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REPRODUCTIVE CHOICES AMONG HIV POSITIVE PATIENTS IN EKURHULENI DISTRICT, GAUTENG PROVINCE

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements for the degree

of

Master of Public Health

Johannesburg, June 2014

DECLARATION

I, Samuel Onoja Agbo, declare that this research report is my own work. It is being submitted for the degree of Master of Public Health in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



_____

Signed on this 2nd day of June, 2014

DEDICATION

My parents, late Omago Agbo (nee Odah) and Agbo Ameh

ABSTRACT

Background

There is now global recognition of the reproductive health rights of all individuals, including people living with HIV (PLHIV). These include inter alia, decisions on the number, spacing and timing of their children. In light of limited information on the reproductive choices of PLHIV at primary health care (PHC) level, the aim of this research study was to develop new knowledge on the reproductive concerns and desires of PLHIV and to determine current services provided for HIV positive individuals in the Ekurhuleni district of Gauteng Province.

Methods

A cross-sectional study design was used to explore the reproductive choices and the factors influencing these choices among HIV positive patients in the Ekurhuleni district. During 2013, a random sample of HIV positive patients attending community health centres was selected. After informed consent was obtained, trained fieldworkers administered a structured questionnaire that elicited information on socio-demographics, reproductive choices, and knowledge on available reproductive services. Survey data were analysed using STATA version 13.

Results

The majority of survey participants (n=430) were female (70%) and unemployed (57 %). The mean age of participants was 36 years (SD 8.6): 40.8 years (SD 8.7) for men and 34.5 years (SD7.8) for women.

The expressed desire for children was 46% (95% CI: 41.4 – 50.9). In the multiple logistic regression analysis, predictors of desire for children were: age less than 49, marriage or living together, and no biological children. The odds of wanting children was 51.5 [95% CI: 14.8–178.8] times higher for those without children, compared to those with two or more children, while for those less than 25 years, the odds of wanting children was 22.0 [95% CI: 1.9-254] compared to those older than 50 years.

Conclusion

PHC clinics and health care providers should be capacitated to address the reproductive health needs of PLHIV, and these needs should be reflected in provincial and national policies.

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ACRONYMS & ABBREVIATIONS

ACOG	American College of Obstetrics and Gynaecology
AI	Artificial insemination
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ART	Assisted reproductive technology
CDC	US Centres for Disease Control and Prevention
CHC	Community health centres
CHCs	Community health centers
DHS	District health system
DNA	Deoxyribonucleic acid
DoH	Department of Health
GDoH	Gauteng Department of Health
ESDR	Eastern sub-district region
HAART	Highly active antiretroviral therapy
HCWs	Health care workers
HCP	Health care provider
HIV	Human Immunodeficiency Virus
ICI	Intra-uterine insemination
ICSI	Intra-cytoplasmic sperm injection
IUI	Intrauterine insemination
IUTPI	Intra-uterine tubo-peritoneal insemination
IVF	In-vitro fertilisation

NSDR	Northern sub-district region
PEP	Post-exposure prophylaxis
PHC	Primary health care
PMTCT	Prevention of mother to child transmission
PLHIV	People living with HIV
PrEp	Pre-exposure prophylaxis
SANAC	South African National AIDS Council
SSDR	Southern sub-district region
STI	Sexually transmitted infection
TB	Tuberculosis
UN	United nations
VCT	Voluntary counselling and testing
VL	Viral load
WLHIV	Women living with HIV
WHO	World Health Organization

CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

1.1 Background

Human immunodeficiency virus (HIV) infection is a global pandemic with great impact on population health (1, 2). In 2000, at the United Nations (UN) millennium summit, the United Nations Millennium declaration which was adopted gave birth to the eight Millennium Development Goals (MDGs). At this summit, the health impact of HIV & AIDS was acknowledged and an effective global response was considered essential. Among the eight Millennium Development Goals, MDG 6 is to combat HIV and AIDS, malaria and other diseases. One of MDG 6b targets was to ensure universal access to treatment for HIV and AIDS for all those who need it by the year 2010 while another target is to halt and reverse the HIV epidemic by the year 2015 (1, 2).

A decade after the MDGs were launched, the United Nations General assembly in 2011 endorsed the UN Political Declaration on HIV and AIDS and committed member states to work towards the elimination of HIV & AIDS by the year 2015 with set targets, among which are: 50% reductions of new infections; improvement in treatment coverage; elimination of inequalities and gender based violence, stigma and discrimination; and the integration of HIV with other health services (3-5). The World Health Organization (WHO), thereafter, developed a global health sector strategy on HIV & AIDS, 2011-2015, as part of the broader multi-sectorial HIV response to guide the health sector's response to HIV (5, 6).

In 2012, worldwide, there were an estimated 35.3 million people living with HIV (PLHIV), 2.3 million new infections and 1.6 million deaths from AIDS and related conditions (7, 8). Sub-Saharan Africa accounts for 69% of the global HIV burden. Women bear the brunt of the epidemic with an estimated HIV prevalence rate of 60% among women in sub-Saharan Africa (5, 6). Among the 15-49 year age group, HIV prevalence rate is 17%. In South Africa, the total number of PLHIV increased from an estimated 4 million in 2002 to 5,3 million by 2013, with HIV prevalence estimated at 10% of the total population (9-12).

Sexual transmission of HIV infection accounts for more than four-fifths of global HIV infections (13). The knowledge on contracting HIV infection has not reduced the risk of PLHIV from engaging in unprotected sexual intercourse, often because of their desire for children (14-

16). The improvement in HIV management especially the introduction of highly active anti-retroviral therapy (HAART) has transformed the disease from a death sentence to a chronic condition, and has resulted in improved quality of life and increased life expectancy of HIV positive persons. Consequently, there has been the re-emergence of debates and concerns regarding reproductive choices and desires among HIV positive people (17-19).

Sub-Saharan African countries, including South Africa, have limited resources to provide adequate health services for the public at large. Health services for HIV positive individuals have mainly been in the area of voluntary counselling and testing (VCT) to identify HIV positive people and to prevent transmission between sexual partners and from mothers to infants through the use of antiretroviral (ARV) drugs, contraception and exclusive breastfeeding (20-22). The provision of reproductive assistance for HIV positive persons has not received much attention. Hence, the focus of reproductive health has been tailored towards the avoidance of pregnancy. Thus, HIV positive persons are commonly counselled on the utilisation of contraceptives and the use of condoms (23-25). Worst still, there are reported cases of coerced abortion and sterilization as well as pressures to use long-acting contraceptive methods (26).

There is now global recognition of the reproductive health rights of all couples and individuals, which include decisions on: sexuality, the number, spacing and timing of their children and the information and means to do so (27, 28). Consequently, health programme managers, policy-makers and care providers need to understand and promote the reproductive health of couples and individuals and to provide health services that meet their needs. Thus, they are obliged to devise mechanisms to ensure that the reproductive rights and needs of PLHIV are protected and addressed (29).

In light of limited information on the reproductive choices of PLHIV at primary health care (PHC) level, the aim of this research study was to develop new knowledge on the reproductive concerns and desires of PLHIV and to determine current services provided for HIV positive individuals in the Ekurhuleni district of Gauteng Province. The remainder of this chapter sets the scene for the study that was conducted by describing the study setting, outlining the problem statement, presenting a review of existing literature, and summarising the rationale for the study. The chapter concludes with the study aim and objectives.

1.2 Study Setting

This study was conducted out in the Ekurhuleni health district, one of the five current health districts in Gauteng province in South Africa. The other districts in Gauteng province are Johannesburg, West Rand, Sedibeng, and Tshwane-Metsweding (30).

Ekurhuleni district is the second largest district in Gauteng province and is divided into three operational health sub-districts namely Eastern sub-district (ESDR), Northern sub-district (NSDR) and Southern sub-district (SSDR). The estimated population of the district is 2.9 million people (30, 31). The population with no medical insurance (uninsured population) dependent on public health facilities within the Ekurhuleni district of Gauteng province is estimated at 1.8 million (32). The major languages spoken in the province are: isiZulu (19.8%), English (13.3%), Afrikaans (12.4%), and seSotho (11.6%) (30).

The Ekurhuleni district health system (DHS) consists of a district hospital; Bertha Gxowa (previously Germiston) hospital, seven community health centres (CHCs) and 87 clinics. The CHCs are well resourced and offered the full package of PHC services including HIV diagnosis, treatment and care services (32, 33). In the ESDR, the CHCs are Nokuthela Ngwenya, Kwathema and Phillip Moyo. In the NSDR, there is one CHC which is Esangweni CHC and the SSDR has Jabulani Dumane, Phola Park and Ramokunopi CHCs (32). In 2012, Ekurhuleni health district had 98% of the primary health care facilities providing HIV management services. A total 39 344 new patients were initiated on treatment bringing the total number of patients on HAART to 100 796 as at the end of March 2012 (32, 33).

The management and governance of PHC facilities involve formulating policy for PHC and implementing operational management decisions at these clinics. This also involves the provision of infrastructure, equipment, pharmaceuticals, the employment of health workers and, the monitoring and evaluation of service delivery goals.

A total of 572 464 people have been tested through the HIV Counselling and Testing (HCT) Campaign in 2012 of which 19 % tested positive for HIV. The HIV first test positive rate fell from 24% in 2012 to 22% in 2013. The PCR positive rate at 6 weeks also fell from 3% to 2% in the same period (32, 33).



Figure 1: Map of South Africa, Gauteng province and Ekurhuleni district.

These public health facilities are staffed primarily by nurses and supported by generalist medical doctors and family physicians. Health care services are provided free of charge i.e. there is no out of pocket payment at these PHC facilities.

1.3 PROBLEM STATEMENT

In light of the high prevalence of HIV in South Africa, government's stated commitment to address the HIV epidemic in order to meet the millennium development goals (MDGS), policy-makers and implementers must make all the necessary efforts to improve health services for PLHIV. As HIV affects mostly individuals in the 15-49 year age-group, (34) the provision of reproductive health services is of particular concern. This group constitutes the reproductive age group and contribute significantly to the economy of the country.

However, little information is available on the reproductive choices of HIV positive patients and as well as available reproductive health services in the Ekurhuleni district of Gauteng province, where there is an estimated HIV prevalence of 24% (33). The lack of adequate information on the reproductive concerns of PLHIV makes the provision of reproductive health care and related services difficult. This was one of the first studies to examine reproductive choices and desires among HIV patients attending the public PHC facilities in the Ekurhuleni district of Gauteng Province, and the availability of such choices.

1.4 Literature Review

1.4.1 Definition of terms

HIV positive patient

An individual who is infected with HIV and who tested HIV positive or reactive to HIV antibodies using a recognised, standardised test (35-37). HIV positive (HIV+) patient is used interchangeably in this report with the term, people living with HIV (PLHIV).

Sexual and reproductive health

This is a state of physical, emotional, mental and social well-being related to sexuality, not merely the absence of disease, reproductive disease, dysfunction or infirmity. Sexual health

requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence (38, 39).

Furthermore, sexual and reproductive health also implies that people have the capability to reproduce and the freedom to decide; when and how often to do so. Integrally, is the right of men and women to be informed and have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of choice of fertility regulation and the right of access to appropriate health care services that will enable women to go safely through pregnancy and childbirth and to provide couples with the best chance of having a healthy infant (38, 39).

Sexual and reproductive health services

The main components of sexual and reproductive health services are: improvement of antenatal, perinatal, postpartum, and new-born care; provision of high-quality services for family planning, including infertility services; elimination of unsafe abortions; prevention and treatment of sexually transmitted infections, including HIV, reproductive tract infections, cervical cancer, and other gynaecological morbidities; and promotion of healthy sexuality (40).

Reproductive Rights

WHO defines reproductive rights as basic rights for all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to the highest attainable standard of sexual and reproductive health. It also includes the right of all to make decisions concerning reproduction free of discrimination, coercion and violence (41, 42).

Assisted reproductive technology (ART)

This is defined as all treatments or procedures that include the in-vitro handling of both human oocytes and sperm, or embryos, for the purpose of establishing a pregnancy. This includes, but not limited to, in-vitro fertilization and embryo transfer, gamete intra-fallopian transfer, zygote intra-fallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donation, and gestational surrogacy. This definition is not inclusive of assisted insemination/artificial insemination (43-45).

