

Childbearing in a Time of ART:

Birth Rates, Childbearing Desires and Family Planning in
a Rural HIV Treatment and Care Programme in South
Africa

This thesis is submitted for the degree of

Doctor of Philosophy

By

Lorna Benton

Institute of Global Health, UCL

Declaration of own work

I, Lorna Benton, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis

Abstract

Mixed methods investigate the association between HIV, ART and fertility following scale-up of HIV treatment and care in South Africa. Two longitudinal analyses of surveillance data from the Africa Centre for Health and Population Studies compare factors associated with live birth by HIV and ART exposure. Semi-structured interviews with women enrolled on ART and healthcare providers explore perceptions of childbearing and contraceptive use.

A quantitative study reports on one open cohort analysis and a subsequent closed cohort. Crude Birth Rates declined since 2005 and an open cohort analysis (2007-2013) found consistently lower birth-rates amongst women on-ART, compared to HIV-positive ART-naïve women and HIV negative women. One exception was found in the 25-29year age group: incidence was 38% higher to women on ART than ART-naïve women. Crude incidence of live birth was 6.6 births/100 women-years and decreased with increasing age, higher parity, poorer self-reported health, urban area of residency, knowledge of own HIV status, being single or engaged/married, not living with a partner, awareness of the benefits of ART, use of contraception and use of injectable methods. Annual likelihood (aHR, 0.39; 95% 0.347 – 0.441) was 61% lower to HIV positive versus negative women in multivariable Poisson analysis and exposure to ART was associated with 38% reduced likelihood (aHR, 0.62; 95% 0.487 – 0.799). In a subsequent closed cohort, HIV 'unknown' women demonstrated similar incidence and associated factors of live birth compared to HIV negative women. HIV positive women were less likely than HIV negative and HIV 'unknown' women to use contraception.

Women described inconsistent injectable use in semi-structured interviews due to side effects and perceptions that injectables make women 'watery' or are unnecessary on ART. Family planning counselling was under-prioritised within the health care service and women were unaware of safer conception topics. Recent pregnancies were considered unintended and most women desired to avoid childbearing considering current family size, economic and health risks. Partner expectations could override strong concerns for health, however, and HIV positive women were at similar risk of live birth to HIV negative women when in a regular relationship or living with a partner.

Acknowledgments

I owe a special thanks to the women and health care workers interviewed for this thesis, who shared their stories. Ngiyabonga to the fieldworkers of Africa Centre, without whom this data would not exist. I would like to thank staff at the Africa Centre that supported my professional and personal development while I called Mtubatuba home. To James, Portia, Doreen, Nora, Andrea, Kobus, and Till for their STATA expertise and unending patience. To Colin for his infinite data knowledge and Scottish humour. To Vicky and Nuala, for pushing me forward with the right questions and Richard and Tamsin, for their well-timed words. The ladies of the Africa Centre, Sonia, Rhana and Suzette for always making a plan, U'bab Nkosi and Deli for resolving any transport issue I could muster, and the Funbus: I am sorry I scratched you. Dumo, for first introducing me to the strength and friendship of a Zulu woman. Nokuthula, your humour, hard work and dedication as research assistant brought joy to this study. Kevi, your programmatic knowledge was equalled only by your enthusiasm for life and the lives of others. My Ilala family: Terusha, Jaffer, Gavin, Andy, Jan, Kyle, Stephen, Melanie, Kat, Bronwyne and Mauz. 'You guys!' You have a special place in my heart. Eri, my sis, your courage and values inspire me every day. Janet for her insatiable addiction to cake.

I owe a huge thank you to colleagues at the Institute of Global Health, UCL, particularly Anthony for the opportunity to learn from the work of IGH, Audrey for her qualitative advice and wisdom, Shivani and Jenny for the supportive coffee breaks and Faye for countless admin support. Also to MRC for funding my research.

Marie-Louise, it has been inspiring to learn from your insurmountable knowledge and eye for detail and I will be endlessly grateful for the many ways you have looked after me. Zelee, I have been humbled by your ability to make the complex sound simple. Thank you for your unquestionable support which continued to keep me on this journey at all times.

Finally, Mum, Dad and Jack B, this would be simply unimaginable without your love and humour. Mum, you have been a formidable force of positivism, strength and support. I dedicate this to you.

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Glossary

3TC <i>Lamivudine</i>	An anti-retroviral therapy drug
ACDIS <i>Africa Centre Demographic Information System</i>	A collection of multiple datasets housed by the Africa Centre, each corresponding to a different household surveillance questionnaire and year
ANC <i>Antenatal Care</i>	Healthcare delivered during a pregnancy
Anderson-Gill	Statistical model to handle recurrent event data, used to structure a bespoke dataset in this study
ART <i>Anti-retroviral therapy</i>	Drugs administered for the treatment of HIV, according to national eligibility criteria
<i>ARTemis</i>	Clinical database used in this study, containing information about HIV treatment and care
ASFR <i>Age specific fertility rates</i>	The number of births occurring during a given year or reference period per 1,000 women of reproductive age classified in five-year age groups.
AZT <i>Zidovudine</i>	An anti-retroviral therapy drug
CBR <i>Crude Birth Rates</i>	The number of live births per 1,000 people per year
CD4 <i>Cluster of differentiation 4</i>	White blood cell count, measured at clinics to determine immunological control of HIV virus
CDC <i>Centers for Disease Control and Prevention</i>	National Public Health Institute in the United States of America
COC <i>Combined Oral Contraception</i>	Form of hormonal contraception
<i>Cox Proportional Hazards</i>	Survival model for time to event analysis, used in a cohort analysis reported in section 4.3
DHS <i>Demographic Health and Survey</i>	Programme collecting national data on health and population in South Africa
DMPA <i>Depot medroxyprogesterone acetate</i>	Hormonal injectable form of contraception
EC <i>Emergency Contraception</i>	Methods used after unprotected sex to prevent a pregnancy. Usually refers to a progesterone pill taken up to 72 hours after sex
EFV	A type of anti-retroviral therapy drug

<i>Efavirenz</i>	
ELISA <i>Enzyme-Linked Immunosorbent Assay</i>	Technique to measure the concentration antibodies or antigens in a blood sample
<i>Fertility 'desire'</i>	Measure of pregnancy planning that precedes 'intention' and 'behaviour' along the Theory of planned behaviour. Often interchanged with 'intention', 'desire' reflects respondent's feelings according to Miller (1994).
<i>Fertility 'intention'</i>	Measure of pregnancy planning that follows 'desire' and precedes 'behaviour' along the Theory of planned behaviour. Often interchanged with desire, 'intention' describes a commitment to act that incorporates external factors according to Miller (1994).
FTC <i>Emtricitabine</i>	An anti-retroviral therapy drug
HC <i>Hormonal Contraception</i>	Birth control methods that act on the endocrine system and include the combined oral pill, DMPA and Nur-Isterate
HCT <i>HIV Counselling and Testing</i>	One of the primary entry points in to the HIV continuum of care, in which an individual receives counselling prior to being tested for HIV
HIV <i>Human Immunodeficiency Virus</i>	Pathogen that affects the immune system and develops in to Acquired Immunodeficiency Syndrome
<i>Hlabisa</i>	A municipality situated in the Umkhanyakude District of KwaZulu-Natal in South Africa, where this study took place
ICPD POA <i>International Conference on Population and Development Programme of Action</i>	The steering document for the United Nations Population Fund (UNFPA) to guide action on a range of population issues, including reproductive rights
IEC <i>Information Education and Communication</i>	Programme strategy to improve knowledge on family planning issues
<i>Inhlawulo</i>	Damages paid to the family of a woman who became pregnant out of wedlock by the father of the future child
<i>Injectable</i>	Hormonal form of contraception, usually referring to DMPA and occasionally Nur-Isterate in this setting
IPPF <i>International Planned Parenthood Federation</i>	A global non-governmental organisation promoting sexual and reproductive health

<i>Isilobola</i>	Bride price' paid in cash or cattle by a prospective husband or head of his family to the head of a prospective wife's family before marriage
IUCD <i>Intrauterine contraceptive Device</i>	A method of birth control that is inserted into the uterus. It is often a small 'T'-shaped device containing either copper or levonorgestrel.
ND <i>Neonatal Death</i>	The death of a baby within the first 28 days of life
NSFG <i>National Survey of Family Growth</i>	A survey conducted by the Centres for Disease Control and Prevention to understand trends related to fertility, family structure, and demographics in the United States
NVP <i>Nevirapine</i>	An anti-retroviral therapy drug
PEPFAR <i>President's Emergency Plan for AIDS Relief</i>	An initiative launched by the US government to provide HIV treatment and care to resource limited settings
PHC <i>Primary Health Care</i>	The first point of contact in the South African healthcare system, providing 'essential healthcare' services such as HCT and family planning
PLHIV <i>People Living with HIV</i>	Individuals that have received a positive HIV diagnosis
PMTCT <i>Prevention of Mother to Child Transmission</i>	A cascade of interventions to prevent transmission of HIV from an infected woman to her child during pregnancy, labour, delivery or breastfeeding
<i>Poisson</i>	Model used for count analysis reported in section 4.2
SADoH <i>South African Department of Health</i>	Governmental department responsible for health policy development
<i>Safe conception</i>	Approaches to minimize transmission in HIV-affected couples planning to have children
SB <i>Stillbirth</i>	Foetal death after 20 weeks of gestation
SGA <i>Small-for-gestational-age</i>	Babies that weigh below the 10th percentile for the gestational age
STI <i>Sexually Transmitted Disease</i>	Infections that are commonly spread by vaginal intercourse, anal sex and oral sex
TB <i>Tuberculosis</i>	A bacterial infection spread through inhaling tiny droplets from the coughs or sneezes of an infected person. It usually infects the lungs and is particularly prevalent amongst HIV-infected persons
TDF	An anti-retroviral therapy drug

<i>Tenofovir</i>	
TFR <i>Total Fertility Rate</i>	The average number of children born to a woman over her lifetime if she were to experience the exact current age-specific fertility rates (ASFRs) through her lifetime and she survived to the end of her reproductive life
TOP <i>Termination of Pregnancy</i>	The medical process of ending a pregnancy so it does not result in the birth of a baby
<i>Umkhanyakude</i>	A district of KwaZulu-Natal that includes the Hlabisa administrative municipality
UNAIDS <i>Joint United Nations Programme on HIV and AIDS</i>	A member of the United Nations Development Group, with a mission to lead, strengthen and support an expanded response to HIV and AIDS
WHO <i>World Health Organisation</i>	A specialized agency of the United Nations Development group concerned with international public health

Conceptualisation of thesis

The concept of this thesis arose from a personal interest in the social impact of HIV on life-course activities, a gap in the HIV and fertility literature in an era of ART, and a reported need for improved integration of family planning and HIV services in South Africa. A preliminary review of the literature of HIV on childbearing and fertility was conducted in 2011 and published as a chapter in the book 'No time for children' (Buchanan and Rotkirch, 2013). The review identified gaps in:

1. Studies investigating a possible increase in fertility rates amongst women living with HIV after initiation of treatment
2. Implementation of family planning services for women living with HIV that caters for those who do and do not desire a child.

A systematic review of the literature identified that studies had found different effects of ART on fertility and fertility desires in various settings in sub-Saharan Africa. Studies had different comparison groups, with some comparing the fertility of ART-naïve women living with HIV to those initiating HIV treatment, but none included HIV negative women. Furthermore, none addressed the issue in KwaZulu-Natal. These findings highlighted the importance of exploring the impact of ART on fertility in KwaZulu-Natal, and of including HIV negative women as the comparison group.

National policy documents and publications from the South African clinician's society identified family planning on ART as an important issue. They described a progressive policy for integrated family planning and HIV services and successive gaps in implementation. The South African clinician's society published recommendations for operational guidelines to reduce this gap but did not report on the use of these recommendations in HIV services in South Africa. Formative discussions with clinicians in the Hlabisa sub-district and health managers for KwaZulu-Natal emphasised that family planning had been historically neglected and its importance was being increasingly recognized. Particularly, safer conception of wanted pregnancies were not viewed as well supported or implemented. This confirmed the importance of the topic.

The Africa Centre for Health and Population Studies (hereafter the Africa Centre) was well placed to address the topic of HIV and fertility in a rural setting. Demographic surveillance data allowed a unique comparison of fertility rates between HIV positive women on ART, HIV positive ART-naïve, and HIV negative women living in the Hlabisa sub-district of KwaZulu-Natal. The setting and the novel comparison to HIV negative women in this study are unique contributions to the current literature investigating ART and fertility. To gain a richer understanding of the topic a qualitative study was conducted. The study aimed to achieve a deeper understanding of the contribution of HIV treatment and care towards childbearing decisions, and perceptions and experiences of family planning for those on ART in this setting. The Africa Centre has a well-established relationship with the local Department of Health, and this collaboration facilitated the qualitative data collection.

Rationale to investigate childbearing within South African HIV treatment and care

Use of combination ART has led to reduced mortality (Ndirangu et al., 2010, Herbst et al., 2009), improved physiological capabilities of women to carry a pregnancy to term (Newell and Bunders, 2013, Turner et al., 2013, Kaida et al., 2013) and changes in reproductive behaviours across sub-Saharan Africa (Smith and Mbakwem, 2007, Ndlovu, 2009, McClellan et al., 2010, Kaida et al., 2011, Ezeanochie et al., 2009, Kaida et al., 2010, Kaida et al., 2008). The impact of ART use on fertility in this setting, and the implications for family planning to women on ART in this area, are unknown. Male partners can provide an important perspective to the family planning literature, and use of ART is also likely to affect male physiological capacity to father a child. This study on the complex topic of childbearing does not address male perspectives to childbearing, following an early decision to prioritise interaction with health workers and clinic observations for the qualitative work.

Widespread access to contraception was a key driver of the slow and consistent transition to low fertility in South Africa since the 1960s (Moultrie et al., 2012, Lopez et al., 2013, Swartz, 2009). Contraception is the dominant proximate determinant of aggregate fertility patterns (Bongaarts et al., 1984, Stover, 1998), can be a behaviour modified by a change in childbearing desires and associated factors or HIV-related health (Kaida et al., 2008), and is commonly used for monitoring

and evaluation of unintended pregnancies (Trussell et al., 1999, Stanford et al., 2000, Sedgh et al., 2014).

Family planning is now an important component of HIV prevention strategies. Antiretroviral therapy and prevention of mother to child transmission (PMTCT) programme have made huge gains in reducing the burden of high HIV prevalence in South Africa since 2004 (Goga et al., 2012, Shisana et al., 2013). Efforts to integrate are recommended by the Department of Health but no universal consensus exists for the operationalization of such services (Schwartz et al., 2014, SAdoH, 2012). 'One-stop shop' services aim to deliver integrated FP at the HIV point of care (SAdoH, 2012). However, services often neglect the concept of an 'intended pregnancy' and create missed opportunities for comprehensive care for women of reproductive age (Smit et al., 2012). Progress is further restricted by the absence of appropriate measures for pregnancy planning, as western concepts of intention often fail to address the underlying structural and cultural mechanisms driving changes in HIV and fertility in sub-Saharan Africa (Johnson-Hanks, 2007).

Structure of thesis

Aim and objectives

This study aims to determine how national scale up of anti-retroviral therapy has influenced rates of live birth and attitudes to childbearing amongst women living with HIV in a rural setting of South Africa. Three objectives were outlined to address the research question, as follows.

- I. Investigate whether use of ART is associated with an individual woman's likelihood of experiencing a live birth in the Hlabisa sub-district of KwaZulu-Natal.
- II. Explore how use of ART influences fertility and family planning desires amongst women on ART.
- III. Determine the role that HIV treatment and care programs play in the provision of family planning services, including client's expectations of family planning and whether they feel their expectations are being addressed.

Chapter One: This chapter introduces the drivers of transitioning fertility in South Africa. Cultural norms are important to childbearing in Hlabisa, shaped by; a historical context of population control, work based migration, disruption of marriage and the role of children to ideologies of masculinity. Widespread use of injectable contraception has asserted female autonomy over fertility, resulting in wide birth intervals and long-term fertility decline. An effect of ART influencing fertility in this context may, therefore, differ to settings where fertility is high, or contraceptive use is rare.

Chapter Two: A literature review details demographic theory of proximate determinants of fertility and cognitive models of pregnancy decision-making (Kaida et al., 2006, Hall, 2012) and describes literature on the 'postponement' of childbearing in South Africa as an established reproductive strategy. Studies present evidence of reduced fertility amongst HIV positive women in sub-Saharan Africa and a possible reversal of this effect associated with use of ART. The review identifies the absence of HIV negative comparisons and limitations in current measures of pregnancy planning.

Chapter Three: Chapter three outlines quantitative methodology used to a) create a bespoke longitudinal dataset of women of reproductive age, using surveillance datasets from the Africa Centre for Health and Population Studies b) link information about HIV treatment from the clinical database, ARTemis and c) construct two cohorts for survival analysis. Chapter three then describes qualitative methodology used to conduct observations of five clinics and semi-structured interviews with 23 clients and 12 health workers from the local HIV treatment and care programme.

Chapter Four: Quantitative results first present descriptive crude birth rates to show declining fertility since 2005. Two longitudinal (one open and one closed) analyses then compare likelihood of live birth to women living with HIV on ART, HIV positive naïve women and HIV negative women. Multivariable analyses assess associated proximate and distal determinants of fertility between 2007 and 2012. A final analysis compares factors associated with contraceptive use in the closed cohort.

Chapter Five: The first of two qualitative results chapters, chapter five presents results from semi-structured interviews with 23 clients. It describes key themes that influence attitudes to childbearing on ART and previous experiences of reproductive management in an environment where planning for a child is considered rare.

Chapter six: This chapter reports on attitudes to contraception and safe conception strategies in HIV treatment and care. Results from semi-structured interviews and clinic observations inform this discussion on the barriers and facilitators to use of contraception, and structural factors that influence women's ability to implement their childbearing intentions once they have entered the 'one-stop-shop' continuum of care.

Chapter seven: Findings from this thesis are discussed in relation to current literature on this topic and moves on to draw implications of this research and consequent recommendations for operationalization of family planning services for women on ART and future research.

Chapter One

Transition to low fertility and rapid onset of the HIV epidemic in South Africa

1.1 Introduction to history of fertility and HIV in South Africa

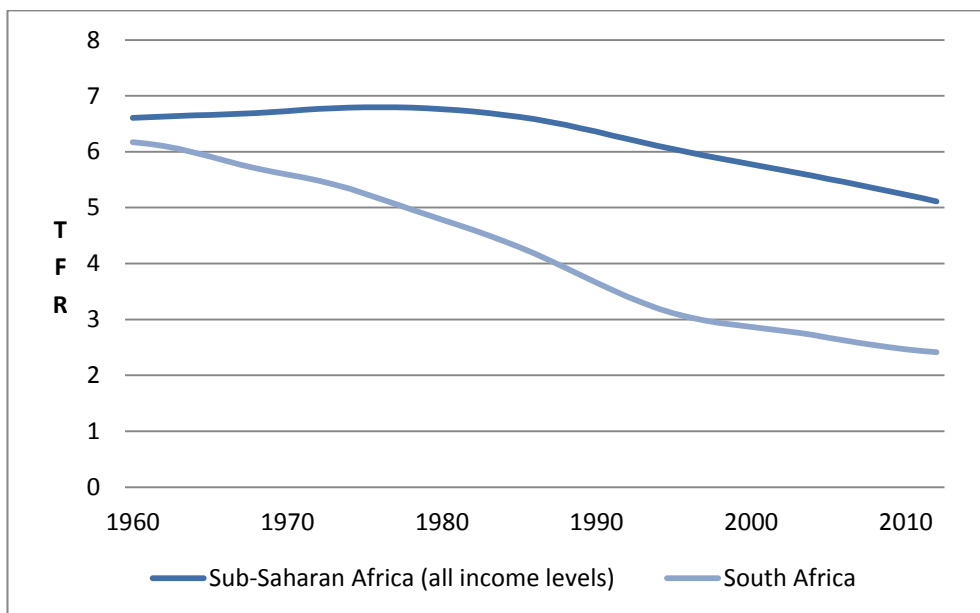
Childbearing is rarely considered in isolation to family ties, relationships and sex (Preston-Whyte, 1993). In the context of HIV and treatment, the decision to have another child can be even more nuanced (Awiti Ujiji et al., 2010, Berhan, 2008). South Africa has experienced political, economic and geographical transformations of low fertility in an extreme HIV epidemic (Swartz, 2009). Vast inequities persist and experiences of these trends vary by geography and gender. State-mediated changes have shifted cultural perspectives to pre-marital childbearing and contraceptive use in the context of poverty, migration and often loving, concurrent partnerships in KwaZulu-Natal (Hosegood et al., 2009, Lurie et al., 1997). In an ethnographic study of Mandeni, a town about 150km from Hlabisa, the study area of this thesis, Hunter describes ‘the changing political economy and geography of intimacy’ and how expansive changes in ‘intimate relations’ including concepts of gender, fertility, pleasure and love have altogether contributed to the rapid onset of the HIV epidemic (Hunter, 2010).

In an era where antiretroviral therapy has become widely accessible, the effects of the virus upon mortality and health are potentially lessened. Yet women have asserted control of their own fertility, primarily using injectable contraception, for decades (Swartz, 2009, Moultrie and Timaeus, 2002). Chapter One compares the structural drivers of a slow transition to low fertility and rapid onset of the HIV epidemic, resulting in inequitably high HIV prevalence against a backdrop of low fertility in KwaZulu-Natal. Chapter Two then examines the potential consequences that HIV may have on fertility in this area.

In South Africa birth rates have fallen steadily to less than half the rates in 1980 and are the lowest in sub-Saharan Africa (The World Bank 2008). The 2013 Total Fertility Rate (TFR) was 2.34 births per

women in South Africa and it has been predicted that by 2035 the TFR could reach below replacement level, both nationally and amongst the black African population (WorldBank, 2013, Kane-Berman and Holborn, 2012). TFRs are frequently used measures of fertility and defined by the World Bank as the number of children that would be born to a woman if she were to live to the end of her childbearing years and bear children in accordance with current age-specific fertility rates (WorldBank, 2013).

Figure 1.1. Total Fertility Rates in South Africa compared to sub-Saharan Africa (including all countries of all income levels (1960 – 2012) *World Development Indicators, (WorldBank, 2013)*



The causes of a sub-Saharan transition compared to the earlier European transition have been explored (Moultrie and Timæus, 2013). Lower mortality followed by reduced fertility instigated the start of a demographic transition that has since spread globally and at a diversity of pace (Espenshade et al., 2003). TFRs have accelerated below 2.0 children per woman in the ‘global north’: in Europe the TFR has remained at 1.4 for some time and in Asia and North America, the TFR is 1.8. Yet in sub-Saharan Africa as a whole the TFR remains higher at 5.1 in 2012 (WorldBank, 2013). In 1989, Caldwell speculated that HIV would be the catalyst for the onset of the sub-Saharan fertility

transition (Caldwell et al., 1989). He and others speculated that HIV-related mortality rates are highest in men and women of reproductive age and would remove the most fertile cohort of individuals. They predicted a population fertility effect through a) increased mortality amongst reproductive age groups b) reduced fecundity of HIV infected women and men and c) changes in reproductive behaviour to avoid pregnancy and prevent spread of the disease.

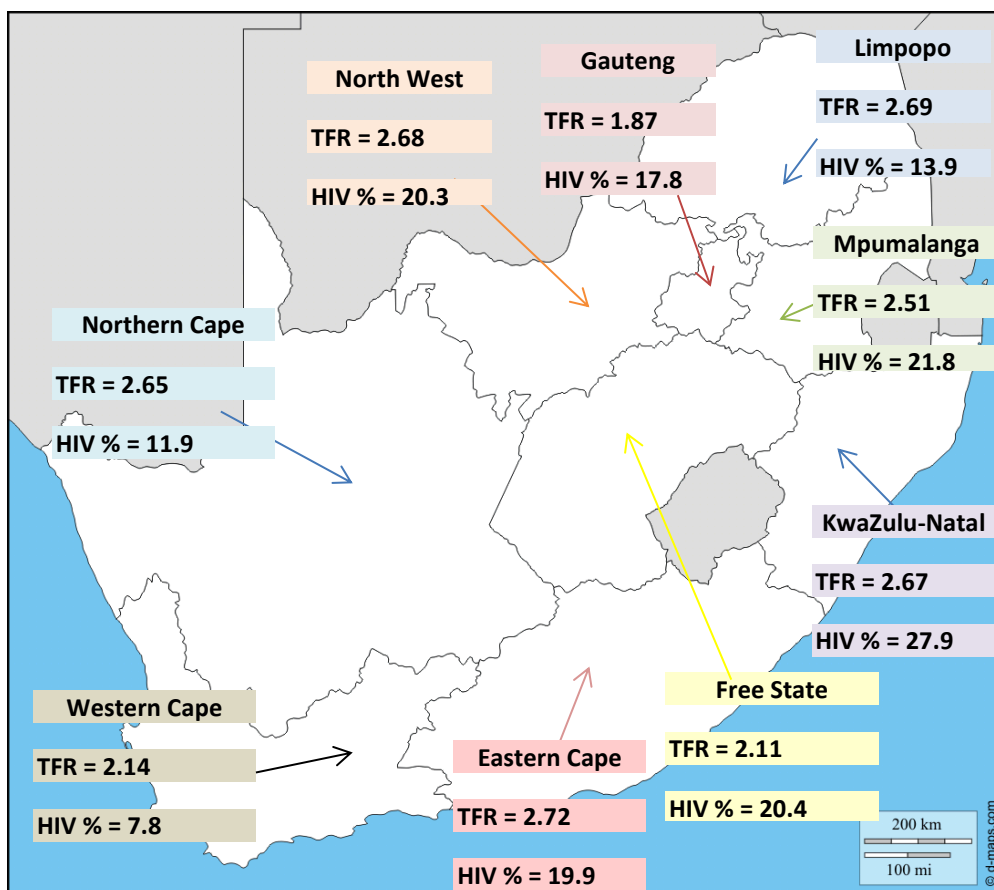
Sub-Saharan countries represent distinct historical, political and cultural contexts and have disparate experiences of the demographic transition decline in the context of HIV [Galloway 1986]. South Africa faces one of the fastest growing and heaviest burdens of HIV in the world with 6,300,000 people living with HIV at an adult prevalence of 19.1% in 2013 (UNAIDS, 2013). The arrival of a major HIV pandemic coincided with a long-established and steady decline in fertility within South Africa (Terceira et al., 2003). HIV is not considered a driver of the fertility transition, but an understanding of the mechanisms through which HIV may have accelerated or stalled this transition must include the impact of the inequities in fertility, and effects of HIV, resulting from decades of social unrest. South Africa has one of the largest economies in Africa but shows characteristics of both a developed and developing country, with the greatest inequalities across both racial and geographical divisions (Swartz, 2009).

1.2 Shared structural drivers of high HIV prevalence and low fertility in South Africa

HIV is primarily transmitted through heterosexual sexual intercourse in South Africa and the risk of HIV acquisition or transmission and pregnancy stems from the same coital act. Yet the South African HIV epidemic is disproportionately distributed by age, sex, race, locality type and province (Shisana et al., 2013). South Africa is composed of nine provinces, each with their own legislature and premier. The current nine provinces were established under the Constitution of the Republic of South Africa, 1996, and shortly after the first non-racial democratic elections in South Africa. Prior to this constitution, South Africa was divided in to four provinces and twelve homelands under a discriminative apartheid system of rule. The 1996 Constitution served to restructure existing

provinces, incorporate prior homelands and to equalise the provision of state services such as health and education. Inequitable HIV prevalence and, to a lesser extent, fertility rates, illustrates a lasting legacy of geographical discrimination. KwaZulu-Natal, a prior homeland region, bears the highest burden of HIV prevalence and one of the highest total fertility rates in the country. In 2012, HIV prevalence was 27.9% in KwaZulu-Natal, compared to 7.8% in the Western Cape. Using the same comparison, the total fertility rate recorded in KZN was 2.67 compared to 2.14 in the WC. Figure 1.2 serves to show that neither trends in HIV or fertility are homogenous by province.

Figure 1.2 HIV prevalence (2012, %) and Total Fertility Rate (2013 mid-year, *TFR*) by province (*Shisana et al., 2013*)



Deep inequities in areas of education, health care, employment, and resettlement along racial and geographical lines were inherited from an era of apartheid policies, and are pervasive still (Shisana et al., 2013, Burgard, 2004). The Population Registration Act of 1950 divided South Africa into four major ethnic groups: African, Asian, White and Coloureds, and the Group Areas Act allocated 'nation states' or 'homelands' by racial grouping (SADoH, 2003). Discriminative welfare, education and job reservation policies forced many men in KwaZulu-Natal to relocate to urbanised areas for long periods in search of employment (Newitt, 1973). A rise in migration for industrial employment and growth of an informal work sector further opened the corridors for increased female mobility in to employment (Muthwa, 1995), but also transmission of HIV to rural women when migrant men returned to their homestead (Pison et al., 1993, Decosas, 1996). However a study in the Hlabisa sub-district of KwaZulu-Natal found that reverse direction of infection from rural women to returning migrant partners was often likely before ART was made available (Lurie et al., 2003).

Marriage is still highly regarded but expensive and rates have almost halved since the 1960s as a consequence of repressive apartheid policies of labour migration, tribal homelands and living restrictions placed on most African couples (Harwood-Lejeune, 2001, Hosegood et al., 2009). Ambiguity in the definition and changes in the legal recognition of customary marriages make exact estimates difficult to compare over time (Budlender, Chobokoane et al. 2004), but census data from 1996 and 2001 reported lower rates of marriage amongst Africans and Coloured compared to Whites and Asians. Black Africans were more likely to live with a partner or avoid marriage and cohabiting altogether, a trend that has been attributed to a culture of female empowerment that has situated higher levels of education and employment at odds with marital rates (Gustafsson and Worku, 2006).

Values for marriage and childbearing in the province are deeply respected and intrinsically tied to income (Preston-Whyte, 1993). Traditionally, the practice of *isilobola* involves an exchange of cattle from the hopeful husband to the father of the future bride (Evans-Pritchard, 1931). To this day both monetary and cultural values of *isilobola* are high. Cultural expectations for children, and the efforts taken to save for *isilobola* placed a huge value on marital fertility and a man may even see his *isilobola* returned if his wife is infertile, resulting in some to refer to *isilobola* actually as a 'child

price' (Evans-Pritchard, 1931). A formal expectation of 21 cows and the rising price of cattle has rendered marriage more of a middle class institution (Hunter, 2010), and unaffordable for most people living in the Hlabisa sub-district (Hosegood et al., 2009).

Divergences in acceptable courting behaviour arose under new opportunities in the way that men might choose to use their limited resources and have led to a re-working of relationships and ways in which men and women make a living (Preston-Whyte, 1993, Moultrie and Timæus, 2001). When partners ceased to send income or were unable to earn enough to support the household, women were increasingly forced to enter employment to support their households, leaving less time for childcare (Gustafsson and Worku, 2006). Childbearing is culturally tied to the concept of *isilobola* but now relates to the reality of 'making a living' in newly altered ways. Individuals engage in new, often loving, models of 'material' sexual relationships based on forms of gift exchange (Hunter, 2002). Changes to household structures affect not only fertility, but transmission risks for HIV also: currently unmarried cohabiting couples have longer term sexual partners and the highest HIV prevalence nationally (Shisana et al., 2013).

1.3 Childbearing and making a living

Tradition is not static. Men have traditionally paid *inhlawulo*, a fine for impregnating a woman outside of marriage, so that the woman's family receive financial compensation and the child takes on the surname of the father (Evans-Pritchard, 1931). Now, when pre-marital childbearing is increasingly common, there is greater acceptability and modifications to the practice of *isilobola* and *inhlawulo*, and in some instances, no money may be exchanged at all (Hunter, 2010). Economic uncertainty and structural distrust in the absence of supportive family policies have guided behaviours towards postponed childbearing in Europe (Mills et al., 2011), and in KwaZulu-Natal, women also face uncertainty where contact with partners is easily lost and men can, and often do, abandon children (Timæus and Moultrie, 2008). Childbearing outside of marriage has become more culturally acceptable and gift relationships have replaced the practice of *isilobola*, at a lower cost. A

man's ability to pay for gifts can thus ensure his status as a lover and it is more acceptable for women to take 'secondary' partners, according to the 'main' partner's ability to support her (Hunter, 2010). The South African National HIV prevalence, Incidence and Behaviour Survey found multiple partnerships were still less common in women than men: 20.1% of males reported to have more than one sexual partner in the last 12 months compared to just 4.6% of women (Shisana et al., 2013). Financially successful men tend to be older and have more disposable means to attract younger women, leading to what is commonly described as a 'sugar daddy' culture, and a steady increase of age-disparate relationships amongst women aged 15-19 years old in a context of high unemployment and poverty (the unemployment rate was 52.6% in Hlabisa in 2013) (Ott et al., 2011, Shisana et al., 2013). A study of 458 HIV seroconversions amongst women living in Hlabisa, the setting of this thesis, found that age-disparate relationships are common but not associated with HIV acquisition risk in this setting of high HIV prevalence between 2003 and 2012 (Harling et al., 2014).

1.4 Apartheid-era family planning for population control

A slow and steady decline of fertility in South Africa is the consequence of widely accessible injectable contraception available to all women wishing to control their own fertility (Swartz, 2009). Unique to South Africa was an apartheid-era policy targeting African fertility since the 1970's and driving an earlier onset of fertility decline compared to neighbouring countries (Swartz, 2009). Restrictive family planning policies and discriminatory provision of contraceptive methods under the 1974 National Family Planning Programme mostly limited the contraceptive method mix to long-term hormonal injections for African women (Swartz, 2009), and many African women chose to adopt the available contraceptive methods in order to limit their own childbearing in a difficult economic climate (Mokomane and Khan, 2009, Moultrie and Timaeus, 2002). The result was increased contraceptive use and a prevailing disparity in childbearing found along closely aligned racial, geographical and socio-economic margins (SADoH, 2003, Cooper et al., 2004). Multiple Demographic Health Surveys (DHS) show how the South African fertility decline actually pre-dated

the arrival of the 1974 programme, indicating an early effect of economic growth upon household choices for childbearing (Moultrie and Timæus, 2003).

Sustained use of hormonal contraceptives for the postponement of childbearing is a key factor in driving the South African fertility transition, yet high numbers of women relying solely on oral, injectable or sterilisation methods places them at prolonged risk of acquiring a sexually transmitted infection (Timæus and Moultrie, 2008). In South Africa, Demographic and Health Survey (DHS) data on birth intervals, calculated as the average number of months between birth dates, was last collected more than a decade ago. A study suggests that birth intervals increased to 6 years among women aged 25-29 in the late 1990s, an interval longer than observed in other sub-Saharan African countries with higher fertility rates (Camlin et al., 2004, Timæus and Moultrie, 2008). Access to Central to the ability to postpone births for such long periods is women's ability to access long lasting and effective injectable contraceptive methods. Moultrie and Timeaus found that postponement, of childbearing was important in the lengthening of birth intervals and the slow pace of a gradual decline in total fertility rates observed in South Africa since the 1960s (Timæus and Moultrie, 2008). Patterns of delaying a decision are consistent with a continuously changing political economy and political environment and have been noted as an established family building strategy across sub-Saharan Africa (Moultrie et al., 2012) and elsewhere (Mills et al., 2011).

1.5 Resulting inequities in fertility and HIV

As a result of the homeland policy of racial segregation, fertility rates are tightly associated with ethnicity and province. Prevalence of the HIV epidemic is also highly disparate with respect to sex, age, race and locality type, placing the heaviest burden amongst Black Africans, a demographic that also accounts for 79.4% of the total population and a disproportionate 95% of the poverty gap (Statistics South Africa, 2010, Shisana et al., 2010).

The South African National Survey found that black African's were more than 85% less likely to live in urban formal settlements and have access to formal housing and health services than any other

racial grouping. Black Africans also had the lowest rates of marriage. Black African women reported increased use of modern contraceptives in 2003, reaching 63% in comparison to a contraceptive prevalence of around 50% in 1990. Even in light of this increase, Black Africans, nulliparous women and people living in rural areas were less likely to report using contraception (Burgard, 2004). Fertility remains highest amongst Black Africans since a steady decline from a TFR of 6.6 in 1960 to TFR of 2.9 in 2006 (Department of Population and social development, 1998, Statistics South Africa, 2006).

Data presented in Table 1.1 from the 2012 HSRC survey illustrate variations in HIV prevalence for men and women of reproductive age (Shisana et al., 2013). KwaZulu-Natal had the highest prevalence of HIV in South Africa, approaching 27.9% in 2012 (Shisana et al., 2013). A rise in prevalence in this area has been attributed to successful scale up of ART coverage, and resultant improvements of life expectancy amongst people living with HIV (Bor et al., 2013). Average life expectancy increased in the Hlabisa sub-district from 49.2 years in 2003, just before roll-out of ART in 2004, to 60.5 years in 2011. At this time, authors also report that all-cause mortality declined by over 50% amongst all individuals aged 25-44 years old. These findings reflect the survival and social benefits of roll-out of ART. One consequence for this setting is an observed increase in HIV prevalence due to a greater number of individuals living to older age on ART (Bor et al., 2013).

Table 1.1 HIV prevalence among adults in the 15-49 age group by race province and locality type, South Africa 2012 ((*Shisana et al., 2013*))

Variable	N	(%)	95% CI
Sex			
Male	6,468	14.5	12.8 – 16.3
Female	8,252	23.2	21.3 – 25.1
Race			
Black African	9,363	22.7	21.1 – 14.3
White	881	0.6	0.2 – 1.8
Coloured	3,013	4.6	3.3 – 6.4
Indian/ Asian	1,418	1.0	0.5 – 2.0
Locality type			
Urban formal	7,882	14.7	12.7 – 17.0
Urban informal	1,815	29.9	25.9 – 34.2
Rural informal	3,408	22.6	20.5 – 24.9
Rural formal	1,615	16.1	11.7 – 21.8
Province			
Western Cape	1,890	7.8	5.5 – 10.9
Eastern Cape	1,963	19.9	17.1 – 23.0
Northern Cape	1,207	11.9	6.8 – 20.2
Free State	1,071	20.4	15.4 -26.5
KwaZulu-Natal	3,536	27.9	25.2 – 30.8
North West	994	20.3	17.5 – 23.4
Gauteng	1,673	17.8	14.6 – 21.6
Mpumalanga	1,125	21.8	17.5 – 26.9
Limpopo	1,261	13.9	10.2 – 18.7
Total	14,720	18.8	17.5 – 20.3

NB figures for 'whites' are considered unreliable due to low response rates

1.6 Rights-based dialogue reprioritising family planning in the public health agenda

Programmes of action have directed signatory state obligations to promote sexual and reproductive health and rights. The 1994 International Conference on Population and Development (ICPD) Programme of Action (POA) defines reproductive rights as the rights of couples and individuals to:

“Decide freely and responsibly on the number, spacing and timing of their children, and to have the information, education and means to do so; and to attain the highest standard of sexual and reproductive health, and make decisions about reproduction free of discrimination, coercion and violence.” (ICPD, 1994)

The first democratic election in 1994 launched a new Department of Health and a transition towards holistic primary health care services that required a restructuring of district health systems, away from a centralized hospital (Maharaj and Cleland, 2005). Progress was originally confounded by an era of AIDS-denialism when an estimated 330,000 HIV infected people died without access to treatment between 2000 and 2005 (Chigwedere et al., 2008). The country has since seen a rapid implementation of biomedical prevention strategies, including access to ART, PMTCT, HIV Counselling and Testing (HCT) and medical male circumcision (Goga et al., 2012). Since 2001, PMTCT programmes have provided free and accessible antiretroviral therapy for pregnant women and a framework to address maternal health in the global response to AIDS (Stevens, 2008). ART was made available to all people with advanced HIV via HIV treatment and care services after 2004 (SADoH, 2004).

Exposure to ART has increased among PLWHIV from 16.6% in 2008 to 31.2% in 2012. Gender differences in health seeking are widely observed in South Africa, a trend that resulted in a greater increase in the number of women accessing HIV treatment compared to men in 2012 (25.7% vs. 34.7% respectively) (Shisana et al., 2013). One of the major successes of national scale up of HIV treatment and care is the broadly equitable access to ART for individuals irrespective of their residency in either urban or rural areas. In the Hlabisa sub-district, 37% of all HIV infected adults had

initiated ART by 2011 (Zaidi et al., 2013). Rapid scale up of ART also has a protective effect for the community: the risk of a HIV uninfected individual acquiring HIV was 38% lower in areas where ART coverage was high (30-40% compared to less than 10%) in the same site as this study (Zaidi et al., 2013). The protective effect was also measured in a study of serodiscordant couples, which found a reduced risk of HIV acquisition associated with increased household coverage of ART in this setting (Vandormael et al., 2014).

Millennium Development Goal target five outlines universal access to family planning, and South Africa responded by setting national targets of 100% contraceptive use for all women with unmet need using all methods, and 100% antenatal care coverage (at least one visit and at least four visits respectively) (STATSSA, 2013). South Africa has already been successful in achieving 100% antenatal care coverage but is lacking appropriate data on contraceptive use (STATSSA, 2013) since the 2003 DHS round, reported as 50.2%. The country did not set an initial target towards adolescent birth rate or unmet need for family planning among married women or those in a union.

Indicators suggest that South Africa still has some way to go in addressing maternal and reproductive health. Since 1998, the maternal mortality ratio has increased from 150 deaths per 100,000 live births to 269 deaths per 100,000 live births, far from a 2015 target of 38 deaths per 100,000 live births. Data was sourced from civil registration and vital statistics systems, as there has been no comparable DHS round since 2003 (STATSSA, 2013). The WHO defines a maternal death as the death of any woman while pregnant, or up to 42 days after the termination of a pregnancy, from any cause related to, or aggravated by, the pregnancy or its management, but not accidental or incidental causes. The maternal mortality ratio (MMR) describes the number of maternal deaths per 1,000 live births and the 1998 South Africa Demographic and Health Survey was used to measure national maternal mortality ratio in order to set a target for MDG Five by 2015. No maternal mortality data has been collected in subsequent Demographic and Health Surveys, and information on MMR is sparse. Instead, estimates since 1998 have been calculated using information on household and pregnancy-related deaths in the South Africa Population Census or Community Surveys.

A series of reports from Saving Mothers indicate five major causes of maternal death: AIDS and other non-pregnancy related infections, complications of hypertension, obstetric haemorrhage, pregnancy related sepsis and pre-existing maternal disease. An increase in each of these causes of death, with the recent exception of complications of hypertension, reflects a gap in the implementation of progressive sexual and reproductive policies in to adequate health services (SADoH, 2007b)

Family planning can reduce transmission of HIV from mother to child, contribute to birth spacing, lower infant and maternal mortality risk and lower maternal morbidity associated with unplanned pregnancies, abortions and particularly unsafe abortions (Tsui et al., 2010, Sedgh et al., 2014).

The 2012 National Contraception and Fertility Planning Policy and Service Delivery Guidelines frames contraception as both an important tool for public health and a critical element of women's health (SADoH, 2012). Safe conception conceptualises methods and interventions aimed to reduce HIV transmission to a HIV uninfected partner in sero-discordant couples or minimising the risk of superinfection in HIV-seroconcordant couples, and civil society groups have recently addressed the issue (Bekker et al., 2011). Bekker et al provide guidance on risk reduction strategies for a range of scenarios including when the partner is on ART and in low-income settings. These guidelines include a flow diagram of questions to approach pregnancy-related issues in HIV infected women and men, suggestions for other options to consider in making a decision around fertility and childbearing, effectiveness of contraceptive methods for PLWHIV, guidance on topics to be covered in pre-conception counselling and optimal conception support strategies according to resources available in the setting and the HIV status of each partner. Support strategies may include ART regimen changes, adherence support and CD4 monitoring, sperm collection with self-insemination, safer conditions for unprotected sex, including timed sexual intercourse and limited exposures, preconception HAART for male partners, mono- or dual-therapy PrEP, on-going HIV testing or antibody testing and male medical circumcision (Bekker et al., 2011).

Abortion became legally accessible with the 1997 Choice on Termination of Pregnancy (TOP) Act, (SAFLII, 1996), and government commitment has been resilient to legal and moral objections, but

barriers to access stem from the number of trained healthcare providers citing conscientious objection and the absence of formal systems to guide providers through this process, in some cases encouraging women still to seek unsafe abortions (Cooper et al., 2004, Harries et al., 2014). In Cape Town, some even felt that abortion was more stigmatised than a HIV positive status (Orner et al., 2011).

1.7 Approaches to integrated HIV treatment and family planning

In response to the global HIV pandemic, the WHO, the World Bank and the European union specifically recommend the integration of FP services and HIV care as an efficient way to combine resources and address the comprehensive HIV and Sexual and Reproductive Health needs of women living with HIV (UNFPA, 2013). The Hlabisa HIV treatment and care programme is a joint initiative launched by the Department of Health and supported with funding from the US President's Emergency Plan for AIDS Relief.

When the PMTCT programme was launched in 2001, HIV infected pregnant women were issued single dose Nevirapine (NVP). The regimen changed to dual therapy in accordance to updated guidelines in 2008 adding Zidovudine (AZT) (SADoH, 2008), and in 2010 switched to lifelong ART amongst all pregnant women with a $CD4^+ \leq 350 \text{ cells/mm}^3$. Lifelong ART composed of a triple first line regimen of Tenofovir (TDF) + Lamivudine (3TC) or Emtricitabine (FTC) + Efavirenz (EFV) or NVP (SADoH, 2010) and in 2012, HIV infected pregnant women became eligible for lifelong ART irrespective of $CD4^+$ count (SADoH, 2011). Under the early years of PEPFAR, use of HIV resources for family planning activities was prohibited and no measures of family planning indicators were taken in these programmes. Since then, studies have demonstrated the cost effectiveness of integrated services (Reynolds et al., 2006, Stover et al., 2003, Sweat et al., 2004), with 120,256 unintended HIV-positive births averted in South Africa annually through contraceptive use (Reynolds et al., 2008).

A Cochrane review assured feasibility from 20 intervention studies exploring the impact of integration, representing 19 peer-reviewed articles, but warned against the dangers of 'add-on'

services due to the absence of evidence that integration does improve healthcare delivery or health status (Dudley and Garner, 2011). In the absence of integration, 'routine' or non-integrated care refers HIV clients onwards to Maternal and Child Health services or a Family Planning clinic with a separate appointment. Full integration suggests that all services for people living with HIV be provided under one roof. Partial integration could involve a number of options; a reproductive health room designated in the continuum of HIV care, two services linked under the same management to preserve role specialisation or a form of management integration to allow same day 'one-stop-shopping' appointments with a central check in/out, use of the same patient chart and consistent and structured messaging on all FP methods (Kosgei et al., 2011).

"Patterns of integration depend on local situations. A single blueprint is unlikely to be appropriate" (Lush, 2002)

The 2003 National contraceptive guidelines outline a commitment to integrated Sexual and Reproductive Health services for people living with HIV, delivered through free and universal point of care services (Mokomane and Khan, 2009). It provides guidance for a client-centred, rights-based approach for comprehensive sexual and reproductive services delivered through a 'one-stop-shopping' integrated service, including referrals for family planning services, complications of pregnancy, delivery and abortion, infertility, reproductive tract infections, breast cancer and cancers of the reproductive system, and sexually transmitted infections (STIs) including HIV/AIDS (Ravindran, 2005). Family planning is a highly cost-effective strategy to minimise mother to child transmission of HIV and maternal mortality when provided to HIV infected women. Implementation is determined at decentralised service level and siloed avenues of funding, vertical organisation and limited co-ordination between departments and service providers hindered implementation efforts (Delvaux and Nöstlinger, 2007).

"In South Africa, healthcare providers in HIV care settings identified the need for additional training, including in family planning. Some HIV programmes refer women to family planning services but do not really ensure there is follow-up." (Delvaux and Nöstlinger, 2007)

A 2012 study of key policy and service level challenges to integration of sexual and reproductive health and HIV services in KwaZulu-Natal identified lack of policy guidance and weak referral systems, high client load and insufficient training for skills in sexual and reproductive health delivery (Smit et al., 2012). Considering the high work load of health workers and the need for specialist medical competencies, a partial facility-led integration was deemed by respondents as more realistic than a form of full, provider-led integration. The review noted that such a strategy would rely on internal referral systems within the same facility and emphasised the need for 'provider-initiated SRH' discussions with clients (Smit et al., 2012). Breaks in the continuum of care have still led to missed opportunities for FP integration within the HCT to ART initiation stages (Scott et al., 2011), and other authors have raised the question of how best to monitor and evaluate integration efforts (Chabikuli et al., 2009).

The 2007-2011 HIV and AIDS and STI Strategic Plan for South Africa galvanised a vast scale up of access to ARVs between 2009 and 2001, while recognising that 'fertility options for women known to be HIV positive are still lacking' and financial contribution was too low (SADoH, 2007a). The Department of Health has since responded with the 2012 National Contraception and Fertility Planning Policy and Service Delivery Guidelines to provide an expanded scope to policy, inclusive of both contraception and conception services for women living with HIV, under a framework for human rights, quality and integration. A focus on health systems strengthening calls for a 're-engineering of primary health care' mandated to provide specific counselling on fertility intentions, and prioritises the engagement of men (SADoH, 2012). The current national strategic plan (2012-2016) is shaped around the UNAIDS philosophy of zero new infections or AIDS-related deaths and zero stigma, adding to this pot, zero new infections through mother to child transmission (SADoH, 2011).

Chapter Two

A review of the association between HIV and use of ART on childbearing

2.1 HIV and fertility trends in sub-Saharan Africa before the availability of ART

Early research investigating the link between HIV and fertility, conducted before HIV treatment was made widely available, presumed that, at a population level, high HIV prevalence would lower population fertility through increased mortality, infection avoidance behaviours and adverse physiological capacities for childbearing. Some definitions of fertility used in this section are presented in Box 2.1.I.

Box 2.1.I Study definitions of fertility presented in this section

- Total Fertility Rate: the sum of the age-specific fertility rates over all ages.
- Population Attributable Change (PAC) in Total Fertility: the difference between current total fertility rates and estimated rates of total fertility in the absence of HIV, based on cohort or antenatal data and modelled in a regression analysis on national HIV prevalence (Zaba and Gregson, 1998).
- Fertility differentials: the difference in age-specific fertility rates between HIV infected and uninfected women based on aggregated data from antenatal surveys (Carpenter et al., 1997, Hunter et al., 2003), Gray, Wawer et al. 1998, Allen, Serupilira et al. 1993).
- Difference-in-difference analysis: as above for fertility differentials but using individual based data from HIV population testing (Fortson, 2009).

A review of sub-Saharan Africa studies published during the pre-ART era determined that HIV is strongly associated with reduced fertility: clinical and population based surveys estimated a 25-40%

reduced fertility compared to uninfected women from Uganda, Zimbabwe, Tanzania, Rwanda and Democratic Republic of Congo (Lewis et al., 2004).

Mathematical modelling has been used to estimate the population fertility effect of HIV prevalence in sub-Saharan African settings. Zaba and Gregson modelled a 'population attributable change' (PAC) in total fertility, defined as the difference between current total fertility rates and estimated rates of total fertility in the absence of HIV. First, the sum of all age-specific fertility rates determined the 'total fertility' of HIV infected and uninfected women. A population attributable change in total fertility was then derived from the difference between the total fertility of all women and of uninfected women. A regression of PAC on HIV prevalence then deduced a 0.4% reduction in fertility per 1% increase in HIV prevalence in six countries across sub-Saharan Africa with low rates of contraceptive use (Zaba and Gregson, 1998). They identified HIV-associated illness and mortality of male partners, women's reduced fecundity and higher risk of adverse pregnancy outcomes as principal mechanisms through which HIV lowers fertility in these settings.

An additional 13 studies were analysed using the same methodology applied by Zaba and Gregson to calculate a fertility rate ratio of pregnancy rates between HIV infected and uninfected women. This review by Lewis (Lewis et al., 2004), described above, determined a similar population attributable reduction in total fertility of 0.37% per 1% increase in HIV prevalence and ascertained no effect of HIV prevalence on fertility amongst HIV uninfected populations before the availability of ART.

However, the generalizability of evidence from this time should be carefully interpreted. Studies largely emerged from countries where contraceptive use was low and fertility high. South Africa carries one of the highest HIV burdens in sub-Saharan Africa but also low total fertility rates and high contraceptive prevalence compared to neighbouring regions. Consequently, such studies are likely to overestimate the effect of high HIV prevalence in South Africa.

There are some limitations to these findings. Primarily, these models do not take into account a reduction of births due to premature mortality amongst women of reproductive age, and does not adjust for proximate determinants of either fertility or HIV, such as contraceptive use. They also do not account for prevalence of STIs in the absence of a HIV pandemic, or changes in behaviour.

Accordingly, the study found a much smaller PAC in countries where contraceptive use was high, and was likely to overestimate the negative effect at a population level.

2.2 HIV associated mechanisms of sub-fertility in the pre-ART era

Advanced HIV can result in a reduced coital frequency and amenorrhoea (Gray et al., 1998), and may also lead to adverse pregnancy outcomes such as prematurity and perinatal or neonatal death (Rollins et al., 2007). Early work of Zaba and Gregson, suggested that underlying sub-fertility (associated with risk factors for HIV but not directly measured in these studies) would affect a decline in population fertility.

A systematic review of 31 prospective studies, investigating perinatal outcomes in both developed and developing countries before 1998, found increased risk of stillbirth and infant mortality to women living with HIV in the absence of antiretroviral treatment. The review found significant heterogeneity between reported outcomes between studies and countries, illustrated in Table 2.1 (Brocklehurst and French, 1998). Greater risk of adverse pregnancy outcomes in HIV infected women could be driven by high background rates of STIs such as syphilis, the nutritional status of pregnant women and progression to advanced HIV disease.

A significant mechanism of sub-fertility amongst HIV infected women would be the increased risk of co-infection with sexually transmitted infections (STI) such as syphilis, Chlamydia or gonorrhoea (Bracher and Santow, 2001). Co-infection can dramatically increase risk of pelvic inflammatory disease (Cates et al., 1988), leaving women unable to bear children after two episodes in 20% of cases (Bracher and Santow, 2001).

Findings from industrialized countries in the pre-ART era were mixed and suggested an increased risk of spontaneous abortion amongst HIV infected women (De Vincenzi et al., 1997, Johnstone et al., 1988) or no difference by HIV status (Sunderland et al., 1992, Selwyn et al., 1989). Higher rates of spontaneous abortion were found amongst HIV infected women in the sub-Saharan (Ryder and

Temmerman, 1991), and studies have since noted the possible underreporting of sexually transmitted disease in women with HIV (De Vincenzi et al., 1997).

Table 2.1: Odds of perinatal outcome measures amongst HIV infected women versus HIV uninfected women. Adapted from Brocklehurst and French, 1998 (*Brocklehurst and French, 1998*)

Perinatal Outcome	Odds Ratio (95% CI)	Number of studies reporting outcome
Spontaneous abortion	4.05 (95% CI 2.75, 5.96)	4/31
Stillbirth	3.91 (95% CI 2.65, 6.77)	11/31
Foetal abnormality	1.08 (95% CI 0.7, 1.66)	7/31
Perinatal Mortality	1.79 (95% CI 1.14, 2.81)	6/31
Neonatal mortality	1.10 (95% CI 0.63, 1.93)	3/31
Infant mortality	3.69 (95% CI 3.03, 4.49)	8/31
Growth retardation	1.70 (95% CI 1.43, 2.02)	12/31
Low birth weight	2.09 (95% CI 1.86, 2.35)	17/31
Pre-term delivery	1.83 (95% CI 1.63, 2.06)	22/31

Studies of pregnancy outcomes in Tanzania determined that untreated HIV infected women were at higher risk of small-for-gestational-age births (SGA), pre-term birth and perinatal death (Habib et al., 2008). Similar results were found in a prospective cohort of 2368 live births in KwaZulu-Natal, South Africa, where HIV-infected women were more likely to give birth to small-for-gestational-age babies and were less likely to carry a pregnancy to term than HIV-negative women in the same setting, but did not experience any difference in rates of pre-term birth (Ndirangu, 2013).

Evidence from high HIV prevalence countries suggests that underlying sub-fertility associated with STI prevalence could lead to reduced fertility (Gregson et al., 2009), in addition to stress, a weakened immune system and weight loss, and that an association between HIV and adverse pregnancy outcomes may be stronger at advanced stages of disease progression. Research from Uganda found that 85% of pregnancies to HIV infected women resulted in a live birth and the physiological effects were most established at later stages of an infection (Ross et al., 2004). Other early studies emerging from sub-Saharan Africa report an association between HIV infection and low birth weight amongst women living with HIV (Temmerman et al., 1990, Taha et al., 1995) (Bulterys et al., 1994), and more recently, have estimated a higher risk of adverse outcomes in HIV infected women associated with lower CD4 physiological measures of health. In South Africa, HIV infected women had a 63% increased risk of adverse pregnancy outcomes (Rollins et al., 2007). Risk was doubled in women with a CD4 count below 200 cells/ μ l compared to women with a CD4 of 500 cells/ μ l or greater, and specifically when adjusted for mothers micronutrient status. In comparison, HIV infection and CD4 count were not associated with risk of mortality at 6 weeks (Rollins et al., 2007).

2.3 Fertility projections for a generalised HIV epidemic in the pre-ART era

Population-based or antenatal surveys often use aggregated data for estimates of HIV prevalence or fertility which makes it difficult to disentangle heterogeneous behavioural or physiological causal pathways (Glynn et al., 2001). Early cohort studies from Uganda and Tanzania used aggregated data to calculate fertility differentials between HIV infected and uninfected women and found reduced overall age-adjusted fertility rates in the range of 0.74 to 0.84 compared to HIV negative women (Carpenter et al., 1997, Hunter et al., 2003), and even as low as 0.45 before ART was made widely available (Gray, Wawer et al. 1998). Lower fertility rates were determined in women of all age groups except 15-19 year olds and differentials increased with age (Allen, Serufilira et al. 1993, Gray, Wawer et al. 1998), possibly due to the reduction in fertility at later clinical stages (Ryder et al., 1991). It was not possible to assess the importance of behavioural changes or fertility preference but

a study found lower fertility amongst HIV positive women whether or not they were using contraception (Hunter, Isingo et al. 2003).

A subsequent 12-country analysis of multiple DHS rounds employed a differences-in-differences analysis with the benefit of more recent population based HIV testing and individual level data, which were aggregated to achieve more precise fertility estimates (Fortson, 2009). This analysis determined a small effect of HIV on fertility at the individual level, but found no correlation between HIV and population fertility or individuals not infected with HIV. Studies are often conducted in vastly different contexts of fertility and HIV burden and it is possible that a minimal association between HIV and population fertility is explained by a heterogeneous behavioural response to HIV in the general population (Durevall and Lindskog, 2011). Findings from Fortson (2009) are supported by other studies reporting little or no impact of HIV prevalence on population fertility, or a positive association in high prevalence countries such as Kenya and Lesotho (Juhn et al., 2008).

A study from South Africa examined the likely causes of recent stalls in fertility decline in the Hlabisa sub-district until 2005 (Moultrie et al., 2008b). Authors report that 'the fertility of HIV infected women at that time was less affected by their infection than it was previously'. Furthermore, recent stalls in fertility decline in Hlabisa coincided with an increase in contraceptive use between 2003-04 and 2005. Together findings suggest that predictions of a decline in total fertility, directly proportional to HIV prevalence, do not generalise to this setting (Lewis et al., 2004).

2.4 HIV and fertility choices in the pre-ART era

European studies have found little effect of knowledge of own HIV diagnosis in shaping fertility desires and decision-making (Fiore et al., 2008). Rather, HIV infected women have continued to desire children in line with existing cultural norms and encouragement from HIV services (Cliffe et al., 2011). Cultural perspectives to childbearing in sub-Saharan Africa are likely to be shaped by different individual concerns for future health, risk of transmission to future children and the welfare of existing children (Rutenberg et al., 2000). Stigmatised views from partners, family or the

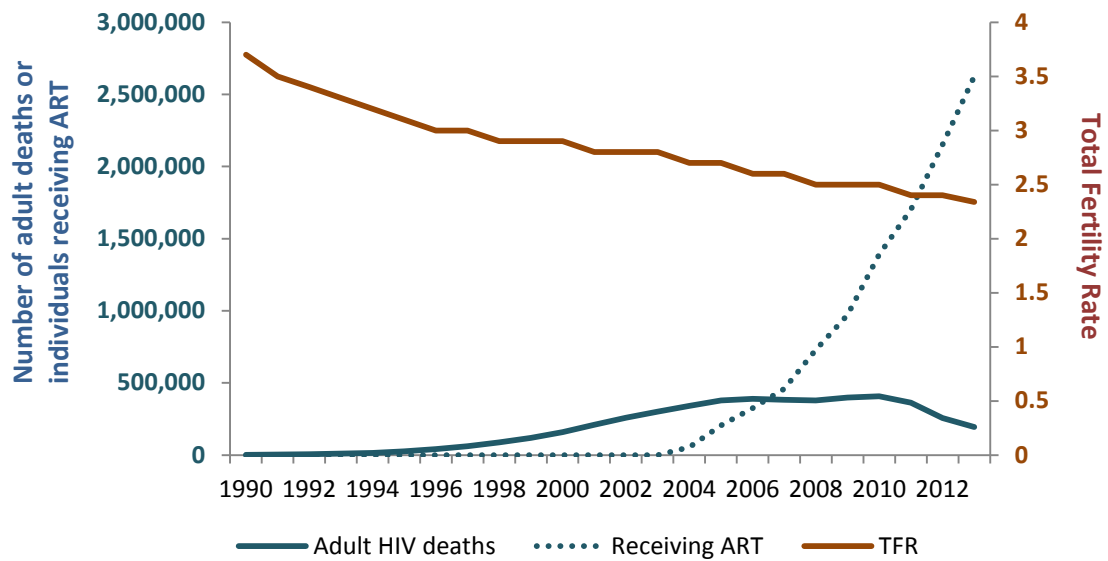
community have the potential to also discourage fertility amongst HIV infected women (Rutenberg et al., 2000, Gregson et al., 2004).

In a survey of women living in South Africa before ART was widely available, childbearing desires were lower amongst HIV positive women than HIV negative women (Peltzer et al., 2009). In this study knowledge of PMTCT was associated with increased desire amongst HIV positive women, suggesting that women were deciding to limit their own childbearing in response to their HIV status at this time (Peltzer et al., 2009). Even at a time where ART was not widely available, women described decisions that were influenced by factors beyond their HIV status. For example, negative attitudes of health workers reportedly deterred some women living with HIV in South Africa from childbearing, although strong desires for parenthood did override such concerns in others (Harries et al., 2007).

2.5 Fertility in South Africa at a time of high HIV prevalence and roll-out of ART

National trend across South Africa reflects little population effect of HIV on fertility. National rates of contraceptive use have been high, and the TFR has remained low in the midst of high HIV prevalence. UNAIDS estimated a peak mortality of 207,865 AIDS-related deaths in 2010, before national scale up of access to ART brought about a decline as shown in Figure 2.1. Access to ART has reduced mortality amongst children and adults by 43% and 20% (Mayosi et al., 2012), with a resultant increase in life expectancy and HIV prevalence in the Hlabisa area (Bor et al., 2013). Figure 2.2 illustrates the consistent decline towards low fertility during an era of high AIDS-associated mortality and a subsequent reduction in mortality attributed to ART.

Figure 2.1. Annual HIV Deaths (at all ages), number of individuals receiving ART and TFR in South Africa between 1990 and 2011. Data taken from UNAIDS (*AIDSinfo Online Database, last accessed 07.09.14*)



National data can often obscure a range of hidden inequalities, and HIV associated mortality has had an inequitable impact upon the age population structure of South Africa. Prior to ART availability, the proportion of children younger than 9 years old declined relative to other age groups in a rural area of KwaZulu-Natal, indicative of demographic transition (Herbst et al., 2011). However, improved survival of mothers and children living with HIV through antiretroviral treatment helped to alleviate the impact of changes to the population age structure attributable to HIV (Herbst et al., 2011, Herbst et al., 2009). Since the introduction of PMTCT and ART services in 2005, reduced under-5 mortality rates have brought a reversal of this trend, with infants under-5 now accounting for the single largest age group in the area (Herbst et al., 2011).

A consequence of scaled up access to ART has been a shift in burden towards older women. National HIV prevalence is now highest amongst females aged 30-34 years and males aged 35-39 years, which could be attributed to improved survival on ART and also new infections in these age groups. Issues

of fertility on ART in South Africa thus appear pertinent to a demographic of women that have progressed within their reproductive lifespan. The effect of HIV on fertility may be heterogeneous according to risk group, and small population attributable changes to total fertility may mask opposing fertility effects. Additional research in to both biological and behavioural effects may elucidate these trends amongst women on ART.

2.6 Theoretical frameworks to address the impact of ART on childbearing

Theoretical frameworks have guided the demographic investigation of fertility and are well established in the current literature. Early work of Davis and Blake (Davis and Blake, 1956) and later developed by Bongaarts (Bongaarts, 1978) presents a framework aimed to understand the numerous mechanisms affecting fertility in the developed world. Bongaarts was the first to provide a quantitative framework to analyse the heterogeneous effects of multiple proximate determinants of fertility and to assess the most important determinants of fertility decline in various contexts. It is now one of the most frequently used models for evaluating fertility and fertility changes (Stover, 1998). The framework supposes that structural factors such as education and areas of residence are important distal determinants of fertility and may indirectly influence population-level changes through a range of biological and behavioural mechanisms through more proximate (or intermediate) determinants. The proximate determinants outlined by this framework include the proportion of women married, contraceptive use, rates of induced abortion, postpartum infecundability, frequency of intercourse, onset of permanent sterility and spontaneous intrauterine mortality (Bongaarts and Potter, 1983). Together, the framework explains how marriage (or stable union) and permanent sterility will determine the duration of a woman's reproductive lifespan, while the other proximate determinants (use of contraception, abortion, lactational infecundability, sexual activity and intrauterine mortality) will determine rate of childbearing and interval between births (figure 2.2).

According to Bongaart's framework, the 'conception wait' period is the most variable factor determining birth intervals, a time when women may decide to control or lengthen time between births. Accordingly, the framework considers birth control as one of the most important proximate determinants of fertility (Bongaarts, 2006). Chapter one described that, in line with Bongaart's framework, women employed the use of contraception to postpone childbearing and created extremely long average birth intervals that drove a slow decline to low fertility in South Africa even prior to the arrival of a huge HIV epidemic. Bongaart's framework has since been updated for sub-Saharan context (Bongaarts et al., 1984), and the context of a high HIV prevalence (Gregson et al., 2009, Ntozi, 2002) via the same behavioural and biological proximate determinants of fertility.

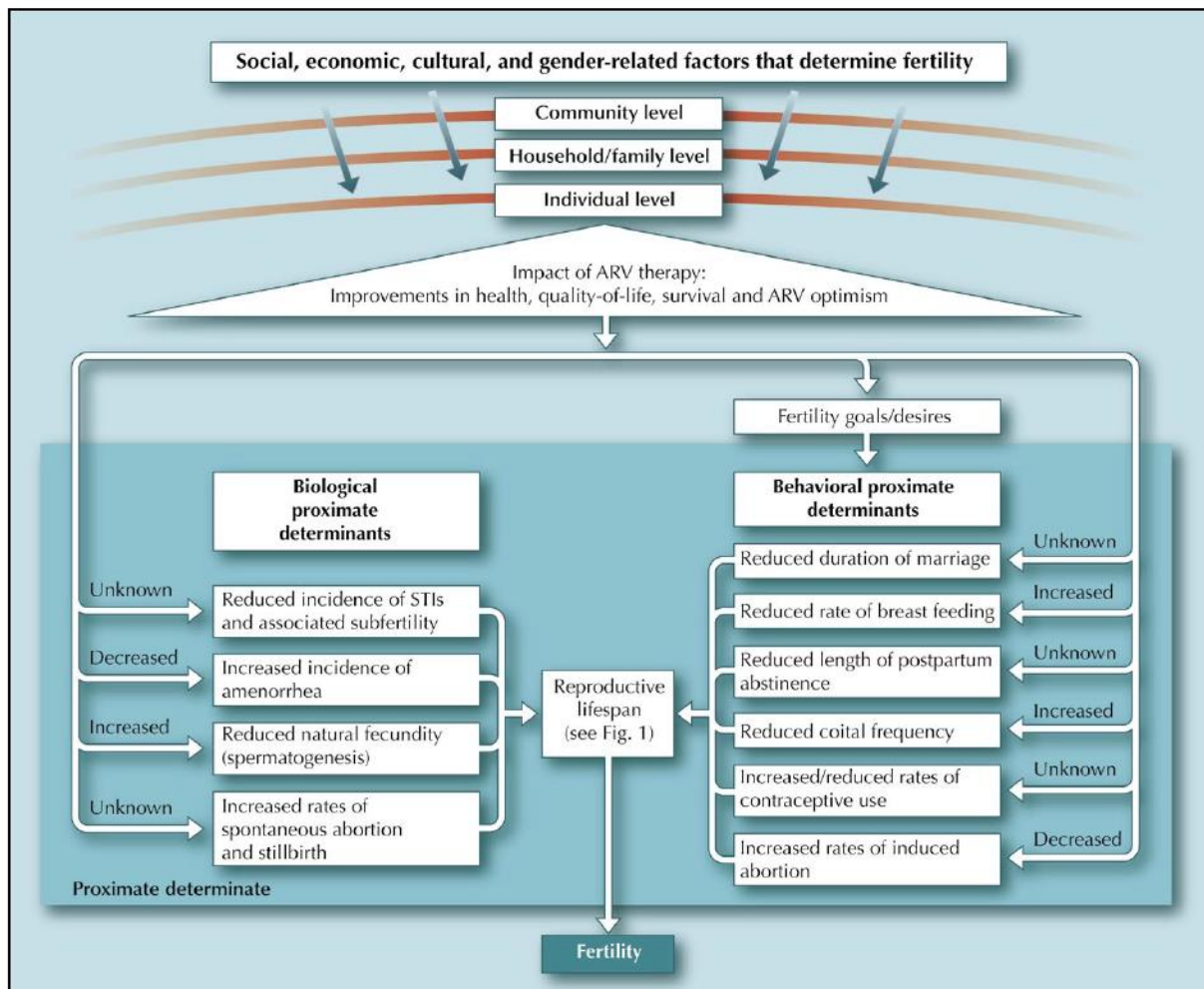
Recently, Kaida et al further developed Bongaarts model for the impact of ART therapy on fertility (Kaida et al., 2006). This framework recognises the influence of broader social, economic, cultural and gender related determinants of fertility and conceptualises the effects of these broad factors at the community, household and individual level, suggesting individual improvements in health, quality of life, survival and ART optimism related to ART use. Using this framework illustrated in Figure 2.2, Kaida et al demonstrate that ART could either increase or decrease fertility rates of HIV infected women via multiple mechanisms and the population impact of ART on fertility will be largely contextual.

Kaida and colleagues demonstrated the possible directions through which use of ART may either increase or decrease trends in each of Bongaart's proximate determinants of fertility (Kaida et al., 2006). The biological and physiological mechanisms through which HIV and HIV treatment are able to affect fertility are clearly identified, and this is really the key virtue of Kaida's model. The model presents each proximate determinant as a quantitative measure, such as rates, duration or length, and the hypothesised effect of ART. The external arrows illustrate the hypothesised increased, decreased or unknown effect of ART on each proximate determinant, already assuming a prior change associated with HIV. For example, Kaida suggest that ART could counter the 'reduced' effect of HIV, and increase rates of coital frequency amongst women living with HIV. Rates of other determinants are hypothesised to increase in response to HIV infection, such as induced abortion or

amenorrhea. In these examples, Kaida et al hypothesise that use of ART will reverse this effect and decrease the rates of induced abortion or amenorrhea amongst HIV positive women.

Importantly the model highlights areas where the effect of ART remains largely unknown. The model is explicitly quantitative and its limitation, for the purpose of this study, is the absence of any comment on the decision making processes hypothesised to lead to the direction of these changes, or the possibility of changes in behaviour that are not necessarily cognitive. I thus continued to search the theoretical literature to elucidate how HIV treatment might influence fertility desires and the different possible dimensions to childbearing decisions.

Figure 2.2. Illustrating the effect of ART on fertility through Bongaart’s proximate and distal determinants of fertility, taken from (Kaida et al., 2006)



It is the more distal links between successful family planning implementation and changes in fertility that are difficult to quantify, particularly in the absence of appropriate indicators of assorted mechanisms through which programmes can effect behaviour change. Fundamentally, family planning is a political issue: politics have shaped international discussions about funding, the societal role of contraception and implications of population control (SADoH, 2011). Family planning services

play an important structural role by regulating the cost and availability of contraception that ultimately determines the use and effectiveness of birth control (Bongaarts, 2006). In South Africa, public services determine free access to contraception and can encourage behavioural changes for women living with HIV.

Economic and fertility models have been used to quantify the role of family planning programmes in national transitions to low fertility. Economic studies measure the 'cost' of children and the value of a woman's time through indicators such as female wages and education or costs of contraception (Gertler and Molyneaux, 1994). Such models consider state mediated factors as key to lengthened birth intervals, but are imperfect in their absence of biological and other behavioural determinants of individual fertility.

Fertility preferences strongly influence reproductive behaviour in Europe, where contraception is widely available, although preferences are realised differently in regional contexts (Régnier-Loilier and Vignoli, 2011). In South Africa, the issue is also culturally nuanced. Women may assert control of their own fertility through covert use of contraception, an act that is considered representative of engendered conflicts under modern day reworkings of the 'patriarchal bargain' (Hunter, 2010).

Behavioural changes are the most powerful determinants of fertility decline in South Africa (Chimere-Dan, 1994).

Fertility preferences and intentions are causally intermediary to the socio-economic and the proximate determinants of fertility' (Timæus and Moultrie 2008).

Both desires and intentions are commonly used constructs to describe the motivational antecedents of a behavioural outcome (typically conception) and are sometimes used interchangeably (Stanford et al., 2000, Miller, 1994, Trussell et al., 1999). Definitions of 'intended/unintended' or 'wanted/unwanted/mistimed' are standardised in DHS survey questions for simplicity and comparability of measuring childbearing desires. Surveys such the National Survey of Family Growth (NSFG) measure retrospective perception of planning and timing using the following standardised definitions of intendedness in figure 2.3.

Figure 2.3 Definitions of an Unintended, Mistimed and Unwanted pregnancy according to the National Survey of Family Growth (*Chandra et al., 2005*)

Unintended:

Not wanted at the time conception occurred, irrespective of whether contraception had been used

Mistimed:

Unintended but wanted by women at some time, but which occurred sooner than they were wanted.

Unwanted:

Unintended and occurred when the woman did not want to have any more pregnancies at all

These definitions are included in South Africa DHS rounds and allow limited understanding of fertility intentions in this setting, for four reasons. Firstly, individual intentions extrapolated from population data (i.e. DHS) cannot reflect the complexity of decision-making. Second, western concepts of planning do not always hold the same meaning for respondents and do not often consider enhanced patterns of migration, disrupted family units and high levels of single parenting found in areas of sub-Saharan Africa. Third, survey date by nature is retrospective, and risks under-reporting due to abortion (Moos et al., 1997). Fourth, these surveys are founded in the social principle that pregnancies within marriage are intended: early surveys did not recognise that pregnancy within marriage may not be wanted or, as in South Africa, a pregnancy outside of marriage could be wanted (Moos et al., 1997).

All measures of intention assume individual cognition of a woman's ability to control number and timing of future births and in fact many theories assume direct pathways between desire, intention and behaviour. Childbearing can hold a great cultural significance and many women still decide to continue having children even when it doesn't make economic sense. Further complexity may be

introduced when women's actions are mediated by factors other than intention, or in the absence of an actionable intention.

The Theory of Planned Behaviour (TPB) identifies intention as the antecedent of behaviour (Fishbein et al., 1994, Ajzen, 1991). It assumes that behaviour is the result of rational decision-making, attributed to an individual's beliefs, and perceived social norms and own ability to adopt the behaviour (Montano et al. 2002). This model prioritises the individual woman's own perceptions and normative beliefs (Denison, 1996), so that external negative perceptions of childbearing amongst people living with HIV may dissuade individual intentions. Miller distinguished between 'planning for' and 'wanting' a child in his four step psychological 'Traits-Desires-Intentions-Behaviour' sequence (Miller, 1994). Childbearing decisions are dynamic and desires may relate to current desires or a future wish to have a child (Hofferth, 1983), so Miller's framework positions desire as a precursor to intention and supposes that desires for a child can exist without further intention to act. Stanford's model further classifies five retrospective dimensions of pregnancy intention and emotive responses to a pregnancy (Stanford et al., 2000).

