinely provided with feedback on their performance. During the first week of data collection, daily meetings were held with interviewers to review progress and plan and strategize for subsequent fieldwork. During these meetings we discussed any issues and difficulties that might have arisen and possible ways to mitigate them. The daily work output was at least one interview and not more than two interviews per day. All the completed questionnaires were edited by the principle investigator and any mistakes were discussed with all fieldworkers. Some mistakes in the questionnaire could easily be resolved in the office, while those that could not were resolved with the respondents following revisits. There were also spot-checks done for some cases upon editing. The basis for spot-checks mainly focused on questions that entailed skipping a whole section of the questionnaire or a substantial part of it. For example, an indication that the person was pregnant, sterilised, not on ART or sexually abstinent entailed a skip to the relevant sections. This (spot-checking) was meant to catch the interviewers that might be tempted to

misrepresent information in order to evade workload. No research assistant was found to have misrepresented the information.

Qualitative interviews were taped using a digital recorder. Debriefing was done on a daily basis to obtain information on the clarity of the questions in the interview guide and their relevance to the study research questions. Debriefing also involved the principal researcher listening to the taped transcripts for the purposes of reviewing interviewer performance and feedback for improvement. This helped us to focus our subsequent interviews by more probing for sufficient answers and new information. Each interview was saved on the computer and backed up in the USB and deleted from the digital recorder before its subsequent use. This was done for purposes of keeping confidentiality and safety of the information collected, especially in the context of insecurity in the research setting.

#### *3.6.6. Data management*

Quantitative data were edited, and entered into visual basic (VB6) data entry forms and saved in SQL server database. This was transferred into Stata for storage and analysis. After entry, frequencies were run for each variable to flag any missing, inconsistent and out of expected range values. Anomalies were corrected by referring to the survey questionnaire hard copy. The cleaned data was stored on a computer drive with restricted access. Hard copies of the questionnaires were kept at the APHRC archives and archived in accordance with internal data regulatory guidelines.

Qualitative recorded information was saved on a password-protected computer drive and backed up on a password protected USB. Two RAs experienced in transcription listened to, transcribed and translated data simultaneously as a first draft. The principal investigator (candidate) listened to and went through all the draft transcribed data to come up with the final copy, checking for accuracy. At this stage, emotional content such as laughs, coughs, clicks were added as were specific language forms such as expressions in the local language (Kiswahili). The candidate read and re-read a sample of the transcripts to develop a codebook. The codebook was tested by independent coding on a 10<sup>th</sup> (6) of the transcripts by the candidate and his supervisor. The two codings were compared for consistency and the codebook was modified by consensus. All the coding was done by the candidate in NVivo 8, with adjusting and fine-tuning

the codebook as the need arose. More details about coding will be presented in the next section on data analysis.

### **3.7. Stage Five: Data Analysis**

The final stage at which integration is achieved using the Yin integrative framework is data analysis. Having an integrated process right through the stages of research questions, case selection and instrumentation and data collection set the stage for integrated data analysis and interpretation. Evidence shows that an integrated analytic strategy, critical in mixed method research, is dependent on integration in the first four stages (Bazeley 2009; Woolley 2009). The data from the two methods were meshed in order to unfold complex relationships in the topic of the study. Such integration was undoubtedly facilitated by software such as NVivo version 8 (QSR International) (for qualitative data) and Stata version 11 (StataCorp LP) (for quantitative data). The following is an account of how the two data streams were prepared using the software for eventual integration.

#### *3.7.1. Quantitative data analysis*

All quantitative analysis was conducted in Stata to derive univariate descriptive, bivariate and multivariate analysis. Descriptive statistics were derived to describe the socio-demographic and medical factors (e.g. sex, age, education, marital status, treatment status, duration of being HIV positive) as well as SRH outcomes (e.g. condom use, unmet need for family planning, fertility desires and contraceptive use). Categorical variables were described using actual numbers and percentages while continuous variables were described by means, standard deviations, medians, and ranges. Bivariate analysis was done to assess the association between different explanatory variables and outcome variables. Chi-square test was used to test associations between two categorical variables, and a t-test and Anova for the relationship between categorical and continuous variables.

Multivariate logistic regression analysis was done to assess the independent net effect of explanatory variables on outcome variables of interest. Logistic regression models were used because all of the outcome variables were created as dichotomous with values of 0 and 1 for no and yes respectively (appendix 6).



Logistic regression is a method used to analyse data where the outcome variable is dichotomous. The outcome variable is first transformed into a logit variable which is the natural log of the odds of the event (outcome variable) occurring or not. Therefore, logistic regression estimates the probability of the event occurring. The logit model is denoted by:

$$\log\left(\frac{p}{1-p}\right) = a + b_1x_1 + b_2x_2 + \dots + b_jx_j$$

Logistic regression is similar to linear regression in that logit coefficients are the same as coefficients of linear regression. However, logistic regression does not assume a linear relationship between the outcome variable and explanatory variables nor does it require normally distributed variables.

A  $P < 0.05$  was considered statistically significant in all tests of significance. The regression coefficients of the logistic models were interpreted in terms of odds ratios, controlling for other explanatory variables. Model selection was achieved through stepwise forward and backward selection of variables. Backward selection starts with all variables and removes non-significant ones while forward selection proceeds by adding one variable at a time, but in practice a combination of the two is done. Variables that demonstrated a bivariate association with outcome variables at  $p < .05$  were entered into a multivariate logistic regression to assess predictors of the outcome variables. Stepwise forward and backward model selection was used to develop parsimonious models of significant predictors of outcome variables. Prior to running the final logistic regression models explanatory variables were tested for interaction effects and multicollinearity.

#### Independent variables

Independent variables are defined as “those that (probably) cause or influence or affect outcomes” (Creswell 2009, 50). Other names for independent variables are explanatory or predictor variables. The variables used in this study emerged from the literature review (Chapter 2). For example, factors that affect sexual behaviour include stigma and non-disclosure of status (Courtenay-Quirk et al. 2008; Parsons et al. 2005); ART use (Chen et al. 2002; Diamond et al. 2005; Wilson et al. 2002) psychological distress

(Parsons et al. 2003; Olley 2008) use of drugs and alcohol (Brooks et al. 2008); treatment optimism (Kennedy et al. 2007); gender–power relations (Moore and Oppong 2007) marital status (Luchters et al. 2008); and poverty (Allen et al. 2010). Fertility intentions are affected by age, gender, number of living children, ethnicity, subjective health and stigma both globally and SSA (Nattabi et al. 2009). Contraceptive use among PLWHA has been found to be affected by age, parity, gender, use of ART, and future fertility desires in both Kenya and South Africa (Todd et al. 2010).

Appendix 6 presents a full list of potential explanatory variables of sexual and reproductive health outcomes. Age, duration of HIV status, and duration of being on ART were derived by subtracting the date of interview from the date of birth, diagnosis and ART initiation respectively. Most of the variables (e.g sex, ethnicity, marital status) were categorical. Some social factors such as internalised stigma, psychological distress, social support, treatment optimism and knowledge on ART/HIV were assessed by item scales adapted from different sources (Appendix 5). Knowledge about HIV/ART and internalised stigma were assessed using 10 and 15 item scales respectively, with response options of yes/no for each item. Having “correct” knowledge on an item such as “Using a condom correctly every time protects against HIV” was scored as “1”, and “0” if the person disagreed with it. Similarly, a “yes” on the statement “I feel ashamed that I have HIV?” was scored “1” to indicate presence of internalised stigma, while a “no” was scored “0”.

Treatment optimism was measured using an 8 item scale with response options ranging from 1= “strongly disagree” to 4 “strongly agree”. A “1” on a statement such as “HIV is less serious than it used to be because of the new ART treatment” indicated less treatment optimism while a “4” indicated more optimism. The item “It is never safe to have sex without a condom regardless of the viral load was reversed scored because a “1” here indicated more optimism as compared to the rest. Social Support was assessed using a 6 item scale with response options ranging from “1= none” to “5= All the time”. This was used to assess the presence of material support (e.g “someone to take you to hospital if needed”); emotional support (eg “someone to confide in or share you problems with”) and informational support (e.g “someone to give you advise or information if needed”). Psychological distress was assessed using a 10 point scale to

measure the presence and severity of depressive symptoms such as sadness, guilt, self-hatred and sleeplessness. The rating scale ranged from 1 to 4 with high scores indicating presence and severity of the condition (e.g 1= “I don’t feel sad” and 4=“I am so sad or unhappy that I can’t stand it”).

Five indices (Social support, HIV treatment optimism, Depression and distress, Internalised stigma and HIV/ART knowledge) were derived from self-rating scales.

The scores from the measurement scales were averaged into a composite score for each construct using Cronbach’s Alpha (appendix 7). Cronbach’s Alpha is commonly used for latent variables because, in addition to deriving a composite measure, it also assesses internal consistency or reliability of the measuring instrument. It ranges from 0-1 with higher scores indicating high inter-correlations among scale items. That is, the closer it is to 1, the greater the internal consistency of the items in the scale. It is, therefore, an indicator of how well the items form a single scale in measuring the same concept. Usually, Cronbach’s Alpha scores of .06 and above are acceptable, but below 0.5 is unacceptable (Gliem and Gliem 2003). Only scales that had an alpha over 0.6 were selected. Overall the scales showed good reliability with most scales yielding an alpha of above 0.74. Examination of the Cronbach’s Alpha values if the items were deleted from their respective scales showed that the only internal consistency (reliabilities) that greatly improved after item deletion were treatment optimism (#6), social support (#5) (Appendix 7). The 2 items were subsequently deleted from their respective scales, leaving 5 items for treatment optimism and 5 for social support. Appendix 7 shows the descriptive statistics and Cronbach’s alpha for the scales. The coefficients ranged from 0.6008 to 0.8267, indicating high internal consistency.

Household wealth was measured by wealth quintiles based on a wealth index generated from information on housing characteristics and a list of household assets using principal components analysis (PCA). PCA creates summary indices from related indicators and derives PCA scores (Filmer and Pritchett 2001). The wealth scores were obtained from APHRC’s NUHDSS. Similar wealth indices have been shown to be good proxies of permanent economic status and are used routinely for DHS data (Rutstein and Johnston 2004).

### Dependent (outcome) variables:

Dependent variables are “those that depend on the independent variables; they are the outcomes or results of the influence of the independent variables” (Creswell 2009, 50). These are also commonly referred to as response or outcome variables. For this study the following are the sexual and reproductive health outcomes treated here as outcome variables (appendix 6): Sexual activity, consistent condom use, multiple sexual partnerships, fertility desire, contraceptive use and unmet need for family planning (see chapter 6-8 for definitions).

#### 3.7.2. *Qualitative data analysis*

Qualitative data analysis followed 4 generic steps including: 1) getting a general sense of data; 2) code the data; 3) generating themes; 4) making an interpretation and meaning of data and constructing a narrative (Creswell 2009). The first avenue to a general feel of data was presented during transcription. As already mentioned, the candidate went through the first draft of the transcribed data to produce the final copy. During this process, the candidate made notes of the general ideas coming out of the data. After transcription, 4 transcripts were randomly picked (one for each gender per study site) for the candidate to read through, jotting down memos on the margins. This was compared with the other notes, clustering together similar topics to produce a codebook. The codebook was tested on a sample of transcripts by the candidate and his supervisor and revised. We compared our independent coding and discussed disagreements and discrepancies, arriving with consensus at an initial codebook.

Coding the data was the next step. A code has been defined as “the most basic segment or element of the raw data...that can be assessed in a meaningful way...” (Braun and Clarke 2006, 88). It follows, therefore, that coding is the process of segmenting and labelling text to bring meaning to information. There are two types of coding – a priori and a posteriori categorisation of data. A priori coding involves the use of theory, literature and experts in the field to derive codes, while a posteriori coding derives codes from the data (Sinkovics, Penz, and Ghauri 2005). This study used the latter where the codes derived were data-driven. Coding can be done manually or by use of some computer software. Coding for this study was done with the help of NVivo version 8, a programme that is organised around 4 central elements: documents, nodes, attributes and sets. Typed transcripts were imported into the

programme and coded at “tree nodes”. The nodes are ordered hierarchically in treelike structures, enabling codes to be built up. The programme helps qualitative data management and analysis by offering features for organising, coding, linking, searching and modelling the text. The programme only helps to organise data but does not replace the human being to do the analysis.

The next stage was generating themes, which is essentially data analysis “proper”. Themes are the units of analysis, and hence, more broader than codes (Braun and Clarke 2006). Themes are developed by aggregating similar codes into meaningful patterns. They capture some important patterned information in relation to the research questions. This study used thematic analysis, which involves searching for themes or patterns in the entire data set. Braun and Clarke (2006) suggest for the recognition of thematic analysis as a separate method of qualitative analysis from discourse analysis and grounded theory for example. They contend that unlike others such as grounded theory, which is “theoretically-bounded”, that is, geared towards generating a plausible theory grounded in the data, thematic analysis is not.

Generating and interpreting a story from the data constituted the next item on the qualitative analytic agenda. This was accomplished by connecting and interrelating themes into “a storyline” (Creswell 2009). The themes were clustered into larger and shared issues to generate a coherent story. To tell a coherent story, commonalities within a theme and across themes were given priority, although differences were highlighted and discussed. The storyline was juxtaposed with the quantitative data to see the extent to which it answers research question and raises new questions in relation to extant literature.

Above all the integrative analytic strategy was never lost. Having followed requisite analytical steps for each method, an effort was devoted to integrating the two. Yin’s framework suggests that this can be accomplished by carrying out counterpart analysis, whereby the data from each method are used to explore “the same sets of relationships between variables” (Woolley 2009). This was easily achieved here, not least because the design had an integrated research question and collected data from an integrated sample. As already indicated in figure 3.0.2, qualitative and quantitative data were brought and analysed together. The two sets of data were used to address the same

research question during interpretation and reporting of the findings. Parts of the two data streams were used to, understand, qualify and elaborate each other. When conflicting evidence was identified, it was not seen as a contradiction, but rather as an avenue of these two pieces of information to be reconciled (Slonim-Nevo and Nevo 2009). This ensured that conclusions were drawn based on the evidence from the two strands of data.

### **3.8. Ethical considerations**

This study was done under the auspices of the African Population and Health Research Centre (APHRC) as a collaborative exercise with the London School of Economics (LSE). To this end, the study had to undergo the ethical review process of the two institutions. Consequently, the study was reviewed by the Institutional Review Boards/ Ethics Committees at the LSE and APHRC. Additional ethical clearance was sought from and granted by the National Ethical Review Board at the Kenya Medical Research Institute (KEMRI).

Informed consent from all respondents (PLWHA and key informants) was a vital aspect of this research project. It was essential to ensure that the respondent understood the implications of consenting to participate in the research process. Before interviews we carefully explained to all participants the aims and methods as well as the intended and possible outcomes of the research. It was brought to their attention that they had a right to refuse to participate in the interview and this right could be exercised at any time during the research process. All the respondents signed a consent form which was read to them explaining the purpose of the study and their role in participating in the research. We tried the best we could to avoid doing any harm to our research participants. Despite our best efforts to obtain informed consent, it was possible that some of our participants may not have given entirely independent informed consent. For one, community health workers were the first people to contact our potential respondents. Because the nature of client-provider relations which sometimes are reflected in differential power relations between community health worker and their clients, the latter may have felt obliged to accept the interview.

Care was taken to ensure that all interviews were done in places where respondents felt safe and comfortable. It was, therefore, vital that we asked respondents where they would like to be interviewed. All the information provided by the research participants were treated as confidential. This was done through anonymisation by removing names and other identifying information in the dataset, and this was explained to respondents before seeking their consent. Since most of our respondents live in single rooms in densely populated and overcrowded settlements, it was impossible to rule out completely the possibility of our conversation reaching the listening ears of their neighbours.

As had been anticipated, during the interview, some PLWHA interviewees asked the interviewer for medical help or advice concerning their treatment or condition. The research team had beforehand met with potential health care providers and discussed with them types of services that they provide. The research team drew up a list of available health care resources to provide to respondents when the need arose. We advised our respondents to seek professional medical advice from these health facilities when they sought medical advice from us. However, from the disbelieving look on some of our respondents' faces, one could not help wondering if they believed that we genuinely had the information but were unwilling to share with them.

As a matter of course we provided a small token for compensation in respect of the respondent's time and effort in the form of grocery package (packet of milk, sugar, maize meal and fruits) as it is culturally expected to do this when visiting a "sick" respondent. We believe that provision of such small food items was fair and reasonable and was not excessive so as to unfairly influence the respondents to agree to participate. However, given the level of poverty in the slums this may have acted as an incentive for them to take part in the interview, especially those who were followed up with in-depth interviews. That some men asked us to give them money instead of the foodstuffs in our subsequent qualitative interviews lends some credence to that perception.

Finally, undertaking research on PLWHA presents a minefield of ethical dilemmas as, in many respects, they constitute a vulnerable population. This issue became even more apparent in the course of our interviews. Some respondents had a horrid time narrating their experiences of living with HIV, and we had counsellors in the research team who went to provide counselling services for some of our respondents as needed. However, this might not have wiped away the negative effect of our interview for our respondents. That said, the majority of our respondents appeared to be quite happy to share their stories with us. It was sometimes us who could feel quite “distressed” to hear some of their stories, especially at the beginning of the research project.

### **3.9. Reflexivity and positionality**

Reflexivity refers to the “recognition of the influence a researcher brings to the research process” (Kuper, Lingard, and Levinson 2008, 689). It involves evaluating the potential influence of power relations between the researcher and respondents, the social distance between the researcher and respondents and researcher’s gender, ethnicity, social status on the data collected. It also involves sensitivity to the influence of the researcher’s position, values and intellectual biases that influenced choices in the study such as the research question and the methods of data collection (Kuper, Lingard, and Levinson 2008; Mays and Pope 2000). In the main positionality is at the heart of the researcher’s analytical and cognitive framework. In this respect five points warrant recognition for this thesis.

First, I should establish my personal interest in the research topic. I became interested in this topic when conversing with a health provider, while conducting qualitative interviews on adherence to ART in 2007 in the same study sites. Asked about the issues they face with adherence to ART with their clients, one provider’s response surprised me. The provider used an example of a woman to illustrate how some of his clients are “crazy” (his word). The woman in question had dropped out of the treatment programme and became pregnant, two actions that the provider could not understand. This conversation raised a number of questions in my head, including: Which of the two events preceded the other? If the pregnancy came first, did she perhaps default treatment for fears of being scolded by health providers? Was the pregnancy wanted or unwanted? The providers’ response touched a raw nerve of my personal values. My



personal position is that PLWHA should enjoy similar sexual and reproductive health-related rights, needs and aspirations with the general population.

Intrigued by this conversation I decided to study sexual and fertility preferences for my PhD dissertation research. My choice of the study sites was influenced by my previous research experience. I worked as a research assistant at the African Population and Health Research Centre (APHRC), Nairobi, from 2000 - 2006, where I gained experience in conducting population and health-related research using both qualitative and quantitative techniques. APHRC's research areas included urbanisation and poverty, reproductive health (including HIV/AIDS), fertility, mortality and migration in SSA, but most of the work was in Nairobi slums and that is how I became familiar with the research site and its population.

As with all researchers, my positionality on SRH might have affected the way I analysed and reported the findings. I endeavoured to maintain objectivity as a researcher, but "objectivity does not mean (and has never meant) value neutrality" (Bernard 2006, 372). For example, although sexual activity and sexual abstinence are two sides of the same coin, my decision to create an outcome variable with sexual activity taking the value of "1 and abstinence taking "0" and examining predictors (factors) of sexual activity rather than inactivity may have been influenced by my position on the issue. A person with a different position will have done it the other way round, although the factors will remain the same, only stated differently. In the same vein the way I highlighted sexual abstinent narratives that are not related to HIV risk reduction might have been affected by my position as well. Similarly, my reporting of future fertility desires and its predictors rather than no desires for future fertility may have reflected my personal attitudes towards the rights of PLWHA. A person with "anti-natal" stances against PLWHA might have highlighted desires to stop childbearing, albeit the determinants would be the same; only stated differently.

Secondly, I need to recognise my position on behaviour change vis-à-vis technological innovations (biomedical interventions) in HIV/AIDS prevention. We know that behaviour change strategies have failed to end HIV/AIDS despite massive investment (Stillwaggon 2009). I consider that the solution to HIV/AIDS eradication lies in biomedical interventions such as ART, PMTCT, male circumcision and ultimately

HIV/AIDS vaccine, whose efficacy has been demonstrated (Attia et al. 2009; Bailey et al. 2007). My position is that behaviour change strategies such as condom use, important as they are, are impossible to be implemented consistently for different reasons. Although I have presented the ABC among the PLWHA as objectively as possible, my enthusiasm for ART might have unwittingly led to the extensive discussion on Treatment for Prevention, an emerging policy agenda.

Thirdly, the impact of using research assistants to collect data needs to be acknowledged. Research assistants were instrumental in data collection and did the majority of both quantitative and qualitative interviews, helping accomplish the task that would have taken me considerably longer to do. These were straight-forward structured and semi-structured research items easily implementable by an interviewer with requisite research experience. Supervision and data quality checks are critical in a research conducted by a team of research assistants (Collumbien et al. 2012). My task was mainly on maintaining data quality throughout the research process and overseeing logistics. The research assistants work for APHRC and mostly come from the community and therefore know the local context very well. In my opinion this helped in eliciting sensitive information about sexual and reproductive behaviour. They were all experienced and I trained them prior to beginning fieldwork. On the whole they did a fantastic job. However, going through the transcripts, there are a few cases where I feel that I could have got more or different information had I done the interview and probed in relation to my research agenda. All researchers have some kind of research “agenda” or hypothesis that they would like to prove right or wrong, which might bias their investigation. I could not help noticing, in the transcripts, cases where the two research assistants, who were ART/HIV counsellors, probed more about treatment literacy and condom use than fertility and contraception as compared to other research assistants. That said, however, my theoretical framework was developed by the existing literature. I therefore, did not set out to prove a particular political disposition or theoretical framework.

Fourth, my being Kenyan, male, native-Kiswahili speaker and foreign educated needs to be recognised. There is no final agreement on whether studying “your people” is a good or bad thing. However, it is incredibly difficult to reflect on “indigenous” research because “you are likely to take a lot of things for granted that an outsider

would pick up right away” (Bernard 2006, 373). As with all research, my personal background, especially my dual identity as an “outsider” (London student) and insider (Kenyan) could potentially influence responses and reactions. My gender, ethnicity and social status might have impacted on the responses I got, because some respondents might feel uncomfortable discussing sensitive matters to foreigners or people from a different gender, ethnicity and social class and they may alter their responses to reflect this dynamic. However, this effect was minimal as I conducted only n=6 interviews. My background, nonetheless, brought positionality to the analysis as it creates the lenses through which I view the world. On the positive side my knowledge of the local language meant that I was able to engage with the respondents and transcripts, picking out metaphors and idioms that a non-native speaker would be unable to. On the other hand as a native speaker I might be more inclined to tone down some explicit words used by respondents to describe sexual activities and sexual organs, which are viewed as dirty in the local language. As a male researcher I might, for example, be more or less likely than a female to flag up narratives that contradict hegemonic masculinity, its dynamic nature, and more likely to see how hegemonic masculinity ideals create vulnerabilities for men as well.

Fifth, my long standing affiliation with APHRC needs to be fully acknowledged. Three things stand out. One, it facilitated phenomenal access to a hard to reach study setting –slums. Two, APHRC has laid down research protocols in the study sites, including material and non-material assistance to respondents so we did not have to deal individually with ethical dilemmas that might have arisen. Respondents are also aware of what they may or may not ask from APHRC. Respondents are also aware of the different roles of research team members. For example, one woman was perturbed when I conducted a spot-check interview with her. The field supervisor, who took me to her house, introduced me as his *mdosi* (boss) and so she wondered what was “wrong” with her to warrant *mdosi* to re-interview her. Normally, spot-check interviews are done by team leaders and field supervisors and not by *mdosi*. Three, my previous work in the data unit – providing linkage between office and field operations – meant that I had established working relationships with data programmers and field supervisors. However, there was some level of confusion regarding the pecking order. In my previous work the programmers and field supervisors/coordinator were not

subordinate to me. But now as PI of my project, they were, by defacto, subordinate to me, which sometimes speeded the processing.

Working under the APHRC framework was not without challenges. First, I had to organise my fieldwork to coincide with the DSS data collection rounds. This had logistical and financial implications. One, this necessitated more research assistants than initially planned. Two, reconciling respondent's identification particulars with the DSS database was no mean task and it took quite some time, especially in some cases where names did not match those in the database. Three, studying people who are research subjects of APHRC's longitudinal study immediately brings up expectations and worries of respondent fatigue. However, to my surprise this did not seem to be an issue to many of our respondents. None of the respondents complained to us about being tired of our interviews. On the contrary, most respondents indicated that they were happy with our interviews because they got the opportunity to talk about their "real" daily life issues this time round.

There are other surprises in my study that are not associated with my APHRC affiliation. First, the literature tends to present the view that Africans are guarded about sexual matters and do not talk about sex. Readings the transcripts I was quite surprised that the respondents were quite open and free about sexual matters. For example one woman asked a research assistant for advice on how to reduce her heightened libido that was, according to her, caused by ART. Their responses were sometimes very explicit on some sensitive sexual experiences – occasionally I could not believe my ears hearing some Kiswahili terms used to refer to sexual activities and genitalia. This might suggest that respondents were at ease during the interviews because of research assistants' extensive experience in similar roles and their local familiarity. Second, I was surprised that people could be open about some sexual practices. For example, there was a male respondent who said that he will never, ever use a condom in his life and refuses protected sex and avoids women who suggest or insist on condom use. Even when his interview was briefly interrupted by his friends who had walked in he continued narrating his sexual exploits and was unfazed by their presence. The interviewer briefly stopped the interview until they had left, but this man kept on telling him not to mind them and continue with the interview.

Last but not least is some reflection on data quality. Overall, the quality of data depends on careful preparation, piloting, and pretesting of instruments, adequate training and supervision of fieldworkers, and careful data management (Collumbien et al. 2012), procedures that were followed in this study. The quality criteria of validity and reliability in quantitative corresponds to reflexivity and triangulation/validation in qualitative research (Bauer and Gaskell 2000). In mixed methods, the emerging quality criterion that combines the two is “legitimation” of the results (Onwuegbuzie and Johnson 2006). A mixed method approach allowed me to validate information from two sources, which was largely “corroborated”. Three PLWHA, however, contradicted their survey responses on sexual behaviour and fertility preferences during in-depth interviewing. To make sense of such inconsistencies is always difficult, as they might reflect differences of methods used, differences in time of data collection or even differences of interviewer characteristics. I highlight these cases in order to shed light on mode effects of data collection, rather than reflecting wrong data. Another way of legitimisation was to examine the research question from different angles through survey, IDI and KI interviews and compare findings with available literature.

The subsequent five chapters present the research findings and their analyses, presented in line with the conceptual framework and research questions detailed in chapter 1. The qualitative research participants are anonymised by using four- digit identification numbers (e.g KC06) for PLWHA and (e.g KNS1) for health care workers or use of pseudonyms. The first digit represents the slum site (i.e K for Korogocho and V for Viwandani). The second digit represents the in-depth interview group type. For health care workers the second and third digits represent their designation ( i.e NS for Nurse, CO for Clinical officer, CS for Counsellor and CW for community health worker). The last digit represents the serial number within each group type. A small bracket “()” represents an equivalent English translation, while a big bracket “[ ]” represents my own word insertion for clarity or emphasis and also emotional content.

## Chapter 4: Setting the context: The life of a PLWHA in the slums

### 4.1. Introduction

“We are living a difficult life because I am jobless and I don’t have a family to support me. My wife has already died and so the challenges are food, rent, education...I have no money because I am jobless. I cannot get manual jobs because of this disease [HIV/AIDS]... I am being evicted from this house very soon. As you can see I have no [Kerosene] stove, no mattress...the landlord says he cannot tolerate me anymore because I have a debt of Ksh.4000 (£30)” [KA14] (widower aged 38).

Conversations such as this one during my fieldwork highlighted the need to incorporate understandings of the everyday experience of living with HIV in a slum setting. This chapter presents qualitative and quantitative data on living conditions as a context for subsequent chapters, showing how poverty and HIV/AIDS interact and reinforce each other in general and in relation to sexual and reproductive health in particular. Poverty is a multifaceted and complex concept (Barnett and Whiteside 2002; Marais et al. 2008), and it was beyond the scope of this study to measure it. This description, therefore, relies on the self-reported income and its sources, combined with respondents’ own descriptions of their daily living to illustrate some aspects of poverty. Income reported here is a rough subjective approximation by the respondent, elicited by one item question<sup>4</sup> and will have its own inherent reporting error. Income is just one dimension of poverty, but its importance in overall poverty measurement should not be underestimated in an urban money-based economy.

My data and the literature indicate that narratives of living with HIV/AIDS in resource-poor settings revolve around three factors, namely poverty, food insecurity and coping mechanisms. Scholars have been debating the relationship between HIV/AIDS and poverty for some time. An emerging strand of thought is that poverty and HIV/AIDS have a vicious cycle relationship where each may cause or exacerbate the other (Piot, Greener, and Russell 2007). The central premise of this school of thought is that poverty may lead to coping strategies such as transactional sex that may increase the risk of contracting HIV, and that experience of HIV further impoverishes individuals (Masanjala 2007). Similarly, scholars have been discussing the relationship between HIV/AIDS and food insecurity for the last two decades. The discourse centres around the physiological interactions between HIV and malnutrition that makes the body more

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<sup>4</sup> What is your approximate monthly income?

susceptible to HIV infection and progression to full-blown AIDS (Gillespie and Kadiyala 2005). Hunger and food insufficiency has also been shown to affect adherence to ART (Hardon et al. 2007) and increased incidence of transactional sex (Weiser et al. 2007). I will discuss the sexual and reproductive health and treatment outcomes in detail in subsequent chapters.

Chapter Four is divided into three major sections. I will begin by presenting descriptive statistics on the income, sources of income, and respondents' descriptions of their daily living conditions and how they earn their living (4.2). This will be discussed in light of the poverty line of one dollar a day used by the World Bank (Coudouel, Hentschel, and Wodon 2002). This will be followed by the socio-economic effect of living with HIV/AIDS on individuals and households in 4.3. Extant literature (e.g Barnett and Whiteside 2006) theoretically assesses different pathways of the socio-economic impact of HIV/AIDS on individuals, but what is missing is the views of PLWHA themselves and in particular, the views of PLWHA who live in slums. I will then move on to living with HIV/AIDS and food insufficiency in 4.4 and finally coping mechanisms in 4.5

#### **4.2. Living with HIV/AIDS and poverty: A vicious cycle**

The relationship between poverty and HIV/AIDS is by no means simple and straight forward. However, a strand of thought, represented by (e.g Piot, Greener, and Russell 2007) represents the relationship as a vicious cycle: each causes and exacerbates the other. The relationship is bidirectional in that, poverty increases people's susceptibility to HIV and infection with HIV/AIDS increases vulnerability towards poverty. Before examining the interplay between HIV/AIDSs and poverty in much more detail, a brief background on urban slum life is germane to understanding the genesis of such conditions of life and the big picture on urbanisation and slums in these resource- poor settings.

##### *4.2.1. Living in urban slums: a brief background*

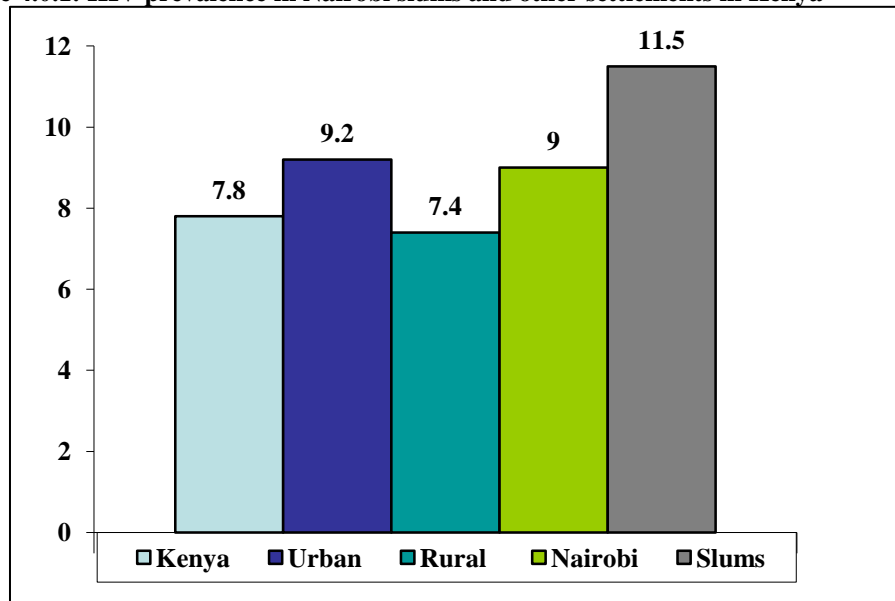
Urban living at least from historical western world experience provides a false sense of opulence for the poor rural folk in most parts of SSA. So in a genuine desire to better their lot, people migrate to Nairobi in pursuit of the urban dream. Most of the growth of Nairobi is rural-urban migration-driven (APHRC 2002). The iconic skyscrapers on

the horizons as they approach the city such as the landmark Kenyatta International Conference Centre and the Times Tower conjure up images of a good life indeed. But the picture of good life in the cities is an illusion for most city dwellers in this part of the world. To be sure, Nairobi, on average, scores highly on virtually all wealth and well-being indicators in comparison with other parts of the country (World Bank 2008). This average is, however, misleading given the inequality between the cities' wealthiest inhabitants and poorest in slums. Urbanisation in conditions of poor economic performance has created new slums and worsened urban poverty (UN-HABITAT 2003a). It is estimated that about 72% of urban residents in SSA reside in slums (UN-HABITAT 2003b) . Commenting on living conditions in African urban cities Potts (1995, 247) observes that “not only that urban poor have become much poorer in many countries, but their lives have become an almost incredible struggle”.

The story of the Nairobi slums is paradoxical. Despite comprising 60% of Nairobi's population, they only occupy 5% of the Nairobi land mass (APHRC 2002). As home to 60% of its population, the slums are in essence, demographically speaking, the dominant city in Nairobi, and yet are not officially recognised. Secondly, as affordable places, they provide accommodation for the low-cost labour force, which is the engine that propels Nairobi city, yet lack basic facilities for healthy and fulfilling living. Slum dwellers live in filthy and un-hygienic living conditions. Homes are typically packed closely together and consist mainly of single rooms constructed from mud, iron sheets, cardboard boxes and polythene paper (Amuyunzu-Nyamongo et al. 2007). These living conditions stand in stark contrast to those in well to do Nairobi's residential suburbs such as Karen and Runda.

The so-called “urban advantage” in health outcomes does not hold for slum settlements in the developing world (Montgomery 2009). For example, mortality levels in Nairobi slums approximate and often exceed those observed in rural areas (APHRC 2002). Urban HIV prevalence rates are almost double what they are in rural areas (Dyson 2003; Montgomery 2009). In Kenya HIV prevalence is higher in Nairobi slums compared to other settlements (figure 4.0.1). The poor health status of slum residents is due to many factors: poor environmental conditions and infrastructure; limited access to treatment and preventive services; and reliance on poor quality and mostly informal and unregulated health services (Zulu et al. 2011).



**Figure 4.0.1: HIV prevalence in Nairobi slums and other settlements in Kenya**

Source: APHRC and KAIS

Having provided a brief overview of the development of slums in African cities in general and Nairobi in particular, I now turn my attention to how residents earn their living in these settlements. This information helps us to understand the general living conditions of slum residents and how infection with HIV/AIDS might further worsen their quality of life.

#### 4.2.2. *Means of earning a living in the slums*

##### Income for PLWHA in Nairobi slums

This study uses reports on individual's monthly income as a quantitative description of one aspect of poverty. Since this was not a poverty study, no effort was made to develop comprehensive instruments to measure poverty in all its dimensions, and the results here are based on a one-item question about the respondent's monthly income. Although income based approaches to poverty have been recognised as inadequate (Barnett and Whiteside 2002), not least because poverty is multi-dimensional, the importance of income for daily subsistence needs, especially in a cash-based urban economy should not be underestimated. Poverty is, at its most basic, whether individuals or households have enough resources or abilities to meet their daily needs. That is why the bulk of its measurement tends to revolve around comparisons of individuals' income or consumption, against some threshold below which individuals

are designated as poor (Coudouel, Hentschel, and Wodon 2002). That said, it is important to mention as well, that capturing an individual's income has its own difficulties, not least in a slum setting with a large informal sector where income flows are erratic.

The mean monthly income for survey respondents was 2,289 Kenya shillings (\$28), which is below the conventional poverty line of one dollar a day (Table 4.0.1). The World Bank uses this poverty line as a benchmark to describe people living in absolute poverty as they lack the means to meet the most basics of life's requirements of housing, food or clothing. Over 75% of the sample lives below the poverty line of less than one dollar a day. The PLWHA in the study sites seem to be worse-off when compared with the general population. For example, de Laat et al. (2008) found that 62% of the households in Viwandani and Korogocho slums had incomes that were below the official poverty line (per adult equivalent). Gulyani & Talukdar (2008), using a more generous measure of poverty line of expenditure of \$42 a month, on a nationally representative sample, inform us that 73% of the slum households in Kenya are poor. When categorised further by gender, my study reveals that women earn far less than men, with their average monthly income being less than half than of men at shillings 1557(£12) and shillings 3482 (£26) respectively (Table 4.0.1).

**Table 4.0.1: Monthly individual income by sex in Kenya Shillings**

MONTHLY INCOME	SEX		
	Female	Male	Total
Mean income	1557	3482	2289
Standard deviation	1639	3103	2487
95% confidence interval	1377-1738	3043-3940	2073-2504
P value= <0.0001			

Poverty lines tell only part of the story by merely revealing the kind, not degree – failing to account how far people live below the poverty line. There is, therefore, a growing recognition for the need to pay attention to people's own accounts of how they experience poverty. This study collected perspectives of poor men and women to provide first-hand experience of poverty:

INTE: To start with how are you and your family doing generally?

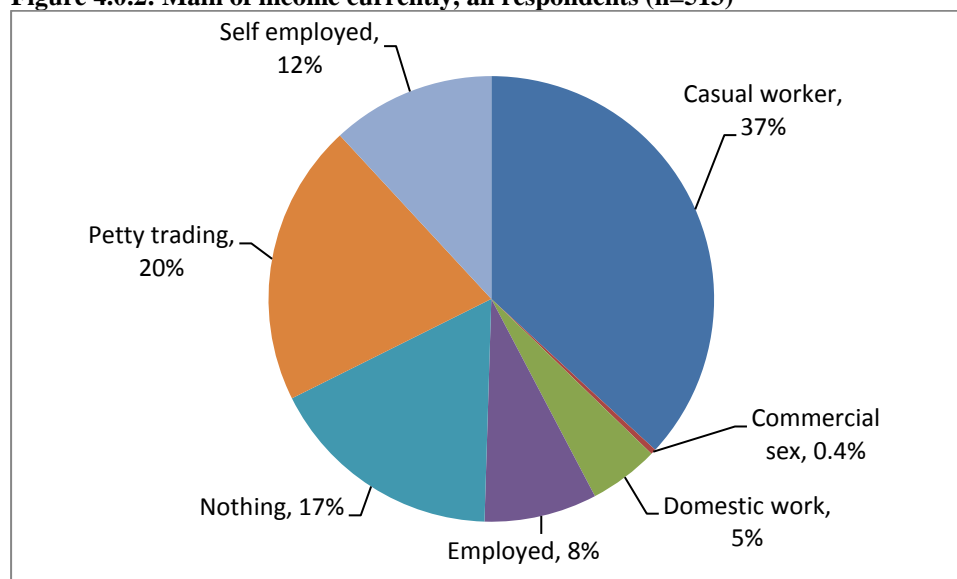
KC06: I just get on *kimashida shida* (with problems); I don't even have a job. Life is a gamble –I just try my luck here and there in life. And so even this disease [HIV/AIDS] will never go away. You have to get money for rent, food, school fees and so on and there is no job. So you see *ukimwi*( HIV/AIDS) will never end. (woman aged 39)

The above quote illustrates the struggles that a PLWHA in a slum setting grapple with on a daily basis. It represents PLWHA who are unable to afford basic necessities such as food, housing and school fees due to unemployment and limited income earning opportunities. This respondent explicitly links poverty and HIV/AIDS. I will discuss this in more detail in the section on coping mechanisms. First, let us turn our attention to the sources of income for PLWHA in the slums.

#### Sources of income for PLWHA in slums

The data shows that PLWHA in Nairobi slums earn incomes from different sources ranging from formal and informal employment to support from civil society organisations, government, family, friends and relatives:

Slum dwellers generally have limited formal sources of income. They tend to engage in casual or unstable employment or income generating activities (UN-HABITAT 2003a). The situation is worse for PLWHA whose illness affects their ability to participate in waged labour. Most PLWHA in the slums are engaged in seasonal and short-lived jobs such as casual work, small scale/ petty trading and self-employment (*Jua Kali*) (Figure 4.0.2). Only 8 % reported they were employed in longer-term jobs, with almost a fifth reporting that they are not involved in any income earning activity and depend on others. It should be noted, however, that individuals are reporting their main source of income, so people with multiple sources reported the main one. The low and temporary level of engagement in income generating activities undermines their ability to fend for themselves and for their households.

**Figure 4.0.2: Main of income currently, all respondents (n=513)**

Those reporting “employment” tend to be employed in unskilled and unstable jobs such as security guarding, *mjengo* (construction) packing, loading and *matatu* (taxi) drivers. These jobs tend to be short term, temporary and transitory:

VC14: We pack goods in shops, mostly Indian shops; we pack biscuits inside wholesalers. We are called [when work is available] and we go do that kind of work. (Man, aged 39)

VC09: My husband also relies on some casual labour jobs like those in the *mjengo*, but sometimes they are not forthcoming and he ends up sitting around here for three months without any job. So I am the bread winner of this family most of the time and it’s a problem getting food, soap and so on. (Woman aged 41)

There are male-female differences in paid labour participation and income earning potential. Nearly three quarters (72%) of women reported that they did not earn any income last month, and women’s reported monthly income is less than half of men’s (Table 4.0.1), although this might be because they are reliant on a male partner for their income. Women’s relatively low participation in wage employment and low income might be due in part to their low education and skills levels compared to men. Only a fifth of women in the study reported having at least secondary level education compared to 41% of the men (chapter 3). Women are predominantly engaged in petty trading and earn daily income as domestic workers, and these gender differences in

income earning potential can have implications for sexual behaviour (Chapters 6 and 7).

VC03: I don't have a job. I only do casual labour work like washing people's clothes if I am lucky to get it... if I am lucky I can get it thrice a week and they pay me 100 (less than £1) or 200 shillings ( £1.50) for each washing (Woman aged 36)

KC03: I do *vibarwa* (casual jobs)... like washing peoples' clothes [for pay]. Sometimes *naenda rodi* (I hit the road/streets, meaning commercial sex work). Other times I just do household or domestic help work and get paid (Woman aged 26)

A substantial number (17%) of the respondents reported that they did not engage in any income generating activities. Many of these thus depend on support from other household members or other external sources. Given the erratic nature of employment opportunities and other sources of income in slum settlements, PLWHA who, from time to time, are jobless depend on immediate family members for their upkeep. The bulk of family support comes from spouses.

KB10: Right now I don't have any job. I used to sell boiled maize, but right now maize is out of supply so I have nothing to do...I just sit here. It is my husband who does some *kibarwa* (casual job) to at least get us food.(woman aged 25)

In traditional African community systems, relatives in the extended family are expected to provide for the needy in the family, lineage and clan (Suda 1997; Abebe and Aase 2007). A minority of respondents acknowledged that members of the extended family help them occasionally:

INTE: You mentioned that your family assists you. How does your family assist you?

VA12: My sisters and maternal aunt

INTE: How do they assist you?

VA12: When I don't have money they send some food to me and when I don't have paraffin for my lamp they provide.(separated woman aged 25)

The role of the extended family is in a state of flux and its support role in urban African settings is changing rapidly. A predominant theme in sociological and anthropological writings on modern African societies is the declining role of the extended family in support of its members. Whereas extended family values may still

be preserved in rural areas, in more urbanised contexts, extended family networks tend to be substantially weakened (Foster and Williamson 2000). Respondents categorically denied the existence of extended family support mechanisms. Asked if he gets support from the family, a man (VB10) observed “I just struggle on my own, I don’t get any help from my extended family”. Another one (KA17) added “No, I don’t get any help from my family. I don’t have anybody to help me”. Family support tends to be either non-existent or at best unreliable.

INTE: What about support from your family?

KA07: I can’t depend on my family because they can only give when they feel like. I cannot go begging them since they don’t know how I feel in my body even though on the outside I may seem to be alright. Sometimes they come around and buy clothes for the children or pay their school fees, but that is all.(man aged 59)

A point that is rarely mentioned in the literature on extended family support is the expectations of donors and recipients in the system. Certainly, not everyone is expected to contribute equally and in terms of expectations by residence, the remittance flow is by and large unidirectional – from the urban to rural areas. Therefore, simply by living in an urban area there is an expectation from rural kin that they will be expected to send money back – no matter how poor their circumstances in the slums:

INTE: Do you get help from your family?

VC14: I am the one who helps my family, but... it is very hard because I am here in Nairobi and they are upcountry so they just depend on farming and so expect me to send them something. (Man aged 39)

The situation of PLWHA in the slums is sometimes partially ameliorated by support from external sources such as governmental and non-governmental organisations. Respondents reported support from civil society organisations (e.g.: Kenya Network of women with AIDS (KENWA), Redeemed Gospel Church, Feed the Children, Concern Worldwide), mainly in the form of food. Support also takes the form of school fees, clothing, counselling and spiritual support:

INTE: Do you receive support from anywhere else?

KB07: Umh, Just a little bit here and there. For instance the Redeemed Gospel church help me in the education of my children though there is some little money we usually pay.

INTE: How much do you pay?

KB07: I pay Ksh. 50 per month per child. So in a year I pay Ksh. 1200(£10) for two children.

INTE: Could there be any other support?

KB07: The other support is from KENWA (Kenya Network of women with HIV) through Redeemed and they send to us Ksh 1,500 through M-pesa. Feed the Children Kenya also gives us a ration of maize once every month.(widower aged 60)

Respondents also reported support from government and state agencies. We identified some support in the form of a standing monthly stipend to people in one slum site, based on means testing mechanism, although this was just a pilot project in one slum community and was yet to be fully implemented on a wider scale. Other support to some PLWHA took the form of food usually distributed by the lowest local echelon of government at the chief's office:

INTE: Do you receive any support from the government?

KA07: No at this point in time, except that there has been this programme which has been giving us ksh. 1 500 a month, but that comes to an end in April so it does not count. So don't note that one down.(man aged 59)

INTE: Is there any kind of support that you receive?

VB06: There is none (support) that we receive. Except for the food rations that come once in a while at the Chief's camp. (woman aged 35)

Despite the role that this kind of external support can play for poor PLWHA, respondents reported that they were inadequate and unreliable. Most respondents reported that they do not receive any external support or are unaware of its existence. They reported that the support they sought was either unreliable or not forthcoming:

INTE: Do you get any support from anywhere?

KC09: No my friend, I had wished for that [support] because I have no means to earn a living. The only people who can help me is our hospital down there. Initially they used to aid me with food, but they stopped it. Some people go there...but since they cut supplies to us I have had many challenges.(widower aged 55)

PLWHA earnings are meagre and sources of income are few and far between and at best unstable, which has been made worse by HIV infection. Let us turn our attention

to the socio-economic effect of HIV/AIDS on individuals and their households, in order to understand how poverty and HIV/AIDS might reinforce each other.

#### *4.2.3. The socio-economic effect of HIV/AIDS on individuals and households*

Whereas the macro-economic impact of HIV/AIDS on national growth and poverty levels has received much attention (Gillespie, Kadiyala, and Greener 2007), the effect of HIV/AIDSs on individuals and household has not received commensurate attention. However, households and individuals bear the direct brunt of the pandemic and hence the greatest impact is felt at this level. Studies (e.g Fox et al. 2004) on households and individuals tend focus on measurable economic variables such as income. Yet the impact of HIV/AIDSs goes beyond these conventional measures (Barnett and Whiteside 2002). This section examines both economic as well as social effects of HIV.

#### Economic effects

Once a person is infected and/or diagnosed with HIV/AIDS a number of economic issues that affect the well-being of individuals and their households come to the fore. Narratives suggest that the two most important economic pitfalls revolve around income loss and property loss.

HIV/AIDSs can cause the loss of income and resources for the individuals and their households. This happens in a number of ways. HIV/AIDSs tends to affect the prime-aged breadwinning adults, the most economically productive segment of the household economy (Barnett and Whiteside 2002; Fox et al. 2004). Respondents indicated that infection with HIV/AIDS had affected their work ability and productivity. Illness following HIV infection may lead to chronic absenteeism and sometimes cessation of work altogether. Most employment opportunities for residents in the slums are casual, manual and physical energy-intensive. Respondents were unable to meet the physical energy demands of their jobs as a result of HIV conditions:

VC11: You know the kind of job I do requires a lot of energy and in the past I was strong enough and would do it very fast and go and look for another opportunity. You know when working on “contract” (self-employment) you need to finish one piece of work fast so that you get another “contract”. But nowadays it is not possible to do that. (man aged 46)



When working adults fall ill, substantial income is lost. Several respondents narrated how their individual incomes had declined following their HIV/AIDS related illness:

KB06: matters have gone worse since [HIV]. It has not been OK because I used to do tough jobs that required energy. But when I got sick I could not do the same amount of work as I used to do before and that reduced our family earnings. Before I could perform work worth K.shs 400, but nowadays I can only do work that is worth k.shs 200 in a day.(man aged 35)

KC01: You see like now I have to choose the kind of job I can do because my body is really wasted and I lost a lot of weight. I used to weigh between 65-68 kilograms before but this dropped to 48 kilograms. So I have to choose some light work to do; I can only carry light loads. This means that my earnings also dropped drastically... But because of this treatment (ART) right now I have started to regain my weight and I am getting back doing the level I used to do ( widower aged 41)

This is echoed by Fox et al (2004) that showed that tea pickers in Kenya experienced an 18% drop in productivity and income per day as a result of HIV-related illnesses.

In slum settlements where the majority of paid work is done on piece rate, the effect of illness on earnings can be substantial. Frequently there is more than one person in a household who is affected by HIV-related illness, making impoverishment more extensive. High levels of insecurity in urban slums mean that getting ill and being hospitalised can risk household assets; burglars take advantage of absences caused by hospitalisation:

KA14: When I was admitted in hospital, everything was stolen from my house.... I don't even have a stove, no charcoal burner; I have only 2 plastic cups. I felt I had taken many steps back. I don't even have a blanket; I use a simple cloth [to cover myself when sleeping]. Mosquitoes bite me.(widower aged 38)

There are also other repercussions of the epidemic on households that go beyond the economic sphere to encompass the social domain.

### Social Effects

One of the social consequences of HIV/AIDs is household dissolution. If households dissolve following the death of the household head then dependents, usually women, children and the elderly, either have to fend for themselves or are taken in by other households (Barnett and Whiteside 2002; Nyambedha, Wandibba, and Aagaard-

Hansen 2003). One of the consequences of household dissolution is forced migration, mainly of women who are unable to stay in their marital homes following the death of their husband. Instances were reported where a husband's family may blame a widow for the death of her husband and refuse to accept her or her children into the family support system.

KA17: That one [marriage] broke down completely. You know since my late husband is not there, his family cannot believe that I was not having it [HIV] when I came, and that it was him [my late husband] who infected me with it. It would have been easier to discuss it with him if he was alive, but now his family will just say that I am the one who infected their son. So you have to leave and go away. You know your people cannot leave you because you are like that, they will be on your side until the end. That is why I moved here. (Widow aged 30)

One of the most tragic impacts of the HIV/AIDS pandemic is the staggering number of orphans it continues to create. In SSA alone, an estimated 12 million children under the age of 18 have lost one or both parents to AIDS (UNAIDS 2008). These children are disadvantaged, for example, as their education, is disrupted either through dropping out of school completely or transferred to cheaper, but poor performing or failing schools (Case, Paxson, and Ableidinger 2003). The disadvantage orphans face is due to, among others, the poverty of the households in which they are raised as a result of loss of a parent. The quote below gives us a glimpse of conditions of orphaned children and how the surviving parent responds to the prevailing circumstances by changing their schools and sending them to relatives:

VC03: I am just struggling. I have had to sell some household items to pay for my children fees. I have had to transfer my children to other [cheaper] schools after my husband died. I have had to take some of my children to our home in the village; they stay with my dad and my brother. (woman aged 36)

Without proper schooling coupled with the absence of parental capital, the future of orphaned children is compromised. Education is an economic asset with potential to break the cycle of poverty. Studies in SSA show that orphanhood is associated with poor socio-economic and educational outcomes (Case, Paxson, and Ableidinger 2003).

HIV/AIDs continue to cause growing numbers of adult deaths leaving behind widows and widowers. Consequently, new forms of households are developing as responses to

the impact of HIV/AIDS, including female headed, child headed and grandparent headed household (Barnett and Whiteside 2002) Hoosegood (2008) as male breadwinners die or are incapacitated by the recurrent episodes of HIV/AIDS related illnesses, thus:

KA12: Even the children got into problems because previously we had all depended on my husband for sustenance, but since he died I have had to provide for the whole family single-handedly. I am now the mother and father of the family. (Widow aged 39)

KB06: I still pay... rent; or rather it is my wife who pays [laughs]. You know nowadays *bibi ndio mambo yote* (my wife is everything). I am unable to work now, but I used to pay before. (man aged 35)

Female headed households and single-parent households are common in the study sample. The sample includes more widows (27% of women) than widowers (9% of men), suggesting that men are likely to remarry than women when widowed. More than half (58%) of women are not in any marital union mainly as a result divorce/separation and widowhood, as compared to 25% of their male counterparts (chapter 3).

PLWHA face ostracism from their marital homes and loss of social support from their families upon discovery of their HIV status. Both women and men are abandoned by their spouses and families when they test HIV positive, leaving them to take care of their children single-handedly:

KB08: Since my husband knew about my HIV status he abandoned me. Even his family doesn't want to see me. They are just here in Nairobi, but cannot get anywhere close to me. (Woman aged 45)

VNS3: I can remember a client who came to me, they had already been tested and we were just sharing with the client and he was a man. He told me when he went home and shared with the wife, the wife packed and left, I don't know whether she went up country or where. (Nurse)

Living with HIV/AIDS can further worsen the living conditions of PLWHA in the slums. One consequence of the poor living conditions of PLWHA is an inability to access sufficient food to meet their nutritional requirements. The following section

examines how food insufficiency may affect the health and SRH of PLWHA in the slums.

### **4.3. Living with HIV/AIDS and food insecurity**

Good nutrition and food security are important components in ARV treatment. Moreover, hunger and food insecurity may force people to engage in risky sexual behaviour as a survival mechanism. Evidence of the relationship between HIV/AIDS and food insufficiency continues to grow in the literature. Studies, although limited, indicate yet again that the relationship between HIV/AIDS and food insecurity is a vicious cycle: HIV/AIDS is both the cause and effect of food insecurity. For example, Gillespie and Kadiyala (2005) demonstrate that food insecurity and malnutrition may accelerate the spread of HIV, both by increasing people's exposure to the HIV virus and by increasing the risk of infection following exposure. On the other hand, infection with HIV/AIDS reduces individual or household capacity to obtain food through frequent morbidity, mortality, and loss of income, assets and skills (de Waal and Whiteside 2003). HIV/AIDS also increases fatigue and decreases physical activity among PLWHA, thereby decreasing their income earning potential (Piwoz and Preble 2000). De Waal and Whiteside (2003) call the co-existence of HIV/AIDS pandemic and food insecurity in southern Africa "a new famine variant".

#### *4.3.1. Hunger and lack of food among PLWHA in slums*

Although having close links with poverty, lack of food or what is technically called food insecurity in urban slums has seldom been recognised (Faye et al. 2010). Food security as defined by the World Food Summit refers to the condition "when all people at all times have physical and economic access to sufficient, safe and nutritious food for a healthy and active life" (FAO 1996). Food security, therefore, implies certainty on food availability and sufficiency in the amounts and kind of food to meet the required dietary requirements. Food security is usually measured through a composite score from a list of food deprivation indicators (Faye et al. 2010). It was beyond the scope of this study to measure food security in all its components, but the survey did include a question that asked respondents how often they go without food<sup>5</sup>.

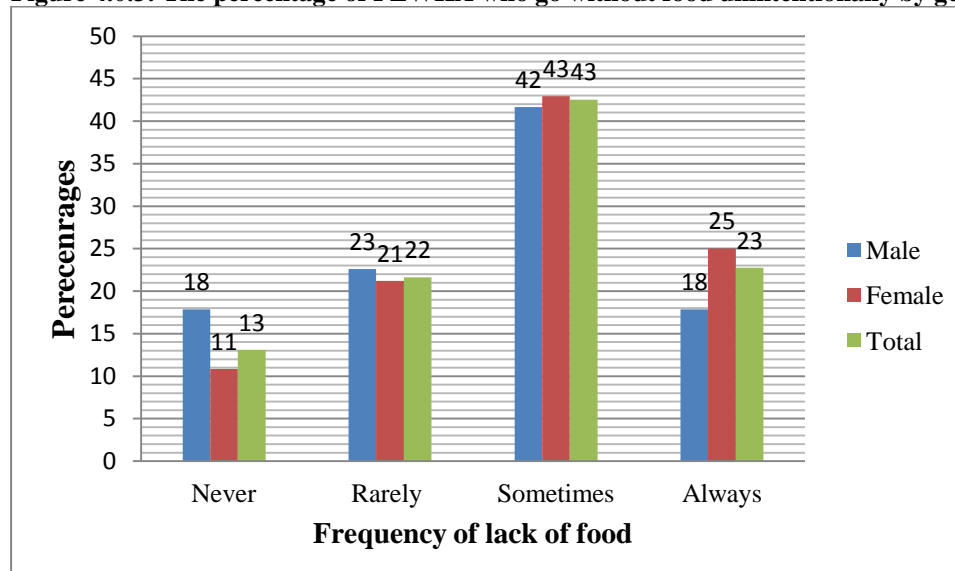
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<sup>5</sup> How often do you go without food unwillingly?

Food security exists when all people at all times have both physical and economic access to sufficient food to meet their dietary needs for a productive and healthy life. Food security is at the top of the list of Millennium Development Goals (MDGs) with the goal of eradicating poverty and hunger. Achieving food security in SSA, however, remains a great challenge. In SSA, one person in every four, lack adequate food for a healthy and active life (FAO 2010),

In slum settings it is expected that quite a number of PLWHA would go without food unintentionally. Only 13% of the survey respondents on ARV treatment said that they had never missed taking food in the previous 12 months. The rest (87%) go without food some of the time or on a daily basis, with women faring relatively worse than men (see figure 4.0.3).

**Figure 4.0.3: The percentage of PLWHA who go without food unintentionally by gender**



The presence of food insecurity was highlighted in in-depth interviews. PLWHA were finding it difficult to buy food:

VA13: Getting the required food is a problem for me. As I already told you I can go for weeks without any job and therefore there is no money to buy food. (widower aged 46)

KNS1: The other one is lack of food. Some of these clients when you visit them in their homes and look at their situation you will not leave that house with your twenty bob that you were carrying in your wallet. I will say it is poverty; they live from hand to mouth. The mothers go and wait from a particular place, waiting for people to come and pick them to wash their cloths and then they are given 50 bob (less than 1\$). So it is this 50 bob that will feed the family for

that day and tomorrow she has to look for another way again. So they tell you that they have not eaten for days, may be just taken porridge for the last two days. (Nurse)

One of the consequences of food insecurity is that it causes nutritional deficiency that may lead to mortality and morbidity. One sign of the nutritional consequences of HIV is the wasting of infected individuals, hence its common name “slim”. Respondents mentioned the names that people use in the community to refer to PLHWA:

INTE: Are there names by which PLWHA are referred in this community?

KA1: They call us *konda* (slim).(woman aged 36)

KB06: People can refer to you as *mukingo*...initially people who had the HIV virus were identifiable by their neck taking a certain shape (elongation) as a result of wasting [laughs].

That is where the name [*mukingo*] (in Kikuyu) came from.(man aged 35)

In addition to undermining the immune system, HIV impairs nutrient uptake, absorption and use (Fawzi 2003). Additionally, PLWHA have about between 20-30% higher energy requirements than those without HIV (WHO 2003). That is why health care workers prescribe dietary requirements for PLWA. However, many respondents do not have the means to access the diets prescribed:

VA13: Sometimes the doctor tells you to eat certain foods like white meat. Now if you cannot even afford *Kitheri* (beans and maize) of 20 shillings, how are you going to afford white meat? Sometimes you are told to drink milk in the morning and not to eat cabbage. My friend how are you going to afford it? (Widower aged 46)

Optimal nutrition is needed to ensure survival and longevity of PLWHA and effectiveness of ART (Paton et al. 2006). ART use may actually increase the appetite for food as a physiological response and there is some evidence that individuals who take ART without adequate nutrition have lower survival rates (Paton et al. 2006). Food insecurity and hunger have been reported to undermine ART adherence – a critical aspect of treatment effectiveness (Hardon et al. 2007). Our respondents reported that they experience problems when taking ART on an empty stomach:

KB08: Well, there are times when you take [ART] drugs and without having eaten anything, you become very weak and sleepy. You even become dizzy and see blackouts at times when you are walking on the road.(woman aged 45)

Given the importance of adherence in the effectiveness of treatment and avoidance of viral resistance to first line drugs (Mills et al. 2006; Remien et al. 2007), food and nutritional security is crucial for sustaining treatment. However, my data confirmed that some (38%) of PLWHA are non-adherent to ART in part as a result of lack of food. Adherence was defined as taking ART in prescribed quantities on schedule and observing dietary instructions 100%:

VCO1: We have experienced some clients who complain that they cannot take the drugs as instructed due to lack of food since the drugs are quite strong. (Clinical officer)

In response to the absence of adequate food and diet among poor PLWHA, HIV treatment and care programmes (e.g.: KENWA) try to provide some nutritional supplements in the study sites. The recurrent discourse, nonetheless, revolved around the irregularity and unreliability of this food support mechanism, thus:

KC01: KENWA is just near us here. They give porridge and food. Nowadays they don't give food though, but porridge is there. You just go with a 5 litre container and you are given porridge. So when you are taking the drugs you have some energy. (widower aged 41)

KA02: They used to give milk to people who were enrolled in their programme, but when I got there they said they were not enrolling new entrants. So I just decided to remain there because I had already opened a file with them for medication (ART). (Divorced woman aged 24)

Living with HIV/AIDS as a chronic illness not only destroys the biological body, but also exacerbates people's poor living conditions. Many PLWHA live in precarious conditions of income and asset poverty, vulnerability and food insecurity. The chronic illness affects people's prime asset – physical strength. Many PLWHA in slums rely on manual and casual trades, and physical strength is crucial for the way they earn their living. Medical interventions such as ART may restore the body to some extent for those who are eligible or can access it. However, it does not restore their former socio-economic conditions. The following section looks at how people try to mitigate the disruption that HIV causes to their wellbeing.