Artificial Insemination

Artificial insemination (AI) is a procedure that involves the direct insertion or introduction of semen into a woman's vagina or womb other than by coitus. The most commonly used method of artificial insemination is intrauterine insemination (IUI) and other types such as intra-uterine tubo-peritoneal insemination (IUTPI), intra-cervical insemination (ICI), intra-tubal insemination (ITI) (46-49).

1.4.2 Studies in high income countries

In the early stages of the HIV epidemic, the advice given to HIV positive patients was to postpone pregnancy due to the anticipated poor health condition of women and vertical transmission of the infection to their babies. This was the policy position of the Centres for Disease Control and Prevention (CDC) in 1985 (50, 51). The American College of Obstetrics and Gynaecology (ACOG) added its voice to the debate in 1987, and urged physicians to discourage women infected with HIV from falling pregnant, and to inform pregnant HIV infected women of termination options (52, 53).

In 1994, the attitude towards reproductive concerns of persons living with HIV started softening. The Ethics Committee of the American Society for Reproductive Medicine (ASRM) among its guidelines for HIV positive patients requesting reproductive assistance, advised physicians to counsel couples about the consequences of using potentially infected sperm and to discuss the options of donor sperm, adoption, or not having children. At this period, the life span was considered to be short for the potential child’s parent and also HIV was regarded as a contra-indication for a healthy pregnancy (54-57). Subsequently, the provision of

reproductive services in several high income countries was recognised as a legitimate right. These services are currently being offered in Europe and in France where assisted reproductive techniques have been offered free of charge since 2001 (58).

In 2001, the CDC revised its previous position and recommended that HIV-infected pregnant women should receive information about all reproductive options and that reproductive services should be guided by a patient decision (59).

There is a significant body of literature on reproductive choices of and issues faced by PLHIV. In a 1996 study by Chen et al, among HIV positive patients receiving treatment in HIV clinics in the United States of America (USA), 28% of men and 29% of women expressed their desire to have children in the future irrespective of HIV infection. Factors influencing this desire included younger age and personal health status. Race and ethnicity were found to play a role as those of African descent were more likely to desire children than others (60). In Canada a study by Ogilvie in 2007, reported that 25.8% of women living with HIV (WLHIV) expressed an intention to have children. In the multivariate model analysis, non-aboriginal ethnicity, younger age and having a regular partner were associated with an increased likelihood of the reported intention to have children (61).

A French study by Heard *et al* in 2007 reported that among heterosexual PLHIV receiving treatment in various hospitals, 32% of women and 20% of men expressed a desire for children. The motivating factors were similar to those found by Chen et al (60). In London Sherr et al found that 43.8 % of HIV positive men attending HIV clinics wanted children, (62) while the 2003 Panozzo *et al* study in Switzerland, found that among PLHIV, 38% of men and 45% of women expressed a desire for parenthood (63).

1.4.3 Studies in low and middle-income countries

In general, several studies have reported the immense pressure on women in sub-Saharan Africa to have children regardless of their HIV status (64). The situation for men was reportedly grave as well, with not having children often resulting in stigmatisation and loss of social status among peers (41). Thus, there is strong desire among PLHIV to bear children. This means that

couples who lack services to guide them on their reproductive choice, are left with no alternative than to be involved in unprotected risky sexual behaviour (42, 62, 65-67).

Several research studies on the reproductive concerns of HIV positive patients have been published with interesting findings. In a cross sectional study in Uganda to investigate desire for children and pregnancy risk behaviour among HIV infected men and women, it was found that 33% practised pregnancy risk behaviour, and 18% desired more children. Men were almost four times more likely to want more children than women (27% vs. 7%) (68). Beyeza-Kashesya et al examined determinants of the desire for children among 114 mutually disclosed sero-discordant couples receiving care at four centres in Kampala, Uganda. They found out that 59% of the participants desired to have children and they believe that their partner wanted children was a major determinant of the desire to have children irrespective of the person's HIV sero-status. Among couples where the woman was HIV-positive, younger age and relatives' expectations for children and among couples where the man was HIV positive, knowledge of ART effectiveness was associated with increased fertility desire (69). Availability of information on contraception was associated with decreased fertility desire (69). Although this study was done in a different context than South Africa, it highlights the fact that HIV disclosure and HIV treatment are not the only motivating factors for the desire to have children.

In another study on 'Sexual relationship and childbearing decisions of HIV-discordant couples: an exploratory study in South Africa and Tanzania', more than half of the South Africans and almost three-quarters of the Tanzanians reported that intimacy had been affected by their discordant status. Those without children were more likely to desire children (17/23) than those who already had children (16/44). In this study among HIV discordant couples, this desire was influenced by fear of HIV transmission to the negative partner and medical professional advice (70). The study points to the need for targeted information for HIV discordant couples, as well as couple counselling and support services.

The desire for children among women living with HIV (WLHIV) was also reported in research conducted in Brazil, Uganda, and Zimbabwe (71-73) and was found to be independent of HAART (74-76). In Uganda and Zimbabwe, younger age and stable relationship status were factors associated with reproductive desire, (77, 78) while in Brazil the desire to have a child

with the current partner was reported as a reason (71). In India, desire for a male child was the strongest determinant among PLHIV, (79) while in Fiji, Papua New Guinea and Botswana, the cultural dictate of motherhood was the main determinant for desiring children (80, 81).

Coerced sterilization, the performance of female sterilization without informed consent by the concerned individuals, have been reported among PLHIV in Namibia (82) and Brazil (71). In these instances health care providers (HCPs) decided on sterilization options for women (71, 83). In 2011, coerced sterilisation was also reported by the International Community of Women Living with HIV/AIDS in Namibia (82, 84), Thailand (85, 86), Chile (83, 87), Mexico (88, 89) and Jamaica (90). The International Federation of Gynaecology and Obstetrics released an update on female contraceptive sterilization guidelines that recognized coerced sterilization as violence against women (91).

Several articles have been published examining the legal and human rights issues of people living with HIV and their reproductive concerns. In an article "At risk: Rights violations of HIV-positive women in Kenyan health facilities", those who expressed the desire to have children were faced with biases and negative attitudes by health care providers and they reported being stigmatised in their communities (92). In this hostile environment and the health care workers not providing the opportunity for HIV positive persons to raise their reproductive concerns, PLHIV often conceal their desires, leading to grave consequences of engaging in risky sexual practices and sexual transmission of HIV infections (92). The article "Desire to have children: gender and reproductive rights of men and women living with HIV: a challenge to health care in Brazil", re-iterates the sexual and reproduction rights of HIV positive persons (93).

Negative attitudes about pregnancy among HIV positive women were also reported. HIV positive women are sometimes advised to abstain from sex, pressured to abort current pregnancies or refused health care. This situation has been reported in India, Kenya and other developing countries (74, 94-99). Many HIV-positive women want to discuss their sexual and reproductive plans with their health care providers, but do not feel comfortable. This was the findings of research studies in Mexico, Brazil, South Africa and Chile (94, 100-102). Stigma, hostility and discrimination were also reported. In some instances PLHIV are reported to have refused to attend antenatal care or avoided hospitals at the time of delivery

because of the perceived high levels of stigma, discrimination and even hostility. This has been reported in India, Swaziland, Mozambique and other countries (94, 103, 104).

There are numerous challenges in the provision of ART services for women living with HIV (WLHIV) in these developing countries. In Kenya, financial constraints were the major obstacle (105) while in Vietnam the government policy placed prohibition on the provision of this service (106). The situation in eight Latin America countries is that ART is excluded from the national strategic plan (107). Due to lack of ART, women living with HIV are exposed to risky sexual behaviour and thus faced with the increased risk of horizontal and vertical transmission of HIV.

The reported findings that HIV affects fertility of WLHIV has made the provision of the ART service difficult as the chances of positive outcomes with ART is reduced compared to those without the infection (108-113).

1.4.4 Studies in South Africa

In the study report by Cooper et al, to investigate the fertility intentions and reproductive health care needs of PLHIV attending health care facilities in Cape Town, 57% of men and 45% of women expressed their intention to have children. Overall, intentions to have children were associated with being male, having fewer children, living in an informal settlement and use of antiretroviral therapy. There were important gender differences in the determinants of future childbearing intentions, with being on highly active antiretroviral therapy (HAART) strongly associated with women's fertility intentions. The study participants gave some insights into the reproductive desires of HIV positive patients attending these clinics (114).

In Soweto, Kaida et al reported in 2007, the desire for children among HIV positive women on HAART was 31% and was associated with younger age and being in a stable relationship (74).

In the study report by Strode et al, participants gave accounts of discrimination and coerced sterilization of HIV positive women in two provinces between 1996 and 2010 (115).

1.4.5 Reproductive options for PLHIV

Several articles have been published to examine reproduction options that can assist PLHIV achieve their reproductive desires, dignity and right and as well as reduce HIV transmission. These include services for the prevention of mother-to-child transmission (PMTCT) of HIV programme during pregnancy and delivery, elective Caesarean section and avoidance of breast feeding. The reduction in transmission, if all these measures are implemented, is less than 2% from about 30% without any intervention (116, 117).

Natural reproduction through unprotected sexual intercourse is supported by current research findings that the risk of HIV transmission is reduced if the viral replication is completely suppressed to an undetectable level. It has been reported in research findings that HAART taken for 4-6 months could lead to suppression of the viral replication to an undetectable level. Thus, the risk of HIV transmission is reduced but not completely eliminated (118). The study, known as HPTN 052, found that early initiation of anti-retroviral therapy (HAART) by HIV infected individuals substantially protect their HIV uninfected sexual partners from acquiring HIV infection at 96% reduction in risk of HIV transmission (119). This finding holds promise for countries that are currently struggling to cope with declining health budgets, yet increasing health care needs. As a consequence of this finding, the recommendations are natural reproduction through unprotected sexual intercourse, and the restriction of these sexual encounters to ovulation periods and a maximum of 12 attempts, in order to minimise HIV transmission and maximise conception (16, 119). However, caution is advised in these proposals since the risk of HIV transmission can only be minimised but never eliminated (120-122).

Assisted reproductive methods have been advised in light of the finding that in discordant partners where the man is HIV positive and the woman is HIV negative, the risk of HIV transmission through unprotected sexual intercourse is still present even if HIV is suppressed. This is because men with undetectable plasma viral load (VL), such as those on HAART can still transmit HIV in semen. The explanation is that viral load in semen correlates poorly with that in serum. HIV test of semen for the detection of HIV antigen in the ejaculates of semen is unreliable (123-126). The recommended approach to achieve pregnancy is through methods such as insemination using donor sperm after the donor sperm is screened and free of HIV and

other infections or by means of sperm washing of the infected male sperm before intrauterine insemination (IUI), in-vitro fertilisation (IVF) or intra-cytoplasmic sperm injection (ICSI) (127, 128).

In the case where the woman is HIV-positive and the man is negative, the finding is that despite full viral load suppression in the woman through HAART, detectable HIV has been identified in follicular fluid and endometrial samples (21, 129). In this situation, since it is still not safe for unprotected sexual intercourse, to achieve pregnancy, the advice is by way of self or assisted insemination of semen. This service is available in low income countries and many HIV positive patients have benefited from it.

Generally, the means through which risk of HIV transmission can be reduced for safer conception in sero-concordant and sero-discordant couples now include giving HAART for viral load suppression in the positive partner(s) and practising timed, limited, peri-ovulatory unprotected sexual intercourse. Another option is the intra-uterine insemination and intra-vaginal insemination of sperm free of HIV, through sperm washing of semen from a HIV positive individual (67). Male circumcision have been found to reduce HIV transmission by 60%, post-exposure prophylaxis (PEP) in the negative partner and partner pre-exposure prophylaxis (PrEp)) in the negative partner show promise of reducing transmission of HIV through sexual intercourse but at experimental stages (52, 67).

In summary, the review of the literature shows that desire for children among PLHIV is a reality in all countries, and several complex factors determine the reproductive choices. The knowledge of methods to reduce HIV transmission via reproduction processes is available and the right for reproductive options for HIV patients have been well articulated. Notwithstanding the various options available, many of which are accessible in high income countries, these services are neither available nor affordable in resource-constraint settings such as South Africa.

As indicated earlier the availability of services and reproductive desires and choices of HIV patients at PHC facilities in Ekurhuleni district were unknown. This study was conducted to address this knowledge gap, and to contribute to the discussions on improvements in service delivery to PLHIV within the district specifically, but broadly within the province of Gauteng.

1.5 JUSTIFICATION FOR THE STUDY

There were several reasons for conducting a study on the reproductive choices of HIV positive individuals attending the HIV clinics in Ekurhuleni for care and treatment. Firstly, the study generated locally, context specific information on the: choices of HIV patients with regards to reproduction and the factors influencing these choices, and PLHIV's knowledge of fertility options and services available to them at the PHC facilities in Ekurhuleni area.

