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# Sexuality in patients with human immunodeficiency virus at Embhuleni Hospital in Mpumalanga province

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## Abstract

**Objectives:** This study explored issues of sexuality in people living with AIDS who were on highly active antiretroviral therapy (HAART).

**Design:** This was a descriptive quantitative study. Data were collected with an administered questionnaire and entered in Excel®. Statistical analysis included frequency tables, summary statistics and 95% confidence intervals.

**Setting and subjects:** The respondents were purposively sampled from the 850 patients attending the antiretroviral clinic at Embhuleni Hospital in Mpumalanga province.

**Outcome measures:** The questionnaire included questions on sexual practices, number of partners, sexual experience and fertility wishes, comparing respondents' experience before and after HAART.

**Results:** There was a response rate of 100%, with 102 questionnaires completed. There was a significant difference between the responses to questions on sexual desire, sexual performance, sexual enjoyment and satisfaction regarding frequency of intercourse before and after HAART. Respondents reported a better sexual experience before HAART ( $t = 2.4387$ ,  $p$ -value = 0.0165). There was a statistically significant difference between the number of partners before and after initiation of HAART ( $p$ -value = 0.000). Although 96% of respondents rated condom use as being very important, 11% never used condoms during sex and 21% indicated that they had had unprotected sex in the previous six months. Eighteen per cent of respondents said it was very important for them to have a child and 20% were planning to have a child in the future. A quarter of respondents had not disclosed their HIV status to their partners. The majority (95%) of respondents indicated that it was very important to them that health workers discussed their sexual needs with them.

**Conclusion:** Sexuality in HIV is complex, with components described as the "Ps" of sexuality: practices, partners, pleasure, pressure and pain, procreation and power. In this study, participants reported a better sexual experience before HAART. Healthcare professionals need to develop the skills to discuss sexuality, intimacy and fertility wishes with patients. This discussion will enhance healthcare professionals' understanding of patients' experiences of their illness and should allow for a more effective patient-centred approach to care.

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## Introduction

People living with human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) (PLWHA) 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. The components of sexuality have been described as the "Ps" of sexuality: practices, partners, pleasure, pressure and pain, procreation and power.<sup>1</sup> Because sexuality is seen as a potential determinant of ill health, safer sex has been the mainstream theme, while sexual health, pleasure and rights

have remained on the margin.<sup>1,2</sup> There has been reluctance among healthcare professionals to discuss sexuality with their patients.<sup>3-5</sup>

The sexuality of PLWHA, faced with the constraints of a serious disease, its treatment and risks of transmission and exclusion, is highly disrupted.<sup>6</sup> El Fane et al found that 70% of participants reported that they did not have satisfying sexual activity.<sup>7</sup>

While studies on the impact of highly active antiretroviral therapy (HAART) on sexuality by Lamba et al<sup>8</sup> and Keegan et al<sup>9</sup> have found that patients report a decrease in libido,

lowered enjoyment and reduced intimacy, it was argued by Guaraldi et al<sup>10</sup> that psychological dimensions probably have the largest effect on sexual function.

In a Ugandan study, Bunnell et al found a decrease in risky sexual behaviour in patients enrolled in a HAART programme.<sup>11</sup> Differences in urban versus rural living were demonstrated in a study conducted by Lurie et al among HIV-infected patients in urban and rural South Africa.<sup>12</sup> This study found that urban respondents were more likely to report consistent condom use with regular partners (78.4% vs. 48.3%).

The fertility intentions of HIV-positive women have been studied in Soweto<sup>13</sup> and Cape Town.<sup>14,15</sup> In a qualitative study that was carried out in Soweto,<sup>13</sup> many participants agreed that the risks associated with childbearing following HIV diagnosis outweighed the benefits of future fertility. Fears about future pregnancies extended to the fact that the child would be born HIV-positive, that the family would be burdened with more children if HIV shortened the mothers' lives, that pregnancy could have negative consequences on their own health, and that there was a risk of re-infection with a different strain of HIV transmission or partner while trying to conceive. A study of fertility intentions of PLWHA in Cape Town<sup>14</sup> found that 52% of respondents on HAART did not intend on having children. Another Cape Town study among postpartum women<sup>15</sup> found that 73.2% of HIV-positive respondents did not plan on having another child.

Most of the research about sexuality in HIV has been conducted in developed countries. Not enough is known about the sexual experiences of rural South African patients on HAART.

The aim of this study was to explore issues of sexuality in patients on HAART at Embhuleni Hospital. The objectives included comparing libido, sexual performance, sexual enjoyment and frequency among participants before and after HAART; assessing changes in the number of partners before and after HAART; describing safer sex practices in this sample, as well as reasons for unprotected sex; determining the desire for parenthood in this sample and whether or not participants planned to have children; and evaluating disclosure and the need for participants to discuss sexuality with health workers.

