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TITLE

“If I could properly understand and get the right information...”: The Sexual and Reproductive Health Needs and Rights of Women Newly Diagnosed with HIV: A Qualitative Study in the Western Cape Province South Africa

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of Masters in Public Health
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2009



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ACKNOWLEDGEMENTS

The study was supported by the Population Council, New York, and the University of Cape Town. The author thanks: the fieldworkers for conducting the interviews, the participants at the research health facility, Smruti Patel for her contribution, Jane Harries for her supervision and Di Cooper for her support.

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LIST OF ABBREVIATIONS

ABC.....	Abstain, Be faithful or Condomise
AIDS.....	Acquired Immune Deficiency Syndrome
ARVs.....	Antiretrovirals
DALYs.....	Disability-adjusted-life-years
HAART.....	Highly active antiretroviral therapy
HIV.....	Human Immunodeficiency Virus
HSRC.....	Human Sciences Research Council
PMTCT.....	Prevention-of-mother-to-child transmission
TOP.....	Termination of Pregnancy
UNAIDS.....	Joint United Nations Programme on HIV/AIDS
UCT.....	University of Cape Town
WHRU.....	Women's Health Research Unit
WHO.....	World Health Organization

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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 analyzed with fourteen women from Gugulethu, Cape Town, who screened HIV-positive during enrolment or who seroconverted during the course of the larger microbicide, Carraguard study carried out by the Population Council and University of Cape Town. This study is novel in its exploration of these issues amongst women who are newly diagnosed and who were recruited outside of a health-care setting. The results revealed that a positive diagnosis produced a major shift in sexual and reproductive desires for these women, with the respondents almost unanimously no longer wishing for children nor wanting sex. The rationale for such alterations involved five levels of meaning: fear, blame, guilt, bodily antipathy as well as difficulties in negotiating safe sexual practices. These sentiments appear to have been shaped by the lack of information afforded to them, as well as the stigmatizing and ideologically laden social discourses which surrounds 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. Recommendations are provided for meeting these needs, and synergizing public health goals with human rights objectives.

CHAPTER 1

BACKGROUND AND RATIONALE

Since the HIV/AIDS epidemic was first recognized 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). In South Africa, the HIV and AIDS epidemic has reached unprecedented heights, being the top single cause of mortality, and the greatest contributor to DALY (Bradshaw et al., 2003; Health Systems Trust, 2006). As in most countries around the world, women of reproductive age in South Africa are disproportionately affected by the virus (WHO, 2006). An estimated 29% of women of reproductive age (15-49 years) in South Africa are HIV-positive, having an incidence rate of 6.3 percent compared to 2.4 percent for men in the same age range (HSRC, 2006). This feminization of the epidemic has primarily been attributed to women's subordinate status within South African society. Women's low socioeconomic status, their economic dependence on men and consequent difficulties in negotiating safer sex, as well as high levels of gender-based violence and sexual assault interact to make women particularly vulnerable to the virus (De Bruyn, 2005; Doyal, 1995; Strebel, 1995; Walker, Reid & Cornell, 2004).

Despite the fact that women of child-bearing age constitute the fastest growing group diagnosed with HIV infection, internationally, and particularly in South Africa and other countries of Sub-Saharan Africa heavily affected by HIV/AIDS, a dearth of attention has been placed on the sexual and reproductive health needs and rights of these women (Cooper et al., 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 (Cooper et al., 2004; Fonn et al., 1998), and internationally (Yanda, Smith & Rosenfield, 2003) in policy developments which recognize sexual and reproductive rights as fundamental to human well-being.

With the improvement of ARV treatment and PMTCT programs availability and access in a relatively short space of time in South Africa, many HIV-positive individuals now enjoy the prospect of living longer and healthier lives, forging sexual relationships and considering having children. This 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). An understanding of these rights in this region is thus crucial, and urgently needed.

This study, a collaborative initiative between WHRU at the University of Cape Town and the Population Council in New York, focuses on the sexual and reproductive needs and rights of women newly diagnosed with HIV. The women chosen for this study seroconverted in a much larger study that was run between March of 2004 and March 2007 by the Population Council and University of Cape Town, which conducted a Phase 3 efficacy trial of its leading vaginal microbicide, Carraguard.

Thus, this sub-study assessed whether these 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 will be explored from the women's own perspectives, rather than imputing the viewpoints of policy makers and health service providers onto this topic. By giving voice to their predominantly muted subjective views, this study will 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 recognize such rights.

The study objectives were:

1. To explore whether women *newly diagnosed* with HIV have *specific* sexual and reproductive needs, as expressed from their own perspective.
2. If so, to explore how these subjective needs translate into their human rights.

CHAPTER 2

LITERATURE REVIEW

This review consists of three interrelated parts. It will begin with a critical discussion of some of the baseline medical, human rights and public health debates circulating the literature around reproduction and sexuality in the context of HIV/AIDS. An understanding of these issues is crucial for assessing and contextualizing the sexual and reproductive needs of HIV-positive people. Thus, such discussions will provide a background for the second and third parts of this review, involving an analysis of some of the studies that have attempted to explore the subjective reproductive and sexual needs and desires of those individuals infected with the virus.

Reproduction and sexuality in the context of HIV/AIDS: Medical, public health and human rights debates

Although reproductive and sexual rights are now acknowledged as necessary for well-being, the extension of such rights to HIV-positive individuals has received surprisingly little attention (Bell et al., 2007; de Bruyn, 2005; Thornton, Romanelli & Collins, 2004). Consequently, to date, there is still no consensus within academic circles about the sexual and reproductive rights of HIV-positive individuals, nor has any binding international or regional policies in this area been developed (Bell et al., 2007; Center for Reproductive Rights, 2005).

It has been argued that that there are compelling medical and public health reasons to favour restrictions on the fertility and sexual activity of HIV-positive persons. In the realm of sexuality, it

has been argued for example, that the continued sexual activity of HIV-positive individuals hinders efforts that attempt to prevent HIV transmission and alleviate the negative health consequences amongst persons infected with the disease (Kelly & Kalichman, 2002; Myer et al., 2006).

In the domain of reproduction, even greater controversy and contestation exists, with highly charged debates taking place. Some have argued that HIV-positive persons should be discouraged from having children due to the risks unprotected sex, a precursor for 'natural' pregnancy, carries for sexual transmission, perinatal HIV infection and re-infection with mutated viral strands of HIV. For example, it has been shown that the cumulative risks of HIV-transmission to an uninfected partner during sex are estimated at about 4% to 5% (Williams et al., 2003). Furthermore, without any prevention-of-mother-to-child treatments, perinatal transmission rates are about 25% (Williams et al., 2003). Amongst arguments against permitting HIV-positive women from bearing children, it has also been postulated that pregnancy might accelerate the progression of HIV disease to AIDS (Kass, 1994; Minkoff, Willoughby & Mendez, 1990). Finally, it is argued that by recognizing 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). For example, Beckerman (2002) highlights that 3–4% of HIV-positive sub-Saharan mothers die within a year of delivery, resulting in their children being orphaned.