Traditionally, a one-decision model of fertility decision-making suggests that couples follow a plan for an ideal number of children they would like to have, and strive to achieve this goal regardless of changes in their circumstances (Udry, 1983). Sequential decision models are rooted in utility theory and instead propose a constant re-evaluation of the costs and benefits of the number of children that individuals or couples wish to have, in relation to their economic and social environment. They allow for changes over time resulting in decisions to have another birth, postpone another birth or to stop reproducing (Udry, 1983).

Current understanding tells us that planning is not always a meaningful concept, that concepts of intention are not clear cut and simple typologies of limiting and spacing are of limited value to specific contexts (Trussell et al., 1999). For example, Moultrie and colleagues showed that current patterns of fertility in South Africa were largely inconsistent with ideologies relating to limiting and spacing (Moultrie et al., 2012). Current definitions consider limiting as the cessation of childbearing when a desired family size has been achieved, and spacing as the decision to have another child

when the current youngest child has reached a certain age (Moultrie et al., 2008a). These typologies are problematic in South Africa where the formation and maintenance of sexual relationships have been disrupted by the legacy of apartheid era policy, economic and political instability and the dissolution of marriage (Hosegood et al., 2009). In South Africa, Moultrie suggested that patterns of childbearing are principally shaped by 'uncertainty' faced by individuals in response to their environmental instability, affecting a pattern of childbearing that is more akin to a concept of 'permanent postponers' (Lightbourne, 1985, Moultrie et al., 2012).

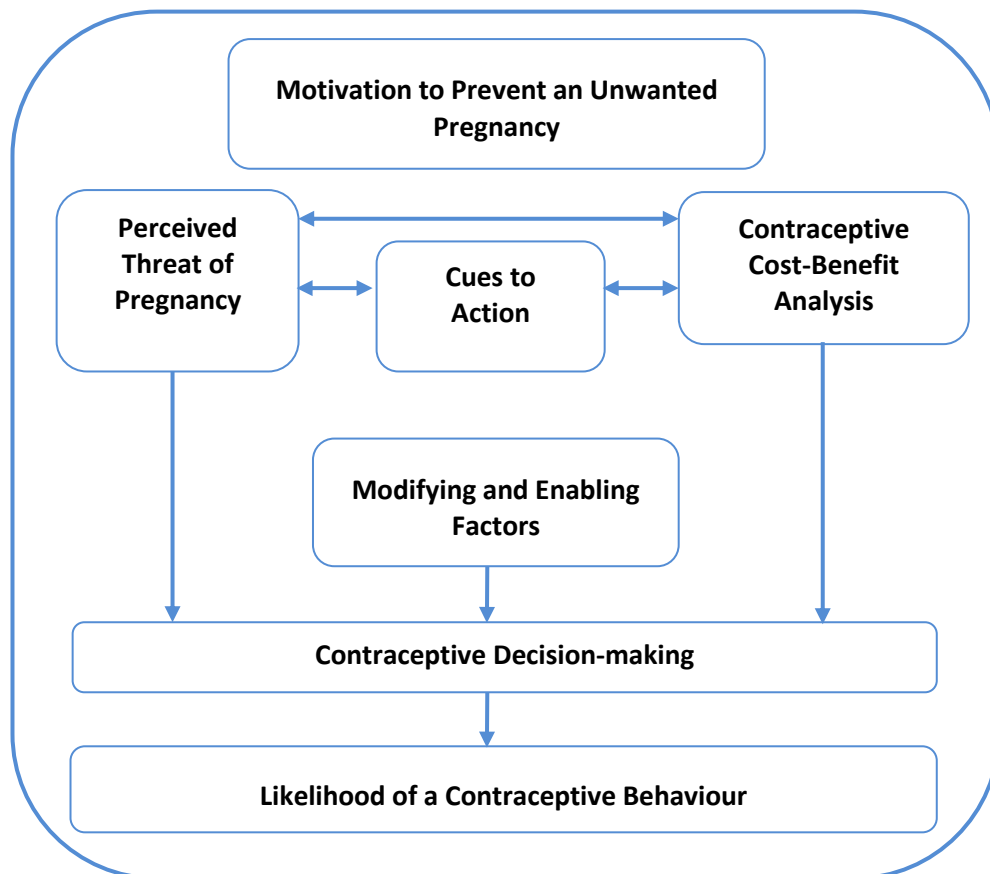
Models that assume a linear pathway of desire and intent before a behavioural act to conceive a pregnancy, cannot accurately account for the evolving 'uncertainty' determined amongst postponing women in South Africa. Other psychometrically validated measures of pregnancy intention are available and in sub-Saharan Africa but not yet in isiZulu, the predominant language of KwaZulu-Natal (Hall et al., 2013).

Lightbourne considers postponement as an 'economic survival strategy' in South Africa where women consider 'a vague and weak desire to have additional children in the future coupled with a stronger desire to avoid one in the present' (Lightbourne, 1985). The concept suggests that women are in fact not planning a set timeframe at which point they intend to get pregnant and stop using contraception. Instead, women described a desire to avoid pregnancy in the present while being potentially amenable to one in the future. It considers multi-faceted challenges that women living in South Africa may face inequitably, such as HIV and general health, the cost of marriage, relationship instability and infidelity, inadequate and overcrowded housing, saving for existing children's education, gender relations and family planning policy and services (Timæus, 2014).

Postponement is viewed as a delayed decision about childbearing, rather than a delay of the birth itself, that later becomes a permanent avoidance of childbearing and a key driver of long birth intervals and the subsequent decline in population fertility in South Africa (Timæus and Moultrie, 2008). During periods of postponement women may still discontinue contraceptive use for reasons other than childbearing and desires are subject to change, with implications for family planning programmes. A study of the influence of ART on contraceptive behaviour in Hlabisa requires

grounding in health and behavioural theory that encapsulates changing structural (economic and relationship) uncertainties. Socio-cognitive models such as the Health Belief Model (HBM) are commonly used in family planning research and recently academics have modified this framework to encapsulate the complexities of fertility intentions in the study of modern contraceptive behaviour (Hall, 2012).

Figure 2.4 Contraceptive Behaviour Health Belief Model for science and practice (*adapted from Hall, 2012*)



The model illustrated in figure 2.4 fits well within the more complex context of ‘uncertainty’ documented in South Africa. The adapted Health Belief Model (HBM) for contraceptive behaviour states that an unplanned pregnancy is not always viewed as a negative health condition, as asserted

in other HBM frameworks. It recognises a possible ambivalence to a pregnancy or the risk that a pregnancy may pose to the individual woman. It includes multiple and modifiable dimensions of decision-making, which allows for complex and sequential childbearing behaviour. Key constructs of contraceptive behaviour include perceived threat, cost-benefit analysis, cues to action and modifying and enabling factors. Another benefit of such a model is that it also encompasses structural and health facility factors that are known to be important to the South African fertility decline, and are discussed in Chapter one. Consequently, HBM provides a useful tool to elucidate the complex motivations pre-empting contraceptive decisions of women on ART in Hlabisa.

2.7 Biological mechanisms through which ART may impact fertility

ART use may influence changes in both biological and behavioural determinants of fertility. While a comprehensive review of the physiological mechanisms through which ART may affect fertility is outside the scope of this thesis, recent research suggests multiple possible mechanisms that will be summarised here.

HIV has been previously noted as a risk indicator for adverse pregnancy outcomes and subsequent studies from Europe and the US indicate a higher risk preterm delivery amongst women using antenatal combination ART, between 1.5 and 3.5- fold greater than HIV infected women on single or dual therapy (Study, 2010, Thorne et al., 2004). A review of these studies noted high heterogeneity in the association between combination ART and preterm delivery that could not be explained by methodology but were attributed to differences in ART regimen comparisons (Townsend et al., 2010).

Few studies have evaluated the effect of combination ART therapy (or highly active antiretroviral therapy, ART) with attention to the type of regimen used, in sub-Saharan Africa. HIV infection was associated with a higher adjusted odds between 1.3 – 1.8 greater for stillbirth (SB), pre-term delivery (PTD), SGA and neonatal death (ND) outcomes in Botswana (Chen et al., 2012). Relative to HIV infected women not yet enrolled on treatment, risk of PTD, SGA and ND was higher still amongst

women that had continued on ART from before pregnancy. Use of ART compared to Zidovudine alone was associated with higher odds of all adverse outcomes. These findings demonstrate possible adverse effects of combination ART on pregnancy outcomes, and the need for careful consideration of ART regimen choice in studies of pregnancy outcomes or used in PMTCT programmes for women that do not yet require ART for their own health (Watts and Mofenson, 2012). The applicability of these findings to the South African context are limited due to the absence of a comparison with Efavirenz-based ART, which is part of South Africa's first line regimen (SADoH, 2010), and possible population fertility effects are yet to be determined.

There is strong biological plausibility for an association between hormonal contraceptives and reduced ART efficacy, although clinical associations have not been widely assessed or determined for progesterone injectables (Robinson et al., 2012). Pharmacokinetic studies have shown evidence to suggest that hormonal contraceptives (HCs) may interact with ARVs to reduce contraceptive efficacy when taken in combination. HCs are metabolized in the liver by cytochrome P450 enzymes such as CYP3A4 (Rhoda Lee, 2009). Protease inhibitors used in combination ART can disrupt this metabolism by inhibiting the cytochrome P450 pathway (El-Ibiary and Cocohoba, 2008). The effects are dependent on hormonal contraceptive type and appear to be smaller in studies of depot medroxyprogesterone acetate, a high-dose progestogen-only contraceptive, compared to combined oral contraception (COC), which includes a mixture of oestrogen and progestin (Robinson et al., 2012). Clinical studies have found little evidence of an association (Watts et al., 2008), and the Centres for Disease Control and Prevention considers DMPA use to be Category 1 (no restriction for use of contraceptive method) for all women living with HIV on ART (Control and Prevention, 2010).

A reverse association between HC use and efficacy of ART has been recently discussed in the literature. The REACH cohort study in the U.S determined a link between duration of hormonal contraception and average reduction in viral load amongst adolescent females on ART, specifically ZDV (Johnson et al., 2011). The sample constituted 107 adolescents, surveyed every 3 months and found a significant association between duration of hormonal contraceptive use and average VL decrease per day. It is important to note the small sample size and that women primarily used COC while Depo-Provera accounted for just 28.2% of contraceptive use (Johnson et al., 2011). HC has

subsequently been associated with both increased risk of transmission and acquisition of HIV between sero-discordant partners (Heffron et al., 2012), but an extensive review found no strong evidence of a definite association and led the WHO to endorse continued DMPA use amongst women living with HIV (WHO, 2012).

A speculated reversal of reduced fertility amongst HIV infected women through reduced mortality and behaviour changes attributed to access to ART has been explored in the literature in recent years. The topic is nuanced with difficulties in finding an appropriate counterfactual to women living with HIV on ART.

2.8 Systematic reviews of the association between ART and fertility in South Africa

2.8.1 Review methodology

This section presents the methodology of two systematic reviews of the literature that are later presented in Sections 2.8.2 and 2.8.3. An initial scoping exercise identified the different disciplines studying HIV and fertility, and included a preliminary search for fertility studies and studies of childbearing desires amongst women on ART. The initial search conducted in February 2011 generated more than 10,000 responses in Google scholar and UCL MetaLib. It was most feasible to divide the topic into two systematic literature searches that investigate:

1. The effect of ART on fertility rates amongst women living with HIV in sub-Saharan Africa, when used for either personal health or prevention of mother-to-child transmission.
2. The use of ART and attitudes to, and desire for, childbearing amongst women living with HIV in sub-Saharan Africa.

Search criteria

Studies from any sub-Saharan African country were included in both searches. The preliminary search of the HIV, ART and fertility literature informed the key word criteria for two systematic searches. The final key words were:

- Search One: (ART) OR (antiretroviral therapy) OR (HAART) OR (antiretroviral) AND (pregnancy) OR (fertility) OR (birth) AND (rates) OR (incidence) OR (risk) AND (sub-Saharan Africa) OR (Africa).
- Search Two: (ART) OR (antiretroviral therapy) OR (ARV) AND (pregnancy) OR (fertility) OR (birth) OR (child*) AND (intention*) OR (desire*) OR (planning) AND (sub-Saharan Africa) OR (Africa).

The searches using the above search terms in PubMed were conducted in September 2014; the University College London's own e-library database called 'Metalib' was also searched, which extended the search to five additional data bases: Geobase, JSTOR, SCOPUS, UCL Library catalogue (Explore) and Zetoc. The dates of the searches were not limited as the roll out of antiretroviral therapy is a recent intervention, and I anticipated that no relevant studies on the effect of ART on fertility would be published prior to 1990.

Inclusion criteria for Search One specified that studies:

- Were population, individual or facility-based
- Used a cohort or cross-sectional design
- Had an exposure group of HIV positive women enrolled and using ART
- Had a comparison group of HIV positive women not on ART, or HIV negative women (for cross sectional studies)
- Included time since initiation on ART (cohort studies)
- Had pregnancy or birth outcomes
- Included an analysis of multiple factors associated with the described outcome

- Were conducted in sub-Saharan Africa

Inclusion criteria for Search Two specified that studies:

- Reported a qualitative study or quantitative survey design
- Included question about pregnancy intention or desire to get pregnant
- Described themes related to attitudes to childbearing
- Reported perspectives from HIV positive women using ART at time of conception
- Were conducted in sub-Saharan Africa

Screening process and eligibility

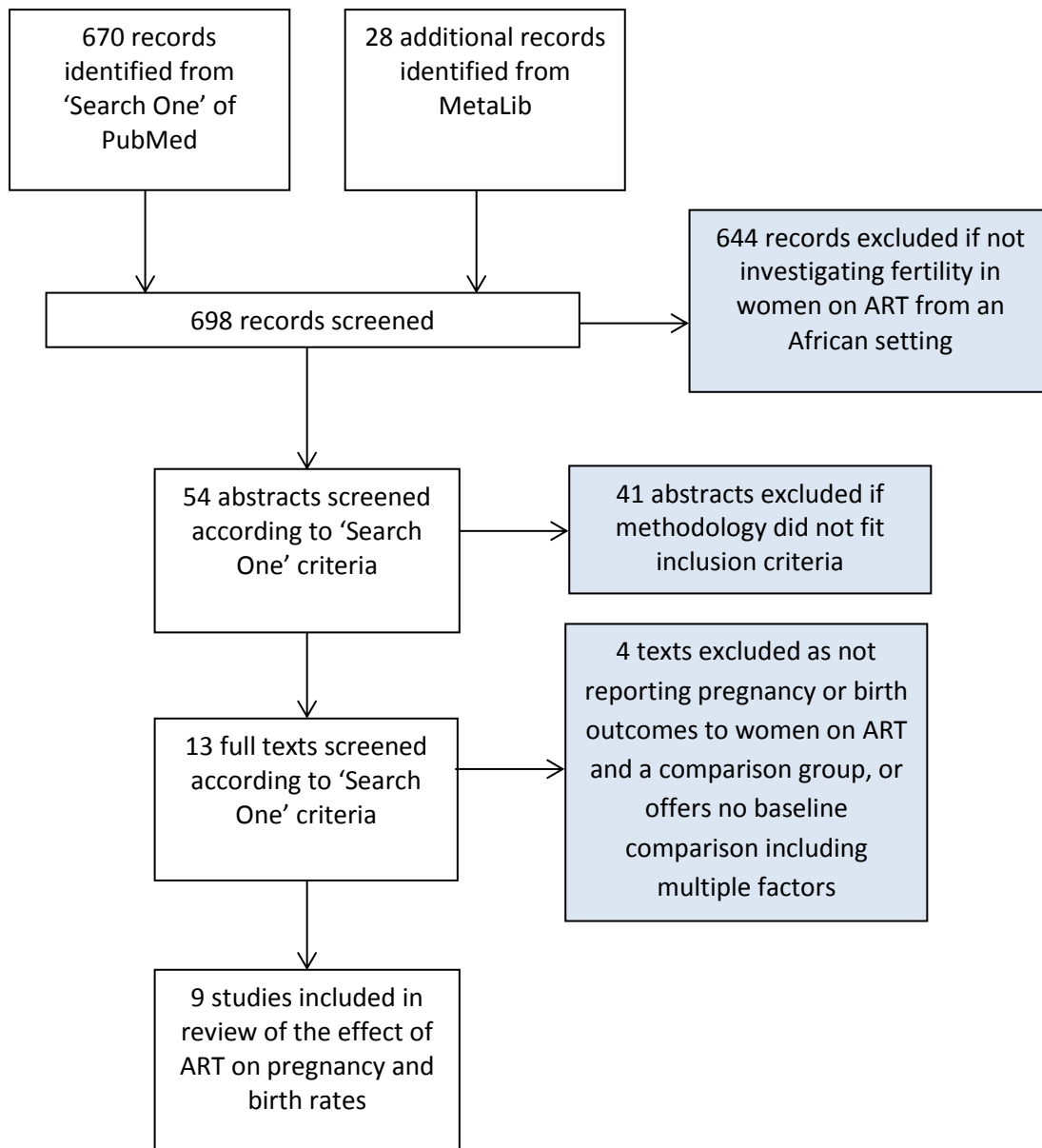
Search One: The search of PubMed returned 670 unique titles and the search of MetaLib a further 28 unique titles. These 698 non-duplicate titles were screened against the above criteria.

Subsequently 54 abstracts and 13 full texts were screened. Nine studies met the eligibility criteria and were included in the review.

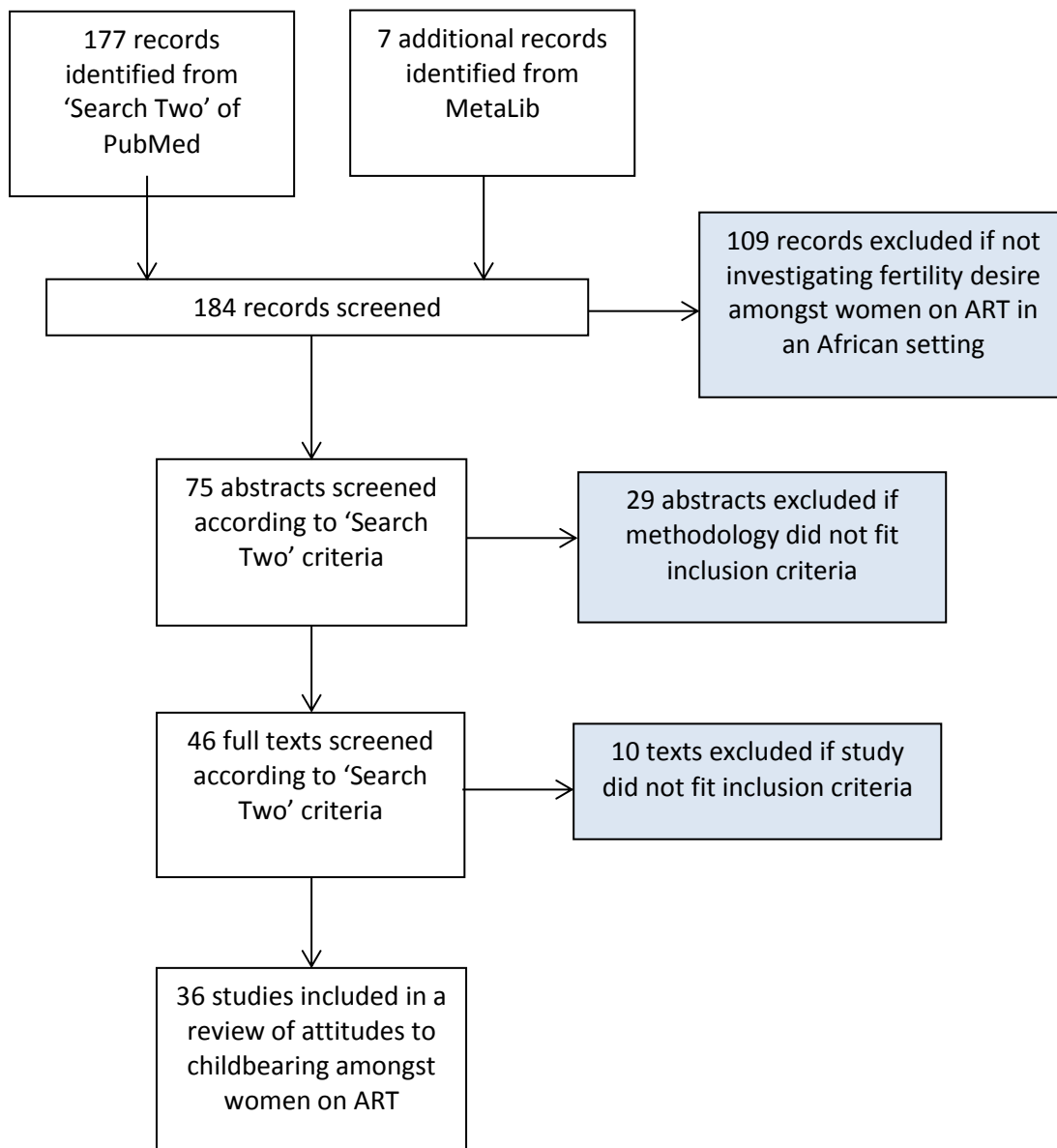
Search Two: The search of PubMed returned 177 unique titles and the search of MetaLib a further 7 unique titles. These 184 non-duplicate titles were screened against the above criteria. Subsequently, 75 abstracts and 46 full texts were screened. Thirty-six studies met eligibility criteria and were included in the review.

Figure 2.5 Flow diagrams to illustrate the systematic process of two systematic literature searches

a) Flow diagram of screening and exclusion for Search One



b) Flow diagram of screening and exclusion for Search Two



Abstraction and summary

The reported outcomes, comparison groups and design of the nine eligible studies retrieved by Search one were detailed in an Excel spread sheet. Studies were ordered by publication date and novel findings or methodological approaches were then summarised. Factors associated with outcome were also noted according to study authors', and researcher explanations of the results. These factors later informed the methodological approach for this thesis. No formal assessment of quality was done but study limitations were noted and described in the discussion.

In Search two the qualitative studies were grouped according to region of study and date of publication. This was important considering the possibility of a changing 'effect' of ART as an influence on attitudes to childbearing. Reported desires and emergent themes were summarised for each publication. Summaries helped to identify regional variations in childbearing desires and consistency with quantitative studies. No formal quality assessment was done; the utility of such an assessment for qualitative studies is debated (Buchanan and Rotkirch, 2013, Dixon-Woods et al., 2005).

2.8.2 Search One: The Effect of ART on Birth Rates in sub-Saharan Africa

Results from this search identified nine studies of the impact of lifelong ART on incidence of pregnancies or birth. Eight were cohort studies and one presented cross-sectional results. Two studies reported findings from multi-country cohorts, four studies originated from Uganda, two from South Africa and one from Malawi. There was broad heterogeneity in clinical, behavioural and socio-demographic characteristics measured at baseline and presented for multivariable analysis (Table 2.2). All studies reported pregnancy as the key outcome, which was either self-reported, clinically determined or both. Of these studies, four also reported measures of desire and intentions, including one that measured planning and unmet need for contraception associated with incidence of pregnancy.

Multiple cohort studies in the U.S. reported conflicting effects of ART on fertility rates. Early work suggested an increase in pregnancy rates among HIV positive women since ART became available. Blair et al provided a comparison of pregnancy rates amongst HIV infected women in pre-ART (1992-1996) and post-ART (1997-2001) years to determine 20% higher rates of pregnancy in the post-ART era (Blair et al., 2004). Pregnancies were less likely in women with a history of AIDS-related illness and CD4 below 200cells/ μ l. Yet two subsequent multicentre studies did not find a significant association between use of ART and fertility in the time periods 1994 to 2002 and 2002 to 2009 (Massad et al., 2004, Linas et al., 2011). The earlier study determined a reduced risk of abortion during pregnancy amongst women on ART and also a lower risk of conception (Massad et al., 2004) . Both studies reported lower pregnancy rates amongst HIV infected women; approximately half of those compared to HIV uninfected women.

Table 2.2: Studies reviewing effect of exposure to lifelong ART on incidence and predictors of pregnancy

Author	Setting	Design	Comparison	Key finding	Outcomes	Sample size	Follow up (months)
(Burgos-Soto et al., 2014)	leDEA West Africa: Benin, Burkina Faso, Cote d'Ivoire, Togo, Guinea-Bissau, Mali, Nigeria and Senegal	Retrospective analysis of leDEA database, with data from 15 HIV/AIDS clinics	Predictors of pregnancy on ART	Incidence of pregnancy after ART associated with higher CD4 at initiation and ART regimen	<ul style="list-style-type: none"> - Incidence rate of 2.85 pregnancies/100PYs in first 12 months, increased thereafter. Low comparative to region. - Overall pregnancy probability of 11% by 4 years of follow up on ART - CD4 count was a good indicator of pregnancy and recurrent pregnancies. - Increase in incidence highest amongst women aged 25-29 years old. - Women initiating with Nevirapine based regimens had higher risk compared to Efavirenz-based regimen in adjusted analysis. - No measure of family planning indicators such as contraceptive use or marital status 	29,425 women followed, with 2,515 pregnancies to 2,304 women	Follow up between 1998 and 2011
(Homsy et al., 2009)	Uganda	Prospective cohort of women receiving ART as part of the Home-Based AIDS Care study.	Time since initiation Trends in desire and predictors of pregnancy on ART	Low desire for children not associated with time ↑ Incidence of pregnancy with time on ART up to 24	<ul style="list-style-type: none"> - Over a median follow up time of 2.4 years, desire for more children remained constant and less than 7%. Low childbearing desires were reported amongst women experiencing an increase in incidence of pregnancy from 3.46 per 100 women-years (at 3 months) to 9.5 per 100 women-years at 24 months ($p < 0.0001$). - Women also reported increased sexual activity from 	718 HIV infected women	Followed up 24 months post ART initiation

				months	<ul style="list-style-type: none"> - 24.4% at baseline to 32.5% at 24 months of follow up (p=0.0001). - Family planning use was around 14% after 2 years of follow up 		
(Kaida et al., 2013)	Uganda	Prospective cohort	Time since initiation on ART	<p>Peak in incidence between 6-12 months after initiation</p> <p>↓ incidence of pregnancy after 12 months on ART</p>	<ul style="list-style-type: none"> - Pregnancy incidence 9.40/100 WYs - Cumulative probability of pregnancy was 28% after 3 years - Incidence peaked between 6-12 months after ART initiation and declined thereafter until 48⁺ months - Recurrent pregnancies were responsible for a peaks in pregnancy at 24-30 and 48⁺ months - Younger age and having disclosed status to partner were associated with risk of pregnancy 	351 women, with 105 pregnancies to 84 women	2005 - 2011
(Maier et al., 2009)	Uganda	Cross sectional study of single HIV clinic.	Pre-ART vs. receiving ART	<p>↑ odds of fertility desire on ART vs. no ART</p> <p>↓ odds of pregnancy on ART vs. no ART</p>	<ul style="list-style-type: none"> - Increased odds of fertility desire associated with ART use (AOR 2.99, 95% CI 1.30-6.28) in multivariate analysis (not significant in bivariate) - ART associated with decreased odds of pregnancy (AOR 0.56, 95% CI 0.33-0.95) and live birth (AOR 0.30, 95% CI 0.13-0.66). Lower odds of pregnancy were also associated with increasing age, which was significantly higher in exposed group. - Limited by non-random distribution of ages, ethnicity and other baseline characteristics between ART-naive and exposed groups. 	501 Ugandan women aged 18-50 yrs attending HIV clinic	Total survey conducted over 8 months
(Makumbi	Uganda	Prospective	Pre-ART vs.	↑ Incidence	<ul style="list-style-type: none"> - Incidence of pregnancy was 13.1/100 py among 	712 HIV+	Follow up

et al., 2011)	longitudinal study of HIV positive women	receiving ART	of pregnancy on ART vs. no ART Non-significant association between desire and incidence. Association greater when both partners report desires.	women in pre-ART care and 24.6/100 py among women on ART. (IRR= 0.54; 95% CI 0.37, 0.81, p<0.0017). - Incidence of pregnancy associated with higher CD4 counts or improved CD4 beyond 100cells/mm ³ after 12 weeks post ART initiation. - Use of family planning methods was not significantly associated but this study did not separately address hormonal contraceptives. 'Other' revealed a significantly lower incidence in comparison to use of condoms only. - Interviews revealed a non-significant trend of incidence by reported desire for children. Incidence was higher amongst women initiated on ART when both partners reported a desire for children and lower when just the women reported a desire, compared to neither reporting wanting more children. - Prevalence of pregnancy at ART initiation was associated with CD4 count; 12% for those with CD4 counts 100-250 compared with 3.2% for those with CD4<100 (PRR=3.24, CI 1.51-6.93)	pre-ART women and 244 HIV+ women initiating ART	for 48 weeks post initiation of HIV care or ART. Followed weekly for first month, biweekly for next two months, monthly until one year and every 2 months thereafter. Pre-ART Individuals seen every 3 to 6 months.
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(Myer et al., 2010)	Multi-country	Cohort study 11 PMTCT programmes in 7 sub-Saharan African countries.	Pre-ART vs. receiving ART	↑ Incidence of pregnancy on ART (9.0/100 PY amongst women on-ART compared to a pre-ART of 6.5/100 PY)	<ul style="list-style-type: none"> - Use of ART associated with increased incidence of pregnancy (adjusted HR, 1.74) - South Africa has the lowest fertility of all countries (3.29 pregnancies/100 PY compared to a crude rate of 7 pregnancies/100PY) and one of the strongest associations between ART use and fertility out of 11 countries (HR 2.33; 95% CI 0.70-7.73). - Pre-ART risk of pregnancy is relatively constant, peaking at 3 years. On-ART shows increasing risk with duration of treatment. - Non barrier contraceptives were associated with reduced risk of pregnancy (primarily IUD and injectables) 	4531 women, 589 pregnancies	4 years. Every 3-6 months for pre-ART and every month for on-ART
(Schwartz et al., 2012)	South Africa	Prospective cohort from four public ART clinics in Johannesburg	Time since initiation on ART. Planned vs. Unplanned	Unmet need for contraception, but not incidence of pregnancy, associated with time since ART initiation.	<ul style="list-style-type: none"> - Limited to women aged 18-35 - Incidence rate was 21.6 pregnancies/100PYs - 62% of incident pregnancies were unplanned - No significant association with ART duration. Also found upon exclusion of women with a prior pregnancy on ART (data not shown) - Unmet need for contraception was higher in first year since ART initiation and associated with CD4 ≤ 250 cells/mm³ 	850 women enrolled, with 170 pregnancies to 161 women	August 2009 – March 2011
(Tweya et al., 2013)	Malawi	Retrospective cohort using a routine electronic	Time since initiation on	↑ incidence of pregnancy since initiation on ART	<ul style="list-style-type: none"> - Pregnancy incidence was 9.3/100pys - In multivariable Poisson analysis, incidence of pregnancy was significantly associated with current age, WHO clinical stage at ART initiation, BMI during 	4,738 women	July 2007 – December 2010

		data system of a single ART clinic	ART.		follow-up, and time on ART longer than 6 months (RR = 3.25; 95% CI 2.47–4.28).	
(Westreich et al., 2012)	South Africa	Retrospective clinical cohort	Time since initiation on ART.	Incidence of pregnancy and ART regimen	<ul style="list-style-type: none"> - Incidence of pregnancy 5.2/100PYs - Increase in incidence with annual time since initiation - Cumulative incidence of pregnancy was 22% by 6 years on ART - Higher adjusted rate ratio associated with CD4 \geq100 and younger age - Use of lopinavir-ritonavir and Nevirapine based regimens associated with higher univariate incidence compared to Efavirenz, but not in adjusted analysis. 72% of pregnancies exposed to EFV. 	5,996 women, 727 pregnancies

- **Different outcomes reported**

Six studies reported on changes in incidence of pregnancy associated with time since initiation on ART. All presented multivariable analysis of characteristics at baseline and time-updated. These studies were better able to measure maternal clinical characteristics such as CD4⁺, viral load and mental health. Two studies explored whether any changes in incidence of pregnancy differed by type of ART regimen, but few presented comparisons to women before ART initiation and none to HIV negative women.

Four studies presented relative risk of pregnancy and associated indicators compared to ART-naïve women. Two of these also compared desires for a pregnancy between on-ART and pre-ART women. The studies provide evidence for an increased incidence of pregnancy following initiation with ART in sub-Saharan Africa.

- **Direction of an effect of ART on fertility**

A MTCT-Plus study conducted across seven African countries determined higher risk of pregnancy amongst women on ART over time, reaching 80% greater than women not yet enrolled on ART but receiving post-partum care (Myer et al., 2010). The study followed 4,531 pregnant or recently post-partum HIV infected women receiving PMTCT services across seven countries between 2003 and 2007, and women receiving ART experienced more pregnancies (9 per 100 person years) compared to women solely receiving PMTCT services (6.5 per 100 person years). They determined an increased risk of pregnancy with duration of follow up 'on-ART', and reported annual pregnancy rates of 6.8, 9.9, 10.5 and 13.7 pregnancies per 100 WYs at each year for four years since initiation with ART. Independent predictors of lower incidence of pregnancy included younger age, lower educational status, use of injectable contraception, severe HIV progression and low CD4 count. In particular the study noted an association between ART and incidence of pregnancy in South Africa at a hazard ratio of 2.33 (95% CI 0.70–7.73) although this hazard ratio did not reach significance. Disaggregated data was not presented, and authors attributed large variations between cohort sites to differences in

patient demographics and access to contraception and counselling (Myer et al., 2010). However, the large increase in incidence over time in this study may well be attributed to the selection of post-partum women that have already established their fertility to ascertain entry in to the study. This may not reflect generalised population fertility, particularly in HIV infected women, as HIV is a known risk factor for STI acquisition and reduced fecundity.

Regional cohort studies largely show an increased risk of pregnancy with time since initiation. Much recent evidence has emerged from a context of high fertility including Uganda, Malawi and West Africa (Kaida et al., 2013, Homsy et al., 2009, Makumbi et al., 2011) and most studies indicate increasing risk of pregnancy to women over time since initiation following restoration of health on ART (Homsy et al., 2009, Myer et al., 2010, Makumbi et al., 2011); this effect was slight (Westreich et al., 2012) or found not to exist (Schwartz et al., 2012) in studies emerging from South Africa. An initial increase in risk after initiation with ART may be short-lived depending on the context: women were most likely to become pregnant if they had recently initiated ART, with a peak at 6-12 months after ART and a consistent decline until 36 months interrupted by subsequent smaller peaks attributed to recurrent pregnancies at 24 and 48 months (Kaida et al., 2013). In this cohort of women enrolled in the Uganda AIDS Rural Treatment Outcomes study between 2005 and 2011, incidence was high at 9.40 pregnancies per 100 woman years since ART initiation, and partially explained by much higher total fertility rates in Uganda by comparison to South Africa (TFR=6 in Uganda Vs. TFR=2.4 in South Africa). Multiple pregnancies to the same woman were common during follow-up, but only 54% of pregnancies resulted in a live birth, with 21% ending in a stillbirth or miscarriage. 13% of women were still pregnant by the end of study. Of 84 women reporting an incident pregnancy, 15 reported a second and three women experienced a third incident pregnancy. Findings suggest that an association between ART and population fertility could be stronger following recent ART roll out and that a contextual interpretation of results is needed. Predictors associated with higher incidence of pregnancy were younger age and disclosure of HIV status to a partner after more than one year after initiation on ART, suggestive that couples may have been planning to have more children after this time.

- **Factors associated with likelihood of pregnancy on ART**

Factors associated with higher likelihood of pregnancy to women on ART in these nine studies include: younger age, lower levels of education, being married or cohabiting, having a male partner enrolled in a program or disclosure of HIV status to a male partner, non-barrier forms of contraception, duration on ART, an Efavirenz-based ART regimen and higher current CD4 counts.

- **The association between a desire for a child and likelihood of pregnancy**

Four studies evaluating the role of pregnancy desire or planning do not illustrate a straightforward association. Longer duration on ART treatment was associated with desire to have more children in Uganda, although reported desire did not correspond to reproductive behaviours as women on ART for more than nine months had lower odds of pregnancy over 3 years of follow up (Maier et al., 2009). Two further studies from Uganda found no association between desire and incidence (Homsy et al., 2009, Makumbi et al., 2011) Homsy et al determined consistently low pregnancy desires that were not reflective of increasing incidence of pregnancy since initiation on ART (Homsy et al., 2009) and later Makumbi et al found a non-significant trend of incidence by reported desire for children. Incidence was higher amongst women initiated on ART when both partners reported a desire for children and lower when just the women reported a desire, compared to neither reporting wanting more children (Makumbi et al., 2011). Just one study from South Africa determined recorded measures of pregnancy planning to women on ART and reported that 62% of pregnancies were unplanned amongst women aged 18-35 years old on ART (Schwartz et al., 2012). This study reported a large unmet need for contraception and found that unmet need for contraception was higher in first year since ART initiation and independently associated with $CD4 \leq 250 \text{ cells/mm}^3$. Furthermore, women reporting use of only condoms had similar cumulative incidence rates of unplanned pregnancies to women with no contraceptive use, while 34% of women using hormonal contraception reported problems with their method and most (61%) did not discuss this with providers.

An effect of ART on fertility in a population where contraceptive prevalence is high would likely be driven by improvements in quality of life leading to increased sexual activity and/or changes in fertility preferences and contraceptive behaviour (Myer et al., 2010). Major cohort studies are limited by the absence of data on sexual activity or reported fertility desires and information on these factors required a separate search of the literature.

2.8.3 Search Two: The effect of ART on Fertility Aspirations

Deeper understanding of the effects of exposure to antiretroviral therapy on fertility intentions typically emanate from qualitative studies reporting changing needs of women after initiation of treatment and in some areas, higher rates of intended pregnancies that follow the restoration of health on ART (King et al., 2011).

Survey and cross-sectional studies have evaluated the influence of ART use on decisions about childbearing and contraceptive behaviour. All studies report desire to continue childbearing, to varying extents, amongst women on ART. Desires were contextually specific and the following review describes some of the familial, medical, cultural and socio-economic complexities.

- **The prevailing importance of social norms**

Perspectives on childbearing vary according to setting and existing social norms. A systematic review from 12 sub-Saharan countries found no change in reproductive desire associated with HIV prevalence, at a time that authors considered ART coverage as 'sub-optimal' (Nattabi et al., 2009). Educational and economic status and area of residence have been shown to affect reproductive intentions (Hoffman et al., 2008) (Desgress-Du-Lou et al 2002; Nebie et al, 2001). A strong negative association between HIV and fertility aspirations was reported by outpatients of a HIV programme in Uganda, after access to ART became widespread but irrespective of individual ART use (Snow et al.,

2013). In the high fertility setting of Nigeria, however, personal aspirations or intervening social needs for a child would often supersede clinical health concerns (Wekesa and Coast, 2014, Smith and Mbakwem, 2007).

Studies from South Africa show the prevailing social importance of parenthood in the context of HIV and use of ART in this setting of low national fertility (Cooper et al., 2007, Cooper et al., 2009).

Continued or increased desire for parenthood was reported amongst 61 men and women living with HIV, and treatment with ART greater than six months was associated with favourable attitudes to childbearing (Cooper et al., 2007). A cross-sectional study of 311 HIV infected men and women attending a public sector ART service found increasing duration of ART was associated with fertility desire (Myer et al., 2007), and a later survey of women living in Soweto found duration of ART use had no impact on childbearing decision-making (Kaida et al., 2011). ART use was strongly associated with women's fertility intentions in a cross-sectional survey of 459 HIV infected men and women both on ART and pre-ART living in Cape Town (Cooper et al., 2009).

Continued desires for childbearing on ART in South Africa are in accordance with literature from other developing countries (Wekesa and Coast, 2014, Kaida et al., 2006, Kipp et al., 2011, Berhan, 2008). Women that reported a desire for childbearing were typically younger, in a relationship and had fewer biological children. Clinical studies suggest that women are most likely to report intentions for childbearing with higher CD4 count, if partners also desire a child or if they have no living children (Negash et al., 2013, Mmbaga et al., 2013, Kipp et al., 2011). Women appear more likely to desire more children contingent upon availability of both ART and PMTCT services (Cooper et al., 2007), disclosure of HIV status to a partner (Makumbi et al., 2011, Kisakye et al., 2010) and the HIV status of a regular partner (Heard et al., 2007). Other important determinants of fertility include partner desire (Beyeza-Kashesya et al., 2010), pressure from family and desire for an heir (King et al., 2011) and stigma of HIV and childlessness (Kisakye et al., 2010).

- **Desire to preserve health on ART**

Perception of an individual's own health and quality of life appears to be an important indicator of fertility aspirations (McClellan et al., 2010, Mmbaga et al., 2013) and can drive fertility aspirations in spite of serostatus (Kisakye et al., 2010). In a study from Cameroon, 55% of women on ART desired another child, a finding associated with a good physical quality of life and greater knowledge of HIV (Marcellin 2010).

The role of ART in perceptions of well-being is nuanced: in-depth interviews with HIV positive women planning to conceive or recently having delivered indicated that good health related to taking antiretrovirals and eating for optimal nutrition were sufficient to achieve goals for motherhood (Awiti Ujji et al., 2010). Furthermore, consultation with healthcare providers was viewed as interference with fertility aspirations.

- **Partner desires for childbearing**

A limitation of much recent work is the focus on women intentions, ignoring the importance of partner preferences or relationship complexities. In comparison to women, men have expressed greater desires to have a child when on ART (Kipp et al., 2011, Myer et al., 2007, Berhan, 2008) and an association with pregnancy incidence was stronger when both men and women reported desires for a child (Makumbi et al., 2011). Although largely cultural, gender discrepancies may, in part, be explained by the greater risk to woman's health posed by a pregnancy (Berhan, 2008). In-depth research found substantial tensions between sero-discordant couples related to differences in HIV status, also impacting on reduced couple-desires to have children (Rispel et al., 2011). Sero-discordant couples that had enrolled in a PreP study in East Africa expressed largely convergent fertility aspirations (76%). Discrepancies in fertility desire between partners were primarily reported in couples where the HIV-1 uninfected male partner desired additional children but their HIV-1 infected female partner did not (Mujugira et al., 2013). The applicability for the study setting is uncertain however, where marital rates are low and relationship dynamics, more fluid. 41% of

recent mothers reported that they did not know the HIV serostatus of the father of their child in a peri-conception risk cohort of sero-discordant partners in South Africa (Matthews et al., 2014), indicating wider barriers to disclosure and pregnancy planning for women on ART.

- **Contraceptive use on ART**

Contraceptive knowledge is high in South Africa, with 97% reporting knowledge of one modern method. However, knowledge of a modern contraceptive method does not implicitly lead to its adoption (Subramanian et al., 2009). ART may result in changes to fertility through altered contraceptive behaviours, related to either fertility decision-making, or for reasons beyond a woman's own desires for childbearing. Determinants of contraceptive use can vary with setting but access and knowledge of modern methods determined higher rates of contraceptive use in studies from Uganda, Ethiopia and South Africa among women using ART compared to ART-naïve women (Andia et al., 2009, Kaida et al., 2010, Asfaw and Gashe, 2014).

Evidence suggests that women on ART in South Africa tend to choose methods of a less permanent nature than women not on ART (Cooper et al., 2007, Myer et al., 2007). In a cross-sectional study of HIV positive women receiving regular care in Brazil, South Africa and Uganda, current ART users were more likely to report condom use if sexually active (crude OR: 3.64; 95%CI: 1.419-38) but no other methods of contraception (crude OR: 2.15; 95%CI: 0.77-5.99), indicating priorities for both HIV and pregnancy prevention in contraceptive choice (Kaida et al., 2008).

Fertility desire was a dominant factor in contraceptive discontinuation in Brazil and Kenya but not South Africa, where unpleasant side effects such as amenorrhea, excessive menstruation and weight gain were listed as major determinants of contraceptive discontinuation (Kaida et al., 2008).

Perceptions of health are important to contraceptive choice in South Africa: current health concerns were primary barriers to use of the IUCD amongst HIV positive women, with 20.5% of women stating this as a reason compared to 3.9% of HIV negative women (Credé et al., 2012). Side effects of contraceptive use deterred contraceptive use amongst HIV positive women in Soweto, where

perceived vaginal wetness and amenorrhea related to injectable contraceptive use were barriers to use of this method (Laher et al., 2009). Elsewhere, overall contraceptive use remained low due to fears of side effects, despite high knowledge amongst sero-discordant couples from Zambia and Rwanda (Grabbe et al., 2009).

- **Planning for a pregnancy**

Little evidence was found of an association between fertility desires and patterns of contraceptive use or fertility rates, before the introduction of ART (Gray et al., 1998, Rutenberg et al., 2000, Bova and Durante, 2003). Further, the HIV epidemic is reported to have had little impact on sexual behaviours in some settings (Oster, 2005). Importantly, a relationship between reported desires and resulting fertility to women on ART is not well established (Homsy et al., 2009, Makumbi et al., 2011, Maier et al., 2009). This may be attributed to inadequate measures of fertility intentions or demand for family planning in the wake of ART roll out (Kaler et al., 2012).

Rates of unintended pregnancies remain high in South Africa and in this context, an effect of ART on childbearing desires may be negligible: a study found 62% of recent pregnancies were unplanned in a cohort of women on ART and aged between 18 and 35 years old (Schwartz et al., 2012). Despite an association between HIV status, fertility desire and incidence of pregnancy, 69% of recorded pregnancies were unplanned amongst women in Zimbabwe before ART was available (Feldman and Maposhere, 2003). In KwaZulu-Natal, around one half of women who did not intend to have a child reported using contraception (Subramanian et al., 2009). Other qualitative studies have found that women on ART continue to have children 'accidentally' (King et al., 2011), feel satisfied with current family size, or do not wish for more children (Kaler et al., 2012, Heys et al., 2012). Women reporting intentions to have children are more likely to engage in risky sexual activity (Ezeanochie et al., 2009, Dessie et al., 2011), while concerns regarding re-infection pose a deterrent to childbearing for some, even in the era of ART (Forrest et al., 2009).

- **Family planning services and planning for a child**

Family planning services have an important role in determining access to services, provision of the available contraceptive method mix, fees charged, attitudes of clinic workers and the comprehensive nature of family counselling (Grabbe et al., 2009). Convenience and provider recommendations were important in contraceptive method choice to women in the Western Cape, while exposure to family planning counselling strongly determined method use (Credé et al., 2012). Elsewhere, perceived negative attitudes of health workers have also been cited as deterring women from future childbearing (Cooper et al., 2007). Many clients reported discussing contraceptive use with a healthcare provider in a cross-sectional study of 227 women attending an ART outpatient clinic in Cape Town, yet women revealed very little knowledge of emergency contraception (7%) and termination of pregnancy (13%) despite these services being free and available (Myer et al., 2007).

2.9 Gaps this thesis addresses

Few studies address attitudes to contraceptive use and safe conception practices amongst women living with HIV on ART in sub-Saharan Africa. Many studies investigating an impact of ART on fertility rely on data from Europe and the U.S or countries in sub-Saharan Africa where contraceptive use is low. Studies are often limited by lack of behavioural and physiological data or the absence of an appropriate counterfactual group for women on ART. This study provides a novel comparison of fertility between HIV positive women on-ART, ART-naïve HIV positive women and HIV negative women.

Data on childbearing decisions have relied on survey measures that do not often explore nuances in the way that ART may affect long term desires to avoid or achieve pregnancy (i.e. in a period of postponed decision-making.). Furthermore, interpretations may be limited by measures that depend on 'Western' concepts of planning for a pregnancy. This study uses semi-structured interviews to determine emergent themes amongst women on ART.

National contraceptive guidelines have outlined a commitment to delivering integrated contraception and HIV services, yet implementation is still lacking. Studies report high levels of unplanned pregnancy, an absence of support for safe conception and frequent discontinuation of contraceptive methods amongst women on ART in South Africa. There is a gap in the understanding for how family planning can be optimally delivered to HIV positive women accessing HIV treatment services in rural areas of South Africa, and specifically, the Hlabisa district of KwaZulu-Natal. This thesis seeks the perspectives of health workers on family planning, with the intention to determine how services could be adapted to respond to family planning needs of HIV positive women in the specific context of Hlabisa in KwaZulu-Natal.

Chapter Three

Methodology and Data Analysis

3.1 Aim and objectives

A literature review described in Chapter Three was conducted to inform the study aim and three research objectives, outlined below.

Study aim

To determine how national scale up of anti-retroviral therapy has influenced rates of live birth and attitudes to childbearing amongst women living with HIV in a rural setting of South Africa

Research objectives

- I. Investigate whether use of ART is associated with women's likelihood of experiencing a live birth in the Hlabisa sub-district of KwaZulu-Natal.
- II. Explore how use of ART influences fertility and family planning desires amongst women on ART.
- III. Determine the role that HIV treatment and care programs play in the provision of family planning services, including client's expectations of family planning and whether they feel their expectations are being addressed.

Methodological approach

Three research objectives were addressed in this study using both qualitative and quantitative methodology. An analysis of demographic surveillance data emphasised the value of a qualitative investigation, which forms the primary data collection component in this thesis. The following describes the methodology used to achieve each objective:

Objective I: Investigate whether use of ART is associated with women's likelihood of experiencing a live birth in the Hlabisa sub-district of KwaZulu-Natal?

The first objective was addressed with an analysis of demographic surveillance data collected by the Africa Centre, to:

- Describe the rates of live birth in the Hlabisa sub-district since roll out of ART in 2004
- Quantify the likelihood of live birth associated with use of ART, allowing for potential confounders and compared to HIV positive ART naïve women and HIV negative women.
- Assess the influence of ART on rates of contraceptive use as a proximal behavioural determinant of fertility.

Objective II: Explore how use of ART influences fertility and family planning desires amongst women on ART.

The second objective was answered through qualitative semi-structured interviews to explore:

- How being on ART influences childbearing desires
- How being on ARTs influences attitudes to contraceptive use and where family planning services are accessed.
- How clients expect to be supported by ART services at conception or during a pregnancy

Objective III: Determine the role that HIV treatment and care programs play in the provision of family planning services, including client's expectations of family planning and whether they feel their expectations are being addressed.

The third objective was answered through qualitative semi-structured interviews and clinic observations to explore:

- Satisfaction with the availability of the contraceptive method mix and provision amongst women accessing the ART programme

- The family planning experiences of women that have delivered a child within the ART programme (i.e. access to safe conception counselling and information in the clinics, referral services, attitudes of health care providers)
- Facilitators and barriers to optimal family planning for women on ART relating to partner, family and community values or service delivery.

Results are presented in three chapters in the sequence that each objective was studied. Chapter Four presents' results of objective one, Chapter Five objective two, and finally, Chapter Six presents objective three.

3.2 Candidate's role in study design and conduct

Overview

This section describes the candidate's role in each phase of this study. Details of the methodology can be found in sections 3.3 and 3.4. My role in the conceptualisation of the study is described at the beginning of this thesis.

Once the study had been conceptualized and the research questions developed, I conducted a sequence of quantitative analyses, and used these results to inform the following qualitative study. I began with a preliminary analysis of demographic surveillance data, then designed and constructed a unique cohort from a compilation of existing datasets, performed data consistency checks and finally selected and applied survival analysis techniques to the cohort. The details of my role are presented below.

Role in the quantitative analysis

Upon arrival to the Africa Centre, I conducted descriptive analysis of crude birth rates in the demographic surveillance area to familiarise myself with the data available in the Africa Centre

Demographic Information System and to describe general fertility in the setting. A summary of the surveillance procedures and the data available are shown in Box 3.2.I.

Box 3.2.I An overview of demographic surveillance undertaken by the Africa Centre

- Since 2001 the Africa Centre has annually captured demographic information from a defined surveillance area.
- This surveillance includes 16 ‘core’ questionnaires and 5 additional ‘modules’
- ‘Core’ questionnaires capture household and individual information including births, deaths and migrations
- A key informant, usually the head of household, is asked to give consent for participation and to respond to core surveillance questions.
- Additional ‘modules’ include Women’s General Health and HIV surveillance.
- Core questionnaires and modules are all administered at the household by trained fieldworkers.
- Data capturers then enter information in to separate datasets that are each unique to a questionnaire round and compose the ‘Africa Centre Demographic Information System’, known as ACDIS.

I used these analyses to inform the design of a unique cohort of HIV positive and HIV negative female residents. In April 2010, I submitted a request for data to the Africa Centre data manager to access all ‘core’ and three of the five ‘module’ datasets: Women’s General Health, HIV, and Household Socio-Economic. I requested every annual dataset since 2001 and later updated this request for new surveillance rounds until December 2012.

The 2007 HIV surveillance dataset served as the basis for my unique dataset, to which I first merged annual HIV surveillance datasets between 2008 and 2012. Merges were possible by linking individuals through a unique identification number and I used this feature to add variables from other core and module datasets between 2007 and 2012. Variable selection is described in greater detail in section 3.3.6. With each merge I also cleaned the data; duplicate, missing and erroneous data were identified through cross-tabulations and resolved through consistency checks with other variables. I corrected any errors in the merge coding or discussed discrepancies with data managers and removed duplicate records. Once clean, I applied exclusion criteria to prepare this cohort

dataset for analysis, as detailed in section 3.3.4. This unique cohort dataset provided the basis of three longitudinal analyses.

I received training in techniques for longitudinal analysis during a short course on ‘advanced statistical methods in epidemiology’ at the London School of Hygiene and Tropical Medicine. I also received consistent informal support from staff and researchers at the Africa Centre to conduct complex analysis using STATA 11. The training helped to inform my decision to use Poisson and Cox statistical techniques for an open and a closed cohort analysis as presented in Chapter Four.

Role in qualitative study

To address this study’s qualitative research aims I decided to conduct semi-structured interviews with clients and health workers of the local HIV treatment and care programme. I was responsible for the design of this study and developed both client and health worker interview protocols. I decided a semi-structured tool was most appropriate because I had identified thematic areas of interest, but also hoped to capture emerging themes during the interviews. Before piloting, I sought and received ethical approval from University College London and the University of KwaZulu-Natal. I recruited an isiZulu speaking research assistant (RA) and prepared a training booklet, which I used during a week of training. I arranged and attended practice interviews between the RA and researchers within the Africa Centre and a later pilot in a local clinic, so that I could provide further training and gain an understanding of the contexts of the interviews.

I observed three initial interviews conducted by the RA with clients in the clinics and provided feedback on how to improve interview conduct and probing. I waited outside of the room for the remaining interviews and arranged an immediate debrief with the research assistant, including a review of her field notes. The research assistant transcribed and translated all client interviews, with added details and interpretations of local or cultural nuances.

I conducted all health workers interviews in English. I piloted the health worker interview tool in a local clinic, conducted 12 interviews and made field notes during each interview. I transcribed electronic recordings of interviews on an on-going basis and used these results to inform areas that needed additional probing. When needed I sought the perspective of my research assistant to explain cultural nuances that I did not understand and to check consistency with client interviews. Finally, I adapted a tool from Johns Hopkins to conduct standardised observations of family planning delivery in each HIV treatment and care facility where interviews were conducted.

I undertook the qualitative analysis of both client and health worker interviews. I first summarised data using an excel spreadsheet as interviews were conducted. I later completed a QSR two-day course to inform my conduct of a framework analysis using Nvivo software. Details of the qualitative methodology are provided in section 3.4 and the discussion from this analysis is provided in Chapters Five and Six.

3.3 Quantitative Methodology

3.3.1 Population

The Africa Centre Demographic Surveillance Area

The Africa Centre for Health and Population Studies is situated in the Hlabisa sub-district, in the remote uMkhanyakude district of northern KwaZulu-Natal, South Africa. The area is largely rural and unemployment in Hlabisa is high (52.6%), with most individuals engaging in household-based subsistence. Of these, 60% of households are female headed, reflecting common patterns of male migration. Where local employment is available, it is typically in the form of commercial sugar cane farms, forestry or tourism. The population is predominantly Black African (99.4%), and isiZulu is the most commonly spoken language (94.4%) (STATSSA).

The Wellcome Trust established the Africa Centre in 1997/8 with the mission to 'conduct policy relevant health and population research, in an ethical manner, in partnership with the community in which it works'. The Africa Centre conducts demographic, epidemiological and evaluative health and population research in this setting where the HIV burden is immense. The Africa Centre Demographic Information System (ACDIS) is a collection of datasets, each containing information gathered by fieldworkers who administer different demographic surveillance questionnaires during frequent household visits. ACDIS is explained in more detail in section 3.3.2. The demographic surveillance area (DSA) spans a 438km², including 12,000 households and approximately 90,000 Zulu-speaking individuals. At any point in time, about a third of these individuals are non-resident members of households, and one quarter are women of childbearing age (Tanser et al., 2009).

Residents are defined as 'a member of a household who normally lives at the same bounded structure as the household, whereas a non-resident member does not' (Herbst et al., 2009). To 'normally' reside in a household, the Africa Centre makes the distinction that residents would 'have spent most of their nights at the bounded structure in the six months since the last round', while non-resident members 'live elsewhere for most of the time, and whenever they visit the household at its bounded structure, they always leave again'. The distinction between resident and non-resident is made by the fieldworker according to the following three criteria: the opinion of the key informant, how much time the person spends at the bounded structure and whether the person has recently moved into or out of the bounded structure. Most residencies are clearly defined by the presence or absence of an individual in the homestead within the last 6 months and labelled with a unique individual identifier 'IntID' in the datasets.

Patterns of migration are frequent in the area and 'residency' differs to the concept to household membership. Membership reflects the household social structure that changes usually through birth or marriage. In this definition, migrant workers may remain a member of a household but may be considered a non-resident if living outside of the DSA at that time.

Residents of the Centre's surveillance area are served under the health infrastructure of the Hlabisa-sub-district, typical of many other rural health districts in KwaZulu-Natal. Hlabisa district hospital offers primary health care services, including routine antenatal, prenatal and postnatal care, family planning, preventive child health services, treatment for TB, STI's and non-communicable diseases, in-patient care, additional curative and emergency services.

The Hlabisa HIV Treatment and Care Programme (ART programme)

The Hlabisa HIV Treatment and Care Programme was initiated in 2004 as a joint effort between the South African Department of Health and Africa Centre to provide 'safe, effective, efficient, equitable and sustainable ART' free of charge (Africa Centre for Health and Population Studies). It supports the integration of HIV services into PHC, aiming to link treatment and care with prevention services (Houlihan et al., 2011).

ART is provided at the 17 local primary health care clinics in the sub-district, staffed with counsellors and ART nurses. Six of these clinics and 40% of patients are located within the Centre's surveillance area. One of the six clinics is particularly large and the only clinic to offer 24 hour delivery facilities for uncomplicated cases (Houlihan et al., 2011). Figure 3.1 illustrates the distribution of the 17 PHC clinics and shows the boundaries of the Africa Centre surveillance area (in yellow) and Hlabisa district hospital.

The programme follows the South African DoH guidelines on HIV diagnosis, ART eligibility, screening, treatment regimens and follow-up (Houlihan et al., 2011). In 2011, national guidelines on ART eligibility were revised and extended to include any HIV infected person with a CD4 <350cells/mm³, all pregnant women and anyone with TB irrespective of their CD4 count (WHO, 2010a). Efavirenz constitutes standard first line regimen but women that are pregnant, or planning pregnancy, are placed on alternatives such as Nevirapine or Lopinavir-ritonavir due to concerns for teratogenicity (SADoH, 2007a, SADoH, 2010). Clients are initially followed up at two weeks in order to assess

adherence and toxicity and are then seen monthly by a nurse and counsellor. Monthly visits include group and individual counselling sessions before collection of treatment.

Guidelines were updated in 2004 and again in 2010 and 2011. 2010 guidelines included all HIV positive patients with CD4 <200 cells/mm³ as eligible to start treatment, irrespective of clinical stage (SADoH, 2010). People with TB and HIV and pregnant women could start treatment at CD4 <350 cells/mm³. People with WHO stage 4 or drug resistant TB should start ART irrespective of CD4 count. The 2004 guidelines only included adults with clinical stage 4 disease or a CD4⁺ count <200 cells/mm³ (SADoH, 2004). The 2011 guidelines increased eligibility to <350 cells/mm³ (SADoH, 2011).

The National Health Laboratory Services at the Hlabisa district hospital have provided CD4 and Viral Load monitoring for HIV positive individuals for the Department of Health since 2008 and 2009 respectively. A first positive rapid HIV ELISA is confirmed by a second test; a venous blood ELISA is requested if results are discordant. If the first rapid test is negative, repeat testing is recommended every 6 months. CD4 and viral load monitoring are performed 6-monthly. CD4 counts are analysed using Beckman Coulter EPICS® XL flow cytometer (Beckman Coulter, Inc.); viral loads using Nuclisens EasyQ® HIV-1 assay (Biomérieux) with a lower detection limit of 25 copies/ml (Houlihan et al., 2011).

Most people access treatment at their nearest clinic. Reflective of elsewhere in South Africa, ART initiation in this setting is more likely in women at a time of pregnancy, individuals older than 25 years, in patients with low CD4 counts and those engaged in HIV treatment and care prior to eligibility (Bärnighausen et al., 2013, Plazy et al., 2014). Incidence of disengagement from care was estimated at 3.4 per 100 person years (95% CI 3.1 – 3.8) amongst individuals initiating ART between 2004 and 2011 (Mutevedzi et al., 2013).

3.3.2 Existing Data systems

The Africa Centre Demographic Information System (ACDIS)

The Africa Centre Surveillance has collected data on births, deaths, migration, and marriage since 2000. Trained fieldworkers administer a range of demographic questionnaires to resident and non-resident members of all households included in the demographic surveillance area.

The initial household surveillance in 2000 involved a complete census of all homesteads (places of residence), households (social groups) and individuals, and collected demographic data as well as detailed reproductive histories from all women of reproductive age (Tanser et al., 2008). Since then, fieldworkers have collected socio-demographic data at six-monthly intervals (every 4 months from 2012). Responses are recorded from a key household informant, usually the head of the household or the most senior member present when fieldworkers visit (Tanser et al., 2008). Key informants decide on household membership, and continue to provide information on members of their household who live elsewhere (Herbst et al., 2009). Fieldworkers administer 16 'core' questionnaires on individuals, households, bounded structures, residencies, conjugal relationships, deaths, household residencies, migrations, pregnancies and vaccinations

Fieldworkers also administer five individual 'module' questionnaires once a year, in addition to the 'core' questionnaires, including Women's General Health, Men's General Health, HIV surveillance, Household Socio-Economic status, Illness and Death, and Verbal Autopsies. Depending on the module, questions are usually directed to the individual of interest where available rather than a key informant. Core and module questionnaires may be administered at different times (rounds), as to not overburden the fieldworker and the household.

Data capturers collate and enter the information from each questionnaire round into a corresponding dataset, unique to that questionnaire and round. It is these individual datasets that constitute the Africa Centre Demographic Information System (ACDIS) (Tanser et al., 2008). Each

dataset contains an individual identification number so that individual information may be linked from any dataset and any round. Data managers at the Africa Centre link information from the 16 'core' datasets to provide a general 'Demography' dataset that is accessible to visiting researchers.

ACDIS is the collective term to describe a suite of 16 'core' demographic datasets, 5 additional 'module' datasets, and the composite 'Demography' dataset.

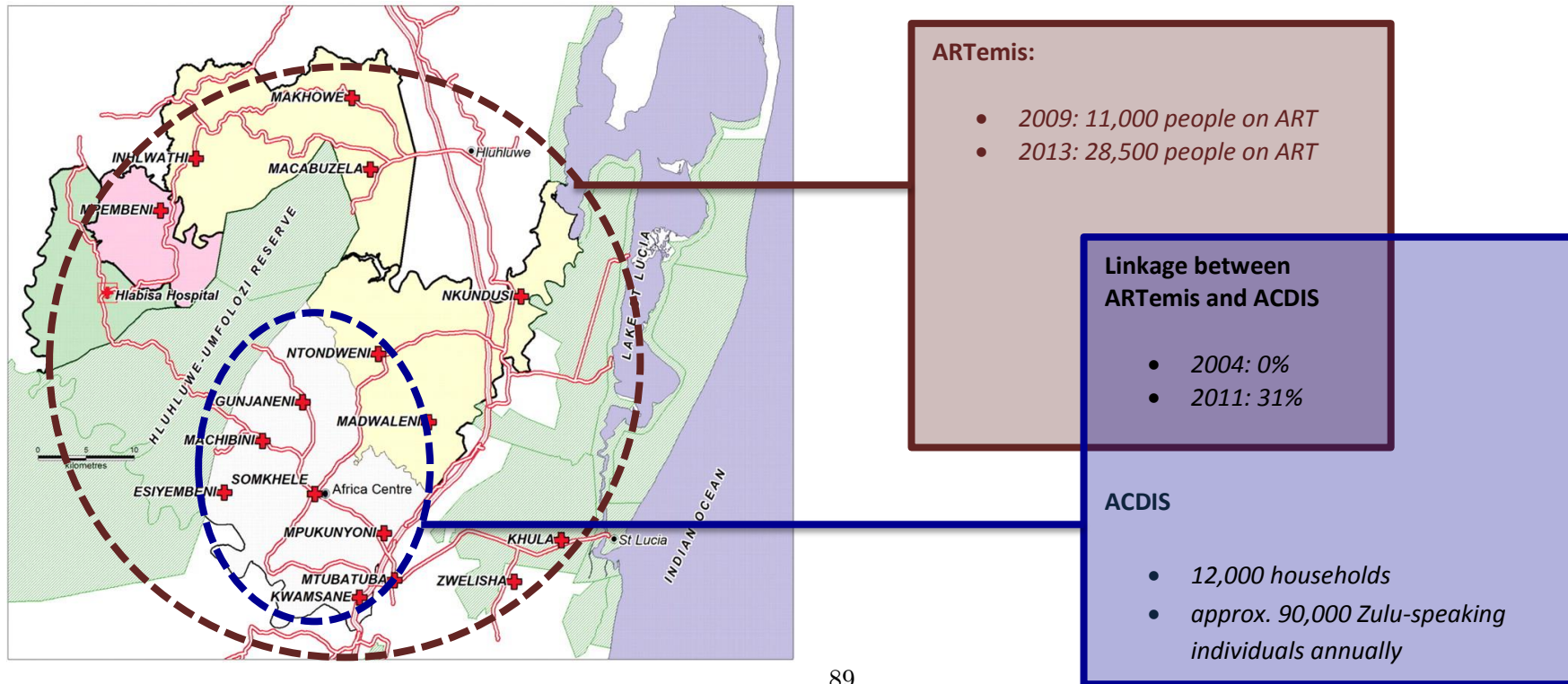
ARTEMIS: the clinical database

Clinical ART data is recorded in ARTEMIS, a large operational database developed and hosted at the Africa Centre. ARTEMIS contains information on any person that has accessed services for HIV testing, CD4 counts and dates of ART initiation and follow up visits. The ARTEMIS database recorded women's first line regimen but health providers did not always update changes and this information was not available for analysis (Colin Newell, personal communication).

By the end of 2009, more than 11,000 patients were on treatment in Hlabisa with approximately 300 new patients being initiated on treatment every month; by end September 2013 there were over 28,500 people on ART in the sub-district. In the surveillance area, ART coverage of all HIV infected individuals was scaled from zero in 2004 to 31% in 2011, at a time when HIV prevalence increased from 21% to 29%, and was attributed to improved survival of people living with HIV on ART (Zaidi et al., 2013).

With ethics permission it is possible to link data from the HIV treatment and care database to that of the surveillance database, for people that reside in the surveillance area (Plazy et al., 2014) as illustrated in Figure 3.1.

Figure 3.1: A map of the Hlabisa sub-district, showing coverage by the Africa Centre Demographic Surveillance Area and the HIV treatment and care database, ARTemis. The distribution of the 17 PHC clinics and Hlabisa district hospital are marked with red crosses. Coverage of the HIV treatment and care programme area, and data captured by ARTemis, is circled in red. The Africa centre demographic surveillance area is circled with a blue line and includes 6 PHC clinics (excluding Mtubatuba) (Houlihan et al., 2011)



3.3.3 Dataset construction

I created my own unique dataset for the purpose of this thesis. The use of individual woman identification numbers made it possible to extract and link information from the Africa Centre Demographic Information System (ACDIS) and the clinical database, ARTemis. Initially, I used two ACDIS module datasets, the Women's General Health and HIV surveillance, as the basis of this new dataset. Additional ACDIS datasets and clinical ARTemis data linked to this bespoke cohort are summarised in Table 3.1.

ACDIS datasets used to define entry to cohort

Women's General Health (WGH)

This questionnaire asks all women questions about self-reported health, sexual partnerships and contraceptive use. Since 2000, information has been collected once a year and is entered and stored in separate annual WGH datasets. Every year, a new dataset lists women that participated in the WGH round, the date of the household visit, and their categorical responses to individual questions. Individual data are anonymised and listed according to a unique identification number. With some minor modifications to the questionnaire design over time, annual WGH datasets include the same variables and woman row structure each year. The unique identification number allows researchers to merge these annual WGH datasets, and indeed any core or module dataset, to create a longitudinal cohort for follow up and analysis.

HIV surveillance

Introduced in 2003, HIV surveillance includes approximately 10,000 adults of 15 years or older each year (Tanser et al., 2008). The HIV surveillance includes a questionnaire that asks about topics such as knowledge of HIV status, awareness of treatment, serious morbidity and health. HIV surveillance also asks participants to provide a finger prick blood sample to be tested in the Africa Centre virology

laboratory in Durban. Results of individual tests are not given to the participants, who are instead encouraged to access the well-functioning HIV treatment and care programme in the area (Houlihan et al., 2011). Information about individual HIV status is thus included in the HIV surveillance dataset even if individuals are not aware of their own HIV status.

Operational design of HIV surveillance

Operational changes have been made to the HIV programme's design since 2003 (Reynolds et al., 2013). For those interviewed adults who wished to access their results, HIV test results were initially delivered by trained counsellors at community centres within the DSA (Welz et al., 2007). However, consent rates to test for HIV declined from approximately 60% in 2003-2004 to 40% in 2006 (Tanser et al., 2008). In response to a decline in consent rates for participation, rapid HIV testing was offered during home visits in 2007 in addition to the anonymous finger-prick sample. Fieldworkers made 10 different requests for consent to partake in HIV testing, and allowed the individual the choice to receive results at home, at a counselling clinic or for referral for another test. However, attendance at purpose built counselling clinics was low and fieldworkers raised ethical issues of result communication and household confidentiality. This approach was replaced with a system of referral from HIV surveillance to the local HIV treatment and care programme, whereby individuals that wish to have their result may do so through linked, anonymous voluntary HIV testing. The strategy was informed by an internal operational review, discussion with the Community Advisory Board (Reynolds et al., 2013) and recommendations of the Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO) Guidelines for Using HIV Testing Technologies in Surveillance, first published in 2001 and updated in 2009 (Martin et al., 2001).

An ethical review process followed in 2010 and described extensive confusion around the purpose of HIV testing during surveillance. The HIV programme has since been clear to articulate a difference between 'surveillance' and 'testing', separating the philosophies of population surveillance and individual knowledge. Informed consent now explains the purpose of surveillance as to assist the community. Language of 'testing' shifted towards 'analysis' and the collection of bloods specimens

expanded to include more biomesasures (Reynolds et al., 2013). Mobile testing services now visit households after HIV surveillance has been conducted, to offer voluntary HIV testing and counselling as a distinct service under the Department of Health Hlabisa HIV treatment and Care programme. It was hoped that the separation would improve participation in the DSA. Further, shorter travel distances and the immediacy of access to HIV testing and counselling, without lengthy referrals through the Africa Centre, are advantageous to individuals. However, a high frequency of HIV testing within the DSA could prevent individuals from participating in the surveillance where they see no added benefit.

Table 3.1 A description of data contained in the Africa Centre Demographic Information System datasets and the ARTemis database used in this study. Adapted from (Houlihan et al., 2011) and <http://www.africacentre.ac.za>

Africa Centre Demographic Information System (ACDIS)	
Dataset	Examples of data collected
Individual socio-economic data	Annually collected information regarding age, sex, membership of household, education, employment, receipt of grants.
HIV surveillance	VCT history, dried blood spot for HIV status determination offered
Women's General Health	Pregnancy history, contraceptive use, sexual activity (Women are still included if they are resident but they or a key informant refused to answer questions that year.)
Deaths	Location of death, description of circumstances, verbal autopsy data
Pregnancy	Pregnancy outcomes, delivery environment, birth weight
Demography	Composite dataset linking most household and module data to residency for all years. Most data manipulation is already done in this composite dataset.
HIV Treatment and Care database (ARTemis)	
Basic details	Age, sex, address, South African ID number, contact details, treatment clinic
ART record	WHO clinical stage, Previous ART and/or PMTCT, ART regimen at initiation, changes in ART regimen during treatment
Laboratory data	Baseline and 6-monthly CD4 and HIV viral load, baseline haematology and biochemistry
Clinic visits	Receipt of treatment

3.3.4 Process of dataset construction

Women were included in a unique longitudinal dataset if they participated in at least one round of Africa Centre HIV surveillance between 2007 and 2012. The 2007 HIV surveillance dataset formed the basis, to which subsequent 2008-2012 annual HIV surveillance datasets were then added. This process is depicted in Figure 3.2. Exclusion criteria were first applied to each annual HIV surveillance dataset. Individuals were excluded if they were:

- Non-resident
- Male,
- Aged under 15 years old or above 49 years old
- Not included in the Women's General Health survey that year

Non-residents were excluded because changes in ART use, relationship status and contraceptive use are unlikely to be captured as often during surveillance. Men and women aged <15 or >49 years old are routinely captured during HIV surveillance but were not of interest to this study. Participation in Women's General Health was required for analysis of sexual and health characteristics. Participation and the proportions excluded with each criterion were comparable between annual datasets (Figure 3.2). Further eligibility criteria were determined by each cohort design and analysis strategy and are reported in sections 3.3.9 and 3.3.10.

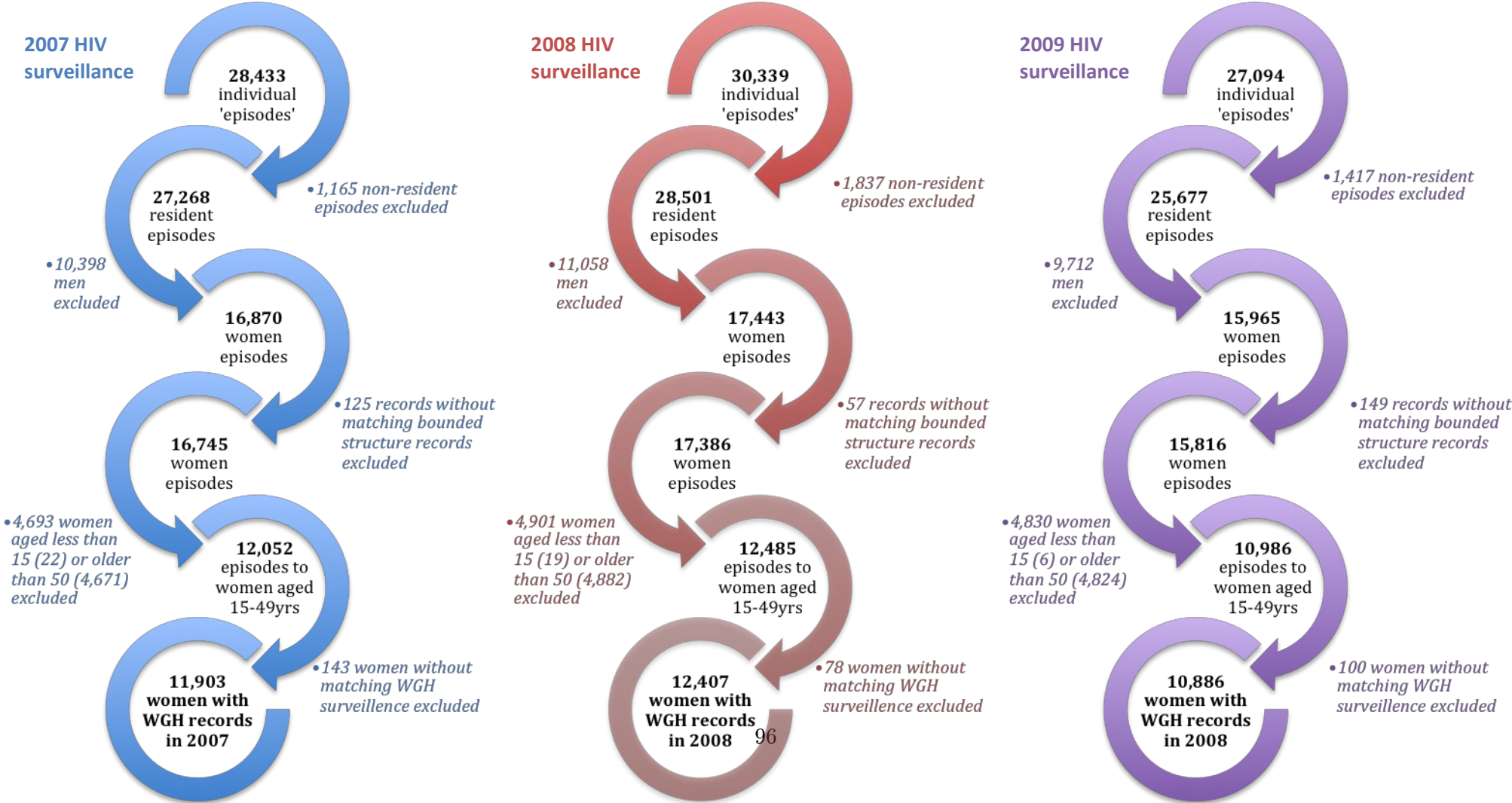
The modified annual datasets were merged in Stata 11 to create a longitudinal cohort. Socio-economic and birth data was linked from additional ACDIS datasets and a demographic composite dataset. Inconsistencies in the data were checked using cross-tabulations and were removed. Duplicate records and records following a gap in participation were also excluded. This latter criterion aimed to exclude any women that migrated and could have had an unrecorded pregnancy outside the DSA.