#### **4.4. Coping mechanisms of PLWHA in the slums**

Individuals and households respond to different shocks in life such as the debilitating effects of HIV/AIDS. Households and individuals adopt local strategies and adjust them to their changing circumstances and context to mitigate the effects HIV/AIDS

(Gillespie 2006). HIV/AIDS is an additional load to poor urban residents and we need to understand how they respond to the multiple stresses in life. The concept of “coping mechanism” is often used to describe the local strategies adopted to deal with HIV/AIDS, almost exclusively in rural areas. However, some authors (e.g Barnett and Whiteside 2002) have questioned the appropriateness of the term “coping” in describing such responses. They suggest that the concept of coping is a misnomer and an outsider’s value judgment, which may not reflect the local feeling and the actual reality, and is tantamount to avoiding responsibility.

Results from this study show that poor urban residents are forced to adopt strategies, which may enable them to survive in the short term, including income, consumption and migration strategies. Income strategies, for example, include selling household assets to meet the extra financial demands caused by HIV/AIDS. In some cases, families have no alternative but to sell productive assets (e.g. livestock, tools), as a survival strategy or because they no longer have the wherewithal to maintain them, thus further diminishing their income generation potential and future investments:

VA13: I used to have a vehicle, a Datsun, which I sold. .... I did not have the energy to do that kind of business because of my HIV condition. I also sold some cattle to meet illness related expenses.(widower aged 46)

When productive assets are sold in response to HIV/AIDS, it limits future income generating capacity and can entrap people in chronic poverty. In this way their poverty situation is further exacerbated and the chances of recovery are reduced.

Breadwinners are forced to expand the spectrum of their income generating activities to include potentially hazardous occupations. Without commodities or services to sell women can resort to transactional or survival sex (Zulu, Dodoo, and Ezeh 2002), earning in cash or in kind:

INTE: Do you have any other source of income?

KC03: Sometimes *naenda rodi* (I hit the road/streets) [slang for commercial sex work]. Other times I just do household or domestic help work and get paid.

INTE: What do you mean by hitting the road?



KC03: I mean going to the clubs...in town and if you find a man who wants to go with you, then that's it. Even here if I get a man who wants us to go and gives out money, we do it. (Single mother aged 26)

Other women who cannot afford to meet the increased burden of household expenditure invite men into a union of sorts to help take care of the mundane expenses of rent and food.

KA09: Since I was not able to pay for my house rent, I invited him to stay so that he can assist me and he offered to pay for my rent. After infecting me with the [HIV] virus, he ran away and up to now my brother is still looking for him. (Widow aged 45)

These kinds of survival sex are different from formal commercial sex work, which is a profession of selling sex as an occupation (Wojcicki 2002). In contrast people in survival sex happen to involve themselves in some relations that involve sexual encounters for survival as a consequence of their impoverished and poor living conditions (Wojcicki 2002). As professionals, formal commercial sex workers are in a much stronger position to negotiate for condom use as a condition of service to their clientele (Campbell 2003). They are also less likely to experience sexual abuse (Wojcicki 2002). However, women involved in informal transactional sexual unions have less power and tend to lack the ability to negotiate for safer sex:

KC03: Look, you meet a man, he tells you he doesn't want [to use] a condom; *anataka nyama kwa nyama* (He wants flesh to flesh) [laughs]. So you just accept it, *shauri yake* (it's up to him); as long as I get the money. (Single mother aged 26)

Unprotected sex is not only risky for the wellbeing of the PLWHA, but wider populations as it carries the risk of transmission of HIV/AIDS to sexual partners and reinfection with new strains of the virus that are resistant to first line drugs commonly in use in these resource-poor settings (Kennedy et al. 2007).

Poor PLWHAs in slums register with multiple ART care programmes that provide nutritional support. This is done as a survival strategy to get a regular supply of food for the family and to meet the nutritional demands of the body following uptake of ART:

KA02: We were taken somewhere for counselling where we were given one packet of *unga* (maize flour). There I made friends who told me that we could go and get milk at a different place as well; so that when you give birth you have a variety of places to pick from because milk from one source was not enough. You share a lot with them and they tell you that you can register in as many hospitals as you want so that you can get more food. We get two packets of milk and fare in one place in a week. You even find that in a week you get six packets of milk for your child because you visit three hospitals in a week. (single mother aged 24)

This kind of strategy stretches the limited nutritional support mechanism available, and is also a danger to adherence to ART from multiple sources as explained by a nurse:

KNS1: ...In korogocho we have other organisations like the KENWA, which provide drugs and material support. So you find that some clients want to benefit materially. May be in KENWA they are giving drugs as well as pay rent and so this client wants to benefit and our side we are not giving that. So you get this person is double dealing, she is coming at our place and also going to the other place. And in so doing she gets mixed up with so many different drugs. You know like in KENWA, it is the drugs that will make you get additional support, so the person will offer to take their drugs again just to get their incentives (Nurse)

Another consumption strategy is to cut down on food intake or reduce the number of meals per day. Narratives showed that poor urban PLWHA, faced with unstable income streams, deny themselves a host of important things including food, which are seen as luxuries:

VC05: It is like this, when I get work like for 2 weeks or 1 month and get some money, then I have to use it very sparingly and keep some amount on the side to use in the future when the works become unavailable. So you have to be frugal and deny yourself some things like food...you just eat once a day. (man aged 52)

Poor nutrition is detrimental to the health and wellbeing of PLWHA as good nutrition is critical for prolonging productive life. Nutrition is an important dimension in the prevention, treatment and care of HIV/AIDS. (Piwoz and Preble 2000).

Mobility strategies used by urban poor PLWHA include moving to cheaper house and sending children to relatives' and friends' homes. Some PLWHA experience a sharp drop in income, which might force them to move out of their original home to cheaper housing:

VC11: My living arrangements have changed. Initially, even if was in the *kijiji* (slum) I used to live in a better house with electricity and had things like TV. But now I stay in a house that

does not even have electricity and I also sold the things I had like TV to meet other needs like school fees for the children.(woman aged 46)

Others send some of their members to the extended family:

VC03: I am just struggling. I have had to take my children at our home in the village, they stay with my dad and my brother.(woman aged 36)

The extended family has been assumed to absorb orphans, but there is evidence to the effect that this communal support system has been overwhelmed and is less able to cope with the magnitude (Barnett and Whiteside 2002; Nyambedha, Wandibba, and Aagaard-Hansen 2003)

#### **4.5. Conclusion**

PLWHA in the slums live in poor conditions. The relationship between HIV/AIDS and poverty is complex and bi-directional. On the one hand poor living conditions in the slums increases people's biological and social susceptibility to HIV/AIDS. Biologically, diminished immunity owing to malnutrition, which is prevalent amongst the urban poor, increases the chances of infection to HIV and progression to full-blown AIDS once infected. Socially, poor living conditions force people to adopt behaviour that is risky for HIV infection such as survival and/or commercial sex. Infection with HIV/AIDS also increases people's vulnerability to chronic poverty. HIV/AIDS diminishes productivity among PLWHA, mainly as a result frequent opportunistic infections and loss of assets or savings due to high expenditure on health care. In addition, access to adequate food is also undermined due to diminished incomes and savings. The effect of this is more pronounced in poor urban settings where the ability to put food on the table depends on peoples' purchasing power, rather than subsistence production. People are more likely to buy poor quality and less nutritious foods as incomes shrink. There is a vicious cycle relationship between HIV/AIDS, poverty and food insecurity.

Coping strategies for HIV/AIDS can lead to people making forced choices that may have negative long term consequences. It is questionable whether the constant struggle for survival in people's daily lives can be termed as coping. In fact, these strategies such as selling productive assets, skipping meals, survival sex, looking for multiple

sources of food aid can undermine their own well-being and future survival. These responses may be seen as coping for now, but their costs will be paid further down the line in the long run. What is important is recognition that these short term strategies, aiming to give some immediate relief, often have negative long term effects. For example, if children are withdrawn from school or taken to relatives for care, this may help lessen the strain on the sending household, but the opportunity cost of them not attending school are massive such as loss in human capital accumulation and productivity for the future.

The discourse of “coping mechanisms” has as implicit assumption of presence of some resources of some kind, (material or non-material) at their disposal that need strengthening. But this may only work for a few households that have assets and resources and neglect the poorest. Many of the mitigation strategies by civil society and state actors have focused on provision of food aid and hand-outs. Despite the important role played by these strategies in ameliorating immediate HIV/AIDS related shocks, they do little in restoring livelihood capacity.

The chapters that follow examine how this socio-economic context shapes self-identity (Chapter 5) and subsequent sexual behaviour (Chapters 6 and 7) and fertility intentions and contraceptive use (Chapter 8).

## **Chapter 5: Becoming HIV Positive: Self-identity**

### **5.1. Introduction:**

Living with HIV/AIDS requires an individual to adjust to life with a new a chronic condition. Studies show that knowledge of infection with HIV/AIDS is disruptive and hence PLWHA strive to return to normalcy after a period of initial turmoil (Baumgartner 2007; Carricaburu and Pierret 1995; Kralik 2002). This body of evidence shows that PLWHA undergo a transition to a new sense of self-identity as they incorporate HIV/AIDS into their lives and as they interact with others (Russell and Seeley 2010). Emerging evidence shows that perceptions of self-identity and lived experience have a bearing on sexual and reproductive behaviour of PLWHA (Bartos and McDonald 2000). Sexual and reproductive behaviour is reflective of some PLWHA's quests for normalcy after disruption to their identity (Smith and Mbakwem 2010). This chapter examines the process of identity disruption and reconstruction among PLWHA and how it might affect their SRH behaviour. Since self-identity is an experiential process, the data presented in the chapter are predominantly qualitative, although some descriptive statistics will be used. The chapter contributes to answering the first research question: How do men and women living with HIV/AIDS perceive their own sense of self and life prospects as related to sexual and reproductive outcomes in the current era of treatment?

Self-identity can be defined as "internal thinking of what it is being a person... [as] shaped by external or social interactions with others (Kralik, Koch and Eastwood 2003,13). As such PLWHA might ask themselves: "who am I now that I have HIV/AIDS?" Baumgartner (2007, 919). While an HIV positive status is confirmed through the administration of the antibody HIV test, the process of self-identifying as an HIV positive person is much more complex.

The onset of illness, as life-threatening as HIV/AIDS, constitutes a threat not only to the body but also to the issues of self-identity (e.g Bury 1982; Ciambone 2001; Williams 2000). For example illness might trigger a status change from well person to patient (Kleinman, Eisenberg, and Good 1988). A diagnosis with HIV/AIDS, a potentially fatal condition for which there is no cure, can profoundly alter individuals'

sense of self-identity. In a bid to make sense of their illness people usually draw on a wide range of discourses emanating from, among others, folk knowledge of illness, biomedicine, alternative medicine and mass media (Lupton 2003).

The organising theoretical construct in sociological and anthropological literature on chronic illness and identity has been the concept of biographical disruption (Baumgartner 2007; Carricaburu and Pierret 1995; Williams 2000). First conceived by Bury, biographical disruption generally views chronic illness as a disruptive experience to an individual's everyday life and social relations (Bury 1982). It entails at least three things: One, disruption of one's former behaviour or assumptions (Ciambrone 2003). Two, changes in one's perception of self. In times of chronic illness one's biography; the "who am I at any point along biographical time line?" (Corbin and Strauss 1987: 253) is re-examined. Three, mobilizing helpful networks and other resources to help repair the disrupted biography to regain personal integrity in society (Carricaburu and Pierret 1995; Ciambrone 2003).

Research on chronic illness experience have mainly been focused on how living conditions and socio-cultural context affect self-identity, while overlooking structural factors such as medical, scientific and political contexts (Pierret 2007). First, the key medical and scientific advance that has relevance for this study is ART, which has transformed HIV/AIDS from an imminent death sentence into a manageable chronic illness. Recent advances in HIV medications have improved health and life expectancy of PLWHA and shifted their notions on self-identity (Pierret 2007; Russell and Seeley 2010; Seeley and Russell 2010). Secondly, in a review of the literature on biographical disruption, Williams (2000, 62) suggested that more attention should be placed on the timing, context and circumstances in which illnesses are "normalised or problematized" and identities are "threatened or affirmed".

This chapter is structured along the three main phases of the process of self-identity transition, using the biographical disruption framework. Section 5.2 deals with the first transition process namely, HIV diagnosis and immediate reactions to the diagnosis. The second section (5.3) examines the second phase of the transition process namely disclosure and managing the information flow about their condition. The final section (5.4) explores the resources mobilized by PLWHA to manage their condition, repair

their “spoiled” identity if at all and generally live positively. It should be pointed out at the outset that this transition is not linear, but rather an iterative, back and forth and even recurring and on-going process throughout somebody’s life.

## **5.2. HIV Diagnosis: Testing and reactions**

Undergoing a test and subsequent diagnosis marks the first step of incorporating HIV/AIDS into PLWHA’s identity (Baumgartner and David 2009). Confirmation of an HIV status is done through the antibody test, which detects the presence of the antibodies to the HIV virus in an individual’s blood (Whelehan 2006). Generally it takes some time, usually between one and three months from infection before HIV antibodies become detectable in blood (Hecht et al. 2002; Whelehan 2006). There are different testing models that have been adopted in different countries. The WHO guidelines of Voluntary Counselling and Testing (VCT), still holds sway, although routine provider-initiated HIV testing and counselling (PITC) and self-testing are gradually becoming available in SSA (Gersovitz 2011). The VCT framework advocates for self-initiated testing where individuals voluntarily seek and accept an HIV test. PITC is provider-initiated testing of expectant mothers undergoing antenatal care or for diagnostic testing of people with HIV-related symptoms (De Cock , Marum, and Mbori-Ngacha 2003; Hardon et al. 2011). Regardless of which testing model prevails, the three norms of HIV testing are informed consent, confidentiality and pre- and post-counselling (UNAIDS/WHO 2004). HIV testing is seen as part of a comprehensive package of universal prevention, treatment and care, not least because it is a gateway to treatment and provision of prevention messages (UNAIDS 2008).

Most studies on HIV testing in SSA have mainly concentrated on its benefits, costs and barriers (Kaler and Watkins 2010; Gersovitz 2011). There is a dearth of information on its process, circumstances and people’s views of undergoing an HIV test. Information on the experience of testing is necessary to understand how HIV testing guidelines are implemented in practice for policy and program improvement of HIV testing services (Obermeyer and Osborn 2007). Moreover, the context and circumstances under which a person gets tested might have a bearing on subsequent (SRH) behaviour. Evidence shows that VCT is associated with adoption of preventive sexual behaviour (Bunnell et al. 2006; Sweat et al. 2000). This section presents data on the experience of PLWHA in this study who underwent an HIV test, highlighting the

similarities and differences in their experience of testing and associated counselling. It is divided into two parts: circumstances of HIV counselling and testing and immediate reactions to the diagnosis.

### *5.2.1. Reasons and circumstances of testing*

HIV testing is done for different reasons and purposes and under varying circumstances. Respondents gave different reasons and circumstances that necessitated their undergoing an HIV test to include: Frequent illness, routine antenatal screening, provider initiated diagnostic testing, partner suggestion, own volition to know status, and tested without knowledge.

#### Frequent illness or symptoms

Narratives show that most respondents (25/41) were tested only when they became ill and sought contact with the health care system. Most respondents reported that they went for the test because they had HIV-like symptoms or were experiencing frequent illnesses. Some sought health care that culminated into an HIV test because of the symptoms that are commonly associated with HIV such as diarrhoea, fever, headaches, body wasting, and mouth sores:

INTE: How did you discover that you were HIV positive?

KC01: It was in June 2007. I suspected myself after a series of illness episodes and then decided to go for the HIV test. I used to get ill quite frequently. I used to feel exhausted, could not bath with cold water. I could feel very cold in the mornings and in the evenings. There were also sores in my mouth. But I was not bedridden as such.(Widower aged 41).

INTE: How did you come to know your status?

VC03: I came to learn about it in December 2006. I used to suffer from fatigue, often feeling like I was running out of energy. I was also suffering from frequent bouts of malaria, headaches, fever, joint pains and feeling nauseated. That is why I went for medical advice (cohabiting woman aged 36).

In some cases an HIV test was sought as an emergency following a severe, usually recurrent illness. Some of the common illnesses reported are the clinical symptoms of HIV/AIDS in its advanced form such as Tuberculosis (TB). A common theme that runs across respondents' accounts was that the diagnosis tended to be done during a period of health crisis. In which case respondents were admitted to hospital or had to



undergo an HIV test to determine a way forward in the treatment of their illness. The HIV test was, for the most part, health care provider-initiated:

INTE: How long ago was it that you discovered that you were HIV positive?

VA15: It was eight years ago. I used to be sickly with TB. I was then taken to the hospital and tested for HIV. I had suffered from TB of the spinal cord, but I did not understand what all this meant. But when I was tested I was found to be HIV positive. (Divorced woman aged 45).

In such conditions of medical emergency both pre-test counselling by the provider and informed consent by the client appears to be overlooked according to some respondents:

INTE: Please explain to me what transpired during the test.

VA15: On the day I was tested I was too sick, I could not understand a thing... I was like losing my memory. I did not even realize when the doctor took blood out of my hand. It was not until the following day that the doctor came and told me that I had tested positive for HIV and that I would be admitted at the hospital. (Divorced woman aged 45)

Evidence suggests that those infected with HIV/AIDS are tested relatively late in the course of their illness, more often with the presentation of symptoms of AIDS (De Cock, Marum, and Mbori-Ngacha 2003; Dixon-Mueller 2007; Gersovitz 2011). Late diagnosis undermines timely treatment and prevention interventions. In an effort to increase early testing, in the context of treatment, provider initiated routine testing in health care facilities has been recommended by the WHO and UNAIDS (WHO/UNAIDS 2007). However, provider-initiated testing has long raised concerns about ensuring clients' right to consent and confidentiality and effective counselling (Yeatman 2007). Some respondents reported violation of their rights to adequate counselling before undergoing the test.

INTE: What exactly did he [doctor] tell you before testing?

VA13: No, he didn't tell me anything. I was tested everything, urine and blood but not told anything. Just a letter to Dr. [name withheld] for further action

INTE: And then you took the results to Dr. [name withheld]

VA13: Yes.

INTE: And then what did he tell you?

VA13: He told me that "now you are like this". He told me that I had the HIV virus.

INTE: Did he counsel you before he told you the results?

VA13: He did not counsel me or tell me anything before. He just told me like that. (widower

aged 46)

Lack of counselling prior to or after HIV testing is not only a violation of an individual's rights, but is also a lost opportunity for behavioural change information to avoid future HIV infection, and if already infected, prevent transmission of the HIV virus to others. The effect of HIV counselling in reducing subsequent risky sexual behaviour has been demonstrated by various studies in SSA (Wanyenze et al. 2006; Weinhardt et al. 1999).

### Routine antenatal testing

Routine testing of expectant mothers during antenatal care is another HIV testing model promoted by the WHO. Kenyan health care providers routinely test all pregnant women who seek antenatal care services (NASCO 2009). This is meant to screen mothers who could then receive prevention of mother-to-child transmission (PMTCT) services to prevent vertical transmission of HIV/AIDS (NASCO 2009). A number (8/23) of women respondents came to learn of their HIV status when they went for antenatal care:

INTE: Let's now talk about how you learnt of your HIV Status.

VB06: It was in 2007 when I was pregnant with my last child. It [pregnancy] was two months old. I had gone to confirm if indeed I was pregnant at *matter* hospital. They tested my urine and confirmed that I was pregnant. Then they asked me if I could go to the *VCT* and I agreed. The results turned out to be HIV positive. (Cohabiting woman, aged 35)

Testing during antenatal care was one of the routes by which spouses came to know their HIV status. Women who tested positive were sometimes asked to bring their spouses to the clinic for HIV testing and PMTCT service guidelines in Kenya call for partner involvement in the services (NASCO 2009). This is one of the ways that disclosure of HIV status to significant others can occur, though the outcome of the disclosure is not always positive.

INTE: How far back was it when you realized that you were HIV positive?

KA02: It was when I was pregnant with my second child and it was mandatory for me to take an HIV test. That is when I was found to have the virus and was told to go and bring my husband. I brought him along and we went and got tested together; I was confirmed to be positive while he turned out to be negative. That is when he started discriminating against me and stressing me a lot (Separated woman, aged 24)

Similar to when testing was done during conditions of health concerns or severe illness, it is not very clear, from some women's accounts, that informed consent was sought and given during routine antenatal testing. Other women, nonetheless, reported that they were asked for their consent and then accepted the HIV test. The following excerpts illustrate the two contrasting experiences in as far as informed consent is concerned during antenatal testing:

INTE: How did you come to know that you were HIV positive?

VA14: I was never sick; I just went for antenatal care when I was pregnant and was tested at that time.

INTE: What did the doctor tell you before?

VA14: So when the doctor took my blood is when I knew I had it [HIV].

INTE: Did he just take your blood? Or he asked you... telling you he was going to test for what?

VA14: You know when we went there we were told it was a must that everybody knows their status, and then he took the blood.(Never married woman aged 22)

INTE: Please tell me the process you underwent at the hospital before you took the test?

KA02: Being pregnant we were advised that it was good and important to take the [HIV] test. I sat and thought about it and made the decision to take it and know my status. Before that we were counselled.(separated woman, aged 24)

Routine testing of antenatal attendees is meant to identify HIV positive would be mothers so that they receive PMTCT to prevent vertical transmission of HIV. There are nearly 1.4 million women annually who require PMTCT services globally (WHO/UNAIDS/UNICEF 2010). Most new cases of vertical transmission occur in SSA despite increasing availability of PMTCT. Factors constraining its effectiveness include poor adherence to components of PMTCT, including failure of women to collect test results and failure to initiate ART appropriately (Bancheno, Mwanyumba, and Mareverwa 2010) and poor doctor-patient relationships (Barry et al. 2012). As the narratives show, not all women undertake the test with informed consent. A study in Tanzania showed that about half (49%) of women attending ANC clinics preferred to be given the drugs for preventing vertical transmission rather than learning their HIV status (Urassa et al. 2005).

### Self-initiated voluntary testing

Self-initiated voluntary testing is the hallmark of the voluntary counselling and testing (VCT) model widely promoted by UNAIDS and WHO (UNAIDS/WHO 2004). In this approach the testing is done at the initiative of the individual to be tested, usually by voluntarily visiting a VCT centre (Marum, Taegtmeier, and Chebet 2006). It primarily targets asymptomatic persons. This protocol has been adopted by governmental and non-governmental testing sites in SSA (Gersovitz 2011). In Kenya, some private practitioners and community based organisations have adopted it and even opened non-registered VCT sites (Marum, Taegtmeier, and Chebet 2006). The VCT campaign in Kenya is promoted under the banner: “*Jua hali yako, tembelea kituo*” (Know your status, visit a VCT) in the media and billboards. Some respondents reported self-initiated voluntary testing without an illness:

INTE Please describe the process you went through before the test

KC03: I just used to hear people talk about AIDS. Then another girl told me – let’s go so that you can also now your status. I told her that I didn’t think I was ill. After testing the doctor came after 15 minutes and told me that I had it [HIV]. So I told the doctor- but my body is okay, I feel okay, how come? He told me it’s all in the blood. So I said - no problem, I will just take the drugs, *nitado?* (slang for *What else would I do?*) [Married woman aged 26]

Other respondents reported cues that made them suspect themselves of having contracted HIV, such as having had unprotected sex. Some respondents began to question their HIV status when their former or current sexual partners died of HIV-related conditions or suspicious circumstances. Others may want to know their status if their spouses become sickly or start experiencing recurrent sickness that are associated with HIV/AIDS.

INTE: When did you get to know that you were HIV positive?

VC11: After my first wife died in 2005, I thought on my own volition to go and get tested just in case I had the [HIV] virus... because you know nowadays you could be sick and fail to know what you are suffering from. Then later on I sweet-talked my other wife to also go and get tested and she agreed and we got tested.(married man aged 46)

INTE: What made you go for the test? Were you falling ill before you decided to get tested or what?

KA01: I was having a lot of stress and even lost weight. I just saw that my body was not the same as before so I suspected myself. That is what made to go to VCT to be tested. When I was tested, it was found that I was HIV positive. (Divorced man, aged 36)

Yet other respondents got prompts and recommendation to go for the HIV test from other people. Most often the suggestion to test for HIV comes from spouses who either had gone for the test themselves or were suspicious of their partners' risky sexual behaviour. Other recommendation comes from outside the household to include friends, relatives and even outreach community health workers. Suggestions to test for HIV were usually prompted by HIV-related symptoms:

INTE: How did you come to learn of your HIV status?

VC01: I was tested in 2008 in February. My wife said that we should go for testing because it was free of charge, so that we can know our status instead of living with fear. It was good to know if you are sick so that you can take medication instead of waiting until you are too sick. (Married man aged 42)

KB06: I used to fall sick. I could get so sick that even going for a call of nature I used support myself on the walls. So I went to one woman who was a community health worker, told her that I was sick, but I did not have a way forward. She is called [name withheld] from Kariobangi. She wrote me a note on a piece of paper and asked me to go to Catholic clinic to be tested. For sure I went and got tested, but before this, I got counselled. But when I saw the results, I came back crying and even became more sick. (Cohabiting woman, aged 35)

Narratives of those who went on their own volition to the VCT almost exclusively paint a picture of receiving counselling prior to testing. Some respondents expressed satisfaction with their VCT experience.

(VB10): I found another doctor who counselled me very well and I agreed to go for the VCT. When the doctor counselled me, I got encouraged and well prepared for the outcome of the VCT. I was tested and found to be positive. The result did not surprise me at all because she [doctor] had made me see how life would continue even if I was found to be positive. So when they confirmed it [HIV] I just said it was fine. As long as there are drugs I would just continue with drugs but I did not worry much. The fear I had initially had gone after being counselled well. (Married man aged 43)

The contents of HIV counselling revolve around general information about the HIV condition, the meaning of a test result, preparing the client to receive the test, and how to conduct themselves thereafter, whether they test positive or negative. Some of the

information given during counselling included living with HIV and SRH matters. The health care provider's narrative gives us an idea of the nature of information that is given during counselling sessions, which was collaborated by PLWHA:

INTE: What issues are covered when counselling PLWHA?

VNS1: During counselling we talk about opportunistic diseases; disclosure; nutrition; sexual and reproductive issues where we talk of dual protection and, interventions required for those who want to get pregnant.(Nurse)

INTE: Were you counselled before taking the test?

VC03: The nurse counselled me and told me about the availability of drugs that people with HIV were using. She told me that if I took the drugs well and avoided frequent sexual contact with men, I would live for long, and sure enough I have lived all this while thanks to that. She also advised me to always use condoms.(Cohabiting woman aged 36)

Testing, even when self-initiated, is not an autonomous individual voluntary decision; it is often done in response to some trigger such as illness or prompts from healthcare workers and significant others. That is, arguably, one of the main reasons why individual-based VCT model has not raised the level of testing in SSA as nearly 80% of HIV infected adults in SSA are unaware of their status despite VCT promotion (Granich et al. 2009).

#### Tested without consent

The issue of people being tested without their knowledge is a minefield of controversy. The proponents and opponents of universal routine testing both invoke the "right", the former emphasising the right of person to be tested, while the later flagging up the right of the public not to be infected by the person unaware of his HIV status (Gersovitz 2011). This debate is beyond the scope of this study, although testing people without their knowledge has been reported in Kenya (De Cock , Marum, and Mbori-Ngacha 2003), something that is in contravention of the National testing protocol. The national testing guidelines state that:

"prior to receiving an HIV test, the health care provider will explain the procedure and the reasons for requesting the test to the client or patient. Upon the recommendation of the health care provider, if the client or patient agrees to learn their HIV status s/he will receive an HIV test and will be informed of their results"(NAS COP 2008, 4).

However, there is evidence that not all medical practice adheres to the guidelines. For example, De Cock, Marum, and Mbori-Ngacha (2003, 1848) observe that “anecdotal reports suggest patients are sometimes tested without their knowledge” and express permission. Some respondents in this study reported that they were tested without their knowledge:

INTE: Who advised you to go for HIV testing?

KB07: Nobody did. In fact the person who tested me first at [name of clinic withheld] did not even inform me that he was carrying out an HIV test. He just came and told me that I was HIV positive. He asked that I be tested for TB, which was also found to be positive. I was referred to the *Kariobangi* City Council health centre I was tested again and they confirmed the results. (Widower aged 60)

INTE: Can you please tell me how you came to know that you were HIV positive?

VA08: It was in May 2002. I was pregnant when I got tested at [name of clinic withheld]. But they did not tell me. At that time things were so bad, not as they are right now. These days you are called and counselled well before being told your status. Those who tested me did not tell me anything. They just talked in English thinking that I did not hear what they said, but I did. (widow, aged 36)

HIV testing in Kenya follows both the VCT and PITC models. VCT was introduced in SSA in the 1990s with international guidelines developed by UNAIDS. (Hardon et al. 2011). However, despite promotional efforts uptake of VCT is relatively low and only 1/5 of Kenyan adults get tested in VCT centres (NASCO 2007). This means that most infected people get tested late when the disease is advanced. In a bid to improve testing globally WHO and UNADS recommended PITC, with opt-out guidelines (WHO/UNAIDS 2007). Whether testing is done under VCT or PITC the most important issue is counselling. Counselling is a core element of international and local testing protocol in Kenya (NASCO 2008, 2010). These guidelines propose pre- and post- test counselling. However, as the narratives show, these protocols are not always adhered to in practice.

Counselling is an opportunity to provide up to date information on HIV prevention and transmission so that people are educated on safe behaviour whether or not they test negative or positive. Evidence suggests that HIV testing and counselling leads to adoption of safer sexual behaviour (Painter 2001). Pre-test counselling is meant to

provide the individual with sufficient information to help them make an informed choice to undergo an HIV test. Kenyan testing guidelines state that pre-test counselling may be provided to an individual, couple or group, but should be personalised in all cases (NASCO 2008). A positive test can provoke intense distress, so counselling should help to prepare people for the results and identify sources of medical and social support. The remainder of this section examines different responses to the test reported by respondents in this study.

### *5.2.2. Reactions to Diagnosis: Initial disruptions*

Being diagnosed with HIV/AIDS – a potentially life threatening event – elicits a myriad of reactions, both negative and positive such as shock or relief (Baumgartner 2007; Baumgartner and David 2009). Despite the availability of treatment (ART) there is no cure for HIV/AIDS and people diagnosed with HIV/AIDS have to come to terms with a potentially fatal condition. Narratives show that many struggled initially as they grappled with the meaning of a positive test and its implication for their own life and that of their family, friends and society at large. Their biographies were initially disrupted and needed reworking to accommodate HIV/AIDS. Five themes were identified in my analysis of the IDIs to describe typical reactions in the aftermath of an HIV-positive diagnosis: fear, denial, distress, relief and bravery. These initial emotions evolved and changed with time.

#### Fear

A HIV positive diagnosis produced worry and fear in many respondents. The immediate fear was that an HIV status represented an imminent death, the availability of ART notwithstanding, which for many meant leaving behind orphaned children. The worry of leaving behind children was voiced more commonly by women respondents, perhaps ascribing to their gender role of caring and good mothers (Wilson 2007). Other respondents were worried about the negative reactions that they would receive from family, friends and community. Others were worried about how they will inform their family and significant others about their conditions. Others thought this was their “doomsday”, a moment when their whole life came crashing to a halt. The following quotes are illustrative:

INTE: What fears did you have then?



(KA015): I was afraid of death because I saw people dying when they got this disease. I knew I was going to die even if I took the [HIV] drugs. I thought that I would die within three years even if I took ART... you know... I was born alone, my husband is dead and I don't have any one whom I would leave my children with. That was what was worrying me (widow, aged 46)

INTE: How did you feel at that point?

(KC04): The only stress I had was how I would tell this person, the owner of the house... my husband about it. I was thinking now how would I inform my husband?... how will I start?. You don't know if you tell him, he might beat you up, he might chase you away or he might even kill you [thinking] that you are the one who infected him.(woman aged 27)

Fears were largely driven by the fact that HIV was seen as a death sentence and the thought of their life coming to an imminent end was a distressing prospect. Accepting HIV as a chronic condition and maintain hope in ART was a challenge for some (Barroso and Powell-Cope 2000).

### Denial

Feelings related to denial were some common reactions to an HIV diagnosis. Some, especially married women, were surprised to test positive because they perceived themselves to be at low risk of infection because they had not engaged in behaviour considered risky for HIV infection. Some did not believe it when their health care provider delivered a positive result and sought another test elsewhere. For some, it meant refusing the results of an HIV positive test altogether. Others were in denial to the extent of being fatalistic, suicidal and avoiding support groups:

INTE: Please tell me how you felt when you realized that you were HIV positive?

VA12: when I was tested, it was confirmed I was HIV+ but I did not accept it. The doctor told me about medication, I said: "get lost! You are lying"! - I was angry with him (laughter) (separated woman aged 25)

INTE: How exactly did you feel?

KA17: I thought about killing myself. I wanted to kill my children but it was just that they were still very young. That thing is very painful that I even don't want to think about it. I don't even want be going to the NGOs to read those things about HIV/AIDS because I know I have it. I just want to stay "*bubu*" (dumb) style because if it is death, I know I will die.(Widow aged 30)

Denial was especially common in those who did not have symptoms. Narratives suggest that suspecting that one was HIV positive, often from tell-tale symptoms alleviated feelings of distress and denial. Denial and fatalism mirror similar experiences in the literature termed “shattered meanings”(Barroso and Powell-Cope 2000), where HIV represented an insurmountable and massive loss.

### Distress

Some respondents were consumed with feelings of distress, bitterness and vengefulness. Women and men developed vengeful feelings towards their spouses whom they suspected to have infected them with the HIV virus. Others lost the will to live and just awaited imminent death:

INTE: How did you react when the doctor informed you?

VC09: When he told me I broke down and cried for long... I thought that it must be that my husband had had extra marital affairs and therefore was the one who infected me. I felt hatred towards him, and though we continued to stay together, I swore not to tell him. I felt a lot of resentment towards him.(woman aged 41)

INTE: What were your reactions when you learnt that you were HIV positive?

VA08: From there I went home and got really stressed; I was sick, very sick for a month. I was just waiting to die just like I had heard them say, but surprisingly I woke up [alive] every morning for a whole month.(man, aged 35)

Diagnosis with HIV is bound to create emotional distress due to stigma and social disapproval that it elicits (Mahajan et al. 2008; Stutterheim et al. 2011). Some respondents especially women loathed themselves because of the fear that they would be associated with prostitutes, a highly marginalised and stigmatised group (5.3.3).

### Relief

Some respondents reported being relieved after diagnosis. The feeling of relief was occasioned by the long illness that they had endured, but did not know its source before. Such people felt a gush of relief in that now at least they came to know the cause of their recurrent ailments and its appropriate remedy. Others, despite initial denial, accepted their condition, usually after sessions of post-testing counselling. Some of them rationalised that HIV/AIDS was just like any other illness and that there was nothing much they could do to reverse the condition anyway.

INTE: How did you feel when you realized that you were HIV positive?

KB06: For me, given that I had suffered for a long time with this illness (TB) and was not responding to any treatment, I used to look at HIV infected people and envy them because I would see their conditions improving while mine never got any better. At times I wished I had the HIV virus than the TB (laughs). So when I got tested, I felt relieved since I would get the drugs and get better since I had suffered for so long. And my condition has improved a little bit since being put on treatment.(man, aged 35)

VC05: I was scared and I feared at first, but later after counselling I accepted myself and said that it was a disease like any other and there was nothing I could do about it. You know there is nothing you can do about sickness.(Man, aged 52)

For these people, receiving information about their HIV status was a relief, in part because they expected to get enrolled on ART, which would extend their lives.

#### Brave and masculinity script reactions

Putting on a brave face in the face of a positive result is a reaction that is rarely reported in the few studies that have documented diagnosis reactions. These studies (eg Baumgartner 2007; Ciambone 2003) report traumatic and depressing reactions to an HIV diagnosis. Some male respondents displayed “masculinity scripts”, a strong- and tough-guy script (Mahalik, Good, and Englar-Carlson 2003). Some men stayed true to these masculine scripts by appearing to be brave, fearless, and emotionless upon testing HIV positive. The conversations below moderated by male and female interviewers respectively illustrate these feelings:

INTE: Now tell me your reactions when you found out that you were HIV positive?

KC09: I wasn't angry because I am a man. Again it's not bad to inform a man something like this. It has to be diagnosed, and on you [man] for that matter. Were you not moving out with women? You are a man, so you cannot say, No, I don't have this disease and yet you have been having sex with women.

INTE: Implying you used to move with women

KC09: Yes, as a man you can't just stay *ndeee!* (staying idle without having sex).(Widower, aged 55)

INTE: How did feel at that point?

KA11: I did not feel bad. I felt my body was calm. I said to myself if a problem has a risen...you have to be strong and face it. I only wondered how and why but said to myself now

that I have it, I will face it like a man. You cannot run away from problems...you have to face them as a man. (Widower aged 52).

Respondents reacted in a variety of ways to their HIV diagnosis. Many experienced, shock, distress, fear, denial and fatalism suggesting initial biographical disruption. Similar responses have been observed in studies done in the global North (Baumgartner 2007; Baumgartner and David 2009; Ciambrone 2003). Although they were aware of treatment for HIV, the fear of imminent death was omnipresent for many. It took some time for many to come to terms with living with the condition. Others reported that they were calm, brave and relieved to have the diagnosis. These were respondents who might have suspected themselves following frequent illness or death of a significant other from HIV/AIDS-related symptoms. It should be noted that some respondents might be describing emotions that they had many years ago – so liable to be affected by some kind of a reporting bias.

Diagnosis was, therefore, the first step of HIV- identity formation, similar to what Barroso and Powell-Cope (2000, 343) call finding meaning in HIV/AIDS, which involves the “assimilation of the diagnosis into one’s life, one’s view of the self, and one’s worldview”. The section that follows explores how PLWHA managed the information flow about their diagnosis.

### **5.3. HIV status disclosure: To tell or not to tell.**

“Surprisingly little is known about the actual processes and outcomes of disclosure in different personal situations and socioeconomic and cultural environments” (Dixon-Mueller 2007, 291)

Managing the information flow on the HIV/AIDS is the next central phase of living with HIV (Carricaburu and Pierret 1995). Disclosure of HIV status is central to HIV/AIDS discourses in the literature; it has implications for both the individual and public health. Studies have established advantages and disadvantages associated with HIV status disclosure. On the one hand disclosure has been associated with safer sex, treatment adherence and social support provision (Gielen et al. 2000; Izugbara and Wekesa 2011; Stutterheim et al. 2011). On the other hand disclosure has been found to elicit stigmatizing attributes such as discrimination, rejection and other negative reactions (Carricaburu and Pierret 1995; Anderson and Doyal 2004; Paxton 2002). Despite its importance, evidence about when and how disclosure is done and its

consequences remain largely unanswered (Chaudoir, Fisher, and Simoni 2011). This information is needed to help devise effective disclosure strategies for PLWHA.

The majority (90%) of PLWHA in this study reported that they had disclosed their HIV status to another person apart from health care providers and researchers. Female respondents were significantly more likely to have reported disclosure than men (93% versus 86%, respectively,  $p=0.004$ ). Healthcare providers almost without exception suggested that women tend to disclose more than men:

INTE: According to your experience would you say that women or men are better at disclosing?

VNS1: According to me...the analysis I have done, women are good in disclosing. I would rather put it that women tend to open up more and share their issues more. But men usually keep it to themselves. But women so long as they find someone friendly, they will open up and share their problems (Nurse).

The high level of disclosure may be a reflection of our sample since we recruited PLWHA known to community healthcare workers and sometimes their peers. Other studies among PLWHA, nonetheless, similarly report high rates of disclosure. For example 88% of PLWHA in the US had at least disclosed their status to a friend or family member (Kalichman et al. 2003) and 95% of PLWHA had disclosed to someone in Uganda (Ssali et al. 2010).

Narratives show that disclosure of status is not a one-off event, but rather a process. This section looks at the process of disclosure, highlighting reasons for disclosure and nondisclosure and some of the consequences of disclosure.

### *5.3.1. The process of disclosure*

The process of disclosure is very complex. Two theories have been proposed by Serovich (2001) to explain disclosure of HIV status: Disease Progression Theory and Consequences Theory. The former suggests that people disclose their status when their HIV condition advances, with potential tell-tale signs (e.g. wasting or rashes) and possibly hospitalisation that make non-disclosure almost impossible. In the latter, a decision to disclose is arrived at after weighing the benefits against the costs (Emlet 2008). However, these theories have been criticised for focusing on the end point of disclosure and neglecting the consequences of disclosure – both beneficial and detrimental (Chaudoir, Fisher, and Simoni 2011). And indeed my data shows that after

weighing the beneficial and detrimental consequences, respondents decided between full disclosure, selective disclosure or non-disclosure:

INTE: How difficult or easy was it to tell people about your status?

KA11: I wasn't afraid of telling people. My only worry was if they could keep it a secret. So I disclosed my status cautiously. Again if I got bedridden how will they know I was suffering from HIV/AIDS so that they could help accordingly? That is what made me to tell some selected people about my status. (Widower aged 54)

Deciding to disclose was not easy, and many took time before being able to disclose. For others, disclosure was a process that begins with non-disclosure whilst people can hide their status, but moves into forced disclosure once this is no longer an option. Disease progression theory suggests that individuals are bound to disclose their HIV condition because the disease advances to a point where it becomes no longer possible to keep it a secret (Emlet 2008).

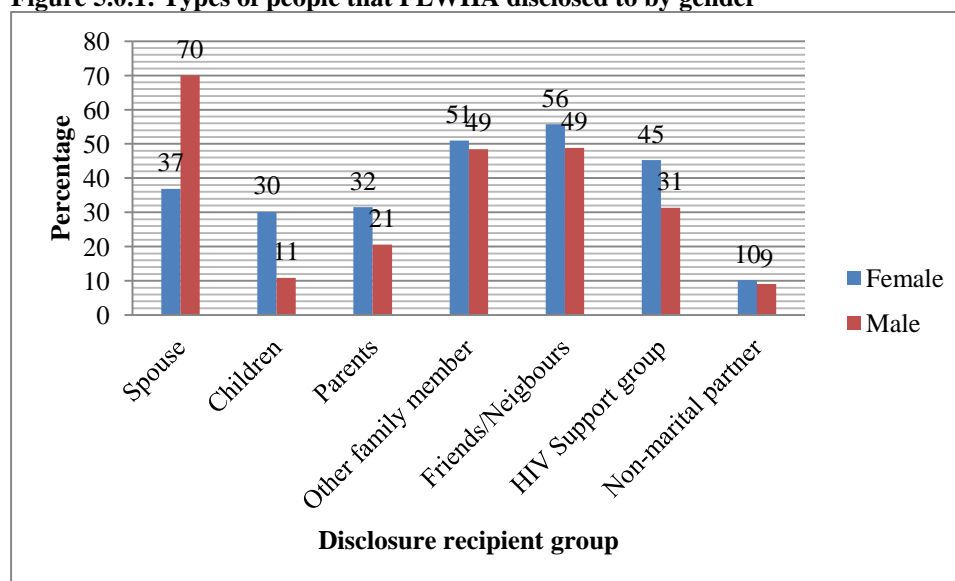
INTE: How easy or difficult was it to disclose your status to someone?

KB06: I kept it a secret for long...it took me quite some time, years, like for four years, before I could gather the courage to do it. There was no point of keeping the secret anymore. After all my body had betrayed me. (Man, aged 35)

INTE: So why did you decide to tell your mother?

KA02: I told her (mother) only because I suffered from "herpes zoster" and got paralyzed at the back and my mother had to come and assist me. She asked me to tell her the truth since she had a friend who had a similar condition and had been told that such a condition only affects people who had HIV. So I told her tell her the truth. If it was not for that condition, I would not have told her of my HIV status.(separated woman aged 24).

Those who decided to disclose faced another level of decision making; who to tell and who not to tell, and how to go about it. Many disclosed to close family members, friends and confidants, and HIV support group members. Women were less likely to disclose to their spouses, but more likely to other relatives, friends and HIV support groups than men (5.0.1). This might suggest that women might fear negative consequences of disclosing to husbands such as abandonment (5.3.3). Very few disclosed to non-marital sexual partners and religious group members (Figure 5.0.1). Evidence from other studies shows that PLWHA are more likely to disclose to close family members, friends and regular sexual partners than to co-workers and casual sexual partners (Chaudoir, Fisher, and Simoni 2011; Peretti-Watel et al. 2006).

**Figure 5.0.1: Types of people that PLWHA disclosed to by gender**

Once PLWHA decide to disclose how do they communicate this sensitive information? A few disclosed it straight away in a matter of fact way. But many did so in subtle and non-direct ways such as scenario building as the excerpts below show:

INTE: What mechanism did you use to tell these people about your status?

KA11: Like that friend of mine, I asked him: "what kind of problems they were facing as doctors when handling patients. How can you help somebody who doesn't have HIV? What about the one with HIV already?" Then he wondered why I was asking him such questions. Then I asked him, "what if I am one of them?" He got shocked and that is when I started telling him about my status.(Man aged 52)

INTE: How did you disclose your status to your mother?

KA04: She [mother] came and asked me why I was taking those drugs [ART] and yet I was not sick. So I asked her: "what if I told you I had *ukimwi* (HIV/AIDS), how would you take it?". She [mother] told me no problem, we shall just stay. That is when I told her about my status.(woman aged 49)

A review of studies suggests that PLWHA are more likely to disclose when they have strong goals for disclosure and less likely to disclose when they have strong goals against disclosure (Chaudoir, Fisher, and Simoni 2011). What then are the motivations for and against disclosure in the study?

### 5.3.2. *Motivations for disclosure: positive consequences*

Disclosure has both positive and negative consequences for the PLWHA and his/her relationship (Chaudoir, Fisher, and Simoni 2011; Emlet 2008). Anticipation of positive consequences facilitates disclosure while negative consequences act against disclosure. A number of goals or motivations emerged as primary facilitators of HIV status disclosure to significant others. The first one was to seek social support. Social support comprises material, instrumental and emotional aspects (Sherbourne and Stewart 1991). Some informed their close associates so that they could come to their aid when they were bed-ridden or needed to be taken to hospital when it was required.

INTE: Can you please tell me why you decided to tell your friend?

KB10: I told my friend with whom we are very close that I am like this and like that, so that she could take me to Blue House[Clinic] if need be. When I am very sick she comes to attend to me. Like there was a time I had a stroke and she used to come and wash me.(woman aged 25)

Respondents, who disclosed their HIV status, narrated the emotional support that they obtained from friends and family following disclosure of their sero-status. The emotional support they obtained included empathic, compassionate and reassuring gestures and words:

INTE: How did different people react when you disclosed your status to them?

KA02: For instance my mother when I informed her she encouraged me a lot and “strengthened” me by saying that nowadays AIDS is just like *homa* (common cold) and so many people were living with it. So she gave me a lot of hope. (Separated woman aged 24).

Others who disclosed obtained HIV-related information on how to live with, and manage, the condition:

INTE: What about your friend, why did you tell him about it?

KA11: I told him because he is a doctor and may help me with advice on how to live positively. There are some pamphlets he even gave me to read. I sometimes ask my doctors questions that they even can’t understand how I came to know of. They call me “graduate” and want me to teach PLWHA. He advised me to follow every doctor’s advice and seek help immediately I encountered a problem. (man aged 52)

Studies (eg Kalichman et al. 2003) show that PLWHA who disclose their status obtain



social support, which mitigates HIV related stress, anxiety and depression and contributes to overall social and psychological wellbeing of PLWHA (Lam, Naar-King, and Wright 2007; Stutterheim et al. 2011).

The second motivation for disclosure was a sense of responsibility. Some PLWHA felt a sense of obligation to disclose their status so as to decide on the way forward in their lives and that telling their partners or family members would help them plan their future lives, including sexual and reproductive lives. This included decisions to use condoms to avoid infecting their partners:

INTE: Why did you decide to tell your wife?

VC05: I just felt that since I had been tested and found to be HIV positive, it would be important to tell her. You know I stay with her and so it was not good to hide it from her. So I decided to tell her *liwe liwalo* (come what may). I wanted my wife to know so she can get tested so that we may jointly see how to plan our lives.(man aged 52)

The third motivation was driven by a desire to educate and inform others about HIV/AIDS. Some were prepared to be open about their status if this would help their relatives and friends decrease their risky sexual behaviour. Others wanted to share the HIV-related information that they had acquired in the course of their life with HIV and interaction with the health care system:

INTE: Why did you tell them, let us start with your mother?

VB01: I wanted her to decide whether to change her life because the way she was living her life was risky. I told her so she could know her status and also tell the others, because her behaviour was not good. She had involved herself in drugs and I saw her getting the virus easily.

INTE: Why did you tell other relatives then?

VB01: I told some of the relatives because they had discriminated me and I had enough information. So I wanted to educate them more about HIV/AIDS. How you can get it and how to take care of it and how you can live with it. (woman aged 34)

The desire to educate and inform others about HIV/AIDS as a motive of disclosure has been documented in other studies done in the US (Derlega et al. 2004).

### 5.3.3. *Reasons for non-disclosure: negative consequences*

Reasons given by respondents for non-disclosure of their HIV status were diverse, and I identified four main groups in my analysis. The first barrier to disclosure was fear of

stigma and discrimination. Respondents feared discrimination from the community in the form of a rejection, avoidance, contempt, and scorn. They feared that people would shun them for fear of acquiring it through physical contagion:

INTE: Why do you think it is difficult to disclose your status?

KA17: It is very difficult for me to disclose my status because people will start talking ill about me, they will not feel good when their children play together with my children and they will look down upon me. That is why I don't want to disclose it to any one and just want it to be my secret.(woman aged 34)

INTE: Why have you not disclosed your status to other people?

KC06: Because they would hate me. You know people fear this disease and when you ask someone even for water, they would not give it you, they think you will infect them by sharing the cup. (woman aged 39)

Others feared abandonment and other forms of violence. Most of respondents who harboured these fears were women, who for the most part feared desertion or loss of support from their partners. Others dreaded the possibility of violence from their spouses if they let them know about their HIV condition:

INTE: Why didn't you inform your husband...?

VA12: It was hard because if I did inform him of my HIV status he would abandon me and would not help raise these kids because the first 2 are not his; his child is this last born. So I decided to remain quiet till the day he gets to know his status by himself, we shall see if we can then reach an understanding...(woman aged 25)

Women in particular reported having been deserted by their spouse when they disclosed their status to them:

INTE: Do you know anybody who was treated like that once they disclosed?

KB08: Well, I will not say they are just one or two people. They are so many, one of them being myself because since my husband knew about my HIV status he abandoned me. Even his family doesn't want to see me. They are just here in Nairobi, but cannot get anywhere close to me.( Separated woman aged 45)

Some narrated instances of abuse and insults towards them by family as well as community members:

VB01: My cousin that I was staying with started insulting me. You know he is the one who provided the money for my treatment in Jericho.

INT: What did he say?

VB01: He said that we move around and get diseases and viruses, diseases that put you down. He said that I had something that was being announced on the radio that has no cure. That I had a curse; the condition affects people who had slept with their uncles among the Kamba people... I started crying.... and I sat and thought, maybe I had the curse.(Woman aged 34)

KA11: There was a time my child was fighting with another child of my neighbour, when I told them not to fight and live like brothers. My neighbour insulted me saying that she was not responsible for condition that led to my wife's death; that my wife died like a dog and that I will also die like that. Some even removed my shirt from the hanging line and threw it away.(widower aged 52)

Second, concerns about confidentiality prevented some PLWHA from disclosing their status. Some feared that the people they could disclose to might "broadcast" their status all over the community and expose them to negative reaction.

INTE: So why is it that you have not shared it [HIV status] with anyone?

VA12: It's because not many people can keep a secret so when you inform them of your status they will spread the word and your original friends will segregate you. People will say: "oh, she has AIDS, I can't even take food at her home, I can't even drink water from her place, she might infect me...(woman aged 25)

Others thought that their HIV status was a private matter and no one whatsoever had a right to know it.

INTE: Have you informed anyone about your status?

KC09: I haven't. What for? Who are you? Are you the doctor? How can I reveal matters affecting my body to anyone? How can I inform someone that I am sick and I am HIV+...or I have diarrhoea? What drug will you prescribe for me? Who are you to ask questions relating to my life...no way! I can only talk like in this session we have...why should I tell others about my health?. (Widower aged 55)

The third reason that worked against disclosure was the need for self-protection. Some wanted to protect their social standing and character given the position they occupy in the community or protect the jobs that they do. Others wanted to protect the family from the emotional distress that their knowledge of HIV would cause, especially those who were perceived as emotionally fragile.

KB04: It has not been easy disclosing my status. For someone like me who is a pastor and a community leader for that matter, some people may decide to character assassinate me, and discredit my preaching because of my [HIV] status. So I tried to protect my image and integrity by not revealing my status to them. (man aged 36)

KCS1: We usually talk to our clients in support groups. And you will hear them say that at the workplace no one knows that they are sick. They would not want it known that they are themselves positive because they have experienced such people being sacked. Mostly they work in the food industries where they do packaging and other duties and the stigmatization that a HIV positive person should not handle the foods to be used by others is still prevalent. (HIV counsellor)

The fourth reason for non-disclosure was a feeling of shame. HIV is regarded by people as a shameful condition because it is sexually transmitted and associated with moral impropriety. The condition is also associated with social transgressions such as promiscuity, prostitution and taboo breaches in SSA (Ilfie 2006). The excerpts below are illustrative of the shame that HIV/AIDS elicits:

INTE: Why is it so hard for you to disclose your status?

KC09: It is bad...that's a shameful disease and you acquired it from women. Or were you born with the disease? [Laughs]. You acquired this ailment from women- or do you have sex with yourself?...If you are HIV+, then you are a man "*ambaye alitiana na mwanawake*" [slang for who had sex with many women] (man aged 55)

Because of the association of HIV/AIDS with moral breaches, some PLWHA faced rejection and ostracisation from friends or family and social groups upon disclosing their HIV status. A man who was a pastor and a PLWHA narrated how members of his congregation rejected a woman when she disclosed her status during a church sermon:

INTE: Might you be having a real example of someone who faced such a predicament because of disclosing their status?

KB04: Yes, I do. There was a new member who came to our church and disclosed to the church on the pulpit that she had been sent away from another church because of her [HIV] status. Immediately she did that, some members of our church picked the microphone and started condemning the lady for her status and saying that she was not suitable for our church either. Some members of the church even started singing *maiti* (dirges/mourning) songs. Little did they know that even I, their pastor, was also infected. When she sat down no one even

bothered to go and talk to her, but I did and disclosed to her that I was also infected.(Married man aged 36).

Fear of stigmatising attributes and behaviour such as rejection, discrimination and other negative social responses as a reason for non-disclosure has been documented (Stutterheim et al. 2011; Visser, Neufeld, et al. 2008). Non-disclosure of HIV status to sexual partners has been shown to compromise the practice of safer sex (Simbayi et al. 2007b) (see chapter 7). Stigma is broadly defined as an attribute that is discrediting that renders the person bearing the characteristic tainted, flawed and inferior in the eyes of others (Mahajan et al. 2008; Stutterheim et al. 2011). Stigma against PLWHA comes from a number of negative perceptions, including that: HIV is a contagious condition; HIV is associated with sexual behaviour that breaches social norms such as promiscuity, prostitution and homosexuality; and, and PLWHA are responsible for acquiring HIV (Ostrom et al. 2006; Stutterheim et al. 2011). Structural theorists view stigma not just an individual attribute, but a product of socio-cultural, economic and political power and inequality. According to this school of thought, power is needed to create stigma and that stigmatization is key to producing and reproducing power and control, thereby making others feel devalued and others to feel superior (Mahajan et al. 2008; Parker and Aggleton 2003). In addition to the humiliation and distress it causes individuals, stigma is a barrier to accessing HIV prevention, care and treatment services (Mahajan et al. 2008; Anderson et al. 2008).

Reasons for and against disclosure identified in this study are consistent with previous research elsewhere in the North and SSA (Derlega et al. 2004; King et al. 2008; Ssali et al. 2010). PLWHA are faced with the dilemma of disclosing their status because of potential consequences. Disclosure is not a linear, straight forward event, but an iterative selective process that occurs over the course of HIV/AIDS. It is a process where individuals have to come to terms with the diagnosis, and then decide to whom to disclose by weighting the pros and cons. After going through this process some decide against disclosure completely.

Evidence presented here has demonstrated that HIV-positive identity is shaped by social interaction and how others react to their HIV status. It is a transition process –

from a potential initial phase of shock and distress to a phase that involves incorporating illness – and, as the next section will show, restoring some normality. Kralik (2002) refers to this process as “a transition” to “ordinariness”, involving actions to confront life with illness and a conscious effort to return to “normal” conditions or a phase of normality. The remainder of this chapter explores the resources that are mobilised by PLWHA to restore some level of normality.

#### **5.4. Resources for identity normalisation and restoration**

Restoration to some semblance of normality requires resources for support and encouragement (Russell and Seeley 2010). Mobilising support and resources were common themes in respondents’ narratives, and referred to three main resources that people utilised in their efforts to return to normalcy after initial turmoil: ART, Social support network groups and spirituality.

##### *5.4.1. ART use*

The restorative effect of ART has been well-documented in SSA (Russell and Seeley 2010; Seeley and Russell 2010). These studies have shown that ART does not only restore the health of PLWHA, but also their social relationships and self-identity. Once they meet the social and biological criteria (understanding of adherence and CD4 counts) and were put on ART many respondents reported that they began to get better. Their narratives show that their health has greatly improved since enrolment, with opportunistic infections that used to affect them on a frequent basis substantially reduced. For some, there is some semblance of normality as the frequency of sickness reduces ex-post ART initiation.

INTE: What is your view concerning ART treatment?

KA02: Those drugs are very good given that initially when I was not using them I used to fall sick very often. I used to be sick even twice a week, but since I started this medication I can go for even a year without falling sick from even common cold. I used to vomit a lot and diarrhoea, but since I started using the drugs I have not experienced them.(woman aged 24, 2 years on ART).

It was not just their health that improved, but also their sense of self-worth. Recovery of health while on ART has profound implications for respondent’s identity and social and economic lives. The recovery of a normal body image is important for self-esteem and identity. PLWHA reporting feeling normal in the sense they can no longer

be picked out from the rest on account of say, an emaciated body mass that was characteristic of the epidemic in the pre-treatment era.

KC06: They [ART] are very good because they have really helped me. They have rebuilt my body and restored my health. No one can even know that I am HIV positive. So long as I eat well. I just look like those who are not positive. It builds up your body so that you just look like a normal person.(widow, 1 year on ART)

KA11: I can tell you I had an infection in my “pubic area”... I had rashes and wounds all over my body. I tried using other drugs from the chemistry [pharmacy] which were never effective. When I started using ART drugs for 3 months that problem disappeared. Also my skin has smoothed out because of ART. Look at how my skin is smooth...I don't use any oil on this skin; I just use *sabuni ya kipande* (bar soap) [laughter] (widower, 8 months on ART)

ART also improved people's capacity to work, important for social and economic viability and validation in society, permitting them to play their expected roles in society as breadwinners, parents or adults. This not only ensured that they were able to put food on the table, but was also reported as a way of gaining some degree of control of their lives by, among other things, reducing their dependence on others. PLWHA reported that they now could engage with friends and family as a normal person who was doing normal things.

(KB06). They [ART] have improved my health and given me strength. I even gathered the strength to come to Nairobi and try out on my own instead of depending too much on my mother. I can now work a little bit. They have given hope and faith in life once again.(man, 4 years on ART)

VC14: They [ART drugs] have really helped me. When I go to work, I can do a lot of work even more than those who do not have the virus and people love me more. I also have a lot of energy.(man 4, months on ART)

Use of ART also created new hope and future life prospects for some PLWHA, enabling some respondents to live positively and plan for the future. That said, the looming prospect of uncertainty of the future could not be ruled out for some. The co-occurrence of hope and uncertainty is as a result of the knowledge that ART was not a cure for HIV and the possibility of death still loomed large for many. The excerpts below illustrate the existence of the contrasting future prospects:

INTE: How has the use of ARTs changed your views about the future?

KA04: My view of the future has indeed changed. I can now plan for my future and live with the hope of seeing my children grow. Not like before when I thought I would die anytime soon. You know previously [before ART] I had no hope and could not plan anything because I knew I would be dying soon. But that's not the case anymore. I can now plan for my future. (woman, 2 years on ART)

INTE: How has the use of ARTs changed your views about the future?

KB08: My view is that, they should have gotten a drug that finishes this virus completely so that we just become normal as we used to be. We don't want to be taking drugs every day in order to survive. We were told that we will be taking those drugs up to the end of time. I keep asking myself, for how long will I be taking these drugs? You keep on thinking so I will take them until the day of my death and when will that be? (Woman, 2 years on ART)

However, PLWHA had to incorporate ART in addition to HIV into their lives. They had to adapt to the treatment regimens involving daily dosage of drugs at regular intervals, with known and unknown side-effects. They had to reorganise their lifestyles and daily routines to accommodate ART. This incorporation poses significant challenges in the slum settings of poverty and treatment insecurity:

KC01: Ever since I started taking these drugs [ART] I have never missed to take my scheduled pills. If I am going on a journey I have to carry my pills with me. I have to arrange so I never miss. When the time for taking the pills comes and I am with someone I will excuse myself to go and buy soda, milk or water and take them together with the drugs so that the other person cannot know. I have to know where we are going and how long it will take us there before I agree to accompany someone. (Man, 5 months on ART)

VCO2: There are periods when we have stock outs, like for the past three months we have not been having drugs, and so we have not been able to start new patients because we cannot be able to sustain them and most of my patients are on ARVs. So the ones I am having I am unable to sustain them. Things are erratic; there are no regular drug supplies (Clinical officer)

ART adherence and drugs supply security are issues of some concern in SSA in spite of recent ART rollout initiatives (Balcha, Jeppsson, and Bekele 2011; Orrell et al. 2003).



#### 5.4.2. *Social support Networks*

Social support groups formed by PLWHA played an integral role in creating an HIV positive identity and managing living with HIV/AIDS. This is where PLWHA met, and embraced “positive living”. These social support groups were key avenues and spaces in the formation of bio-sociality – “the forging of a collective identity” based on biomedical categories or diagnosis (Whyte 2009). This is where biomedical information such as CD4 cell counts, viral loads, treatment side-effects were deciphered – in addition to individual consultations at clinics. Members of these organisations introduced themselves publicly to other members and shared stories on their experiences with living with HIV and ART. The narratives indicate that information exchange typically ranged from issues of side-effects and treatment adherence to fertility and sexuality matters. Upon reflection, participant observation of these groups might have brought out the issues better. However, this was not used in this study because of financial and time constraints, and we have to rely on the reports of participants about their involvement and activities these groups.

INTE: What types of information do they usually talk to you about at [the support groups]?

VB10: They mostly talk to us verbally. They have also charts that show how men undergo vasectomy; the use of condoms; women fitted with coils; women taking pills and other methods. (man aged 35)

INTE: What types of information do they usually talk to you about at [the support groups]?

