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**SEXUALITY ISSUES IN PATIENTS ATTENDING
ANTIRETROVIRAL CLINIC AT EMBHULENI HOSPITAL
IN MPUMALANGA PROVINCE (SOUTH AFRICA)**

By

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requirements for the degree of**

MASTER OF PHILOSOPHY

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DECLARATION

I, **MANDLENKOSI REX MKHABELA**, declare that:

**"SEXUALITY ISSUES IN PATIENTS ATTENDING
ANTIRETROVIRAL CLINIC AT EMBULENI HOSPITAL
IN MPUMALANGA PROVINCE (SOUTH AFRICA)"**

is my own work and that all the sources I have quoted have
been acknowledged by means of references.



Dr M.R. Mkhabela
Date: March 2008

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Abstract

Background

People living with HIV/AIDS experience many losses, one of which may be loss of sexual expression. Sexuality has a broader meaning than mere sexual intercourse; it encompasses intimacy and impacts on psychosocial and spiritual realms. Despite the broader meaning of sexuality and that HIV is mainly a sexually transmitted disease; carers generally avoid real issues of sexuality. This study explored issues of sexuality in people living with AIDS who are given an optimistic outlook to life by the availability of HAART.

Methods

This is a descriptive quantitative study. The respondents were purposively sampled from the 850 patients attending the ARV clinic at Embhuleni Hospital. Anonymity was assured. The questionnaire was available in English as well as two local languages i.e. Zulu and SiSwati. The data obtained was entered in Excel. Statistical analysis included frequency tables, summary statistics and 95% confidence intervals.

Results

102 questionnaires were completed. There was a significant difference between the responses before and after HAART for questions on sexual desire, sexual performance, sexual enjoyment and satisfaction with frequency of intercourse ($t=2.4387$ $p=0.0165$).

There was a statistically significant difference between the number of partners before and after initiation of HAART.

Although 98/102 (96%) of respondents rated condom use as very important, 11/102 (10.78%) of respondents never use condoms during sex, and 21/102 (20.58%) indicated that they have had unprotected sex in the past 6 months. The most common reasons for unprotected sex were that of the partner refusing to use condoms (14.7%) followed by that of a desire for pregnancy (7.84%) and condom unavailability (6.86%).

18/102 (17.64%) of respondents said it was very important for them to have a child and 20/102 (19.6%) were planning to have a child in the future. 26/102 (25.29%) of respondents had not disclosed their HIV status to their partners. 97/102 (95%) of respondents indicated that it is very important to them that health workers discuss their sexual needs with them.

Conclusion

Sexuality in HIV is complex, with participants reporting better sexual experience before HAART and a significant number still planning to have children. Health workers need to be aware of the complexities to be able to discuss it with their patients.

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ACRONYMS/DEFINITIONS

Sexuality: The constitution of an individual in relation to sexual attitudes and behaviour¹. As it involves attitudes and behaviour it is governed by spiritual, psychosocial and physical elements.

HIV: Human Immunodeficiency Virus, of which there is type 1 and type 2.

AIDS: Acquired Immune Deficiency Syndrome. The disease caused by HIV by compromising the body's defence mechanism from disease.

HIV/AIDS: Used to denote either the pre-clinical stage and or the clinically manifested stage of a compromised immune system of an individual.

ARV: Anti-Retro-Virus/Viral. An agent that impacts negatively on the multiplication of Retro-Viruses specifically used for retro-viruses that cause AIDS in this study.

ARVs: A plural denoting more than one agent of ARV sometimes used interchangeably with HAART. See below.

HAART: Highly Active Antiretroviral Therapy. Used to denote the use of at least three different antiretroviral drugs².

CD4 Count: A measurement of a sub-type of T-lymphocytes in blood used in staging of HIV/AIDS and or assessing response to HAART.

Viral Load: A measurement which correlates to the amount of virus in the blood commonly used together with CD4 Count in monitoring HIV/AIDS.

SABC TV: South African Broadcasting Corporation Television.

CHAPTER 1

Introduction

Palliative care seeks to address the physical, psychosocial and spiritual well-being of the patient who has an incurable disease. The WHO defines palliative care for adults as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual³. The HIV/AIDS epidemic and the availability of HAART has added a new dimension in palliative care which initially was provided more for cancer patients but today we have more AIDS patient with even more years of mostly normal life. The WHO further expands the definition to include the following points among others³. Palliative care:

- Is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life, such as chemotherapy or radiation therapy, (note the conspicuous absence of HAART) and includes those investigations needed to better understand and manage distressing clinical complications;
- Provides relief from pain and other distressing symptoms;
- Intergrates the psychological and spiritual aspects of patient care;
- Will enhance the quality of life, and will positively influence the course of illness.

Loss of sexual expression is recognized as one of the losses, which are real or perceived by people living with HIV/AIDS. Sexuality has a broader meaning than mere sexual intercourse; it encompasses intimacy and impacts on psychosocial and spiritual realms. Despite the broader meaning of sexuality and that HIV is mainly a sexually transmitted disease; carers generally avoid real issues of sexuality⁴. There has been a tendency among carers to concentrate on protective

sex rather than giving space and receptiveness to patients living with HIV/AIDS in terms of their sexuality and reproductive rights⁵.

It is beginning to dawn on carers that reducing issues of sexuality to merely condom use or non-condom use as far as HIV/AIDS is concerned may deprive us of the broader understanding and hence better communication with patients and above all, deprive patients of the total care we strive to deliver physically, psychologically and spiritually.

More research on sexuality pertaining to HIV/AIDS is needed in South Africa as we grapple with the apparent resistance to changes in sexual behaviour. The spread of HIV in our population is mainly related to heterosexual relationships, not only among those who have the virus and have not yet progressed to AIDS, but also from those who have AIDS but can now live longer because of HAART. The question of re-infection and transmission of resistant strains of the HIV becomes a concern.

This study attempts to explore some issues of sexuality that may be at play in people living with AIDS who are given hope by HAART. Knowing about these issues will not only enrich us as carers in offering total care to these patients, but may also impact on preventative measures.

CHAPTER 2

Literature Review

Research articles and paper publications from 1995 to 2008 were searched for using the Pubmed, Googlescholar, Biblioline AIDS search and African Healthline databases. The search keywords used were "HIV and Sexuality" and "HAART and Sexuality". References from relevant articles led to further articles being found.

Research in sexuality presents unique challenges both to the researcher and participant in that sexuality has a lot to do with life history and experience, which presents complexities in data collection⁶. Whyte and Samis contrasted the conventional non-democratic nature of researcher-participant relationship with a non-structural conversational interview and found that the latter appears to yield more rich information, though it is time consuming and presents analytical challenges⁶. Studies cited here relied mainly on structured non-narrative data collection.

It is worth noting that earlier studies on sexuality in people living with HIV/AIDS were done abroad and among men who have sex with men (MSM). There are also more studies abroad covering the Highly Active Antiretroviral Therapy (HAART) era than there are in Africa. The reason for the above, needless to say, is due to the fact that HIV is mainly heterosexually transmitted in sub-Saharan Africa and that HAART has only recently been available in South Africa in particular. Research in sexuality relating to HIV/AIDS is needed in South Africa as we need to fully understand the apparent resistance to change in sexual behavior if we are to impact on the rising number of new cases in parts of the country.

The importance of addressing sexuality issues therefore stems from an epidemiological perspective and in the context of development in medical

treatment of AIDS⁷. Studies done in foreign countries may assist us as South Africans but their findings may not necessarily apply, South Africa being a culturally diverse society and a nation of dual economy. Even with the research cited in literature, sometimes the findings are contrary to expectation as compared to previous studies on the same research question.

Presented here and briefly discussed are some of the themes in the literature regarding sexuality in people living with HIV/AIDS.

Some studies cover more than one theme in that they have more than one research question, which may not be inferred from the title of the study. Most studies will cover the theme of risky behavior, though this has been cited as a deficiency in sexuality studies regarding HIV/AIDS i.e. the apparent preoccupation with protected sex. I must add that it is not a question of either/or but a caution not to reduce human sexuality to condom or non-condom use⁵. I have classified the research into three themes. Risky behavior is covered by most even though it may not be apparent from the research title.

Theme 1: Effect of HIV on sexuality^{5,7,8,9}

- 1.1 In women living with HIV/AIDS it was found that:⁸
 - the majority continue to be sexually active after testing positive
 - sexual function does not change with disease progression
 - few women reported that HIV itself caused worsening of sexual function
 - there was a higher level of sexual function associated with better mental health, better quality of life and those who never used intravenous drugs.
- 1.2 Some women, in particular those with regular new partners since learning of their HIV status, reported satisfying sex⁹.

Theme 2: Effect of HAART on sexuality^{10,11,12,13,14,15}

- 2.1 HAART was found to decrease libido and lead to an increase in erectile dysfunction among MSM and there was an associated increase in serum estradiol¹⁰.
- 2.2 Another study found no adverse effect on sexuality among HIV-positive adults on HAART¹¹.
- 2.3 A study on HIV-positive women on HAART found that¹²:
- They had lowered libido, lowered enjoyment and reduced intimacy.
 - They had barriers to forming relationships due to fears of disclosure and fears of infecting partners.
 - They had coping strategies, which involved relationship avoidance, having casual partners to avoid disclosure.
 - They had personal dislike for condoms, lack of control, and lack of suitable alternatives as far as safe sex was concerned.
- 2.4 A study among women comparing pre-HAART and after HAART became widely available, found that in both eras women frequently discussed decreased sexual activity, loss of sexual interest and diminished sense of sexual attractiveness following their HIV infection¹³. Reported reasons for discontinuation of sexual activity or diminished interest in sex included the following:
- Anxiety about HIV transmission
 - Loss of freedom and spontaneity during sex
 - Fears of emotional hurt
 - Not wanting the hassle of sexual relationships
 - Loss of sexual interest

- Diminished sense of sexual attractiveness

There was no difference of types of changes in the women's sexuality nor the reasons offered for these changes pre-HAART and HAART eras.

2.5 HAART availability was reported to have impacted on elective pregnancies in Cuba¹⁴. In this study 64% of women interviewed became pregnant while they were aware of their HIV status or that of their partner and almost all became pregnant after HAART became widely available in Cuba. It was concluded that introduction of effective therapy for HIV by changing the social and clinical course of HIV/AIDS and allowing the possibility of having HIV-negative children, contributed to decreased HIV/AIDS related fears and stigma hence reshaping reproduction.

2.6 A Ugandan study which enrolled adults and provided a comprehensive home-based ART program, reported 70% reduction in risky sexual behavior and that over 85% of risky sexual acts occurred between married couples¹⁵.

Theme 3: Risky Behavior In People Living With HIV/AIDS

Most research on sexuality in HIV/AIDS, whatever its purpose is, tends to focus on risky behavior and the practice or the non-practice of protected sex. Sometimes, it is felt that this focus is at the expense of other considerations, given the fact that human sexuality is a complex issue. It is, however, gradually becoming clear that for us to understand risky behavior we have to look at human sexuality in a broader way than the issues of condoms and sexual

sanctions⁵. Many studies have simply quantified how many people did or did not use condoms, only a few have attempted to find out what is behind safe and unsafe sexual practices among people in general and those living with HIV/AIDS in particular.