ARTemis data was linked to 26% of the resident women episodes in this cohort, including women that have enrolled on ART and HIV positive ART naïve women in the DSA. The date of ART initiation was recorded in the ARTemis database and used to censor the end of an 'ART-naïve' episode and the beginning of a new 'ART-exposed' episode for this time dependant covariate.

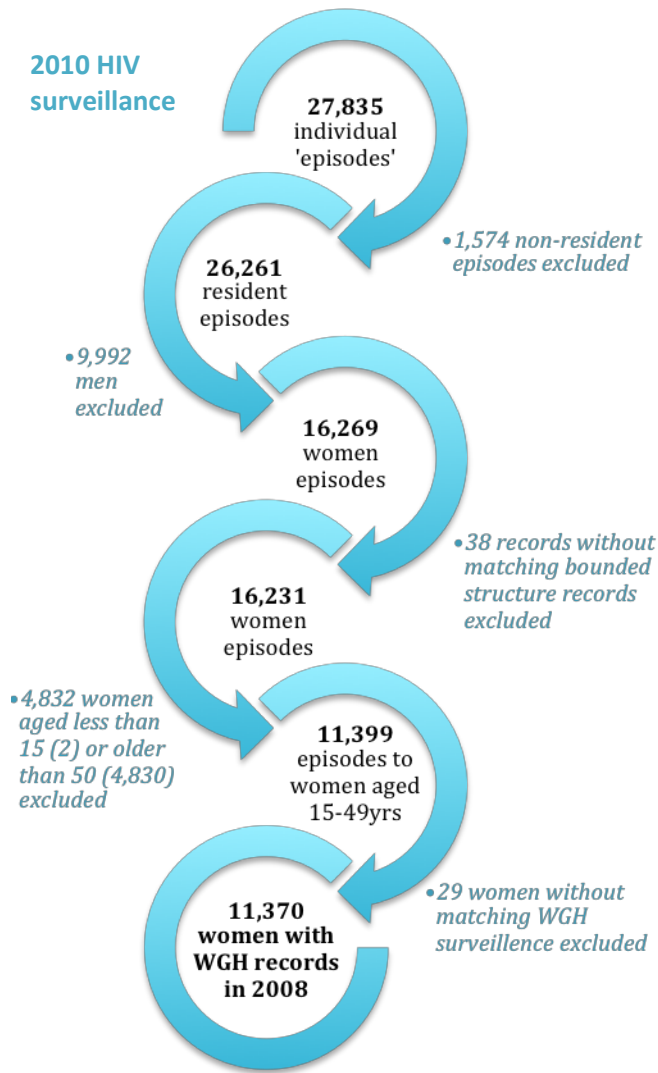
Two cohort analyses were conducted using this bespoke dataset. Based on a preliminary analysis of the data reported in section 4.1, women were excluded from both cohorts if they reported never having sex or refused to answer the question 'have you ever had sex?' in the Women's General Health survey. The purpose was to avoid a biased comparison of birth rates between HIV negative and HIV positive women in a setting where HIV infection is a strong predictor of sexual intercourse.

Women of unknown HIV status were excluded from the first (open) cohort. The second closed cohort excluded entry after 2007/2008 but included women with missing information about HIV status. The final number of women and corresponding 'episodes' in dataset are presented in figure 3.2.

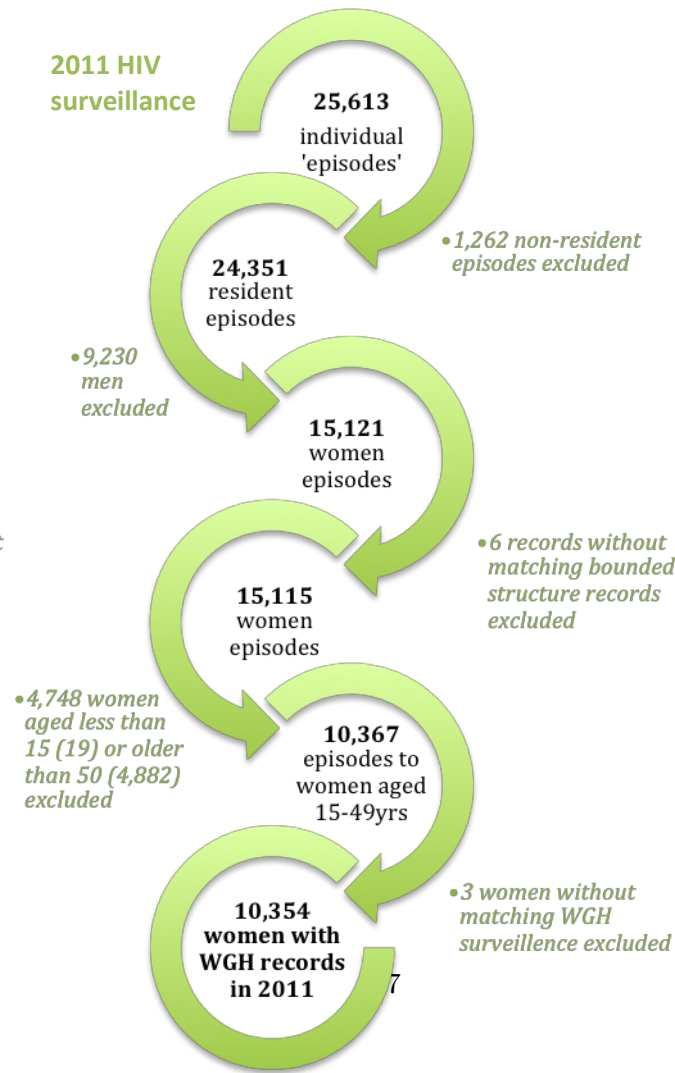
Figure 3.2 A series of flow diagrams to depict a) the application of exclusion criteria to each annual HIV surveillance dataset and b) the cohort dataset construction process



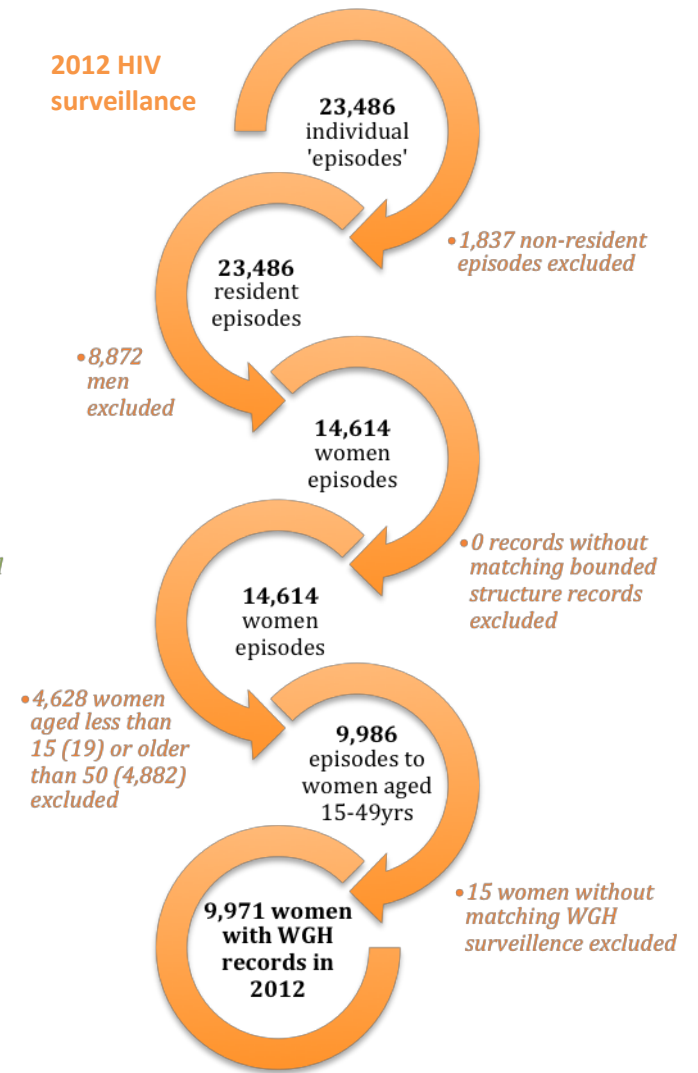
2010 HIV surveillance

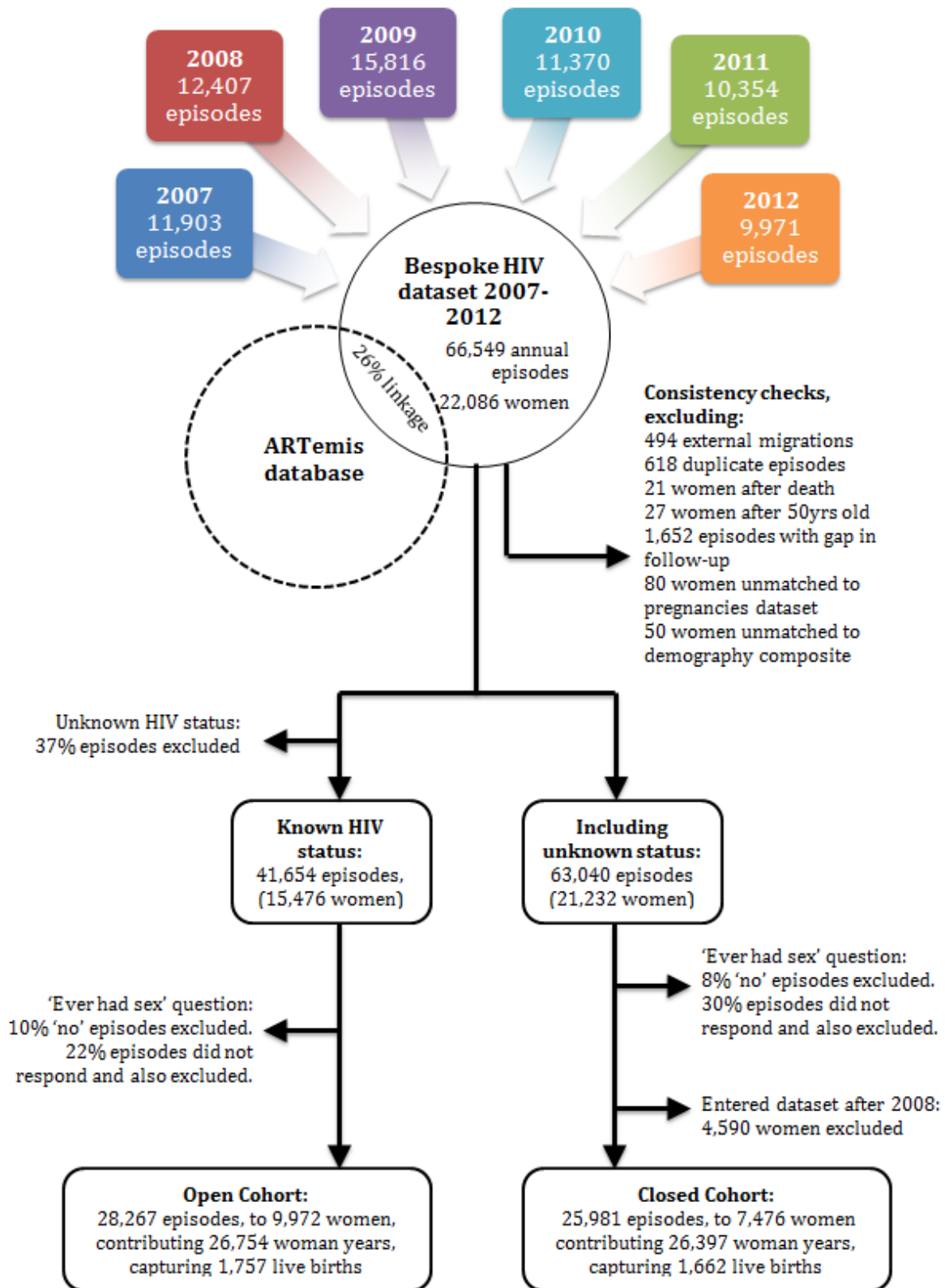


2011 HIV surveillance



2012 HIV surveillance





3.3.5 Description of dataset and woman 'episodes'

Women could first enter the unique dataset via 2007 household HIV surveillance and have multiple annual records, dependent on participation in subsequent years of HIV surveillance. Each record has a start and end date that describes the time a woman is observed. Records were further split to allow for time-updated survival analysis of characteristics, such as a change in age category or initiation on ART. 'Episodes' refers to these woman-specific and time-updated records in the dataset.

The start of a 'women episode' is determined by the date of a household visit during HIV surveillance. Women-episodes were measured in days until censored by the next annual surveillance, or right censoring. Women were included in the unique dataset in later rounds even if they did not participate in 2007, or earlier rounds. All women were categorised as HIV positive, HIV negative or HIV 'unknown' and information was updated with each survey round. A new positive HIV diagnosis marked the start of a new episode, with a new start date estimated from the date of sero-conversion.

Individuals exit the cohort if they migrate or do not participate in the next annual round. Women were censored at 365.25 days after first observation if they either refused to participate in next annual HIV round or had a 50th birthday during that year and were no longer eligible for analysis. Loss to follow up was determined by information in the 'EndofResidency' variable taken from the Individual residencies dataset. 494 women were dropped due to lack of follow up information after migration. A small number of cases (80) could not be linked and were not included.

3.3.6 Quantitative analysis plan

Outcome measures

I selected a live birth outcome, and not conception, as the least biased description of the available data. A conception outcome would better to compare behaviours leading to a pregnancy. However,

bias could be introduced in this analysis because HIV positive women are known to experience more adverse pregnancy outcomes than HIV negative women, and this information was likely not well captured by surveillance. Analyses that estimate a date of conception from birth data would overlook differences in stillbirths, miscarriages and abortions. Inferences would then risk incorrectly attributing all variance in rates of 'conception' to differences in pre-conception behaviour, without accounting for the unknown adverse physiological effects of being HIV positive or taking HIV treatment.

I chose to report the likelihood of live birth because this is an important demographic indicator for population growth that captures the effects of ART on both behavioural and physiological mechanisms of fertility. Chapter Four presents the results of four demographic surveillance data analyses, using different analytical approaches to report either rates or likelihood of live birth.

- I. Annual trends in live birth between 2005 and 2012
- II. Incidence and factors associated with risk of live birth amongst women known to be either HIV negative or positive during annual surveillance rounds 2007-2012 (open cohort)
- III. Birth-free survival in a cohort of women including 'unknown' HIV status (closed entry in 2007/2008)
- IV. Incidence and factors associated with contraceptive use

Analysis one presents crude annual birth rates to women included in the Africa Centre composite 'demography' dataset. It spans Jan 1st, 2005 until Dec 31st, 2012 and excludes women that were not resident or aged 15-49 years old. This analysis refers to the United Nations (UN) definition of Crude Birth Rates (CBR) and Age-specific Fertility Rate (ASFR) as study outcomes:

Crude Birth Rate:

“The number of births over a given period divided by the person-years lived by the population over that period. It is expressed as number of births per 1,000 population”.

- *World population prospects glossary. United Nations population division*
-

Age-specific Fertility Rate:

“The annual number of births to women of a specified age or age group per 1,000 women in that age group. Unless otherwise specified, the reference period for the age-specific fertility rate is the calendar year”.

- *World Fertility Report 2009*
-

Analyses two and three report cohort analyses of likelihood of live birth. They report univariate and multivariable survival analysis of factors associated with likelihood of live birth.

The outcome in analysis four is likelihood of contraceptive use. Contraceptive use is measured as a binary ‘Yes’ or ‘No’ outcome and compared in a univariate likelihood analysis for a range of proximate and distal factors.

Variables for analysis

A woman’s knowledge of own status and awareness of ART were recorded as self-reported categorical variables ‘KnowsHIVStatus’ and ‘UnderstandsBenefitsART’ in HIV surveillance. Also

recorded in HIV surveillance was 'HIVResult', the results of a rapid test administered at the household.

Other covariates were added by linking different questionnaire datasets or selected variables using unique woman identifiers in Stata 11 software. Information about contraceptive use, method of contraception chosen, self-reported general health, relationship status and co-residency with a current partner were added to the unique dataset when annual Women's General Health surveillance datasets were linked. Highest attained level of education was sourced from annual individual household socio-economic status datasets. The delivery date of pregnancies, area of residence and a woman's parity were sourced from the Africa Centre composite 'demography' dataset.

To retrieve clinical data, I submitted a customised query to the data manager for ARTemis. This query returned data from the variables 'Datelastfollowedup', 'DateofDeath', 'DateLastART', 'DateFirstART' and 'Followed'. It included the most recent CD4 count per woman, measured within 6 months before or after an episode start date in the unique dataset. Women known to be using ART during the cohort period, meaning they had both a date of ART initiation and a date last known to be on ART, were recorded as 'on ART' in a new variable.

A description of all variables included in the unique cohort dataset, the source of the variable and hypothesis are given in detail in Table 3.2.

Table 3.2: Description and origin of variables used in each of the four quantitative analysis presented in Chapter 4

Characteristic	Description	Survey question	Survey response	Hypothesis/comment	Variable in unique dataset
HIV surveillance datasets					
HIV Status	HIV status determined by testing in annual HIV surveillance. Presented as ' <i>HIV Result</i> ' in dataset	N/A	N/A	HIV positive women will have a lower incidence of live birth compared to HIV negative women.	<i>Categorical</i> Negative / Positive / Unknown
Heard of ART	Question about awareness of the benefits of using antiretroviral therapy to health. Presented as ' <i>UnderstandsBenefitsART</i> '	Have you ever heard about anti-retroviral treatment?	Yes / No / Refused	Women will become increasingly aware of ART after 2005 and could result in higher birth rates to 'replace' postponed children.	<i>Categorical</i> Yes / No / Unknown
Knowledge of HIV status	Question asking whether women know their own HIV status from previous HIV surveillance or alternative testing facilities. Presented as ' <i>KnowsHIV</i> ' variable.	Do you know your status from previous testing?	Yes / No / Refused	Knowledge of HIV status may influence desire for more children. HIV positive women may wish to limit childbearing compared to HIV negative counterparts if aware of their HIV diagnosis. While some HIV positive women may not be aware of their own status, all women on ART are. An association between HIV diagnosis and childbearing desires may be confounded by perceptions of general health. Use of ART is expected to increase self-perceived health and therefore intention to continue childbearing.	<i>Categorical</i> Yes / No / Unknown

Visit date	Recorded date of household visit. Used to calculate two variables for date of cohort entry and year of entry.	Year – Month - Day	Date	An effect of ART on childbearing decision-making may be most effectual in the earlier years of roll out, i.e. 2007 onwards. Unrelated to roll out of ART, rates of childbearing are likely to follow national fertility decline, or plateau according to a recent reported stall in fertility decline.	<i>Date</i> (Start date) and <i>Categorical</i> (Year) 2007, 2008, 2009, 2010, 2011, 2012
Women's General Health datasets					
Relationship Status	Question about current marital status, and coded from a list of 18 options.	What is your marital status?	One of 18 possible codes corresponding to options for civil, traditional, polygamous marriage, divorce, widowed or never been married	ART may encourage sexual activity when feeling in good health. This is a proxy measure for sexual activity, and a mechanism through which ART could increase rates of conception. ACDIS collects information about more than one current partner at a time. This analysis includes information only regarding the status that a woman perceives for her first or 'main' partner.	<i>Categorical</i> (collated in to six levels) Single / Casual Partner / Regular Partner / Engaged or Married / Divorced, Widowed or Separated / Unknown
Using contraception	Question asking for self-reported use of contraception in that annual round of WGH. This answer may apply before or after the actual	Skip questions 1. 'Have you ever used contraceptives?' → 2. Which method are you currently using	Yes / No / Refused	Hlabisa is likely to reflect national trends of injectable contraceptive use. Women on ART may desire more children and modify their use of contraception accordingly. Alternatively, women on ART may have increased access to contraception and choose to use contraception to preserve their own	<i>Categorical</i> response to the second part of the skip question: Yes / No / Unknown

	date of conception of a live birth event.			health status. However, there is little evidence so far to suggest that women have changed contraceptive use in response to the HIV epidemic.	
Contraceptive Method	Question asking for self-reported method of contraception selected from a list of multiple options. This question is asked only if women respond yes to a filter question, have you ever used contraception.	Which method are you currently using?	(Tick all that apply) None, Male Condom, Female Condom, Female Sterilisation, Male Sterilisation, Injections, Pill, Other, Refused	HIV positive women may report more dual protection to avoid HIV transmission and pregnancy at the same time. Women on ART may follow national preferences for injectable methods to prevent an unwanted pregnancy. ART-related side effects may affect preferences for reasons unrelated to childbearing towards barrier methods, which can be less user-efficacious and thereby increase rates of conception.	<i>Categorical</i> Barrier / Injectable / Dual / Other or unknown / No method / Use unknown
Currently living with partner	Question asking if a woman's most recent sexual partner is living with her in the same bounded structure.	Skip pattern questions: Remembering the last time you had sex, what was your relationship to that partner? → Are you still in a relationship with him → Where does he normally reside?	With member, not with member, don't know, refused	Women do not commonly co-reside with their partner. This may occur before marriage and typically after initiation of childbearing.	<i>Categorical</i> Yes / No / Unknown

Self-reported health	Question asking about a woman's self-reported health status, out of three categorical choices.	How would you describe your health at present?	Excellent/Very good/Good, Fair or Poor	Health sits on the hypothesised pathway between knowledge of HIV status and childbearing intention. Women on ART are more likely to feel improved health and those reporting good overall perceived health are more likely to desire a child in the future, resulting in higher rates of conception.	<i>Categorical</i> Excellent/Very good/Good, Fair/Poor, Unknown
Individual notification form dataset					
Date of Birth	Date of birth recorded on individual notification form	Year – Month - Day	Date	I would expect to see a stronger association between age and fertility than that of HIV status or exposure to ART. Women on ART are likely to be older, already have children and have reached the desired family size. Incidence of live birth will be higher when adjusted for age and parity.	<i>Categorical</i> 15-19 / 20-24 / 25-29 / 30-34 / 35-39 / 40-44 / 45-49 years old
Household Socio-economic Status datasets					
Education	Highest level of education attained by women over the age of 6 years old	Skip questions: 1. Highest grade at school → 2. Highest level of education completed after school	Grade (code 1-12) or never, less than one year, don't know, refused → None, certificate, diploma, bachelor's degree, bachelors and diploma, masters, don't know, refused.	Women with higher education attainment are more likely to use contraception and reduce rates of conception. Education also influences risk of HIV acquisition and access to treatment.	<i>Categorical</i> None / Uncompleted / Primary / Secondary / Tertiary / Unknown

Demography composite dataset

Parity	Number of live children at start of episode. A sum of answers to four questions asking for a complete pregnancy history using the Pregnancy Notification Form when women first become a member of the DSA.	1. Have you ever given birth? 2. Do you have any sons /or daughters to whom you have given birth who are living with you? 3. Do you have any sons or daughters to whom you have given birth who are alive but do not live with you? 4. Have you ever given birth to a boy or a girl who has been alive but later died?	Numerical	Primiparous women are more likely to desire to continue childbearing, increasing rates of conception. Parity above one may reflect nearing completion of family size and a lower desire for more children, reducing rates of conception. Age will influence a woman's current parity and so increased rates will be found only at comparable ages.	<i>Categorical</i> 0 / 1 / 2 / 3 / 4 / 5 / 6+
Live birth	A new birth reported captured in the Pregnancy Notification Form.	What was the date of birth / did the pregnancy end?	Date	Date at which a live birth occurred (outcome event)	<i>Date and binary 'event' variable</i>
Area of residence	Area of residence – is urban or rural?	Using GPS point location and the ACDIS definition: Rural is a population density below 400 per km ² , peri-urban means over 400 per km ² , and urban is defined as	Rural / Peri-urban / Urban	Women living in rural areas of residence are known to experience higher rates of fertility.	<i>Categorical</i> Rural / Peri-urban / Urban

KwaMsane Municipality					
ARTEMIS query					
CD4 count. Clinical measure of health	CD4 measured at start of episode	Query for CD4 count closest to the specified episode start date within 6 months.	Numerical count	Women with poorer physiological health at start of observation will experience lower rates of fertility	<i>Categorical</i> <200 / 200-350 / 350-500 / >500 / Unknown
On ART	Which women are enrolled in Hlabisa HIV treatment and care and using ART?	Query for date of initiation of ART and follow up visits for all women in unique cohort.	Query results determined when women became a 'Yes' or was lost to follow up	Women on ART will be more likely to experience a live birth compared to ART-naïve HIV positive women, between comparable age groups and measures of health (CD4 categories or self-reported general health).	Yes / No

3.3.7 The Andersen-Gill model of ordered events

This multiple event analysis defines live births as ordered events: a live birth may occur at multiple times throughout cohort analysis time but more than one event cannot occur to the same individual at the same time (Andersen and Gill, 1982). The Anderson-Gill method assumes that all events are equal and counts the number of events k that occur at time t to calculate time to first event and time to second event. The risk set is defined as the number of women being observed at time t . Each analysis employs the Anderson-Gill method for ordered events to model the hazard that a woman experiences a live birth where multiple events are possible. Women-years provided the denominator to the hazard of birth at time t , assuming that the woman has remained birth-free until the beginning of the time interval. It transpired that there were relatively few sequential birth events to the same woman but this format also allowed for changes in HIV status at any time relative to an event (Cleaves, 2009).

A woman is also at risk of changing HIV status at any time, if HIV negative or her status is unknown. Each woman may therefore have multiple observations during which time only one event can occur. The first observation spans the time from entry in to the study until the time of the event or a change in HIV status, and the second observation spans the time from the event/change in HIV status until the next event or change in status or until the end of follow up.

3.3.8 Time and time-varying covariates

Women can be observed from 2007 until 2013 but may not experience a live birth in this time, or may be lost to follow up but experience a live birth after exclusion (Kirkwood and Sterne, 2003). Data on social and health characteristics at baseline were measured at the date of the first HIV surveillance round and at each annual round whilst the woman remained resident in the DSS.

A change in woman's: age, relationship status, parity, HIV status, ART use, knowledge of status, self-reported health, use of contraception, type of contraception used and most recent CD4 counts were

all updated at each annual HIV surveillance round. Time-updated analysis allowed women to contribute more than one 'annual episode' determined by the start date of each annual HIV surveillance round: the denominator in this cohort being woman-exposure years while reported as either HIV negative or HIV positive.

Stata allows for co-variate data to be updated over time with a command to specify which variables are to be treated as time varying. Following the Anderson-Gill data structure, any change in one of the following time-varying covariates will result in a new 'time zero' and so the time-updated command does not need to be explicitly stated (Cleaves, 2009).

3.3.9 Poisson statistical analysis of incidence and factors associated with risk of live birth amongst women known to be HIV negative and positive during annual surveillance rounds 2007-2012 (open cohort)

Analysis two presents an open cohort of women of reproductive age participating in surveillance years 2007 through to 2012, for a longitudinal analysis of risk of live birth. It explores how HIV-related factors are associated with birth rates, including knowledge of own HIV status, awareness of ART, use of ART and CD4 count measures. Roll out of access to ART began in 2004, and 2007 was selected as the first cohort year, as HIV treatment and care approached full scale. Entry to the cohort was determined by participation in the HIV and WGH surveillance round that year. This approach has its limitations; consent to participate in HIV surveillance is approximately 50% for any single year and could risk selection bias (Tanser et al., 2013). Reasons to refuse the HIV surveillance may include, already knowing one's status and fatigue with the DSS, or cultural and stigma barriers to participation. If HIV positive women are most likely to refuse then it is possible that the analysis will overestimate birth rates. Alternatively, if women of reproductive age are most likely to migrate for work then the analysis may underestimate birth rates in the area. While non-participation poses the risk that this analysis will not represent the wider community, operational and analytical approaches hope to minimise this bias. Household participation has always been high and these factors are unlikely to influence a comparison of fertility amongst women known to be HIV positive or HIV

negative. Fertility rates are relatively stable in this province and are unlikely to fluctuate greatly according to the decision to participate in HIV surveillance. Furthermore, prior studies of HIV surveillance have used imputation, modelling and community analysis techniques to show that there is little effect of selection bias by participation (Tanser et al., 2013). Finally, this analysis presents 'unknown' responses for transparency about potential differences in non-response according to each characteristic, and the possible influence in fertility analysis. This methodology makes no assumption that information is missing at random.

Women could enter this open cohort in any year between 2007 and 2012 and were excluded if: they were not a resident, had a HIV status that was 'unknown', or were above or below the reproductive ages of 15-49 years old during that annual HIV surveillance round. The HIV programme rapidly expanded after 2007 and an open cohort captures more women as they enter the DSS on ART, or initiate ART in later years, than a closed cohort would. These stringent exclusions result in smaller sample sizes but reliable estimates to compare HIV positive or negative women.

The event in this survival analysis was incident birth. Unadjusted analysis presents crude incidence of live birth and tested for significance using the Mantel-Haenszel procedure. Incidence and rate ratios of live birth were estimated using Poisson regression, allowing for multiple events to the same woman using a robust variance estimator (Kirkwood and Sterne, 2003) and Andersen-Gill modification (Cleaves, 2009). Cumulative incidence curves for live birth were estimated using Kaplan-Meier estimators. Incidence rates of birth event, including recurrent events, were calculated per 100 woman years of follow up with a 95% confidence interval (95% CI). Poisson was chosen as the estimation method as the outcome frequency was around 10% (Zou, 2004) and goodness of fit tests were used to establish suitability of Poisson compared to negative binomial models.

Rates included only time as the denominator and each woman contributed to the denominator from time of first observation in the open cohort until the end point or until censored. Variables selected for multivariable analysis were based on prior hypothesis, according to a review of the literature presented in chapter two, and according to the availability of data in ACDIS and ARTemis datasets (Houlihan et al., 2011). To identify associated factors of the live birth event, I ran univariable and

multivariable Poisson regression models with a manual backward selection method and assuming all associations with p values <0.05 as significant. Optimal categories for quantitative variables such as age group and CD4 groups were similarly tested using likelihood ratio tests.

A Wald test was used to adjudicate between different parametric models and to ascertain the Poisson assumption of mean-variance equality (Cameron and Trivedi, 1990). A lognormal model was selected on the basis that a k value that was not significantly different to zero ($p = 0.7888$) and strong evidence that p did not equal 1 ($p < 0.0001$). Due to missing data in some variables, sensitivity analyses were also conducted without the inclusion of 'unknown' levels for selected variables and were included to allow for a wider sample. A Lexis Expansion split of the dataset to create current age bands tested the potentially confounding effect of time and age. Rate of live birth did not change very rapidly with time and so the Anderson-Gill dataset, with time updated age and year of entry, suitably considered the effect of time for multivariable analysis.

3.3.10 Cox Proportional Hazards for statistical analysis of birth-free survival in a cohort of woman including 'unknown' HIV status (closed entry in 2007/2008)

The key differences between analysis three compared to analysis two is a closed cohort design, including only women that participated in the 2007 and 2008, and the added inclusion of all women irrespective of HIV status and including those of 'unknown' status. Analysis three compares factors associated with annual trends of live birth to women whose HIV status was unknown to the surveillance. An intention of this inclusion is to allow inferences of a wider effect of roll out of ART on fertility in the Hlabisa area. Exclusion criteria and structure of the dataset was the same as for analysis two, with the key exception of the inclusion of women with 'unknown' HIV status: women were excluded if not resident or aged above or below the reproductive ages of 15-49 years old.

Entry to the closed cohort was determined on a woman's participation in the HIV and WGH surveillance round in years 2007 and 2008 and women were followed until the end of cohort in 2013 or exclusion. Women could not enter the cohort after 2008. This closed cohort includes all women

that participated in the HIV and Women's General Health surveillance in the years 2007 and 2008. A closed time to event cohort provides a measure of time to live birth from a standardised baseline for an appropriate comparison. A Cox proportional hazard model was used for a multivariable analysis of risk of live birth. Cox is a semi-parametric model that relies on an assumption that hazards are proportional for individuals with different values of the explanatory variables and makes no parametric assumptions about the baseline hazard.

Unlike Poisson, Cox does not assume a constant baseline rate or estimates the changing baseline rate over time. Instead Cox uses a different parameter at each survival time point to model the proportional change in the hazard for each of the explanatory variables, while allowing for rates to change over time. Cox Proportional Hazard was selected to control for time in survival data and to allow rates to change with time since entry to this closed cohort, under an assumption of declining fertility since 2008. The proportional hazards assumption was tested and non-proportional for women of different HIV status (positive, negative or unknown) and multivariable analysis were then stratified according to HIV status.

3.3.11 Estimation of the variance with multiple observations

Estimates of the variance refer to the estimated standard errors used to produce confidence intervals and significance tests in Cox proportional hazards analysis. Live birth events are assumed to be independently distributed between women but may not be independently distributed within clusters of individual women episodes. The Huber and White, or sandwich estimator is a robust estimator of the standard errors and accounts for possible variation in the distribution of the error term. Robust estimation is therefore most appropriate for a valid statistical inference of this dataset (StataCorp, 2009).

Stata 11 uses the `vce(robust)` command to specify the robust estimator of the variance-covariance matrix, corresponding to the parameter estimates. An addition to this command is `vce(cluster variable)`, which groups women according to the hypothesis that women episodes are not

independent of each other. In this analysis it was not necessary to set the cluster option because the `id()` option was used in the `stset` command: when declaring the data to be survival data, the `id()` option informs Stata that these episodes occur to the same woman ID (Cleaves, 2009).

3.3.12 Efron method for handling ties

Tied events, or multiple live births, occur by chance to different women after the same duration of follow up. In this dataset, the mean number of events per failure time is 2.1 births, with a range between 1 and 185 births per failure time. The Efron method for handling such tied events is an approximation to the exact marginal method, which calculates the conditional probability of tied failures. Approximations are commonly used in statistical computer packages for feasibility and Efron's method for handling ties differs in that it adjusts the risk sets using probability weights. It is more accurate than other methods of approximation such as Breslow and is specified in Stata's 'stcox' survival analysis using the 'efron' command (Cleaves, 2008).

3.3.13 Cox Proportional Hazards of incidence and factors associated with contraceptive use

The aim of analysis four was to determine whether likelihood of contraceptive use changed in response to HIV- or ART-related factors associated with risk of live birth. It tests for associations with the likelihood of contraceptive use analysis amongst all women included in the closed cohort described in analysis three. This cohort also follows the whole population of women that participated in the HIV and Women's General Health surveillance in the years 2007 and 2008 and were followed to a maximum until 2013. The design of this cohort regarding entry, follow up and exclusion of women is as presented in analysis three. Unadjusted cox regression was used to test for associations between time-updated social and health characteristics and likelihood of contraceptive use. The Cox proportional hazards model was selected to account for variation in time sensitive data such as HIV status and exposure to ART over the observation period. It does not require knowledge

of absolute risk or that a particular probability model be selected to represent survival times, and is therefore more robust than parametric methods (Leffondré et al., 2003).

3.3.14 Software for quantitative analysis

All analysis was performed using the statistical package Stata 11 software for windows (Cleves, 2008).

3.3.15 Analytical framework of proximal and distal factors associated with rates of live birth to women living with HIV and on ART in the Hlabisa sub-district

The following section describes an analytical framework for the mechanisms through which ART may influence proximate determinants of fertility on both behavioural and physiological pathways for women living in Hlabisa, KwaZulu-Natal, presented in figure 3.3.

Based on the existing literature and an established effect of HIV on fertility, I hypothesise that HIV positive women are less likely to experience a live birth compared to HIV negative women of a similar age in this area. Improved health following initiation and adherence to ART has led to reduced mortality and health outcomes in the area (Herbst et al., 2009, Zaidi et al., 2013). In this study I consider that reduced mortality, improved physiological ability to carry a child to full term and changes in reproductive behaviour associated with use of ART will therefore result in a higher likelihood of live birth compared to HIV positive ART naïve women.

An increase in rates of live birth should be associated with an observed improvement in measures of health if this effect is predominantly driven by improved physiological capacity, or women are changing behaviours in response to improved health. Research in the area found that 'self-reported' health was a reliable predictor of actual health and mortality within four years of follow up, when adjusted for HIV status and use of ART, in a sample of 9,217 adults (Olgati et al., 2012). Further, a comparison of older people (50 years or older) in Uganda and South Africa found socio-economic

circumstances to be important in shaping perceptions of self-health when HIV positive. Despite lower functional ability and higher rates of obesity, hypertension and unemployment, older people living with HIV reported greater subjective well-being in South Africa compared to Ugandans when adjusted for multiple socio-demographic factors. This unusual finding was attributed to the availability of social services for older people in South Africa, such as the pension (Nyirenda et al., 2013). Consequently, I will draw on two complimentary measures of improved health attributed to use of ART for the purposes of this analysis: I included CD4 count as a clinical measure of physiological improvement in a woman's ability to carry a child to term. I also measured self-perceived improvements in health which has been determined as a reliable indicator of health and rests on the casual pathway between improved health and greater pregnancy intentions.

For there to be any effect of HIV related factors on pregnancy desire and live birth as an associated outcome, women must be aware of their own HIV status. By virtue of being on treatment, women are aware of their HIV positive status. However, some HIV positive women and HIV negative women may be included in the surveillance without seeking the outcome of a HIV test. Hence some of these women will be unaware of their status and so 'Knowledge of HIV status' acts as a determinant of whether women are on ART and may also act upstream on the causal pathway to an effect of ART on pregnancy intention or contraceptive use.

Contraceptive use is a proximate determinant of fertility that can be modified by distal factors influencing a woman's childbearing intention. Generally it is unclear what advice HIV infected women receive on use of contraception or approaches to safe conception. If use of ART was associated with a change in desire for childbearing, I would only expect to see a related change in contraceptive behaviour where women are able to access family planning services. Any observed changes in rates of live birth, as attributed to a greater ability to access contraception through HIV treatment and care, are likely to be delayed by time taken to utilise contraception and for this extra contraceptive use to prevent births at a minimum of 9 months later. Thus a behavioural effect of access to contraception through HIV treatment and care on general rates of live birth would likely be observed as a delayed decline in rates of live birth sometime after ART initiation. This lag effect has

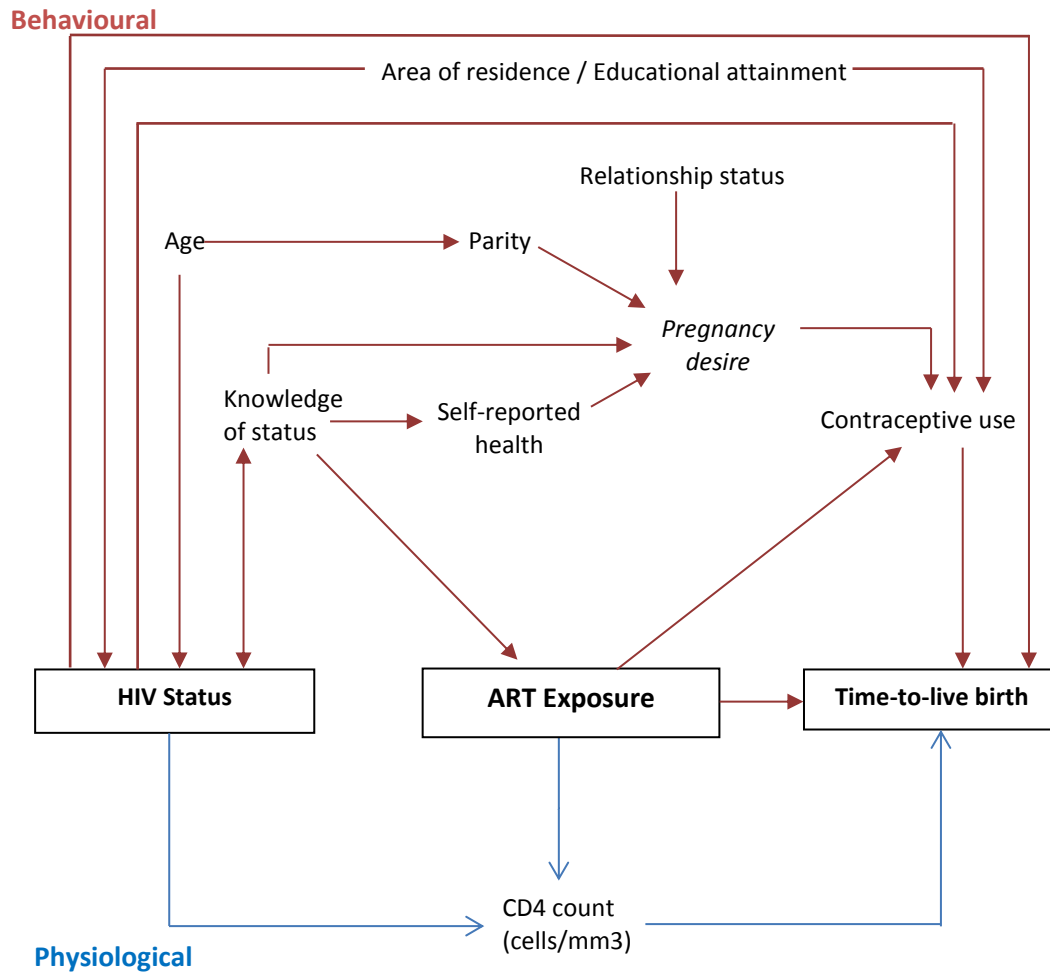
not been widely captured by other shorter-term studies and a benefit of this study is the ability to assess the long-term risk of live birth amongst women on ART.

Alternatively, access to the HIV treatment and care programme could encourage initiation or continuation of contraceptive use unrelated to pregnancy intentions. In this situation, we could observe a decrease in rates of live birth amongst women on ART if family planning services have encouraged a change in contraceptive behaviour. A switch to less efficacious methods could alternatively result in higher rates of pregnancy amongst women on ART.

Use of contraception can be associated with other factors such as a partner's attitudes to contraceptive use and a wish to protect her self-perceived health. It is possible that these factors may change with ART initiation. I am unable to adjust for partner attitudes to contraception as data are not available but will include relationship status and self-perceived health as a measure of motivation for contraceptive use.

Age and parity are typical predictors of birth spacing and associated with woman's pregnancy intentions independent to a change in HIV status or initiation of ART. It is important to adjust for age and parity in an analysis of HIV negative, positive but ART-naive and HIV positive women on-ART as women on ART are likely to be of higher median age and at a further stage in their reproductive lives. As age and parity are associated with the likelihood that a woman will be on ART and also the outcome, a live birth, these factors will be included as a confounder of possible lower rates of live birth amongst women on ART. However, women in South Africa are thought to use postponement strategies for family building and long birth intervals that are largely independent of age and parity, so the overall effect may be small in this instance.

Figure 3.3: Analytical Framework of HIV, proximal and distal factors associated with rates of live birth in the Hlabisa sub-district



3.4 Qualitative aims and methodology

3.4.1 Semi-structured interviews with clients and healthcare providers

Qualitative interviews are commonly used to evaluate experiences and expectations of people within a program. This methodology allows for a detailed exploration of a client's experience of family planning service delivery related to the HIV treatment programme and health provider's attitudes and opinions on family planning. It is an appropriate method to explore perspectives and behaviour related to contraceptive use when on ART, and to explore how women are supported in their decisions to continue childbearing within the programme, considering cultural, community and service delivery factors. The aim was to achieve deep experience-orientated data that is informationally representative of different family planning clients and needs.

Limitations of this method include the risk of courtesy bias, in which women do not wish to speak badly of the program they are currently accessing. To address this issue, participants were assured of the confidential nature of the study and importance of their own perspectives. As per the nature of qualitative research, the results will intend to provide a deeper understanding of client family planning experiences within the Hlabisa HIV treatment and care programme. While the quantitative component of this thesis may strive to be generalizable, this is not usually the aim of qualitative research. The qualitative findings presented in this thesis are descriptive of the women resident to Hlabisa. As the researcher, I have aimed to describe the context of this setting in which women are making their childbearing decisions and the assumptions and methods of this study design in order to enhance the trustworthiness of this qualitative work (Krefting, 1991). Finally, design of the study was informed by limiting factors such as time and cost, in order to mitigate against the time-intensive requirements of transcription, translation and analysis activities.

Interviews with female clients were conducted at the clinic in order to limit transportation costs. A resulting constraint is the exclusion of male partners or HIV negative women not attending the clinic. I prioritised interviews with healthworker's for their important perspective in this case study of the HIV treatment and care programme, which allowed time to train a research assistant and for

iterative feedback on interviews and transcription quality and preliminary analysis. This design prevented any compromise on data quality and process. The results are not intended for a comparison with ART naive women, or to comprehensively explain the household dynamics of childbearing. Rather, the constraint described here is that results are confined to a programmatic setting.

3.4.2 Eligibility of ART clients

Inclusion criteria for participation in this study were determined by the age criteria also used in my quantitative analysis, and to allow a reasonable duration of participation within the ART programme. The minimum age for inclusion was set at 18 years old, as opposed to 15 years old per the quantitative analysis. This is because girls aged between 15 and 18 years of age require permission from a legal guardian to participate, this would be sensitive given the nature of the discussions; including this age group was deemed unnecessary to meet the objectives of this study. Additionally, women must have been enrolled within the ART programme for a minimum of one year so that interviews are informationally representative to this study (Sandelowski 1995).

3.4.3 Sample size and sampling methods for ART clients

A total of 23 interviews were conducted with HIV positive women attending an HIV clinic in the demographic surveillance area. The planned sample size of 24 was not achieved due to time limitations and because responses had achieved saturation, meaning no new themes emerged in later interviews. The initial sample size was determined through a purposeful sampling strategy to achieve both demographic and phenomenal variation in relation to family planning experiences amongst women by age and reproductive history. The sample was stratified according to a woman's pregnancy experience in the programme. Half the sample had experienced a pregnancy within the programme since 2008 (12 women), and half of the women had never had a pregnancy within the

programme (12 women). Views on the optimal purposeful sample size in are mixed, but samples of 12 were generally regarded as sufficient to achieve maximal data codes and saturation in analysis while maintaining feasibility (Guest, Bunce et al. 2006). Results from my quantitative analysis indicated that the likelihood of experiencing a live birth differs by age. Consequently, women were selected for inclusion according to reproductive age groups of; 15-24, 25-34 and 35-49 years old.

A total of 4 interviews with women of each age group resulted in a total of 12 interviews per reproductive history strata as illustrated in Table 3.3.

Table 3.3: Stratification of study sample for client interviews

Age Group	Reproductive experience in ART programme	
	Never experienced a pregnancy within the ART programme	Experienced a pregnancy in the ART programme since 2008
18-24	4	3
25-34	4	4
35-49	4	4

3.4.4 Eligibility and sampling of health providers

Interviews with 12 health care providers were conducted by the researcher, in English, to seek their perspectives on the role of FP for women on ART in the HIV care and treatment programme, and missed opportunities to provide comprehensive SRH and HIV services in the primary health care clinic.

Participants were purposively sampled to include an equal mix of both ART nurses and HIV Counselling and Testing Counsellors, as these are key roles for the delivery of family planning services and counselling. No demographic criteria were used to select participants as the aim is simply to obtain views of health care workers providing HIV treatment and care.

3.4.5 Sample area

Women accessing HIV care and treatment in the Hlabisa district may do so at one of 6 primary health care clinics within the Africa Centre Demographic Surveillance Area. Prior analysis of the ACDIS data indicates that clients are most likely to choose their clinic based on closest proximity. The primary health care clinics within the Hlabisa sub-district show significant variability on several indicators of ART treatment and PMTCT service delivery. The following table demonstrates the variation in patient load determined by the number of clients attending the HIV services to pick up their medication in a single month.

Table 3.4: Number of clients receiving ART at each clinic within the Africa Centre DSS as an indicator of clinic size

Clinic	Clients receiving medications (Nov-11)
1	107
2	251
3	2,018
4	253
5	535
6	759

Clinics were situated in either urban, rural or peri-urban locations and can differ in proximity to main roads, size of clinic, typical patient load and health professionals available for SRH and HIV services. It is anticipated that the number of ART nurses and other characteristics such as size of the clinic could influence the provision and uptake of family planning.

For feasibility for this study, a purposeful sampling approach was used to identify 4 out of the total 6 clinics for inclusion in this study. Clinics were included if located within the DSA borders to limit additional costs of travelling and purposively sampled to include a variation of areas (i.e. peri-urban, rural), size and location within this region. However, due to poor recruitment at one clinic and a

limited timeframe, sampling was later opened to a fifth clinic within the DSA. An equal sample of clients and health care providers were obtained from each clinic (Table 3.5).

Table 3.5 Number of client and health worker interviews per clinic

	Sampled Clinics				
	Clinic 1	Clinic 2	Clinic 3	Clinic 4	Clinic 5
ART Clients	6	3	6	4	4
ART nurses	1	2	1	1	1
HCT counsellors	1	2	1	1	1

3.4.6 Themes of client interviews

Section one of the semi-structured interview schedule investigates how use of ART affects factors relating to childbearing by exploring their current childbearing desires, followed by a series of probes based on the answers (figure 3.4). Follow up questions explored participants perceptions of how initiation on ART has affected their views on childbearing, partner desires and the attitudes of family and friends in their decision.

Section two consists of six questions on current and previous contraceptive use, awareness of methods, self-perceived effects of concurrent use of treatment and contraception and partner attitudes to contraceptive use. The third and final section explores participants' experiences of accessing contraceptive and family planning services on ART. It asks where women typically seek family planning and if this has changed with initiation of ART, what family planning information they have received at the clinic and participant attitudes to delivery of family planning education and counselling for women on ART. Women that have experienced a pregnancy in the ART programme prior to interview were further asked about their experiences and expectations of counselling for safer conception within the HIV treatment and care programme. The full interview schedules can be found in appendix B and C.

Figure 3.4: Interview questions to explore childbearing desires

Would you like to have more children now or in the future?
(Exploring treatment, health and all other reasons why)

[Yes]

When would you like to have your next child? Why that time?

Do you think you will actually have more children/children at this time?

What things do you think will decide when you have another child?

[No]

Can you tell me what made you decide this?

How do you feel about this?

[Unsure]

What things do you think will decide when you have another child?

How do you feel about this?

3.4.7 Themes of healthcare provider interviews

Semi-structured interviews with health care providers probe perspectives on service provision and integration of family planning within the HIV treatment and care programme. A series of questions explore service provider perspectives on: prioritisation and delivery of family planning to women on ART, the IntraUterine Contraceptive Device (IUCD) and Emergency Contraception (EC), which are considered underutilised methods in a review of the literature, and the availability of pre-conception counselling and pregnancy planning. Interviews concluded by asking about alternative sources of family planning and perceived barriers to family planning in the programme. The full interview schedule can be found in appendix D.

3.4.8 Conduct of interviews with clients

The study was explained to staff from the selected clinics and I sought advice on the best way to approach women for participation. Strategies involved asking a nurse to introduce women to the Research Assistant (RA) or the RA directly approached women in the waiting area between counselling and treatment visits. The characteristics of each respondent were recorded on a log sheet to ensure the required sample and strata were obtained. The study was explained to participants with the help of an information sheet before written consent was obtained.

The client interview topic guide and information sheets were translated into isiZulu by a research assistant and checked for consistency by another isiZulu speaking researcher. Interviews took place on site in a private room within the clinic with an isiZulu-speaking research assistant trained on the use of the topic guide, and on when and how to refer women to appropriate services where available. Interview tools were pre-tested with two clients in a nearby clinic and refined as required. Interviews lasted between 30-45 minutes and electronic recording devices were used, and field notes were taken, upon permission of the participant. Both oral and written records were transported back to the Africa Centre on the same day of the interview and backed up on multiple hard drives. All files are anonymised and labelled by a unique identification.

3.4.9 Conduct of interviews with healthcare providers

For convenience, individual participants were nominated by a program manager and invited by the researcher to participate in advance of the interview. A convenient date was arranged with service providers to minimise disruption to their work. Health workers were provided with refreshments as a courtesy for their time. Healthcare provider interviews were also conducted on site at the sampled clinic by the researcher in English, as the standard language used in training workshops and that of the researcher. Interviews lasted approximately 1 hour. Electronic recordings were taken and consent obtained from the participants with the use of information sheets and a consent form. Electronic recordings were made and labelled by clinic, date and a code for type of health provider

(ART nurse or HCT counsellor and the number of this interview). Field notes were also taken in the course of the interview and returned to the Africa centre and filed for storage using the same code.

3.4.10 Transcription and translation

The same research assistant that conducted the interviews also transcribed client interviews in isiZulu, using audio files in Sony Digital Voice Editor V3.3. Data from the electronic recorder was transcribed with comparisons to hand written notes to fill inaudible phrases or gaps in the recording. The same research assistant translated interviews into English, and early samples of transcripts were checked for accurate translation by another isiZulu speaking researcher. The research assistant was asked to provide annotations for the researcher to explain nuances or slang terms for the purpose of analysis. Interviews were transcribed and translated on an on-going basis during the data collection period. Regular meetings between researcher and the assistants allowed for iterative feedback and tailored approaches to probing women on questions such as new concepts like the Intra Uterine Contraceptive Device. Health provider interviews were transcribed by the researcher from English also using audio files in Sony Digital Voice Editor V3.3 and with reference to field notes made during the study.

3.4.11 Methods for framework analysis

Transcripts were systematically coded with input from field notes to provide contextualised data on aspects such as the flow and context, and a preliminary content analysis was performed manually using Microsoft word during data collection (Seale 2004). During this initial stage, interviews were read and re-read to familiarise myself with the data.

Framework analysis was performed once data collection was complete. Framework analysis is commonly used in policy relevant research where time-scales are often short and starts with a deductive approach whereby objectives are often set in advance (Ritchie and Spencer, 2002) and is

therefore well suited to the aims of this study. Analytical methods for framework analysis tend to be more explicit than other qualitative methods and I followed the five stages of framework data analysis illustrated in Figure 3.5 (Pope et al., 2000). Client and Health worker interviews were semi-structured and the pre-determined themes were used initially to identify a framework as per stage two, to which emergent themes were later added. Nvivo 10 software was used to categorise and store quotes that represented common and emergent themes (Bender and Ewbank 1994). Interviews were originally indexed by hand, during the process of data collection, and then via Nvivo once all the data had been collected and entered. Nvivo software was used to display matrices of coded data according to pre-determined themes and emergent themes, which I then summarised. Data reliability was established through group comparisons of themes to test that similar responses have been given. Key themes that explain childbearing desires to women on ART were interpreted and discussed in Chapter Five, while factors influencing attitudes to contraception on ART were mapped and later explained through a Health Belief Model for contraceptive use, presented in Chapter Six (Ulin et al., 2004).

This method allows a focus on the whole dataset rather than an individual interview and places the emphasis on the individual's experience rather than constructing abstract concepts and theory, as with grounded theory analysis (Corbin and Strauss 1990). It enabled identification of unexpected themes grounded in the data once most of the data had been collected (Seale 2004).

Figure 3.5: Five stages of data analysis in the framework approach (Pope, et al. 2000)

1. *Familiarisation*—immersion in the raw data (or typically a pragmatic selection from the data) by listening to tapes, reading transcripts, studying notes and so on, in order to list key ideas and recurrent themes
2. *Identifying a thematic framework*—identifying all the key issues, concepts, and themes by which the data can be examined and referenced.
3. *Indexing*—applying the thematic framework or index systematically to all the data in textual form by annotating the transcripts with numerical codes from the index, usually supported by short text descriptors to elaborate the index heading.
4. *Charting*—rearranging the data according to the appropriate part of the thematic framework to which they relate, and forming charts. The charts contain distilled summaries of views and experiences.
5. *Mapping and interpretation*—using the charts to define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to providing explanations for the findings.

3.4.12 Checklist of communication materials and counselling activities in the HIV treatment and care clinic

Observations on the availability of communication materials counselling and contraception methods at the service delivery point were made at each of the clinics in which the interviews are conducted. Information, education and communication materials are an important component of primary health care and reproductive health specifically (WHO 2001), and have been used as a process

outcome indicator for integrated HIV and SRH services at primary health care facilities (WHO 2009). The quality of IEC materials on family planning topics for PLHIV accessing HIV treatment, including aspects of safe conception and health concerns for those on ART has not been explored in the area of Kwazulu-Natal.

Each of the clinics sampled for client interviews were assessed using a checklist for the availability of contraception and communication materials. Specific indicators were based upon a search of the literature of tools used to assess communication materials in line with national policy standards for comprehensive primary health care. The tool used was adapted from a Johns Hopkins observation tool and the International Planned Parenthood Federation (IPPF) rapid assessment tool for service integration (see appendix E) to formulate a checklist of responses on the following indicators of service availability:

- Contraceptive Methods available
- Frequency of availability at study site
- IEC materials available
- Group talks/counselling
- Materials used in talks
- Format of talks
- Topics in counselling (pre-planning for safe conception)

Where observation was not possible a health care professional was asked to provide guidance on the frequency and availability of services. These indicators were tallied and presented in tables as descriptive data. The complete tool can be found in appendix D.

3.4.13 Ethics

The study aim and research tools were presented to the Community Advisory Board at Africa Centre to discuss any cultural and ethical considerations. Ethical approval and annual recertification for this

study has been granted by the Research Ethics Committee of the Nelson R. Mandela School of Medicine, University of Natal (Ref: BE231/12) and the UCL Research Ethics Committee (ethics application 4032/001) (Appendix F). The right to stop the interview or not answer questions was clearly explained to women during the consent process, but all were able to continue the interview until completion.

Chapter Four

Live births by HIV status and ART exposure among women resident in the Africa Centre Surveillance area between 2005 and 2012

4.1 Annual trends in live birth between 2005 and 2012

4.1.1 Description of women included in annual 2005-2012 surveillance rounds

The annual mid-year population of resident women of reproductive age was 25,143 women and this varied little by year. Annually, only 3-6% of these women answered yes to being married. Low marital rates are in accordance with the literature and pregnancy remains common outside of marriage (Swartz 2009). Further, the high non-response rate for this question suggests that the variable has limited value to this analysis.

Information about marital status comes from the Women's General Health survey, in answer to the question 'what is your marital status?' (Figure 4.1.) This question may be answered by the head of the household rather than the individual themselves but was not answered for the majority of women (71.35%). A higher proportion of women responded to the question 'have you ever had sex' (Figure 4.2).

Amongst respondents to the question about marriage, more women reported being married or widowed in older ages (Figure 4.3). Rates of marriage peaked amongst women aged 45 – 49 years old at 15%. Reported rates of divorce were consistently lower than 0.2% and on average 3.41% of women were engaged at any time.

Table 4.1: Marital, sexual and HIV characteristics of women included in annual 2005-2012 surveillance rounds

Year	Mid-year population	Number of married women	Number of women that have made sexual debut	Number of women with a known HIV positive status from HIV surveillance
2005	24,253	1,513 (6%)	6,509 (27%)	1,951 (8%)
2006	24,640	1,286 (5%)	8,243 (33%)	2,221 (9%)
2007	25,103	885 (4%)	8,869 (35%)	2,452 (10%)
2008	25,071	651 (3%)	9,127 (36%)	2,706 (11%)
2009	25,788	849 (3%)	9,320 (36%)	2,883 (11%)
2010	26,029	745 (3%)	8,406 (32%)	3,023 (12%)
2011	25,323	805 (3%)	8,794 (35%)	3,442 (14%)
2012	24,933	792 (3%)	8,895 (36%)	3,386 (14%)

Figure 4.1: Annual WGH survey question asking about marital status

Section 4. Marital Status

1. What is your current Marital Status? *CHECK: Is Status 'NBM', 'NVE' or 'NNE'?*

No Yes → Skip to Section 5

Age at first marriage years old

Are you currently living with a husband/partner? Yes No Refused

Is Status 'PLG', 'PCM' or 'PTM'? Yes No → Skip to Section 5

How many co-wives are there in your marriage? (including yourself)

Figure 4.2: Annual WGH survey question asking about sexual debut

1. Have you ever had sex?

Explain what is meant by "Having sex".

Check answer is consistent with answers on pregnancy

Yes No → FORM COMPLETE

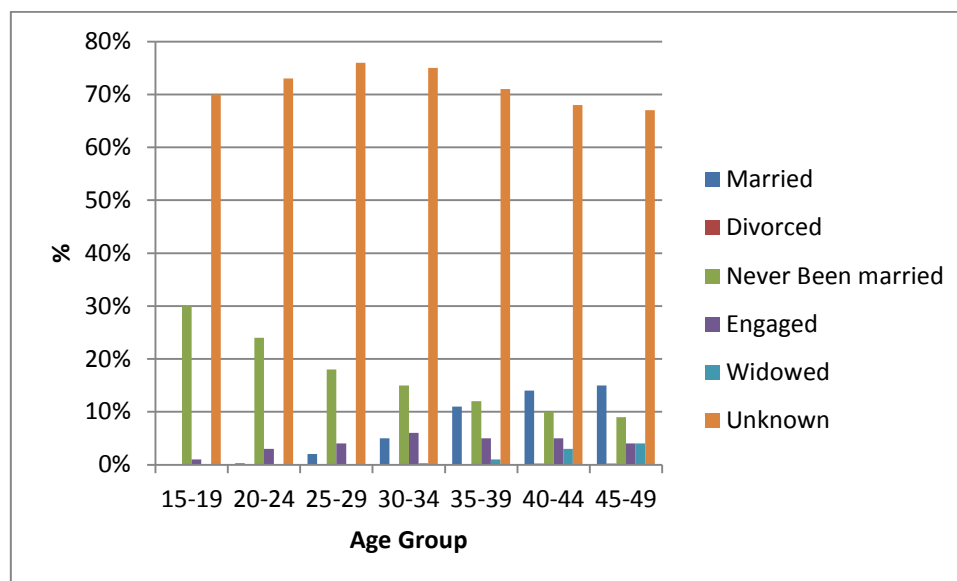
How old were you when you first had sex? years

Don't know/remember

Refused

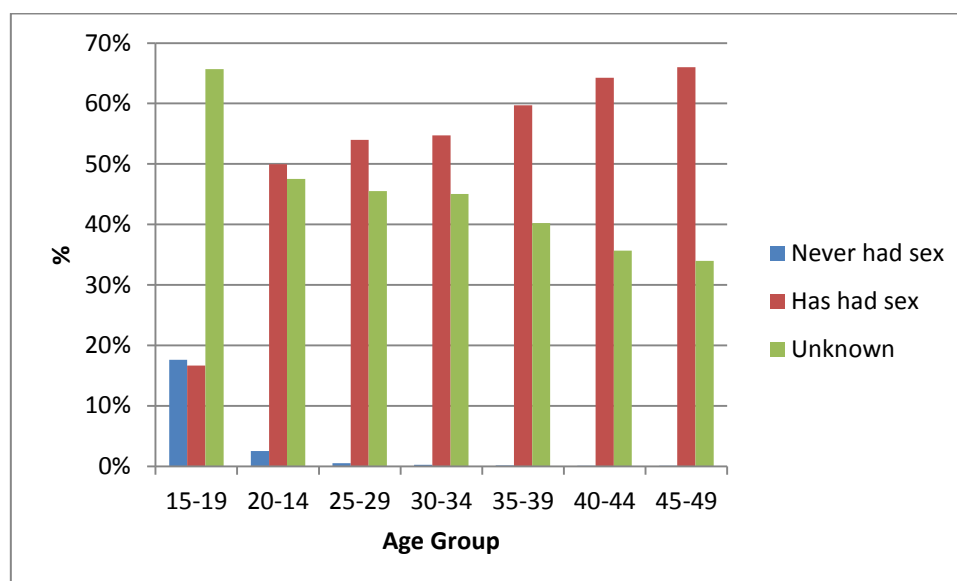
This question provided a more useful restriction, to adjust for possible variation in sexual activity between HIV positive and HIV negative women. A limitation of this approach is that it does exclude a higher proportion of women from younger age groups, as can be seen in a comparison of Figures 4.3 and 4.4.

Figure 4.3 Proportion of responses to question about marital status amongst resident women between 2005-2012, by age group



Age Group	Married	Divorced	Never been married	Engaged	Widowed	Unknown
15-19	9	<0.1%	2	<0.1%	14,013	30%
20-24	113	0.3%	1	<0.1%	7,974	24%
25-29	383	2%	0	<0.1%	4,472	18%
30-34	946	5%	8	<0.1%	2,734	15%
35-39	1,620	11%	11	<0.1%	1,900	12%
40-44	1,898	14%	28	0.2%	1,402	10%
45-49	2,043	15%	23	0.2%	1,187	9%

Figure 4.4 Proportion of responses to the question ‘Have you ever had sex?’ by age group



Age Group	Never had sex		Has had sex		Unknown	
15-19	8,363	17.63%	7,909	16.67%	31,164	65.70%
20-24	837	2.53%	16,526	49.96%	15,717	47.51%
25-29	127	0.52%	13,238	53.99%	11,153	45.49%
30-34	48	0.26%	10,228	54.71%	8,419	45.03%
35-39	19	0.12%	9,231	59.68%	6,217	40.20%
40-44	9	0.07%	8,802	64.27%	4,884	35.66%
45-49	8	0.06%	8,805	65.99%	4,530	33.95%

4.1.2 Decline in Crude Birth Rates between 2005-2012

The number of live births that occurred each calendar year was divided by the total woman-years of residency observed amongst women of reproductive age in order to calculate annualised crude fertility rates.

Crude rates of live birth have declined annually in this setting, before adjusting for variation in sexual activity or marital status. A small stall in fertility decline is apparent between the years of 2009 and 2011 (Table 4.2). And this finding supports other studies that also determined a brief stall in fertility decline and a recent return to decline (Moultrie et al., 2008b).

In an analysis restricted to women that answered yes to the question 'Have you ever had sex?', rates were approximately half those calculated for all resident women and a stall in decline was observed between the years 2010 and 2011 only (Figure 4.5).

Figure 4.5: Crude annual birth rates to all resident women and resident women that responded 'yes' to ever had sex

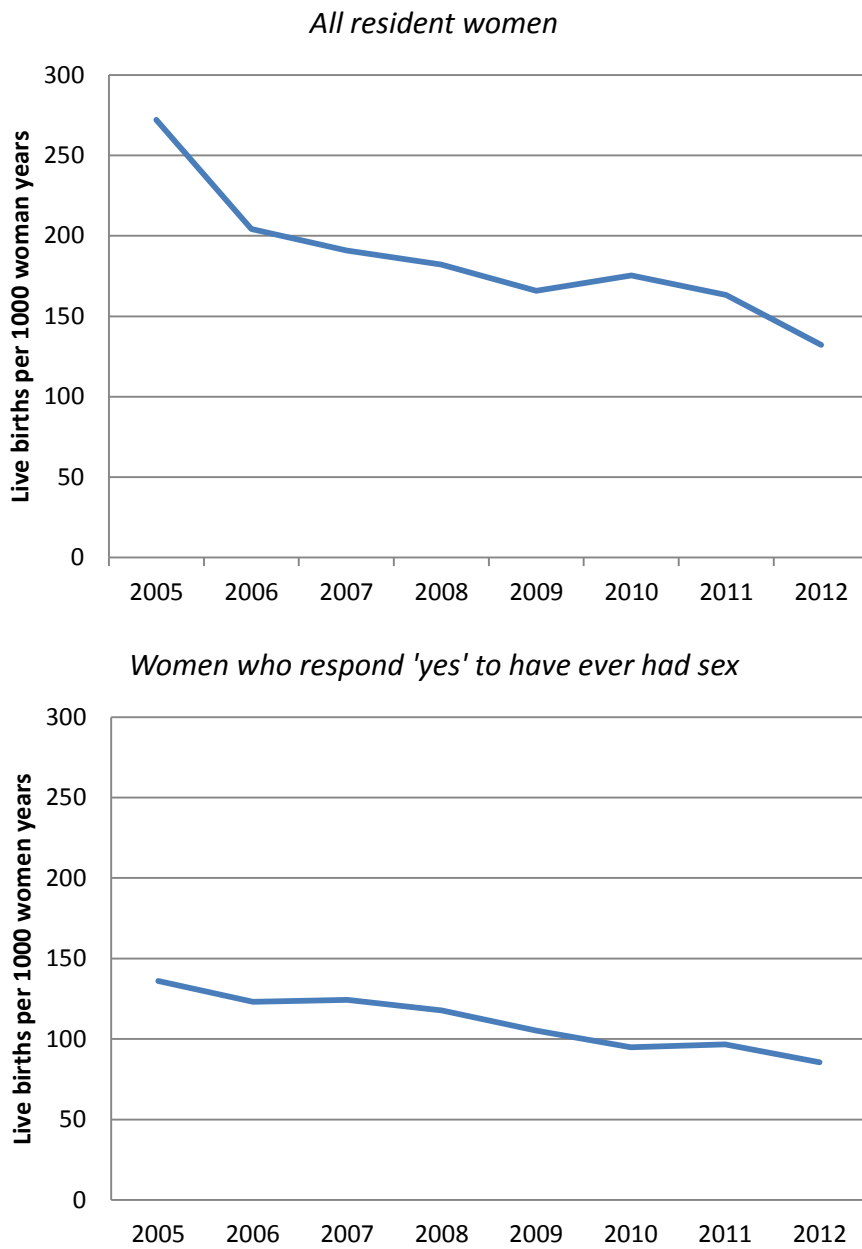
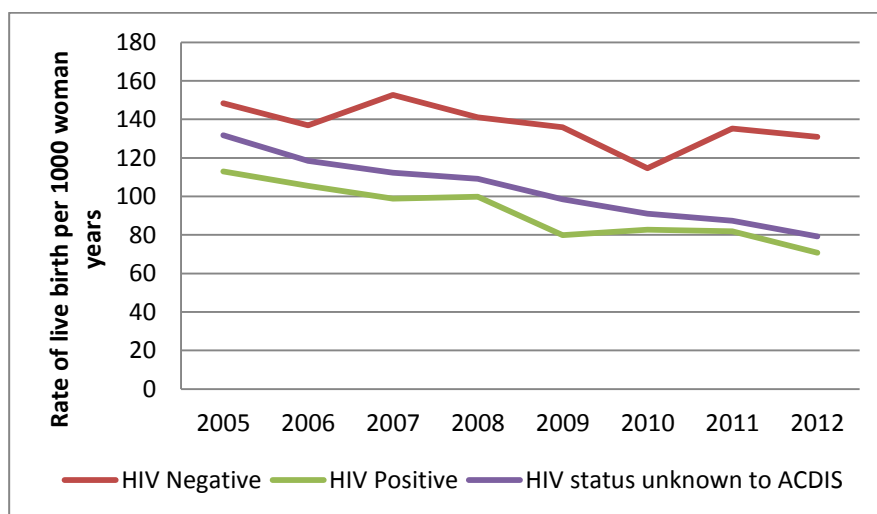


Table 4.2: Number of live births amongst resident women of reproductive age between 2005 and 2012

Calendar Year	Number of live births	Woman years observed	Births/1000 women-years
<i>All resident women of reproductive age</i>			
2005	1,851	17,240.91	272
2006	1,829	17,373.30	204
2007	1,857	17,872.39	191
2008	1,817	17,966.31	182
2009	1,704	18,154.78	166
2010	1,644	18,034.62	175
2011	1,585	17,890.77	163
2012	1,317	17,284.98	132
<i>Restricted to women that have ever had sex</i>			
2005	884	6,496.36	136
2006	1022	8,295.61	123
2007	1108	8,907.33	124
2008	1081	9,178.31	118
2009	984	9,346.38	105
2010	800	8,426.72	95
2011	852	8,810.32	97
2012	764	8,935.62	86

A stall in CBR decline began in 2009 amongst women tested as HIV positive during annual HIV surveillance rounds. This is a slightly earlier transition when compared to HIV negative women episodes, which started in 2010. A decline in CBR followed a steeper gradient amongst HIV positive women between 2005 and 2012 ($m=-5.73$, $R^2=0.913$) compared to women that were HIV negative at that time ($m= -2.97$, $R^2=0.398$). Women whose HIV status was unknown to the surveillance followed the same pattern of fertility decline and stall as HIV positive women and declined at the steepest rate between 2005 and 2012 ($m=-7.11$, $R^2=0.984$) (Figure 4.6)

Figure 4.6 Crude Birth Rates between 2005 and 2012 to all women by HIV status as known to ACDIS



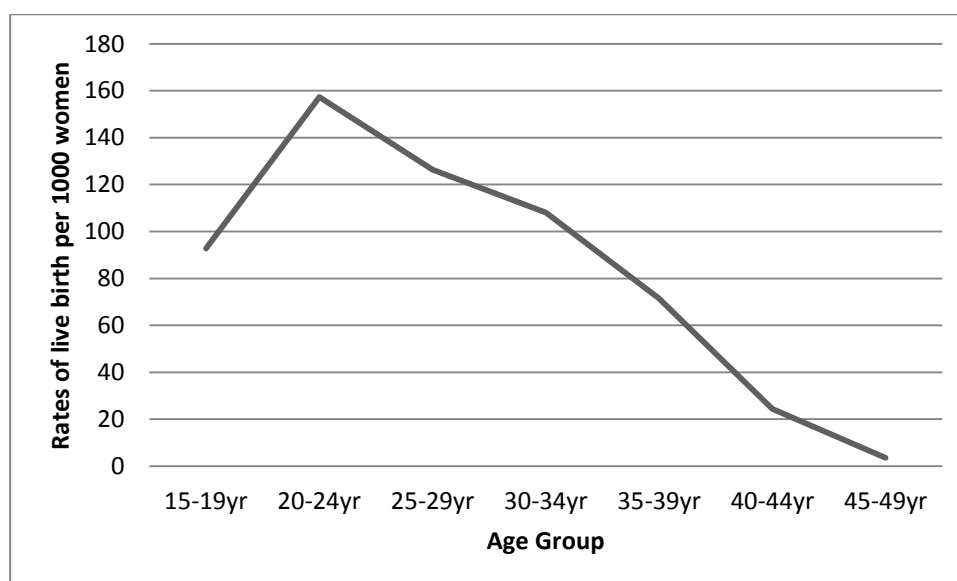
Year	Crude rates of live birth per 1000 woman-years		
	HIV Negative	HIV Positive	HIV unknown
2005	148	113	132
2006	137	106	118
2007	153	99	112
2008	141	100	109
2009	136	80	99
2010	115	83	91
2011	135	82	87
2012	131	71	79

(HIV Status determined from the HIV surveillance only)

4.1.3 Age-Specific Fertility Rates: 2005-2012

Age-specific fertility rates were calculated from the number of live births divided by the total number of years women were observed to belong to five-year age bands: 15-19, 20-24, 25-29, 30-34, 35-39, 40-44 and 45-49 years old. The denominator, woman-years, is the sum of the number of days that each woman was observed to be resident in the surveillance area within a specific age group. Trends demonstrate the typical ASFR pattern. Rates peak amongst women aged 20-24 years old and declined with increasing age, before adjusting for sexual activity.

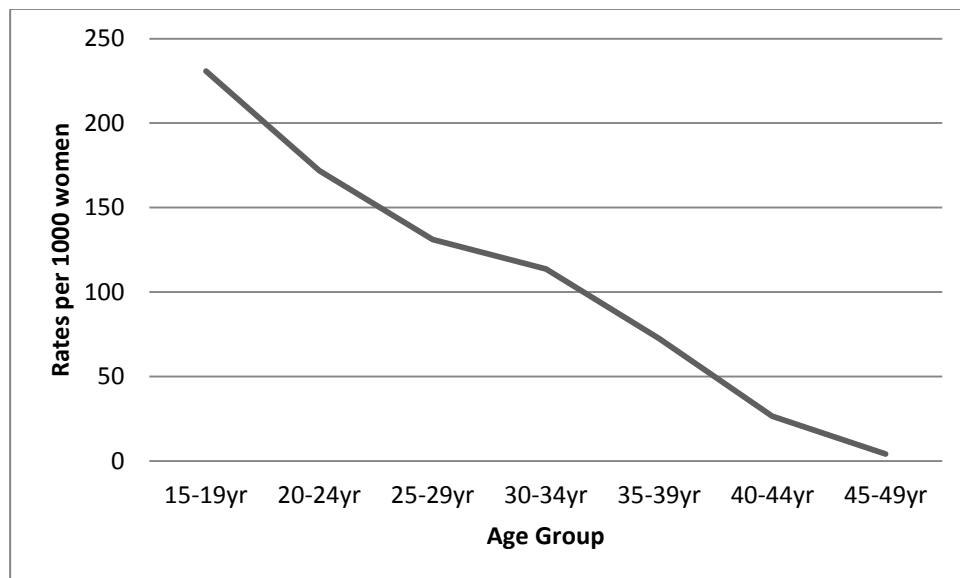
Figure 4.7 Age-Specific rates of live birth to all women aged 15-19 years



Age Group	Live births	Woman years at risk	Rate per 1000 woman years
15-19yr	3,349	36101.89	93
20-24yr	4,388	27899.30	157
25-29yr	2,678	21208.55	126
30-34yr	1,803	16690.62	108
35-39yr	1,027	14368.89	71
40-44yr	314	12883.36	24
45-49yr	45	12665.45	4

Patterns of age-specific fertility rates were very similar to the general population of resident women who had entered their sexual debut (figure 4.8), except for an apparent inflated rate amongst women aged 15-19 years old, which may be due to the exclusion of sexually inactive women that would otherwise comprise the majority of this age group. Analysis restricted to entry of sexual debut allows for an appropriate comparison between HIV negative and positive women.