More recent evidence however, particularly in relation to reproduction, is emerging that calls into question the strength of these medical and public health arguments for limiting the sexual and reproductive rights of HIV-positive individuals. Firstly, the medical literature is replete with evidence showing that with effective ARV regimens, the risks of HIV-transmission are significantly

reduced. For example, effective antiretroviral therapy in infected persons can significantly decrease the risk of sexual transmission of HIV to the uninfected partner, or re-infection. This has been shown both in developing and developed countries (Cohen et al., 2007). Similarly, the use of HAART during pregnancy drastically reduces the risk of an HIV-positive woman transmitting infection to her child, with reported rates of mother-to-child-transmission being less than 2% (Kirshenbaum et al., 2004; Williams et al., 2003). In addition, more recent studies have found no deleterious effect of pregnancy on the progression from seroconversion to AIDS (Saada et al., 2000; Williams et al., 2003). Finally, potent ARV treatment is increasing the well-being and longevity of many infected persons, even in resource-poor environments, enabling many HIV-positive parents to raise their children who will in turn not become orphans (Jelsma et al., 2005).

It is thus clear that while there are certain threats involved with HIV-positive individuals continuing to have sexual relations and children, these risks have been significantly reduced with recent medical advances. The significance of these possible risks are diminished further when viewed in conjunction with the fundamental, arguably nonderogable rights, that are infringed upon, as well as the many negative public health repercussions that result, by failing to support and promote HIV-positive individuals' childbearing and sexual rights.

Restricting HIV-positive individuals from engaging in sexual relations and having children if and when they choose, infringes their fundamental rights. These include, amongst others, the right to free and informed reproductive and sexual choice; the right to have control over one's own body, the right to dignity, respect and non-discrimination as well as the right to access of information, health and life (London et al., 2008; Myer, Morroni, Nachega & Cooper, 2005). Such restrictions also

infringe on the right to health of HIV-positive individuals. As pointed out by London et al (2008) dominant understandings of health, by the likes of the WHO, emphasize that health is the complete state of physical, mental and social well-being, and not merely the absence of disease. From this perspective, denying HIV-positive individuals the right to engage in and forge sexual relations impinges on their health, as a healthy sexuality is a fundamental component of quality of life and well-being (Siegel & Schrimshaw, 2003).

In addition, an HIV-positive woman's inability to have children could have highly negative effects on her health. For example, a number of qualitative studies have shown that being childless leads many HIV-positive women to experience a heightened sense of despair and psychological dis-ease (Nebie et al., 2001; Rutenberg, 2000). In addition, the strong social and cultural norms around fertility in many African societies can result in women who are involuntarily childless, being marginalized, stigmatized and rejected (Aka-Dago-Akribi, et al., 1997; Dyer, Abrahams, Hoffman & van der Spuy, 2002; Myer et al., 2005).

It is also important to stress that autonomy and freedom in decisions regarding reproduction is explicitly supported by the section on 'Freedom and Security of the Person' in the Bill of Rights in the South African Constitution, and thus denying people this right due to an HIV-positive status, infringes established legal and ethical conduct (Myer, & Morroni, 2005).

Over and above the intrinsic ethical and human rights imperatives, failing to recognize HIV-positive individuals' sexual and reproductive rights also has a number of negative public health repercussions. For example, limiting their rights further stigmatizes the disease (Gruskin et al., 2007). Increased

stigma in turn leads to 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; Myer, & Morroni, 2005). It has been highlighted that HIV-related stigma serves as one of the “greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact” (Parker, & Aggleton, 2003, p. 15).

In addition, failing to address the sexual and reproductive needs and desires of HIV-positive persons could be detrimental to provider-patient relationships that are particularly important in the context of long-term HIV care and treatment (Myer et al., 2005). Finally, it is arguable that even if the reproductive and sexual rights of HIV-positive individuals are not supported or enshrined within formal policy, such individuals will continue to engage in sexual activities, and continue to have children, possibly in circumstances less conducive to protecting the health of the partners concerned, the future infant and the social environment. Thus, ultimately, as London et al (2008, p. 21) argue, “Interventions that support reproductive [and sexual] choices for HIV-positive persons serve to advance both human rights and public health in complementary ways”.

Having highlighted some of the key medical, human rights and public health debates around reproduction in the context of HIV/AIDS, we now shift away from these more academic discussions to a review of what reproductive and sexual needs HIV-positive people actually appear to have.

The reproductive needs of HIV-positive individuals

Turning to the literature on the reproductive needs, desires and intentions of HIV-positive individuals, it is clear that a dearth of work to date in the developed world, and even less in the developing world, has been done on assessing these issues (Berger, 2004; Chen et al., 2001; da Silveira Rossi et al., 2005; Flanagan et al., 2005; Paiva, Latorre, Gravator, & Lacerda, 2002; Sowell et al., 2002). Only in very recent years, with the development of wider reproductive options available to HIV positive individuals, are we beginning to see studies being conducted in the area of HIV and reproductive health. The scarcity of evidence that is emerging from the developed world indicates that diversity exists, with HIV-infectivity both promoting and deterring men and women from having children (Flanagan et al., 2005).

Thus, despite reproduction in the context of HIV/AIDS still remaining a disputed issue, the ARV roll out, and development of PMTCT programs appears to be encouraging HIV positive individuals receiving treatment to reassess their choices in favour of childbearing (Barreiro, Duerr, Beckerman & Soriano, 2006; Bungener, Marchand-Gonod & Jouvent, 2000). Studies carried out in the USA (Kirshenbaum et al., 2004; Smits et al., 1999; Sowell et al., 2002) and Europe (de Vincenzi et al., 1997; Sherr, Barnes & Johnson, 2000; Sherr & Barry, 2004) have shown that being HIV-positive altered, but did not remove reproductive desires for a significant proportion of HIV positive men and women. For example, in a survey involving the first nationally representative sample in the USA, Chen et al. (2001) found that 28% to 29% of HIV-positive infected adults desired to have children sometime in their lives.

Similar research in the developing world, particularly in Sub-Saharan Africa, remains limited however, leaving it unknown whether such results can be generalized to third world populations, given cultural and structural regional differences (du Plessis, 2003; Flanagan et al., 2005). Although a number of countries in Southern Africa, including South Africa, have recently introduced public sector PMTCT programs and increased public access to ARV therapy, little research is available on their impact on the reproductive decision-making of HIV-positive individuals (Cooper et al., 2007; Myer & Morroni, 2005).

There are however a few notable exceptions within developing regions. For example, evidence from Rwanda, Africa (Allen et al., 1993; Nebie et al., 2001) and paralleling findings from Brazilian research (da Silveira Rossi et al., 2005; Paiva et al., 2002, 2003, 2007; Santos, Filipe & Paiva, 1998) show that childbearing is an important feature of life for many HIV-positive men and women. Although minimal studies have been conducted in Sub-Saharan Africa, studies in Zimbabwe (Feldman & Maposhere, 2007) and Zambia (Rutenberg, 2000) both found that many HIV-positive women still desired, and continued to have children. Similarly, moving closer to home, survey data collected from public sector health facilities in Cape Town, South Africa shows that over 50% of HIV-positive women and men attending HIV care may desire to have children or are undecided, and 19% of women have become pregnant since becoming aware of their HIV-positive status (Cooper, et al., 2006).