3.1 Studies have found that to some extent the same determinants of unsafe sexual behavior are operative among HIV-positive people as they are among people in general¹⁶.

- A study in Russia showed that 50% of people living with HIV/AIDS engaged in unprotected sex and condoms were not used in 1/3 of the time with discordant partners¹⁶.
- Non-anonymous data collection may underestimate high risk behavior⁴
- Participants expressed dissatisfaction with healthcare providers in addressing their concerns regarding relationships, sexuality and fertility^{7,17}.

3.2 Factors that have been associated with risky behavior in studies as primary research and meta-analytical studies are:

- Gender
- Cultural and economic factors
- Urban living versus Rural living
- Level of education
- Knowledge that one is already infected with HIV

3.2.1 An African study cited vulnerability of women to unsafe sex as being due to cultural norms, economic dependency and ignorance about reproductive and anatomical factors¹⁸.

3.2.2 A study in Zimbabwe found that¹⁹:

- Women were unaware of risk before diagnosis due to gender norms and economic dependence.

- Women did not disclose their status to health workers due to perceived prejudices that HIV-positive people should not be sexually active or have children.
- Condom use was considered inappropriate in marriage
- Younger women wanted to become pregnant
- Safe abortion was inaccessible.

3.2.3 A study in rural KwaZulu/Natal South Africa found that the historical process of cultural and religious integration and the contemporary resurgence of traditionalism prevented a healthy discourse about healthy sexuality among adolescents²⁰. This appeared to be due to stigmatization of sexual activity particularly for teenage women, resulting in ambivalence to love and romance versus stigma and secrecy; a setting which impedes the prevention of HIV.

3.2.4 Differences in urban versus rural living were demonstrated in a study conducted among HIV-infected patients in urban and rural South Africa²¹.

In this study, findings were:

- Urban respondents were more likely to have current regular sexual partners (75.1% vs 46.0%)
- Urban respondents more likely to have any current sexual partners (75.3% vs 51.2%)
- Urban respondents more likely to report consistent condom use with regular partners (78.4% vs 48.3%)
- Urban respondents more likely to report consistent condom use with casual partners (68.6% vs 48.3%)
- Predictors for consistent condom use with regular partners include, across gender, urban residence and higher education level, for women an association with disclosure and younger age, for men, no history of alcohol consumption.

- Male and female participants with a casual sexual partner were less likely to use condoms consistently with regular partners.
- Predictors of having a regular sexual partner were urban residence and a CD4 count above 200 cells/mm³ as well as (for women) higher household income and history of alcohol consumption.

3.2.5 High prevalence of risky behavior among men attending a sexually transmitted disease clinic in Durban, South Africa was found to be still as high as in a previous study in 1988/1989 comparing almost twenty years in the HIV/AIDS epidemic²². In this study among men with genital ulcer disease (GUD):

- Between 33.3% and 43.9% reported sex since the start of symptoms compared to 36% in 1988/1989.
- 34.4% of men with confirmed herpetic genital ulceration had had sex since the start of symptoms and 93.3% of these had unprotected sex.

It was suggested that this high risk behavior could be due to disinhibition because many were already infected with HIV, a low level of education or other unknown factors²².

3.3 Age Factor

In one study, youth were found to engage in unsafe sex and substance use; more so in the post HAART era than pre-HAART.²³

3.4 HAART initiation as a factor

3.4.1 Women were found to engage in unsafe sex after HAART initiation irrespective of therapeutic response²⁴

3.4.2 Among MSM it was found that any decrease in per contact risk of HIV transmission due to HAART appeared to have been counterbalanced or overwhelmed by an increase in the number of unsafe sexual episodes²⁵.

- 3.4.3 Another study with MSM found that HAART initiation may play a minor role in contributing to high risk behavior, instead the HIV-status of partners (serosorting), safe sex fatigue, and the use of poppers (drugs) appeared to be more important in understanding the sexual risk behavior of HIV-positive MSM²⁶. This study indicated a high level of unprotected sex among MSM particularly with HIV-negative or unknown serostatus partners.
- 3.4.4 A meta-analysis of HAART and sexual risk behaviour²⁷ demonstrated that HIV-positive patients on HAART did not exhibit increased sexual risk behavior even when the viral load was undetectable. The study found that the prevalence of unprotected sex was elevated among those who believed that having an undetectable viral load protects against transmitting HIV or who had reduced concerns about unsafe sex given availability of HAART whether they were HIV-negative, HIV-positive on HAART, or of unknown serostatus. It was concluded instead that people's beliefs about HAART and viral load may promote unprotected sex and such behavior was amenable through educative messages²⁷.
- 3.4.5 Another study found that use of and adherence to HAART and suppression of viral load were associated with decreased prevalence of self-reported risky sexual behaviour²⁸.
- 3.4.6 A short term increase in unsafe sexual behavior was observed in a study in Canada after HAART initiation²⁹. The study reported that unprotected sexual behavior rose from 20.4% to 30.1% after initiation of HAART.
- 3.4.7 A study in Thailand examined risky sexual behavior among men and women on HAART and the relationships between CD4 levels and unprotected sex³⁰

This study reported that:

- 23% who were not sexually active after learning of their status started having sex after receiving HAART with a twelve week median duration from starting HAART and having first sex.
- 56% of patients had sex during the previous six months; of these 25.5% had sex with commercial partners and 28.4% with non-regular partners.
- Inconsistent condom use with commercial or non-regular partners was higher in females (35.3%-36.8%) and lower in males (7.8%-11.1%).
- Participants with known HIV-negative regular partners were 0.25 times more likely to have unprotected sex than those with known HIV-positive regular partners.
- No association between CD4 levels and unprotected sex was found.

3.4.8 A cross-sectional survey of HIV-infected 18-49 year old women in Brazil, South Africa and Uganda looked at current HAART use and recent sexual intercourse and secondarily to practicing protected sex and contraceptive use among HAART users and non-users³¹.

The findings were:

- 65% did not want any (more) children.
- Women on HAART were just as likely as women not on HAART to report recent sexual intercourse.
- Reporting of recent sexual intercourse was associated with:
 - Higher HAART optimism scores rather than HAART use itself.
 - Higher education.
 - Being currently married.
 - Having an HIV-positive primary partner or spouse.

- Desire for more children.
- Not having been diagnosed with AIDS.
- 63% of women who reported recent sexual intercourse were using condoms and women on HAART were significantly more likely to practice protected sex.
- 76% were using contraceptive methods and; again women on HAART were more likely to use contraceptives albeit non-significantly.

3.5 Psychosocial needs as a factor for risky behavior

3.5.1 Desire for parenthood^{32,33}

3.5.2 Social validation search³⁴

A study in Brazil among heterosexual men, heterosexual women and MSM found that social validation or acceptance appeared to be the main issue rather than availability of HAART. This was found to be the psychosocial determinant of unsafe sex and was due to shame, denial and fear of disclosure related to HIV but not limited to HIV.

3.5.3 Stress caused by disclosure³⁵

3.5.4 A study of sexuality among HIV-positive women since HAART showed a high prevalence of sexual difficulties including infrequent sex, avoidance, non-communication and dysfunction¹². Enjoyment was found to be associated with reduced sexual frequency and sexual dysfunction while sexual dissatisfaction was associated with avoidance and non-communication.

3.5.5 Societal attitudes impacting on stigmatization of sexuality in people living with HIV/AIDS. Community attitudes towards sexual activity and childbearing were examined in a South African study.³⁶

This study found that:

- 43% of women interviewed thought that people living with HIV/AIDS should remain sexually active if they choose to.
- Only 13% thought that people living with HIV/AIDS should have children if they wished.
- Negative attitudes towards both sexuality and childbearing were persistently associated with not knowing someone infected with HIV.

In summary, published research has focused on the effect of HIV on sexuality, the effect of HAART on sexuality as well as risky behavior in people living with HIV/AIDS. Most of the research has been conducted in developed countries. Not enough is known about the sexual experiences of rural South African patients on HAART.

CHAPTER 3

3.1 Aim

To explore issues of sexuality among mainly heterosexual patients on HAART at Embhuleni Hospital.

3.2 Objectives

The outlook for people living with HIV/AIDS in South Africa has changed since the introduction of HAART in public clinics. This study attempts to look at the effect of this optimism on sexuality by asking specific questions to participants covering areas pertaining to libido, safe sex, reproductive concerns, beliefs and attitudes.

The objectives therefore are:

- To compare libido, sexual performance, sexual enjoyment and frequency among participants before and after HAART.
- To describe safer sex practices in this sample.
- To assess the depth of need for participants to discuss sexuality with health workers
- To assess the desire for parenthood in the sample, and whether participants are planning to have children.
- To assess changes in the number partners before and after HAART.
- To assess whether participants have disclosed their status to their partners.
- To find out what could be the most common reason for engaging in unprotected sex.

- To assess whether participants believed that taking HAART and having an undetectable viral load protects against transmitting HIV.
- To find out whether participants thought some people who are HIV-positive deliberately infect others.

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CHAPTER 4

4.1 Methods

Type of Study

This is a descriptive quantitative study.

Study setting

Embhuleni hospital is a 220 bed hospital in the district of Gert Sibande at Albert Luthuli Municipality in Mpumalanga province, South Africa. The hospital serves a mostly rural population. The HIV prevalence is estimated at 14.1%.

Sampling

Eligible participants were selected by the clinic staff as they presented for their scheduled or unscheduled visit, and were entered into a potential respondents' list. One hundred and two questionnaires were completed. This size of sample was based on the fact that, for proportions near a 50 to 50 split (50%), a large sample was required for precision as compared to proportions at extremes e.g. 10% to 90% split.³⁷

The study in Russia cited in the literature review showed that 50% of people living with HIV/AIDS engaged in unprotected sex and condoms were not used 1/3 of the time¹⁶. A larger sample would even have been better but it was beyond the means of this study in terms of the number of patients in the clinic, time and resources of the investigator.

The respondents were purposively sampled from the 850 patients attending the ARV clinic at Embhuleni Hospital. It was established that the clinic operates twice a week and has a clientele enrolled over a period of about three years. Some of

the clients have been on HAART for longer than three years, as they have been transferred from other ARV clinics.

Inclusion Criteria

All patients at Embhuleni Hospital over 18 years who were on HAART for at least three months were eligible to participate in the study.

Exclusion Criteria

Patients who were not yet on HAART or on HAART for less than three months were excluded. Because of the stigma associated with homosexuality, especially in rural areas, participants were not asked about their sexual orientation and participants who could be homosexual were not excluded from the study.

Data Collection Tool

The items in the questionnaire were generated from the themes identified in the literature. A structured questionnaire, Likert type, was administered to respondents. The questionnaire was in English and has been translated into two local languages i.e. Zulu and SiSwati. The questionnaire in all three languages was piloted among student nurses to ensure validity, reliability and, in the case of the Zulu and SiSwati translations, also to test for appropriateness of language. No changes were deemed necessary based on the pilot study. Above all this, an expert in these languages and in the Nguni cultures has been consulted (see under Ethical Considerations below for details).

Volunteer student nurses, suitably trained, administered the questionnaire. These student nurses did not form part of the clinic staff, but were in full time block at the Clinical Teaching Department under Mrs. A.N. Mkhabela (Principal Tutor). For logistic reasons the respondents were grouped in groups of at least ten before

the assistants were called in. The principal tutor was familiar with all three questionnaire languages, having assisted in, particularly, the Zulu translation.

