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**‘If I Could Properly Understand  
and Get the Right Information’:  
A Qualitative Study on the Sexual  
and Reproductive Health Needs  
and Rights of HIV-positive Women**

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# **‘If I Could Properly Understand and Get the Right Information’: A Qualitative Study on the Sexual and Reproductive Health Needs and Rights of HIV-positive Women**

## **Abstract**

*Women of reproductive age in South Africa are disproportionately affected by HIV and represent the fastest growing group diagnosed with the virus. Despite this epidemiological picture, very little attention has been placed on the sexual and reproductive health needs of these women, particularly in South Africa and other developing countries. This study, a sub-study of a much bigger study, explored the sexual and reproductive health needs of women newly diagnosed with HIV and how these translate into their human rights. In-depth interviews, within qualitative methodologies, were conducted and analysed with fourteen women from Cape Town, who seroconverted during the larger microbicide, Carraguard study carried out by the Population Council (USA) and University of Cape Town. This study is novel in its exploration of these issues amongst women who are newly diagnosed. The results revealed that a positive diagnosis produced a major shift in sexual and reproductive desires for these women, with respondents almost unanimously no longer wishing for children or sex. The rationale for such alterations involved four levels of meaning: fear, blame, guilt, and difficulties in negotiating safe sex. These sentiments appear to have been shaped by the lack of information afforded to them, as well as the stigmatising and ideologically laden social discourses surrounding them. The findings from this study offer insights into both the unique sexual and reproductive health needs and rights of recently diagnosed women, as well as the more general sexual and reproductive needs and rights pertaining to all HIV-positive persons, at all stages of the disease. An underlying argument throughout this paper is the need for closer attention from policy makers and health care providers in recognising and supporting the sexual and reproductive needs and rights of HIV-positive women. Recommendations are provided for meeting these needs and synergising public health goals with human rights objectives.*

## **Introduction: Background and Rationale**

Since the HIV/AIDS epidemic was first recognised in the early 1980s, more than 60 million individuals have become infected with HIV and 28 million people have already died, with the majority of infections occurring in developing countries, and specifically sub-Saharan Africa (UNAIDS, 2006). As in most countries around the world, women of reproductive age in South Africa are disproportionately affected by the virus (WHO, 2006).

Despite the fact that women of child-bearing age constitute the fastest growing group diagnosed with HIV infection, a dearth of attention has been placed on the sexual and reproductive health needs and rights of these women (Cooper, Harries, Myer, Orner, Bracken, & Zweigenthal, 2007; de Bruyn, 2005; London, Orner & Myer, 2008; Myer, Morroni & Cooper, 2006). To date, no binding international and regional policies on the sexual and reproductive health rights specific to HIV positive men and women have been developed (Bell et al., 2007; Center for Reproductive Rights, 2005). Furthermore, existing public health policies and programs frequently fail to respond to the sexual and reproductive health related rights of people living with HIV (Gruskin, Ferguson & O'Malley, 2007; Lusti-Narasimhan, Cottingham, & Berer, 2007). This silence around, and failure to support, the sexual and reproductive rights of people infected with HIV is surprising, given that substantial advances have been made, both in South Africa and internationally, in policy developments which recognise sexual and reproductive rights as fundamental to human well-being (Cooper et al., 2004; Fonn et al., 1998; Yanda, Smith & Rosenfield, 2003).

The improvement of ARV treatment and PMTCT programs availability and access in a relatively short space of time in South Africa, underscores the need for closer attention from health policy makers and health providers on meeting the sexual and reproductive health needs of HIV-positive individuals of childbearing and sexual ages (Cooper et al., 2004; Myer & Morroni, 2005).

This paper is based on a sub-study of the Population Council's (New York) vaginal microbicide (Carraguard) Phase 3 efficacy trial, which assessed whether women, who have recently seroconverted, have certain distinctive or specific sexual and reproductive needs, and if so, how these needs translate into their human rights. These issues were explored from the women's own perspectives, rather than imputing the viewpoints of policy makers and health service providers onto this topic. This study aimed to offer opportunities to identify if there are specific sexual and reproductive needs and rights of these women and,

if so, to inform policy and program developments that better accommodate such needs and recognise such rights.

An underlying current that will run throughout this paper is the need for closer attention from policy makers and health care providers in recognising and supporting the sexual and reproductive needs and rights of newly seroconverted women specifically, and positive individuals at all stages of the disease generally. In light of this undercurrent, this paper will shed light on specific interventions that are required, including increased counselling and information, both biomedical and psychosocial, around sex and childbearing for HIV-positive women; provider guidelines and training in the sexual and reproductive rights of all HIV-positive persons; and policies that explicitly recognise the sexual and reproductive rights of HIV-positive individuals. Ultimately, through this paper, the authors wish to demonstrate that supporting the sexual and reproductive rights of HIV-positive individuals will only be possible if sexual and reproductive health services and HIV care and treatment are better amalgamated and integrated.

## **Literature Review**

With the recent advent of ARVs many infected individuals are now considering having children and continue to establish and engage in sexual relationships (Bova & Durante, 2003). In the domain of reproduction, firstly, it is clear that HIV-infectivity can both promote and deter men and women's desire for a(nother) child (for example Barreiro et al., 2006; Chen et al., 2001; Kirshenbaum et al., 2004; Nebie et al., 2001; Sherr & Barry, 2004; Sowell et al., 2002). Secondly, seeking pregnancy when aware of HIV-positive status is stigmatised, leading to avoiding discussions with providers for fear of negative reactions, especially for women (Cooper, et al., 2007; Feldman & Maposhere, 2007). Thirdly, HIV-positive persons are frequently given inaccurate, ambivalent, or incomplete information and counselling on their reproductive options (Cooper et al., 2006; Kendall and Pérez-Vázquez, 2004; Pachauri 2006).

In the domain of sexuality, studies have indicated that an HIV-diagnosis can produce significant disruptions in their sexuality, particularly in the early stages of disease (Denis & Hong, 2003). A high prevalence of cessation or reduction of sexual activity, diminished sexual desire and interest, and poor satisfaction have been observed (Adam & Sears, 1994; Maticka-Tyndale & Adam, 2002; Schiltz & Sandfort, 2000). Given that almost no studies have been conducted in the developed world, it is unknown whether such results can be generalised to third

world populations, given cultural and structural regional differences (du Plessis, 2003).

Very little research however, particularly in Sub-Saharan Africa, has been done on the sexual and reproductive needs of HIV-positive persons (Berger, 2004; Flanagan et al., 2005; Schiltz & Sandfort, 2000). This underscores the need for more studies in Africa (and other developing countries) in order to avoid ill-informed assumptions, and prevent uncritical transposition of findings from western contexts to Africa, given cultural and structural regional differences. The current study thus attempts to address this geographical gap.