Embhuleni Hospital is a 220-bed hospital in the district of Gert Sibande in the Albert Luthuli Municipality in Mpumalanga province. The hospital serves a rural population mostly. The HIV prevalence in Mpumalanga was estimated to be 12.2% in 2008.<sup>16</sup>

## Method

This was a descriptive, quantitative study. The respondents were purposively sampled from the 850 patients who attended the ARV clinic at Embhuleni Hospital in 2008. Inclusion criteria were clients over 18 years of age who were on HAART for at least three months. 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. Participants who might be homosexual were not excluded from the study.

Anonymity was assured. Data were collected by means of a structured, administered questionnaire. The items in the questionnaire were generated from the themes that were identified in the literature. The themes ranged from sexual practices and number of partners, to sexual experience and fertility wishes. The questionnaire was available in English, as well as two local languages, i.e. Zulu and *SiSwati*. The translation to *SiSwati* and Zulu was carried out with due consideration and sensitivity to the culturally preferred terminology, particularly regarding issues of sexuality, as direct translation might have been deemed vulgar or disrespectful. The obtained data were entered in Excel®. Statistical analysis included frequency tables, summary statistics and 95% confidence intervals. Ethics approval for the study was obtained from the Research Ethics Committee at the University of Cape Town (Ref 097/2007). Permission to approach respondents was given by the Department of Health in Mpumalanga.

## Results

No-one refused participation in the study. There was a 100% response rate. One hundred and two questionnaires were completed. Ages ranged from 20-65 years, with a median of 36 years. The median duration of antiretroviral treatment was 12 months, with a maximum duration of 94 months and a minimum of three. The demographic information of participants is detailed in Table I.

The results of the Likert-type questions were very similar, with a score of 0-4 for sexual desire, sexual performance, sexual enjoyment and satisfaction with frequency of intercourse. A composite score was created for these questions. The higher score indicated a more positive response. 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 ( $p$ -value = 0.0165) (Table II).

Before the initiation of HAART, 38.2% of respondents had more than one partner, compared to 10.8% on HAART (Figure 1). This is a statistically significant difference ( $p$ -value < 0.0001, with McNemar chi-square of 35.15).

Although 96% of respondents rated condom use as very important, 10.8% never used condoms during sex, and 20.6% indicated that they had had unprotected sex in the previous six months. The most common reasons for unprotected sex were a partner refusing to use condoms (14.7%), followed by a desire for pregnancy (7.8%) and condom unavailability (6.9%).

A minority of respondents (17.6%) said that it was very important for them to have a child and 19.6% planned to have a child in the future. There was no association

**Table I:** Demographic information

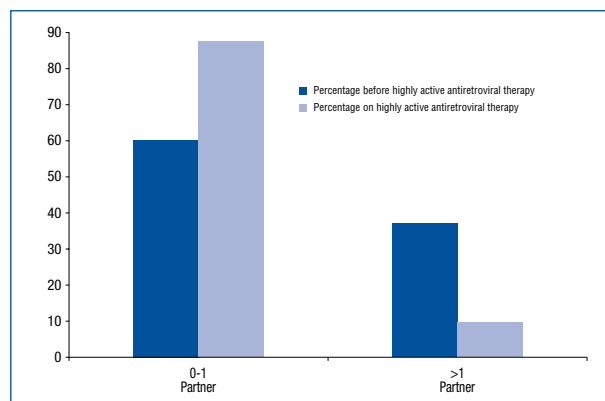
Characteristics	Total (n = 102)	Percentage
<b>Gender</b>		
Female	76	74.5
Male	26	25.5
<b>Highest level of education</b>		
No formal schooling	8	7.84
Grade 1-7	41	40.2
Grade 8-12	51	50
Tertiary qualification	2	1.96
<b>Current relationship status</b>		
Married	32	31.4
Single	59	57.8
Cohabiting	10	9.9
Divorced	1	1
<b>Number of partners</b>		
None	26	25.5
One	71	69.6
More than one	5	4.9
<b>Employment</b>		
Formally employed	16	15.7
Informally employed	11	10.8
Unemployed	73	71.6
<b>Number of children</b>		
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

**Table II:** Paired t-tests of the responses that related to sexual experience before and after highly active antiretroviral therapy

Variable	Participants n = 102	Mean	Standard deviation
<b>Before</b>	102	9	4.61
<b>After</b>	102	7.37	5.29

t = 2.4387, p-value = 0.0165

between those who said that it was very important for them to have a child or those who were planning to have a child in the future, and the desire to fall pregnant, which scored only 7.8% as a reason for engaging in unprotected sex. A quarter (25.3%) of respondents had not disclosed their HIV status to their partners. The majority of respondents (95%) indicated that it is very important to them that health workers discussed their sexual needs with them.