KA05: They (group members) advise you about so many issues that you do not know, the side-effects, adherence, those things they have been through which you, yourself have not experienced and generally how they are making it in life.(man aged 40)

KC04: We joined support groups where we learned a lot together. From there you just feel you belong to the society. You just feel you are negative and not positive. We were taught so many things about living positive with the disease.(widow aged 27)

Membership of these organisations enabled people to access emotional and psychological support, which played an important role in coping with HIV as a chronic condition. PLWHA reported that these support group meetings helped them to adapt to life with HIV/AIDS and life on ART by giving them the opportunity to share their knowledge and experiences and educate the community about HIV.

VB01: I used to hate myself before, but now I am a very informed person... I chair a support group and have a dream of educating the community about HIV/AIDS. I disclosed to many people and they began calling me “*mama ukimwi*” (mother AIDS), but I did not see anything wrong with it because I had already overcome stigma and I was doing this to help people... people overcome stigma and joined support groups” ( Never married woman aged 34)

The second type of support was a treatment supporter. A treatment supporter, commonly known as a “treatment buddy”, is usually a family member or a close friend who was a source of social support for PLWHA. The tasks performed by the treatment supporter include among others, accompanying the PLWHA to the health facility if needed, picking up medication on behalf of the PLWHA and reminding the PLWHA to take his/her ARV drugs as required. The following excerpts illustrate the roles of a treatment supporter.

(VB10): First I told my sister because they asked me at the hospital who I would want to bring in as a treatment supporter, someone who would assist me in case I got bed-ridden or unable to go for drugs on my own. My wife was at *gishagi* [rural home] so it was only my sister who would be of assistance to me.(man aged 43)

INTE: What is the significance of treatment buddies?

KNS2: The treatment buddy is important in reminding the client about the time of taking the drugs so that adherence is enhanced. This is because the client and treatment partner are counselled together and also choose the time for taking the drugs together as well.(Nurse)

The support from both clinics and community health workers was a crucial resource in the management of HIV/AIDS as chronic illness. These were the only sources of assurances of longevity and normality, especially for those who had neither disclosed to family nor friends. Interviews with key respondents revealed that each PLWHA who went for care was meant to be assigned a community health care worker who operated in the PLWHA’s area of residence. They met their CHWs at least once a week. However, some CHWs reported that they sometimes fail to this as they have to look for means survival given that their work is voluntary.

(KCS1): We have the Community Health workers (CHWs) who we say are the backbone of our work here. We serve people living within our reach. We have the CHWs going to the *kijiji* (village). In each village a CHW is assigned a group of patients to monitor them. We make the client feel very free with the CHW. In case the client is unwell, the CHW will quickly know and inform the nurses who will go there. If a client disappears for more than a month then it is the CHW who will most often come to report that so and so travelled to rural homes. It is these

close monitoring and home visits that help us to monitor and support adherence. (HIV Counsellor)

Whereas treatment buddies, predominantly provided adherence support, community health workers provided information on HIV/AIDS and ART and encouraged adherence by motivating patients and providing emotional support. Emerging evidence shows that the availability of treatment buddies, CHWs, and social support groups, significantly and consistently improves treatment outcomes and hence longevity for PLWHA with access to ART (Wouters et al. 2009).

#### 5.4.3. *Spirituality: Prayer is medicine*

Prayer and religiosity played a pivotal role in some PLWHA's lives and their quest for normalcy. Faith and the social networks of the church/mosque were an essential source of spiritual support, which helped some PLWHA cope challenges of HIV. Narratives show that PLWHA found comfort in their personal relationship with God:

KA11: I love God because... He is my personal saviour.. My wife used to stay upcountry and she knew me well... that I was a straight forward man. Even though she died, it was God's plan. My death will be God's plan. God cannot give us children and take both our lives at the same time and leave our children to suffer. The children that I have are blessings from God.(widower aged 52)

Some believe that God had worked all this long to keep them alive with or without medication. They believed that their life was God's will and that everybody dies or lives as God wishes, irrespective of their HIV status. Some respondents believed that they will only die when God wishes, but not because of their HIV condition.

VC09: Anyone can die whether you are HIV positive or not, so it is not only those who are HIV positive who die. When your day for it comes you will go because all of us are just visitors on this world. *Kuishi ni bahati* (Living is just luck) and the will of God.(Woman aged 41)

Some PLWHA believe that God would cure them of HIV:

KB04: Most of our members are HIV positive and I encourage them a lot by telling them that God is so much able and if you trust in him you can find the disease disappearing.(man aged 36)

VB01: Because I am not taking ART I know one day, God will heal me by faith. It has been 15 years since I knew my status but I have not taken any of these drugs.(woman aged 34)

Studies in the UK among the black PLWHA have demonstrated that strong religious faith and recourse as a major coping mechanism, not least because religion can help to manage anxiety and depression (Anderson et al. 2009).

How then do PLWHA view them-selves over the course of this transition?

#### *5.4.4. Duality of identity: Same but different*

The quest for normalcy may sometimes mean having a dual identity: being the same with some groups and different with others (Baumgartner 2007; Kralik 2002). Some respondents expressed the view that they were not any different from the rest of society; not least because they can practically do anything that a normal person would. The feeling of sameness is sometimes driven by the feeling that with treatment, HIV is just like any other, if not less serious than, chronic condition such as diabetes. In this respect HIV is not the most serious of all conditions in life; daily struggles in the context of poverty are just as or even more problematic. The feelings of being the same can enhance self- esteem, whilst those of being different can erode it

INTE: How do you view yourself as one living with HIV?

VC14: Same as the others because we are not any different from others, there is no colour or badge that shows we are infected [with HIV], we are all the same. Even at work, we do the same kind of jobs... We are of the same colour and there is nothing a normal person can do that I cannot do.( man, 4 months with HIV)

(VB06): We are all the same. It is not that those with HIV use water while those without it use blood to have their bodies run(Woman, 2 years with HIV)

INTE: How do you see yourself as someone who is HIV positive?

VC09: For me I view myself as a normal human being and I just go on with my life without any fear. ...HIV is just a condition like any other, such as that of sugar (diabetes) or blood problems. That is how I encourage myself and live on; that HIV is just like any other disease, even less serious than that one of the sugar (diabetes). (woman, 3years with HIV)

At the same time other respondent's narratives suggest that being infected with HIV makes them feel different from the rest of society. Their accounts reveal deep-seated

feelings of a damaged identity:

KB06: I thought there are people called prostitutes. That is where I will be put and I will be put with people who are cursed in life. A person called a prostitute is a cursed person. People would think that I came to Nairobi to be a prostitute. I hate myself.(woman, 4 years with HIV)

To some the idea of taking medication reminds them of their different identity:

(VC14): When I am taking medication, I find myself thinking and it hits me I have the virus or the days I go to pick my medication (man, 4 months on ART)

Other studies show that another area of difference is the view that PLWHA own abnormal bodies in the sense that their bodies have become medicalised (Izugbara and Wekesa 2011) although this did not come out in the study.

### **5.5. Conclusion**

Using the biographical disruption framework, this chapter has shown that incorporation of HIV into PLWHA's identities is a transition process starting from a phase of initial disruption and turmoil to a quest for restoration to normality. Indeed there was biographical disruption for some, but not all PLWHA, suggesting that contextual factors in which disruption and repair occurs are important. In the slum context with multiple shocks in terms of daily survival, HIV/AIDS is just one of the many life stressing events. As Carricaburu and Pierret (1995) observe, HIV infection does not just lead to biographical disruption, but also to biographical reinforcement of an identity already built prior to HIV infection. Moreover, in the ART era, HIV is increasingly being seen as a normal condition by some PLWHA. Therefore, despite its initial unsettling experience, HIV is being incorporated into people's biographies (Baumgartner 2007) rather than completely being disruptive for everyone. It takes some time before a PLWHA incorporates HIV into his or her identity. For some the process was quicker while for others it is slower and still on-going given the varying lengths of time since diagnosis. Whether or not biographical disruption occurred, PLWHA had to rework their sense of identity, which has a bearing on SRH. The next three chapters examine SRH among PLWHA.

## **Chapter 6: Sexual (in) activity and experience among PLWHA**

### **6.1. Introduction**

The last two chapters have presented data on the living conditions and self-identity of PLWHA, factors that have a bearing on sexual and reproductive health experiences and outcomes. ART restores health and helps PLWHA to regain some normality (Chapter 5), including the resumption of sexual and reproductive lives. This chapter will focus on sexual (in) activity among PLWHA living in Nairobi slums. It addresses the first part of the second research question: What factors contribute to an explanation of sexual and reproductive intentions and behaviour of men and women living with HIV and AIDS?

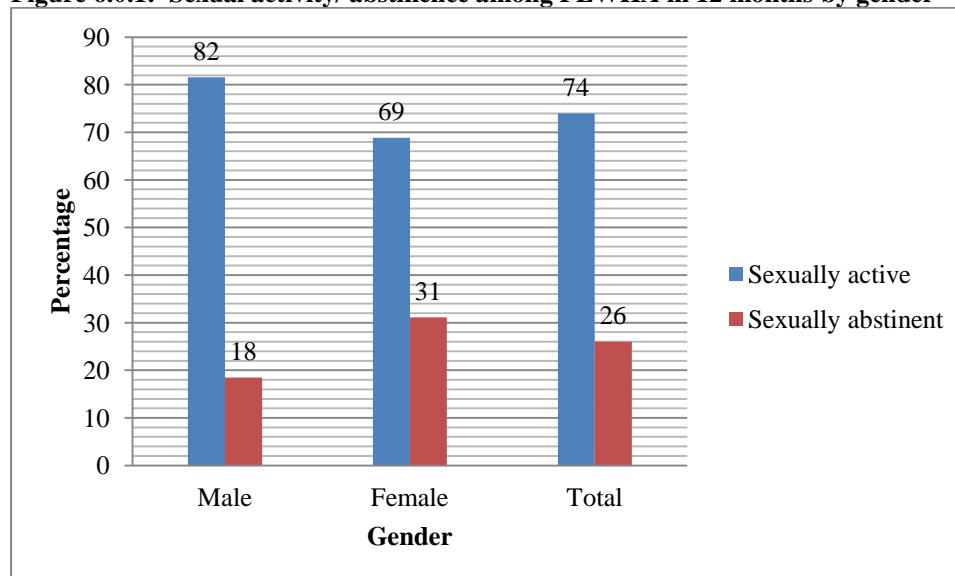
Sex is a crucial element of being human and of having a fulfilling and quality life and sexual health (pleasurable and safe sex) is an important component of overall health (De Ryck et al. 2011). But sexual behaviour of PLWHA has received scant attention in general (Kennedy et al. 2007; Luchters et al. 2008; Schiltz and Sandfort 2000) and in SSA in particular (Luchters et al. 2008; Undie et al. 2009). Where PLWHA are the subject of sexual behaviour (eg Brooks et al. 2008; Campsmith et al. 2004; Courtenay-Quirk et al. 2008; Crepaz, Marks, and Hart 2004; Moore and Oppong 2007; Sarna et al. 2008), the focus has, predominantly, been on risks of sexual behaviour, neglecting other aspects of sexual experience. Given the skewed focus on sexual risk behaviour, little is known about other aspects of sexual experiences among PLWHA. One of the neglected sexual experiences is sexual pleasure and satisfaction, an important component of quality of life (Keegan, Lambert, and Petrak 2005; Siegel and Schrimshaw 2003). Sexual health of PLWHA encompasses sex for pleasure and satisfaction not just disease prevention, but the attention on sexual pleasure and satisfaction is more obvious by its absence from research. Furthermore, the potential effect of ART on the sexuality of PLWHA in SSA is under-explored (Seeley et al. 2009).

In this chapter I draw on both the survey based quantitative and the in-depth qualitative interviews with PLWHA. The quantitative data provide the magnitude, illustrating levels and predictors of sexual activity. Qualitative data from the in-depth interviews

contribute to an explanation of how the predictors of sexual activity play out. The chapter is divided into three parts. Section 6.2 presents quantitative and qualitative data on sexual activity, describing patterns and levels of, and explanations for sexual activity among PLWHA. Section 6.3 deals with sexual experiences – desire, frequency, pleasure, performance and satisfaction – in the last 12 months relying predominantly on qualitative data. The final section presents data and narratives on sexual abstinence for reasons other than HIV risk reduction. Narratives for reasons of HIV risk reduction are presented in chapter 7 together with condom use and faithfulness.

### **6.2. Sexual activity among PLWHA in the last 12 months**

Respondents in this study were asked to report on their sexual activity and experiences in the last 12 months. Sexual activity in this study refers to penetrative penile-vagina sex. Sexually active PLWHA were captured in 3.11 and 3.18 (appendix 1) for those with regular and non-regular partners respectively. It is important to remember that self-reporting about sexual behaviours may be subject to reporting bias. There is evidence of social desirability bias, that is, where people tend to conceal or underport socially proscribed sexual behaviour such as extra-marital and homosexual relations (Chillag et al. 2006; Gregson et al. 2002). Although conscious efforts to reduce it were done during recruitment and training of interviewers on procedures of securing the comfort, trust, and cooperation of respondents (see chapter 3), social desirability bias can not completely be eliminated. Also, sexual behaviour in the 12 months preceding the interview may not adequately reflect lifetime sexual behaviour and experience. It is also possible that some people might not recall certain sexual practises that happened during this time period. This period was picked for comparison purposes as many demographic (DHS) and public health studies use this time period.

**Figure 6.0.1: Sexual activity/ abstinence among PLWHA in 12 months by gender**

Almost three quarters (74%) of respondents reported having sex in the previous 12 months (Figure 6.0.1). This mirrors other studies' findings that PLWHA are sexually active and that HIV infection does not eliminate their sexual desires. Studies elsewhere, albeit with different timeframes, report sexual activity for PLWHA, including 59% in the preceding 3 months in the Caribbean (Allen et al. 2010) and 45% in the preceding 6 months in Mombasa, Kenya (Sarna et al. 2008). Evidence from high income countries report more than 70% of PLWHA as sexually active (Crepaz and Marks 2002; Niccolai et al. 2006). Qualitative data illustrate sexual activity among PLWHA, with some of them using metaphors to describe their sexual activity. A man, for example, observes that he still has the sexual urge in common with being human and so there is no way he can claim to be practising *ramadan*, a Muslim fasting practice that involves going without food and drinks.

INTE: Last time you said you had had sex in the last 12 months, right?

VC14: The urge to have sex is still there, when I see a girl, I still want her because a man was created with the [sexual] urge, and it is also there in women. So you cannot say *umefunga ramadan* [muslim type fasting, meaning you are abstaining completely]; it is not possible (Single man aged 39).

A woman equates sexual activity with cooking *ugali* (food from maize flour).

INTE: Have you had sex in the last 12 months?

KB08: You cannot say when your body has blood running it; it cannot be cooked for *ugali* (food). Yes, I have had sex (Divorced woman, aged 45 years, HIV+ for 5 years)



Their metaphorical descriptions of sexual intercourse involved using symbols related to food or water, implying that sexual desire is just like hunger and thirst, which are basic wants that needed satisfying (Diegnan 1997). Similar metaphorical descriptions relating to sexual intercourse have been reported in SSA. Such descriptions often relate to food preparation where the cooking pot is the symbol of the female sex organ while the wooden spoon (that stirs) symbolizes the penis in some communities in Tanzania, Uganda and Mozambique (Martin Hilber et al. 2012; Tamale 2006).

PLWHA narratives were alive to the challenges they face daily in their sexual activities and experiences as residents of a slum. Living arrangement in the slums – where typically one room is used as a bedroom, kitchen and living room – was mentioned as presenting a formidable challenge to their decency and privacy of their sexual activities:

KA14: As you can see I have one room, others have even smaller rooms. Your bed is here and the children's is there.... you come home drunk, start having sex there and the children peep from the curtains... Children are looking at you. After ejaculation the child hears you clean each other. So a boy tells his friends how he saw his mother and father having sex and they share ideas. Later you will leave your children alone and they will engage in sex with neighbours' children while you are away. (Man, aged 38)

Housing arrangements and space constraints in the slums does not only hinder people's ability to maintain sexual privacy, but can also introduce their children to early sexual exposure and socialization of sexual activity that contributes to their early sexual debut, which in and of itself presents a risk of HIV infection and unwanted adolescent pregnancies (Dodoo, Zulu, and Ezeh 2007; Zulu, Dodoo, and Ezeh 2002). These issues are, of course, common to all slum residents, not just PLWHA.

#### *6.2.1. Factors associated with sexual activity/inactivity in the last 12 months*

What might explain differences in sexual (in)activity in the preceding 12 months? To explore this, bivariate and multivariate and binary logistic regression statistical tests were performed. Bivariate analysis (Table 6.0.1) suggest that respondents who reported having been sexually active in the past 12 months were more likely to be men, married or cohabiting, younger adults (under 50), of Kamba ethnicity, with fewer years

of knowledge of living with HIV, and not on ART. Marital status, ART status, age, and ethnicity remained significant predictors of sexual activity in both bivariate and multivariate analyses (Table 6.0.2) . Respondent's education, slum site residence, self-perceived health status duration of treatment, household wealth, internalised stigma and depression were not associated with a report of being sexually active in the preceding 12 months.

**Table 6.0.1: Bivariate analysis of factors significantly associated with sexual activity in the 12 months preceding interview.**

CHARACTERISTIC	SEXUALLY ACTIVE (SAC) (N=378)	SEXUALLY ABSTINENT (SAB) (N=135)	UNADJUSTED ODDS RATIOS FOR SAC
	Percentages	Percentages	OR and 95% CI
<b>Sex of respondent</b>			
Male	82	18	2.00** (1.30-3.08)
Female	69	31	1.00
<b>Age</b>			
18-29 years	79	21	3.24*** (1.59-6.59)
30-39 years	76	24	2.74*** (1.52-4.94)
40-49 years	76	24	2.83*** (1.52-5.28)
Over 50 years	53	47	1.00
<b>Marital Status</b>			
Married/cohabiting	94	6	16.07*** (9.24-27.97)
Single (NWD)	49	51	1.00
<b>Ethnicity</b>			
Kikuyu	64	36	1.00
Luo	75	25	1.72* (1.02-2.89)
Luyia	81	19	2.35** (1.31-4.23)
Kamba	84	16	2.84** (1.47-5.49)
Other	67	33	1.12 (0.54-2.30)
<b>Duration of HIV*</b>			
Under 1 year	82	18	2.44** (1.35-4.38)
1 and 2 years	77	23	1.78* (1.07-2.97)
3 and 4 years	72	28	1.43NS (0.82-2.48)
5 and more years	65	35	1.00
<b>Treatment status***</b>			
On ART	66	34	1.00
Not on ART	82	18	2.35*** (1.55-3.55)

Significance levels \*\*\* <0.001; \*\*<0.01, \*<0.05, NS – Not significant  
NWD= Never married, widowed, divorced or separated.

**Table 6.0.2:** Multivariate analysis of predictors of sexual activity in 12 months

Variable	TOTAL		WOMEN		MEN	
	Odds Ratio	95% CI	Odds Ratio	95% CI	Odds ratio	95% CI
<b>Sex</b>						
Female	1.00					
Male	0.80ns	0.43-1.48				
<b>Age</b>						
50+ (ref category)	1.00					
18-29	3.48**	1.33-9.12	5.05*	1.23-20.70	3.34 ns	0.47-23.75
30-39	4.41***	1.98-9.86	7.10**	1.88-26.77	3.11 *	1.01-9.54
40-49	5.59***	2.42-12.88	9.59***	2.45-37.62	3.65*	1.17-11.40
<b>Marital status</b>						
Single (NWD) (ref )	1.00		1.00			
Married/cohabiting	22.9***	11.46-43.0	29.52***	11.06-8.84	15.31***	5.92-39.57
<b>Ethnicity</b>						
Kikuyu (ref category)	1.00		1.00			
Luo	1.32ns	0.68-254	1.27 ns	0.56-2.86	1.62 ns	0.52-5.04
Luhya	2.07*	1.01-4.24	1.89 ns	0.78-4.59	2.62 ns	0.73-9.49
Kamba	2.84**	1.30-6.22	2.83*	1.14-7.02	2.71 ns	0.55-13.41
Other	0.88ns	0.35-2.22	0.71ns	0.21-2.45	1.11 ns	0.27-4.64
<b>Treatment status</b>						
On ART (ref category)	1.00		1.00			
Not on ART	2.85***	1.69-4.82	3.38***	1.75-6.52	2.15 ns	0.83-5.53

Significance levels \*\*\* <0.001; \*\*<0.01, \*<0.05, NS – Not significant

NWD= Never married, widowed, divorced or separated.

### Gender

Bivariate analyses show that men were twice as likely to report sexual activity as women (OR: 2.00) and in the multivariate analysis without marital status as a covariate. Some studies (e.g Njogu and Martin 2005) have similarly documented higher reported sexual activity among men (not necessarily PLWHA) in comparison to women in Kenya.

Two plausible explanations for expected and observed gender differentials in sexual activity can be offered. One is reporting bias. Reporting of sexual activity is influenced by socio-cultural beliefs in SSA (Caldwell, Caldwell, and Quiggin 1989). Cultural norms define appropriate sexual behavior for men and women. Masculinity ideals exert powerful influences on men to prove their virility often through having sexual intercourse (Gage 1998). Since men are thought and expected by society to have stronger sexual drives than women, and the stereotypical notion that men cannot do without sex (Kenya et al. 1998), some men might over-report their level of sexual activity including the number of sexual partners (Nnko et al. 2004)

INTE: So did you have it [sex] in last 12 months then?

KC09: Yes of course, as a man you cannot just stay *ndeee!* (Idle without having sex)... you are a man, so you cannot say – No (you are abstaining).(widower, aged 55)

Secondly, ideologies of masculinity and femininity can help explain differential sexual activity between men and women. In African societies, cultural expectations that women should take a passive role and men take a dominant role can influence the reporting of sexual behavior (Varga 2003). This notion is illustrated in the excerpt, below, in a conversation with a female and male respondent respectively. However, as the narratives show this norm is not necessarily observed by both men and women and is changing. Similar evidence of some men and women challenging or going against dominant sexual gendered norms has been documented in studies in Namibia (Brown, Sorrell, and Raffaelli 2005), and South Africa (MacPhail 2003; MacPhail and Campbell 2001)

INTE: How is an ideal man or woman expected to behave in regard to sexual relations according to your society?

VA07: What I know is that it is the man who is expected to “tune” the woman and then if she accepts they can go and have sex. But an ideal women, leave alone the modern ones, cannot take the lead. Even if you like him you let him initiate it. But the modern ones just seduce men these days [laughter].(Single woman, aged 44).

INTE: So please tell me, how is an ideal woman and man expected to behave in respect to sexual relations according to your society?

KA14: In our society I hear men are the ones expected to or have the “authority” to initiate sexual intercourse. For, instance, a man would just come home and tell the wife that they must

have it [sex] and she is expected to obey. Women have absolutely no rights at all to ask. For me that is not right. They should agree both of them. I think everybody's feelings should be considered (Widower aged 38)

Studies on adolescents in SSA show that these social norms on appropriate sexual behavior for men and women are inculcated early on in life. Socialisation prepares women to accept men's dominance in sexual matters and prepares men to take the initiative. Any woman who actively takes the initiative in sexual matters can run the risk of being labeled loose (Gage 1998; Ragnarsson et al. 2008).

However, when marital status was included as a covariate in the multivariable analyses, the relationship between respondent's sex and sexual activity was no longer significant (Table 6.0.2). This implies that the relationship between respondents' sex and sexual activity is mediated by marital status. Women included in this study were significantly more likely to be in non-marital unions (divorced/separated and widowed) than men (chapter 3). It was, therefore, these single women who were less likely to be sexually active, owing in part to lack of a sexual partner rather than being female. When marital status is controlled for in the model (table 6.0.2), the relationship between sex and sexual activity disappears. This study, therefore, contrary to expectations, did not find any difference between respondents' sex and the likelihood of being sexually active, net of other factors. That said, however, respondent's sex is just a proxy, but does not fully capture gender effects.

### Age

The proportion of those who were sexually active significantly reduced with age, in bivariate analyses (Table 6.0.1). Those aged 18-29, 30-39 and 40-49 had the odds of being sexually increase by more – than 3 times (OR: 3.24), 2 times (OR: 2.74) and 2 times (OR: 2.83) respectively compared to those aged 50 and over years. In the multivariate analysis (Table 6.0.2), the odds of being sexually active for younger age groups were 3 and more times higher than those aged 50 and over years. In the combined model for men and women, the odds of being sexually active relative to the older (50+) increased with age. However, when separate models were run for men and women (Table 6.0.2) the odds of being sexually active only increased with age in the younger age groups (relative to 50+) for women. For men, however, the odds although

significantly higher (as compared to 50 years and over) were relatively stable among different age groups.

Although respondents in the qualitative interviews did not specially mention the effect of age on their sexual activities and sexual lives, an analysis of the narratives among those aged 50 years and over reveals reports of some sexual difficulties and diminished desire in their sexual lives. The conversation below is illustrative of this point:

INTE: What do you mean you are not getting warmth?

VC05: The body's warmth. It's over a year since I slept with a woman. I can't have a woman because my wife ran away because she could not understand what was happening [with me] for a whole year... I have lost all my [sexual] energy and that's what led us to separate [with my wife]. (Man, aged 52)

Diminished sexual desire is a well-established concomitant of aging (Siegel and Schrimshaw 2003). Research shows that as adults age, hormonal changes may reduce sexual libido (e.g. erectile dysfunctions in men and decreased vaginal lubrications in women) (Lovejoy et al. 2008). A similar finding among PLWHA was reported in the US by Siegel and Schrimshaw (2003) who observed that in general, older adults have difficulties resuming sexual relationships following HIV diagnosis. However, it could also be possible that older people are subject to perceived societal pressure to have reduced sexual activity and hence some older PLWHA might under-report their sex activities. Limited studies show that reporting of sex among the elderly in SSA is either frowned upon or at least treated with ambivalence (van der Geest 2001).

### Marital status

Respondents who were married or cohabiting were more likely to be sexually active than those who were not currently in a marital union (separated, divorced, widowed and never married). Marital status was significant in both bivariate (Table 6.0.1) and multivariate analysis (Table 6.0.2). Those who were married or cohabiting were more than 22 times (OR: 22.19) more likely to be sexually active than those who were single, other things held equal in the combined model. Marital status was still a significant predictor of sexual activity for men and women when separate models for them were run using the same covariates. Qualitative findings show that being in marital union increases the chances of being sexually active in two ways. First is that a

co-residential marital union provides a readily available sexual partner. Narratives show that some PLWHA were forced to be sexually abstinent for lack of a sexual partner:

INTE: Why is it that you have not engaged in sex in the past 12 months?

KA11: First I have not had a [sexual] partner and secondly the [societal] rules do not allow me to have sex with someone who is not my wife. I have not had anyone that I can call my wife during this time period. (Widower aged 52)

INTE: What is the reason why you have not had sex in the past 12 months?

KA02: The reason is that I don't have a *beshite* (slang for friend/ lover). It is not that I have been unable to find one, actually so many try *kunikatia* (to seduce me) but I turn them down [laughter] (Never married woman aged 24).

Secondly, marital unions come with conjugal obligations that involve sex. For married PLWHA couples, sexual intercourse was narrated more in terms of conjugal obligations: A woman who has been living with the virus for five years and has been taking ART for a year illustrates how some PLWHA engaged in sex as a matter of duty, even when there was neither urge nor satisfaction.

INTE: Can you please tell me how your sexual life was during this time?

KB10: For me I feel like I no longer have the desire to engage in sex with my husband like before. Even those four times [in a month] I just do it, but I don't enjoy it at all. I just give it to him because he is mine. (married woman aged 25)

The excerpt for a man who had known his HIV status for 22 months shows how some PLWHA engaged in sex, not for desire, but in a bid to prevent their spouses from seeking sex from elsewhere:

INTE: How has your sexual life changed since you discovered that you are HIV positive?

KB04: Yes something has changed. My libido has dropped. I don't enjoy sex much. I only do it as a matter of obligation, but not that I enjoy it much. I have to do it because I fear that if I don't then someone would do it with my wife on my behalf and that is what I fear most. (Married man aged 36)

A similar finding of an independent association between marriage and being sexually active was documented in study of PLWHA in Uganda (Bunnell et al. 2006). Similarly, a study of PLWHA in Mombasa, Kenya found that married or cohabiting couples were 8.3 times more likely to report sexual activity than single/divorced/widowed respondents (Sarna et al. 2008).

### Ethnicity

Ethnic differences in reporting sexual engagement are observed. The Kamba and Luhya ethnic groups reported significantly higher sexual activity while Kikuyu reported the least sexual activity in the bivariate analysis (table 6.0.1). Kamba and Luhya ethnicities remained significant predictors of sexual activity in the multivariable model that included male and female PLWHA (Table 6.0.2). Members of the Kamba and the Luhya ethnicity were 184% and 107% respectively more likely to be sexually active compared to Kikuyu respondents, net of other factors (OR: 2.84 and 2.07). However, when separate models were run for women and men, the relationship between ethnicity and sexual activity remained among women, but disappeared among men. In this model only the Akamba women were significantly more likely to report sexual activity compared to the Kikuyu women (OR 2.83).

The significance of ethnicity indicates that social and cultural factors influence sexual behaviour of PLWHA. This suggests that some ethnic socio-cultural norms are either permissive or restrictive of female sexual activity or its reporting and these issues might have come up had the study adopted some ethnographic perspective.

### ART use

Although ART use has been associated with sexual functioning and activity (Seeley et al. 2009), this study found less sexual activity among those on ART in both bivariate (Table 6.0.1) and multivariate (Table 6.0.2) analysis. Those who were not on treatment were almost 3 times more likely to be sexually active than those who were on ART (OR: 2.85) (Table 6.0.2). Similar results were reported by a study in New York, for example, which found diminished sexual activity and desire among PLWHA after ART initiation (Siegel, Schrimshaw, and Lekas 2006). However, the findings contradict those found in Mozambique where sexual activity among PLWHA on ART increased after ART initiation (Pearson et al. 2011). Two studies on PLWHA in Mombasa, Kenya did not find any differences in being sexually active between those on ART and those not yet enrolled on ART (Luchters et al. 2008; Sarna et al. 2008).

However, when separate models were run for men and women the negative relationship between ART use and sexual activity remained significant only for



women but disappeared for men. What might explain this? Two plausible explanations: The first one is the physiological effects of ART; the association between sexual dysfunction and use of some antiretroviral drugs (e.g.: protease inhibitors) has been documented (Scanavino 2011). However, when it comes to the current ART that is available in resource-poor settings of SSA, the evidence is mixed, albeit based on studies in the global North. While some studies have shown the effect of these ARTs on sexual dysfunctions (Asboe et al. 2007; Collazos et al. 2002; Trotta et al. 2008) other studies have shown no effect (Crum-Cianflone et al. 2007; Cove and Petrak 2004). Despite high levels of reported sexual dysfunctions with the current ART, it is still unclear to date how ART might be related to sexual dysfunction (Scanavino 2011).

The second plausible explanation, and one which might account for the gender differences is differential behavioural responses following ART initiation. Qualitative data suggest that counseling during ART initiation tends to discourage sexual activity by stressing abstinence rather than lower risk sexual activity.

INTE: So what did they do before putting you on the [ART] drugs?

KB07: We underwent a lot of counselling and training; that training helps to teach people on how to use the drugs as well as *kujilinda* (protection).

INTE: Can you please explain further what you mean by *kujilinda*?

KB07: It is about not engaging in sex when you are HIV positive; knowing when to take your drugs... (Widower aged 60)

INTE: Did they give you counselling regarding sexual and reproductive health?

VC01: Yes, they told me that when I start using these drugs [ART], I should reduce the frequency of engaging in sex, or better still stop it altogether. (Married man aged 42)

A study in Nairobi slums, similarly reports that counselling during ART initiation tends to stress abstinence (Undie et al. 2009).

The dampening effect of counselling during ART initiation on sexual activity of women and not men suggests that women may adhere more to health care recommendations and messages than men. Studies elsewhere in SSA show that women are not only more likely to seek HIV care services (Bila and Egrot 2009; Skovdal et al. 2011), but are also more likely to adhere to ART and other medical

recommendations including staying on treatment (Coetzee et al. 2004; Kipp et al. 2010). It might be that women are also more likely to adhere to healthcare advice, including abstaining from sex when on ART than men.

### **6.3. Sexual experiences: Desire, pleasure, frequency and satisfaction**

“...most people who engage in sex...are not thinking about disease, they are thinking about enjoying themselves” (Thomsen, Stalker, and Toroitich-Ruto 2004, 433)

Research focusing on the sexual experiences of PLWHA tends to be in relation to risk behaviours and transmission of HIV rather than other sexual experiences such as pleasure and desire. Yet research shows that the search for pleasure and gratification is one of the main reasons that make people engage in sex (Philpott, Knerr, and Boydell 2006; Thomsen, Stalker, and Toroitich-Ruto 2004). Furthermore sexual satisfaction has been shown to be positively related with the quality of life (De Ryck et al. 2011) and quality of and fidelity in sexual relationships (Schwartz and Young 2009). In this study respondents were asked to narrate their sexual experiences in the last 12 months. It should be acknowledged that this is limited by the fact that PLWHA who had a lot of sex in this time period are less likely to be able to report fully on all of their experiences. I present these narratives using three themes: sexual desire, sexual frequency and performance.

#### *6.3.1. Sexual desire and pleasure*

Narratives show that there are reductions in sexual desire following HIV infection for most, but not all PLWHA. Although most are sexually active (Table 6.1), many felt that sexual activity had been affected by HIV infection, with substantial reductions in both desire and pleasure.

INTE: Are their changes in your sexual life since HIV infection?

KC02: My sex life has been affected because my *nguvu za kiume* (libido) is gone down. Prior to knowing my status my sex drive was high but as of now I feel my body is *baridi* (cold/not responsive) (Married man, aged 46, 3 years with HIV).

INTE: Would you say that your sexual life has changed or has it remained the same since you discovered that you are HIV positive?

VB06: Yes, there have been changes. For instance, nowadays we just do it but I don't enjoy like I used to enjoy before [HIV infection]. Sometimes I realize that even him he is not

enjoying it but we just have it for the sake. You know sometimes you just eat food even if you are not hungry. We just get on with it because it is not our wish to be in that situation.  
(Cohabiting woman aged 35, 2 years with HIV)

Studies that have documented sexual experiences among PLWHA have similarly observed diminished sexual desire. In many PLWHA sexual desire decreases as a result of fatigue, body wasting and depression associated with HIV infection (Siegel and Schrimshaw 2003). Desire may reduce owing to fear and anxiety around infecting others or re-infecting themselves. Due to the possibility of HIV transmission and re-infections (Courtenay-Quirk et al. 2008; Maclachlan 2007) many PLWHA may feel that sex is mired with too much anxiety, worry, danger, and stress to still be desirable or pleasurable (Siegel, Schrimshaw, and Lekas 2006).

Diminished sexual urge was not universally reported by respondents in this study. A minority insisted that nothing has changed for them in terms of sexual desire and arousal following their HIV diagnosis. For example, a woman observed that libido is natural and this “forces” her to engage in sex, although her narrative appears to express some guilt or shame towards sex. Relf et.al (2009) refers to this condition as dissonance associated with sexual intimacy and HIV status.

VB01: Can you describe to me how your sexual life since you found out that you are HIV positive has been?

Res: Nothing has changed... because to control the [sexual] urge without having sex “bores” someone. I do not know whether it is the foods we eat or whether God created it like that? Sometimes you find your body forcing you to do something that you do not want to do in your life. You force yourself to have sex because it is the body that wants it (Single woman, aged 34 years, HIV+ for 15 years)

Reduced sexual desire was, however, reported as having been reversed by ART for some PLWHA, with some stating that sexual desire had increased following ART initiation. For example, a woman who has been living with HIV for 5 years and has been taking treatment for a year reported of her elevated libido following her enrolment on ART:

KB08: To be honest, these ART drugs raise one's libido. They make your blood hot, make you to want a man, and if you are that kind of woman who cannot control herself you will be here and there. This thing even has perplexed us. In fact it is good that you asked me this question. Now, what can be done to lower this high libido in us? (Divorced woman aged 45)

This was corroborated, by a nurse, who remarked that some of her clients have complained to her that condoms get in the way of ART induced sexual desire:

VNS1: Women also say they are not enjoying sex [with a condom] especially those on [ART] drugs. They [those on ART] say the sexual urge is so great; they want to be "rubbed" (have sex with a man) all the time [laughs]. They say they are not getting what they need with a condom because for them the main thing is not protection, but the satisfaction. But you know it is just psychological; it's all in your mind. (Nurse)

The data suggests that, on the whole, diagnosis with HIV infection can have far-reaching sexual implications: PLWHA's sexual interest, the pleasure they derive from sex, may diminish considerably irrespective of their age, sex, ethnicity, and duration of time living with HIV/AIDS. Reduced libido among PLWHA has been documented in studies in the North (eg Keegan, Lambert, and Petrak 2005) as well as SSA (eg Sarna et al. 2009). The emotional distress of living with HIV and fears and worries around infections and re-infections can take its toll on sexual interest (Rispel et al. 2011; Siegel, Schrimshaw, and Lekas 2006), notwithstanding the restorative effect of ART (Seeley et al. 2009). This can have implications for coital frequency.

### 6.3.2. *Coital frequency*

Most respondents, almost without exception felt that the frequency of their sexual activities had been reduced following knowledge of their HIV status. Despite their reported involvement in sexual intercourse for the majority (Figure 6.0.1), narratives show that the frequency of their coitus has seen a substantial drop. For example, a woman, who has been on treatment for 5 months, reported that hitherto, she had sex on a daily basis, but that this has now reduced to once a week, if at all.

INTE: Has there been any other change? Say in the frequency in which you have sex?

VB06: Previously we would have sex even more than four times a day but currently we can even stay up to a whole month without it. If we are lucky may be once a week. (Cohabiting woman aged 36, HIV+ for 2 years).

A similar story emerges in the extract from a conversation with a man who has been living with HIV for four years and not yet started treatment:

INTE: So what has changed in your sexual life?

KB06: For me the change is that I don't have sex as much as I used to. I can do it say twice a week or stay without it for two weeks. It is not like before when I could do it every day. But when I do it I just do it like normal people. (Married man aged 35, HIV+ for 4 years)

The most common reasons given for reduced coital frequency is lack of desire and satisfaction due, in part, to fatigue, emotional distress and fears of infection and re-infection (Keegan, Lambert, and Petrak 2005):

INTE: Please describe your sex life in the last 12 months?

KC02: It is 2 weeks since I had sex with my wife. I would love to [have sex] more, but my body is cold. My spirit is willing, but my body is weak [laughs]. (Married man aged 48 years)

Other reasons include not wanting to have to use a condom because of inhibited pleasure, or sporadic interest in sex attributed to use of ART, which is perceived to reduce its effectiveness (Sarna et al. 2009) or its associated side-effects that make it difficult to have sex.

INTE: Can you please tell me your sexual experience since you discovered that you were HIV positive?

KA04: It was good, but I really did not enjoy it. He used a condom, but the feeling was not good. So I decided to cut links with him. Since then I have decided to abstain (single woman, 40 years)

INTE: What else has changed in sexual life?

VC01: The other thing, I cannot have sex with my wife every time because of the medication I am taking as it will affect the "dose" in the body. (Married man aged 42, 2 months on ART)

How has your sexual life been since you were HIV positive?

KC01: I really no longer give much consideration to sexual matters because some of the [ART] drugs like the one I take at night really exhausts me. You get intoxicated like for 3 hours. You might think it is "*dawa ya kulevya*" (Illicit drugs). So, I hardly think about sex. I think about my pills first.(widower, aged 41 years)

Reduced coital frequency among PLWHA has been documented in studies from a range of settings in the North (eg Keegan, Lambert, and Petrak 2005). A study in Mombasa, Kenya among PLWHA on ART found reduced sexual frequency and attributed this in part to “fairly common” misconceptions that frequent sexual activity reduced ART effectiveness (Sarna et al. 2009, 786).

### 6.3.3. *Sexual performance*

Narratives touched on sexual performance at two levels. The first was to do with the process of negotiating for sex soon after diagnosis. Narratives suggest that, in general, people went from an initial phase characterised by avoidance of sex due to lowered libido. This was often followed by a period when they finally came to terms with their condition culminating in the resumption of sexual relations. The first quote shows how a male respondent lost sexual desire for half a year:

INTE: Can you please describe your sexual life since you found out that you are HIV positive?

VB10: After being tested I felt no urge to do sex and so I stayed for about six months without engaging in sex. But after a while I started doing it again. (Married man aged 43 years)

The second quote, from a woman exemplifies the notion that some PLWHA saw a dissonance between being HIV-positive and being sexually active, which took some time to elapse:

INTE: Please describe your sexual experience in the last 12 months?

KB08: I started having sex just recently. I saw no point of staying without sex because it is not written on my face that I am HIV positive (Divorced woman, aged 45 years)

The second way in which respondents discussed their sexual performance is their physical ability to engage in sexual intercourse to level that is satisfactory to them. Men in particular talked about the effect of HIV on their ability to perform sexually. Almost all narratives try to make the point that, despite being sexually functional, HIV/AIDS has affected their sexual prowess and vitality, if not virility. A man laments about his declining number of “shots” (ejaculations):

INTE: What is it can you say has changed in your sexual life since HIV infection?

VC14: Most things have changed, because before [HIV infection] I was able to have sex for long like three to four “shots”, but now the maximum I can have is just two “shots” (Single man, aged 39 years)

Another man feels that his HIV condition with concomitant TB has reduced his energy levels to perform as well as he would like, but he feels that he must put in a “good enough” sexual performance in order to keep his marriage intact.

INTE: Have you seen any changes in your sexual life as a result of your HIV condition

KB06: With my lung [TB] problem I can no longer perform [in bed] with my wife as well as I used to previously [without HIV]. I cannot do strenuous activity because of *kuhema* (panting). I cannot do it [sex] as good as someone who is healthy, but my wife understands me and demands less of it [sex]. But on the whole it is not very bad, because if it were so she would be long gone [laughs].

INTE: And what is it that has not changed in your sexual life?

KB06: What remains the same is the “experience” [prowess] one has in *kufinyana* (slang for doing sex) [laughs]. That is the most important thing. It is what counts most even when the energy level is low. With that [prowess] she will at least feel that a man was with her. Otherwise having just energy without “experience” in having sex is useless. [laughs] (married man, aged 35)

It is interesting to note that only male respondents talked about this aspect of sexual performance. It is possible that females are less inclined to talk sexual performance, in keeping with a feminine sex role. In traditional Africa, the onus of a leading role in sexual matters tends to rest almost exclusively on men, while women are by and large expected to be passive participants (Njovana and Watts 1996; Long 2009). So the propensity of male respondents to articulate this aspect is in line with playing their masculine gender roles, perhaps more than anything else.

The first part of this section has looked at the sexual experiences of PLWHA who were sexually active in the previous 12 months. In line with other studies globally (e.g. Siegel, Schrimshaw, and Lekas 2006; Siegel and Schrimshaw 2003) and SSA (Sarna et al. 2009), this study also found diminished sexual desire and concomitant reduced coital frequency and pleasure among most PLWHA, although not all. Diminished sexual urge and activity was not universally experienced, which suggests that in addition to HIV infection, other social and psychological factors, such as quality of life and mental health of PLWHA (Bova and Durante cited in Keegan, Lambert, and Petrak 2005) – issues that were beyond the scope of this study – may have an influence on sexual functioning. While libidinal energy may be lowered, it

does not diminish entirely and may, in some instances, be restored by ART. Even though reduced desire may continue to affect sexual activity, many PLWHA have functional and satisfactory sexual lives (Keegan, Lambert, and Petrak 2005). That said, however, a number PLWHA reported that they did not involve themselves in sexual intercourse in 12 months preceding the survey. The next subsection examines reported sexual abstinence among PLWHA.

#### **6.4. Sexual abstinence**

This study collected quantitative and qualitative data on the magnitude and experience of sexual abstinence (lack of sexual activity/ intimacy) in the last 12 months. This information may be limited by its snapshot cross-sectional nature. Episodes of sexual abstinence can be interspersed between other periods of sexual activity (Aidala et al. 2006). More than a quarter (26%) of PLWHA in the survey was sexually abstinent in the last 12 months (Figure 6.0.1). A similar study in Nigeria found comparable rate of 24% of sexual abstinence (Chama, Morrumpa, and Gashau 2007). Significant predictors of sexual abstinence (inactivity) in the last 12 months were marital status, age and ART treatment (Table 6.0.2). In sum: those who were not in any marital union, were aged 50 and over years, were from the Kikuyu ethnic group and are on ART were significantly more likely to be sexually abstinent net of other factors. Previous research has shown that sexual abstinence is associated with age, marital status (Siegel and Schrimshaw 2003), lack of sexual desire and fears of re-infections (Courtenay-Quirk, Zhang, and Wolitski 2009; Keegan, Lambert, and Petrak 2005).

The in-depth interviews help to understand the circumstances that led to some PLWHA to remain sexually inactive, an issue that is under researched (Siegel and Schrimshaw 2003). Narratives of sexual abstinence show a range of motivations for PLWHA to remain abstinent. This section explores the abstinence narratives that are not related to HIV prevention; risk reduction abstinence is examined in chapter 7. The abstinence narratives in this respect can be grouped into three themes: Positive living, sexual dysfunction and internalised stigma.

##### *6.4.1. Positive living*

The idea of positive living has become the mainstay organising concept for many PLWHA to manage their conditions. Living positively involves adopting a prescribed



lifestyle, designed to deal with the daily challenges brought by HIV and have a positive outlook. It entails an observance of a raft of measures, including acceptance of HIV status, disclosing HIV status, consuming nutritious diets, preventive sexual behaviours, and, adequate sleep and exercise (Levy and Storeng 2007). Positive living is communicated through HIV support groups and healthcare providers (Levy and Storeng 2007) (Chapter 5). Our conversation with a health care provider helps to demonstrate that sexuality is one element of the positive living communicated to PLWHA during counselling:

INTE: Can you explain further how sexuality is an issue of positive living that you just raised?  
 KCS1: Aaaa, did I say sexuality? Remember I defined adherence as not just dealing with [ART] drugs alone, but also encompasses adherence to positive living behaviour. Their sexuality is, therefore, a case of positive living in order to prevent re-infections. Some people [PLWHA] fail to adhere to positive living as advised. You find that someone tests positive, but still goes on to have sex without protection and there by falling pregnant, which in turn affects their health and can lead to death. They also risk re-infection or infecting others.(Counsellor).

Respondents' narratives showed that some PLWHA understood positive living that was discussed during ART adherence counselling to include avoidance of sex altogether, and sexual abstinence was one way of coping with HIV/AIDS (Siegel and Schrimshaw 2003) so as to extend their lives as advised by health care providers:

INTE: You are saying doctors discouraged you from having sex, what did they say?  
 KA14: They said that if "you are HIV+ and you continue having sex you will die quickly because you have no energy, you would be consuming the little energy left by your "*umalaya*" (promiscuity)". So I decided I want nothing more, I have enjoyed life, borne children so I have no need for a lover. Let me raise my children so that I regain my energy and my parents would know I am their strong son. (Widower, aged 38 years)

A key question that arises from the accounts of abstinence in relation to positive living is whether the decision to abstain arose from personal informed decision or from pressure from the wider community and medical practitioners. Evidence from the data suggests that decisions to remain sexually celibate might be motivated more by external rather than internal forces (Undie et al. 2009), as the above excerpt demonstrate

This should not, however, mean that all decisions to abstain came from outside forces and that all healthcare providers steered PLWHA away from sex. Far from it. Although they were reported by PLWHA as having a bias in favour of abstinence in the advice they provided, some health care workers were reportedly providing other options available for safer sex (see chapter 7). Narratives showed that some decisions to abstain were internal, personal issues associated with HIV such as sexual dysfunctions and internalized stigma. The next section considers reports of HIV-related sexual dysfunction.

#### 6.4.2. *Sexual malfunctions.*

Respondents reported a number of sexual problems that have contributed to their avoidance of sex, related to changes in sexual interest and performance. Some PLWHA, especially women who were sexually abstinent expressed the view that they experienced a cessation of sexual libido since their diagnosis with HIV:

INTE: Last time you said that you were not sexually active in 12 months, right?

KA17: No, I have not had sex since I knew about my status. I lost sexual desire completely. I don't even long for a man... that I want to have sex with him. You know when a woman loses feelings? I don't have the [sexual] feelings at all. (Widow, aged 29 years)

INTE: Can you please tell me why it is that you have not had sex in the past 12 months?

VA07: For me sex is no longer meaningful to me because I have developed a negative attitude towards men... I don't think about it because sex is all in your mind [laughs]. The desire only comes when you think about it. (Never married woman, aged 44 years)

The second aspect was a reduction in energy to physically engage with sex, a narrative that tended to come from men:

INTE: You said that you engaged in sex in the past 12 months, is that right?

VC05: No, I stopped having sex so I concentrate on my treatment.

INTE: Could you please elaborate?

VC05: I have lost all my energy and that's even what led us to separate [with my wife]. I decided on my own to stop because there is no reason to strain yourself and yet the body has not regained full strength. I decided to concentrate on my medication first. If it is sex I will do it in the future. (Separated man, aged 52 years)

The above quotes highlight interesting gender differences in decisions to be sexually abstinent. While the women almost without exception attributed their sexual inactivity to loss of libido, almost all men commenting on this aspect attributed it to lack of physical energy to engage in sex. Unlike women, none of the abstinent men openly indicated that they did not miss sex. Studies in the global North have reported sexual dysfunctions among HIV-infected men (Asboe et al. 2007) as well as women (Green and Goldmeier 2008). Sexual dysfunctions among PLWHA are attributed to physiological and psychological factors associated with HIV, opportunistic infections and HIV treatment (Scanavino 2011; Trotta et al. 2008; Trotta et al. 2007). Sexual dysfunctions among PLWHA have been associated with risky sexual behaviour and non-adherence to ART (Scanavino 2011; Trotta et al. 2008). Studies in the UK and Europe show that most physicians do not screen for sexual dysfunctions among PLWHA due to a number of reasons, including lack of training, fear of awkward situations and time constraints (Green and Goldmeier 2008; Trotta et al. 2007).

#### 6.4.3. *Internalised stigma*

HIV/AIDS remains a highly stigmatized condition and many respondents experienced stigma in one way or another (Chapter 5). Internalised stigma has been defined as the “shame” associated with and/or “fear” of encountering stigma (Lekas, Siegel, and Leider 2011). Internalised stigma, also called felt or self-stigma (Visser, Kershaw, et al. 2008), therefore, is experienced or felt by PLWHA as a response to stigma. This can be manifested in self-hatred, isolation, shame, fear and avoidance of certain things and situations (Visser, Kershaw, et al. 2008). Although internalised stigma was positively associated with abstinence, the relationship was not significant in either bivariate or multivariate analyses. However, qualitative data shows that internalised stigma was an important factor in sexual inactivity among PLWHA. Some respondents’ narratives of abstinence reflected felt stigma in various forms. There were two levels in which internalised stigma was articulated: feelings of dissonance and penance in respect to sexual activity.

The feeling of dissonance (an inner conflict) associated with sexual activity and HIV status has been documented in prior research on abstinence among PLWHA in the US (Relf et al. 2009). These authors found feelings of dissonance or “internal struggle with competing thoughts” in managing their HIV condition prevented some PLWHA

from sexual activities. Respondents' narratives show that fears of disclosing their status to the sexual partners and difficulties in getting the right partners, preferably of same sero-status (sero-sorting) led to dissonance motivated abstinence:

INTE: What is the reason why you have not had sex in the past 12 months?

KA02: Obviously your man would want to have sex with you and that means that we have to use condoms according to what I was told at the clinic. And if you insist on condom use your partner would want to know why and I don't want those questions... So I decided to just stay like that. (Separated woman, aged 24 years)

INTE: Could you please tell me why you haven't engaged in sex for the past 12 months?

KA04: Because it is difficult finding someone [sexual partner] who is faithful. Besides, those men who are not infected would just want to engage in sex with me without a condom. At least those living with the virus can understand me. (Never married woman, aged 40 years)

Feelings of dissonance may be related with loss of the element of spontaneity in sex with HIV diagnosis (Rispel et al. 2011; Siegel, Schrimshaw, and Lekas 2006). Because of the fears of transmissions, sex was arguably no longer spontaneous, because PLWHA had to first think of protection, disclosure issues or sero-sorting for sexual partners. Consequently, some tried to manage dissonance feelings and fears around these issues by avoiding sex altogether (Relf et al. 2009).

The second level where internalised stigma was articulated is that sexual abstinence was motivated by feelings of penance. This is where PLWHA harboured feeling of guilty with HIV infection and hence were deserving of the punishment of contracting HIV/AIDs (Undie et al. 2009). These feelings were driven by the notion that their past sexual activity was responsible for their infection:

INTE: Can you please tell me why you have not had sex in the last 12 months?

KA05: I decided in my heart that if it is sex that brought all this [HIV] then I should forget about it. Even the bible says if it is the *kidole* [finger/toe] that will prevent you from getting to heaven, then is better to chop it off. (Divorced man, aged 30 years).

INTE: You said you did not have sex in the last 12 months, right?

KA07: Sex is the cause of many problems in the world. Sex is where all problems start, but for me I just want to stay that way [without sex]. (Married man, aged 59 years).

The third aspect of internalised stigma in PLWHA narratives were feelings of hurt as a

result of having HIV/AIDS. This was particularly articulated by women respondents who felt bitter and a sense of victimization for being infected by a spouse or sexual partner. Feelings of bitterness might have been fuelled by the belief that those sexual partners might have infected them knowingly and concealed their sero-status from them. For some women, anger, which was transformed into a general dislike and distrust of men, translated into avoidance of intimate relationships and sexual engagement with men (Siegel and Schrimshaw 2003):

INTE: Can you please tell me why it is that you have not had sex in the past 12 months?

VA07: For me sex is no longer meaningful to me because I have developed a negative attitude towards men. I actually hate them... (Never married woman, aged 44 years)

INTE: What would say made you stop engaging in sex?

KA09: I said that I will never do sex again because the man who infected me ran away.(Widow, aged 45 years)

The narratives relating to abstinence suggest differential expressions for men and women, with the decision to abstain in respect to felt stigma and sexual functioning emotionally more driven for women than men (Siegel and Schrimshaw 2003). Women were more likely to express feeling of being hurt by men who infected them and fearful of any sexual contact with them. Men on the other hand were more likely to explain their inactivity as the outcome of their lack of energy to rise to the occasion or lack of financial resources to maintain sexual relationships.

## **6.5. Conclusion**

How do PLWHA negotiate their sexual life with the virus? How does sex for pleasure being negotiated in the context of potential re-infections and infections? These are the questions that this chapter grappled with. Findings show that about three quarters (74%) of the respondents were sexually active during the 12 months preceding the survey. However, diagnosis with HIV has had a negative impact on sexual experiences of the majority of respondents. PLWHA's sexual interest, the pleasure and satisfaction they derive from sex and the frequency of sexual activities have all been negatively affected in one way or another. The emotional distress of living with HIV/AIDS, fears around infections and reinfections among other factors, take its toll on sexual interest,

functioning and satisfaction. Even though reduced desire and interest may continue to affect sexual activity, many a PLWHA have functional sexual lives.

## **Chapter 7: HIV Risk reduction: The ABC for PLWHA**

### **7.1. Introduction**

The availability of ART has increased life expectancy, improved health and brought new hope to some PLWHA (Auerbach 2004; Coetzee et al. 2004; Mocroft et al. 2003). The global initiative for universal access to treatment, prevention and care has brought new challenges, including: how to meet the prevention needs of PLWHA against infecting others and re-infecting themselves with other strains of HIV (Allen et al. 2011; Crepaz et al. 2006). The need to direct prevention strategies toward PLWHA has led to development of the term: Positive Prevention (Auerbach 2004). This refers to improving the capacity of PLWHA to protect their own health and that of others, by making safer sex and reproductive choices (Allen et al. 2011; Keegan, Lambert, and Petrak 2005). This chapter will examine the extent of, and barriers to, safer sex practises among PLWHA. It addresses a component of the second research question: What factors contribute to an explanation of sexual and reproductive intentions and behaviour of men and women living with HIV and AIDS?

In the HIV prevention arena, the most commonly used health behaviour models such as the Health Belief Model, The Theory of Reasoned Action, and Social Learning Theory tend to focus on the individual as an autonomous decision maker, based on motivation, knowledge, skills, self-efficacy or feeling of control (Evans and Lambert 2007). Individual-level interventions for the general population thus seek to influence knowledge, attitudes, behaviour in relation to ABC (Abstinence, Be faithful and Condomise) (Gupta et al. 2008). Reviews of positive prevention strategies have revealed the continued focus on individualised models, in the ABC approach with little attention to broader contextual factors (Crepaz et al. 2006; Kennedy et al. 2010). These approaches overlook the fact that sexual activity is just not an individual attribute, but a relational one involving two partners in a wider socio-cultural context. Coates, Richter, and Caceres (2008) show that the success of individual-level interventions improve substantially when the broader context that shape individual behaviour is addressed. This chapter details contextual factors, including social and gender norms, economic survival issues, and relationship issues that influence the ABC-related sexual

behaviour among PLWHA. The chapter is divided into three parts, each dealing with each constituent of the ABC HIV prevention model: Abstinence, Be faithful and Condomise.

## 7.2. Abstinence

Sexual abstinence is one of the HIV transmission prevention tools that is advocated by the HIV/AIDS community (Chama, Morrumpa, and Gashau 2007; Coates, Richter, and Caceres 2008). Abstinence is a core preventive strategy among PLWHA in order to prevent transmission of HIV to sero-negative partner and self-reinfection with new strains status (Kennedy et al. 2010; Kalichman and Simbayi 2010). Just over a quarter (26%) of the respondents were sexually abstinent in the 12 months preceding the survey (chapter 6). This section explores the narratives of abstinence that relate to HIV infection prevention; narratives that did not touch on HIV risk reduction were examined in chapter 6. There were two ways in which PLWHAs' narratives engaged with prevention: Self-protection and altruistic protection of others.

### 7.2.1. *Self-protection*

There were three levels of self-protection that led PLWHA to abstain from sex: against re-infections of other strains of HIV, other sexually transmitted infections and pregnancies. A number of respondents reported that they were motivated to stay clear of sexual relations in a bid to protect them-selves from acquiring other strains of HIV, which might compromise their state of health:

INTE: Have you had sex for the last 12 months?

KA09: No. I said no because you might get somebody who has a different HIV strain that is much stronger than yours who will infect you.(Widow, aged 45)

The second aspect of self-protection articulated by abstaining respondents was against other types of sexually transmitted infections and unwanted pregnancies:

INTE: You said that you have engaged in sex in the last 12 months, right?

KA17: Yes that is right, these days "nimechill" (slang for abstinence for mass media campaigns).

INTE: Could you please tell me why you haven't engaged in sex for the past 12 months?



KA17: The way my body is weak like this, I can get somebody and get infected with gonorrhoea. I don't want to get another disease. I just want to remain the way I am. (Widow, aged 30)

INTE: Is there any reason why you have been sexually inactive?

VA15: Yes, I am afraid that I could get the STIs or I could engage in sex and get pregnant. (Divorced woman aged 45 years)

Narratives show that respondents were informed about the potential danger of re-infections, demonstrated by the excerpts from conversations with a male PLWHA respondent and a health care provider respectively:

INTE: Were you also given counselling on sexual and reproductive health at the clinic?

KB06: I was advised... to avoid *kuongezana virusi* (re-infecting each other). You know you can have 21 viruses and then she adds you other viruses and you end up with 23 [laughs]. (Married man aged 35 years)

INTE: How should they conduct themselves in terms of sexual relations?

VCO2: There is the option of abstaining, and, uhm,... you know sex on its own has got STIs, you have to talk about STIs by the way. Sex on its own can predispose them to or accelerate the rate of OIs (opportunistic infections). If the other partner is positive and is not on medication you can easily get a re-infection or you can get STI or you can easily get new strains of HIV. So all those things you have to mention (Clinical officer)

There is emerging evidence to support this concern around the potential development of re-infections and spread of new strains of HIV. Sexual intercourse (without protection) between PLWHAs carries the risk of transmitting sexually transmitted infections, including other strains of HIV that are resistant to the current first line ART available in poor resource settings (Auerbach 2004; Crepaz et al. 2006; Kalichman and Simbayi 2010). In addition, sexual intercourse between PLWHA risks transmission of HIV to non-infected sexual partners.

### 7.2.2. *Altruistic protection*

The second aspect of preventive narratives on abstinence is protecting against transmission of HIV to other partners who might be sero-negative. Several PLWHA felt that the choice not to get involved in sex was motivated by a moral responsibility

to protect others from HIV. This was especially so for women respondents, who felt victimised by being infected by their partners who did not disclose their status. In a way this kind of reaction might highlight the fact that these PLWHA had projected the guilt of HIV transmission towards themselves and internalised it (Long 2009). The conversations, below, with female respondents, highlight the other-preventative stance. They spoke of the guilt they would experience if they would put others at risk of HIV infection:

INTE: You said that you have not had sex in the last 12 months, right?

KA02: Umhuu, that is right

INTE: What is the reason why you have not had sex in the past 12 months?

KA02: ... I don't want to infect innocent people like was done to me. So I decided to just stay alone until that time that God will see fit to provide me with a man (Divorced woman aged 24 years)

INTE: Could you please tell why you haven't engaged in sex for the past 12 months?

VA07: Right now so many people [men] may want to seduce you and want to sleep with you, yet they don't know your status. But it becomes very difficult for me to agree to sleep with any of them.

INTE: So you mean you will refuse to go with them because you don't want to infect them?

VA07: Yes, you do not want to infect them, but the man may see that you are healthy and just wants to sleep with you. (Never married woman aged 44)

The feelings of responsibility to prevent HIV were a strong deterrent to sexual activity among some PLWHA. In the context of PLWHA, both self-interest and concern for others are important in adopting risk reduction sexual behaviour as abstinence. This phenomenon has been referred to as altruism in the positive prevention literature. It involves not only concern about protecting sexual partners, but also protecting friends, family and community from HIV (O'Dell et al. 2008). Altruistic feelings have been shown to lead to personal responsibility in adopting HIV protective sexual behaviour (Wolitski et al. 2007). However, most HIV prevention models tend to emphasise self-interest in adopting safer sexual behaviour (O'Dell et al. 2008).

In relation to prevention of re-infections and HIV transmission to sero-discordant sexual partners, PLWHA narratives seemed to suggest that healthcare workers seemed to steer them away from being sexually active:

INTE: Were you counselled about sex and reproductive life?

KC06: Yes I was told about it. I was told that there was no need to have sex anymore.

(Cohabiting woman aged 39)

However, narratives from health care providers, almost without exception, presented a view that all preventive sexual behaviours for PLWHA were presented and promoted on an equal footing.

INTE: What do you advise the PLWHA as far as sex and reproduction is concerned?

