Behavioural research examining contraceptive practices and fertility intentions of women living with HIV (WLHIV).

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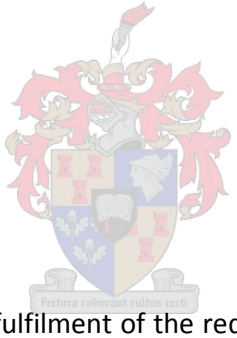

An assignment presented in partial fulfilment of the requirements for the degree of Master of Philosophy (HIV/ AIDS Management) at Stellenbosch University

Study leader: Burt Davis March 2010

Declaration

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

22 February 2010

Acronyms

AIDS	Acquired Immuno Deficiency Syndrome
ARVs	Antiretroviral drugs
DMPA	Depot-Medroxyprogesterone acetate
DOH	Department of Health
HIV	Human Immuno Virus
IEC	Information, Education and Communication material
IUD	Intra-uterine device
JHHESA	Johns Hopkins Health and Education South Africa
NSP	HIV and AIDS and STI Strategic Plan for South Africa, 2007-2011 (NSP)
PMTCT	Prevention of Mother to Child Transmission
STIs	Sexually Transmitted Diseases
TAC	Treatment Action Campaign
WLHIV	Women Living with HIV

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ABSTRACT

This study examines whether an HIV positive status will influence fertility decision-making and contraceptive practices of women in living with HIV (WLHIV) or if improved antiretroviral therapy (ART) and regular HIV care can also make a contribution to their choices.

The study was qualitative and it utilized a document analysis, a focus group discussion and interviews held in Khayelitsha, South Africa. A total of 30 women living with HIV aged between 18-45 years formed part of the study. Additional interviews were conducted with the health care worker and the Support Group Coordinator. Data was analysed through the identification of emerging themes and grouping of similar data.

The responses given by the participants provided an understanding of the thought processes around contraceptive use and fertility decision-making for WLHIV. Evidently, contraceptive practices and fertility intention change over time (due to knowledge change of plans, partner or family opposition, side effects, or changes to their economic or educational situation among other reasons).

Although the study population (n=30) was too small to make definite conclusions, the findings seem to tell of a transition towards the realisation of the rights of WLHIV. In spite of the many challenges that are faced by WLHIV, there seems to be a fairly conducive environment (both in terms of policy and resources) to enable WLHIV to fulfil their fertility intentions. However, there is need for programme planners to enhance ways of putting policy into practice. Finally, it would be useful to invest further into research to obtain a broader list of WLHIV's experiences, their rationale for making certain decisions regarding their reproductive health choices and the level of importance assigned to each reason. This was beyond the scope of this study.

ABSTRAK

Hierdie studie ondersoek of 'n HIV positiewe status vrugbaarheidsbesluitneming en voorbehoedpraktyke van vroue wat met HIV leef sal beïnvloed en of verbeterde antiretrovirale terapie (ART) en gereelde HIV sorg ook 'n bydrae sal maak tot hul keuses.

Die studie was kwalitatief en dit het gebruik gemaak van dokumentanalise, 'n fokusgroep-bespreking en onderhoude wat in Khayelitsha, Suid-Afrika, gevoer is. In totaal het 30 vroue wat met HIV leef (WLHIV), tussen die ouderdomme van 18-45 jaar deel uitgemaak van die studie. Bykomende onderhoude is met gesondheidsorgwerkers en die Koördineerder van 'n ondersteuningsgroep gevoer. Data is geanaliseer deur middel van die identifikasie van temas wat na vore gekom het en die groepering van soortgelyke data.

Die deelnemers se antwoorde verskaf 'n begrip van die denkprosesse rondom die gebruik van voorbehoeding en die vrugbaarheidsbesluitneming van WLHIV. Dit blyk dat voorbehoedpraktyke en vrugbaarheidsbegeertes verander met verloop van tyd (weens, onder meer, kennis verandering van planne, opposisie van 'n lewensmaat of familie, newe effekte of verandering aan hul ekonomiese of opvoedkundige situasie).

Alhoewel die studie populasie (n=30) te klein was om definitiewe gevolgtrekkings te maak, blyk dit dat die bevindinge dui op 'n transisie in die realisering van die regte van WLHIV. Ten spyte van die vele uitdagings wat WLHIV in die gesig staar, blyk dit dat daar 'n redelik gunstige omgewing (in terme van beide beleid en hulpbronne) is om WLHIV in staat te stel om hul vrugbaarheidsbegeertes te vervul. Tog is dit nodig dat programbeplanners die manier waarop beleide in praktyk omgesit word, verbeter. Uiteindelik sal dit handig wees om verder in navorsing te belê om 'n wyer lys van WLHIV se ondervindings te kry, sowel as hul redes vir sekere besluite rakende hul voorplantingsgesondheid en die vlak van belangrikheid wat aan elke rede geheg word. Hierdie is buite die bestek van hierdie studie.

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BEHAVIOURAL RESEARCH EXAMINING CONTRACEPTIVE PRACTICES AND FERTILITY INTENTIONS OF WOMEN LIVING WITH HIV (WLHIV)

CHAPTER 1: INTRODUCTION

Chapter 1 will encompass the introduction which comprises of the background and rationale, research problem/question, significance of the study, aims and objectives; Chapter 2 will summarise the literature review; Chapter 3 will outline the approach and methodology; while Chapter 4 will address the key findings and Chapter 5 will give the conclusion and recommendations for future planning.

1.1 Background and Rationale/Everyday Problem

After almost three decades of trial and error, governments in Africa have grudgingly come to terms with the fact that indeed HIV and AIDS is not only a health issue but a development problem because of the extent to which it has shaken the very foundation of the continent, robbing it of its most valuable asset – its people. According to the United Nations Development Programme (UNDP), HIV has inflicted the "single greatest reversal in human development" in modern history *(UNDP, 2008).*

Although HIV has been affecting all age groups, women now account for about half of all people living with HIV, and for more than 60% of infections in Africa. For the Sub-Saharan region as a whole, women are disproportionately affected in comparison with men, with especially stark differences between the sexes in HIV prevalence among young people. Although globally, the percentage of women among people living with HIV has remained stable for several years, women's share of infections is increasing in several countries *(UN Report on the Global AIDS Epidemic, 2008).*

Gender inequity in southern Africa cuts across many, if not all, issues, both in contributing to the spread of HIV and impeding prevention efforts, and in the coping responses to the epidemic. Gender inequity-essentially, the exploitation of women-is a fundamental human rights issue to which the AIDS epidemic adds a new, frightening dimension.

Heterosexual intercourse remains the epidemic's driving force in sub-Saharan Africa. The high rate of sexual transmission has also given rise to the world's largest population of

children living with HIV *(UN Report Global AIDS Epidemic, 2008)*. However, recent epidemiological evidence has revealed the region's epidemic to be more diverse than previously thought.