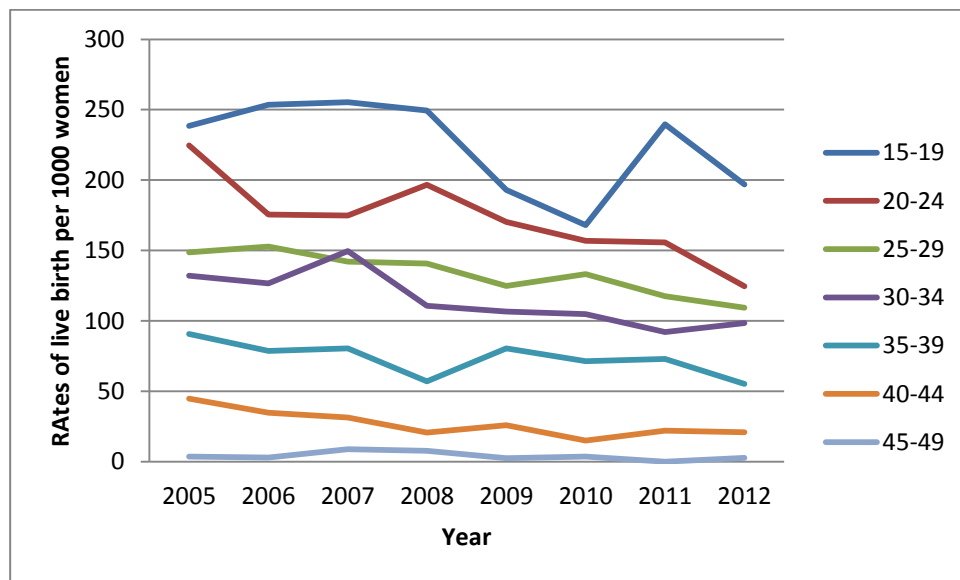
Figure 4.8 Age-specific rates of live birth to all women aged 15-49 years between 2005 and 2012 when limited to only women that had entered their sexual debut



Age Group	Live Births	Woman years at risk	Rate per 1000 woman years
15-19yr	1412	6118.26	231
20-24yr	2484	14450.63	172
25-29yr	1597	12184.05	131
30-34yr	1096	9634.20	114
35-39yr	645	8896.91	72
40-44yr	226	8536.22	26
45-49yr	35	8576.38	4

ASFRs presented by calendar year illustrate a general trend of fertility decline amongst women of all ages since 2005. Annualised rates of live birth fluctuated more amongst adolescent women aged 15-19 years old in the years of 2009 to 2011. Fertility decline was more consistent for older age groups.

Figure 4.9: Crude live birth rates according to age group by calendar year



4.1.4 Decline in age-adjusted rates of live birth between 2005 and 2012 by HIV Status

Patterns of annual ASFRs were similar amongst women of different HIV status but were consistently lower for HIV positive women per corresponding age. Rates declined over calendar time amongst all age and HIV status groupings although there were exceptions to these trends amongst women aged 20-24 and 35-39 years old.

Live birth rates amongst HIV positive women aged 35-39 years old increased consistently between 2006 and 2011 from 40 births/1000 women to 73 births/1000 women. This was against the crude

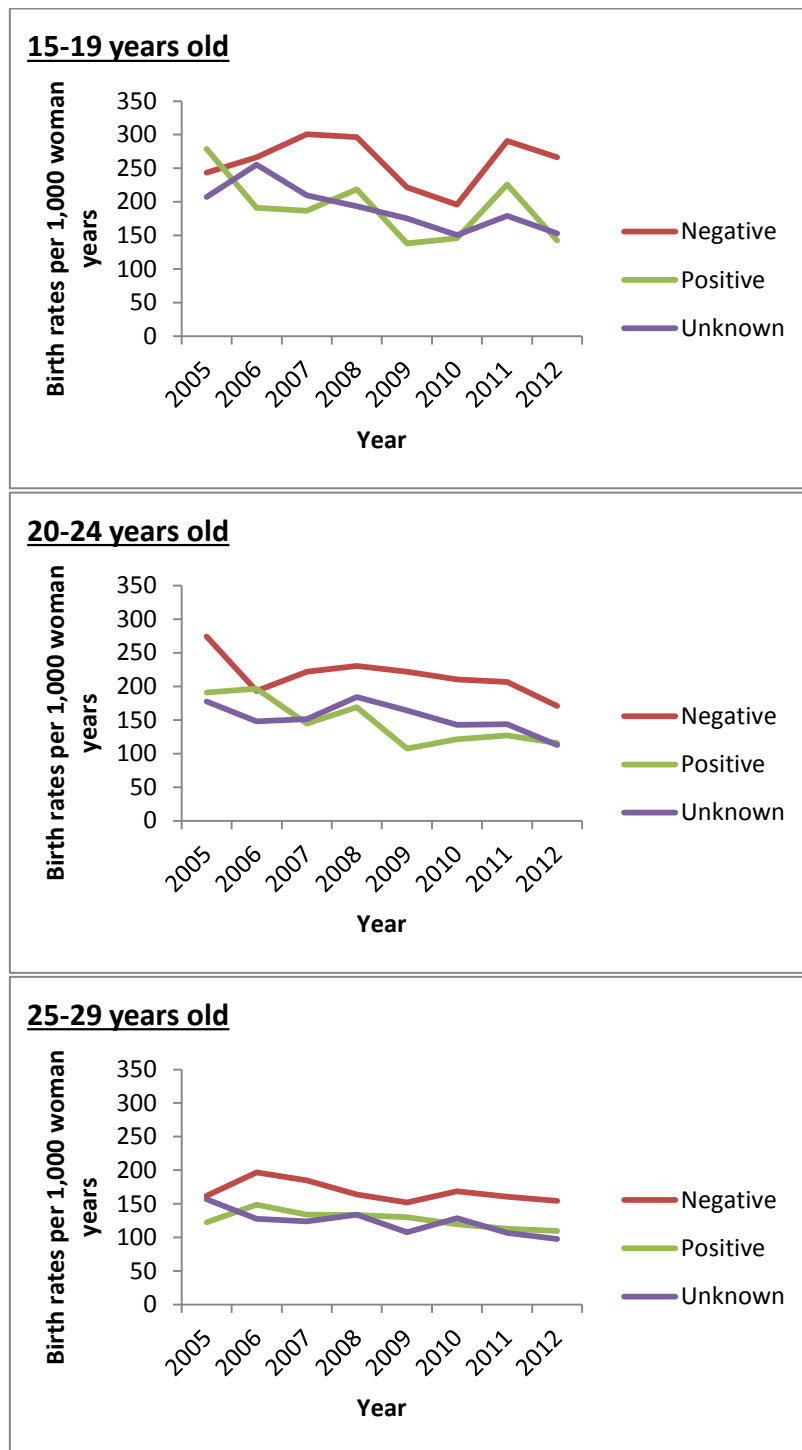
overall trend for declining birth rates and the only age/HIV group to show a constant increase in birth rates over time. In contrast, rates amongst HIV negative women of the same age group were consistently higher and dipped briefly in 2008 to 91.7 births per 1000 women before returning to 134.2 and 125.4 births/1000 women in 2009 and 2010 respectively.

Fertility decline appears to be more consistent amongst HIV negative women in the most fertile age group of 20-24 years old. ASFR declined constantly amongst HIV negative 20-24 year olds from 230 births/1000 women in 2008 to 164 births/1000 women in 2012. In comparison, HIV positive women of the same age experienced a shorter and earlier decline from 197 births/1000 women in 2006 to 108 births/1000 in 2009, followed by a stall in ASFR decline between years 2009 to 2012.

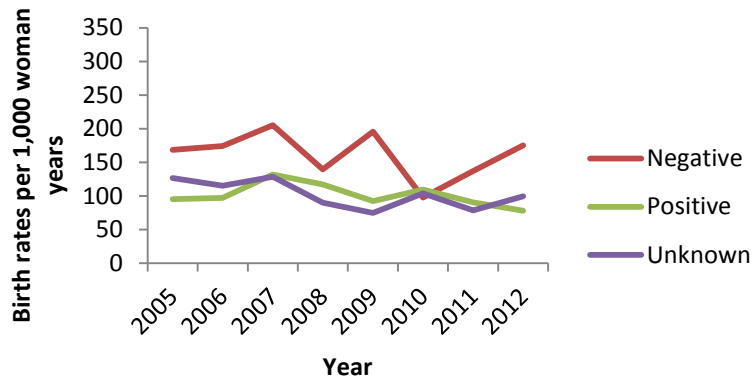
This analysis determined a bimodal peak of ASFRs amongst HIV negative women only. The first peak in live birth rates occurred amongst 15-19 years old or 20-24 years old and then a second peak at either 25-29 or 30-34 years old, occurring in the years 2005, 2007, 2009, 2010 and 2012.

In contrast, ASFRs peaked only once amongst women living with HIV. A corresponding second peak within the ages 29-35 years old was absent amongst HIV positive women and women whose HIV status was unknown to the surveillance, with one exception in 2007 amongst women aged 30-34 years old.

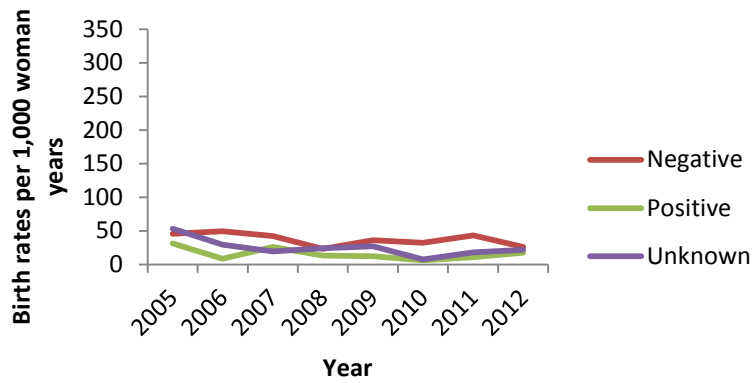
Figure 4.10 Age-specific fertility between 2005 and 2012, disaggregated by HIV status



30-34 years old



40-44 years old



45-49 years old

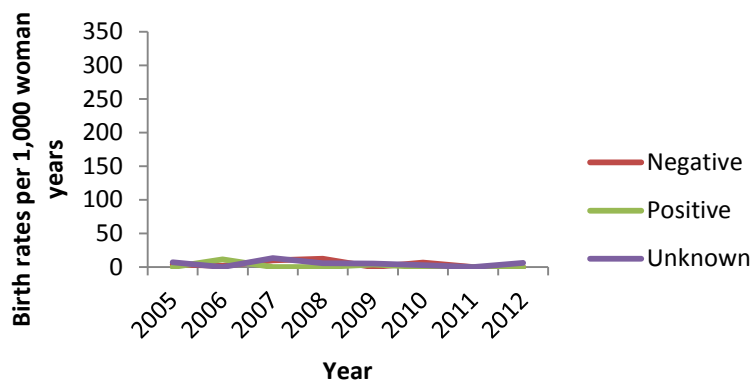


Table 4.3 Crude birth-rate by HIV Status, calendar year and age group between 2005 and 2012

Year	Annual ASFR by HIV status						
	15-19yr	20-24yr	25-29yr	30-34yr	35-39yr	40-44yr	45-49yr
<i>HIV negative women episodes</i>							
2005	243.62	274.28	161.81	168.43	110.73	45.60	3.68
2006	266.30	193.07	196.79	174.37	105.28	49.24	1.64
2007	300.72	221.60	184.63	205.29	122.30	42.49	9.79
2008	296.54	230.49	164.07	139.59	91.74	23.08	12.14
2009	221.65	221.58	151.84	195.55	134.24	35.94	0.00
2010	195.71	210.46	168.74	97.42	125.36	32.12	6.50
2011	290.62	206.75	160.53	136.80	90.31	43.47	0.00
2012	266.57	170.62	154.30	175.08	91.45	25.86	0.00
<i>HIV positive women episodes</i>							
2005	278.99	190.76	122.49	95.05	63.42	31.13	0.00
2006	191.21	196.55	148.77	97.26	39.66	8.56	11.44
2007	186.72	144.83	133.74	131.65	45.68	26.09	0.00
2008	218.58	169.07	133.34	117.24	42.94	13.36	0.00
2009	137.89	107.57	129.99	92.21	51.57	12.19	3.87
2010	145.82	121.26	119.28	109.27	67.23	6.09	0.00
2011	225.99	127.12	113.02	90.32	72.99	10.94	0.00
2012	142.16	115.49	109.59	77.95	53.28	17.45	0.00
<i>Episodes where HIV status is unknown to surveillance</i>							
2005	207.20	177.26	156.64	126.33	79.24	53.43	7.01
2006	255.37	148.10	127.58	115.16	78.43	29.61	0.00
2007	209.77	151.53	123.68	128.29	67.27	19.62	13.35
2008	193.21	184.13	133.83	89.69	40.68	24.03	5.74
2009	175.18	163.94	107.49	74.69	67.29	27.27	5.35
2010	150.28	142.67	128.73	103.66	39.70	7.52	2.63
2011	179.28	143.51	106.39	78.29	64.28	18.06	0.00
2012	152.96	112.59	97.45	99.31	45.86	21.85	5.90

4.1.5 Section summary

- The average mid-year population of resident women of reproductive age was 25,143 and this population varied little annually.
- Crude Birth Rates declined from 272 births/1000 women in 2005 to 166 births/1000 women in 2009. At this time a decline in CBR stalled until 2011.
- Sexual debut is the most appropriate restriction for a comparison of HIV positive and HIV negative woman episodes: according to surveillance data only 4% of the annual mid-year population reported being married and 34% answered 'yes' to ever having had sex.
- CBR were lower and decline stalled between 2010 and 2011 when restricted to women who had entered their sexual debut.
- HIV positive women experienced consistently lower CBR than HIV negative women, since 2005. Women with missing HIV status followed a similar trend to HIV positive women.
- ASFRs followed a typical pattern with a peak at ages 20-24 years old at 157 births/1000 women. After restricting to women who had made their sexual debut, rates were inflated to peak in the adolescent age group 15-19 years old at 231 births/1000 women.
- A pattern of bimodal fertility was observed in HIV negative women only. HIV positive women showed consistent decline with age group and calendar year, indicating that HIV infected women typically limit childbearing at older ages and earlier than HIV negative women.
- ASFRs declined between 2005 and 2012, with the exception of HIV positive women aged 35-39 years old who experienced an increase in rates between 2006 and 2011. This increase in fertility amongst these HIV positive women coincided with a rapid scale up of access to ART through the Hlabisa HIV treatment and care programme after 2005 and could indicate a cessation of postponed childbearing amongst these women once ART was made available.

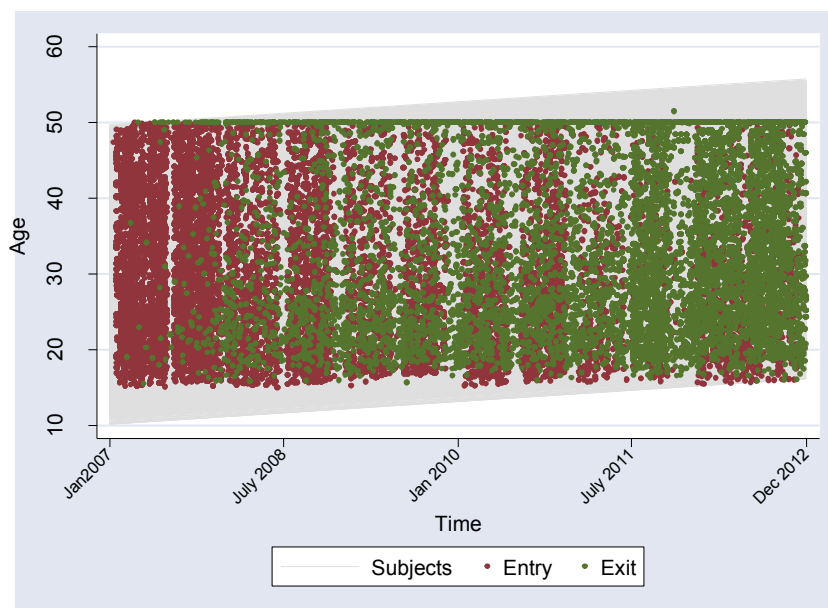
4.2 Incidence and factors associated with likelihood of live birth amongst women known to be HIV negative and positive during annual surveillance rounds 2007-2012 (open cohort)

4.2.1 Cohort characteristics

A total of 9,972 women entered an open cohort during surveillance years 2007 until 2012 (Figure 3.2). The dataset included 28,267 annually updated woman episodes, allowing women to contribute 26,754 women years of follow up (over multiple episodes) in the cohort (Table 4.4).

Most women entered the cohort in the first two years of inclusion: 57% of women entered the cohort in years 2007 or 2008 and in smaller equal proportions in each subsequent year. Median follow up time was 1.97 years per woman although this differed by HIV status. Median duration of follow up was 1.95 years for HIV negative women, 1.83 years for HIV positive ART-naïve women and 2.6 years for HIV positive women on ART.

Figure 4.11: Lexis diagram of individual entry date and exit date by age between 2007 and 2013



4.2.2 Participant characteristics

The number of woman-years and live birth events observed in this open cohort are presented in Table 4.4. The proportions of all woman-years are further listed according to HIV group, to compare denominators for following analysis.

Demographic characteristics

Notably, women differed by age and parity between HIV statuses at entry and during follow up. Women were a median age of 28 years old and had two children at entry (Table 4.4): HIV negative women were younger (25 years old) and had one child on average, compared to HIV positive women (31 years old) who had a median of two children. During all annual woman episodes median age was 31 years old and a trend by HIV status remained. Overall, 61% of women lived in a rural area of residence as would be expected in the predominantly rural Hlabisa sub-district, although more HIV positive women lived in peri-urban or urban areas compared to HIV negative women.

Relationship and contraceptive use characteristics

Reported rates of marriage were low: just 11% of women years were to engaged or married women in this cohort (Table 4.4). The majority of women reported being in a regular relationship both at entry and during follow up. Fewer HIV positive women responded to this question or were in a relationship compared to HIV negative women (34% and 55% respectively). HIV positive women were less likely to have a regular partner when exposed to ART than during ART-naïve observations. Responses to the current relationship status question were high and approximately 70% of women answered during each annual episode.

Women reported using contraception during 29% of all observation time in this cohort (Table 4.4). This question was asked to all women regarding contraceptive use at time of last sex. Most women preferred to use hormonal methods of contraception, although fewer HIV positive women reported using hormonal methods in comparison to HIV negative women. However, more ART-exposed women chose to use barrier methods at last sex when compared to ART-naïve women. Reported use of dual contraception was very low in this cohort overall (1%), although a higher proportion of dual

contraceptive users were HIV positive (70%) compared to the proportion of single injectable users (47%) and suggests a positive influence of family planning messaging to women living with HIV.

HIV characteristics

Women were distributed equally according to HIV status at first entry: 52% women were HIV negative, 36% of women were HIV positive ART naïve and 13% of women were HIV positive and using ART (Table 4.4). Women of unknown HIV status were excluded for the purpose of this cohort. Time-dependant covariates were updated with the next annual HIV surveillance visit and of 26,754 woman-years in the cohort between 2007 and 2012, a total of 46% were HIV negative, 34% HIV positive and 20% on-ART (Table 4.6).

There were 399 sero-conversions amongst HIV negative women that occurred during observation in this cohort. The date of sero-conversion was estimated by calculating a halfway point between last known HIV positive and last known HIV negative test. Recently infected individuals may be considered a distinct group; they are likely to have recently engaged in unprotected sexual intercourse, are less likely to have initiated ART and are at higher risk of HIV transmission to partners. The timing of conception to before or after sero conversion may not be accurately modelled for these women, suggesting a best approach could be to exclude this group. However, longitudinal data spanning before and after sero-conversion is not typically available in clinical studies and these women contribute important information to describe fertility in the Hlabisa setting that may be adjusted for with CD4 count and self-reported health measures. This group of women were therefore included for analysis.

As ART was rapidly brought to scale, the proportion of all women in the cohort using ART increased from 10% in 2007 to 33% in 2012. Of these women, 9% initiated ART while observed in the cohort. The proportion of women on ART is reported in table 4.4 by calendar year. This proportion is likely to continue to grow as more people enrol on ART and survive to older ages in this setting. Additionally, more women are likely to remain on lifelong ART after a pregnancy if South Africa is to adopt WHO recommendations for PMTCT option B+.

Knowledge of own HIV status is high in the area, with 70% of women reporting to know their own status during cohort follow up (Table 4.4). Of all women-years that women knew their HIV status, 60% were to HIV positive women (Table 4.4). Furthermore, a sub-analysis that stratified women by HIV status found 79% of HIV positive women and 60% of HIV negative women were aware of their own HIV Status (data not shown). This 'HIV positive' grouping also included ART-exposed women and thus, more women were aware of their HIV positive status compared to HIV negative women. When episodes to ART-exposed women were not included, knowledge was equitable, with only 60% of HIV positive women reporting knowledge of their HIV status.

Awareness of the benefits of ART was not widespread amongst either HIV negative or HIV positive women. Overall, 52% of women reported knowing about ART and 15% reported no awareness about this treatment. This question also had a high non-response rate of 33% of all women-years (Table 4.4).

CD4 count measures were available for 62% of HIV positive women at baseline entry to the cohort and for 68% of all observed episodes during which a woman was considered HIV positive. The closest CD4⁺ measure recorded in the ARTemis database within 6 months of the woman-episode start date was linked to the corresponding annual episode and so it was possible that a CD4⁺ count not taken or recorded in that time period would result in a missing CD4⁺ measure in time-updated analysis.

Self-reported general health characteristics

Most women reported good self-health (58%), although less of the women describing 'Excellent, Very good or Good' health were enrolled on ART compared to the general cohort (Table 4.4). The proportion of women reporting positive health varied substantially by HIV Status: a separate analysis showed that just 53% of women living with HIV reported feeling healthy compared to 85% of HIV negative women. More HIV positive women did not answer the question on perceived health and of these, ART-exposed women were most likely to not respond to this question or perceive their own health as fair or poor.

Table 4.4: Number of women-years observed and birth events to women between 2007-2013, by characteristic and stratified to compare HIV negative, positive ART naïve and positive onART groups.

Characteristics	Women-years (wy) observed				Births			
	Total wy per category (%)	% of wy to HIV group			Total number of births	% of births to HIV group		
		HIV-	HIV+ and ART naïve	HIV+ and onART		HIV-	HIV+ and ART naïve	HIV+ and onART
CHARACTERISTICS AT ENTRY								
Proportions of wy at entry	26,754 (100%)	51%	36%	13%	-	-	-	-
Median Age	28	25	29	34	-	-	-	-
Median Parity	2	1	2	2	-	-	-	-
Education								
Never attended	4,085 (15%)	50%	30%	20%	101 (6%)	57%	27%	16%
At least Primary	5,379 (20%)	44%	35%	21%	436 (25%)	76%	17%	7%
Secondary	9,236 (35%)	48%	35%	17%	743 (42%)	72%	20%	8%
Tertiary	5,748 (21%)	46%	35%	19%	366 (21%)	71%	19%	10%
Unknown	2,307 (9%)	41%	35%	24%	111 (6%)	66%	19%	15%
Area								
Rural	16,256 (61%)	53%	31%	16%	1,242 (71%)	75%	18%	7%
Peri-Urban	8,857 (33%)	38%	40%	22%	455 (26%)	63%	24%	13%
Urban	1,642 (6%)	30%	38%	32%	60 (3%)	65%	22%	13%
TIME-UPDATED CHARACTERISTICS								
Total proportions	26,754 (100%)	46%	34%	20%	1,757(100%)	72%	19%	9%
Median Age	31	28	30	35	-	-	-	-
Median Parity	2	2	2	3	-	-	-	-
Age								
15-19	2,774 (10%)	74%	22%	4%	514 (29%)	90%	9%	1%
20-24	5,175 (19%)	58%	35%	7%	513 (29%)	76%	20%	3%
25-29	4,547 (17%)	38%	44%	18%	311 (18%)	50%	32%	18%
30-34	3,892 (15%)	29%	39%	32%	232 (13%)	54%	25%	21%
35-39	3,670 (14%)	54%	26%	20%	138 (8%)	60%	21%	19%
40-44	3,515 (13%)	44%	31%	26%	40 (2%)	80%	10%	10%
45-49	3,181 (12%)	54%	26%	20%	9 (1%)	78%	0%	22%
Knowledge of own HIV status								
No	4,894 (18%)	67%	33%	0%	333 (19%)	83%	17%	0%
Yes	18,731 (70%)	40%	32%	28%	1,095 (62%)	63%	23%	15%
Unknown	3,129 (12%)	54%	46%	0%	329 (19%)	89%	11%	0%
Most recent relationship								
Single	4,937 (18%)	41%	35%	24%	268 (15%)	75%	15%	10%
Casual / partner	423 (2%)	51%	39%	10%	30 (2%)	67%	33%	0%
Eng / Married	3,037 (11%)	68%	19%	13%	132 (8%)	77%	17%	6%
Regular partner	8,947 (33%)	57%	31%	12%	680 (39%)	70%	22%	8%
Div / Wid / Sep	1,220 (5%)	50%	31%	19%	80 (5%)	68%	25%	8%
Other/ unknown	8,190 (31%)	29%	43%	28%	567 (32%)	71%	18%	11%

Living with partner								
No	10,131 (38%)	55%	32%	12%	701 (40%)	71%	23%	6%
Yes	3,730 (14%)	62%	24%	14%	188 (11%)	65%	22%	13%
Unknown	12,893 (48%)	35%	39%	27%	868 (49%)	73%	16%	11%
Parity								
0	3,616 (14%)	57%	31%	12%	637 (36%)	89%	10%	2%
1	6,735 (25%)	51%	35%	14%	454 (26%)	68%	24%	9%
2	5,124 (19%)	37%	40%	23%	273 (16%)	52%	32%	15%
3	3,745 (14%)	36%	36%	28%	169 (10%)	56%	27%	17%
4	2,570 (10%)	43%	32%	25%	94 (5%)	59%	19%	22%
5	1,910 (7%)	48%	31%	21%	54 (3%)	63%	22%	15%
6+	3,054 (11%)	46%	34%	19%	76 (4%)	71%	19%	9%
Self-reported Health								
Fair/Poor	3,498 (13%)	43%	28%	30%	122 (7%)	61%	22%	16%
Excellent / Very good / Good	15,412 (58%)	57%	31%	12%	1089 (62%)	73%	20%	7%
Unknown	7,844 (29%)	28%	44%	28%	546 (31%)	70%	18%	12%
Heard of ART								
No	4,009 (15%)	62%	38%	0%	279 (16%)	81%	19%	0%
Yes	13,993 (52%)	38%	25%	37%	745 (42%)	60%	18%	22%
Unknown	8,753 (33%)	52%	48%	0%	733 (42%)	80%	20%	0%
Year								
2007	4,310 (16%)	52%	39%	10%	274 (16%)	74%	23%	3%
2008	5,414 (20%)	49%	37%	11%	337 (19%)	75%	19%	6%
2009	4,919 (18%)	48%	35%	18%	299 (17%)	71%	23%	6%
2010	4,922 (18%)	44%	35%	21%	318 (18%)	62%	23%	15%
2011	4,187 (16%)	42%	31%	27%	324 (18%)	72%	15%	13%
2012	3,003 (11%)	43%	24%	33%	205(12%)	77%	11%	13%
Using contraception (updated annually)								
No	3,985 (15%)	62%	28%	10%	319 (18%)	73%	23%	5%
Yes	7,660 (29%)	51%	32%	17%	280 (16%)	59%	26%	15%
Unknown	15,109 (56%)	40%	37%	23%	1158 (66%)	74%	17%	9%
Form of Contraception								
Barrier methods	1,973 (7%)	41%	33%	27%	105 (6%)	50%	32%	18%
Oral / IUCD / Microbicides	324 (1%)	64%	26%	10%	13 (1%)	46%	31%	23%
Injectable	2,563 (10%)	53%	30%	17%	80 (5%)	64%	23%	14%
Dual	368 (1%)	30%	40%	30%	10 (1%)	20%	60%	20%
Other/unknown method	2,431 (9%)	58%	32%	10%	72 (4%)	75%	17%	8%
None	3,985 (15%)	62%	28%	10%	319 (18%)	73%	23%	5%
Unknown if using	15,109 (56%)	47%	34%	19%	1158 (66%)	71%	19%	9%

4.2.3 Incidence of pregnancy in open cohort

There were a total of 1,757 live births among 9,972 women between the years of 2007 and 2013 (Figure 3.2 and Table 4.4). Overall crude incidence of live birth was 6.6 births per 100 woman years.

Incidence of live birth was approximately 3 times greater for HIV negative woman than in HIV positive woman episodes at any year of follow up. Cumulatively, 14% of HIV negative women experienced 1,286 births at an incidence of 9.7 births/100 HIV negative woman years (95% CI 9.2 – 10.2), compared to 4% in HIV positive women who experienced 472 births at an incidence of 3.5 births/100 woman years (95% CI 3.2 – 3.8).

A total of 998 women were pregnant at entry to cohort, calculated using a retrospective estimate of date of conception 9 months prior to the date of birth. Women that were pregnant at entry later experienced 83 (2nd) and 6 (3rd) recurrent births. There were 118 recurrent births in total (70% to women that were pregnant at entry to cohort). Women on ART delivered 9% of all first births, 12% of second births and 0% of third births. Incidence of first and second births was highest in the youngest age group and contrariwise, third births were equally distributed by age.

Figure 4.12 presents the cumulative proportion of women experiencing a live birth during each annual surveillance episode according to HIV status category for that episode. If women were to seroconvert, she may contribute to both graphs at different time-points.

Figure 4.12 Cumulative proportion of HIV negative and HIV positive women that remain 'birth-free' during each annual year of follow up

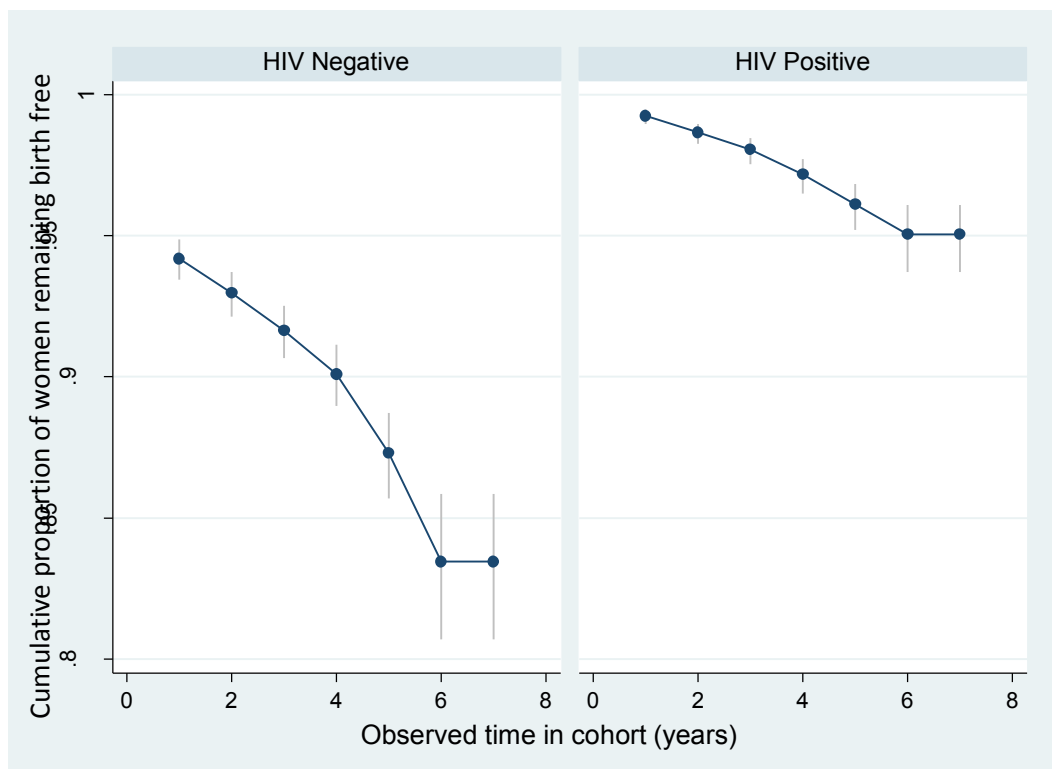


Table 4.5 Cumulative numbers of births and attributable birth-free women during each annual year of follow up according to HIV status

Interval (years observed)	Total at risk	Live birth Events	Lost to follow up	Survival	Error	95% Conf. Int.
<i>HIV Negative</i>						
0 – 1 years	4852	245	1257	0.942	0.0036	[0.9345 - 0.9486]
1 – 2 years	3350	38	877	0.9297	0.0041	[0.9213 - 0.9372]
2 – 3 years	2435	30	683	0.9164	0.0047	[0.9067 - 0.9251]
3 – 4 years	1722	24	568	0.9011	0.0055	[0.8896 - 0.9114]
4 -5 years	1130	25	661	0.8729	0.0077	[0.8569 - 0.8872]
5 – 6 years	444	12	343	0.8345	0.0131	[0.8069 - 0.8585]
6 – 7 years	89	0	89	0.8345	0.0131	[0.8069 - 0.8585]
<i>HIV Positive</i>						
0 – 1 years	5120	34	1023	0.9926	0.0013	[0.9897 - 0.9947]
1 – 2 years	4063	22	875	0.9866	0.0018	[0.9826 - 0.9897]
2 – 3 year	3166	17	813	0.9805	0.0023	[0.9754 - 0.9846]
3 – 4 years	2336	18	668	0.9717	0.0031	[0.9650 - 0.9772]
4 -5 years	1650	14	735	0.9611	0.0042	[0.9521 - 0.9685]
5 – 6 years	901	6	724	0.9504	0.006	[0.9372 - 0.9609]
6 – 7 years	171	0	171	0.9504	0.006	[0.9372 - 0.9609]
HIV Status		Events Observed		Events Expected		
Negative		1256		760.67		
Positive		501		996.33		
Total		1,757		1,757.00		
		Chi2		570.27		
		Pr>chi2		0.0000		

4.2.4 Live birth rates after initiation on ART

After initiation of ART, women delivered 24 incident births with no recurrent events. Median time to birth was 25 months after initiation on to ART (inter quartile range (IQR) 15, 39), twice as long as those reported in Johannesburg (Westreich et al., 2012). After 76 months of observation, cumulative incidence of live birth was 8% (95% CI 7%, 10%). Comparatively, this is also lower than the 22.9% reported in Johannesburg over similar time of observation. CD4 count at ART initiation was known

for 82% of women and was not a significant predictor of crude birth rates in unadjusted analysis, excluding women pregnant at entry ($p=0.2898$).

4.2.5 Factors associated with incidence of live birth

Table 4.6 presents incidence rate of live birth for a range of time-updated socio-economic, self-reported health and clinical characteristics. Crude incidence is presented for the whole cohort and then stratified for HIV infected and HIV uninfected women. Details of the woman-year denominators and number of birth events are provided in Table 4.4

Overall crude incidence of live birth in this cohort decreased with increasing age group, higher parity, poorer self-reported health, an urban area of residency, knowledge of own HIV status, being single or engaged/married, not living with a partner, an awareness of the benefits of ART, use of contraception and use of injectable methods of contraception (Table 4.6).

Bivariate Poisson analysis of each characteristic adjusted for HIV status. It is notable that adjusting for HIV had a minimal effect on associations between individual proximate and distal determinants of live birth. Trends for each characteristic remained significant or unchanged to that of univariate analysis for all variables, with the exception of an effect of living with a partner and the year of annual surveillance round.

In this open cohort crude birth rates did not decline annually as indicated by results from analysis one. This could be explained by the slow pace of decline in recent years, inclusion criteria for women of known HIV status only which excludes a proportion of the general population, and that these selected years are at a time of a reported stall in fertility decline. In univariate analysis of HIV negative or HIV positive women only, year of annual surveillance was not associated with rates of live birth.

The following sections will discuss results for demographic, relationship and HIV related proximate and distal determinants of fertility.

Table 4.6: Characteristics associated with crude incidence of live birth to all women and by HIV status (women can contribute more than once)

Characteristics	Woman-years observed		Incidence Rate [95% CI]			
	Total	% HIV Positive	Overall Incidence (N=26,754)	HIV Status		Trend adjusted for HIV (p-value)
				HIV Negative (N=12,437 woman years)	HIV Positive (N=14, 317) woman years)	
Overall	n=26,754	49%	6.6 [6.3 – 6.9]	9.7 [9.2 – 10.2]	3.5 [3.2 – 3.8]	p<0.001
Characteristics at entry						
Education at entry						
Never attended	4,085	50%	2.5 [2.0 – 3.0]	2.9 [2.2 – 3.7]	2.0 [1.4 – 2.8]	p<0.001
At least Primary	5,379	46%	8.1 [7.4 – 8.9]	13.2 [11.9 – 14.7]	3.5 [2.9 – 4.3]	
Secondary	9,236	52%	8.0 [7.5 – 8.6]	11.5 [10.5 – 12.5]	4.5 [3.9 – 5.1]	
Tertiary	5,748	54%	6.4 [5.7 – 7.1]	9.4 [8.4 – 10.6]	3.4 [2.8 – 4.1]	
Unknown	2,307	59%	4.8 [4.0 – 5.8]	7.3 [5.9 – 9.2]	2.7 [1.9 – 3.8]	
			p<0.001	p<0.001	P=0.044	
Area at entry						
Rural	16,256	47%	7.6 [7.2 – 8.1]	10.5 [9.8 – 11.2]	4.1 [3.7 – 4.6]	p<0.001
Peri-Urban	8,857	62%	5.1 [4.7 – 5.6]	8.1 [7.2 – 9.1]	3.0 [2.6 – 3.5]	
Urban	1,642	70%	3.7 [2.8 – 4.7]	7.2 [5.3 – 9.7]	1.8 [1.1 – 2.8]	
			p<0.001	p<0.001	p<0.001	
Characteristics updated annually						
Age						
15-19	2,774	26%	19.5 [16.9 – 20.2]	22.4 [20.4 – 24.5]	6.9 [5.2 – 9.2]	p<0.001
20-24	5,175	42%	9.9 [9.1 -10.8]	12.6 [11.4 – 13.9]	5.9 [4.9 – 7.0]	
25-29	4,547	62%	6.7 [6.1 – 7.7]	9.0 [7.7 – 10.4]	5.3 [4.5 – 6.3]	
30-34	3,892	71%	5.9 [5.2 – 6.8]	10.0 [8.4 – 11.9]	3.9 [3.3 – 4.8]	
35-39	3,670	46%	3.8 [3.2 – 4.4]	6.2 [5.0 – 7.6]	2.2 [1.7 – 2.9]	
40-44	3,515	57%	1.1 [0.8 – 1.6]	1.9 [1.4 – 2.6]	0.4 [0.2 – 0.9]	
45-49	3,181	46%	0.3 [0.1 – 0.5]	0.4 [0.2 – 0.8]	0.1 [0.0 – 0.6]	
			P<0.001	P<0.001	P<0.001	
Knowledge of own HIV status						
No	4,894	33%	6.8 [6.1 – 7.6]	8.3 [7.4 – 9.3]	3.6 [2.7 – 4.7]	p<0.001
Yes	18,731	60%	5.9 [5.5 – 6.2]	9.0 [8.3 – 9.7]	3.6 [3.3 – 4.0]	
Unknown	3,129	46%	10.5 [9.4 – 11.7]	14.5 [12.9 – 16.2]	2.5 [1.7 – 3.7]	
			P<0.001	P<0.001	P=0.233	
Most recent relationship						
Single	4,937	59%	5.4 [4.8 – 6.1]	9.9 [8.6 – 11.4]	2.3 [1.8 – 2.9]	p<0.001
Casual friend / partner	423	49%	7.1 [5.0 – 10.1]	9.2 [5.9 – 14.3]	4.8 [2.6 – 9.0]	
Engaged / Married	3,037	32%	4.3 [3.7 – 5.2]	4.9 [4.1 – 6.0]	3.1 [2.2 – 4.4]	
Regular partner	8,947	43%	7.6 [7.1 – 8.2]	9.3 [8.5 – 10.2]	5.3 [4.6 – 6.1]	

Divorced / Widowed / Separated	1,220	50%	6.6 [5.3 – 8.2]	8.8 [6.7 – 11.4]	4.3 [2.9 – 6.3]	
Other or unknown	8,190	71%	6.9 [6.4 – 7.5]	16.8 [15.3 – 18.5]	2.8 [2.4 – 3.3]	
			P<0.001	P<0.001	P=0.424	
Living with partner						
No	10,131	44%	6.9 [6.4 – 7.5]	8.9 [8.2 – 9.7]	4.3 [3.7 – 5.0]	p<0.001
Yes	3,882	38%	5.0 [4.4 – 5.8]	5.2 [4.4 – 6.2]	4.7 [3.7 – 6.0]	
Unknown	12,893	66%	7.5 [5.5 – 10.2]	10.4 [7.4 – 14.7]	3.3 [1.6 – 6.8]	
			P=0.993	P=0.001	P<0.001	
Median Parity at entry						
			2	2	2	
Parity (time-updated)						
0	3,616	43%	17.6 [16.3 – 19.0]	26.7 [24.6 – 28.9]	4.7 [3.7 – 5.9]	p<0.001
1	6,735	49%	6.7 [6.1 – 7.4]	8.7 [7.8 – 9.8]	4.4 [3.7 – 5.2]	
2	5,124	63%	5.3 [4.7 – 6.0]	7.2 [6.2 – 8.5]	4.0 [3.4 – 4.8]	
3	3,745	64%	4.5 [3.9 – 5.2]	6.6 [5.5 – 8.1]	3.1 [2.4 – 3.9]	
4	2,570	57%	3.7 [3.0 – 4.5]	4.7 [3.6 – 6.2]	2.7 [2.0 – 3.8]	
5	1,910	52%	2.8 [2.2 – 3.7]	3.8 [2.8 – 5.3]	1.8 [1.1 – 2.9]	
6+	3,054	63%	2.5 [2.0 – 3.1]	3.2 [2.5 – 4.2]	1.4 [0.9 – 2.3]	
			P<0.001	P<0.001	P<0.001	
Self-reported Health						
Fair/Poor	3,498	58%	3.5 [2.9 – 4.2]	4.7 [3.7 – 5.9]	2.5 [1.9 – 3.3]	p<0.001
Excellent / Very good / Good	15,412	43%	7.1 [6.7 – 7.5]	9.0 [8.4 – 9.6]	4.3 [3.8 – 4.9]	
Unknown	7,844	71%	7.0 [6.4 – 7.6]	15.2 [13.7 – 16.7]	2.9 [2.5 – 3.4]	
		55%	P<0.001	P<0.001	P=0.446	
Heard of ART						
No	4,009	38%	7.0 [6.2 – 7.8]	9.0 [7.9 – 10.3]	3.6 [2.7 – 4.7]	p<0.001
Yes	13,993	62%	5.3 [5.0 – 5.7]	8.3 [7.6 – 9.1]	3.5 [3.1 – 3.9]	
Unknown	8,753	48%	8.4 [7.8 – 9.0]	11.3 [10.5 – 12.3]	3.6 [3.0 – 4.3]	
			P<0.001	P<0.001	P=0.863	
Year of annual surveillance episode						
2007	4,310	49%	6.4 [5.6 – 7.2]	9.1 [7.9 – 10.4]	3.4 [2.7 – 4.3]	P=0.063
2008	5,414	48%	6.2 [5.6 – 6.9]	9.5 [8.4 – 10.7]	3.1 [2.4 – 3.8]	
2009	4,919	53%	6.1 [5.4 – 6.8]	9.0 [7.9 – 10.3]	3.4 [2.7 – 4.2]	
2010	4,922	56%	6.5 [5.8 – 7.2]	9.2 [8.0 – 10.6]	4.3 [3.6 – 5.2]	
2011	4,187	58%	7.8 [7.0 – 8.7]	11.3 [10.0 – 12.8]	3.8 [3.1 – 4.8]	
2012	3,003	57%	6.8 [5.9 – 7.8]	10.1 [8.7 – 11.7]	2.5 [1.8 – 3.6]	
			P=0.022	P=0.057	P=0.678	
Using contraception (updated annually)						
No	3,985	38%	8.0 [7.2 – 9.0]	9.4 [8.3 – 10.7]	5.8 [4.7 – 7.2]	p<0.001
Yes	7,660	49%	3.7 [3.3 – 4.1]	4.2 [3.6 – 4.9]	3.0 [2.5 – 3.6]	
Unknown	15,109	50%	7.7 [7.2 – 8.1]	13.1 [12.3 – 14.0]	3.3 [2.9 – 3.7]	
			P<0.001	P<0.001	P<0.001	
Form of Contraception						
Barrier methods	1,973	60%	5.4 [4.4 – 6.4]	6.2 [4.7 – 8.0]	4.5 [3.5 – 6.1]	p<0.001
Oral / IUCD / Microbicides	324	36%	4.0 [2.3 – 6.9]	2.8 [1.2 – 6.1]	6.5 [3.1 – 13.7]	

Injectable	2,563	47%	3.1 [2.5 – 3.8]	3.7 [2.8– 4.8]	2.4 [1.6 – 3.5]
Dual	368	70%	2.7 [1.5 – 5.0]	3.2 [1.2 – 8.4]	2.5 [1.1 – 5.5]
Other/unknown method	2,431	42%	3.0 [2.4 – 3.7]	3.8 [2.9 – 5.0]	1.8 [1.1 – 2.8]
None	3,985	38%	8.0 [7.2 – 9.0]	9.4 [8.3 – 10.7]	5.8 [4.7 – 7.1]
Unknown if using	15,109	53%	7.7 [7.2 – 8.1]	13.1 [12.3 – 14.0]	3.3 [2.9 – 3.7]
			P<0.001	P<0.001	P=0.235

HIV characteristics

HIV positive status was associated with crude rates of 3.5 births per 100 women [95% CI 3.2 – 3.8], three times lower compared to HIV negative periods in a woman episode analysis.

Knowledge of own HIV status was associated with lower incidence of live birth in overall univariate analysis, but not when stratified to HIV negative or HIV positive women only. Lower incidence to all women reporting HIV status knowledge conceals an opposite trend amongst HIV negative women, who demonstrate higher incidence associated with knowledge, compared to no knowledge, of HIV status. Higher incidence to women that know they are HIV negative seems intuitive: HIV negative women do not face issues of stigma or risks to health that are associated with a HIV positive status and may be encouraged to have children in light of this information. However, the difference was non-significant. HIV positive women, alternatively, experienced no difference in incidence of live birth associated with knowledge of their status. This finding is more surprising. The hypothesis that a HIV diagnosis might encourage women to curtail childbearing behaviours, or use of ART may reverse this effect, requires that they are aware of their status. Absence of a univariate trend may be due to lack of adjustment for age and parity, as women on ART are likely to be older and have more children, and potentially later in their reproductive life than HIV negative women.

The lower overall cohort incidence associated with HIV status knowledge, while incidence increases with knowledge to HIV negative women and shows no difference amongst HIV positive women, could be explained by a higher contribution of HIV positive person-years to the ‘Yes’ category, while these women demonstrate lower birth rates than HIV negative women. Most women in the cohort were aware of their status: 70% of all woman-years were to women that responded ‘yes’ to this

question. Of these, the majority were HIV positive: HIV positive women accounted for 58% of all woman-years with a 'yes' response (Table 4.4). Yet HIV positive women experience lower incidence of live birth compared to HIV negative women. Consequently, a HIV positive majority results in the lower overall incidence reported in the 'yes' category of knowledge of a status in this cohort.

Table 4.6 provides no evidence that HIV positive women chose to alter their childbearing behaviours in this setting. However, all women on ART are aware of their HIV status and this analysis does not present associations between knowledge and live birth rates amongst ART naive women and those that are exposed to ART. This analysis is presented in Section 4.2.7.

A significant trend overall, and to HIV negative women, appears to be driven by high birth rates to non-responders to this question, categorised as 'unknown'. Non-response may be because individuals already know their status and do not feel the need to disclose this to surveillance. Individuals can seek HIV testing and counselling (HCT) from local primary health facilities and already be aware of their HIV status when asked to participate in HIV surveillance. Avoidance of HCT is more likely to be associated with riskier sexual behaviour and higher rates of live birth. Others may choose to participate in HIV surveillance without prior knowledge of their status. Informed consent procedures ask for consent at multiple stages and clarify that the purpose of surveillance is to assist with community based research rather than individual knowledge. It is this process that can result in discrepancies between participation in surveillance, and individual knowledge of HIV status. The process of HIV surveillance is described in more detail on page 85.

Women experienced a lower incidence of live birth when aware, rather than unaware, of the availability of ART (Table 4.6). Awareness of ART was not associated with incidence of live birth to HIV positive women and offers no support to the hypothesis that ART would encourage decisions to have children. ART is now widely available in this setting and known to women in 52% of observed woman-years. The proportion of women aware of ART may well be higher, as responses were missing to this question during 33% of woman years.

In this context, there is no evidence to suggest that awareness of ART is associated with fertility amongst HIV positive women and incidence of live birth is lower amongst HIV positive women

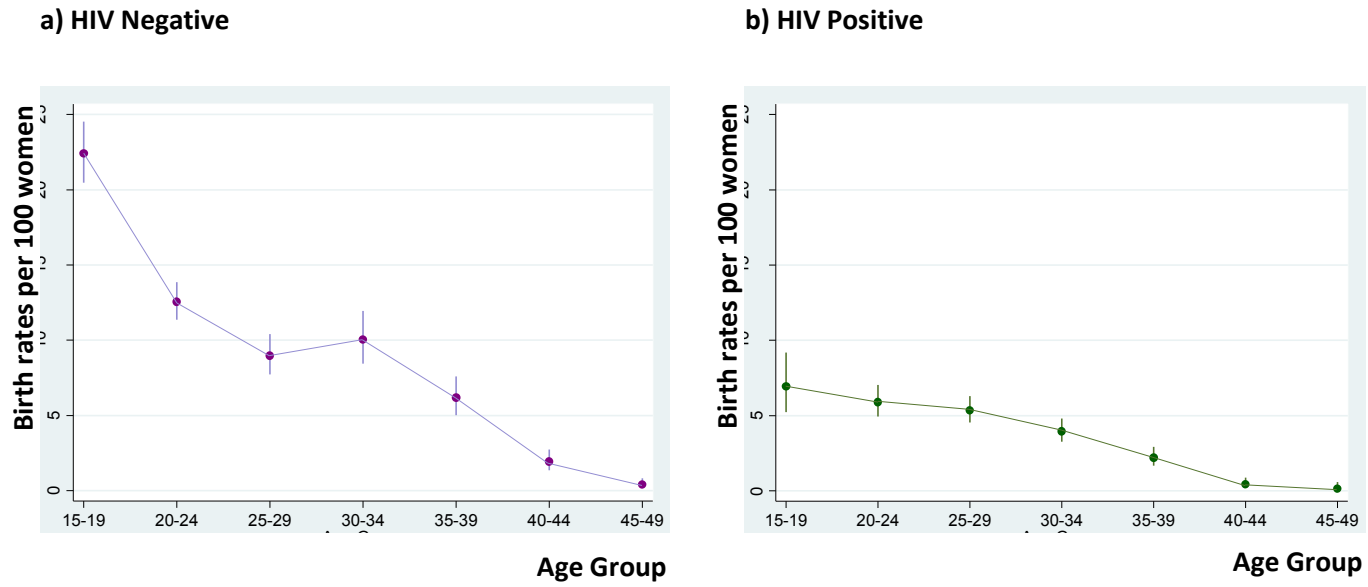
compared to HIV negative women. HIV positive women contribute more woman-years to 'Yes' responses to survey questions about awareness of HIV status and awareness of ART. As a result, the lower incidence rates of HIV positive women may drive a lower overall incidence to 'yes' responses in a combined HIV negative and HIV positive cohort.

Demographic characteristics

As expected from the literature, higher educational attainment was associated with lower rates of live birth. Univariate analysis found education to be significantly associated with live birth and to be likely confounder of the association between HIV status and live birth. Crude incidence was lowest amongst women who had never attended school and highest for women who had achieved at least primary level education and then declined with increased educational attainment. This association remained significant when stratified to only HIV negative or HIV positive woman-years observed, or in bivariate analysis adjusted for a woman's HIV status.

Rates of live birth declined with age and parity in an overall analysis and when stratified by HIV. Crude birth rates were consistently lower during HIV positive episodes at each age group, as illustrated in figure 4.13. HIV is associated with approximately halved rates of live birth at any age and rates were disproportionately high amongst younger women aged 15-19 and 20-24 years old. Live birth rates appear inflated amongst women aged 15-19 years old during HIV negative episodes due to the exclusion of women that had not yet entered their sexual debut, women that are most likely to lie within this age group. Further, a peak in birth rates amongst women that had entered sexual debut and were aged 15-19 years old is in accordance with results from analysis one.

Figure 4.13 Age group specific crude birth rates during HIV negative and HIV positive episodes



A pronounced effect of HIV occurred amongst women aged 30-34 years old. Crude birth rates amongst HIV negative women followed a bimodal trend and a second peak in crude birth rates at 30-34 years. A second peak was not found in episodes to HIV positive women aged 30-34 years old.

Incidence of live birth reduced significantly with increasing parity overall and when stratified by HIV status. Rates were also consistently lower amongst HIV infected women at any parity level. Most live births occurred during HIV negative episodes to women with no prior children (26.7 births/1000 women [24.6 – 28.9]) at a rate 3 times higher than HIV negative women with one child and almost 6 times higher than HIV positive women with no children. Unique to HIV positive women, crude rates of live birth did not significantly differ between women with parities of zero or one.

Relationship Characteristics

As discussed in analysis one, rates of marriage were low in this setting and typically occurred at older ages. The number of married women disaggregated by age and year is presented in appendix A to show that more women aged 15 – 34 years old were in a regular relationship rather than married but that after this age, the trend is reversed.

Median parity amongst women not living with their partner was one child compared to four children to women living with a partner. Overall, crude incidence of live birth was lowest amongst married women and highest amongst unmarried women in a casual or regular relationship. Incidence of live birth was consistently lower during HIV positive women episodes at all categories of relationship. Rates did not differ between those reporting a casual or regular relationship and were significantly lower in single and married women or those reporting to be divorced, widowed or separated. The trend remained significant in an analysis stratified by HIV status.

Co-residency with a partner was not significantly associated with incidence of live birth in univariate analysis. However, the trend became significant once adjusted for HIV status. Against expected findings, this analysis determined highest rates of live birth amongst women not living with a partner. High rates of live birth to women not living with their partners are likely in the context of

low marital rates in the Hlabisa sub-district, as women traditionally live with their parents until marriage and new homes are largely unaffordable until later in life. As typical of other characteristics, rates of live birth were halved amongst women not living with a partner during HIV positive women-years of observation (4.3 births per 100 women [95% CI 3.7-5.0]) compared to HIV negative women-years (8.9 births per 100 women [95% CI 8.2-9.7]) ($p < 0.001$).

In contrast, incidence of live birth during episodes of co-residency did not differ significantly between HIV negative and HIV positive women ($p = 0.513$). This finding could be attributed to lower rates of live birth observed amongst women that do not co-reside with their partners. Appendix A illustrates that incidence of live birth did not significantly differ between HIV positive women that were or were not living with a partner and provides evidence that HIV positive women only alter their patterns of childbearing outside of less formal relationships.

Contraceptive use characteristics

Use of contraception is strongly associated with rates of live birth although half of women were not using contraception, overall and when stratified by HIV status. Crude incidence of live birth was also significantly lower during HIV positive women episodes at all levels of contraceptive use.

This study still found high rates of 3.7 births per 100 women [95% CI 3.3 -4.1] to women reporting contraceptive use during that annual surveillance round compared to not 8.0 [95% CI 7.2 – 9.0]. Information about contraceptive use is recorded during the same annual surveillance round that HIV status is established a live birth event occurred. In this cohort, women episodes are censored with a live birth event and consequently, contraceptive use could actually be recorded at a time that is either pre or post conception of a live birth. Women are often initiated on to DMPA injectable contraception during their 6-week postpartum visit and this would be captured in the next annual episode.

Respondents were first asked 'Have you ever used contraceptives', before being asked to select a method they are currently using. Responses to this question were low, with 44% missingness overall.

Figure 4.14 Question asked to respondents of the WGH survey regarding contraceptive use

2. Have you ever used contraceptives?

Yes No Refused

➤ Skip to Part B

➤ Which method are you currently using?

Tick all that apply

- None
- Male condom
- Female condom
- Female Sterilisation ("Tubal Ligation")
- Male sterilisation
- Injections
- Pill
- Other ➤ Specify _____
- Refused

HIV positive non-responders to this question on contraceptive use experienced rates of live birth four times lower than HIV negative women (3.3 [95% CI 2.9-3.7] births per 100 HIV positive women compared to 13.1 [95% CI 12.3-14.0] births per 100 HIV negative women). This provides some evidence to suggest that HIV positive women tend not to answer this question due to lower sexual activity while HIV negative women may be more sexually active during non-contraceptive episodes.

Barrier methods of contraception were associated with the highest rates of live birth at 5.4 births per 100 women [95% CI 4.4 – 6.4] and dual use of barrier plus a hormonal method of contraception was associated with the lowest rates amongst all women 2.7 births per 100 women [95% CI 1.5 – 5.0]. There was no significant difference between rates of birth amongst dual or injectable users and trends were the same for overall analysis and when stratified by HIV status.

General Health

Rates of live birth were double amongst women reporting excellent, good or very good health compared to women reporting fair or poor health. This trend was still significant when stratified by HIV status: rates were significantly higher amongst HIV positive women reporting good versus poor health, but an overall association was non-significant due to the inclusion of missing responses.

Information for self-perceived health is determined as a self-reported checklist response to the question 'How would you describe your health at present?'

Figure 4.15 Question asked to respondents of the WGH survey regarding perceptions of their own health

Section 3. Health

1. How would you describe your general health at present?

Excellent, Very Good or Good Fair Poor

Single item measures of self-reported health have been commonly used in community studies. Five point scales for response (Excellent, Very Good, Good, Fair, or Poor) quantify different aspects of health that operate within in an individual's perceptual framework. These measures have successfully predicted mortality in some, mostly developed, settings (Idler and Benyamini, 1997). A strong association has been reported in this study site: an analysis of Africa Centre demographic surveillance data using 'Excellent' as baseline self-reported health, showed an ordered increase in the adjusted hazard of mortality to women reporting 'Very Good', 'Good', 'Fair' and 'Poor' health after 4 years of follow up (Olgati et al., 2012). The same study also described an ordered decrease in response rates (from Excellent to Poor).

An internal review found that participants could not easily distinguish between options for 'Excellent', 'Very Good', 'and Good' and that conflation could boost response rates to this question. Since 2009, responses have been conflated to three options for 'Excellent, Very Good and Good', 'Fair' and 'Poor'. The final two categories 'Fair' and 'Poor' were conflated for the purpose of analysis in this study due to low response rates to these categories and to provide a more appropriate counterfactual to 'Excellent, Very Good or Good' (E/VG/G).

Table 4.4 demonstrates that, even after this conflation, response rates disproportionately favour the E/VG/G category in 58% of woman years, compared to 13% of woman years with a F/P response. An implication for this study is that the association reported between E/VG/G and F/P categories may be an exaggerated measure of the effect of general health on birth rates in the setting. A five-point measure may present a weaker association, assuming that response rates to 'Excellent' would be higher and that the difference between 'Excellent' and 'Poor' would be larger than 'Very Good' or 'Good' to 'Poor'.

In preliminary univariate and bivariate analysis, the conflated variable was found to be a robust predictor of live birth rates in the cohort. It offers a valid comparison of the effect of perceived health between HIV status and treatment groups and a better predictor of birth rates than knowledge of HIV status in univariate analysis.

An unstated assumption suggests that HIV negative and positive women view health through the same perceptual framework. In reality, concepts of general health may differ between HIV negative and HIV positive women and these differences may affect response rates and category choice. Differences in how HIV positive women consider general health in this setting require more qualitative understanding. The results presented in Chapters Five and Six aim to elucidate more on this issue.

Results presented in Table 4.4 suggest patterns of non-response differ according to HIV status for this question. Non-response may occur when individuals already know their status and see no added value in disclosing this to surveillance or because they have not sought HIV testing and counselling. Avoidance of HCT could be associated with riskier sexual behaviour and higher rates of live birth.

Responses to 'Excellent, Very Good and Good' were roughly proportionate between HIV negative (57%) and HIV positive (43%) woman years. In contrast, HIV positive women accounted for a higher proportion of 'Fair/Poor' (58%) and missing (unknown, 72%) woman-years.

Overall, birth rates to non-responders were comparable to women reporting excellent, good or very good health for this question. The same trend was observed in an analysis limited to HIV negative women and suggests that non-response was not related to the issue of health being surveyed in this question. In contrast, rates of live birth to HIV positive non-responders were almost half those of women reporting excellent, good or very good health and similar to women reporting fair or poor health. Consequently, HIV positive women were more likely to not respond due to poor health and these same women experienced lower rates of live birth.

4.2.6 Multivariable analysis of factors associated with incidence of live birth amongst HIV negative and positive women

In a multivariate Poisson analysis adjusted for: education, area of residency, HIV status, age at episode, knowledge of HIV status, most recent relationship status, co-residency with partner, parity, self-reported health, an awareness of ART, year of annual surveillance, contraceptive use and form of contraception used, being HIV positive was associated with a 61% reduced annual likelihood of live birth compared to the HIV negative counterfactual group (aHR, 0.39; 95% 0.347 – 0.441) (Table 4.7).

I found no evidence that use of ART is associated with a return to high fertility rates in HIV positive women. Rather, in an analysis limited to only HIV infected women and adjusted for: education at entry, area, exposure to ART, age, knowledge of HIV status, most recent relationship status, co-residency with partner, parity, year of annual surveillance and contraceptive use, exposure to ART was associated with a 38% reduced likelihood of live birth in this group (aHR, 0.62; 95% 0.487 – 0.799).

Univariate analysis of HIV positive women only found no association between knowledge of HIV status and rates of live birth. In a cohort multivariable analysis, adjusted for significant determinants of live birth, knowledge of HIV status was associated with a 46% reduced likelihood of live birth.

Co-residency was associated with a 27% reduced likelihood of live birth in univariate analysis. Once other proximate determinants of fertility were included in this model for adjustment, living with a partner was associated with a 73% increased likelihood of experiencing a live birth. In a multivariable analysis limited to HIV positive women, this likelihood increased further to 78%.

Excellent, good or very good self-reported health was associated with doubled likelihood of live birth in the cohort of all women. Once adjusted for significant determinants of fertility, likelihood was removed entirely and became non-significant. Self-reported health was not a significant predictor of live birth amongst HIV positive women and so was not included in a multivariable sub-analysis of this group of women. These findings suggest that health is an important contributor to likelihood of live birth but the variance was most likely explained by inclusion of other factors, such as HIV status.

An awareness of ART was no longer significant in multivariable models and this is most likely due to the inclusion of HIV positive women in the cohort analysis or exposure to ART. Furthermore, this variable was not significant in univariate analysis of HIV positive women, reflecting a uniform awareness of treatment.

Contraceptive use is strongly associated with reduced annual rates of live birth in HIV infected women, as women reporting use of any method at most recent sex experienced 75% reduced rates in this adjusted analysis. Increasing age group was independently associated with reduced rates in this analysis, while being in a relationship and living with a partner alone were not sufficient to explain variation in rates of live birth between HIV positive women.

Table 4.7 Crude and adjusted hazard of live birth comparing trends by time-updated characteristics for HIV positive women and overall cohort

Crude and Adjusted Hazard ratio [95% CI]								
Characteristics	All episodes				HIV positive episodes			
	Crude HR	95% CI	AHR	95% CI	Crude HR	95% CI	AHR	95% CI
Characteristics at entry								
Education at entry								
Never attended	1	-	1	-	1	-	-	-
At least Primary	3.286	2.647 – 4.080	1.486	1.187 – 1.861	1.721	1.191 – 2.484	-	-
Secondary	3.254	2.643 – 4.005	1.160	0.932 – 1.446	2.183	1.554 – 3.065	-	-
Tertiary	2.576	2.066 – 3.210	1.091	0.863 – 1.378	1.662	1.151 – 2.399	-	-
Unknown	1.947	1.487 – 2.549	1.194	0.908 – 1.571	1.378	0.841 – 2.097	-	-
Area at entry								
Rural	1	-	1	-	1	-	1	-
Peri-Urban	0.672	0.603 – 0.748	0.740	0.663 – 0.825	0.739	0.609 – 0.897	0.748	0.592 – 0.946
Urban	0.478	0.369 – 0.619	0.569	0.438 – 0.739	0.433	0.272 – 0.688	0.490	0.279 – 0.862
Characteristics updated annually								
HIV status								
Negative	1	-	1	-	-	-	-	-
Positive	0.362	0.326 – 0.403	0.391	0.347 – 0.441	-	-	-	-
Exposure to ART								
No	-	-	-	-	1	-	1	-
Yes	-	-	-	-	0.825	0.682 – 0.998	0.624	0.487 – 0.799
Age at episode								
15-19	1	-	1	-	1	-	1	-
20-24	0.535	0.473 – 0.604	0.739	0.646 – 0.846	0.851	0.609 – 1.189	0.709	0.460 – 1.094
25-29	0.370	0.322 – 0.426	0.597	0.502 – 0.710	0.772	0.556 – 1.071	0.557	0.354 – 0.875
30-35	0.322	0.275 – 0.376	0.488	0.398 – 0.598	0.571	0.405 – 0.804	0.396	0.244 – 0.645
35-39	0.203	0.168 – 0.245	0.244	0.190 – 0.313	0.316	0.213 – 0.473	0.153	0.086 – 0.273
40-44	0.061	0.045 – 0.085	0.061	0.042 – 0.089	0.062	0.029 – 0.131	0.042	0.018 – 0.101
45-49	0.015	0.008 – 0.030	0.013	0.006 – 0.026	0.021	0.005 – 0.086	0.006	0.001 – 0.045
Knowledge of own HIV status								
No	1	-	1	-	1	-	-	-
Yes	0.647	0.556 – 0.754	0.635	0.509 – 0.792	1.004	0.757 – 1.332	-	-
Unknown	0.557	0.492 – 0.629	0.891	0.732 – 1.083	0.704	0.441 – 1.122	-	-
Most recent relationship status								
Single	1	-	1	-	1	-	1	-
Casual partner	1.307	0.896 – 1.906	0.797	0.545 – 1.167	2.140	1.101 – 4.162	2.214	1.063 – 4.610
Engaged/Married	0.801	0.650 – 0.986	1.510	1.207 – 1.888	1.367	0.888 – 2.105	2.116	1.345 – 3.329
Regular partner	1.400	1.216 – 1.613	1.149	0.991 – 1.332	2.339	1.772 – 3.087	2.351	1.568 – 3.526
Divorced/ Widow / Separated	1.208	0.941 – 1.550	1.382	1.074 – 1.777	1.894	1.203 – 2.982	2.731	1.630 – 4.475
Other/ unknown	1.275	1.103 – 1.475	1.214	0.790 – 1.866	1.252	0.941 – 1.665	1.282	0.9233 – 1.781
Living with partner								
No	1	-	1	-	1	-	1	-

Yes	0.727	0.619 – 0.855	1.732	1.426 – 2.104	1.093	0.823 – 1.452	1.782	1.236 – 2.569
Unknown	1.079	0.782 – 1.490	1.014	0.329 – 3.124	0.755	0.355 – 1.605	0.210	0.008 – 5.332
No partner	0.967	0.875 – 1.069	-	-	0.654	0.538 – 0.796	-	-
Parity								
0	1	-	1	-	1	-	1	-
1	0.383	0.339 – 0.432	0.456	0.402 – 0.519	0.941	0.706 – 1.254	0.931	0.648 – 1.338
2	0.303	0.263 – 0.350	0.525	0.447 – 0.617	0.854	0.637 – 1.147	1.200	0.817 – 1.761
3	0.256	0.216 – 0.303	0.574	0.470 – 0.700	0.658	0.472 – 0.916	1.056	0.677 – 1.647
4	0.208	0.167 – 0.258	0.622	0.482 – 0.803	0.584	0.394 – 0.867	1.557	0.932 – 2.600
5	0.160	0.121 – 0.211	0.656	0.476 – 0.903	0.382	0.225 – 0.649	1.314	0.681 – 2.534
6+	0.141	0.111 – 0.179	0.899	0.662 – 1.219	0.304	0.181 – 0.510	1.629	0.812 – 3.267
Self-reported Health								
Fair/ Poor	1	-	1	-	1	-	-	-
Excellent/ Very good/ Good	2.028	1.682 – 2.445	0.977	0.806 – 1.184	1.750	1.284 – 2.385	-	-
Unknown	1.996	1.640 – 2.428	1.004	0.783 – 1.287	1.181	0.852 – 1.638	-	-
Heard of ART								
No	1	-	1	-	1	-	-	-
Yes	0.765	0.667 – 0.879	0.994	0.834 – 1.184	0.976	0.724 – 1.292	-	-
Unknown	1.205	1.050 – 1.383	0.971	0.808 – 1.167	1.001	0.731 – 1.390	-	-
Year of annual surveillance episode								
2007	1	-	1	-	1	-	1	-
2008	0.979	0.834 – 1.148	0.831	0.687 – 1.004	0.902	0.658 – 1.237	0.906	0.658 – 1.247
2009	0.956	0.812 – 1.126	0.720	0.571 – 0.908	0.993	0.726 – 1.359	1.051	0.717 – 1.541
2010	1.016	0.865 – 1.195	0.861	0.685 – 1.082	1.268	0.946 – 1.701	1.706	1.192 – 2.440
2011	1.221	1.040 – 1.434	1.068	0.859 – 1.328	1.124	0.813 – 1.553	1.359	0.873 – 2.115
2012	1.073	0.896 – 1.287	0.817	0.644 – 1.036	0.745	0.491 – 1.126	1.189	0.641 – 2.203
Using contraception (updated annually)								
No	1	-	-	-	1	-	1	-
Yes	0.455	0.388 – 0.534	-	-	0.523	0.394 – 0.694	0.350	0.250 – 0.489
Unknown	0.954	0.843 – 1.080	-	-	0.574	0.450 – 0.730	0.653	0.446 – 0.957
Form of Contraception (updated annually)								
Barrier methods	1	-	1	-	1	-	-	-
Oral / IUCD / Microbicides	0.754	0.423 – 1.341	0.881	0.494 – 1.571	1.410	0.640 – 3.111	-	-
Injectable	0.586	0.438 – 0.784	0.638	0.475 – 0.856	0.509	0.318 – 0.818	-	-
Dual	0.510	0.267 – 0.976	0.652	0.340 – 1.250	0.538	0.231 – 1.254	-	-
Other unknown	0.556	0.412 – 0.751	0.520	0.378 – 0.716	0.385	0.225 – 0.660	-	-
None	1.509	1.211 – 1.881	1.662	1.308 – 2.112	1.249	0.881 – 1.770	-	-
Unknown if using	1.440	1.179 – 1.758	1.684	1.358 – 2.089	0.716	0.530 – 0.968	-	-
CD4 count (time-updated) (cells/μl)								
\leq 250	-	-	-	-	1	-	1	-
250-350	-	-	-	-	0.774	0.538 – 1.114	0.964	0.624 – 1.490
350-500	-	-	-	-	1.025	0.744 – 1.412	1.259	0.844 – 1.879
$>$ 500	-	-	-	-	0.756	0.544 – 1.050	0.905	0.597 – 1.371
Unknown	-	-	-	-	0.596	0.460 – 0.772	0.341	0.235 – 0.495

4.2.7 Factors associated with rates of live birth in a sub-analysis of HIV positive women

A sub-analysis of HIV positive women was conducted using the open cohort data after excluding HIV negative women. Incidences of live birth observed during HIV positive women years are reported by characteristic and by ART exposure in Table 4.8. For the purpose of this analysis, exposure refers to enrolment on lifelong ART and use of ART for the purposes of PMTCT.

Univariate analysis found a minimal association between exposure to ART and reduced crude rates of live birth ($p=0.0468$). This result is contrary to the hypothesis that HIV positive women would be encouraged to continue childbearing after initiation on ART. Some women may have enrolled onto ART for the purpose of prevent mother-to-child transmission: inclusion of these women would likely result in an inflated estimation of incidence of live births during 'on ART' woman-years.

Consequently, women enrolled on lifelong ART may experience even lower incidence of live birth and this finding lend more evidence to suggest that HIV positive women are more likely to limit their childbearing after they initiate ART.

In the total cohort analysis, urban area of residence, higher age group, poor self-perceived health, higher parity and use of contraception were associated with lower rates of live birth during HIV positive woman episodes. Table 4.8 presents trends according to exposure to ART.

Age-specific rates of live birth were lower amongst ART-exposed compared to ART-naive women at all ages, except for women episodes in the 25-29 year old age group. ART exposed women in this age group experienced 38% higher rates of live birth (6.9 births/100 ART-exposed woman episodes [5.4-9.0]) compared to ART-naive women (4.6 births per 100 ART-naïve woman episodes [3.7-5.7] ($p=0.017$)). This was the only age group in which a trend of lower rates amongst HIV positive women was reversed. It is an important finding as it provides evidence that ART may increase fertility amongst women of reproductive age that have not yet completed their childbearing. ART exposure reverses the mitigating effects of a HIV positive status, either a decision to limit childbearing or reduced sexual activity, on fertility. Social norms for small family sizes and low fertility rates suggest that women would usually curtail childbearing after this age and so women that wish to have a child are encouraged to do so on ART. Figure 4.16 presents Kaplan-Meier time-to-event analysis

estimates comparing incidence by time-updated HIV status and ART exposure for women aged 25-29 years old.

Relationship status was not associated with crude incidence of live birth during HIV positive woman episodes although this trend was unclear. Women exposed to ART while in a 'casual relationship' did not give birth at all during ART-exposed periods, compared to an incidence of 6.1 births per 100 ART-naïve women episodes ($p=0.0524$). Yet crude rates of live birth were equal amongst women amongst ART-exposed and ART-naïve women seeing a regular partner 5.3 [4.3 – 5.9] and 5.3 [3.5 – 6.0] births/100 woman episodes respectively. Crude rates were also lower amongst women that were not living with their partner or their living arrangements were unknown to this study while on ART and did not differ according to exposure to ART.

Rates of live birth amongst contraceptive users were less than half those of non-contracepting HIV positive women in an analysis of HIV positive as a whole and ART-naïve women. ART-exposed women did not follow this same trend. Rates of live birth were similar by use or non-use of contraception during ART-exposed women episodes ($P=0.500$). The key driver of this non-difference appears to be due to reduced rates amongst women on ART not using contraception. These findings are indicative of sexual activity amongst non-contraceptors on ART rather than an effect of more efficacious contraceptive behaviour amongst women on ART. There was no association between selected form of contraception and crude rates of live birth amongst ART-exposed women.

$CD4^+$ count was included as a clinical measure of physiological improvements to health, but no trend between $CD4^+$ measure and incidence of live birth was established. An analysis limited solely to HIV positive women found no significant association between $CD4$ count and exposure to ART ($p=0.5563$), suggesting that continued childbearing for these women is not associated with clinical health.

Poor self-perceived health was not associated with lower rates of live birth when episodes were stratified by exposure to ART although birth rates were significantly higher amongst women reporting themselves to be in good versus poor health across all stratification.