VNS1: We tell them that having HIV/AIDS does not mean they stop having sex. But we tell them that they should protect themselves from getting re-infected and infecting others....dual protection and sticking to one sexual partner (Nurse)

A health care provider, however, discussed his concern for sexual activity among PLWHA:

KCS1: Ok, for one, sex is a matter of thinking and not a “mechanical” act. I would like PLWHAs made to think about themselves first. People should use their heads; not just saying “let me take a condom or pills”. Some of these drugs make people behave like gadgets and not like people with their minds. Some PLWHAs reason that since they are on pills or have been injected, then they can just go around and have sex without considering that they are increasing their viral load and lowering their immunity. I would like PLWHA made to understand their HIV status and what it means to be HIV positive, what are the repercussions on themselves and the other person. People should understand that they can still have sexual gratification without penetrative sexual intercourse. I would really make sure that PLWHA understand their condition and the repercussions of any sexual behaviour without thinking that they are being discriminated against by being told not to have sex. (Counsellor)

What was striking in the PLWHA narratives are accounts that seemed geared towards pushing the abstinence agenda, rather than providing an informed choice between abstinence and using protection (principally condoms) during sex. The latter (condom use) seemed to be presented as a last resort if abstinence was neither possible nor pragmatic, particularly for married couples. Narratives from health care providers, almost without exception, presented a view that all preventive sexual behaviours for PLWHA were promoted equally. This suggests that some health care providers were reporting socially acceptable and desirable responses to us, whilst not necessarily

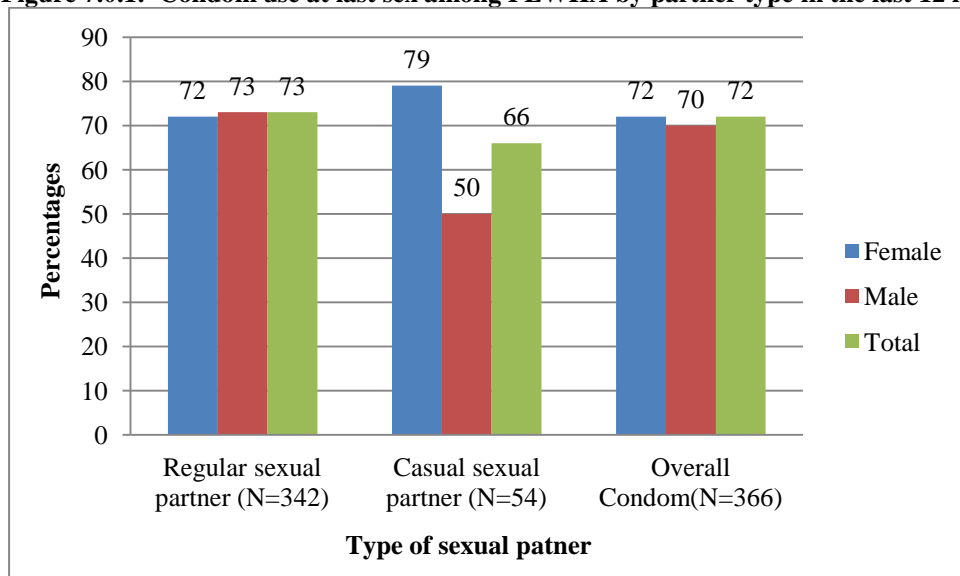
doing this in their counselling sessions. Even if this study had been able to do participant observation of counselling sessions, it is possible that this reporting bias would have still been present. It is also possible that some respondents were referring to post-diagnosis counselling that happened several years ago, when anti-sexual activity sentiments towards PLWHA were highly prevalent among health care workers (GNP+ 2009). ART initiation is theoretically accompanied by education and counselling of sexual behaviour alongside adherence (Allen et al. 2011), which may encourage abstinence. The next section looks at condom use in these settings as a second risk reduction strategy.

### **7.3. Condom use among PLWHA**

Condoms remain one of most cost effective tools available of HIV prevention (Coates, Richter, and Caceres 2008; Philpott, Knerr, and Maher 2006). Information on condom use among PLHWA is crucial to understand their protective behaviour to prevent the transmission of HIV to sero-negative sexual partners and reinfections of others with different strains of the virus (Auerbach 2004; Crepaz et al. 2006). This study collected information on the use of condoms in 12 months preceding the survey, including the use of condoms at last sexual encounter, and the consistency of its use in the previous 12 months, by partner type. Sexual partners were categorised as regular and non-regular/casual. A regular sexual partner was defined as a married/cohabiting partner or a person whom they considered to have sexual relationship on regular basis (e.g. boyfriend/girlfriend, fiancé). A casual partner was defined as a non-regular or commercial sexual partner.

#### *7.3.1. Condom use at last sex*

Condom use at last sex is used as an indicator of many HIV prevention interventions as it gives a cross-sectional indication of the prevalence of protective sexual behaviour. However, it may overestimate the level of condom use because consistency is not always maintained (Allen et al. 2010). Therefore, this study measured both condom use at last sex and the consistency of condom in the 12 months preceding the survey. However, self-reporting on protective behaviour such as condom use among PLWHA may suffer from over-reporting bias due to social desirability bias.

**Figure 7.0.1: Condom use at last sex among PLWHA by partner type in the last 12 months**

Almost three quarters (72%) of those who were sexually active used condoms during their last sexual encounter (Figure 7.0.1). Studies in the US found that nearly four fifths (Golin et al. 2009) and three quarters (Courtenay-Quirk et al. 2008) of sexually active PLWHA used a condom at last sex. In the Caribbean 54% of PLWHA said they used a condom during last sex (Allen et al. 2010). Reported condom use at last sex by PLWHA who know their status appears to be higher than those who do not know their status, suggesting more protective sexual behaviour with sero-status knowledge. For example, the 2008 KDHS showed that only 13% of HIV-infected who do not know their status used a condom at last sex compared (KNBS 2008).

Similar proportions of males (70%) and females (72%) respondents reported condom use at last sex in the current study, although the proportion of women who reported use of condoms with casual sexual partners was significantly higher than that of men, although the number of reported casual partnership was small (N=54). The proportion of those who used a condom for both partnerships was significantly lower for relatively younger (18-29) and older cohorts (50 and over) than the middle aged (30-49) PLWHAs. The proportion of the discordant partners who used a condom was significantly higher than of concordant and partners of unknown status, suggesting more concern for HIV transmission to sero-negative partner was paramount (Table 7.0.1)

**Table 7.0.1:** Condom use at last sex by partner type in the last 12 months

	<b>REGULAR SEXUAL PARTNER (N=342)</b>	<b>CASUAL SEXUAL PARTNER (N=54)</b>	<b>OVERALL CONDOM (N=366)</b>
<b>Sex</b>		*	
Female	72	79	72
Male	73	50	70
<b>Age</b>	***		***
18-29	57	45	55
30-39	75	74	74
40-49	85	78	83
50 and over	53	50	55
<b>Marital status</b>			
Married	71	65	70
Singles	78	68	75
<b>Education</b>	*		
None	69	80	67
Primary	77	59	75
Secondary	63	83	64
<b>Partners sero-status</b>	***		***
Concordant	76	59	74
Discordant	86	100	86
Unknown	54	54	52

**Significance levels \*\*\* <0.001; \*\*<0.01, \*<0.05, NS – Not significant**

Respondents were asked to give reasons why the condom was used or not used during last sexual act. Table 7.0.2 lists these reasons by partnership and sex of respondents. The most commonly cited reasons for using the condom for both regular and casual partner during last sex was prevention of re-infections (61% and 53% respectively), followed by the need to avoid infecting other sexual partners (28% and 36% respectively) and dual protection against HIV and pregnancies (9% and 6% respectively). In terms of self-protection versus protecting others, women were more likely to express feelings of altruism than men. The proportions of men who reported prevention of re-infections as a reason for the most recent condom use was higher than women for both regular and casual sexual partnerships. In contrast, the proportion of

women who mentioned preventing HIV transmission to the other partners was higher than men for both regular and casual sexual partners.

Those respondents who did not use a condom at the most recent sexual encounter were asked the reasons for non-use (Table 7.0.2).

**Table 7.0.2:** Reasons for condom use and non-use during last sex (%)

Main reasons for condom use	REGULAR			NON-REGULAR		
	Women	Men	Total	Women	Men	Total
Prevent reinfections	58	64	61	50	58	53
Protect partner from HIV	30	24	28	38	33	36
Prevent HIV+ pregnancy	11	9	10	4	8	6
Other	1	2	2	8	0	6
<b>Reasons for condom non-use</b>						
Not available	4	5	4	0	8	6
Partner Objected	49	0	29	33	33	33
Don't like them	20	26	23	33	17	22
Used another contraception	0	3	1	0	0	0
Not Necessary	11	11	11	33	8	17
Love partner (intimacy)	11	18	14	0	8	6
Did not think of it	15	15	18	17	25	22

The most commonly mentioned reason for both regular and casual partners was partners' objection. This was only mentioned by women respondents in regular sexual partnerships, while the male-female proportion that cited this reason was evenly split in casual sexual partnerships. This finding is possibly a reflection of the effect of differential gender power relationships in condom use in close regular and marital partnerships. Some studies have found less condom use with close regular partners than with casual partners. Researchers have attributed this to gender-based power imbalances that render women powerless to successfully negotiate for condom use (Pulerwitz et al. 2002; Campbell 1995). This was reinforced by qualitative interviews, which however, show that the opposing partner is not always the man; sometimes women also refuse to use condoms:

INTE: Why did you not use a condom?

VC03: He [my partner] did not want to use condoms. We don't use them (condoms) because he doesn't want. He says "uuh, you cannot eat a sweet with its wrapper on".

INTE: Have you ever refused to use condoms when your partner wanted to use?

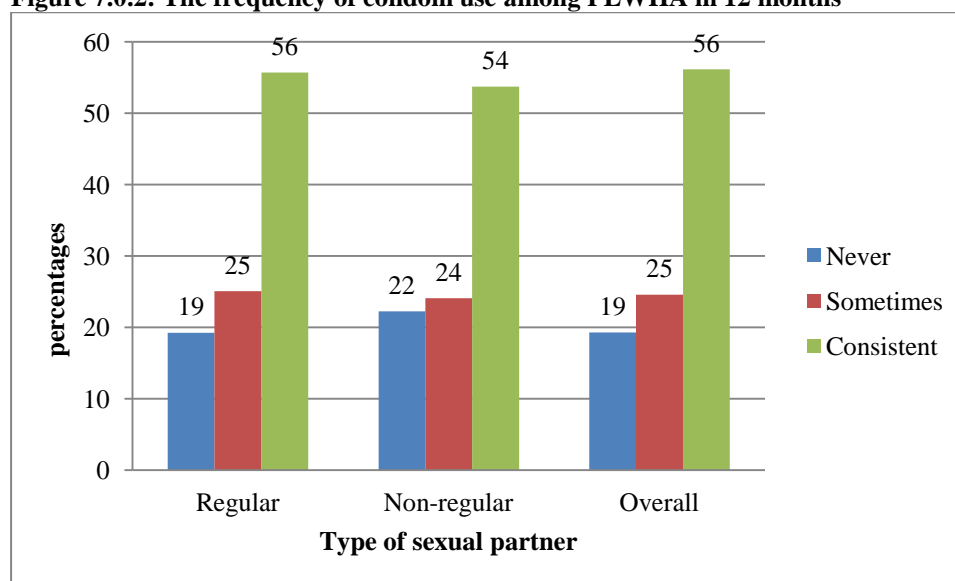
VC03: Yes, I also refused just the same way he had tried to refuse the first time... You know I had never used condoms before and it was the first time I was experiencing it. So I told him to use because I knew my status. But the second time I refused because it (condom) hurt me... I told him it was hurting me. So on the second occasion we did not use. (Cohabiting woman aged 36)

Other reasons commonly endorsed were that condoms were disliked and deemed unnecessary and not thought of at that point. I return to the gender power dynamics and why condoms are unpopular amongst some PLWHA, in much more detail, in the next section on consistent condom use.

### 7.3.2. Consistent Condom Use

The most critical issue in the effectiveness of use of condoms for HIV prevention among PLWHA is correct and consistent use (Coates, Richter, and Caceres 2008). Respondents were asked to indicate the consistency of condom use for both regular and casual sex partners in the 12 months preceding the survey, and coded into three categories: Never, Sometimes and All the time (Figure 7.0.2). As a response variable for logistic regression consistent condom use was defined as 1 (Yes) for all the time and 0 (No) for Never and Sometimes.

**Figure 7.0.2: The frequency of condom use among PLWHA in 12 months**





Tables 7.0.3 and 7.0.4 present bivariate and multivariate analyses of predictors of reported consistent condom use respectively among respondents who were sexually active in the previous 12 months. Marital status, age, household wealth, ART use, disclosure of HIV status, partner sero-status, duration of HIV, fertility desire, social support and depression were significantly associated with consistent condom use in the bivariate analysis.

This study did not document any significant association between consistent condom use and treatment optimism, internalised stigma, and alcohol use and drug use. This might underscore our inadequate knowledge of the factors that are associated with protective sexual behaviour in different populations and settings (Courtenay-Quirk et al. 2008). Individual level factors such as treatment optimism, internalised stigma, drug and alcohol use have consistently been associated with non-protective sexual behaviour among MSM populations settings in the North (Chapter 2), but were not associated with condom use in our study population. Marital status, age, household wealth, disclosure of sero-status, fertility desire, years of living with HIV and social support remained significant predictors of consistent use in the multivariate analysis (Table 7.0.4).

**Table 7.0.3: Bivariate analysis of consistent condom use**

CHARACTERISTIC	CONSISTENT USE (CU) (N=201)	INCONSISTENT/NONE USE (N=165)	UNADJUSTED ODDS RATIOS FOR CU
	Percentages	Percentages	OR and 95% CI
<b>Sex of respondent</b>			
Male	51	49	0.76 ns (0.50-1.15)
Female	58	42	1.00
<b>Age</b>			
18-29 years	33	67	1.00
30-39 years	62	38	3.30*** (1.81-6.00)
40-49 years	62	38	3.26*** (1.74-6.10)
Over 50 years	42	58	1.47 ns (0.63-3.46)
<b>Marital Status</b>			
Married/cohabiting	52	48	1.00
Single (NWD)	63	37	1.60* (1.00-2.55)
<b>Wealth quintiles</b>			
Poorest quintile	56	44	1.00
Richest quintile	73	27	2.11* (1.05-4.21)
<b>Duration of HIV</b>			
Under 1 year	27	73	1.00
1 and 2 years	59	41	3.90*** (2.15-7.07)
3 and 4 years	64	36	4.89*** (2.52-9.49)
5 and more years	72	28	6.99*** (3.60-13.58)
<b>Treatment status</b>			
On ART	66	34	1.00
Not on ART	45	55	0.41*** (0.27-0.63)
<b>Disclosure to partner</b>			
Never	38	62	1.00
Sometimes	54	46	1.93ns (0.92-4.05)
All the time	60	40	2.43*** (1.43-4.13)
<b>Sero-status with partner</b>			
Unknown	42	58	1.00
Sero-concordant	56	44	1.75* (1.03-2.96)
Sero-discordant	65	35	2.56** (1.32-4.97)
<b>Fertility desire</b>			
Wants more	43	57	1.00
No more	60	40	1.94** (1.25-3.03)
<b>Social support</b>	NA	NA	1.59* (1.10-2.27)
<b>Depression</b>	NA	NA	0.63* (0.44-0.91)

Significance levels \*\*\* <0.001; \*\*<0.01, \*<0.05, NS – Not significant

**Table 7.0.4: Predictors of consistent condom use**

<b>VARIABLE</b>	<b>ODDS RATIO</b>	<b>P-VALUE</b>	<b>95% CI</b>	
<b>MARITAL STATUS</b>				
Married/Cohabiting)	1.00			
Single ( SWD) (Ref category)	2.20	0.015	1.17	4.16
<b>Age</b>				
18-29 (Ref)	1.00			
30-39	2.33	0.016	1.17	4.64
40-49	2.03	0.054	0.99	4.20
50+	1.05	0.93	0.37	2.00
<b>TREATMENT STATUS</b>				
Not on ART (Ref category)	1.00			
On ART	1.80	0.029	1.06	3.06
<b>Disclosure of status to partner</b>				
Never (Reference category)	1.00			
Sometimes	2.22	0.015	1.17	4.16
All the time	2.60	0.009	1.28	5.33
<b>Fertility Desire</b>				
Wants more (Ref category)	1.00			
No more	2.11	0.005	1.26	3.54
<b>HIV DURATION</b>				
Under 1 year (Ref category)	1.00			
1-2 years	2.80	0.003	1.40	5.54
3-4 years	2.55	0.019	1.17	5.68
5+ years	3.21	0.003	1.49	6.94
<b>Social Support</b>				
<b>Wealth (5 Quintiles)</b>				
Poorest (Ref category)	1.00			
Second	1.02	0.97	0.46	2.22
Third	0.88	0.75	0.42	1.87
Fourth	1.32	0.52	0.57	3.08
Wealthiest	2.40	0.034	1.07	5.37

### 7.3.3. *Facilitators of consistent condom use*

Results from a multivariable logistic analysis (Table 7.0.4) and qualitative data show that the facilitators of consistent condom include: use of ART, disclosure of HIV status to sexual partners, positive living dictum and social support and female partner insistence (agency).

#### Use of ART

Respondents who were on ART were significantly more likely to consistently use condoms than those not yet on treatment. Being on ART increased the likelihood of consistent condom use almost two fold (OR 1.80; 95% CI 1.06-3.06;  $p=0.029$ ) net of other factors. This finding runs counter to earlier studies from the North, which found that ART increased unsafe sex (Chen et al. 2002; Katz et al. 2002) a phenomenon that was linked to treatment optimism (Kennedy et al. 2007; Kerrigan et al. 2006). However, this finding is in alignment with newer research from the North and SSA that ART initiation is not necessarily associated with increased unsafe sex behaviour (Crepaz, Marks, and Hart 2004; Kennedy et al. 2007). Prospective studies from Kenya, Uganda, South Africa confirm the association between ART use and reduced unsafe sexual behaviour (e.g Eisele et al. 2009; Luchters et al. 2008; Pearson et al. 2011).

Qualitative data provide insights to a plausible explanation for the positive association between use of ART and consistent condom use. These data show that the process of ART initiation is accompanied by positive prevention messages, with the consistent use of condom taking centre stage in many counselling sessions. This was illustrated by excerpts below with a clinician and a PLWHA respectively. As the narratives show counselling on condom use to prevent (re)-infections have helped some PLWHA to use condoms despite constraints such as partner opposition and fertility desires:

INTE: You mentioned earlier that you talk about reproductive health during ART initiation. What do you advice PLWHA about sexuality and reproduction?

VCO2: As far as sex is concerned we tell them to be using condoms every time, whether they know the status of their sexual partners or not because if they have unprotected sex with HIV positive partners then they would expose themselves to re-infections. If the partner is HIV negative then they would be spreading the virus to them [discordant partners]. We also tell them about the dangers of having STIs and this comes hand in hand with HIV (Clinical officer)

INTE: Did you get counselling on sex and reproductive matters at the time you were put on ART?

KB10: They advised that I must be using condoms every time I was to have sex with my husband. The reason was that he was already on ARVs and that if we had sex with him without protection, then I could be infected by some other virus that is untreatable and that would really complicate things for me. I asked them how it would be if we wanted a child and they told me that when that time comes we would just go[to clinic] and the doctor would advise us appropriately because we would need only one day [of unprotected sex] to realise conception. (Married woman aged, 25 years)

At ART enrolment, consistent condom use was emphasised as one risk reduction option in addition to abstinence, reduction of sexual partners and reduced frequency of sex. Counselling emphasised consistent condom use with all partners with HIV-positive or unknown status, including married partners and free condoms were provided to clients where possible, with an emphasis on avoiding re-infections. Even though ART may be associated with renewed sexual urge and functioning for some PLWHA (Seeley et al. 2009), the counselling provided during initiation helped motivate subsequent condom use. Emerging evidence shows that ART may prevent HIV transmission through reduced infectivity (Persson 2010). The different effect of ART on sexual behaviour in resource-poor settings may be due to less familiarity with treatment effects such as diminished infectivity (Venkatesh et al. 2011).

#### Disclosure of status to sexual partners

Those who disclosed their HIV status to their sexual partners were more than twice as likely to use condoms consistently as those who did not. Respondents who disclosed their status all the time were 160% times more likely to use condoms consistently than those who have never disclosed their sero-status (OR 2.60; 95% CI 1.28-5.33;  $p=0.009$ ) (Table 7.4). A study in South Africa found unprotected sex to be less common among respondents who had disclosed their status to all (sero) discordant and concordant partners (Simbayi et al. 2007b). This finding is not surprising as it is expected that with knowledge of partners' status, precautionary measures will be taken to avoid getting infected or re-infected. That is why disclosure to sexual partners is recommended during post-testing counselling as a risk-reduction strategy (King et al.

2008). Narratives of respondents also illustrated that disclosure of sero-status to sexual partners facilitated condom use as illustrated below:

INTE: Do you discuss about your status with your partner? Did you tell your partner that you had sex with about your HIV status?

KA09: Yes, I told him that I have HIV and if he wants us to *fanya mapenzi* (make love), he should use a condom. He told me that it was not a big deal and that he had condom with him. (Widow, aged 45 years)

Even though disclosure of HIV status to sexual partners promotes protective behaviour (condom use) and access to care services (King et al. 2008; Simbayi et al. 2007b), it is not always easy to do it. In chapter 5, we explored various reasons that make it difficult for PLWHA to disclose their status, chief among them fear of stigma and discrimination. The fear of rejection by potential sexual partners was a recurrent theme in the conversations with respondents. In slums where sometimes commercial sex is sought for survival purposes (Chapter 4), disclosure of status can have a negative impact on earnings from sex:

INTE: Did you tell them about your status?

KC06: You see my problem is the money. My concern is to get money from sex. So if I tell them about my status they will desert me, they will run away. (Commercial sex worker aged 39)

A male respondent cannot bring himself to disclosing to any sexual partner, including his wife, for fear of the consequences:

INTE: Do you inform your sexual partners that you are HIV+?

KC09: I can't reveal that, can you? Can you tell anyone "I am infected, but I will still want to go with you (have sex)? Won't you fight? Can you tell your wife, for instance, that "I am infected with HIV, but let me sleep with you dear?" Will you agree really? She can even poison you so you die. Let her get to know about it when she feels ill and gets tested in hospital. (Widower, aged 55 years)

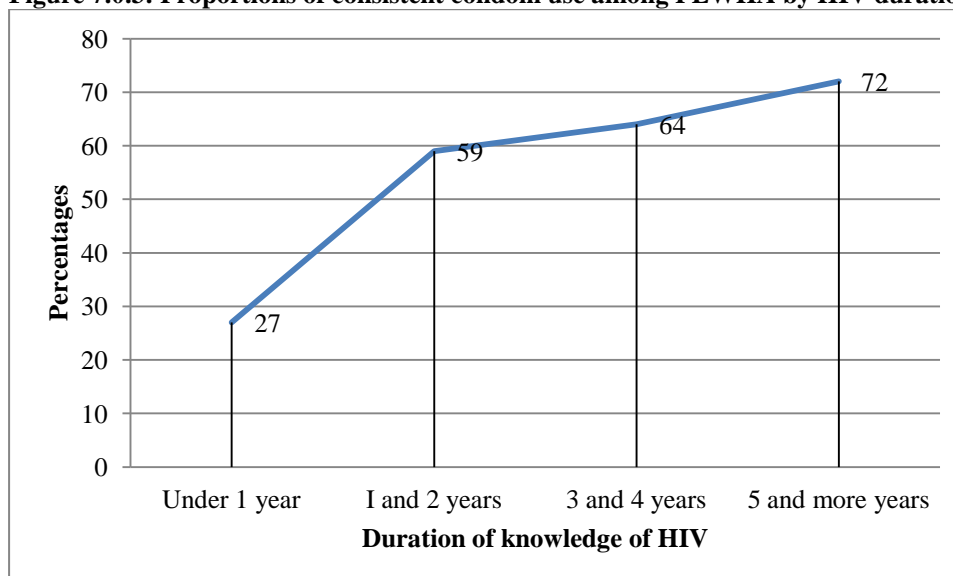
Although disclosure of HIV status is recommended, it is difficult to do and poses dilemmas for many PLWHA. It is a process that entails decisions about when, how and to whom to disclose if at all. In chapter 5 it was shown that some PLWHA conveyed a sense of responsibility to inform others about their HIV status in order to give a partner

the opportunity to make an informed choice about whether to expose themselves to the potential risk of infection. However, these feelings of responsibility to warn others of the physical risk of infection conflicted with their need to protect themselves against negative consequences of disclosure. This was done by concealing their HIV status and maintaining their protective barrier around their HIV positive identity. Therefore, disclosure of HIV status brings about a competing tension between protecting oneself (by concealing one's identity) and the need to protect others (by revealing one's HIV status). This suggests that most HIV infection in this setting occurs in the context of unawares of HIV status of sexual partners. Other studies have similarly shown that, even though it may be emotionally draining, disclosure of HIV status to sexual partners is associated with adoption of protective sexual behaviour (King et al. 2008) and social and medical support (Kalichman et al. 2003).

#### Duration of Knowledge of HIV

Consistent condom use was positively associated with respondents' duration since knowing their HIV status (Figure 7.0.3).

**Figure 7.0.3: Proportions of consistent condom use among PLWHA by HIV duration.**



Duration of knowledge of HIV increased the odds of consistent condom use, net of other factors (Table 7.0.4). Those with knowledge of HIV for one and two years were 2.80 times more likely to consistently use a condom relative to less than one year (OR 2.80; 95% CI 1.40-5.54;  $p < 0.003$ ), while knowledge of status for five and more years increased the odds of consistent condom use by a factor of 3.2 (OR 3.21; 95% CI 1.49-

6.94;  $p < 0.003$ ). This finding suggests that the motivation to adopt protective sexual behaviour increases over time as people adjust to living with HIV. The principle of positive living (chapter 6), which can develop over time, may foster a moral feeling that intentionally infecting others is wrong and hence use condoms as a preventive mechanism (O'Leary and Wolitski 2009). A more positive outlook can as well make people to be optimistic about life prospects and use condoms to maintain their health and extend their lives by protecting against re-infections and transmission as illustrated below:

INTE: How do you manage to use condoms every time you have sex?  
 KB10: We use condoms all the time, except if on one day when we will want to have a child, so that we can extend our lives. That is the instruction we always get from the hospital in order to prevent *kuambukizana* (re-infections). (Married woman aged 25, 5 years with HIV)

The feeling of responsibility to protect others has been referred to as HIV prevention altruism (O'Dell et al. 2008; O'Leary and Wolitski 2009). The above quotes suggest PLWHA's believed self- responsibility and shared responsibility with sexual partners, to protect themselves or their uninfected partners. Consistent condom use appears to be motivated by both self-interest and altruistic concerns for other sexual partners (O'Dell et al. 2008), not just motivations of self- interest as suggested by theories such as the Health Belief Model. Duration of HIV may also be positively related with knowledge about living positively with HIV. Irregular condom use was found to be related to less knowledge about living with HIV/AIDS in a study among the gay/bisexual men and women in New York (Lovejoy et al. 2008).

### Social Support

Social support was shown to have an independent positive relation with consistent condom use. Higher scores of respondent's perceived social support were positively associated with the likelihood of consistent condom use (OR 1.65; 95% CI 1.05-2.60;  $p=0.031$ ). For a one unit increase in social support, the odds of using condoms consistently (vs not using consistently) increases by a factor of 1.65, net of other factors. Social support is channelled via support group membership and counselling and follow up by health care providers and outreach community health workers (Chapter 5). Receiving counselling and membership of a social group showed a stronger association with condom use in a study on PLWHA in South Africa (Gaede et



al. 2006) and in Las Vegas (Reilly et al. 2010). One of the pathways through which social support can boost consistent condom use is that increased social support would decrease stigma and make disclosure easier. This study showed that disclosure to sexual partners was associated with condom use. Social support from social networks enhances positive living and a positive outlook among PLWHA.

KB04: I had a lot of thoughts until my wife told me to stop thinking. She told me we were already positive, so we should think of the future. She told me if I continued thinking like that I would bring more problems to myself. She told me to think about doctors and care givers who could help me. I then stopped thinking and decided to live well. I usually go to seminars, when I hear there is a seminar I have to go, so that I can know how we can take care of ourselves and also to find friends and share (Married man aged 32).

Social support groups provide confidential spaces where experiences and issues about HIV such as disclosure, sexuality and adherence are shared. Many of the messages about positive living and prevention are shared in support group meetings with members of similar status:

KC04: We visit support groups where we learn a lot together. From there you just feel you belong to the society. You just feel you are [like HIV] “negative” and not “positive”. We were taught so many things about living positively with the disease. (Widow, aged 27 years)

Social support has been suggested to increase wellbeing, provides positive experiences and outlook as integration into a social network may help reduce negative experiences such as psychological distress. Depressive conditions and psychological distress were negatively associated with consistent condom use in the bivariate analysis (Table 7.0.3) and other studies (Golub et al. 2011; Crepaz and Marks 2002).

#### Female agency

Although sex of respondent was not significantly associated with consistent condom use (Table 7.0.3), narratives with female respondents suggest that some consistent condom use was made possible at their insistence. Some women explained that in the midst of opposition from their male counterparts, they insisted on condom use and so the men had to comply to use condoms, although sometimes this brought conflicts. Some women reported that they helped their male sexual partners to wear condoms, thereby leaving no room for manoeuvre for reluctant male sexual partners:

INTE: How do you manage to use condoms all the time with your sexual partner?

KB08. When it is time for sex, I make sure that I put it [condom] on for him. I am usually firm and difficult. You know a man's desire is to have children, but you know you cannot have children when you use condoms. You have to have sex *kimwilimwili* (body to body) in order to have children. But *Nakaa ngumu!* (I stand firm) and insist on condom use because I don't know his strain of the virus and he also doesn't know my strain of virus. Everyone should just carry his/her own cross. (Divorced woman, aged 45 years)

INTE: How do you manage to use condoms with your husband all the time?

VB06: I always insist that we use a condom, even when my husband hesitates, I put it on myself, but at times he tears it off. But I inspect it before we get started. I really try to insist and nowadays he cooperates. You know when I started treatment I told him either to choose my life or death, in which case I will leave behind our children and his women [laughter]. (cohabiting woman, aged 35 years)

The women's insistence on condom use was corroborated by a male respondent, a 55 year old widow not yet on ART, whose efforts to have unprotected sex failed after several attempts led him to call off their relationship:

KC09... On the material she came along with condoms and insisted I had to use them.

INTE: Why do you think she insisted on condoms?

KC09: This is normal with today's girls-they cannot go blindly with you before they get to know you...today's girls believe everybody could be infected [with HIV] and it's a problem if you want to have unprotected sex; you have to use condoms.

INTE: So did you reach a compromise

KC09: when she insisted on using condoms every time, I left her alone... I forgot about her. (Widower aged 55 years)

There is a plethora of literature on how differential power relations prevent women from successfully negotiating for condom use (Gupta et al. 2008; Long 2009; Mane and Aggleton 2001; Pulerwitz et al. 2002; Pulerwitz and Dworkin 2006; Stevens and Galvao 2007). These studies have taken the dominant position in the literature that women have less power than men, which inhibits their ability to use condoms. While this is the case for many women, if not, the majority in SSA (Mill and Anarfi 2002) emerging evidence suggests that in some cases women are not as powerless as portrayed (Tawfik and Watkins 2007). However, in comparison, little is known how women exercise agency to ensure that their partners use condoms. From a social

constructionist perspective, men and women are not just passive victims of gender norms, but rather active agents in reconstructing them (Courtenay 2000). The qualitative data demonstrate that women can enforce condom use, and are not powerless victims devoid of agency. A more nuanced analysis of gender that considers women's power and agency in matters relating to sexuality is more meaningful (Persson and Richards 2008).

#### *7.3.4. Barriers to consistent condom use*

Quantitative and qualitative data show that barriers to consistent condom use among PLWHA include: Demographic factors (e.g. fertility desire, age) marriage, perceived condom hazard, feelings of revenge and poverty. I explore each of them in turn.

##### Demographic factors

Consistent condom use was negatively associated with fertility desire. Respondents who do not want a/nother child in the future were more than twice more likely to use a condom consistently than those respondents who wanted a/another child in the future (OR 2.11; 95% CI 1.26-3.54;  $p=0.005$ ). This was reinforced by qualitative data, as exemplified by the quote below:

INTE: Did you use a condom at your last sex.

KC02: No...My wife wants us to use them [condoms], but personally I feel we shouldn't because I have not achieved my objective

INTE: What is it you are looking for?

KC02: I am still looking for that baby boy and once I get him the matter ends there (married man aged 48).

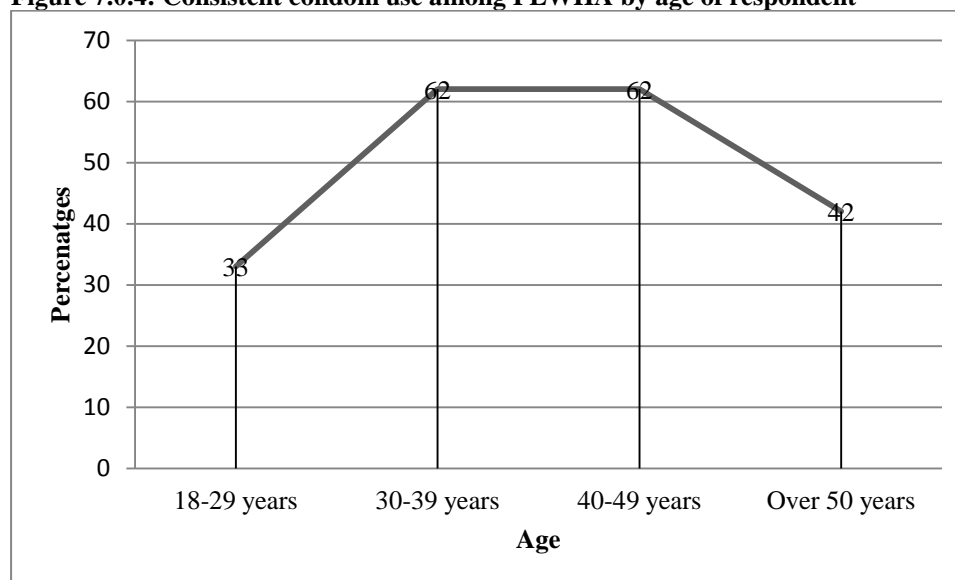
Fertility desire and age are related in their influence on condom use. Fertility desire is higher among the relatively younger PLWHA (chapter 8) not least because they are still young in their reproductive careers and may have yet to achieve their fertility desires and intentions. A childless female PLWHA suggests:

VC10: It is normal and a must to have children, when you get a child, you feel happy, because you have your own children. (Single woman aged 24)

The use of condoms for prevention of pregnancies is therefore expected to be low among those with higher fertility desire. In the older age groups (50 and over), especially among females prevention of pregnancy may not be an issue for many due

to declining fecundity. In line with this expectation, consistent condom use was lowest among the younger age groups and among those beyond their reproductive careers (50 years and above). (Figure 7.0.4)

**Figure 7.0.4: Consistent condom use among PLWHA by age of respondent**



In the multivariate analysis (Table 7.0.4) the odds of using condoms consistently increased by more than two-fold among those aged between 30 and 39 (OR 2.33; 95% CI 1.17-4.64;  $p=0.016$ ) in comparison to those aged 18-29.

Erectile dysfunctions – the inability to achieve or maintain an erection – are commonly reported among PLWHA. In these studies age has been found to be the strongest predictor of erectile dysfunctions, especially after 40 years of age (Crum-Cianflone et al. 2007; Shindel et al. 2011). Inconsistent condom use among older male PLWHA may also be due to erectile problems:

INTE: You have said that you have not used a condom all the time in the last 12 months, right?

KC05: yes that's right.

INTE: Please explain why that has been the case.

KC05: My husband is weak because he just started treatment the other day and so it is difficult sometimes to use a condom. Sometimes he does not have a good enough erection so it becomes difficult to put it on. (Married woman aged 32).

In pro-natal African societies, the societal pressure to procreate is immense (Cooper et al. 2009), making the inconsistent condom use that is associated with fertility desire and age unsurprising. The desire to have children to overcome social stigma may take

precedence over the risk of HIV infection (Moore and Oppong 2007). Childbearing is preferable when done young and within marriage in SSA settings (Agadjanian 2005).

### Marriage

Marital status was significantly associated with consistent condom use. Those who were married or cohabiting were less likely to use condoms consistently compared to those who were single (widowed, divorced/separated and never married). Being single was associated with a 2-fold increase in the odds of consistent condom use in comparison to being married or cohabiting (OR 2.20; 95% CI 1.17-4.16;  $p=0.015$ ). This finding contradicts Allen's (2010) finding among Caribbean PLWHA "that condoms appear heavily used in regular partnerships perhaps symbolising trust and commitment when one or both partners is HIV positive" and motivated by the desire to prevent HIV transmission to them. It is nonetheless in line with other studies in both HIV infected (Moore and Oppong 2007) and general populations (Pulerwitz et al. 2002; Akwara, Madise, and Hinde 2003). It is possible that some women and men do not consider using a condom in the context of marital unions (Moore and Oppong 2007). Condoms may be used initially in the relationship, but may be difficult to sustain (Allen et al. 2011), because they are perceived as incompatible with committed relationships (Undie et al. 2009). Narratives from a woman who has been living with HIV for two years and not yet on ART and a male respondent give us a glimpse into these issues and how consistent condom use with marital and cohabiting partners is problematic:

INTE: Can you please explain why at other times you did not use condoms?

VC03: Eeh, it is difficult to answer that question... At the beginning of our relationship we used condoms all the time but later on it changed. Later on ...you know... you get free with each other and you don't even think of using condoms; sometimes you don't even have those condoms with you. (Cohabiting woman, aged 36).

INTE: Why don't you use condoms?

VC01: I do not have sex outside my marriage. When I want to have sex, I have sex with my wife only. So I do not have to walk with condoms, I do not see the need, because I am faithful (married man, aged 42).

Issues of trust, fidelity and power are important factors inhibiting consistent condom in marriages. In studies in the general population in a variety of settings, condoms are

frequently used in non-regular and commercial than in regular or married partnerships, because they signify mistrust and unfaithfulness (Visser and Smith 2001; Westercamp et al. 2010) and gender power imbalance in close sexual relationships (Pulerwitz et al. 2002) . Whereas non-married women may have some ability to negotiate safer sex, married women face extra challenges because of the fear of being suspected of promiscuity by their spouses, which may lead to separation or divorce (Akwara, Madise, and Hinde 2003).

Economic dependence also prevented women from insisting on condom use or even disclosing their status (chapter 5) to facilitate consistent condom use for fear of abandonment or losing support from the male partner. This is illustrated by a woman who appeared to contradict her survey response of consistent condom use.

INTE: Do you use condoms all the time with your husband?

VB02: Now that is where the problem comes in.

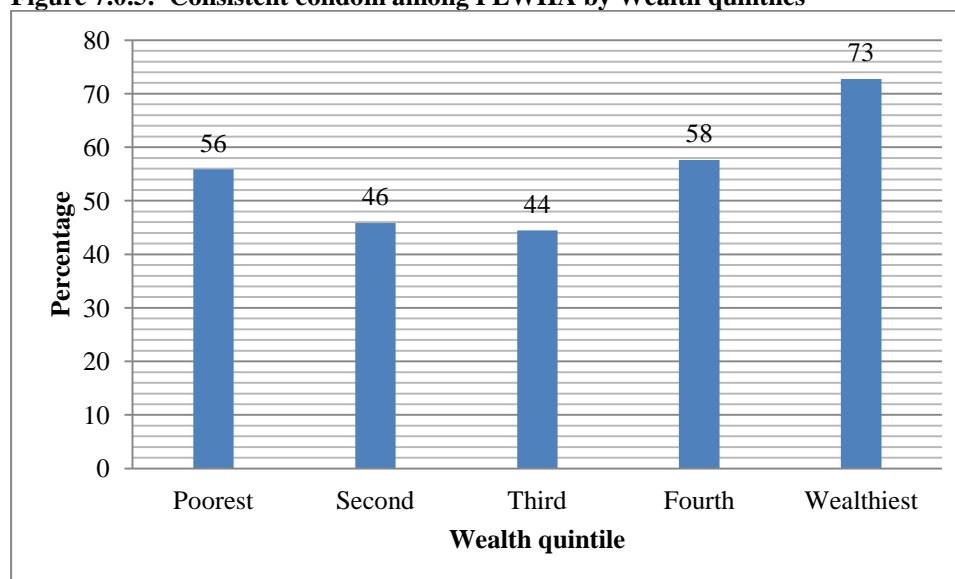
INTE: Can you please explain what that means?

VB02: Like sometimes he does not want to use “Trust” (a brand of condoms) and when I force him to use it he denies us food. That is the bit that is a problem, but I have faith in God that I will make it all the same. (Married woman, aged 35).

The fear and consequences of losing economic support in the slum settlements cannot be under-estimated (see chapter 4). Economic dependence on men has been associated with women’s inability to negotiate for protected sex in other studies among PLWHA and the general population (Allen et al. 2010; Mane and Aggleton 2001; Masanjala 2007; Dodoo, Zulu, and Ezeh 2007).

### Poverty

Respondents from poorest household are less likely to use condom consistently than those from wealthiest households (Figure 7.0.5). Household wealth was categorised into 5 quintiles based on ownership of assets (Rutstein and Johnston 2004). In the multivariate analysis the odds of consistently using condoms in the last 12 months among the wealthiest quintile were 2.4 times higher than those in the poorest quintile (OR= 2.40; 95% CI = 1.07-5.37; p=0.034).

**Figure 7.0.5: Consistent condom among PLWHA by Wealth quintiles**

Poverty as a major barrier to condom use was apparent in the qualitative interviews. Female headed households are the more poor in the slum community (de Laat et al.2008). Women from such poor households may be forced to seek sexual relations that have some survival motives. Economic deprivation and the need for survival support were cited by respondents as the reason for non-condom use with their partners (chapter 4 and 7.3.4). In commercial sexual work non-condom use sexual transactions are common:

INTE: How would you describe your sexual relations since HIV infection?

KC03: If I get a man and he says we shouldn't use a condom, I tell him I want us to use it, but if he refuses we just do it (have sex) without it (condom), *shauri yake* (that is his problem) as long as I get the money. You get others who are willing to use a condom and in fact I have a lot of them in the house. But others refuse (single woman, aged 26, and commercial sex worker).

A study among commercial sex workers in India showed that, because of their need for money, they were sometimes unable to insist on condom use for fear of losing their clients who were averse to them (Cornish 2004).

Studies in the general population in SSA similarly show that poorer youth are less likely than their wealthier counterparts to use condoms (Madise, Zulu, and Ciera 2007). A study among PLWHA in the Caribbean found that of the socio-economic indicators (including education and employment) only economic security emerged as an independent predictor of condom use during last sex (Allen et al. 2010). These

findings tend to lend support to the view that poverty is a major contributor to the spread of HIV/AIDS in resource poor settings.

#### Condoms perceived to be hazardous and inhibit pleasure

Several reasons given in the narratives against use of condoms centred on the inhibiting and perceived harmful effects of condoms. The first and most commonly mentioned effect of condoms is they inhibit pleasure. Both men and women PLWHA expressed lack of sensation and pleasure when using condoms. The most common expression was that “one cannot eat a sweet with the wrapper on” and for many respondents the best sex was “*mwili kwa mwili*” (flesh to flesh).

INTE: You said that using condoms is hard for some PLWHA, why?

KB10: There are some women we meet with at the support group who say that their husbands don't want to use condoms because they say that they don't feel the sweetness [sexual pleasure]... They don't want to eat the sweet with the wrapper on [laughter]. They just want to do it “*mwili kwa mwili*” [flesh to flesh]. (Married woman, aged 25 years).

Some respondents, especially men, felt that women needed their sperms to feel pleasure and satisfaction and as a show of intimacy. The condom prevents the exchange of sexual fluids between partners – a mark of completion of sexual activity – and hence a waste of semen (Coast 2007). A man expressed a passionate dislike of condoms to the extent of suggesting a preference to masturbate rather than use them.

INTE: Did you use a condom during your last sex?

KC09: Aaahi! How can I have sex with a woman while using a condom? Am I to fuck the condom or her vagina...so my blood gets into her?! Then I go and throw away my semen in the toilet, why?

INTE: So you would rather ejaculate inside of her

KC09: Of course yes, in her body; that's how I will know she is my “friend”....[if not] I would rather masturbate.... You know when you sleep with a woman or girl and you ejaculate inside her body, that is time that she also feels good, she needs it; that's is also a sign that she is your lover and vice versa, but if you use a condom and dispose (semen), what was the point of having sex? (Widower, aged 55).

Sexual pleasure and satisfaction are paramount and the need for immediate sexual gratification may overshadow the use of a condom. Similar findings have been reported among PLWHA in Uganda (e.g Allen et al. 2011) and the general population in Kenya (Thomsen, Stalker, and Toroitich-Ruto 2004). This adds further evidence to



studies that show that sex in African settings is not only meant for procreation (Undie and Benaya 2006). Most studies dealing with sexuality in SSA tend over-emphasize procreation rather than pleasure as the main driver for sex. However, evidence suggests that, as everywhere else, both procreation and pleasure are important aspects in African sexuality. In Kenya, sex is traditionally perceived as a joyful activity, with men and women responsible for maximising sexual pleasure for their partners and themselves (Kimani 2004). In some communities in Malawi, Uganda and Rwanda the practise of labia elongation is meant to enhance sexual pleasure (Koster and Price 2008; Tamale 2006).

Condoms were also perceived to be harmful and were reported as being physically injurious by causing pain and irritation to the genitalia during and after sexual intercourse.

INTE: Why don't you use condoms then?

KC09: I once used a condom...the moment I removed the condom...my friend! The feeling I had on my penis... it's like someone had applied pepper in your mouth... I decided not to use condoms...I don't want it, If it's a question of condoms, I would rather do away with a vagina because it will not benefit me in any way (Widower, aged 55)

Some respondents believed that condoms were laced with HIV/AIDS and hence using them would lead to re-infections anyway. This point was articulated by a respondent who seemed to harbour conspiracy theories around HIV transmission. He also believed that the oily lubrication on condoms would aggravate his HIV/AIDS condition

INTE: Please tell me what else makes you not to like condoms?

VC01: In fact it was being said that it was dangerous to use a condom because the condoms had the HIV virus inside. Weren't condoms introduced just recently after AIDS was discovered? Did you see or hear of condoms in earlier times? So how can I put it?... Again you are using something which you don't know about...what is it? It is lubricated with oil... you don't even know if this oil is responsible for aggravating your disease...this oil can create problems for you; you can die faster. (Married man aged 42)

The belief that condoms are laced with the HIV virus has been documented elsewhere in Kenya. In a survey in Kisumu, it was found that 44% thought that condom lubricants contained HIV (Volk and Koopman 2001). A qualitative study on condom use among men with commercial sex workers in Mombasa, Kenya shows that these

beliefs were prevalent (Thomsen, Stalker, and Toroitich-Ruto 2004). The belief that condom lubricants can aggravate the HIV/AIDS condition among PLWHA is new, to the best of our knowledge. These beliefs tie in with HIV/AIDS conspiracy beliefs or theories – the belief that HIV/AIDS was created to decimate certain populations. Studies have found that HIV/AIDS conspiracy beliefs negatively impact people's acceptance of condom use in the US (Bogart and Bird 2003) and South Africa (Bogart et al. 2011). The final section examines the B (e faithful) component of ABC risk reduction.

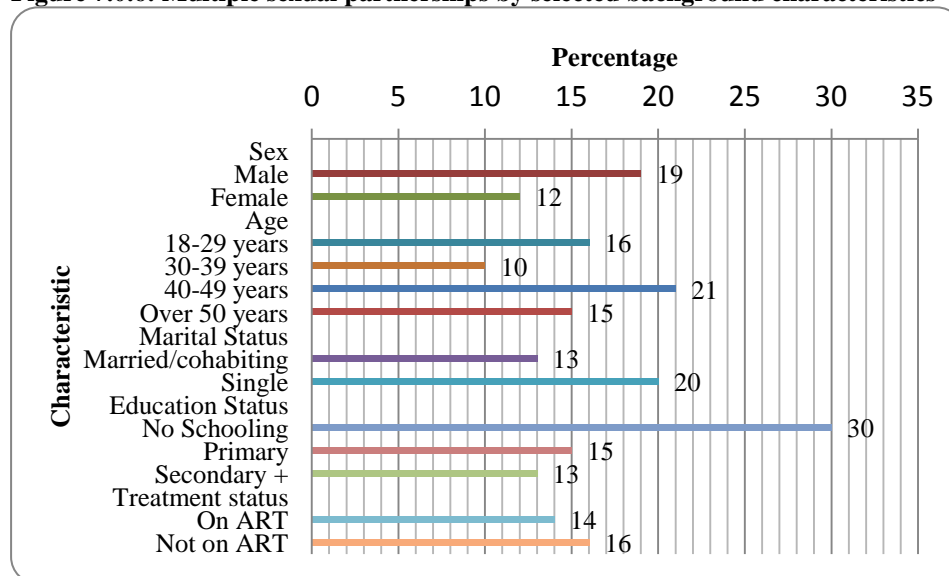
#### **7.4. Multiple sexual partnerships**

This study asked survey respondents who were sexually active about the number of sexual partners in the last 12 months. Multiple sexual partners were sexual partners that were more than one irrespective of their marital relations. This, therefore, included partners that were in polygamous marriages. There is one major data limitation though: the timing or duration of these partners was not collected and so it is impossible to tell whether partner change or multiple sexual partnerships occurred serially (having sexual partners one after another) or concurrently (having sexual partners at the same). This distinction is important because studies show that the rate of HIV transmission is higher, at least in the general population, in concurrent partnering than sequential sexual partnering, especially in heterosexual transmission in SSA (Mah and Halperin 2010; Halperin and Epstein 2004). However, recent studies that account for coital dilution – the reduction in per-partner coital frequency following acquisition of a new partner – question the concurrency hypothesis as a driver of HIV in SSA (Sawers, Isaac, and Stillwaggon 2011).

Of those respondents who were sexually active, 15% reported to have had sex with multiple sex partners in the last 12 months (19% and 12% for men and women, respectively) (Figure 7.0.6). There were notable differences in some demographic profiles of those who reported multiple sexual partnerships. The proportions of those who engaged in multiple sex among males, singles (widowed, divorced/separated and never married) and those without formal schooling was higher than females, married and cohabiting couples and those with primary and above education.. There were no

notable differences in sexual partnership between those on ART and those not on ART.

**Figure 7.0.6: Multiple sexual partnerships by selected background characteristics**



Respondents were asked to report on the number of sexual partners in the last 12 months. Men reported, on average, higher numbers of sexual partners than women (mean number of sexual partners for men was 1.6 (SD=2.6; range=1-30) while that of women was 1.3 (SD= 1.3, range= 1-14)). Studies in SSA and elsewhere have shown that men are more likely than women to have, if not, report multiple sexual partners. For example, a study among PLWHA in Mombasa found that 17% of men reported multiple sexual partners compared to only 6% of women (Luchters et al. 2008). In the general population, the latest Kenyan DHS reported that among the 15-49 year olds, 9% of men reported multiple sexual partners compared to only 1% of women in the 12 months preceding the survey (KNBS 2008). Men's reported multiple sexual partnerships has led to a common position in the literature that men are more likely to expose their sexual partners to HIV/infection (Kalichman, Cain, and Simbayi 2011).

#### 7.4.1. Factors associated with multiple sex partners among PLWHA

Quantitative and qualitative data show that the following socio-demographic and social relationship factors are associated with multiple sexual partnerships among PLWHA in the slum setting. The demographic characteristics that were independently associated with multiple sexual partnerships were gender and education, while the social

relationship included disclosure of HIV status, pleasure seeking and revengeful feelings. I explore each of these in turn.

### Gender

Gender was significantly associated with multiple sexual partnerships in both bivariate (Table 7.0.5) and multivariate analyses (Table 7.0.6). Male respondents were more than twice (2.4 times) more likely to report having more than one sexual partner than female respondents net of other factors (OR 2.41; 95% CI 1.28-4.52 p=0.006). This finding is in line with extant literature that has documented higher prevalence of multiple sex partner among males in PLWHA (Luchters et al. 2008) and the general population (KNBS 2008). Some of the difference is possibly due to reporting bias. Multiple sex partners are stigmatised for women in Kenya and SSA in general, producing a rationale to either under-report or at least no incentive to over-report them, relative to men (Kajubi et al. 2011).

**Table 7.0.5: Bivariate analysis of multiple sex partnership**

CHARACTERISTIC	MULTIPLE PARTNERS MP (N=57)	SINGLE PARTNER (N=321)	UNADJUSTED ODDS RATIOS FOR MP
	Percentages	Percentages	OR and 95% CI
<b>Sex of respondent</b>			
Male	19	81	1.77* (1.01-3.13)
Female	12	88	1.00
<b>Education status</b>			
None (ref)	30	70	1.00
Primary	15	85	0.41ns (0.15-1.13)
Secondary plus	13	87	0.34* (0.10-1.04)
<b>Disclosure to partner</b>			
Never	26	74	1.00
Sometimes	33	67	1.40ns (0.64-3.06)
All the time	08	92	0.25*** (0.13-0.49)

Significance levels \*\*\* <0.001; \*\*<0.01, \*<0.05, NS – Not significant

**Table 7.0.6: Predictors of multiple sexual partnerships among PLWHA**

VARIABLE	ODDS RATIO	P VALUE	[95% CI	
<b>Sex</b>				
Female(ref category)	1.00			
Male	2.41	0.006	1.28	4.52
<b>Education</b>				
None(ref category)	1.00			
Primary	0.40	0.094	0.13	1.17
Secondary plus	0.24	0.020	0.07	0.80
<b>Disclosure to partner</b>				
Never (Ref category)	1.00			
Sometimes	1.45	0.369	0.65	3.24
All the time	0.23	0.000	0.11	0.46

Gender – the socially constructed attitudes and behaviours which are associated with biological sex – is usually the most common explanation of differential sexual partnerships between men and women (Kerrigan et al. 2008). In the literature, the concept of vulnerability of women is one organising concept in the gendered multiple sexual partnership, with women’s vulnerability due in large part to the relatively poor economic status of women relative to men (Gupta 2002; Dodoo, Zulu, and Ezeh 2007; Masanjala 2007). Women in this study are more likely to be unemployed or employed in low paying jobs in the domestic sphere and around homes. Research has shown that women’s economic vulnerability can force them to engage in sex for money or favours (Dodoo, Zulu, and Ezeh 2007) as the conversation with a woman respondent who has been living with HIV for 15 years illustrates:

INT: In your opinion why do you think some HIV positive people have multiple sexual partners?

VB01: I have friends who have multiple sexual and have been asking myself why. But when I look at them I think it is poverty. For one woman the husband passed on and she has children to see through school. So she does not have money to take care of her children. So she is looking for money from men.

INTE: You said that you had sex with more than one man, how did you start?

VB01: I started like maybe I am with one as my boyfriend. But my friend told me ladies don't take just one man. That you need more than one so that when one fails to help you the other will.

INTE: How would they help you?

VB01: She told me to look for one man for bread and another one for advance, a night man. I was wondering and I asked her, what was a night man? A man should just be one. If I get pregnant what will happen? She told me no, there is a drug called *Kamuti*, it will take care of everything. (Never married woman, aged 34)

Women's social vulnerability can also be seen in terms of their potential economic dependence on men; women are less likely to confront their male partner's multiple sexual behaviour for fear of losing economic support or of facing violence (Kalipeni, Flynn, and Pope 2009). However, relatively little attention in the literature is directed towards men's vulnerability, which in heterosexual transmission means a woman can only get HIV from a man (who might have been vulnerable as well) who was infected by a woman (Persson and Richards 2008).

Furthermore, infection with HIV infection can reduce some men's financial ability to attract and sustain female sexual partners.

INTE: So how would you describe your sexual life since you found that you are HIV+?

KC09: Very tough for me. I can have sex but then it's tough

INTE: Meaning you engage in it but not always?

KC09: I mean I don't like it...nowadays friendship is tied to money. If you want to sleep with a woman...she will ask for money and that is what I don't have. So if you are sick and infect her, she will come back to you to ask for money because you infected her...every time she will ask for money and you have no jobs. These girls of today...you know you need money to get love (sex). Once you start having affairs, you are no longer alone. You have someone by your side and she will want you to meet her needs. I don't have financial means... (Widower, aged 55)

Some literature, drawing on concepts of male as providers, suggest that males with more resources have greater access to female sexual partners (Kimuna and Djamba 2005). The positive relationship between wealth and HIV prevalence in SSA has been attributed in part to the ability of wealthier men to maintain multiple and concurrent sexual partners because of their wealth (Madise, Zulu, and Ciera 2007; Shelton, Cassell, and Adetunji 2005).

For some men, multiple sex partners validate their manhood as prescribed by cultural expectations, a phenomenon that is known as hegemonic masculinity, rooted in patriarchy and a masculinity ideology (Devries and Free 2010). Patriarchy as a system of male domination over women creates privileges for men and results in power asymmetries and socio-economic inequalities between men and women (Kalipeni, Flynn, and Pope 2009). As a system of differential privileges, there are double-standards for sexual behaviour of men and women. While multiple sexual partnerships by men is tolerated, if not, celebrated, it is frowned upon in women (Peplau 2003)

However, masculinities that traditionally celebrated multiple sexual partners are, in the current era of HIV/AIDS increasingly being questioned by both men and women. In the current HIV/AIDS era, hegemonic multiple sexual partnerships are increasingly viewed as irresponsible behaviour for both males and females (Long 2009). What was expressed in the narratives was the fact that in the modern day, both men and women are increasingly becoming wary of multiple-partner sexual relations. A female respondent observes that nowadays men actually fear having sex with many women as a result of HIV and that *mipango ya kando* (slang for extra marital affairs) is not as common as before:

INTE: How is the sexual behaviour of men and women in this community in this era of HIV/AIDS?

KA02: Nowadays you find that if men or boys see a lady in the streets, you hear them saying that *labda huyo ameibeba* (that one could be carrying it [HIV])

INTE: So there is fear on the side of men or what?

KA02: Yes they fear women; they fear getting infected by women

INTE: So you mean their behaviour has changed or what?

KA02: It has changed because initially men would prefer to have multiple partners even outside their marriages, but nowadays they have to stick to their marriages. Even some women liked to move around with men and had extra marital affairs. But these days *mpango ya kando* is very risky. (Divorced woman, aged 24).

A male respondent reports that in his ethnic group (luhya) extra-marital affairs were discouraged both for men and women, a norm that he observes to date:

INTE: How is an ideal man and woman expected to behave in respect to sexual relations in your community?

KA011: In my community (Luhya) it is required of women that once they have identified a partner and married, they must remain faithful. Even the husband should remain faithful. My community believed that if you are a person *wa kurugaruga* (who jumps) here and there (meaning who moves around with many partners) then you bring some curse to your children; they would have mental problems or completely loose direction in their lives. So that is why I have also kept my faithfulness. (Widower aged 52)

These results appear to suggest that there is change as well as continuity in multiple sex partnering. The gender stereotype of “hegemonic masculinity” and femininity, where men are normatively expected to be sexually dominant, aggressive and philanderers while females are supposed to be timid, passive and monogamous (Devries and Free 2010; Kalipeni, Flynn, and Pope 2009) may still hold. However, these gender normative attitudes and behaviours are viewed in static and fixed terms (Long 2009), where the man in SSA is a potentially polygamous patriarch with a ferocious appetite for multiple sexual partners. Polygamy thrived in an era without HIV, but with HIV such practices are being questioned. Several men stated avoiding multiple partners for fear of reinfections, appearing to reconfigure masculinity to suit their HIV status. Studies show that masculinity is constantly changing (Long 2009). For some respondents, HIV/AIDS is working to associate multiple partners for females and males alike with irresponsibility. Some women, at least in this urban setting, are not as sexually passive and timid as commonly believed and men are not behaving in ways consistent with the hegemonic masculinity ideals as far as multiple sexual partnerships is concerned. This lends credence to the idea that traditional gender roles are dynamic and in a state of flux (Devries and Free 2010).

The notion of men’s engagement in multiple sexual partnerships, thereby putting their female counterparts at risk of HIV (re-)infection is pervasive in SSA HIV literature. However, emerging evidence (with biomarkers) appears to question the commonly held notion that extra marital sex among males is responsible for the spread of HIV in marriages in SSA. A recent analysis of DHS HIV status data in 5 SSA countries reveals that the proportion of female discordant couples (where the wife is infected and not the husband) is higher than male discordant couples (where the husband is infected and not the wife) (de Walque 2007). This shows that more females than males did not get their HIV from their spouses; they got elsewhere. It is true that some of these



women got the virus before marriage. However, it may also imply that the reporting of more multiple sex partners among men in comparison to women may reflect a reporting bias; women may be more likely to under-report extra-marital or multiple sex partners in response to societal values and norms (Nnko et al. 2004).

### Disclosure

Those respondents who consistently disclosed their status to sexual partners were 77% less likely to have engaged in multiple-partner sexual relations in the last 12 months than those who never disclosed their sero-status to partners (OR 0.23; 95% CI 0.11-0.46  $p < 0.001$ ). This findings mirrors a similar study in South Africa, which found that PLWHA who did not disclose their status reported more sexual partners than those who did (Simbayi et al. 2007b). Qualitative data illustrate that people who engage in sexual with multiple partners are less keen on disclosing their status or find it problematic doing so:

INTE: How often do you disclose your status to your partners?

KC01: Not really... like that last one I did not disclose to her. There were no many stories. We just did it without asking each our HIV status. It is very difficult to start telling people that you want to have sex [with them] and that you are HIV Positive. (widower, aged 41)

INTE: Why do you think they do that (not disclose to partners)?

KA09: It depends with one's heart. Some women will just get young boys and bring them to the house and don't disclose their status. So many people do not want to disclose their status to their partners. (Widow, aged 45)

Disclosure is associated with safe sexual behaviour such as condom use (section 7.3). People who consistently disclose their status are less likely to engage in unsafe behaviour such as having multiple sexual partners. It is possible that lack of disclosure may be due to fear of rejection by potential partners after their sero-status is known, the consequence of which may not only be denial of sex, but may also lead to loss of economic support as illustrated by this quote from a nurse:

KNS1: These are people who pass through all the counselling, but some pick up partners whom they don't know their status and even do not bother disclosing to them. When you ask them why, mostly the ladies will tell that if they did [disclose] the man will leave them so they will have no one to pay rent or buy food for them. So it becomes difficult to control infections and reinfections.(Nurse)

Not disclosing HIV status to sexual partners mirrors a larger social context of concealment of status as a result of stigma and discrimination against PLWHA, making disclosure of HIV status to sexual partners less likely to occur especially if a person has experienced previous negative outcomes for doing so (Simbayi et al. 2007b). Given that disclosure has both pros and cons for PLWHA (chapter 5), it has been suggested that perhaps prevention programmes' should emphasise consistent condom use – regardless of decisions on disclosure (Simbayi et al. 2007b).

### Revenge and malicious intent

Some respondents observed that PLWHA, both male and female, might engage in multi-partner sexual relations with a malicious intent to *sambaza* (spread) the HIV virus as a form of revenge for having been infected. Some respondents said that some PLWHA think that their days on earth were numbered and so are bound to become carefree:

INTE: In your opinion, why do you think some PLWHA have multiple sexual partners?