In Sub-Saharan Africa, ignorance, poverty and unwholesome traditional practices have been identified as factors driving the epidemic. Wife sharing, wife inheritance, skin scarification, genital mutilations of all sorts, funeral rites especially of men which are forced on women, gender inequalities and other traditional practices are rife and contribute considerably to the epidemic. According to Jackson, "gender inequity only too often means that sexual relations actually kill." *(Jackson, 2000).*

Women particularly those of in the reproductive age group or child-bearing age are the most vulnerable to HIV infection through the means described above. Culturally, women are expected to have children and this often places them in complicated positions where they are prone to stigma and discrimination especially if they do not disclose their HIV status. Studies conducted in South Africa showed that between 1997 and 2005, total deaths (from all causes) increased by 87% and during the same period death rates more than tripled for women aged 20–39 *(Statistics South Africa, 2005; Statistics South Africa, 2006).*

These and other factors have provoked critical considerations for policy and programmes targeted towards mitigation of adverse effects caused by HIV. Governments and civil society organisations are rolling-out Anti-Retroviral treatment (ART) in order to improve the health and well-being of women, through programmes that couple prevention of mother-to-child transmission with continuing treatment to help mothers remain alive and in good health to care for their children. Integration of HIV initiatives with programmes addressing sexual and reproductive health is helping to ensure that women have access to the information and services they need to make informed reproductive decisions.

The year 2004, also saw the creation of the Global Coalition on Women and AIDS (GCWA), a worldwide alliance of civil society groups, networks or women living with HIV, women's organizations, AIDS service organizations, and the United Nations system, committed to strengthening AIDS programming for women and girls. The mission of this body is to mobilize leadership and political will to influence laws, policies, programmes, and funding that will give girls and women the power to prevent HIV infection, and to live fulfilling and productive lives when living with HIV (http://womenandaids.org/about-gcwa.aspx, 2009)

It has also been recommended that scale-up of programmes must be coupled with an intensified effort to address cross-cutting issues that impede an effective response through a*ddressing* societal factors that increase HIV risk and vulnerability, and deepen the epidemic's impact. This is especially important in hyper endemic settings where marginal changes in risk behaviour are likely to have only limited impact on the epidemic's trajectory.

All stakeholders have been encouraged to work to promote gender equality and women's empowerment, reduce HIV stigma and discrimination, and alleviate the social marginalization of groups at highest risk of exposure to HIV.

1.2 Research Problem

Pregnancy in an HIV-positive woman often carries serious consequences. Without treatment, about a third of HIV-infected mothers pass the virus to their newborns. Many of these children eventually sicken and die of AIDS. Worldwide, some 3.8 million children younger than 15 years old have already died in this way *(FHI, 2004).* Some HIV-positive women choose to conceive, despite the chances of a poor pregnancy outcome. Other sexually active, HIV-positive women want contraception.

"The desire of women to have children is rooted in a context of a need for both love and financial security, especially where women are economically vulnerable," *(Feldmen, R & Maposhere, C, 2005).* Furthermore, Feldmen explained that "Marriage, especially if *lobola* or bride-price has been paid by a man's family to a woman's family, is based on an expectation of having children. Also, many women find personal satisfaction in having children."

Providers of health care services in some cases do not understand how to counsel and serve HIV-positive women. In some cases, HIV-positive women will not reveal to them that they are infected. In settings where HIV prevalence is high, family planning providers should discuss with clients how HIV could affect family health. Ideally, contraceptive counseling should include a description of HIV risk factors and an evaluation of the client's risk of infection yet also leave room for the client to make their own decision concerning family planning.

It is currently unknown whether an HIV positive status will influence fertility decision-making and contraceptive practices of women in living with HIV (WLHIV) or if improved antiretroviral therapy (ART) and regular HIV care can also make a contribution to their choices.

1.3 Research Question

What are the contraceptive practices and fertility intentions of WLHIV and why?

1.4 Significance of Study

This research is for all stakeholders who are likely to play important roles in the shaping and delivery of reproductive health services that target WLHIV. It focuses on issues that impact reproductive choice and decision making and identify critical policy, health service, and research related matters to be addressed.

1.5 Aim

To establish methods of contraception and fertility intentions of WLHIV in order to align reproductive health support services to their needs.

1.6 Objectives

1. To identify methods of contraception used by WLHIV.
2. To establish the fertility intentions of WLHIV.
3. To identify discrepancies between their contraceptive practices and their fertility intentions.
4. Establish whether improved access to ART and other HIV services will influence fertility decision-making and contraceptive practices of WLHIV.
5. To identify gaps between the needs and the present reproductive health support services.
6. To recommend guidelines for more needs driven support services.

CHAPTER 2: LITERATURE REVIEW

There are multiple factors that influence WLHIV's reproductive health choices. Such factors range from social influences, perceptions of health care providers, role of PMTCT and ART programmes in shaping reproductive intentions, clients' knowledge and experience of reproductive health and HIV prevention and treatment services *(Population Council, 2004)*.

2.1 Fertility Intentions

While many HIV-infected individuals do not wish to have children, others desire children despite their infected status. The desire and intent to have children among HIV-infected individuals may increase because of improved quality of life and survival following commencement of anti-retroviral treatment. In developing countries such as South Africa, where the largest number of people living with HIV AND AIDS worldwide reside, specific government reproductive health policy and service provision for HIV-infected individuals is underdeveloped *(Cooper et.al. 2005)*.

A multi-country study conducted in Kenya, Cameroon, Uganda and Zimbabwe identified various factors which influence the fertility intentions of women living with HIV.

In Kenya, the findings suggested that WLHIV who do not have any children tend to want to have at least one baby even in the absence of Prevention of Mother to Child Transmission (PMTCT) regimens regardless of the risks involved. A 27-year-old Kenyan housewife explained in an interview why she wished to conceive, despite the fact that both she and her husband are HIV-positive. "My husband doesn't want any children. ... But I want a child. I cannot live without kids. I am always alone and I am not barren. If I have a child, I will take care of my child and I will be active. I can work because I know I have somebody to take care of. I will have a responsibility" *(Qureshi, Z in FHI; 2009)*

In a similar study conducted in Yaoundé, Cameroon, a third of 40 HIV-positive men and women responding to a questionnaire said that they had unprotected sex primarily because they wished to have a child or their partner objected to the use of a barrier method. (About half continued to be sexually active without revealing their HIV status to their sexual partners.) *(Money, D; 2007)*.