Secondly, the study was important from a human rights perspective as the information could inform the establishment and/or improvement of reproductive health services as part of PHC services for HIV patients in the Ekurhuleni district.

In light of the renewed emphasis on quality of care, the study findings also provided a baseline for programme or service monitoring in the district.

Lastly, the study findings are relevant to similar districts in Gauteng province and in the country.

1.5.1 Aim

The aim of this research study was to investigate the reproductive choices of HIV positive patients in Ekurhuleni district, Gauteng Province.

1.5.2 Objectives

The specific objectives of the study were to:

1) Determine reproductive desires of HIV positive individuals attending HIV clinics
2) Explore factors influencing reproductive choices of HIV positive patients.
3) Determine the knowledge of HIV positive patients on the reproductive options available to them.
4) Explore the reproductive services received at the Ekurhuleni clinics by HIV positive patients.

The next chapter, materials and methods describes in detail the processes undertaking to conduct the research.

CHAPTER 2: MATERIALS AND METHODS

2.1 Introduction

This chapter describes the overall study approach and methods (sampling, data collection and analysis) which were in line with the study aim and objectives.

2.2 Study population

The study population consisted of all the HIV positive patients attending the primary health care facilities within the Ekurhuleni district.

2.3 Study Design

This was a cross-sectional study conducted during 2013 to describe the reproductive choices of HIV positive patients in Ekurhuleni district of Gauteng province.

2.4 Ethical considerations

Standard ethical procedures were followed: ethical clearance for the study was obtained from the University of the Witwatersrand's Human Research Ethics Committee (Appendix 1a), the study approval was also obtained from the Ekurhuleni health district research ethics committees (Appendix 1b), a detailed patient information sheets were given to patients (Appendix 2), informed consent form was obtained from every patients (Appendix 3) and there was voluntary participation in the study.

Patients attending the HIV clinics were informed about the research project. Those who were selected were informed that participation was entirely voluntary, with no direct benefits or penalties irrespective of their decision about study participation. All selected participants were given the information form and consent form (see appendices 2 &3).

The information form and the research process were explained to each participant. Those who decided to participate in the study then signed the informed consent to participate. Following informed comment, the questionnaire thereafter was administered by their fieldworker.

Those who needed support and counselling as a result of emotional trauma experienced from the contents of the questionnaire were referred to the lay counsellor based at each clinic. Participants requesting more information on the research that could not be handled by the field workers were referred to the researcher.

The nurse dedicated to the research and the fieldworkers ensured that participants did not lose their place in the queue at the PHC facility, because of participation in the study.

Also as part of the information on the information leaflet, it was clearly stated that there was no direct benefit to participants and this research may not result in additional or improved services by the government. This was necessary to ensure that possible unmet expectations from the research did not lead to resentment towards health workers at the PHC facilities involved in the study.

2.5 Eligibility criteria

The eligible age for inclusion in the study was 18 years to avoid ethical and legal issues with obtaining consent from minors to participate in the study. Women between their reproductive years of 18-49 years were eligible while men aged 18-60 years were included in the study. All those who are too sick to be interviewed or who declined participation were also excluded from the study.

2.6 Sampling

2.6.1 The sampling frame

The sampling frame consisted of all HIV positive patients attending the seven CHCs in Ekurhuleni heath district. The CHCs were selected as they are well resourced, provide comprehensive PHC services, have dedicated HIV clinics and attend to a large number of the HIV positive patients. The CHCs in the whole district are grouped into the sub-districts of east (ESDR), north (NSDR) and south (SSDR) as indicated in Chapter 1.

Each HIV clinic in the sampled facilities has an average head count per week of 500 HIV positive or 2 000 patients per month. The female to male ratio is 70:30.

2.6.2 Sample size calculation

The study sample size was determined using the sample size calculation formula:

$$N = \frac{Z^2 \times p\,(1-p)}{D^2}$$

(Where N is sample size, Z is 95% (1.96) confidence interval (CI); p is proportion of the outcome variable (desire for a child/ children) from previous study (60%) and D margin of error (5%).

Thus, $N = \frac{1.96^2 \times 0.6\,(1-0.6)}{0.05^2} = 369.$

Therefore, the total number of HIV positive patients required for the study was 369 patients and with the assumption of about 20% refusal rate, the sample was then adjusted to 442.

2.6.3 Sampling approach

One CHC from each of the two sub-districts - east and south - was sampled randomly using a simple ballot method while the only CHC from the north was selected. This sampling approach was used to account for the geographical distribution of the PHC facilities in the district. The study participants were selected from these sampled CHCs. The female: male ratio of 70:30 was maintained in the sampled participants.

The participants were selected using systematic sampling with a random start (between 1 and 10). All the patients attending the HIV clinics on each day were given serial numbers, with separate codes given to men and women. The numbering started from M001 for men while women had W001 until the last patient. The total number of participants expected for each particular day was firstly determined and the interval then derived by dividing the total number of patients attending the clinic by the expected number of study participants to be interviewed. The selection of participants was then started from the random number selected and the interval followed to get the exact number of expected participants for both men and women respectively.

Every eligible patient within the determined intervals who was willing to participate in the study was selected and included in the study. This approach was adopted for each working day in the months of May to July 2013 until the sample size was reached.

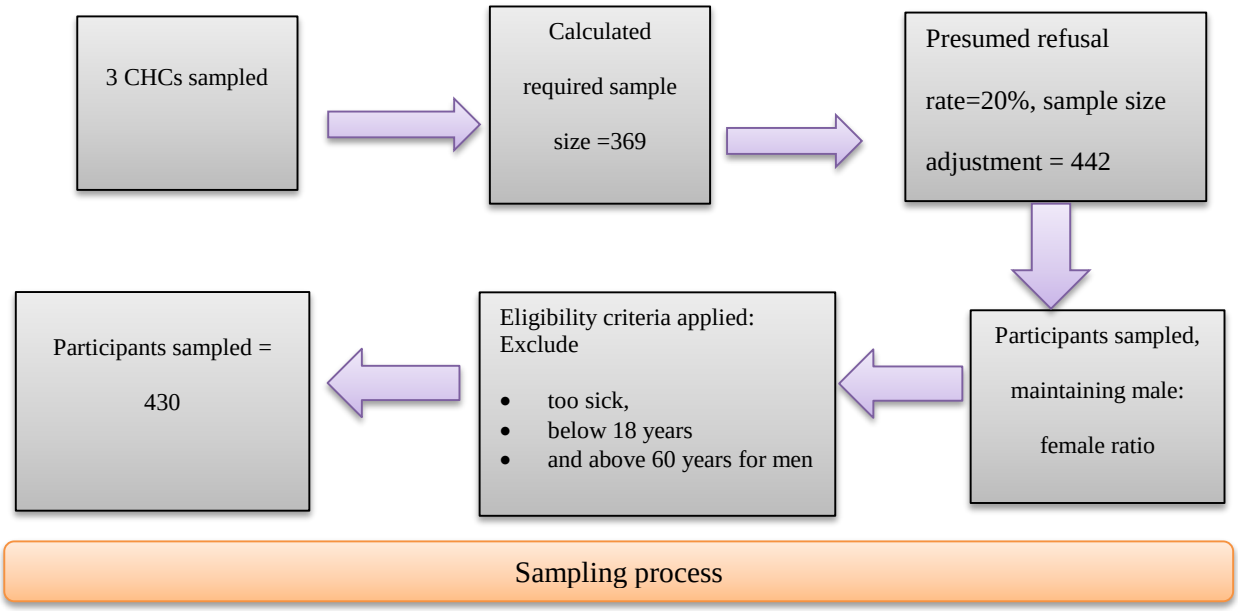


Figure 2: Overview of sampling approach

A dedicated nurse at each health centre assisted to identify the files of attending HIV positive patients and to allocate the serial numbers. The field workers then sampled the participants from these patients using the sampling sequence.

Arrangements were made for all patients participating in the study to maintain their position or number on the queue for the clinic services.

2.7 Measurement Tools and Data Collection

2.7.1 Questionnaire design, content and validity

A semi-structured questionnaire, developed in line with the study objectives, was used to collect data (see appendix 4). The questionnaires were administered by trained field workers. The questionnaire covered the following key domains: background characteristics; HIV disclosure and treatment; reproductive choices; and the available clinic services. In the domain of reproductive choices, the questionnaire included the following: sexual relationship(s); desire to have a child / children in future; reasons for the expressed choice; condom use; contraceptive

use; and choice of reproductive method (e.g. natural, artificial insemination, assisted reproductive technology, etc.). The questionnaire also explored the participants' reasons for not wanting children in the domain of reproductive choices.

The validity of the questionnaire was ensured by accuracy of translation from English to the other languages, the pilot study that was done, the sequence of the content and the consistent usage for all participants.

2.7.2 Questionnaire translation

The content of the questionnaire were developed from findings of the reviewed literature. These variables contained in the questionnaire have been validated and used in several research studies relating to reproductive health of PLHIV as evident in published research. The questionnaire was developed in English, but was translated into seSotho and isiZulu, because these are the predominant languages spoken in the district. The translations were done by capable persons who are health care providers, fluent in speaking, reading and writing in these languages. The back translations were done by other individuals at the health facilities who were fluent in speaking, reading and writing these languages to ensure accuracy and validity of the translations.

This processes revealed differences in some of the meanings in the translated documents from what were intended in the English version. These differences were resolved by another group of individuals who were also competent in these languages.

The final document, a product of these rigorous activities ensured the questionnaire was valid and that enabled appropriate data collection.

2.7.3 Field workers

The fieldworkers who collected the data were recruited from the district. Criteria used for their recruitment included among others: experience in research, fluency in in English, isiZulu and seSotho, and ability and willingness to travel to research site. A training workshop was

organised for the field workers. These fieldworkers were taught appropriate conduct and behaviour during research and with study participants and the training also focused on their important role in the research. The workshop covered limited theoretical aspects to understand the research process and the administration of the questionnaires. Thereafter, a practical session on the administration of the questionnaires was conducted.

Assessments were done and those who demonstrated good understanding of the research process and use of the information document, consent and questionnaire were selected. Nine candidates, four females and five males, participated in the recruitment exercise, seven made the final list.

The practical assessment of the fieldworkers continued at the pilot site and one of the candidates was dropped due to poor performance. Eventually, three females and three males administered the study questionnaires.

The field workers then signed a contract which explained the relationship between them and the researcher. These included among others: the amount of stipends to be paid, responsibility in the completeness of data collected, signing of attendance and most importantly, that this research field work was neither an employment nor a promise of eventual employment. This last aspect is important in South Africa because of the high unemployment rates.

2.7.4 Pilot study

A pilot study was carried out at a CHC not included in the study, but located within the district. The pilot study was aimed at testing the duration of the questionnaire as well as to ensure the validity of the elements contained in it. The time to administer a questionnaire determined through this process was 30 minutes on average and the elements in the questionnaire were found valid for the research study.

This pilot study also helped to determine acceptability, suitability, understanding and willingness of PLHIV to participate in the study.

It also helped to assess the field workers ability to question participants, complete the questionnaires, respond to questions and handle emotional issues experienced by respondents.

2.7.5 Data collection

Six field workers were used to collect the data. Two field workers, one female and the other male, were used to administered questionnaires to the participants in each clinic. The female fieldworker administered the questionnaires to female patients while the male fieldworker focused on the male patients.

The data collection started on 15 April 2013 and ended on 30 May 2013, and took place between 7.30am and 4.30 pm each clinic day. About ten to twenty patients were interviewed on a daily basis. The average time for each participant was between 20-30 minutes.

Some of challenges encountered during the data collection period included among others: delays in starting in some clinics due logistical issues, some clinics did not operate on some days of the week, all clinics were closed during weekends and some of the field workers were absent for social reasons on some days of the week.

There was general willingness among patients to participate when the purpose of the study was explained to each of them in the private room used by the research fieldworkers.

2.7.6 Quality and reliability of the data

The interview was conducted in a private room in each of the facilities. This enabled open discussions and confidential completion of the questionnaires.

The researcher ensured each data collection centre (namely the selected CHC) had dedicated numbered questionnaires. All completed questionnaires were checked daily or within two days for: completeness; appropriateness of responses to all of items; and legibility of the writing.

Thereafter the completed questionnaires were put in an envelope, sealed and the date of data collection written on them.