KB06: Some people get bitter and are out to revenge which is not good since they infect some innocent people in the process. It is not that they have more sexual desire than others or don't get satisfied with one partner. It is just that they want to revenge. (Married man, aged 36)

INTE: What other reason makes PLWHA have multiple sexual partners?

VB01: May be, she will be looking for revenge. You know some people decide they will not die alone. And even this lady said "I have the virus and it's my husband who infected me so I am going to *sambaza* (spread) it around. Some people do not want to die alone; they want to ensure they have finished people. (Single woman, aged 34)

Revenge as a motivator of multi-partner sexual relations among PLWHA has been documented in a study in South Africa (Cloete et al. 2010). What is of note is that in my study, the feelings of vengeful spread were attributed to other PLWHA; none of the respondents admitted that they harboured such feelings. In fact almost everyone seemed to be disproving of this kind of feeling and behaviour. It is possible that their narratives depicted their own behaviour or even general perceptions of society about PLWHA. It is also possible that PLWHA are viewed by society as vengeful individuals who are out to intentionally infect as many as possible. PLWHA are

depicted as a separate promiscuous group by society and that this depiction in turn fuels stigma, rejection and discrimination.

### Sexual pleasure

A number of respondents reported that PLWA may engage in extra-marital affairs or multi-partner relations for the sake of sexual satisfaction and pleasure. Multiple sexual partners could provide variety in sexual performance or a new experience of sexual performance that was missing in their current spouse or partner. One man sought sex with an extra-marital sexual affair with a female sexual partner from another community:

KA14:...It is said the one who is uncircumcised is more responsive, more sensitive and has more heat than the circumcised. When you touch her the *nyege* (slang for libido) comes very fast. And so I tried a Luo who was not cut (circumcised) and I felt like divorcing my wife [laughter]. Their [Luo's] bean [clitoris] is long and that helps them to pour water [get orgasms]. (widower, aged 38)

A male respondent claimed that women will also seek extra-marital affairs for sexual pleasure:

INTE: In your opinion, why do some HIV positive people have multiple sexual partners?  
 VB10: Some of them are not satisfied or contended with the partner they have so they go out looking for alternatives. In fact, the Kikuyu Woman is very bad. She is never satisfied even if you slaughtered a cow for her. When she feels you cannot satisfy her [sexually], she goes out to look for another man, a Luo or Luhya may be. She complains that you have a small one; she wants a big one, a stout one. That's what I have heard out there.

INTE: What is it that's small?

VB10: The penis. The long penis satisfies them. When they start saying its small, they are going to stray.(married man, aged 43)

A female respondent observed that ART can increase libido in women and that this might be a contributing factor towards having sex with multiple partners.

INTE: In your own opinion why do you think some HIV persons have multiple sexual partners?

KB08: To be honest, these ART drugs raise one's libido. They make your blood hot, make you to want a man, and if you are that kind of woman who cannot control herself you will be here and there.(Divorced woman, aged 45)

Sexual satisfaction is important in sexual relationships and it deserves due attention in HIV prevention programmes. People, including PLWHA might seek sexual satisfaction from elsewhere if they cannot get it from their present sexual relationship. It is just not simply the case that men will seek multiple sexual partners to express their hegemonic masculinity ideals or that women are so poor and powerless and only engage in sex with many partners for survival. While the fact that poverty, power and masculinity cause vulnerability for women is not in dispute, other issues like pleasure and satisfaction need due recognition. Other studies have started to question the ubiquitous notion that women are powerless, passionless and poor victims of male sexual aggression in SSA settings. For example, Tawfik and Watkins (2007) observe that in rural Malawi, women are not only motivated by money for survival, but also by passion and revenge for their men's infidelity, in their active search for extra-marital affairs.

### **7.5. Conclusion**

This chapter explored risk-reduction behavior - ABC- and its context among PLWHA. Levels of condom use among PLWHA in this study are higher than levels observed in the general population. Nearly three quarters (73%) of PLWHA used a condom during last sex. Condom use at last sex among PLWHA ranges from 54%-80% among PLWHA in different settings while in the general population in Kenya is around 13%. Also of relevance, however, is the consistency of condom use. Even though 74% were sexually active only 56% of them used a condom consistently to prevent re-infections and infections. Consistent condom use among PLWHA has been reported to range from 33%-65% while that in the general population in Kenya is about 7%. Otherwise, the levels of abstinence and multiple sexual partnerships among PLWHA is not that different from what has been reported by studies in the general population. Reported abstinence was 23% and being faithful was 85% in this study. Reported faithfulness to one sexual partner in studies among PLWHA and the general population is about 80% and over.

Facilitators of safer sexual behavior included ART use and disclosure of HIV status, and the barriers included gender relations, poverty, the search for pleasure and misconceptions about the harmful effects of condom use. The findings suggest that interventions for safer sex behavior among PLWHA in resource-poor settings require attention to treatment access and understanding of poverty, identity, gender dynamics, and relationship issues (chapter 9). The next chapter builds the discussion on sexual behaviour by examining reproductive preferences, including how they affect as well as are affected by safer sex concerns.

## **Chapter 8: Fertility intentions and contraceptive behaviour among PLWHA.**

### **8.1. Introduction**

The previous chapter showed that about three quarters of the study respondents were sexually active, highlighting the existence of reproductive health needs among this population. The majority of PLWHA in SSA are of reproductive age (WHO/UNAIDS 2008). Reproduction is central to family and household life in SSA (Cooper et al. 2007; Heys et al. 2009; Hosegood 2009). PLWHA might continue to pursue parenthood in order to avoid societal disapproval associated with childlessness (Awiti Ujji et al. 2010; Cooper et al. 2009; Myer, Morroni, and Rebe 2007). Other PLWHA might, however, want to stop or postpone having children (McCarragher et al. 2008; Delvaux and Nöstlinger 2007). Yet very little is known about whether HIV infected individuals desire to have children, their need for and use of contraception and what factors influence these decisions in SSA in general (Cooper et al. 2009; Kanniappan, Jeyapaul, and Kalyanwala 2008; Myer, Morroni, and Rebe 2007). This chapter explores fertility desires and intentions and family planning need and use among HIV positive men and women and the factors that influence them in Nairobi slums. This chapter contributes to answering the research questions: What factors contribute to an explanation of sexual and reproductive intentions and behaviour of men and women living with HIV and AIDS? What are the barriers to achieving sexual and reproductive intentions of men and women living with HIV/AIDS?

It is important to study fertility desires and intentions and contraceptive use among PLWHA because HIV can be transmitted in the same way that pregnancy is achieved, that is, through unprotected hetero-sexual intercourse (Spaulding et al. 2009). Thus, unprotected sex among PLWHA, in order to conceive, carries the risk of transmitting HIV to sexual partners and subsequently to children during birth or breast feeding. The reproductive decisions made by PLWHA and their partners have long-term consequences for the survival and wellbeing of their families and society at large (Hosegood 2009). However, the availability of ART and PMTCT programmes has dramatically reduced levels of infectiousness (Persson 2010; Quinn et al. 2000) and the chances of transmission of HIV from mother to child (Howard 2003; Iliyasu et al.

2009). This has given rise to the growing recognition of the rights of PLWHA to have children or prevent unintended pregnancies (Delvaux and Nöstlinger 2007; Segurado and Paiva 2007). Understanding fertility desires and contraceptive need among PLWHA is, therefore, crucial for two reasons: to provide fertility and family planning counselling and services in order to protect their new-borns', partners' and their own health; and, support for children born to infected parents (Kaida et al. 2011).

The availability of ART and PMTCT programmes, in theory, should make pregnancies and childbirth among PLWHA possible with minimal risks of horizontal and vertical transmission of HIV/AIDS (Hayford and Agadjanian 2010). The integration of HIV/AIDS services and family planning services, in theory, should ensure that PLWHA who desire to postpone or terminate childbearing have access to family planning services (Spaulding et al. 2009). However, in practise, considerable logistical, financial and cultural barriers constrain the implementation of these programmes and the realisation of reproductive health needs and goals among PLWHA (Bharat and Mahendra 2007; Boonstra 2006; Delvaux and Nöstlinger 2007). This chapter examines how men and women living with HIV/AIDS in a slum setting navigate the socio-cultural landscape and logistical challenges in accessing and using family planning services to realise their reproductive intentions and goals. Family planning prevents unwanted pregnancy, which contributes to substantial health benefits for women and children, including reduced maternal morbidity and mortality and increased infant survival primarily through birth spacing (Cleland et al. 2006; Smith et al. 2009).

Fertility intention, as an area of focus in demographic research, has attracted a great deal of debate, centred around its validity and reliability and its predictive value for future fertility (Bongaarts 1992; Kodzi, Johnson, and Casterline 2010). The assumption inherent in fertility preferences – based on the theory of planned behaviour – is that individuals are able to make rational choices about the number of children they would like to have and then implement such choices (Berrington 2004). A considerable literature (eg Casterline, El-Zanaty, and El-Zeini 2003; Voas 2003) challenge this assumption, that the number of births that are reported as unwanted is evidence that individuals are not always capable of implementing their fertility goals. However, a growing body of literature (e.g Bankole and Westoff 1998; Kodzi, Johnson, and Casterline 2010) has demonstrated a correspondence between prior

intentions and subsequent fertility, suggesting that fertility intentions predict future fertility. Fertility intentions and desires are used interchangeably here, although it is recognized that they denote different aspects of fertility preferences (chapter 2); this slight difference is not substantively interesting for this study, not least because the questions and their translations do not clearly distinguish between the two.

In fertility research fertility intentions and contraceptive behaviour are usually viewed together as two aspects of the complex process of fertility change and regulation (Agadjanian 2005). Fertility intentions in terms of desire and timing of future children can affect contraceptive use (Agadjanian 2005; Casterline and Sinding 2000). Studies attempt to link the two sets of reproductive behaviour by assessing how well contraceptive use matches reproductive intentions and goals (Agadjanian 2005; Montgomery and Casterline 1996). Studies have established that there is a mismatch between fertility preferences and contraceptive use, the product of which is the concept of unmet need for family planning – non-use of contraception despite expressed desire to stop or postpone childbearing (Casterline, El-Zanaty, and El-Zeini 2003; Casterline and Sinding 2000). The chapter looks at how fertility preferences (mis-) match contraceptive use among PLWHA and explores the reasons for this.

This chapter is structured using attributes of reproductive preference: fertility desires and intentions, contraceptive use and unmet need for family planning. Section 8.2 provides quantitative and qualitative data on the prevalence and determinants of fertility desires and intentions among PLWHA. Section 8.3 examines prevalence of contraceptive use and unmet need for family planning, juxtaposing it with the general population in the study area. Finally, 8.4 discuss factors that influence contraceptive use and causes of unmet need for family planning using quantitative and qualitative data.

## **8.2. Fertility desires and intentions: Are they fraught with ambivalence?**

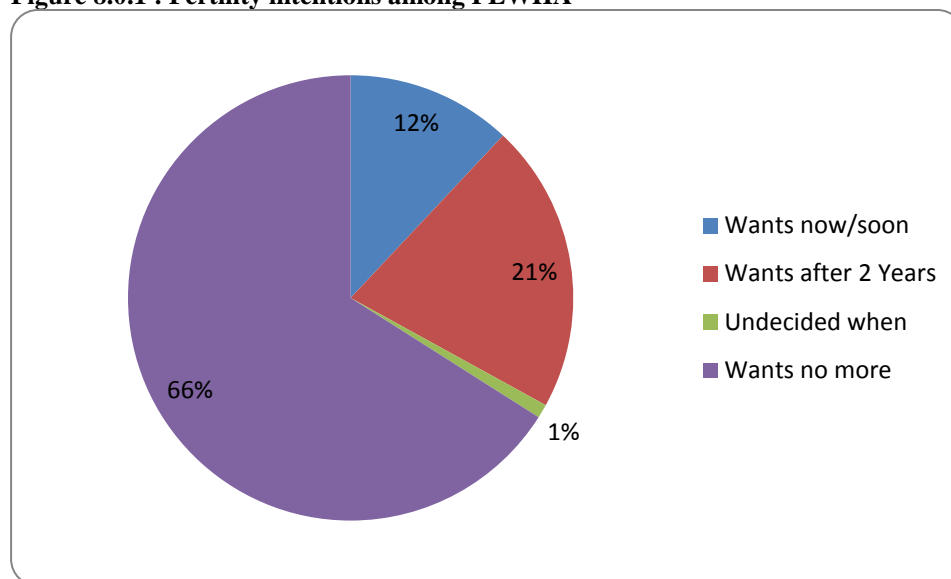
Fertility desires in this study were elicited by asking the following question to eligible women (18-49 years) and men (18 years and older): Would you like to have (a/another) child or would you prefer not to have any (more) children? Those who indicated that they wanted a/another child were asked the total number of children they would like to have and their sex composition. They were also asked how long they



would like to wait before having a/another child. These are standard questions that are routinely asked in the Kenyan DHS and were adopted for comparison purposes. However, given established anti-natalist policies towards PLWHA (Nattabi et al. 2009), and negative attitudes from society and healthcare providers towards PLWHA's childbearing (Boonstra 2006; Lusti-Narasimhan, Cottingham, and Berer 2007), some PLWHA may under-report their desire for any/more children. In addition, fertility intentions are influenced by circumstances (such as existing family size) and so are bound to change over time, and the results presented here are cross-sectional.

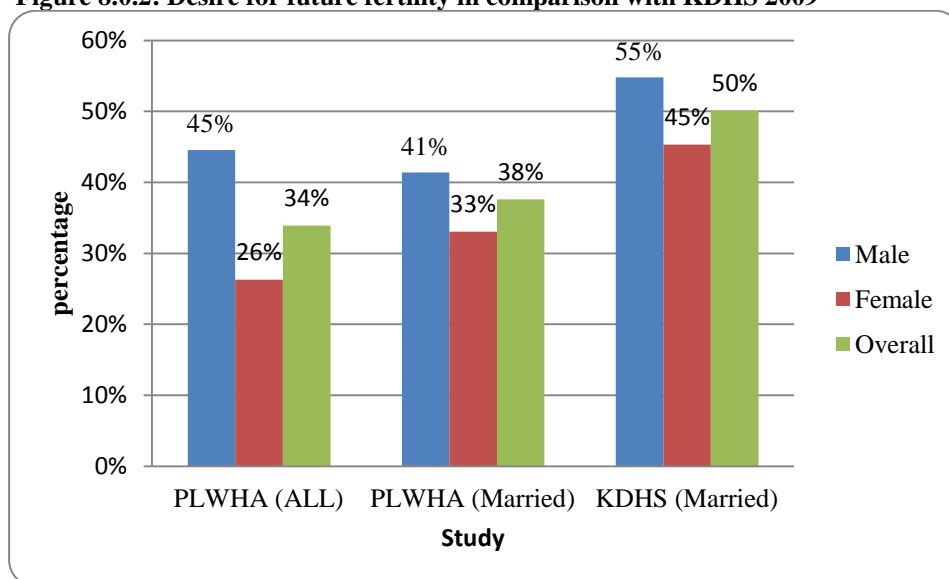
More than a third (34%) of PLWHA in the study desire children (Figure 8.0.1). Over one fifth (21%) of women and men with HIV/AIDS would like to wait two years or more for their child, and 12% would like to have a child soon (within two years). Just one per cent of PLWHA is undecided on when they would like to have their next child. Two thirds (66%) of PLWHA do not want to have any/more children.

**Figure 8.0.1 : Fertility intentions among PLWHA**



Source: Candidate data

Desire for more children among PLWHA, even though substantial (34% overall, 38% among the currently married, and 45% among men and 26% among women), is less than that of the general population in Kenya (50%) using recent DHS data (Figure 8.0.2) and slum population (57% among married women) (APHRC 2002).

**Figure 8.0.2: Desire for future fertility in comparison with KDHS 2009**

This confirms other studies (e.g Cooper et al. 2009; Myer, Morroni, and Rebe 2007), which have shown that infection with HIV depresses, but does not eliminate, desire for future fertility. However, these figures are comparable with or higher than studies conducted elsewhere among PLWHA with HIV/AIDS in SSA. A study from South Africa found that 29 % of PLWHA (36% among men and 26% among women) wanted to have children in future (Myer, Morroni, and Rebe 2007). In a Ugandan study 35% of PLWHA reported that they wanted to have more children (Heys et al. 2009). Another study in Uganda reported that 28.6% of PLWHA expressed the need to have a child in future (Kakaire, Osinde, and Kaye 2010). While in Nigeria, a similar study found a relatively higher proportion (64%) of PLWHA who expressed a desire to have more children (Iliyasu et al. 2009).

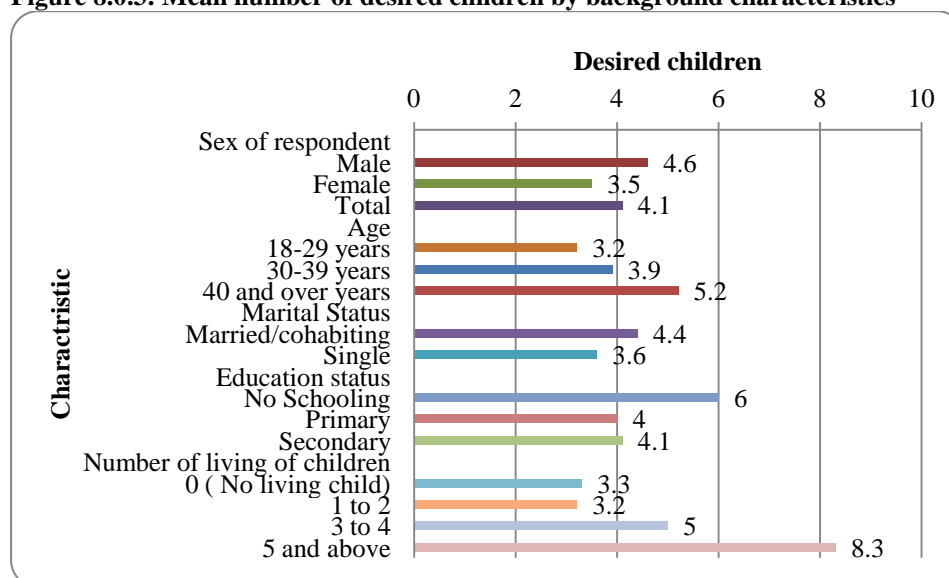
### 8.2.1. *Desired fertility*

Respondents who expressed desire for a child/more children in the future were asked about the number of children they would like to have and their sex composition. The number of living children was captured in question 4.02 and number of more children desired was captured in question 4.06 (appendix 1). “Desired fertility” was derived here by adding the number of living children to the number of more children desired for those who desire future fertility. This is just a simple summation and does not in any way attempt to derive the Desired Fertility Rate. Studies show that desired fertility predicts future fertility (Bankole and Westoff 1998; Kodzi, Johnson, and Casterline

2010); and does not suffer from “ex-post” rationalisation of children, as the case is for ideal number of children (Bongaarts 1990; Pritchett 1994) ( Chapter 2).

The mean number of desired children for the study sample was 4.1 (Figure 8.0.3). There is a significant difference in the number of desired children by sex, with males wanting more children than women (4.6 vs 3.5). There is significant variation of respondent’s desired fertility with their age, with desired fertility rising from 3.2 children for those aged 18-29 and surpassing 5 children after age 40, indicating that older cohorts of PLWHA desire more children compared to their younger counterparts. Desired fertility size decreases significantly with education, falling from 6.0 children among respondents with no education to 4.0 children among those with at least some primary schooling. Currently married or cohabiting respondents have larger desired fertility (4.4 children) compared to the single (3.6 children). The mean number of desired children for those without a child was 3.3 compared to over 5 for those with 3 and over.

**Figure 8.0.3: Mean number of desired children by background characteristics**



The quantitative description of fertility desires based on survey responses may suggest that all the respondents were able to clearly state and articulate their reproductive intentions. However, this does not necessarily hold true. When we consider our qualitative data we see that respondents’ fertility desires and intentions could sometimes be ambiguous and even change and become contradictory over the course

of the interview for some. The following quotes illustrate the ambivalent, ambiguous and sometimes contradictory accounts of reproductive intentions. In the first quote a female respondent aged 34 years seems to contradict her survey response in the course of the qualitative conversations:

INTE: Now let us talk about reproductive and family planning matters. The last time you said you did not want to get any children?

VB01: I said I did not want a child at all.

INTE: Why did you say you did not want more children?

VB01: I don't want a child right now, later I may get a child, but not for now.( Single mother of 1)

In the second quote a male respondent appears to contradict himself about future children, making it difficult for the analyst to clearly place his fertility intentions. He starts by saying that he would like to have another child if he marries. And when asked further why he would like to have another child, he appears to retract, or rather contradict, his earlier expressed wish with an assertion that he has no desire for a child because that child might get infected with HIV.

INTE: Would you like to have another child?

KC09: If I had a wife it would be the right thing to get a child. When I have another wife, I will get a baby...

INTE: Why would you like to have another baby?

KC09: If you get another child who is HIV-positive why should you have another one? You have brought a burden in your life; your household will be ailing all the time

INTE: So you do not wish to have a child or?

KC09: I don't want [anymore children]...I have borne many children...some have died and others are alive. One was killed by the *Mungiki* (a gang group) and I was left with one here, others are married.(widower, aged 55, father of 3 living children)

For some people, future fertility intentions are fraught with ambivalence, owing to uncertainties about the future, in part due to their sero-status. A widow, who is expecting to remarry soon, expresses these ambivalent feelings about her future child bearing now, although she had indicated in the survey that she wants another child:

INTE: You said that you want another child, right?

KC04: Well, I might but I can't have more than one child with him so that they are just four in total. But my mind does not want to give birth at all, because of my status. You know we were told [during counselling] that if you know your status you should not give birth frequently and shedding blood, as this may weaken you. So I don't know.(widow aged 27, mother of 3)

Fertility desires and preferences are shaped by different, sometimes conflicting set of circumstances, including socio-cultural norms and values and economic climate (Agadjanian 2005; Delvaux and Nöstlinger 2007; Heys et al. 2009). PLWHA have additional considerations such as the health of themselves and their families, to take into account, in their decisions on childbearing. PLWHA in slums come under a range of pressure from various sources as well: traditional expectations, cultural and religious values on procreation; economic constraints of an urban life; new family size values, and the official family planning movement (Agadjanian 2005; Heys et al. 2009). Because peoples' reproductive intentions and preferences have to negotiate these multiple and sometimes incompatible socio-cultural and economic circumstances, fertility intentions for some are often ambiguous, tentative and changeable (Agadjanian 2005). The following section looks at factors that affect fertility intentions among the study population.

### 8.2.2. *Factors that affect fertility desire among PLWHA.*

Fertility desires and intentions are complex and are influenced by a multitude of factors. At the bivariate analysis (Table 8.0.1) fertility desire was significantly associated with sex, age, number of living children and household wealth of the respondent. Education, marital status, ART use, ethnicity, disclosure of status, internalised stigma were not significantly associated fertility desires. In the multivariate analysis (Table 8.0.2) independent predictors of fertility desire for this study were: Sex (gender), number of living children (parity), respondent's age, household wealth and social support. Qualitative data in addition to elaborating these factors highlighted other factors, namely: socio-cultural values, availability of PMTCT and ART programmes, fear of infecting one's child and partner, and concerns about adequate finances to raise a child.

**Table 8.0.1: Bivariate associations of fertility desire with background characteristics**

CHARACTERISTIC	HAVE FERTILITY DESIRE (FD) (N=157)	NO FERTILITY DESIRE (N=306)	UNADJUSTED ODDS RATIOS FOR FD
	Percentages	Percentages	OR and 95% CI
<b>Sex of respondent</b>			
Male	45	55	2.25*** (1.52-3.34)
Female (ref)	26	42	1.00
<b>Total</b>	<b>34</b>	<b>66</b>	
<b>Age</b>			
18-29 years	48	52	2.77*** (1.62-4.76)
30-39 years	36	64	1.74* (1.12-2.72)
40+ years (ref)	25	75	1.00
<b>Marital Status</b>			
Married/cohabiting	38	62	1.48 ns ( 1.00-2.20)
Single (NWSD) (ref)	29	71	1.00
<b>Number of children</b>			
0 (No child)	79 (19)	21(5)	26.01*** (8.39-80.95)
1- 2	55	45	8.27*** (4.35-15.69)
3 - 4	31	79	1.87ns (0.96-3.66)
5 + (ref)	13	87	1.00
<b>Wealth quintiles (5)</b>			
Poorest quintile (ref)	26	74	1.00
Second quintile	33	67	1.46ns (0.77-2.75)
Third quintile	40	60	1.91* (1.04-3.51)
Fourth quintile	35	65	1.58ns (0.81-3.09)
Wealthiest	35	65	1.55ns (0.82-2.94)
<b>Duration of HIV</b>			
Under 1 year (ref)	37	63	1.43ns (0.82-2.49)
1 - 4 years	35	65	1.30ns (0.81-2.10)
5 and more years	29	71	1.00
<b>Treatment status</b>			
On ART	32	68	1.00
Not on ART	36	64	1.23ns (0.84-1.81)
<b>Social support</b>	-	-	1.65* (1.09-2.36)

Significance levels \*\*\* <0.001; \*\*<0.01, \*<0.05, NS – Not significant

**Table 8.0.2: Predictors of fertility desire among PLWHA**

CHARACTERISTIC	ODDS RATIO	P-VALUE	95% CI	
<b>Sex</b>				
Female (Ref)	1.00			
Male	4.17	0.000	2.46	7.07
<b>Age</b>				
18-29 years	2.50	0.017	1.18	5.28
30-39 years	1.57	0.119	0.89	2.78
40+ years (Ref)	1.00			
<b>Living children</b>				
0 (No child)	29.07	0.000	8.51	99.33
1 to 2	8.99	0.000	4.29	18.83
3 to 4	2.03	0.059	0.97	4.24
5+ (ref)	1.00			
<b>Social support</b>	1.59	0.019	1.08	2.34
<b>Wealth (5 quintiles)</b>				
Poorest (Ref)	1.00			
Second quintile	1.54	0.250	0.74	3.22
Third quintile	2.15	0.033	1.06	4.37
Fourth quintile	2.19	0.048	1.01	4.76
Wealthiest	1.68	0.172	0.80	3.51
<b>ART status</b>				
On ART (Ref)	1.00			
Not on ART	0.75	0.222	0.47	1.19

### Gender

Men (aged over 18) reported higher fertility desires than women (aged 18-49 years). Just over a quarter (26%) of women want to have a child in future compared to almost half (45%) of men (Table 8.0.1). The odds of desiring a/another child for men were 4.17 times higher those of women, net of other factors (OR 4.17; 95% CI 2.46-7.07;  $p < 0.0001$ ) (Table 8.0.2). Although, in general, all couples are expected to have children in SSA, the premium for more children is higher for men than women given the patrilineal lineage system in most SSA settings. In most Kenyan ethnic groups, children belong to the paternal clan and the continuation of the lineage is of paramount

importance, associated with support for pro-natalist cultures (Isiugo-Abanihe 1994; Smith and Mbakwem 2007). For many men, their esteem and status in society and the future security and survival of their lineage depends on the number of children and grandchildren. In-depth interviews illustrate the differential importance of children to men and women. The first quote, from a male respondent, indicates the importance attached to children in the perpetuation of their paternal lineage and name and old age care:

INTE: Last time you said that you wanted to have more children, why is it important to you?

VC05: It is important because that is taking the community or family forward. It is for continuity of your lineage and clan.

INTE: Can you explain further on this concept?

VC05: We always refer to children as the bearers of the family name. So if you don't have a child no one will be named after you. Your child will name after you whenever he/she gets a kid. Again, if you don't have children you won't have someone to take care of you in the old age (Divorced father of 4, aged 52)

Although the desire for fertility is lower among women than men, women bear children in part in order to fulfil their husband's or familial wishes despite their own preferences not to have another child. A quote from a woman respondent shows the pressure that women face from their husbands in order to fulfil their gender-related interests in the clan or lineage:

INTE: Do you talk about having children with your husband?

VB06: Yes, we always talk about it. He wants me to have more children, but I am not for the idea. He wants to name after his dead father. But I am not interested in those things because my parents are still alive.(Cohabiting mother of 3, aged 35)

Even though men's interest in lineage perpetuation might be greater than women's, both men and women traditionally achieve status and social prestige through children. A woman with children is traditionally admired and respected and may be called the respectful title "*mama watoto*" (mother of children"). It is, therefore, likely that some women, with or without pressure from their husbands would want to have children to gain respect and prestige.(Cooper et al. 2007).



Asymmetry in reported fertility desire between men and women is reflected in different reproductive preferences between couples. Although this is not studied here—we can only compare male and female responses. Differences in fertility desires play out during reported spousal discussions about reproductive preferences. In the first quote, a woman, reports that she remained consistent, citing her health status as a reason for not desiring fertility, despite her husbands' remonstrations.

INTE: Have you talked to anyone about not having more children?

KC06: Yes I have told my husband.

INTE: How did he react?

KC06: *Alijibeba vibaya sana* (roughly translates into: He reacted negatively and was disappointed), but I told him that I personally have my problems with my health so it would not be wise to have [other] children. (Cohabiting mother of 4, aged 39 years)

In the second quote a woman narrates that she had a long discussion with her partner about future childbearing. The discussion did not yield any agreement given the contrasting views that each had on having another child. As such matters were left pending, in part due to uncertainty, underlining that reported current fertility desires are dynamic for some people.

INTE: What discussions have you had with your partner concerning having a child/children?

VB01: The last time we had the discussion was last week on Friday, we talked a lot... It is him who started it. He told me I had to add another child because the other one has grown up. We sat down and talked and he said I should get a child even if it was one.

INTE: Did you agree or disagree?

VB01 We disagreed; I told him I was not ready. I told him to give me time. I told him until further notice, because it depends... I am the mother you know. Life has many financial challenges. So we just left it there. There was no agreement, we just left it there. (Mother of 1, aged 34 years).

Gender differences in fertility preferences have been documented in studies in the general population in SSA (eg Bankole and Ezech 1999; KNBS 2008). Differential gendered fertility desires among PLWHA have been observed in studies in South Africa (Cooper et al. 2009; Myer, Morroni, and Rebe 2007), Ethiopia (Tamene and Fantahun 2007), and Uganda (Heys et al. 2009). All these studies, save for Heys et al. 2009, found that desire for future fertility was higher in men than women. Women infected with HIV are less likely to want more children than men because of the potential health concerns and because women have relatively lower stakes in the perpetuation and continuity of patrilineal societies.

### Age of respondents

Age has a significant negative relationship with desire for (more) children, with fertility desires decreasing with increasing age of the PLWHA (Table 8.0.1). Those aged 18-29 are as twice as likely as 40 and plus to desire fertility (OR 2.50; 95% CI 1.18-5.28;  $p=0.017$ ). There are a number of possible explanations for the inverse relationship between age and fertility desire. Relatively young PLWHA may not have started their childbearing or may not yet have achieved their desired fertility levels. A 25 year woman narrates that she is still young and has not yet achieved her reproductive goals. She, therefore, wants another child, a son, for her husband to carry the paternal lineage forward. This will not only cement her social relationship with affinal and consanguineal relations, but possibly also her marital bond:

INTE: You said that you would want more children in the future. Why is that so?

KB10: I am still very young and I have only one child. If I just stay with this one like that then people might start wondering what is wrong with me, especially my mother. Besides, I have a girl child and in my community they value boys so much. This will bring out some marital problems in our house in the future. So I would want to give my husband a son (married mother of 1, aged 25).

Relatively older PLWHA are less likely to want more children because they might have already achieved, or are closer to achieving, their desired family size than younger PLWHA:

INTE: Would you like to have any more children?

KA11: Many people have asked me about it, but I don't want to have any more children, the six are enough. Maybe if my daughter gets a child and asked me to raise I cannot refuse... that would be a blessing. (Widower father of 6, aged 52)

An inverse relationship between age and fertility desire has been documented in studies among the PLWHA in SSA settings including Uganda (Kakaire, Osinde, and Kaye 2010) and Nigeria (Olufemi et al. 2005). Qualitative data show that people might want to experience parenthood for social approval or adherence to cultural norms, among other things. Younger adults are therefore under immense societal pressure to experience parenthood. It may be the case that the pressure to have children becomes

even more compelling for HIV-positive young adults out of the fear of the possibility dying of AIDS sooner (Olufemi et al. 2005).

### Number of living children

The number of living children is an independent predictor of fertility desire; those respondents with more living children were significantly less likely to desire more children than those with fewer children (Table 8.0.2). Only 5 of the respondents without children (24) report that they would prefer to remain childless. The odds of fertility desires among PLWHA with one child were more than 29 times higher than those with 5 and more (OR 29.07; 95% CI 8.51-99.33;  $p < 0.0001$ ). The negative relationship between fertility desire and number of living children has been documented in other studies done elsewhere in the general population in Kenya (APHRC 2002; KNBS 2008) and PLWHA in South Africa (Myer, Morroni, and Rebe 2007); Nigeria (Iliyasu et al. 2009) and Uganda (Heys et al. 2009). PLWHA, like anyone else, continue to desire (more) children until they achieve their desired family size. Qualitative interviews show that PLWHA are determined to achieve their reproductive goals despite their status:

INTE: Do you want to have more children?

VC09: Yes I want to have one more child.

INTE: Why do you want to have another child?

VC09: I always wanted to have five children but now I have four so if I get another one that will be ok (married mother of 4, aged 41)

The desire for more children does not just end with the desired number, but sometimes may extend to the sex composition of children. This pressure may become more urgent if the couple does not have sufficient male children, the traditional heir apparent in the patrilineal systems that are common in many SSA settings:

INTE: Why do you want another child?

VC03: I wouldn't want to have more than one child. I currently have one boy and two girls and I wish to have another boy.... to "balance the equation" [laughter] (cohabiting mother of 3)

INTE: Why would you want another child?

KB04: I have two daughters, so I need a son to continue the lineage. (Married man aged 36)

For many men it is important to leave at least one male heir in order to guarantee continuation of the lineage. For women a male child can also be important as well because it establishes her in the family marital home and also considered to enhance marital stability (Isiugo-Abanihe 1994). The desire to ensure that at least one son survives in contexts of high child mortality can maintain fertility desires among people with lower parity.

### Social Support

Social support was independently associated with desires for future fertility. A unit increase in the constructed social support score was associated with 1.52 odds of desires future fertility, net of other factors (OR 1.52; 95% CI 1.08-2.34;  $p < 0.001$ ). The fact that those with higher perceived social support were more likely to intend to have children in the future may suggest having social support helps people cope with stigma and negative reactions from society in general (Chapter 5) and fears against having children. In a study in Uganda, stigma and nondisclosure of status were associated with PLWHA feeling uncomfortable about having and then discussing their fertility intentions with health care providers (Wagner et al. 2011). People who disclose their status to close family members and significant others are able to obtain social support (emotional and physical) from the spouse and significant others and might be less fearful of discussing her/his fertility desires with spouses or health care providers for example. With disclosure of status, couples might more likely to discuss fertility intentions together:

INTE: Have you discussed the issue of children with your wife?

KB06: We have discussed that issue [childbearing] with my wife several times; we even talked about it before marriage and continue doing so even now. So we agreed not to use a condom at some time so that my wife could conceive. We had sex without protection a number of times, without success, but somehow on one occasion she conceived. It was a surprise because we had sort of given up. She was sickly and when she went to hospital she was told that she was pregnant. She did not believe it either. It was great! (Married father of 2, aged 36)

Recent studies suggest that PLWHA in SSA perceive stigma and disapproving attitudes regarding their childbearing from their healthcare providers (Agadjanian and

Hayford 2009; Wagner et al. 2011), and this may be accentuated among PLWHA who experience greater shame for being HIV positive and have difficulty disclosing their HIV status. It is highly likely that stigma towards child bearing is greater among PLWHA with no or low social support and hence feel less inclined to have children or to tell their providers or other people if they do.

#### Household poverty/wealth

Household wealth was positively associated with desiring fertility in both bivariate and multivariate analysis. At the multivariate analysis, however, a positive relationship was only maintained in the middle quintiles. Those in the 3<sup>rd</sup> and 4<sup>th</sup> wealth quintiles were more than twice likely to desire fertility when compared to those in the poorest quintile (OR 2.15 and 2.19) respectively. The comparison between the poorest and wealthiest quintile did not yield any independent significant association with fertility desire. This implies that fertility desires are highest among those in the middle economic strata and lower among the poorest and the wealthiest.

Two different reasons can provide plausible explanation of the closer similarity between the wealthiest and the poorest fertility desire. First, the poorer are less likely to be able to afford children as compared to their relative wealthier counterparts in the middle strata in current economic climate of living with HIV/AIDS in the slums. The quote below is illustrative of this point.

INTE: Could you please explain why you don't want any more children?

VA08: Life these days is hard; the "economy" right now is not good. We don't have any stable source of income and so bringing up children is really a burden. (Widowed mother of 2 aged 36).

INTE: Please tell me why you do not want any more children?

KA04: It all has to do with ... the income that I get. Taking care of children is a heavy task. Even the two that I have I am struggling to provide for, so it would be senseless adding others (Never married woman, aged 40).

The wealthiest on the other hand may have lower fertility desires than those in the middle economic strata in a bid to limit themselves to having a few children that they invest in via education (the quality-quantity trade-off). Respondents also emphasised

the rising costs of children education as a motivation for fewer children. This brings to the fore emergent quality concerns of children in the modern capitalist urban society, and also reflects the perception of its growing importance for social advancement, a phenomenon observed in other parts of SSA (Agadjanian 2005). The appearance of a few relatively prosperous families in the impoverished Nairobi slums might point to emergence of a group for whom children constitute an opportunity cost for paid employment and investment in economic ventures.

Suffice it to say that there should be no expectation of a simple association between household wealth/poverty and fertility desires. Although some studies in the general population have similarly shown that fertility desire is positively associated with wealth in SSA, the effect of wealth is more pronounced on the ability to implement and achieve reproductive goals rather fertility desires per se (Amin and Casterline 2005).

#### Socio-cultural values

Health improvements with ART reshapes identity and restores normality (chapter 5), and “normal” couples in SSA are expected to have children (Kisakye, Akena, and Kaye 2010), with childlessness often perceived negatively:

INTE: What is the importance of children in your tribe?

VC11: In my community if you don't have a child you are not taken as a human being. So it is a must to have children. A child gives you a name and respect within the community. The child also offers support to the parents in their older age. And you also know that if you have no children then other people will come and take over your property when you die. (Polygamous man, aged 46, father of 11).

KB08: I tell you they (childless people) get regarded badly.

INTE: How for instance?

KB08: You see even at the homestead when you say anything, they are like ‘what is she saying and she is childless?’ So even me with the [HIV] virus, let me give birth to the kid and it will be like, “she died of the virus but she left a kid behind. A child is a sign that a mother and father existed [coughs] (Divorced mother of 5, aged 46).

Childbearing for women can bring social approval, ensure marital stability and the possibility of insurance for old age care:

VC03: For women, if you give birth it gives you grounding and cements your position in that *boma* (home). Plus the child will help me in future isn't it...if he/she obtains a degree and gets employed as a manager, pilot...she/he will not forget about the mother...he will help [laughter] (widow, mother of 3, aged 36)

The socio-cultural environments in which individuals grow up affect their reproductive preferences. Depending on their cultural backgrounds some men and women residing in urban areas are just as traditional as the rural residents (Isiugo-Abanihe 1994; Smith and Mbakwem 2007).

#### Availability of PMTCT programmes

The availability of reproductive technologies to prevent mother to child transmission of HIV was a factor in influencing childbearing intentions. These medical advances to facilitate the delivery of HIV-free children include use of ART and PMTCT programmes, together with elective caesarean section and breast milk substitution can decrease vertical transmission to about 2% (Howard 2003; Quinn et al. 2000). As this information becomes more widely known, PLWHA are seeing parenting as viable option to pursue, at least in settings where these programmes are available:

INTE: Explain why you said giving birth to healthy children is possible for you (PLWHA)?

KC04: Because there are drugs that will prevent the child from getting HIV. But that does not mean that you go there and give birth anyhow. They [clinicians/doctors] don't encourage people with HIV to give birth to more children... And it depends on the individual. Maybe somebody got it [HIV] when she was 18, 20 or 24 years and therefore wants to get married and have a child. So you cannot deny them the right to do that. The doctor can advise them on how to do it [birthing] without the baby getting the virus.(widowed mother of 3, aged 27)

INTE: What is your personal view concerning PLWHA engaging in sexual relationships or having children?

KCO2: what I can say about that, and it's very challenging, is that PLWHA have a right to have sex. What we usually tell them is to use a condom or do dual protection that is family planning. They also have a right to have a baby. You know like the case of Asunta (the AIDS NGO director who has publicly disclosed her status). They have seen her giving birth to a

negative child so these women are really coming up and they want to get babies. So for those that are pregnant we usually tell them to follow PMTCT. Usually we have 2 choices if they deliver a healthy baby. The baby is either breastfed for 6 months or given alternative feeding from birth.(Clinical officer)

The availability of ART and PMTCT programmes has led to the realisation among some HIV positive women that they can deliver HIV negative babies. As this information filters through society, it has been suggested that PLWHA irrespective of their ARV treatment status might reactivate previously dormant fertility desires (Maier et al. 2009; Coll, Lopez, and Hernandez 2008). However, there was no significant association between those on ART and fertility desires, suggesting the information on ART and PMTCT programmes does not differ by treatment status.

#### Fears of infections and re-infections

Respondents' fertility desires were also influenced by fears of causing infections and reinfections. While men and women living with HIV were aware of the availability of prevention of vertical transmission programmes they tended to emphasise the risk of vertical transmission:

INTE: Please tell me why you don't want another child?

VA12: Because I know I have HIV and if I get a child I fear that the child will definitely have HIV. (Separated mother of 3, aged 25)

INTE: So you don't want to have another baby?

KC09: No, if I get another one he will also be HIV+, now what's that? The burden will fall on me...taking him to hospital for treatment and later you know he will die. So will I continue taking drugs as the father or will it be the child? (Widowed father of 2 aged 55)

The second fear was the potential risk of re-infection with a different strain of HIV or partner transmission while trying to conceive. Even if some women were aware of the PMTCT programmes to prevent vertical transmission, they did not lose sight of the ever-present risk of horizontal transmission of HIV to sexual partners, through unprotected sex in order to conceive:

INTE: What kind of advice or counselling have you received about further childbearing given your HIV status?



KA17: I always hear that there are drugs that people are given to prevent the baby from getting infected with the virus. But then don't you think that I will infect the person that I am going to sleep with (in order to conceive), with the HIV virus? I cannot give somebody the virus knowingly like that just for him to impregnate me and then go and take drugs that will prevent the child from getting the virus. What about that man? He will be in great problems. I don't see the reason of doing that.(widowed mother of 2, aged 30)

Additionally, HIV positive women have fears about the effect of pregnancies or giving birth on their own health and HIV condition. The main worry seemed to centre on the possibility that a pregnancy might exacerbate their already compromised immunity and hasten AIDS progression. In addition there were fears of premature death and leaving behind orphaned children:

INTE: Can you please explain why you do not want more children?

KB08: With this condition, if I happen to get pregnant or add another kid now; I don't know whether I will reach a point and be down and my CD4 count also reduce. So that makes me to worry a lot. That is why I have to use family [planning].(Divorced mother of 5, aged 45)

KA17: Because I don't see the need of mistreating my children. God might bless me and I give birth to another child who is HIV negative and then I die shortly after that, nobody including my own brother will want to take care of my children. I don't see the need of having many children and then die and leave them to suffer. (widowed mother of 2, aged 30)

Fears of infection and re-infections and the effect of pregnancy on the general health of the mother have been documented in qualitative studies among PLWHA in South Africa (Laher et al. 2009). What arose during our discussions about fertility intentions was that those who have children after knowing their HIV status exhibited lack of responsibility towards oneself, one's child and one's family. This was because such an action was fraught with the danger of vertical and horizontal transmission of HIV, weakening one's own health conditions and causing more mortalities and orphanhood. However, PMTCT and ART programmes have dramatically reduced the risk of vertical transmission from 25% to 1-2% (Howard 2003; Ilayasu 2009).

Desires to have children among PLWHA in the study were reported by 34%, for a range of reasons including cultural and social expectations and obligations and gender norms. However, 66% wish to postpone or stop child bearing altogether for several reasons including fear of infections, health concerns and economic hardships. The

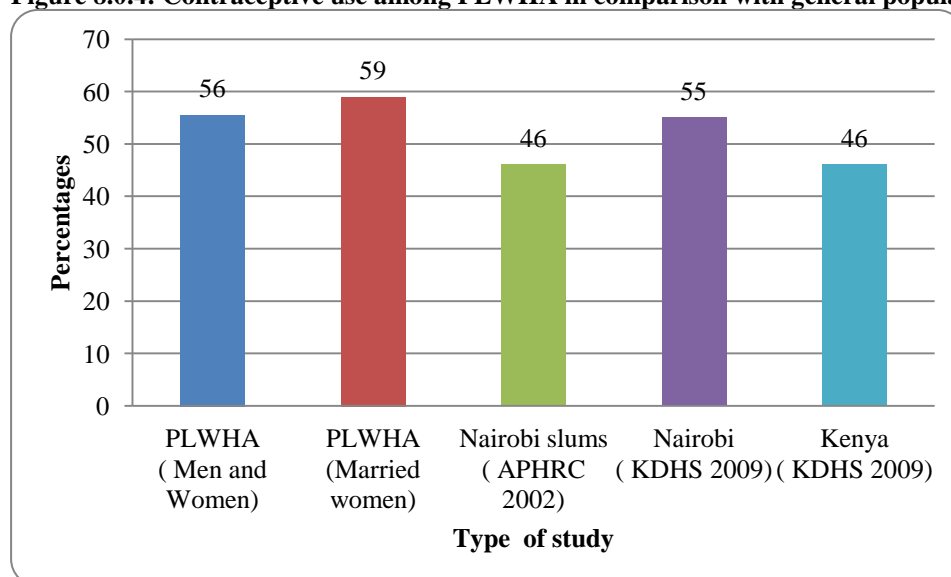
reminder of the chapter examines contraceptive use to implement these reproductive preferences. Although abortion may also be used for fertility regulation (Lauro 2011), this study only focused on contraception because abortion is not a contraceptive method.

### **8.3. Contraceptive use**

The level of contraceptive use is an important indicator of conscious efforts of a population to regulate fertility. Of all the proximate determinant of fertility, contraception has the strongest influence on fertility (Bongaarts, Mauldin, and Phillips 1990; Donaldson and Tsui 1990). Contraception is important for PLWHA because it not only prevents unwanted pregnancies, but also vertical transmission of HIV/AIDS (Smith et al. 2009; Cleland et al. 2006).

This study asked women aged 18-49 and men above 18 years about their use of contraception (both modern and traditional), using the question: “Are you /your partner doing something or using a method to avoid or delay getting pregnant?” The responses to this question may suffer from reporting bias. While some PLWHA may over-report use of contraceptive because of societal disapproval of child bearing (Agadjanian and Hayford 2009), others may under-report its use if they do it without their partner’s explicit approval. Studies in other parts of SSA among the general population have suggested that such secret use is widespread (Agadjanian 2005).

Figure 8.0.4 presents a comparison of the percentage of men and women living with HIV/AIDS in Nairobi slums using any method (modern and traditional) of family planning, and compared the results of this study with data from (2009 KDHS and 2002 APHRC data for Nairobi slums). The KDHS and APHRC use the contraceptive rate among currently married women and so, for comparison purposes, this study reports both the overall contraceptive use among all PLWHA as well as among married women. The overall level of contraceptive use by PLWHA in the slums is higher than the general population Nairobi slums and KDHS Nairobi and national rates. Further afield, studies have found comparable levels of contraceptive use among HIV infected individual in SSA. For example, a study in Uganda found that 58% of men and women living with HIV/AIDS were currently using a family planning method (Wanyenze et al. 2011).

**Figure 8.0.4: Contraceptive use among PLWHA in comparison with general population**

### 8.3.1. Contraceptive mix

There is a substantial variation in the method mix between PLWHA and the general population in Kenya (figure 8.0.5). While the condom is by far the most popular among PLWHA (73% overall and 67% for married women), it is the least popular method among the general population in Nairobi slums and Kenya as a whole (less than 2%). The popularity of the condom among PLWHA is because it is principally used for dual protection against unwanted pregnancies and infection and re-infections of HIV/AIDS and other sexually transmitted diseases:

INTE: Now, which method of family planning do you use?

VC11: We only use condoms to prevent pregnancies and re-infections with the [HIV] virus.

You know most often doctors talk about the need to use a condom for preventing the spread of the virus and pregnancies. (Married man, aged 46)

Two female respondents reported that they prefer to use condoms over hormonal methods such as pills and injectables because of the fear of their side effects or/and contra-indications with ART (see 8.3.4).

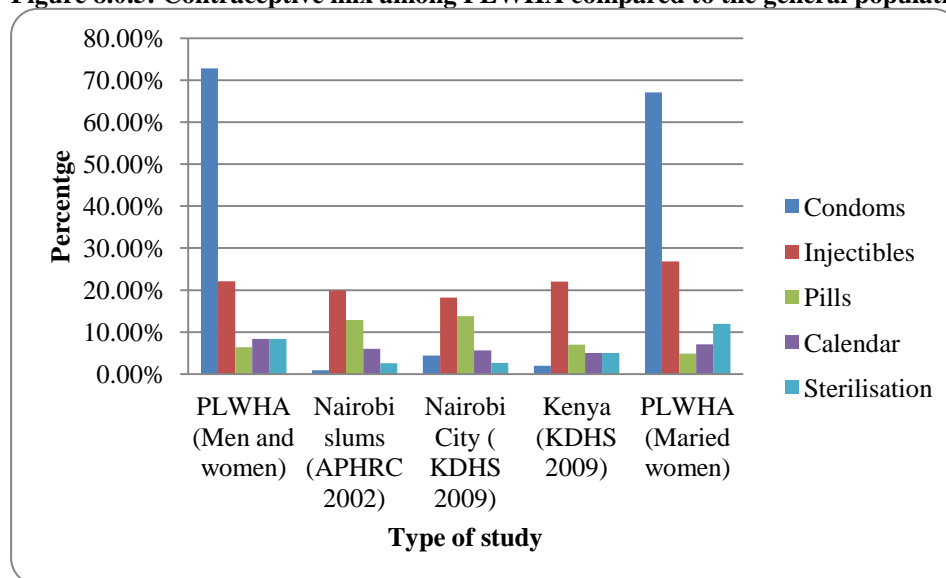
INTE: Do you know of any method that a PLWHA can use for family planning?

KB08: The one that I would say that I know is good is the use of pills. The problem I see with them is their side effects. Also it is not easy for me to be taking ARVS and at the same time

using the pills. I prefer condoms to other methods. (Divorced mother of 5, aged 45)

KB10: I was using injections but they were giving me problems. I used to bleed a lot and after giving birth to my child I asked them to permanently block my reproductive track but they said that I was still too young for that procedure. So I just use condoms. (Married mother of 2, aged 25)

**Figure 8.0.5: Contraceptive mix among PLWHA compared to the general population**



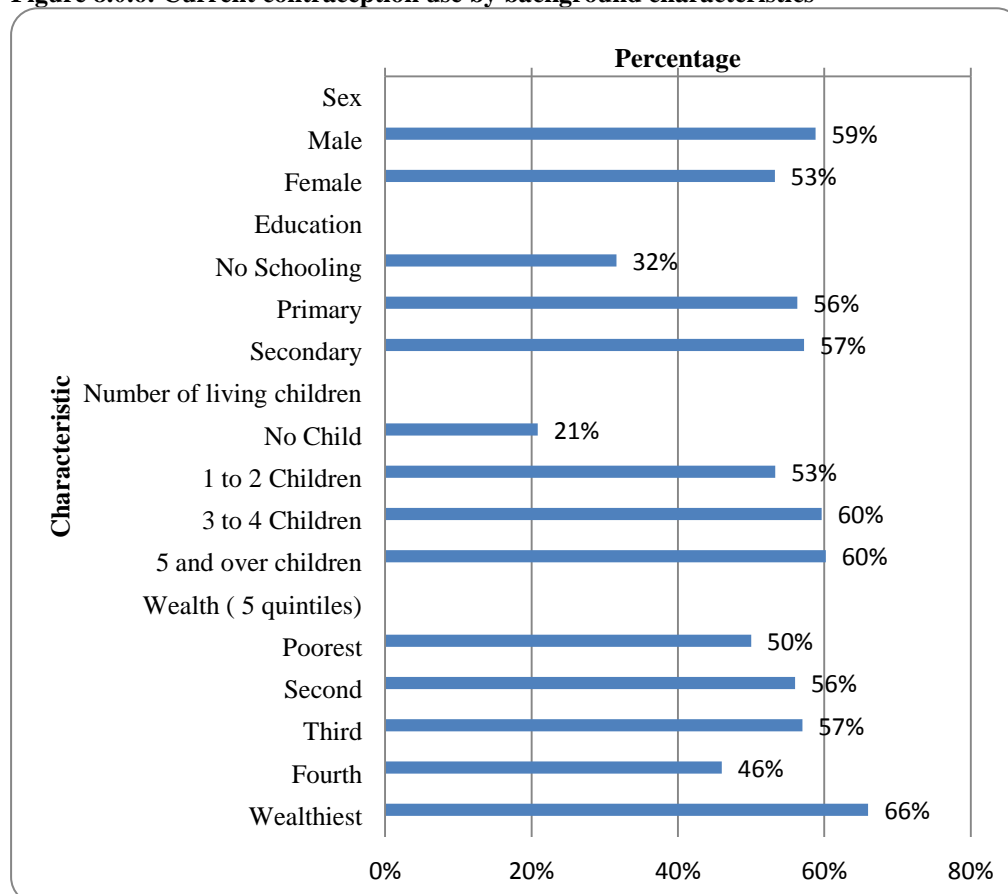
The pill is the least popular method among PLWHA, in part owing to its perceived side effects and harmful interaction with ART. However, the pill was also unpopular because it contributes to the pill burden for women on ART (8.3.4). Injectable contraceptives may have been preferred over pills because of their convenience and perhaps ability to use them in secret (Laher et al. 2009). The notable prevalence of sterilization among PLWHA suggests that more PLWHAs are keener on stopping childbearing than the general population. In a study of PLWHA contraceptive use from South Africa, the most frequent used method was condoms followed by hormonal injections and pills (Peltzer, Chao, and Dana 2009).

### 8.3.2. Current use of contraception by background characteristics

Nulliparous PLWHA are less likely to report using contraception than PLWHA who have living children; 21% of childless PLWHA (one man and 4 women) use contraception, compared to 53% of PLWHA with 1-2 surviving children, and 60% of PLWHA with 3-4 and 5 and over surviving children (Figure 8.0.6). Overall,

contraceptive use increases steadily with the level of education. PLWHA with secondary or higher education (57%) are substantially more likely to use contraception than PLWHA with no formal education (32%). Males have a higher contraceptive use (59%), than female (53%) despite their lower fertility desire, reinforcing gendered barriers. (8.3.4). The wealthiest have highest contraceptive use (66%) far more than the poorest (50%).

**Figure 8.0.6: Current contraception use by background characteristics**



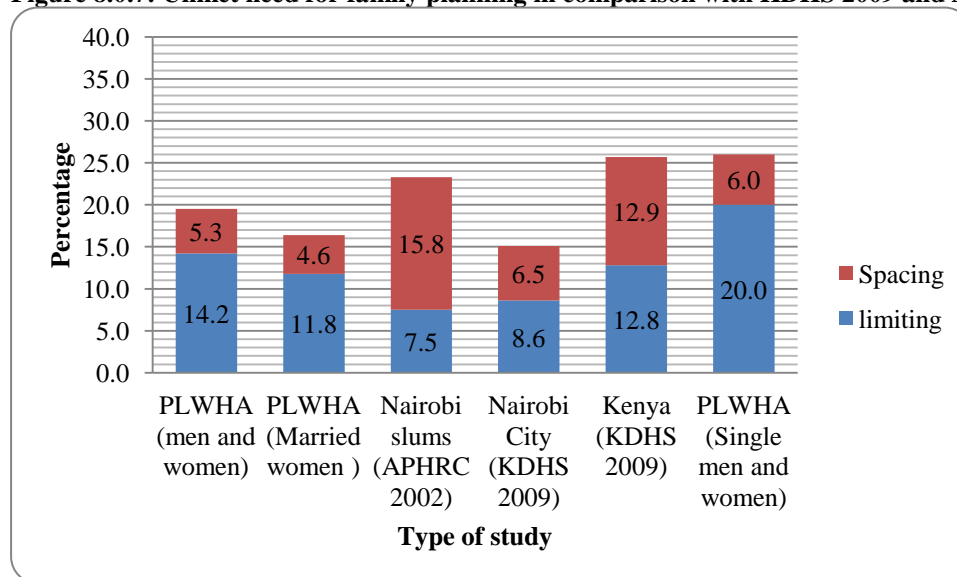
### 8.3.3. Unmet need for family planning among PLWHA

The concept of unmet need for family planning has been revised and refined over the past three decades but its basic components have basically remained the same (Westoff 2006; Casterline and Sinding 2000). Unmet need is derived from two aspects of fertility preferences: fertility intentions and contraceptive use. Broadly defined unmet need for family planning refers to the proportion of sexually active people who want to stop or postpone childbearing, but are not using any contraception. It is, therefore, an indicator of the demand for family planning services. There are two types of unmet need: limiting and spacing. Unmet need for limiting refers to those who do not want a

child in the future and are not using contraception, while unmet for spacing refers to those who want to postpone childbearing for at least 2 years, but are not using contraception (Casterline, El-Zanaty, and El-Zeini 2003; Casterline and Sinding 2000).

The DHS defines unmet to refer to the proportion of currently married women who want to postpone their next birth for two or more years or who want to stop childbearing altogether, but are not using a contraceptive method (Casterline and Sinding 2000). This definition has been criticized for being narrow, and calls have been made to include all women and men and even couples in the definition of unmet need (Bankole and Ezeh 1999; Casterline and Sinding 2000). This study included men and women who were sexually active in the last 12 months in its construction of unmet need.

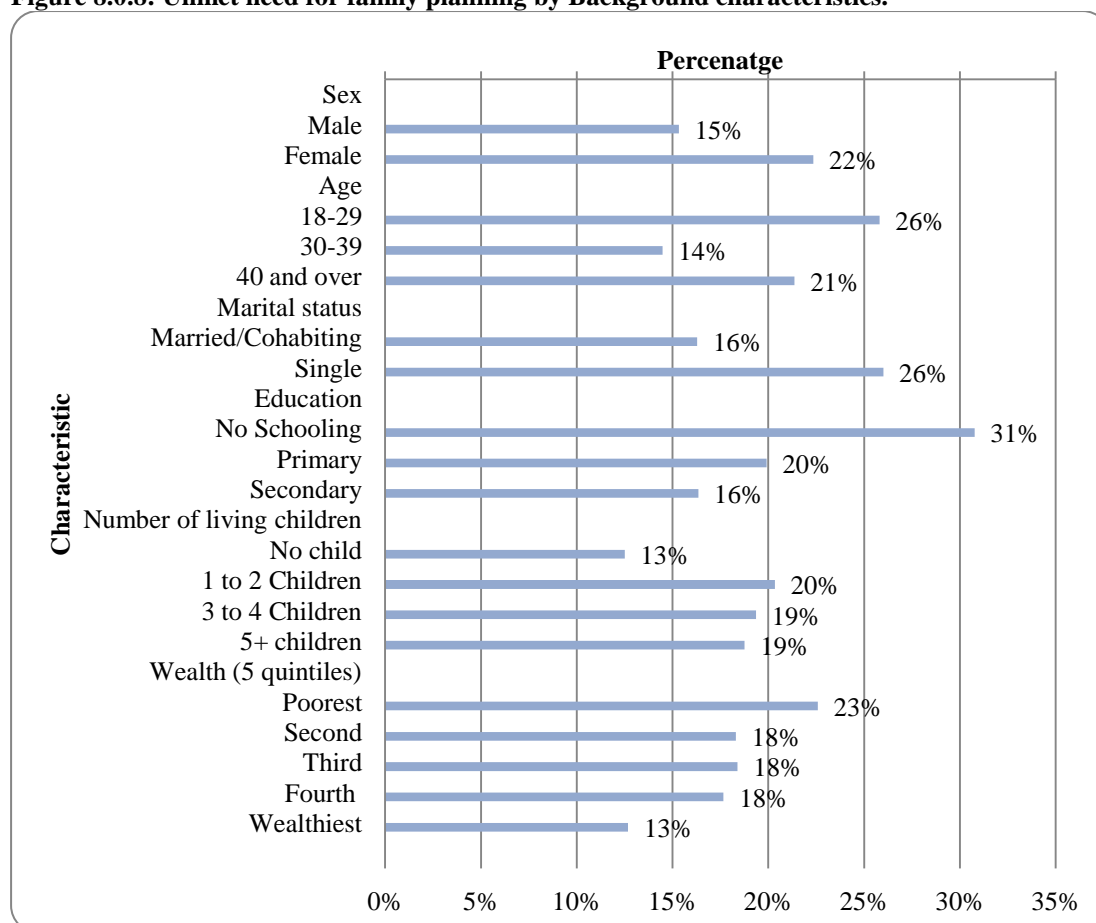
**Figure 8.0.7: Unmet need for family planning in comparison with KDHS 2009 and APHRC 2002**



Overall unmet among sexually active PLWHA is 19.5%, which is higher than the general population in Nairobi City (15%), but lower than Kenya overall (25%) and Nairobi slums 23% (Figure 8.0.7). There are two main differences in the unmet need among PLWHA and the general population in Kenya. One, while unmet need is evenly split between limiting and spacing in the general population in Kenya and Nairobi city, and predominantly for spacing in Nairobi slums; unmet need is predominantly for limiting purposes among PLWHA. This implies that PLWHA are keener to stop childbearing than space their birth. Secondly, whereas unmet need is higher in married

women than singles in the general population, unmet need is higher among the singles than the married among PLWHA. This might imply low demand for children among the singletons, who are mostly widows or divorcees (chapter 3).

**Figure 8.0.8: Unmet need for family planning by Background characteristics.**



The level of unmet need varies by background characteristics (Figure 8.0.8) and is higher among women compared to men. Unmet need is highest amongst the younger (18-29) and older cohorts (40 plus) of PLWHA and increases with the number of living of children. These findings highlight two related issues: high levels of unmet need for spacing among young cohorts who intend to have children in the future and high levels of unmet need for limiting among older women who have reached or exceeded their desired family size. Unmet need reduces with educational level highlighting the importance of education in empowerment in terms of knowledge and female autonomy (8.3.4). Finally, unmet need reduces with increasing wealth status,

further reinforcing poverty as a significant barrier to contraceptive access. I explore these factors in more detail in the next section.

*8.3.4. Factors that influence contraceptive use: Demand level factors*

Quantitative and qualitative data show that the following demand-side factors influence use of family planning to either stop or space childbearing: Education, parity, marital status, and desire to avoid HIV/STI infections and lack of economic means (Table 8.0.3 and 8.0.4).