And, a study among some 10,000 men and women in Rakai district, Uganda, who received HIV testing and counseling showed that, despite these services, HIV-positive women were no more likely than HIV-negative women to use female-controlled family planning methods. Condom use was moderately (but not significantly) higher among HIV-positive than HIV-negative men. A strong desire for children may have reduced HIV-infected respondents' acceptance of family planning methods, the study's authors concluded *(Money, D; 2007)*.

That many HIV-infected women actively seek and continue pregnancies despite potential risks for their infants has been demonstrated in several U.S. studies, as well. In interviews with 82 HIV-positive U.S. women, awareness of HIV infection or knowledge that risk of mother-to-child HIV transmission can be decreased by prenatal zidovudine treatment did not significantly influence pregnancy planning, contraceptive choice or use, or consideration of induced abortion *(Kaida, A; 2007)*

Reasons why many HIV-infected women do not contracept are abundant. Not only is motherhood a primary source of self-esteem for many women, but an HIV-infected woman may want to replace a child lost to AIDS. Pregnancy may provide hope for the future: A dying woman can console herself if she has healthy children to survive her *(Williams, H et.al.; 1996).*

The prospect of caring for a child may give an HIV-positive woman reason to go on living. Motherhood means "I do not have to dwell on my misfortune," said one of 11 HIV-positive women in a U.S. study in which participants learned both of their pregnancy and HIV infection before 24 weeks gestation *(Hutchison M, Kurth A; 1991).*

The role of significant family members in fertility decisions cannot be undermined. Some WLHIV may not be able to accept the seriousness of their diagnosis and, denying it, become pregnant. On the other hand, other HIV-positive women may become pregnant to conceal their HIV status from relatives, especially in-laws *(Hutchison M, Kurth A; 1991).*

In a study conducted in 2005, married women, in particular, reported strong family pressure to reproduce, especially if they had not disclosed their HIV status. One woman stated that if she did not bring children into a marriage, her child from a previous relationship would be stigmatised. In other cases, where women had disclosed their status to family, they were discouraged from bearing children *(Cooper et.al. 2005).*

Finally, some WLHIV using contraception believe the incorrect idea that HIV-related symptoms are a result of contraceptive use. In Family Planning Association of Kenya clinics, "HIV cases are guided through counseling to choose a contraceptive method that provides dual protection against both pregnancy and HIV transmission". "However, it is difficult to convince women who are HIV-infected that their ailments or symptoms have nothing to do

with family planning methods. As a result, they tend not to use contraception." *(Hutchison M, Kurth A; 1991).*

In other instances, researchers found that the main factors distinguishing women who wanted to have a child and those who did not were their levels of anxiety about the future and available family support. Women who indicated that if they did not have family support and were stigmatized by the family they were reluctant to opt for a pregnancy as they were not sure of the future, including child care in event of parental death *(Kanniappan, S., M.J. Jeyapaul, and Kalyanwala, S. 2008).*

Although contraceptive services for WLHIV is one of the four cornerstones of a comprehensive program for prevention of mother-to-child transmission of HIV (PMTCT), a review of PMTCT programs found that implementers have not prioritized family planning. The 'Response Analysis' as discussed in the *HIV & AIDS and STI Strategic Plan for South Africa (2007-2011)* states that "Fertility options for women known to be HIV positive are still lacking."

The availability of regular HIV care and treatment services appears to be influencing contraceptive practices of HIV-positive women. As access to HAART expands, associated positive impacts are being observed with respect to reproductive health and fertility decision-making *(Kaida et.al.2007).*

2.2 Contraceptive Options

HIV-infected women need to know that, aside from abstinence, condoms offer the best protection against STIs. Male or female condoms should be used every time intercourse occurs. This is to avoid HIV transmission to partners and to protect the woman herself from other STIs, including other strains of HIV. If she does not wish to become pregnant, an HIV-positive woman should consider dual method protection - using a condom for disease prevention and another, more effective method for contraception. Because some women erroneously believe that a method effective in preventing pregnancy also will be effective in preventing disease transmission, HIV-infected women must understand which methods are appropriate for pregnancy versus disease prevention *(Kuyoh, M. & Best, K., 2001).*

In typical use, diaphragms and cervical caps are associated with relatively high rates of pregnancy. Twenty percent of diaphragm users experience an unintended pregnancy within the first year of typical use. Twenty percent and 40 percent of nulliparous and parous cervical cap users, respectively, experience an unintended pregnancy during this time. But there are no medical restrictions on HIV-infected women's use of these methods *(Hatcher RA, Trussell J, Stewart F, 1998).*

Other experts say, for HIV-infected women who have decided against childbearing, female sterilization is a good option. However, they go on to say that the procedure should be delayed, if a woman has an AIDS-related illness. All hormonal contraceptive methods are good options for HIV-positive women (using the same clinical criteria as with HIV-negative women), even women who have developed AIDS *(WHO Guidelines for Improving Access to Quality Care in Family Planning: Medical Eligibility Criteria for Contraceptive Use, 1996).*

Hormonal contraceptives tend to be more effective for preventing pregnancy than barrier methods. However, there is concern that sexual partners of HIV-positive women using more effective contraception may not use condoms as consistently as partners of women using less effective contraception *(Díaz T, Schable B, Chu S, et al.; 1995).* Also, there is some evidence that anti-retroviral drugs can reduce the effectiveness of oral contraceptives, thus requiring an adjustment in dosage or change to another contraceptive *(Leitz G, Mildvan D, McDonough M, et al;2000).*

Due to concerns about pelvic infection and increased blood loss, use of intrauterine devices (IUDs) by HIV-infected women is usually undesirable. HIV-infected women can generally use the levonorgestrel intrauterine system, according to WHO guidelines *(FHI, 2004).* However, recent research by the University of Nairobi and FHI suggests that the IUD can be safely used by appropriately selected, HIV-infected women with regular access to medical services. Another method is the Lactational Amenorrhea Method, also known as LAM, is a temporary contraceptive option used for up to six months postpartum by women who are fully or nearly fully breastfeeding and continue to have no menses *(Morrison C, Sekadde-Kigondu C, Sinei S, et al.; 1999).*

2.3 Contraceptive Practices

Women who are HIV-positive may want to end childbearing for various reasons. Some worry that pregnancy will further compromise their health. They are concerned about transmitting

their infection to children they might conceive. They realize that, particularly without treatment, HIV infection will shorten their own lives, and they fear leaving orphans. A regional study that was conducted by FHI in 2004 revealed different factors which influence the contraceptive practices and fertility of WLHIV.

In that study, a 25-year-old, HIV-positive Kenyan housewife who suspected that her husband also is infected explained in an interview why she was contracepting with the injectable depot-medroxyprogesterone acetate (DMPA): "I feel the two children I have are enough. If I continue to give birth, I will have no energy to take care of those many children. If I get more children, maybe I will die and leave them suffering. Also, if my husband goes first and I be rendered a widow, I will have no way of taking care of them."