The questionnaire was self-administered or partially or completely assisted, depending on the need of the respondent in terms of their literacy, understanding or otherwise.

Data Analysis

The data obtained was entered in Excel. Statistical analysis included frequency tables, summary statistics and 95% confidence intervals. There was no expressed hypothesis or null hypothesis. This was a descriptive study looking for a pattern of feelings, thoughts, beliefs and actions. The conclusiveness of results using this instrument is not our primary concern as a negative or positive answer would be equally significant as much as a neutral one. The objective of the study is to explore issues of sexuality. A single person's experience, however unique or isolated, may provide a point of departure to innovative breakthroughs. Statistical significance or insignificance is not necessarily a requirement for clinical importance of a result.³⁶

4.2 Ethical considerations

This study was voluntary and participants were fully informed and had consented as per the attached patient information sheet (Appendix 2) and consent form (Appendix 3). Anonymity was assured by assigning a number to each questionnaire self-picked by the participant from a bag of numbered cards, simulating what many would have seen in popular SABC TV games shows.

The questionnaire was in English (Appendix 1), Zulu (Appendix 7) and SiSwati (Appendix 10), which are the languages mostly spoken by participants and clinic staff. The translation to SiSwati and Zulu was done with due consideration and

sensitivity to the culturally preferred terminology particularly in issues of sexuality as direct translation may be deemed vulgar and/or disrespectful. The principal investigator is Swati, married to a Zulu and is in touch with the Nguni cultures. Further consultation had been sought from Mr Moses N. Mkhabela, a locally renowned linguist who has vast knowledge in Zulu and SiSwati (see Appendix 4).

Ethics approval for the study was obtained from the Research Ethics Committee at UCT (ref 097/2007), see Appendix 5. Permission to access respondents had been given by the Department of Health in Mpumalanga, Hospital services, under Dr K. Michaels (Appendix 6).

The clinic operates twice a week. As stated above on methods, diversion of clinical staff from their duties was minimised by the use of student nurses suitably trained to interface with the respondents, mainly those who, for literacy reasons found it difficult to read any of the documents i.e. the information sheet, the consent form and the questionnaire. Tentative talk to the clinical staff before the study suggested very low literacy levels in vernacular languages i.e. SiSwati and Zulu. Privacy was assured by conducting individual interviews in cubicles.

Participants were warned about the intrusiveness of the questions in the information sheet. As discussed in the literature review, these questions have been asked before. There is no report of any undue emotional upset or harm on the participants. However, should these questions have provided any adverse emotions, participants were asked to contact the principal investigator who would arrange a free consultation with himself and/or a clinical psychologist.

CHAPTER 5

Results

5.1 Demographic data

No one refused to participate in the study. There was a 100% response rate. 102 questionnaires were filled in.

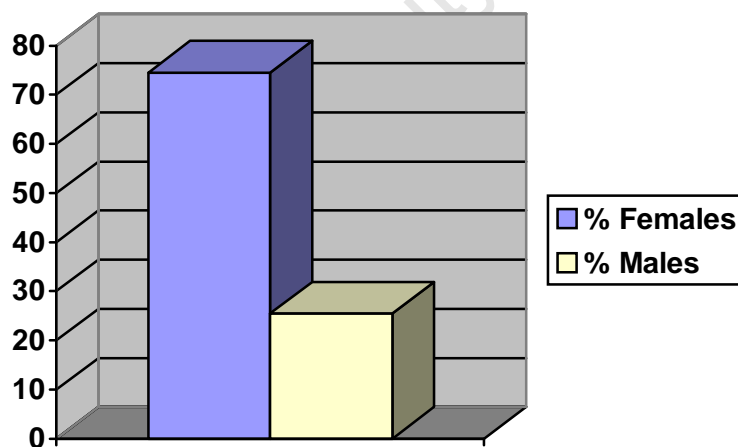
Ages ranged from 20yrs to 65yrs with a mean of 37.37 years and a median of 36yrs.

There were 76 females (74.51%) and 26 males (25.49%) (Figure 1).

31.37% were married, 57.84% were single staying alone or with relatives, 9.90% were cohabiting and 0.98% were divorced.

25.49% had no partners. 70% had one partner and 5.88% had more than one partner as reported on demographic data.

Figure 1: Gender Distribution



The number of children ranged from 0 to 9 with a mean of 2.67 and a median of 2 (Table 1).

The median of educational standard was standard 8 with a range of no education (0) to a higher education diploma (Table 2).

15.69% (16) were formally employed, 10.78% (11) informally employed and 71.57% (73) were unemployed (Figure 2).

The median duration of antiretroviral treatment was 12 months with a maximum duration of 94 months, and a minimum of 3 months.

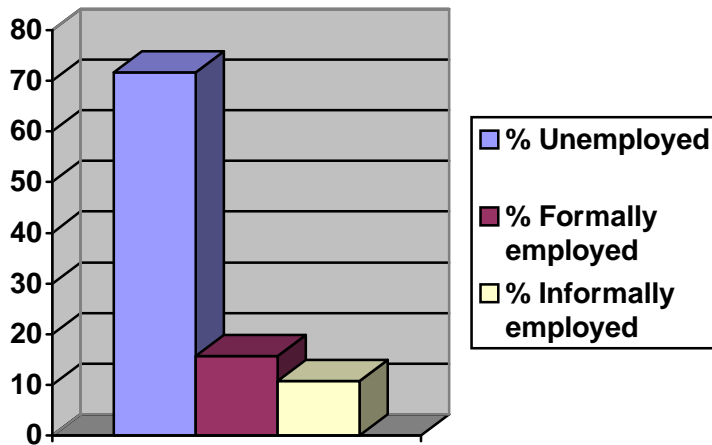
Table 1: number of children

Children	Frequency	Percent
0	11	11.78
1	24	23.53
2	22	21.57
3	18	17.65
4	8	7.84
5	8	7.64
6	4	3.92
7	5	4.90
8	1	0.98
9	1	0.98
Total	102	100%

Table 2: Educational standard

Standard	Frequency	Percent
0	8	7.84
1	4	3.92
2	1	0.98
3	4	3.92
4	4	3.92
5	9	8.82
6	14	13.73
7	5	4.90
8	7	6.68
9	15	14.71
10	29	28.43
Diploma	2	1.96
Total	102	100%

Figure 2: Employment



5.2 Sexual desire, performance, enjoyment and satisfaction with frequency of intercourse

The results of the Likert type questions on sexual desire, sexual performance, sexual enjoyment and satisfaction with frequency of intercourse were very similar. A composite score was created for these questions with the higher score indicating a more positive response.

The questions for pre-HAART were:

- How good was your sexual desire (libido) before you started antiretroviral treatment?
- How good was your sexual performance before you started antiretroviral treatment?
- How good was your sexual enjoyment before you started antiretroviral treatment?
- Were you satisfied with your frequency of sexual intercourse before you started your ARV treatment?

The questions for after HAART were:

- How good is your sexual desire (libido) now that you are on antiretroviral treatment?
- How good is your sexual performance now that you have started antiretroviral treatment?
- How good is your sexual enjoyment now that you are on antiretroviral treatment?
- Are you satisfied with your frequency of sexual intercourse now that you are on ARV treatment?

There was a significant difference between the responses before and after HAART. The paired t-test was applied to determine the difference in score before and after HAART, and a significant difference was found, with a better sexual experience before HAART ($p=0.0165$) ref to table 3.

Table 3: Paired t-tests of the responses before and after HAART

Variable	Obs N=102	Mean	Std dev.
Before	102	9	4.61
After	102	7.37	5.29

$t=2.4387$ $p=0.0165$

5.3 Number of sexual partners

There was a statistically significant difference between the number of partners before and after initiation of HAART. The number of respondents who had more than one partner before HAART was 39 (38.24%) and on HAART 11 (10.78%). It is interesting to note the difference of the response to “more than one partner” on completing the demographic data which was the first thing to do on the questionnaire, with a score of only 5.88%, against 38.24% on virtually the same question coming later in the questionnaire. This possibly demonstrates a more relaxed state of mind suggesting a possible under-reporting at first.

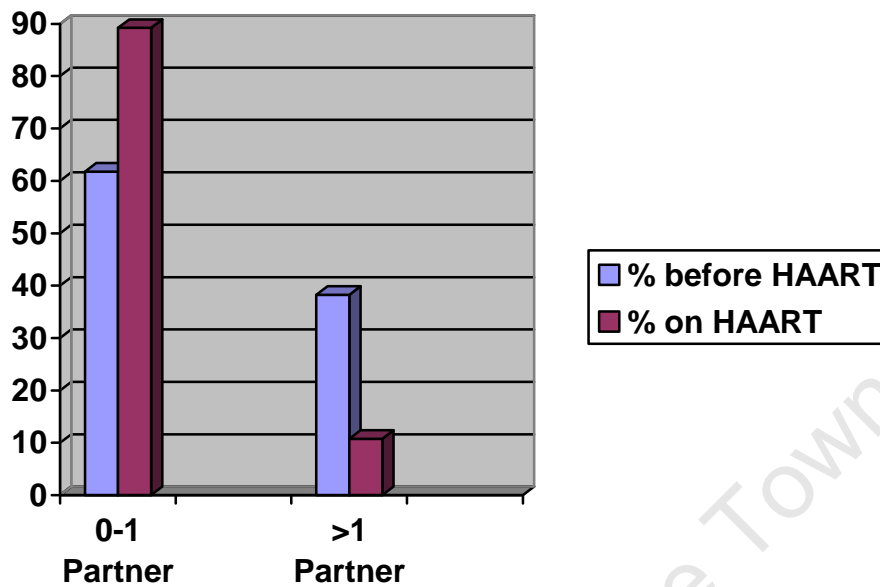
Table 4: Number of partners before HAART

	Frequency N= 102	Percentage	95% CI
0-1 Partner	63	61.76	28.8%-48.4%
>1 Partner	39	38.24	
Total	102	100	

Table 5: Number of partners on HAART

	Frequency N= 102	Percentage	95% CI:
0-1 Partner	91	89.22	5.5%-18.5%
>1 Partner	11	10.78	
Total	102	100	

Figure 3: Number of partners before HAART and on HAART



5.4 Importance of using condoms

On answering the question how often they use condoms during sex, 11 (10.78%) indicated never, 80 (78.43%) indicated always and 11 (10.78%) said sometimes.

In response to the question whether they have had unprotected sex in the past 6 months 21 (20.58%) said yes, 81 (79.4%) said no; which correlates with the number that said they always use condoms. Regarding the importance of using condoms, the majority regarded it as important as shown in table 6 below.

Table 6: Importance of using condoms

	Important N = 102	Percentage
Importance of using a condom	98	96%
Condom with HIV+ partner	92	90%
Condom with HIV- partner	98	96%
Condom if both on HAART	93	91%

5.5 Reasons for engaging in unprotected sex (Table 7)

The responses to the question, "If you were to engage in unprotected sex, what would be the most common reason", are listed in table 7 below.

Nine (9) respondents did not provide any reason on the self administered, non-assisted filling of the questionnaire.