**Table 8.0.3: Bivariate analysis of contraceptive use by selected factors**

CHARACTERISTIC	CURRENTLY USING FP (N=250)	NOT USING FP (N=200)	UNADJUSTED ODDS RATIOS FOR FP
	Percentages (n)	Percentages (n)	OR and 95% CI
<b>Sex of respondent</b>			
Male	59 (110)	41 (77)	1.26ns (0.86-1.83)
Female (ref)	53 (140)	47 (123)	1.00
<b>Age</b>			
18-29 years (ref)	53 (42)	47 (37)	1.00
30-39 years	57 (110)	43 (83)	1.17ns (0.69-1.98)
40+ years	55 (98)	45 (80)	1.08ns (0.63-1.84)
<b>Marital Status</b>			
Married/cohabiting	71 (181)	29 (74)	4.47*** ( 3.00-6.66)
Single (NWD) (ref)	35 (69)	65 (126)	1.00
<b>Education status</b>			
No formal education (ref)	32 (6)	68 (13)	1.00
Primary	56 (165)	44 (128)	2.79* (1.03-7.55)
Secondary +	57 (79)	43 (59)	2.90* (1.04-8.08)
<b>Number of children a live</b>			
0 (No child) (ref)	21 (5)	79 (19)	1.00
1- 2	53 (81)	47 (71)	4.33** (1.54-12.21)
3 - 4	60 (99)	40 (67)	5.61*** (2.00-15.77)
5 + (ref)	60 (65)	40 (43)	5.74*** (2.00-16.54)
<b>Wealth quintiles (5)</b>			
Poorest quintile (ref)	50 (43)	50 (43)	1.00
Second quintile	56 (53)	44 (41)	1.29ns (0.72-2.33)
Third quintile	57 (62)	43 (47)	1.32ns (0.75-2.33)
Fourth quintile	46 (33)	54 (38)	0.87ns (0.46-1.62)
Wealthiest	66 (59)	34 (33)	1.90* (1.04-3.49)
<b>FP discussion with provider</b>			
Never	43 (70)	57 (92)	1.00
Ever	63 (180)	37 (108)	2.19*** (1.48-3.24)
<b>Treatment status</b>			
On ART	52 (119)	48 (111)	1.00
Not on ART	60 (131)	40 (89)	1.37ns (0.95-1.99)
<b>Social support</b>			
Low (ref)	44 (58)	56 (85)	1.00
Moderate	60 (92)	40 (61)	1.89** (1.20-2.97)
High	63 (90)	37 (54)	2.08** (1.31-3.31)

Significance levels \*\*\* <0.001; \*\*<0.01, \*<0.05, NS – Not significant

**Table 8.0.4: Predictors of contraceptive use among PLWHA**

CHARACTERISTIC	ODDS RATIO	P-VALUE	[95% CONF. INTERVAL	
<b>Education</b>				
No schooling (ref)	1.00			
Primary	3.40	0.026	1.16	9.93
Secondary plus	3.12	0.043	1.04	9.40
<b>Marital status</b>				
Single ( DSN) (ref)	1.00			
Married/cohabiting	5.25	0.000	3.30	8.27
<b>Number of surviving children</b>				
No Child (ref)	1.00			
1 and 2 children	3.37	0.036	1.08	10.52
3 and 4 children	4.04	0.016	1.30	12.57
5 plus children	3.85	0.023	1.20	12.31
<b>Discussion with provider</b>				
Never (ref)	1.00			
Ever	2.54	0.000	1.60	4.04
<b>Social support</b>	1.55	0.017	1.08	2.24
<b>Sex</b>				
Female (ref)	1.00			
Male	1.01	0.956	0.63	1.64

#### Education level

Education is positively associated with contraceptive use in both bivariate and multivariate analysis (tables 8.0.3 and 8.0.4). The likelihood of using contraception increased by more than three times for respondents with at least primary level education (OR 3.40; 95% CI 1.16-9.3;  $p=0.026$ ) and at least secondary level (OR 3.12; 95% CI 1.04-9.40;  $p=<0.043$ ), compared with respondents with no formal schooling (Table 8.0.4). A large body of demographic literature has shown a consistent relationship between female education and contraceptive use (Moursund and Kravdal 2003; Saleem and Bobak 2005).

The main pathway through which education is thought to affect contraceptive use and fertility regulation as suggested by some authors (e.g Jejeebhoy and Sathar 2001) is

that formal schooling increases women's autonomy through relative freedom in decision making related to reproduction and health care, independent of men's authority (Saleem and Bobak 2005; Moursund and Kravdal 2003). In terms of contraceptive use, two levels of women's autonomy as suggested by Jejeebhoy (Jejeebhoy 1995 cited in Moursund and Kravdal 2003) are paramount: "Knowledge autonomy" and "decision making autonomy"

Education empowers women (and men as well) by facilitating acquisition of knowledge about fertility regulation and contraceptives methods. Low contraceptive use has been found among women with poor contraceptive knowledge and awareness (Bankole, Rodríguez, and Westoff 1996; Campbell, Sahin-Hodoglugil, and Potts 2006). Educated women and men are more likely to be knowledgeable about contraceptive methods and the role of contraception and to have an inclination to use family planning:

INTE: Tell me the methods PLWHA can use for family planning?

VB01: There is a condom, pills, injections, coil, counting days and the one that produces a lot of foam. A person living with the virus can use condoms and the injection at the same time or they use the condom and pills at the same time. I use the latter, for the simple reason that the injection protects one from pregnancy and the condom can tear and when you do not have the injection you get pregnant. The condom protects you from the virus or spreading it or being infected and pregnant.(single mother of 1, aged 34)

Knowledge about contraception diffuses through the processes of social learning (Agadjanian 2005). However, knowledge alone does not necessarily translate into action, which implies that other factors are in play:

INTE: Are you aware of family planning methods?

KA17: You can use coil, injection, Norplant, TL [Tubal ligation], condom, and the one of counting days, how do you call it? I learnt so many of them. I know all these but I have never used any.(widow, mother of 2 aged 30)

Decision making autonomy of women can facilitate contraceptive adoption and use, even in the midst of men's opposition:

INTE: When was the last time you had discussions over the issue of condoms with your husband and who started the talks?

VB06: It was about two months ago and it was him who started it. He wanted us to stop using it (condom). He asked me: "So you decided that I should be eating the sweets with wrappers on every day?"[laughter]. I told him if that is the case then we had better end our marriage. Otherwise we would not be having sex because "*hata kitu yangu haiumi*" (my thing does not itch- meaning no sexual desire). I told him he can get lost... After all men do not face the same problems we as women face... It is me who carry the pregnancy for 9 months; all they do is to ask if the child has eaten, but are not even involved in childcare.(Cohabiting mother of 3, with secondary education)

Decision making autonomy refers to the ability and freedom of the woman to decide to act as they choose relative to those of men. Education builds this capacity through a number of ways. One, the autonomy to act independently is due to the empowerment of educated women through economic independence. This is because education increases the chances of finding higher paying jobs, leading to greater economic independence of women and equality (Dalal, Andrews, and Dawad 2011). A more equal relationship between the wife and her husband will most probably favour the use of contraception, through more equitable spousal discussion and agreement. In addition, waged employment may motivate fertility regulation because frequent childbearing will, undoubtedly, incur some opportunity cost. Though the focus on fertility studies and contraceptive use has largely been on female education, its effect may also capture the husband or partner's education, given some evidence that wife's and husband's education are positively associated, as educated women tend to marry educated men (Basu 2002).

#### Number of surviving children (Parity)

The proportions of those using contraception increased with number of living children (Table 8.0.3). The likelihood of using contraception increased by more than three times for those with more than 2 children relative to the childless. There is a fourfold increase in the odds of using contraception among those with 3 to 4 children (OR 4.04; 95% CI 1.30-12.57; p=0.016) relative to those who were childless (Table 8.0.4).

The direct association between number of living children and contraceptive use imply that parents who have achieved their desired family size are more likely to use

contraception than those who have not. This was illustrated by a male respondent when asked about his motivation to use contraception.

INTE: Could you explain your use of family planning?

KA07: I closed that “chapter” (of getting children) in 2007 when my last borne was delivered. The five [children] that I have are enough.(widower aged 59)

When the number of surviving children is affected by the death of a child, the use of contraception might be temporarily stopped in a bid to have another child:

INTE: You said that you currently not using any form of family planning, right?

KB10: I was using family planning, but when my child died my husband brought problems with it, that we should get another child. I went to the doctor and he told me to stop using for a while until I got pregnant.(married mother of 2)

As a determinant of family size, high child mortality is an inhibiting factor for the use of contraception. In conditions of high child mortality in Nairobi slums (APHRC 2002; Fotso et al. 2007), parents are uncertain about the survival of their offspring, which might explain why resistance to permanent methods of family planning (sterilization) is high in SSA (Agadjanian 2005). In a culture that still places premium on reproductive capacity, terminating it prematurely in a context of uncertainties about child survival is a difficult decision for people to make.

#### Marriage and spousal support

Being married or having a cohabiting partner was associated with contraceptive use in both bivariate and multivariate analysis. Being in a marital union increased the odds of using contraception by a factor of 5.2 relative to being single (OR 5.25; 95% CI 3.30-8.27;  $p < 0.001$ ) (Table 8.0.4). Married status has similarly been found to be associated with contraceptive use in the general population (Magadi and Curtis 2003) and PLWHA (Anand et al. 2009). One reason why married couples are more likely to be using contraception is because they are more likely to be sexually active more frequently (chapter 6), given the availability of a sexual partner.

The second reason could be that married couples gain social support, both material and emotional, from their spouses that may facilitate contraceptive use. Social support was positively associated with contraceptive use in both bivariate and multivariate analysis. One unit increase in social support was associated with 1.55 increased odds of using

contraception, net of other factors (OR 1.55; 95% CI 1.08-2.24;  $p=0.017$ ) (Table 8.0.4). One way through which marital partnership can facilitate contraceptive use is spousal discussion about contraception:

INTE: Have you discussed with your husband about family planning?

KB05: Yes... we agreed with my husband that we first of all bring up the child that we already have. So I am using family [planning]. If the child is old enough we shall go for the check-up, because the issue of immunity is not only applicable to me as a woman. It also applies to my husband as well as his immunity level must be high enough. [Married mother of 2, aged 42]

Partner discussion has long been shown to improve contraceptive use (Lasee and Beeker 1997), although it does not necessarily improve one's knowledge about partner's contraceptive attitudes (DeRose et. al 2004).

#### Fear of side-effects and health concerns

Side-effects and health concerns, whether real or perceived, affect contraceptive use, and in our data. Most contraceptives were reported to cause a number of side-effects. Women feared these side-effects either as a result of having experienced them or having heard rumours from their social networks. For example, potential increased menstrual flow was a matter of concern for PLWHA because it was thought to reduce the volume blood in the body:

INTE: You mentioned that you had problems with some methods of family planning?

VC09: I used to use those pills but I would have extended blood flows during my periods. Now every month having periods three times for a PLWHA, you lose a lot of blood in the body and become very weak. Then I tried using the injections and that led to my irregular periods, then at times my heart beat goes up and my breathing gets irregular. So I stopped using them completely. (Married mother of 4, aged 41)

Other respondents avoided contraceptives as a result of hearing rumours and having heard from their close associates about their side-effects:

INTE: Any other problem?

VB01: The use of Norplant, there is a lady, my friend, she has used it and her hand is giving her problems.

INTE: What has it done?

VB01: The hand is weak and when she is working it is like paralyzed. I was afraid and I figured it is because she has used Norplant for so long. So I started fearing them. There is also one of my friends who used a coil, and now it is in the stomach... It has moved in so the only way to get it out is through an operation. She has grown fat and it has disappeared into the body. She was referred to Kenyatta [hospital]. So I was very scared, I did not know it was that risky. (Single mother of 1, aged 34)

The second level of side-effects were related to sexual functioning and perceived interference of contraception with sexual arousal. Some respondents, especially males reported that women who were on contraception had lower libidos:

INTE: Do you have any concerns about family planning?

KA14: Uuuh! Women who use [family planning] injections have *nyege baridi* (cold libido)! They get wet. So if you have sex with her you don't want to do it again with her. (widowed father of 4, aged 38)

INTE: What do they complain about?

KA05: Some men say that women who take pills are *baridi* [cold] in the bed [laughs]. The men claim that during sexual intercourses with women who use pills, these women are non-responsive and lack that warmth... you see what I mean? So this discourages them a lot. (Divorced father of 2, aged 30).

A woman explains how the perceived side-effects affected her choice of the contraceptive method.

INTE: Are you using family planning right now?

KB10: I was using injections but they were giving me problems. I used to bleed a lot and after giving birth to my child I asked them to permanently block my reproductive track but they said that I was still too young for that procedure. So I just use condoms. There is another one I have heard of called the coil but I have not yet gone for it. I hear it is the best as of now. (Married mother of 2, Aged 25)

Fear of side-effects is the most reported barrier to modern contraceptive use the world over, especially the developing world (Campbell, Sahin-Hodoglugil, and Potts 2006). Fears about real or imagined side-effects abound, which makes many women to view contraceptive use as more dangerous than being pregnant (Campbell, Sahin-Hodoglugil, and Potts 2006; Casterline, Sathar, and Haque 2001). Sexually related side-effects have similarly been reported among PLWHA in Soweto, South Africa. In

this study injectables were perceived to increase vaginal wetness, and this was thought to impact negatively on women's sexual relationships with their male partners, who value dry sex (Laher et al. 2009). There were gender differences in the perceptions of contraceptive side-effects. Women were typically concerned with such real or perceived health side-effects as haemorrhage, hypertension, infections and weight loss or gain. Men's concerns centred rather more on how contraceptive use might affect their enjoyment of sex.

### Spousal opposition

Spousal opposition was a recurrent theme in the discussions about the impediments to family planning use, especially for women. Some women expressed fears of husband's disapproval or retribution if they use family planning, as illustrated by excerpts from health care providers:

INTE: Any other challenge that you face when dealing with PLWHA?

VCO2...Another thing is that some women are attached to their husbands, before you give them family planning they have to go and consult the husband.(Clinical officer)

INTE: What do you see as barriers to the effectiveness of family planning programs and contraceptive use when it comes to PLWHA?

VNS1: Sometimes you find that clients know what they are supposed to do but do not do it. For instance you ask someone if they are using dual methods as required but then they tell you that their husband does not want them to use condoms. It is the main barrier (Nurse)

The most common reason for men's refusal to use condoms is that it inhibits pleasure:

INTE: Is there any problem you face with condom use?

VB01: The problem is the man that I have sometimes says that the condom is not good. When having sex with condoms they [men] do not feel the sweetness of a woman. They want to feel that warmth, but the condom prevents it. They do not get the pleasure; it is like it takes time for them to ejaculate. It takes a long time and sometimes they are unable to "come". They do it and do it and do it, but they do not finish, they get very tired. (Single mother of 1, aged 34)

The importance of men's opposition in the adoption of contraception has been discussed widely in demographic and family planning literature. This factor features prominently in a recent review of barriers to fertility regulation (Campbell, Sahin-Hodoglugil, and Potts 2006). Stephenson and Hennink (2004) found that urban poor women in Pakistan were 10 times likely to use family planning if their husbands



approved of it. That said, however, some men's narratives were positive about contraception:

INTE: What is your view concerning PLWHA using contraceptives?

KC09...it [FP] is of benefit to those who are bearing children...because you could be having a woman who bears children like chicken so you have to do family planning".(widowed father of 2, aged 55)

KB07: It is important to have children you able to feed and take through school comfortably, so that you don't have problems. That is the reason for family planning. So it is a good idea.

(Widowed father of 4 aged 60)

Furthermore, given the fact that men are more likely to report contraceptive use than women, misperceptions by women of husbands' disapproval might be another issue, if not the real issue (Cleland et al. 2006).

#### Perceived incompatibility of contraception with ART

Discussions around ART use and contraceptive use elicited trepidation about their concomitant use. There was expressed anxiety by PLWHA that the power of ART can extinguish the efficacy of some family planning methods and so should not be used together:

KA11: These ART drugs also make the [family planning] pills to be ineffective so people who use them can still conceive. ARVs are very strong...they "blow" *hiyo kitu* (that thing meaning, they overpower the pills). So that is why condoms are the best means of preventing conception. I asked and that is what I was told...I don't fear asking them [providers] anything. (widower aged 52)

There was also apprehension that family planning methods may interfere with ART's efficacy:

INTE: Could you name the family planning methods that you were told?

KA04: We are told about injections, coil and Norplant. But you know with treatment there are some methods that are not compatible with ART such as pills. Some of the pills can reduce the effectiveness of ART (Single mother of 2, aged 25).

The perception of contraindications between ART and contraception were also articulated by health care workers. Some health workers said that there was no contra-

indication between the two. Others on the hand felt that either the efficacy of the two is somewhat reduced when used together or that there are negative interactions between some ART drugs and hormonal contraceptives. These contrasting views are highlighted:

INTE: What is your view about family planning among PLWHA?

VCO1: There was a notion that clients on ART should not use contraception, but I am not seeing any contra-indication; there is no contraindication really so long as they received adequate counselling. I do not see any contraindication why they should not take unless the patient is in the terminal stage, that is, stage 4. Again in stage 4, they do not need any family planning because the urge of having sex is dead anyway. For these general patients I don't see any contraindication. (Clinical officer)

KCO1: Some family planning methods are not safe when you are taking ART drugs. Like I have said earlier the oral contraceptives... oral pills with [not audible], they make the pill to fail and somebody will become pregnant. It is not like tubal ligation or IUD. (Clinical officer)

Contra-indication concerns and uncertainty expressed by the PLWHA and their health workers are reflective of scientific concerns, including potential contradictions between ART and hormonal contraceptives, not least because they are both metabolized in the liver with the same enzymes (Gates 2006). As such theoretical concerns exist about the possibility of their decreased efficacy or increase in side-effects related to their concomitant use. But no conclusive evidence exists, to date, of the harmful effects of simultaneous use of hormonal contraception and ART (WHO 2010). A recent literature review further states that the use of hormonal or IUD neither increases the risk of HIV disease progression nor transmission to un-infected sexual partners (Curtis, Nanda, and Kapp 2009).

### 8.3.5. *Factors that influence contraceptive use: Supply level factors*

The family planning supply environment and the manner in which services are provided emerged as one of the factors that have a bearing on contraceptive use. The delivery of family planning is shaped by the health system in place both at the community and national levels. The data shows that the health system's capacity to provide family planning was a key barrier to contraceptive use among the respondents. These barriers can be grouped broadly into four: inadequate supplies and commodities; inadequate infrastructure; cost of services and health care providers' attributes.

To ensure that women and men can obtain the contraceptive method they want, a secure supply is needed. However, our interviews with healthcare providers revealed frequent stock-out of contraceptives:

INTE: How equipped do you feel you and your facility are to handle the family planning needs of PLWHA?

KNS2: Right now we don't even have depo (Depo-Provera injection) for family planning and they have to buy yet some of them cannot afford. Sometimes we have stock-outs for these family planning methods (Nurse)

KCO1: Actually we are not well equipped.

INTE: How and why?

KCO1: Because sometimes we find that we are lacking family planning methods. Right now, we don't have the injectables, we don't have the inter-uterine devices which are the best applicable to PLWHA. These are things which are only provided in public hospitals at a cheap price or free... It will be expensive or unimaginable like the tubal ligation in a private hospital can go up to Ksh 20,000[£160]. We can do it here freely, but sometimes we cannot do because we lack some few things here and there.(Clinical officer)

Supply problems become more acute in urban slums, which tend to be excluded from formal government health service and have to rely on poorly regulated informal providers (Ezeh, Kodzi, and Emina 2010). Financial constraints continue to frustrate efforts to ensure commodity security. International funding, which plays a major role in family planning in SSA has been dwindling in the last two decades as new challenges such as HIV/AIDS have diverted funds from family planning (Ezeh, Kodzi, and Emina 2010; Van Dalen and Reuser 2008).

Infrastructural limitations such as space and health care personnel can reduce the effectiveness of service integration in the slums of Nairobi. Some providers felt that more rooms and staff in the health facility for simultaneous counselling on HIV and family planning would increase the likelihood of their clients receiving contraceptive counselling and methods:

INTE: What about integration in the sense that if someone came for HIV services, they would get the family planning service that they require? I mean a one-stop-shop.

VC01: That is usually not possible because of manpower constraints. If we have one person doing all that, counselling, giving drugs, providing family planning, then we would not be able to achieve much. So since we have the family planning services already being offered for other regular clients then we just refer the HIV/AIDS clients to the same. (Clinical officer)

INTE: Does this facility integrate HIV/AIDS services with family planning or are these services offered differently?

VCS1: We are trying to integrate HIV and family planning services, but it has not picked up well because of the shortages we have with staff. So it has not gone the full integration as it were. One member of staff will have to attend to a very large number of clients. So the clients may not necessarily receive the proper service that they want. (Counsellor)

Historically HIV/AIDS and reproductive health services have been offered in parallel to each other in Kenya. Donor financing, which is an important funding stream, has contributed in keeping HIV and family planning as separate and parallel fields for a long time (Gruskin, Ferguson, and O'Malley 2007). When family planning and HIV services are linked and provided together, available evidence suggests that such integration produces better outcomes, both in terms of reproductive health and HIV (Spaulding et al. 2009). In principle, integration can improve coverage, access and reduce stigma in use of SRH and HIV services (Askew and Berer 2003; Spaulding et al. 2009), especially among vulnerable populations, including PLWHA and those living in areas with limited access to formal health services such as urban slums.

The third health system barrier is user fees. PLWHAs and their health care providers pointed out that the user fees levied on some contraceptives is unaffordable to some of the poor PLWHA in the slums:

INTE: What barriers do you face when seeking family planning services?

VC14: I can see there are services, but most of us are locked out, we don't often get the service. A woman may not be able to afford the pills and she ends up with a child that she did not want (Never married man aged 39).

KNS2: The other reason is affordability. For instance our community based distributors sell the pills for only 20 [Kenya shillings] since we don't pay them. Some clients say they cannot

afford and that leads to them not taking the pills. Considering that most of your clients come from low-income areas, is it possible that the 20 shillings levied on them could be a barrier in seeking these services. (Nurse)

The process of accessing family planning, can incur a number of indirect costs for PLWHA. Even when contraception is offered free of charge at the point of delivery the indirect costs may hamper their access to poor slum residents. Poor urban residents have little disposable income to spend on contraception, let alone the transport as they often must travel outside their neighbourhoods for high-quality, free or low-cost family planning (Ezeh, Kodzi, and Emina 2010). This might partly explain why unmet need for contraception is highest amongst the poorest wealth quintile (Figure 8.0.8).

Provider attributes in terms of attitudes and skills and knowledge constitute an impediment to use contraception by PLWHA. Health providers' personal opinions and values as well as skills may influence family planning information and services they provide to their clients. Provision of information and family planning counselling was found to be an independent predictor of contraceptive use (Table 8.0.4). Those respondents who had been told about family planning by their health providers were more than twice as likely to be using contraception than those who did not discuss family planning with their providers (OR 2.54; 95% CI 1.60-4.04;  $p < 0.0001$ ):

INTE: why aren't you using any means of FP?

VC09: I have not because whenever I go to the hospital they don't tell me about family planning. They give me the drugs I want and then ask me if I have a question for them, and I do not then that is it. No one talks to me about family planning. (Married mother of 4 aged 41)

Studies have shown that people seeking HIV/AIDS services have unmet need for contraception despite being receptive to receiving contraceptive services. In a study in Ethiopia among PLWHA, receiving contraceptive counselling increased the odds that a client would obtain family planning (Bradley et al. 2010).

Health care providers need the skills to effectively respond to the SRH needs of PLWHA. These range from counselling on fertility, contraception and ability to perform surgical procedures related to contraception (GNP+ 2009). Healthcare

providers mentioned their inadequate skills and out-of-date knowledge around HIV and SRH issues:

INTE: Do you think that the training that you have received was adequate for you to handle PLWHA?

KNS2: I can say that I need an update. The training was way back in 2005 or 2006 and you can see how I am confused about some of these [SRH and HIV] matters [laughs]. I need some updates to bring me up-to-date with the emerging changes around HIV. (Nurse).

VCO1: As you know the HIV/ART field is very dynamic and things keep on changing. So I may not have all the skills. That is why we need to keep going for updates, but I can say I have got most of the skills required in this field. But it's also good for [HIV] counsellors to be trained on family planning or rather reproductive health. (Clinical officer)

System level factors such as contraceptive commodity insecurity, provider practices and infrastructure have been shown to be impediments to contraceptive adoption in the general population and among PLWHA (Bradley et al. 2010; Campbell, Sahin-Hodoglugil, and Potts 2006).

The Kenyan policy environment has recently been conducive to linking HIV/AIDS services with reproductive health service (Liambila et al. 2009). However, there are major impediments to integration. One of the most formidable hurdles for effective integration is a lack of resources (Spaulding et al. 2009). Donors have been generous in supporting HIV/AIDS services compared to family planning services. Donor funding for family planning as a share of total population assistance has fallen from about 54% in 1995 to about 7% in 2005 (Van Dalen and Reuser 2008). In addition, international funding, which plays a major role in family planning programmes in Kenya has been dwindling in the last decade. For example, USAID – the leading donor for family planning cut its support for family planning by 1/3 from 1995 to 2002, but increased funding for HIV by 6 times in the same time period (FHI 2004).

#### **8.4. Conclusion**

This chapter has explored the fertility preferences among PLWHA, a relatively neglected area in population and health research until recently. Most demographic

research has tended to focus on the effects of HIV/AIDS on fertility rates in the general population and rarely does it interrogate fertility preferences of people infected with HIV. For PLWHA, life is still going on and socio-cultural factors continue to shape their reproductive intentions and contraceptive use. PLWHA, just like anyone else, value children because they can enhance their social status, and for the extension of the lineage in patrilineal settings. Women in particular depend on sons to solidify their marriage and positions in their matrimonial homes. PLWHA's fertility intentions in this study were lower than the general population and contraceptive use is relatively higher, although there are still high levels of unmet need for family planning in this population.

PLWHA have unique issues to grapple with in their reproductive preferences and choice and have additional considerations to take when deciding whether or not to have children. These include the possibility of infecting the child and sexual partner, pregnancy accelerating the progression of AIDS, and the possibility of dying before their child reaches adulthood. Some PLWHA continue to have children for a range of personal, cultural and economic reasons. Others decide to stop childbearing and rely on contraception to achieve their reproductive goals. It is not surprising that their contraceptive behaviour is wrought with anxiety, fears and worry. They face several barriers and their reproductive health needs are not necessarily met by an overstretched health care system.

These fears persist partly because little effort is made to provide correct scientific information to the PLWHA, that ART extends life, is associated with good pregnancy outcomes, reduces horizontal and vertical transmission and pregnancy and contraceptive use is not associated with disease progression (Howard 2003; Laher et al. 2009; Quinn et al. 2000; Smith et al. 2009) However, this information is not systematically relayed to PLWHA to ameliorate their fears about HIV, fertility and contraception. Health care providers and the public health community have a duty to relay accurate reproductive health information, free of personal bias, to allow for informed choice by PLWA. However, their attitudes seem to be strongly influenced negatively by perceived biomedical and public health concerns.

## Chapter 9: Conclusions, policy implications and future research

### 9.1. Introduction

This chapter discusses the contributions of this research to, and its relationship with, the literature and considers the implications for policy and programme interventions. The chapter is divided into four sections. The first section provides a brief summary of the findings; by presenting an overview of the research questions, how each one was answered, the main conclusions drawn from each research question and how this relates to the literature. The second section is dedicated to policy implications of the study and consequent recommendations for policy and programmes. Suggestions are made on how policy makers and programme practitioners might better meet the SRH needs of men and women living with HIV in poor contexts. The third section discusses the strengths and limitations of the study in order to further put its interpretations into perspective. And, finally, the chapter closes with thoughts on possible directions for future research.

### 9.2. Summary of main findings

This study sought to understand how people living with HIV negotiate their sexual and reproductive lives in Nairobi slums, Kenya. The study was driven by the overall research question: How do men and women living with HIV/AIDS consider, and manage, their sexual and reproductive lives? From this broader question, three further research questions were derived:

*9.2.1. How do men and women living with HIV/AIDS perceive their own sense of self and life prospects as related to sexual and reproductive outcomes in the current era of treatment?*

Chapter 5 presented a detailed picture of the experiential process of self-identity and its relation to SRH, from the time of HIV sero-status knowledge, in the context of living in a slum setting, relying mainly on qualitative data. The analysis of the data was guided by the biographical disruption framework, which suggests that an infection with a chronic illness such as HIV is a disruptive experience, resulting in an reassessment of one's life and relationships with others (Bury 1982), and an effort to repair the disrupted biography and return to normalcy or ordinariness (Carricaburu and Pierret 1995; Ciambone 2003; Kralik 2002). A person diagnosed with HIV may



undergo a transition to a new self-identity by incorporating HIV and ART into their lives (Russell and Seeley 2010). This may entail assessing which parts of a person's identity must remain and which aspects must be redefined (Carricaburu and Pierret 1995; Ciambone 2001; Wilson 2007).

The narratives showed that the transition to an HIV positive identity can be grouped into broad 4 phases: Diagnosis and subsequent reactions, managing the information flow on the HIV condition, positive living and associated restraints, and repair and return to normalcy. I provide a brief overview of these phases below and show how they can influence the SRH behaviour of PLWHA.

#### Diagnosis and reactions

A diagnosis was the first step in the process of self-identity although many dreaded it. Their accounts show that the majority were diagnosed late in the course of their infections when they were already experiencing AIDS symptoms. A diagnosis of HIV/AIDS brought considerable disruption to people's lives, compounded in the context of poverty in the slums and diminished resources for the management of the HIV condition. Although each PLWHA was affected differently, diagnosis of HIV was a profound event in their lives and it took some time for many PLWHA to come to terms with. The diagnosis elicited varying responses ranging from shock, shame, fear, denial to relief and stoicism. Some made changes in their lives while others maintained the status quo. The process of moving forward seemed impossible for some at times. Many of them were worried about what might happen to their children and other family members in the event of their death, and also the way they would be treated by society.

The manner in which PLWHA reacted to their HIV notification had a bearing on their subsequent SRH behaviour. The primary barrier to safe sex in their relationships, especially for several female participants, was fear. Fears related to potential negative reactions, including rejection, violence and loss of financial support prevented partner notification of HIV status. Narratives show that lack of disclosure of status to sexual partners worked against use of condom for dual protection against HIV (re) infections and unwanted pregnancies, a finding that was illustrated by the quantitative data in Chapter 7. Narratives show that feelings of denial and a general lack of self-acceptance

undermined protective sexual practices. A number of participants opined that some PLWHA who engaged in unprotected sex were intentionally trying to infect others. Feelings of anger, revenge and denial or lack of acceptance of their HIV status was reported to fuel malicious attempt to infect others. However, when these conversations shifted to participant's own personal life experiences and sexual relationships there was virtually no acknowledgement of malicious intent, perhaps a reflection of social desirability bias.

#### Managing the information flow: Disclosure dilemma

HIV infection is associated with sexual promiscuity, high risk groups (for example, commercial sex workers and long distance truck drivers) and societal moral breaches (Iliffe 2006). Those diagnosed with HIV face various forms of stigma and social disapproval (Ostrom et al. 2006; Parker and Aggleton 2003). Anticipation of stigma and discrimination prevents PLWHA from disclosing their status (Ostrom et al. 2006; Stutterheim et al. 2011). The decision to disclose demands a careful consideration because of its potential consequences – both positive and negative – which may include rejection, abandonment, violence and social support. Much as both men and women experienced these negative outcomes, women appeared to be more negatively affected as many reported being sent away from matrimonial homes or ostracised by both in-laws and family members.

These experiences and public perceptions and discourses about HIV/AIDS shape individual experience of illness and subsequent SRH behaviour. Some respondents reported that they chose to disclose their status to a sexual partner because of altruistic desires to protect them from infection. Others chose not to disclose to their sexual partners for fear of losing the relationship and its associated financial support. These decisions about disclosure affected whether or not condoms were used for dual protection. Stigma fears and experience might prompt PLWHA's desire of re-establishing their self-worth in the face of social disapproval. They are under heightened urgency to carry on with their life in a manner that looks normal to partners, family and the society at large. Re-establishing their sexual lives and having children was seen as one way of mitigating stigma and of feeling socially validated (Kerrigan et al. 2006; Smith and Mbakwem 2010), underlying the importance of parenthood to women's and men's legitimacy and identity. On the other hand, the

quest for moral validation may work against fertility desires. Some women expressed reluctance to get pregnant and give birth to an infected child and in the process potentially infecting the father and exacerbating her condition, an act that they perceived to be immoral.

#### Positive living

Living positively involves observing a prescribed lifestyle in order to effectively manage life with HIV/AIDS, which involves matters touching on diet, sexual behaviour, acceptance and disclosure of HIV status (Levy and Storeng 2007). It is geared towards finding ways to stay healthier through proper diet, preventive sexual and reproductive practices and developing positive attitudes. PLWHA were counselled to give up some activities that were incompatible with their new status (drinking and smoking), take ART for life, avoid herbal medicine and maintain protective sexual behaviour.

The way PLWHA understood positive living had a bearing on their sexual and reproductive behaviour. Narratives show that some PLWHA understood this to mean that they must not have sex and that they could no longer bear children. This affected their sexual lives as well as plans for having children. Some of them become sexually abstinent and acquiesced to involuntary infertility. Others understood it to mean consistently using a condom, something which some have managed to do, while others find more difficult to achieve.

#### Mobilisation of resources for identity repair

Following initial disruption PLWHA try to give a sense of continuity to their lives by mobilising resources – social, physical, financial, medical – to deal with the condition (Carricaburu and Pierret 1995; Williams 2000). Many PLWHA looked for emotional, material and palliative resources to deal with the HIV condition. The most significant in the narratives include social groups, prayer and religious congregations, and enrolling for ART or prophylaxis care for opportunistic infections. Many respondents reported that they joined HIV social groups as advised by healthcare workers, although some (more likely to be men) refused to join. Joining support groups provided an avenue for sharing and management of their new identity and image. They shared illness experiences and treatment testimonies which shaped their identities as PLWHA.

Such groups appear to provide some much needed social support to mitigate psychological distress associated with HIV and promote well-being (Kalichman et al. 2003).

Membership of a faith based organisation provided spiritual nourishment and encouragement to live with HIV, despite concerns and even experiences of rejection from members of these spiritual congregations. The healing potential of prayers was mentioned by some, although respondents reported cases of healing prayers negatively affecting adherence to ART. Some studies in SSA have documented a positive relationship between prayer/spirituality and quality of life among PLWHA (e.g Friend-du Preez and Peltzer 2010). Despite their apparent ambivalent rhetoric towards HIV/AIDS prevention strategies such as condoms, and stigmatising stances, religious groups provide spaces for therapeutic resources (both physical and socio-psychological) and social ties for PLWHA.

The use of ART was another significant resource in their survival strategy. It was clear from the narratives that that the treatment and care they received was a major resource, despite initial side-effects. ART enables PLWHA to regain their value as economically and socially productive members of society thereby fending off stigma (Campbell et al. 2011; Castro and Farmer 2005). The search for healthcare ensured contact with health care providers who were also relied on for psycho-social support in managing their condition.

With ART initiation many PLWHA had begun reviewing their personal situations, intimate and sexual lives, family, and job prospects. Social support and ART use were reported to facilitate safer sexual behaviours and fertility desires, a finding that was supported by quantitative data in chapter 7. In the context of the high premium placed on parenthood for identity and recognition in SSA societies (Awiti Ujiji et al. 2010), HIV/AIDS condition posed a potential threat to their identities as mothers and fathers. To this end, many PLWHA mobilised material and non-material resources to survive for the sake of their children, a finding confirmed in the UK (Wilson 2007).

The conclusion drawn in relation to the research question is that there is evidence of biographical disruption and concerted efforts to attain some semblance of normalcy for

many PLWHA, although not all. For many it is a long drawn, iterative transition process that takes some time, perhaps on-going for others. The transition is akin to a “quest for ordinariness” (Kralik 2002) – which involves moving from a phase of turmoil and distress to a phase of trying to live positively with the illness. It involves mitigating the disruption and striving to normalise their everyday lives and social relationships. For some, however, no disruption seemed to have occurred and the status quo was maintained. Some narratives seemed to downplay the disruptive effect of HIV infection on their lives in the light of multiple difficult life experiences in their setting. In some of these cases, it even may have contributed to what Carricaburu and Pierret (1995) call “biographical reinforcement” of the identity already built following experiences of negative life events prior to HIV infection. Whether or not biographical disruption occurred, all respondents had to rework their sense of identity, and their SRH outcomes appeared partly to be a product of this process.

*9.2.2. What factors contribute to an explanation of sexual and reproductive intentions and behaviour of men and women living with HIV and AIDS?*

- In what ways does the use of ART affect sexual and reproductive behaviour and intentions of men and women living with HIV/ AIDS?
- What other factors influence their SRH decisions and experiences and what are the barriers to achieving SRH needs of men and women living with HIV/AIDS?

Chapter 6, 7 and 8 provided part answers to the second research question and its constituent subsidiary questions. Chapter 6 examined the sexual experiences and functioning as well as sexual inactivity among the PLWHA. Chapter 7 extended the focus on sexual behaviour by examining risk reduction sexual behaviour, highlighting its facilitators and barriers. Chapter 8 looked at the fertility intentions and contraceptive use, examining their determinants and causes of unmet need for contraceptives. What follows is a summary of the main factors affecting SRH outcomes of PLWHA.

Sexual experience among PLWHA

The study explored sexual experiences and functioning alongside risk reduction behaviour. The findings show that almost three quarters (73%) of PLWHA were

sexually active in the last 12 months which was independently and positively associated with being male, married or cohabiting, being young, and negatively associated with ART use and duration of HIV. Although the majority were sexually active, findings show that their HIV infection and sometimes even treatment had negative consequences to their sexual lives. Though sexually functional, PLWHA reported that their desires were diminished and their sexual activities less frequent and satisfactory. Their sexual experience is plagued with fears about HIV transmission and status disclosure, loss of sexual interest and libido, concerns about their sexual performance and partner rejection. Although all these issues affected both genders, women's concerns centred more on transmission risks and diminished desire, while men were more concerned about sexual performance and their inability to meet their own or their partners' expectations. This does not mean that issues of sexual performance and pleasure do not matter as much to women as they do to men. But rather it is a reflection of gendered roles where this part of sexuality is important in defining masculinity (Hirsch 2007) – and because of HIV – men face challenges in meeting their sexual and economic expectations associated with their masculinity ideas.

When it comes to sexual abstinence narratives, what was striking was the difference in explanations between men and women respondents. There were feelings of anger and victimisation among women, who felt hurt and betrayed by men whom they believed had infected them knowingly. Their narratives left the impression that the decisions to abstain were driven by mistrust and wariness of sexual engagement in the future. For men the decisions to abstain were more likely to be driven by their sexual performance concerns such as lack of libido or physical strength to effectively engage in sex. Unlike abstinent women who appeared strong in their resolve to remain abstinent, men seemed less inclined to abstinence if their libidinal and physical circumstances improved. Both genders felt that HIV infection was damaging to their self-esteem and identity as women and men as well as potential sexual partners. The decisions to abstain for some was a way of living positively with HIV/AIDS (Undie et al. 2009) following perceived dissonance between HIV positive status and sexual activity (Relf et al. 2009).

The conclusion from analysis of findings is that there is sex after HIV infection for the majority of PLWHA, and the need for PLWHA to express themselves sexually needs to be recognised as their right and supported. PLWHA face dilemmas in initiating, resuming or continuing sexual relationships, set against a context where public debates about morality and responsibility in HIV control and negative attitudes towards their sexual activities abound. People make decisions in their day-to-day life to reconstruct their sexuality with HIV. For many the tendency was to eschew or even express revulsion of sex activities soon after HIV-positive testing, but with time they resumed it. They, nonetheless, had to contend with issues of disclosure of their sero-positivity to partners, fears about (re) infections, diminished sexual desire and anxiety about sexual performance. As a result their sexual experience is blighted by discomfort, anxiety and feelings of guilt, victimization and anger.

#### ART use and sexual and reproductive behaviour of PLWHA

The effect of ART on sexual and reproductive behaviour is an issue that is attracting academic and policy attention in the face of recent unprecedented ART rollout in resource-poor settings. The findings of the few studies that have examined how treatment affects sexual and reproductive behaviour in resource-poor settings have produced mixed results, highlighting the need for a better evidence base (Kaida et al. 2011; Luchters et al. 2008; McClelland et al. 2010; Sarna et al. 2009).

The improvements of health and wellbeing associated with ART use (Coetzee et al. 2004; Mocroft et al. 2003) was anticipated to increase levels of sexual activity among PLWHA on ART treatment. However, contrary to this expectation, findings show that use of ART was negatively associated with sexual activity in the last 12 months. Those who were not on treatment were almost 3 times more likely to be sexually active than those who were on ART (OR: 2.85), net of other factors. This finding was unexpected based on the literature, albeit most of it comes from MSM populations in the North. However, a few studies in SSA have found no significant relationship between ART and sexual activity (Luchters et al. 2008; Sarna et al. 2008). One qualitative study

suggested diminished sexual activity following ART initiation (Sarna et al. 2009). Qualitative findings suggest that reduced sexual activity among those on ART is due to the fact that counselling during ART initiation tends to stress abstinence, combined with the perception of some PLWHA that sexual activity negatively affects ART effectiveness (Sarna et al. 2009; Undie et al. 2009). ART use has also been associated with sexual dysfunctions and side-effects (Collazos et al. 2002) among PLWHA, which might explain their diminished sexual activity.

The effect of ART use on protected sex (condom use) is also mixed, with prospective studies in SSA showing that protected sex increased (Luchters et al. 2008; Sarna et al. 2009), remained the same (Bateganya et al. 2005) or decreased among PLWHA following ART initiation (Diabaté, Alary, and Koffi 2008). This study found that ART use was positively associated with consistent condom use in the last 12 months. Being on ART increased the likelihood of consistent condom use almost two fold (OR 1.80). The explanation for the positive association from qualitative data is that ART initiation is accompanied by positive prevention messages, with the consistent use of condom taking centre stage in many counselling sessions.

Evidence on the effect of ART on fertility desires in the literature is mixed (Kaida et al. 2009; Kaida et al. 2011). Since ART is associated with longer and healthier lives it was expected that those on ART would be more inclined to have fertility desires. This study, however, did not document any significant association between ART use and desiring future fertility, net of other factors. Qualitative findings show that irrespective of treatment status many respondents felt that pursuing parenthood was fraught with potential risks of HIV transmission, health deterioration and orphaning. Hence their reproductive preferences are wrought with anxiety, fears and worry.

The conclusion drawn is that ART is not associated with riskier sexual and reproductive behaviour among PLWHA. On the contrary, ART use was positively associated with safer sexual behaviour such as condom use and abstinence in this study. Emerging prospective studies in SSA show that protected sex does increase following ART initiation (e.g. Eisele et al. 2009; Luchters et al. 2008). Emerging clinical studies also show ART use substantially reduce a person's infectiousness, in both horizontal and vertical transmission (Granich et al. 2009). Taken together these results support the importance of ART as one of the tools for reducing HIV



transmission and the potential importance of ART as a prevention strategy. Secondly, the lack of a relationship between ART use and fertility intentions suggests that fertility desire is unlikely to be an issue of discussion between health providers and PLWHA during ART enrolment. It also suggests that knowledge of positive effects of ART on safer childbearing is not communicated by health providers who are inordinately concerned with promoting protected sex and correct use of ART.

In the ART era, there is a growing recognition of the need to support the rights of PLWHA to be sexually active and achieve their fertility goals, while minimizing the risk of HIV transmission. A recent special supplement on AIDS and Behaviour on HIV, ART and fertility in SSA observed the dearth of literature on the topic and called for research to inform care and SRH services of PLWHA in the region (Kaida et al. 2009). This study is an effort in that direction. The findings show that the SRH outcomes of PLWHA are somewhat different from the general population, but similar with other PLWHA in similar settings in terms of magnitude. Condom use at last sex is higher (74%) than that observed in the general population although consistent use (56%) is problematic. PLWHA exhibit fertility desires (34% desire fertility) and contraceptive behaviour (59% use contraception) that is more geared towards limiting fertility compared to their uninfected peers, but face barriers (both demand and supply) in accessing services, which explain in part the relatively high (19.5%) unmet need for contraception. Several socio-cultural, demographic, health and institutional shape these SRH outcomes and provide barriers to realising their sexual and reproductive goals. These include among others gender, poverty, relationship issues, socio-demographics and health related issues.

#### Poverty, Gender and survival sex

Poverty, food insecurity and gender power inequality interact to drive the HIV/AIDS epidemic and cause poor SRH outcomes in SSA (Barnett and Whiteside 2002; Gillespie, Kadiyala, and Greener 2007; Krishnan et al. 2008; Madise, Zulu, and Ciera 2007; Weiser et al. 2007). The findings of this study show that the effect of this interaction is a serious concern among PLWHA in slums as HIV infection further escalates their poverty condition and vulnerability. Rural-urban migration does not necessarily create improved opportunities for slum residents, who invariably live below the poverty line and have little access to formal employment. Most PLWHA

living in the slums are characterised by poverty by any conventional definition. For example about 75% of the respondent's estimated their monthly income to be less than 1 dollar a day. Much as income does not cover all dimension of poverty, its role in the subsistence in an urban cash-based economy is my no means small. The majority of PLWHA in slums are in low paying informal economy- petty trading, selling food by the roadside, casual work, and commercial sex.

Findings show that HIV infection has undermined their already insecure sources of livelihood, further exacerbating their poverty conditions. HIV related illness or death was reported to lead to reduced levels of productivity, income and loss of property and other social consequences such as household and marital dissolution and orphanhood. Poorer PLWHA in the slums are forced to adopt strategies- selling assets, commercial sex work, multiple sources of food aid, withdrawing children from school- which enable them to survive now, but do not improve their wellbeing. These strategies demonstrate that they are merely surviving rather than coping (Amuyunzu-Nyamongo et al. 2007; Barnett and Whiteside 2002). The effects of HIV infection and survival strategies that have a bearing on SRH of PLWHA in the slums are gendered in nature.

There is little disagreement among scholars that there exists gender inequality between men and women in terms of power and access to resources in society, and principles governing their roles and behaviour in most SSA settings. The gender disparity in HIV infection in SSA, where the odds of infection among women are 60% higher than men (Magadi 2011), has largely been attributed to the gender inequalities that create vulnerability among women (Kalipeni, Oppong, and Zerai 2007; Mill and Anarfi 2002; Varga 2003) in addition to biological susceptibility (Glynn et al. 2001). The findings of this study show that PLWHA are not immune to the gender asymmetry and gender norms that define their roles and power in society. Women in the study are less likely than men to have any formal education and consequently less likely to access paid jobs outside home. This makes more women than men economically dependent on their spouses and sexual partners. Being dependent on men for survival makes it hard for women to implement the preventive sexual behaviour such as demanding faithfulness and consistent condom use from their partners. While some reported success in negotiating for condom use, many reported that men's opposition prevented them from using condoms consistently.

Fears of retribution reduce women's ability or willingness to negotiate condom use. A study in Botswana found that women who were economically dependent on their partners were less likely to suggest condom use (Langen 2005). Much as many women cited their partners' refusal, partner's opposition to condom use was not just the province of men. Men also alluded to their partners' refusal to use condoms. When it comes to faithfulness, being male increased the odds of reporting multiple sexual partnerships by more than 2 times (OR 2.4). Whether or not it is a reflection of gendered reporting bias of extramarital and multiple partnerships should not obscure the role of such sexual behaviour in creating men as well as women vulnerability to HIV re (infections).

Many women and, to some extent, men also took into consideration their partners' opinions in their contraceptive uptake. Perceived husband disapproval negatively affected women's utilization of contraception because their male partners thought that contraception made them sexually non-responsive. Men's fertility desires were significantly higher than women's to the order of four (OR 4.17) and their influence on contraceptive use cannot be underestimated. Perceived or real male partner opposition to contraception is, therefore, not by any means an insignificant factor in the higher unmet need for contraception among women than men in the study. Cleland et al. (2006) observe that given positive attitudes of men toward contraception in surveys, the real issue might be misconceptions by women of the husbands' negative attitudes, an indication of lack of spousal discussion.

While the findings confirm that gender relations play an important role in women's vulnerability to adverse SRH outcomes, it is imperative to note that the same gender roles might create vulnerabilities in men as well. The findings of this study show that men were less likely than women to be on ART, and that they tested for HIV and enrolled for ART later than women. Although men, in general, have greater access to resources than women, which, in theory, should facilitate their access to HIV services, research has documented their limited use of HIV service compared to women in SSA. Men are less likely to test for HIV and enrol for and adhere to ART in SSA settings and this differential utilisation of services has been attributed to cultural constructions of masculinity and femininity (Bila and Egrot 2009; Kipp et al. 2010; Obermeyer et al.

2009; Skovdal et al. 2011). The social values attached to femininity such as maternity, reproductive capacity and child care create favourable conditions for women's HIV and other health care utilization, while ideologies of masculine invincibility and a sense of manhood constrain men's use of HIV services. Men's disinclination to test for HIV or use HIV services and subsequent preventive information and service, create vulnerability to themselves as well as women partners.

Secondly, the findings show that the notion of women's powerlessness and passiveness does not always hold. Some women reported that they manipulate condom use in their sexual relations with men by their unyielding insistence or even refusal. Qualitative evidence from Malawi show that women are often far from being passive and powerless victims in sexual relations, but rather sometimes actively manipulate them for pleasure, revenge and material support among other reasons (Swidler and Watkins 2007; Tawfik and Watkins 2007; Verheijen 2011). Furthermore, material support is not just an economic exchange (transactional) for sex for men, but rather support with multiple meanings including expression of love, commitment, appreciation and social responsibility and obligation (Poulin 2007; Swidler and Watkins 2007). In the same vein the notion of men being irresponsible and abusive sexual partners does not always hold. There is evidence in this study that quite a number of men disclosed their status and used condoms as a matter of responsibility to, and care for, their female partners, and also provide them with financial and emotional support. Therefore, a more nuanced understanding of gender relations where men and women are active agents in (re) constructing gender norms is needed.

#### Disclosure, stigma and social support

PLWHA face a dilemma in disclosing their status because it may lead to positive (social support) as well as negative (stigma) outcomes. While both men and women reported apprehension about disclosure, women were more likely to express fears around abandonment and expulsion from their marital homes. Some women reported no-disclosure of their status for fear of rejection and consequently losing financial support. Some men who did not disclose might have done so for fear of compromising their positive sense of masculinity and manhood. A man who contracts an embarrassing disease such as HIV can be perceived as having a weak, diseased and irresponsible sexuality (Skovdal et al. 2011). Lack of disclosure of status to sexual

partners had an influence on SRH outcomes among PLWHA. Those who always disclosed their status to sexual partners had an almost 3 fold (OR 2.6) increase in the odds of consistent condom use relative to those who never disclose.

On the other hand those who disclose can gain social support, which has a positive effect on SRH outcomes. Higher levels of perceived social support in this study were positively associated with increased odds of consistently using condoms (OR 1.65) and desiring future fertility (OR 1.59). Social support helps relieve HIV-related stress and depressive conditions caused by stigma and negative social responses (Golub et al. 2011; Crepaz and Marks 2002). People who disclose their status to close family members and significant others are able to harness social support. With disclosure and consequent spousal support, couples, for example, are more likely to discuss protected sex and pursue fertility intentions together and may not fear discussing them with health care providers.

#### Socio-Demographic factors

Demographic factors that influence reproductive decisions include age, marital status, education and parity. Similar to other studies, age of the respondent was found to be an independent predictor of fertility desire and contraceptive use. Younger respondents were more likely to desire more children and less likely to use contraception. This finding is not surprising given that younger people are earlier in their reproductive careers and may still have some way to go towards fulfilling their desired family size. Qualitative data show that this can be attributed to the societal norms that place a high premium on fertility and children. Child bearing outside culturally sanctioned heterosexual relationship/union is usually socially unacceptable. This finding has implications for HIV transmission among younger aged and married discordant couples.

Number of living children is another factor that was independently associated with desiring fertility and using contraception. Those with no child or one or two children had significantly higher desires for children to either experience parenthood or achieve their desired number of children (average desired fertility was 4.1). In the context of high infant mortality due to mother-to-child transmission of HIV, PLWHA may be under heightened urgency to have children, either for insurance or replacement.

Studies in SSA settings conclude that women irrespective of HIV status will continue to conceive until their ideal family size is achieved and for social validation (Smee et al. 2011).

Educational attainment had an effect on the fertility preferences and contraceptive use among PLWHA. Respondents with at least primary education had a 3-fold increase in the odds of using contraception compared to those without formal education (OR 3.4). Education, especially of women, contributes to decision-making autonomy on fertility issues and knowledge of family planning. Studies show that women's relative decision-making autonomy, independent of men authority facilitates fertility regulation (Saleem and Bobak 2005; Moursund and Kravdal 2003).

#### Health concerns and side-effects

Experienced and perceived side-effects, health concerns and (mis)information combine to negatively affect the use of SRH services among PLWHA. Most contraceptives have side-effects and this can affect their uptake and discontinuation. Reported experienced side-effects included excessive bleeding, heightened pulse rates and body temperatures, which raised alarm bells about the potential deterioration of their perceived precarious health condition. In others cases perceptions of side-effects are based on rumours and (mis)-information circulated by their peers and other social networks. Some reported rumours included that IUD can disappear in a woman's body, condoms are laced with HIV or condom lubricants can exacerbate their HIV/AIDS condition. A common (mis)-conception around family planning use included the belief that it reduces women's libido. Another misconception is that some family planning, especially hormonal methods are either incompatible with ART treatment or can make the treatment ineffective. Similar misconceptions have been reported in other studies in SSA (Laher et al. 2009).

#### Health system barriers

The health service environment influences the use of SRH services. Irregular supplies of SHR commodities is a common problem in public health facilities in Kenya and this problem is even worse in slums, which tend to be excluded from formal government health service and rely on poorly regulated informal providers (Ezeh,

Kodzi, and Emina 2010) Therefore, better access to reproductive and other health services and information associated with urban residence does not hold for slums (Montgomery 2009; Ezeh, Kodzi, and Emina 2010). Some contraceptive methods were not accessed by many PLWHA either because they were not consistently available or out of stock, too expensive, or health facilities were not equipped to provide the services. Although the government has committed to making SRH services available to all those who need them, resources have been insufficient to make this access a reality. International funding, which plays a major role in family planning in SSA has been dwindling in the last two decades as new challenges such as HIV/AIDS have diverted funds from family planning (Ezeh, Kodzi, and Emina 2010; Van Dalen and Reuser 2008).

User fees and related cost were also reported to form a significant barrier to use of SRH service among poor PLWHA. Healthcare providers reported that a token user fee levelled on family planning commodities was still beyond the reach of a number of PLWHA. The use of family planning service also incurs additional costs in the form of transport and absence from income earning activity, since poor urban residents often must travel outside their neighbourhoods for high-quality, free or low-cost family planning (Ezeh, Kodzi, and Emina 2010). In the cash-based urban economy, many poor PLWHA have little disposable income to spend on SRH services. This finding reinforces the need to provide cost-free family planning services that are physically and economically accessible to women and men in urban slum areas.

Health providers sometimes affect the uptake of SRH services by their bias or lack of information. Narratives with providers suggest that they focus almost exclusively on ART adherence and positive prevention counselling. Most of them did not mention fertility and contraception counselling until prompted. Although their prompted narratives show they offer fertility and contraceptive information and services without any bias, PLWHA narratives show that providers tended to demonstrate anti-natal or dual protection (condom use) biases, perhaps partly explaining why condom was the method of use for more than 3/4 of respondents. Some providers were as misinformed as their clients concerning the use of ART and hormonal contraceptives. Some providers said that there were no contradictions between the two, while others believed there were, and hence, were reluctant to provide hormonal methods for those on

certain types of ART. In addition, poor health infrastructure and staffing constraints were reported by health care providers to hamper their efforts to provide integrated SRH and HIV/AIDS services.

The conclusion drawn from the data in relation to the research question is that PLWHA are sexually active, continue to desire children and want to space and limit their fertility. But for a number of reasons their SRH care needs are not being met. The overarching issue is that the urban poor as a subgroup do not enjoy the infrastructural and service “urban advantage” and so are both economically and physically disadvantaged in their access to SRH services. Yet despite these disadvantages, socio-cultural issues also reign supreme in influencing, sexual behaviour, fertility desire and demand for contraception. This implies that socio-cultural norms surrounding sexual behaviour and fertility preferences are significant regardless of place of residence and HIV status. Parenthood is an important facet of PLWHA social status as well and childbearing is sometimes seen as a sign of health. The inherent social rewards of childbearing, in the context of poverty and limited access to social security, and its inherent risk of transmitting the virus are complex issues in reproductive decisions among PLWHA. Consequently, as the data shows, PLWHA face a dilemma about what constitutes “proper” sexual and reproductive behaviour. As such the SRH behaviour among PLWHA in the ART era is fraught with tension between social pressures and moral pressures.

Overall, the fertility desire of PLWHA is lower than the general population, not least because they are more likely to be widowed, divorced and have health and (re)infections concerns to contend with, among other reasons. The evidence of relative high levels of unmet need for contraception means that PLWHA in slums need access to SRH services. Interventions that target economic and physical access as well as socio-cultural barriers in the slums are more likely to be successful. In addition, service delivery needs to duly recognise reproductive health goals and consider the complexity of the SRH decision making among PLWHA and provide them with



practicable SRH options. I consider these policy implications and recommendations in the next section.

### **9.3. Policy implications and recommendations**

Ideally, policy recommendations and objectives should meet S.M.A.R.T (Specific, Measurable, Attainable, Relevant and Time-bound) criteria. It is not always possible to meet some of these ideal requirements of recommendations. For example, it is not possible to impose a specific time frame on a particular stakeholder from the comfort of the university. That said, however, efforts are made here to provide specific and feasible recommendations as much as possible. The policy implications and recommendations are organised around themes and topics derived from the data.

#### *9.3.1. Poverty alleviation and socio-economic wellbeing*

The findings that gender, poverty and lack of access to and control of resources and socio-cultural norms are key obstacles to SRH among PLWHA in slums, speak to a general need to shift the focus away from targeting risky individual behaviour in isolation in favour of recognising and addressing these structural and societal factors that create vulnerability and shape individual SRH behaviours. The combined effects of gender inequality and poverty put many women in a position of vulnerability given few viable survival strategies. Programmes that empower women to reduce their cultural and economic dependence on men might go a long way in changing the dynamics of relationship between men and women and improving SRH. Men's influence on condom use and women's reproductive decisions was documented. This, however, should neither to be understood to mean that women have no agency in these situations nor that men are unconcerned about their partners' wellbeing. Better understanding of the interaction between gender, poverty and the experience of HIV in a particular context will help design feasible strategies to improve SRH and treatment and prevention.

The findings that HIV has exacerbated the living conditions of PLWHA in slums suggest a need to build more sustainable livelihoods. Livelihood is defined generally as comprising the capabilities, material assets and social resources required for making a living (Masanjala 2007). In the current ART era, the policy focus among PLWHA needs to shift from singularly focusing on their physical survival to include economic

survival and livelihood rebuilding to strengthen their capacities to cope well HIV/AIDS. Sporadic interventions for PLWHA in slums largely focus on the provision of food aid and hand-outs, which does little in restoring livelihood, and might foster dependency. Longer-term strategies could include communal income generating activities. Community action is important, especially for slum residents who are largely employed in the informal economy. PLWHA could be assisted to form micro-credit associations, with a social insurance element, where PLWHA can pool their earnings to start business ventures, for example. Micro-credits of this nature, for example, the Village Savings and Loan Microfinance programmes in Malawi have been successful in alleviating poverty among PLWHA (Heymann and Kidman 2009).

While earning their way out of poverty is the long-term solution, stopgap measures such as cash and food transfers are necessary. Studies in similar settings show that such transfers improve the SRH of the poor and most vulnerable. A recent randomised controlled trial in Zomba District of Malawi shows that cash transfers to adolescent girls and their families improved their SRH over an 18 month period. Those who received cash payments were less than half as likely to be seropositive, less than quarter as likely to have an STI, had relatively younger sexual partners and engaged in sex less frequently than those who did not (Baird et al. 2012). Combining income generating activities with strategic food aid and cash transfers could go some way in building self-reliant and sufficient ways of earning a living and fostering economic independence.

### *9.3.2. Sexual functioning: Continuous psychosocial help*

The findings of fears of sexual functioning, guilt, dissonance, anger and resentment around sexual activity among PLWHA have policy implications. The evidence points to psycho-social factors playing a prominent role in sexual functioning, echoing other studies which show that diminished sexual interest and sexual abstinence are strongly associated with psychological distress, depression, anxiety and low quality of life, over and above disease factors such as CD4 cell counts and duration or severity of illness (Florence et al. 2004). The findings suggest that PLWHA could benefit from counselling around sexuality as a whole, not just risk reduction as is usually the case. The findings speak to the need for interventions to help PLWHA to safely become

sexually active if they want to. Safe sexual activity is an important facet of the overall quality of life of PLWHA (Keegan, Lambert, and Petrak 2005).

### *9.3.3. ART use and treatment for prevention*

The finding that ART use and associated counselling is associated with consistent condom use has implications for HIV prevention and supports the potential importance of ART as one of the tools of HIV prevention. In addition to positive prevention information at its initiation, ART has been shown to decrease infectivity among its users by reducing their viral loads, with virtually no transmission by PLWHA with undetectable viral load (Attia et al. 2009). With decreased infectivity and without concomitant behaviour “disinhibition” as shown by this study and confirmed by emerging longitudinal studies (Bunnell et al. 2006; Eisele et al. 2009; Luchters et al. 2008; McClelland et al. 2010), provision of ART for those who need it can effectively reduce HIV transmission. Mathematical modelling studies (De Cock et al. 2009; Granich et al. 2009) suggest an optimistic picture of virtually eliminating HIV incidence within 10 years if all persons with HIV could be identified and treated with ART immediately. These findings reinforce the arguments that the solution for HIV elimination might lie in universal access to HIV testing and ART in addition to safer sex behavioural strategies.

These findings reinforce the evidence for the emerging HIV prevention discourse, namely; treatment for prevention. With the prevailing financial and health system constraints in many SSA settings, it may not be feasible to achieve it in the next 10 years. This study showed that HIV testing was done late for most PLWHA when they became symptomatic. HIV testing rates in SSA are very low with an estimated 80% of those infected unaware of their status (WHO/UNAIDS 2008). A number of strategies to improve testing and ART uptake in Kenya and slums are possible.

First, existing testing models in Kenya should be implemented and improved to increase chances of early testing and timely ART initiation. As the narratives show client-initiated VCT and provider-initiated HIV testing and counselling (HTC) models co-exist in Kenya. The former is an opt-in process operating on the “logic of choice” while the latter is an opt-out that operates on the “logic of care” (Hardon et al. 2011). In the former the emphasis is on good pre-test counselling to enable informed choice,

while the latter is where healthcare workers test people in order to treat them if they test HIV-positive (Hardon et al. 2011). However, these two logics do not need to be mutually exclusive. Respondents in this study were as concerned with good counselling as with good health care. Although human rights advocates have expressed ethical concerns with HTC (Hardon et al. 2011), these debates need be balanced with the freedom of choice as well as the need for good counselling and health care. Kenya national testing guidelines already support this framework, meaning that what is needed is to deliver the existing opt-in and opt-out protocols (NASCO 2008).