Some HIV-positive women, however, continue bearing children because they do not know how to stop. In the same study in Zimbabwe, out of a study of 52 HIV-positive women -- 16 became pregnant after diagnosis -- seven of nine women who reported unplanned pregnancies were married with children. Researchers concluded that "long-term married women, particularly in rural areas, often have no history of contraceptive use before they are affected by HIV. They may be ready to terminate childbearing, but often cannot put that decision into practice because they lack control over contraception and access to abortion", *(FHI, 2004)*.

To control contraception, women must be able to negotiate contraceptive use with their partners and have access to family planning services. However, some providers may limit or deny HIV-positive women's access to such services *(MMWR, 1994)*.

Even when family planning services are available, they may not address the needs of HIV-positive women. One reason is that HIV-positive women seldom reveal their HIV status to family planning providers, particularly if those providers do not ask. Of the six HIV-positive women interviewed in the Kenya study, none had revealed their HIV status to family planning providers. One 32-year-old woman who tested positive for HIV in 1990 shared the test result with her husband. Although the couple already had two children, her husband wanted more due to pressure from family members. "He started insisting that I had to have a baby ... that there are some HIV people who are having healthy babies and that it was OK to take a risk," she said *(FHI, 2004)*.

Women view providers as a helpful resource with whom they would consult, including getting advice about when to begin using contraceptives and/or what method to use. Many

policymakers and health care providers are ambivalent about HIV-infected individuals becoming pregnant. While acknowledging the need for women's reproductive choice, some providers feel that it is unwise with respect to public health and of questionable ethics for HIV-infected women to become pregnant. *(Cooper et.al.2005).*

Providers who are aware of a woman's HIV-positive status still may not offer adequate counseling about reproductive options. Most of 69 HIV-positive women in a U.S. study said they had access to methods to prevent conception and sexually transmitted infections (STIs), including HIV. But fewer than half felt that the family planning counseling they received was adequate *(Dugan, J et.al.; 1999).* Anyone counseling women known or suspected to be HIV-positive should support the client's family planning decisions, even if the counselor disagrees with the client *(Chervenak FA, McCullough LB, 1996).*

Most of 150 HIV-positive women seen at an HIV and AIDS clinic in São Paulo, Brazil, rated clinic services very highly. Yet, they lacked correct information about contraception, reproduction, and the reduced possibility of mother-to-child HIV transmission with use of antiretroviral drugs *(Santos N, Ventura-Filipe E, Paiva V, 1998).*

Various African studies show that counseling HIV-positive women does not substantially increase contraceptive use, often because HIV-infected women -- fearing abandonment -- hide their status from their partners *(Ryder RW, Batter VL, Nsuami M, et al; 1991).*

CHAPTER 3: RESEARCH DESIGN AND METHODS

This study utilized qualitative methods through the use of document analysis, a focus group discussion guide and a questionnaire containing both closed and open-ended questions which was a guiding tool for the interviews.

3.1 Target group and Sampling Method

The characteristics of my target population were as follows:

- Women living with HIV aged between (18-44 years)

- Women living with HIV who are members of the **Ichibi Women's support group** in Khayelitsha, South Africa.
- Study participants were randomly selected and a total of 20 women were interviewed as one on one interviews and a focus group with 10 participants.
- Ichibi Women's Support Group Coordinator
- 1 Health care worker at the nearest health institution (one who deals directly with the HIV positive women). In this case the institution was Michael Mapongwane Hospital.

3.2 Data Collection

In order to collect data, 1 focus group discussion with 10 participants who had attended a support group meeting on the day of the interview and 20 interviews with PMTCT clients were conducted. The research tools captured the methods of contraception that are being used by the HIV positive women as well as their fertility intentions pre- and post knowing their status. Lastly, the questionnaire allowed the Researcher to explore how the existing reproductive health services meet the needs of the target group.

3.3 Data Analysis

Qualitative data was analysed through the identification of emerging themes and grouping of similar data. Quantitative data, in this case socio-demographic data was analysed in Excel using frequencies.

Table 1 below describes the socio-demographic characteristics of the 30 women interviewed as part of the study.

Table 1: Socio-demographic characteristics of the study population

	N	%
	30	
Age		
25 or less	4	13.3
26-34	18	60.0
35+	8	26.7
Marital Status		
In union	18	60
Not in union	12	40
Education		
Primary	7	24
Secondary	20	66
Tertiary	3	10
Occupation		
Self employed	9	30
Employed	7	23.3
Unemployed	14	46.7
Contraceptive method		
Pill	3	10
IUD	10	33.3
Injectables	13	43.3
None	4	13.3
Intention to have children		
Yes	9	30
No	12	40
Not sure	9	30

Most of the women interviewed were 34 years of age or below which is the aged group were most women have children. Although only a small number of participants took part in the study, the results seem to indicate that most participants seemed to prefer using the injectable DMPA and IUD as compared to other methods of contraception. Some women used dual

protection i.e. combined the DMPA, IUD or pill with other natural practices of contraception such as the withdrawal method or with the male latex condom.

Table 2 presents a comparison between women who have and those who have not had children after discovering their status. Of the 20 women who were interviewed individually, 50% did not bear any children after discovering their HIV status. Seven out of the ten had one child after discovering their status while the other three women had more than one child after discovering their HIV status. Two women reported having lost their children before the age of 3 months.

Number of children after discovering HIV status N=20	
None	10
One	7
Two or more	3
Status of child	
Positive	4
Negative	10
Don't know	3

To understand the factors that could possibly influence decision-making by WLHIV regarding contraceptive practices and fertility intentions, a selection of factors which influence decision making were identified and these are listed below and discussed in turn:

- knowledge and awareness of contraceptive practices
- contraceptive use by WLHIV
- influences in family planning practices
- the relationship between HIV and AIDS and pregnancy outcomes
- available means to prevent perinatal transmission and;

- stigma and discrimination affecting WHA

Knowledge and awareness of contraceptive practices

From the study, it appears that many WLHIV receive a fair amount of information about their contraceptive options. The main sources of this information as identified by the participants are as follows:

- ***Health facilities e.g. clinics, hospitals***: It was reported that the health care workers present a brief education session (of about 30 minutes) before providing service to the women. This can either be at the ARV clinic or at the PMTCT clinic. This is an interactive session which also presents the women with an opportunity to ask any reproductive health related questions that they may have;

- ***Awareness campaigns held in the communities***: The participants reported that there are community based organisations such as Treatment Action Campaign (TAC) and Simelela in Khayelitsha that hold awareness campaigns and distribute Information and Education Material (IEC) which is useful for the women. Also these campaigns target the communities as a whole hence reduce stigmatisation of WLHIV.