2.8 Data Management and Analysis

The questionnaires were coded for each facility and participant using the following abbreviation; the Eastern clinic: E (E001, E002 etc.), Southern clinic: S (S001, S002 etc.) and Northern clinic: N (N001, N002, etc.). To maintain confidentiality, the names of participants were not written on the questionnaire and at the end of the research they were filed in a folder securely locked in the family medicine office in the district which can only be accessed by the researcher.

The data were captured in excel file (data entry). The descriptive and inferential statistical analyses were done using STATA® 13.

2.8.1 Data analysis

The descriptive analysis included calculation of the numbers and frequencies of the following: socio-demographic characteristics of the study participants such as age, educational qualification, marital status and home language; reproductive choices expressed by participants (e.g. desire to have a child / children); knowledge of the reproductive options available; and reproductive services received at the CHCs.

In the **i**nferential statistical analysis, the variables examined included the following: associations between socio-demographic characteristics such as: age, marital status, number of children, and level of education, employment and home language, and reproductive desires, reasons for reproductive desires, availability of reproductive services, and knowledge of reproductive options and disclosure of HIV status.

The Chi square test was used to determine the level association of the factors influencing decision to have a child / children. The odd ratio and p-value were determined for each of the factors. Univariate logistic regression models were fitted to find factors which were

independently associated with desire to have children. Only factors associated with desire for children that were found to be statistically significant were considered in the model building exercise using a multiple logistic regression model. All statistical tests were carried out at 5% significance level.

2.9 Addressing potential sources of bias in the study

In any research project, the possibility of bias existed and several measures were taken in this research study to minimise bias.

- The calculated sample was increased by 20% to deal with potential refusals or non-respondent bias.
- Random sampling was used in the research to identify the clinics and to select the patients. Thereby, all patients had an equal chance of being selected, thereby avoiding sampling bias.
- The validity of the questionnaire was ensured through clear questions, quality control, trained fieldworkers, pilot testing and ensuring the same questions were asked consistently.
- The data collection was done by trained research fieldworkers.
- The data was collected within a time frame of two weeks. This was done to avoid duplication of selection of patients returning for their monthly medications.
- The researcher ensured quality, by checking data collection on a daily basis.
- Patient records were readily available should a participants not remember any requested information. Thereby, recall bias was minimised.
- Double data entry was done and was verified by the researcher before analysis was done. This was ensure accuracy of the captured data

The following chapter focuses on the research findings.

CHAPTER 3: RESULTS

3.1 Introduction

The study recruited 439 participants, there were no participant refusals, representing a 100% response rate.

Nine participants were older than the eligible age and were excluded from the analysis. Therefore, the final number of participants was 430 participants: 128 men and 302 women. The main study findings are summarised in Box 1 below.

Box 1: Summary of main study findings

SUMMARY OF MAIN RESULT FINDINGS

1. ***Socio-demographic characteristics of study participants*:** the majority of the sampled participants (420) were females (70%). The mean age of participants was 36 years (SD 8.6): 40.8 years (SD 8.7) for men and 34.5 years (SD7.8) for women. The majority of participants (57%) were unemployed
2. ***HIV Diagnosis, Disclosure and Treatment:*** *93*% of participants were on HAART and disclosure of HIV status was done by the majority (95%) but mainly to own family members.
3. ***Current health status and discrimination*:** 77% of participants described their health status as good or excellent.
4. ***Contraception:*** The preferred family planning method for women was the injectable contraceptive (60%).
5. ***Reproductive choice*:** (46% of participants expressed the desire for children, and the majority (55%) wished to have doctors' advice on reproductive options.
6. ***The predictors of the desire for children were*: age younger than 49** {below 25 years (AOR=22.0; 95% CI: 1.9-254)}, **being married** (AOR=3.0; 95% CI: 1.0 – 8.6) **or living together** (AOR=3.7; 95% CI: 1.3 – 10.6) and **having no child** (AOR=51.5; 95% CI: 14.8–178.8).

3.2 Socio-demographic characteristics of study participants

The majority of study participants sampled (70%) were women. The mean age of all participants was 36 years (SD 8.6). The mean age of men was 40.8 years compared to 34.5 years for women, and this difference was statistically significant (p-value <0.05). Marital status also differed significantly by gender with women (49%) being more likely to be single than men (33%) shown in Table 1. The majority of the participants have either completed primary or secondary school (44% and 41% respectively). There is no significant difference in educational qualification between men and women (Table 1).

The level of employment stands at 43% for all participants while Nguni languages were mostly spoken as the home language at 62% and followed by Sotho languages (32%).

Study participants had an average of two children (1-3) as shown in Table 1.

Table 1: Socio-demographic characteristics of study participants

	Men (N = 128)	**Women (N = 302)**	**P-value**	**Total (N = 430)**
Mean age (SD)	40.8 (8.7)	34.5 (7.8)	< 0.001	36.4 (8.6)
Age categories n (%)				
24 years and below	2 (1.6)	29 (9.6)	< 0.001	31 (7.2)
25 – 34 years	30 (23.4)	125 (41.4)		155 (36.1)
35 – 49 years	77 (60.2)	148 (49.0)		225 (52.3)
50 years and above	19 (14.8)	0 (0)		19 (4.4)
Marital status n (%)				
Single	42 (32.8)	148 (49.0)	0.004	190 (4.2)
Living together	35 (27.4)	81 (26.8)		116 (27.0)
Married	38 (29.7)	48 (15.9)		86 (20.0)
Divorced	7 (5.5)	9 (3.0)		16 (3.7)
Widowed	6 (4.7)	16 (5.3)		22 (5.1)
Education				
No schooling	17 (12.7)	26 (8.6)	0.375	43 (9.9)
Completed primary	62 (46.3)	128 (42.5)		190 (43.7)
Completed secondary	49 (36.6)	129 (42.9)		178 (40.9)
Tertiary	6 (4.5)	18 (6.0)		24 (5.5)
Currently Employed	65 (50.8)	120 (39.7)	0.034	185 (43.0)

Home Language				
Nguni (isiZulu, isiXhosa, isiNdebele, or siSwati)	80 (62.5)	186 (61.6)	0.930	266 (61.9)
Sotho (seSotho, Setswana, or isiPedi)	40 (31.3)	98 (32.5)		138 (32.1)
Others	8 (6.3)	18 (6.0)		26 (6.0)
Mean number of own children (SD)	2.3 (1.6)	1.9 (1.4)	0.0129	2.0 (1.4)

3.3 HIV Diagnosis, Disclosure and Treatment

3.3.1 Duration since HIV diagnosis

Most participants (79.5%) have known about their HIV status for more than a year, with 9% finding out about their HIV status in the preceding six months (Figure 4). The duration since HIV diagnosis was not significantly different (P-value=0.969) between men and women (figure 3)

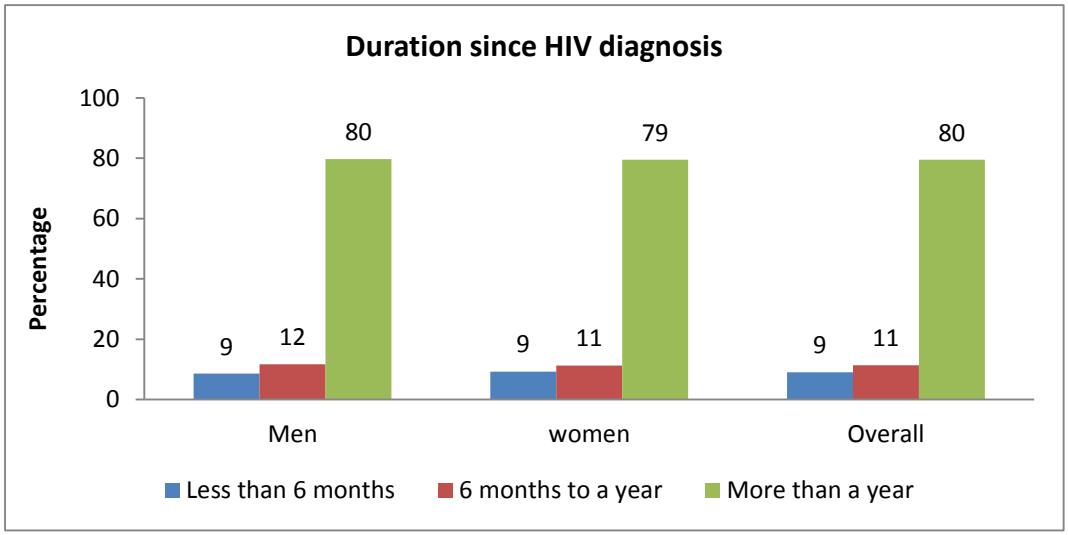


Figure 3: Duration since HIV diagnosis

3.3.2 HIV Disclosure

The majority of participants indicated that they had disclosed their HIV status (95%). There was no significant difference in HIV disclosure by gender: 97% in men and 94% in women (p-value = 0.232).

More women (71%) compared to men (54%) had disclosed their HIV status to family members; while more men (33%) compared to women (16%) disclosed their status to their partner (Table 2). These differences were statistically significant (p-value<0.001).

Only 9% of study participants reported that they were living openly with HIV, with more men (12%) in this category.

Table 2: HIV disclosure

	Men	Women	P-value	Total
HIV disclosure n (%)				
No	4 (3.2)	18 (6.0)		22 (5.2)
Yes	122 (96.8)	283 (94.0)		405 (94.9)
To whom disclosed n (%)				
Own family member only	66 (54.1)	200 (70.7)	< 0.001	266 (65.7)
Partner only	40 (32.8)	45 (15.9)		85 (21.0)
Living openly with HIV	15 (12.3)	23 (8.1)		38 (9.4)
Others	1 (0.8)	15 (5.3)		16 (4.0)

3.3.3 Antiretroviral treatment

Most participants (93%) were on antiretroviral treatment (HAART), although this differed significantly by gender (p-value=0.018). Men (97.6%) were more likely to be on HAART than women (91.3%). Among those on HAART, there were no significant gender differences in the duration on ART (Table 3), with 19% of participants being on ART for more than five years.

	Men (N = 128)	Women (N =302)	P-value	Total (N = 430)
Currently on HAART n (%)	124 (97.6)	274 (91.3)	0.018	398 (93.2)

Duration on treatment n (%)				
Less than a year	31 (25.4)	58 (21.1)	0.777	89 (22.4)
One year to less than three years	35 (28.7)	78 (28.4)		113 (28.5)
Three years to less than five year	34 (27.9)	86 (21.3)		120 (30.2)
Five years and above	22 (18.0)	53 (19.3)		75 (18.9)

Table 3: HAART and Duration

3.3.4 Current Health Status

Overall, most participants (77%) described their current health status as good or excellent. Only 4% perceived their health to be poor. Perceived differences in health status by gender were not statistically significant (Figure 4).

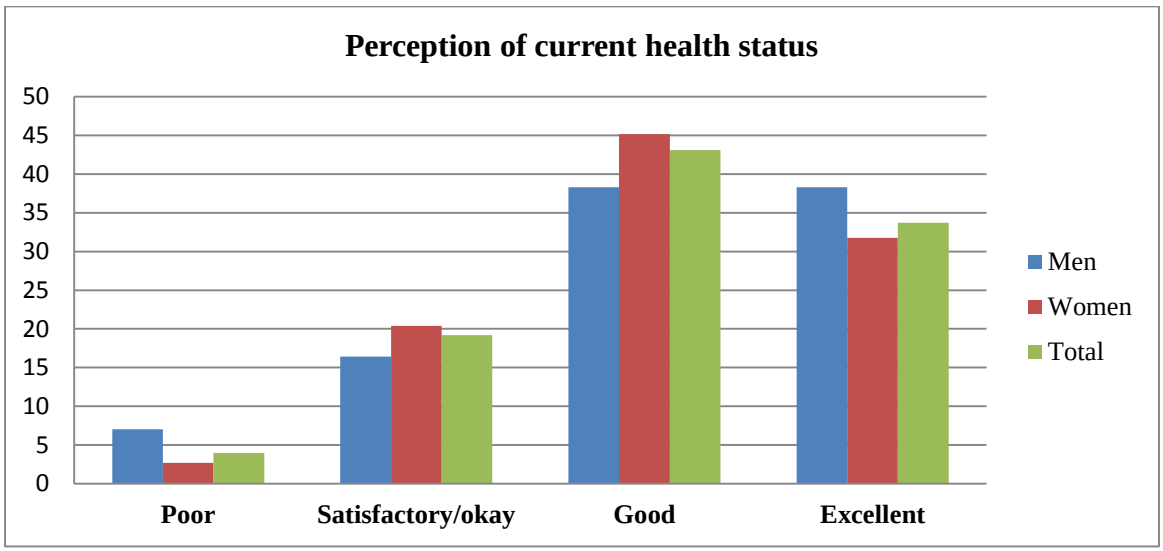


Figure 4: Participants' perception of their health status

3.3.5 Experience of discrimination

The majority of participants (Table 4) reported no experience of discrimination (83%) However, women were twice more likely to report experience of some forms of discrimination (20%) compared to men (9.5%) (p-value=0.008).