This is not to say however that all HIV-positive individuals desire, or intend to have children.

Various studies in both the developed (Chen et al., 2001; Kirshenbaum et al., 2004) and developing

world (Paiva et al., 2007; Cooper et al., 2007) have shown that health-related concerns may deter some infected individuals from wanting children.

Besides the general paucity of research, and the geographical bias that has tended to characterize the literature thus far, there are additional gaps and limitation in current research around the reproductive desires and intentions of HIV positive people. Firstly, as indicated by Flanagan et al. (2005) and Kanniappan, Jeyapaul and Kalyanwala (2008) studies tend to draw on clinic-based populations, thus ignoring the views and opinions of those populations not in care, who may not have access to the support and information afforded to those receiving care. Furthermore, a large majority of studies are quantitative in nature, and tending to reside within a narrow and rational biomedical model of reproductive choice (da Silveira Rossi et al., 2005; Kline, Strickler & Kempf, 1995; Sherr et al., 2000; Sowell et al., 2002). These studies fail to take cognizance of the more nuanced, complex and socially shaped pressures HIV-positive people face and have to balance when making reproductive choices. If the reproductive rights of HIV-positive individuals are to be recognized and addressed, an understanding of the myriad subjective, social and biomedical considerations underlying pregnancy decision-making is crucial (du Plessis, 2003).

The sexual needs of HIV-positive individuals

As in the case of childbearing, the prospect of living longer, more fulfilling lives brought about by the recent advent of ARVs, has meant that many infected individuals continue to establish and engage in sexual relationships (Bova & Durante, 2003; Siegel & Schrimshaw, 2003). Research on the sexuality of HIV-positive individuals however has primarily focused on understanding the

factors associated with unsafe sexual practices and evaluating the efficacy of interventions aimed at altering these behaviors (Siegel, Schrimshaw & Lekas, 2006). This narrow focus has meant that comparatively little is understood about the full range of sexual needs and experiences of individuals living with HIV/AIDS. Such issues thus remain somewhat of an uncharted area (Denis & Hong, 2003; Green, 1994; Schiltz & Sandfort, 2000). Furthermore, the skeletal work that has attempted to explore some of the broader issues around sexuality in the context of HIV/AIDS has tended to be limited to HIV-positive men (Siegel & Schrimshaw, 2003). In their overview of the current knowledge of sexuality in HIV-positive persons, Schiltz and Sandfort (2000) indicate that women's experiences of sexuality following HIV-infection remains largely unattended to, with almost nothing being known about such issues amongst HIV-positive women in developing countries.

The handful of studies that have been conducted amongst women indicate that an HIV-diagnosis can have far-reaching implications for women's sexual relationships and sexual health. Research findings from developed countries suggest that the majority of women who learn of their positive HIV status experience significant disruptions in their sexuality, particularly in the early stages of disease (Denis & Hong, 2003; Hankin et al., 1997). Remarkably similar themes have emerged in various different studies. A high prevalence of cessation or reduction of sexual activity, diminished sexual desire and interest, and poor satisfaction have been observed (Adam & Sears, 1994; Green, 1994, 1995; Maticka-Tyndale & Adam, 2002; Schiltz & Sandfort, 2000; Sherr, 1995).

For example, quantitative studies in Canada (Denis & Hong, 2003; Hankin et al., 1997; Maticka-Tyndale & Adam, 2002) and paralleling studies in the UK (Green, 1994, 1995) and USA (Bova & Durante, 2003) found that compared to HIV-negative women, HIV-positive women reported having lower sexual interest, lower satisfaction and lower overall sexual functioning. Although only a few

qualitative studies have been conducted on the sexuality of HIV-positive women, studies coming out of the USA (Adam & Sears, 1994; Siegel & Schrimshaw, 2003; Siegel et al., 2006) found that for many HIV-positive women, being diagnosed HIV-positive had a myriad of adverse effects on their sexual lives, including a diminished sense of sexual attractiveness, decreased libido and sexual desire as well as increased support for, or engagement in, abstinence.

Although the skeletal literature on sexuality is documenting changes in sexuality following an HIV-diagnosis among women living with HIV/AIDS, knowledge of the reasons for these changes is extremely limited. Even less is known about women's subjective understandings and experiences of these changes (Siegel & Schrimshaw, 2003). In order to promote and facilitate HIV-positive women's right to healthy and satisfying sexual relationships, a greater understanding of how such individuals view and experience their sexuality post-diagnosis is essential.

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, discussed and addressed. Despite prevailing debates, acknowledging and supporting the sexual and reproductive rights of HIV-positive individuals holds immense ethical, human rights and public health imperative. In order to ensure that these rights are realized, it is essential to place more attention on the actual needs and experiences of HIV-positive individuals themselves.

CHAPTER 3

METHODOLOGY

Study design and site

This study represents a sub-study of a much larger study that was conducted between March of 2004 and March 2007 by the Population Council, USA and South African collaborators, which implemented a Phase 3 efficacy trial of its leading vaginal microbicide, Carraguard, to assess the efficacy of Carraguard in reducing sexual transmission of HIV among women. Women were recruited for the research by widely distributed advertisements within the community, including at taxi ranks, clinics, hairdressers, loudhailers, in newspapers, and on the radio. They were thus recruited outside of a health-care setting. A total of 6,203 women were enrolled, with final study visits completed by March 31, 2007 (Population Council 2007). The Phase 3 clinical trial took place at three study clinics in South Africa: the Setshaba Research Centre, through the University of Limpopo/Medunsa campus; the Empilisweni Centre for Wellness Studies, through the University of Cape Town; and the Isipingo Clinic, in Kwa-Zulu Natal, through the Medical Research Council of South Africa.

A small subset of HIV-positive women who seroconverted during the course of the trial were contacted and asked to participate in a small qualitative study, a collaborative initiative between the WHRU at UCT and the Population Council, New York. This sub-study was conducted between October 2007 and October 2008 in the Nyanga district of Gugulethu. This was one of the sites for the Carraguard (microbicide) Phase III trial, and is situated in a low socio-economic urban area in

the outskirts of Cape Town, with a population of approximately 340 000 and an antenatal HIV prevalence of approximately 29% (Cooper, et al., in press).

Prior to the data collection process, ethical consent was obtained from the Research Ethics Committee, Faculty of Health Sciences at the University of Cape Town, as well as the Population Council's International Review Board. A qualitative approach was used, whereby in-depth interviews and one focus group discussion were conducted by field workers with prior qualitative methods experience and who were fluent in both Xhosa and English. The interviews were conducted in Xhosa, the local vernacular of participants.