- ***Support groups***: Support groups were seen to be relevant social support structures where WLHIV receive peer support, counselling and even information that pertains to their reproductive health options. In the case of Ichibi, the head of the Ichibi Support Group is a retired nurse and she possesses important knowledge on women's reproductive health. In addition, Ichibi has since been registered as a Non-Profit Organisation under the section 22. This has enabled them to receive support from the Department for Social Development in the form of stipends for volunteer community health workers and running costs of the organisation. In addition to this, this support group is also part of networking associations such as the Networking AIDS Communities of South Africa (NACOSA) which exposes them to current policy and practices around the subject of HIV and AIDS.

- ***Media***: With an increase in the use of technology, more people have access to television and the radio. Every participant who was part of this study had access to either a radio or television or both. There are some programmes which address HIV and AIDS issues which were well known by the participants. Such programmes included Tshisa (a programme funded by John Hopkins Health and Education South Africa (JHHESA)), Siyayinqoba! Beat it! and Soul City programmes among others. In addition to this, organisations such as Mindset Health have installed programmes in clinics and hospitals around South Africa. They install televisions in waiting rooms so that patients can watch and learn about important issues in the subject of HIV and AIDS, TB and other related issues while they wait to be served. In some cases, there are facilitators who moderate a discussion after viewing a video and allow the patients to contribute and clarify issues for their own benefit. Although this service was not reported to be there at the nearest hospital, key informants knew about this service at another clinic in the neighbouring suburb of Langa.

- ***Significant family members, friends and workmates***: Family and acquaintances were also important sources of information. Naturally, people have a tendency to seek information from the people closest to them. This is why it is important to ensure that the public has accurate information.

Contraceptive use by WLHIV

When the participants were asked about the contraceptive practices that they know of and use, they mentioned the following:

- Condoms (this referred to male latex condoms)
- Injectables
- Intrauterine device (IUD)
- Pill
- Natural methods e.g. abstinence

WLHIV were asked about their motivations for using the different contraceptives. It emerged that the decision was based on:

  - Comfort

- Fertility desires/intentions
- Availability
- Protection against re-infection (e.g. through the use of condoms)
- Advice from the Health Care Worker

The health care worker stated that in general, most contraceptive methods are said to be appropriate for WLHIV but some do have side effects that should be considered. No increases in infectious complications have been noted for IUD use by WLHIV as suggested in the 2004 FHI study; however, some respondents reported an increased menstrual flow and anaemia. IUDs are further contraindicated for women at increased risk of STIs because they contribute to increased risk of pelvic inflammatory disease. The combination of a male latex condom and other contraceptive methods was common and this was commendable as it helps prevent re-infections. The participants seemed to know that condoms offer the best protection against STIs.

The participants in this study agreed that contraceptives are generally available through clinics, hospitals, pharmacies and/or community-based distributors. It emerged though, that emergency contraception was a little known option to prevent pregnancy for the large majority of women.

It seems WLHIV do not have particular problems regarding the contraceptive itself, however, they noted external barriers to use. These included:

- Male partners' refusal to use condoms because:
    - they simply do not wish to use them;
    - both partners are sero-positive and they do not consider it urgent to prevent re-infection;
    - they are unaware of their female partners' sero-status and the women fear requesting condom use because then they would have to reveal their sero-status.

Most of the participants agreed that they could access information on appropriate contraceptive practices when they needed them. The remaining few remarked that some

people, including health-care providers, assume that WLHIV do not have sexual lives and this can restrict the information they are given. When WLHIV seek contraceptives, counsellors' preferences may determine the kind and amount of information they receive.

This however, cannot be made a general statement about health care workers' attitudes towards WLHIV; it is very much a case of individual characters. It is important in this case for the Department of Health (DOH) to continue with educating their staff on patient rights particularly the rights of people living with HIV.

The relationship between HIV and AIDS and pregnancy outcomes

Pregnancy in itself does not accelerate HIV progression in women who are in the earlier and asymptomatic stages of infection; the situation may be different for women with high viral loads and diagnoses of AIDS (De Bruyn, 2002). Most participants who had children after an HIV positive status were aware of their CD4 count. The study also showed that with PMTCT in place, there are increased chances of an HIV positive mother having an HIV negative child. Most of the women reported having used nevirapine to protect the children from infection hence the children were HIV negative. According to De Bruyn, pregnancy complications that have been observed more frequently among pregnant WLHIV than HIV-negative women include genital and urinary tract infections, more frequent and severe blood loss, anaemia, bacterial pneumonia, intrauterine growth retardation, preterm labour and premature rupture of membranes, premature delivery and low birth weights. None of the participants reported having genital and urinary tract infections, however, some reported having suffered blood loss. Most respondents felt that if WLHIV wish to have information on HIV and pregnancy outcome, they need to seek it specifically. They suggested that organisations like TAC can assist with distribution as they are closer to the communities.

Fertility Intentions

As illustrated in table 2 above, fertility intentions differed with individuals and they all had their motivations for those choices. The majority of the women (40%) said they did not intend to have any more children, 30% of the women still desired to have children while 30% were not sure. Out of the 20 women who were asked whether they had children after an HIV positive test, 50% had children after an HIV positive test while the other 50% did not have

children after HIV positive test. Most of the children who were born after positive test were HIV negative. Of those who had tested HIV positive, most of them had been born in a health facility, only one had been born at home. The decrease in number of children testing negative while they are born to HIV positive parents might be an indication of the effectiveness of PMTCT programmes.

Age did not seem to be a significant factor in influencing fertility intentions in women. There were some women above 35 years of age who still wanted to have children. It was interesting to note however, that even the women who reported wanting to have children were using contraceptives that prohibit them from getting pregnant. This may not be because they are not aware of the barrier; they could have been talking about future plans which are dependent on various other factors.

The participants were further asked about into the factors that influence their fertility intentions. These are briefly discussed below:

- ***Available means to prevent perinatal transmission*:** As PMTCT programmes are strengthened, WLHIV also feel confident about having children as they have a greater chance of having healthy babies. One women was quoted saying:

  "There is nothing that hurts a mother more than having a sick child. It is better for the mother to die than to see their child suffering."

- ***Improved access to ART and other HIV services:*** Some women reported that improved access to ART has encouraged them to lead 'normal lives' and have children if they want to as they will still be able to stay longer and take care of their children. The South African government is also providing alternative feeding (10 bottles of formula milk per child per month) for the first six months to prevent transmission of HIV to the child during the breast-feeding. In addition to this, some participants had access to social grants that are also provided by the government. Though this is not exclusively for people living with HIV, it was a source of help for those in need. One woman exclaimed "*I survive with my six children's grant...*"

- ***Natural desire:*** As cited in *Williams, H et.al; 1996*, motherhood is a primary source of self-esteem for many women. Some informants reported that as a 'woman', it was natural to want to have a child or children of your own.