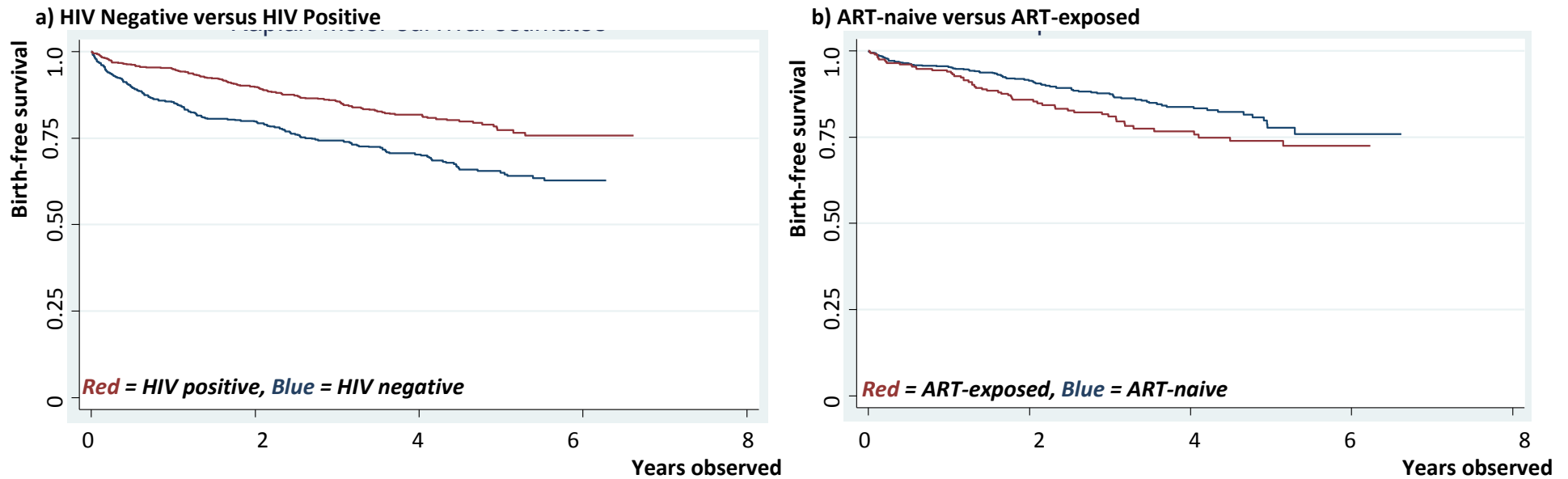
Table 4.8: Characteristics associated with incidence of live birth in HIV positive women episodes stratified by exposure to ART

Characteristics	Incidence Rate [95% CI]			
	HIV Positive (N=14,341 episodes)	ART Exposure (HIV positive women only)		Trend for characteristic adjusted for exposure to ART (p-value)
		ART-naïve (N=8,502 episodes)	ART-exposed (N=5,839 episodes)	
Overall Incidence	3.5 [3.2 – 3.8]	3.8 [3.4 – 4.2]	3.1 [2.7 – 3.6]	P=0.0468
Characteristics at entry				
Education at entry				
Never attended	2.0 [1.4 – 2.8]	2.1 [1.4 – 3.2]	1.9 [1.2 – 3.1]	P=0.047
At least Primary	3.5 [2.9 – 4.3]	4.0 [3.2 – 5.1]	2.7 [1.9 – 3.9]	
Secondary	4.5 [3.9 – 5.1]	4.7 [4.0 – 5.5]	4.0 [3.1 – 5.1]	
Tertiary	3.4 [2.8 – 4.1]	3.6 [2.8 – 4.5]	3.1 [2.2 – 4.3]	
Unknown	2.7 [1.9 – 3.8]	2.4 [1.5 – 3.8]	3.1 [1.9 – 5.0]	
	P=0.0435	P=0.2630	P=0.0702	
Area at entry				
Rural	4.1 [3.7 – 4.6]	4.5 [3.9 – 5.2]	3.4 [2.8 – 4.2]	P<0.001
Peri-Urban	3.0 [2.6 – 3.5]	3.0 [2.5 – 3.7]	3.1 [2.4 – 3.9]	
Urban	1.8 [1.1 – 2.8]	2.0 [1.1 – 3.6]	1.5 [0.8 – 3.0]	
	p<0.0001	p=0.0001	P=0.0410	
Characteristics updated annually				
Age (updated annually)				
15-19	6.9 [5.2 – 9.2]	7.2 [5.3 – 9.7]	5.5 [2.5 – 12.0]	P<0.001
20-24	5.9 [4.9 – 7.0]	6.2 [5.1 – 7.5]	4.6 [2.9 – 7.4]	
25-29	5.3 [4.5 – 6.3]	4.6 [3.7 – 5.7]	6.9 [5.4 – 9.0]	
30-35	3.9 [3.3 – 4.8]	4.6 [3.7 – 5.1]	4.0 [3.0 – 5.3]	
35-39	2.2 [1.7 – 2.9]	3.9 [3.0 – 5.1]	2.3 [1.6 – 3.4]	
40-44	0.4 [0.2 – 0.9]	0.4 [0.2 – 1.1]	0.4 [0.2 – 1.2]	
45-49	0.1 [0.0 – 0.6]	0.0 [-]	0.3 [0.1 – 1.2]	
	P<0.0001	P<0.0001	P<0.0001	
Knowledge of own HIV status (updated annually)				
No	3.6 [2.7 – 4.7]	3.6 [2.7 – 4.7]	-	P=0.306
Yes	3.6 [3.3 – 4.0]	4.0 [3.5 – 4.6]	3.1 [2.7 – 3.6]	
Unknown	2.5 [1.7 – 3.7]	2.5 [1.7 – 3.7]	-	
	P=0.2329	P= 0.3062	-	
Most recent relationship per annual episode				
Single	2.3 [1.8 – 2.9]	2.3 [2.4 – 3.5]	2.3 [2.2 – 3.4]	P=0.417
Casual friend /partner	4.8 [2.6 – 9.0]	6.1 [3.4 – 11.0]	0.0 [-]	
Engaged/Married	3.1 [2.2 – 4.4]	3.9 [2.3 – 7.5]	2.0 [1.2 – 7.0]	

Regular partner	5.3 [4.6 – 6.1]	5.3 [4.3 – 5.9]	5.3 [3.5 – 6.0]	
Divorced/Widowed/Separated	4.3 [2.9 – 6.3]	5.3 [1.7 – 4.3]	2.7 [1.2 – 4.6]	
Other or unknown	2.8 [2.4 – 3.3]	2.8 [2.3 – 16.4]	2.8 [0.7 – 7.0]	
	P=0.424	P=0.394	P=0.706	
Living with partner				
No	4.3 [3.7 – 5.0]	4.6 [3.9 – 5.5]	3.5 [2.6 – 4.7]	
Yes	4.7 [3.7 – 6.0]	4.7 [3.5 – 6.4]	4.7 [3.2 – 7.0]	
Unknown	3.3 [1.6 – 6.8]	5.5 [2.1 – 14.7]	2.1 [0.7 – 6.5]	P<0.001
No partner	2.8 [2.5 – 3.2]	2.9 [2.4 – 3.5]	2.7 [2.2 – 3.4]	
	P<0.0001	P=0.0001	P=0.0666	
Median Parity	2	2	3	
Parity (time-updated)				
0	4.7 [3.7 – 5.9]	5.5 [4.1 – 7.1]	2.8 [1.6 – 5.0]	
1	4.4 [3.7 – 5.2]	4.5 [3.7 – 5.5]	4.2 [3.1 – 5.7]	
2	4.0 [3.4 – 4.8]	4.3 [3.4 – 5.3]	3.6 [2.7 – 4.9]	
3	3.1 [2.4 – 3.9]	3.4 [2.5 – 4.6]	2.8 [1.9 – 4.0]	
4	2.7 [2.0 – 3.8]	2.3 [1.4 – 3.7]	3.3 [2.1 – 5.0]	P<0.001
5	1.8 [1.1 – 2.9]	1.7 [0.9 – 3.2]	2.0 [1.0 – 4.0]	
6+	1.4 [0.9 – 2.3]	1.3 [0.7 – 2.4]	1.6 [0.9 – 3.2]	
	P<0.0001	P<0.0001	P=0.0130	
Self-reported Health (updated annually)				
Fair/Poor	2.5 [1.9 – 3.3]	3.1 [2.1 – 4.5]	1.9 [1.3 – 3.0]	
Excellent/Very good/Good	4.3 [3.8 – 4.9]	4.5 [3.9 – 5.1]	4.0 [3.2 – 5.0]	P=0.418
Unknown	2.9 [2.5 – 3.4]	2.9 [2.4 – 3.6]	2.8 [2.2 – 3.6]	
	P=0.4457	P=0.0945	P=0.4819	
Heard of ART (time-updated)				
No	3.6 [2.7 – 4.7]	3.6 [2.7 – 4.7]	-	
Yes	3.5 [3.1 – 3.9]	4.0 [3.4 – 4.7]	3.1 [2.7 – 3.6]	P=0.851
Unknown	3.6 [3.0 – 4.3]	3.6 [3.0 – 4.3]	-	
	P=0.8626	P=0.8509	-	
Year of annual surveillance episode				
2007	3.4 [2.7 – 4.3]	3.9 [3.0 – 4.9]	1.7 [0.8 – 3.4]	
2008	3.1 [2.4 – 3.8]	3.2 [2.5 – 4.1]	2.6 [1.7 – 4.1]	
2009	3.4 [2.7 – 4.2]	4.1 [3.2 – 5.1]	2.1 [1.3 – 3.3]	
2010	4.3 [3.6 – 5.2]	4.1 [3.3 – 5.2]	4.7 [3.5 – 6.2]	P=0.268
2011	3.8 [3.1 – 4.8]	4.0 [2.8 – 5.5]	3.7 [2.8 – 5.1]	
2012	2.5 [1.8 – 3.6]	2.3 [1.1 – 4.9]	2.6 [1.7 – 3.8]	
	P=0.6782	P=0.8760	P=0.1139	
Using contraception (updated annually)				
No	5.8 [4.7 – 7.2]	6.5 [5.1 – 8.1]	3.9 [2.3 – 6.4]	
Yes	3.0 [2.5 – 3.6]	3.0 [2.3 – 3.8]	3.1 [2.3 – 4.2]	P=0.002
Unknown	3.3 [2.9 – 3.7]	3.5 [3.0 – 4.1]	3.0 [2.5 – 3.7]	
	P=0.0008	P=0.0009	P=0.4997	
Form of Contraception (updated annually)				
Barrier methods	4.5 [3.5 – 6.1]	5.6 [3.9 – 7.9]	3.6 [2.3 – 5.7]	
Oral/IUCD/Microbicides	6.5 [3.1 – 13.7]	5.3 [2.0 – 14.2]	9.3 [3.0 – 28.7]	P=0.457

Injectable	2.4 [1.6 – 3.5]	2.3 [1.4 – 3.7]	2.5 [1.4 – 4.5]	
Dual	2.5 [1.1 – 5.5]	3.1 [1.2 – 8.4]	1.8 [0.4 – 7.0]	
Other/unknown method	1.8 [1.1 – 2.8]	1.5 [0.9 – 2.7]	2.6 [2.3 – 6.4]	
None	5.8 [4.7 – 7.1]	6.5 [5.1 – 8.1]	3.9 [2.3 – 5.9]	
Unknown if using	3.3 [2.9 – 3.7]	3.5 [3.0 – 4.1]	3.0 [2.5 – 3.7]	
	P=0.2347	P=0.3312	P=0.5164	
CD4 count (time-updated) (cells/μl)				
<=250	4.8 [3.9 – 6.0]	10.9 [7.5 – 15.9]	3.7 [2.8 – 4.9]	
250-350	3.7 [2.8 – 5.0]	5.3 [3.3 – 8.4]	3.1 [2.2 – 4.5]	
350-500	4.9 [3.9 – 6.2]	9.3 [6.8 – 12.8]	3.2 [2.3 – 4.5]	
>500	3.6 [2.9 – 4.6]	7.4 [5.4 – 10.0]	1.9 [1.3 – 2.8]	P<0.001
Unknown	2.9 [2.5 – 3.3]	2.8 [2.4 – 3.2]	3.8 [2.6 – 5.7]	
	P<0.0001	P<0.0001	P=0.5563	

Figure 4.16 Kaplan-Meier estimates of live birth-free survival to women aged 25-29 years old by a) HIV status and by b) ART exposure, in an open cohort with a maximum observation time of 6 years. *Chart a) illustrates birth survival for HIV positive women in red and HIV negative women in blue and chart b) illustrates birth free survival for HIV positive ART-exposed women in red and HIV positive ART-naïve women in blue*



4.2.8 Strengths and limitations of dataset and factors measured by demographic surveillance

This analysis describes the likelihood of live birth to women that: participated in HIV surveillance and Women's General Health between 2007 and 2012, responded 'yes' to the question 'have you ever had sex?' and were resident in the DSA. Exclusion criteria have reduced the overall sample size for inclusion in this open cohort. They may also pose a number of limitations for interpretation, which will be discussed in this section.

Non-residents constituted 5-6% of women included in each annual HIV surveillance round. Just over 50% of residents and non-residents were under the age of 50 years old during the years spanning this cohort. Preliminary analysis determined that the proportion of non-residents within each age and HIV category were roughly equal and exclusion was unlikely to result in bias. Furthermore, analysis restricted to resident women is likely to describe the demographic facing HIV treatment and care in this setting.

A limitation of the Women's General Health questionnaire design is that questions may be asked to a key informant when women are not present during a household visit. Family members may not be aware of accurate responses and older or male residents may feel uncomfortable answering such questions. These issues are likely responsible for the high degree of missing data for questions in this survey, including self-reported health, relationship status and contraceptive use.

This design better captures women that are more likely to be present in the household on an Africa Centre visit date. Consequently, younger age groups were disproportionately excluded and this analysis is unlikely to well represent the childbearing behaviours of adolescents. Personal communication with fieldworkers suggest that younger household members are usually more willing to provide answers of a personal nature than older members of household, but participation from adolescents is not as high. This limitation is important as older women may experience lower fertility and so this cohort may underestimate actual fertility rates in this setting. However, this effect may be outweighed by another restriction to only women that answered 'Yes' to ever had sex, resulting in a probable overestimation of actual fertility rates within the DSA by this cohort.

'Ever had sex' was the most valuable exclusion criteria for this dataset to ensure an appropriate comparison between HIV negative and HIV positive women. Restrictions around marriage are neither culturally appropriate nor statistically useful, as discussed in section 4.1. The proportion of women responding to this question increased from 36% to 50% between 2005 and 2012, resulting in decreased exclusion according to this variable in later cohort years. Furthermore, the most fertile age range of 20-39 years old are less likely to be affected by this exclusion, and the determinant of interest, use of ART, is common in older age groups.

Missing data is a strong limitation of this dataset. Non-response was high and varied by question, as described in Table 4.4. Several approaches to treatment of missing data were considered for this analysis. High proportions of missing data, up to 56%, meant this dataset did not lend well to multiple imputation. Furthermore, the data could not be confidently determined as missing at random. Exclusion to women that responded 'yes' to 'Ever Had Sex' removed a high degree of missingness in other variables. In a preliminary analysis, HIV status was unknown to 72% of women that refused to answer this question. Excluded women were also less likely to respond to questions on contraceptive use or self-reported general health. A complete case analysis would further exclude a substantial proportion of this dataset and was considered inappropriate for the purpose of this analysis. Finally, inclusion of an additional 'missing' category for variables with non-response is considered suitable for epidemiological studies and includes more information and transparency of analysis.

4.2.9 Analysis Two: Section Summary

- Between 2007 and 2013 there were a total of 1,757 live births among 9,972 women
- Crude incidence of live birth in this cohort was 6.6 births per 100 woman years overall and rates were three times higher amongst HIV negative women compared to HIV positive women. Exposure to ART was minimally associated with reduced crude birth rates ($p=0.0468$).
- Multivariable Poisson regression adjusted for significant proximate and distal determinants of fertility found being HIV positive was associated with a 61% reduced annual risk of live birth (aHR, 0.39; 95% 0.347 – 0.441) and exposure to ART was associated with a 38% reduced risk of live birth (aHR, 0.62; 95% 0.487 – 0.799) compared to ART naïve women.
- Crude incidence of live birth in the total cohort of HIV negative and positive women decreased with increasing age group, higher parity, poorer self-reported health, an urban area of residency, knowledge of own HIV status, being single or engaged/married, not living with a partner, an awareness of the benefits of ART, use of contraception and use of injectable methods of contraception.
- Inclusion of HIV status and exposure to ART in multivariable analysis resulted in little change in trends of live birth per characteristic, with the exception of self-perceived health, which was no longer associated with birth rates in multivariable analysis. Variance may be explained by actual HIV status and more proximate determinants such as contraceptive use
- Knowledge of HIV status was associated with a 46% reduced risk of live birth. Non-responders to this question had different patterns of live birth according to HIV status, which could be indicative of different health seeking and risky behaviours.
- Childbearing was not strongly associated with current parity in HIV positive women. Risk of live birth was higher to women in more formal relationships and a reduced risk of live birth was strongly associated with contraceptive use. HIV positive women had generally lower birth rates compared to HIV negative women except when co-residing with a partner, at which time rates were similar irrespective of HIV status. No women initiated on ART and reporting to be in a casual relationship experienced a live birth in this cohort.

4.3 Birth-free survival in a cohort of woman including 'unknown' HIV status (closed entry in 2007/2008)

A closed cohort analysis presented in this section 4.3 includes all women who participated in the 2007 or 2008 surveillance years until censored in 2013 or lost to follow up. This analysis extends upon the prior analysis two by including all resident women including those with a HIV status that is 'unknown' to the HIV surveillance. The aim was to provide a comparison of factors associated with likelihood of live birth between HIV negative, HIV positive and women with missing data for HIV status. I hypothesised to see similar incidence amongst HIV negative and HIV positive women as determined in the prior analysis two, due to similar sampling and inclusion criteria, with the exception of a closed cohort structure. The effect of ART exposure may be more strongly associated with incidence of live birth soon after national roll-out, although I would not expect to see a large difference in this setting of low fertility. In which case, analysis two may capture a smaller estimate of reduced risk of live birth to women on ART compared to ART-naïve women. Findings were mostly comparable between cohorts and the following section will present a summary of the important findings.

4.3.1 Characteristics over analysis time

A total of 1,662 births occurred over 26,397 woman years of follow up. And median follow up was longer in this cohort at 3.9 years per woman. During follow up, 1,148 women sero-converted from HIV negative to HIV positive and 622 women were observed to initiate ART. These individual women-episodes were censored at the date of initiation and categorised as 'ART-exposed' in subsequent woman-episodes. Characteristics at baseline entry in 2007 or 2008 are presented in Table 4.9 and characteristics reported during 'unknown HIV status' women-years of follow were very similar to HIV negative women episodes. HIV positive women differed from both HIV negative and HIV unknown women in education, area of residence, relationship status, contraceptive use and health.

HIV status was known from the HIV surveillance for 75% of the 7,476 women who participated in the HIV surveillance round in years 2007 and 2008. Overall, 56% of women reported to know their own status, independent to the whether their status was recorded during surveillance or not.

Median age at baseline was 32 years and women had a median parity of two children. Age increased sequentially amongst HIV unknown, negative and positive women, and women on ART were a median of 6 years older than ART-naïve women. Women in all HIV categories had a median of two children except when HIV positive women were stratified by exposure to ART: women 'on-ART' had the highest median age of 37 years old and parity of three children.

Most (52%) women reported being in a regular relationship and these trends were similar amongst women categorised as HIV negative or HIV 'unknown' at baseline. HIV positive women were more likely to report being single: only 39% were in a relationship compared to 61% of HIV negative women. Self-reported current use of contraception was 36%. Fewer HIV positive women answered 'yes' to using contraception at last sex at entry (27%) compared to HIV negative (41%) and HIV unknown (40%) women and ART-exposed women were least likely to report contraceptive use (24%). Overall, 78% of women answered the question on which form of contraception they were using. Fewer HIV positive women reported not using any contraception at last sex but this group were more likely to not respond at baseline.

Most women reported themselves as being in good health (73%) but this proportion varied by HIV Status as 49% of HIV positive women reported feeling healthy compared to 88% of HIV negative women and 84% of women with unknown HIV status. More HIV positive women did not answer the question on perceived health. ART-exposed women were most likely to not respond or to perceive their own health as fair or poor at baseline.

Table 4.9 Demographic, relationship and HIV related characteristics to women at first entry to closed cohort in 2007 or 2008, disaggregated by HIV and ART exposure

Characteristics	Overall			All women N=7,476 (100%)									HIV Positive Women N= 2,624 (100%)					
				HIV Unknown			HIV Negative			HIV Positive			ART-Naïve			ART-Exposed		
	Births N=1,692 (100%)	Women N=7,476 (100%)		Births N=563 (33%)	Women N= 1,852 (25%)		Births N=744 (44%)	Women N=3,000 (40%)		Births N=355 (21%)	Women N= 2,624 (35%)		Births N=271 (76%)	Women N=2,123 (81%)		Births N=84 (24%)	Women N= 501 (22%)	
Median parity	2			2			2			2			2			3		
Median age	32			30			32			33			31			37		
Attained secondary level education	1,190	4,873	65%	438	1,369	74%	520	1,859	76%	232	1,645	62%	192	1,348	63%	40	297	60%
Rural residency	1,202	4,744	63%	387	1,165	63%	589	2,150	72%	226	1,429	54%	181	1,168	55%	45	261	52%
Relationship Status																		
Single	858	1,592	21%	385	227	12%	322	167	6%	151	1,198	46%	109	915	43%	42	283	56%
Casual Friend/Partner	18	149	2%	2	43	2%	8	67	2%	8	39	2%	8	30	1%	0	9	2%
Engaged/Married	69	945	13%	9	274	15%	46	556	19%	14	115	4%	11	95	4%	3	20	4%
Regular Partner	655	3,916	52%	147	1,069	58%	349	1,834	61%	159	1,013	39%	129	884	42%	30	129	26%
Div/Widow/Sep	70	847	11%	17	234	13%	34	368	12%	19	245	9%	12	187	9%	7	58	12%
Unknown	22	27	0.4%	3	5	0.3%	15	8	0.3%	4	14	1%	2	12	1%	2	2	0.4%
Self-reported Health																		
Fair/Poor	85	508	7%	18	79	4%	35	248	8%	32	181	7%	21	128	6%	11	53	11%
Excellent/Very good/Good	903	5,468	73%	199	1,562	84%	502	2,625	88%	202	1,281	49%	163	1,114	52%	39	167	33%
Unknown	704	1,500	20%	346	211	11%	237	127	4%	121	1,162	44%	87	881	42%	34	281	56%
Reported use of Contraception	236	2,682	36%	36	768	41%	121	1,211	40%	79	703	27%	57	585	28%	22	118	24%

Form of Contraception																		
Barrier methods	69	377	5%	11	126	7%	23	147	5%	35	104	4%	23	88	4%	12	16	3%
Oral/IUCD/Microbicides	8	26	0.3%	2	7	0.4%	4	13	0.4%	2	6	0.2%	2	6	0.3%	0	0	0%
Injectable	68	223	3%	12	71	4%	37	113	4%	19	39	1%	15	32	2%	4	7	7%
Dual	8	41	1%	0	17	1%	3	13	0.4%	5	11	0.4%	4	9	0.4%	1	2	2%
Unknown	83	2,015	27%	11	547	30%	54	925	31%	18	543	21%	13	450	21%	5	93	19%
None	415	3,156	42%	110	852	46%	224	1,593	53%	81	711	27%	71	613	29%	10	98	20%
Unknown if using	1,041	1,638	22%	417	232	13%	429	196	7%	195	1,210	46%	143	925	44%	52	285	57%
Knows HIV status	914	4,206	56%	210	1,008	54%	424	1,557	52%	280	1,641	63%	196	1,140	54%	84	501	100%
Heard of ART	642	2,027	27%	154	490	26%	290	677	23%	198	860	33%	114	359	17%	84	501	100%
Median CD4		-			-			-			363			348			374	

4.3.2 Multivariable analysis of time-to-live birth after participation in the 2007 or 2008 HIV surveillance

4.3.3.1 Testing the proportional hazards assumption

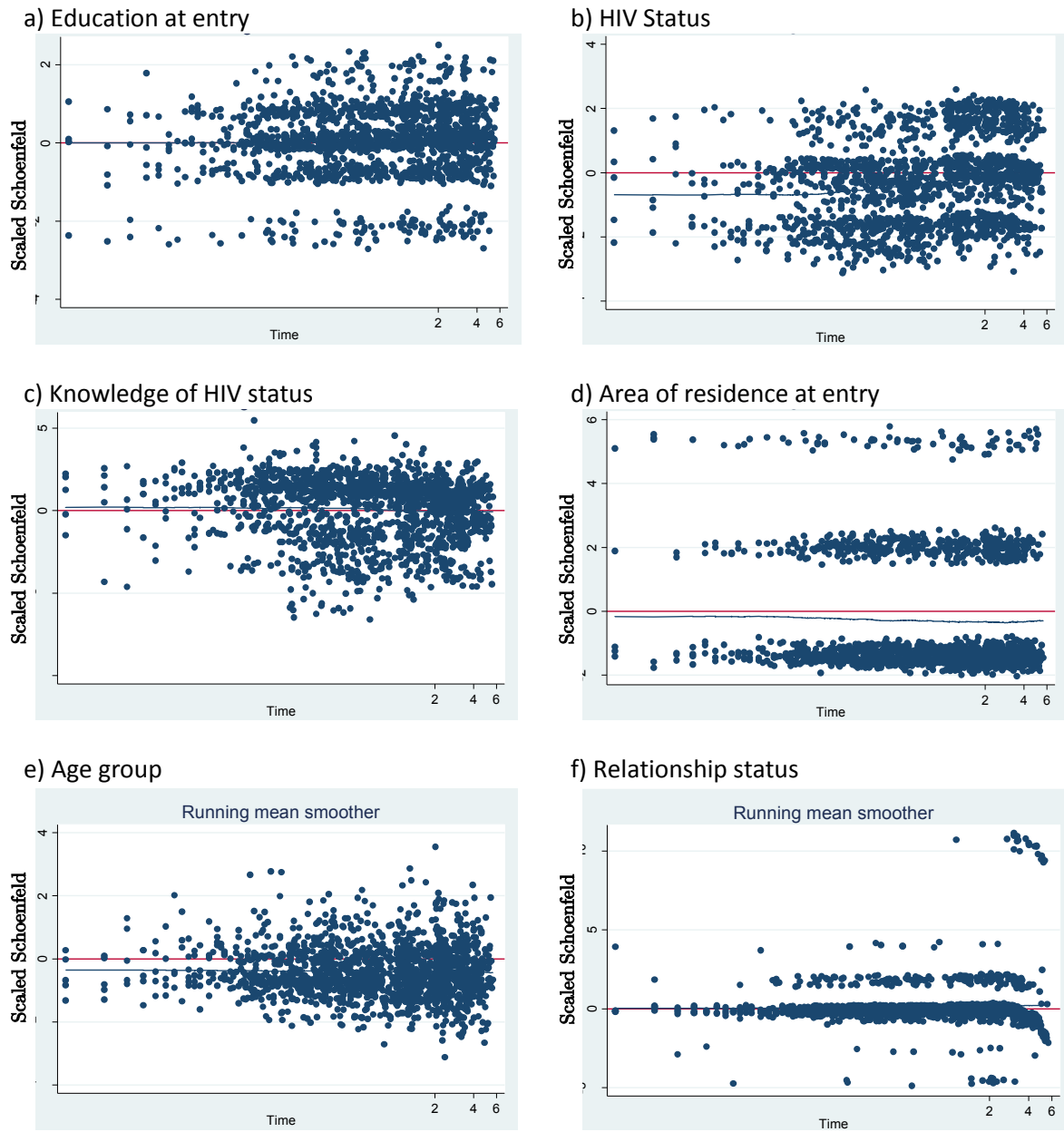
A key assumption of the Cox model, the proportional hazards assumption, states that the hazard ratio remains constant over the entire follow up time. The proportional hazards assumption may be tested graphically and formally using a post-estimation command that tests for a non-zero slope in a regression of the scaled Schoenfeld residuals (Grambsch and Therneau, 1994)

In a complete cohort analysis, HIV status and other proximal and distal determinants of fertility, including: relationship status, parity, self-reported health and method of contraception, violated the proportional hazards assumption. This violation is unsurprising and suggests that rates of live birth vary over time, with increasing age of participants. It indicates that changes in fertility also occur at different (non-proportional) rates over time. Particularly, fertility declines at different rates for HIV negative and positive women.

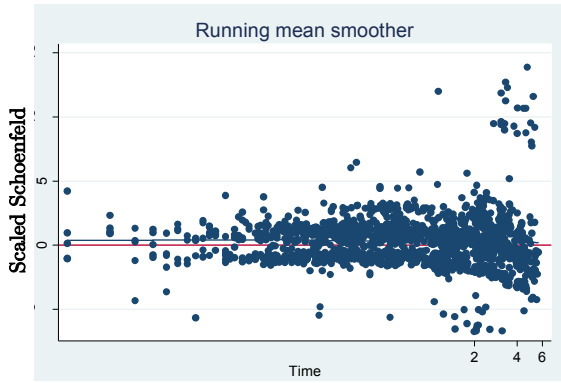
Table 4.12: Test of proportional-hazards assumption per variable

	rho	chi ²	Df	Prob>chi ²
Education at entry	0.04200	3.03	1	0.0817
HIV Status	0.23244	94.58	1	>0.0001
Knowledge of HIV status	-0.09111	14.80	1	0.0001
Area of residence at entry	-0.03752	2.56	1	0.1093
Age group	-0.05056	4.43	1	0.0352
Relationship status	0.07113	7.87	1	0.0050
Living with partner	-0.02128	0.76	1	0.3820
Parity	0.06218	6.55	1	0.0105
Self-reported health	-0.05074	4.31	1	0.0380
Aware of benefits of ART	0.14810	36.55	1	>0.0001
Using contraception	-0.12213	24.90	1	>0.0001
Global Test	-	528.58	11	>0.0001

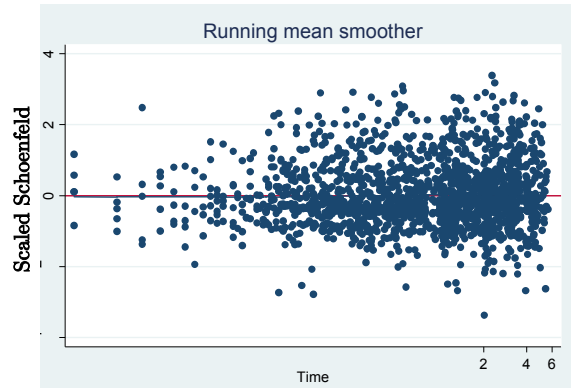
Figure 4.17 Plot of scaled Schoenfeld residuals for each variable against time



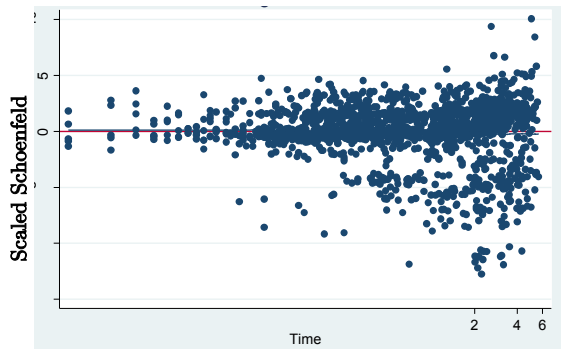
g) Currently living with partner



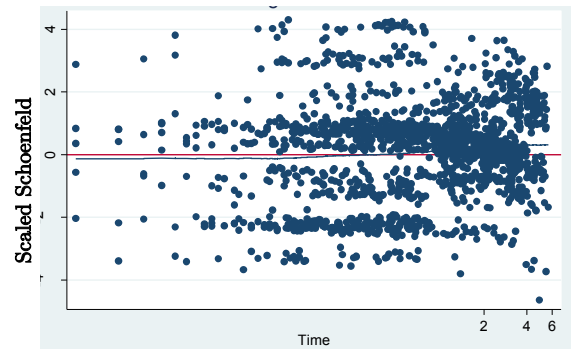
h) Parity group



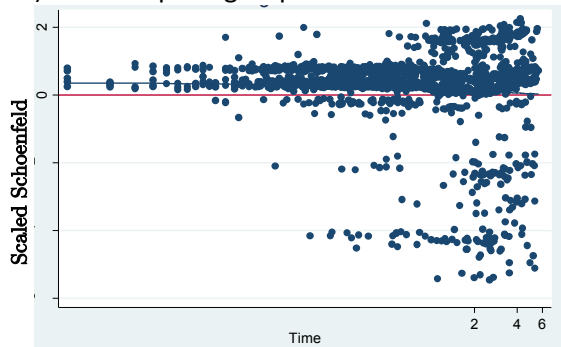
i) Self-reported health



j) Aware of benefits of ART



k) Contraceptive group



A Cox model will not yield reliable interpretations of the complete cohort and stratification was required. Some variables of interest became proportional when stratified by HIV status (Table 4.11). Section 4.3.3.3 presents results from a multivariable Cox Proportional Hazard analysis stratified by HIV status and including only non-volitional variables.

Table 4.11 Test of proportional hazards when stratified by HIV status

	Prob>chi2		
	HIV status unknown	HIV negative	HIV positive
Education at entry	0.6104	0.3730	0.2480
Knowledge of HIV status	0.0202	0.0002	0.1716
Area of residence at entry	0.2852	0.3033	0.1291
Age group	0.0002	0.2599	0.4989
Relationship status	0.0094	0.0093	0.4032
Living with partner	0.1542	0.0004	0.3638
Parity	0.0017	0.1453	0.7125
Self-reported health	>0.0001	0.0001	0.8284
Aware of the benefits of using ART	>0.0001	0.0010	0.0190
Using contraception	>0.0001	>0.0001	>0.0001
CD4 count	-	-	0.0191
On ART	-	-	0.3614

4.3.3.2 Factors associated with time to live birth in univariate analysis

Crude incidence of live birth in a closed cohort of all women participating in HIV surveillance rounds in 2007 and 2008 was 6.4 births per 100 women years [95% CI 6.1– 6.7]; there was significant variation in rates amongst women by HIV status. Highest rates of 9.0 births per 100 woman years [95% CI 8.2 – 9.7] were recorded in women with 'unknown' status and the lowest rates were reported for women with an HIV positive status at 3.6 births per 100 woman years [95% CI 3.2 – 4.0]

This analysis found similar trends in rates of live birth by characteristics as reported in analysis two (table 4.12). Trends were also similar when disaggregated by HIV status category and significantly lower amongst HIV positive women by each level of characteristic compared to women of unknown HIV status. In summary, a univariate analysis of all women episodes detected higher rates of live birth amongst women who had attained secondary level education, lived in rural area of residence, aged 15-19 years old, had a regular partner, did not have any children, did not report contraceptive use at most recent sex and had not yet initiated ART (if HIV positive).

Use of contraception was associated with a 49% lower risk of live birth. However, this association did not change proportionally over time and so could not be included in multivariable analyses.

Many women experience a birth while reporting themselves as single, suggesting that they may engage in more casual relationships during this time. The results suggest being HIV positive may prevent the formation of casual relationships. Single women experienced slowest rates of live birth when HIV positive: 2.7 births per 100 single HIV positive women [95% CI 2.3 – 3.2] compared to 8.0 births per 100 single HIV negative women [95% CI 7.2 – 9.0]. Incidence was highest for women in the HIV positive category reporting to have a regular or casual partner, compared to being single.

Comparatively, women with unknown HIV status had the highest incidence of live birth at 11.6 [95% 10.5 – 12.8] when reporting to be single.

Rates were also highest amongst women that did not respond to questions on self-reported health, HIV status, knowledge of HIV status, co-residency with partner and awareness of the benefits of ART. Higher rates amongst non-responders in these categories may reflect less care seeking behaviour.

Amongst respondents, women who reported to be in excellent, very good or good health experienced higher rates of live birth than those reporting poor or fair health. This finding is comparable to the effect of general health observed in an open cohort and presented in Section 4.2. CD4 count was used to determine a physiological effect of ART on health and although this variable was associated with rates of live birth, there was no clear trend.

Table 4.12 Crude incidence of live birth per characteristic for overall cohort and by HIV status category

Characteristics	All women (26,386.2 woman years)			HIV unknown (6,276.1 woman years)			HIV Negative (10,116.7 woman years)			HIV Positive (9,993.4 woman years)		
	Births	Women years exposed	Incidence Rate	Births	Women years exposed	Incidence Rate [95% CI]	Births	Women years exposed	Incidence Rate [95% CI]	Births	Women years exposed	Incidence Rate [95% CI]
Overall Incidence	1692	263.8	6.4 [6.1– 6.7]	562	62.8	9.0 [8.2 – 9.7]	774	101.2	7.7 [7.1 – 8.2]	356	99.9	3.6 [3.2 – 4.0]
Characteristics at entry												
Education at entry												
Never attended	109	42.7	2.6 [2.1 – 3.1]	29	7.3	4.0 [2.8 – 5.7]	51	18.8	2.7 [2.1 – 3.6]	29	16.6	1.7 [1.2 – 2.5]
At least Primary	341	49.4	6.9 [6.2 – 7.7]	101	9.9	10.2 [8.4 – 12.3]	166	20.3	8.2 [7.0 – 9.5]	74	19.1	3.9 [3.1 – 4.9]
Secondary	764	93.7	8.1 [7.6 – 8.8]	243	22.9	10.6 [9.3 – 12.0]	363	36.1	10.1 [9.1 – 11.2]	158	34.5	4.6 [3.9 – 5.3]
Tertiary	399	60.4	6.6 [6.0 – 7.3]	163	18.8	8.7 [7.4 – 10.1]	158	19.6	8.1 [6.9 – 9.4]	78	22.0	3.5 [2.8 – 4.4]
Unknown	79	17.7	4.4 [3.6 – 5.6]	26	3.8	6.9 [4.7 – 10.1]	36	6.4	5.7 [4.1 – 7.8]	17	7.6	2.2 [1.4 – 3.6]
			<i>P<0.0001</i>			<i>P=0.042</i>			<i>P<0.0001</i>			<i>P<0.014</i>
Area at entry												
Rural	1199	165.1	7.3 [6.9 – 7.7]	384	40.5	9.5 [8.6 – 10.5]	589	70.1	8.4 [7.6 – 9.1]	226	54.5	4.1 [3.6 – 4.7]
Peri-Urban	423	81.8	5.2 [4.7 – 5.7]	146	16.4	8.9 [7.6 – 10.5]	161	27.0	6.0 [5.1 – 7.0]	116	38.5	3.0 [2.5 – 3.6]
Urban	70	16.8	4.1 [3.3 – 5.2]	32	5.9	5.5 [3.9 – 7.7]	24	4.1	5.8 [3.9 – 8.7]	14	6.9	2.0 [1.2 – 3.4]
			<i>p<0.0001</i>			<i>P=0.0007</i>			<i>P=0.0016</i>			<i>P=0.0009</i>
Characteristics updated annually												
Age (updated annually)												
15-19	372	22.8	16.3 [14.7 – 18.1]	127	6.2	20.3 [17.1 – 24.2]	212	12.3	17.3 [15.1 – 19.8]	33	4.3	7.7 [5.5 – 11.0]
20-24	533	49.7	10.7 [9.8 – 11.7]	181	14.1	12.8 [11.1 – 14.8]	253	21.1	12.0 [10.6 – 13.6]	99	14.6	6.9 [5.5 – 8.3]
25-29	319	44.4	7.2 [6.4 – 8.0]	105	11.4	9.2 [7.6 – 11.2]	119	14.3	8.3 [7.0 – 10.0]	95	18.7	5.1 [4.2 – 6.2]

30-35	265	38.9	6.8 [6.0 – 7.7]	85	9.0	9.4 [7.6 – 11.7]	95	10.5	9.1 [7.4 – 11.1]	85	19.4	4.4 [3.5 – 5.4]
35-39	143	37.3	3.8 [3.2 – 4.5]	46	8.0	5.7 [4.3 – 7.7]	62	12.1	5.1 [4.0 – 6.6]	35	17.2	2.0 [1.5 – 2.8]
40-44	49	37.2	1.3 [1.0 – 1.7]	14	7.5	1.9 [1.1 – 3.2]	27	15.0	1.8 [1.2 – 2.6]	8	14.7	0.5 [0.3 – 1.1]
45-49	11	33.6	0.3 [0.2 – 0.6]	4	6.5	0.6 [0.2 – 1.6]	6	16.0	0.4 [0.2 – 0.8]	1	11.1	0.1 [0.0 – 0.6]
			<i>P<0.0001</i>			<i>P<0.0001</i>			<i>P<0.0001</i>			<i>P=0.2163</i>
Knowledge of own HIV status (updated annually)												
No	331	49.3	6.7 [6.0 – 7.5]	83	11.0	7.9 [6.1 – 9.3]	198	30.0	7.6 [6.6 – 8.8]	50	12.3	4.1 [3.1 – 5.4]
Yes	914	160.0	5.7 [5.4 – 6.1]	210	25.9	8.1 [7.1 – 9.3]	424	55.5	7.6 [6.9 – 8.4]	280	78.6	3.6 [3.2 – 4.0]
Unknown	447	54.5	8.2 [7.5 – 9.0]	269	25.8	10.4 [9.2 – 11.7]	152	19.7	7.7 [6.6 – 9.1]	26	9.1	2.9 [2.0 – 4.2]
			<i>P<0.0001</i>			<i>P=0.042</i>			<i>P<0.0001</i>			<i>P<0.014</i>
Most recent relationship per annual episode												
Single	859	129.3	6.6 [6.2 – 7.1]	383	33.1	11.6 [10.5 – 12.8]	324	40.3	8.0 [7.2 – 9.0]	152	56.0	2.7 [2.3 – 3.2]
Casual friend /partner	18	4.1	4.4 [2.6 – 6.9]	2	0.8	2.3 [0.6 – 9.2]	8	1.7	4.8 [2.4 – 9.6]	8	1.6	5.1 [2.5 – 10.1]
Engaged/Married	69	19.8	3.5 [2.8 – 4.4]	9	4.7	1.9 [1.0 – 3.7]	46	11.5	4.0 [3.0 – 5.4]	14	3.6	3.9 [2.3 – 6.5]
Regular partner	654	88.5	7.4 [6.8 – 7.9]	148	19.8	7.4 [6.3 – 8.8]	347	38.8	9.0 [8.1 – 9.9]	159	29.9	5.3 [4.5 – 6.2]
Divorced/Widowed/Separated	70	18.6	3.8 [3.0 – 4.7]	17	3.7	4.5 [2.8 – 7.2]	34	7.2	4.7 [3.4 – 6.6]	19	7.6	2.4 [1.6 – 3.9]
Other or unknown	22	3.5	6.3 [4.2 – 9.6]	3	0.6	5.0 [1.6 – 15.6]	15	1.7	8.8 [5.3 – 14.6]	4	1.2	3.4 [1.3 – 9.0]
			<i>P<0.0001</i>			<i>P<0.0001</i>			<i>P<0.0001</i>			<i>P<0.0001</i>
Living with partner												
No	635	94.0	6.8 [6.3 – 7.3]	148	21.7	6.8 [5.8 – 8.0]	339	39.9	8.5 [7.6 – 9.4]	148	32.3	4.6 [3.9 – 5.4]
Yes	174	36.7	4.7 [4.1 – 5.5]	28	7.4	3.8 [2.6 – 5.5]	94	19.0	4.9 [4.0 – 6.1]	52	10.3	5.0 [3.8 – 6.6]
Unknown	24	3.9	6.2 [4.2 – 9.3]	3	0.7	4.5 [1.5 – 14.0]	17	1.9	9.1 [5.6 – 14.6]	4	1.3	3.0 [1.1 – 8.1]
No partner	859	129.3	6.6 [6.2 – 7.1]	383	33.0	11.6 [10.5 – 12.8]	324	40.3	8.0 [7.2 – 9.0]	152	56.0	2.7 [2.3 – 3.2]

		<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0001					
Median Parity	2				2				2				2			
Parity (time-updated)																
0	472	28.8	16.4 [15.0 – 18.0]	165	7.3	22.5 [19.3 – 26.2]	258	12.0	21.5 [19.0 – 24.2]	49	9.5	5.2 [3.9 – 6.8]				
1	466	66.2	7.0 [6.4 – 7.7]	153	18.3	8.4 [7.1 – 9.8]	212	25.5	8.3 [7.1 – 9.5]	101	22.4	4.5 [3.7 – 5.5]				
2	335	51.4	6.5 [5.6 – 7.3]	122	13.0	9.4 [7.9 – 11.2]	116	16.4	7.1 [5.9 – 8.5]	97	22.0	4.4 [3.6 – 5.4]				
3	172	37.9	4.5 [3.9 – 5.3]	54	8.6	6.2 [4.8 – 8.2]	69	12.0	5.8 [4.6 – 7.3]	49	17.3	2.8 [2.1 – 3.7]				
4	99	26.8	3.7 [3.0 – 4.5]	27	5.6	4.8 [3.3 – 7.1]	42	10.3	4.1 [3.0 – 5.5]	30	11.0	2.7 [1.9 – 3.9]				
5	61	20.1	3.0 [2.4 – 3.9]	17	4.0	4.2 [2.6 – 6.8]	8.7	8.7	3.4 [2.3 – 4.8]	15	7.4	2.0 [1.2 – 3.4]				
6+	87	32.6	2.7 [2.2 – 3.3]	24	5.9	4.1 [2.7 – 6.1]	16.3	16.3	2.9 [2.2 – 3.9]	15	10.4	1.4 [0.9 – 2.4]				
		<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0001					
Self-reported Health (updated annually)																
Fair/Poor	85	28.6	3.0 [2.4 – 3.7]	18	3.4	5.2 [3.3 – 8.3]	35	12.0	2.9 [2.1 – 4.0]	32	13.1	2.4 [1.7 – 3.4]				
Excellent/Very good/Good	900	142.6	6.3 [5.9 – 6.7]	200	32.2	6.2 [5.4 – 7.1]	498	65.4	7.6 [7.0 – 8.3]	202	45.0	4.5 [3.9 – 5.1]				
Unknown	707	92.6	7.6 [7.1 – 8.2]	344	27.2	12.7 [11.4 – 14.1]	241	23.7	10.1 [9.0 – 11.5]	122	41.7	2.9 [2.4 – 3.5]				
		<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0001					
Heard of ART																
No	338	46.2	7.3 [6.6 – 8.1]	87	11.4	7.6 [6.2 – 9.4]	198	21.0	9.4 [8.2 – 10.8]	53	13.9	3.8 [2.9 – 5.0]				
Yes	644	115.8	5.6 [5.1 – 6.0]	155	18.4	8.4 [7.2 – 9.8]	291	37.9	7.7 [6.8 – 8.6]	198	59.5	3.3 [2.9 – 3.8]				
Unknown	710	101.8	7.0 [6.5 – 7.5]	320	32.9	9.7 [8.7 – 10.8]	285	42.2	6.7 [6.0 – 7.6]	105	26.6	3.9 [3.3 – 4.7]				
		<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> =0.2868					
Using contraception																
No	415	46.4	8.9 [8.1 – 9.8]	111	11.4	9.7 [8.1 – 11.7]	223	22.2	10.1 [8.8 – 11.4]	81	12.9	6.3 [5.1 – 7.8]				
Yes	236	72.2	3.2 [2.9 – 3.7]	36	15.3	2.4 [1.7 – 3.3]	121	30.6	4.0 [3.3 – 4.7]	79	26.4	3.0 [2.4 – 3.7]				
Unknown	1041	145.2	7.2 [6.7 – 7.6]	415	36.1	11.5 [10.5 – 12.7]	430	48.5	8.9 [8.1 – 9.8]	196	60.7	3.2 [2.8 – 3.7]				
		<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0001			<i>P</i> <0.0002					
Form of Contraception																

Barrier methods	69	15.6	4.4 [3.5 – 5.6]	11	3.0	3.6 [2.0 – 6.6]	23	5.6	4.1 [2.7 – 6.2]	35	7.0	5.0 [3.6 – 6.9]
Oral / IUCD / Microbicides	8	2.6	3.1 [1.6 – 6.3]	2	0.5	4.2 [1.0 – 16.8]	4	1.4	2.9 [1.1 – 7.8]	2	0.7	2.8 [0.7 – 11.2]
Injectable	68	20.9	3.2 [2.6 – 4.1]	12	3.8	3.1 [1.8 – 5.5]	37	9.6	3.9 [2.8 – 5.3]	19	7.5	2.5 [1.6 – 4.0]
Dual	8	2.9	2.7 [1.4 – 5.5]	0	0.5	0 [-]	3	0.8	3.5 [1.1 – 11.0]	5	1.6	3.1 [1.3 – 7.4]
Other / unknown method	83	30.2	2.7 [2.2 – 3.4]	11	7.5	1.5 [0.8 – 2.6]	54	13.2	4.1 [3.1 – 5.3]	18	9.4	1.9 [1.2 – 3.0]
None	415	46.4	8.9 [8.1 – 9.8]	111	11.4	9.7 [8.1 – 11.7]	223	22.2	10.1 [8.8 – 11.5]	81	12.9	6.3 [5.1 – 7.8]
Unknown if using	1041	145.2	7.2 [6.7 – 7.6]	415	36.1	11.5 [10.5 – 12.7]	430	48.5	8.9 [8.1 – 9.8]	196	60.7	3.2 [2.8 – 3.7]
			<i>P<0.0001</i>			<i>P<0.0001</i>			<i>P<0.0001</i>			<i>P<0.0001</i>
CD4 count (time-updated) (cells/μl)												
<=250	-	-	-	-	-	-	-	-	-	59	12.1	4.9 [3.8 – 6.3]
250-350	-	-	-	-	-	-	-	-	-	44	8.3	5.3 [3.9 – 7.1]
350-500	-	-	-	-	-	-	-	-	-	53	10.7	4.9 [3.8 – 6.4]
>500	-	-	-	-	-	-	-	-	-	49	12.6	3.9 [2.9 – 5.1]
Unknown	-	-	-	-	-	-	-	-	-	151	56.3	2.7 [2.3 – 3.1]
												<i>P<0.0001</i>

4.3.3.3 Multivariable analysis

Multivariable analysis adjusting for area of residence, age group, parity and self-reported health found HIV positive women were 57% less likely to experience a live birth compared to HIV negative women (Table 4.13). Women whose HIV status was unknown experienced comparable rates of live birth to HIV negative women in this adjusted analysis. However this analysis did not meet the proportional hazards assumption and the remaining results are presented after stratification.

Trends in age and parity characteristics were comparable across HIV grouping: rates of live birth reduced with increasing age and parity greater than one amongst HIV positive, negative and unknown woman episodes.

An analysis of only HIV positive women adjusted for education and area of residence at baseline and time updated age, knowledge of HIV status, relationship status, parity, self-reported health, method of contraception used and CD4 count at start of episode, found exposure to ART was associated with a 47% reduced risk of live birth. There was no evidence of increased risk within specific age groups but data presented here is not stratified by ART exposure, as seen in analysis two. Live birth was 64% more likely to HIV positive women in a casual relationship and more than twice as likely in married or engaged women, compared to those reporting to be single. Health factors (CD4 count and self-reported health) were not associated with rate of live birth.

Table 4.13 Crude and adjusted Cox proportional hazards of live birth to women in closed cohort entering in 2007 or 2008, per characteristic and by HIV status

Crude and Adjusted Hazard ratio [95% CI]										
Characteristics	All episodes				HIV Status Unknown		HIV Negative		HIV positive	
	Crude HR	95% CI	AHR	95% CI	AHR	95% CI	AHR	95% CI	AHR	95% CI
Characteristics at entry										
Education at entry										
Never attended	1	-	-	-	-	-	-	-	1	-
At least Primary	2.650	2.108 – 3.332	-	-	-	-	-	-	1.308	0.807 – 2.121
Secondary	3.127	2.526 – 3.871	-	-	-	-	-	-	1.233	0.771 – 1.973
Tertiary	2.584	2.066 – 3.233	-	-	-	-	-	-	1.083	0.668 – 1.756
Unknown	1.725	1.275 – 2.335	-	-	-	-	-	-	1.026	0.547 – 1.923
Area at entry										
Rural	1	-	1	-	1	-	1	-	1	-
Peri-Urban	0.728	0.649 – 0.817	0.770	0.689 – 0.861	0.954	0.808 – 1.126	0.740	0.621 – 0.881	0.755	0.595 – 0.958
Urban	0.562	0.444 – 0.711	0.648	0.516 – 0.813	0.719	0.526 – 0.982	0.806	0.555 – 1.171	0.431	0.245 – 0.758
Characteristics updated annually										
HIV status										
Negative	1	-	1	-	-	-	-	-	-	-
Positive	0.474	0.417 – 0.539	0.427	0.370 – 0.493	-	-	-	-	-	-
Unknown	1.138	1.022 – 1.267	0.951	0.855 – 1.057	-	-	-	-	-	-
Exposure to ART (HIV positive only)										

No	1	-	-	-	-	-	-	-	1	-
Yes	0.741	0.571 – 0.962	-	-	-	-	-	-	0.534	0.390 – 0.730
Age at episode										
15-19	1	-	1	-	1	-	1	-	1	-
20-24	0.792	0.696 – 0.901	0.955	0.836 – 1.091	1.142	0.929 – 1.403	1.063	0.877 – 1.289	0.793	0.514 – 1.223
25-29	0.572	0.493 – 0.662	0.759	0.642 – 0.898	1.008	0.770 – 1.319	0.924	0.713 – 1.197	0.596	0.380 – 0.932
30-35	0.539	0.461 – 0.631	0.678	0.563 – 0.816	0.917	0.673 – 1.250	0.913	0.674 – 1.235	0.475	0.295 – 0.766
35-39	0.312	0.256 – 0.380	0.340	0.267 – 0.433	0.602	0.409 – 0.886	0.458	0.313 – 0.669	0.196	0.109 – 0.353
40-44	0.110	0.081 – 0.149	0.100	0.072 – 0.140	0.191	0.105 – 0.350	0.152	0.097 – 0.239	0.047	0.020 – 0.114
45-49	0.027	0.015 – 0.049	0.022	0.012 – 0.041	0.060	0.022 – 0.163	0.029	0.012 – 0.069	0.007	0.001 – 0.054
Knowledge of own HIV status										
No	1	-	-	-	-	-	-	-	1	-
Yes	1.174	1.033 – 1.334	-	-	-	-	-	-	1.163	0.827 – 1.636
Unknown	2.077	1.781 – 2.421	-	-	-	-	-	-	1.055	0.601 – 1.852
Most recent relationship per annual episode										
Single	1	-	-	-	1	-	-	-	1	-
Casual friend /partner	0.430	0.267 – 0.693	-	-	0.050	0.012 – 0.207	-	-	1.375	0.617 – 3.060
Engaged/Married	0.304	0.234 – 0.396	-	-	0.079	0.039 – 0.158	-	-	2.357	1.195 – 4.648
Regular partner	0.672	0.596 – 0.758	-	-	0.164	0.131 – 0.205	-	-	1.639	1.053 – 2.552
Divorced/Widowed/Separated	0.339	0.262 – 0.439	-	-	0.125	0.075 – 0.209	-	-	1.064	0.577 – 1.960
Other or unknown	1.458	0.930 – 2.287	-	-	0.740	0.197 – 2.777	-	-	2.212	0.772 – 6.337
Living with partner										
No	1	-	-	-	-	-	-	-	-	-
Yes	0.681	0.574 – 0.808	-	-	-	-	-	-	-	-
Unknown	2.163	1.410 – 3.320	-	-	-	-	-	-	-	-
No partner	1.622	1.437 – 1.830	-	-	-	-	-	-	-	-
Parity										

0	1	-	1	-	1	-	1	-	1	-
1	0.518	0.456 – 0.589	0.545	0.478 – 0.621	0.493	0.394 – 0.616	0.488	0.405 – 0.589	1.052	0.730 – 1.515
2	0.506	0.439 – 0.583	0.691	0.592 – 0.807	0.631	0.488 – 0.817	0.536	0.419 – 0.685	1.271	0.874 – 1.850
3	0.360	0.301 – 0.430	0.643	0.528 – 0.783	0.540	0.384 – 0.759	0.535	0.391 – 0.733	1.133	0.738 – 1.740
4	0.292	0.235 – 0.363	0.744	0.585 – 0.947	0.582	0.378 – 0.894	0.563	0.390 – 0.813	1.549	0.942 – 2.547
5	0.239	0.183 – 0.312	0.845	0.628 – 1.137	0.731	0.431 – 1.239	0.630	0.405 – 0.981	1.566	0.817 – 3.004
6+	0.205	0.160 – 0.263	1.212	0.913 – 1.608	1.092	0.689 – 1.730	0.923	0.612 – 1.394	2.166	1.107 – 4.240
Self-reported Health										
Fair/Poor	1	-	1	-	-	-	-	-	1	-
Excellent/Very good/Good	1.595	1.273 – 1.998	0.746	0.589 – 0.944	-	-	-	-	1.382	0.910 – 2.097
Unknown	2.576	2.047 – 3.242	1.795	1.416 – 2.274	-	-	-	-	1.225	0.726 – 2.070
Heard of ART										
No	1	-	-	-	-	-	-	-	-	-
Yes	1.426	1.241 – 1.639	-	-	-	-	-	-	-	-
Unknown	2.003	1.742 – 2.304	-	-	-	-	-	-	-	-
Using contraception										
No	1	-	-	-	-	-	-	-	-	-
Yes	0.512	0.437 – 0.600	-	-	-	-	-	-	-	-
Unknown	1.771	1.547 – 2.028	-	-	-	-	-	-	-	-
Form of Contraception										
Barrier methods	1	-	-	-	-	-	-	-	1	-
Oral/IUCD/Microbicides	0.938	0.448 – 1.965	-	-	-	-	-	-	0.742	0.174 – 3.151
Injectable	0.976	0.688 – 1.385	-	-	-	-	-	-	0.570	0.320 – 1.015
Dual	0.771	0.368 – 1.618	-	-	-	-	-	-	0.565	0.216 – 1.475
Other/unknown method	0.329	0.237 – 0.456	-	-	-	-	-	-	0.262	0.145 – 0.473
None	1.110	0.853 – 1.444	-	-	-	-	-	-	1.204	0.792 – 1.829
Unknown if using	2.044	1.577 – 2.651	-	-	-	-	-	-	1.166	0.750 – 1.812

CD4 count (cells/ μ l) (HIV positive only)									
<=250	1	-	-	-	-	-	-	1	-
250-350	1.157	0.773 – 1.733	-	-	-	-	-	1.208	0.797 – 1.830
350-500	1.134	0.777 – 1.655	-	-	-	-	-	1.244	0.846 – 1.830
>500	0.932	0.626 – 1.389	-	-	-	-	-	0.957	0.640 – 1.430
Unknown	0.543	0.400 – 0.738	-	-	-	-	-	0.323	0.230 – 0.454

4.3.3.4 Risk of live birth during follow up

Risk of live birth declined with duration of follow up to all women. Figure 4.18 presents cox proportional cumulative hazard models, to illustrate the consistently lower risk of live birth amongst HIV positive women throughout duration of follow up.

Birth-free survival to HIV positive women, according to ART exposure is presented in figure 4.19. A survival model adjusted for education and area of residence at baseline and time updated: age, knowledge of HIV status, relationship status, parity, self-reported health, method of contraception used and CD4 count at start of episode illustrates the proportion of HIV positive women that remained 'birth-free' throughout follow up. This information is stratified by ART exposure to illustrate that ART-exposed women were consistently at lower risk of live birth and experience fewer births during follow up compared to women not yet on treatment.

Figure 4.18 Adjusted Cox Proportional cumulative hazard of experiencing a live birth in a closed cohort up to 6 years of follow up since entry

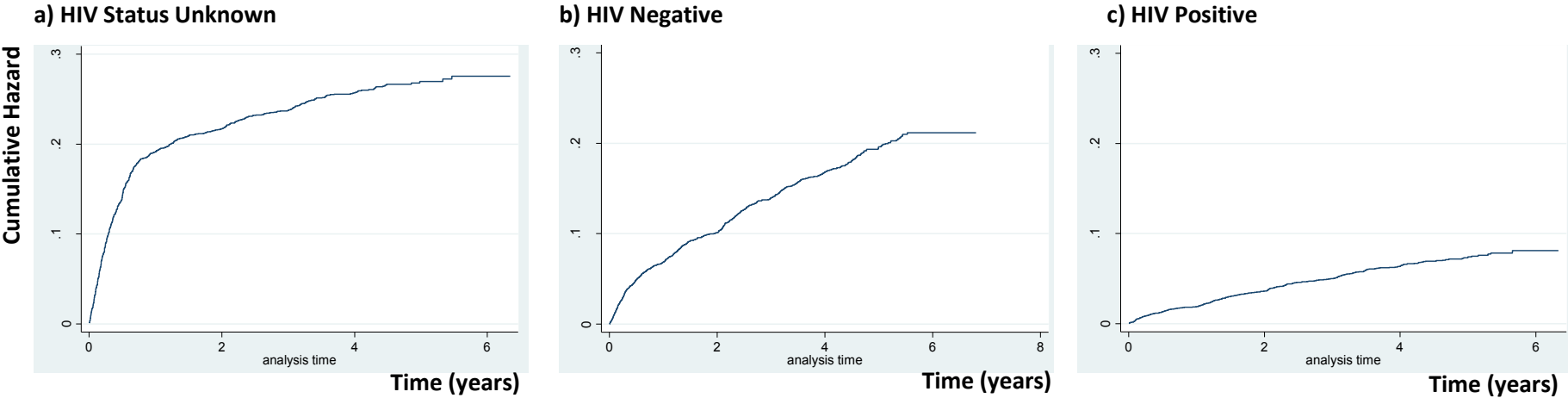
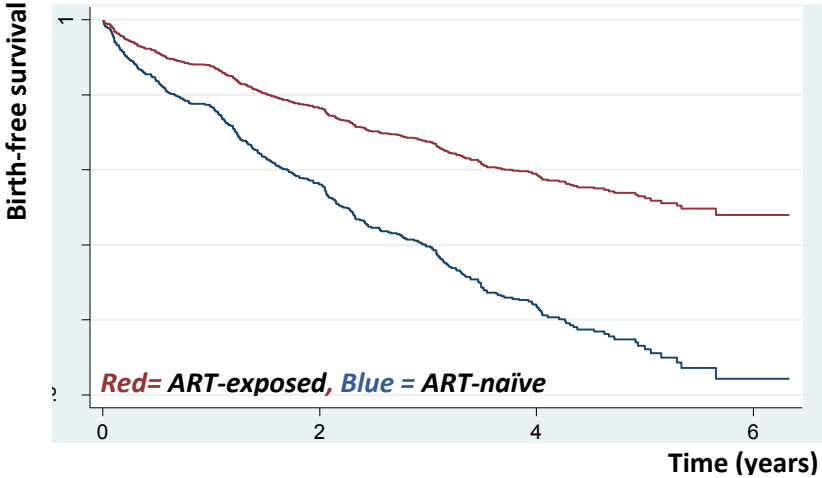


Figure 4.19 Adjusted Cox proportional cumulative birth-free survival amongst HIV Positive women, stratified by exposure to ART



4.3.3 Analysis Three: Section Summary

- This analysis determined similar trends in rates and factors associated with risk of live birth by HIV status compared to the open cohort presented in analysis two.
- Complete closed cohort analysis violates the cox proportional hazards assumption and interpretations should be taken from analysis stratified by HIV status.
- HIV positive women were 57% less likely to experience a live birth than HIV negative women and exposure to ART was associated with a 47% reduced risk of live birth.
- The purpose of this analysis was to compare trends and factors associated with risk of live birth with women of 'unknown' HIV status. Risk amongst women of 'unknown' HIV status was highest of all three HIV categories and not significantly different to HIV negative women in multivariable analysis. Women with an unknown HIV status were demographically similar to HIV negative women, with higher proportions in a relationship, reporting current use of contraception and being in good health, compared to HIV positive women.
- In a stratified analysis, and contrary to an open cohort analysis, CD4 count and self-reported health were not associated with rate of live birth amongst HIV positive women. Trends for self-reported health persisted but did not achieve significance, which may be due to low numbers.
- HIV positive women were more likely to be single and had lowest incidence of live birth: only 39% of HIV positive women were in a relationship compared to 61% of HIV negative women. HIV 'unknown' women were typically younger, more likely to be in a relationship and experienced highest incidence of live birth when single. Results suggest positive women may be less likely to engage in new childbearing relationships.
- Incidence of live birth was highest amongst non-responders to questions on self-reported health, HIV status, knowledge of HIV status, co-residency with partner and awareness of the benefits of ART. Higher rates in these categories may reflect less care seeking or more risky sexual behaviour.

4.4 Descriptive analysis of contraceptive use amongst women in the closed cohort

The purpose of this supplementary analysis is to describe likelihood of contraceptive use according to HIV status and exposure to ART amongst a cohort of women reported in section 4.3.

Contraceptive use is one of the strongest proximate determinants of fertility through which a more distal effect of ART may operate (Kaida et al. 2006). Contraception is freely available in South Africa, although initiation on ART may impact upon patterns of contraceptive behaviour. For example, women that wish to preserve their health on ART may experience increased sexual activity and chose to use more protective barrier methods, while others may experience lower sexual activity and select abstinence.

The effect of ART use on rates of contraceptive use is not well known in this setting. Contraceptive use was a strong proximate determinant of lower rates of live birth in univariate analyses presented in sections 4.2 and 4.3. This association persisted in an adjusted analysis presented in section 4.2. Contraceptive use was not included in the stratified adjusted analysis presented in section 4.3, as it violated the model assumptions.

HIV positive women and women enrolled on ART demonstrated lower rates of live birth compared to HIV negative women in both sections 4.2 and 4.3. This descriptive analysis aims to determine whether HIV positive status and use ART are factors associated with higher or lower likelihood of women's contraceptive use in this setting. Contraceptive use may also be influenced self-reported health and other potentially confounding factors. However, limitations such as missing data and the temporality of this measure meant that further analysis was not feasible within the scope of this study. Unadjusted analysis is presented here to describe trends in contraceptive use within the cohort discussed in section 4.3. Further studies of contraceptive use in this setting have been published elsewhere (Raifman et al., 2014).

Crude incidence of contraceptive use, associated with other social and health characteristics are presented in table 4.14. Results show that HIV infected women were 10% less likely to use contraception at last sex than HIV negative women. Comparatively, women of unknown HIV status

were 20% less likely to report contraceptive use compared to HIV negative women. There was no evidence to suggest that knowledge of HIV status is associated with contraceptive use, counter to the proposed hypothesis of modified contraceptive use through childbearing intentions on ART. It could reflect an absence or heterogeneous effect of HIV knowledge in an era when ART is widely available. Alternatively, women that perceived their health as excellent, good or very good were 40% more likely to use contraception. This finding may be indicative of increased sexual activity and a wish to preserve good health.

The characteristics illustrated in this table were selected as determinants of fertility in two cohort analyses presented previously. Socio-demographic factors were strongly associated with contraceptive use in this area. Women with secondary level education attainment were most likely to use contraception, and likelihood decreased at higher levels of educational attainment after this. Residents of rural or peri-urban area of location were more likely to use contraception compared to women living in urban areas.

Women aged between 15 and 24 years old reported highest use of contraception and rates of contraceptive use declined thereafter with age, although remaining high. Using 15-19 year old women as baseline, likelihood of contraceptive use was 30% lower amongst women aged 35-39 years old, the median age category of women on ART.

Although highest rates of live birth were observed to women with a regular partner, these women were also most likely to report contraceptive use at last sex. This could reflect both higher sexual activity or inconsistent contraceptive use, or both. It is possible that this trend could also represent some planned behaviour, as partners use contraceptive at last sex and discontinue when trying to conceive a child. However, little evidence of such planned behaviour was found in a subsequent qualitative study, described in Chapter Five. The likelihood of contraceptive use was reduced by 20% when women reported living with their partner compared to women not living with their partner.

Table 4.14 Unadjusted likelihood of contraceptive use according to proximate and distal determinants of fertility and HIV status

Characteristics	All women (26,386.2 woman years)			
	No. of contraceptive users	Women years exposed	Incidence Rate	HR
Overall Incidence	6853	263.9	26.0 [25.4– 26.6]	-
Characteristics at entry				
Education at entry				
Never attended	747	42.7	17.5 [16.3 – 18.8]	1
At least Primary	1299	49.4	26.3 [24.9 – 27.8]	1.5 [1.4 – 1.6]
Secondary	2815	93.7	30.1 [29.0 – 31.2]	1.7 [1.6 – 1.9]
Tertiary	1660	60.4	27.5 [26.2 – 28.8]	1.6 [1.5 – 1.7]
Unknown	332	17.7	18.7 [16.8 – 20.9]	1.1 [0.9 – 1.2]
			P<0.0001	
Area at entry				
Rural	4348	165.1	26.3 [25.6 – 27.1]	1
Peri-Urban	2121	81.8	25.9 [24.8 – 27.0]	1.0 [0.9 – 1.0]
Urban	384	16.8	22.7 [20.6 – 25.1]	0.9 [0.8 – 1.0]
			P=0.0422	
Characteristics updated annually				
Age (updated annually)				
15-19	673	22.8	25.5 [27.4 – 31.8]	1
20-24	1662	49.7	33.4 [31.8 – 35.1]	1.0 [0.9 – 1.1]
25-29	1447	44.4	32.6 [31.0 – 34.3]	0.9 [0.9 – 1.0]
30-35	1152	38.9	29.6 [28.0 – 31.4]	0.9 [0.8 – 0.9]
35-39	871	37.3	23.3 [21.8 – 24.9]	0.7 [0.6 – 0.7]
40-44	638	37.2	17.2 [15.9 – 18.6]	0.5 [0.4 – 0.5]
45-49	410	33.6	12.2 [11.1 – 13.4]	0.3 [0.3 – 0.4]
			P<0.0001	
Knowledge of own HIV status (updated annually)				
No	1445	49.3	29.3 [27.8 – 30.8]	1
Yes	5269	160.0	32.9 [32.0 – 33.8]	1.0 [0.9 – 1.0]
Unknown	139	54.5	2.5 [2.2 – 3.0]	0.07 [0.06 – 0.09]
			P<0.0001	
Most recent relationship per annual episode				
Single	1000	129.3	7.7 [7.2 – 8.2]	1
Casual friend /partner	148	4.1	36.0 [30.6 – 42.3]	6.4 [5.4 – 7.6]
Engaged/Married	746	19.8	37.8 [35.1 – 40.6]	6.8 [6.2 – 7.5]
Regular partner	4350	88.5	49.1 [47.7 – 50.6]	8.5 [7.9 – 9.1]
Divorced/Widowed/Separated	535	18.6	28.7 [26.4 – 31.2]	5.0 [4.5 – 5.6]
Other or unknown	74	3.5	21.3 [16.9 – 26.7]	1.4 [1.1 – 1.8]

P<0.0001				
Living with partner				
No	4369	94.0	46.5 [45.1 – 47.9]	1
Yes	1402	36.7	38.2 [36.2 – 40.2]	0.8 [0.8 – 0.9]
Unknown	82	3.9	21.3 [17.1 – 26.4]	0.2 [0.2 – 0.2]
No partner	1000	129.3	7.7 [7.3 – 8.2]	0.1 [0.1 – 0.1]
P<0.0001				
Parity (time-updated)				
0	655	28.8	22.8 [21.1 – 24.6]	1
1	1960	66.2	29.6 [28.3 – 30.9]	1.2 [1.1 – 1.3]
2	1501	51.4	29.2 [27.8 – 30.7]	1.2 [1.1 – 1.3]
3	1062	37.9	28.0 [26.4 – 29.7]	1.1 [1.0 – 1.2]
4	656	26.8	24.5 [22.7 – 26.4]	1.0 [0.9 – 1.1]
5	429	20.1	21.3 [19.4 – 23.4]	0.8 [0.7 – 0.9]
6+	590	32.6	18.1 [16.7 – 19.6]	0.7 [0.6 – 0.8]
P<0.0001				
Self-reported Health (updated annually)				
Fair/Poor	961	28.6	34.0 [32.0 – 36.0]	1
Excellent/Very good/Good	5882	142.6	41.0 [40.0 – 42.0]	1.4 [1.3 – 1.5]
Unknown	10	92.6	0.1 [0.1 – 0.2]	<0.0 [0.002 – 0.006]
P<0.0001				
HIV status (updated annually)				
Negative	2920	101.2	28.9 [27.8 – 29.9]	1
Positive	2519	99.9	25.2 [24.2 – 26.2]	0.9 [0.8 – 0.9]
Unknown	1414	62.8	22.5 [21.4 – 23.7]	0.8 [0.8 – 0.9]
P<0.0001				

4.4.1 Analysis Four: Section Summary

- HIV status was associated with a small change in contraceptive use and there was no evidence for an effect of awareness of own HIV status. Rather, self-reported health was a better predictor of contraceptive use in this cohort. HIV infected women were 10% less likely to use contraception at last sex than HIV negative women. Alternatively, reporting excellent, good or very good were 40% more likely to use contraception.
- Socio-demographic factors were strongly associated with use of contraception in this area. Likelihood of contraceptive use was associated with secondary level education attainment, rural or peri-urban residency, age less than 24 years, seeing a regular partner, not co-residing with a partner.
- Rates of contraceptive use remained high in older age groups.
- Findings demonstrate that HIV positive women are not reporting large changes in contraceptive use. Results from this and prior analysis suggest that reduced sexual activity, independent to awareness of HIV status, and related to poorer perceived health may explain small changes in contraceptive use.

Chapter Five

The influence of ART on childbearing desires, attitudes to safer conception and contraceptive use in HIV positive women

5.1 Introduction to chapters presenting qualitative results

Chapters Five and Six explore how the use of highly active anti-retroviral therapy (ART) influences childbearing and contraception amongst women living with HIV, and currently enrolled in a HIV treatment and care programme. These chapters' present results of 35 semi-structured interviews with women on ART and healthcare providers in the Hlabisa HIV treatment and care programme. Interviews addressed topics of childbearing desires, attitudes towards contraceptive use and methods, and safer conception strategies. A discussion of these results is supported by clinic observations made by the researcher using a standardised checklist of contraception and safer conception activities.

Section 5.2 outlines the qualitative sample used in chapters five and six, and then presents characteristics of sampled women, health workers and clinics. Section 5.3 describes the childbearing desires of 23 women using ART in the treatment and care programme. Chapter five concludes with a description of the themes relating to factors that influence childbearing desires, and whether women follow these desires, including the impact of being on ART and the perspective of health workers. Chapter six uses these findings as the context for the findings on contraceptive use amongst women in the ART programme, and structural barriers and facilitators affecting access to contraception and safe conception services amongst women on ART.

5.2 Client characteristics

Twenty-one of a total twenty-three women reported a current partner. Definitions ranged from casual partners, such as seeing her partner once a month or less through to more frequent visits, living together or being married and one woman reported having two male partners. For simplification I used the following categories: no partner, has more than one partner, with a partner that has not paid *isilobolo*, has a partner who has paid *isilobolo*, or married (Table 5.1). Three clients were married, and four reported that *isilobolo* had been paid to their family and they were in the process of getting married. The majority (13) has a single partner where *isilobolo* had not been paid.

As is common in this area, twenty women reported not living with partners, but living in a homestead with parents, grandparents, sisters or aunties, and usually with their own children. One married woman with five children was also living with her family rather than her partner. Male partners were often working in cities such as Johannesburg or Durban, and where partners had migrated for work, women would see their partners during weekend, monthly or less frequently.

All women had at least one child at the time of the interview, and about half had given birth while living with HIV. Women had between 1 to 6 children with a median parity of 2, which is in line with the national and local total fertility rate of 2.2. Of the twenty multiparous women, nine reported having had children by more than one partner.

Only one woman was in employment at the time of study, which reflects an area where approximately 75% of individuals are unemployed. This woman was 48 years old, had no current partner, and had sought employment to support her children and grandchildren. Other women in the study received support from child grants, and relied on a mixture of economic support from family members, fathers of their children or current partners. Table 5.1 presents the demographic characteristics of women participating in this study.

Table 5.1 Characteristics of female clients interviewed

Characteristic	Frequency (n)
Ethnicity	
<i>Zulu</i>	23
Clinic	
<i>A</i>	6
<i>B</i>	3
<i>C</i>	6
<i>D</i>	4
<i>E</i>	4
Age group	
<i>18-24</i>	7
<i>25-34</i>	8
<i>35-49</i>	8
Relationship Status	
<i>No partner</i>	2
<i>Partner (No isilobolo paid)</i>	13
<i>Partner (isilobolo paid)</i>	4
<i>Multiple partners</i>	1
<i>Married</i>	3
Duration on ART (years)	
<i>1</i>	8
<i>2</i>	9
<i>3</i>	0
<i>4</i>	4
<i>5</i>	2
Experienced a pregnancy whilst in the programme	
<i>Yes</i>	11
<i>No</i>	12
Parity	
<i>1</i>	3
<i>2</i>	10
<i>3</i>	5
<i>4</i>	1
<i>5</i>	2
<i>6</i>	2
Route of entry	
<i>ANC</i>	14
<i>HCT</i>	9
Employed	
<i>Yes</i>	1
<i>No</i>	22
Currently living with partner	
<i>Yes</i>	6
<i>No</i>	17

5.2.1 Route of entry into the HIV treatment and care programme

Women were aware that a person could be HIV infected and look or feel healthy and some said that this knowledge had encouraged them to test for HIV, although most had actually discovered their HIV status due to a pregnancy or poor health. Referral from antenatal care was the most common route of entry in the HIV treatment and care programme, with about half of women diagnosed with HIV during a prior pregnancy. Reasons that women specifically sought HIV Counselling and Testing (HCT) related to health problems such as recurrent sexually transmitted infection and shingles, or one woman, because she suspected her partner was infected with HIV. The maximum time any woman had used ART was 5 years with a median duration of 2 years.