In terms of ART access, local and international resources need to ensure that those who are need of ART have uninterrupted access as cases of stock-outs were reported in the narratives, with some healthcare providers having to borrow from other clinics or having to postpone ART enrolment. The question of when to start ART is the subject of therapeutic discussions, with frequent calls for earlier initiation of ART, although the benefits of treatment for those over 350 CD4 cell counts is unknown as clinical trials for such counts are yet to be done (Jaffe, Smith, and Hope 2009). The 350 CD4 cell counts and below cut-off could be standardised in all health facilities, rather the current state where some facilities use 350 while others use 250 as cut-off for ART enrolment.

Third, implementing “treatment for prevention” requires some task-shifting – the delegation of responsibilities from higher to lower cadres of health staff, in some cases non-professionals and community participation (Zachariah et al. 2009). In the context of staff shortages, some key activities – HIV testing, ART pill delivery, adherence counselling could be shifted where possible to appropriately trained lay workers including, “expert” PLWHA already on treatment, community health workers (CHWs) and community-based organisations. Lay counsellors have helped improve uptake in HIV testing and CHWs) have played an important role in supporting adherence in a number of SSA settings (Zachariah et al. 2009). Although task shifting is a pragmatic way to deal with staff shortages, the appointment of the “non-professionals” is not necessarily sustainable. The CHWs and lay counsellors who support HIV and ART are unpaid volunteers without any form of monetary allowance. They reported to us that on many occasions they did not do their HIV support work because they had to go

and earn their own living. Volunteerism is certainly not sustainable in the long-term as evidence shows that lack of payment contributes to high dropout rates of CHWs (Kironde and Klaasen 2002; Zachariah et al. 2009). Some form of work-related allowances have been shown to be feasible and effective in some SSA settings (Harries et al. 2005). Involving CHWs in the community-based distribution of some contraceptives could help to improve some of the access issues experienced by slum residents, especially as a critical mass can be reached cost-effectively given the high population density in slums.

#### *9.3.4. Transmission fears, ART and reproductive rights*

The prevalence of fears, anxiety, worries and health concerns surrounding childbearing and a lack of association between ART use and fertility intention has policy and service delivery implications. The findings reflect limited knowledge among PLWHA about the positive effect of ART on reducing the infectivity of the users and mother-to-child HIV transmission. ART improves life expectancy, is associated with better pregnancy outcomes, reduces horizontal and vertical transmission and pregnancy and contraceptive use is not associated with disease progression (Howard 2003; Laher et al. 2009; Quinn et al. 2000; Smith et al. 2009) . However, this information is not relayed to the clients by providers to ensure informed reproductive decision making. Three policy recommendations can thus be made in reference to this.

First, healthcare providers should provide comprehensive, balanced and up-to-date information on the benefits of ART, not just the potential negative pregnancy outcomes among PLWHA. Clinicians have a duty to relay accurate reproductive health information, free of personal bias, to allow for informed choice by PLWHA in order to achieve their reproductive goals. The responsibility of health care providers in relaying accurate reproductive health information to PLWHA, devoid of personal bias, has been underscored (Laher et al. 2009). To this end, healthcare workers who provide ART and SRH services should be equipped with up-to-date information on ART vis-a-vis horizontal and vertical transmission of HIV. They should be provided with continuous training and skills on how to provide this information to their clients. During interviews, health care providers expressed a need for IEC materials for them to use.

Secondly, fertility desire screening by health care providers could form part of guidelines and counselling protocols of routine HIV/AIDS care. Meeting SRH of PLWHA means more than just counselling those who want to avoid pregnancy; a balanced counselling approach also includes supporting those who desire future childbearing. Health care workers in Kenya rarely give HIV infected women the opportunity to articulate their fertility desires (CRR and Fida-Kenya 2008). Proactive screening will ensure that all PLWHA who are considering having children are identified at the earliest opportunity so that appropriate counselling and requisite safe measures are put in place to deal with it. The policy to proactively engage HIV positive women in discussions about their fertility intentions – to achieve or avoid pregnancy – will help families and societies to benefit from existing services that can help them achieve their reproductive goals, while reducing the risk of HIV transmission to partners and infants. Provision of contraception to HIV positive women who need it is cost-effective compared with other PMTCT interventions in SSA (Reynolds et al. 2008).

Third, methods of safer conception should be pursued. There are technologies in resource-rich settings that can ensure safer conception for PLWHA such as artificial intrauterine insemination and sperm washing (Matthews and Mukherjee 2009). However, these are out of the reach of resource-poor settings in SSA. The practical method at the moment is adequate couple counselling on the ovulation cycle. PLWHA need to be given correct information about the ovulation cycle, when conception is likely to happen and counselling them on the least risky timing of their sexual intercourse. HIV positive couples can be counselled about timed unprotected sexual intercourse during ovulation only and using condoms all the other time. Although evidence about the feasibility of this method is limited in SSA, a study in Kinshasa, Congo, has shown its effectiveness in preventing HIV transmission to sexual partners (Matthews and Mukherjee 2009).

### 9.3.5. *Men involvement and couple counselling in SRH services*

Although evidence exists (as documented in this study and literature review) of men's roles in shaping sexual, fertility and contraceptive use decisions, men are rarely involved in SRH services (Montgomery et al. 2006). If men do not know their HIV status in time, they deny themselves the opportunity for treatment and care thereby not only endangering their own lives, but also their female sexual partners. Some women also perceive their husbands as the ultimate authority for approval on when and where to seek SRH services, including family planning. Disregarding partner involvement in the provision of SRH services creates asymmetry of information and a paradox of use. Women who might have the SRH services and information to use them might have little say on their use. Men may have considerable power over SRH decisions but have little information on SRH services.

Studies show that men are amenable and receptive to involvement in family planning programmes, but lack knowledge and are ignored by SRH service providers (Kaida et al. 2005; Paiva et al. 2007). Men in my study reported they are rarely involved in family planning discussions. Paiva et al.(2003) report that Brazilian healthcare providers were 'stunned and unprepared' when confronted with HIV-positive men who wanted to discuss their childbearing desires with them. Efforts to involve men might include recruiting them as community based distributors (CBD) of condoms and other contraceptives. Evidence shows that CBD increases demand and access to contraceptives in resource poor settings (Janowitz, Stanback, and Boyer 2012).

Couple counselling during HIV/AIDS and SRH services might also enhance male involvement. Health care providers need to pay attention to the needs of couples, rather than individuals, when appropriate. They should assist couples to make informed reproductive decisions. Providing couples with information and support can improve their relationships and SRH outcomes. Couple counselling facilitates communication and adoption of preventative sexual behaviours among couples as well. Misinformation and rumours that undermine contraceptive use can be corrected during couple counselling. The introduction of couple VCT services has been shown to have an overall positive impact on condom use among couples in SSA settings (Desgrées-du-Loû and Orne-Gliemann 2008).

### 9.3.6. *Disclosure, stigma and social support*

Our finding that disclosure of HIV status facilitates consistent condom use and fertility desire and social support, but is a dilemma in the light of potential positive and negative consequences, has important policy implications. Firstly, it points to the need for culturally sensitive counselling for PLWHA. Given the negative consequences of disclosure and high prevalence of stigma in SSA (Kalichman and Simbayi 2004), health care workers should not assume that disclosure is inherently good and easy for PLWHA. Rather they should consider the context in which disclosure occurs and potential negative reactions to disclosure. Providers need to offer a conducive and supportive environment for disclosure, where costs and benefits are weighed and strategies for disclosure developed if perceived as beneficial by PLWHA. Secondly, I recommend the implementation of skill-building interventions that aid and support PLWHA to disclose in ways that are most advantageous and least likely to generate negative responses. Support groups for PLWHA and on-going counselling programmes can contribute to advantageous disclosure and ameliorate the negative impact of disclosure.

Third, community education programs and social support groups to reduce HIV - related stigma could improve the wellbeing of PLWHA. Empirical evidence indicates that some of the most effective responses have involved affected communities mobilizing themselves to fight stigma and discrimination (Campbell and Cornish 2010; Parker and Aggleton 2003). PLWHA are increasingly organising themselves in support groups and networks focusing mostly on their individual needs around treatment and fighting stigma. Local HIV support groups are involved in offering advice on positive living with HIV, ART and act as intermediaries between technical medical staff and lay PLWHA. Some support groups seek funding to start income generating activities for PLWHA. To this end, formation of support groups should be encouraged and ways to involve men in these groups pursued. Evidence suggests that gender inequalities are exposed and challenged in PLWHA groups with “men learning to work with rather than dominate women”(Beckmann and Bujra 2010).



### *9.3.7. Altruism: Responsibility, love and care*

Narratives of disclosure and use of protection as both a personal and moral responsibility of both men and women to avoid infecting their sexual partners can be harnessed for policy and programmes interventions. Positive prevention should encourage PLWHA to acknowledge their crucial role and responsibility in avoiding transmitting HIV to others. PLWHA who used condoms and those who did not cited similar relationship issues - love, intimacy, trust and responsibility, which were either barriers or facilitators depending on the individual. The cross cutting element in these narratives is that sexual relationship should be based on love, care and responsibility. Policies and programmes should exploit these altruistic feelings of love, trust, care and responsibility to draft condom promotion messages. Programmes could take advantage of altruistic discourses and connect condoms use with love and responsibility rather than portraying them as methods to prevent them from transmitting or contradicting a deadly disease. Many condom promotions focus on the dangers and deadly risks of unprotected sex, reinforcing the association of condoms with casual, irresponsible and stigmatized partners (Smith 2003).

### *9.3.8. SRH and HIV/AIDS Service integration*

Integrating SRH and HIV/AIDS services is an issue that has attracted international policy attention and support. SRH and HIV integration is considered a promising approach for addressing both HIV/AIDS prevention and care and reducing unintended pregnancies (Askew and Berer 2003; Cleland and Sinding 2005; GNP+ 2009). Increasing awareness of this need is reflected in recent policy statements including: New York Call to Commitment: Linking HIV/AIDS and Sexual and Reproductive Health and the Glion Call to Action on Family Planning and HIV/AIDS in Women and Children (UNFPA 2004; WHO 2004). However, the findings of this study show that service integration has been hampered by health system barriers, including staff, space and commodity insecurity constrains. Despite some conscious efforts towards integration, the linkages between HIV/AIDS and SRH services are still weak. This creates challenges and incurs costs and stigma in the process of accessing vertical services, loss to follow-up of PLWHA who are referred across the health care system.

There is, therefore, need for an integration model that responds to the prevailing context and service environment in the slums.

First, there is need to strengthen existing health facilities to allow for effective context-specific integration of SRH and HIV/AIDS services. This will ensure that there is no missed opportunity when PLWHA seek either of the services separately. This will result in improved access for family planning as it removes stigma that PLWHA usually face when seeking such services. To this end, mobilization of local and international resources for family planning and health system improvement is crucial. While the funding shift from family planning to HIV/AIDS creates challenges, it also creates opportunities. Programmes can tap into HIV/AIDS resource base by including family planning as an HIV prevention strategy.

Secondly, integration of services in the slums should involve linkages between public and private health facilities, not just intra-clinic service delivery. The opportunity for public health facilities, which mostly are on the outskirts of the slums and a host of private-informal providers inside the slums, could form working partnership to improve SRH service delivery. An inter-health facility referral system could be developed since most facilities are not equipped to offer both HIV and family planning services. This will ensure that SRH services not available at service delivery sites are accessed through linkages with other providers. Linking SRH and HIV services has been found to reduce stigma in the use of services, enhance programme effectiveness and efficiency by eliminating redundancies in parallel vertical programmes, and ensure that multiple SRH and HIV service needs are addressed simultaneously (Askew and Berer 2003; WHO 2005). That said, however, structural deficiencies within the delivery of either HIV/AIDS or SRH services are likely to persist even when offered as an integrated package.

Policies and programmes to meet the SRH needs of PLWHA need be based on the promotion of SRH rights of PLWHA as human rights. PLWHA, like all human beings, have a right to safe, pleasurable sex and a right to start or build a family. They have a right to make SRH decisions without coercion, stigma or discrimination. PLWHA should be informed and supported to make informed decisions about sexuality and

positive living and parenting. When PLWHA make an informed decision to have children they should receive appropriate services to prevent horizontal and vertical transmission of HIV. Those who do not want to have children should be provided with family planning services. Structural barriers to the realisation of their SRH needs should be duly appreciated and tackled, not just their risk reproductive behaviour.

#### **9.4. Study limitations**

The first major limitation of this study lies in its design. Three design limitations must be acknowledged. First, this study adopted a sequential mixed design, which involved a phase of quantitative interviews followed by a qualitative phase on a subsample to help explain and interpret relationships. One weakness is that the two data streams cannot be used for triangulation. Triangulation – confirmation/disconfirmation and corroboration/contradiction – is best achieved using concurrent mixed designs where separate quantitative and qualitative methods are done at the same time (Creswell 2009). Therefore, contradictory data was not given the platform to manifest itself. Another weakness is how the subsample was picked. This study sampled “typical” cases from the survey respondents for qualitative investigation, which helped explain their typical behaviour outcomes. However, it was apparent to me that the study could have gained more from having the participants who did not exhibit the typical SRH outcomes. Moreover, the sampling selection strategy produced a qualitative sample of which the majority were sexually active (groups B and C).

The second design weakness is its cross-sectional nature, which precludes the determination of causality between the explanatory variables and the outcome variables or constructs. The SRH outcomes were just a snapshot picture in the previous 12 months, although qualitative interviews interrogated relevant issues since HIV diagnosis that went beyond the 12 month period. This limited its ability to track changing sexual behaviour and fertility desires with duration of HIV and ART. We, therefore, do not know what will happen over and beyond 12 months for the reported behaviour. Although, this cross-sectional relationship between ART and safer sexual behaviour has been confirmed in prospective studies in SSA (e.g Eisele et al. 2009; Luchters et al. 2008; Pearson et al. 2011) caution must be exercised. The third design

weakness was that it relied on structured and semi-structured interviews, which is also a reflection of my method bias. However, upon reflection the study might have gained from an ethnographic perspective and participant observation.

The second major limitation is that the study had a strong heterosexual and consensual sex bias. The way the research questions were framed, it is highly unlikely that respondents would volunteer their homosexual or forced sex activities. Since these sexual identities and activities are stigmatised in Kenya, a different approach might have helped the research process, although their under-reporting might still persist.

Thirdly, this was not a strictly probabilistic sample, but rather a sample of PLWHA who self-identified as being HIV positive living in the DSS sites in Nairobi slums. This limits the generalisability of the findings to all PLWHA in other research settings and settlements in Kenya and SSA. Fourth, our definition of multiple partnerships was based on numbers of sex partners in the previous 12, without differentiating whether these were serial or concurrent and yet the two have different risks of HIV transmission.

Finally, information on sexual behaviour and fertility preferences were entirely based on self-reports using face to face interviews. Given the sensitive nature of these topics, there is likely to have been social desirability bias. Evidence shows that both men and women misreport their sexual behaviour (Buvé et al. 2001). PLWHA might be inclined to underreport their unsafe sexual behaviour such as non-condom use and multiple sexual partnerships. PLWHA may also underreport their childbearing intentions as result of perceived negative social approval from the community and health care providers. Although we took precautions to limit social desirability bias – such as training interviewers to create a climate of trust that allows free talk about such matters and using non-clinical community interviewers – its effect cannot be completely eliminated.

### **9.5. Contribution to Knowledge and strength of the study**

In spite of the limitations discussed above, this thesis contributes to the empirical literature on SRH of PLWHA in a poor setting, an under-researched topic. PLWHA experience life with HIV and face challenges around stigma, managing ART,

negotiating sexual intimacy and reproduction, but most work does not address sexual and reproductive health matters. Where the evidence exists, these life challenges facing PLWHA are addressed separately. This fragmentation produces evidence that is not holistic. This state of affairs speaks to the need to address living with HIV/AIDS holistically, asking broad questions about lived experience of PLWHA, paying attention to structural elements of poverty, gender and socio-cultural norms and how they intertwine with reproductive lives. This study provides a unique contribution to the extant literature by providing an integrated approach to living with HIV, addressing horizontal and vertical transmission prevention and recognising PLWHA as sexual and reproductive human beings. This integration contributes to a deeper understanding of how PLWHA in diverse contexts manage what might seem to be the opposed goals of positive prevention and reproduction. This study from Nairobi slums augments the literature on how PLWHA engage with HIV and ART and craft their sexual and reproductive lives in the context of poverty, gender inequality, stigma and negative social approval in resource-poor contexts.

Research in developing countries that has addressed sexual behaviour of PLWHA has focused on risky behaviour mostly using quantitative data from surveys (Bateganya et al. 2005). More recently, studies have considered the sexual behaviour of PLWHA from their perspective of reproductive goals (Cooper et al. 2007; Myer, Morroni, and Rebe 2007). The trajectory of this research suggests that sexual and reproductive behaviour of PLWHA should be understood by connecting sexuality to gender, reproductive goals and larger socio-economic contexts (Laher et al. 2009; Persson and Richards 2008). But surprisingly little mixed methods research has been undertaken on the sexual and fertility preferences of PLWHA (Nattabi et al. 2009, 2011). A mixed methods approach provides the magnitude of SRH behaviour as well its social and cultural contexts and hence a pragmatic approach to a more holistic analysis of the issues (Nattabi et al. 2009). Importantly, this study included both men and women as respondents, which enabled an assessment of gender differences in sexual behaviour and fertility preferences. Most studies on reproductive preferences focus on women perhaps because childbearing is generally associated with women.

Sampling participants from the community was also strength of the study. Most studies on PLWHA, if not all, recruit their participants from health clinics and NGOs

that provide services to people with HIV. Such participants are likely to have better access to services and to have been better informed about SRH services and HIV prevention than the general population of PLWHA, which limits the generalisability of the findings. A new generation of studies has responded to this challenge by utilising population-based DHS samples with biomarkers on HIV status (e.g Bankole, Biddlecom, and Dzekedzeke 2011; Johnson et al. 2009). The trajectory of evidence from population-based studies is a step in the right direction. However, given the low levels of HIV status knowledge in SSA, most of those who test HIV-positive in the DHS are unaware of their HIV status. HIV status is more likely to affect sexual and reproductive behaviour if it is known. This study used an innovative sampling strategy of getting a population-based sample of respondents who aware of their HIV status.

#### **9.6. Recommendation for future research**

This study makes a call for more diverse studies to augment the evidence base on SRH of PLWHA in resource-poor settings. Specifically, the cross-sectional nature of this study limited its ability to track evolving and changing fertility desire with duration of ART or HIV. Therefore, longitudinal studies will make comparisons of sexual behaviour, fertility preferences and contraceptive behaviour overtime and subsequent changes as they learn their status, enrol for ART and live with HIV. Secondly, the findings that ART is negatively associated with sexual activity and not associated with fertility desire were unexpected if not controversial. It will be interesting to replicate these findings in different contexts in SSA. Finally, there are a number of questions that stem from this study, which require further research. These include: How is the delivery of SRH services targeted for PLWHA done? What factors enhance and constrain the success of these programmes targeting PLWHA? Does the level of unwanted pregnancies differ by HIV status? Given the level of high unmet need for family planning, to what extent is abortion used to terminate unwanted pregnancies among PLWHA?

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## Appendix 1: Questionnaire

London School of Economics and APHRC Questionnaire: ART use and Sexual and Reproductive Behaviour													
<b>1.0</b>	<b>BACKGROUND</b>												
1.01	START TIME <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>												
1.02	FIELD WORKER'S CODE <input type="text"/> <input type="text"/>												
1.03	DATE OF INTERVIEW (DD/MM/YYYY) <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>												
1.04	PERSON'S NAME.....												
1.05	SEX (M=MALE; F=FEMALE) <input type="checkbox"/>												
1.06	DATE OF BIRTH <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> (DD/MM/YYYY) 98 if day and month unknown												
1.07	CLIENT'S ETHNICITY 1=Kikuyu; 2= Luo , 3=Embu/Meru, 4= Luhya, 5=Kamba, <input type="checkbox"/> 6=Kisii 7=Mijikenda 8=Kalenjin 9= Other( specify).....												
1.08	MARITAL STATUS (1= MARRIED 2= LIVING TOGETHER(COHABITING) 3= DIVORCED/SEPARATED 4=WIDOWED 5=SINGLE( NEVER MARRIED) <input type="checkbox"/>												
1.09	HIGHEST LEVEL OF SCHOOLING AND GRADE COMPLETED												
	<table border="1"> <thead> <tr> <th>LEVEL</th> <th>GRADE</th> </tr> </thead> <tbody> <tr> <td>1 NO SCHOOLING</td> <td></td> </tr> <tr> <td>2 INFORMAL</td> <td></td> </tr> <tr> <td>3 PRIMARY</td> <td></td> </tr> <tr> <td>4 SECONDARY</td> <td></td> </tr> <tr> <td>5 TERTIARY</td> <td></td> </tr> </tbody> </table>	LEVEL	GRADE	1 NO SCHOOLING		2 INFORMAL		3 PRIMARY		4 SECONDARY		5 TERTIARY	
LEVEL	GRADE												
1 NO SCHOOLING													
2 INFORMAL													
3 PRIMARY													
4 SECONDARY													
5 TERTIARY													
1.10	MAIN SOURCE OF INCOME.....												
1.11	WHAT IS YOUR APPROXIMATE MONTHLY INCOME Amount in ksh. <input type="text"/>												
1.12	LOCATION ID <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>												
1.13	For how long have you stayed at this location? (1= 0-4 months; 2= 5-12 months; 3=Over 1 year) <input type="checkbox"/>												
1.14	INDIVIDUAL ID <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>												
<b>2.0</b>	<b>MEDICAL INFORMATION AND ADHERENCE</b>												
	Now I would like to ask you some questions about your illness and treatment												
2.01	How would you rate your health, in general? Is it (1= Poor 2= Fair 3=Good 4=Very good 5=Excellent) <input type="checkbox"/>												
2.02	When were you first diagnosed with HIV?( DD/MM/YYYY) <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> [Record 98 in the appropriate cells if the day and month is Unknown]												
2.03	Are you currently on Antiretroviral Treatment? [1=Yes; 2=NO] <input type="checkbox"/> [If 2 skip to 2.05]												
2.04	When did you start treatment? DD/MM/YYYY) <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> [Record 98 in the appropriate cells if the day and month is Unknown] [skip to 2.06]												



2.05 Are you currently on any treatment for opportunistic infections(OIS)?  
 [1=Yes; 2=NO]   
 [skip to 3.01]

2.06 How would you assess your health status since you started treatment?  
 Is it (1=BETTER; 2=SAME; 3= WORSE)

2.07 Please tell me how you are supposed to take each of the medicines(FW: Record the quantity of pills and sequence as reported by the user)

Name of drug	Dosage per day	Time to be taken
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>

2.08 Now I would like to ask you about the ARV medications that you missed over the last 4 days.  
 (FW:Record the number of missed pills in space provided.  
 If the respondent cant remember record 98)

NAME OF DRUG	Number of prescribed Pills per day	How many pills did you miss.....			
		Yesterday	Two days ago	Three days ago	Four days ago
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

2.09 CHECK: FW: Were pills missed in the last 4 days? (check 2.08) [1=Yes; 2=NO]   
 {if 1 skip to 2.11}

2.10 When was the last time you missed a dose of medi [1=5-7 days ago; 2=2-4 weeks ago  
 3= 1-6 months ago; 4= 6-12 months ago; 5=More than 1 year ago; 6 =Never;  
 8= Don't remember]

2.11 Most of the ART medications need to be taken on a schedule, such as 2 times  
 How closely have you been following this schedule  
 (1=Never; 2= Some of the time; 3= About half of the time)  
 (4= Most of the time; 5= All the time)

2.12 Does any of your of your medications have special instructions such as plenty of water or on empty stomach?  
 [1=Yes; 2=NO]   
 [If 2 skip to 2.14]

2.13 How often did you follow those special instructions?  
 (1=Never; 2= Some of the time; 3= About half of the time)  
 (4= Most of the time; 5= All the time)

2.14 { **CHECK: FW: is the answer "2" in 20.9 & "6" in 2.10 & "5" in 2.11 & or 2.13?**  
 [1=Yes; 2=NO]   
 [If 1 skip to 2.16]

2.15 We appreciate how difficult it can be to take medicines on schedule and follow dietary prescriptions on the daily basis. Please tell me what causes you to miss pills or fail to take them as prescribed?  
**FW: Probe: any other? And record in the order in which they are mentioned**  
 .....  
 .....  
 .....  
 .....  
 .....  
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 .....

**Source and Cost of medication**

2.16 What is the name of the facility and area where you get your medications?  
 (Name of facility.....Area.....)

2.17 Do you currently fully or partially pay for your medication or is it for free?   
 (1=Fully pays; 2= Partly pays; 3= Provided for free)  
 [if 3 skip to 2.20]

2.18 How much do you pay for a monthly supply of your ARV medicines? in K.SH

2.19 For how long has this been? (1=Since inception; 2= For the last 6 months;  
 3= For the last 12 months; 4=For over a year)

2.20 How much do you pay for the following?

Item	Amount in Kenya shillings
1 Transport to the clinic for ART	<input type="text"/>
2 Registration fees for health facility	<input type="text"/>
3 Informal payments at the health facility	<input type="text"/>
4 Any other(specify) .....	<input type="text"/>
.....	
.....	

**If treatment cost is 0(2.17= 3 and 2.20=0) skip to 2.22**

2.21 Does medication- related costs pose a problem to you? [1=YES; 2=NO]

2.22 How often do you go without food unwillingly?  
 (1=Never; 2=Rarely; 3=Sometimes; 4= Often)

2.23 How often, if at all, do you sell/barter your ARVs for food etc?  
 (1=Never; 2=Rarely; 3=Sometimes; 4= Often)

2.24 How often do you share your ARVs? (1=Never; 2=Rarely; 3=Sometimes; 4= Often) \_\_\_\_\_

**Clinical consultation**

2.25 When put on treatment for the first time were you given the following information?	Yes	No	Cant Remember
1 The disease progress(i.e HIV and AIDS)	1	2	3
2 How ARVs work	1	2	3
3 How to use ARVs	1	2	3
4 What to do if a pill is forgotten	1	2	3
5 The likely side effects and what to do if experienced	1	2	3
6 Given written information on how to take medications	1	2	3
7 Information on how you could remind yourself to take pills	1	2	3
8 Information on sex life	1	2	3
9 Information on contraception	1	2	3
10 Information on condom use	1	2	3
11 Information on fertility(child bearing)	1	2	3

2.26 When put on treatment for the first time	YES	NO	NOT SURE
1 Were you given a chance to state your problem?	1	2	3
2 Were you given a chance to ask questions?	1	2	3
3 Did you feel listened to?	1	2	3
4 Did you feel you had ample time with your provider	1	2	3
5 Was the advice given clear to you	1	2	3
6 Were you treated with respect?	1	2	3
7 Did you have privacy during consultation and conselling?	1	2	3
8 Were you satisfied with consultation and counselling proces	1	2	3

2.27 Do you receive any adherence-related follow-up from the health provider? (1=YES; 2=NO)

[ if 2 skip to 2.29]

2.28 How often does this happen? 1=Rarely 2= Occasionally 3=Regurally

2.29 Do you use any of the following in conjunction with ART treatment?	YES	NO
1 Tradional herbs	1	2
2 Other modern drugs	1	2
3 Conventional prayer/ritual healing/spritual healing	1	2
4 Traditional spiritual/ritual healing	1	2
5 Any other(specify).....	1	2
.....		
.....		

2.30 Why do/don't you use these other forms of therapy?.....  
 .....  
 .....  
 .....

2.31 Do you experience any side effects asociated with the use of ART? (1=YES; 2=NO)   
 [ if 2 skip to 3.00]

2.32 Please tell me all kind of side effects that you experience? ( Probe: Any other)  
 .....  
 .....  
 .....  
 .....

3.00 SEXUAL BEHAVIOUR in 12 months																	
3.01	[F.W: current marital status, Check 1.8] (1= MARRIED 2= LIVING TOGETHER 3= DIVORCED/SEPARATED 4=WIDOWED 5=SINGLE( NEVER MARRIED) [ if 3, 4 and 5 skip to 3.07] <input type="checkbox"/>																
3.02	Do you currently stay with your spouse? (1=YES; 2=NO) <input type="checkbox"/> [ if 2 skip to 3.04]																
3.03	For how long have you been staying together																
	<table border="1"> <tr> <td>1</td> <td>Since marriage</td> <td></td> </tr> <tr> <td>2</td> <td>Months</td> <td></td> </tr> <tr> <td>3</td> <td>Years</td> <td></td> </tr> </table>	1	Since marriage		2	Months		3	Years								
1	Since marriage																
2	Months																
3	Years																
3.04	When did you marry or start cohabiting with your current spouse <table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> </table> <b>[Record 98 in the appropriate cells if the day and month is Unknown]</b>																
3.05	Is your spouse also infected with HIV/AIDS? (1=YES; 2=NO; 3= Don't know) <input type="checkbox"/>																
3.06	How many wives do you/your spouse have? Number of wives <input type="text"/> <input type="text"/> <b>[Skip to 3.11 ]</b>																
3.07	[F.W: current marital status, Check 3.01] 3= DIVORCED/SEPARATED; 4=WIDOWED 5=SINGLE( NEVER MARRIED) <input type="checkbox"/> if 5 skip to 3.09																
3.08	When were you divorced/separated or widowed? (DD/MM/YYYY) <table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> </table> <b>[Record 98 in the appropriate cells if the day and month is Unknown]</b>																
3.09	Do you have a boyfriend/girlfriend/fiance) with whom you have sex on a regular basis (1=YES; 2=NO) <input type="checkbox"/> [ if 2 skip to 3.18]																
3.10	Is your boyfriend/girlfriend/fiance) infected with HIV/AIDS? (1=YES; 2=NO; 3=Don't know) <input type="checkbox"/>																
3.11	When was the last time you had sexual intercourse with your spouse/ boyfriend/girlfriend/fiance																
	<table border="1"> <tr> <td>1</td> <td>DAYS AGO</td> <td></td><td></td> </tr> <tr> <td>2</td> <td>WEEKS AGO</td> <td></td><td></td> </tr> <tr> <td>3</td> <td>MONTHS AGO</td> <td></td><td></td> </tr> <tr> <td>4</td> <td>YEARS AGO</td> <td></td><td></td> </tr> </table> <b>[If 4 skip to 3.18]</b>	1	DAYS AGO			2	WEEKS AGO			3	MONTHS AGO			4	YEARS AGO		
1	DAYS AGO																
2	WEEKS AGO																
3	MONTHS AGO																
4	YEARS AGO																
3.12	Did you use a condom the last time you had sex with your spouse/partner? (1=YES; 2=NO) <input type="checkbox"/> [ if 2 skip to 3.15]																
3.13	Who suggested use of condom at the time? (1=MY SELF; 2= MY PARTNER, 3=JOINT DECISION) <input type="checkbox"/>																
3.14	What is the main reason you used a condom on that occasion 1 Wanted to prevent HIV infection to my sexual partner 2 Wanted to prevent myself from other strains of HIV 3 Wanted to prevent pregnancy 4 Wanted to prevent both STI/ HIVinfection and pregnancy 5 Does not trust partner/partner has other sexual partners 6 Partner insisted 7 Other (specify)..... ..... ..... <b>[Skip to 3.16]</b>																

3.15	Why didnt you and your partner use a condom at that time? <b>FW: Allow for unprompted responses</b> <b>Probe any other</b> <b>Multiple responses possible</b>	<table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th style="width:50%;">YES</th> <th style="width:50%;">NO</th> </tr> </thead> <tbody> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> <tr><td style="text-align: center;">1</td><td style="text-align: center;">2</td></tr> </tbody> </table>	YES	NO	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	Not available Too expensive Partner Objected Don't like them Used other contraception Thought it was not necessary Trust/love partner Didn't think of it Other(specify)
YES	NO																								
1	2																								
1	2																								
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1	2																								
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3.16	With what frequency did you and your regular sexual partners use a condom during the last 12 months? [(1=Never; 2=Rarely; 3=Sometimes; 4= Almost every time; 5= Every time [Check: If 3.15 and 3.16=1 skip to 3.19]	<input type="checkbox"/>																							
3.17	What is your main source of condoms (1= Government hospital/health centre/dispensary; 2= Private hospital/clinic; 3=Family planning Clinic (4=Mission, church Hospital/clinic; 5=Pharmacy/chemist; 6=Nursing/maternity home; 7= Shop; 8=Friend (/relative; 9= Mobile clinic; 10=Community distributor; 11=NGO; 12=Other (specify)..... [Skip to 3.19 ]	<input type="checkbox"/>																							
3.18	Have you had sex with any man/woman in the last 12 months(include transactional or forced sex) (1=YES; 2=NO; 9= No response)	<input type="checkbox"/>	[ if 2 skip to 3.31] [ If 1 or 9 skip to 3.20]																						
3.19	Other than this spouse/ fiance/boyfriend/girlfriend, have you had sexual intercourse with another man/woman? (1=YES; 2=NO; 8= DON'T KNOW; 9= No RESPONSE)	<input type="checkbox"/>																							
3.20	In the last 12 months have you ever given or received money, gifts or favours in return for sex? (1=YES; 2=NO; 9= No response)	<input type="checkbox"/>																							
3.21	How many sexual partners in total have you had in the last 12 months	<table border="1" style="width:100%; border-collapse: collapse;"> <tr> <td style="width:5%; text-align: center;">1</td> <td style="width:75%;">Men</td> <td style="width:10%;"></td> <td style="width:10%;"></td> </tr> <tr> <td style="text-align: center;">2</td> <td>women</td> <td></td> <td></td> </tr> </table>	1	Men			2	women																	
1	Men																								
2	women																								
3.22	How many of the sexual partners were regular, non regular and commercial? <b>FW: Regular = Spouse or livein/stead sexual partner,or fiance</b> <b>Non regular =Sexual partners that you are not married to/ living with fiance and did not pay</b> <b>Commercial = partners with whom you had sex in exchange for money</b> [If regular only skip to 3.29]	<table border="1" style="width:100%; border-collapse: collapse;"> <tr> <td style="width:5%; text-align: center;">1</td> <td style="width:75%;">Regular</td> <td style="width:10%;"></td> <td style="width:10%;"></td> </tr> <tr> <td style="text-align: center;">2</td> <td>Non-regular</td> <td></td> <td></td> </tr> <tr> <td style="text-align: center;">3</td> <td>Commercial</td> <td></td> <td></td> </tr> </table>	1	Regular			2	Non-regular			3	Commercial													
1	Regular																								
2	Non-regular																								
3	Commercial																								
3.23	The last time you had sex with any of these non-regular and/ or commercial partners was a condom used?	<input type="checkbox"/>	(1=YES; 2=NO) [ if 2 skip to 3.27]																						
3.24	Who suggested use of condom at the time? (1=MY SELF;2= MY PARTNER, 3=JOINT DECISION)	<input type="checkbox"/>																							
3.25	What is the main reason you used a condom on that occasion 1 Wanted to prevent HIV infection to my sexual partner 2 Wanted to prevent myself from other strains of HIV 3 Wanted to prevent pregnancy 4 Wanted to prevent both STI/ HIVinfection and pregnancy 5 Does not trust partner/partner has other sexual partners 6 Partner insisted 7 Other (specify).....	<input type="checkbox"/>																							

3.26	What was the source of your condom that you used? (1= Government hospital/health centre/dispensary; 2= Private hospital/clinic; 3=Family planning Clinic (4=Mission, church Hospital/clinic; 5=Pharmacy/chemist; 6=Nursing/maternity home; 7= Shop; 8=Friend (/relative; 9= Mobile clinic; 10=Community distributor; 11=NGO; 12= Other (specify)..... <input type="checkbox"/> [Skip to 3.28]																															
3.27	Why didnt you and your partner use a condom at that time?  <b>FW: Allow for unprompted responses</b> <b>Probe any other</b> <b>Multiple responses possible</b>	<table border="1" style="margin-left: auto; margin-right: auto;"> <thead> <tr> <th></th> <th>YES</th> <th>NO</th> </tr> </thead> <tbody> <tr><td>Not available</td><td>1</td><td>2</td></tr> <tr><td>Too expensive</td><td>1</td><td>2</td></tr> <tr><td>Partner Objected</td><td>1</td><td>2</td></tr> <tr><td>Don't like them</td><td>1</td><td>2</td></tr> <tr><td>Used other contraception</td><td>1</td><td>2</td></tr> <tr><td>Thought it was not necessary</td><td>1</td><td>2</td></tr> <tr><td>Trust/Love partner</td><td></td><td></td></tr> <tr><td>Didnt think of it</td><td>1</td><td>2</td></tr> <tr><td>Other.....</td><td>1</td><td>2</td></tr> </tbody> </table>		YES	NO	Not available	1	2	Too expensive	1	2	Partner Objected	1	2	Don't like them	1	2	Used other contraception	1	2	Thought it was not necessary	1	2	Trust/Love partner			Didnt think of it	1	2	Other.....	1	2
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3.28	With what frequency did you and non regular sexual partner use condoms in the last 12 months? (1=Never; 2=Rarely; 3=Sometimes; 4= Almost every time; 5= Every time	<input type="checkbox"/>																														
3.29	How often did you disclose your HIV status to your sexual partners in the last 12 months? (1=Never; 2=Rarely; 3=Sometimes; 4= Amost every time; 5= Every time	<input type="checkbox"/>																														
3.30	During the past 12 months did any sexual partner(s) force you to have sex with them even though you did not want to have sex? (1=YES; 2=NO)	<input type="checkbox"/>																														
3.31	Have you ever had a genital discharge in the last 12 months? (1=YES; 2=NO)	<input type="checkbox"/>																														
3.32	Have you ever had a genital ulcer/sore in the last 12 months (1=YES; 2=NO)	<input type="checkbox"/>																														
4.00	<b>FERTILITY INTENTIONS</b>																															
4.01	Do you have any living children? (1=YES; 2=NO) [IF 2 skip to 4.04]	<input type="checkbox"/>																														
4.02	How many living children do you have?	<table border="1" style="margin-left: auto;"> <tr><td>1</td><td>Number of boys</td><td></td><td></td></tr> <tr><td>2</td><td>Number of girls</td><td></td><td></td></tr> <tr><td>3</td><td>Total number of children</td><td></td><td></td></tr> </table>	1	Number of boys			2	Number of girls			3	Total number of children																				
1	Number of boys																															
2	Number of girls																															
3	Total number of children																															
4.03	When was the last you/your partner had your child?( DD/MM/YYYY)	<table border="1" style="margin-left: auto;"> <tr> <td style="width: 20px;"> </td><td style="width: 20px;"> </td><td style="width: 20px;"> </td><td style="width: 20px;"> </td><td style="width: 20px;"> </td><td style="width: 20px;"> </td><td style="width: 20px;"> </td><td style="width: 20px;"> </td> </tr> </table>																														
4.04	Are you sterilised ? [ if 1 skip to 5.01]	<input type="checkbox"/>																														
4.05	Would you like to have a/another child or would you prefer not to have any(more) children? 1=Yes wants a/another child; 2= Undecided/don't know; 3= No more/none 4=She/partner cant get pregnant [IF 3 and 4 skip to 4.09]	<input type="checkbox"/>																														
4.06	How many more children would you like to have?	number of children <input style="width: 30px;" type="text"/> 98= Don't know/ Upto God																														
4.07	If you were to choose the sex of these children how many more boys and girls would you like to have?	<table border="1" style="margin-left: auto;"> <tr><td>1</td><td>Boys</td><td></td><td></td></tr> <tr><td>2</td><td>Girls</td><td></td><td></td></tr> <tr><td>3</td><td>Either</td><td></td><td></td></tr> <tr><td>8</td><td>Upto God</td><td></td><td></td></tr> </table>	1	Boys			2	Girls			3	Either			8	Upto God																
1	Boys																															
2	Girls																															
3	Either																															
8	Upto God																															
4.08	How long would you wait before getting a/another child?	<table border="1" style="margin-left: auto;"> <tr><td>1</td><td>Now/soon</td><td></td><td></td></tr> <tr><td>2</td><td>Months</td><td></td><td></td></tr> <tr><td>3</td><td>Years</td><td></td><td></td></tr> </table>	1	Now/soon			2	Months			3	Years																				
1	Now/soon																															
2	Months																															
3	Years																															

**Contraception**

4.09 Are you/your partner pregnant? (1=YES; 2=NO; 8= Don't know/unsure)   
 [IF 1 skip to 4.14 ]

4.10 Are you/your partner doing something or using a method to avoid or delay getting pregnant?   
 (1=YES; 2=NO)  
 [IF 2 skip to 4.14 ]

4.11 Which method are you/ is your partner using?  
**FW: Allow unprompted responses. Multiple responses possible**

	YES	NO
Sterilisation	1	2
IUD	1	2
Injectibles	1	2
Implants	1	2
Pill	1	2
Condom	1	2
Diaphragm	1	2
Foam/Jelly	1	2
Lactational Ame. Method	1	2
Periodic abstinence/Calendar/beads	1	2
Withdraw	1	2
Other(specify).....	1	2
.....		
.....		

4.12 When did you/your partner start using the current method?  
 DD/MM/YYYY)

4.13 Where did you obtain the current method the last time?  
**FW: Allow unprompted responses. Multiple responses possible**

	YES	NO
Government hospital/health centre/dispensary	1	2
Private hospital/clinic	1	2
Family planning Clinic	1	2
Mission, church Hospital/clinic	1	2
Pharmacy/chemist	1	2
Nursing/maternity home	1	2
NGO/Civil society organisation		
Shop	1	2
Friend/relative	1	2
Mobile Clinic	1	2
Other.....	1	2
.....		
.....		

**[Skip to 4.18 ]**

4.14 Have you/your partner used anything or tried in anyway to delay or avoid getting pregnant?  
 (1=YES; 2=NO)   
 [IF 2 skip to 4.18]

4.15 When was the last time you/your partner tried something or used a method to delay/avoid getting?  
**DD/MM/YYYY**

4.16 What have you/your partner done or used?  
**(1= Sterilisation; 2= IUD; 3=Injectibles; 4= Implants; 5= Condom; 6= Diaphragm; 6= Foam/Jelly  
 (7=Lactational Ame. Method; 8= Periodic abstinence; 9 Withdraw; 10 Other(specify)**

.....  
 .....

4.17 How many children did you have the first you/your partner tried something or used a method to delay  
 or avoid getting Pregnant? **Number of children**

4.18 Have you ever been told by the health worker about any/other methods of family planning?  
**(1=YES; 2=NO)**  
**[IF 2 skip to 4.21 ]**

4.19 When was the last time you discussed family planning with the health care provider  
**DD/MM/YYYY**

4.20 Which method did you discuss?  
**FW: Allow unprompted responses. Mutiple responses possible**

	YES	NO
Sterilisation	1	2
IUD	1	2
Injectibles	1	2
Implants	1	2
Pill	1	2
Condom	1	2
Diaphragm	1	2
Foam/Jelly	1	2
Lactational Ame. Method	1	2
Periodic abstinence/Calendar/beads	1	2
Withdraw	1	2
Other(specify).....	1	2
.....		
.....		

4.21 **FW: Check 4.05 and 4.10. Is 4.05= 3 and 4.10= 2** **(1=YES; 2=NO)**   
**[IF 2 skip to 5.01 ]**

4.22 You said that you do not want a child soon nor any more children and yet you are not using any method  
 Please tell me why this is so.....  
 .....  
 .....  
 .....

4.23 Do you think you will use any contraceptive method to delay or avoid pregnancy at any time in future?  
**(1=YES; 2=NO)**   
**[IF 2 skip to 5.01 ]**



4.24	Which contraceptive method would you prefer to use? (1= Sterilisation; 2= IUD; 3=Injectibles; 4= Implants; 5= Condom; 6= Diaphragm; 6= Foam/Jelly (7=Lactational Ame. Method; 8= Periodic abstinence; 9 Withdraw; 10 Other(specify)..... <input type="checkbox"/>					
<b>Knowledge</b>						
5.01	I am going to read you a series of statements. Please tell me whether you agree or disagree with each statement	<b>Agree</b>	<b>Disagree</b>	<b>Don't know</b>		
	1 Using a condom correctly everytime protects against HIV/AIDS	1	2	3		
	2 Having one uninfected sexual partner protects against HIV/AIDS	1	2	3		
	3 ARVs cure HIV/AIDS	1	2	3		
	4 ARVS prolong lifes	1	2	3		
	5 ARVs improve the quality of life	1	2	3		
	6 ART is a life long treatment	1	2	3		
	7 Skiping ART once in a while teaches the body to fight HIV/.AIDS	1	2	3		
	8 Cessation/reduction of symptoms is a sign of being cured	1	2	3		
	9 A mother can infect HIV to her baby at birth or though breastmilk	1	2	3		
	10 Pregnant women deliver HIV free baby by use of medication	1	2	3		
<b>Treatment optimism</b>						
5.02	Now I would like to read you the folowing statements. For each one , please indicate if you strongly agree agree, disagree or strongly disagree	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Don't Know</b>
	1 A person with undetectable viral load cannot pass on the virus	1	2	3	4	5
	2 New HIV treatments will take the worry out of sex	1	2	3	4	5
	3 If every HIV person took the new treatments the AIDS epidemic would be over	1	2	3	4	5
	4 HIV is less of a serious threat than it used to be because of new treatment	1	2	3	4	5
	5 Because of new treatments fewer people are becoming infected with HIV	1	2	3	4	5
	6 It is never safe to have have sex without a condom regardless of the viral load	1	2	3	4	5
<b>Alcohol and drug use</b>						
5.03	Do you drink alcohol? (1=YES; 2=NO)		[if 2 skip to 5.05]		<input type="checkbox"/>	
5.04	How often do you usually drink alcohol in a week? (1= Very often; 2= sometimes; 3= Rarely <input type="checkbox"/>					
5.05	Do you take drugs such as Miraa ( 1=YES; 2=NO)		[if 2 skip to 5.07]		<input type="checkbox"/>	
5.06	How often do you use such drugs (1= Very often; 2= sometimes; 3= Rarely <input type="checkbox"/>					

<b>Social support</b>																																											
5.07	Who do you stay with in you household? (1=alone 2= Spouse 3= Spouse and children 4= Children and other relatives 5=With other relatives 6=With friend(s)/non-relatives 7= Spouse, children and relatives 8= With children; 9 = Other(specify)..... <input style="float: right;" type="checkbox"/>																																										
5.08	Is there relative to whom you talk about your condition? (1=YES; 2=NO) <input style="float: right;" type="checkbox"/> [if 2 skip to 5.10]																																										
5.09	How often do you see or hear from these relatives? (1= Daily; 2= At least once a week; 3= Atleast once a month; 4= Atleast twice a year; 5= A least once a year 6= Never/hardly ever <input style="float: right;" type="checkbox"/>																																										
5.10	Do you have any friends or neighbours to whom you can talk about your HIV condition (1=YES; 2=NO) <input style="float: right;" type="checkbox"/> [if 2 skip to 5.12]																																										
5.11	How often do you see or hear from these friends and neighbours? (1= Daily; 2= At least once a week; 3= Atleast once a month; 4= Atleast twice a year; 5= A least once a year 6= Never/hardly ever <input style="float: right;" type="checkbox"/>																																										
5.12	People sometimes look to others for companshanship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?																																										
	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 50%;"></th> <th style="width: 10%;">None of the time</th> <th style="width: 10%;">A little of the time</th> <th style="width: 10%;">some of time</th> <th style="width: 10%;">most of the time</th> <th style="width: 10%;">all the time</th> </tr> </thead> <tbody> <tr> <td>1 Someone to help you( daily chores) if you were confined to bed</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> </tr> <tr> <td>2 someone to take you to hospital/ doctor if you needed it</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> </tr> <tr> <td>3 someone to give you advise or information if needed</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> </tr> <tr> <td>4 Somebody to confide in or share your problems and fears</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> </tr> <tr> <td>5 Someone who shows you love and affection</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> </tr> <tr> <td>6 Someone to do things with for relaxation and enjoyment</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> </tr> </tbody> </table>		None of the time	A little of the time	some of time	most of the time	all the time	1 Someone to help you( daily chores) if you were confined to bed	1	2	3	4	5	2 someone to take you to hospital/ doctor if you needed it	1	2	3	4	5	3 someone to give you advise or information if needed	1	2	3	4	5	4 Somebody to confide in or share your problems and fears	1	2	3	4	5	5 Someone who shows you love and affection	1	2	3	4	5	6 Someone to do things with for relaxation and enjoyment	1	2	3	4	5
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5.13	Do you belong to any of these social groups? <table border="1" style="float: right; margin-top: 10px;"> <thead> <tr> <th>YES</th> <th>NO</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> </tr> </tbody> </table> a Religious group b Self-help group c PLWHA group d Sports club e Drama/Dance group f Professional association society l Other(specify)..... ..... .....	YES	NO	1	2	1	2	1	2	1	2	1	2	1	2	1	2																										
YES	NO																																										
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		Not at all satisfied	Not quite satisfied	Moderately satisfied	Very satisfied
5.14 a	In general, how satisfied are you with the overall social support at home?	1	2	3	4
b	In general, how satisfied are you with the overall social support from outside your home?	1	2	3	4
<b>Stigma and disclosure</b>					
5.15	I am going to read you a series of statements. Please tell me whether you agree or disagree with each statement				
				Agree	Disagree
	1 Getting HIV/AIDS is a punishment for bad behaviour			1	
	2 If I was in public or private transport and someone knew I had HIV they would not sit next to me			1	2
	3 I sometimes feel worthless because I am HIV positive			1	2
	4 My neighbours would not like me living next door if they knew I had HIV			1	2
	5 I am hurt by how people reacted to learning I have got HIV			1	2
	6 Because of HIV people would not court me			1	2
	7 People are afraid of me because I have HIV			1	2
	8 I feel that It is my fault that I got HIV			1	2
	9 Most employers would not employ me because I am HIV positive			1	2
	10 If I drank from a tap/cup) and people knew I had HIV they would not drink from the same tap/cup			1	2
	11 I must have done something wrong to deserve getting HIV			1	2
	12 I feel ashamed that I have HIV			1	2
	13 When people know that I have HIV I feel uncomfortable around them			1	2
	14 I have lost my friends by telling them that I have HIV/AIDS			1	2
	15 I work hard to keep my HIV/status a secret			1	2
5.16	Have you disclosed your HIV status to any one else apart from health workers and researchers? (1=YES; 2=NO) [if 2 skip to 5.18]				
5.17	To whom have you disclosed your HIV/AIDS ? Status?		Yes	No	NA
	<b>Spouse/husband</b>	1	2	3	
	<b>Regular sexual partner</b>	1	2	3	
	<b>Children</b>	1	2	3	
	<b>Parents</b>	1	2	3	
	<b>Other family members</b>	1	2	3	
	<b>Friends/Neighbours</b>	1	2	3	
	<b>Religious group members</b>	1	2	3	
	<b>HIV/AIDS group members</b>	1	2	3	
	<b>Other(Specify).....</b>	1	2	3	
	.....				
	.....				

5.18

**Depression, anxiety, and apathy**

Now I would like to read to you a group of statements. Please pick out one statement in each group which best describes the way you have been feeling over the past week including today (FW: Circle the number besides the statement as picked by the respondent).

- A** I don't feel sad..... 1  
 I feel sad..... 2  
 I am sad all the time and I can't get out of it..... 3  
 I am so sad or unhappy that I can't stand it..... 4
- B** I am particularly not discouraged about the future..... 1  
 I feel discouraged about the future..... 2  
 I feel I have nothing to look forward to..... 3  
 I feel that the future is hopeless and things can not improve..... 4
- C** I don't feel particularly guilty..... 1  
 I feel guilty sometimes..... 2  
 I feel guilty most of the time..... 3  
 I feel guilty all the time..... 4
- D** I don't feel I am being punished..... 1  
 I feel I may be punished..... 2  
 I expect to be punished..... 3  
 I feel I am being punished..... 4
- E** I don't feel disappointed in myself..... 1  
 I feel I am disappointed in myself..... 2  
 I am disgusted with myself..... 3  
 I hate myself..... 4
- F** I don't feel I am any worse than anybody else..... 1  
 I am critical of myself for my weaknesses or mistakes..... 2  
 I blame myself all the time for my faults..... 3  
 I blame myself for everything bad that happens..... 4
- G** I am no more irritated now than usual..... 1  
 I get annoyed or irritated more easily than I used to..... 2  
 I feel irritated all the time now..... 3  
 I don't get irritated at all by the things that used to irritate me..... 4
- H** I don't feel I look any worse than I used to..... 1  
 I am worried that I am looking unattractive..... 2  
 I feel that there are permanent changes in my appearance that make me look unattractive..... 3  
 I believe that I look ugly..... 4
- i** I can work just as well as before..... 1  
 It takes an extra effort to get started at doing something..... 2  
 I have to push myself very hard to do anything..... 3  
 I can't do any work at all..... 4
- J** I can sleep as well as usual..... 1  
 I don't sleep as well as I used to..... 2  
 I wake up 1-2 hrs earlier than usual and find it hard to get back to sleep..... 3  
 I wake up more than 2 hrs earlier than usual and I find it hard to get back to sleep..... 4



## Appendix 2: In-depth interview guide

### In-depth interview for Group A

Date of interview (DD/MM/YY): \_\_\_ \_\_\_ / \_\_\_ \_\_\_ / \_\_\_ \_\_\_

Name of the Interviewee: .....

Name of Interviewer: .....

**Age..... Sex.....Marital status.....**

**Location..... ART status.....**

#### *Introduction and Consent*

Thank you so much for meeting with me today. My name is [Name]. I am from the African Population and Health Research Center in Nairobi. We are following you on an interview we had a few months ago to better understand the experiences and problems of PLWHA. We do research in this community to gain a better understanding of the problems people like you face and share it with policy-makers and encourage them to make proper decisions that will assist PLWHA. We've requested an interview with you because we believe that you have experience which may be helpful to others. As a PLWHA, you are the real expert, and there's a lot we can learn from you. So today I would like to have a conversation with you about your experiences with HIV, your thoughts about parenthood, your experiences with contraception, family planning services, and any sexual concerns you may have.

This is very informal; you can talk about anything you think is important for us to know. The interview should take about an hour. I will be taping the session and taking notes because I don't want to miss any of your comments. All your responses will be kept confidential and will not be shared with anyone else outside our research team members. We will ensure that any information we include in our report does not identify you as a respondent. Remember you don't have to talk about anything you don't want and if there are any questions you'd rather not answer, just let me know -- that's fine. Is there anything you'd like to ask me at this point? [**Answer any questions regarding the interview**].

#### *Introduction and Consent*

Asante sana kwa kukutana na mimi leo. Jina langu ni [Jina]. Nafanya na shirika la African Population and Health Research Center lililoko Nairobi. Sisi hufanya utafiti katika jamii hii ili kupata ufahamu zaidi kuhusu matatizo ya watu wanaoishi na Virusi. Kisha tunawajulisha wanaobuni sera, yale yote tuliojifunza kutoka kwa jamii na kuwahimiza kufanya maamuzi mema yatakayowasaidia watu wanaosihhi na Virusi.

Tumeomba tuwe na mahojiano na wewe kwa sababu tunaamini kuwa una uzoefu ambao huenda ukawa ni wenye usaidizi kwa wengine. Kama mtu ambaye anaishi na virusi vya UKIMWI wewe ndio mtaalam, na kuna mengi ambayo tunaweza kujifunza kutoka kwako. Leo ningependa kuongea kuhusu matukuio yako, mawazo yako ya uzazi, matukio yako kuhusu kinga, upangaji wa uzazi, na chochote kingine kinachohusu ngono ambacho kinakusumbua.

Maongeo si ya rasmi, unaweza ongea chochote unachofikiri ni cha maana sisi kujua. Nitakua naandika wakati tunapongea, lakini pia ningetaka kunasa/ rekodi maongeo yetu kuhakikisha sijakosa lolote. .Majibu yako yatakuwa ya siri na hayatazungumziwa na mtu yeyote nje ya watu wa kazi yetu. Tutahakikisha ya kwamba habari yenye

tutaweka kwa ripoti haitakutambulisha wewe kama muhojiwa. Kumbuka kuwa si lazima uongee kuhusu kitu ambacho hutaki kukizungumzia. Ikiwa wakati wowowote ugetaka kuwacha mazungumzo, ama kuna swali amabalo hungetaka kulijibu, nieleze nijue—hiyo ni sawa. Je una swali ambalo ungetaka kuniuliza hadi sasa?

Signature of respondent.....

**Interviewer:** *To begin our conversation, I would like to ask you some information regarding yourself and your life in general*

**Interviewer:** *Tukianza mazungumzo yetu, ningetaka kukuuliza mambo Fulani kuhusu maisha yako na vile ulivyo kwa ujumla.*

1. How are you and your family doing generally?  
*Je, wewe na familia yako mnaendelea aje kwa ujumla?*
2. How long have you lived in this community?  
*Umeishi katika mtaa huu kwa muda upi?*
3. What do you do for a living? Do you receive any support? (*Probe for support from government, family, Church*)  
*Wewe hufanya nini kujikimu kimaisha? (Dadisi je, wewe hupata usaidizi wowote kutoka kwa serikali, familia, kanisa).*
- 3b. Could you please give a brief history (description) of your life? (*Probe for life-course from childhood, education, social life, plans for the future then and now*)  
*Tafadhali nipe historia fupi kuhusu maisha yako (Dadisi maisha ya kutoka utotoni, elimu, maisha ya jamii, mipango yake wakati huo mpaka watiki huu)*

#### **HIV History and experience**

**Interviewer:** *Now I would like to ask you some information regarding your status.*

**Interviewer:** *Sasa ningependa kukuuliza mambo fulani kuhusu hali yako ya Virusi*

4. Let me start from when you first learned that you were HIV positive: How long ago was this?  
*Wacha tuanze na wakati ulijua kuwa una Virusi: ilikuwa lini?*
5. Tell me how you came to learn that you were HIV positive (*probe for sickness prior to test, decision to go for test, who accompanied him/her, when, where and what happened during the test*)  
*Nielezee vile ulivyogundua kuwa una Virusi?(Dadisi kama alikuwa mgonjwa kabla ya kupimwa, uamuzi wa kupimwa, alienda peke yake kupimwa ama na mwenzake, lini na wapi, nini kilichofanyika).*
6. Tell me your reaction when you found out you were HIV positive(*Probe for fears, concerns about dying, care and treatment, marriage, having children, e.t.c*)  
*Ulijihisi vipi ulipojua hali yako ya Virusi (Uliza kuhusu woga, mawazo kuhusu kifo, utunzi na matibabu, ndoa, na kupata watoto).*
7. Have you disclosed your HIV status to anyone? If yes whom have you told about your HIV status (*Probe if parents, relatives, closer friends, clergy, community leader, in-laws*). For each person mentioned, probe reasons for disclosing to them (*Probe why non-disclosures to others, what made them not to disclose*)  
*Je, umejulisha mtu yoyote kuhusu hali yako? Ni watu wapi haswa ambao umewajulisha kuhusu hali yako? (Dadisi kama ni wazazi, familia, marafiki wa karibu, kanisa, wazee wa kijiji, mashemeji) kwa kila alietajwa dadisi sababu za*

- kuwajulisha). Dadisi mbona wengine hawakujulishwa na sababu za kutojulishwa)*
8. How easy or difficult was it/is it to disclose your status( *probe for the process of disclosing, frequency of disclosing, fears surrounding disclosure*)  
*Je, ilikuwa (ni) rahisi ama vigumu kiasi gani kujulisha mtu yeyote kuhusu hali yako (Dadisi jinsi ya kujulisha, hofu, na hali ya kujulisha)*
  9. In your opinion, why do some HIV positive people have difficulties in disclosing their status (*Probe for live examples from them*)  
*Kwa maoni yako, mbona watu wengine walio na Virusi wana ugumu wa kujitambulisha kuwa wanaishi na Virusi? (Uliza mifano ya kutoka kwake).*
  10. Tell me how different people reacted when you told them about your HIV status (*Probe for all possible reactions, what happened*)  
*Hebu nielezee vile watu walivyo hisi wakati ulipowajulisha kuhusu hali yako ya kuwa na Virusi? (Dadisi namna za kuhizi zote, nini kilitokea)*
  11. How has your family or living arrangements changed as a result of HIV? (*Probe for marriage or household dissolution, death or migration of family, children?*)  
*Ni jinsi gani familia na makao yako imebadilika kwa sababu ya hali yako(virusi) (Dadisi kuhusu hali ya ndoa, uhamiaji ama kifo ya familia na watoto?)*
  12. In your opinion how did you get infected with HIV/AIDS  
*Kwa maoni yako, ulipata aje Virusi?*
  13. What other explanations have you heard people give about HIV infection(*probe for examples*)  
*Ni maelezo yapi umeyasikia watu wakisema kuhusu hali ya kuambukiswa na Virusi? (uliza mifano?)*
  14. How do people in this community view a PLWHA? (*probe for local names they use to describe a PLWHA or HIV*)?  
*Je, watu wanaoishi na ukimwi wanachukuliwa aje na watu wa jamii hii(Dadisi majina ambayo hutumika hapa kuwaita wanaoishi na Virusi na Virusi vyenyewe)*
  15. How do you view yourself as a person living with HIV/AIDS?(*Probe for views about self identity, negotiation of identity and roles assigned to that identity, body image etc*)  
*Unajiona aje vipi kama mtu anayeishi na Virusi?(Dadisi huhusu utambulisho wa binafsi na kuafikiana, majukumu)*
  16. What is your view concerning Antiretroviral treatment? (*probe for benefits, problems*)  
*Unamaoni gani kuhusu madawa ya ART? (Dadisi manufaa, matatizo)*
  17. How has the availability of treatment changed your prospects about the future?(*probe for prospects in education, employment, family and marriage etc*)  
*Kuwepo kwa matibabu/madawa ya ARV umebadili vipi fikira zako juu ya siku za usoni?(Dadisi elimu, kikazi, kijamii, kindoa)*

### **ART History (If on ART (otherwise skip to 24)**

**Interviewer:** *Now I would like to ask you some questions regarding your experiences with ART treatment*



**Interviewer:** Now I would like to ask you some questions regarding your experiences with ART treatment: Sasa ningependa tuongee kuhuzu matukio/ozeofu wako na ART

18. Please take me through the process of how you enrolled for ART (for when and why ART enrolment, what happened, counseling and education, Sexual and reproductive education)

Tafadhali nielezee kinaganaga jinsi ulivyo wekwa kwa haya madawa (**Dadisi lini na kwa nini akawekwa kwa dawa, nini kilitendeka uko, ushauri na elimu ya ART, elimu ya mapenzi na afya ya uzazi**)

19. Tell me the type of or show me ART drugs that you have and how and when you were advised to take them.

Nielezee/nionyeshe aina ya madawa ya ART yako na jinsi na nyakati ulishauriwa kuyameza

**Interviewer:** You said that you have not missed taking any of these drugs since you enrolled, right?

**Interviewer:** Ulisema ya kwamba hujawahii kukosa kuyamemeza haya madawa, ndivyo? (**Interviewer: If the respondent says that he/she has ever missed taking the pills go to module C-20?**)

20. How do you manage to take your medications regularly and go for the re-supply on time?(probe for reminders, faith in ART, self motivation, support from family, friends and community, and other strategies ie secrecy etc)

Ni, nini haswa hukusaidia ama hukuezesha kumeza tembe zako kila mara na kuyaenda tembe zingine kwenye wakati ufao (**Dadisi vifaa vya kukumbusha, imani kwa madawa, motisha, msaada ya kwa jamii, marafiki na jamaa, na mikakati nyingine kama kwa siri**)

21. What kind of information and support are you given by the health workers to help you adhere to your medications?

Je, ni msaada upi ambayo unapewa na waadumu wa afya ili ukunywe haya madawa inavyotakikana.