Sampling

All women who seroconverted during the Phase 3 Carraguard trial were contacted and invited to attend the clinics for a one-time monitoring visit that included an assessment of their health. At this visit, women were asked whether they would be interested in enrolling in this small qualitative study. In total, nineteen women were interviewed. Of these nineteen women, fourteen women met the eligibility criteria and were included in this study. Eligibility criteria included being identified as HIV-positive during the Microbicides Phase III Carraguard study and returning for screening; newly diagnosed; citizen or permanent resident of South Africa; at least 18 years of age, the cognitive ability to participate in the study, and willingness to be audio-taped. There is currently no clear and standardized definition of what 'newly diagnosed' entails (Universitywide AIDS Research Program, 1997; S. Patel, personal communication, September 15th, 2008). Based on advice obtained from clinical health professionals and researchers in the field of HIV/AIDS, 'newly diagnosed' in this

study was defined as having seroconverted no more than 12 months prior to being interviewed, and not being on ARVs.

In-depth interviews were conducted with twelve participants, and one focus group was conducted with five participants. Two of the focus group participants opted not to be interviewed individually, and thus the sample size for the study was fourteen participants in total. 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. Furthermore, unlike dominant studies in this field of work, the participants represent a nonclinical sample, recruited outside of any health care setting, and thus the focus was "rich in details about what life is like 'back home'" (Strauss, 1975 as cited in Adam & Sears, 1994). In terms of certain demographic details, all of the respondents were residents of Nyanga, ranging between the ages of 20 and 56 years, with a mean age of 28.58 years. In addition, over half of the women were unemployed and only one participant had completed high school. None of the women were on ARVs, approximately 83 percent were currently using contraceptives, and 50 percent had 1 or no children. Furthermore, 75 percent of the women were involved in a relationship, but only 16.67 percent were married (for more socio-demographic details see Appendix 3).

Data collection

Two female Xhosa speaking field researchers trained in qualitative research methods conducted the in-depth interviews and focus group. Kitzinger and Barbour (1999) emphasize that the major advantage of focus groups lies in their ability to mobilize 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. Statements are challenged, extended, developed, undermined and qualified in a way that generates rich and in-depth data. 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.

With the exception of one, all of the interviews were conducted at Empilisweni Centre for Wellness Studies (one of the study sites for the Carraguard trial). One interview was conducted at Crossroads Clinic which was nearer to the respondent's home. Participation was voluntary. Written informed consent was obtained from all participants prior to the start of the interview. Participants received remuneration for expenses incurred for attending the sessions. With the consent of individual participants, all sessions were digitally recorded and transcribed verbatim from Xhosa into English. All digital recordings were erased following transcription, and all identifying information was removed from all transcripts. Confidentiality and anonymity was thus ensured.

The interview guides were semi-structured and open-ended and included probes for potential additional issues that could emerge as significant concerns (see Appendix 1). 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; social network resources and influences; referral services accessed; emotional wellbeing; 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. 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). Demographic and socioeconomic factors that may influence health outcomes, such as living arrangements, income, experiences of interpersonal violence, and nutritional needs were also collected.

Data analysis

The analysis was undertaken using a grounded theory approach, and incorporating strands of discursive analysis. 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 analyzed (Strauss & Corbin, 1998). The objective is to build and expand, rather than test theory. This allows for the discovery of new insights and enhanced understandings that are derived from the coded categories, themes and patterns. They form the building blocks of theory. 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.

Situated within the broad grounded theory approach, the analysis also involved exploring the discursive purposes of the data. Discourse analysis explores how people deploy language to make sense of their reality, and interrogates how such language or 'discourse' is produced and maintained in the social context (Terre Blanche & Durrheim, 1999). The explanations people give, the arguments they make and the assumptions they hold are not individually-determined phenomena, but are shaped by historicized, socialized and overtly institutionalized statements and practices (Terre Blanche & Durrheim, 1999). Thus, discourse analysis involves exploring how people draw on these

social ways of speaking or ‘interpretative repertoires’, and how such language both structures and constrains meaning (Henning, 2004).

Therefore, grounded theory enabled me to inductively identify categories, themes and patterns that emerged from the data, whilst discourse analysis allowed me to interpret and contextualize the text at greater depth and uncover deeper meanings and themes. A coding list was created by the study team, where after I conducted the coding and analysis of the data. *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.

University of Cape Town

CHAPTER 4

RESULTS

This analysis will be structured somewhat like a journey, moving through the transformative feelings, experiences and desires these fourteen women have undergone since seroconversion. It will become clear that the shape of this analysis also corresponds to the form in which so many of the interviews unfolded, with the women undergoing significant changes within the interviews themselves. Being diagnosed with HIV evoked a myriad of difficult emotions, feelings which appear to continue to consume many of these newly diagnosed women. The analysis will thus begin by shedding light on these sentiments, followed by a demonstration of how since diagnosis, these women have received very limited and narrow guidance in the realm of sexuality and reproduction. 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 severe shock a positive diagnosis produced, as well as the dearth of support afforded to them.

Having provided this backdrop, the bulk of this analysis will track the major changes in sexual and reproductive desires and intentions these newly diagnosed women have recently experienced, shedding light on both the explicit and implicit subjective and socially determined rationale for such alterations. Doing somewhat of a full circle, this analysis will end by returning to the issue of support, shedding light on the important role the provision of appropriate guidance can play for these women.

1. **The emotional effect of the HIV-positive diagnosis**

“I was totally shocked. I knew that my whole life is going to change now...”

The fourteen newly diagnosed women voiced a myriad of difficult emotions they have experienced since hearing about their new positive status. Extreme shock and horror was almost unanimously expressed, with an abundance of comments such as *“I got a shock...I could not even eat ...”*, *“I couldn’t believe it was possible”* and *“I thought that the results couldn’t be so”*. Knowledge of their new positive status appears to have sent some of the women into a kind of subliminal state, as reflected by the utterance *“I was in a state of panic... It was like a dream...I felt like I was sleeping”*. In addition, many of the women became immersed in a sense of fear and terror, as indicated by the ubiquitous remarks such as *“I was terrified”*, *“I was so scared”*, *“I am so worried”*, and *“my anxiety level shot up”*.

For a number of the women, their positive diagnosis produced an immediate sense of hopelessness. Numerous informants reflected on how their previous expectations and aspirations for the future were now challenged by an apparently imminent life-threatening disease. Utterances such as *“I thought about death”*, *“my life will now be very short”*, *“my life had ended”* and *“how far will I go now”* sadly reflect how sentiments of death and dying had permeated these women’s lives. This sense of despair is most poignantly reflected by one woman’s narratives:

I was shocked... I knew that my life is going to change now. I am not going to be that _____[her name] anymore... and also I would not be able to have a second child. And also I had messed up my future, it is messed up ... I am sick now and when I think about it, nothing will ever be the same again...[starts crying]

Similarly, another woman lamented, indicating suicide intention:

I was in huge shock - I just became very quiet - and did not speak at all and could not be made to speak by anyone. I was crying and crying, like could it really be me who had got this thing. Did I imagine it, or are they are lying ... So I was like lost...It's like as if I could kill myself or throw myself in front of a train...