5.2.2 Healthcare provider characteristics

I selected twelve healthcare providers to include six nurses and six HIV counsellors. The characteristics of participating health workers are described in table 5.2. The operational manager of one clinic was the only nurse trained to initiate woman on ART, and I considered her as an ART nurse for the purpose of this study according to her clinical role in the ART programme.

All health workers were aged over 25 with substantial experience within the HIV treatment and care programme at their present clinic, and in some cases, within other programme clinics. Nurses and counsellors were employed either by the Department of Health (five) or via the Africa Centre for Health and Population Studies (seven), but all were trained and functioned according to the South African Department of Health recommendations for care of people living with HIV.

Table 5.2 Characteristics of health workers interviewed

Characteristic	Frequency (n)
Ethnicity	
<i>Zulu</i>	12
Clinic	
<i>A</i>	2
<i>B</i>	4
<i>C</i>	2
<i>D</i>	2
<i>E</i>	2
Age group	
<i>25-34</i>	5
<i>35+</i>	7
Occupation	
<i>ART Nurse</i>	5
<i>Counsellor</i>	6
<i>Nurse / Operational Manager</i>	1
Employer	
<i>Africa Centre</i>	5
<i>Department of Health</i>	7

5.3 Desires for childbearing on ART

5.3.1 Women on ART expressed clear personal views on childbearing

Semi-structured interviews aimed to identify childbearing desires amongst women on ART, and explore the factors that influenced these desires, and whether desires were followed. A research assistant asked women a variation on the question 'do you wish to have a child either now or in the future?' I characterised responses into: a wish to have children now, to have a child in the future (postpone), or not to have any more children (Hofferth, 1983). These categories are described below.

5.3.2 Does not aspire to have more children at any time (seventeen women)

The majority of women did not wish to have any more children at all. These women tended to be older and have more children than women that wanted to have children in the future, but there were no other key demographic differences between desire groups. Most were in a relationship where the partner had not paid *isilobolo* to the woman's family, although some had a partner who had paid *isilobolo*, were married, or had no current partner. One woman had multiple partners. According to the stratification described in Chapter 3, seven women had given birth in the HIV treatment and care programme and ten had not. Views on not wanting more children were often strong:

No ways! My sister I don't think so. That thing is not on my mind... the first thing is that I am not married and I have 2 children at home, the second child I got from this person I said that our relationship is not clear. Even now I cannot say where we are going with our relationship. You know what I am talking about, when I get another child what will people say about that and even at home they will say there is something wrong in my mind. With the father of my child I trusted him very much. I know now that it is true if people say you better trust a stone than a person.

- *23-year-old mother of two with multiple partners. No experience of being pregnant while enrolled in the HIV programme, clinic A*

5.3.3 Would like a child in the future (five women)

The wish to postpone childbearing is common in KwaZulu-Natal (Hosegood et al., 2009), and some said that they would like to have a child at some time in the future. Women wanted to postpone childbearing to let existing children grow older, and to look after her current health.

I will see it, when he comes to pay isilobola and get married that is when I can see how much does he loves my children. After that I will get pregnant for him.

- 23 year old woman with one child and a partner that has not paid isilobolo

5.3.4 Would like a child now (one woman)

Only one woman said she would like to have another child, and felt that she would like to have this child at any time. This woman was in the youngest age group (18-24 years old), and wanted to have a son in addition to her current daughter. She felt that this was influenced by the knowledge that she would soon be married, and that her aspirations were unaltered following diagnosis with HIV and initiation on to ART.

I always wanted to have 2 children... nothing has change my mind

- 24 year old woman with one child born within the HIV treatment and care programme and a partner who has not paid isilobolo (clinic A)

5.4 Themes influencing childbearing desires amongst women on ART

5.4.1 Women on ART had largely achieved their desired family size

Interviews found that a desire for a family size of two or three children was common, and this figure had largely not changed since initiation on ART. All women currently had at least one child, and many were satisfied with the age and current number of children they had, and did not want more. Desired family size was largely influenced by familial, economic, health and cultural factors. The

majority of childbearing had occurred outside of marriage, and unstable relationships, linked to unstable financial contributions, also meant women were reluctant to have more children:

If I can say the truth I don't have parents I stay with my grandparents so for me to have children is a disaster even those two that I have are huge load to my grandparents. I am not working now so there is nothing that I do for my children I depend on my other people. At the moment you find out that when a man impregnated you he will leave you for somebody else even this partner that I have I don't know what he is going to do. That is why I don't want to have a child anymore I will have to find job and take care of my children.

- *22-year-old woman with two children and a partner who had not paid isilobolo. Does not wish to have children in the future. Clinic D*

Some women explicitly said they did not feel like they had enough money for more children, because they were unemployed, or that their living arrangements were unsuitable, because they lived with extended family members and there would not be room for another child:

My sister to have a child is something that is out of my mind; it will be better if I am working. As I have two children the first one is doing grade 12 and the second one is doing grade 7, I am not working I am getting a grant for my second child. All the things I do for my children, where will I get the money to raise that child.

- *42 year old woman with two children and a partner who has not paid isilobolo*

One nurse, who felt that reliance on the child grant created 'stress' for women in her care that could not afford more children, reiterated the potential financial stress of childbearing;

You see that person that is pregnant; you see that she is ashamed... Crisis. Most of them, they are poor, so they depend on their boyfriend. So that's why.

- *Department of Health Counsellor, clinic A*

Researchers asked women directly about the effect their diagnosis and being on ART had played on childbearing desires. Most women said that a HIV diagnosis had not been enough to change lifetime goals for childbearing, and while it was difficult news at the time, 'nothing had changed' in the time

since their HIV diagnosis. For example, a 23-year-old woman said that when she first discovered her pregnancy she had felt *'angry and confused'*, and at the time of the interview she was still *'adjusting'* to her treatment, but that she still wished to have two more children in order to achieve her lifetime desire for family size. In an era of ART, women generally said that they no longer perceived an HIV diagnosis as life threatening. Health workers reassured women that they could live 'normal' lives if they properly adhere to treatment and women felt encouraged to have long and healthy lives. One woman reflected that she felt no different to another person suffering from 'the flu'.

You see, my life, I won't lie to you, I feel better because I have flu like any other person and this HIV treatment that I am taking at the moment makes me feel good.

- *32-year-old woman with five children and a partner who had paid isilobolo. Does not want a child, clinic A*

A few women considered having another, third, child in the future after feeling encouraged by initiation of treatment, but these were the exception.

When I was pregnant and I found out that I was pregnant I told myself that I would never have children again. [It] is the last one that I will carry... but now (since starting ART) I see that if I can get 3 children, it will be fine

- *28 year old woman in a polygamous marriage with two children and no experience of childbearing in the programme (clinic C)*

5.4.2 Societal, partner and financial pressures influenced desires to limit childbearing on ART

As described in sections 1.2 and 1.3, the isiZulu tradition of *isilobolo* requires a man to pay bridal wealth to the family of the bride before marriage or sexual intercourse is permitted, and in return for this investment, women were expected to prove their fertility soon after marriage. Clients and health workers described weddings as an expense that most men could not afford and that they thought marriage was no longer a pre-requisite to the decision to have a child in this setting.

It can cost you thousands... there's no more marrying. They are now free to be together. Your family knows me, my family knows you. So what? It's like we are extended family, but it's not a family!

- *Department of Health Nurse, Clinic C*

Consequently, women described feeling pressure from partners to bear a child even if they had not paid *isilobolo*; although once this was paid pressure was increased. Women held quite specific childbearing desires, but many felt a conflict between their desires not to have a child, and traditional expectations of childbearing held by partners. This pressure was particularly pronounced when women did not have any children with their current partner, but appeared to lessen for one woman whose partner already had children.

We never talked about that because he already has children from the other woman

- *28 year old woman in a polygamous marriage with two children and no experience of childbearing in the programme (clinic C)*

Women discussed scenarios in which they hoped to delay a pregnancy, or find a partner that did not want to have more children, but they did not feel they would overcome cultural expectations of childbearing with a long-term partner. For example, a 32-year-old woman felt that it would be possible to delay childbearing, but her partner had paid *isilobolo* so cultural expectations would take precedence after she was married. For another, being married meant that she would be 'forced' to have more children.

My problem is that as [my partner] is the father of this child we have together, and he paid isilobolo, it will be selfish of me if I say I will not get other children with him. My parents-in-law will want me to have children as it is our culture to have a child after marriage, and although my partner understands that I am HIV positive, other people will not understand. But it will take time for me to have another child.

- *32-year-old woman with five children and a partner who had paid isilobola. Does not want a child, clinic A - Currently pregnant*

I will be forced if we are married, if we get married I will get a child for him because he find me with children which are not his besides that I don't have love for children. I will be happy if I can find a person who says he does not want children.

- *23 year old mother of two with multiple partners and no desire to have more children (clinic A)*

Some women that did not wish to have another child, would sometimes use qualifiers to illustrate when they would be willing to modify their decision to align with cultural expectations, for example, that a partner would need to first find employment, or prove his love for her and her children. There was a general mistrust of partners, and not all women trusted men to pay *isilobolo*. Even after *isilobolo* was paid, there was still a risk that he may leave her after a child is born, which influenced attitudes to childbearing.

I depend on other people. At the moment you find out that when a man impregnated you, he will leave you for somebody else. Even this partner that I have I don't know what he is going to do. That is why I don't want to have a child anymore I will have to find job and take care of my children.

- *22-year-old woman with two children and a partner who had not paid isilobolo. Does not wish to have children in the future. Clinic D*

Health workers agreed that there is a strong cultural importance attributed to marriage and childbearing. One nurse suggested that women living with HIV felt pressure to have a child after marriage. Women raised a concerning point that the only time they would expect to consult with nurses at the ART programme about planning to have a child would be once she was married.

I think it depends on the individual because some of them discover they are HIV positive while they still do not have a child, or you do have a child but now you are married to somebody else and you don't have a child with him. And... You just can't wait to have a child with him. Culturally... children are needed.

- *Department of Health Nurse, clinic B*

It will happen when I get married because I will have to get a child after marriage. That is when I will consult the clinic and ask 'what can I do?' as my partner wants a child

– 27 year old women with three children, a partner who has not paid isilobolo and no desire to have a child at any time (clinic E)

5.4.3 Personal experiences shaped perceptions of the risk of pregnancy to health

Interviews probed the post-conception perceptions further, as summarised in Table 5.3. Under Stanford's model for post-conception, I categorised woman's attitudes to their most recent pregnancy as 'positive', 'negative' or 'ambivalent' to understand and define attitudes to future planning in the context of a most recent pregnancy. Terms such as 'planned' or 'unplanned' were not at first volunteered by women during interviews until the interviewer, at which time all of these women described the pregnancy as unplanned, then introduced the concept. When they were asked why the pregnancy was unplanned, women generally expressed 'there is nothing to explain what happened' or that it 'just happened', usually when a partner had refused to use a condom or injectable contraceptive use was inconsistent. In this sense women reflected little planning towards having a child, but discussed factors relating to readiness and health, family and partner attitudes, religious values, and a lack of contraceptive use or method failure (Stanford et al. 2000).

We didn't plan it. It was a mistake; there was no condom that day. He just started at his work. His plan does not include a child but it happened

- *35 year old woman with five children and currently pregnant with 6th child. She has a partner who had paid isilobola. Does not wish to have a child in the future, clinic C*

Despite little planning, three women viewed a previous pregnancy positively because they had wanted another child, felt supported by a partner or because they were married and felt the decision was in God's control. Two women did not report strong positive or negative reactions to their most recent pregnancy (Table 5.3). The majority of these women (eight) described negative feelings towards their most recent pregnancy due to a mixture of health reasons, because the pregnancy was unwanted, or her partner had abandoned them after birth.

Many experienced poor health during a previous pregnancy, saying they were unable to adapt well or felt dizzy or weak. Having received a HIV diagnosis during a prior pregnancy was particularly traumatic for these women and further compounded the seriousness of these perceptions of ill health. In more extreme cases some women felt that they had 'nearly died' during their most recent

pregnancy because of their HIV status. Typically these women with adverse experiences were more resolved in their desire to stop childbearing, and half of the women in these interviews discussed their most recent pregnancy as an important contributing factor that discouraged desires for more children.

I was sick when I was pregnant with this child and she also got sick. I was up and down when I was pregnant and even after birth of her. When I was pregnant I didn't have much time to enjoy it. It's not that I don't want children because I am HIV positive, what I am afraid of is that I can die if I can have another child. To be on HIV treatment that does not give me a problem at all. The reason is that when I have a child it happens that I am the one who is sick or else the child.

- 34-year-old women with five children. Married. Clinic A

Some women who had bad past experiences with pregnancy, and did not wish to have another child, said that they could not rule out having another child completely.

I nearly died; I nearly died when I found out that I was HIV positive. I was pregnant by that time with child that passed away. I was weak and I was sick so I don't think to have a child. I cannot say I will not have a child, I will, but I nearly died. No-one was taking care of me, not even my sisters; I saw that when you are HIV positive you are a problem to people, even your relatives. I was ill so what if something like that happens again? When I found out I was HIV positive it changed me a lot. I know that my child may not get the HIV virus but I am afraid.

- 42-year-old woman with two children and a partner who has not paid isilobolo. Has been pregnant while enrolled in the HIV programme and does not want a child, clinic A

Table 5.3: Post-conception attitudes to planning of previous pregnancies (adapted from Stanford et al. 2000)

Post-conception attitudes to pregnancy	Interview question(s) relating to previous childbearing	Dimensions of pregnancy intentions applied to most recent pregnancy	Description of pregnancy intention dimension	Quotes related to planning for most recent child	Category of prospective childbearing desire	Self-described current contraceptive use
WOMEN WITHOUT EXPERIENCE OF GIVING BIRTH WHILE ENROLLED IN THE HIV TREATMENT AND CARE PROGRAMME						
36-year-old woman, with three children. Has a partner who has not paid <i>isilobolo</i>. Clinic C						
Negative	When did you find out about your HIV status?	Readiness related to own health	HIV diagnosis and discovery of pregnancy at same time accentuated feeling of surprise and concerns for health	<i>I started HIV treatment in July 2008. You know what I also found out that I am pregnant ay! Everything was on me and I thought I was going to die.</i>	Does not want to have more children	None
		Stigma from family	Concerns for stigma from family against further childbearing	<i>I don't want something that will make [people] talk [about me] because with these children their grandparents will talk.</i>		
		No support from partner	Perceived lack of support from partner	<i>I do not want to have children those I have are enough.</i> <i>The main reason [related to pregnancy intention] is that I was alone raising the children that I have there is no one who was helping me so I don't want anything that will make me suffer.</i>		
36-year-old woman with two children. Has a partner who has not paid <i>isilobolo</i>. Clinic D						
Negative	Have you been pregnant since you started your HIV treatment? When did you find out that you are pregnant? Did you plan for this pregnancy?	Readiness related to own health	Felt that the pregnancy was not planned according to clinic advice to time a pregnancy according to appropriate CD4 counts.	<i>I don't remember very well but what happened is that they said my womb is not good to carry a child. They said I would have to choose whether I keep the child or I die and I said its fine they can take out the child because my life is important. By that time I was 3 months pregnant and my BP was high. I was swollen the entire body. I was 2 months pregnant and I was swollen then I came to the clinic and they confirmed that I am really pregnant. They also told me that I must go to the hospital because my BP was high.</i> <i>I didn't plan for it.</i> <i>I was shocked because they told us here at the clinic that before we get pregnant we must talk to them first so that they will find out whether the CD4 count is good or if we need to change treatment they can do that.</i>	Does not want to have more children	None
23-year-old woman with two children. Has a partner who has not paid <i>isilobolo</i>. Clinic C						
Negative	When you didn't know about your HIV status how many children you were planning to have?	No planning or contraceptive used	Contraception was discontinued without express purpose of getting pregnant. Method discontinued due to side effects of DMPA	<i>I was planning to have 3 children.</i> <i>I didn't plan for it; it just happened but I was not using any contraceptive.</i> <i>When I gave birth to my first child at hospital they gave me injectable and I was using it since then. One of the months I miss an appointment date. I was afraid to</i>	Does not wish to have a child in the future	None. Hopes to use condom.

	Did you plan for this pregnant?			<i>go the clinic because [I thought] they will shout at me. After that I lasted for about 6 months [until] I got pregnant.</i>		
		Readiness related to own health	Retrospective observed that pregnancy negatively impacted on her own health. Influencing future attitudes to childbearing	<i>The worst thing that happened; after I delivered my child I was very sick and I thought I would die. It is bad when you are sick while you have a child. They [family] have to take care for both of you.</i> <i>The serious issue is that I was sick. While I was pregnant and after delivery of my child I was sick and now I am afraid that something the same might happen. I don't want to take risks because in all what I am doing I must think of my children.</i>		
32 year old woman with five children and currently pregnant with her sixth child. Has a partner who has paid isilobolo. Clinic A						
Positive	When did you find out about your HIV status? Did you plan for your pregnancy?	Religious values	Christian belief places the locus of control of pregnancy planning externally to herself	<i>I used to say I would have children as long God is able to give [them to] me because there are so many people who want children and don't have.</i>	Does not want a child in the future	Injectable only
		No planning related to contraceptive use	Ambivalence suggests pregnancies were not actively avoided.	<i>No, there is nothing that I used. Before we were using condoms, but not all the time because the child came. If we were using it all the time no child will come.</i> <i>To be honest I never used contraceptive before maybe that is why I have so many children.</i>		
		Readiness related to health of child	Pregnancy was accepted quickly following ambivalence to planning	<i>It was not something that I planned but it happened and when I find out about my pregnancy I had no problem with that. What I was praying for is that my child to be alright and be alive</i>		
39-year-old woman with four children. Married. Clinic C						
Positive	When you find out that you are pregnant what happened? Did you plan for your pregnancy?	Adapted positively. Value of marriage	Values the importance of childbearing within a marriage mean that the pregnancy was wanted.	<i>I was happy because as I was married I never had a child it was a blessing for me.</i> <i>It was not something that I planned but I knew that it would happen at any time as I was married.</i>	Does not wish to have a child in the future.	None. Clinic has suggested sterilisation
30-year-old woman with two children. Has a partner who has paid isilobolo. Clinic B						
Positive	If you can tell me what changes your mind about having children?	Partner wish for child	Personal life-time goals for children and cultural values towards having children after isilobolo is paid	<i>I wanted to have 2 children [and] I have 2 children but one of them is for me only is not for my partner</i>	Would like to have a child in the future	Condom
WOMEN THAT HAVE BEEN PREGNANT WHILE ENROLLED IN THE HIV TREATMENT AND CARE PROGRAMME						
34-year-old women with five children. Married. Clinic A						
Negative	Do you wish to have children now or in future?	Readiness related to health	Concerns about mother-to-child transmission and her own personal feeling	<i>Never, I don't want to have children now even this one I am having it was a mistake.</i>	Does not wish to have more children	Condoms and injectable. Wants

		of sickness		<p><i>You know what I was thinking of abortion when I find out that I am pregnant. It was hard to accept it because I didn't know whether my child would be HIV negative or not. I was worried when I became sick and my child was also sick. When her result came back saying that she is HIV negative I was very happy and I thank God for that. I am happy because I see that it was just sickness not that he was positive.</i></p> <p><i>I was sick when I was pregnant this child and she also got sick. I was up and down when I was pregnant and even after birth of her. When I was pregnant I didn't have much time to enjoy and it is not that I don't want children because I am HIV positive what I am afraid of is that I can die if I can have another child.</i></p>		sterilisation.
		Partner readiness for a child	Partner did not want a child and was felt to be unsupportive	<p><i>We don't know what happened. He used to ask me why I fell pregnant because he mentioned that we mustn't get children now.</i></p> <p><i>My family said nothing because this is my 5th child. It was hard for [my partner] to accept but now it's better because the child is born.</i></p>		
		No planning and no contraceptive used	Contraception was not used but without intention of getting pregnant	<i>He used to call me a foolish woman who allowed [herself to] fall pregnant while she knew very well that she is HIV positive. He said all these things while he is the one who refused to use a condom.</i>		
28 year old woman with one child and currently pregnant with second child. Polygamous marriage. Clinic B						
Negative	How many children do you have? As you are pregnant have you planned it? What makes you feel to find out that you are pregnant?	No planning and no contraceptive used	Imperfect use of condoms without express purpose of getting pregnant	<i>This is the second child that I am carrying. (Referring to current pregnancy.) It just happened I didn't plan it. There is nothing to explain what really happened because I don't know what happened. Most of the time we used condoms, I don't know what happened to make me to be pregnant.</i>	Would like to have a child in the future	Imperfect use of condom
		Readiness related to health	Ambivalence: Pregnancy felt to be mistimed according to her current child and her HIV-related health but the pregnancy was accepted retrospectively	<p><i>I said to him I think it will be better if we can use a condom because I don't want to fall pregnant at the moment I don't want a child. I knew that I am protecting him, as our status is not the same. At first he didn't understand but at the end he agreed. Other times he didn't use it.</i></p> <p><i>I hate that that I am pregnant because my plans were not involving a child I was telling myself that the one that I have is still young. But I accepted it. I was upset. But it passes. The reason for that is my CD4 count rises slowly.</i></p>		
37 year old woman with five children and currently pregnant with sixth. No partner. Clinic C.						
Ambivalent	Do you want to have another child as you are on HIV treatment? Have you planned this pregnancy?	No planning and no contraceptive used	Contraception was discontinued due to side effects and not with intention of getting pregnant	<p><i>The reason is that I fall pregnant fast after I stopped using injectable. I was taking a break things got bad. Let me explain it for you. I was using injectable for almost 9 years, then I stopped I told myself that let me take a break.</i></p> <p><i>I never told myself that I can fall pregnant so fast because I heard people say that if you used injectable for a long time you can stay for about 6 months or a year you cannot fall pregnant without using any contraceptive. So it would happen like that to me but I didn't even last for 3 months.</i></p>	Does not wish to have a child in the future	None. Seeks sterilisation after giving birth

		Partner readiness for a child	Belief in that partner's use of traditional medicine can be used to impregnate a woman	<i>We [my partner and I] never talk about that, the only thing that I used to say to him is that I don't a child now. You know I don't know what he did because men are clever sometimes they used traditional medicines so that I can get pregnant. I have a feeling that he did something that I can get pregnant.</i>		
35 year old woman with five children and currently pregnant with sixth child. Has a partner who had paid isilobolo. Clinic C						
Negative	When did you tell your partner about your pregnancy?	Readiness related to health	Imperfect use of condoms and misunderstanding that Disprin acts as a contraceptive. Feeling that the pregnancy was not wanted	<i>I was not ready to have this child because that one that I have she [was born via] caesarean. I was thinking that my child would have a problem. They told us during initiation [on ART] that it is important to use a condom. It is not easy to use condom some times because your partner agrees for the first time but when time goes on he changed. Even now my partner does not know his HIV status although I asked him.</i>	Does not wish to have a child in the future	Disprin
		Religious values	Interested to seek abortion but felt dissuaded according to values against abortion	<i>I even thought of doing abortion and I knew that if I told him earlier he would be against it. I bought a newspaper because I wanted to see advert that used to be there for an abortion. I told my sister and she said to me it is not a good thing to do an abortion because a child is a gift from God. I was one month pregnant. My sister stopped me to do it otherwise I was willing to do it. The way she used to say about abortion I was afraid.</i>		
		Stigma to seeking abortion advice	Felt pregnancy was unwanted but feared stigma at clinics prevented action to terminate pregnancy.	<i>There are no other places and I was afraid to ask at the clinic about it because I thought they would say why I want to do an abortion, as I am old. I went to the main clinic for the pregnancy test and they said I must come where I collected my HIV treatment and let them know that I am pregnant. I was afraid.</i>		
23-year-old woman with two children. Has a partner who has not paid isilobolo. Clinic C						
Negative	How do you find out that you are HIV positive? How did you feel when you find out that you are pregnant while you are on HIV treatment?	Readiness related to health	Mistimed in relation to current children. Feeling not ready to cope with a pregnancy at the same time as HIV treatment initiation	<i>It came as a shock to me. I was not ready for it because I wanted to raise my child in a good way. To have a child quickly made my child not to get the love that I wanted him to have. I was angry because I was not ready to have a child and I was adjusting the child and myself to HIV treatment. To find out that I am pregnant I confused me a lot.</i>	Would like to have a child in the future	3 month injection
		Stigma from family	Fear of stigma from family	<i>It came as a shock to him; he even asked himself what happened. [My family] never said anything but there was that shame that I'm pregnant again while the child is still young. The reason I thought it made them to keep quiet I think they were afraid that it might happen that I will do an abortion. I was worried as they were quiet not saying anything. I decided to run away, I went to my uncle's house. My mother phoned telling my uncle that as I ran away it's because I am pregnant at the same time they are quiet about my pregnancy. I</i>		

				<i>was worried because it was not normal that when a child is pregnant at home for them to keep quiet.</i>		
		No planning and contraceptive failure	Imperfect use of condom and no use of other contraception, without express intention to get pregnant	<i>What shocked us is that we were using a condom as I said earlier. Here at the clinic told us that we have to use a condom all the time we didn't know what happened.</i> <i>I was not using anything besides condom. I never thought of using it because I was using a condom and here at the clinic they always tell us to use a condom all the time when we are having sex. They say it prevents HIV virus for spreading and also prevent pregnancy.</i>		
		Adapted positively to news	Wider definition of adaptation to pregnancy also included acceptance of HIV diagnosis and impact on health	<i>There was no change because I told myself that as I am diagnosed with this disease there is no turning back I need to focus on it on how to keep myself healthy.</i>		
22-year-old woman with two children. Has a partner who has not paid isilobolo. Clinic D						
Negative	How do you feel as you are saying that you don't want to have children? If I may ask at first when you didn't know that you are HIV positive how many children were you wish to have? How do you feel when you find out that you are pregnant while you are on HIV treatment?	Readiness related to health of child	Adherence to ART affected perceptions towards planning	<i>I was hurt because I defaulted on HIV treatment and I thought that what if my child came out HIV positive.</i>	Does not wish to have a child in the future	None. Never used contraception
		No planning and contraceptive failure	Discontinuation of injectable without express intent to get pregnant	<i>I used [injectable] but it didn't work for me.</i> <i>I failed to wait for the time they said at the clinic I must wait after I get injectable. They told me to wait for 7 days before I have sex but it was in the morning and we had no condom in the room so we did unprotected sex. It was after 3 days I got injectable.</i> <i>It was not my first time [to miss an appointment]. I did it before and I missed my date. I waited for a month without getting it so I decided to do it, then they told me to wait for 7 days [before having sex] and I didn't.</i> <i>We didn't plan it. It was a mistake there were no condom that day. He just started at work his plan does not include a child but it happened.</i>		
		No planning or contraceptive used	Values towards contraceptive use	<i>My wish when I was growing up I wanted to have 1 child my entire life but things didn't go my way and I am not blaming anyone but me. I should have used contraceptives from the beginning.</i>		
		Religious values towards abortion	Considered abortion but felt it was against Christian values	<i>We talked about that with my partner but I was afraid to do it thinking that how will I forgive myself if did something like that taking life of an innocent child. He gave me money to go and do an abortion but I failed to do it.</i>		
37-year-old woman with three children. Has a partner who has not paid isilobolo. Clinic E						
Ambivalent	How did you feel when you find out that you pregnant? Have you planned	Readiness related to current children	Pregnancy felt to be mistimed according to readiness of current children but another child	<i>I did not plan for it because my child was still young not even 4 years. I told myself that I will get pregnant after my child has 5 years like the other one, it happened when my child was 4 years</i>	Does not wish to have a child in the future	Injectable only

<p>this pregnancy? As you have said that you did not plan the pregnancy, did you think of having abortion? Before you became pregnant did you ever used any contraceptive?</p>	<p>No planning or contraception used</p>	<p>was wanted Belief that she could not get pregnant on ART</p>	<p><i>I asked myself how I became pregnant because people say if you are on HIV treatment you do not get pregnant. I asked myself how I became pregnant. I came to the clinic to check and they told me I am pregnant. I asked them how I become pregnant because I am on HIV treatment. They said who told me that a person doesn't become pregnant when she is on HIV treatment.</i></p> <p><i>I heard people saying you don't become pregnant easily when you are on HIV treatment.</i></p> <p><i>No I never planned for it to happen.</i></p> <p><i>I used nothing. Because I was taking HIV treatment, I saw that if I used injectable while I am on it I would get sick.</i></p>
	<p>Adapted positively according to religious values</p>	<p>Abortion would be against Christian values</p>	<p><i>No I hate abortion, I told myself that children are blessing from God. I conceive because God wanted to give me. Children are blessing from God.</i></p>

5.4.4 HIV positive women wished to preserve their general health on ART

Decisions about family size had largely already been made both before diagnosis and the initiation of ART, and only a few women said they had reduced the number of children that they would like to have since their diagnosis with HIV. As described above a bad HIV related health experience in a previous pregnancy strengthened women's resolve to not have more children:

I was planning to have 3 children. The serious issue is that I was sick while I was pregnant and after delivery of my child I was sick and now I am afraid that something the same might happen. I don't want to take risks because in all what I am doing I must think of my children.

- *23-year-old woman with two children, a partner who has not paid isilobolo and no experience of childbearing in the HIV treatment and care programme, clinic C.*

Health risks did not necessarily bring a decisive end to childbearing desires for women that wished to remain flexible to their circumstances. Although it seemed to be rare, in the event that a partner might pay *isilobola*, the risks to personal health were considered secondary to partner and family expectations of the woman to 'give' a child. Discussions about health focused on adverse effects that ranged from the toll that another pregnancy would take on their bodies if they were already unwell, to the loss of current good health if they were to go through another pregnancy, through to concerns that another pregnancy could be life threatening:

Eish, I don't want to have children now they are enough those I have. Yah, you see when you are HIV positive, you find out that a person is pregnant and that person doesn't take HIV treatment the child end up being HIV positive. You see to give birth it makes a person to look old. The children that I have are enough for me because is a boy and a girl.

- *23 year old mother of two, with a partner who has not paid isilobolo*

In addition to the risk that another pregnancy could cause to themselves, health risks were often described in the context of the 'stress' of managing their current children, partners and economic factors. For example, a woman's financial situation was felt to be a source of added 'stress' to her health, experiences of being abandoned by a previous partner, and the subsequent lack of both economic and emotional support, linked to poor health:

I am not working at the moment at the same time my health life is not good. My parents died 2 years back. I stay with my children including this man that came back to my life. My 11 year old is on HIV treatment and we survive with the grant money. It is hard for me to go and look for work because there is no one who will take care of my child...

Seriously I am not good but I am trying not to think about this because it might affect my health and also of my unborn child. If a person does this while he is working its painful. Immediately [after] I told him that I am pregnant he ran away. The pregnancy also caused my sickness... I am staying at the rented room. There is no one else who can help me; I have to take care of my child. I had a quarrel with my brothers because I am having lots of children.

- *36-year-old woman with three children and a partner who has not paid isilobolo. Has experience of being pregnant in the HIV programme and does not want to have more children, clinic C*

In fact family members would often encourage women to preserve their health and stop having children after diagnosis with HIV, despite access to ART.

My family don't say anything besides that they I must stop having children at the moment because I am HIV positive because that will put my life in danger. My mom used to say she sees other people who are HIV positive getting sick so she doesn't want me to be like that. I will need to take care of my health.

- *23-year-old woman with two children and a partner (isilobolo not paid)*

Marriage was rare, and married women did not discuss the risk of being 'abandoned'. Married women had less agency to limit childbearing, and the issue of health raised concerns when pregnancies were expected. For example, a 28 year old woman in a polygamous marriage and pregnant at the time of interview said that she did not plan or want her current pregnancy because she had felt unwell during a prior pregnancy, but that she had accepted it and still intended to have more siblings for her two current children.

Despite strong desires to avoid further childbearing, many women did still not use contraception at the time of these interviews, and women often felt 'not ready' for a pregnancy due to a lack of planning according to their HIV-related health. For those who did use contraceptives, the injectable method of contraception was most popular as it could be used either with or without partner knowledge and lasted a long time, whereas condoms required negotiating with partners, and only one woman reported dual use of condoms and injectables with her current partner.

The reason is that I don't want to get a child from him, I am not denying that I will have a child because is a gift from God. This man has a wife. He can leave me any time when I fall pregnant so my solution is to avoid being pregnant for him by using an injectable, as I believe that it will prevent me from having a child.

- 42 year old woman with two children and does not want another child

Although an impact on health was mentioned as an outcome of pregnancy, other HIV specific health issues such as risk of HIV transmission during unsafe sex, or concerns that the virus could be passed on to future children were not salient in the course of these interviews (Box 5.3.1). Women discussed being aware that ART can reduce the risk of a child being born HIV positive through Prevention of Mother to child Transmission (PMTCT), that their 'baby will be fine'. Being pregnant was seen as an incentive to adhere to ART by one woman, who wished to protect the health of her child. Few women viewed the risk of mother to child transmission as a deterrent to childbearing.

There was no problem. I told myself that I will be alright and my child will be alive, my child will not have a problem as HIV treatment prevents my child from getting HIV.

- 37 year old woman with 3 children, a partner who had not paid isilobolo and no desire to have any more children, clinic E

It was hard to accept it because I didn't know whether my child would be HIV negative or not. I was worried when I became sick and my child was also sick... to be on HIV treatment does not give me a problem at all. The reason is that when I have a child, it happens that I am the one who is sick, or else the child. I am the one who can lose my life, or my child. If I die what will happen to my other children?

- *34 year old married women with five children with no experience of childbearing in the HIV treatment and care programme and no desire for another child, clinic A*

Box 5.3.I THE INFLUENCE OF HIV-RELATED HEALTH UPON ATTITUDES TO CHILDBEARING

Risk of unsafe sex

They are enough, those I have. Three is enough. I have HIV now; I don't want to have children with the fact that if you have children it means you are doing unsafe sex.

- *27 year old women with a partner who has not paid isilobolo, clinic E*
-

Risk of mother to child transmission

It [being HIV positive] changes a lot. I told myself that I will not get another child because they tell us that we must protect ourselves by using a condom but when the time goes on I find out that you can have children even if you HIV positive. After I started HIV treatment everything was clear that I am like any other people and I will take my HIV treatment accordingly [but] I am afraid that my child will be infected.

- *23 year old woman with one child and would like a child in the future. Clinic E*
-

Feeling sick while using ART

I am on HIV treatment I don't know what will happen to my body if it happens that I get pregnant maybe my body will be weak. Maybe my child will not be right. As we are taking HIV treatment me and my partner it will be a big problem, as I was pregnant and I find out that I am HIV positive I started my HIV treatment and luckily my child is HIV negative. I will get sick because as I am on HIV treatment I have illness.

- *32-year-old mother of three children with a partner who has not paid isilobolo. Does not want a child, clinic E*
-

Impact of pregnancy on HIV

They used to say when you keep on bearing children while you are HIV positive the virus multiplies itself. I was worried because I didn't know whether I would die or not.

- *35 year old woman with five children and currently pregnant with 6th child*
-

Negative experiences of being pregnant while HIV positive

When I have another child I will have a problem with my life because when I was pregnant with this child I was so sick and I came across so many problems.... The serious issue is that I was sick while I was pregnant and after I delivered my child I was sick. Now I am afraid that something the same might happen. I don't want to take risks because in all what I am doing I must think of my children.

- *23-year-old woman with two children and a partner who has not paid isilobolo.*
-

Ability to care for children

As I have two children the first one is doing grade 12 and the second one is doing grade 7, I am not working I am getting a grant for my second child. All the things I do for my children, where will I get the money to raise that child.

- *42 year old woman with two children and does not want another child*
-

5.5 Chapter Summary

Women did not typically wish to have another child either now or at any time in the future, because they felt satisfied with their family size and another child presented economic, health and relationship instability risks. A mix of changing economical, societal, partnership and health factors that were inclusive, but not limited to use of antiretroviral therapy shaped childbearing and spacing aspirations. Desired family size had only changed for a few women since they entered the HIV treatment and care programme, or delayed for a small group of women saying they might still like to have children in the future.

Cultural pressures to have a child persisted for women on ART. Theoretical literature, that situates desire for a child along a pathway to intention and behaviour (Stanford et al., 2000, Miller, 1994, Trussell et al., 1999), may be limited in the Hlabisa setting due to an assumption that women make an active decision leading to a pregnancy. First and foremost, women considered partnership dynamics and financial stability as key influences of future childbearing intentions, and pressures to have a child persisted for women on ART particularly when women did not already have children with their current partner. Considering whether they expected to achieve their desires in the future and reflecting on their previous pregnancy several women discussed the cultural practice of *isilobolo* and partner preferences as the 'need' to have a child.

Women balanced the 'need' for a child with economic and HIV related factors. HIV accentuated the perceived risk of another pregnancy and deterred some women from having more children in preference to protect their own health. Health was considered in broad terms including the stress of social issues and more proximate factors including risk of HIV transmission. For these women, a HIV positive status added more than uncertainty to childbearing and strengthened a resolve to avoid childbearing. Many described postponement of childbearing without a specified endpoint and reported using injectable contraception as a way to effectively avoid another pregnancy without the need to discuss their desires with a current partner. Yet most recent pregnancies amongst these women had been unplanned and had occurred due to inconsistent contraceptive use, suggesting that desires and intentions on ART were not always congruent with behaviour.

These interviews highlight a concern that HIV treatment and care services are not being utilised by women for family planning discussions in order to avoid unwanted pregnancies or for referral for termination of pregnancies. Women described a lack of engagement with health services before their most recent unplanned pregnancy, suggesting that a traditional concept of family planning 'for a planned pregnancy' does not apply in this context.

Chapter Six

Factors Associated with Contraceptive Preferences amongst Women on ART

6.1 Introduction to chapter six

Chapter five determined that social and cultural norms powerfully influenced the childbearing decisions of women on ART, and that most women wished to postpone or limit their childbearing. A subset of women strongly aspired to limit childbearing altogether through contraceptive use or remaining without a partner. Women indicated very little or no planning towards their previous pregnancies: all of the thirteen most recent pregnancies to women after their HIV diagnosis were considered unplanned. Of women that wished to have a child in the future, women preferred to postpone the decision to a time when a partner might find employment or existing children had grown older. Some felt that they would have a child if they married, even if that was against their own desires for childbearing. At present however, women would often use contraception to postpone childbearing without a specific end point in mind. Yet inconsistent use and discontinuation of methods had resulted in many unplanned pregnancies amongst these women after HIV diagnosis.

Chapter 6 builds on findings from chapter five with an investigation on attitudes to contraceptive use, and planning for safer conception on ART. This chapter begins with an overview of current contraceptive practices amongst women interviewed while 'on ART', and then presents themes influencing contraceptive preferences and use while enrolled in the HIV treatment and care programme in section 6.3. This is followed by a broader discussion of facilitators and barriers to family planning in the Hlabisa HIV treatment and care programme in section 6.4. Section 6.5 concludes with a summary of factors influencing how women make their contraceptive decisions in the Hlabisa HIV treatment and care programme.

6.2 Current contraceptive use amongst women on ART

Interviews determined a universal awareness of a range of contraceptive methods amongst women on ART, and also a pervasive fatigue towards consistent use of any form. About half of women were using contraception and preferred to use injectable methods, and less frequently, condoms.

Commonly women preferred to use the injectable Depot Medroxyprogesterone Acetate (DMPA); a

long acting reversible progestin-only contraceptive injection administered every 3 months or Nuristerate, a progesterone only injectable administered every two months. These methods offered a long lasting protection but required quarterly visits to either the primary health clinic or the HIV treatment and care facility, depending on a woman's preference, and also presented a range of possible side effects that deterred some from jeopardising their newly improved or current health. Consequently discontinuation of injectable methods was also common, and women discussed periods of injectable use separated with times they were 'taking a break'.

Condoms were used inconsistently and only when women wanted to use them, partners would consent and the method was available. Many were aware of the benefits of barrier contraceptive methods for safer sex, but reflected that they could not rely on them as a form of pregnancy prevention because of inconsistent use. Other methods were not widely discussed by participants until raised by the interviewer. The oral pill and the emergency contraceptive pill were not well known or liked, and three women had never used contraception because they were 'lazy towards contraception' or abstaining after a recent pregnancy.

6.3 Themes influencing attitudes to contraceptive use in women on ART

Ease and reliability of use were the major themes influencing method preference, while side effects and knowledge of other methods modified a woman's ability to use contraception consistently. General perceptions of health on ART were a continuous theme throughout the course of these interviews and influenced women's perceptions of contraceptive need in balance with a dislike of adverse side effects.

6.3.1 Condoms were used inconsistently to protect health and avoid hormonal side effects

Condoms were viewed favourably by women, who repeated health advice that they had received at the clinic that barrier methods would protect the woman's own health and in some cases, the health of a partner by preventing the transmission of viruses. Women were very aware of the risks of HIV transmission to a partner or acquisition of other STI's, and spoke generally about their wish to '*prevent diseases*' or '*protecting each other from diseases*' as their primary incentive to use condoms. Some further expressed feeling that condoms were the only appropriate method for women living with HIV and that it is '*not right*' to use any other methods as an alternative.

In addition to this awareness, most women still found it difficult to convince partners to consistently adhere to use, and in more pragmatic light women did not consider condoms as a reliable method to prevent a pregnancy. Trust in condom efficacy was a prominent barrier for women even in the event that they were used, as some felt that condoms would burst or *'you cannot trust condoms'*, government condoms were viewed to be more likely to burst. More than half of the women said that they were either currently using condoms or had been using them at the time of their most recent pregnancy.

Healthcare providers encouraged condom use and some women that were motivated to avoid a pregnancy said they were using dual protection based upon clinic advice. Other women viewed this information as right but at times impractical in the context of difficult partner negotiations. Most reflected on a partner's inconsistency to adherence because they disliked the method or thought it led to cramping. One woman even said that her partner threatened to sleep with other women that would be willing to do so without a condom, and so she *'ends up sleeping with him without a condom'*.

At the clinic they tell us to use condoms. Yes, they are right [but] when we have to do it becomes very hard. Your partner sometimes refused to use it, like my husband. So I decided to use an injectable at the moment because I know that when he refused to use a condom but I am safe.

- *34 year old married women with five children with no experience of childbearing in the HIV treatment and care programme and no desire for another child, clinic A*

Initiation of ART had a small encouraging effect on couple's willingness to use condoms as some said that partners were more open to using this method since they were on treatment, either because the partner was sero-discordant or did not know his own HIV status.

We are protecting each other from diseases but I am using injectable because I don't want to get pregnant you will never trust a condom because it happens we don't use it always.

- *32-year-old mother of three children with a partner who has not paid isilobolo. Does not want a child, clinic E*

Not all women felt that dual contraception was necessary however. Some women said they had switched completely from injectable use to condoms because they had did not like the adverse side

effects they had experienced while using injectables, but felt it was important to use a method of contraception. Injectable discontinuation was common and although some substituted injectables for condom use during these periods, most said they did not.

While male partners were often portrayed as reluctant to use contraception, there were exceptions amongst women who felt empowered to lead condom use, or partners who also wished to protect their health. One woman said she *'forced'* her partner after telling him *'he is going to die as I am on HIV treatment and he is not'*. And another woman described her partner as more open to condom use since both were diagnosed with HIV, in order to avoid that their antibodies drop. In addition, not all women saw it as a bad thing that they did not always use condoms and followed the sentiment that *'it happens that we don't use it always'*.

6.3.2 ART did little to change preferences for the long-lasting and covert nature of DMPA

Women emphasised that 'nothing had changed' in respect to contraceptive preferences since they were enrolled in the HIV treatment and care programme and continued using injectable methods of contraception after initiating ART. A subset of women emphasised strong aspirations to avert further childbearing through use of DMPA as they felt this would be the most efficacious method to ensure that they did not fall pregnant in the future and also meant that women did not regularly need to return to the clinic as in the case for condoms or oral pills.

I chose injectable because it is something that is in my blood I will not take it daily.

Injectables can help me when the condom burst or when with my partner we decided not to use it

- *23-year-old woman with two children. Has a partner who has not paid isilobolo. Clinic C*

It is better to use it because you do not keep on coming to the clinic.

- *23 year old woman with two children, a partner (isilobolo not paid) and no experience of childbearing in the HIV treatment and care programme, clinic C*

Yet discontinuation was common and all reported taking 'breaks' between injections, which would have left times when they were unprotected. Injectable contraception remains effective for 2-3 months and women favoured the long lasting effect of DMPA because they were not required to come back to the clinic frequently or to remember to take the oral contraceptive pill every day.

None of the interviewed women were currently using the pill and very few reported an interest in this method. Women felt that both HIV treatment and the oral contraceptive pill can be occasionally missed and that it would be difficult to adhere to a method that required daily attention. Health workers supported this sentiment so rarely discussed oral pills while actively encouraging injectable forms. At the time of interviews, the Intra Uterine Contraceptive Device (IUCD) was in early stages of being rolled out across the Hlabisa sub-district. While no women had yet initiated this method, women were encouraged by information about the IUCD because it offered protection against an unwanted pregnancy for even longer time periods and did not require repeat visits to a clinic.

The ability to hide contraceptive use strongly facilitated a woman's preference and ability to adhere to injectables as a way of avoiding a pregnancy without discussing this desire with a partner. Eight women sought contraception secretly and these women tended to have more children than other participants (Box 6.3.1). Covert use allowed women to assert control over fertility when partner consent to condom use was inconsistent or sometimes refused. Some said that partners would initiate sex whilst drunk or were 'cheating' by not using a condom properly or removing during sex.

Practically, covert contraceptive use allowed women to enact desires to postpone childbearing decision-making until another time but these women often still wished to disclose their contraceptive use to partners eventually. While faced with unpredictable condom use and expectations of when a woman may 'need' to have a child, injectables provided a safer alternative to the risk of another pregnancy in the meantime.

Clinics facilitated women's covert contraceptive use by allowing clients to store their family planning cards within the facility. Health workers further noted that interest in the IUCD was growing in popularity as it allowed women to protect themselves against childbearing for a long time without need to negotiate with her partner.

Box 6.3.I PARTICIPANTS VIEWS TO COVERT CONTRACEPTIVE METHODS

Women's views on covert contraceptive use on ART

Even if we speak I told him that I am not using contraceptives I don't know what is wrong that makes me not to conceive.

- *33-year-old woman with one child and a partner who has not paid isilobolo. Does not wish to have another child, clinic A*

He is cheating when he uses a condom... one day while he was using a condom his sperm was on me. I will be in a problem one day and find myself being pregnant. That is when I decided to come to the clinic for contraception.

- *42-year-old woman with two children and a partner who has not paid isilobolo. Has been pregnant while enrolled in the HIV programme and does not want a child, clinic A*

Your partner sometimes refused to use it like my husband. So I decided to use an injectable at the moment because I know that when he refused to use a condom but I am safe.

- *34 year old married women with five children with no experience of childbearing in the HIV treatment and care programme and no desire for another child, clinic A*

Health worker views on covert contraceptive use

They don't tell their partners. Most of the women they use it but they don't disclose to their partners because they know the response they are going to get from their partners.

- *Africa Centre Counsellor, clinic E*

You can have injection and leave your card here.

- *Africa Centre Counsellor, clinic E*

[Some women] say 'I hide it'. We carry a card for family planning for one lady who's afraid to tell her husband that she's using contraceptives. So we said we can keep the card with us. She just comes to clinic, has an injection and goes home. Innocent. She mustn't tell the... I don't if he's a husband or boyfriend...we have those challenges

- *Department of Health Nurse, clinic A*
-

6.3.3 Side effects of hormonal contraception prevented consistent use on ART

Many women described patterns of discontinuation, which had often resulted in an unplanned pregnancy. Experiences of unplanned pregnancies encouraged a stronger resolve to adhere to the method currently. Various side effects were discussed in relation to use of hormonal contraception and these factors were prevalent barriers to a woman's willingness to continue using or adhere correctly to the method. Patterns of continuation and discontinuation were fluid according to when women felt tired of side effects or needed a 'break' from hormonal contraception. Practically, some had decided to 'take a break' from quarterly injections in the hope that they would remain protected for slightly longer. Few actually switched to another method but in this case would protect themselves with condoms. As fatigue to hormonal side effects was the main barrier to adherence, no women spoke about switching to oral contraception and some had tried to find emergency contraception after unprotected sex.

An emerging and prominent theme was a perception that DMPA made women 'watery' or caused them to produce excess fluids during sexual intercourse (Box 6.3.II). Health worker's also found that women reported objections from partners that were aware or speculated that a woman was using an injectable contraception.

Prior research has discussed the use of intravaginal insertions amongst women as a long standing traditional practice in this setting and use of modern products such as medications, hygiene products and commercial products in the vagina amongst women aspiring to be 'hot', 'tight' and 'dry' during sex (Gafos et al., 2010). The primary aim of using insertions is to improve sexual pleasure (although it is uncertain whether this also refers to the woman's own pleasure), by ensuring the woman is in an 'alright' state before sex. In opposition, women on ART saw being 'watery' as a negative state because it reduced the pleasure of male partners who described the effect as 'cold' or 'watery' or 'not nice'. Other research suggests that being 'wet' also refers to an unhealthy state for the vagina associated with STI-related discharge, which may further reinforce women's wishes to avoid the stigma of this label. Just one client described experiencing the effect of being watery herself, and did not comment on her own sexual pleasure, but said that it caused her to discontinue injectable contraception.

Prior research determined that partners also viewed the use of intravaginal insertions negatively due to the secrecy surrounding this practice, causing partners to be suspicious of sexual inadequacy, infidelity and promiscuity (Gafos et al., 2010). Women on ART in this study revealed a parallel between the negative dialogue surrounding use of intravaginal insertions and injectable

contraception. Although some did not believe this phenomenon to be true, those who had not experienced being watery themselves felt the risk could act as a barrier to using that method. One woman worried that being 'watery' would reveal her covert contraceptive use and said that some men seek traditional medicine to make a woman pregnant when they suspected women of using injectables. Fearing that traditional medicine would be used to make her pregnant added to the risk of hiding her own contraceptive use. Consequently, health workers and clients felt this could encourage the acceptability of the IUCD, as it is not thought to alter the desirability of women during sex.

Box 6.3.II PERCEPTIONS OF BEING "WATERY"

Women's views on being 'watery'

I was hiding from him. Men know when you are using injectable [and] he can go and use traditional medicine to make you pregnant. Sometimes he can tell you that you are watery.

- *37 year old mother of 6 with no partner and no desire to have more children, No experience of being pregnant in the HIV programme, clinic C*

I thought of using injectable but I heard people saying that when you are using injections you become watery.

- *35-year-old woman with six children and a partner who had paid isilobolo. Does not wish to have a child in the future, clinic C*

While I was at the hospital I thought of using injectable but I heard people saying that when you use injections you become watery. I can I believe it because I never used injections.

- *35 year old woman with five children and currently pregnant with 6th child. She has a partner who had paid isilobolo. Does not wish to have a child in the future, clinic C*

We do talk about it. He used to say injectables make a woman to be watery and I said to him that if I don't use injectables I would get pregnant.

- *25-year-old woman with three children and a partner who has not paid isilobolo. Does not wish to have a child in the future and has not been pregnant while enrolled in the HIV treatment and care programme. Clinic D*

Health worker views on the effect of injectables making women 'watery'

Most of the time they say if you are using injection, you have a lot of water. Mm, it's not true... The man will not notice. Unless you tell that I'm doing the family planning, then that's when the man can say you have a lot of water [otherwise] he can't complain about anything

- *Africa Centre Counsellor, clinic B*

A lot of water, to be cold, to be, not nice. You don't feel as nice. Don't give your partner happiness.

Africa Centre Nurse, clinic B

More than half of the women also discussed an aversion to excessive menstruation, amenorrhea, weight gain, looking old and generally feeling unwell. Particularly, women were concerned for the impact of these side effects on their health, and some felt that use of ART at the same time as hormonal contraception might somehow amplify these effects.

Women said they avoided contraceptive methods that would negatively affect their health and added that they were at times confused as to whether it was their hormonal contraceptive or ART that was causing them to feel sick. Irregular menstruation was the most common complaint amongst clients using hormonal contraception and in most experiences ended in discontinuation of the method. 'Heavy bleeding' was a known side effect and perceived as a sign of ill health amongst women on ART. One woman felt that amenorrhea was caused by DMPA when a 'cloth' [clot] develops inside the woman and this was perceived to be unhealthy in a culture where traditional medicine was described to be used to 'clean the dirt' from the body. Women were also confused about how being on ART affected the strength of either drug. Health workers mentioned that interactions between hormonal contraceptive methods and ART were possible and some understood this message that injectables were 'stronger' than oral pills when combined with ART.

Because I was taking HIV treatment, I saw that if I used injectable while I am on it I would get sick

- *37 year old woman with 3 children, a partner who had not paid isilobolo and no desire to have any more children, clinic E*

As I am on treatment when I am on my periods I only go 2 days and it is heavy one and I don't know whether is HIV treatment or is injectable.

- *42-year-old woman with two children and a partner who has not paid isilobolo. Has been pregnant while enrolled in the HIV programme and does not want a child, clinic A*

Many simply disliked the pain of using an injection. Other side effects influenced the way in which women felt they would no longer be attractive to partners. Weight gain and 'feeling hungry all the time' while one woman reported avoiding injectable use as her partner claimed it would cause her to 'look old'.

The immediacy with which a contraceptive method allowed a woman's return to fertility was also an important factor in a woman's decision to use this method and interviews found differing views of the efficacy of injectable methods. Primarily women believed that prolonged DMPA use could delay her return to fertility for when a child might be wanted in the future. Concerns further extended to the IUCD: health workers described beliefs that IUCD insertion could damage a woman's body.

They do want to go for family planning but... like, maybe I'm taking a contraceptive method for 5 years and [then] when I want to have a baby, I might [be] delayed to conceive. They feel that contraception can maybe delay them [from] having a baby.

- Department of Health Counsellor, clinic A

Women might experience just one or multiple side effects and where the medical implications were not widely understood; differing experiences caused women to discuss these effects in terms of generally feeling 'sick'. One health workers summarised the off-putting nature of multiple side effects

What I know is that, mm like medroxyprogesterone, it has a tendency of making your appetite too big. So you can eat and eat and eat until you are too fat. And then with nurosterate, from experience it makes you nauseous almost the whole month. Every morning, you just feel ill from it. Even in the afternoons, it's terrible. It's not nice. And then you have these periods, which are so irregular, yeah very irregular periods. Sometimes this will go for five days, the following month for 3 days, the following month for 7 days, you see and then there's spotting in-between. So yeah, they're good but then again...

- Department of Health Nurse, clinic C

Box 6.3.III PERCEIVED SIDE EFFECTS OF INJECTABLE METHODS OF CONTRACEPTION

HEAVY MENSTRUATION

I don't know really but last I was using injectable and I was bleeding and I decided to stop using it. It was hard because it was after I lost my child and find out that this injectable makes me sick I was stressed. I don't remember very well but its long time ago because I used to do injectable only to find that I am going to bleed for a long time and decided to stopped using it. I used to go to doctor when I bleed a lot I never come to the clinic.

- *36-year-old woman with three children and a partner who has not paid isilobolo. Has experience of being pregnant in the HIV programme and does not want to have more children, clinic C*

AMENORRHEA

I used to hear people say if you are using injectable not menstruating can form cloth [clot] when the time goes on and that will make you sick and I don't know whether they are right or wrong. I don't like when the blood is lock inside my body.

- *23 year old mother of one, with a partner who has not paid isilobolo and does not want a child in the future, clinic B*

LOOKING OLD

I do talk but my recent partner does not like a woman who is using injectable, he used to say it is better if we use a condom because I will look old when I am using injection

- *23-year-old mother of two with multiple partners. No experience of being pregnant while enrolled in the HIV programme and no desire to have more children, clinic A*

PAIN

I am afraid of even when I am sick I hate when a doctor use it.

- *23-year-old woman with one child and a partner that has not paid isilobolo. Would like a child in the future and has not been pregnant while enrolled in the HIV treatment and care programme. Clinic E*

WEIGHT GAIN

I felt hungry all the time

- *30 year old mother of two, with a partner who has paid isilobolo, clinic B*

RETURN TO FERTILITY

Maybe pill can be the right thing to use because when I want a chid it will easy.

- *27 year old women with three children, a partner who has not paid isilobolo and no desire to have a child at any time, clinic E*
-

6.3.4 Misconceptions about ART, contraception and pregnancy persisted despite common knowledge about contraceptive availability

Women were widely aware of injectable and oral contraception, condoms and sterilisation but had only a conceptual or no awareness of the intrauterine contraceptive device and emergency contraception. Where women would often discontinue injectable contraception, they described condom use as an unreliable back up. Consequently, women had relatively few alternatives to contraceptive use when wishing to 'take a break' from long-term hormonal injectable use.

Health workers deterred women from using the oral contraceptive pill as they considered it less effective than injectable forms of contraception. In addition, health worker's advised women to return for a DMPA injection after two months rather than three in some clinics as they said they had received guidance that ART reduces the efficacy of hormonal contraception. This advice was contrary to the client's perceptions of longer lasting protection on injectable or a perceived lack of need for contraception while on ART, although this advice was not consistent across all clinics.

We explain to them, if you're on ARVs you must use injection. Prefer injection. And we explain to them that as they are on ART when they choose the three month injection, they must come back after two months. If you choose the two month injection, you must come back after one month.

- *Counsellor, Department of health, Clinic A*

Especially we talk about [the] injectable; we recommend injection because the pills have an effect on ARVS, and so we used to encourage them to do injection for family planning.

- *Counsellor, Department of health, Clinic C*

The IUCD was recently re-introduced as a method that is safe to use by women living with HIV, unless diagnosed with AIDS. No women had initiated the IUCD at the time of this study but some were aware of a method that could be inserted in the womb. For one 48-year-old woman, her knowledge of the IUCD stemmed from when this method had been available in clinics in the past.

However, a belief that IUCD users could still get pregnant was common and purported as an analogy those women could get pregnant and deliver a child 'holding an IUCD in its hand'. Use of this phrase

was entrenched in the programme, which health worker's attributed to a fear of using a new method.

I heard people talking about loop but I don't know much about it.

- *37 year old mother of 6 with no partner and no desire to have more children, No experience of being pregnant in the HIV programme, clinic C*

DoH guidelines were supported by nurse training sessions within the Hlabisa district on how to use a WHO developed Family planning provider handbook and how to insert the IUCD. In this context, health workers felt that IUCD insertion was favourable as a one off procedure for women who would not need to return to the clinic. Health worker felt that the IUCD was well liked but could be difficult to educate women to use, and presented mixed views on how well the IUCD was understood within the programme. Women compared the values of the IUCD to the injectable, as both could be used covertly while the IUCD lasts longer and does not require repeat attendance to the clinic.

Most of them they are interested, cause every morning for health education we encourage them for IUCD

- *Department of Health Counsellor, clinic C*

It's too hard to understand, some they understand, and some they don't understand.

- *Department of Health Counsellor, clinic A*

People say it's the best. You don't go all the time to the clinic for contraceptives.

- *23 year old mother of one, with a partner who has not paid isilobolo and does not want a child in the future, clinic B*

Sterilisation was the only remaining option for a small group of women who wished to avert further childbearing yet these women did not report any immediate plans to act upon this wish. Most women had discussed their wish to seek sterilisation with their partners and of these only one said that her partner was against the idea but most felt there was still a stigma against seeking this procedure. For example, a 39 year old mother of 4 felt feared being stigmatised by her partner's

family and did not seek sterilisation secretly because she felt she would need to stay in hospital too long, which could alert family members to her procedure.

I cannot stay for such a long time at hospital because my in-laws will want to know what I am doing there at the hospital. I thought it [sterilisation] would be something for one day. They are going to talk. This thing is between me and my husband; no one else should know about it.

- 39-year-old married woman with four children. Has not been pregnant while enrolled in the HIV treatment and care programme and does not wish to have a child in the future. Clinic C

Misconceptions surrounded the use of ART at the same time as contraception and these were relayed during interviews with both health workers and clients. In particular, two women said they had believed that it was not possible to get pregnant while using HIV treatment and a 37 year old woman attributed her most recent pregnancy to a belief that she was not at risk of conceiving after hearing friends discuss that women were less likely to get pregnant while taking ART.

I asked myself how I became pregnant, because people say if you are on HIV treatment you do not get pregnant. I asked [health worker's] how I became pregnant because I am on HIV treatment? They asked who told me that a person doesn't become pregnant when she is on HIV treatment... I heard people saying you don't become pregnant easily when you are on HIV treatment.

- 37 year old woman with 3 children, a partner who had not paid isilobolo and no desire to have any more children, clinic E

Some believed that the contraceptive effect of DMPA would last longer than 3 months, and thought they were at less risk of a pregnancy than was actually true. As a result, these women did not reportedly seek another contraceptive method during periods of discontinuation from DMPA or Nur-lsterate.

I heard people say that if you used injectable for a long time you can stay for about 6 months or a year. You cannot fall pregnant without using any contraceptive. So it would happen like that to me but I didn't even last for 3 months.

- 37 year old mother of 6 with no partner and no desire to have more children, No experience of being pregnant in the HIV programme, clinic C

Health workers from one clinic also perceived an increased libido to be a side effect of ART. A nurse and counsellor both reported seeing clients with 'hyperactivity', an increased sexual appetite following ART initiation and one nurse claimed to have successfully administered the injectable contraception as a counter to this effect of ART:

That's why they falling pregnant even though they are using injection the visit is today, maybe she will come next month for injection. I think it won't work.

- Department of Health counsellor, clinic C

There is a saying that ARVs makes people more, I don't know how to say this, but they desire sex more than normal. I once saw a lady who was complaining that ever since I started ART, I am so active that I feel like ripping every man. She said I can't even find satisfaction without sex, I just feel like I can have sex and sex and sex and sex, like every hour. I just thought that if medroxyprogesterone decreases sexual desire, then it might help this woman. And she came, she was glowing, fit, and she said thank you!

– Department of Health Nurse, clinic C

Only one woman reported using traditional methods of contraception. This woman described drinking 'imbiza' after unprotected sex with the purpose to 'drain all the dirt'. This concept of removing internal 'dirt' was a theme overlapping with discussions about amenorrhea, where the absence of menstruation was perceived as the retention of dirt and was a disliked side effect of injectable contraception.

Women discussed traditional methods of contraception such as tying wool around a woman's waist under her clothes to prevent falling pregnant whilst wearing it. Women and health workers viewed traditional methods as 'old fashioned' and reported that women on ART did not typically seek them after exposure to health education in the HIV treatment and care programme.

6.3.5 Emergency contraception was rarely discussed and not well understood

In comparison to the IUCD, emergency contraception was scarcely discussed within the HIV treatment and care programme. Health workers only considered emergency contraception (EC) as suitable in emergency cases, such as incident of sexual violence, and were concerned that clients would engage in risky sexual behaviours if this method was promoted during health education sessions.

That's a serious note. I think, when you do education with emergency pills, we think that they always sleep without condom. Wow emergency pills, emergency pills. So that's why we don't emphasise the emergency pills. Yes we do the counselling, but we don't emphasise... (EC)

- Department of Health Nurse, clinic C

Women learned about this method from sisters, family, boyfriends or on the radio. Two women had experience of using this method in the past but most were either unaware of this method or, contrary to the concerns of health workers, were reluctant to rely on it as a sole form of contraception because they mistrusted its efficacy, disliked the idea of unsafe sex, or felt that it was not appropriate to use during marriage (Box 6.3.IV).

Some women described alternatives to the concept of taking a pill after unprotected sexual intercourse. Antibiotics and an aspirin (Flagyl and Disprin respectively) were both cited as forms of emergency contraception that women had used after unprotected sex with a partner. Furthermore, one woman reported a friend's belief in the use of marijuana seeds as a successful form of EC that remains in the womb.

These discussions re-iterated an overlap between traditional practices of intravaginal insertions and contraceptive use, and were not tied to women's use of ART. Women described similar use of modern medications and commercial products for the purposes of emergency contraception and as intravaginal insertions. For example, Disprin has been reportedly used and associated with the idea of 'tight sex' (Gafos et al., 2010), but in the context of these interviews about contraception, has been used for pregnancy prevention. Similar concepts of 'cleaning the dirt' were applied to stopping a pregnancy with Disprin as also discussed in avoiding the sexually undesirable effect of being 'watery' when using injectables.

Box. 6.3.IV ATTITUDES TO USE OF EMERGENCY CONTRACEPTION ON ART

I know emergency contraceptive. I think is the same as morning after pill? I used it but I got pregnant

- *22-year-old woman with two children and a partner who had not paid isilobolo. Does not wish to have children in the future, clinic D*

Long time ago I heard people talking about that thing but I never see it.

- *48-year-old woman with two children. Does not have a partner or desire to have more children, clinic D*

I will be afraid because I will be doing unsafe sex

- *27 year old women with three children, a partner who has not paid isilobolo and no desire to have a child at any time, clinic E*

Emergency contraceptive I don't like it because I will have to take pill every time I had sex with my husband"

- *34 year old married women with five children with no experience of childbearing in the HIV treatment and care programme and no desire for another child, clinic A*

But my sister fell pregnant while using it

- *23 year old mother of two, with a partner who has not paid isilobolo and does not want a child in the future, clinic B*

As I said earlier, when I was having sex with [my] partner, I would take 2 Disprin. But I think this time it didn't work for me.

- *35-year-old woman with six children and a partner who had paid isilobolo. Does not wish to have a child in the future, clinic C*

I use Flagyl pills when I have sex with my partner. I am feeling good because they are working for me... I have never been pregnant since I started using them.

- *33-year-old woman with one child and a partner who has not paid isilobolo. Does not wish to have another child, clinic A*

[My friend] said that when you swallow marijuana seeds it will go straight to the womb and you will never have children.

- *36-year-old woman with three children and a partner who has not paid isilobolo. Has experience of being pregnant in the HIV programme and does not want to have more children, clinic E*
-

6.3.6 Section summary: Factors influencing contraceptive use and preferences on ART

As is common in the Hlabisa setting, women preferred easy to use and long lasting injectable methods of contraception. The women interviewed in this study generally had experience of injectable use prior to their enrolment in the ART programme, and continued to use these methods after initiation of ART to avoid childbearing and preserve their own health. Side effects of hormonal contraception could at times counter the wish to look after health and deterred women from consistent use. Many women reported unplanned pregnancies during times when they said they were 'taking a break' from injectable methods.

Cultural understandings and practices strongly influenced the way in which women used contraception in this setting. The undesirable effect of being 'watery' during sex was an entrenched theme and significant barrier to use of injectable methods as it conflicted with the cultural onus on women to be 'dry' in order to be sexually desirable. Partner desires for childbearing facilitated a preference for covert use of injectables amongst women on ART. Some women did choose to discuss their use with partners however, and especially when condoms were often used inconsistently. However, women were concerned that the 'watery' effect of injectable use would not only make them unattractive to men, but would further reveal covert injectable use to partners, of whom, some would turn to traditional medicine in a bid to make her pregnant.

Some aspects of the cultural practice of intravaginal insertion traditionally performed to achieve 'cleanliness' and desirability were applied to contraceptive practice. Women in other studies have used modern products such as Disprin as a form of intravaginal insertion, and in this study some said they had used disprin or marijuana after sex as emergency contraception.

ART use could enhance the severity with which women perceived adverse contraceptive side effects, at a time when they may also perceived general health to be poor. This study also determined some misunderstandings that were further specific to the use of injectable contraception on ART. Some believed that use of ART meant that they did not need contraception, or needed less frequent injections, and others felt that concurrent use might adversely affect health or fertility. It highlights the need for tailored and culturally sensitive family planning advice for women living with HIV on ART, particularly in long periods of postponement when injectable methods are not always used consistently.

6.4 Structural barriers and facilitators to safer conception and contraceptive use in a rural 'One-Stop-Shop' HIV treatment and care programme

Section 6.4 describes the structural barriers to access to contraception and safer conception planning faced by women enrolled in this HIV treatment and care programme. This discussion is based on results from interviews with clients and healthcare providers and a checklist of communication materials and counselling activities in a 'one-stop-shop' model of HIV treatment and care for family planning services.

Most women currently using contraception relied solely on DMPA or Nur-Isterate and occasional condom use, and typically sought their methods during the same consultation with the ART nurse that they received treatment. This meant receiving contraception and treatment in the same room, although less frequently clients were escorted to another room, directed to see another practitioner in the mobile HIV clinic, or referred up the Primary health clinic main building (on the same facility site). These times were mostly in the event that a method was out of stock in the HIV clinic or that women wished to seek the newly rolled out IUCD, in which case they were asked to return on a specific day when a trained practitioner would be available to fit the device.

6.4.1 Facilitators to safer conception and contraceptive use

Task shifting co-ordinated ART and contraceptive delivery in a single consultation room

Operational managers in all five HIV clinics answered 'Yes' to the question: "*Are family planning services such as provision of contraception and counselling of safe conception integrated with the HIV services here?*". Health workers believed integration was achieved through a 'one-stop-shopping' system that provided both HIV treatment and care and contraceptive methods during a single client visit, and that family planning was just one of many activities they were expected to deliver during a consultation.

Each of the five clinics determined their own family planning practices, involving health worker task identification and systems of referral between the HIV treatment and care building and the main (primary health clinic) building. Each of the five clinics were similar in infrastructure and availability of resources, and integrated delivery of family planning services were comparable between observed clinics within the HIV programme. In all facilities, consultation with an ART nurse provided both treatment and contraception in the form of condoms, oral contraceptive pills or DMPA,

following separate counselling with the ART counsellor. In four facilities, HIV services were delivered in separate HIV treatment and Care park home. One facility integrated HIV services within then Primary Health Care (PHC) main building. Health workers felt that a comprehensive 'one-stop shop' service was the optimal model of care for clients to receive all services under one roof during a single consultation, with referral for additional services.

We do it together, there is a link. If you come for ART, I can give you ART and if you are having another need, like family planning, I can do it here. I can give you hypertensive treatment, I can give you diabetic, and I can take your sputum. We do everything in each and every consulting room in the clinic. Whether it's the main clinic or the park homes, it's the same. Yes, at the end of the month we collect the statistics and we make one graph of family planning, whether it's going up or going down

- Africa Centre Nurse, clinic B

A range of contraceptive methods were stored in the same consultation room that HIV treatment was administered to clients. These methods were visible to clients only when used during family planning counselling and were usually stored in cupboards behind the desk where the HIV nurse would sit, in a similar manner to boxes of HIV treatment. Methods stored in the consultation room included; DMPA, Nuristerate (a progesterone only injectable administered every two months), the oral pill, male and female condoms and the emergency contraceptive pill. Health workers reported that these methods were available every treatment visit (i.e. on each monthly visit to the clinic when women would return to pick up HIV treatment). Male condoms were also available by registration desks, in waiting areas and within both counselling and treatment rooms and so were readily accessible to all clients. Other methods of family planning and also psycho-social and financial support services were available to women upon referral, as illustrated in figure 6.1.

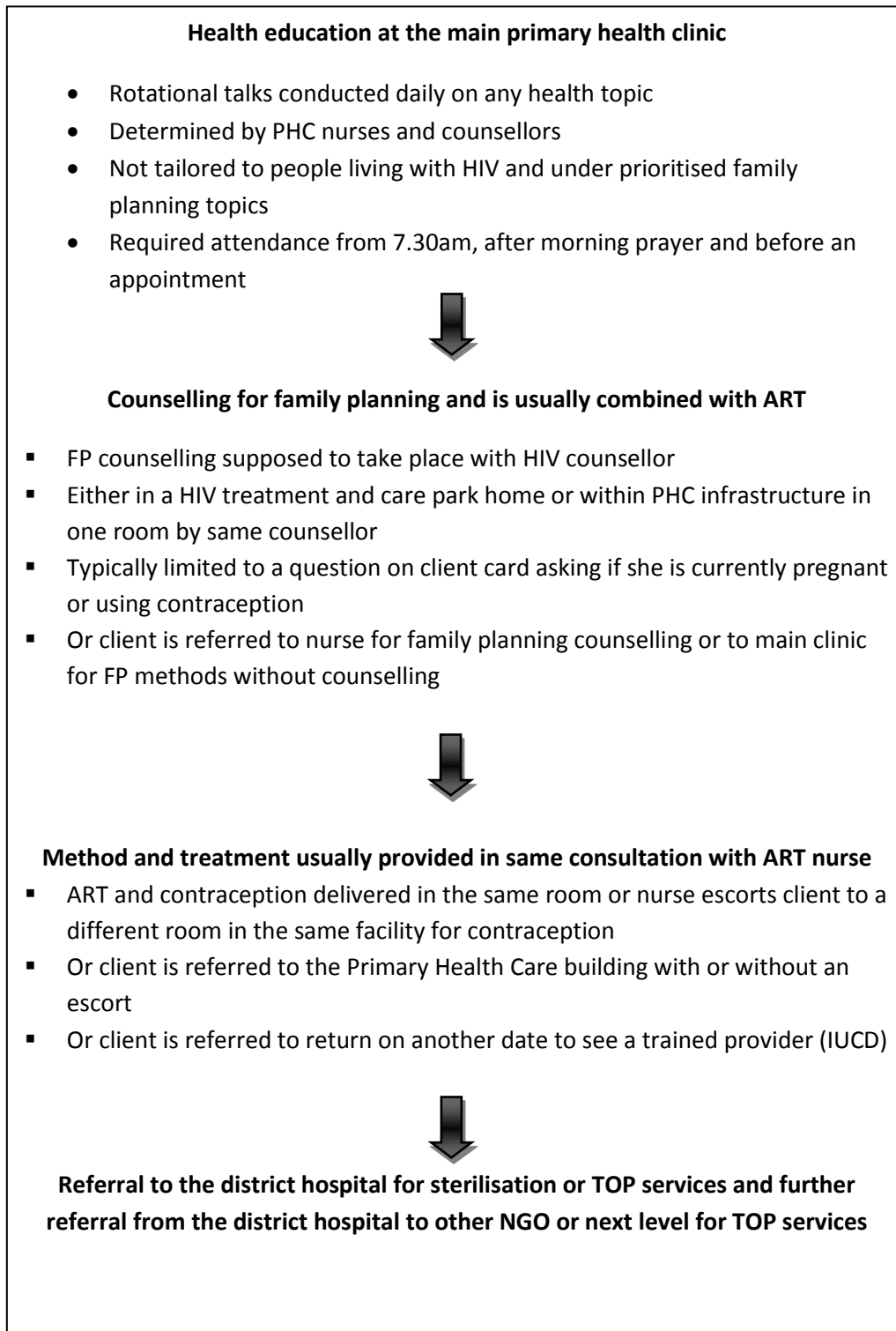
In all clinics, clients would first visit the HIV counsellor who would also be expected to deliver family planning information and education. Clients would then typically wait in a designated waiting area or proceed directly in to the next (different) room, for consultation with an ART nurse, where clients can also seek injectable or oral contraception and condoms. A typical pathway of how family planning activities were operationalised within the continuum of HIV care is illustrated in figure 6.III. There were nuances in which ART nurses were expected to conduct specific or more technical elements of FP counselling such as information about the newly available IUCD, and how to achieve a safe pregnancy, while nurses themselves felt they had limited time for these discussions. In

instances where supplies were out of stock, two clinics described a system of personally escorting clients to the relevant offices. In other cases, referrals were done verbally and were not followed up by the referee (figure 6.2).

Figure 6.1 Sexual and reproductive health and related services offered on referral from the HIV treatment and care programme

- Sterilisation was available on referral to the district hospital.
- Unavailable methods included: spermicidal jellies, creams or foams, diaphragm, contraceptive patch (a weekly oestrogen and progestin patch applied to the skin), vaginal ring, cervical caps.
- A specifically trained nurse was required to insert the IUCD and so this procedure could not take place in the same consultation room but this method was available upon appointment within treatment rooms. At the time of this study the delivery of IUCD was limited by the availability of trained service providers. Clients were asked to attend an appointment when a trained service provider was visiting the clinic and in the early stages of roll out, healthcare providers reported that clients were interested but some missed appointments.
- Prevention of mother-to-child transmission (PMTCT) was delivered within antenatal care (ANC) services and each clinic operationalized specific days when PMTCT services were made available.
- Termination of pregnancy was available through referral to the district hospital in Hlabisa or the Empangeni Marie-Stopes NGO clinic, an average distance of 100km return journey.
- Support for victims of gender violence or sexual assault was outlined by clinic guidelines on referral from police, provision of PreP and the emergency contraceptive pill and further referral on to psychological and social support.
- Support groups were cited as sources of information and training to develop skills that encouraged clients to grow their own fruit and vegetables but no groups were practising during the time of this study.
- A trained psychologist and a nutritionist visited clinics on a monthly rotation
- Temporary social grants could be occasionally supported and required doctor consultation.
- Strategies for safer conception were limited.