22. Please explain your experience with ART( probe for problems/benefits with ART, going to the clinic, lifestyle changes, availability of drugs, compatibility with daily schedule)

Tafadhali nieleze uzoefu wako wa matibabu/madawa ya ART? (**Dadisi shida na manufaa ya madawa, muda na hali ya kusafiri hadi kituo cha afya, mabadiliko ya hali ya maisha, uwepo/ukosefu wa madawa, mpangilio waya shughuli zako za kila siku**)

23. How has being on treatment changed things in life and future plans if at all

Utumizi wa matibabu/madawa ya ARV umebadili vipi maisha yako na mipango yako ya uzoni.

### III. SEXUAL AND REPRODUCTIVE BEHAVIOUR

**Interviewer:** Now I would like to ask you some questions regarding your sexual and reproductive life and experience

**Interviewer:** Sasa ningependa kukuliza maswali kuhusu kushiriki ngono, maisha ya uzazi na matukio yako

**Interviewer:** You said that you have not had sex in the last 12 months, right?

**Interviewer:** Ulisema ya kwamba hujawahii fanya mapenzi ama kushiriki ngono kwa miezi 12, si ndio?

**(Interviewer: If the respondent says she/he has had sex go to group B guide-24**

24. Why haven't you had sex in the last 12 months (*probe for fears of re-infection, discouragement by health workers, lack of partner, lack of libido etc*)  
**Tafadhali nieleze kwanini hujafanya mapenzi/shiriki ngono kwa miezi 12? ( Dadisi hofu ya kuambukiswa tena, kukataswa na waaguusi, ukosefu wa mpenzi ama nyege)**
25. Have you had sex since you learnt that you were HIV positive? **If yes** describe how your sexual relationship was (*probe for sexual partners, use of protection*).  
**Je, ushawahi fanya mapenzi/shiriki ngono tangu ugundue ya kwamba unavirusi? Kama ndio, elezea vile hali yako ya kushiriki ngono imekuwa?(Dadisi wapenzi wako, matumixi ya kinga)**
26. How does an ideal woman and man expected to behave in respect to sexual relations according to your society (*probe for gender differences?*)  
**Ni vipi mwanaume au mwanamke wakawaida anapaswa kuishi ama kutenda kulingana na kushiriki ngono kuambatana na jinsia kwa jamii yako? (Dadisi tofauti ya Jinsia)**
27. How has this behaviour changed if at all with HIV/AIDS?  
**Hii hali imebadilika vipi kufwatia Virusi/Ukimwi**

**Interviewer: You said that you do not want any more children, right**

**Interviewer: Ulisema ya kwamba hutaki kupata watoto wengine si ndio?**

**Interviewer: If respondent says that wants a child/more children go to Guide C -33)**

28. Could you please explain why you don't want a child/more children?  
**Tafadhali nielezee kwa nini hutaki mtoto ama watoto wengine**
29. Have you discussed this with anyone? If **YES** what was their reaction?  
 If **No** why haven't you discussed it with anyone?  
**Je, ushawahi zungumza na mtu yeyote kuhusiana na kutotakazaa watoto? Kama ndio, mawazo yao yalikuwa vipi? Kama la kwanini? What importance is attached to having a child in your community? Kuwa na mtoto kuna umhimu gani katika kwa kabila lako?**
30. In your opinion why do you think some HIV positive people still want children?  
**Kwa maoni yako, mbona unafikiri mtu ambaye na Virusi bado angependa kupata watoto?**
31. What is the view of the community concerning PLWHA having children?  
**Maoni ya jamii kwa ujumla kuhusu watu wanaoishi na virusi kupata watoto ni yapi?**
32. What kind of advice or counseling have you received about further childbearing given your HIV positive status? (*Probe from whom and when advice was received*)  
**Ni ushauri wa aina gani umepata kuhusu kupata watoto ukizingatia hali yako? (Uliza kutoka kwa nani na ushauri ulipatwa lini)**
33. What kind of discussion or advice have you received about family planning? What were you told? (*probe from whom and when advice was received, Family Planning methods discussed*)

Ni ushauri ama mazungumzo ya aina gani umepata kuhusu mpango ya uzazi? Uliambiwa nini? (*Uliza kutoka kwa nani na ushauri ulipatwa lini, njia za kupanga uzazi mlizozungumzia*)

34. What is your view about family planning for PLWHA?  
Je, unamaoni gani kuhusu upangaji wa uzazi ama kuzuia mimba kutumiwa na watu wanaoishi na virusi?
35. Based on your experience, what factors make it difficult for PLWHA to use contraception?  
Kulingana na matukio yako, ni nini kinacho fanya kuwe na ugumu wa watu wanaoishi na Virusi kutumia njia za kupanga uzazi?
36. Given your own experiences, what would you like to add to our discussion about PLWHA?  
Kulingana na matukio yako, ni nini ungependa kuongezea katika mjadala wetu kuhusu watu wanaoishi na Virusi.

*Thank you for sharing your thoughts and experiences with me. If you like to know to get more information on any of the topics we discussed today, contact our site office in this community. If we have anything we will keep in touch with you.*

*Asante sana kwa kunieleza mawazo na matukio/uzoefu yako nami. Kama ungependelea kupata maelezo zaidi kwa mambo ambayo tumekuwa tukiyazungumzia leo, tafadhaili tembelea afisi yetu iliyoko hapa mtaani. Kama hakuna chochote unacho weza sema sasa, unaweza wasiliana nami wakati mwingine.*

## In-depth interview for Group B

Date of interview (DD/MM/YY): \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_

Name of the Interviewee: .....

Name of Interviewer: .....

**Age**..... **Sex**.....**Marital status**.....

**Location**..... **ART status**.....

### *Introduction and Consent*

Thank you so much for meeting with me today. My name is [**Name**]. I am from the African Population and Health Research Center in Nairobi. We are following you on an interview we had a few months ago to better understand the experiences and problems of PLWHA. We do research in this community to gain a better understanding of the problems people like you face and share it with policy-makers and encourage them to make proper decisions that will assist PLWHA. We've requested an interview with you because we believe that you have experience which may be helpful to others. As a PLWHA, you are the real expert, and there's a lot we can learn from you. So today I would like to have a conversation with you about your experiences with HIV, your thoughts about parenthood, your experiences with contraception, family planning services, and any sexual concerns you may have.

This is very informal; you can talk about anything you think is important for us to know. The interview should take about an hour. I will be taping the session and taking notes because I don't want to miss any of your comments. All your responses will be kept confidential and will not be shared with anyone else outside our research team members. We will ensure that any information we include in our report does not identify you as a respondent. Remember you don't have to talk about anything you don't want and if there are any questions you'd rather not answer, just let me know -- that's fine. Is there anything you'd like to ask me at this point? [**Answer any questions regarding the interview**].

### *Introduction and Consent*

Asante sana kwa kukutana na mimi leo. Jina langu ni [**Jina**]. Nafanya na shirika la African Population and Health Research Center lililoko Nairobi. Sisi hufanya utafiti katika jamii hii ili kupata ufahamu zaidi kuhusu matatizo ya watu wanaoishi na Virusi. Kisha tunawajulisha wanaobuni sera, yale yote tuliojifunza kutoka kwa jamii na kuwahimiza kufanya maamuzi mema yatakayowasaidia watu wanaosihia na Virusi.

Tumeomba tuwe na mahojiano na wewe kwa sababu tunaamini kuwa una uzoefu ambao huenda ukawa ni wenye usaidizi kwa wengine. Kama mtu ambaye anaishi na virusi vya UKIMWI wewe ndio mtaalam, na kuna mengi ambayo tunaweza kujifunza kutoka kwako. Leo ningependa kuongea kuhusu matukio yako, mawazo yako ya uzazi, matukio yako kuhusu kinga, upangaji wa uzazi, na chochote kingine kinachohusu ngono ambacho kinakusumbua.

Maongeo si ya rasmi, unaweza ongea chochote unachofikiri ni cha maana sisi kujua. Nitakua naandika wakati tunapongea, lakini pia ningetaka kunasa/ rekodi maongeo yetu kuhakikisha sijakosa lolote. Majibu yako yatakuwa ya siri na hayatazungumziwa na mtu yeyote nje ya watu wa kazi yetu. Tutahakikisha ya kwamba habari yenye tutaweka kwa ripoti haitakutambulisha wewe kama muhojiwa. Kumbuka kuwa si

lazima uongee kuhusu kitu ambacho hutaki kukizungumzia. Ikiwa wakati wowowte ugetaka kuwacha mazungumzo, ama kuna swali amabalo hungetaka kulijibu, nieleze nijue—hiyo ni sawa. Je una swali ambalo ungetaka kuniuliza hadi sasa?

**Signature of respondent.....**

***Interviewer:*** *To begin our conversation, I would like to ask you some information regarding yourself and your life in general*

***Interviewer:*** *Tukianza mazungumzo yetu, ningetaka kukuuliza mambo Fulani kuhusu maisha yako na vile ulivyo kwa ujumla.*

1. How are you and your family doing generally?  
*Je, wewe na familia yako mnaendelea aje kwa ujumla?*
2. How long have you lived in this community?  
*Umeishi katika mtaa huu kwa muda upi?*
3. What do you do for a living? Do you receive any support? (*Probe for support from government, family, Church*)  
*Wewe hufanya nini kujikimu kimaisha? (Dadisi je, wewe hupata usaidizi wowote kutoka kwa serikali, familia, kanisa).*
- 3b. Could you please give a brief history (description) of your life? (*Probe for life-course from childhood, education, social life, plans for the future then and now*)  
*Tafadhali nipe historia fupi kuhusu maisha yako (Dadisi maisha ya kutoka utotoni, elimu, maisha ya jamii, mipango yake wakati huo mpaka watiki huu)*

#### **HIV History and experience**

***Interviewer:*** *Now I would like to ask you some information regarding your status.*

***Interviewer:*** *Sasa ningependa kukuuliza mambo fulani kuhusu hali yako ya Virusi*

4. Let me start from when you first learned that you were HIV positive: How long ago was this?  
*Wacha tuanze na wakati ulijua kuwa una Virusi: ilikuwa lini?*
5. Tell me how you came to learn that you were HIV positive (*probe for sickness prior to test, decision to go for test, who accompanied him/her, when, where and what happened during the test*)  
*Nielezee vile ulivyogundua kuwa una Virusi?(Dadisi kama alikuwa mgonjwa kabla ya kupimwa, uamuzi wa kupimwa, alienda peke yake kupimwa ama na mwenzake, lini na wapi, nini kilichofanyika).*
6. Tell me your reaction when you found out you were HIV positive(*Probe for fears, concerns about dying, care and treatment, marriage, having children, e.t.c*)  
*Ulijihisi vipi ulipojua hali yako ya Virusi (Uliza kuhusu woga, mawazo kuhusu kifo, utunzi na matibabu, ndoa, na kupata watoto).*
7. Have you disclosed your HIV status to anyone? If yes whom have you told about your HIV status (*Probe if parents, relatives, closer friends, clergy, community leader, in-laws*). For each person mentioned, probe reasons for disclosing to them (*Probe why non-disclosures to others, what made them not to disclose*)

Je, umejulisha mtu yoyote kuhusu hali yako? Ni watu wapi haswa ambao umewajulisha kuhusu hali yako? (*Dadisi kama ni wazazi, familia, marafiki wa karibu, kanisa, wazee wa kijiji, mashemeji*) kwa kila alietajwa dadisi sababu za kuwajulisha). Dadisi mbona wengine hawakujulishwa na sababu za kutojulishwa)

8. How easy or difficult was it/is it to disclose your status( *probe for the process of disclosing, frequency of disclosing, fears surrounding disclosure*)

Je, ilikuwa (ni) rahisi ama vigumu kiasi gani kujulisha mtu yeyote kuhusu hali yako (*Dadisi jinsi ya kujulisha, hofu, na hali ya kujulisha*)

9. In your opinion, why do some HIV positive people have difficulties in disclosing their status (*Probe for live examples from them*)

Kwa maoni yako, mbona watu wengine walio na Virusi wana ugumu wa kujitambulisha kuwa wanaishi na Virusi? (*Uliza mifano ya kutoka kwake*).

10. Tell me how different people reacted when you told them about your HIV status (*Probe for all possible reactions, what happened*)

Hebu nielezee vile watu walivyo hisi wakati ulipowajulisha kuhusu hali yako ya kuwa na Virusi? (*Dadisi namna za kuhizi zote, nini kilitokea*)

11. How has your family or living arrangements changed as a result of HIV? (*Probe for marriage or household dissolution, death or migration of family, children?*)

Ni jinsi gani familia na makao yako imebadilika kwa sababu ya hali yako(virusi) (*Dadisi kuhusu hali ya ndoa, uhamiaji ama kifo ya familia na watoto?*)

12. In your opinion how did you get infected with HIV/AIDS

Kwa maoni yako, ulipata aje Virusi?

13. What other explanations have you heard people give about HIV infection(*probe for examples*)

Ni maelezo yapi umeyasikia watu wakisema kuhusu hali ya kuambukiswa na Virusi? (*uliza mifano?*)

14. How do people in this community view a PLWHA? (*probe for local names they use to describe a PLWHA or HIV*)?

Je, watu wanaoishi na ukimwi wanachukuliwa aje na watu wa jamii hii(*Dadisi majina ambayo hutumika hapa kuwaita wanaoishi na Virusi na Virusi vyenyewe*)

15. How do you view yourself as a person living with HIV/AIDS?(*Probe for views about self identity, negotiation of identity and roles assigned to that identity, body image etc*)

Unajiona aje vipi kama mtu anayeishi na Virusi?(*Dadisi huhusu utambulisho wa binafsi na kuafikiana, majukumu*)

16. What is your view concerning Antiretroviral treatment? (*probe for benefits, problems*)

Unamaoni gani kuhusu madawa ya ART? (*Dadisi manufaa, matatizo*)

17. How has the availability of treatment changed your prospects about the future?(*probe for prospects in education, employment, family and marriage etc*)

Kuwepo kwa matibabu/madawa ya ARV umebadili vipi fikira zako juu ya siku za usoni?(*Dadisi elimu, kikazi, kijamii, kindoa*)

### **ART History (If on ART (otherwise skip to 24))**

*Interviewer: Now I would like to ask you some questions regarding your experiences with ART treatment*

*Interviewer: Now I would like to ask you some questions regarding your experiences with ART treatment: Sasa ningependa tuongee kuhusu matukio/ozeofu wako na ART*

18. Please take me through the process of how you enrolled for ART (*for when and why ART enrolment, what happened, counseling and education, Sexual and reproductive education*)

Tafadhali nielezee kinaganaga jinsi ulivyo wekwa kwa haya madawa(*Dadisi lini na kwa nini akawekwa kwa dawa, nini kilitendeka uko, ushauri na elimu ya ART, elimu ya mapenzi na afya ya uzazi*)

19. Tell me the type of or show me ART drugs that you have and how and when you were advised to take them.

Nielezee/nionyeshe aina ya madawa ya ART yako na jinsi na nyakati ulishauriwa kuyameza

*Interviewer: You said that you have not missed taking any of these drugs since you enrolled, right?*

*Interviewer: Ulisema ya kwamba hujawahii kukosa kuyamemeza haya madawa, ndivyo? (Interviewer: If the respondent says that he/she has ever missed taking the pills go to module C-20?)*

20. How do you manage to take your medications regularly and go for the re-supply on time?(*probe for reminders, faith in ART, self motivation, support from family, friends and community, and other strategies ie secrecy etc*)

Ni, nini haswa hukusaidia ama hukuezesha kumeza tembe zako kila mara na kuyaenda tembe zingine kwenye wakati ufao (*Dadisi vifaa vya kukumbusha, imani kwa madawa, motisha, msaada ya kwa jamii, marafiki na jamaa, na mikakati nyingine kama kwa siri*)

21. What kind of information and support are you given by the health workers to help you adhere to your medications?

Je, ni msaada upi ambayo unapewa na waadumu wa afya ili ukunywe haya madawa inavyotakikana.

22. Please explain your experience with ART( *probe for problems/benefits with ART, going to the clinic, lifestyle changes, availability of drugs, compatibility with daily schedule*)

*Tafadhali nieleze uzoefu wako wa matibabu/madawa ya ART?(Dadisi shida na manufaa ya madawa, muda na hali ya kusafiri hadi kituo cha afya, mabadiliko ya hali ya maisha, uwepo/ukosefu wa madawa, mpangilio way a shughuli zako za kila siku)*

23. How has being on treatment changed things in life and future plans if at all

*Utumizi wa matibabu/madawa ya ARV umebadili vipi maisha yako na mipango yako ya uzoni.*

## SEXUAL AND REPRODUCTIVE BEHAVIOUR

*Interviewer: Now I would like to ask you some questions regarding your sexual and reproductive life and experience*

*Interviewer: Sasa ningependa kukuliza maswali kuhusu kushiriki ngono afya ya uzazi na matukio yako*

*Interviewer: You said that you have had sex in the last 12 months, right?*

*Interviewer: Ulisema ya kwamba umewahii fanya mapenzi ama kushiriki ngono kwa miezi 12, ndivyo?*

*(Interviewer: If the respondent says she/he has not had sex go to group A guide (III-24)*

24. How would you describe your sexual life since you found out that you are HIV positive? ( *probe for what has changed and not*)

*Unaweza sema maisha yako ya kufanya mapenzi yako vipi tangu ugundue uko na virusi? (Uliza nini kilicho badilika na kipi hakijabadilika)*

25. Could you describe your sexual relationships for this time period ( *probe for Number and types of sexual partners*)

*Tafadhali nieleze jinsi kushiriki ngono/kufanya mapenzi kwako kwa miezi 12 (Dadisi idadi na aina ya watu ambao mlishiriki ngono nao)*

26. How have you been choosing your sexual partner(s)(*probe for serosorting*)

*Umekuwa ukichagua mpenzi/wapenzi wako vipi? (dadisi kama amwkuwa akichagua wa penzi wa hali sawa naye au la)*

27. How often do you disclose your HIV status to your partner(s)? How easy or difficult is it to disclose your HIV status to each of sexual partner(s)

*Ni mara ngapi wewe hujulisha wenzio hali yako? , huwa (ni) rahisi ama ngumu kiasi gani kuwajulisha*

28. How often do you have sex with your partner(s)

*Tafadhali nielezee nimarangapi wewe hushiriki ngono na mwenzio(wenzio)*



29. How do you manage do you use condoms all the time?(*probe for any support*)  
Je, umeweza aje kutumia mipira wakati wowote
30. In your opinion why do you think some HIV positive people do not use condoms?  
Kwa maoni yako, mbona unafikiri watu wengine ambao wanaishi nna Virusi hawezi kutumia mipira?
31. What discussions have you had with your partner(s) about using condoms? (*probe when last discussion occurred, who initiated it, key issues discussed, areas of disagreements, resolutions reached*)  
Ni mazungumzo yapi mmekuwa nayo kati yako na mkeo/mumeo/mwenzio kuhusu kutumia mipira? (*Uliza wakati mazungumzo hayo yalifanyika, nani aliyeanzisha, mambo makuu yaliyozungumziwa, mambo ambayo mulikubaliana, na suluhu zilizofikiwa*)
32. In your opinion why do you think some HIV positive people have multiple sexual partners?  
Kwa maoni yako, mbona unafikiri watu wengine walio na Virusi wanawezafanya mapenzi/shiriki ngono na wapenzi zaidi ya mmoja.
33. What do you think is the view of the community concerning PLWHA having sex?  
Maoni ya jamii yako kuhusu watu wanaoishi na virusi/ukimwi kushiriki ngono/kufanya mapenzi ni yapi?
34. What kind of advice or counseling have you received about engaging in sex given your HIV positive status?. Did you get all the information that you needed? (*Probe from whom and when advice was received; was it sufficient*)  
Ni ushauri wa aina gani umepata kuhusu kufanya mapenzi/kushiriki ngono ukizingatia hali yako? Je ulipata maelezo yote ambayo ulihitaji (*Dadisi kutoka kwa nani na lini, ushauri ulikuwa wa kutosha*)

**Interviewer:** *You said that you want to have a child/ more children in the future, right?*

**Interviewer:** *Ulisema ya kwamba unataka kupata mtoto/watoto wengine Ndivyo?*

**(Interviewer: if he/she says that he/she does not want to have a child/ more children go to A 28)**

35. Why do you want to have a child/ more children?  
Mbona ungependa kupata mtoto/watoto?
36. What importance is attached to having a child in your community?  
Kupata mtoto kuna umuhumi gani katika kabila lako?
37. How are childless couples perceived in this community? How is childlessness perceived differently for men and women? (*Probe for local words used to describe people who do not have children*).  
Wanawake na wanaume waishio pamoja na hawana watoto wanachukuliwa aje kwa katika jamii? Kutokuwa na watoto kunachukuliwa aje kwa wanaume na wanawake (*Uliza majina yanayotumika kwenye jamii kuwaita wasio na watoto*)

38. What kind of advice or counseling have you received about having a child/children given your HIV positive status? (*Probe from whom and when advice was received*)

Ni ushauri wa aina gani umepata kuhusu kupata mtoto/watoto ukizingatia hali yako? (*Uliza kutoka kwa nani na ushauri ulipatwa lini*)

39. What discussions have you had with your partner concerning having a child/children? (*Probe when last discussion occurred, who initiated, key issues discussed, areas of disagreements, resolutions reached etc.*)

Mmejadiliana yapi wewe na mke/mume wako kuhusu mipango ya kupata motto/watoto? (*Uliza wakati wa mwisho kujadiliana, nani aliyeanzisha, mambo kuu yaliojadiliwa, yale waliokosa kupatana, vile walivyofikia uamuzi.*)

**Interviewer:** *You said that you are using contraception or you intend to use in future, right?*

**Interviewer:** *Ulisema ya kwamba unatumia mpango ya uzazi ama unanuiia kutumia? (Interviewer: If the respondent says that she/he is not are using contraception nor intend to use in future, go to guide C-38)*

40. Which method is this/ methods are these? What is your experience?

Je, ni njia ya mpango ya uzazi gani ambayo unatumia ama unanuiia kutumia? Matukio yako ni yapi?

41. Tell me what you know about methods that PLWHA can use. Where did you learn about them? (*Probe which one if any he/she has used and why*)? Also, probe for history of use or intention to use

Nielezee njia unazozijua ambazo mke/mume anayeishi na Virusi. anaweza tumia? Ulizijulia wapi? (*Uliza ipi ikiwa iko / kama ashawahi tumia, na kwanini*)

42. What kind of discussion or advice have you received about family planning? What were you told? (*probe from whom and when advice was received, Family Planning methods discussed*)

Ni ushauri ama mazungumzo ya aina gani umepata kuhusu Kuhusu mpango wa uzazi? Uliambiwa nin? (*Uliza kutoka kwa nani na ushauri ulipatwa lini, njia za kupanga uzazi zilizozungumziwa*)

43. Do you have concerns about using contraception?

○ If yes, probe what they are?

If no, Probe, why respondent has no concerns?

Una maswala/hofu yoyote kuhusu matumizi ya njia za kupanga uzazi?

- Kama ndiyo ni yapi?  
○ Kama la, uliza kwa nini?

44. Based on your experiences, what would you say are FP needs of PLWHA? (*Probe for many examples*)

Kulingana na matukio yako, ungesema ni mahitaji yapi ya upangaji wa uzazi watu walio na virusi wanayo?

45. Based on your experience, what factors make it difficult for PLWHA to use contraception?

**Kulingana na matukio yako, ni nini kinacho fanya kuwe na ugumu kwa watu wanaoishi na Virusi kutumia njia za kupanga uzazi?**

46. From your experience in this community, what FP/RH services are available for PLWHA?

**Kutokana na matukio yako katika jamii hii kuna huduma zipi za upangaji na afya ya uzazi zilizopo kwa watu walio na Virusi?**

47. What is your own experience of using any of such service (s)? (*Probe for the problem (s) for which services were sought, for negative and positive experiences with service providers etc seek as many as possible examples.*)

**Una matukio yapi kwa kutumia huduma kama hizo (*Uliza shida walizo kuwa nazo wakitafuta huduma, kwa matukio mabaya na mazuri na wanaotoa huduma uliza mifano mingi iwezekanavyo*).**

48. Given your own experiences, what would you like to add to our discussion about PLWHA?

**Kulingana na matukio yako, ni nini ungependa kuongezea katika mjadala wetu kuhusu watu wanaoshi na Virusi.**

*Thank you for sharing your thoughts and experiences with me. If you like to know to get more information on any of the topics we discussed today, contact our site office in this community. If we have anything we will keep in touch with you.*

***Asante sana kwa kunieleza mawazo na matukio/uzoefu yako nami. Kama ungependelea kupata maelezo zaidi kwa mambo ambayo tumekuwa tukiyazungumzia leo, tafadhaili tembelea ofisi yetu iliyoko hapa mtaani. Kama hakuna chochote unacho weza sema sasa, unaweza wasiliana nami wakati mwingine.***

## In-depth interview for Group C

Date of interview (DD/MM/YY): \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_

Name of the Interviewee: .....

Name of Interviewer: .....

**Age..... Sex.....Marital status.....**

**Location..... ART status.....**

### *Introduction and Consent*

Thank you so much for meeting with me today. My name is [Name]. I am from the African Population and Health Research Center in Nairobi. We are following you on an interview we had a few months ago to better understand the experiences and problems of PLWHA. We do research in this community to gain a better understanding of the problems people like you face and share it with policy-makers and encourage them to make proper decisions that will assist PLWHA. We've requested an interview with you because we believe that you have experience which may be helpful to others. As a PLWHA, you are the real expert, and there's a lot we can learn from you. So today I would like to have a conversation with you about your experiences with HIV, your thoughts about parenthood, your experiences with contraception, family planning services, and any sexual concerns you may have.

This is very informal; you can talk about anything you think is important for us to know. The interview should take about an hour. I will be taping the session and taking notes because I don't want to miss any of your comments. All your responses will be kept confidential and will not be shared with anyone else outside our research team members. We will ensure that any information we include in our report does not identify you as a respondent. Remember you don't have to talk about anything you don't want and if there are any questions you'd rather not answer, just let me know -- that's fine. Is there anything you'd like to ask me at this point? [**Answer any questions regarding the interview**].

### *Introduction and Consent*

Asante sana kwa kukutana na mimi leo. Jina langu ni [Jina]. Nafanya na shirika la African Population and Health Research Center lililoko Nairobi. Sisi hufanya utafiti katika jamii hii ili kupata ufahamu zaidi kuhusu matatizo ya watu wanaoishi na Virusi. Kisha tunawajulisha wanaobuni sera, yale yote tuliojifunza kutoka kwa jamii na kuwahimiza kufanya maamuzi mema yatakayowasaidia watu wanaosihia na Virusi. Tumeomba tuwe na mahojiano na wewe kwa sababu tunaamini kuwa una uzoefu ambao huenda ukawa ni wenye usaidizi kwa wengine. Kama mtu ambaye anaishi na virusi vya UKIMWI wewe ndio mtaalam, na kuna mengi ambayo tunaweza kujifunza kutoka kwako. Leo ningependa kuongea kuhusu matukio yako, mawazo yako ya uzazi, matukio yako kuhusu kinga, upangaji wa uzazi, na chochote kingine kinachohusu gonono ambacho kinakusumbua.

Maongeo si ya rasmi, unaweza ongea chochote unachofikiri ni cha maana sisi kujua. Nitakua naandika wakati tunapoongea, lakini pia ningetaka kunasa/ rekodi maongeo yetu kuhakikisha sijakosa lolote. Majibu yako yatakuwa ya siri na hayatazungumziwa na mtu yeyote nje ya watu wa kazi yetu. Tutahakikisha ya kwamba habari yenye tutaweka kwa ripoti haitakutambulisha wewe kama muhojiwa. Kumbuka kuwa si

lazima uongee kuhusu kitu ambacho hutaki kukizungumzia. Ikiwa wakati wowowte ugetaka kuwacha mazungumzo, ama kuna swali amabalo hungetaka kulijibu, nieleze nijue—hiyo ni sawa. Je una swali ambalo ungetaka kuniuliza hadi sasa?

**Signature of respondent.....**

***Interviewer:*** *To begin our conversation, I would like to ask you some information regarding yourself and your life in general*

***Interviewer:*** *Tukianza mazungumzo yetu, ningetaka kukuuliza mambo Fulani kuhusu maisha yako na vile ulivyo kwa ujumla.*

1. How are you and your family doing generally?  
*Je, wewe na familia yako mnaendelea aje kwa ujumla?*
2. How long have you lived in this community?  
*Umeishi katika mtaa huu kwa muda upi?*
3. What do you do for a living? Do you receive any support? (*Probe for support from government, family, Church*)  
*Wewe hufanya nini kujikimu kimaisha? (Dadisi je, wewe hupata usaidizi wowote kutoka kwa serikali, familia, kanisa).*
- 3b. Could you please give a brief history (description) of your life? (*Probe for life-course from childhood, education, social life, plans for the future then and now*)  
*Tafadhali nipe historia fupi kuhusu maisha yako (Dadisi maisha ya kutoka utotoni, elimu, maisha ya jamii, mipango yake wakati huo mpaka watiki huu)*

#### **HIV History and experience**

***Interviewer:*** *Now I would like to ask you some information regarding your status.*

***Interviewer:*** *Sasa ningependa kukuuliza mambo fulani kuhusu hali yako ya Virusi*

4. Let me start from when you first learned that you were HIV positive: How long ago was this?  
*Wacha tuanze na wakati ulijua kuwa una Virusi: ilikuwa lini?*
5. Tell me how you came to learn that you were HIV positive (*probe for sickness prior to test, decision to go for test, who accompanied him/her, when, where and what happened during the test*)  
*Nielezee vile ulivyogundua kuwa una Virusi?(Dadisi kama alikuwa mgonjwa kabla ya kupimwa, uamuzi wa kupimwa, alienda peke yake kupimwa ama na mwenzake, lini na wapi, nini kilichofanyika).*
6. Tell me your reaction when you found out you were HIV positive(*Probe for fears, concerns about dying, care and treatment, marriage, having children, e.t.c*)  
*Ulijihisi vipi ulipojua hali yako ya Virusi (Uliza kuhusu woga, mawazo kuhusu kifo, utunzi na matibabu, ndoa, na kupata watoto).*
7. Have you disclosed your HIV status to anyone? If yes whom have you told about your HIV status (*Probe if parents, relatives, closer friends, clergy, community leader, in-laws*). For each person mentioned, probe reasons for

*disclosing to them (Probe why non-disclosures to others, what made them not to disclose)*

Je, umejulisha mtu yoyote kuhusu hali yako? Ni watu wapi haswa ambao umewajulisha kuhusu hali yako? (Dadisi kama ni wazazi, familia, marafiki wa karibu, kanisa, wazee wa kijiji, mashemeji) kwa kila alietajwa dadisi sababu za kuwajulisha). Dadisi mbona wengine hawakujulishwa na sababu za kutojulishwa)

8. How easy or difficult was it/is it to disclose your status( *probe for the process of disclosing, frequency of disclosing, fears surrounding disclosure*)

Je, ilikuwa (ni) rahisi ama vigumu kiasi gani kujulisha mtu yeyote kuhusu hali yako (Dadisi jinsi ya kujulisha, hofu, na hali ya kujulisha)

9. In your opinion, why do some HIV positive people have difficulties in disclosing their status (*Probe for live examples from them*)

Kwa maoni yako, mbona watu walio na Virusi wana ugumu wa kujitambulisha kuwa wanaishi na Virusi? (Uliza mifano ya kutoka kwake).

10. Tell me how different people reacted when you told them about your HIV status (*Probe for all possible reactions, what happened*)

Hebu nielezee vile watu walivyo hisi wakati ulipowajulisha kuhusu hali yako ya kuwa na Virusi? (Dadisi namna za kuhizi zote, nini kilitokea)

11. How has your family or living arrangements changed as a result of HIV? (*Probe for marriage or household dissolution, death or migration of family, children?*)

Ni jinsi gani familia na makao yako imebadilika kwa sababu ya hali yako(virusi) (Dadisi kuhusu hali ya ndoa, uhamiaji ama kifo ya familia na watoto?)

12. In your opinion how did you get infected with HIV/AIDS

Kwa maoni yako, ulipata aje Virusi?

13. What other explanations have you heard people give about HIV infection(*probe for examples*)

Ni maelezo yapi umeyasikia watu wakisema kuhusu hali ya kuambukiswa na Virusi? (uliza mifano?)

14. How do people in this community view a PLWHA? (*probe for local names they use to describe a PLWHA or HIV*)?

Je, watu wanaoishi na ukimwi wanachukuliwa aje na watu wa jamii hii(Dadisi majina ambayo hutumika hapa kuwaita wanaoishi na Virusi na Virusi vyenyewe)

15. How do you view yourself as a person living with HIV/AIDS?(*Probe for views about self identity, negotiation of identity and roles assigned to that identity, body image etc*)

Unajiona aje vipi kama mtu anayeishi na Virusi?(Dadisi huhusu utambulisho wa binafsi na kuafikiana, majukumu)

16. What is your view concerning Antiretroviral treatment? (*probe for benefits, problems*)  
 Unamaoni gani kuhusu madawa ya ART? (*Dadisi manufaa, matatizo*)
17. How has the availability of treatment changed your prospects about the future? (*probe for prospects in education, employment, family and marriage etc*)  
 Kuwepo kwa matibabu/madawa ya ARV umebadili vipi fikira zako juu ya siku za usoni? (*Dadisi elimu, kikazi, kijamii, kindoa*)

### **ART History (If on ART (otherwise skip 23))**

**Interviewer:** *Now I would like to ask you some questions regarding your experiences with ART treatment*

18. Please take me through the process of how you enrolled for ART (*for when and why ART enrolment, what happened, counseling and education, Sexual and reproductive education*)  
 Tafadhali nielezee kinaganaga jinsi ulivyo wekwa kwa haya madawa (*Dadisi lini na kwa nini akawekwa kwa dawa, nini kilitendeka uko, ushauri na elimu ya ART, elimu ya mapenzi na afya ya uzazi*)
19. Tell me the type of or show me ART drugs that you have and how and when you were advised to take them.  
 Nielezee/nionyeshe aina ya madawa ya ART yako na jinsi na nyakati ulishauriwa kuyameza
20. We appreciate that it is difficult to take these drugs everyday. When was the last time that you missed a pill? Tell me what causes/caused this to happen?  
 Tunaelewa ya kwamba ni vigumu kuyameza haya madawa kila siku. Je Ni lini mwisho ulikosa kumeza tembe, Tafadhali nieleze/niambie nini hasa husababisha hali hii?
21. Please explain your experience with ART (*probe for problems/benefits with ART, going to the clinic, lifestyle changes, availability of drugs, compatibility with daily schedule*)  
 Tafadhali nieleze uzoefu wako wa matibabu/madawa ya ART? (*Dadisi shida na manufaa ya madawa, muda na hali ya kusafiri hadi kituo cha afya, mabadiliko ya hali ya maisha, uwepo/ukosefu wa madawa, mpangilio way a shughuli zako za kila siku*)
22. How has being on treatment changed things in life and future plans if at all  
 Utumizi wa matibabu/madawa ya ARV umebadili vipi maisha yako na mipango yako ya uzoni.

### III. SEXUAL AND REPRODUCTIVE BEHAVIOUR

**Interviewer:** Now I would like to ask you some questions regarding your sexual and reproductive life and experience

**Interviewer:** Sasa ningependa kukuliza maswali kuhusu kushiriki ngono afya ya uzazi na matukio yako

**Interviewer:** You said that you have had sex in the last 12 months, right?

**Interviewer:** *Ulisema ya kwamba umewahii fanya mapenzi ama kushiriki ngono kwa miezi 12, ndivyo?*

**(Interviewer: If the respondent says she/he has not had sex go to group A guide (III-24))**

23. How would you describe your sexual life since you found out that you are HIV positive? (probe for what has changed and not)

*Unaweza sema maisha yako ya kufanya mapenzi yako vipi tangu ugundue uko na virusi? (Uliza nini kilicho badilika na kipi hakijabadilika)*

24. Could you describe your sexual relationships for this time period (probe for Number and types of sexual partners)

*Tafadhali nieleze jinsi kushiriki ngono/kufanya mapenzi kwako kwa miezi 12 (Dadisi idadi na aina ya watu ambao mlishiriki ngono nao)*

25. How have you been choosing your sexual partner(s)(probe for serosorting)

*Umekuwa ukichagua mpenzi/wapenzi wako vipi? (dadisi kama amwkuwa akichagua wa penzi wa hali sawa naye au la)*

26. How often do you disclose your HIV status to your partner(s)? How easy or difficult is it to disclose your HIV status to each of sexual partner(s)

*Ni mara ngapi wewe hujulisha wenzio hali yako? , huwa (ni) rahisi ama ngumu kiasi gani kuwajulisha*

27. How often do you have sex with your partner(s)

*Tafadhali nielezee nimarangapi wewe hushiriki ngono na mwenzio(wenzio)*

**Interviewer:** You said that you have never used a condom or you have not used all the time in the last 12 months, right?

**Interviewer:** *Ulisema ya kwamba hujawahii tumia mipira kila wakati kwa miezi 12?*

**(Interviewer: If respondent says has used condoms all the time in last 12 months go to Guide B-29)**

28. Could you explain why this has been the case?

*Je, nieleze kwa nini hujatumia mipira wakati wowote*

29. What discussions have you had with your partner(s) about using condoms? (probe when last discussion occurred, who initiated it, key issues discussed, areas of disagreements, resolutions reached )

*Ni mazungumzo yapi mmekuwa nayo kati yako na mkeo/mumeo/mwenzio kuhusu kutumia mipira? (Uliza wakati mazungumzo hayo yalifanyika, nani*



*aliyeanzisha, mambo makuu yaliyozungumziwa, mambo ambayo mulikubaliana, na suluhu zilizofikiwa)*

30. Have you ever refused to use a condom when your partner has asked you to? If so why?

*Je, umewahi kukataa kutumia kondomu wakati mpenzi wako alikuuliza mtumie? kama ndio kwa nini?*

31. What do you think is the view of the community concerning PLWHA having sex?

*Maoni ya jamii yako kuhusu watu wanaoishi na virusi/ukimwi kushiriki ngono/kufanya mapenzi ni yapi?*

32. What kind of advice or counseling have you received about engaging in sex given your HIV positive status?. Did you get all the information that you needed? (*Probe from whom and when advice was received; was it sufficient*)

*Ni ushauri wa aina gani umepata kuhusu kufanya mapenzi/kushiriki ngono ukizingatia hali yako? Je ulipata maelezo yote ambayo ulihitaji (**Dadisi kutoka kwa nani na lini, ushauri ulikuwa wa kutosha**)*

***Interviewer:** Do you want to have a child/ more children in the future?*

***Interviewer:** **Je ungependa kupata mtoto/watoto wengine?***

*(Interviewer: If the respondent says that she/he does not want to have a child/ more children in the future, Go to 37)*

33. Why do you want to have a child/ more children?

*Mbona ungependa kupata mtoto/watoto?*

34. What importance is attached to having a child in your community?

*Kupata mtoto kuna umuhimi gani katika kabila lako?*

35. How are childless couples perceived in this community? How is childlessness perceived differently for men and women? (*Probe for local words used to describe people who do not have children*).

*Wanawake na wanaume waishio pamoja na hawana watoto wanachukuliwa aje kwa katika jamii? Kutokuwa na watoto kunachukuliwa aje kwa wanaume na wanawake (**Uliza majina yanayotumika kwenye jamii kuwaita wasio na watoto**)*

36. What kind of advice or counseling have you received about having a child/children given your HIV positive status? (*Probe from whom and when advice was received*)

*(Interviewer: skip to contraception section-43)*

37. Could you please explain why you don't want a child/more children?

*Tafadahli nielezee kwa nini hutaki mtoto ama watoto wengine*

38. Have you discussed this with anyone? If **YES** what was their reaction? If **No** why haven't you discussed it with anyone?

Je, ushawahii zungumza na mtu yeyote kuhusiana na kutotakazaa watoto?  
Kama ndio, mawazo yao yalikuwa vipi? Kama la kwa nini?

39. What importance is attached to having a child in your community?

Kuwa na mtoto kuna umhimu gani katika kwa kabila lako?

40. In your opinion why do you think some HIV positive people still want children?

Kwa maoni yako, mbona unafikiri mtu ambaye na Virusi bado angependa kupata watoto?

41. What is the view of the community concerning PLWHA having children?

Maoni ya jamii kwa ujumla kuhusu watu wanaoishi na virusi kupata watoto ni yapi?

42. What kind of advice or counseling have you received about further childbearing given your HIV positive status? (*Probe from whom and when advice was received*)

Ni ushauri wa aina gani umepata kuhusu kupata watoto ukizingatia hali yako?  
(*Uliza kutoka kwa nani na ushauri ulipatwa lini*)

*Interviewer: You said that you are not using contraception, right?*

*Interviewer: Ulisema ya kwamba hutumii mpango wa kupanga uzazi, ndivyo?*

*(Interviewer: If the respondent says that she/he is using contraception go to guide B-41)*

43. Could you explain why this is the case? Do you have concerns about using contraception. (*probe what are they*)

Nielezee kwa nini? Una swala lolote/hofu yoyote kuhusu matumizi ya njia za kupanga uzazi? (ni yapi)

44. Have you ever been counseled about FP since you found out your HIV status? When was the last counseling? What did they tell you?

Je, ushawahi pata ushauri kuhusu upangaji uzazi tangu ujue hali yako ya Virusi vya UKIMWI? Ushauri wa mwisho ulikuwa lini? Na uliambia nini, lini na nani?

45. What common complaints about available FP/RH services do you hear among HIV positive people?

Ni malalamiko yapi unayo yasikia kuhusu huduma za upangaji uzazi/afya ya uzazi kutoka kwa watu walio na virusi.

49. Given your own experiences, what would you like to add to our discussion about PLWHA?

Kulingana na matukio yako, ni nini ungependa kuongezea katika mjadala wetu kuhusu watu wanaoishi na Virusi.

*Thank you for sharing your thoughts and experiences with me. If you like to know to get more information on any of the topics we discussed today, contact our site office in this community. If we have anything we will keep in touch with you.*

*Asante sana kwa kunieleza mawazo na matukio/uzoefu yako nami. Kama ungependelea kupata maelezo zaidi kwa mambo ambayo tumekuwa tukiyazungumzia leo, tafadhaili tembelea afisi yetu iliyoko hapa mtaani. Kama hakuna chochote unacho weza sema sasa, unaweza wasiliana nami wakati mwingine.*

### Appendix 3: Key informant interview guide with health care workers.

#### IDENTIFICATION

Date of interview (DD/MM/YY): \_\_\_/\_\_\_/\_\_\_

Name of Interviewer: .....

Name of respondent: .....

Title of respondent (eg nurse, Doctor): .....

Role in HIV/ART programme.....

#### Introduction and consent

Thank you so much for meeting with me today. My name is [Name]. I am from the African Population and Health Research Center in Nairobi. We do research in the community to gain a better understanding of the problems PLWHA and their healthcare workers face and share with policy-makers and encourage them to make proper decisions that will assist PLWHA and their health care workers. We are conducting a study to learn more about, ART use, sexual and reproductive health needs of PLWHA. You were selected to participate in this interview because in your capacity as a [Job Title], you deal directly with PLWHA who may or may not be on ART treatment. We hope that you will participate in this study because your views are very important. The interview should take less than an hour. I will be taping the session because I don't want to miss any of your comments. All your responses will be kept confidential and will not be shared with anyone else outside our research team members. We will ensure that any information we include in our report does not identify you as a respondent. Remember you don't have to talk about anything you don't want to. If at any point you would like to stop, or if there are any questions you would rather not answer, just let me know.

#### Tasks, training and skills

*Interviewer: I would like to start by asking you about the work that you do.*

*Interviewer: Tukianza ningependa kukuuliza kuhusu kazi unayo fanya*

- 1 Briefly describe your role and responsibilities in the HIV/AIDS or ART Programme

*Kwanza kabisa, tafadhali nielezee dhima/kazi yako kwa huu mradi wa Virusi Vya Ukimwi au dawa ya ART*

- 2 What specific training have you received for this job in relation to HIV/ ART programme? Tell me about the training details

*Nieleze mafunzo yoyote yanayo husika na hii mradi/kazi ya HIV/ARV ambayo ushahudhuria/pata? Nieleze kwa kinaga ubaga kuhusu haya mafunzo.*

- 3 Do you think this training has been sufficient?

*Je, haya mafunzo yalikuwa yakutosha?*

- 4 Are there any other staff in your health facility that have been trained to deal with PLWHA? (*probe: how many and what kind of training they received*)

*Je, kuna wafanyikazi wengine katika kituo chako cha afya ambao washahudhuria mafunzo kuhusu kazi ya watu wanaoishi na virusi? (Dadisi: ni ngapi na zilikuwa na aina gani)*

### Treatment and adherence issues

Interviewer: Now I would like to ask you about ART use by PLWHA

Interviewer: *Sasa ningependa kukuuliza kuhusu utumizi wa madawa ya ART*

5. Which treatment guidelines for HIV/AIDS management do you use in this facility? (Give details if necessary, eg national guidelines)  
*Je, kuna maongozi/miongozo yoyote ambayo hutumiwa/hufwatwa katika hiki kituo cha afya kwa usimamizi/utendaji wa kazi ya wagonjwa wa ukimwi?Tafadhali fafanaa.*
6. What is your procedure when a patient is put on ART drugs for the first time?  
*Ni utaratibu upi ambao unafwata kwa kumueka mtu wavirusi kwa madawa kwa mara ya kwanza.*
7. In what ways do you inform and prepare your patients for ART treatment?(  
(*probe: what kind of information do they receive?* )  
*Nieleze jinsi mnavyo mshauri na kumuandaa/mtayarisha mgonjwa kwa matibabu ya ukimwi. (Dadisi: habari na mafunzo ambayo wanapewa)?*
8. Are the drugs you prescribe always available? Have you had periods where your patients have not been able to get their medications because they were out of stock? Please give details  
*Je, dawa ambazo munawaandikia wagonjwa wa ukimwi huwa zinapatikana kwa kituo hichi wakati wote? Kunao wakati ambapo wagonjwa wa ukimwi wamekosa madawa yao kwa sababu yameisha kwenye akiba? Tafadhali fafanaa?*
9. In your opinion, what sorts of people are good at adherence and what sorts of people are less good?(*Probe are there gender differences*)  
*Kwa maoni yako, ni aina ya watu ni wazuri/wema kwa kuzingatia/kushikamana na madawa ya ART na aina ya watu ambao si wema kwa kushikamana?(Dadisi: Kuna tofauti kwa jinsia)*
10. How do you determine adherence (*probe: appointments, refills?*)  
*Ni njia zipi ambazo mnatumia kupima au kutambua jinsi watu wa virusi wanashikamana/zingatia na maagizo ya matibabu ya ART? (Dadisi: Tarehe ya matibabu; kurudia madawa)*
11. What strategies do you employ to monitor and support adherence?  
*Ni njia zipi ambazo mnatumia kufuatilia na kusaidia wanaoishi na virusi kuzingatia/kuambatana na maagizo za ART?*
12. From your experience which factors affect adherence? (*Probe: barriers and facilitators*)  
*Kutokana na matukio yako ni sababu gani ambazo huathiri kuzingatia madawa ya ART (Dadisi: vizuizi na uwezesaji)*
13. What challenges do you face in terms of helping PLWHA to adhere?

Ni changamoto zipi ambazo unapata katika kusaidia wanaosohi na virusi kuzingatia/kushikama na matibabu ya ART?

### Sexuality and reproduction.

14. What issues are covered when counseling PLWHA? (*Probe: Does it involve sexual and reproduction matters?*)

Ni maswala gani ambayo yanaguziwa katika ushauri wenu na wanaoishi na virusi (probe: kuna mambo ya ngono na uzazi)

15. What do you advise PLWHA in as far sex and reproduction is concerned?

Huwa munawashauri watu wanaoshi na virusi nini kulingana na mambo ya kushiriki ngono ama uzazi?

16. What is your personal view concerning PLWHA engaging in sexual relations or having children? Please explain your answer

Maoni yako ni yapi kulingana na watu wanaoishi na Virusi kufanya mapenzi/shiriki ngono au kupata watoto? Tafadhali fafana

17. Does your health facility offer family planning services. If so what sort of family planning services do they offer?

- If yes does your facility integrate HIV/AIDS services with family planning or are these services offered in different clinics?

Je kituo chako cha afya hutoa huduma za mpango wa uzazi.

- Kama ndio , kituo hiki huunganisha huduma za Ukwimwi na za mpango ya uzazi ama huduma hizi ziko kwa vituo tofauti?

18. How do different programs here integrate family planning counseling and sexual and reproductive health related services, if at all? If not integrated why?

Ni kwa njia zipi mipango mbalimbali zinaunganisha huduma za ushauri wa upangaji wa uzazi na afya ya uzazi, iwapo zipo? Kama hakuna ni kwanini?

19. What are your thoughts about FP counseling and contraceptive use among PLWHA? What level of support/resistance is there for FP counseling and contraceptive use, in your experience?

Una maoni yapi kuhusu ushauri wa upangaji wa uzazi, Kutumia upangaji wa uzazi kwa watu wanaoshi na virusi? Ni kiwango kipi cha usaidizi/pingamizi kilichopo kwa ushauri wa upangaji wa uzazi na kinga kulingana na matukio/uzoefu yako?

20. From your experience what sorts of partners are more likely to come for FP? And what are their HIV statuses? (*Probe if they are HIV positive partners or negative*) What are your feelings on that?

Kutokana na matukio yako ni wapenzi wa ina gani wana uwezokano mkubwa wakuja kwa wingi kutafuta huduma za upangaji wa uzazi? Na hali yao ya virusi ipo vipi? (*Dadisi kama wote wana Virusi vya UKIMWI ama la*) hizia zako ni zipi kuhusu hayo?

21. How equipped do you feel you/your organization is to handle the family planning needs of PLWHA? (*Probe for skilled personnel composition and training of service providers, existence of necessary infrastructure, review of training needs and other resources?*)

Je unahizi wewe/shirika lako una/lina uwezo wa kuhudumia mahitaji ya upangaji wa uzazi kwa watu wanaoishi na virusi? (*Ulizia kuhusu wataalamu*)

*wanaopeana huduma(jinsi na mafunzo yao), kuwepo kwa muundo msingi,kuangalia mara kwa mara mahitaji ya mafunzo na mahitaji mengine).*

22. What do you see as the barriers to the effectiveness of family planning programs and contraceptive use when it comes to PLWHA?

*Kuna vikwazo vipi katika utoaji wa huduma za mpango wa uzazi na matumizi ya njia za upangaji uzazi kwa watu wanaoshi na Virusi vya UKIMWI?*

23. What have you/other staff found most challenging about working with PLWHA

*Ni changamoto zipi wewe/wenzako mnakumbana nazo mnapofanyakazi na watu wanaoshi na Virusi vya UKIMWI?*

24. Last question -- when it comes to family planning programs for PLWHA, what would you like to see happen, if you had all the decision-making power? *(Probes: What would you focus on first? How would you implement that?)*

*Swali la mwisho- Tunapoangazia kwa mipango ya upangaji uzazi kwa watu wanaoshi na Virusi vya UKIMWI, ungependa kuona nini kikifanyika, ungalikuwa na uwezo wa kutoa maamuzi? Ungelenga nini kwanza? Ungefanya nini kutekeleza hayo?*

**Interview Closing:**

*Thank you so much for your time. This has been very interesting and I've certainly learned a lot more about your experiences and sexual and reproductive health needs of PLWHA.*

*Asante sasa kwa wakati wako. Mazungumzo yetu yamekuwa ya manufaa sana na nimejifunza mengi kuhusu matukio yako na vile ambavyo mnahudumia watu wanaoishi na virusi.*

### Appendix 4: Project timeline

Activities	Time (Yearly)			
	2008	2009	2010	2011/2
<b>Phase One</b>				
Major review write up and submission				
Quantitative and qualitative modules				
Development of research instruments				
Ethics approval (LSE and Kenya)				
<b>Phase Two</b>				
Training of research assistants				
and pre-test of instruments				
Community mobilisation				
Quantitative interviews with PLWHA				
Quantitative data entry and cleaning				
Preliminary analysis of Quantitative data				
Sample selection of Qualitative interviewees				
Qualitative interviews with PLWHA, Key informants				
<b>Phase Three</b>				
Transcription of qual. Interviews				
Coding of Qualitative interviews				
Mixed methods Data analysis				
Thesis Write- up and submission				

### Appendix 5: Sources of questionnaire items

QUESTION NUMBERS	DESCRIPTION	SOURCE OF QUESTION
1.1 - 1.09; 1.12, 1.14	Background characteristics	APHRC (DSS)
1.10, 1.11 and 1.13	Background characteristics	Candidate
<i>Medical information and adherence:</i>		
2.01	Self-rated health status	Jylha 2009
2.02	Diagnosis date	Candidate
2.03	Whether on ART	Candidate
2.04	Whether on IOS	Candidate
2.05	ART enrolment date	Candidate
2.06	Self-rated health status after ART	Candidate
2.07	Name of drugs and prescriptions	Candidate
2.08	Measuring adherence(pill adherence)	PMAQs-patient medication adherence questionnaires (eg Chesney et al 2000; Remien et al 2007, Garcia et al 2006)
2.10	the last time the dose was missed if not in the last 4 days	Candidate
2.11	schedule adherence	Population council (Horizons)
2.12	dietary adherence	Population council (Horizons)
2.13	dietary adherence	Population council (Horizons)
2.15	self-reported reasons for non-adherence	patient medication adherence questionnaires (Chesney et al 2000; Remien et al 2007; Garcia et al 2006)
2.16 - 2.17	Source of medication	Candidate
2.18 - 2.21	Cost of treatment	Candidate
2.22	food insecurity	Candidate
2.23 - 2.24	selling/battering medicines	Candidate
2.25	Clinical education and counselling	Hardon et al 2007; Candidate
2.26	Doctor-patient relationship	Hardon et al 2007; Candidate
2.27- 2.28	Adherence follow up	Candidate
2.29 - 2.30	Use of alternative treatment	Candidate
2.31-2.32	Side effects	Candidate



<i>Sexual Behaviour</i>		
3.01	Current marital status	Candidate
3.02	Co-residence with spouse	Candidate
3.03	Duration of co-residence with spouse	Candidate
3.04	Date of marriage/cohabiting	Candidate
3.05	HIV status of partner	Candidate
3.06	Number of wives/spouse	FHI- BSS
3.08	Date of end of marriage dissolution	Candidate
3.09	Regular sexual partner(not married)	Candidate
3.10	HIV status of regular partner	Candidate
3.11	last term had sex with regular partner	Candidate
3.12	Whether condom was used last time	FHI- BSS
3.13	Condom use suggestion	FHI- BSS
3.14	Reason for condom use	FHI- BSS
3.15	why Condom was not used	FHI- BSS
3.16	Frequency of condom use with regular	FHI- BSS
3.16	sex with a different partner	Candidate
<b>Question Numbers</b>	<b>Description</b>	<b>Source of question</b>
3.17	Source of condom use	FHI- BSS
3.13 - 3.14	Number of sexual partners in 12 months	FHI- BSS
3.15 - 3.17	condom use and source	FHI- BSS
3.18	Frequency of condom use	FHI- BSS
3.19	Frequency of disclosure of status	Candidate
3.20	Forced to have sex	FHI- BSS
3.21 - 3.22	other STI infection	FHI- BSS
<i>Reproduction/fertility behaviour</i>		
4.01 - 4.02	Number of living children	DHS
4.04	Whether wants a/ another child	DHS
4.05 - 4.06	Number and sex composition of wanted children	DHS
4.07	When is child wanted	DHS
4.08	whether pregnant (for skip)	DHS
4.09 - 4.12	Current use and source of contraception	DHS
4.13 - 4.16	Ever use and source of contraception	DHS

4.17 - 4.20	Discussion of FP with care provider	DHS
4.21 - 4.22	Perception/Explanation of unmet need	Candidate
4.23 - 4.24	contraceptive use intentions	DHS
<b><i>Other social factors</i></b>		
5.01	HIV/ART knowledge	Candidate; FHI-BSS
5.02	Treatment optimism	Van De Ven 2000 ; International Collaboration of HIV Optimism 2003
5.03 - 5.06	Alcohol and drug use	Candidate
5.07 - 5.11	Sources of social support from extended family	Candidate
5.12	Brief scale for measuring social support(tangible, emotional and informational)	Sherbourne and steward, (1991)
5.13	Membership to social support groups	Candidate
5.18	Forms of social support	Candidate
5.14	Appraisal of social support	Population council (Horizons)
5.15	Scale for measuring stigma(internalised/enacted)	Visser et al 2008; Bunn et al 2007; Kalichman 2005
5.16 - 5.17	Disclosure of HIV status	Candidate
5.18	Scale for measuring stigma depression and psychological distress	Africa Mental Health Foundation (Penny Holding)

### Appendix 6: List of variables

#### Independent variables

VARIABLE	CODING	LEVEL/ TYPE
Sex	1=Male; 2= Female	Categorical
Age	Count	Continuous
Ethnicity	1=Kikuyu; 2=Luo; 3=Luhya; 4=Kamba; 5=Other	Categorical
Education	1=None; 2= Primary; 3=Secondary+	Categorical
Marital status	1= Married/cohabiting; 2=Divorced/Separated; 3=widowed and 4=Never Married	Categorical
Slum of residence	1=Korogocho; 2= Viwandani	Categorical
Monthly income	Count	Continuous
Perceived health status	1=Poor, 2=Fair, 3= Good, 4= Excellent	Categorical
Treatment status	1= On ART; 2= Not ART	Dichotomous
Duration of being HIV	Count	Continuous
Duration of being on ART	1=less than 1yr 2= 1 and 2 yrs 3= 3 and 4 yrs; 4= 5+ yrs	Dummies
Adherence	1= Yes; 2=No	Dichotomous
Disclosure of status others	1= Yes; 2=No	Dichotomous
Sero-discordance	1= Yes; 2=No; 3=Unknown	Categorical
Frequency of Disclosure of status sexual partners	1= Never; 2=Sometimes; 3=All the time	Categorical
Alcohol use	1= Yes; 2= No	Categorical
Drug use	1= Yes; 2= No	Categorical
Knowledge on HIV/ART (10 items)	1= Agree; 2= Don't know; 3=Disagree	Index (continuous)
Treatment Optimism	1=Strongly disagree;	

(6 items)	2=disagree; 3=Agree; 4=Strongly agree; 5= don't know	Index (continuous)
Social Support (6 items)	1= None of time; 2=A little; 3=Sometimes; 4= most times; 5= All the time	Index (continuous)
Stigma (15 items)	1= Agree; 2 Disagree	Index (continuous)
Depressive symptoms (10 items)	1=None; 2= less severe 3= severe 4= very severe	Index (Continuous)
Counselling during ART initiation (11 items)	1= Yes; 2= No; 3= Don't know	Index (Continuous)
Doctor patient relationship (8 items)	1= Yes; 2=No; 3= Not sure	Index (continuous)
Adherence follow up	1= Yes; 2= No	Categorical
ART side effects	1= Yes; 2=No	Categorical
Use of alternative therapy	1= Yes; 2= NO	Categorical
Number of living children	Count	Categorical

#### Dependent (outcome) variables

VARIABLE	CODING	LEVEL/ TYPE
Sexually active in last 12 months	1=Yes; 2= No	Dichotomous
Use of condom during last intercourse	1= Yes; 2=No	Dichotomous
Frequency of condom use	1= Never; 2= Sometimes; 3=All the time	Categorical
Had sex with regular partner	1= Yes; 2= No	Dichotomous
Had sex with non-regular or casual partner	1= Yes; 2=No	Dichotomous

Number of sexual partners in last 12 months	Number/count	Continuous
Multiple sexual partners	1=Yes; 2= NO	Categorical
Desiring fertility	1=Yes; 2= NO	Categorical
Number of desired children	Count	Continuous
When next child is wanted	Count	Continuous
Currently using Family Planning (FP)	1=Yes; 2= NO	Categorical
Method: IUD, injectibles, implants, pill, Condom, Diaphragm, Foam, lactational, calendar, withdraw	1=Yes; 2= NO	Categorical
Ever use of FP	1=Yes; 2= NO	Categorical
Intended future use of family planning	1=Yes; 2= NO	Categorical
Intended method: IUD, injectibles, implants, pill, Condom, Diaphragm, Foam, lactational, calendar, withdraw	1=Yes; 2= NO	Categorical
Ever use method: IUD, injectibles, implants, pill, Condom, Diaphragm, Foam, lactational, calendar, withdraw	1=Yes; 2= NO	Categorical
Unmet need for Family Planning	1=Yes; 2= NO	Categorical

## Appendix 7: Alpha scores

### Cronbach's Alpha for 5 measurement scales

VARIABLE	NO.OF ITEMS	NO.OF ITEMS DELETED	OVERALL ALPHA	ALPHA AFTER ITEM DELETION
HIV Knowledge	10	0	0.7382	0.7382
Treatment optimism	6	1	0.5244	0.6008
Social support	6	1	0.6308	0.6728
Internalised stigma	15	0	0.8267	0.8267
Depressive or psychological distress	10	0	0.7956	0.7956

## Appendix 8: Sero-prevalence study sample

Socio-demographics of sero-prevalence study respondents

CHARACTERISTIC	SAMPLE SIZE	HIV PREVALENCE	PROPORTION INFECTED
	%	%	%
<b>Slum of residence</b>			
Korogocho	58	13.9	71
Viwandani	42	8.1	29
<b>Sex</b>			
Female	68	13.2	63
Male	32	9.5	37
<b>Ethnicity</b>			
Kikuyu	30	8.3	20
Luo	19	22.4	35
Luyia	17	13.7	20
Kamba	19	8.8	13
Other	15	7.5	11
<b>Education</b>			
No Schooling	4	20.5	08
Primary	65	12.7	69
Secondary+	31	8.9	23
<b>Marital Status</b>			
Married/Cohabiting	62	11.5	60
Formerly married	11	29.8	29
Never Married	27	5	11
<b>Age</b>			
15-19	15	5	06
20-24	23	7.2	14
25-29	21	12	21
30-34	15	14.2	18
35-39	11	17.8	17
40-44	8	18.1	12
45+	7	20.2	11