Besides the paucity of empirical studies in developing countries, there is also little consensus concerning the sexual and reproductive health rights of HIV-positive persons. Indeed, sexual relations and reproduction in the context of an HIV epidemic is a highly contested and controversial area, with charged debates occurring in academic circles about the sexual and reproductive rights of HIV-positive individuals. On the one hand, a number of scholars have argued that restrictions should be placed on the fertility and sexual activity of HIV-positive persons. Firstly, it is argued that unprotected sex carries a significant risk for: sexual and perinatal transmission (Kelly & Kalichman, 2002; Williams et al., 2003), re-infection with mutated viral strains of HIV, and accelerating the progression of HIV disease to AIDS (Kass, 1994; Minkoff et al., 1990). Secondly, it is argued that by recognising HIV-positive individuals' right to have children, the number of AIDS orphans could increase, due to the early death of the parents, making the care of future orphans a public health concern (Monasch & Boerma, 2004).

On the other hand, a number of scholars have argued that restrictions should not be placed on the fertility and sexuality of HIV-positive persons. Firstly, it is emphasised that with the recent advances in effective ARV regimens, the risks of HIV-transmission through unprotected sex are significantly reduced (Cohen et al., 2007) and the likelihood of pregnancy speeding up the progression of seroconversion to AIDS is substantially diminished (Saada et al., 2000). Secondly, it is argued that placing such restrictions infringes many of their fundamental human rights, and in light of such reduced health risks, such violations are not justified. The rights violated include the right to free and informed reproductive and sexual choice; the right to have control over one's own body; the right to dignity and respect; and the right to access of information, health and life (London et al., 2008). In addition, the strong social and cultural norms around fertility in many African societies can result in women who are childless being marginalised, stigmatised and rejected (Dyer et

al, 2002; Myer et al., 2005). Thus, their rights to equality and non-discrimination are violated. Finally, it is argued that failing to recognise HIV-positive individuals' sexual and reproductive rights further stigmatises the disease, and the consequent decreased uptake of HIV-related testing, care and treatment services for HIV-positive persons and people who do not know their status (Castro & Farmer, 2005; Gruskin et al., 2007). Overall, the authors of this paper support London et al's (2008: 21) argument that, 'Interventions that support reproductive [and sexual] choices for HIV-positive persons serve to advance both human rights and public health in complementary ways'.

In conclusion of this review, it is clear that the sexual and reproductive health rights of HIV positive individuals presents unique medical, ethical, psychological and social dilemmas, issues which have remained inadequately researched, insufficiently discussed and unsatisfactorily addressed.

## **Methodology**

The sample for this study was drawn from the group of women who seroconverted in the Population Council's (USA) Phase 3 efficacy trial of its leading vaginal microbicide, Carraguard. This trial assessed the efficacy of Carraguard in reducing sexual transmission of HIV among women (Population Council, 2007). The sub-study was a collaborative initiative between the Women's Health Research Unity (University of Cape Town) and the Population Council (New York). In total, fourteen women agreed to participate. Participation was voluntary and informed written consent was obtained from all of the participants. Furthermore, in line with ethical considerations surrounding confidentiality, the names of the participants in the study have been omitted, with participants being given pseudonyms. Relevant socio-demographic characteristics of the women are depicted in table 1.

Based on the literature, and advice obtained from clinical health professionals<sup>1</sup> these women have been defined as 'newly diagnosed', having seroconverted no more than 12 months prior to being interviewed and not being on ARVs. To the researcher's knowledge, no other studies exploring the reproductive intentions of HIV-positive individuals have been conducted amongst recently seroconverted HIV-positive individuals in South Africa.

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<sup>1</sup> Universitywide AIDS Research Program, 1997; S. Patel, personal communication, September 15<sup>th</sup>, 2008

*Table 1: Socio-demographic characteristics of participants<sup>2</sup>*

<i>Characteristic</i>	<i>Number</i>	<i>Percentage</i>
Mean age (standard deviation)	28.58 (9.67)	
Median age	28	
Age range (years)	20-56	
Age Group		
<20 years	0	0.00
20-29 years	9	75.00
30-39 years	2	16.67
40-49 years	0	0.00
50-59 years	1	8.33
Highest grade obtained		
≤Grade 7	1	8.33
Grade 8	1	8.33
Grade 9	1	8.33
Grade 10	2	16.67
Grade 11	6	50.00
Grade 12	1	8.33
Employment status		
Employed	5	41.67
Unemployed	7	58.33
Marital status		
Married	2	16.67
Not married	10	83.33
Partner status		
No partner	3	25.00
Lives with partner	3	25.00
Partner not cohabiting	6	50.00
Contraceptive use		
Currently on contraceptives	10	83.33
Currently not on contraceptives	2	16.67
ARV treatment		
Currently taking ARVs	0	0.00
Currently not taking ARVs	12	100.00
Number of living children		
0	3	25.00
1	3	25.00
2	4	33.33
> 2	2	16.67

<sup>2</sup> Note: Socio-demographic data is unavailable for two of the participants



## Data Collection and Analysis

A large majority of studies in this area have been quantitative in nature, and reside within a narrow and rational biomedical model (da Silveira Rossi et al., 2005). In an attempt to redress this methodological bias, this study employed qualitative methodologies, taking cognizance of the more nuanced, complex and socially shaped issues at stake. Furthermore, in contrast with much of the medical and social research which has made HIV-positive people the objectives of analysis, this study sought to explore the 'subjectivity' of HIV-positive individuals, giving voice to their frequently muted voices (Adam & Sears, 1994).

In-depth interviews were conducted with twelve participants. The interview guides were semi-structured and open-ended and included probes for potential additional issues that could emerge as significant concerns. One focus group was conducted with five participants. Kitzinger and Barbour (1999) emphasise that the major advantage of focus groups lies in their ability to mobilise participants to generate their own questions in their own vocabulary and to respond to and comment on each other's contributions on their own terms. For this reason, the data collected from the single focus group both enhanced and expanded upon some of the issues that emerged within the individual interviews. Both the interviews and focus group discussion explored topics such as sexual behaviour since diagnosis; partner change dynamics; disclosure; family and community responses to HIV status and child-bearing intentions; referral services accessed; contraceptive and reproductive needs, and fertility intentions and decision-making. The meanings, contexts and dynamics associated with these issues following an HIV diagnosis were explored.

The interviews and focus group discussion were transcribed verbatim and analysed from a grounded theory approach. As the name implies, grounded theory refers to generating theory and understandings which are 'grounded' or which emerge from the data that is systematically gathered and analysed (Strauss & Corbin, 1998). This allows for the inductive discovery of new insights and enhanced understandings that are derived from the coded categories, themes and patterns. Grounded theory is appropriate, as the situation described above is constructed by a number of interacting factors that need to be explored and verified in this context. *ATLAS.ti* (version 5.2), which is a computer program that aids in the sorting and management of qualitative data, was used to facilitate the analysis.