Table 4: Participants' experiences of discrimination

	Men (N = 128)	Women (N = 302)	P-value	Total (N = 430)
Experience of discrimination n (%)				
No	114 (90.5)	240 (80.0)	0.008	354 (83.1)
Yes	12 (9.5)	60 (20.0)		72 (16.9)

3.4 Sexual Behaviour

3.4.1 Sexual partnerships and condom use

The majority of participants reported only one sexual partner (76%). However, significantly more men (10.3%) compared to women (4.3%) reported having more than one current sexual partner (Table 5).

On the frequency of condom use in the past year, 60% of participants reported being consistent condom users. Men were more likely to be consistent users (73%) compared to women (55. %), and 9% of women participants reported no condom use in the preceding year.

Table 5: Participants' sexual relationship and condom usage

	Men (N = 128)	Women (N = 302)	P-value	Total (N = 430)

Current sexual partnership n (%)				
Not having sex	15 (11.7)	63 (20.9)	0.01	78 (18.2)
One sexual partner	98 (77)	226 (74.8)		324 (75.4)
More than one sexual partner	13 (10.2)	13 (4.3)		26 (6.1)
Frequency of condom use n (%)				
Never	2 (1.6)	26 (8.6)	< 0.001	28 (7.0)
Sometimes	27 (21.1)	74 (25.0)		101 (23.5)
Always	83 (65.0)	157 (52.0)		240 (56.0)

3.5 Reproductive Choices

3.5.1 Reproductive desire and contraception use

Among study participants, 46% (95% CI: 41.4 – 50.9) expressed a desire to have children in the future, while 44% indicated that they do not wish to have children in the future. There were no significant differences in reproductive desire by gender (p-value = 0.582), although a slightly higher proportion of men (50%) than women (44%) wished to have children in the future (Table 6).

Table 6: Reproductive desire

	Men (N = 128)	**Women (N = 302)**	**P-value**	**Total (N = 430)**
Wish to have children in future n (%)				
No	52 (41.3)	137 (45.5)	0.582	189 (44.3)
Yes	63 (50.0)	134 (44.5)		197 (46.1)
Unsure	11 (8.7)	30 (10.0)		41 (9.6)

Although 189 respondents (Table 6) indicated that they did not wish to have children in the future, only 71 reported the use of contraceptives. The injection was the most common form of contraception (60%).

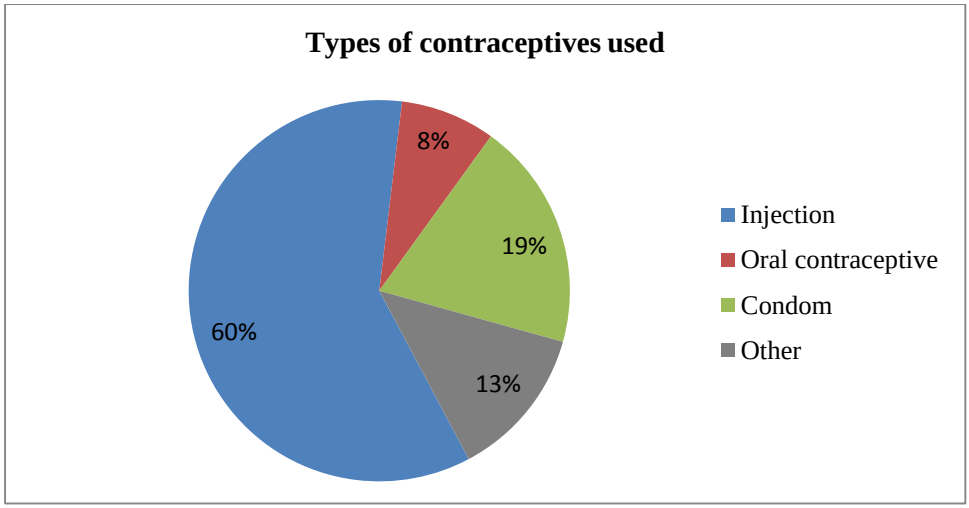


Figure 5: Types of contraception used

3.5.2 Reasons for not wanting children

Participants' reasons for not wanting to have children included: already having children (54%); lack of money to care for another child (12%), while the least common reason was stigma and the reproductive desires of partner (Figure 6). A breakdown of these reasons by gender showed that men were more likely than women to say that they already have children: 64% and 50% respectively. However, women (15%) were more likely than men (3%) to indicate the lack of money to care for another child as a reason for not wanting children.

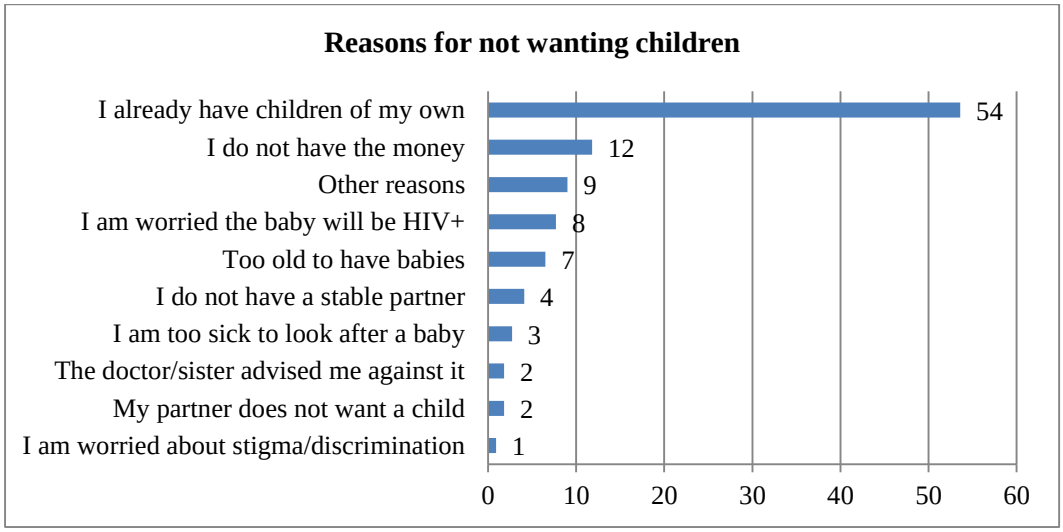


Figure 6: Reasons given by participants for not wanting children.

3.5.3 Reasons for wanting children

Reasons given by participants for wanting children were several and the commonest were wanting more children (36%) and 'I do not have any child of my own' (22%).

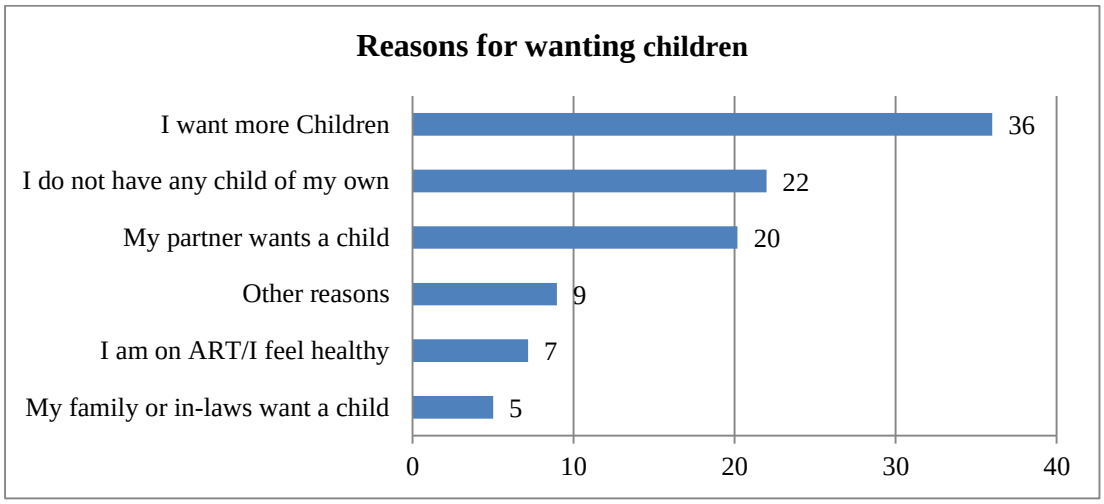


Figure 7: Reported reasons for wanting children

3.5.4 Reproductive options

The majority of the participants (55%) indicated that they will wait for the doctors' advice on the appropriate fertility option and 20% of the respondents were in favour of the natural method of conception. Participants who expressed a desire for artificial insemination made up 10% while those who are not certain about the reproductive options available to them were 13% (Figure 8).

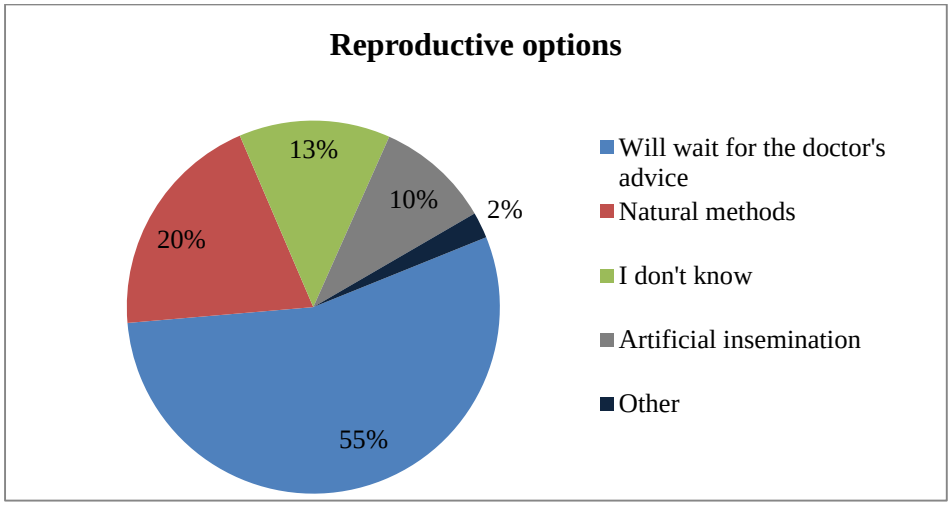


Figure 8: Reproductive options

3.6 Factors influencing reproductive desires

Reproductive desire was dichotomised as *yes* and *no*. The 41 respondents (10%) who reported being unsure were excluded from the analysis. The final analysis therefore included the 197 respondents who answered '*yes*' and the 189 who answered '*no'*. The explanatory variables considered and reported below are gender, age, marital status, and home language, number of children, educational level, employment, and HIV disclosure status, antiretroviral therapy, health status, duration on ART and experience of discrimination (Table 7).

3.6.1 Gender

Although more males (55%) than females (50%) indicated the desire to have children in the future, the difference was not statistically significant.

3.6.2 Age

As age increased the desire to have children decreased significantly (p-value < 0.01), with 80% of those younger than 25 years indicating the desire to have children.

3.6.3 Marital status

Marital status was also associated with the desire to have children (p<0.01). Those who were divorced or widowed (29%), as well as those who were married (45%), were less likely to have the desire to have children than those who described themselves as single (50%) or living together (65%).

3.6.4 Home language

There was no significant association (p=0.576) between home language and desire to have children.

3.6.5 Number of children

The majority of participants with no children (90%) expressed the desire to have children in the future as compared to those who have two or more children (38%). This difference was statistically significant (P<0.01).

3.6.6 Education

Education was also associated with reproductive desire (p<0.01). The higher the level of education, the higher was reproductive desire. While about 60% of those with tertiary

qualification expressed the desire to have children in the future, only 27% of those with less than primary education desired to children in future.

3.6.7 Currently employed

There was no significant association between being employed and wanting to have children in the future (p=0.566).

3.6.8 HIV status disclosure

Although respondents who had disclosed their HIV status were more likely to express desire to have children (51%), the difference was not statistically significant (p-value=0.589).