Table 7: Reasons for engaging in unprotected sex

Answer	Respondents N=102	Percentage
Would dare not Not for any reason Never dare, will not fall in love again It will not happen, I am now a Christian Never did Not doing Dare not-fear of falling pregnant -fear of disease progression -fear of infecting the other	44	43.14%
Partner refusing to use condom/sometimes Partner forces Partner complaining condom too tight	15	14.7%
Only if being raped	9	8.82%
Desire for pregnancy	8	7.84%
Condom availability	7	6.86%
Other (1 each)	10	9.8%

Fear of disclosure		
If your status was not known by the other		
Will not have sex again husband died		
If viral load is undetectable		
Condom tear		
Fear of condom bursting harming partner		
Dissatisfaction if using condom		
Not feeling good if using condom		
Being overwhelmed with desire		
Not a frequent occurrence		
No answer	9	8.82%

The above results can be grouped in two categories, namely those who would not engage in unprotected sex, all things being equal, and those who consciously decide not to use a condom (Table 8). The 9 (8.82%) respondents who gave no answer to the question were excluded from either category.

Table 8: Classification of reasons for engaging in unprotected sex

1. Would not engage in unprotected sex all being equal N=69	Percentage
1.1 Partner refusing	14.7%
1.2 Being raped	8.82%
1.3 Torn condom	0.98%
1.4 Dare nots	43.14%
Total	67.64%
2. Conscious deciders not to use condom N=24	
2.1 Desire for pregnancy	7.84%
2.2 Condom unavailable	6.86%
2.3 Other	10%
Total	23.52%

5.6 Importance of discussing of sexual needs with healthcare workers

97(95%) of respondents indicated that it is very important to them that health workers discuss their sexual needs with them.

5.7 Plans to have children

In response to the question “Now that you are on antiretroviral treatment, how important is it to you to have a child” 18 (17.64%) indicated very important. Of those who indicated very important, 12 (66.67%) are females.

Table 9: Importance of having a child

Having a child	Respondents N=102	Percentage
Very important	18	17.64
Not important	70	68.62%
Undecided	14	13.72%

Table 10: Gender differences in the importance to have a child

Answer	Gender	Respondents	Percentage
Very important	Females	12	66.67%
	Males	6	33.33%

Table 11: Future plans to have a child

Planning to have a child in future	Gender	Respondents	Percentage
	Females	13	65%
	Males	7	35%

5.8 Disclosure

26 (25.29%) had not disclosed their status to their partners while 75 (73.53%) had disclosed.

5.9 Belief about HIV transmission

Responding to the question if participants believed that taking ARV protects against transmitting HIV, 41 (40.20%) did not believe it did; 15 (14.70%) were unsure and 46 (45.10%) did believe that receiving ARV treatment protects against transmission of HIV.

Asked if having an undetectable viral load protects against HIV transmission, 42 (41.18%) participants did not believe it did, 20 (19.60%) were unsure while 40 (39.22%) believed that having an undetectable viral load protects against HIV transmission.

In response to the question whether participants thought some people who are HIV positive deliberately infect others, 56 (54.90%) indicated yes. 25 (24.51%) participants did not think so and 21 (20.58%) were unsure.

CHAPTER 6

Discussion

6.1 Demographic data

The limitation of the study includes the small sample and the overrepresentation of females among the participants, (74.51%). This was to be expected since the clinic is a small volume clinic and operates only twice a week. The female predominance may be partly explained by Ante Natal Care (ANC) pickup of HIV-positive cases as they attend routine ANC clinics which are not attended by their male partners. Many studies show that there are more HIV-positive females than males and there is anecdotal evidence that males are more likely to have multiple partners and that one HIV-positive male would infect many females. The female predominance therefore could still be a reflection of the prevalence of HIV-infection patterns in the population. Despite the median standard of education being standard 8, most participants had to be assisted in filling in the questionnaire even in vernacular languages. This might have presented perceived non-anonymity of the questionnaire by introducing an element of an interviewing process which might have resulted in over-reporting of non-risky behavior as was found in the Swiss cohort study⁴.

6.2 Sexual Experience

The significant difference in sexual experience with pre-HAART being better, suggests adverse effects of HAART on sexuality among participants. This would agree with findings in studies among MSM¹⁰ and women on HAART¹¹ which reported negative sexual experiences. Other studies report either no adverse effect of ARV among adults¹⁰ or no difference pre-HAART and post-HAART¹³.

It is difficult to interpret the results on HAART as some studies report effects of HIV itself on sexuality with negative sexual experiences reported among HIV-positive MSM⁵ and among people with HIV⁷. Other psychosocial factors were reported to be at play in contributing to negative sexual experiences among HIV-positive people in general^{7,8,9} as well as people on HAART^{12,13,30}. These psychosocial determinants were reportedly similar both pre-HAART and post-HAART. Moreover the analysis becomes even more difficult since “before HAART” in our questionnaire could mean before the diagnosis of HIV itself spanning the time through diagnosis right up to before HAART. After HAART on the other hand could include a period when the participants were very sick; seeing the cut off CD4 count for initiating treatment among participants is 200 vs 350 in developed countries. The median time for resuming sexual intercourse was reported to be twelve weeks after HAART initiation in the Thailand study³⁰.

6.3 Number of sexual partners

The statistically significant drop in number of sexual partners on HAART from 38.24% with more than one partner before HAART, to 10.78% after HAART is encouraging. It is worth noting that some of those who requested assistance in answering this question did not consider a casual sexual encounter as a “partner”. This could mean a once-off sexual experience with someone would not be reported as a “partnership” by some participants. On the other hand, how many sexual encounters would one describe as casual or regular? It means having “one partner” could mean having one regular partner and at least one casual partner. This is important since studies show that fears of disclosure could lead to casual sexual encounters^{12,30} as, for example, suggested by the study in Thailand in which 28.4% of those who started having sexual intercourse after HAART initiation had sex with non-regular partners and 25.5% had sex with commercial partners³⁰. Therefore in this study, fears of disclosure may decrease

the number of “partners” but increase the number of episodes of unprotected sex due to engagement in unprotected sex with casual partners.

6.4 Importance of using condoms

The importance of using condoms in general scored 96% among participants. There was a drop in importance of 6% in using condoms with a HIV-positive partner and almost similar drop (5%) if both partners are on HAART. Importance of condom use if partner is HIV-negative remained the same as the general score of 96%. It appears as though the importance of using condoms in all four instances does not translate to actual condom use; as suggested by 78.3% of participants who said they always use condoms and 79.4% who reported that they have not had unprotected sex in the past six months. There is a difference of up to 17.57% (96% minus 78.43%) or 16.6% (96% minus 79.4%).

The above results suggest that if both partners are on HAART or one partner is on HAART and the other HIV-positive, they would be more likely not to use a condom, on the other hand if one partner is on HAART and the other is HIV-negative, they would be more likely to use a condom. This result would be contrary to that of the Thailand study which reported a 0.25% more likelihood of engaging in unprotected sex if one partner was HIV-negative than if HIV-positive³⁰.

Conceding the participants in this study are rural dwellers; compared to the study in urban rural South Africa²¹; consistent condom use among participants (78.43%) is higher than the reported 48.3% for rural dwellers. In fact it is more comparable to either the 78.4% for urban with regular partners or the 68.6% for urban with casual partners as reported in the South African study²¹.

Assuming that this study was perceived to be anonymous by participants, the results for consistent condom use is comparable but higher than the 73% reported among HIV-discordant heterosexuals⁴. The result is however lower than the 88% consistent condom use obtained by interview in the Swiss HIV cohort study which was contrasted with the 73% result⁴. The higher score in the Swiss study was interpreted to be due to over-reporting of consistent condom use with interviews than with anonymous data collection.

A Russian study reported that 50% of people living with HIV/AIDS engaged in unprotected sex and condoms were not used in 33.33% of the time with discordant partners¹⁶, while the Brazilian, South African and Ugandan cross-sectional survey reported that 63% of women who reported recent sexual intercourse were using condoms³¹. Compared to above studies, participants in this study reported a (significantly) higher condom usage (78.3%).

6.5 The most common reason to engage in unprotected sex

The most common reason for engaging in unprotected sex is that of the partner refusing to use a condom (14.7%). This reason came exclusively from females. The next reason for engaging in unprotected sex was that of a desire to fall pregnant (7.84%), followed by that of condom unavailability (6.86%).

Those who would not engage in unprotected sex all being equal as depicted in table six, scored 67.64% which is lower than the percentage of participants who said they always use condoms (78.43%).

If the reasons for engaging in unprotected sex; "only if being raped" and "torn condom", plus the "dare nots" are combined, it adds up to 52.94%. Assuming

that these are the likely ones to have reported consistent condom use we fall far too short of 78.43% who actually reported consistent condom use. This could only mean there are those whom we have classified as “conscious deciders not to use condom”, (table 6) who nevertheless reported consistent condom use.

6.6 Importance of discussing sexual needs with healthcare workers

This study shows that 95% of the participants thought that it was very important that healthcare workers discussed their sexual needs. Our study did not look at dissatisfaction directly. It was reported in a study that 50% of participants felt that healthcare providers did not sufficiently address their concerns regarding relationships, sexuality and fertility intentions⁴. Participants in other studies have expressed dissatisfaction with healthcare providers in addressing sexuality matters^{7,17}. Further importance of discussing sexuality especially among patients on HAART of childbearing age is supported by the Cuban study which reported that 64% of women who fell pregnant were aware of their HIV status or that of their partner¹⁴.

6.7 Plans to have children

68.62% of respondents reported it was not important to have children. This is comparable with the 65% among 18yrs-45yrs who did not want to have children in the Brazilian, South African and Ugandan cross-sectional survey³¹. 65% of females and 35% of males were planning to have a child in future. For females, the result is much higher than the 45% of HIV-positive females who expressed desire for children in the Swiss study⁴ and comparable to the 38% which was reported for males⁴. The Zimbabwean study reported that younger females wanted to fall pregnant though there was no percentage breakdown¹⁹.

There is no correlation between either those who said it was very important for them to have a child or those who are planning to have a child in future, and the desire to fall pregnant which scored only 7.84% as a reason for engaging in unprotected sex. This could mean participants who desire to fall pregnant are faced with a dilemma but still use condoms because there is no choice of safe reproductive methods.

6.8 Disclosure

25.29% of participants had not disclosed their status to their partners and 73.53% had disclosed. Several studies have commented on fears of disclosure as negatively affecting the sexuality of people living with HIV/AIDS. The dilemma in terms of disclosure was mentioned as compromising the sexuality of people living with HIV⁷. Disclosure was also cited as a barrier to forming relationships leading to casual sexual partners among women on HAART; to avoid having to disclose¹². Having disclosed your status was reported to be a predictor for consistent condom use among women in the study among HIV-infected patients in urban and rural South Africa²¹. Based on the latter study, one would predict consistent condom use among participants to be 73.53%. The reported condom use was 78.43% in our study which is close enough. Fear of disclosure related to HIV was also mentioned as a determinant for unsafe sex³⁴ and disclosure was described as stressful³⁵. The above studies however did not examine percentage breakdown of disclosure and non-disclosure among participants.