## Results

This analysis will be divided into two parts. Part I will demonstrate how an HIV-diagnosis appears to have produced a major shift in the women's sexual and reproductive desires. Both the explicit and implicit subjective and socially determined rationale for such changes are explored. It became clear that the almost unanimous shift in sexual and reproductive desires and intentions the women appear to have undergone since diagnosis needed to be understood in terms of the dearth of information and guidance afforded to them. Accordingly, part II of the analysis demonstrates that these women have received very limited, narrow and ideologically infused support in the realm of sexuality and reproduction following their HIV diagnosis. The results will end by demonstrating the important role the provision of appropriate guidance can play for these women.

### **Part I: The Shift in Reproductive Intentions and Sexual Desires and Functioning:**

‘I no longer want sex or children, period...’

With one exception, all of the women directly or indirectly revealed that their HIV-diagnosis had produced a shift in their attitudes about, and desires for, childbearing and sex. The one exception was Johanna. Her decision to bear no more children was based on the fact that she already had three children, and was thus not related to her HIV-diagnosis. She was also married and reported no change in her sexual desires and functioning. For all of the other women, seroconversion appears to have counterbalanced any preceding wish for children and significantly altered their previous desires for sex. During the interviews, all of the women were asked directly about whether their sexual desires and attitudes towards having children had changed post-diagnosis.

A major theme to emerge in discussions around sexuality was centred on how their seroconversion had impacted negatively on their sexual lives. There was an overwhelming agreement between the women that they had experienced a loss of interest in sex since their diagnosis, with almost all of the women expressing that their sexual desires had declined, as articulated in the following comment by Yoliswa:

‘My interest in sex is not the same as it was before... I no longer like sex ... I just get listless when I meet with him...I no longer want it... I do not need a man in life anymore...’ (Yoliswa, age 26, 2007)

Similarly, when talking about how her diagnosis has affected her sexual desires Judith noted:

‘Like now, it’s not the same as before, there is a difference...Like now I am not interested in sex even if the person I sleep with says we must use a condom. I have no interest at all. I have no feelings...I do not want to have sex anymore...I have no desire... It [HIV] has taken all my sexual feelings away...’ (Judith, age 21, 2007)

There seemed to be consensus among participants that this thwarting of sexual desire has resulted in a sharp tapering of sexual contacts and less fulfilling sexual interactions than prior to their diagnosis. Some women actually appeared to exhibit a strong aversion to sex, highlighting the benefits of, and their support for, abstinence. Some women emphasised that ‘the best thing to do now is not to have sex at all’ as it was suggested that avoiding sex ‘saves you from a lot of things’ including ‘diseases’, ‘pregnancy’, ‘STIs’ and ‘any kind of trouble’. Tembeka movingly pointed out that ultimately,

‘You can have a life like all other people. You can still have fun with your friends, but when it comes to sex, just let it go...’ (Tembeka, age 28, 2007)

Similarly, Yandiswa commented that

‘Now, I must just behave well...to behave well is to not sleep around...to just entertain myself in my house, and live by myself...if you don’t do sex, nothing will happen to you...’ (Yandiswa, age 23, 2007)

In the same way that seroconversion appears to have diminished the women’s interest in sex, their desire for children also appears to have dissipated. Most of the women were particularly vocal about the importance of child-bearing and motherhood in their lives, but how since hearing about their positive status, they no longer wished to have children. Being ‘hopeless’ and ‘unable to have children now because I am sick’ were common phrases on this subject, with the women repeatedly expressing their current desires for children in these terms.

The way in which an HIV-diagnosis appears to have outweighed many of the women's prior desires for children is illustrated by these two comments:

'Before I found out I had this thing [HIV], my thoughts were to have more than the one child, maybe to have two or more children. But the situation of my health changed that...' (Lerato, age 26, 2007)

'For me it is important to have children but unfortunately I won't have them now... But it is very important to have them... but I can't now so it's not a nice feeling...' (Judith, age 21, 2007)

A number of women expressed similar sentiments, foreseeing that their previous hopes for children are 'all finished' as they will 'never arrive for those plans' because they are 'unable to have children now'. One is struck by the way in which many of the women have already begun to reformulate their previous expected life trajectories, such as having children, in the light of HIV.

This change in reproductive desire produced by their HIV-diagnosis is captured most pertinently by this exchange with Nomawethu (age 26, 2007):

Interviewer: 'Before becoming HIV-positive did you have thoughts in connection with having children?'

Nomawethu: 'Yes, I did.'

Interviewer: 'What were your thoughts before you became HIV-positive?'

Nomawethu: 'That I should have a child, because lots of my friends have children and I am the one without a child. So like when I see people playing sweetly with their children it seems nice ... .. like that. So then I really did want children.'

Interviewer: 'And when you compare that with now?'

Nomawethu: 'Now I do not have any hope. I know that I am HIV positive and so I am unable to have children anymore... I don't want more children now... I just can't... I just can't...'

It appears that this participant is experiencing a degree of internal dialogue, persuading herself somewhat that she must not or should not have children. One heard echoes of the words 'I just can't', 'I mustn't even try get pregnant', and 'I shouldn't think about it' throughout the interviews, constantly being struck by the self-persuasive manner in which they were spoken.

Other women conveyed their present strong desires to avoid having children in a more indirect manner, through the importance that they placed on their need for birth-control, as reflected in this dialogue with Miriam (age 25, 2007):

Interviewer: ‘As a woman living with HIV, which reproductive and sexual health services are the most important to you?’

Miriam: ‘I think for me it is contraception.’

Interviewer: ‘Contraception? Why contraception?’

Miriam: ‘To use contraception in order not to have a baby if you are HIV+. Not to have a baby total...’

Similarly, when talking about her current sexual and reproductive needs, Ntobeleni explained:

‘It is important to use contraception now that I am HIV...Contraception is important in preventing birth. I think to me being HIV, you should not be pregnant. You should use a condom and not get pregnant...’ (Ntobeleni, age 29, 2007)

Like various other women, Miriam and Ntobeleni only started using contraceptive methods since being diagnosed with HIV, implying that they now wish to avoid having children. A few of the women suggested more permanent methods, suggesting that abortion and sterilisation may be possible options for HIV-positive women. For example, Zenzi (age 28, 2007) remarked when considering a hypothetical case of a pregnant HIV-positive woman, ‘One might think about abortion. There is no way they can continue. They just can’t continue...’ and Yoliswa (age 26, 2007) asserted that ‘I think that people that already have HIV must sterilise’.

The subjective rationale for why the women’s feelings towards child-bearing and sexuality had changed surfaced in three different ways. Justifications emerged, for the most part, when participants were asked directly about why they thought they had experienced a major shift in attitudes and desires. On other occasions, a number of the women spontaneously volunteered their thoughts on these issues. Finally, when reading each interview in their entirety more subtle motivations materialised.

A coalescence of shared and varied reasons emerged as to why the women had unanimously experienced a reduction in sexual involvement and a diminished desire for children. Some of the underlying reasons for no longer desiring sex and disavouring child-bearing were the same. The women’s understandings of

these changes were discussed and revealed, for the most part, with four levels of meaning: fear, guilt, blame, and difficulties in negotiating safe sex. However, fear associated with sex and reproduction was an overriding concern.