3.6.9 Antiretroviral therapy

Being on antiretroviral therapy was not associated (p-value = 0.574) with the desire to have children in the future.

3.6.10 Duration on ART

The percentage of respondents who expressed a desire for children increased as the duration on ART increased (p-value=0.104).

3.6.11 Health status

Perceived health status was significantly associated with desire to have children (p-value=0.04) in the future. Those who described their health as good or excellent (54%) were more likely to express reproductive desire than those who described their health as poor or okay.

3.6.12 Experience of HIV discrimination

There was no association between experience of discrimination due to HIV status and the desire to have children in the future (p-value=0.631).

Table 7: Associations of reproductive desire with socio-demographic and other variables

	N	**%**	**P-value**
Gender			0.337
Male	115	54.8	
Female	271	49.5	
Age			< 0.01
less than 24years	25	80	

25-34 years	136	66.18	
35-34 years	208	41.35	
Home language			
Nguni	241	48.96	0.576
Sotho	123	54.47	
Other	22	54.6	
Marital status			< 0.01
Single	167	49.70	
Living together	105	64.76	
Married	80	45	
Divorced/widowed	34	29.41	
Number of children			< 0.01
None	52	90.38	
one	97	77.32	
2-3	178	37.64	
Four and above	59	13.56	
Highest educational qualification			< 0.01
Less than primary	37	27	
Completed primary	164	48.17	
completed secondary	160	58.13	
Tertiary	22	59	
Employment			0.566
unemployed	221	49.77	
Employed	165	52.73	
HIV disclosure			
Have not disclosed	18	44.4	0.589
Have disclosed	365	50.7	
On antiretroviral therapy			0.574
No	21	57.14	
Yes	362	50.83	
Duration on ART			0.104
Less than a year	79	54.43	
One year to less than three years	106	58.49	
Three years to less than five years	107	46.73	

Five years and above	68	41.18	
Health status			0.04
Poor/Okay	91	41.76	
Good/Excellent	292	54.11	
Experienced HIV discrimination			0.631
No	317	51.74	
Yes	66	48.48	

3.6.2 Factors influencing reproductive desire

Of the 12 explanatory variables analysed, five were significantly associated with reproductive desire at p-value<0.05. These factors were: younger age, married or living together, no own children, higher educational qualification and good or excellent health status. All five variables were considered for inclusion in the multivariate model. Three were independently associated with the outcome (i.e. reproductive desire). These three variables were: ***age below 49 years*** {35-49 years (AOR=11.8; 95% CI: 1.3 – 107), 25-34 years (AOR=28.1; 95% CI: 3.0-265), below 25 years (AOR=22.0; 95% CI: 1.9-254)}, **being married** (AOR=3.0; 95% CI: 1.0 – 8.6) or living together (AOR=3.7; 95% CI: 1.3 – 10.6) and ***having no child*** (AOR=51.5; 95% CI: 14.8–178.8), are the independent explanatory variables associated with reproductive desires (Table 8).

Table 8: Multivariate logistic regression of factors influencing reproductive desire (=outcome)

	Unadjusted OR (95% CI)	**Adjusted OR (95% CI)**	**P-value (AOR)**
Age group			
50 years and above	1	1	
35 to 49 years	11.3 (1.5 – 87)	11.8 (1.3 – 107)	0.029
25 to 34 years	31.3 (4.0 – 243)	28.1 (3.0 – 265)	0.003
Less than 24 years	64.0 (6.8 – 604)	22.0 (1.9 – 254)	0.014
Marital status			
Divorced/Widowed	1	1	
Married	2.0 (0.8 – 4.6)	3.0 (1.0 – 8.6)	0.046
Living together	4.4 (1.9 – 10.2)	3.7 (1.3 – 10.6)	0.014
Single	2.4 (1.1 – 5.3)	1.3 (0.5 – 3.7)	0.571

No of children			
Four and above	1	1	
Two to three	3.8 (1.7 – 8.6)	3.1 (1.4 – 7.2)	<0.01
One	21.7 (9.0 – 52.6)	22.0 (8.4 – 57.4)	<0.01
None	60.0 (18.3 – 196.1)	51.5 (14.8 – 178.8)	<0.01
Highest qualification			
Less than primary	1	*	
Completed primary	2.5 (1.1 – 5.5)	*	
Completed secondary	3.7 (1.7 – 8.3)	*	
Tertiary	3.9 (1.3 – 11.9)	*	
Health status			
Poor/Okay	1	*	
Good/Excellent	1.6 (1.0 – 2.6)	*	

3.7 HIV Services at PHC facilities

Table 9 shows the various HIV or related services received at the PHC facilities.

3.7.1 Participants requesting information on reproductive health at the clinic

The participants who had requested information from a doctor or a nurse in the preceding year on ways of having a baby were 21%.

3.7.2 Information / counselling sessions provided

The majority of participants indicated attendance at counselling sessions on how to lower the risk of HIV transmission and having a baby while on ART (88% and 76% respectively) while only 38% attended sessions on different ways of having a baby when one is HIV positive.

3.7.2 Desired topics for counselling sessions by participants

The majority of participants (86%) expressed an interest in counselling sessions on sexual relationships; 72% indicated interest in attending a session on how PLHIV can have children while 75% preferred a session on family planning.

Table 9: HIV or related services received at PHC facilities

	Men (n = 128)	Women (n = 302)	P-value	Total (n = 430)
Participants requesting information from health staff				
Has talked to a doctor or nurse about having a baby in the past 12 months	37 (29.4)	50 (16.7)	0.003	87 (20.5)
Information or counselling sessions				
Attended session on family planning or contraception for People Living with HIV	40 (32.3)	154 (51.3)	<0.01	194 (45.8)
Attended session on counselling on how to lower the risk of transmitting HIV to others	106 (82.8)	272 (90.4)	0.027	378 (88.1)
Attended session on prevention of mother-to-child transmission of HIV	76 (61.3)	187 (62.5)	0.809	263 (62.2)
Attended session on different ways of having a baby when one is HIV positive	60 (47.2)	101 (33.8)	0.009	161 (37.8)
Attended session on ART and having a baby (PMCT)	69 (54.8)	252 (84.6)	<0.01	321 (75.7)
Desired topics of counselling sessions by participants				
Would be interested in attending a session on sexual relationships for PLHIV	110 (86.6)	258 (86.3)	0.928	368 (86.4)
Would be interested in attending a session on family planning or contraceptives for PLHIV	103 (83.1)	212 (70.9)	0.009	315 (74.5)
Would be interested in attending a session on how PLHIV can have a child/ children	108 (85.0)	195 (65.7)	<0.01	303 (71.5)

3.8 Preferred Setting for Sessions on Reproductive Health

When asked about the preferred setting respondents would prefer to receive reproductive health information, the majority chose a seminar or workshop. There were no gender differences observed in the responses (p-value <0.388), shown in Figure 9.

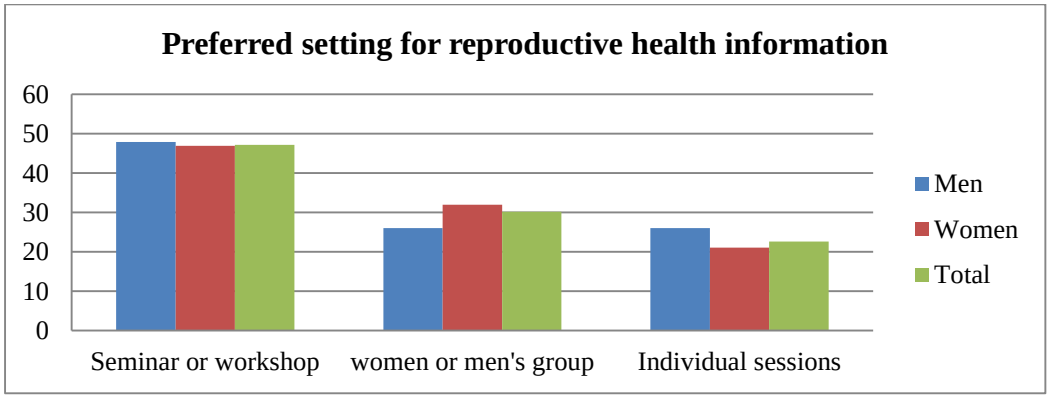


Figure 9: Preferred setting for reproductive health information

CHAPTER 4: DISCUSSION

4.1 Introduction

This research study explored reproductive choices among HIV positive patients attending PHC clinics in Ekurhuleni district, the factors influencing their desires, their knowledge of available reproductive options and the reproductive health services received at these clinics. This is one of the first studies that examined an aspect of sexual and reproductive health of PLHIV in the Ekurhuleni district in Gauteng Province.

In this chapter, the findings of the study are discussed in light of the study objectives and the existing literature on the topic.

4.1.1 Socio demographic characteristics

The majority of the participants were 25-49 years of age, thus confirming existing evidence that HIV primarily affects the economically active section of the population (6, 11). Hence, the importance of addressing the sexual and reproductive health needs of this sub-group of the population.

Sadly, but not surprisingly, there were high levels of unemployment, which implies dependence on the public health facilities (30, 32). Hence, the importance of addressing the sexual and reproductive health needs of PLHIV, particularly in the public health sector.

4.1.2 HIV Diagnosis, Disclosure and Treatment

Encouragingly, the majority of participants were on ARV (93%), showing very good retention and coverage of the large HIV management programme of the South Africa government (130). More men (98%) than women (91%) were on treatment in contrast to other studies where higher proportions of women were on ARVs than men. Muula et al found in a systematic review that in most Southern African countries, there were more females accessing HAART than males which cannot be explained by the higher HIV prevalence among females compared to males (131). The situation was found to be similar in other studies (132-135).

This could be due to the efficient and effectiveness of the initiation and treatment programme provided in most PHC facilities in the district.

This study found that there was a low level of disclosure of HIV status to sexual partners by participants, with only 16% of women reporting disclosure to their sexual partners. The finding

is similar to the study by Simbayi et al, 2006, in Cape Town, where 42% of participants had not disclosed their HIV status to their sexual partners (136). Another South African study done by Olley et al also found that 78% of participants had not disclosed their HIV status to their sexual partners (137). Others studies also reported similar findings (138-141). This study finding is worrisome from the stand point of transmission of HIV infection and the difficulty it might pose for HIV positive sexual partners seeking reproductive assistance.

This study found that most participants (83%) had not experienced any form of discrimination which is an improvement when compared with the high level of stigma reported about the experiences of HIV positive patients at the onset of the disease epidemic (132-135). However, only a small proportion of the participants (9%) indicated that they were 'living openly' with HIV and this may explain the reportedly low level of discrimination experiences. A study done by Simbayi et al in 2007, reported that 40% of the study participants in Cape Town reported discrimination on the basis of HIV positive status (142). As the primary focus of the study was not on experiences of stigma and discrimination, the exact level of stigma would require further investigation to determine whether and how it affects attitudes towards sexual and reproductive choices and rights of PLHIV.

4.2 Reproductive Desires among Participants

In this study 50% of men and 44% of women expressed a desire to have children. This expressed desire for children is similar to other studies. Cooper et al also found that in Cape Town, 55% of female and 43% of male participants in their study wanted children (143). Similarly Beyeza-Kashesya et al, 2010 also found that 64% of female and 55% of male HIV positive participants expressed the desire for children (69). Rispel et al also found that the desire to have children was high amongst HIV-discordant couples interviewed in South Africa and Tanzania (70). Chen et al reported similar high rates in their study of fertility desires and intentions of PLHIV in the United States of America (60). Oladapo *et al* also reported a high expressed desire for children in their study in Nigeria (144).

Numerous studies have found that the desire for children among Africans is higher, compared to non-Africans (145, 146). Heard et al, reported that men and women of African ethnicity living in France expressed desire for children was three times higher compared to Europeans (147). This was attributed to the socio-cultural background of people of African origin: for

women, motherhood is considered as a high social status and identity, and as a prestige among peers while for men, on the other hand, fatherhood is critical as it ensures the continuation of the family name and lineage (42, 62, 64, 66, 68, 148, 149). In this study, the population was homogeneous and ethnicity was not a considered a variable.

Interestingly, although this study was conducted at a time when levels of HIV&AIDS knowledge are high, the study findings suggest that there have not been much change with regards to the desire for children among PLHIV. Hence, reproductive health services for HIV patients are even more relevant and important in the current context.

4.3 Factors influencing reproductive choices of HIV positive patients

In this study, the multi-variate analysis found that age below 49 years, being married or living together; and having no child were the predictors of reproductive desire (Table 8).