6.9 Belief about HIV transmission

45.10% of participants believed that taking HAART protects against transmission of HIV and 39.22% believed that having an undetectable viral load protects

against HIV transmission. Meta-analytic studies demonstrated that patients on HAART did not exhibit increased sexual risky behavior even when the viral load was undetectable, instead people's belief about HAART and viral load may promote unprotected sex²⁷. Various studies which examined the relationship between HAART and risky behavior reported inconsistent result perhaps due to different belief-systems amongst the groups studied. Women were found to engage in unprotected sex irrespective of therapeutic response²⁴. Among MSM the number of unsafe sexual episodes increased after HAART initiation²⁵ while another study among MSM found that HAART initiation itself may play a minor role, ascribing risky behavior to be due to serosorting, safe sex fatigue and drug usage²⁶. A Canadian study reported a short-term increase in unsafe sexual behavior after HAART initiation from 20.4% to 30.1%²⁹. There was a decrease in prevalence of self-reported risky sexual behavior reported in another study²⁸. It appears as though the variability of results in the above studies would support the finding of meta-analytic studies that beliefs are at play. On that score a 45.10% belief that HAART protects against HIV transmission and a 39.22% belief that having an undetectable viral load protects against HIV transmission would be unacceptably high since this can be easily changed by education.

54.90% of participants thought that some people who are HIV-positive deliberately infect others. We have found no precedence in research about this question, whether there is truth in it or not. This question was conceived of after several patients mentioned that they were deliberately infected. Mostly women tend to think this. The result viewed with that of "partner refusing to use a condom" as the most common reason for engaging in unprotected sex (14.7%) suggests stressful relationships which may compromise sexuality further, as would the fear of disclosure. There is a need to make female condoms widely available and continue the search for microbicides as an alternative to condoms hence empowering women not to depend upon men to have protected sex.

6.10 Limitations of the study

In summary, the limitations of the study included the small sample size and the under-representation of males. Biases might also have been introduced by the narrow definition of the word 'partner' as explained above. Having had to assist a number of participants in filling in the questionnaire might have jeopardized the sense of anonymity of the process by introducing a feeling of being interviewed.

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CHAPTER 7

7.1 Conclusion

Our objectives to explore issues of sexuality among respondents have largely been met. The knowledge gained may contribute to the care of patients with HIV/AIDS especially those on HAART, or at least provide a point of departure for further research in this field of palliative medicine in developing countries.

Like in other studies, sexual experience appears to be adversely affected by HAART.^{10,11}

The deterrents of risky behavior are important in order to prevent new infections, re-infections and the transmission of resistant strains of HIV from participants on HAART. The drop in the number of sexual partners after HAART initiation is encouraging, although the adverse effects of HAART must be born in mind.

Safer sex practices have further been demonstrated among participants with a 78.43% reported consistent condom use. There was a demonstrated potential of condom use of up to 96% if one were to work on the 90%-96% who said it was very important to use condoms. The 4%-10% of those who could engage in unprotected sex due to either beliefs about HAART, that it was not important to use a condom with an HIV-positive partner, that it was not important to use a condom with an HIV-negative partner or that it was not important to use a condom if the partner was also on HAART; demonstrated an attitude amenable by educative messages. Similarly the 45.10% of participants who believed that receiving HAART protects against HIV transmission and the 39.22% who

believed an undetectable viral load protects against the transmission of HIV can be changed by education.

The desire to have children must not be underestimated as a potential for unsafe sex and also as a dilemma to couples who want to have children but nevertheless use condoms consistently. There are also those who would otherwise use condoms consistently but are forced into unsafe sex by partner refusing to use a condom.

It appears as though disclosure may be used to measure consistent condom use as demonstrated by the close scores of 73.53% and 78.43% for disclosure and consistent condom use respectively. This was also demonstrated in the Swiss study.⁴ From this study it seems there is another fear that operates among participants; of being deliberately infected by others with HIV as demonstrated by an almost 55% of participants who thought this happens.

7.2 Recommendations

We would recommend that the study be repeated with a larger sample with gender parity and being well resourced to eliminate contact with participants as they fill in the questionnaire. Time frames should be well defined in terms of before and after HAART and time frames should not include the period when participants were very sick. The duration on HAART should possibly be 6 months to 12 months not 3 months as suggested by the Thailand study which demonstrated the median duration to resumption of sexual activity to be 12 weeks³⁰. This is recommended since HAART is initiated at a CD4 count of less than 200/mm³ according to the South African Department of Health policy and actual enrollment occurs at much lower CD4 levels, hence patients take longer to feel well. This is supported by the same study cited above which found recent sexual intercourse to be associated with not having been diagnosed with AIDS³⁰.

We recommend a clear definition of the word "Partner", "casual" or "regular" partner.

We propose the following model about determinants of risky behavior which might explain the inconsistent findings in different studies and we think might be of use:

Intrinsic determinants

- Egocentric - for myself
- Partnercentric - for my partner
- Omniscenic - for the good of all

The above constitute the character of the individual and are governed by culture and beliefs.

Extrinsic determinants

- Socio-Economic factors

These can be viewed as modulating factors to the intrinsic determinants

- Education
- Health (physical or mental)
- Gender
- Age
- Marital status
- Urban vs rural
- HAART optimism
- Desire for parenthood
- Drugs and Alcohol etc

Disclosure; which was found to be a predictor of condom use²¹ and this seems to be the case with our study, may also be based on the same determinants.

A further look at indirect ways of determining condom use which may be more sensitive than self reported condom use especially in interviews is recommended; eg. "Disclosure", "Desire to have child", "Unprotected sex in past 6 months" and "The most common reason to engage in unprotected sex ", should be compared with self reported condom use results.

The result about importance of condom use and beliefs about HIV transmission would warrant strengthening of education messages.

A recommendation of widespread availability of condoms especially female condoms is warranted. Knowledge about alternative reproductive methods as well as provision thereof is recommended to cater for those who still want to have children.

We recommend that healthcare workers be empowered with sufficient knowledge to be able to anticipate and discuss issues of sexuality with participants as 95% of participants indicated that this was very important to them.

CHAPTER 8

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APPENDIX 1 QUESTIONNAIRE

Sexuality issues in patients attending ARV clinic at Embhuleni Hospital in Mpumalanga.

1. Demographic data

Please fill in information and tick the correct answer where you are given options.

1.1 Age _____

1.2 Male

Female

1.3 Married

Single

Cohabiting

Other

Please specify e.g. living with kin or non-kin (living with relatives or non-relatives)-----

1.4 No partner

One partner

More than one partner

1.5 Number of children _____

1.6 Level of education _____

1.7 Employment _____

1.8 Duration on antiretroviral treatment _____

On a scale of 0-4

2. How good was your sexual desire (libido) before you started antiretroviral treatment? With 0 indicating poor and 4 indicating excellent.

0	1	2	3	4
---	---	---	---	---

3. How good is your sexual desire (libido) now that you have started antiretroviral treatment? With 0 indicating poor and 4 indicating excellent.

0	1	2	3	4
---	---	---	---	---

4. How good was your sexual performance before you started antiretroviral treatment? With 0 indicating poor and 4 indicating excellent.

0	1	2	3	4
---	---	---	---	---

5. How good is your sexual performance now that you have started antiretroviral treatment? With 0 indicating poor and 4 indicating excellent.

0	1	2	3	4
---	---	---	---	---

6. How important is it to you to engage in protected sex i.e. use a condom? With 0 indicating not important and 4 indicating very important.

0	1	2	3	4
---	---	---	---	---

7. If you have sex with an HIV-positive partner, how important is it to have protected sex i.e. use a condom?

With 0 indicating not important and 4 indicating very important.

0	1	2	3	4
---	---	---	---	---

8. If you have sex with an HIV-negative partner, how important is it to you to have protected sex i.e. use a condom?

With 0 indicating not important and 4 indicating very important.

0	1	2	3	4
---	---	---	---	---

9. If both you and your partner are on antiretroviral treatment, how important is it to you to have protected sex i.e. use a condom?

With 0 indicating not important and 4 indicating very important.

0	1	2	3	4
---	---	---	---	---

10. Indicate how often you use a condom during sex.

With 0 indicating never and 4 indicating always.

0	1	2	3	4
---	---	---	---	---

11. How good was your sexual enjoyment before you started antiretroviral treatment?

With 0 indicating poor and 4 indicating excellent.

0	1	2	3	4
---	---	---	---	---

12. How good is your sexual enjoyment now that you are on antiretroviral treatment?

With 0 indicating poor and 4 indicating excellent.

0	1	2	3	4
---	---	---	---	---

13. How important is it to you that health workers discuss your sexual needs with you?

With 0 indicating not important and 4 indicating very important.

0	1	2	3	4
---	---	---	---	---

14. Now that you are on antiretroviral treatment, how important is it to you to have a child?

With 0 indicating not important and 4 indicating very important.

0	1	2	3	4
---	---	---	---	---

15. Were you satisfied with your frequency of sexual intercourse before you started your antiretroviral treatment?

With 0 indicating not at all and 4 very much satisfied.

0	1	2	3	4
---	---	---	---	---

16. Are you satisfied with your frequency of sexual intercourse now that you are on antiretroviral treatment?

With 0 indicating not at all and 4 indicating very much satisfied.

0	1	2	3	4
---	---	---	---	---

17. Before you started your antiretroviral treatment, your number of sexual partners were as follows:

0 indicating nil/none ;1 indicating one partner;2 indicating two partners;3 indicating three partners;and 4 indicating four or more

0	1	2	3	4
---	---	---	---	---

18. Now that you have started your antiretroviral treatment, your number of sexual partners are as follows:

0 indicating nil/none; 1 indicating one partner; 2 indicating two partners; 3 indicating three partners and 4 indicating four partners or more.

0	1	2	3	4
---	---	---	---	---

19. Have you disclosed your HIV status to your partner or partners?

Tick appropriate box.

Yes

No

20. In the past six months, have you had unprotected sex. Tick the appropriate box.

Yes

No

21. If you would engage in unprotected sex what would be the most common reason? _____

22. Are you planning to have children in the near future? Tick appropriate box.

Yes

No

Unsure

23. Do you believe that receiving antiretroviral treatment protects against transmitting HIV? Tick appropriate box.

Yes

No

Unsure

24. Do you believe that having an undetectable viral load protects against transmitting HIV? Tick appropriate box.

Yes

No

Unsure

25. Do you think some people who are HIV-positive deliberately infect others?

Yes

No

Unsure

APPENDIX 2 PATIENT INFORMATION SHEET

Prospective study of issues of sexuality among patients attending ARV clinic at Embhuleni Hospital.

Patient Information Sheet

Translations in SiSwati and Zulu

You are attending the ARV clinic and receiving your treatment as per the schedule given to you.

The University of Cape Town is training doctors to be able to offer better care to people living with HIV/AIDS and other challenging diseases. Such doctors are required to do some research in this field.

If you agree to participate, you shall be given a list of questions by the research team, which will take 15 minutes to answer. Only a number will be assigned to each questionnaire and not your name. Please ask for help, if you need any, in answering the questions. These questions are very intimate, as they require information about sex and other related issues. Some questions need either yes or no answers but most are answered using a scale of 0-4. Please answer honestly and truthfully and without fear, as these answers cannot be traced back to you. There is no right or wrong answer. Only your true feelings shall make this research useful. Your answer may be 0,1,2,3 or 4, just mark the number closest to your feelings.

This study, like many others that have been done in other countries, explores matters of sexuality that may be challenging people living with HIV/AIDS who are taking ARVs. In most cases the same challenges that you faced before starting treatment are compared to the present to see how these have changed for better or for worse.