### **Fear: 'I am forever scared...'**

Women spoke with candour about the fears and anxieties their newly discovered condition evoked for them and how their desires for sex and reproduction were overcast by such fears. Apprehension of transmitting the virus emerged as an all-pervasive concern in realm of both sex and reproduction.

When talking about their fears around having children, trepidations tended to centre on possibly infecting their future child with HIV. Comments such as 'I am afraid that the child might be infected' and 'I worry about my child getting the virus' repeatedly occurred through-out the interviews. For many of the women, the risk of having an infected child was reason enough to avoid having children.

It seems that such fears of perinatal transmission were profoundly influenced by some of the attitudes circulating within their communities. Several women spoke about how people they knew had said that if an HIV-positive woman falls pregnant, 'the baby will get AIDS'. As Monica (age 35, 2008) indicated, 'People out there, they say it is not a good idea to have a child when you are HIV positive because you will infect the child while you are pregnant'. A number of the women tended to reiterate and draw on these social discourses when conveying their fears about infecting their future child.

For many of the women the related worry that they may transmit the virus to an uninfected partner or re-infect themselves featured prominently as a powerful deterrent to desiring sex. When talking about their current sexual activities, even when protection was used, many women feared that viral transmission would ensue. A number of women questioned the efficacy of safer sex, and explained that they are preoccupied throughout their sexual interactions that the condom might break. During the interviews, various women questioned the efficacy of condoms, underscoring the fact that 'mistakes do happen'. When speaking of the anxiety associated with sex since her diagnosis, Francis contended:

'Even if we are using a condom I keep saying what if a mistake happens and I infect him, so I constantly check the condom. That is why I sometimes ask myself 'is it worth it to be in a relationship' because I am forever scared...' (Francis, age 31, 2008)

Like so many other women, Francis went on to suggest that she felt the principal factor for her reduction in sexual interest was attributed to her fear of infecting her partner. Sex for her appears to be laden with fear and anxiety, precluding any possible enjoyment. Similarly, Yolandi spoke about the anxiety she felt around re-infection, and the consequent diminished sexual enjoyment she experienced,

‘We have sex but I do not enjoy that. I had fear even when we were using condoms, like a condom is not a hundred percent safe - maybe it breaks, and then his disease enters me again... So, I can’t say we are really safe because condoms do break...’ (Yolandi, age 29, 2008)

Once again, these fears appear to be mediated by talk occurring within the women’s social environment. Many of the women spoke about how their community believed that HIV-positive people will ‘infect more people’ by having sex. When talking about her neighbours’ views, Patricia remarked:

‘They say if people with HIV have sex, they are going to infect others...so they are warning them that they should stay away from sex...’ (Patricia, age 22, 2008)

Apprehension around the supposed severe repercussions that both pregnancy and sex could have on their own health was a further predominant theme that emerged. Notions that pregnancy would hasten the progression of illness were common, as reflected in assertions that ‘pregnancy would make the HIV increase’ or that the ‘CD4 cells will drop too much’, resulting in ‘very quick weight loss’ and possibly a ‘quicker death’. Perceptions of getting thin following childbirth appeared to be a typical concern for many of the women, with a number of the informants giving elaborate descriptions about how HIV-positive women lose considerable amounts of weight following child-birth, as suggested in the end of one Tembeka’s narrative:

‘So, if I can have a child, it is not going to be the same - even though I am fat now, because I have HIV it [body weight] will go down. Like your body weight will go down and down...’ (Tembeka, age 28, 2007)

Similar sentiments were echoed by Miriam. When asked about her feelings towards HIV-positive women having children, she said:

‘I think that if someone is HIV and then gets pregnant and gives birth maybe she will get a problem...like very quickly lose weight. She will lose all her strength...get really thin...This thinness is connected to her HIV...’ (Miriam, age 25, 2007)

Similar health-related concerns featured prominently in narratives pertaining to sexuality, with some women suggesting that having sex, even safe-sex, could be detrimental to their health. A number of women directly or indirectly linked their changes in sexuality to the fact that they are afraid their ‘health might become worse’ or that their ‘CD4 count will go right down’. Some women wondered whether their ‘immune system will decrease’ due to sex. Yandiswa appeared to associate sex with death, when she describes that

‘I think you are killing yourself, I think if you are HIV positive and have sex that thing eats your cells up, so you are killing yourself...’ (Yandiswe, age 23, 2007)

Many women emphasised that they had overheard people in their communities discussing the detrimental consequences pregnancy and sex may have for an HIV-positive person’s own health. As Ntobeleni suggests:

‘I once heard someone saying people who die being positive die because they have sexual relationship...’ (Ntobeleni, age 29, 2007)

Similarly, Francis indicated that:

‘They say by having a child you start getting sick ... because HIV goes to places that have lots of blood. So maybe you would then start to get sick...’ (Francis, age 31, 2008)

### **Guilt: ‘What are these children going to do when you die?’...**

When talking about why they no longer wish to have children, the women frequently alluded to or explicitly described the inevitable guilt child-bearing would invoke for them. The women were very sensitive to the apparent pain and ‘suffering’ the future child may experience, as well as the ostensible ‘burden’ that they would inflict on the community. These issues presented special concern for many of the women. Having indicated that they fear that they may transmit the HIV-virus onto their future child, many women went further to



reflect on the negative repercussions such an infection would produce for the child. Fears of their child's early death became a major focus for many of the women, with rhetorical questions being posed such as 'How long will the child really live?' and 'Will my child survive?'. Other women spoke about the painful life their 'infected' child would have, constructed as something she would have 'caused' because of her 'choice'. Francis voiced this concern:

'Eish... it is stressful, I think that I would infect the child and then you find that the child has a painful life...the parents of other children if they find out that a child is HIV positive, they have concerns and are scared for their children and you find that your child is not well received with other people. You find them saying you must take care not to bleed, do not touch people's blood, so if they can find out that your child is positive you find that they are scared of him...' (Francis, age 31, 2008)

Like so many other women, Francis suggests that the possibility of exposing her future child to the social hardships associated with HIV was untenable. Other informants pondered on the consequences of their own possible early death, and the negative implications this would have for the child. Many women during the interviews posed the questions: 'What are these children going to do when you die?'; 'Who will take care of your child?'; and 'You are going to die and you leave an orphan and who is going to raise her?'

Some women proceeded to answer these questions by suggesting that, ultimately, the responsibility of caring for their children would be placed on their family and wider community, a 'burden' they refuse to contend or 'can't face doing'. As Tembeka (age 28, 2007), poignantly pointed out, she is 'reluctant to bother anyone from home' and does not 'want to hassle people in the community', thus her child will be 'left as an orphan' and 'will go needy'. In the words of Yoliswa (age 26, 2007): 'Ultimately, having a baby means please look after my baby'.