Interestingly, although these two women are talking about the day that they had heard about their positive-status, one is made acutely aware of the lingering nature of such emotions, with such sentiments continuing to permeate these women's current thoughts. Numerous participants spoke in the present tense when talking about the day that they heard about their seroconversion. Furthermore, when speaking about their initial responses, many women began to cry, and struggled to articulate their thoughts. This alludes one to the fact that many of the women continue to be overwhelmed by such feelings. Echoes of this alarm became an undercurrent throughout the interviews.

2. Limited, and selective sexual and reproductive support since diagnosis

"We have not talked about those things ever..."

Within the context of having undergone, and continuing to experience, a large degree of emotional turmoil, one is struck by the dearth of support these newly diagnosed women have received to date. 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 counselor 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 counselor 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”*, *“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?” and

“I want to have more children, but I do not know how” and

“I heard that now you can have a baby when you are HIV positive but I ask myself how, how it can be done”? and

“How am I going to get a child if I am using the condom?” and

“Do you know of other options for me?”

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 counselor 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. One woman 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...

Similarly, in recounting her first and only visit to the clinic since her diagnosis, one woman 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...

It is thus clear that the women have been afforded very little, if not a complete lack of information, in the realm reproduction. Furthermore, the limited guidance that some women have received pertaining to sexuality has been selective in nature, and ideologically infused. Unfortunately, the

newly diagnosed women have received no support for the major shift in sexual and reproductive concerns, desires, and intentions, and associated problems, they appear to be experiencing, the subject of which we shall now turn.

3. 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, both childbearing and sex. The one exception involved an older woman, who prior to diagnosis, had already given birth to three children, after which she desired no more children. 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. In all cases, one was constantly struck by the uneasiness and discomfort the women appeared to experience when talking about sexual and reproductive matters. This is somewhat understandable, given that, as highlighted above, for many of the women, this was *“the first time speaking about this kind of thing”* since being diagnosed with HIV. This uneasiness makes further sense within the context of instructions to behave well and exhibit good behaviour as mentioned above.

3.1. “I no longer desire sex...”

An overriding theme to emerge in discussions around sexuality centered 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:

My interest in sex is not the same as it was before...Now I ... 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...

Similarly, when talking about how her diagnosis has affected her sexual urges, another woman 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...

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. Most women spoke about the consequent “*much less sexual activities*” they are engaging in now. Some women actually appeared to exhibit a strong aversion to sex, highlighting the benefits of, and their support for abstinence. Some women emphasized 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*”. One woman 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...*”. Similarly, another woman 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...

Listening to these women's remarks, one cannot help but be reminded of the ideological underpinnings of the health care providers' rhetoric around sex. As demonstrated above, "*behaving well*" and "*looking after*" oneself were dominant signifiers in the health personnel's discourses on sexuality.

3.2. "I don't want children anymore..."

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 unambiguously illustrated by these two comments:

"Before I found out I had this thing, 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..." and

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...

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 one of the women:

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

WOMAN: Yes, I did.

INTERVIEWER: What were your thoughts before you became HIV+?

WOMAN: 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?

WOMAN: 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...

One is thus left with a sense 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*” and “*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 one woman:

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

WOMAN: I think for me it is contraception.

INTERVIEWER: Contraception? Why contraception?

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

Similarly, also when talking about her current sexual and reproductive needs, one woman exclaimed:

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...

Like various other women, these two participants 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 sterilization may be possible options for HIV-positive women. For example, one woman remarked when considering a

hypothetical case of a pregnant HIV-positive women, *“One might think about abortion. There is no way they can continue. They just can’t continue...”* Another woman asserted that *“I think that people that already have HIV must sterilize”*.

4. Rationale for the shift in sexual and reproductive desires and intentions:

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 as a whole, in their entirety, more subtle motivations materialized.

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 disfavoring child-bearing were the same. The women’s understandings of these changes were discussed and revealed, for the most part, with five levels of meaning: fear, guilt, blame, difficulties in negotiating safe sex, and bodily antipathy. However, fear, associated with sex and reproduction was an overriding concern.

4.1. Fear: “I am forever scared...”

Women spoke with candor about the very real fears and anxieties their new-known 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 center 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 one woman 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 infallible nature of condoms, underscoring the fact that “*mistakes do happen*”. When speaking of the anxiety associated with sex since her diagnosis, one woman 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...

Like so many other women, this woman 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, another woman 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...

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. As one woman remarked when talking about her neighbours' views:

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...

Apprehension around the supposed severe repercussions 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 a possible “*quicker death*”. Perceptions of getting thin as a result of pregnancy 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 childbirth, as suggested in the end of one woman’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 will go down. Like your body weight will go down and down...

Nearly parallel sentiments were echoed by another young woman. 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...

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. One woman 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...”*

Many women emphasized 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 one woman suggests:

I once heard someone saying people who die being positive die because they have sexual relationship...

Similarly, one woman 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...

4.2. Guilt: “Having a baby means ‘please look after my baby’ ...”

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 participants 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*”. One woman 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...

This respondent, like so many other women, 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?*” and “*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 one young woman poignantly pointed out, she is “*reluctant to bother anyone from home*” and does not “*want to hassle people in the community*” and thus her child will be “*left as an orphan*” and “*will go needy*”. In the words of one woman: “*ultimately, having a baby means ‘please look after my baby’*”.

A key informant 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...

The punitive overtones of this woman's remark are clearly revealed by her emphasis on the importance to "*stop creating problems*". In other words, in this woman's 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 emphasized 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 emphasized the supposed social problems HIV-positive people create by having children, as indicated by remarks such as "*that talk troubles*" and "*worries*" them considerably.

4.3. 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 involvements. 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. One woman'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...

This same woman 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, one woman 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*". 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 enjoying sexual involvements. Once again, one cannot help but be reminded of the advice of the health care providers to "*not be careless*" and "*behave well*" now.

4.4. 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, and yet the 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 requirements are now that she is HIV-positive, one woman answered *“Those that make you always protect yourself...like using a condom. I no longer want to what you ma call it...have sex without a condom - I have to use one now”*. Similarly, in describing how she feels that HIV-positive and HIV-negative women have different sexual and reproductive needs, one woman emphasized, *“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...”* 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”* and *“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”*.

The woman who voiced this final quotation 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 two of the fourteen women claimed to have disclosed their status to their partners. 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. One woman 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...

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 their inability, for a number of different reasons, to resist or “stand-up” to their partners. For example, one woman explained that “If you say no, he then forces you to have unsafe sex”. Similarly, another woman 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.

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, one woman 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...

Other women described that denying their partner unsafe sex would result in their partners leaving them, and all sorts of negative repercussions such a break up would involve. As one woman 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". This woman 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 to practice safe sex, and yet the explicit or implicit pressure that denies them this wish has resulted in sex "*now being something that I dread*". One woman explained "*Because he won't wear a condom, it is not nice... You see I no longer enjoy sex when we don't use anything*". Similarly, another woman in a rather embarrassed manner mentioned,

"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".