**Figure 1:** Number of partners before highly active antiretroviral therapy and on highly active antiretroviral therapy

## Discussion

Limitations of the study include the small sample size and the overrepresentation of women among the participants (74.5%). There may have been some recall bias in that the respondents might have remembered pre-HAART sexuality with some nostalgia.

The significant difference regarding better pre-HAART sexual experience could have various explanations. At the time of the data collection (2008), only patients with CD4 < 200 were started on HAART, which means that the study population had advanced disease and that advanced HIV might have played a role in decreased sexual pleasure. Erectile dysfunction has been shown to relate to physical factors, such as a low body mass index.<sup>10</sup> Some studies have suggested that HAART has a negative impact on sexual experience.<sup>8,9,11,17</sup> Other studies have found that psychological factors play an important role in sexual function.<sup>10</sup> Sexual dysfunction can be attributed to the fact that sexuality reminds them of their disease.<sup>7</sup>

The statistically significant drop in number of sexual partners on HAART, from 38.2% with more than one partner before HAART, to 10.8% after HAART (p-value = 0.000), is encouraging. A recent cohort study found that reports of having unprotected sex and more than one sex partner were less at visits following HAART initiation, than at pre-HAART visits.<sup>18</sup>

Barrier methods play an important role in PLWHA to protecting themselves and their partners during sexual intimacy. While 96% of participants reported knowing the importance of using condoms, the knowledge did not translate to actual condom use, as suggested by the fact that only 78.3% of participants said that they always used condoms. This was much higher than the 48.3% condom use reported for rural dwellers in a South African study that compared sexual behaviour in urban and rural HIV-infected patients.<sup>12</sup>

The majority of respondents (68.6%) reported that it was not important to have children. This has to be seen in the context of 88% reporting that they had at least one child. This is comparable with the 65% of 18- to 45-year-olds who

did not want to have children in a Brazilian, South African and Ugandan cross-sectional survey.<sup>19</sup> In addition, a Cape Town study of postpartum women<sup>15</sup> found that 73.2% of HIV-positive respondents did not plan on having another child. Although 19.6% reported planning on having a child in the future, only 7.8% gave the desire to fall pregnant as a reason for engaging in unprotected sex. This could mean that participants who desire to fall pregnant are faced with a dilemma, as found in a study in Soweto, where respondents expressed several fears relating to a future pregnancy.<sup>13</sup>

The most common reason for unprotected sex was reported as a partner refusing to use condoms (14.7%). This is a reflection of the “power” component of sexuality.<sup>1</sup> The unequal power balance in gender relations that favour men translates into an unequal power balance in heterosexual interactions, in which male pleasure supersedes female pleasure and men have greater control than women over when, where and how sex takes place.<sup>1</sup>

It is of concern that 25.3% of participants had not disclosed their status to their partners. Several studies have commented on fear of disclosure negatively affecting the sexuality of PLWHA. The dilemma, in terms of disclosure, was mentioned as compromising the sexuality of people living with HIV.<sup>20</sup> Disclosure was also found to be a barrier to forming relationships, causing women on HAART to have casual sexual partners in order to avoid having to disclose their status.<sup>9</sup> Having disclosed their 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 Africa.<sup>12</sup>

This study shows that 95% of participants thought that it was very important that healthcare workers discussed their sexual needs. It was reported in a Swiss study that 50% of participants felt that healthcare providers did not sufficiently address their concerns regarding relationships, sexuality and fertility intentions.<sup>3</sup> Participants in other studies have expressed dissatisfaction with healthcare providers in addressing matters of sexuality.<sup>20-22</sup> In a study on the fertility intentions and reproductive health needs of PLWHA in Cape Town,<sup>14</sup> only 19% of women had consulted a healthcare provider about fertility intentions, but a third reported wanting to discuss it, if given the opportunity.

## Conclusion

Sexuality in HIV is complex, with components described as the “Ps” of sexuality: practices, partners, pleasure, pressure and pain, procreation and power.<sup>1</sup> In this study, participants reported better sexual experiences before HAART. Eighteen per cent are still planning on having children. The desire to have children provides the potential for unsafe sex and poses a dilemma to couples who want to have children, but nevertheless use condoms consistently. Fourteen per cent reported that they were forced into unsafe sex by partners who refused to use a condom, which is a reflection of the impact of gender inequality. This study has made a start in researching the sexual experiences of PLWHA.

Further studies are recommended to explore these issues in more depth. Healthcare professionals need to develop the skills to discuss sexuality, intimacy and fertility wishes with patients.<sup>5</sup> This discussion enhances healthcare professionals’ understanding of patients’ experiences of their illness and allows for a more effective patient-centred approach to care.

## Conflict of interest

The authors declare that there was no conflict of interest.

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