Nomawethu summed up the situation, most aptly capturing many of the other women's sentiments when she professed:

'I would not have a baby because I feel that I would make my baby suffer, the baby will be orphaned and the baby will grow under tough or difficult conditions. It also means deserting the child...so if you know that you have this disease, it is better not to have a baby. Rather,

look after your own health, take care of yourself and stop creating problems...' (Nomawethus, age 26, 2007)

The punitive overtones of Nomawethu's remark are clearly revealed by her emphasis on the importance to 'stop creating problems'. In other words, in her view, having children would only add to the difficulties that she has supposedly already produced.

The strong sentiments that childbearing would be laden with guilt appear to be produced, or at least exacerbated, by some of the dominant views of community members. There was much agreement amongst the women that 'I normally hear them saying it is unfair to you as an HIV+ person to get pregnant and have a baby and all along you won't last'. It was emphasised that 'people out there' argue that an HIV-positive woman who has a child 'puts the child in trouble' and is only 'leaving behind problems'. Women pointed to the effects of such public opprobrium, which consistently and vehemently emphasised the supposed social problems HIV-positive people create by having children, as indicated by remarks such as 'that talk troubles' and 'worries' them considerably.

### **Blame: 'I blame sex...'**

Another theme specifically underpinning women's discussions around sexuality centred on feelings of self-blame, by linking their positive status with their own prior sexual relationships. The fact that 'sex is what caused this problem' was a commonly cited explanation for the women's recent dislike for sex. Many women blamed sex for their condition, a factor that made many of them turn away from sex. Lerato's summation captures this succinctly:

'I blame, I blame sex - maybe if I had never made love, maybe I wouldn't be in this position...maybe if I had of just behaved well, I don't know...' (Lerato, age 26, 2007)

Lerato went on to say that she no longer enjoys sex, as when she is having sex, she is preoccupied, with the only thought that goes through her mind being 'but really that is the way I got HIV'. Similarly, when asked what she attributed her loss of sexual desire to, Zenzi echoed the views of others by reasoning,

‘It’s because today I am HIV-positive because of sex. That is the reason I am saying if I was not married I would never do sex again’.  
(Zenzi, age 28, 2007)

It thus seems that, for many of the women, sex, or supposedly having not ‘behaved well’, renders them somewhat debarred from continuing to engage in and enjoy sexual involvements.

### **Difficulties in Negotiating Safe Sex: ‘The problem is that I no longer like having sex without a condom...’**

In the women’s discussions around their current sexual practices, a major topic to emerge was the importance of using condoms and practising safe sex now that they are HIV-positive, yet they expressed numerous difficulties this posed for them in their sexual relations. The women unanimously stressed that their recent diagnosis had made safe sex ‘the most important thing now’. For example, when asked what she felt her most important sexual and reproductive needs are now that she is HIV-positive, Judith remarked

‘Those that make you always protect yourself...like using a condom. I no longer want to ...have sex without a condom - I have to use one now.’ (Judith, age 21, 2007)

Similarly, in describing how she feels that HIV-positive and HIV-negative women have different sexual and reproductive needs, Zenzi emphasised,

‘They are different. You see those who are HIV *must* use a condom. They *have* to...but those who are not HIV should use a condom but...it isn’t, well you know what I mean...’ (Zenzi, age 28, 2007)

This remark implies that an HIV-diagnosis increases the significance of safe sex, making condom-use a non-negotiable necessity. So many women shared these sentiments, with ubiquitous phrases scattered throughout the women’s narratives such as ‘I see it is necessary to have safe sex now’, ‘I always tell myself that it is not good to have unprotected sex because I know my status’ and ‘The problem is that I no longer want to have sex without a condom’.

This final quotation, spoken by Miriam (age 25, 2007), sheds light on a number of other women’s feelings, that their recent determination to now practice safe sex brings with it ‘problems’ and difficulties that they now have to grapple with.

Indeed, this current value the women place on practicing safe sex seems to be incompatible with the desires and intensions of their partners, placing many of the women in complicated circumstances. Only Judith and Monica, two out of the fourteen women, claimed to have disclosed their status to their partners. Although this is not the topic for this paper, many of the women attributed widespread stigma and discrimination as the reasons for not disclosing their positive status. Consequently, the majority of the women explained that given their partners' ignorance of their positive status, their partners do not understand why they should now practice safe sex and frequently refuse to use condoms. Nomawethu explained:

‘When I came back from the clinic, I told my partner that starting from now on we must use a condom...but I saw that he didn't understand. He was like ‘why should I use a condom now’...he was pleading and pleading and so we now always argue and fight...He just refuses again and again and becomes really cross with me...’  
(Nomawethu, age 26, 2007)

A number of women described situations when they had tried to insist on using condoms, but that their partners ‘will not allow it’ as ‘it does not arouse him’, ‘takes ages for him to climax’ or is ‘wasting his reproduction because his sperms will be on a plastic so that is a waste’. A dominant theme to emerge in the women's stories about their partner's dislike for, and refusal to use, condoms was the women's inability to resist or ‘stand-up’ to their partners. For example, Patricia (age 22, 2008) explained that ‘If you say no, he then forces you to have unsafe sex’. Similarly, Yoliswa poignantly recounted an incident when her insistence on using a condom resulted in her partner abusing her:

‘There was an occasion when he refused and he didn't want to use it at that time - he had been drinking that day and in the house he likes to beat - so that is what happened...’(Yoliswa, age 26, 2007)

Similarly, a number of other women feared that their partners might beat them if they refuse unsafe sex, something that they were convinced would occur. In explaining why she sometimes ends up having sex without a condom, Yolandi argued:

‘I tried... we fought, but we ended-up having sex without it at that time. You see, it is like he would have beaten me, I know he would have...’ (Yolandi, age 29, 2008)

Other women described that insisting on safe sex would result in their partners leaving them. As Yandiswa elucidated:

‘I am frightened that he might dump me...and you see, well...He supports me with everything...when I need stuff he gives it to me, to the two of us, me and the child... So in the end, I will end up not using the condom.’ (Yandiswa, age 23, 2007)

Yandiswa implies that the dependence she and her child have on her partner pressures her to succumb to his desire for unsafe sex.

From these stories, and many others, it is clear that the women’s intentions and great determination to practice safe sex is thwarted by the fear that they have for their livelihood, their physical health and even their lives. One of the many severe consequences that this situation seems to have produced for the women is their subsequent dislike for sex. It seems that their desire is to practice safe sex, yet the explicit or implicit pressure that denies them this wish has resulted in sex ‘now being something that I dread’. Yandiswa explained further

‘Because he won’t wear a condom, it is not nice...You see I no longer enjoy sex when we don’t use anything.’ (Yandiswa, age 23, 2007)

Similarly, Lerato mentioned in a rather embarrassed manner,

‘If I ask him to wear one, he refuses safe sex and then he will force himself on you and this will be something you do not like it. I don’t feel good if you know what I mean.’ (Lerato, age 26, 2007)

The way in which sex has become fraught with displeasure is most patently revealed by Zenzi’s comment when she movingly says:

‘Now we just fight and fight...I then end up giving in to him, but the whole time I am thinking I just want it to end...’ (Zenzi, age 28, 2007)

## Part II: Sexual and Reproductive Support since Diagnosis

‘We have not talked about those things ever...’