- ***Religion:*** Some key informants attributed their fertility intentions to their religion i.e. it maybe 'God's plan' to have children.

- ***Culture*****:** Through the focus group discussion, some women reported that there were some cultures where women were expected to have children (bring an heir). In such cultures, someone with a child or children was more acceptable.

- ***Stigma and discrimination affecting WLHIV*****:** HIV and AIDS is perhaps one of the most stigmatised medical conditions in the world. Stigma interferes with treatment and reproductive health choices even. In other instances, the Researcher found that the main factors distinguishing women who wanted to have a child and those who did not were their levels of anxiety about the future and available family support. Some participants reported that though they may have wanted to have children, they considered otherwise as they would not want to breast feed the child yet this would sometimes bring suspicion among family and friends and they fear rejection. One participant said:

  "*If you tell your partner your status, then they run away*."

Stigma is very real in the communities. In some cases, WLHIV have had to face the hard reality of being rejected by loved ones. The participants reported that most men living with HIV do not want to be part of support groups for fear of being stigmatised and as a result they miss out on useful information that they can benefit from. In addition to this, some participants also stated that they would not appreciate it if a community health worker was to pay a home visit 'undisguised' with a vehicle and or clothing which suggests the organisation that they are representing. They said this would tell everyone about their status.

- ***Support from partner and significant family members*****:** It was evident from the key informants that WLHIV values support from their partners, families and friends. To an extent, this also helps them to make decisions regarding fertility

issues. This kind of support is obtained in various forms some of which are listed below:

- *Economic:* The key informants valued financial responsibility from the partner to take care of the child. The government support grant also came up as a useful source of income; however, it was much appreciated if the father of the child was responsible. Most of the women admitted that it was difficult for them to take care of the children single-handedly. It was also mentioned that although the government provides milk formula as part of supporting the PMTCT programme, this formula is often not enough as the child continues to grow up yet it is beyond the reach of many in terms of affordability.

- *Social*: Throughout the discussions with WLHIV, the same sentiments were echoed…they long to be '*accepted*' and '*loved*'.

Role of Support Groups in the lives of WLHIV

As stated above, participants for the study were all drawn from the Ichibi Women's Support Group. An interview was held with the Coordinator to gain understanding on the value of a support group in the lives of WLHIV even as it pertains to their reproductive health choices. What came out very strongly is that the support group is a social structure providing love, comfort and empowerment to people living with HIV, '...not pitying them but bringing out the best in them despite their circumstances', the Coordinator said. It is like a 'family' and enables WLHIV to get personalised attention which might be difficult to get at a health facility because of the work pressure. The Coordinator, being a retired nurse, has knowledge on specific health issues to share with the women. Occasionally, they have sessions where they discuss various issues pertaining to WLHIV particularly safer sex practices.

The Coordinator stated that lately, they had been concentrating on Home Based Care (HBC) and nutritional feeding; however, there is an opportunity to bring more information on contraception and addressing WLHIV's fertility intentions. Because of the dynamic nature of

the disease, the Coordinator felt that it is important for the support group to be a source for women to get information on reproductive health.

Asked on contraceptive practices of WLHIV, the Coordinator stated that most of the women use dual contraception i.e. barrier method and a condom. She stated that condom education has been more popular with health care providers and NGOs as it is also a preventive method. She noted however, some barriers to use particularly, women's failure to always negotiate for safer sex.

Regarding fertility intentions of WLHIV, the Coordinator stated that they had noted that there are different motivations for this. In her opinion, younger women were more likely to still want to have children after an HIV positive status and there is need for them to have the relevant information available. Support groups can work with health care workers and NGOs to make such information available.

The Health Care Worker's Perspective

The health care worker felt that generally health facilities had the right platform to inform WLHIV on contraceptive choices and fertility options. Such information was disseminated through interactive sessions at the facilities as well distribution of IEC material which is provided by the Department of Health and other NGOs. At a policy level, the health care worker felt that the South African government has put measures in place to address reproductive health choices of WLHIV. The following two documents were given as references:

- ***HIV and AIDS and STI Strategic Plan for South Africa, 2007-2011 (NSP):*** The NSP stated that "Fertility options for women known to be HIV-positive are still lacking. The effectiveness of this programme is still to be established."

- ***National Antiretroviral Treatment Guidelines (2004):*** South Africa has addressed the issue of pregnancy and anti-retroviral treatment in the National Antiretroviral Treatment Guidelines (2004). These guidelines clearly give guidance to health care workers on how they are to handle cases of pregnancy in WLHIV.

Further, the health care worker stated that because of the strengthened PMTCT programmes, WLHIV have the option to have children should they want to. The desire and intent to have children among HIV-infected individuals has increased because of improved quality of life and survival following ART. It is no longer fully correct to say service provision for HIV-infected individuals in South Africa is underdeveloped as stated in (Cooper et. al. 2005). There is a remarkable improvement in the services offered to WLHIV.

Gaps in the current services

- *Male involvement*: The participants reported that most men living with HIV do not want to be part of support groups for fear of being stigmatised and as a result they miss out on useful information that they could potentially benefit from. This has been a root to many challenges that are faced by WLHIV particularly around issues of negotiating for safer sex with their partners and emotional support required by WLHIV. The women identified areas where men can be reached and these include church gatherings, beer halls, social clubs (e.g. football) and the workplace.

- *Contraceptive counselling:* The participants expressed a desire to have more sessions on contraceptive counselling particularly the practicalities of using the female condom. They felt this would empower them especially in cases where they cannot negotiate for the use of a male condom.

CHAPTER 5: CONCLUSION & RECOMMENDATIONS

Although the study population (n=30) was too small to make definite conclusions, the findings tell of a transition in the realisation of the rights of WLHIV. In spite of the many challenges that are faced by WLHIV, there seems to be a fairly conducive environment (both in terms of policy and resources) to enable WLHIV to fulfil their fertility intentions.

The following methods of contraception were identified to be common among the WLHIV: IUD, injectables e.g. DPMA, male condom, pill and natural methods. Choices were influenced by comfort, availability, partner's preference and advice from health care workers among other reasons.

The participants shared their fertility intentions and these differ with individuals. Age did not seem to be a very significant factor as some women above 34 years of children still expressed a desire to have children. It is highly likely that fertility intentions change over time (due to a number of factors such as partner or family opposition, side effects, or changes to their economic or educational situation and anxiety about the future). During the study, the women were giving the first reason that comes to their minds and this may not necessarily be the most important reason.

A few discrepancies were established among some women who reported wanting to have children yet they are using barrier methods. This is not necessarily because they are not aware; these may just be future plans.