The study found that at age younger than 25 years of age, 80% of respondents expressed the desire for children, compared to 6% at age 50 years and above. These research findings are similar to those of other research studies (42, 62, 64, 66, 68, 148, 149). Oladapo et al, found that the reason that younger HIV positive patients had a greater desire for children, was the socio-cultural pressure on young adults for fulfillment because of the fear of dying early from the disease (144).

Marriage or living together was also found to be one of the predictors of the desire for children. This may imply stability in a relationship and thus increase the desire for wanting children. However, the desire for children decreased among participants with more than one child compared to those with none, so these factors have to be looked at in combination. The inverse relationship between number of children and desire for children was reported by Cooper et al and Chen et al (60, 143).

A further, argument could be advanced that those in marriage or living together might be of advanced age and/or having many children already and consequently may not desire more children. On the other hand married couples might view the main outcome of marriage as having children and so will their desire to have children despite their HIV status. The

explanation for the increased desire for children among PLHIV who are either married or living together as independent variable observed in this study cannot be easily explained. Further research may be necessary to determine which of these variables are more strongly correlated to reproductive desires.

This study did not find self-reported health status or being on HAART to be a predictor of reproductive desire. This contrasts with other research findings (63,68,150). In the study by Oladapo et al, ill-health due to advancing HIV infection, evidenced by low CD4 count, was found to be an independent predictor of fertility desire (144). The socio-cultural fulfilment of child bearing made very sick individuals want to have children before dying (144).

In this study 44% of participants indicated that they do not want to have children. Among the reasons given by participants for not wanting children were: already had own children, lack of enough money to care for another child, fear of a baby being born with HIV infection, old age and lack of a stable partner. However, among those not desiring children only 36% reported contraceptive use. This may mean that they are not entirely against having children or that male respondents were not sure of the use of contraception by their female partners. It could also mean that condoms were used as the main method of contraception.

4.4 The Knowledge of HIV Positive Patients on Reproductive Options

Most of the respondents who expressed a desire to have children were in favour of the natural method of reproduction (20%). This could be that the natural method is the only one known by the majority of participants. Although natural reproduction is recommended for PLHIV especially HIV sero-discordant couples, there are specific requirements and guidelines which may not be understood by PLHIV (151). Hence, the research participants favouring natural methods may need guidance on the most appropriate method.

Thirteen present of respondents did not know the various types of reproductive options available. This lack of knowledge of PLHIV on fertility options limits their ability to make informed reproductive decisions. It could be due to lack of information on reproductive issues among these PLHIV. The knowledge of available reproductive options by PLHIV has not being a focus of most research studies; hence this finding cannot be compared with the findings of other studies.

Most of the respondents (55%) wanted guidance from the medical personnel on the appropriate reproductive options available to them. This could be due to many participants' lack of knowledge about other options such as artificial insemination and assisted reproductive technologies (ART). In the context where ART services are not included in the reproductive services, it is unlikely that patients will be informed about them as has been reported in Latin American countries (107), Vietnam (106) and Kenya (105). In several instances the inadequacy on the part of HCWs on the provision of reproductive services and negative attitudes of HCW towards PLHIV on sexual and reproductive health made it difficult to meet the needs of their patients (93, 152).

The possibility of adoption was not explored in our study but it would be interesting to understand how the situation in Ekurhuleni compares with the negative attitude towards adoption found in Cape Town (143).

4.5 Reproductive Services Offered At PHC facilities

In our study, although the PLHIV interviewed expressed their reproductive desires, they were not engaging the HCWs at the clinics about the necessary information on reproductive services. Only 21% of respondents who expressed the desire for children had requested information about it in the preceding year. This could mean that the staff may not be approachable or receptive to such discussions. Some research findings cited negative HCW attitudes towards child-bearing by PLHIV. Equally too, it could be due to poor or lack of coordination of services at the clinics (83,153,154). Harries et al reported in their study in Cape Town, South Africa, that research respondents cited systems problems as a hindrance to the provision of health care services to all patients including PLHIV (153).

Lacks of confidence in health workers ability to address the needs on reproductive options were also expressed by patients in another study (155). In other research reports, it was shown that health workers as well as PLHIV were uncertain about the reproductive rights of PLHIV (62, 98-100).

This study found that counselling was readily provided on family planning and prevention of HIV transmissions (including PMTCT) for 88% of patients, but only a few counselling sessions on reproductive options for PLHIV were organised and attended by respondents (38%) in the preceding year. Inadequate information on reproduction options was also reported by Sherr et al (62). The deduction is that there are probably no clear directives or established programmes by the health authorities on SRH for PLHIV as all service provision at the public clinics are guided by and monitored through the provision of government health policies.

As part of this study, participants were requested to indicate the setting for training or information on reproduction for PLHIV. The majority of participants preferred to receive information through seminars or workshops in men's or women's groupings. This is an important and relevant finding as the practice has been that counselling on any issue about sexual and reproductive care for HIV patients should be done on an individual basis in the private venue or room to maintain confidentiality. A further enquiry to establish the rationale for this choice will shed more light on the issue as it is crucial in tailoring the provision of services in this regards. This finding is novel as no research study could be found that examined this aspect of service provision.

4.6 Study Strength and Limitations

This was a cross-sectional study carried out in a resource limited district in Gauteng province, and the findings cannot be generalised to all districts in South Africa, except those with similar features to Ekurhuleni.

The wide confidence interval in the analysed data indicates inadequate statistical power. Although more than 400 patients participated in the study, a much bigger sample would be needed.

The respondents in this research were those who attended the public clinics for care and treatment and therefore their responses may differ from those attending private facilities or general practitioners. The study relied on self-reported information from PLHIV in a health care setting. Hence there may be social desirability bias, as respondents may have been

concerned about possible victimisation or negative consequences for subsequent care at the clinics. However, considerable efforts were made to use trained fieldworkers, and not the staff that provide care at these facilities where the study was conducted. All participants were given clear information and assured of their privacy and confidentiality during and after the interviews.

There are numerous strengths of this research study. This was one of the first studies to examine various aspects of sexual and reproductive health issues of HIV positive patients at a PHC level in Ekurhuleni district. A 100% response rate was obtained, and collecting date via face to face interviews ensured that the views of PLHIV who are not literate were elicited. This study also determined the preferred setting for information sharing and counselling on reproductive desires, an element hitherto unexplored in other studies on SRH and PLHIV. The study provides valuable information for programme or service planning, which is important in light of the much longer survival of PLHIV because of life-saving ARV treatment.

4.7 Conclusion

The study found that there is expressed desire for children among PLHIV, their knowledge on the available reproductive options was limited and the demand for such services was found to be low. However, the participants expressed desire to be informed about reproductive options was high. The sexual and reproductive services offered at the PHC facilities reported by participants was mainly counselling on prevention of HIV transmission particularly PMTCT and as well as family planning. The respondents in this study indicated preference for men or women group discussions on reproductive health information. The final chapter focuses on the recommendations, based on the findings of the study.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

Using a cross-sectional study design, this study sought to investigate the reproductive choices of HIV positive patients in Ekurhuleni district, Gauteng Province. The study generated locally, context specific information on the: choices of HIV patients with regards to reproduction and the motivating factors for these choices; PLHIV's knowledge of fertility options and services available to them at the PHC facilities in Ekurhuleni area were also elicited. The key results of the study were presented and discussed in the previous chapters. The study findings accentuate the need for the provision of reproductive health services that are responsive, of high quality and that are provided within a human rights framework.

There are encouraging developments within South Africa: the revised national strategic plan (NSP) for HIV, overseen by the South African National AIDS Council (SANAC), provides guidance on interventions and activities that will change the incidence and prevalence of HIV, STIs and TB (130).

One of the NSP objectives; *Prevent New HIV infections*, has a sub-objective that requires the integration of sexual and reproductive health services into the larger PHC programmes. The main areas addressed in the sexual and reproductive package of service include medical male circumcision, provision of male and female condoms, contraception, screening and treatment for cervical cancer. However, there are no clear guidelines on reproductive health services that will motivate the provinces and districts to ensure comprehensive services are established for the reproductive health needs of PLHIV. The NSP falls short of the policy position required to respond to the sexual and reproductive services needs of PLHIV (130).

5.2 Recommendations

As a consequence of this research study, the recommendations are listed in box 2 below.

Box 2: Summary of Recommendations

SUMMARY OF RECOMMEDATIONS

SHORT TERM RECOMMENDATIONS

Clinic services

- Reproductive health service such as counselling on fertility options should be offered at the PHC facilities.
- Sexual and reproductive health service guideline / protocols should be made available to HCWs.
- Dedicated sessions should be organised in men's or women's groups for education on reproduction services for HIV positive patients.
- The clinics should be equipped with educational and demonstration tools to educate PLHIV such as equipment and audio-visual materials.

Health care workers at PHC facilities

- All health professionals (doctors, nurses, etc.) should receive training on the reproductive needs and rights of PLHIV and the provision of SRH services.

Hospital services

- Dedicated centres should be established for assisted reproductive technology (ART) services for PLHIV.

BROAD RECOMMENDATIONS

National policy

- The South National AIDS council (SANAC) strategic policy document should address sexual and reproductive health services for PLHIV.

Provincial and District Health policies

- Similarly, provincial and district health plans should address the reproductive needs of HIV positive patients.

5.2.1 Short term recommendations

Clinic services

Reproductive health service such as counselling on reproductive options and ART should be offered at the PHC facilities across the district at the level determined by resources and capacity.

Sexual and reproductive health service guideline/protocols on reproductive option should be made available to HCWs and visibly displayed at the consulting rooms in the clinics where services are provided for easy reference. Dedicated sessions should be organised in male or female groups for education on reproduction services for HIV patients at the clinics. Appointments with HCWs to discuss any concerns by PLHIV should be made possible. The clinics should be equipped with educational and demonstration tools and audio-visual materials and equipment to educate PLHIV.

Health care workers at PHC facilities

All health professionals (doctors and nurses, and other categories) should receive training on the reproductive needs and rights of PLHIV in other to improve their capacity to provide this service and they should be sensitised perhaps through value clarification workshops to change their attitudes towards the SRH needs of HIV positive patients (62). All health professionals should have access to appropriate guidelines and protocols that enable them to meet the required needs of all HIV positive patients (156).

The HCWs at the clinics should be taught about informed consent to ensure that proper consent is obtained before any procedure is attempted. The doctors and PHC nurses should be trained to provide and teach self-insemination of semen for HIV discordant couples and partners where the male is HIV negative. This will require a mind-shift as well as careful changed management processes.

Hospital services

Dedicated centres should be established in each sub-districts in a level two or three hospitals (provincial or academic hospitals) for assisted reproductive technology (ART) services for PLHIV especially for discordant couple or partners, were the female is HIV positive and also where viral load could not be suppressed to undetectable level among HIV positive partners.

5.2.2 Broad recommendations

National policy

SANAC should revise strategic policy documents to include specific goals, objectives, and outcome measures for the sexual and reproductive health services for PLHIV.

Provincial and district health policies

Similarly, provincial and district health plans should address the reproductive needs of HIV positive patients in line with SANAC strategic plan.

Conclusion

South Africa has been the leader in the provision of government funded ARV treatment programmes, and to provide these services in an affordable manner. The recommendations based on the study findings are realistic and could be achieved with stewardship and leadership at all levels of the health system.