Thus far, the analysis has demonstrated how an HIV-diagnosis appears to have produced a major shift in the women’s sexual and reproductive desires. Light has also been shed on both the explicit and implicit subjective and socially determined rationale for such changes. Such changes and the reasons for them become more understandable when they are juxtaposed with the nature of sexual and reproductive information and guidance that has been afforded to them since diagnosis.

In discussions around reproduction and sexuality, it became evident that the women have experienced a scarcity of conversations pertaining to such issues. Participants were asked directly whether anyone from the health services or a counsellor had ever spoken to them about sexual issues and issues relating to having children. Some of the women replied, in somewhat of a confessional manner, that they had not returned to the clinic since they were diagnosed as positive. All of these women acknowledged that they had not spoken to the counsellor they had initially met with about any issues concerning sexuality and reproduction. Others of the women had returned a few times to the clinic since their diagnosis, but revealed that they, too, had almost never spoken about such issues during their subsequent health care visits. The interviews were saturated with responses such as ‘not often’, ‘never’, ‘this is the first time speaking about this kind of thing’, ‘it does not happen’, ‘I haven’t heard anything’, and ‘we have not talked about those things ever’.

The limited reproductive support these fourteen women have received was most palpably revealed during the course of the interviews. Scattered throughout the informants’ narratives, we witness a plethora of enquiries pertaining to the reproductive options available to HIV-positive women. For example, it was not uncommon to hear questions such as:

‘How am I going to have another child with this condition? Or is there anyway we can have another child in this condition?’ (Zenzi, age 28, 2007)

‘I want to have more children, but I do not know how’ (Miriam, age 25, 2007)

‘I heard that now you can have a baby when you are HIV positive but I ask myself how, how it can be done?’ (Tembeka, age 28, 2007)

‘How am I going to get a child if I am using the condom?’ (Yolandi, age 29, 2008)

‘Do you know of other options for me?’ (Zenzi, age 28, 2007)

These questions, amongst others, posed by the women demonstrate that pressing issues around reproduction in the context of HIV/AIDS have remained unanswered for many of these women.

In the realm of sexuality, although uniformly acknowledging that they have experienced very few conversations with health care providers about such issues, when the women were probed further, it became clear that certain issues had been discussed with them at the clinic. It emerged, however, that such conversations had focused primarily on ‘safe sex’ and more general ‘good behaviour’. Many of the women revealed that at the time of their diagnosis, the counsellor had spoken to them about ‘behaving well’, or having ‘few sexual partners’, ‘not being careless’ and ‘now’ needing to ‘look after’ themselves. Similarly, other women described some of the discussions they have had with health workers on subsequent visits to the clinic. Miriam explained:

‘It is very common for them to tell us how to have safer sex, but nothing else really... The nurses normally would address the group not an individual saying that when you are having sex you must always use a condom because you can contract HIV if you are not using a condom, you can get STDs, and you can become pregnant so there are so many things you can get if you are not using a condom...’ (Miriam, age 25, 2007)

Similarly, in recounting her first and only visit to the clinic since her diagnosis, Nomawethu contended:

‘Mostly they told us about good behavior... like to have safe sex... when you sleep with your boyfriend you must always use a condom and that if you drink alcohol you must not drink too much... things like that...’ (Nomawethu, age 26, 2007)

It seems that this advice is very similar to the women’s own rhetoric around sex, as highlighted above. As demonstrated above, ‘behaving well’ and ‘looking after’ oneself were dominant signifiers in the women’s discourses on sexuality.

It is thus clear that the women have been afforded very little, if not a complete lack of information, in the realm of reproduction. Furthermore, the limited guidance that some women have received pertaining to sexuality has been selective in nature, and ideologically infused. The influence that the health care providers' discourses appear to have had on the women is clearly discernable.

The fundamental role that appropriate and more comprehensive sexual and reproductive knowledge and advice could play for these women became starkly evident during the course of the interviews. This was most palpably revealed when discussions centred around prevention-of-mother-to-child-transmission (PMTCT) programs. Although a handful of the women had heard about such programs, all of the fourteen informants displayed no awareness of what such programs involved. When it became apparent that the women were unclear on the benefits of PMTCT, the interviewer proceeded to explain what such a program entails; thereafter asking whether now having this knowledge would affect their child-bearing desires. Providing various segments of one interview with Monica (age 35, 2008) will most aptly shed light on the fundamental role that this newly acquired information had on many of the women's reproductive intentions. In the beginning of the interview, when asked about her reproductive desires, the conversation went as follows:

Monica: 'It is not important now for me to have children because I am in this situation. So I no longer want children... I am not going to have any more children.'

Interviewer: 'Can you elaborate on why you feel this?'

Monica: 'I think that if someone is HIV and then gets pregnant and gives birth again maybe she will very quickly lose weight... Also, I am reluctant to get pregnant and my child maybe also will have HIV... So, I don't want children...'

Toward the end of the interview, the issue of reproduction comes up again, and the dialogue with the Monica continues as follows:

Interviewer: 'Do you know about PMTCT?'

Monica: 'No.'

Interviewer: 'It is a program in which a pregnant woman can be helped by certain pills that she will take during her pregnancy and when she gives birth in order for the child not to be infected by the virus coming from an HIV positive mother. So it will reduce the incidence of the child being infected, for example to only 2 out of 100 women. If you could get these pills it would help the child not get



infected by the HIV virus. Would it change the way you think about having children or not having them?’

Monica: ‘Yes, this could affect my feelings, if I knew it was safe. You see the way I think is that maybe I can’t get pregnant again because I am HIV or maybe I would infect the child. Now if I could properly understand that it was possible, and get the right information that my child was not going to get infected, my feelings could change... But I would need more information...’

This example reveals that once made aware of PMTCT’s role in preventing transmission of the virus, Monica’s strong feelings towards not having children began to unravel somewhat. One thus begins to gain insight into the fundamental role tangible information could play for these women. Although some women were more outspoken about their change in sentiments, it was unequivocally the case that on hearing about PMTCT, all of the women indicated that they would reconsider their reproductive decisions, as reflected in the words of many women: ‘If that would work, I would feel so much better’ and ‘If there is such program I would change my thoughts. I would want another baby and ask for help inside’ and ‘I would probably think differently because I didn’t know of other options’.

After being provided with such information, many of the women began to consider the possibility that they may now be able to have children. This appears to have created a degree of bewilderment and confusion for many of the women, unsure of what they currently thought or how they now felt. Some began to ask the interviewer questions about PMTCT, in an attempt to reconcile the discrepancy between their past perceptions, and immediately gained insights. Questions such as ‘Would that work?’, ‘Can that really be done?’ and ‘So is there a way we can have another child in this condition?’ were heard across many of the interviews. On reflection, the interview setting provided many of these women with a glimpse of hope, but was neither the time nor place to provide them with more comprehensive guidance.