No harm or strong emotions have been reported in answering such questions in other studies. However, should you feel discomfort, please report this immediately. A free consultation shall be arranged.

The result shall be useful in understanding the challenges that people living with HIV/AIDS, particularly those on ARVs face so that when health workers discuss strategies to prevent the spread of HIV, do so with sensitivity and appreciation of your sexual needs and reproductive rights. It may also help to evaluate where knowledge of both health workers and patients needs strengthening.

Patients who are on ARVs for at least three months can participate in the study. If you can not read or write, a trained assistant shall be assigned to you. These assistants are not part of the clinic staff.

The result of the research will be available at the clinic in early 2008. Please indicate on the consent form if you would like to receive a copy of the results.

Again, this research is confidential. Do not write your name on the questionnaire. The consent form, which identifies you, will be kept in a locked cupboard away from the clinic and since the questionnaire has a number only, it cannot be assigned to anybody by name. If you choose not to take part in this study or decide to withdraw during the questionnaire, you are free to do so and you will still receive the same care and treatment.

Please take these phone numbers home with you. If you need further clarification please call any of the following.

Principal Investigator : Dr M.R. Mkhabela Tel No: 017 883 0655

Assistants (Clinical Teaching Department)

1. Ms A.N. Mkhabela Tel No: 017 883 0093

2. Ms O.P. Buthelezi Tel No: 017 883 0093

3. Ms N.V. Tshabalala Tel No: 017 883 0093

University of Cape Town

APPENDIX 3 CONSENT FORM

Prospective study of issues of sexuality among patients attending ARV clinic at Embhuleni Hospital.

Patient Consent Form

Translation in SiSwati and Zulu

I, _____, have read the patient information sheet and have had the research explained to me by _____.

I understand the information given to me and have been able to ask questions about the research. I know that if I decide to withdraw during the time of the questionnaire my care and treatment will still be the same.

I would like/would not like to receive results of the research study.

Signed _____ Date _____

Witness _____ Date _____

APPENDIX 4 TRANSLATING WITH LANGUAGE APPROPRIATENESS

Mr. Moses N Mkhabela is a retired teacher who taught Afrikaans and English. He has a BA degree with UNISA majoring in Anthropology and languages. He was head of the language Board in the Ka-Ngwane Homeland Government under Minister E.J. Mabuza and is experienced in translations, having translated various English and Afrikaans text into SiSwati including the English Bible.

His work is acknowledged by Dr Mafika Lubisi, a lecturer at the University of Zululand with a doctorate in SiSwati and Prof P.J. Shongwe attached to the Tshwane University of Technology, Nelspruit campus involved in SiSwati language. Recently, Mr. Mkhabela has been invited to participate in the launching of the SiSwati dictionary, the compilation of which his contribution has been invaluable.

Contact Number:(013) 782 0279



APPENDIX 5 UCT ETHICS COMMITTEE APPROVAL

UNIVERSITY OF CAPE TOWN



Health Sciences Faculty
Research Ethics Committee
Room B52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone (021) 406 6338 • Facsimile (021) 406 6411
e-mail: lamees.cmiedi@uct.ac.za

19 July 2007

RBC REF: 097/2007

Dr M Michabela
P O Box 789
Hlukwini
1192

Dear Dr Michabela

**PROJECT TITLE: SEXUALITY ISSUES IN PATIENTS ATTENDING ARV CLINIC AT
EMGHLUJUNI HOSPITAL IN MPTIMALANGA.**

Thank you for your letter to the Research Ethics Committee dated 03 July 2007.

It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study.

Your comments to the queries raised are noted with thanks.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the RBC REF in all your correspondence.

Yours sincerely

**A/PROF. M. BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS**

cmiedi

APPENDIX 6 MPUMALANGA PROVINCE ETHICS COMMITTEE APPROVAL

MPUMALANGA PROVINCIAL GOVERNMENT

Number 7
Government Boulevard
Riverside Park
Extension 2
Nelspruit
1200
South Africa



Private Bag 2011285
Nelspruit, 1200
Tel: (013) 766 3429/30
Int: +27 13 766 3429/30
Fax: (013) 766 3458
Fax: +27 13 766 3472

Department of Health and Social Services

Litiko Letemphile Nemisebenzi
Yeshilakakile Yesimo

Umyango Wazepilo
noZehlakakile

Departament van Gesondheid
en Maatskaplike Diens

Enquiries: Nkhumisani Mphathele (013) 766 3235

Dr. M.R. Mkhabela

P.O. Box 789

Elukwatini

1192

10 September 2007

Application For Research Ethics Approval: Sexuality issues in patients attending ARV clinical Embhuleni Hospital in Mpumalanga

The Provincial Research and Ethics Committee has approved your research proposal in the current format. No issues of ethical consideration were identified.

Kindly ensure that you provide us with the report once your research has been completed.

Kind regards,

Miss N.A. Mphathele: Research—coordinator

Pp: Mpumalanga PHREC

Acting-Chairperson: Prof. J.P. Shongwe

17/09/2007

Date



APPENDIX 7

Zulu Translated Questionnaire

ISINGEZELELO 1 (ZULU TRANSLATION)

IZINDABA MAYELANA NEZOCANSI EZIGULINI EZIHAMBELA EMTHOLAMPILO WAMA-ARV ESIBHEDLELA SASE-EMBHULENI ESIFUNDENI SASE-MPUMALANGA

UHLA LWEMIBUZO

1. IMINININGWANE YENANI LABANTU

Uyacelwa ukuba uphendule lemibuzo elandelayo ngokugcwalisa ezikheleni ezifanele, kokunye ukhethe impendulo ovumelana nayo ngokukhombisa ngophawu u-X ebhokisini elifanele.

1.1 Iminyaka yobudala bakho.....

1.2 Ungowesilisa Ungowesifazane

1.3 Ushadile Awushadile Ukumasihlalisane

Okunye

Nikeza incazelo yokuthi umuntu ohlala naye uyisihlobo sakho, noma wumuntu okuhawukele nje.....

1.4 Awunamngani oya naye ocansini

Unomngani oyedwa oya naye ocansini

Unabangani abeqa koyedwa oya nabo ocansini

1.5 Inani lezingane zakho.....

1.6 Izinga lemfundo.....

- 1.7 Umsebenzi.....
- 1.8 Ubude besikhathi welashwa ngama-ARV.....

University of Cape Town

Esikalini sika 0-4

2. Belingakanani izinga lakho lenkanuko yocansi ngaphambi kokuba uqale ukwelaswaha ngama-ARV?

(Lapho kukhona u-0 kukhombisa ukuthi beliphansi kakhulu lapho kukhona u-4 kukhombisa ukuthi beliphezulu ngokwadolulele)

0	1	2	3	4
---	---	---	---	---

3. Lingakanani izinga lenkanuko yakho yocansi njengoba usuqale ukwelashwa ngama-ARV?

(Lapho kukhona u-0 kukhombisa ukuthi liphansi ngendlela engagculisi kuthi lapho kukhona u-4 kukhombise ukugculiseka okwadolulele)

0	1	2	3	4
---	---	---	---	---

4. Ubusebenza kahle kangakanani ususocansini ngaphambi kokuba uqale ukwelashwa ngama-ARV?

(Lapho kukhona u-0 kukhombisa ukuba phansi kakhulu kuthi lapho kukhona u-4 kukhombise ukwedlulela)

0	1	2	3	4
---	---	---	---	---

5. Ususebenza kahle kangakanani ocansini njengalokhu usuqale ukwelashwa ngama-ARV?

(Lapho kukhona u-0 kukhombisa ukuba phansi kakhulu kuthi lapho kukhona u-4 kukhombise ukwedlulela)

0	1	2	3	4
---	---	---	---	---

6. Kubaluleke kangananani kuwe ukuthi uye ocansini uvikelekile, okusho ukuthi usebenzise i-khondomu?

(Lapho kukhona u-0 kukhombisa ukuthi akubalulekile kuthi lapho kukhona u-4 kukhombise ukuthi kubaluleke kakhulu)

0	1	2	3	4
---	---	---	---	---

7. Uma uya ocansini nomngani onegciwane lengculazi i-HIV, kubaluleke kangakanani ukuthi uye ocansini uvikelekile, njengokusebenzisa i-khondomu?

(Lapho kukhona u-0 kukhombisa ukuthi akubalulekile kuthi lapho kukhona u-4 kukhombise ukuthi kubaluleke kakhulu)

0	1	2	3	4
---	---	---	---	---

8. Uma uya ocansini nomngani ongenalo igciwane lengculazi i-HIV, kubaluleke kangakanani ukuthi uye ocansini uvikelekile, njengokusebenzisa i-khondomu?

(Lapho kukhona u-0 kukhombisa ukuthi akubalulekile kuthi lapho kukhona u-4 kukhombise ukuthi kubaluleke kakhulu)

0	1	2	3	4
---	---	---	---	---

9. Uma nobabili, wena kanye nomngani wakho wezocansi nelashwa nge-ARV, kubaluleke kangakanani ukuba nizivikele uma niya ocansini ngokusebenzisa i-khondomu?

(Lapho kukhona u-0 kukhombisa ukuthi akubalulekile kuthi lapho kukhona u-4 kukhombise ukuthi kubaluleke kakhulu)

0	1	2	3	4
---	---	---	---	---

10. Uvamise kangakanani ukusebenzisa i-khondomu uma uya ocansini?

(Lapho kukhona u-0 kukhombisa ukuthi awukaze kuthi lapho kukhona u-4 kukhombise ukuthi ngaso sonke isikhathi)

0	1	2	3	4
---	---	---	---	---

11. Bewukujabulela kahle kangakanani ukuya ocansini ngaphambi kokuba uqale ukwelashwa ngama-ARV?

(Lapho kukhona u-0 kukhombisa ukuthi bewungakujabuleli kahle kuthi lapho kukhona u-4 kukhombise ukuthi bewukujabulela ngokweqile)

0	1	2	3	4
---	---	---	---	---

12. Sewukujabulela kangakanani ukuya ocansini njengoba sewaqala ukwelashwa ngama-ARV?

(Lapho kukhona u-0 kukhombisa ukuthi ukujabulela kancane kuthi lapho kukhona u-4 kukhombise ukuthi ukujabulela ngokweqile)

0	1	2	3	4
---	---	---	---	---

13. Kubaluleke kangakanani kuwe ukuthi izisebenzi zezempilo zixoxisane nawe mayelana nezidingo zakho zocansi?

(Lapho kukhona u-0 kukhombisa ukuthi akubalulekile kuthi lapho kukhona u-4 kukhombise ukuthi kubaluleke kakhulu)

0	1	2	3	4
---	---	---	---	---

14. Njengoba sewelashwa ngama-ARV, kubaluleke kangakanani kuwe ukuthola ingane?

(Lapho kukhona u-0 kukhombisa ukuthi akubalulekile kuthi lapho kukhona u-4 kukhombise ukuthi kubaluleke kakhulu)

0	1	2	3	4
---	---	---	---	---

15. Beweneliseka yini, ngemvamisa yakho yokuya ocansini, ngaphambi kokuba uqale ukwelashwa nge-ARV?

(Lapho kukhona u-0 kukhombisa ukungeneliseki bese kuthi lapho kukhona u-4 kukhombise ukuthi beweneliseka ngokweqile)