The way in which sex has become fraught with displeasure is most patently revealed by one women'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".

4.5. Bodily antipathy: "Her womb is dirty and not cleaned, maybe because she is living with the HIV virus..."

A final theme emerging in the women's subjective reasons for why seroconversion has impaired their desire for sex pertains to the devaluing manner in which some women seemed to now view their bodies. One woman mentioned that she feels "*unattractive*", while another woman spoke about how her body feels "*uncomfortable*". One participant tended to make associations between being HIV-positive and being "*dirty*". When talking about health services for HIV-positive women, she movingly stated,

Her womb is dirty and not cleaned, maybe because she is living with the HIV virus. Maybe the one who is clean does not live with the HIV virus - she has paid attention to...looked after herself.

Later on in the interview, when talking about her lack of sexual interest, this same woman remarked:

I don't want my body to be touched...I just don't ...

Taking these two quotes together, this woman seems to imply that an HIV-positive body is 'dirty' and 'not looked after' and is thus 'untouchable'. This woman's reference to her "*need to look after herself*" once again has remnants of the health-care providers' emphasis to the women around the need to regulate their sexual behaviour and behave well.

5. The role that sufficient support and information could play

"If I could properly understand and get the right information...my feelings could change".

Nearing the end of this analysis, it seems appropriate to come back to issues of information and support. So far, this analysis has shown that an HIV-diagnosis has invoked a myriad of sexual and reproductive concerns and changes in desire for these still somewhat shocked newly diagnosed

women. The results thus far have also shown that these women have received both limited and selective information and guidance in the realm of reproduction and sexuality. 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 centered 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 of the benefits of PMTCT, the interviewer proceeded to explain what such a program entails, thereafter asking whether now having this knowledge their child-bearing desires would be affected. Providing various segments of one interview with one of the women 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:

WOMAN: 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?

WOMAN: 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...

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

INTERVIEWER: Do you know about PMTCT?

WOMAN: 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?

WOMAN: 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, this woman'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 entertain 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.

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CHAPTER 5

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** and who were **not recruited from a health care setting**.

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; Chen et al., 2001; Cooper et al., 2007; Richter, Sowell & Pluto, 2002). Furthermore, unlike the present study, these other studies have also shown that desires for children frequently outweighed HIV-related fear and concerns, with many women's serostatus not being the primary influence on their pregnancy-related decisions. These studies however were undertaken amongst women recruited from health care settings and who were frequently in much more advanced stages of the disease. In this study, many of the women had not been receiving care, and had only recently seroconverted. As will be demonstrated shortly, these differences in available support and 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 (Chen et al., 2001; Kirshenbaum et al., 2004; Richter et al., 2002) and developing settings (Paiva et al., 2007; Cooper et al., 2007), these health-related concerns have been shown to deter some HIV-positive women from desiring children.

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, now having a diminished sexual drive, as well as less sexual contacts. The results from this study corroborate findings from other quantitative (Denis & Hong, 2003; Hankin et al., 1997; Maticka-Tyndale & Adam, 2002) and qualitative studies (Adam & Sears, 1994; Siegel & Schrimshaw, 2003; Siegel et al., 2006) in the developed world that revealed an HIV-diagnosis can produce significant disruptions for women's sexuality.

Furthermore, the results from this study both confirm and bring new insights to the skeletal literature on the subjective reasons for changes in sexuality post-diagnosis. As shown in a few studies (Sherr, 1995; Siegal et al., 2006) 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, the importance safe sex has become and the resulting quandaries, as well as many of the women's views

of themselves as dirty or tainted, surfaced as further rationale for why many of the respondents turned away from sex. These factors 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 and worry, guilt and blame, danger and disgust, to still be pleasurable or desirable. This picture becomes more clear and understandable when it is contextualized, juxtaposing it with the newness of their diagnosis as well as the limited support that has been afforded to them. In relation to the ‘newness’ of their diagnosis, the results revealed that almost all of the women continue to be beleaguered with the shock and disbelief their recent diagnosis evoked. Extant research has shed light on how horrifying and distressing finding out one is HIV-positive can be, and the adverse effect this knowledge can have on one’s sense of self and future (Cameron, 2005; Doyal & Anderson, 2005; Green & Sobo, 2000).

Perhaps one of the most disquieting aspects of this emotional distress was the limited information and guidance these fourteen women had received to help contain, and deal with it. While issues around more general support structures available to these women was not the central focus of this study, insights gleaned from the women’s commentaries would suggest that they have been left to face their myriad difficult feelings almost in isolation. The results of this study did reveal explicitly that they have received a dearth of information and guidance pertaining to sexuality and reproduction.

In the realm of reproduction, the women’s lack of knowledge around reproductive options available to HIV-positive women is cause for concern. This was evidenced in numerous ways. None of the

women had spoken about issues around reproduction with any health care provider, many of the women continued to ask questions to the interviewer about reproduction in the context of HIV/AIDS and almost all of the participants were completely unaware of and/or had never heard about PMTCT. This was an unforeseen finding for this setting. This is because in South Africa, PMTCT access has improved dramatically in the last few years, being 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.

This finding may become somewhat more understandable if it is contextualized, viewed in conjunction with 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; Harries et al., 2007). 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.

What was clearly revealed in this study was the role that appropriate support and information could play for these women. When the respondents were provided with knowledge of PMTCT's existence, purpose and availability, **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).

Continuing with the scarcity of information afforded to the women, in the domain of sexuality, the findings revealed that the only guidance the women had received focused purely on encouraging safe-sexual practices. This concurs with other qualitative research in South Africa which found that health care providers tended to approach sexuality in the context of HIV/AIDS within a narrow biomedical paradigm (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; Joffe, 1995; Stein, 2003; Williams et al., 2000; Wilton, 1997). The now well-known ABC (abstain, be faithful or use condoms) approach, dominating contemporary HIV/AIDS prevention initiatives assumes however that individuals have the power to implement self-protective behaviours. As revealed in this study, women frequently do not have the social and structural power to exercise such self-protective behaviours. Insisting on condom-use for many of the women in this study resulted in violence and abuse, and possible abandonment and the consequent loss of livelihood. 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). For this reason, the health-care providers' emphasis on practicing safe sex failed to recognize the actual lived realities of the women in this study.