## **Discussion and Recommendations**

This study provides qualitative insights into the reproductive and sexual needs, desires and intentions, and influencing factors, of a group of urban South African women, newly diagnosed with HIV. This study is novel in documenting such issues amongst HIV-positive women who recently seroconverted.

The results suggest that reproductive intentions were fundamentally affected by an HIV-diagnosis, with all of the women no longer desiring children. One is struck by the commonality and homogeneity in the women's current intentions, with none of the women favourably disposed towards childbearing. This is somewhat dissimilar to other studies on the reproductive intentions of HIV-positive women, which have tended to find considerable diversity amongst the participants (for example Aka-Dago-Akribi, 1997; Richter et al., 2002). Unlike these studies that were undertaken amongst women who were frequently in much more advanced stages of the disease, in this study, many of the women had only recently seroconverted. As will be demonstrated shortly, these differences in time since diagnosis, might account for these discrepancies.

This study found that a number HIV-related concerns were central deterrents to the women's desires for children. Key factors included fears that pregnancy could hasten HIV/AIDS progression, apprehension around risks of HIV transmission to infant and partner and the negative consequences of a resulting infection, as well as the supposed burden having children would create for their family and community. In studies from other developed and developing settings these health-related concerns have been shown to deter some HIV-positive women from desiring children (Chen et al., 2001; Cooper et al., 2007; Kirshenbaum et al., 2004; Paiva et al., 2002, 2003, 2007; Richter et al., 2002).

As with reproductive intentions, the results from this study indicate that seroconversion also significantly impacted upon these newly diagnosed women's sexual desires and functioning. Indeed, all of the women reported their sexual lives were fraught with quandaries, corroborating findings from other studies in the developed world (for example Maticka-Tyndale & Adam, 2002; Siegel, Schrimshaw & Lekas, 2006). As shown in other studies (Sherr, 1995; Siegel & Schrimshaw, 2003), anxiety about the efficacy of safe-sex and consequent HIV transmission and re-infection, together with fears around the repercussions sex could have for their health, were common concerns voiced by the respondents. The blame attributed to sex for their condition and the newly discovered importance of safe sex and the resulting quandaries, surfaced as further rationale for why many of the respondents turned away from sex, factors which appear to have not been shown in other studies.

The picture that therefore emerges from the results of this study is one of recently diagnosed women, who felt that sex and childbearing had become too plagued with fear, guilt and blame to be pleasurable or desirable. This picture becomes more understandable when viewed in conjunction with the limited support that has been afforded to them, a finding that was starkly revealed in this

study. When provided with some information during the interviews, all of the respondents envisaged that they would reconsider their attitudes concerning reproduction, with many of the women appearing favourably disposed towards childbearing. This finding is in harmony with research in India which found knowledge and awareness of PMTCT to be a key guiding factor in decisions on child-bearing amongst HIV-positive women (Kanniappan et al., 2008).

It is important to note that the way in which the women appeared to display minimal knowledge about their reproductive options was an unexpected finding, given that in South Africa PMTCT access has improved dramatically in the last few years and has been available to HIV-infected pregnant women who require it in limited service settings since 2004 (Stinson, Myer & Boulle, 2008). Moreover, in Cape Town, PMTCT programmes are currently available at many public sector health centres (Cooper et al., 2007). Given that these women are located within an urban area in Cape Town, with widespread PMTCT services and infrastructure, their complete lack of knowledge is surprising. Their limited understanding may be explained by the health care system and policies within South Africa. The public health care system in South Africa is currently plagued by fragmentation and disintegration between HIV care and reproductive services, not to mention being overburdened, under-resourced and lacking in staff morale. Consequently, the health care system in the country possesses a limited capacity to provide adequate reproductive health care services to the public, regardless of HIV-status (Butler, 2004). In addition, the government's policy on HIV/AIDS has been highly controversial, being reluctant and slow to introduce ARV and PMTCT treatment programs, imparting confusing and contradictory messages regarding the efficacy and safety of ARV treatment, not to mention continued ministerial squabbling and AIDS denialism (Cooper et al., 2004). These problems endemic to the South African health care system may explain why the women appear to have received a scarcity of information and support regarding their reproductive health and choices.

Pulling these different threads together, within the context of limited information and support, the women's sexual and reproductive desires and choices were consequently left to the mercy of the stigmatising and regulating social discourses which surrounds them. Many of the women's sentiments drew on, and were buttressed by, community attitudes which tended to emphasise the negative connotations associated with childbearing and sexual relations within the context of HIV/AIDS. This is supported by Myer et al (2006) who found considerable stigmatisation of sexual activity and childbearing by HIV-positive women among the general population of South Africa.

Dominant community discourses appear to have interwoven with hegemonic discourses prevailing amongst health care providers. As alluded to throughout the analysis, the women repetitively spoke about the importance of ‘behaving well’ and ‘not being careless’. Although these sentiments were often couched as having personal importance and responsibility, the underlying biomedical discourses employed by health care providers is clearly discernable. This is a phenomenon that has been shown in other studies in South Africa (Harries et al., 2007; Orner et al., 2008).

Indeed, this biomedical rhetoric has been the dominant ideology underlying most of the HIV/AIDS education campaigns locally and internationally (for example Campbell, 2003, 2004 & Williams et al., 2000). The focus of the now well-known ABC approach (abstain, be faithful or use condoms) has been on promoting safe sexual practices and discouraging risky behaviours (Stein, 2003). Such initiatives, however, tend to be imbued with morally punitive connotations, dictating what it means to be responsible and assiduous person (Joffe, 1995). Such an approach also assumes that individuals have the power to implement self-protective behaviours (Wilton, 1997). In situations of inequitable gender relations, such as in South Africa, women’s low socioeconomic status, their economic dependence on men as well as high levels of gender-based violence, frequently makes negotiating safe sex very difficult (de Bruyn, 2005; Jewkes & Abrahams, 2002; Strebel, 1995; Walker et al., 2004). This was clearly revealed in this study, where many of the women faced violence, abuse and economic deprivation when insisting on condom-use.

Thus, the health-care providers’ biomedical discourses in this study correspond to contemporary hegemonic AIDS discourse. Not only did such regulatory discourse fail to recognise the actual lived realities of the women in this study, they also appear to have fundamentally contributed to the sentiments of blame that turned so many of the respondents away from engaging in and enjoying sex.

This is not to deny that many of the participants’ fears and anxieties are embedded in some of the brutal realities of sexuality and reproduction in the context of HIV/AIDS, and are not necessarily ‘false’ constructions of reality. Sexual relations and childbearing amongst HIV-positive individuals do carry certain risks. The women’s assessment of these risks, however, appears to be somewhat overestimated and coloured with negative connotations, thus representing a blurring of some of the harsh truths of the epidemic, with potentially denigrating and derogatory social constructions. Ultimately, the women seemed to lack appropriate support structures and sources of reliable information to counterbalance these social and emotional influences.