To an extent, improved access to ART and other HIV services influences fertility decision-making and contraceptive practices of WLHIV. With the availability of ART and PMTCT there WLHIV look forward to an improved quality of life and there are higher chances of an HIV positive mother giving birth to an HIV negative baby. However, these factors do not work in isolation, there are other factors such as social, economic that also influence decision making.

This paper also identified gaps between needs and present reproductive health support: Limited platforms to educate men on contraceptive options and fertility options for people living with HIV and inadequate opportunities for both men and women to get contraceptive counseling. Specifically, the participants wanted to learn about the practicalities of the female condom as this was seen as a potentially effective form of contraception.

The following guidelines for more needs driven support services were identified:

Create awareness through support groups, IEC material on the practicalities of the female condom; disseminate reproductive health information to the men through the workplace and social facilities among other places and invest further into research on whether more opportunities for contraceptive counselling can be made available to WLHIV and the men.

Finally, the researcher appreciates the responses given by the participants as they provided an understanding of the thought processes around contraceptive use and fertility decision-making in that specific group. However, it is highly likely that contraceptive practices and fertility intentions change over time. This kind of a study could benefit from a cohort study where WLHIV's contraceptive practices and fertility intentions are checked at intervals over

a period of time and if there are any inconsistencies establish why this is so. More in-depth qualitative data collection is required to obtain a broader list of WLHIV's experiences, their reasons for certain decisions and the level of importance assigned to each reason especially taking into consideration that there were discrepancies between contraceptive practices and fertility intentions. This was beyond the scope of this study.

REFERENCES

1. Allen, S., Semfilira, A., Gruber, V., et al. (1993). **Pregnancy and contraceptive use among urban Rwandan women after testing and counselling**. *Am J Public Health* 1993; 83(5):705-10.

2. Chervenak, F.A., McCullough, L.B. (1996). **Common ethical dilemmas encountered in the management of HIV-infected women and newborns**. *Clinical Obstetrician & Gynecology* 1996; 39(2):411-9.

3. National Institute of Health. (1994). **Contraceptive practices among HIV exposed women**, http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102211001.html (Accessed June 2009).

4. Cooper, D.; Bracken, H.; Myer, L.; Zweigenthal, V.; Harries, J.; Orner, P.; Manjezi, N. and Ngubane P, (2005). **Reproductive intentions and choices among HIV-infected individuals in Cape Town, South Africa: Lessons for reproductive policy and service provision from a qualitative study,** Policy Brief.

5. Díaz, T., Schable, B., Chu, S., et al. (1995). **Relationship between use of condoms and other forms of contraception among human immunodeficiency virus-infected women**. *Obstet Gynecol* 1995;86(2):277-82.

6. Duggan, J., Walerius, H. Purohit, A., et al. (1999). **Reproductive issues in HIV-seropositive women: a survey regarding counseling, contraception, safer sex, and pregnancy choices**. *J Assoc Nurses AIDS Care* 1999;10(5):84-92.

7. Feldman, R., Maposhere, C. (2000). **Voices and choices: a participatory research and advocacy study of reproductive health and rights of HIV positive women in Zimbabwe**. *The XIII International AIDS Conference*, Durban, South Africa, July 9-14, 2000.

8. Guimaraes MD, Castilho E, Signorini D, Lima LA, Berbara V (1994). **HIV-positive Women Have Different Needs**; International Conference on AIDS (1994) Aug 7-12; 10: 368 (abstract no. PD0652). UFMG, Rio de Janeiro, Brazil.

9. Hatcher RA, Trussell J, Stewart F, et al., eds. ***Contraceptive Technology**, Seventeenth Revised Edition.* (New York: Ardent Media, Inc., 1998)800.

10. Department of Health (DOH) (2007). ***HIV & AIDS and STI Strategic Plan for South Africa (2007-2011)***.Johannesburg.

11. National Institutes of Health (1992). **HIV prevention practices of primary-care physicians** -- United States, 1992. MMWR 1994; 42(51):988-992.

12. Hutchison, M., Kurth, A. (1991). **"I need to know that I have a choice ..." a study of women, HIV, and reproductive decision-making**. *AIDS Patient Care* 1991;5(1):17-25.

13. Jackson, H. **Societal Determinants of Women's Vulnerability to HIV infection in Southern Africa,** Editorial, Volume 2, Number 4**,** http://www.hhrjournal.org/archives

14. Kaida, A., Laher, F., Hogg, R., Money, D., & Gray, G. (2007). **Contraceptive use among HIV-positive women in Soweto, South Africa: The influence of expanding access to HAART.**

15. Leitz, G., Mildvan, D., McDonough M, et al. (2000). **Nevirapine (VIRAMUNE, NCP) and ethinyl estradiol/norethindrone (ORTHO-NOVUM 1/35 [21 pack] EE/NET) interaction study in HIV-1 infected women.** *The 7th Conference on Retroviruses and Opportunistic Infections*. San Francisco, January 30-February 2, 2000.

16. Department of Health (DOH) (2004). **National Antiretroviral Treatment Guidelines**. Johannesburg.

17. Population Council (2004). **Addressing the Family Planning Needs of HIV-positive PMTCT Clients: Baseline Findings from an Operations Research Study,** Research Update.

18. Ryder, R.W., Batter, V.L., & Nsuami, M. (1991). **Fertility rates in 238 HIV-1 positive women in Zaire followed for 3 years post-partum,** 12, 1521-1527.

19. Ideall, K.S., Jeyapaul, M. & Kalyanwala, S. (2008). **"Desire for motherhood: Exploring HIV-positive women's desires, intentions and decision-making in**

attaining motherhood," *AIDS Care* 20(6): 625–630. (offsite link), found on www.populationcouncil.org

20. Piscitelli, S., Flexner, C. & Minor, J. (1996). **Drug interactions in patients infected with human immunodeficiency virus**. *Clinical Infectious Diseases,* 4,685-693.

21. Santos,N., Ventura-Filipe,E. & Paiva,V. (1998). **HIV positive women, reproduction and sexuality in São Paulo, Brazil**. *Reproductive Health Matters,* 12, 31-40.

22. Temmerman, M., Chomba, E.N. & Piot, P. (1993). **HIV-1 and reproductive health in Africa**. *International Journal of Gynecology Obstetritians,* 107-112.

23. UNAIDS (2008), **UN Report on the Global AIDS Epidemic**, Geneva.

24. Williams, H., Watkins, C. & Risby, J. (1999). **Reproductive decision-making and determinants of contraceptive use in HIV-infected women**. *Clin Obst Gynecol* 1996;39(2):333-43.

25. World Health Organization, (1996). **Improving Access to Quality Care in Family Planning. Medical Eligibility Criteria for Contraceptive Use**. Geneva.