In addition to ignoring the structural constraints hindering the women's ability to practice self-protective behaviours, the health-care providers' guidance around sexuality was also laden with morally punitive connotations. It seems that the health-care providers' emphasis on 'safe-sex' was imbued with connotations of 'behaving well', exercising sexual restraint and being a responsible and assiduous person. This phenomenon has emerged in other studies amongst diverse HIV-positive populations (Goldin, 1994; Kirshenbaum et al., 2004; Pachauri 2006; Santos et al., 1998; Sherr & Barry, 2004). The regulatory discourses utilized by many health care workers reflect a number of scholars' contention that the HIV/AIDS epidemic has brought back an old-fashioned sexual morality rooted in Judaic-Christian discourse (Treichler, 1989; Watney, 1989; Weeks, 1989). The central moral framework of familial ideology, prescribing monogamy, fidelity and sexual restraint is increasingly informing constructions of acceptable sexual behaviour amongst HIV-positive individuals (Wilton & Aggleton, 1991). Those individuals who do not prescribe to such behaviour, are commonly described in HIV/AIDS discourses as morally contaminated and indulging in what is 'wrong' (for example Goldin, 1994; Joffe, 1995; Nelkin & Gilman, 1988).

Pulling these different threads together, within the context of severe shock, limited information and support and selective advice, women's sexual and reproductive desires and choices were consequently left to the mercy of their own emotional tumult as well as the stigmatizing and regulating social discourses which surrounds them. The women's sexual desires and reproductive

intentions appear to have been influenced by dominant social discourses around HIV-positive persons having sex and children specifically, as well as constructions of being HIV-positive more generally. Many of the women's sentiments drew on, and were buttressed by community attitudes which tended to emphasize the negative connotations associated with childbearing and sexual relations within the context of HIV/AIDS. This is supported by Myer et al (2006) who in their study found considerable stigmatization of sexual activity and childbearing by HIV-positive women, in the general population of South Africa. The major influence such stigma appears to have had on the participants in this study was both explicitly revealed, and implicitly conveyed by the fact that respondents tended to use many of the same words to articulate their own sexual and reproductive attitudes and those of the community.

Furthermore, dirt and pollution have been some of the common constructions of HIV-positive people generally (Gilmore and Somerville, 1994; Lawless, Kippax, & Crawford, 1996; Ratele & Shefer, 2002). This tendency to construct HIV-positive individuals as polluted reflects Douglas's (1966, p. 35) notion of dirt being an anomaly or "matter out of place". That which is not in its proper place, which transgresses boundaries and taboos is labeled as 'dirty' and 'polluting'. HIV-positive people are seen to have violated the moral sexual order. They are consequently designated as polluted, contaminated and dirty. As Douglas (1966, p. 113) emphasizes, "A polluting person is always in the wrong. He (sic) has developed some wrong condition or simply crossed some line which should not have been crossed". Some of the women's feelings appear to have been filtered through these discourses, by viewing their bodies as profoundly dirty and tainted and consequently 'unattractive' and 'untouchable'. Further probing might have elicited the correlation between these personal sentiments and social discourses more explicitly.

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 disciplinary and regulatory discourses employed by health care providers is clearly discernable. The sentiments of blame that turned so many of the respondents away from engaging in and enjoying sex, resonates too closely with the punitive discourses in which the health care providers invested.

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 thus not necessarily ‘false’ constructions of reality. Sexual relations and childbearing amongst HIV-positive individuals does 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. At present, various reproductive options are available for HIV-positive individuals desiring children. These include for example antiretroviral regimens offered in PMTCT programmes, highly active antiretroviral treatment (HAART) during pregnancy, as well as various assisted reproductive techniques for HIV-serodiscordant couples, including artificial insemination, in vitro fertilization, intracytoplasmic sperm injection, self-insemination and sperm washing (Thornton et al, 2004). Most certainly, not all of these services are available in resource-poor settings in South Africa, but may represent an important option where available.

Despite the diverse options available to HIV-positive individuals, at present, post-HIV testing counselling in South Africa and other international settings does not provide any information and guidance pertaining to such options (Bell et al., 2007; Center for Disease Control and Prevention, 2001). Furthermore, although World Health Organization procedures for reproductive counseling of HIV-infected individuals exist, appropriate guidelines have not been developed and adapted for the South African context (Harries et al., 2007). 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).

Furthermore, notwithstanding the results of this study, most certainly, it may be the case that some newly diagnosed women still do not desire children, after hearing about the options available to them. These women may require counselling and information on effective contraceptive options, including emergency contraception, early identification of unintended pregnancies, along with counseling on and access to abortion (Cooper et al, 2004). Thus, supporting the reproductive health rights of newly diagnosed women also involves providing information and access to contraceptive services (de Bruyn, 2005). This can only be achieved if such services are strengthened and linked to HIV care and treatment in South Africa (Cooper 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 around their sexuality, helping them to more realistically evaluate their fears around sexual involvement. Having a healthy and functional sexual identity is intimately associated with well-being, and is a basic human right, something that has been recognized in policy developments both in South Africa (Cooper et al., 2004; Fonn et al., 1998), and internationally (Yanda et al., 2003). 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).

Meeting the unique reproductive and sexual needs and rights of newly diagnosed women also requires effective referral systems to ensure continuity of care and support (Berer, 2004). Many of the women in this study were unsure about when, how and if they needed to return to the clinic, and almost none of the women had heard about any post-test support groups and services. Ultimately, a lack of continuity of care can lead to missed opportunities to provide sexual and reproductive health care to newly diagnosed women, and endangers the realization of their sexual and reproductive rights.

It is thus clear that newly diagnosed women have certain specific sexual and reproductive needs and rights which need to be recognized 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.

Firstly, 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. Individual behaviour change and safe sexual practices are essential if the spread of HIV/AIDS in South Africa is to be curbed. At the same time, health professionals' focus on purely biomedical considerations and their emphasis on 'behaving well' ignores the lived realities of so many women, fosters a climate of fear and imbues sexual relations for HIV-positive individuals with negative connotations and moral values. 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. The training of health-care providers in the rights of HIV-positive persons needs to be initiated, helping them to become

more aware of the values and attitudes they attach to sexuality in the context of HIV/AIDS. This is essential if public health and human rights objectives are to be synergized. Provider attitudes and practices alone however cannot comprehensively address the sexual needs and rights of HIV-positive women. Ultimately, as the result 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.

Secondly, the results of this study indicate that the censorious moral climate about sexuality and reproduction in the context of HIV/AIDS, as well as more general HIV/AIDS stigma, serve 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. Furthermore, community stigma will only be reduced if health policies and services recognize and reinforce the sexual and reproductive rights of HIV-positive people (Cooper et al., 2007; Gruskin et al., 2007). 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.

CHAPTER 6

CONCLUSIONS

The results from this study underscore the need for closer attention from policy makers and health care providers in recognizing 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 recognize 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.

Concerns about generalizing from a small sample do apply to this study. With this said, Goetz and LeCompte (1984, as cited in Schofield, 2000, p. 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, all recently diagnosed, and all having been recruited from outside of a health care setting, 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 integrated with HIV care and treatment, including, but not isolated to, immediately following diagnosis. HIV post-test counseling 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.