0	1	2	3	4
---	---	---	---	---

16. Uyaneliseka yini ngemvamisa yakho yokuya ocansini njengoba sewelashwa nge-ARV?

(Lapho kukhona u-0 kukhombisa ukungeneliseki bese kuthi lapho kukhona u-4 kukhombise ukuthi wenelisekile ngokweqile)

0	1	2	3	4
---	---	---	---	---

17. Ngaphambi kokuthi uqale ukwelashwa ngama-ARV inani labangani bakho bezocansi belinjengalokhu okulandelayo:

(Lapho kukhona u-0 kukhombisa ukuthi bebengekho, u-1 akhombise ukuthi ubeyedwa nje vo, u-2 akhombise ukuthi bebebabili, u-3 akhombise ukuthi bebebathathu, bese kuthi u-4 akhombise ukuthi bebebane noma ngaphezulu)

0	1	2	3	4
---	---	---	---	---

18. Njengoba sewuqalile ukwelashwa ngama-ARV, inani labangani bakho bezocansi selinjengalokhu okulandelayo:

(Lapho kukhona u-0 kukhombisa ukuthi awunabo, u-1 akhombise ukuthi uyedwa nje vo, u-2 akhombise ukuthi babili, u-3 akhombise ukuthi bathathu, bese kuthi u-4 akhombise ukuthi bane noma ngaphezulu)

0	1	2	3	4
---	---	---	---	---

19. Usivezile yini isimo sakho sengculazi i-HIV, kumngani wakho noma kubangani bakho bezocansi?

Khombisa ngophawu u-X ebhokisini elifanela YEBO CHA

20. Kulezizinyanga eziyisithupha ezedlule, ubusuke waya yini ocansini ungavikelekile?

Khombisa ngophawu u-X ebhokisini elifanela YEBO CHA

21. Uma bewungahle uye ocansini ungakavikeleki, bekungaba yini isizathu esivamile kakhulu ukwedlula zonke?

.....
.....

22. Ingabe upulanela (uhlose) ukuthi ube nezingane yini kulesikhathi esimaduze esizayo?

Khombisa ngophawu u-X ebhokisini elifanela

Yebo Cha Angina(li)qiniso

23. Uyakholelwa yini ekutheni ukwelashwa ngama-ARV kuyavikela ukuthi igciwane lengculazi i-HIV ledlulele kwabanye?

Khombisa ngophawu u-X ebhokisini elifanela

Yebo Cha Angina(li)qiniso

24. Uyakholelwa yini ekutheni ukuba ne-viral load engabonakali kuyavikela ekutheni igciwane lengculazi ledlulele kwabanye?

Khombisa ngophawu u-X ebhokisini elifanela

Yebo Cha Angina(li)qiniso

25. Ucabanga ukuthi abanye abantu abanegciwane lengculazi i-HIV badlulisela kwabanye ngesibomu na?

Khombisa ngophawu u-X ebhokisini elifanela

Yebo Cha Angina(li)qiniso

APPENDIX 8

Zulu Translated Patient Information Sheet

ISINGEZELELO 2

(ZULU TRANSLATION)

UKUFUNDA OKUBUKELELEKILE MAYELANA NEZINDABA ZOCANSI PHAKATHI KWEZIGULI EZIHAMBELA EMTHOLAMPILO WAMA – A.R.V ESIBHEDLELA SASE – EMBHULENI ESIFUNDENI SASE – MPUMALANGA

IPHEPHA LOKWAZISA ISIGULI

Uhambela emtholampilo wama – A.R.V, futhi uthola ukwelashwa ngendlela ehambisana naloluhla onikezwe lona.

I – Nyuvesi yase – Cape Town iqeqesha odokotela ukuthi bakwazi ukunakekela kangcono abantu abaphila negciwane lengculazi nesandulela sayo i-HIV/AIDS kanye nezifo eziyinsalelo. Abanye odokotela kufanele benze ucwaningo-thizeni kulendima.

Uma uvuma ukuzibandakanya kulolucwaningo, uzonikezwa uhlu lwemibuzo, yilabasebenzi abenza lolucwaningo, oluzothatha imizuzwana ethi mayibe yishumi nanhlanu. Uzonikezwa inombolo nje kuphela kulolo nalolo luhla lwemibuzo hayi igama lakho. Wamukelekile ukucela usizo lapho uludinga khona ekuphenduleni lemibuzo. Lemibuzo ijule kakhulu mayelana nezothando, kanti futhi idinga imininingwane mayelana nezocansi nezinye nje izinto eziphathelene nalo. Eminye imibuzo idinga impendulo ka Yebo noma Cha, kodwa eminingi yawo iphendulwa ngesikalo sika 0-4. Uyacelwa ukuba uphendule lemibuzo ngobuqotho nangeqiniso, nangaphandle kokwesaba, ngoba lezimpendulo angeke kuphinde kutholakale ukuthi ziqhamuke kuwe. Akukho impendulo e-right noma e-wrong. Uvo lwakho lweqiniso kuphela oluzokwenza lolucwaningo lube usizo.

Impendulo yakho kungaba wu-0,1,2,3 noma 4. Wena khetha lenombolo eseduzane nalendlela ozizwa ngayo.

Lesifundo, njengezinye ezenziwa kwamanye amazwe, sithungatha imininingwane yezocansi engase ibe yinselelo kubantu abaphila ne HIV/AIDS abelashwa ngama ARV. Ezikhathini eziningi kuqhathaniswa izinselelo owawubhekene nazo ungakaqali ukwelashwa ngama ARV namanje njengoba sewelashwa ngawo, ukuze kubonakale ushintsho noma ngabe luhle noma ngabe sekukubi ukwedlulela.

Akekho owake walinyazwa yilemibuzo noma okwathinteka kuye imizwa kabuhlungu ezifundweni ezinye ezenziwa kodwa uma ungase ungazizwa kahle, uyacelwa ukuba ubike lokhu ngokushesha. Amalungiselelo azokwenziwa ukuze ubonwe ngudokotela ngaphandle kwezindleko.

Imiphumela yalesifundo izoba usizo ekuqondeni ngenselelo ebhekene nabantu abaphila ne HIV/AIDS, ikakhulu labo abakuma ARV. Ngalokho kuzothi lapho izisebenzi zasemtholampilo zixoxa ngokuvikela kokubhebhetheka kwe HIV, zikwenze ngozwelo nokuqondisisa izidingo zakho zezocansi kanye namalungelo enzalo. Lesifundo singahle sibe wusizo futhi ekutholeni ukuthi yikuphi lapho ulwazi lwethu siyiziguli noma siyizisebenzi zasemtholampilo ludinga ukuqiniswa.

Izigulane ezikuma ARV izinyanga ezintathu kuye ngaphezulu zingahlanganyela kulesifundo. Uma unenkinga yokufunda kumbe ukubhala uzonikezwa umelekeleli oqeqeshiwe. Labalekeleli abasiyo ingxenye yabasebenzi balapha emtholampilo.

Imiphumela yocwaningo izotholakala emtholampilo ekuqaleni konyaka olandelayo ka-2008. Uyacelwa ukuba ukhombise kulelifomu lemvume yakho, uma ungathanda ukuthola ikhophi yalemiphumela.

Kuyagcizelelwa futhi ukuthi lolucwaningo olwesifubu sakho, ungabhali igama lakho kuloluhla lwemibuzo. Lefomu yemvume yokho, eyazisa ukuthi wena ungubani, lizogcinwa ekhabetheni ekhiywayo elikude nomtholampilo, futhi ngoba loluhlamibuzo lunezinombolo nje kuphela angeke liyamaniswe negama lomuntu. Uma ukhetha ukungahlanganyeli kulesifundo noma unqume ukuhoxa ngesikhathi saloluhla lwemibuzo wamukelekile ukwenza njalo, futhi uzosolokhu uthola unakekelo nokwelashwa okufanele.

Thatha lezinombolo zocingo uye nazo ekhaya. Uma udinga ukucaciselwa, wamukelekile ukushayela kunoma iyiphi yalezinombolo ezilandelayo:

Umcwaninginhloko: Dr M.R.Mkhabela Tel No: 017 883 0655

Abalekeleli: 1.Ms A.N.Mkhabela Tel No: 017 883 0093

2. Ms O.P.Buthelezi Tel No: 017 883 0094

3. Ms N.V.Tshabalala Tel No: 017 883 0093

APPENDIX 9
Zulu Translated Consent Form

ISINGEZELO 3
(ZULU TRANSLATION)

UKUFUNDA OKUBUKELELEKILE MAYELANA NEZINDABA ZOCANSI PHAKATHI KWEZIGULI EZIHAMBELA EMTHOLAMPILO WAMA-ARV ESIBHEDLELA SASE-EMBULENI ESIFUNDENI SASE-MPUMALANGA

IFOMU YEMVUME YESIGULI

Mina.....ngilifundile leliphepha
lokwazisa isiguli, ngabuye ngachazelwa ngalocwaningo
ngu.....

Ngiyaluqonda lolwazi enginikezwe lona, futhi ngikhonile ukubuza imibuzo mayelana nalocwaningo. Ngiyazi ukuthi manginquma ukuhoxa ngesikathi salohla lwemibuzo, ukunakekelwa kwami kuzosolokhu kufanana.

Ngingathanda/Angithandi ukuthola imiphumela yalocwaningo.

Sayina La.....

Usuku.....

Ufakazi.....

Usuku.....

APPENDIX 10
SiSwati Translated Questionnaire

SENETELELO 1
(SWATI TRANSLATION)

**TINDZABA TETEMACANSI ETIGULANENI LETIHAMBELA
EMFTOLAMPHILO WEMA-ARV ESIBHEDLELA SASE EMBHULENI
ESIFUNDZENI SASE MPUMALANGA**

1. Idata yeLinanibanftu

Wena wekunene gcwalisa lolwati lolufunekako, futsi uthike etikhaleni lapho kunekukhetsa impendvulo lefanele kuletinye:

1.1. Budzala

1.2. Dvuna Sikati

1.3. Shadile Singili Mahlalisana

Lokunye

Sita ucacise e.g. uhlala nesinini sakho kumbe nemuntfu lokuhawukele nje.....

1.4. Ngenamnganicansi Mnganicansi Munye

Mnganicansi kwengca kumunye

1.5. Linanibanfwana:

1.6. Lizingamfundzo:

1.7. Umsenti:

1.8. Budze besikhatsi sekwelashwa nge ARV:

Esikalini 0 – 4

2. Kukhanuka licansi bekukahle kangakanani ngembi kwekube ucale kwelashwa nge ARV?

(Lapho 0 akhomba kusho kutsi bekuphansi kutsi 4 akhombe kutsi bekukahle kwengcelele)

0	1	2	3	4
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3. Kunjani kukhanuka kwakho licansi manje loseucale kwelashwa nge ARV?

(Lapho 0 akhomba kusho kutsi kuphansi kutsi 4 akhombe kutsi kukahle kwengcelele)

0	1	2	3	4
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4. Bewusebenta kahle kanganani sewusecansini, ngembi kwekube ucale kwelashwa nge ARV?

(Lapho 0 akhomba kubaphansi kutsi 4 akhombe kuba kahle kwengcelele)

0	1	2	3	4
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5. Sewusebenta kahle kanganani ecansini manje loseucale kwelashwa nge ARV?