26. Global Coalition on Women and AIDS (GCWA), http://womenandaids.org/about-gcwa.aspx, Accessed June 2009.

27. Family Health International, (2001). **HIV-positive Women Have Different Needs,** Vol.20, and No.4, http://www.fhi.org/en/rh/pubs/network/v20_4/nwvol20-4hivposwomen.htm, Accessed June 2009.

Tool 1: Focus Group Discussion Guide for Women living with HIV and AIDS

Introduction

Ask about how the clients are and how they are feeling? I am here today conducting research on contraceptive practices and fertility intentions of women living with **HIV**.

[Discuss issues in the informed consent form].

We will share a few questions with you and we would like you to be as open and free as you can be, as this will help in planning needs-driven reproductive health programmes. When we ask questions, we kindly ask you to share as much as you can. We expect you to contribute in this very important discussion. This discussion will take approximately 45minutes.

a) Background: Knowledge and Awareness of Contraceptive/Family planning practices:

1. Can you tell us as much as you can about contraceptives /family planning methods?

Probe:

- Types of contraceptives/family planning
- What information gaps exist in contraceptive/family planning education?
- Overall recommendations to address information gaps in contraceptive/family planning education? (IEC materials)

b) Contraceptive Practices/Family planning methods

Probe:

- Dual protection
- Do you get any education on contraceptive/family planning practices?
- Areas of education on contraception received
- What are the sources of this information?

- Nature of services provided
- Adequacy and accessibility of the services
- Usability of the different contraceptives
- Uptake of contraceptives and acceptability
- Overall areas of concern/challenges and strengths
- Overall recommendation for improvement of the family planning programmes

c) Fertility Intentions

Probe:

- Do fertility intentions change after a positive outcome?
- Are there support services for positive women/couples who want to have children?
- Nature of services provided
- Adequacy and accessibility of the services
- Uptake of contraceptives and acceptability
- Overall areas of concern/challenges and strengths
- Overall recommendations for improvement of the family planning programmes

c) Personal Experiences

- Positive experiences (with the health institution, community and family)
- Negative experiences(with the health institution, community and family)
- Personal challenges (their experiences and others)
- Coping strategies
- Issues of disclosure

d) Influences in contraceptive/family planning practices

Probe:

Spousal/Partner Involvement

- Understanding contraceptive practices and fertility issues
- Personal challenges faced
- Recommendations

Significant Family Member Involvement

- Who are the influential members of the family?
- Views of significant family members on family planning
- Expected support from family members
- Recommendations to improve support

Community Involvement

- Role of community in influencing contraceptive/family planning practices
- Views on family planning
- Expected support from community
- Recommendations to improve support

Tool 2: Questionnaire Women Living With HIV in the Community

Questionnaire ID _____

Name of Interviewer _____

Date of interview _____

SECTION 1: CLIENT DEMOGRAPHIC DATA

Age of Client _____/ When were you born? _____

1. Marital Status

    a. Never married

    b. Married

    c. Widowed

    d. Divorced/Separated

    e. Co-habiting

2. Education

    a. Never been to school

    b. Primary

    c. Secondary

    d. Tertiary or more

3. Category of respondents

    a. PMTCT client

    b. Support group

4. Number of children

    a. One

    b. Two

c. Three

d. More than three

5. How old is your last child

a. One

b. Two

c. Three

d. More than three

SECTION 2: KNOWLEDGE AND AWARENESS OF CONTRACEPTIVE PRACTICES (all respondents)

6. Do you know about the contraceptive options that are offered for people living with HIV AND AIDS?

a. Yes

b. No

7. If yes, can you share with us what you know?

8. Did you receive education on contraceptives/family planning?

a. Yes

b. No

9. If yes, what are the main areas of education on contraceptive practices/family planning you received?

10. What additional information would you like to learn about contraceptive practices in order for you to make informed decisions?

11. How would you like that information to reach you and the community at large?

SECTION 3: PARTNER SUPPORT

12. When were you tested for HIV?

13. Would you be willing to share the result?
    a. Positive
    b. Negative
    c. Did not collect result
    d. Do not want to disclose results
14. Currently do you have a partner/spouse?
    a. Yes
    b. No
15. Has your partner been tested for HIV?
    a. Yes
    b. No
    c. Don’t know
16. If yes, is your partner/spouse HIV positive
    a. Yes
    b. No
    c. Don’t know
17. Do you/or your partner still want to have children?
    a. Yes
    b. No
    c. Don’t know
18. If yes, what measures are you taking?
19. Does your partner support you?
    a. Yes

b. No

20. If yes, how does he support you?

21. If no, what would be the reasons?

22. Generally, do men in your community support their partners when they are pregnant?

a. Yes

b. No

c. Don’t know

23. If yes, at what stage do they give support?

a. Before pregnancy

b. Early pregnancy

c. Mid pregnancy

d. Late pregnancy

e. After delivery

24. What factors encourage them to support their wives?

25. If no, what factors discourage them from supporting their partners?

26. In your view are there any benefits in men supporting women when they are HIV positive?

a. Yes

b. No

27. If yes, what are the benefits?

28. In what ways can you influence male members of the community to participate in reproductive health issues?

29. What male gatherings in the community can be used to share information?

a. Church gatherings

b. Funeral gatherings

c. Beer halls

d. Social clubs (football etc)

e. Burial societies

f. Support groups

g. Other

……

Involvement of Significant family Members

30. In your community HIV positive women get support from their family members?

a. Yes

b. No

c. Don't know

31. If yes, who are the key family members who support the HIV positive women?

32. In what ways do they support the HIV positive women?

33. If no, what possible reasons can you give for their failure to support HIV positive women?

34. What do you think family members can do to support HIV positive women?

Community Involvement

35. Has the community ever received education on reproductive health?

a. Yes

b. No

c. Don't know

36. If yes, how was it introduced?

37. Are there current community teachings/meetings on contraceptive practices/ family planning in this community?

    a. Yes

    b. No

    c. Don't know

38. If yes, how often are the teachings/ meetings conducted and what issues are shared/advocated for during these teachings/ meetings?

    a. Every week

    b. Twice a month

    c. Once a month

    d. Once in two moths

    e. Other (specify) …….

39. Do HIV positive women get support from other community members

    a. Yes

    b. No

    c. Don't know

40. If yes, in what ways does the community support them?

41. If no, what possible reasons can you give for the community's lack of support?

42. In what ways can the community support clients in the women living with HIV?

SECTION 4: CONTRACEPTIVE/FAMILY PLANNING SERVICES

43. Do you know of family planning services available in your community?

i. Yes

ii. No

44. If yes, what are they?

45. Where can these services be obtained?

46. Are there factors that inhibit couples from accessing family planning?

a. Yes

b. No

47. If yes, what are they?

In conclusion, are there any other issues you might want to bring to our attention?