Of critical concern in the present study was whether there are sexual and reproductive needs specific to women newly diagnosed with HIV, and if so, how these subjective needs translate into their human rights. The results revealed that there are certain distinct needs pertaining to recently seroconverted women, but also some needs that concern all HIV-positive persons, at all stages of the disease.

In relation to some of the unique needs, the results unambiguously revealed that newly diagnosed HIV-positive women need information and guidance, immediately following a positive diagnosis, on the reproductive options available to HIV-positive individuals, and the associated risks. Immediate knowledge around reproduction may enable newly seroconverted individuals to make more informed, and less shock and fear-instilled decisions about reproduction, having more realistic ideas around the dangers involved. Failure to provide newly diagnosed women with the appropriate reproductive knowledge and information infringes on their rights to make informed reproductive choices and decisions (Gruskin et al., 2007).

Continuing with the unique needs of newly diagnosed HIV-positive women, based on the results of this study and other similar studies (Adam & Sears, 1994; Hankin et al., 1997; Sherr, 1995), as well as Green's (1994, 1995) temporal model of the sexual functioning of HIV-positive individuals, it is clear that immediately following a positive diagnosis, HIV-positive women experience the most acute decrease in sexual desire and functioning. Consequently, recently diagnosed HIV-positive women may require counselling about their sexuality, helping them to more realistically evaluate their fears about sexual involvement. Newly diagnosed women thus require the support structures to help them regain a sense of themselves as appealing, sensual women who can have gratifying, yet safe, relationships with both uninfected and infected partners. Failure to provide such support infringes on their rights to sexual relationships that are healthy and fulfilling (Shapiro & Ray, 2007).

It is thus clear that newly diagnosed women have certain specific sexual and reproductive needs and rights which need to be recognised and supported. The results from this study also indicate that these women have sexual and reproductive needs that pertain to all HIV-positive individuals, at all stages of the disease.

There is a need for healthcare providers to better, and more realistically, address the sexual health needs of HIV-infected women. A possible tension most certainly does arise between HIV/AIDS prevention initiatives and supporting the

sexual rights of HIV-positive individuals. Reconciling this tension is not an easy task. It may require that health professionals take a more nuanced and sensitive approach, addressing the sexual health needs of HIV-positive women from both a psychosocial and biomedical perspective. This is essential if public health and human rights objectives are to be synergised. Provider attitudes and practices alone however cannot comprehensively address the sexual needs and rights of HIV-positive women. Ultimately, as the results from this study show, they must be accompanied by more comprehensive social and structural interventions aimed at improving the status of women in South African society.

The results of this study also indicate that the censorious moral climate about sexuality and reproduction in the context of HIV/AIDS serves as a major barrier and precludes attempts to facilitate the sexual and reproductive needs of HIV-positive persons at all stages of the disease. The findings from this study are thus consistent with the assertion of Myer et al (2006) that the sexual and reproductive health rights of HIV-positive women and men may need to form an important component of more general efforts to reduce HIV/AIDS-related stigma in South Africa. This is essential if the specific sexual and reproductive rights of newly diagnosed, as well as those of all HIV-positive individuals, are to be respected, protected and fulfilled.

## **Conclusions**

The results from this study underscore the need for closer attention from policy makers and health care providers in recognising and supporting the sexual and reproductive needs and rights of newly seroconverted women specifically and positive individuals at all stages of the disease generally. Both in South Africa (Cooper et al., 2004; Fonn et al., 1998), and internationally (Gruskin, 2000; Yanda et al., 2003), substantial advances have been made in policy developments and services which recognise and promote sexual and reproductive rights. Since the advent of democracy in South Africa in 1994, major milestones include the legislation of termination of pregnancy, the sexual assault and domestic violence Acts, as well as the provision of free public sector services for maternal and child health, and contraception (Cooper et al., 2004). At the same time, the last fifteen years has witnessed a remarkable increase in the number of women of sexual and childbearing age becoming infected with HIV, now representing the group most heavily affected by the virus. Unfortunately, a dearth of attention has been placed in extending the advances in sexual and reproductive rights in South Africa to this much needed group.

With the improvement of ART and PMTCT availability and access in South Africa, many of these women now enjoy the prospect of living longer and healthier lives, forging sexual relationships and considering having children. Unfortunately, to date, particularly in developing countries, health services and counselling for HIV-positive people have focused largely on promoting safer sex, the delivery of prophylaxis against opportunistic infections, treatment of co-infection with tuberculosis, and, more recently, antiretroviral therapy and other AIDS-related treatment (de Bruyn, 2005; Cooper et al., 2007; Lusti-Narasimhan et al., 2007). Very little focus has been placed on attending to the myriad sexual and reproductive health needs of HIV-positive individuals. This current study, one of only a handful of such studies in South Africa and other developing countries, showed a multitude of complex sexual and reproductive needs of HIV-positive women that require increased attention.

Concerns about generalising from a small sample do apply to this study. With this said, Goetz and LeCompte (1984, as cited in Schofield, 2000: 75) talk about the notion of ‘comparability’, indicating that in qualitative research, when the ‘units of analysis’ are ‘sufficiently well described and defined’, one ‘can make an informed judgment about whether the conclusions drawn from the study are useful in understanding other, similar sites’. Given the homogeneity and specificity of this group of fourteen women, it does say at least something about the sentiments and experiences of other newly diagnosed HIV-positive women in the general South African population.

Thus, in line with recent suggestions (Askew & Berer, 2003; Gruskin et al., 2007), the findings from this study indicate that sexual and reproductive health services need to be strengthened and integrated with HIV care and treatment, including, but not isolated to, immediately following diagnosis. HIV post-test counselling requires information about, as well as access and referrals to, services that promote and ensure fulfilling, healthy and safe sexual and reproductive choices and options for newly seroconverted women, in South Africa and other countries heavily affected by the HIV pandemic.

Furthermore, explicit health policies that recognise the sexual and reproductive rights of HIV-positive individuals are required. This needs to be accompanied with more general efforts to improve the status of women in society and reduce the prevailing stigmatisation of HIV-positive individuals in relation to their sexuality and reproductive choices. Furthermore, explicit health care provider guidelines, as well as education and training in the sexual and reproductive rights of all HIV-positive persons, need to be developed and implemented, so that their counselling and practices, through wilful intent or unconscious

preference, do not infringe on infected individuals' sexual and reproductive rights (Bharat & Mahendra, 2007)

Ultimately, the words of Monica, one of the women in this study, highlighted in the title of this thesis, is an urgent call to start recognising and supporting the sexual and reproductive rights of newly diagnosed HIV-positive South Africans. Monica says, "If I could properly understand and get the right information my feelings could change". Taking heed of this plea is imperative for ensuring that such individuals are not denied the freedoms and choices enshrined in South Africa's new Constitution.



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