Figure 6.2 Pathways for delivery of family planning services based on observation of five primary health clinics in the Hlabisa HIV treatment and care programme, based on interviews with healthcare providers, operational managers and a checklist of communication (Appendix E)



Integration of family planning into HIV treatment and care helped to minimise stigma

Clients and health workers believed that delivery of contraception within the HIV treatment and care programme helped clients to avoid stigma and long queues up at the 'main' clinic. Women agreed that they preferred to receive their contraceptive injection at the same time as their treatment or during a clinical assessment visit with the nurse. They cited the convenience of seeking all services in one place and that they were able to build trust in health workers as a benefit.

I thought it would be better if I get everything at one place.

- *32-year-old mother of three children with a partner who has not paid isilobolo. Does not want a child, clinic E*

Health care providers felt that private clinics were unaffordable for most of their clients (in this area more than 75% of adults are unemployed) and were aware of clinics in the nearest major cities of Durban and Johannesburg but not of any other potential sources of contraception. Women were aware of limited alternative sources of contraception, such as condoms from the pharmacy or termination of pregnancy services as advertised in local newspapers but preferred to seek methods from HIV clinics situated within local primary health care clinics closest to their home, unless a Department of Health mobile clinic visited closer to their community. These mobile clinics provide maternal and child care, but no HIV treatment and care.

I used to hear people say that there are contraceptives at the chemist and others say you can get injectable from the doctors. Those places need money and here at the clinic I get it free.

- *32-year-old mother of three children with a partner who has not paid isilobolo. Does not want a child, clinic E*

Health workers viewed the delivery of family planning services in to the HIV treatment and care programme as more beneficial than referring clients on to the main PHC for family planning. For example a nurse qualified that she felt that a HIV 'one-stop-shop' avoided stigma by allowing clients to visit park homes, as opposed to the main clinic where HIV uninfected clients also attend. In general health workers indicated a preference to double up on some services between the two PHC and HIV buildings although recognising a greater burden on resources and limited staff.

They fear that if we integrate... if we say they must collect treatment from the main clinic, there's that stigma that people will see them carrying their files. Ah everybody will see. But here, all of them, they are at the same level. They are taking their ARVs if they are on this side. So we have that fear for our clients. What about the clients if they're ashamed because other clients will see them collecting their drugs. Even now, it happens if we are here, they say 'oh it's good that you are here sister. We are getting our treatment here, not up [at the PHC] at that side, they still have stigma

- Nurse, Department of health, clinic A

6.4.2 Structural barriers to safer conception and contraceptive use

Family planning was partially integrated into HIV care and under-prioritised counselling

First and foremost, health workers discussed integration as an issue of shared services and referral between the HIV clinic and 'main' (PHC) clinic. Family planning was considered part of a one-stop shop service, but time for this activity was minimal. Although in practice women received contraception from the HIV services, the extent to which family planning services should be devolved from PHC to HIV treatment and care for individuals on ART was unclear in all clinics. Nurses and Counsellors in the HIV treatment centres had received primary health care and additional HIV training, and so identified as ART nurses or ART Counsellors. Both ART and PHC nurses were selected randomly to attend further training and tasked to disseminate information through a cascade of peer training. Views on how integration was operationalised in each facility differed slightly amongst health workers in the absence of formal guidance for implementation of continuum of care.

One operational manager believed that some ART nurses resisted what they viewed as duplicating PHC services. In effect, elements of family planning such as the administration of injectable contraception were devolved from the main (PHC) clinic, whereas information and education support services were not.

According to me, integration means ... I have to do these clients wholly, completely, not just saying I must go there for ARVs and after for family planning... it has been a resistance yeah with us as nurses. You see, before, we had the ART nurse and Africa centre this side, HIV/AIDS counsellors and department of health and others, and Africa centre... [but] that is integration. You know, no 'I'm an ART sister, full stop' because she is a registered nurse. She knows all the services, besides this ART programme... But then there has been that resistance.

- Counsellor, Africa Centre, Clinic E

Within the HIV treatment and care programme, healthcare providers performed family planning duties allocated according to their ART counselling or nurse expertise, effectively separating the delivery of contraceptive methods from family planning counselling. Task shifting reduced the burden of care upon ART nurses as family planning counselling was presumed to precede a consultation with the ART nurse.

Non-attendance of clients was felt to be a particular issue amongst health workers in the HIV programme. They felt reflected lazy attitudes amongst some women or, due to the costs of transport and childcare and time to reach clinic. Health workers said there was no formal system for handling missed appointments and so one nurse described instances of using her personal mobile phone to encourage clients to attend after they missed HIV treatment appointments. Descriptions of task identification within integrated services are provided in Box 6.4.I.

Box 6.4.I ATTITUDES TO INTEGRATION OF FP/HIV SERVICES

Mostly it just goes hand in hand with our baseline care. When we discover somebody is HIV positive, family planning is part of the health education that we give to them. So sometimes we don't even need to ask because we have to give it to them

- Nurse, Department of health, clinic B

It is the ART sister who does it. So you just ask the questions, yeah

- Department of Health Counsellor, Clinic C

They come to us first and then we hear all the problems that the patient is complaining with. Either it's that she is sick or she want to do the family planning, its everything and then we write it down, then we come and see blah, blah and give treatment.

- Counsellor, Africa Centre, Clinic D
-

In practice counsellors said they had received limited training in family planning, and related counselling was often easily omitted. Clients considered the advice they received during individual consultations in the HIV treatment and care programme as limited and a nurse agreed that some clients were unaware of the availability of contraception within the programme.

They used to say we must prevent ourselves by using condoms only because they prevent spreading of diseases. They don't give us any information or else I have forgotten but something like that.

- 37 year old mother of 5 and currently pregnant with her sixth child, clinic C

They go to the main clinic usually. But even here, should they state that they are also for family planning, we do give them. But then we are still educating them, to understand that they can get all their services here. So not all of them understand that they can get their injections or contraceptives here.

- Nurse, Department of health, clinic C

ART nurses and counsellors regarded 'health education' delivered at the 'main' PHC as an important source of family planning information for all women, inclusive of women on ART. Health workers at the primary health care clinic led sessions on a variety of health topics each morning and ART clients were expected to attend these health education sessions before walking the short distance down to the HIV treatment and care building. Within the programme some viewed family planning as an additional service that could not be fully prioritised due to limited human resources and capacity within the programme. In this sense, FP was considered to be a 'fifth room' activity in a building with four rooms and led to partial integrated efforts, in which some activities (delivery of contraceptive methods) were achieved and tailored counselling activities were omitted.

Daily group health education sessions followed Morning Prayers for all clients beginning at 7.30am each morning in the Primary Health Care facility and messages aimed to address relevant health topics according to a rota determined by nurses and counsellors. However, this session is used to discuss a broad range of health issues and there was no dedicated focus on family planning topics during this study period. After health education, clients then move to visit the HIV counsellors where the family planning counselling during this session is limited to guided questions on the client card.

Health workers and ART clients presented opposing views on the usefulness of these sessions, as illustrated in Box 6.4.II. Women on ART said they had heard of messages related to contraceptive use but were sometimes unable to pay attention during these health education sessions if they were feeling unwell or that the information was not personalised or relevant. As a consequence, these women preferred to avoid attending health education completely in the interest of saving time.

Box 6.4.II ATTITUDES TO FAMILY PLANNING INFORMATION, EDUCATION AND COMMUNICATION

Health worker views on health education for family planning

Is discussed though not daily, but we do discuss it in the morning. After prayers, we give a presentation while they are together in reception, in the main clinic. Because all clients start there before they come here. So we alternate, today's another topic, the other day... you see? And then we do give the individual health education, on different topics

- *Nurse, Department of health, clinic A*

Most of the people they don't come early because they say their time is wasted because of prayer; their time is wasted because of health education. Most come after 10am because they know this thing of health education and prayer will have stopped, so they come late.

Counsellor, Africa Centre, Clinic B

Client views towards family planning counselling in the HIV continuum of care

I would say they have to tell us about contraceptive methods when we are still waiting for our files, even males need to know about contraceptive methods. Because they know about pregnancy and [can] explain to us. After that we can continue with what here to do.

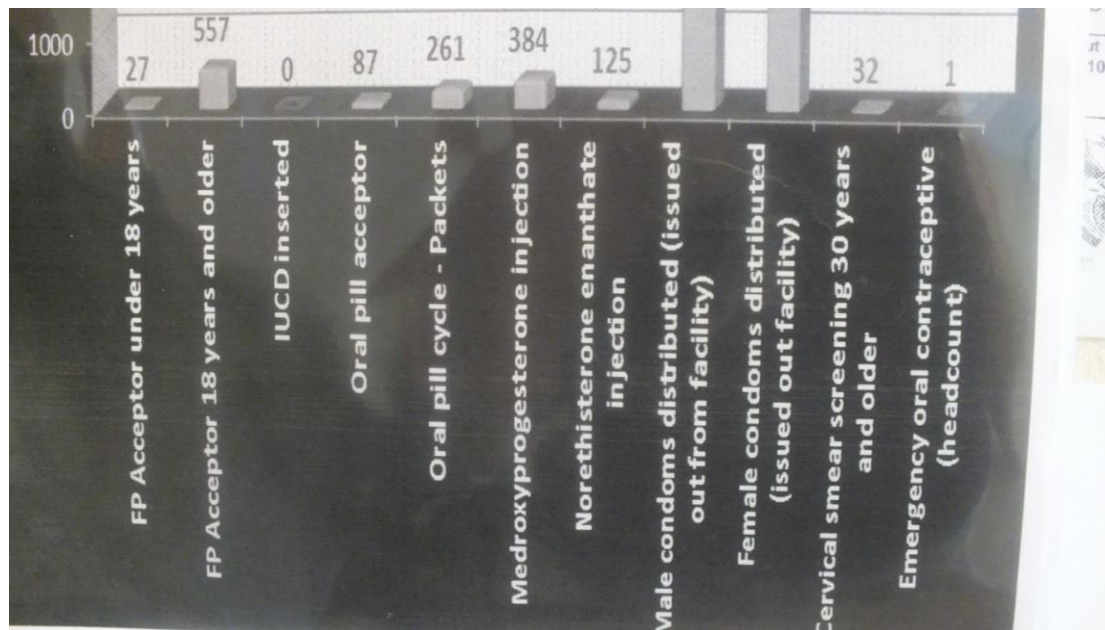
- *32-year-old mother of three children with a partner who has not paid isilobolo. Does not want a child, clinic E*

They never talk about that here when we collecting HIV treatment but at the main clinic they tell them

- *23-year-old woman with one child and a partner that has not paid isilobolo. Would like a child in the future and has not been pregnant while enrolled in the HIV treatment and care programme. Clinic E*

I asked to see any guidelines for family planning service delivery in all of the 5 clinics. The national Department of Health had recently provided training workshops for ART and PHC nurses on the use of the Family Planning provider handbook and how to perform IUCD insertions amongst all women, including women living with HIV who have not yet developed AIDS. Information related to contraceptive methods without mention of safer conception strategies. At this time, three out of five clinics reported currently using this handbook, but some interviewed nurses and counsellors were unaware of this resource. Primary health care facilities measured monthly contraceptive acceptors in total and by individual method (Figure 6.3). This information was displayed in main PHC facilities and aggregated from HIV treatment and care. However, measures of integration were not available and there was no consistent monitoring of family planning use amongst women on ART.

Figure 6.3 Observed indicators of family planning acceptance in five study clinics



Clinics encouraged IEC activities to differing extents. Support groups were widely discontinued at the time of this study due to a shortage of staff. One clinic reported having sought funding to hold an education day to encourage questions from clients, which was felt to address many topics including family planning.

Demonstration tools were available in counsellor rooms to facilitate discussions on how to apply a male condom as illustrated in figure 6.4. One clinic arranged contraceptive methods on a clipboard to illustrate the available method mix. Posters or reading materials were available only in one clinic out of five and were reportedly not well utilised by clients. Materials were published in English and left in a box by the main clinic entrance but health workers reported that clients were uninterested in reading materials and none offered these resources during client consultations.

Figure 6.4 Tools and materials for information and education about family planning



Safer conception topics were not discussed within the HIV treatment and care programme

Guidelines for safer conception strategies among fertile HIV infected individuals and couples have been available from the SA clinicians society since 2011 and these provide recommendations tailored to low resource settings such as Hlabisa (Bekker et al., 2011). None of the health care workers reported knowledge of guidelines for safe conception counselling and withdrawal techniques, natural family planning or lactational amenorrhea methods as recommended in these guidelines were not reportedly discussed or promoted for women on ART within the programme.

HIV counsellors said they did not have formal guidance on how to counsel women about family planning within the HIV treatment and care programme. Both counsellors and nurses said they would ask clients about their pregnancy intentions, but felt women were not planning, and would only return to the clinic after they were pregnant for antenatal care. Unplanned pregnancies were seen to be the norm amongst women in their care and that although being on ART was not a barrier

to childbearing desires, health workers felt that only married women planned their pregnancies and would need advice for safe conception. Difficulties in the absence of firm guidelines led one health worker to explain that she felt supervisors criticised their performance.

They say we don't talk with the patients. Because they say CD4 is low? Viral load is up, she is pregnant. You don't talk with them.

- *Counsellor, Department of health, Clinic A*

Personal medical charts noted current contraception use to provide an indicator for health workers to discuss when methods were being continued or discontinued. The reproductive health section of the client card was limited to a discussion on current contraceptive use and the data of last use. It did not address future pregnancy intentions or adherence to contraception on ART before most recent use, as illustrated in figure 6.5. These charts did not introduce or help health workers to structure more difficult topics such as emergency contraception, termination of pregnancy, methods for safer conception, how to determine a fertile period or alternatives to childbearing that might be relevant to women on ART. Furthermore, health workers did not often record FP use in client charts in case any family member or partner would see the chart and discovered a woman's covert use of this method. Accordingly, some HWs felt that the medical chart was ineffective as a tool to guide discussions on fertility planning for women who wish to have a child or to monitor contraceptive use.

these interviews. Some said that they sometimes found it difficult to plan according to their health and CD4 measures despite health worker advice.

I was afraid that when I became pregnant I would become sick or my CD4 count would drop [and] then I will die. They say if you want a child you need to consult health care workers, [but] sometimes it happens without planning, so it is like that. You don't know about your CD4 count.

- 25-year-old woman with three children and a partner who has not paid isilobolo.

Safe conception topics were not scheduled to be discussed during that month's health education sessions in each of the clinics we sampled and this led to a sense that health workers were withholding information amongst clients.

Here at the clinic they can give me information if I ask them. I don't think they don't know about it. I think they are lazy to give us some information... they want us to ask them sometimes

- 36 year old woman with a partner (isilobolo not paid), two children and no experience of childbearing in the HIV treatment and care programme, clinic D

Gaps in counsellor knowledge and a reliance on health education, fostered by partial integration of family planning, created missed opportunities for continued and tailored counselling along this process. Information regarding use of family planning was not tailored to ART-specific concerns during individual consultations or health education sessions and women mostly felt that health workers only promoted injectable or dual contraceptive use. Women did not consistently receive family planning in the HIV treatment and care programme and wished to receive more on-going support for family planning.

It is not good at all according to my view. They tell you once before you even started HIV treatment. When time goes on sometimes you forget what they told you. [FP] must be something that they always tell us about because we always have sex with our partners, it does not mean that as we are HIV positive we don't do sex. I would be very much happier to get it at the same place. Sometimes the dates are the same and I collect HIV treatment then go to the main clinic and start another line and that makes my life difficult

- 32 mother of three children and does not want a child, clinic E

Box 6.4.III VIEWS AND EXPERIENCES OF SAFER CONCEPTION

Women's attitudes to information on safer conception in the clinic

I don't want to lie; they don't [talk about family planning]. They have to tell us about condoms, contraceptives and also what to do if you want to have a child. What things need to be done before having a child, as you are HIV positive and on treatment because they know more things than us.

- 32-year-old mother of three children with a partner. Does not want a child, clinic E

I never heard of that thing, I would like to know about it

- 34 year old married women with no desire for another child, clinic A

As I want to a child I would like to know what to do

- 24 year old woman with one child and a partner who has not paid *isilobolo*, clinic A

The other nurse [in the main PHC facility] told us that there are days in a month where a woman can get pregnant. Woman needs to be careful and know when she started her periods so that she can know which dates need to be careful with. [Here] there is nothing they say about family planning.

- 23 year old woman with two children, a partner and would like a child in the future

Health worker attitudes to information on safer conception in the HIV programme

I felt that somehow, somewhere, I have to improve there. Maybe to improve asking women. I have to just to help them do it safely. If they want to become pregnant and help them.

- Counsellor, Africa Centre, Clinic E

I've never [discussed how to plan a pregnancy]. I only advise them to come to doctor, when on ARVs they want pregnancy, I only advise them to come to doctor so that they have the session on this

- Counsellor, Africa Centre, Clinic A

The [doctor] said he would treat the other for STIs even if there were no STIs, yes, and also talked about the 28-day cycle. And the other one talked about something I did not understand. Ejaculating in the condom. And then?

- Nurse, Department of health, Clinic D

Health worker's used CD4 counts to subjectively qualify when a pregnancy is appropriate

Health workers viewed childbearing as an individual's reproductive right and stressed that women should not be discouraged from having a child, but should prioritise her health first and 'make a plan' for a pregnancy in advance. Health workers placed strong qualifications upon timing by using CD4 measures as a discernible indicator of when they considered a pregnancy to be appropriate.

Nurses said they were unsure as to the appropriate recommendations for women that would like a child and would refer women to see a doctor for further information, but health workers were concerned that a rights-based attitude could risk encouraging unplanned pregnancies and jeopardise their client's health. In the absence of practical guidelines on this measure, health workers reported mixed views on an appropriate cut-off but suggested CD4 value in the range of 400 – 600 should be attained before a woman could consider a pregnancy.

Women were advised to postpone when CD4 counts were considered too low but many found this advice for planning too difficult to follow (Box 6.4.IV). Some clients were apprehensive to disclose a wish to have a child or a pregnancy after being 'shouted at' in the programme. In one instance a women reported switching clinics for this reason and another had considered this move.

Consequently, health workers felt most clients did not follow their health advice to plan according to their CD4 count.

We tell them... you still have a right to fall pregnant. So we used to tell them before you can fall pregnant as your right, you need to come with your partner and make an appointment with the doctor. And then, so that bloods can be taken to check your viral load, to check your CD4.

- Nurse, Department of health, clinic C

Many held views that it was not appropriate for a woman living with HIV to have another child outside of these circumstances. Failing to plan 'correctly' was interpreted by some health workers as a lack of intention amongst their clients, or that they are hiding something. Facing these difficult issues of planning, health workers varied in their approaches, from emphasising contraceptive use to a flexible attitude to managing the antenatal care of an unplanned pregnancy.

It's not right for a woman to fall pregnant not knowing her CD4, or if to fall pregnant if CD4 is low, or fall pregnant each and every year. So condom is best to prevent everything.

- Counsellor, Africa Centre, Clinic A

When the patient is taking ARVs, she comes to you and says... 'Sister, I'm pregnant'. Mmm. It comes to you as a shock, wow, ok we didn't agree upon this, or we didn't discuss that it's ok now to have a baby. But we cope to manage those problems.

- Nurse, Africa Centre, clinic B

Box 6.4.IV CLIENT EXPERIENCES OF DISCUSSING A DESIRE FOR A CHILD IN THE CLINIC

We are not used to talk about that. Sometimes I used to say it as a joke.

- *24 year old woman with one child born within the HIV treatment and care programme and a partner who has not paid isilobolo (clinic A)*

I became nervous... when she shouted on me

- *30 year old mother of two, with a partner who has paid isilobolo, clinic B*

You know what I worried because I told myself that to be pregnant according to them is not right... It was like I committed a crime. [The nurse] continued saying that they are always teaching us about using condoms so that we will not get pregnant. She said it would be better if I used an injectable after give birth because I don't listen to what they are saying. I was offended. I even think of changing the clinic but my partner said I must not mind them because I know what happened and I know that as I go to the clinic I want my life to be better. Sometimes nurses don't think that you are human being all you need is counselling not people who will shout at you. I even thought that they spoke like this because I am young.

- *23 year old woman with two children, a partner (isilobolo not paid) and no experience of childbearing in the HIV treatment and care programme, Would like a child in the future, clinic C*

I knew that I was wrong, as I didn't speak to a doctor.

- *28 year old woman in a polygamous marriage with two children and no experience of childbearing in the programme, Would like a child in the future, Clinic B*

I didn't do it I was afraid. I thought they would yell at me as they told us that before we get pregnant we should come to them first.

- *25-year-old woman with three children and a partner who has not paid isilobolo. Does not wish to have a child in the future and has not been pregnant while enrolled in the HIV treatment and care programme. Clinic D*
-

Access to emergency contraception or referral for termination of pregnancy were not widely supported

Children were considered a 'gift from God' and women viewed the act of having an abortion as a sin against the Christian faith. Yet, in the context of this study and strong desires to avoid childbearing, two women said that they would still consider seeking a termination of pregnancy if they became pregnant in the future.

My sister, if I find out that I am pregnant I will do [an] abortion because I don't want to have a child. That sin I will find it in heaven.

– 18-24 year old mother of two with multiple partners and no desire to have more children (clinic A)

A pregnancy that was 'hard to accept' had led some women on ART to consider a termination of pregnancy but was deterred by cultural values. One 34 year old woman with 5 children and previous experience of childbearing in the programme said she did not know where to seek termination of pregnancy services and feared health workers would stigmatise against a married woman seeking an abortion

You know what? I was thinking of [having an] abortion when I found out that I am pregnant. It was hard to accept it because I didn't know whether my child would be HIV negative or not.

- *34 year old married women with five children with no experience of childbearing in the HIV treatment and care programme and no desire for another child (clinic A)*

Terminations of pregnancies were legally available in South Africa but awareness about how to seek a termination of pregnancy or to obtain EC in the programme was limited. Health workers did not formally or routinely communicate information about these services to clients within the programme (Box 6.4.V). Counsellors were uncertain of the actual referral chain but women could be referred to the local hospital and services were reportedly administered at the nearest Marie Stopes NGO based in Empangeni. Only one client was aware of this NGO.

A woman described almost seeking Termination of Pregnancy (TOP) services from a newspaper until her sister dissuaded her from seeking this procedure. Women preferred the ease with which they could covertly seek a termination of pregnancy service from adverts in the newspaper. TOP services were not commonly discussed during interviews or as part of HIV treatment and care and a fear of being judged by health workers as 'too old' meant that the only woman to pursue a termination of pregnancy chose to seek this service from a newspaper.

I even thought of doing abortion and I knew that if I told him earlier he would be against it. I bought a newspaper because I wanted to see advert that used to be there for an abortion. I

told my sister and she said to me it is not a good thing to do an abortion because a child is a gift from God... I was one month pregnant. My sister stopped me to do it otherwise I was willing to do it. The way she used to say about abortion I was afraid.

- *35-year-old woman with five children, with a partner that has paid isilobolo. Clinic C*

BOX 6.4.V ATTITUDES TO TERMINATION OF PREGNANCY SERVICES IN THE HIV PROGRAMME

Client experiences of communication about Termination of Pregnancy services

They never say anything like [how to seek an abortion]. Nothing at all.

- *37 year old woman with 3 children, a partner who had not paid isilobolo and no desire to have any more children, clinic E*

I didn't know where to go to for abortion because when you hear people talking they don't tell you all the relevant information that you need. I came here at the clinic but I was afraid to talk to the health care workers because what I thought will say that as a married woman why I want abortion. Sometimes they will think this child is not for my husband

- *34 year old married women with five children with no experience of childbearing in the HIV treatment and care programme and no desire for another child, clinic A*

There are no other places and I was afraid to ask at the clinic about it because I thought they would say why I want to do an abortion, as I am old... I bought a newspaper because I wanted to see advert that used to be there for an abortion. I told my sister and she said to me it is not a good thing to do an abortion because a child is a gift from God. My sister stopped me to do it otherwise I was willing to do it. The way she used to say about abortion I was afraid.

- *35 year old woman with five children and currently pregnant with 6th child. She has a partner who had paid isilobolo. Does not wish to have a child in the future, clinic C*

Health worker experiences of communicating information about Termination of Pregnancy services

No, I don't. I don't. I don't know about my colleagues but I haven't talked about it, abortion and morning after pill, I don't know.

- *Counsellor, Africa Centre, Clinic A*

To Hlabisa... eh I don't know whether they do it at Hlabisa but normally they send them to MPA, I don't know

- *Counsellor, Department of health, Clinic B*

I don't know. But I think they're aware, because in the media they do talk about legal abortion

- *Counsellor, Africa Centre, Clinic A*

6.4.3 Summary of structural barriers and facilitators to contraceptive use and safer conception in the Hlabisa HIV treatment and care programme

HIV treatment and care delivered a 'one stop shop' approach to family planning services whereby women on ART could receive their contraceptive methods, primarily injectable methods or condoms, during the same consultation that they would receive ART. Facility level integration eased client access, adherence and covert use while minimising concerns about possible stigma facing HIV positive women seeking family planning services. Efforts to integrate services were partial however, and limited to contraceptive provision. Family planning counselling and monitoring of indicators were predominantly still perceived as 'main' clinic activities and counselling was not consistently delivered as part of the HIV continuum of care, nor tailored to ART-specific issues of concurrent use and adherence to both ART and hormonal contraception. Adherence to contraceptive use was not measured routinely and discontinuation of injectable contraceptive use was common.

Safer motherhood advice was perceived as limiting rather than supportive. Clinical indicators of appropriate timing according to CD4 count and viral load aimed to protect the mother from adverse risk to health but were practically difficult for clients to follow and rarely implemented. Unplanned pregnancies were reportedly common and highlight the importance of delivering appropriate support that is well timed, prior to unprotected sexual intercourse. Other safer conception practices were not commonly known amongst health workers or discussed with clients. WHO recommended family planning practices for women living with HIV were available at the time of study, but no national or provincial guidelines or formalised systems of referral were in place to facilitate implementation at the time of observation and both groups of clients and health workers wanted more information about safer conception practices. Key structural barriers and facilitators are summarised in figure 6.6.

Figure 6.6 Structural barriers and facilitators to safer conception and contraceptive use in the Hlabisa HIV treatment and care programme

FACILITATORS	BARRIERS
Women preferred the ease of access to methods and treatment in one consultation	Integration of education activities often depended on health worker’s initiative. i.e. referral systems and task identification of HW roles in family planning were not clear
Access to one-stop-shop services facilitated covert use of family planning i.e. allowing clients to store cards in the facilities	‘Health education’ was used as a substitute for individual family planning counselling. FP was not prioritised in health education and is easy to bypass on route to HIV services.
Stigma was felt to be minimised by removing need for a woman to walk to the main PHC building	Opportunities to discuss childbearing desires or support reproductive needs safely during follow up visits are missed
Health workers valued the reproductive rights of clients	HWs used clinical indicators to subjectively assess the appropriateness of a pregnancy.
Introduction of IUCD means women are not tied to repeat visits to the clinic	EC and abortion services were not discussed in the programme
	No guidelines or training to support health workers discuss safer conception topics

6.5 Summary of qualitative findings in chapters Five and Six

Pregnancies to women within the HIV treatment and care programme rarely followed an explicit intent to have a child. These findings highlight a significant absence of planning for a child amongst women on ART within the Hlabisa HIV treatment and care programme, even though women do hold personal desires for small family sizes and ideals about how they would prefer to space pregnancies, as discussed in chapter five. Traditional psychological pathways posit desire as a precursor to intention and behaviour (Miller, 1994), but this study shows that childbearing decisions are changeable still in the context of ART use and that women's behaviour may not always follow reported intent.

Childbearing was culturally valued, but relationship instability and economic adversity were commonly described reasons to avoid having another child. Women weighed the costs and benefits of having another child according to a range of socio-cultural, economic, relationship and health factors, and use of ART was rarely itself a reason to not have a child. Many factors acted as heterogeneous influences affecting the decision to have another child, and the contraceptive health belief model provides a more relevant framework to discuss the kind of decisions that women are making (Figure 6.7) (Hall, 2012).

Figure 6.7 summarises the results presented in both chapters five and six as factors leading to contraceptive decisions specific to women on ART in the HIV treatment and care programme. Initially women discussed their desires to have or to avoid a pregnancy and how they anticipated this desire might change in the future. Originally discussed in chapter five, these factors influence the high 'motivation to avoid an unwanted pregnancy' presented in figure 6.7.

Perceptions of general health prominently added to the perceived threat of another pregnancy, as summarised in the far-left 'perceived threat' box in Figure 6.7. Typically injectables are the preferred method of choice in this setting, and so women on ART are no different to many other women in their, sometimes covert, use of this method. Women on ART were encouraged to prevent unintended pregnancies in Primary Health Care clinics, and further supported through the availability of contraception within the HIV treatment and care programme, as summarised in the centre 'cues to action' box. In addition some women received support to avoid childbearing by partners and family members with shared values for small family sizes or the preserved health of the woman. Despite the wide availability of contraceptive methods in clinics, some important aspects of family planning have been neglected in recent years. Emergency contraception and termination of pregnancy in particular are rarely addressed in the HIV treatment and care programme, and

traditional medicine and newspapers provided significant alternative sources of harmful information. Some women hoping to 'clean the dirt' and prevent a pregnancy used modern medicines such as Disprin or herbal drugs such as marijuana. These alternative forms of EC were described according to use of similar modern products in the cultural practice of intravaginal insertions to achieve 'cleanliness' (Gafos et al., 2010). Women on ART would often still prefer to seek an unsafe abortion from newspaper adverts in order to avoid stigma they anticipated at the clinic. Information on these issues need to be clearly and routinely communicated to women on ART in order to ensure unwanted pregnancies are safely prevented, in an environment in which women are encouraged to seek the services they need.

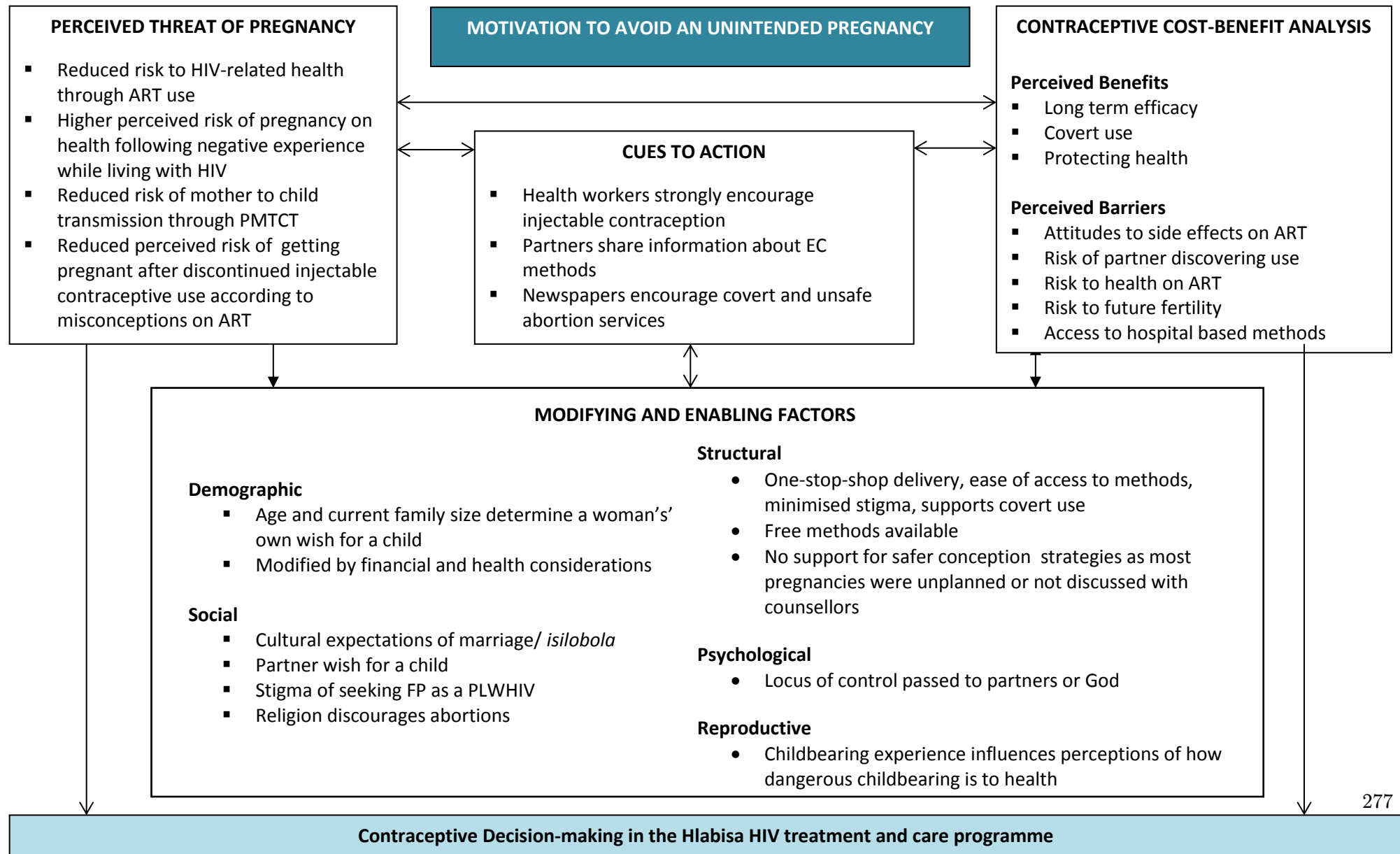
The long lasting nature and ease of adherence to a single injection in addition to the ability to use this method covertly facilitated adherence to DMPA, and allowed women to act independent to a partner's desire for a child. Findings from this study are consistent with other work from South Africa, which suggests contraceptive use in HIV positive women is strongly influenced by the culture (Todd et al., 2011). Selection and continuation of contraception was influenced by multiple costs and benefits, usually related to the long term use of hormonal injectable contraception, summarised in the right hand side 'cost-analysis' box in figure VI. However, side effects attributed to use of hormonal contraception were prominent deterrents to use or continuation. Unique to this context was a strong perception that injectable use could make a woman too 'watery' during sexual intercourse: an important and culturally sensitive deterrent to use amongst some women in this and other studies (Gafos et al., 2010, Todd et al., 2011). Partner's perpetuated the concern that these side effects not only impact on her health but also on a woman's attractiveness and cleanliness. To women themselves, ART use could enhance the severity with which they perceived the side effects of injectable contraception. Of particular concern was the risk of excessive bleeding at a time that women already felt weak on ART.

Family planning recommendations for dual contraception were well versed amongst participants in this study, and added awareness of the risks of transmission had further empowered some women to encourage partners to use condoms. Still, most viewed condoms as unreliable for pregnancy prevention due to inconsistent use. As such, women 'taking a break' from injectable contraception would often put themselves at risk of an unplanned pregnancy. In addition, some thought that the effects of injectable hormonal contraception would last longer than the stipulated three months or even that ART itself would prevent a pregnancy. In this setting, women spend a large proportion of their reproductive life using injectable contraception, and these issues of side effects and cultural barriers pose issues for long-term continuation of this method, particularly to women on ART who

already face concerns for their health. The intrauterine device was in very early stages of being rolled out and presented an interesting long lasting alternative to injectables for some. Oral contraception was viewed as too difficult to adhere to by both health workers and clients, while female condoms were available but not well liked according to health workers.

The HIV treatment and care programme acts as an important structural factor that may modify and enable women's contraceptive use on ART (Modifying and enabling box, figure 6.VI). This study determined a partial level of integration in which a 'one-stop' system provided contraception to any client that wished to use it during an ART consultation, while family planning information, education and counselling (IEC) activities were largely omitted from the HIV continuum of care. Health workers supported the reproductive rights of women living with ART but stressed the burden of including too many health topics within a HIV treatment consultation and saw family planning as a lower priority for these sessions. HIV counsellors were not trained or supported with guidelines to deliver family planning IEC tailored to the needs of ART clients and many used subjective CD4 measures to determine the appropriate timing for conception without practical advice to achieve a safer pregnancy. To the women in these interviews, the uncertain and changing economic and social environment in which relationships were formed and childbearing decisions made, this advice was restrictive and difficult to follow. Women that did wish to have a child saw this as happening at an undefined time in the future and in the absence of further support to have a child; women did not often discuss their wish to have a child in the programme. Health education sessions held in the main PHC building were instead viewed as key sources of family planning information, leaving missed opportunities to address ART-specific concerns for family planning within the HIV treatment and care programme.

Figure 6.7 Summary of qualitative results using constructs of the Health Belief Model as applied to contraceptive behaviour and related to attitudes on ART (Hall, 2012)



Chapter Seven

Discussion

The issue of HIV and fertility is complicated but relevant to demographic, economic, epidemiological, public health and rights-based studies. To set these findings within the wider literature raises questions about appropriate counterfactual groups and comparison of methods. In addition to methodological differences between studies, however, is a huge variation in fertility in different community settings. Childbearing may be culturally determined and vary between settings. Studies investigating fertility and HIV may therefore seek to measure the effect of prevalence at a community level, or individual effects of a HIV diagnosis. Before ART was made nationally available, estimates suggested that fertility would be reduced by 25-40% in areas of high HIV prevalence in sub-Saharan Africa (Zaba and Gregson, 1998). More recent studies suggest that access to ART will likely reverse these lower fertility trends due to improved physiological health and increased sexual activity or fertility desires, although heterogeneous effects of ART on biological or behavioural proximate determinants of fertility could influence fertility in either direction (Kaida et al., 2006).

7.1 Contribution of this study to the wider literature

This study took place in the Hlabisa sub-district of KwaZulu-Natal, South Africa and describes the association between ART use and fertility in a rural setting of high HIV prevalence and high contraceptive prevalence. This study shows that scale up of ART in this rural sub-Saharan African setting did not increase the likelihood of live birth amongst HIV positive women.

This study is important because it describes an effect of individual factors associated with HIV and exposure to ART on fertility. By including HIV negative women as well as women who had not participated in the HIV surveillance, this study allows a comparison of incidence and behavioural factors associated with fertility between women on ART, pre-ART women, HIV negative women, and women with missing information about HIV status. These findings describe the factors that are associated with differences in fertility according to HIV status and are thus contextualised to women that are resident to an area of high HIV prevalence, but may not be easily generalizable to all settings of high HIV prevalence.

Additionally, this study qualitatively described key reasons why women on ART may prefer to limit childbearing, particularly according to perceptions of their health, and how these desires are often in conflict with other socio-cultural reasons for having a child. Women make their childbearing decisions in very different circumstances across the continent and the findings from this thesis differ from those from other sub-Saharan Africa countries, demonstrating the importance of contextualised studies.

Socio-economic and cultural factors have long driven a demographic fertility decline in this setting, and this study suggests that ART does not affect the underlying trend in fertility decline in either direction. This work indicates that roll out of ART may have little demographic implication for fertility, but there are public health implications of unplanned pregnancies and absence of safer conception planning of wanted pregnancies on ART for maternal health.

7.2 Summary of key findings and methodologies

This discussion presents results from a mixed methodology study and key findings are summarised in Table 7.1, reflecting the three study objectives. Findings are displayed according to results sections and methodology, which will be briefly summarised below. Chapter Four presented results from a quantitative analysis of data from the Africa Centre for Health and Population Studies demographic surveillance system (ACDIS), utilising information from approximately 90,000 Zulu-speaking individuals over a 438km² area, starting with a description of annual trends in crude live birth in the surveillance area between 2005 and 2011 by HIV status in section 4.1. Information about antiretroviral therapy use and CD4 count for HIV-positive women was linked from a clinical database (ARTemis) to the demographic dataset (ACDIS) using unique individual identifiers to create two cohorts to compare incidence and identify factors associated with live birth in an open cohort of HIV positive and HIV negative women participating in annual HIV surveillance between 2007 and 2012 inclusive (Section 4.2), and a closed cohort of HIV positive and HIV negative women, also including women that did not respond during HIV surveillance rounds at entry in 2007 or 2008 (Section 4.3). Entry to both cohorts began on 1st January 2007; about three years after roll out of ART began in this area in South Africa. The purpose of the second cohort was to include women with 'unknown' HIV status who were omitted from the initial open cohort due to non-participation in Africa Centre HIV surveillance testing and to investigate incidence of live birth, and associated factors, in the general population of women resident in the Hlabisa area. Finally, section 4.4 presented an analysis of

incidence of contraceptive use and associated factors amongst all resident women in the closed cohort presented in section 4.3 (Section 4.4).

Primary qualitative data from 23 client, 12 health worker semi-structured interviews, and observations of five primary health care clinics within or close to the demographic surveillance area were reported in Chapters Five and Six, to provide a context for the quantitative results on the incidence of live birth in Hlabisa. These interviews were conducted from October until December of 2012 and describe attitudes to childbearing in an established HIV programme. Section 5.3 presented results of semi-structured interviews exploring childbearing desires on ART and section 5.4 followed with themes influencing women's desires to have or avoid more children. Finally Chapter Six presented results from these semi-structured interviews alongside observations at each of the five PHC clinics to explore structural facilitators and barriers to family planning within the HIV continuum of care.

Table 7.1 Summary of key findings

Objective	Hypotheses	Method / section	Key findings
To investigate whether use of ART is associated with likelihood of a live birth in Hlabisa, KwaZulu-Natal.	Birth rates will be lower in HIV positive women compared to HIV negative women.	Section 4.1	Annual CBR was lower in HIV positive than HIV negative women during a consistent decline in CBR between 2005 and 2012 and a brief stall in decline between 2010 and 2011. Women with missing HIV status experienced CBR similar to HIV positive women.
		Section 4.2	HIV positive status was associated with a 61% reduced annual risk of live birth (aHR, 0.39; 95% 0.347 – 0.441) in multivariable Poisson regression adjusted for significant proximate and distal determinants of fertility.
		Section 4.3	HIV positive status is associated with a 57% reduced annual risk of live birth (aHR, 0.47; 95% 0.649 – 0.817) in multivariable Cox regression adjusted for significant proximate and distal determinants of fertility.
	Incidence of live birth has increased amongst HIV positive women since ART roll out, comparable to the general population.	Section 4.1	A decline in CBR followed a steeper gradient amongst HIV positive women between 2005 and 2012 (m=-5.73, R2=0.913) than in women that were HIV negative at that time (m= -2.97, R2=0.398).
		Section 4.2	Calendar year of surveillance was significantly associated with incidence of live birth in univariate analysis but no trend was identified. This association was no longer significant when stratified by HIV status or in analysis adjusted for other proximate and distal factors associated with fertility.
	Incidence of live birth will be higher amongst HIV positive women after exposure to ART, between comparable age groups and health	Section 4.2	Exposure to ART was associated with a 38% reduced risk of live birth (aHR, 0.62; 95% 0.487 – 0.799) in multivariable Poisson regression of HIV positive women adjusted for age, CD4 categories, self-reported general health and other significant determinants of fertility.
		Section 4.3	Exposure to ART was associated with a 47% reduced risk of live birth (aHR, 0.53; 95% 0.39 – 0.73) in multivariable Cox regression limited to HIV positive women adjusted for proximate and distal determinants of fertility. Exposure to ART was associated with a 26% reduced risk of live birth in adjusted Cox analysis of all resident women, irrespective of participation in HIV surveillance. However, this model violated Cox proportional hazards assumption before stratification by HIV status.
	Exposure to ART will encourage women to resume postponed childbearing at older ages	Section 4.1	HIV negative women demonstrated bimodal patterns of fertility peaking at 15-19 years and 30-34 years old. The same trend was not found in HIV positive women, except for an increase in incidence at age 35-39 years old between 2006 and 2011.
		Section 4.2	The same bimodal peak in live birth was observed in 15-19 years old and 30-34 years old to HIV negative women and this bimodal trend was not found in episodes to HIV positive women adjusted by calendar year.
	Differences in birth-free survival on ART are most likely to be	Section 4.2	Contraceptive use was associated with a 65% reduced risk of live birth in adjusted analysis of HIV positive women (aHR, 0.35; 95% 0.250 – 0.489). Missing data on this variable was not at random, as HIV positive non-responders experienced rates of live birth four times lower than HIV negative women (3.3 births per 100 HIV positive women

	due to altered use of contraception in this setting of high prevalence.		[95% CI 2.9-3.7] compared to 13.1 births per 100 HIV negative women [95% CI 12.3-14.0]).
		Section 4.3	Contraceptive use was associated with 49% reduced risk of live birth in univariate analysis of all women (aHR, 0.51; 95% 0.437 – 0.600).
		Section 4.4	HIV infected women were 10% less likely to use any modern method of contraception at last sex, compared to HIV negative women. Women reporting excellent, good or very good health were 40% more likely to use contraception.
	Women on ART will increase childbearing due to improved immunological or perceived health when aware of their HIV status	Section 4.2	Knowledge of own HIV status was associated with a 46% reduced risk of live birth in adjusted analysis (aHR, 0.64; 95% 0.509 – 0.792) but was not significantly associated in an analysis of only HIV positive women, suggesting differences in behaviour according to knowledge of being HIV negative compared to HIV positive women (aHR, 1.00; 95% 0.757 – 1.332). Excellent, good or very good self-reported health was associated with doubled risk of live birth in univariate analysis of all women (aHR, 2.03; 95% 1.682 – 2.445) but risk became non-significant once adjusted for other determinants (aHR, 0.98; 95% 0.806 – 1.184) (page 171). CD4 count was not associated with incidence of live birth in a stratified univariate or multivariable analysis of HIV positive women, or following ART initiation ($p=0.2898$) (page 150).
		Section 4.3	Self-reported health was not associated with likelihood of live birth in this cohort, although HIV positive women were less likely to report being in good health compared to women with an unknown HIV status. This analysis also found no trend for an effect of CD4 count.
Explore the family planning needs and expectations of women on ART under current provincial guidelines for the provision of contraception and safe conception	Women on ART may desire more children either now or in the future	Section 5.3	Lifetime aspirations for small family amongst women did not change on ART. Women had largely fulfilled their reproductive desires. Of twenty-three women, six said they would like to have a child either now or in the future while most did not wish to have a child either currently or at any time in the future.
	Women have ART-specific family planning needs	Section 5.4	Women said they would rather not take risks on their health but viewed this risk differently. The potential health impacts of being pregnant solidified women's desires not to have any more children. The importance of a partner's desire traditionally related to his payment of <i>isilobola</i> but women commonly considered childbearing outside of marriage with implicit expectations of financial support. Negative experiences of childbearing usually reflected situations when partners did not fulfil those expectations and women's health was threatened. A minority of women felt they could not avoid childbearing under cultural expectations, usually when married. Other women wished to have more children sometime in the future.
		Section 6.3	Women preferred long acting and easy to use methods. Some believed that use of ART meant they did not need contraception. Side effects were significant barriers to use of injectable contraception and many women 'took a break' due to concerns about the severity and risk to health. Long-term alternatives to injectable contraception were not widely available, although the IUCD had been recently rolled out at the time of study.

services to women on ART.

Section 6.4

Women who had been pregnant in the program said they did not plan for pregnancies while HIV positive or on ART, a view supported by health workers. Pregnancies were often viewed as unplanned if not well timed, if women experienced poor health, or because partners did not support them. Health workers advised women on ART to time pregnancies according to an appropriate CD4 level but women said they found advice limited and difficult to follow.

Determine where women on ART currently access family planning services, their experiences with them and whether their needs are being met

The family planning needs of women on ART can be addressed in a 'one-stop-shop' continuum of HIV care

Section 6.4

One-stop-shop delivery of injectables and ART facilitated ease of access and helped to alleviate concerns for stigma. Women also sought non-governmental condoms from pharmacies and abortion services from newspaper adverts, while traditional methods and modern medicines were sometimes used inappropriately as emergency contraception.

Structural barriers may result in unplanned pregnancies on ART

Section 6.4

Contraception and ART were typically administered during a single client consultation. Where services were not available, referrals were not formalised and women were required to queue again at the main PHC building. Side effects of injectables often led to discontinuation. Partial facility level integration neglected aspects of family planning, such as monitoring of contraceptive adherence and information, education and counselling in the HIV continuum of care.

7.3 HIV infection and exposure to ART were associated with reduced likelihood of live birth

A mixed methodology investigation found reduced likelihood of live birth to HIV positive women after they initiated ART, between 2005 and 2012, which is consistent with qualitative reports from women who prefer to avoid childbearing on ART. Consistent with the literature (chapter Two), this study found a substantially lower likelihood of a live birth in HIV positive than HIV negative women: HIV positive status was associated with a **61% reduced likelihood** of live birth between 2007 and 2012, in the analysis of approximately 10,000 women of known HIV status in the Hlabisa sub-district, adjusted for significant demographic, relationship and health-related factors.

Contrary to the study hypothesis, and recent studies, women on ART experienced sequentially lower likelihood of live birth over time compared to ART-naïve HIV positive women, HIV negative women and women whose HIV status was not reported during HIV surveillance. In analysis adjusted for demographic characteristics such as age and parity, and proximate and distal determinants of fertility, such as partnership and contraceptive use, exposure to ART was associated with a **38% reduced likelihood** of live birth compared to ART-naïve HIV positive women. Women on ART and ART-naïve HIV positive women experienced consistently lower likelihood of having a live birth along similar trends as HIV negative women at similar age, parity and area of residence.

These findings add to an established body of evidence showing lower fertility in HIV positive women below that of HIV negative women. It found no evidence that ART is associated with increased fertility amongst HIV positive women in an analysis starting three years after national scale up or ART began, but in a setting where fertility is low and HIV and ART common.

7.4 Factors associated with lower likelihood of live birth and desires for future childbearing

Decreased likelihood of live birth amongst HIV positive women was associated with changes in perceptions of health and reproductive behaviours that suggest a preference to preserve health. A quantitative analytical framework presented in Figure 3.2 describes the hypothesised effect of HIV status upon proximate and distal determinants of a live birth. The pathway assumes that awareness

of an HIV positive diagnosis would influence perspectives towards health and relationships that in turn would mediate changes in pregnancy desire, resulting in changes to contraceptive use and live birth outcomes. Age and parity may confound this effect, as HIV positive women and women on ART are typically older and may already have children. This thesis showed evidence to suggest that perspectives towards own health may influence childbearing desires, but provided no evidence that HIV positive women alter their contraceptive use in response to childbearing desires. Two cohort analyses and 23 semi-structured interviews with clients of the HIV programme suggest that women on ART may avoid partnerships to limit childbearing: in cohort analyses, HIV positive women were less likely to experience a live birth outside of a regular relationship, while during interviews women said they had come to prioritise their own health, and fears of a negative health impact strengthened their pre-existing resolve to have no more children, although health usually took priority only after they were satisfied with the current number of children. A discussion on the effect of relationship, demographic and health factors described in the analytical framework is summarised below and then applied to the wider literature in section 7.6.

Socio-cultural and economic factors play an important role in shaping desires for small family size that are related, but not limited, to their health on ART. Most felt that male partners did, or would come to, expect children and women usually asserted individual control of fertility through injectable use in the meantime. Some women who felt they had enough children already, preferred to avoid relationships and traditional expectations of childbearing completely (Section 5.3). A closed cohort analysis (section 4.3) showed HIV positive women may be less likely to enter regular relationships or are less likely to engage in risky sexual practice during 'single' periods compared to the general population, including women with missing information about their HIV status: HIV 'unknown' women were most likely to be in a relationship but experienced highest incidence of live birth when reporting to be single, compared to lower likelihood when in a regular relationship (aHR, 0.164; 95% 0.131 – 0.205). Conversely, HIV positive women were more likely to be single than HIV unknown women and risk of live birth was proportionally higher in HIV positive women when in a regular relationship (aHR, 1.64; 95% 1.053 – 2.552) or married (aHR, 2.36; 95% 1.195 – 4.648) compared to being single.

Rates of marriage were low, with only 15% of women married by ages 45-49 and significantly fewer at younger ages (Section 4.1). Marriage is a poor indicator of fertility in this setting and women

discussed changeable relationships and previous pregnancy experiences as important issues influencing future decisions to have a child (section 5.4). In the open cohort, most births occurred to unmarried women with a regular partner (section 4.2) and typically women with a regular partner were 40% more likely to have a live birth compared to single women (aHR, 1.40; 95% 1.216 – 1.613). HIV positive women were disproportionately more likely to give birth only when in a regular relationship than when being single (aHR, 2.34; 95% 1.772 – 3.087) while no women on ART gave birth in a casual relationship. While HIV positive women had consistently lower birth rates than HIV negative women (aHR, 0.73; 95% 0.62 – 0.855), incidence was similar amongst women co-residing with their partners, irrespective of HIV status, indicating that a reduction in fertility can be attributed to women outside of established partnerships i.e. a regular partner or living together.

As expected, women used contraception to avoid childbearing. Contraceptive use was associated with reduced incidence of live birth in both cohort analyses: contraceptive use was associated with a 54% reduced risk of live birth in the open cohort analysis (aHR, 0.46; 95% 0.388 – 0.534) and a similar, 49%, reduced risk of live birth in the closed cohort analysis which included women of unknown HIV status (aHR, 0.51; 95% 0.437 – 0.600). Also, the lowest incidence was seen in women using injectable and dual contraceptive methods. In an analysis limited to HIV positive women and adjusted for demographic characteristics and proximate determinants of fertility, contraceptive use was associated with a 65% reduced risk of live birth (aHR, 0.35; 95% 0.250 – 0.489) (Section 4.2), indicating that HIV positive women regulate their fertility through contraceptive use. The association between contraception and live birth may be lower when including missing women who appear more sexually active but this variable could not be included in the closed cohort multivariable analysis, as it did not meet the proportional hazards assumption.

Response to this question of contraceptive use reflected variation in sexual activity in a sub-analysis where likelihood of contraceptive use was the outcome (Section 4.4). Not co-residing with a partner was associated with higher likelihood of contraceptive use and so women appeared more sexually active or report more protective sexual behaviour when not living with a partner. HIV positive women were 10% less likely to engage in contraceptive use and appeared more likely not to answer this question due to lower sexual activity compared to HIV negative women. Women reporting themselves as in good, very good or excellent health were 40% more likely to use contraception (table 7.1).

Women on ART tended to be older but otherwise very similar to other women in Hlabisa. Trends and patterns of birth rates in women on ART by demographic determinants of fertility were similar to that in the general population of women in Hlabisa. For all women, incidence decreased with increasing age group, higher parity and an urban residency. Being aware of one's own HIV status, awareness of the benefits of ART and low perceptions of well-being were associated with lower incidence of birth and all women were less likely to give birth while single or engaged/married, not living with a partner or using contraception and particularly, selecting injectable methods of contraception.

Semi-structured interviews support these findings and, although limited to women on ART, key themes relating to economic and relationship uncertainties appear applicable to all women living in the Hlabisa sub-district (Hosegood et al., 2009). These interviews touched upon multiple factors that women on ART discussed in the relation to their decisions to have or avoid another child that is fitting with a framework that captures the complexity of decisions such as the Health Belief Model for contraceptive behaviour discussed in Chapter Two (page 45). An adapted model for women living with HIV and on ART in Hlabisa is presented at the end of Chapter Six (page 246) and frames the decision to use contraception as an on-going cost-benefit analysis that constantly balances the risk of a pregnancy against adverse side effects of injectable contraceptive use. Structural, familial and partner support can also serve to modify contraceptive behaviour in different directions, and indicates reasons why behaviours may not neatly follow reported desires. Previous relationships and current partners were discussed as an important theme during interviews and it is likely that disclosure of HIV status to partner or a partner's enrolment in to a HIV treatment and care programme are important proximate behavioural determinants of live birth that were not measured in this surveillance.

7.5 Comparability of two quantitative cohorts and qualitative methods

Incidence and factors associated with likelihood of live birth were similar in the two quantitative cohort analyses. An open cohort measured the relative risk between HIV negative and HIV positive women according to a range of demographic factors and determinants of fertility (Section 4.2) and a

second closed cohort analysis included women whose information about HIV status is missing from the DSS since entry in 2007 or 2008 (Section 4.3).

Women with missing HIV data are of 'unknown' HIV statuses because their information is not known to the DSS, even though women may themselves know their HIV status. These women with an unknown HIV status were demographically similar to HIV negative women, with higher proportions in a relationship, reporting current use of contraception and being in good health, compared to HIV positive women. Likelihood of a live birth was highest amongst women of 'unknown' HIV status, of all three HIV categories, and not significantly different to HIV negative women in multivariable analysis.

The incidence and trends in likelihood of live birth were comparable between HIV negative and HIV 'unknown' women in a closed cohort analysis (Section 4.3). Incidence was highest in women that did not participate in HIV surveillance testing in these years, at 9 births/100wy and not significantly different from HIV negative women in multivariable analysis. Women may not participate in HIV surveillance for a number of reasons such as they have tested in previous years and do not wish to test again, or have tested elsewhere and are already aware of status. Women are routinely tested during antenatal care and so any woman that had a child since 2001 would likely be aware of their status, while HIV positive women that already know their status may be less willing to test repeatedly. Analysis showed that these women without DSS data for HIV status showed similar characteristics to HIV negative women. A total of 75% of women-years in the analysis were to women whose HIV status was known to surveillance and consequently, open cohort analysis findings of reduced risk of live birth to women on ART were comparable not only to HIV negative women (Section 4.2), but the general population of women resident in Hlabisa (Section 4.3).

In a closed cohort of all resident women followed from entry in 2007 or 2008 until cohort censorship in 2012 or loss to follow up, HIV positive women experienced a 58% reduced risk compared to HIV negative women when adjusting for the inclusion of women with missing HIV data. HIV positive women composed about a third of the surveillance population, and were less likely to experience a live birth than the general population of women residing in Hlabisa. However, this finding should be interpreted with care, due to a violation of the Cox proportional hazards model when including all women. Analyses were stratified by HIV status to describe factors associated with incidence of live

birth in a closed cohort of all resident women, while the open cohort in section 4.2 provides more reliable measures of incidence of, and factors associated with, live birth, generalised to the setting.

Incidence of live birth was generally highest in non-responders across a range of variables. In non-responders, higher incidence was associated with self-reported health, HIV status, knowledge of HIV status, co-residency with partner and awareness of the benefits of ART. Higher rates in these categories may reflect less care seeking or more risky sexual behaviour.

Women were eligible to entry into quantitative cohorts from 1st January 2007; about three years after ART started to roll out in South Africa, and followed until censoring in 2012 or loss to follow up. Consequently, these analyses describe an effect that is more proximate to the start of roll out of ART than primary qualitative interviews that began in October of 2012. Despite this lag in time, findings are largely comparable, finding no evidence of ART being associated with increased childbearing and a preference to limit childbearing by time women enter HIV treatment and care. There were, however, nuances at earlier ages. HIV negative women typically experienced a peak in fertility at ages 15-19 and a subsequent decline with age that is attributed with postponement of childbearing, until a second peak in fertility at older ages of 30-34 years old. The absence of a bimodal trend in HIV positive women suggested that these women are limiting their childbearing at older ages. However, there was a small but substantial resumption of postponed childbearing amongst HIV positive women at ages 35-39 between 2006 and 2012, soon after ART was rolled out.

7.6 Comparison of study findings with the literature

7.6.1 Association between HIV and pregnancy or live birth outcome

An estimated 61% reduced risk of live birth in HIV positive compared to HIV negative women implies a larger reduction than previous estimated effects of HIV on population fertility of 25-40%, calculated using census data from 13 African countries (Juhn et al., 2008) and mathematical models of population-attributable decline in total fertility in Uganda (Lewis et al., 2004) but is smaller than other estimates of population-attributable decline in fertility in South Africa (Young, 2005). Assorted

measures of the impact are likely due to a number of methodological differences, outcomes and variation in settings, and in particular a greater national TFR in Uganda compared to South Africa.

In 2005 Young estimated that high HIV-associated mortality in men and women of reproductive age would effectively remove a cohort of potential childbearing adults. Young speculated that the South Africa population would reach 110 million by 2050. Instead the population has remained below 50 million for almost 50 years (Young, 2005). Demographic health surveys have been utilised to compare fertility between HIV negative and HIV positive women and evaluate local community HIV prevalence effects on population fertility, including changes in fertility of non-HIV infected women (Young, 2005, Juhn et al., 2008). The aggregate impact of HIV is of demographic interest and has implications for economic development across sub-Saharan Africa (Lewis et al., 2004). An estimated 25-40% lower fertility in HIV positive women was based on two reviews of studies from the pre-ART era, totalling 19 studies, used to estimate a population-attributable change in total fertility (PACTF) (Zaba and Gregson, 1998, Lewis et al., 2004). Four of the 19 studies used in this model were cohort studies and were used to calculate 5-year age group differentials in birth rate between HIV infected and uninfected women. Fifteen studies were used to calculate differences in pregnancy risk and relative odds of infection. The PACTF was calculated from the age-specific HIV prevalence and fertility rates. However, the method employed to model an effect in these two reviews was highly limited in scope. Both papers assume a constant effect of HIV on fertility that remains 'fixed over age and time' although authors recognised the absence of common determinants of HIV and fertility such as contraceptive use, marital status and the underlying burden of sexually transmitted diseases (Lewis et al., 2004, Zaba and Gregson, 1998). These unadjusted analyses are not likely to reflect the 'true' effect of HIV on fertility in the absence of ART, or offer accurate comparison to findings from this thesis.

This thesis used individual data to measure the effect of a woman's ART use on fertility as in recent studies (Juhn et al., 2008), but did not take into account an effect of reducing mortality on the risk of fertility as measured by community HIV prevalence (Young, 2005). Literature of cohort estimates from the pre-ART era shows variation in sample size and duration of follow up. In Uganda, around 3500 women of reproductive age in a rural population-based cohort were followed over seven survey rounds and fertility in HIV positive women was 0.74 (95% CI 0.63, 0.87) that of HIV negative women when adjusted for age (Carpenter et al., 1997). In a smaller study, 238 HIV positive women

and 315 HIV negative women were followed for three years in Zaire, now DRC, and described unadjusted and consistently lower fertility rates amongst HIV positive women (Ryder et al., 1991). Cohort studies measure individual incidence and can provide stronger evidence for physiological or behavioural causation than cross-sectional DHS rounds. The open cohort in section 4.2 measured live birth amongst almost 10,000 women between 2005 and 2012, a time when ART was being rolled-out, and considered an individual time 'at-risk' as the denominator, attributed to a range of demographic factors and proximate determinants of fertility in an adjusted analysis. Consequently, the estimated 61% reduced risk of a live birth is likely to provide a reliable estimate of the individual association between HIV, ART and fertility in this setting of low TFR. Furthermore, this study offers evidence that HIV positive women still experience greatly reduced likelihood of live birth in an era of ART.

Information about pregnancy outcomes was limited in the surveillance data used for the analyses in this thesis. Pregnancies were identified through annual surveillance and after birth according to reports from the head of the household or key informant. As such, pregnancies that did not end in a live birth were likely to be under-reported. Live birth as an outcome in this study provides a truer description of the outcome being measured but requires careful interpretation when compared to other studies that report pregnancy as an outcome.

7.6.2 Association between exposure to ART and pregnancy or live birth outcome

A review of the literature identified only three published studies from sub-Saharan Africa comparing pregnancy or live birth outcomes of women on ART against pre-ART women. Two of the three studies measured pregnancy as an outcome and used the estimated date of conception as the incident date. Both studies found higher likelihood of pregnancy amongst HIV positive women exposed to ART: Myer et al reported a 74% increased likelihood of pregnancy in a multi-country study, and an even stronger association in South Africa alone (Myer et al., 2010) and Makumbi et al reported a 46% greater likelihood of pregnancy on ART compared to pre-ART women from Uganda (Makumbi et al., 2011) (see Table 2.2, page 66). Neither study reported the proportion of pregnancies that ended in live birth as opposed to stillbirth, miscarriage, or TOP. Both these studies

show increased incidence of pregnancy on ART associated with lower age, being married, no contraceptive use, lower parity and higher CD4 at screening.

The third study, also from Uganda, compared odds of live birth and pregnancy outcomes according to ART exposure (Maier et al., 2009). Findings presented in this thesis are contrary to the higher likelihood of live birth on ART reported by Makumbi and Myer, and more consistent with results published by Maier et al of 70% lower odds of live birth and 44% lower odds of pregnancy to women that had initiated ART compared to pre-ART women. Maier et al enrolled 501 women attending a HIV clinic in Uganda and recorded self-reported pregnancy and pregnancy outcomes in the last three years, although incidence of stillbirths and miscarriage were not reported. They also conducted a cross-sectional survey of pregnancy intentions and found that women on ART actually had increased odds of planning a pregnancy in the future despite a lower likelihood of live birth or pregnancy (Maier et al., 2009). These three studies may potentially suffer from selection bias due to use of clinic-based population data (Galiwango et al., 2013). A limitation of clinical studies is that pre-ART counterfactuals are also selected from the clinic but have entered care for reasons of poor health that are not measured and could be independently associated with fertility.

All three studies commenced soon after ART became nationally available and ended prior to changes in WHO recommendations to raise eligibility from a $CD4^+ \leq 200 \text{ cells}/\mu\text{l}$ to $CD4^+ \leq 350 \text{ cells}/\mu\text{l}$ in 2010. It is possible that the increased likelihood in fertility thus measures an early response to ART rollout, in women who initiated ART only at advanced HIV progression. Myer et al evaluated the effect of ART in multiple countries in Southern Africa between 2003 and 2007, and although the year of study was not noted by Makumbi et al, women initiated ART at a $CD4^+ \leq 250 \text{ cells}/\mu\text{l}$ in a program launched in 2004 and before the manuscript was submitted in 2010. Finally, Maier et al presented cross-sectional data that included the fertility histories of women on ART that spanned 3 years prior to enrolment in the study between November 2005 and June 2006. The three aforementioned studies therefore follow women from initiation of ART at lower immunological measures of health than for women included in this cohort after 2010. Furthermore, women 'on-ART' were included at any time since they initiated ART in any year of this cohort. Studies reporting fertility amongst women that enrolled on ART at a $CD4^+ \leq 250 \text{ cells}/\mu\text{l}$ are likely to report greater and more rapid immunological restoration subsequent to initiation and are therefore more likely to measure a vast relative difference in fertility according to physiological improvements.

Fertility rates in KwaZulu-Natal are high compared to Johannesburg but crude birth rates have declined in this setting in the past decades (Section 4.1) (Moultrie et al., 2008b), and the overall total fertility rate in this setting is low. Incidence of live birth to women in Hlabisa was double in rural areas of residence compared to urban settings and is consistent with lower overall incidence of pregnancy in three urban South African study sites included in the Myer study. Myer et al analysed 4,531 records from HIV positive women enrolled in the mother-to-child transmission programme in seven sub-Saharan African countries and the median number of women enrolled at each site was 410 (range, 211-666). Several design factors were likely to bias towards higher increase in fertility. Both pre-ART and on-ART women had received PMTCT for a recent pregnancy and so eligibility for this study may be biased towards women with established fertility, by virtue of having a recent pregnancy. Also, median age in this study was 27, much lower than a median age of ART-naïve (31 years) and ART-exposed (37 years) in the closed cohort analysis presented in section 4.3. Myer et al report that 26% of pregnancies did not result in a live birth, lower than reported by another study from Johannesburg, where 47% of pregnancies to HIV positive women were not carried to term (Schwartz et al., 2012). HIV is associated with adverse pregnancy outcomes in these studies and a wider review of the literature (Chapter 2) and so it is possible that a reduced risk of live birth to HIV positive women described in chapter 4 may reflect a disproportionately higher incidence of infecundity, stillbirth, miscarriage or termination of pregnancies to HIV positive women during a pregnancy. A comparison of these studies suggests that women selected for analysis in this Myer study were in a more fertile age category and were less likely to be at risk of infertility than the general population of Hlabisa. The study by Myer et al did not report on fertility intentions and so such inferences would be difficult to make.

Differences in reported effect of ART are likely due to programme and study design, adjustments made in multivariable analysis and importantly, demographic or cultural characteristics. Makumbi et al. excluded women that reported use of Depo-Provera within 2 months of entry, while women were included in this thesis study cohorts irrespective of contraceptive use. A total of 712 pre-ART and 244 women initiating ART were enrolled in to a PEPFAR funded HIV treatment and care programme where family planning activities were a programmatic priority and regularly monitored. Exclusion of women using injectable contraception may result in increased fertility on ART that is attributed to physiological improvements in health, than would otherwise be reported if the analysis was adjusted for the behavioural mechanisms through which ART may reduce fertility. Total Fertility Rates are

higher in Uganda compared to South Africa and prevalent desires to have more children and improved immune status were both risk factors associated with higher incidence of pregnancy amongst women on ART (Makumbi et al., 2011).

7.6.3 Immunological restoration of health and self-perceived health on ART

Studies have found higher incidence of pregnancy following immune restoration after initiation of ART, but unlike Makumbi et al, these do not compare incidence with pre-ART women or adjust for reported fertility desires. This thesis did not compare incidence of live birth according to duration of ART use, but one clinical study from Johannesburg found increasing incidence of pregnancy up to 6 years after initiation and lower rates of incident pregnancy with decreasing CD4⁺ cells/ μ l (Westreich et al., 2012). An important limitation of this latter study is a lack of adjustment for sexual activity or contraceptive use that may explain behavioural differences between studies.

Incidence of live birth declined cumulatively following initiation on ART, consistent with more literature from Uganda of lower incidence of birth or pregnancy after more than 12 months from initiation on to ART (Kaida et al., 2013). Kaida et al reported a peak in pregnancy rates after 6-12 months following initiation and thereafter a decline. Although the Kaida study did not report on fertility intentions, another paper from the same study group found that 85% of women did not intend to become pregnant (Snow et al., 2013). Recurrent (second or third pregnancies) to women on ART resulted in resurgent peaks in pregnancy incidence at 24 and 48 months after initiation of ART. In Johannesburg, multiple pregnancies were particularly common amongst women aged 30-35 years old (Westreich et al., 2012). In contrast, this thesis observed very few (38) recurrent births in a cohort including HIV negative and HIV positive women between 2007 and 2012, and given the long birth intervals and low total fertility rate in this area, low incidence of recurrent pregnancies was to be expected. Follow up of individual women for the entirety of the cohort was rare however: the cohort design was open and half of the sample entered in years after 2007, internal and external migratory patterns were common and some women were lost to follow up, while not all women participated in the HIV surveillance in all years and were categorised as 'missing' and excluded from further analysis. As a consequence, median follow up was only 1.97 years per woman and was therefore unlikely to capture recurrent births in a setting where long birth intervals are common. However, this study did determine increased incidence of childbearing to HIV positive women aged 35-39 years old between 2006 and 2011 and a 38% higher incidence of live birth amongst 25-29

years old when on ART compared to pre-ART, which is contrary to the overall trend of lower likelihood on-ART in all other age groups. These findings suggest that while HIV positive women are less likely to give birth than women in the general population, women do tend to resume childbearing at older ages and the age at which women on ART resume childbearing may be lowering. Such an interpretation is consistent with what other authors have described as the 'now or never' phenomenon of childbearing on ART (Hayford et al., 2012).

Immune restoration after initiation with ART was not associated with an increase in live birth incidence in HIV infected women this area. However, there was limited statistical power for this analysis as CD4 cell count information was missing for approximately 40% of the HIV infected women, and repeat CD4 counts were frequently not available for women on ART. Further, the CD4 count is unlikely to correspond closely to the time of conception of the incident pregnancy. The most proximate CD4 measure from within 6 months of the HIV surveillance visit date was linked from the clinical ARTemis database to a demographic cohort. This value will correspond to CD4 at initiation in time updated analysis of women observed to initiate ART during the cohort time frame but otherwise provides a more distal measure of baseline CD4 than clinical studies. Consequently, this study can say little about the issue of immunological restoration, which is better explored in clinic-based studies.

Awareness of being HIV positive appeared to influence women's behaviour. Knowledge of own HIV status was associated with a 46% reduced risk of live birth in adjusted analysis (aHR, 0.64; 95% 0.509 – 0.792) but knowledge was not significantly associated with a live birth in an analysis restricted to HIV positive women (aHR, 1.00; 95% 0.757 – 1.332). Knowledge of being HIV negative compared to HIV positive thus appears to influence behaviour differently, as might be expected. Awareness of ART was common and was not associated with live birth rates in either univariate or adjusted analysis.

Incidence of live birth was highest to all women self-reporting good, very good or excellent health. Results suggest that HIV positive women may protect good health through contraceptive use (Section 4.4) but do follow clinical recommendations to plan for pregnancies according to an appropriate CD4 count (Section 6.3). The risk to health that another pregnancy could pose was a determined as a key theme in semi-structured interviews. Adverse side effects of injectable contraception were uncomfortable and occasionally viewed as risky to health, something that was

highly valued by women on ART (Section 5.3). Excellent, good or very good self-reported health was associated with doubled risk of live birth in univariate analysis of all women (aHR, 2.03; 95% 1.682 – 2.445) but this association became non-significant once adjusted for other determinants (aHR, 0.98; 95% 0.806 – 1.184) (page 171). These findings suggest that the association between health and incidence of live birth is confounded by the inclusion of other proximate and distal determinants of fertility that may act downstream on the causal pathway, such as contraceptive use and actual HIV status.

One other study included subjective well-being as a variable of interest in the association between ART and fertility (Maier et al., 2009). Maier et al found that a 'very good or excellent' self-assessed health status was more likely to be reported by ART-naïve women but was not significantly associated with unadjusted odds of live birth in Uganda (adOR 1.61 95% CI 0.95, 2.71) (Maier et al., 2009). The five levels of response in the Maier study were identical to those in this study (Excellent, Very Good, Good, Fair, Poor) and also grouped in to a positive vs. negative health variable, as in this thesis. The difference in significance between the studies and this thesis may be attributable to author subjectivity and inclusion of 'Good' in the counter-factual 'negative' group as opposed to the 'positive health' group. It is also likely to be a slightly biased measure of well-being, as the indicator was recorded at baseline in a cross sectional survey of incident births up to three years prior. Furthermore, perceptions of well-being attributable to a HIV diagnosis can vary culturally, and particularly contrast between older people living in Uganda and South Africa (Nyirenda et al., 2013). Despite lower functional ability and higher rates of obesity, hypertension and unemployment, older people living with HIV reported greater subjective well-being in South Africa compared to Ugandans when adjusted for multiple socio-demographic factors. This unusual finding was attributed to the availability of social services for older people in South Africa, such as the pension (Nyirenda et al., 2013). 'Self-reported' health was a reliable predictor of actual health and mortality of people living in Hlabisa (Olgati et al., 2012) and results from this thesis suggests that perceived health may be a more appropriate indicator of live birth after ART initiation. Kaida et al found that maternal mental health was not associated with the hazard of pregnancy after initiation on ART, while physical health as measured by a Medical Outcomes Study HIV Health Survey score, was of borderline significance in unadjusted analysis and not included for multivariable analysis of women also living in Uganda (Kaida et al., 2013).

7.6.4 Desires to postpone or avoid childbearing on ART, in a context of low fertility

This study found little evidence to suggest that women had changed their desired family size in response to diagnosis with HIV or initiation on ART. The finding is not surprising in a setting where national TFR is just over 2. In two cohort analyses, incidence of live birth declined significantly with parity. Chapter 5 reported strong preferences not to have another child, according to social norms for an ideal family size of two or three children. All interview participants had living children and none wished to have another child if they had two or more. Few women changed their optimal family size to between two or three children and were not dramatically different from women whose desires had not changed.

The childbearing desires described in this study may well represent the views of women that had mostly achieved their desired family size, within existing social norms. Women discussed a combination of factors, often operating simultaneously, that influence their own desires, including; previous experiences of childbearing and partner abandonment, current economic and relationship uncertainties, expectations of finding a partner and the cultural expectations of childbearing that payment of *isilobola* and marriage could bring. These perspectives were most often reported by women who felt satisfied with the number of children they already had and who viewed further childbearing as 'risky'.

A group of six women said they would like to have a child in the future, in accordance with prevailing desires for childbearing on ART also reported in Cape Town (Myer et al., 2007, Cooper et al., 2009). They considered that these desires would be susceptible to change, as relationships and circumstances evolved. Of these six women, none had discussed their previous pregnancies at the clinic. In South Africa women traditionally limit fertility through injectable contraceptive use but elements of family planning such as planning for a safer conception and inclusion of male partners have been missing. Male perspectives of planning were not addressed in this thesis and a study of the effect of ART on planning for a child in Hlabisa is therefore limited to women's own experiences. In Uganda, a desire for more children was an important determinant of higher fertility when either the male partner wished to have a child or both the woman and male partner wished to have a child, compared to just the woman alone (Makumbi et al., 2011). These results provide evidence of the value of male perspectives in future studies.

Semi-structured interviews showed that women treated HIV as a manageable chronic condition, upon condition of correct adherence to ART. Women generally prioritised the decision to look after their own health after social norms for childbearing had been achieved. Findings were in agreement with literature that found adherence to ART can encourage positive perceptions of feeling healthy (Awiti Ujiji et al., 2010), and other studies describing partner desires for a child as a strong influence women's own childbearing desires and likelihood of a live birth, elsewhere (Makumbi et al., 2011, Berhan, 2008) and in this setting (McGrath et al., 2011, McGrath et al., 2013).