(Lapho 0 akhomba kubaphansi kutsi 4 akhombe kuba kahle kwengcelele)

0	1	2	3	4
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6. Kubaluleke kanganani kuwe kutsi uye ecansini uvikelekile, lokusho kutsi ufake ikhondomu?

(Lapho 0 akhomba kungabaluleki kutsi 4 akhombe kubaluleka kakhulu)

0	1	2	3	4
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7. Uma uya ecansini nemngani loneligciwane leHIV, kubaluleke kanganani kuya ecansini uvikelekile – njengekusebentisa ikhondomu?
(Lapho 0 akhomba kungabaluleki kutsi 4 akhombe kubaluleka kakhulu)

0	1	2	3	4
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8. Uma uya ecansini nemuntfu longenalo ligciwane leHIV, kubaluleke kanganani kuwe kuya ecansini uvikelekile – njengokusebentisa ikhondomu?
(Lapho 0 akhomba kungabaluleki kutsi 4 akhombe kubaluleka kakhulu)

0	1	2	3	4
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9. Uma nobalili wena nemngani wakho nisekwelashweni ngeARV, kubaluleke kanganani kuya ecansini nivikelekile – njengekusebentisa ikhondomu?
(Lapho 0 akhomba kungabaluleki kutsi 4 akhombe kubaluleka kakhulu)

0	1	2	3	4
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10. Uvamise kanganani kesebentisa ikhondomu ngesikhatsi uya ecansini?
(Lapho 0 akhomba kusho kutsi akaze kutsi 4 akhombe sonkhe sikhatsi)

0	1	2	3	4
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11. Bewukujabulela kahle kanganani kuya ecansini ngembi kwekutsi ucale kwelashwa ngeARV?
(Lapho 0 akhomba kujabulela lokuphansi kutsi 4 kujabulela kwengcelele)

0	1	2	3	4
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12. Sewukujabulela kanganani kuya ecansini nyalo loku sewusekwelashweni ngeARV?

(Lapho 0 akhomba kujabulela lokuphansi kutsi 4 akhombe kujabulela kwengcelele)

0	1	2	3	4
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13. Kubaluleke kanganani kuwe kutsi tisebenti teTemphilo ticocisane nawe ngetidzingo takho nge tekuya emacansini?

(Lapho 0 akhomba kungabaluleki kutsi 4 akhombe kubaluleka kakhulu)

0	1	2	3	4
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14. Manje-ke losewusekwelashweni ngeARV, kubaluleke kangakanani kuwe kutfolo umntfwana?

(Lapho 0 akhomba kungabaluleki kutsi 4 akhombe kubaluleka kakhulu)

0	1	2	3	4
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15. Bewenliseka yini ngemvamisa yekuya kwakho emacansini ngembikwekuba ucale kwelashwa ngeARV?

(Lapho 0 akhomba hhayi nakancane kutsi 4 akhombe kweneliseka kakhulu khulu)

0	1	2	3	4
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16. Wenelisekile yini ngemvamisa yakho kuya emacansini manje losewusekwelashweni ngeARV?

(Lapho 0 akhomba hhayi nakancane kutsi 4 akhombe kweneliseka kakhulu khulu)

0	1	2	3	4
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17. Ngembikwekuba ucale kwelashwa kwakho ngeARV linani lebangani bakho basecansini belinjengalokulandzelako yini?

(Lapho 0 akhomba kutsi bekute kutsi, 1-munye, 2-Babili, 3-Batsatfu kutsi 4-bane nangetulu)

0	1	2	3	4
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18. Manje lokusewucale kwelashwa kwakho ngeARV, linani lebangani bakho basemacansini linjengalokulandzelako?

(Lapho 0 akhomba kusho kutsi kute, 1-munye, 2-babili, 3-batsatfu, 4-bane nangetulu)

0	1	2	3	4
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19. Usivetile yini simo sakho seHIV kumngani wakho / kubangani bakho (basecansini)

Faka X ebhokisini lelifanele

Yebo

Cha

20. Kuletinyanga letisiftupha letengcile, usewaya yini ecansini ungakavikeleki?

Faka X ebhokisini lelifanele

Yebo

Cha

21. Uma bewungase uye ecansini ungakavikeleki, bekungaba yini sizathu lesivamisekakhulu kwengca tonkhe?.....

.....
.....

22. Utimisele kutsi ube nebantfwana yini kulesikhatsi lesimadvute lesitako?

Faka X ebhokisini lelifanele

Yebo

Cha

Angina(li)ciniso

23. Uyakholelwa yini ekutseni kuftola kwelashwa ngeARV kuyakuvikela ekwengceseleleni labanye iHIV?

Faka X ebhokisini lelifanele

Yebo Cha Angina(li)ciniso

24. Uyakholelwa ekutseni na une-viral load lebhacile (lengabonakali) kungavikela kwengcisekela kweHIV kulabanye?

Faka X ebhokisini lelifanele

Yebo Cha Angina(li)ciniso

25. Ucabanga kutsi labanye baftu labaneHIV, bengciselela labanye ngesibomu?

Faka X ebhokisini lelifanele

Yebo Cha Angina(li)ciniso

University of Cape Town

APPENDIX 11

SiSwati Translated Patient Information Sheet

SINETELELO 2: LIPHEPHA LEKWATISA SIGULANE (SWATI TRANSLATION)

KUFUNDZA LOKUBUKELELEKILE NGETINDZABA TASEMACANSINI EMKHATSINI WETIGULANE LETIHAMBELA EMTFOLAMPILO WE-ARV ESIBHEDLELA SASEMBHULENI

Liphepha lekwatisa sigulane

Uhambela emtfolampilo weARV futsi utfola kwelashwa ngalelekuhambisana naleshejuli loniketwe yona.

I-Yunivesi yase-Cape Town icechesha bodokodela kutsi bakhone kutsi banikete lunakekelo loluncono kubantfu, labaphila neHIV / AIDS kanye netifo letiyiselele. Bodokodela labanje kudzingakele kutsi bente luncwaningo tsite kulenzima.

Nangabe uvuma kutibandzakanya kulolucwaningo, utawunikwa luhlu lwemibuto ngulethimu leyenta lolucwaningo, lolutawutsatsa emaminithi langu 15. Kutawuniketwa inombolo kuphela kulolo luhlamibuto, hhayi libito lakho. Na udinga noma ngiluphi lusito ekuphendvuleni kwalemibuto sita-ke ulucele. Lemibuto ingeyebutsandzani njengoba ifuna lwati ngetasemacansini, kanye nalokuphatselene naloko. Leminye imibuto idzinga kulokunye impendvulo ya Yebo kumbe Cha, kodwa liningi layo liphendvulwa ngekusebentisa sikalo sa 0 – 4. Sitake uphendvule ngebucotfo nange liciniso, futsi ngaphandle kwekwesaba ngoba letimpendvulo ngeke phindze kutfolakale kutsi tichamuka kuwe. Akukho impendvulo – right kumbe – wrong. Luvo lwakho lwangasibili kuphela lolutakwenta lolucwaningo lube nelusito. Impendvulo yakho kungaba ngu 0,1,2,3 kumbe 4; wena maka lenombolo lemadvute kakhulu neluvo lwakho.

Imiphumela yalolucwaningo itawutfolakala emtfolamphilo ngekuhamba nakucala umnyaka 2008. Sita ukhombise efomini lemvuma na ungatsandza kutfolo ikhophi yalemiphumela.

Njengaletinyenti letinye lesetentiwe kulamanye mave, lesifundvo sitfungatsa tindzaba tetemacansi lekungase kube tiyinselele kubantfu labaphila ne-HIV/AIDS nalabatsatsa ema-ARV. Kulokunyenti, tona leto tineselele lebe ubukene nato ngembikwekube ucale kwelashwa, ticatsaniswa naletalesikhatsi lesikuso, kubona kutsi letamuva tintjintjele ebunconweni kumbe sekubi kakhulu kunasekucaleni. Akukho lokulimatako kumbe kuvelela lokumatima lokubikiwe nakuphendvulwa lemibuto kuletinye tifundvo. Kodwa-ke nakungenteka ungativa kahle, bika masinyane. Utakwentelwa malungiselelo okubonana nadokodela ngaphandle kwetindleko.

Imiphumela itawuba lusito ekucondzeni letinselele le bantfu labaphila ne-HIV/AIDS ikakhulu labo bantfu labelashwangema-ARV babhekene nato kute kutsi ngesikhatsi tisebenti tetemphilo ticocisane ngetindlelahlasela tekuvikela kubhebhetsaka kwe-HIV, tente kanjalo ngekuvelela nekucondzisisa tidzingo takho tasemacansini kanye netemalungelo akho ekutfolo bantfwana. Kungasita futsi ekuhluteni lapho lwati lwetisebenti temphilo netigulane tidzinga kuqinisiswa.

Tigulane letikuma-ARV tinyanga letiintsatfu kuyengetulu tingahlanganyela kulesifundvo.

Na ungakukhoni kufundza kumbe kubhala utawunika umelekeleli loceceshiwe. Labalekeleli abasiyo incenye yesitafu sasekliniki.

Ngiyaphindza futsi ngitsi lolucwaningo ngelwesifuba. ungabhali libito lakho kuloluhlamibuto. Lefomu yemvume leyatisa kutsi wena ungubani, litawubekwa ekhabethini lelikhiyiwe ekudzeni nemtfolampilo, futsi ngobe loluhlamibuto lunemombolo nje kuphela ngeke iniketwe nome ngubani ngelibito. Na ukhetsa kungahlanganyeli kulesifundvo kumbe uncume kuhoca ngalesikhatsi saloluhlamibuto ukhululekile kwentanjalo, futsi utawusolo utfola lokunakekelwa nekwelashwa lokufanele.

Tsatsa letinombolo telucingo uye nato ekhaya. Na udzinga lokunye kukhanyiselwa, sita ushayele kunobe nguyiphi yaletinombolo letiladzelako:

Umcwaninginhlobo	: Dr M.R. Mkhabela	Tel No: 017 883 0655
Balekeleli	1. Ms A.N. Mkhabela	Tel No: 017 883 0093
	2. Ms O.P. Buthelezi	Tel No: 017 883 0093
	3. Ms N.V. Tshabalala	Tel No: 017 883 0093

APPENDIX 12

SiSwati Translated Consent Form

SINETELELO 3: IFOMU YEMVUME YESIGULANE (SWATI TRANSLATION)

KUFUNDZA LOKUBUKELELEKILE NGETINDZABA TASEMACANSINI EMKHATSINI WETIGULANE LETIHAMBELA EMTFOLAMPILO WEARV ESIBHEDLELA SASEMBULENI

Ifomu Yemvume Yesigulane

Mine ngilifundzile leliphepha lwekwatisa
sigulane, ngabuye ngachazelwa ngalolucwaningo ngu
.....

Ngiyalucondza lolwati lenginiketwe lona, futsi ngikukhonile kubuta imibuto mayelana nalolucwaningo. Ngiyati kutsi nangincuma kuhoca ngesikhatsi saloluhlamibuto, lunakekelo nekwelashwa kwami kutawusolo kufana.

Ngingatsandza / Ngingete ngatsandza kutfola imiphumela yalolucwaningo.

Isayini Lusuku

Fakazi Lusuku