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Appendices

Appendix 1a: HREC WITS-Approval

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Dr Samuel Agbo

CLEARANCE CERTIFICATE	M120932
PROJECT	Reproductive Choices among HIV Positive Patients in Ekurhuleni District, Gauteng Province
INVESTIGATORS	Dr Samuel Agbo.
DEPARTMENT	School of Public Health
DATE CONSIDERED	28/09/2012
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 19/10/2012 CHAIRPERSON .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Prof Laetitia Rispel

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and ONE COPY returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress report.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix 1b: Ekurhuleni Health District approval

Ekurhuleni
METROPOLITAN MUNICIPALITY

RESEARCH ETHICS CLEARANCE CERTIFICATE

Research Project Title: Reproductive choices among HIV positive patients in Ekurhuleni district, Gauteng province

Research Project Number: 29-11-2012-04

Name of Researcher(s): Dr Samuel Agbo

Division/Institution/Company: DoH

DECISION TAKEN BY THE EKURHULENI HEALTH DISTRICT ETHICS PANEL (EHDEP)

- *THIS DOCUMENT CERTIFIES THAT THE ABOVE RESEARCH PROJECT HAS BEEN FULLY APPROVED BY THE EHDEP. THE RESEARCHER(S) MAY THEREFORE COMMENCE WITH THE INTENDED RESEARCH PROJECT.*
- *NOTE THAT THE RESEARCHER WILL BE EXPECTED TO PRESENT THE RESEARCH FINDINGS OF THE PROPOSED RESEARCH PROJECT AT THE ANNUAL EKURHULENI RESEARCH CONFERENCE HELD IN JULY/AUGUST.*
- *THE ETHICS PANEL WISHES THE RESEARCHER(S) THE BEST OF SUCCESS.*

Mr V.G Mlungwana

RESEARCH COORDINATOR: EKURHULENI METROPOLITAN MUNICIPALITY

Dated:

Dr. J. Sepuya

DEPUTY CHAIRPERSON: EKURHULENI METROPOLITAN MUNICIPALITY

Dated: 29/11/2012

Dr. R. Kellerman

CHAIRPERSON: GAUTENG DEPARTMENT OF HEALTH (EKURHULENI REGION)

Dated: 29.11.2012.

Appendix 2: Participant information sheet

TITLE: REPRODUCTIVE CHOICES AMONG HIV POSITIVE PATIENTS IN EKURHULENI DISTRICT, GAUTENG PROVINCE

Participant information sheet

Introduction

Good morning. My name is ……..... I am assisting Dr Samuel Agbo with a study on *Reproductive choices among HIV positive patients in Ekurhuleni district, Gauteng province.* The study is being done for a master's degree.

Why are we doing the study?

The purpose of the study is to learn about reproductive choices of HIV positive people and the reasons why they make these choices. We also want to find out about the reproductive services that are available at the clinics. We hope that the information obtained from the study will be used to assist with the improvement of existing services in the district.

How we will do the study?

As part of this study we want to get the perspectives of people living with HIV on the reproductive choices they make and some of the reasons for their choices. We also want to find out about available services at this clinic.

In every selected health centre, we are asking around 150 patients for their views. You were selected by chance and no staff member or anyone else said we should talk to you. We would like to ask you a few questions. It should take 25 minutes for you to answer the questions. I will be happy to go through the questions with you if you agree.

Many of these questions will be of a personal nature, including questions about your HIV disclosure and your relationships.

Our role is to listen and to understand your view points, but not to pass judgment. It is your views and opinions that are important. There is no right or wrong answers. How you answer the questions will not affect the care that you yourself receive in this health centre positively or negatively, and we will not

tell the nursing staff what you say to us. We will incorporate your answers, anonymously, into an overall report.

We cannot help you with any complaints that you have with your nursing care at the clinic and we cannot tell the nursing staff if you are really happy with their services.

How do I know that the information I give will be kept confidential?

This interview will take place in a private room between you and me. The information that you provide will be kept confidential and will be used for the purpose of this study only. Everything that you say will be treated as private and confidential. I will complete the questionnaire with the answers that you give, but I will not disclose your name or any other information that could be used to identify you. This means that no other person apart from me and the researcher will know that you took part in the study, or know how you answered the questions. Your HIV status will not be disclosed to anyone else.

The answers given by you and other participants will be analysed and combined, and the combined information will be written-up in a form of a report. In the report people who took part in the research may be given false names, but their real names won't be used. The name of the province and townships where participants live may be mentioned, but the names of participants will not be used in any report.

Did you get permission to carry out the study?

Permission to carry out this project was obtained from the University of the Witwatersrand Research Ethics Committees. The health department has also approved the study.

We will appreciate your participation and we will ask you to sign an informed consent form to participate in the study.

Will there be any benefits from participating?

There will be no direct benefits to anyone who participates in the interviews as participation is voluntary. This means you have the right to refuse to answer the questionnaire or if you do agree to answer the questionnaire you can leave out the answers you are uncomfortable with and you can stop the interview at any time.

Will there be any harm from participating?

Some of the questions are of a personal or sensitive nature and you may feel uncomfortable in answering them. Other than the possible discomfort of answering some questions and the possible inconvenience of

taking up your time to interview you, we don't foresee any risks or negative consequences to you taking part in the research. If you feel upset during the interview, we can stop the interview at any time. We will arrange for you to see a counsellor at the clinic. ***If the counsellor in the clinic is not available you will be referred to a counsellor in the nearest clinic or hospital***

If you do not want to be interviewed, there will be no negative consequences. However, we would really appreciate it if you do share your thoughts and feelings about the questions we will be asking you. We hope that the information we will get from you will be used to inform or advocate for health service improvements.

Who do I contact if I want to ask more questions?

We will be happy to answer any questions you have about this study. This research has been approved by the University of the Witwatersrand Research Ethics Committee. If you have any questions about your rights as a study participant, or questions or concerns about any aspect of the study, you may contact the ethics office on (011) 717 1234. If you have questions about the research, you may also contact the principal investigator:

Dr Sam Agbo
Phone: +27 11-8788548.
Email:samnoja@mweb.co.za

Thank you.

Appendix 3: Informed consent form

TITLE: REPRODUCTIVE CHOICES AMONG HIV POSITIVE PATIENTS IN EKURHULENI DISTRICT, GAUTENG PROVINCE

CONSENT FORM

The study has been explained to me and I have had a chance to ask questions and have them answered to my satisfaction. I have freely chosen to take part. I am aware that I can change my mind about taking part at any time and stop the interview without any penalty. I have been told that agreeing to the interview will not be of any direct personal benefit to me. I have been told that my answers to questions will remain confidential and that this consent form will not be linked to the answers I give.

I have been given telephone numbers that I may call if I have any questions or concerns about the research.

---------- ---------- ----------

Participants Name (Print) **Participant's signature** ***Date:***

---------- ----------

Interviewer's Name **Interviewer's signature** **Date**

If verbal consent is provided, the interviewer must sign below in the presence of the participant and a witness.

---------- Date ----------

Signature of interviewer certifying that informed consent has been given verbally by the participant.

_____ Date: _____

Signature of witness certifying that informed consent has been given verbally by the participant.

Statement on Behalf of the Researcher

I _____, declare that I have explained the

(Interviewer's name)

information given in this document to _____

(Participant's name)

He / She has been given the opportunity to ask me questions about the study and to have his / her questions answered.

The interview was conducted in English/Other language (specify language) _____ and no translator was used.

Signed at _____ on _____
(Place) *(Date)*

Signature of interviewer: _____

Signature of witness: _____

Appendix 4: Questionnaire

REPRODUCTIVE CHOICES AMONG HIV POSITIVE PATIENTS IN EKURHULENI DISTRICT, GAUTENG PROVINCE.

Questionnaire

For official use only

1. **Sub-district**		**O** ESDR 1 **O** SSDR 2 **O** NSDR 3
2. **Health Facility ID**		☐☐☐
3. **Participant number**		☐☐☐☐
4. Date of interview:	DD/MM/YY	☐☐☐☐☐☐
5. **Was the interview completed?**	**O** No 0 **O** Yes 1	☐
6. Date checked:	DD/MM/YY	☐☐☐☐☐☐

SECTION 1: BACKGROUND CHARACTERISTICS

For official use only

	101	How old are you**?** *(in completed years)*	_____ years
	102	Gender	☐ Male…1 ☐ Female…2
	103	What is the main language that you speak at home?	**O** English…1 **O** isiZulu, isiXhosa, isiNdebele, or siSwati…2 **O** seSotho, Setswana, or sePedi…3 **O** Other…9
	104	What is your current marital status?	☐ Married...1 ☐ Living together...2 ☐ Single...3 ☐ Divorced...4 ☐ Widowed...5

For official use only

	105	Do you have children of your own?	☐ No... 0-go to 107 ☐ Yes...1
	106	How many children do you have of your own?	_____
	107	What is your highest educational qualification?	☐ No schooling...1 ☐ Completed primary school (grade 7 or standard 5) ...2 ☐ Completed secondary school (grade 12 or matric)...3 ☐ Diploma....4 ☐ University degree ...5 ☐ Other....9 Specify:_____

For official use only

	108	Are you currently employed?	☐ No... 0 ---go to 201 ☐ Yes...1
	109	What kind of work do you do?	Specify:_____

SECTION 2: HIV DISCLOSURE AND TREATMENT

For official use only

	201	When were you diagnosed as HIV positive?	**O** less than 6 months ago--1 **O** 6-12 months ago--2 **O** more than one year ago--3
	202	Have you told anyone else about your HIV status?	**O** No 0---- go to 204 **O** Yes --1

	203	Who have you told about your HIV status	**O**-no one--0 **O** Partner only--1 **O** Own family member only(e.g. sister, brother, mother)--2 O Friends only--**3** **O** Living openly with HIV--4 **O** Other--9 specify ----------
	204	Are you currently on anti-retroviral treatment?	**O** No-- 0---go to 206 **O** Yes--1
	205	How long have you been on anti-retroviral therapy?	**…….. months**
	206	How would you rate your current health status	O Poor—1 O Satisfactory/Okay—2 O Good—3 O Excellent—4
	207	Have you experienced any form of discrimination as a result of your HIV status?	**O** No--0 **O** Yes--1

SECTION 3: REPRODUCTIVE CHOICES

For official use only			
	301	Which best describes your sexual relationship at this time	O Not having sex--0 ---go to 303 O Having sex with one partner only--1 O Having sex with more than one partner--2
	302	In the past 12 months, of all times you had sex with your partner (s), how often did you use a condom?	O Never--0 O Sometimes--1 O Always--2 O Did not have a main partner--9
	303	Do you wish to have a child/children in future	**O** No--0 **O** Yes—1- go to 306 **O** Unsure/don't know --3 **O Other**--9 Specify……
	304	If you do not wish to have a child/ children, what form of contraception are you using?	**O** Oral contraceptive--1 **O** Injection--2 **O** Other--9 Specify……

305 What are the reasons that you do not wish to have children?

O I already have children of my own--1

O My partner does not want a child--2

O I am worried that the baby will be HIV positive--3

O The doctor or sister advised me against it--4

O I do not have money to look after a baby--5

O I am too sick to look after a baby--6

O I am worried about stigma or discrimination--7

O I do not have a stable partner at present--8

O Other--9

Specify……..

306 Could you tell us about the reasons that you want to have a child/ children?

O I do not have a child/ children of my own--1

O My partner wants a child--2

O My family or in-laws want a child--3

O I am worried that people will gossip about me if I do not have a child--4

O I feel healthy--5

O I am now on ART--6

O The sister or doctor spoke to me about having children--7

O Other--9

Specify……

	307	How do you plan to have a child?	O I will wait for the doctor to advise me/us--1 O Natural methods --2 O Artificial insemination--3 O I don't know--4 O Other--9 Specify……

Section 4: Clinic services

For official use only			
☐	401	In the past 12 months, have you talked to a doctor or nurse about having a baby?	**O** No--0 ---go to 404 **O** Yes--1
☐	402	In the past 12 months, has any doctor talked to you about having a baby?	**O** No--0 **O** Yes--1
☐	403	In the past 12 months, has any nursing sister talked to you about having a baby?	**O** No--0 **O** Yes--1
☐	404	Have you attended any information, session on any of the following:	
☐	a	*Family planning or contraception for People Living with HIV*	**O** No--0 **O** Yes--1

	b	*Counselling on how to lower the risk of transmitting HIV to others*	**O** No--0 **O** Yes--1
	c	*Prevention of mother-to-child transmission of HIV*	**O** No--0 **O** Yes--1
	d	*Different ways of having a baby when one is HIV positive (e.g. artificial insemination or sperm washing)*	**O** No--0 **O** Yes--1
	e	*ART and having a baby*	**O** No--0 **O** Yes--1
	f	*Other, specify*----------	**O** No--0 **O** Yes 1
	405	Would you be interested in attending a session on sexual relationships for PLHIV?	**O** No--0 **O** Yes--1
	406	Would you be interested in attending a session on family planning or contraceptives for PLHIV?	**O** No--0 **O** Yes--1
	407	Would you be interested in attending a session on how PLHIV can have a child/ children?	**O** No--0 **O** Yes--1
	408	What type of setting would you prefer for this information (*Choose only one answer?)*	**O** Individual one-on-one counselling--1 **O** A women or men's group--2 **O** A seminar or workshop--3 **O** Other--9 **Please specify……**

SECTION 5. What additional information or support or services, if any, would you like to have available to you at the clinic?

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THANK YOU VERY MUCH FOR YOUR PARTICIPATION