Maier et al reported health preservation behaviours amongst women on ART, who were more likely to have disclosed their serostatus to a partner and were more likely to have used contraception or abstained from sex during the three months before survey, compared to ART-naive women. This thesis that show HIV positive women were disproportionately less likely to give birth in 'less formal' relationships (single, in a casual relationship or not living with a partner) compared to HIV negative women and common preferences to avoid childbearing on ART.

Most childbearing occurred when women were not married or living with their partners, due to the unaffordability of marriage and home ownership in this setting. Marriage rates in Hlabisa are low (13%) and did not significantly predict birth rates overall. Women were also well in to their reproductive lives by the time they came to live with their partners, with a median parity of four children. Modern relationship dynamics appear to provide some autonomy to allow women to limit their fertility before marriage, which was highly valued although rare. During interviews, marriage was viewed as a distal time that women would culturally 'need' or 'give' a child. Qualitative results suggest an anticipated 'need' to give a child was often contradictory to personal preferences to limit childbearing. These accounts may describe a prevailing respect for traditional expectations of fertility and marriage but also a preference of women on ART to limit their own childbearing in the meantime. Indeed, likelihood of live birth doubled amongst married, compared to unmarried, HIV positive women in an adjusted analysis. This increase is contrary to the general trend of lower fertility after marriage and could reflect the greater autonomy of single HIV positive women to limit their childbearing.

Incidence of live birth was lower to women on ART when in a casual relationship or single. This finding suggests that these women are either less sexually active or using more contraception. HIV positive women were 78% more likely to give birth if living with a partner than when not living with a

partner, converse to a cohort trend of lower incidence of live birth when women were cohabiting with a partner. Higher incidence of live birth to HIV positive women living with a partner is unlikely to suggest greater sexual activity amongst women already living with partners after a HIV diagnosis, but instead reflects that HIV positive women are having less unprotected sex when not living with a partner compared to HIV negative women. Semi-structured interviews showed that women on ART were aware of partner expectations of childbearing and in some cases actively chose to avoid entering into new relationships with expectations for more children. Marriage was rather considered by women on ART as a time they would consider an end to their postponement or desires to limit childbearing, whilst avoiding childbearing via contraceptive use or not entering in to another relationship in the meantime. Many of the women interviewed were indeed in a relationship and the cultural 'need' to have a child was more pressing when women did not already have a child with the current partner. In this setting where the concept of relationship status is fluid but masculine values for fatherhood remain strong, a more reliable indicator of the importance of childbearing desires could include whether the woman has a child with current partner, a measure that was not available in the Africa Centre Demographic Surveillance.

7.6.5 Contraceptive and Childbearing decisions on ART

The issue of planning is complex. Many women described their most recent pregnancy to be unplanned, in line with wider literature showing a high proportion of pregnancies to women on ART in South Africa to be unplanned (Schwartz et al., 2012). Health workers agreed with the view that women did not plan their pregnancies and rarely discussed their intentions at the clinic. Cohort analysis estimated an incidence of 3.1 births/100wy [2.3 – 4.2] to women on ART reporting to use contraception at last sex compared to 3.9 births/100wy [2.3 – 6.4] to women on ART not reporting to use contraception at last sex. This difference in incidence was non-significant and results suggest that lower incidence of live birth to women on ART may, in part, be due to lower sexual activity in non-contraceptive users rather than changes in actual use of contraception.

As expected, use of any modern method of contraception at last sex was associated with a 65% lower likelihood of live birth after adjusting for significant variables. Counter to the study hypothesis, however, HIV positive women did not report much difference in their contraceptive use and were

actually 10% less likely to report using contraception at last sex in this closed cohort of all resident women (Section 4.4). Contraceptive use was higher amongst women aged less than 24 years old, with a regular partner and not co-residing with their partner. Further, all women feeling in good, very good or excellent health, were 40% more likely to use contraception. Increased contraceptive use may represent greater sexual activity according to these indicators. In light of lower incidence amongst HIV positive women and women on ART, particularly when single or in less formal relationships, such findings may allude to less risky sexual behaviour amongst HIV positive women when independently charged with the decision to use contraception (i.e. not living with a partner). Furthermore, high incidence of both birth and contraceptive use amongst women reporting to be in good or very good health suggests that women may be choosing to protect restored health through contraceptive use, as described during interviews.

Rates of live birth were high in women reporting contraceptive use in all three HIV groupings. The prevalence of pregnancies amongst women reporting contraceptive use could be due to a time lapse between measurement of contraceptive use 'at last sex' and the actual date of conception. Contraceptive use at last sex was reportedly low (32%) but the large proportion of unknown responses (44%) limits the usefulness of an interpretation of this variable. Information about contraceptive use is recorded during the same annual surveillance round that HIV status is established and a live birth event occurred. In this cohort, women episodes are censored with a live birth event and consequently, contraceptive use could actually be recorded at a time that is either pre- or post-conception of a live birth.

Counter to the perspective that women do not plan, it seems that women are constantly considering their childbearing decisions as part of an evolving risk benefit analysis that is more in line with the health behaviour matrix described on page 246. And for many women on ART, the risk to health often outweighs the benefits of having another child and injectable contraceptive use forms a fundamental strategy to avoid childbearing. Key reasons that women considered previous pregnancies as unplanned were perceptions that the pregnancy had adversely affected her health, were not supported by partners and that contraceptive use was inconsistent at the time of conception.

Three-monthly injectable DMPA was the most common method of contraception reported by all women in this area, including women on ART. The issue of long-term injectable contraceptive use for

the postponement of childbearing raises important issues of side effects during very long birth intervals and sustainability in women on ART. Given the reportedly low desires for childbearing, the incidence of live birth amongst women on ART in this study seems relatively high. Qualitative descriptions of inconsistent injectable use were primarily attributed to a range of unpleasant side effects of these hormonal methods that raised health concerns on ART. A small group of women did indicate that they felt they did not need contraception by virtue of their ART use, as they did not predict being sexually active or they would be less able to conceive. Injectable contraception appears to play a key strategy for family planning, to avoid having a child when a woman's circumstances were not conducive to having a child at that time. Qualitative reports of the absence of planning thus seem to describe times when women cease to use injectables either for the purpose of childbearing, or to 'take a break', and remain sexually active without an explicit intent to have a child. This has wide implications for suitable alternatives to injectables for women on ART that do not wish to become pregnant, counselling to discuss side effects and for the assistance of women with preconception care for safer maternal and child outcomes. Women were aware that contraceptive methods were available but alternatives to injectable contraception did not suit the long term needs of women in this qualitative study. Women preferred being able to access long term methods at the clinic and use of methods that required little effort towards adherence, alongside minimal side effects. They reported favourable attitudes to the long lasting nature of the Intra Uterine Contraceptive Device despite being in the early stages of roll out, particularly as it may be used covertly and could be inserted in the clinic as an alternative to injectable use or sterilisation. Health workers were concerned that women would abuse EC as routine contraception and so preferred not to discuss it at all with clients and this led some women to seek traditional medicine or mis-use other clinical products in the place of EC. A limitation of this study is that it did not measure intention related to the incident birth event or consistency of contraceptive use and more rigorous measures of pregnancy planning are required. These findings highlight a need for improved counselling on the availability of EC for the prevention of unwanted pregnancies.

According to Bongaarts, the principal reasons for non-use include lack of knowledge, fear of side effects and social and family disapproval (Bongaarts and Potter, 1983). Qualitative interviews suggested that the side effects of DMPA presented strong barriers to consistent adherence to women in this study (Section 6.3.3) and also other findings from a multi-cohort study including South Africa (Kaida et al., 2008). Further evidence suggests that women on ART need to be better

supported with information about the likelihood of amenorrhea and excessive menstruation or switched to an alternative method (Kaida et al., 2010). Partner disapproval of contraceptive use was frequently circumvented through covert use of injectable methods, but concerns about being 'too watery' during sex presented a strong barrier to even covert use of DMPA. This is in accordance the literature from the area that found a common cross fertilisation of language attributed to contraceptive side effects and cultural ideals of attractiveness (Gafos et al., 2010). Being 'watery' was considered unappealing and jeopardised revealing a woman's covert use of injectable contraception to an unknowing partner, or causing her to become unattractive to her partner during sex. Cultural barriers to injectables were reported by health workers and clients alike and demonstrate the need for counselling with appropriate information and support to adhere to methods, or alternatives to injectable contraceptive use for these women. Social and family disapproval was likely to encourage women to avoid childbearing but posed the strongest barriers to women who wished to seek termination of pregnancy or sterilisation, as they would be required to stay in hospital and explain their stay to household kin.

Implementation of client-centred fertility- and HIV- services that effectively address the needs of women living with HIV requires contextual understanding of which women are likely to become pregnant and what they consider to be unmet needs. The next section will address key implications for delivery of family planning to women on ART.

7.7 Implications and recommendations

Access to ART has been rapidly scaled in South Africa with resulting implications for population projections and delivery of integrated health services.

A major implication of this thesis is that ART will not encourage a rise in population fertility rates in this setting. Quantitative data demonstrated lower fertility amongst HIV positive women compared to negative women, lowest of all in women using ART. Characteristically women on ART were older, generally at a later stage in their reproductive life cycle and were less likely to have children outside of regular or cohabiting relationships compared to HIV negative women. Qualitative results support this perspective that women are limiting their childbearing on ART; women described a preference to avoid future pregnancies on ART as they had achieved desired family sizes in line with cultural norms and because another pregnancy might risk their comprehensive well-being.

Social and behavioural factors associated with lower fertility among women on ART in this analysis are akin to the socio-demographic drivers of a longstanding decline to low fertility in South Africa, where long birth intervals and sustained periods of postponement have expedited decades of fertility decline. ART could influence population fertility through different, survival mechanisms, as increasing numbers of men and women of reproductive age survive a HIV diagnosis on ART. Another study from this setting reported on the substantial improvements in survival since ART became available (Bor et al., 2013). Yet the crude rates of live birth reported in this thesis demonstrate a continual decline since ART roll-out began in 2004 (Section 4.1), according to pervading social norms for smaller families described in the qualitative findings.

The UN projects a world population of 9.2 billion by 2050 under assumptions that fertility will continue to decline as ART coverage expands, but depends on 'significant investment in family planning programmes' (UN, 2007). Access to ART has expanded dramatically since 2004 and quantitative findings from this thesis support the UN assumptions for continued fertility decline. National projections are important for government planning and the effective implementation of such 'significant investment'.

Another major implication of this thesis is that the quality of integration within HIV services could be improved to better meet the family planning needs of women on ART in this setting. Approximately half of women described inconsistent use of injectable contraception, leading to experience of

unplanned pregnancies both prior to and during use of ART, and pregnancies were not usually planned in accordance with health worker advice. These findings suggest that the current model of family planning as an 'essential affiliated service' in the HIV continuum of care does not adequately ensure safer conception and motherhood.

As a general recommendation, more information about safer motherhood and routine contraceptive management, timed early after initiation on ART and tailored to the reproductive needs and local realities of women on ART, is needed to address some of these programmatic gaps. An adapted version of the contraceptive health belief model (page 272) summarises the reasons that women on ART prefer to avoid the 'threat of a pregnancy' in this setting, and the environmental influences that can modify and enable women's childbearing decisions. The model encapsulates the conflicting decisions of women on ART that wish to avoid childbearing through injectable contraceptive use, versus the adverse side effects and cultural stigma that being 'watery' may bring. Finally the model describes the structural ways in which the HIV Treatment and Care programme can facilitate or present barriers to family planning delivery.

Four more specific implications and the resulting policy, programmatic and research recommendations are detailed below.

7.7.1 Implication One: Planning for safer motherhood is not currently practiced amongst women living with HIV

Prevention of unintended pregnancies is a key component of global PMTCT strategies for women living with HIV and an understanding of this issue is thus important. Evidence from this thesis indicates that women on ART and their partners continue to desire or limit childbearing according to social norms and values, other than diagnosis with HIV. Women discussed very little pregnancy planning amongst women on ART and, in line with health worker views, illustrated narrow perspectives towards what planning for a pregnancy involved. Such perspectives on planning were limited to waiting for an appropriate CD4 count before conception.

A small group of women on ART did wish to continue childbearing but no women in this qualitative study had discussed intentions to have a child with health workers and the absence of reproductive

health discussions may lead to unwanted pregnancies amongst women on ART, or risk harm to the mother's health if a wanted pregnancy is not well timed. Considering qualitative desires to mostly limit childbearing and experiences of adverse health during unplanned pregnancies, incidence of live birth observed in Section 4.2 and 4.3 amongst women on ART appears relatively high.

Rates of maternal mortality continue to increase in South Africa (STATSSA, 2013). The South African Saving Mothers report suggests that HIV accounts for 43.7% of facility-based maternal deaths between 2005 and 2007 (McIntyre, 2005) and that safer motherhood programmes should still pay special attention to the needs of pregnant women living with HIV (Zaba et al., 2013).

There is conflicting evidence to suggest that pregnancy adversely affects HIV progression and risk of mortality. Some studies found no evidence of advanced HIV progression to pregnant women in the era before ART (French and Brocklehurst, 1998). Yet mortality was higher amongst women in the post-partum period in Malawi (McDermott et al., 1996) and the Democratic Republic of Congo (Ryder et al., 1994). Recent model based estimates of longitudinal data collected between 1989 and 2012 suggest that HIV positive pregnant or postpartum women living in sub-Saharan Africa had an eight times higher risk of death than HIV negative women (Zaba et al., 2013). A meta-analysis of twenty three countries confirmed these findings, also reporting an eight times greater risk of mortality amongst HIV positive pregnant women compared to HIV negative pregnant women (Calvert and Ronsmans, 2013). In the study by Zaba et al, however, excess mortality attributable to HIV was far lower in pregnant or postpartum women than in HIV positive women that were not pregnant or post-partum, in agreement with the wider literature that suggests evidence for an effect of pregnancy on adverse HIV progression is weak (Khan et al., 2006).

HIV positive women are more susceptible to other direct causes of maternal mortality, such as post-partum haemorrhage, puerperal sepsis and complications of caesarean section, and also faster progression of opportunistic infections such as tuberculosis (McIntyre, 2005). TB is a major maternal health concern in KwaZulu-Natal: co-infection with TB amongst HIV positive pregnant women increased the risk of maternal mortality by 32 fold compared to HIV negative women, and prevalence rates of active TB in HIV infected women were 10 times higher than HIV uninfected women before ART was available (Khan et al., 2001).

Three recommendations for client-centred reproductive planning counselling for women on ART are suggested below:

a. The national framework for integrated health services should be translated into operational guidelines for coordinated implementation of family planning within HIV services

The literature calls for client-centred reproductive planning counselling that can address the diverse and changing needs of women, to either have a child or avoid an unwanted pregnancy over the course of ARV treatment (Cooper et al., 2009, Walter et al., Rutenberg et al., 2000, Peltzer et al., 2009, Bekker et al., 2011).

Strategies are available to support services to meet the reproductive needs of women living with HIV in low resource settings, according to stated desires to either have a child now, in the future or not at all (Bekker et al., 2011, WHO, 2006). However, no guidance for safer conception was available during clinic observations, and family planning activities were not well supported with tools, supervision or monitoring and evaluation of family planning communication within HIV services.

Joint policies such as the HIV and AIDS and STI Strategic Plan for South Africa 2007-2011 have since demonstrated national commitments to co-ordinated SRH and HIV services, although strategies for implementation remained vague (SADoH, 2007a). The most recent South African Department of Health Strategic Plan 2014-2019 has specified an administrative objective to 'improve and co-ordinate integrated planning for health' and aims to achieve health system reform using a 'framework for Integrated Health Service Plans at all levels of the Health care sector be developed and implemented' by 2018 (page 17) (SADoH, 2014).

It is a recommendation of this thesis that a national framework is translated into operational guidance for District Health management. The purpose of this recommendation is to facilitate integration of HIV and family planning in primary health care services. Operational guidance could outline routine and tailored counselling for people living with HIV, supported by health worker training.

b. Reproductive counselling should be conducted routinely and monitored

Clients prefer to receive their ART and family planning services under one roof, but qualitative results showed that women were rarely given the opportunity to discuss planning for a child during a clinic visit.

The WHO continuum of care places family planning as a part of preconception care for maternal health, and this has become recent policy in SA (SADoH, 2012). It is a recent concept that encapsulates interventions for both medical and behavioural aspects of sexual and reproductive health (Schwartz et al., 2012). Client-centred support relies on constant discussion and documentation of contraceptive behaviour to aid future discussions (Bekker et al., 2011). Continued counselling allows time for behavioural interventions to take effect and requires strong PHC infrastructure for referral, workforce training and supportive supervision (SADoH, 2011).

Primary Health Care facilities currently record the number of family planning acceptors per clinic but include no measure of pregnancy planning or method switching. Client files contain a section about planning for a pregnancy but are not regularly completed and are not systematically filled. These files should be actively completed during every counselling session. Due to the sensitive nature, information about contraceptive method use and desires for family planning should be collected electronically and stored at the clinic.

c. Training to support provider-led safer conception counselling should be routine in HIV services

Routine fertility questions can confirm previous decisions and check if intentions have changed (Bekker et al., 2011). However, counsellors were largely unaware of safer conception strategies or how to structure a safer conception discussion. Consequently, counsellors expected client-led discussions, where women should first disclose an intention to get pregnant before they would introduce the topic of planning for a pregnancy. Very few women discussed intentions to have a child at the clinic and health workers reported feeling burdened and frustrated at that women visited the clinic once already pregnant.

In qualitative interviews, HIV nurses and counsellors viewed HIV counsellors as best positioned to deliver family planning counselling, before ART nurses deliver family planning methods, within the HIV treatment and care programme. A recommendation of this thesis is that HIV counsellors receive extra training to deliver safer conception discussions during routine provider-led family planning counselling. Key areas that training could effect a change, as identified by this thesis, were health worker perceptions of oral contraception and emergency contraception. Re-training would need to address the current health worker perspectives needed for gender sensitive counselling to address relationships gender dynamics. Such topics may include sexuality and gender norms and exercises to build skills for couples counselling (EngenderHealth, 2014).

Previous NGO interventions have successfully improved family planning counselling in the context of HIV testing in KwaZulu-Natal (Bruce and Martin, 2008) and recommend a series of on-site refresher training events and the use of clinical aids to facilitate discussions about planning a desired pregnancy in the context of local realities (EngenderHealth, 2014). Other recommendations for pre-conception work-up and counselling as provided by Bekker et al are described in Figure 7.1.

Figure 7.I: Table of optimal support strategies for resource intensive and resource limited settings according to the HIV status of the couple *taken from (Bekker et al., 2011)*

	Seroconcordant (male and female HIV infected)	Serodiscordant (male HIV infected)	Serodiscordant (female HIV infected)
Resource-intensive strategy			
Female partner	<p>If on HAART preconception, adaptation of regimen as needed; ensure undetectable HIV viral load in blood; no use of efavirenz in the first trimester among HIV-infected women trying to conceive</p> <p>Conception: consider sperm collection with intra-uterine insemination; self-insemination possible; peri-ovulatory unprotected sexual intercourse only in the face of demonstrated undetectable viral loads</p> <p>If not on HAART preconception, maternal HAART initiation as soon as possible with appropriate regimen</p>	<p>Repeated HIV PCR testing before pregnancy</p> <p>Conception: undetectable viral load preferable; sperm washing and intra-uterine insemination</p> <p>Repeated HIV PCR during pregnancy with appropriate management if female partner becomes infected</p>	<p>If on HAART preconception, adaptation of regimen as needed; ensure undetectable HIV viral load in blood</p> <p>Conception: sperm collection with intra-uterine insemination</p> <p>If not on HAART preconception, maternal HAART initiation early in the second trimester</p>
Male partner	<p>Preconception HAART until undetectable HIV viral load in blood and semen</p>	<p>Preconception HAART until undetectable HIV viral load in blood, semen</p> <p>Conception: sperm assessment; sperm washing with HIV PCR</p>	<p>Ongoing HIV testing; male medical circumcision where appropriate, especially if couple choose peri-ovulatory unprotected sexual intercourse for conception</p>
Resource-limited strategy			
Female partner	<p>If on HAART preconception, adaptation of regimen as needed; ensure high levels of adherence and CD4 monitoring; no use of efavirenz in women trying to conceive</p> <p>Conception: consider sperm collection with self-insemination; peri-ovulatory unprotected sex possible under safe conditions. This would include undetectable viral loads if possible, timed sexual intercourse and limited exposures (see text)</p> <p>If not on HAART preconception, maternal PMTCT initiation asap with appropriate antivirals</p>	<p>Repeated HIV antibody testing before pregnancy</p> <p>Conception: unprotected sex during the fertile period (preferably while on ART with viral load control)</p> <p>Repeated HIV antibody testing during pregnancy with appropriate management if female partner becomes infected</p> <p>Consider use of mono- or dual-therapy PrEP</p>	<p>If on HAART preconception, adaptation of regimen as needed; ensure high levels of adherence and CD4 monitoring; consider ART for conception and pregnancy regardless</p> <p>Conception: sperm collection with self-insemination at the time of ovulation (avoiding spermicide-containing condoms)</p> <p>If not on HAART preconception, maternal PMTCT initiation as soon as possible with appropriate regimen</p>
Male partner	<p>If required, preconception HAART for at least 6 months with intensive adherence support and CD4 monitoring and viral loads monitoring</p>	<p>If required, preconception HAART for at least 6 months with intensive adherence support and CD4 and viral load monitoring</p>	<p>Ongoing HIV testing; male medical circumcision where appropriate, especially if couple choose peri-ovulatory unprotected sexual intercourse for conception</p>

7.7.2 Implication Two: An injectable-centred culture results in inconsistent use with alternative to the current contraceptive method mix

Low incidence of live birth to women on ART, either in a casual relationship or single, suggests that these women are either less sexually active or using more contraception to prevent a pregnancy. These findings are supported by strong preferences to avoid childbearing amongst women on ART in Chapter Five. Injectable contraceptive use was a key strategy in many women's fertility plans to postpone childbearing but injectable methods often resulted in undesirable side effects or were seen as inappropriate while on ART to some women. Many opted to 'take a break' with few alternatives between long birth intervals.

A strategy of long term injectable use poses issues of adherence and high risk of unplanned pregnancies. Three programmatic recommendations to support consistent contraceptive use within HIV treatment and care are presented here:

a. National and provincial policy to supply alternative long acting methods of contraception at primary health care facilities

There is a clear need for alternative non- hormonal methods or options with fewer side effects than injectable methods currently provide. The need for alternative methods is heightened by recent suggestions that DMPA injectable contraception has been associated with risk of HIV acquisition, although evidence remains inconclusive (Morrison et al., 2012, Heffron et al., 2012). An 'injectable-centred' culture persists in family planning at present and national policy could target this issue with health worker re-training to make clients aware of previously neglected or newly introduced methods such as emergency contraception and the IUCD.

The intrauterine device was being rolled out at the time of study and none of the women interviewed for this thesis yet had experience of the IUCD, but women reported favourably on this method primarily due to the long lasting nature and ease of access, through a single visit to the clinic. Improved information and counselling could make alternative methods viable. In accordance with a situational analysis of reproductive health care for PLWHIV in 10 Primary Health Care clinics and one hospital conducted between 2002 and 2003 in the uMkhanyakude district of KwaZulu-Natal (Maharaj and Cleland, 2005), counselling prioritised contraceptive efficacy and providers were often

reluctant to raise difficult issues such as partnership and HIV or underutilised methods such as the Intrauterine device (IUD) and emergency contraception. Oral contraception and EC are available in both the PHC and HIV treatment and care facility but many health workers were concerned that women would not adhere to oral contraception or would overly rely on EC. Considering the regularity of women 'taking breaks', oral contraceptive pills could be utilised as a short interim method if women remain sexually active.

Findings presented in this thesis inform the recommendation that provincial policy guidelines facilitate the distribution and access to contraceptive implants at primary health care facilities in Hlabisa. This could include additional training for HIV nurses to insert implants at the HIV clinic or for a referral system to the adjacent Primary Health Care facility. Contraceptive implants such as Implanon® and Jadelle® are viewed as efficacious and long acting alternatives to 3-monthly injectables (Jacobstein and Stanley, 2013). Implanon® has been made available at public facilities in South Africa under the latest national contraception and fertility planning policy guidelines (SADoH, 2012), and Jadelle® is now being manufactured and is available at a discounted cost, and studies have shown that nurses are equally as effective in administering this method (Bayer, 2012). Both are progestogen only subdermal implants with similar adverse side effects to DMPA, hence the long term feasibility requires further research but may prove to be limited in this setting.

Finally, some women wished to seek sterilisation in order to limit their childbearing entirely but were deterred by concerns about the cost of transport and time spent at the hospital, which may alert family members about the procedure. Strategies that may help women overcome these barriers to care could involve travel assistance or tools to negotiate stigma of seeking a sterilisation.

b. Counsellors need to discuss the management of contraceptive side effects during counselling

Women make their family planning decisions according to a complex mixture of factors unrelated to childbearing desires. The health belief model for contraceptive behaviour described in Chapter Two and adapted to the local context in Chapter 6 provides a useful tool to elucidate the complex motivations pre-empting contraceptive decisions of women on ART in Hlabisa.

Effective communication to encourage pregnancy planning could respond to the notion of 'stress' that women described in their interviews, and encourage preservation of good health, which women also listed as a motivation to avoid future pregnancies in their interviews.

Side effects of injectable contraceptive use would on occasion inadvertently cause women to seek traditional alternatives such as aspirin or marijuana in their place. Counsellors should discuss the common side effects of injectable contraception and how to manage them. Alternative methods could be offered to clients if side effects occur and persist, under recommendation 1.3.a. Where alternatives are not acceptable, health workers may encourage adherence by addressing perceptions about the efficacy of injectables on ART.

c. Strengthened referral links or full integration requires inclusion of reproductive planning for safer motherhood within HIV treatment and care

HIV treatment and care is currently available within a one-stop-shop model directed to deliver all aspects of HIV treatment and family planning services either in the programme or on referral. This study found different practical levels of integration that helped facilitate access to contraceptive and pregnancy services but omitted more complex discussions about emergency contraception, relationships and safer conception advice (French et al., 2006, French and Mitchell, 2012). The efficacy of one-stop-shop delivery has been challenged in comparison to other models of co-ordinated resources (French et al., 2006). Integrated services have been advocated for as cost-effective interventions for combined delivery of family planning and HIV treatment and care. However, such model's risk quality of delivery and this thesis determined only partial levels of integration, with reproductive counselling largely omitted from the HIV continuum of care.

Interventions that aim to increase social support risk added burden to the health workforce, where Primary Health Care services are already mandated to offer family planning services. WHO explicitly outlines strengthened links between different health system levels for reproductive and sexual health delivery. South African guidelines also describe family planning as an essential affiliated service to HIV treatment and care and recommend strong referral linkages where integration is not possible.

Strengthened referral systems provide an alternative to duplicated family planning services currently offered through partial integration within a HIV treatment and care programme (WHO, 2010b). Some nurses described frequently missed appointments and using personal mobile phones to check on clients that did not attend appointments. Missed appointments are an issue common to both PHC and HIV treatment and care services. The burden may be minimised by strategies such as personally escorting women to the PHC family planning facility, if required services are not available at the HIV clinic, or situating FP counselling earlier in the HIV continuum of care via formal referral to a trained counsellor for information about safer sex and safer motherhood before consultation with an ART nurse. Finally, regular discussions about the availability of referral services in the local district and local hospitals could help to address the perceived stigma around abortion seeking.

7.7.3 Implication Three: Local realities of gender norms and relationships strongly influence family planning practices amongst women on ART

The importance of gender norms and relationship dynamics shaping contraceptive behaviour meant that some women did not feel able to negotiate planning for a child, or the timing of a child during interviews. Health workers traditionally viewed planning as an activity reserved for married women. Findings from this thesis show that women can and often do have a child outside of marriage, and that desires to have a child are often postponed and difficult to predict. Where marriage was a poor indicator of a woman's likelihood to have a child, better indicators could include if a woman has a child with her current partner and time since her most recent birth. Although not definitive, these indicators provide health workers with more information about whether women could feel pressured to have a child now or in the near future.

Motherhood remains an important stage of life for women living in South Africa and is strongly influenced by social values and gender norms, particularly in the absence of marital traditions and under current re-workings of definitions of relationships and childbearing (Hunter, 2010). Men living with HIV have discussed desires for more children in South Africa (Cooper et al., 2009), as childbearing is important to continue their lineage in patriarchal societies (Cooper et al., 2007, Paiva et al., 2003) or prove virility under masculine social identities in South Africa (Dyer et al., 2004). Programs that explore different determinants of fertility intentions between men and women on

ART and different ways of delivering gender sensitive information are likely to be more effective (Cooper et al., 2009).

Two recommendations for interventions that address gender norms towards childbearing in this setting are presented below:

a. National sexual and reproductive interventions include communication with men

The United Nations Family Planning Association aims to improve communication between men and women and ensure joint responsibilities are taken on issues of sexuality and reproductive health throughout adulthood. To this end, the UNFPA advocates that services encourage male participation in family planning and foster responsibility for sexual and reproductive behaviour (UNFPA, 2014). While these goals may be beyond the scope of PHC clinics, national education interventions currently aim to tackle gender issues amongst adolescents (Varga, 2003, Buga et al., 1996) and could be expanded to include basic information on pre-conception topics for maternal health alongside determinants of childbearing decisions. Further, other ecological approaches have aimed to reduce gender-based violence through interventions that target male partners in South Africa and aim to promote constructive roles in sexual and reproductive health, based on current ideologies of masculinity (Peacock and Levack, 2004).

High impact practices to maximise investments in family planning advise a systematic and evidence based health communication strategy, which may occur through multiple health channels and does not solely rely on clinic attendance. Social marketing has been proven effective as a national strategy to deliver contraceptive methods alongside commercial marketing techniques that aim to direct behavioural changes (JHU, 2013).

Social marketing has been effective for distribution of underutilised contraceptive methods such as emergency contraception and oral contraceptives, in addition to methods such as the Cyclobeads® colour coded visual tool, a method developed to help women follow the standard days method and time sexual intercourse to their fertility cycle in order to increase the probability of having a child, or avoid a pregnancy. A national social marketing strategy could help reinforce behaviour changes

messages, directed through community outreach programmes, NGOs, pharmacies and other private institutions, without reliance on attendance to the clinic (JHU, 2013).

b. A couples-based safer conception intervention could be trialled in this setting

The cultural expectation of *isilobola* payment and desires of partners to have more children were influential factors in women's reported desires to have more children, despite a possible risk to their physiological health. Safer conception messages to wait for an 'appropriate' CD4 count before planning a pregnancy were neither tangible to women on ART nor evidence-based. Under such priorities, women rarely followed this advice.

Interventions that promote male involvement in family planning have been shown to encourage couples communication and contraceptive uptake (Shattuck et al., 2011, Hartmann et al., 2012). However, male engagement within safer conception interventions remains challenging.

Recently the feasibility of adding a separate on-site service for safer conception to a one-stop-shop setting was proven in South Africa (Schwartz et al., 2014). The intervention introduced an appointment system and dedicated staff in order to reduce waiting times for safer conception support that aimed to assist couples time pregnancies to when a women's viral load is low, prevent super-infection and minimise the risk of vertical transmission (Schwartz et al., 2014).

A recommendation of this thesis is that future research considers interventions to improve male participation and couples communication in family planning, inclusive of safer conception counselling in this setting. Men may be counselled on the health benefits of planning a pregnancy in a pre-conception planning intervention or by using the existing framework for health education each morning.

There are considerations to this recommendation. Stigma can still prevent HIV disclosure between couples in this setting, where some women interviewed in this thesis were unaware of their partner's HIV status. Therefore future studies would need to measure current dialogue between couples, and test the feasibility of a couple based approach. Furthermore, safer conception interventions often aim to prevent HIV transmission amongst sero-discordant couples. Of the women who did report to know their partner's status, many were known to be HIV positive.

Consequently, a safer conception strategy in this setting may be orientated to prevention super-infection and to preserve women's health. Lower male involvement and sero-discordant male partner reluctance to take a short course of ART as pre-exposure prophylaxis were significant barriers to an integrated safer conception service for couples that wish to have a child. The cost-effectiveness of such an intervention has not been ascertained (Schwartz et al., 2014)

7.7.4 Implication Four: Reliable measures of pregnancy intention are not available in this setting

Studies suggest that women on ART are continuing to desire more children in some areas of South Africa and in line with cultural norms. Findings from this thesis support the view that women on ART do not appear to be planning for more children compared to ART-naïve women. However, this study is limited by an absence of appropriate pregnancy intention measures. Further, planning may be a cultural concept. During interviews women were not planning a set time-frame to become pregnant. They often reported to prioritise their own health while negotiating the stability of relationships and financial income. They had a plan in mind but this was subject to change. Under such uncertainty, women give the appearance of flexibility that is difficult for health workers to respond to.

Child-bearing decisions are not always rational and women did not always view fertility as within their control. Emphasising the cultural importance of *isilobolo* and expectations for a child and Christian views that a child could be seen as a 'gift from God', women often situated the notion of planning for a child outside her locus of control. Children were rarely planned for but health workers felt that married women were more likely to come to the clinic to plan for a pregnancy.

In the absence of rigorous measures of pregnancy planning, there is a lack of evidence to suggest that any changes in childbearing desires following ART initiation directly effect a change in birth rates (Maier et al., 2009). An adequate measure of planning is much needed to answer these research questions. Two recommendations to support future research in this setting are detailed below:

a. Multi-item tools are adapted by SA Demographic and Health Surveys to measure pregnancy intention

The first recommendation is that multi-item survey questions are used to measure pregnancy intention in the next SA DHS round. These measures would include both men and women plan in South Africa and better inform maternal and child health policy and services. They would include dimensions such as stopping contraceptive use, preparation for the pregnancy and agreements with a partner.

Constructs of pregnancy intention have historically been developed in the West and their applicability to a rural African setting is unknown. Additionally, current measures of intentions are out-dated: the last National Demographic Health Survey was conducted in South Africa in 2003, before ART was available. The 2003 SA DHS measured the desired timings of a pregnancy for a woman i.e. wants birth within next two years, wants to delay birth for two or more years. Since this survey was administered, more sophisticated measures of pregnancy planning have emerged (Hall et al., 2013, Barrett et al., 2004) but have not been tested in Hlabisa. New and more relevant measures are needed.

Multiple dimensions of intention have important predictive value for maternal and child health outcomes and recognise that people are rarely definitive about complex decisions like childbearing. Qualitative results from this study confirm that dichotomous 'yes or no' choice may not yield a useful interpretation of intention. More nuanced measures would better consider aspects of partner preferences, expectations of *isilobola*, family views and attitudes to contraceptive use in the setting, that may otherwise appear to conflict with personal desires for childbearing that are difficult to communicate. The need for more nuanced reporting of pregnancy desires could be further generalised to other settings across South Africa, although cultural practices may differ. To support this recommendation, the selected tool should be piloted in local languages and validated for each setting.

b. The Africa Centre include a multi-item measure of pregnancy planning for analysis

The second recommendation is that Africa Centre pilots and includes a multi-item measure of pregnancy intention to the Women or Men's General Health module or includes a new module within the demographic surveillance.

The Africa Centre demographic surveillance does not currently include questions about a woman's fertility intention or post-conception attitudes; the absence of such a measure is a limitation of the quantitative analysis presented in Chapter Four. The Africa Centre is well situated to longitudinally research pregnancy behaviours, with the opportunity to link information about pregnancy intention to reproductive, demographic and socio-economic characteristics. A primary advantage is the ability to include HIV negative women as a comparison group to women using ART, as demonstrated in this thesis.

The Africa Centre may include a regular prospective measure of pregnancy intention in its household surveillance, or collect the perspectives of currently pregnant women as a new and separate module. These options are outlined in greater detail below:

▪ **Add questions to the Women or Men's General Health module.**

Annual household surveillance could capture pregnancy intentions at different times: prospective, during pregnancy and during the post-natal period. Such an approach would include men and women of reproductive age in the DSA. Furthermore, it is the preferential individual that responds to questions in the WGH or MGH, rather than a key informant. However, Women's and Men's General Health questionnaires remain the most problematic for non-response rates and warrant further research into approaches to incentivise pregnancy planning responses.

▪ **Include a new module within the demographic surveillance.**

If Africa Centre were to include a multi-item tool, it would be feasible to introduce this as a stand-alone questionnaire. With the aim to measure further complexity around childbearing decision-making, the London Measure of Unplanned Pregnancy (LMUP) is a psychometrically-validated measure of pregnancy intention with the added benefit that it does not assume that women have pre-determined childbearing plans or that their intentions necessarily lead to a set behaviour (Hall et al., 2013). The LMUP is self-administered and comprises six questions on contraceptive use, timing,

intention, desire for a baby, partner discussion, and pre-conceptual preparations. Each point increase represents an increase in pregnancy intention and can be interpreted as unplanned, ambivalent, and planned. The LMUP is administered in English and has not yet been validated in isiZulu, the predominant language of KwaZulu-Natal, but could possibly be used to provide a reliable measure of how all women are planning pregnancies in this setting. The LMUP would question relevant individuals rather than a key informant. It is most reliable when administered during a current pregnancy or close to conception and would be administered as a separate module at least once a year, similar to other household demographic surveillance. Ideally, the LMUP would be administered during any household visit when a pregnant woman is present. This would incur extra time costs from the fieldworkers and households.

7.8 Strategy for dissemination

A strategy to disseminate findings from this thesis is presented in this section. Results have been presented at two conferences in poster and oral format to date. At the end of the study, qualitative results were directly communicated to management staff at the local tertiary hospital, who are responsible for oversight of the decentralised primary health care services included in this study. Both these activities are described below. In addition, this section begins with detailed plans for publication of four papers from this thesis. All names of participants or clinics were anonymised throughout all dissemination activities.

7.8.1 Publication plan

Current literature suggests that ART use may increase fertility, with unknown implications for population growth in areas of high HIV prevalence. This study offers a new perspective: that in this high HIV, high Art and low fertility setting there is no evidence of a change in fertility associated with ART use. These findings are supported by the comparison of women living with HIV on ART to HIV positive women not yet on treatment and HIV negative women. I intend to publish four papers from this study; these include a literature review and three papers addressing each of the research questions outlined at the start of this thesis.

The proposed order of submission, theme of each paper and the description of the contents are given in Table 7.2.

Table 7.2 Publication list and description of papers from this thesis

Publication	Theme of paper	Description of content
1	A review of the current literature on the effects of ART on fertility in sub-Saharan Africa.	This review will describe a systematic search strategy presented in section 2.8.1 and a summary of the discussion presented in section 2.8.2. It will review 9 quantitative studies with a discussion on the study design, reported outcome and the direction and reported effect of ART.
2	A cohort analysis of the effect of ART on live birth rates.	The paper will report results of an open cohort analysis presented in section 4.2 and addresses research question one. It will describe an analysis of proximate and distal factors associated with the likelihood of a live birth, using demographic surveillance data from the Africa Centre between 2007 and 2012. It will report no increase in likelihood of live birth attributed to use of ART, and a lower likelihood of fertility compared to HIV negative women. The paper will conclude with possible implications for studies reporting fertility desires and health service delivery in South Africa.
3	A description of fertility desires amongst women on ART.	This paper will summarise key findings from Chapter Five and addresses research question two. It will describe semi-structured interviews with women enrolled in a local HIV treatment and care programme and health workers in this programme. Results will describe women's reported fertility desires while on ART and the discussion will expand on themes that women reported to influence their childbearing desires. The paper will conclude with health service implications to support planning for a child or to avoid a pregnancy and the need for more rigorous research

on fertility planning in this setting.

4	Attitudes to contraception and family planning in a HIV treatment and care programme.	This paper will be based on findings from Chapter Six and addresses research question three. It describes semi-structured interviews with women enrolled in the HIV treatment and care programme and observations of the same clinics. It will report client and health worker attitudes to the delivery of family planning services in a one-stop-shop model of HIV treatment and care. Results will present factors that influence contraceptive preference and use and the influence of ART use. The paper will conclude with implications for improved integration of family planning in the HIV treatment and care programme in this local setting.
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7.8.2 Conference and presentations

Results of this thesis have been presented at two conferences to date: one poster of qualitative findings and one oral presentation of quantitative results from this study.

- The poster was entitled ‘Childbearing in the time of ART: Family planning in a decentralised HIV Treatment and Care Programme in rural KwaZulu-Natal’ and displayed at the 6th South African AIDS conference. It presented findings related to research question three on the attitudes to contraceptive use and childbearing reported during interviews with clients of the HIV treatment and care programme.
- The oral presentation was entitled ‘The effect of national scale up of access to anti-retroviral therapy (ART) on rates of live birth in the Hlabisa sub-district of KwaZulu-Natal, South Africa’ and was presented at a conference called ‘Fertility Transition in the South’, hosted by the Oxford Institute of Population Ageing. It presented the results of the open cohort analysis of live birth rates to women living with HIV on- and pre-ART.

In addition to these conferences I have presented findings at three Africa Centre weekly seminars and at the Institute of Global Health's PhD review.

7.8.3 Feedback to the HIV treatment and care programme

An objective of this study was to inform local health practitioners of current barriers and facilitators about the delivery of integrated family planning and HIV treatment and care. Results from research question three were presented to the Hlabisa hospital management team during their monthly meeting in June 2013. I presented an overview of the purpose of my study and methodology and selected key facilitators and barriers to the delivery of integrated family planning.

The format was designed as a PowerPoint presentation, but a projector was not available on that day. As a conclusion to the meeting, the management team agreed that there was a gap in communication particularly around the use of emergency contraception. However, I am not aware of any action that has been implemented in response to this meeting.

7.9 Strengths and limitations of this research

7.9.1 Strengths

- This thesis offers a reliable estimate of the likelihood of having a live birth by HIV status and ART exposure, allowing for proximate and distal determinants of fertility in Hlabisa.
- Use of demographic surveillance data ensured a large study size, with longitudinal follow up of nearly 10,000 women between 2007 and 2012.
- Inclusion of HIV negative women in an analysis with women on ART is novel to the literature.
- Linkage of CD4 and ART data with a HIV treatment and care programme is an advantage as information could be time-updated to provide longer term continuity and prediction compared to other cross-sectional studies.
- The time-updated survival method for longitudinal analysis in both quantitative cohorts appropriately adjusts for changes in demographic, clinical and behavioural characteristics that are not easily captured in clinical cohort studies
- Similarity between two cohort studies assures the reliability of measures of incidence and associations between risk factors and live birth identified in an open cohort that excluded women with missing information about their HIV status from the DSS.
- The findings relating to hazard of live birth in this study confirmed early studies from the same setting
- Qualitative methods supported quantitative findings that perceptions of health is an important determinant of reproductive behaviour to avoid childbearing

7.9.2 Limitations

- Lack of statistical power due to relatively small numbers of women on ART experiencing a live birth may not give accurate estimates of relative risk in stratified analysis. Associations followed a similar direction according to characteristics of ART-naïve HIV positive women and HIV negative women, suggesting that lack of statistical significance was likely due to an issue of sample size and power. However, confidence intervals indicate that these estimates are likely to be a reasonable.

- Use of demographic surveillance data has limitations. Firstly, women were selected to enter the cohort at a specified entry date and visit dates of Africa Centre demographic surveillance rounds do not exactly correspond to dates at which ART use and CD4 count data were captured in the ARTemis database. Therefore, comparisons are drawn on general differences in incidence and factors associated with live birth between HIV positive and HIV negative women. Clinical studies that measure time to a live birth event from the date of ART initiation and with time updated information on other proximate determinants of fertility from this baseline point would provide a more reliable estimate of the effect of improved immunological health associated with likelihood of fertility after recent initiation on ART.
- Additionally, variables of interest were not perfectly aligned to the study question. Ideally, demographic survey measures would have included questions about pregnancy intention prior to conception and detailed relationship questions regarding disclosure of HIV status to partner, a male partner's fertility desire, the number of children that women had with their current partner and whether the partner had paid *isilobola*. However, other indicators such as whether or not a woman was living with her partner and broad categories of relationship status such as regular and casual partner did determine differences in the way that women on ART experienced live birth according to the formality of their relationship. Furthermore, adherence to contraceptive use is an important measure that could further elucidate differences in reproductive behaviours in this setting.
- The absence of physiological measures of health and particularly the presence of underlying STI prevalence is a major limitation of this study as it prevents a comprehensive assessment of the relevance of biological compared to behavioural determinants of fertility. However, findings provide a strong argument for the importance of behavioural determinants of fertility decline in all HIV groupings and suggest that unmeasured physiological differences can otherwise explain a large variation in fertility between HIV positive and HIV negative women.
- High levels of attrition due to migration or non-response meant that women were observed for a median time of around 2 out of 5 possible years, depending on HIV category. Differences in time spent under observation were adjusted for using person-years as the common denominator between HIV groups. It is possible that there may be differences in

residency as women living with HIV and on ART are likely to be older and may be less prone to travel for health reasons and could be over-represented in this study. However, HIV positive women may also be less likely to participate in HIV surveillance after receiving a HIV positive response.

- Information collected in the demographic surveillance was carried out by fieldworkers that visit each individual homestead. Data are systematically checked and verified throughout collection but it is possible that omissions and mistakes in data collection can occur at random. Trends appear to be largely uniform throughout the cohort period.
- A research assistant was hired to conduct qualitative semi-structured interviews in isi-Zulu, as the researcher did not speak the local language. The research assistant received comprehensive and on-going training. Training encouraged the RA to probe on topics of planning for a child that may not otherwise be volunteered during interviews and could lead to skewed responses towards ideals of planning. However, we found that women rarely reported planning for a child and clients were unlikely to have been biased during interviews.
- A major limitation of this study is the absence of male partner viewpoints. The study design prioritised seeking the viewpoints of health workers for the purpose of this study and due to difficulties raised in the recruitment of male partners; the male viewpoint was not addressed in this study and would be an important next step for future research that could explore the feasibility of interventions for gender sensitive family planning.
- The cross-sectional nature of in depth interviews are unlikely to unravel the complex nature of pregnancy decisions to women living with HIV on ART. Long-term follow up over a life course approach and outside of the programmatic setting may offer more insight in to the cultural nuances of decision-making.
- This study found evidence of the need for culturally sensitive assessment of pregnancy intentions and health systems interventions and may, therefore, not be generalizable outside of the Zulu ethnic population in South Africa.

7.10 Conclusion

A review of the demographic literature and findings from this thesis demonstrate that a transition to lower fertility has persisted in this setting for decades and that fertility is likely to continue to decline in an era of ART, in line with prevailing social norms.

Use of ART does appear to influence certain aspects of childbearing in this setting. A reduced likelihood of live birth amongst HIV positive women compared to HIV negative women may be attributed to both physiological and behavioural differences. This thesis suggests some HIV positive women are limiting their childbearing behaviours in order to protect their improved health on ART or to avoid another adverse pregnancy experience.

The cultural context in which women make these choices is important. Women may feel more empowered to disclose a wish to limit childbearing when they no longer see the traditional prospect of marriage as obtainable. Before arriving at this juncture, women describe regular experiences of relationships that end with 'abandonment' after a pregnancy. Women found that male partners rarely met financial and romantic expectations and this contributed significant anxiety to the prospect of 'giving' another child outside the security of marriage. The risk to health of another pregnancy on ART was seen to compound this pre-existing stress under such uncertainty only after some experience of childbearing already in this setting. However, inconsistent injectable contraceptive use was common and regularly resulted in unplanned pregnancies. Some posed extreme risks to the woman's own health. These findings indicate a programmatic gap in family planning in the HIV continuum of care. Some women were more optimistic about having a child in the future and in line with the expectations of marriage. Additionally, women and health workers did not usually discuss desires for a pregnancy or that strategies for safer conception were available, leaving missed opportunities to minimise risks of HIV transmission and super-infection or support safer motherhood.

In a climate family planning services are being internationally re-prioritised, these findings are important. National policies for integration are unlikely to follow one set blueprint and need to reflect local realities. In South Africa, scale up of ART is unlikely to instigate a reversal of the national fertility decline. This thesis argues a public health perspective that 'significant investment' for family planning must prioritise strategies to address the extremely high current rates of maternal mortality,

using safer conception and motherhood strategies as outlined in the recommendations section of this thesis. Specific to women on ART, there is a need for tailored reproductive advice that encourages consistent contraceptive use when a pregnancy is not desired. Both aspects require additional health worker training to change the current 'injectable-centred' family planning culture and encourages awareness of existing and underutilised methods or safer conception discussions where appropriate.

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Appendices

Appendix A: Number of women according to their marital status, disaggregated by age and year

Age	Marital Status	2007			2008			2009			2010			2011			2012		
		Overall	Neg.	Pos.	Overall	Neg.	Pos.	Overall	Neg.	Pos.	Overall	Neg.	Pos.	Overall	Neg.	Pos.	Overall	Neg.	Pos.
15-19	Single	64	41	23	87	60	27	123	75	48	159	92	67	123	70	53	78	45	33
	Casual	27	21	6	24	18	6	35	28	7	27	21	6	11	5	6	7	5	2
	Married	4	4	0	1	1	0	3	2	1	8	5	3	3	3	0	6	5	1
	Regular	384	314	70	385	306	79	247	205	42	231	193	38	155	112	43	125	109	16
	Div/Wid/Separated	26	20	6	17	11	6	32	24	8	43	32	11	14	11	3	7	6	1
	Unknown	49	18	31	146	96	50	89	57	32	62	42	20	62	48	14	108	84	24
20-24	Single	67	44	23	61	39	22	175	98	77	221	126	95	195	107	88	166	98	68
	Casual	10	6	4	14	7	7	51	33	18	34	18	16	10	6	4	14	12	2
	Married	10	5	5	10	7	3	17	11	6	29	19	10	19	14	5	11	7	4
	Regular	599	384	215	526	330	196	447	283	164	501	317	184	418	245	173	245	169	76
	Div/Wid/Separated	36	26	10	47	28	19	40	28	12	57	33	24	27	18	9	36	28	8
	Unknown	149	21	128	341	52	289	228	102	126	165	53	112	195	84	111	270	184	86
25-29	Single	37	11	26	53	22	31	137	60	77	163	81	82	185	79	106	176	67	109
	Casual	5	1	4	2	0	2	13	12	1	5	7	-2	6	2	4	4	2	2
	Married	27	22	5	219	17	202	92	21	71	96	32	64	80	33	47	56	13	43
	Regular	368	168	200	356	144	212	178	117	61	227	159	68	209	111	98	140	93	47
	Div/Wid/Separated	28	10	18	28	8	20	18	14	4	29	12	17	21	8	13	20	14	6
	Unknown	122	3	119	337	78	259	234	61	173	256	38	218	223	85	138	264	134	130
30-34	Single	61	27	34	50	11	39	137	27	110	163	34	129	185	34	151	176	29	147
	Casual	8	2	6	2	1	1	13	3	10	5	1	4	6	1	5	4	1	3
	Married	62	48	14	52	34	18	92	48	44	96	50	46	80	50	30	56	28	28
	Regular	243	93	150	231	80	151	178	70	108	227	80	147	209	55	154	140	62	78
	Div/Wid/Separated	16	5	11	16	4	12	18	8	10	29	10	19	21	4	17	20	5	15
	Unknown	166	5	161	363	81	282	234	43	191	256	31	225	223	40	183	264	74	190

35-39	Single	65	27	38	63	18	45	116	32	84	188	41	147	162	36	126	180	31	149
	Casual	4	1	3	3	0	3	3	0	3	3	0	3	4	0	4	2	0	2
	Married	118	92	26	91	66	25	122	75	47	135	85	50	144	85	59	62	26	36
	Regular	187	99	88	157	68	89	122	58	64	151	55	96	132	34	98	94	29	65
	Div/Wid/Separated	16	10	6	11	7	4	22	7	15	34	5	29	33	10	23	20	4	16
Unknown	150	4	146	323	83	240	227	46	181	196	39	157	209	24	185	234	61	173	
40-44	Single	96	48	48	62	26	36	120	41	79	123	37	86	133	49	84	127	21	106
	Casual	4	1	3	2	1	1	2	0	2	1	1	0	2	0	2	1	0	1
	Married	148	120	28	113	83	30	151	103	48	177	115	62	171	97	74	82	36	46
	Regular	134	84	50	107	68	39	72	40	32	79	37	42	70	20	50	40	14	26
	Div/Wid/Separated	15	8	7	12	8	4	40	17	23	53	22	31	52	22	30	42	10	32
Unknown	138	0	138	369	109	260	221	63	158	212	54	158	185	53	132	203	75	128	
45-49	Single	139	88	51	112	60	52	148	76	72	164	74	90	171	59	112	131	30	101
	Casual	4	4	0	2	1	1	4	1	3	4	0	4	2	0	2	2	1	1
	Married	140	120	20	100	86	14	178	131	47	205	154	51	188	126	62	82	38	44
	Regular	87	61	26	111	82	29	58	39	19	72	39	33	38	24	14	18	10	8
	Div/Wid/Separated	15	13	2	9	5	4	51	30	21	68	40	28	85	44	41	36	9	27
Unknown	103	0	103	344	148	196	197	80	117	183	60	123	153	55	98	219	98	121	

Appendix B

Interview Schedule: Women attending Hlabisa HIV treatment and care programme with no experience of having a child while in the programme

Introduction to interview

Thank you for agreeing to take part in this study. Your views and opinions are very important to this research. As we have discussed before, you are free to not answer a question or end the interview if you feel uncomfortable at any time and this will not affect the treatment you receive at the clinic.

Any information that you provide today will be treated as strictly confidential and your name will not be used in any future reports, so please feel free to give your honest opinions.

Let us begin with some short questions.

1. Eligibility information (also used to keep a tally of strata)

- 1.1 How old are you?
- 1.2 Where do you currently live?
- 1.3 Are you currently working?
- 1.4 When did you find out your HIV status?
- 1.5 When did you first start taking HIV treatment?
- 1.6 How long have you been attending this clinic?
- 1.7 How many children do you have?
- 1.8 Have you been pregnant since receiving HIV treatment here or at any of the clinics in the area? If so, when was this?
- 1.9 What is your marital status?
- 1.10 [If has partner] Do you know your partners HIV status?

2. Introductory questions

- 2.1 What is a normal day like for you?
- 2.2 How did you find out you were HIV positive?
- 2.3 What impact did this diagnosis have on your life?
- 2.4 Did your diagnosis have an impact on your relationships? Did this change when you started treatment? (*Attitude to partner, Desire for a relationship, Sex life*)
- 2.5 Are you currently sexually active?
- 2.6 Who knows about your HIV status?

3. Fertility desires

- 3.1 Would you like to have more children/children in the future? Why/Why not

- *When would you like to have your next child? Why that time?*
 - *What things do you think will affect when you have another child?*
 - *Do you think you will actually have more children/children? Why/why not?*
- 3.2 Did your diagnosis change your views on having children? What about starting treatment did that change your views?
- 3.3 [If has partner] Do you know how your partner feels about having more children in the future? Have you discussed this with him?
- 3.4 What does your family expect from you in terms of having children? What about the community?
- 3.5 What effect would getting pregnant in the near future have on you?
- *Health*
 - *Relationship*
 - *Treatment from the clinic*

4. Attitudes to contraceptive use and awareness of method mix

- 4.1 Are you currently doing anything to avoid pregnancy?
- [Yes]
- *How long have you used this method?*
 - *Why that method rather than any other?*
 - *Likes and dislikes about the method?*
 - *Any problems using with the method? – Forgetfulness, side effects,*
 - *Would you prefer to use another method? [Yes] Which method? Why not changed?*
- [No]
- What are your reasons for not using any forms of family planning?
- 4.2 Have you ever used any other forms of contraception?
- [For each method used]
- *When and for how long?*
 - *Why that method?*
 - *Likes and dislikes about the method?*
 - *Any problems using this method? – Forgetfulness, side effects?*
 - *Why stopped using this method?*
 - *Would you consider using this method again in the future?*
- 4.3 What other forms of contraception have you heard of?
- *Probe if not mentioned: Injections, implants, pills, IUDs, patches, emergency contraception, condoms, sterilization*
- [For each method listed]
- *Would you consider using this method? Why/Why not?*
- 4.4 [If has partner] How does your partner feel about the different family planning methods?
- 4.5 Did diagnosis impact your use of family planning or how you feel about the different methods?

- 4.6 Has being on treatment changed your use of family planning or how you feel about the different methods?
- 4.7 Are there any forms of contraception or that you feel people should not use at the same time as HIV treatment? Why not?

5. Experience accessing contraception and views on services

- 5.1 Where do you usually get advice and supplies of contraceptives?
- *Likes and dislikes about the place*
 - *How could the experience be improved?*
 - *Are you given a choice of methods? Which ones? Would you prefer a wider choice?*
 - *Do you know any other places that you could access advice and contraceptives? Why do you not use those places?*
 - *Did your diagnosis influence where you got advice and supplies from?*
 - *Did starting treatment influence where you got advice and supplies from?*
- 5.2 Have you ever received advice on family planning or pregnancy from this clinic? What advice? Was the advice useful?
- 5.3 Would you like to receive more advice on family planning and pregnancy? What advice? Where do you think is the best place to give the advice?
- 5.4 [If not mentioned in 5.1] Have you ever obtained contraceptives from this clinic?
- [Yes]
- *Why did you not access/continue to access them at the clinic?*
 - *Likes and dislikes about the service?*
 - *How could the experience be improved?*
 - *Were you given a choice of methods? Which ones? Would you prefer a wider choice?*
- 5.5 What attitude do the health workers at this clinic have towards pregnancy and contraception?
- 5.6 Do you feel able to confide in the health workers about your pregnancy and family planning needs? Why/Why not?

Appendix C

Interview schedule: Women *with experience of a pregnancy* in the HIV treatment and care programme

Introduction to interview

Thank you for agreeing to take part in this study. Your views and opinions are very important to this research. As we have discussed before, you are free to not answer a question or end the interview if you feel uncomfortable at any time and this will not affect the treatment you receive at the clinic. Any information that you provide today will be treated as strictly confidential and your name will not be used in any future reports, so please feel free to give your honest opinions. Let us begin with some short questions.

1. Eligibility information (also used to keep a tally of strata)

- How old are you?
- Where do you currently live?
- Are you currently working?
- When did you find out your HIV status?
- When did you first start taking HIV treatment?
- How long have you been attending this clinic?
- How many children do you have?
- Have you been pregnant since receiving HIV treatment here or at any of the clinics in the area? If so, when was this?
- What is your marital status?

2. Introductory questions

- Tell me about your journey to the clinic here today
 - *Did you come alone?*
 - *Who are you staying with?*
- How did you find out you were HIV positive?
- What impact did your diagnosis have on your relationships? Did this change when you started treatment? (*Attitude to partner, Desire for a relationship*)

- Are you currently sexually active / in a relationship at the moment?
 - *How long have you been together,*
 - *How do you feel about it?*
 - *Do you know his HIV status?*

3. Fertility desires

- Would you like to have more children now or in the future? Why/Why not
 - [Yes]
 - *When would you like to have your next child? Why that time?*
 - *What things do you think will affect when you have another child?*
 - *Do you think you will actually have more children/children? Why/why not?*
 - [No]
 - *How do you feel about this*
- Did your diagnosis change your views on having children? What about starting treatment did that change your views?
- [If has partner] Do you know how your partner feels about having more children in the future? Have you discussed this with him?
- Have you ever spoken about your wishes to your family and friends?
 - *What did they say, how did this make you feel*
 - *What expectations do they have, how does that make you feel –do you agree*
- What effect would becoming pregnant soon have on you and your life?
 - *Health*
 - *Relationship*

4. Expectations and experiences with pre-conception counselling and of being pregnant

I would now like to talk to you about your experience of being in the HIV treatment programme during your most recent pregnancy.

- How did you feel when you found out you were pregnant
 - *Can you tell me why?*
 - *When did you find out?*
- *Was the pregnancy planned? Can you tell me more? I.e. how long were they trying for, why now?*
- *If unplanned, did you ever consider a termination? Were you ever offered one, would you know where to go if you wanted one?*
 - *Who did you tell when you first found out you were pregnant? (i.e. Partner, Family, Friends)*
- *How did they react? How did you feel about their reactions? When did you tell them?*
 - *How did you feel about being pregnant for your health whilst taking treatment for your HIV?*
 - *Were you worried that the pregnancy would impact your health?*
 - *Do you think it did have an impact on your health?*

- Before this pregnancy, what support or information did you get from other people or services in this area about getting pregnant as a women living with HIV?

[Potential topics include: ways to get pregnant safer for self or partner i.e. timing unprotected sex to most fertile period in cycle, artificial insemination, constantly checking own health and that of partner]

- *Where did you get this information?*
- *Can you tell me more about what this means for you and your life?*
- *Did you try any of these?*
- *Was the support and information useful?*
- *Did any of the advice also consider her partner*
- *Did she talk about it with her partner*
- *Did you want more information and support?*
- *Where would be the best place to get this? Why that place?*

Pause for definition

We are looking to find out more about your experiences of family planning here at the clinic.

We describe family planning as; “the Information and methods that help you to decide when to have a child at the right time for you. It helps women to decide how to space, limit or prevent births in order to reach their desired number of children. This information can be about which contraceptive methods are available and safer ways to get pregnant for individuals and couples living with HIV”

- Where do you think is the best place to get this advice?
- Have you ever received advice on family planning or pregnancy from this clinic and within this HIV treatment and care programme?
 - *What did they say?*
 - *Was the support and information useful?*
 - *Can you tell me more about what this information means for you and your life?*
 - *Did any of the advice also consider your partner? (if she has one)*
 - *Did she talk about it with her partner*
 - *Was there any more information and support you felt you needed?*
 - *How could the family planning services have been better here within the HIV treatment and care programme?*
- Were you able to confide in the health care providers here in the programme about your pregnancy?
 - [Yes]
 - *When did you tell them and why then?*
 - *What did you hope to gain from talking to them at this time?*
 - *How did they react?*

- *Did you consider talking to them before you got pregnant? Please tell me more about why.*
[No]
- *Please tell me more about why?*
- *Before you became pregnant were you using any methods to prevent pregnancy?*
[Yes]
- *What method were you using?*
- *Tell me about using this method at the time you became pregnant?*
[No]
- *What were the reasons you were not using any method?*
- *Have you ever tried using any? Reasons.*
- *What changed your mind?*

5. Knowledge and experiences of contraception and contraceptive delivery

I would like to know about your views on contraception and condoms.

- *Are you currently doing anything to avoid pregnancy?*
- *(this can be a modern, traditional or any method she considers as contraception)*
[Yes]
- *Please tell me more about what you are using? I.e. what, how it works?*
- *Why that method rather than any other?*
- *Are there any other reasons why this method?*
- *Have you ever had any problems using with the method? – Forgetfulness, side effects,*
- *Would you prefer to use another method? [Yes] Which method? Why not changed?*
[No]
- *What are your reasons for not using any forms of family planning?*
- *Have you ever used any other forms of contraception?*
 - **For each method used**
 - *How did you hear about this?*
 - *When and for how long?*
 - *Why used that method?*
- *Any problems using with the method? – Forgetfulness, side effects?*
- *Why stopped using method? I.e. health or treatment concerns?*
- *Would you consider using this method again in the future?*
- *What other forms of contraception have you heard of?*
 - *e.g. Injections, implants, pills, IUDs, patches, emergency contraception, condoms, sterilization*
 - *Would you consider using any of these methods? Why/Why not?*
- *How do you feel about using other methods such as the IUD or emergency contraception?*

- *Would you consider using this method? Why/Why not?*
- [If has partner] How does your partner feel about the different family planning methods?
- How does being on treatment affect your feelings towards family planning and different contraceptive methods?
 - *I.e. are there any forms of contraception that people should not use at the same time as HIV treatment?*
 - *Which, why?*
- Where do you usually get advice about your chosen method or contraceptive supplies?
 - *Why here?*
 - *Are you offered a choice of methods here? Which ones?*
 - *How could the experience be improved?*
 - *Do you talk to anyone or get any advice whilst collecting this method?*
 - *Do you know of any other places that you could access advice and contraceptives? Why do you not use those places?*
- Did your diagnosis influence where you got advice and supplies from?
 - *Did starting treatment influence where you sought these services?*
- [If not mentioned already] Have you ever received contraceptives from this clinic?
- [Yes]
 - *Were you given a choice of methods? Which ones? Would you prefer a wider choice?*
 - *Did someone talk to you about your options?*
 - *Did they ever discuss emergency contraception or the IUD?*
 - *How could the experience be improved?*

Appendix D

Interview Schedule: Health care providers working in the HIV treatment and care programme

Introduction

Thank you for agreeing to take part in this study. Your views and opinions are very important to this research. As we have discussed before, you are free to not answer a question or end the interview if you feel uncomfortable at any time. Any information that you provide today will be treated as strictly confidential and your name will not be used in any future reports, so please feel free to give your honest opinions.

Let us begin with some short questions.

1. Eligibility information

- How old are you?
- How long have you been working here at this clinic?
- What is your job title at this clinic?

2. Introductory question

- What duties does your job involve?
 - *Time spent with ART clients? Other services. How often?*

3. Situation of Family Planning within the ART programme

- How do you feel family planning is placed in this HIV treatment and care programme?
- When is family planning discussed?
 - *Offered during regular counselling? IEC?*
 - *Which are the most useful methods of education here in the programme?*
- What all possible topics do you counsel on family planning for women here in the programme
- Do you feel women on ART have different family planning needs?
- How is FP being prioritised
 - *What is done well, what is done not as well.*
- How integrated is FP with the main clinic
 - *When are referrals offered? How are these followed up?*
 - *How is counselling/method provision defined by each.*
- How do you view this integration
 - *Challenges / successes?*

4. Use of family planning amongst HIV positive women on treatment

- Are many HIV positive women attending this clinic using family planning?
 - *What for? Or why not?*
- How is contraception discussed here in the programme?
 - *Where do women seek them?*
 - *Which contraceptives are women interested in?*
 - *What information is given at the time contraceptives are provided?*
 - *How is information provided i.e. Individual/group talks/leaflets?*
 - *Who initiates these discussions?*
- Do you think the available contraception mix meets the needs of your patients
 - *Why do you think women chose these methods?*
 - *What methods are available?*
 - *Are you satisfied with the available mix?*
 - *Do you think being on treatment influences the methods women use?*
- Which methods do you feel most comfortable recommending to a woman on treatment, why?
 - *Why?*
 - *Are there any you do not think they should use?*
 - *Probe: Injections, implants, pills, IUDs, patches, emergency contraception, condoms, sterilization*
- Specifically I am interested to know your views on the IUD and emergency contraception. How easy is it to access these methods for women on treatment?
 - *Are these methods available to women within the clinic?*
 - *Do many women choose to use these methods? How?*
 - *Do you face any problems with providing these services here at the clinic?*
 - *Have you been trained to administer these services and would you feel able to do so?*
 - *If not, is there anyone else who can?*

4. Pre-conception counselling and pregnancy planning

- How do you feel women on treatment may be planning their pregnancies?
 - *What influences whether women want to get pregnant?*
 - *What is the effect of treatment?*
- In your experience, how willing are women to talk to health providers about their wish to get pregnant?
 - *When do these discussions happen? Are women ever asked about their pregnancy desires? Who asks? When?*
 - *What do you think prevents women from talking about their desires here at the clinic?*

- How do you feel advising a woman on ART who wants to get pregnant?
 - *Have you experienced this in the past?*
 - *How do you consider woman, partner and child health?*
 - *How do you feel providing this information?*
 - *Have you seen any protocols, guidelines of training related to this?*
 - *Do you think women follow the advice? Why/Why not?*

- What support is offered on ways to achieve a safe conception for women on treatment?
 - *When is this provided?*
 - *What topics are discussed?*
 - *How are couples encouraged to come together?*

5. Alternative family planning services

- If you needed to refer a woman for more family planning services, where would you refer her to?
 - *How would you do this?*
 - *Where to?*

- Are there any other places that women can access Family Planning advice in this area, this can mean for contraception or how to get pregnant or any place a woman feels able to discuss her needs such as traditional healers?
 - *What advice and methods are available at these places?*
 - *Are these services suitable for women on ART?*
 - *Which are most popular? Why?*
 - *Do you ever refer women to these places? When? How?*

6. Barriers to FP in the programme

- What are the main barriers you face delivering family planning services to women in this clinic? How would you improve the services offered at this clinic?

- What additional support would you like to improve provision of conception, advice and family planning counselling?

Appendix E

Checklist of clinic communication materials and counselling activities

1. Facility Identification

Date of observation		
Facility Name		
Type of Facility	PHC - HIV (Facility Level integration)	
	District Hospital (referral to other buildings/departments)	
	Standalone ART clinic	
Location		

2. Integration in the Primary Health Care Clinic with the HIV treatment and care programme

2.1 In addition to HIV treatment, which of the following HIV services are also offered by this facility?

Service	Yes	No	Referred
HIV counselling and testing			
▪ VCT			
▪ Provider initiated testing and counselling			
Home based care			
Psychological and social support			
HIV prevention, information and services for PLHIV			
HIV prevention, information and services for general population			
PMTCT			
Paediatric treatment			
Sexual and reproductive health services			
▪ Medical male circumcision for adults and neonates			
▪ Condom provision			
▪ Termination of pregnancy			
▪ Provision of contraception			
▪ Counselling and information on safe conception			
▪ Youth friendly services			
Access or referral to food security programmes			
Poverty alleviation support / access to benefits			
Support for victims of gender violence / sexual assault			

2.2 Are family planning services such as provision of contraception and counselling of safe conception integrated with the HIV services offered here at the clinic?
(*I.e. are clients routinely counselled or referred on these topics?*)

Yes / No

No: Continue to 2.8

If YES

2.3 Do the hours of operation for family planning in this primary health care clinic coincide with HIV counselling, treatment and care?

Yes. Whenever HIV services are open, FP counselling is also open.	
Sometimes. There are times when FP services are open that HIV services are closed. Please Explain	
No. Whenever FP services are open HIV services are closed.	
Other	

ART Programme (If Separate)

2.4 Which of the following HIV services also deliver family planning services such as contraception and counselling on safe conception, or routine referral?

Service	Yes	No
HIV Counselling and Testing		
▪ Offered during the same clinic visit		
▪ Located in the same service site and with the same provider		
▪ Located within the same service site with a different provider		
▪ Referred to a different service site within the facility		
▪ Referred to a different service site within the facility		
▪ Referred to another facility		
Treatment and care		
▪ Offered during the same clinic visit		
▪ Located in the same service site and with the same provider		
▪ Located within the same service site with a different provider		
▪ Referred to a different service site within the facility		
▪ Referred to a different service site within the facility		
▪ Referred to another facility		
Home based care		
PMTCT		
Following a 'Yes' to any of the above, please comment on service site. <i>I.e. is this the same or a different room/building/department?</i>		

2.5 Do you have a way of following up with FP clients that have been referred to by the HIV treatment and care programme, or after you have referred to the hospital?

Yes/No. Comments:

2.6 How are FP clients referred in case of routine referrals?

Verbally	
Written referral	
Other	

2.7 Are there any indicators for the integration of HIV treatment and care with FP services systematically reviewed in the facility quality monitoring activities (e.g. in monthly meetings)

Yes. Please explain.
No
Other

2.8 Are there any written guidelines and protocols available for health care providers to practice FP here at the clinic? *i.e.*

- *National Contraception Policy guidelines,*
- *KwaZulu-Natal 5 point contraceptive provincial strategy*

Others? Please list

2.9 Do any of these guidelines recommend that safe conception counselling and services are offered to clients of the HIV treatment and care programme?

Yes / No

Comments: _____

- 2.10 Are the following contraceptive methods EVER available to clients accessing Family Planning here in the
- 1) Primary health care clinic
 - 2) HIV treatment and care programme (if separate).

How often is each method available at this ART clinic?

1 = Everyday

2 = At least once a week but not every day

3 = At least once a month but not every week

4 = Less than once a month

Contraceptive Method	ART clinic (Y / N)	Frequency	Main Clinic (Y / N)	Frequency
Combined oral contraceptives (COCs)		1/2/3/4		1/2/3/4
Progestogen-only pills (POP)		1/2/3/4		1/2/3/4
Progestogen only injectables		1/2/3/4		1/2/3/4
Combined injectable contraceptives		1/2/3/4		1/2/3/4
Implants (Norplant)		1/2/3/4		1/2/3/4
Male Condom		1/2/3/4		1/2/3/4
Female Condom		1/2/3/4		1/2/3/4
Intra Uterine Device (copper)		1/2/3/4		1/2/3/4
Intra Uterine Device (levonorgestrel)		1/2/3/4		1/2/3/4
Spermicidal jellies, creams or foams		1/2/3/4		1/2/3/4
Diaphragm		1/2/3/4		1/2/3/4
Female Sterilisation (Tubal Ligation)		1/2/3/4		1/2/3/4
Male Sterilisation (Vasectomy)		1/2/3/4		1/2/3/4
Combined Patch		1/2/3/4		1/2/3/4
Combined Vaginal Ring		1/2/3/4		1/2/3/4
Cervical caps		1/2/3/4		1/2/3/4
Emergency Contraception		1/2/3/4		1/2/3/4

- 2.11 Are the following methods EVER discussed or promoted for women on ART either in the main clinic or in the HIV treatment and care programme?

- | | |
|---|------------------|
| a) Withdrawal (coitus interruptus) | ART / PHC / Both |
| b) Natural family planning/ periodic abstinence | ART / PHC / Both |
| c) Lactational amenorrhea | ART / PHC / Both |

3. Information Education and Communication materials

- 3.1 Are any family planning group talks or counselling sessions available for clients of the treatment and care programme at this clinic?

Yes/No

If yes;

Who is invited to participate? _____

Where are these sessions offered? _____

How often are these sessions held? I.e. Daily / weekly / monthly?

3.2 Which of the following family planning counselling materials are available in the HIV treatment and care programme during

- Individual counselling sessions
- Group talks

Material	Individual Counselling	Group Counselling Sessions
Flip charts		
Leaflets		
Posters		
Contraceptive samples		
Anatomical models		
Audiotapes, videotapes or films		

3.3 What topics are covered in group talks? *(multiple options possible)*

Counselling Topic	Yes / No
Contraceptive methods	
▪ Emergency contraception	
▪ Termination of pregnancy	
Preconception counselling	
▪ Fertility desires	
▪ Partner HIV testing	
▪ Methods for safer conception / risk reduction	
▪ How to determine a woman's fertile period	
▪ Optimal HIV management and other health aspects	
▪ Risks of MTCT	
▪ Possible use of pre-exposure prophylaxis	
▪ Need to identify infertility at an early stage	
▪ Alternatives to childbearing	

If possible to observe group counselling

3.4 What is the format for these talks/counselling session? *(multiple options possible)*

Format	Yes / No
Only the provider speaks	
Provider discussed issues with clients	
Provider asked clients for questions	
Tape, video or film was played without discussion	
Tape, video or film was played with discussion	
Contraceptive samples were shown	

Visibility: For observer to complete individually.

3.5 What family planning information materials are visibly available in clinics for clients of the ART programme

Material	Yes / No	Source i.e. DoH	Location (ART/Main clinic)
Posters			
Leaflets			
Posters			
Contraceptive samples			
Anatomical models			
Other. Comments			

3.6 What topics are addressed in these information materials

Topic	Yes / No	Comments
Contraceptive methods		
Safe conception methods		
Pregnancy and HIV		
Treatment and HIV		
Other		

3.7 Where are these materials available

Location	Yes / No	Comments
At reception		
In the waiting area		
In treatment room		
Other		

Any other comments

Thank you to management for helping with this study. We kindly ask permission to take sample leaflets from the clinic or photos of posters available at these services.

Further notes/comments:

Adapted from Johns Hopkins observation tool and the IPPF rapid assessment tool for service integration (IPPF and WHO),

http://pdf.usaid.gov/pdf_docs/PNACG547.pdf

Appendix E: Ethical approval certification and recertification

UCL Ethical Approval

UCL RESEARCH ETHICS COMMITTEE
GRADUATE SCHOOL OFFICE



UCL Research Ethics Committee, c/o The Graduate School, North Cloisters, Wilkins Building
University College London Gower Street London WC1E 6BT
Tel: +44 (0)20 7679 7844 Fax: +44 (0)20 7679 7043
ethics@ucl.ac.uk
www.ucl.ac.uk/gradschool

University of KwaZulu-Natal ethical approval



**Biomedical Research Ethics Committee
Westville Campus, Govan Mbeki Building**

Postal Address: Private Bag X54001, Durban, 4000, South Africa

Telephone: +27 (0)31 260 2384 **Facsimile:** +27 (0)31 260 4609 **Email:** brec@ukzn.ac.za

Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

INSPIRING GREATNESS





RESEARCH OFFICE
Biomedical Research Ethics Administration
Westville Campus, Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Website: <http://research.ukzn.ac.za/ResearchEthics/BiomedicalResearchEthics.aspx>