In addition, explicit health policies that recognize 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 stigmatization of HIV-positive individuals generally, and specifically 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 one woman in this study, highlighted in the title of this thesis, "*If I could properly understand and get the right information...*" is an urgent call to start recognizing and supporting the sexual and reproductive rights of newly diagnosed HIV-positive South Africans. 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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APPENDIX 1

Interview guide for in-depth interviews

Thank you for agreeing to participate in this interview. As I mentioned, we are conducting a study on sexual and reproductive health for HIV+ women in your community. In this interview, we are going to ask you about how HIV has affected your life, your thoughts about having children and using contraception and your views on and experiences with the reproductive health services available. Everything we talk about is confidential. If there are any questions that you are uncomfortable answering, feel free to tell me to skip those. And if at any time you don't want to continue the interview, that's okay too – just let me know. We really appreciate your agreeing to be part of this study and for sharing information that may contribute to improving the sexual and reproductive health of people living with HIV/AIDS. This interview will take about 1.5 hours. Do you have any questions before we begin?



THIS FORM AND THE ONE FOLLOWING THE INTERVIEW GUIDE MUST BE COMPLETED AND KEPT TO BE ENTERED ON A DATA SET AS BACKGROUND INFORMATION DATA

Study Identification Number THE RECORDING OF THE IN-DEPTH INTERVIEW THAT FOLLOWS MUST BE LABELLED WITH THIS STUDY IDENTIFICATION NO. THAT APPEARS ON THE CONFIDENTIAL ADDRESS FORMS	_____
Interviewer	_____
Date of Interview (dd/mm/yy)	____/____/____
Interview Start Time	
Interview Stop Time	
Data Check Performed by (dd/mm/yy)
Data Entry Date	____/____/____

INTRODUCTORY SECTION. SOCIAL-DEMOGRAPHIC FACTORS & BEHAVIOURAL PRACTICES. We will begin by asking you some questions about your background and personal practices.	
1. Age	_____ (in years)
2. Education – highest grade passed:	____
3. Employment status: (MORE THAN ONE CAN BE CIRCLED)	1 = Employed 2 = Unemployed 3 = Working for self 4 = Seeking work 5 = On grant
4. Who do you live with?	

5. Do you currently have someone who you consider to be your main sexual partner?	1 = Yes 0 = No								
6. <i>IF YES</i> : How many partners do you currently have?	_____								
7. <i>IF YES</i> : How would you describe your main partnership?	1 = Husband 2 = Living together stable partnership 3 = Boyfriend -live in 4 = <i>Boyfriend – stable but not live in</i> 5 = Casual relationship								
8. <i>IF YES</i> : How long have you been in this main relationship?	____ (weeks) ____ (months) ____ (years)								
9. How long have you known about your HIV status?	____ (weeks) ____ (months)								
10. What is your main partner's HIV status?	1 = Positive 2 = Negative 3 = Unknown								
11. How would you rate your current state of health?	<table border="1" style="width: 100%; text-align: center;"> <tr> <td>Poor</td> <td>Fair</td> <td>Good</td> <td>Excellent</td> </tr> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> </tr> </table>	Poor	Fair	Good	Excellent	1	2	3	4
Poor	Fair	Good	Excellent						
1	2	3	4						
12. Have you had any illnesses that a doctor or nurse told you were related to HIV that you have been treated for	1 = Yes 0 = No								
13. <i>IF YES</i> : What has/have this/these been?									
14. Are you currently on antiretroviral treatment/ARV's?	1 = Yes 0 = No								
20. Have you had a CD4 count done yet?	1 = Yes 0 = No								
15. <i>IF YES</i> : Can you explain to me what you understand by it									

.....	
16. <i>IF STILL TO RETURN FOR RESULTS:</i> How do you feel about returning for your CD4 results?	
17. How do you feel about going for HIV care visits?	
18. How many times have you ever been pregnant? This includes miscarriages and terminated pregnancies, or pregnancies where the baby died after birth.	<p>___ ___ Number times pregnant</p> <p>-99 = Refused</p>
19. How many living children of your own do you have?	<p>___ ___ <i>Number of boys</i></p> <p>___ ___ <i>Number of girls</i></p> <p>No</p>
20. Are you currently using male or female condoms?	<p>1 = <i>Male condoms</i></p> <p>2 = <i>Female condoms</i> 3 = <i>both</i></p> <p>= <i>All of the time</i></p> <p>5 = <i>Most of the time</i></p> <p>6 = <i>Some of the time</i></p> <p>7 = <i>None of the time</i></p>
21. (If using condoms) Do you use condoms	<p>1 = <i>With all partners</i></p> <p>2 = <i>Only with some partners</i></p> <p>If only with some, with what partner/partners</p> <p>.....</p> <p>.....</p>
22. Are you currently using a method of contraception	<p>1 = <i>Yes</i></p> <p>0 = <i>No</i></p>
23. <i>IF YES:</i> what method/s are you using?	
24. Where do you go for your contraceptive method?	
25. Before you were diagnosed as HIV positive contraceptive methods did you previously use?	None Method/s

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TOPIC	LEAD QUESTIONS	SECONDARY QUESTIONS & PROBES
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As I have mentioned at the beginning of our interview, I would now like to ask you some questions about how HIV has affected your life.

SECTION 1. LEARNING YOU ARE HIV+

- | | | |
|-----|--|--|
| .1 | I would like to start off asking you to think about when you first learned you were HIV+. What thoughts and feelings went through your head? | PROBE for shock, denial, anger other feelings |
| .2 | After you learned you were HIV+, what did you do? | PROBE for reaction to the news and how you dealt with learning you are HIV+? |
| 1.3 | After learning you were HIV+ who did you feel you could talk to about your HIV status, if anyone, and how did you go about talking with them? | PROBE re: partner, family members, other children; friends, disclosure within the broader community; others e.g. religious person <ul style="list-style-type: none"> • How much time passed? Order of disclosure (who first, who next?)? • Why you chose to disclose to this/these persons? What are the circumstances around your telling? [note: translation – would say telling not disclosing] *** use this question to talk about number of partners. If she mentions a partner, “do you have more than one partner?” |
| 1.4 | How did they react to your being HIV+? (refer to who they talked to) | PROBE for what their reaction to this news was and how this was dealt with; what effect has this had on you? |
| 1.5 | How has being HIV-infected affected/changed your life? | PROBE for: <ul style="list-style-type: none"> ▪ How have you managed this? ▪ How has this affected your moods/feelings compared with before you knew you were HIV positive? ▪ (shows up in 1.6 on its own) ▪ What was the worst thing that happened to you? ▪ What were any good things that happened to you? |
| 1.6 | a) What kinds of support have you found most helpful in dealing with the effects of HIV on your life?
b) What kinds of support would you find most helpful in dealing with the effects of HIV on your life? (ie. what is missing from what you currently can access?) | PROBE for <ul style="list-style-type: none"> ▪ What kinds of support is available to you? ▪ From whom or from what organization/s? ▪ Do you make use of support groups & if so what have been your experiences of this? ▪ For what kinds of things? ▪ Did you feel you needed counseling for coping |

- with the emotion/mental health effects?
- Who would you feel most comfortable in turning to for support?

SECTION 2. FEELINGS ABOUT SEX AND CONTRACEPTION

Now I would like to get your thoughts about sex and using contraception

- 1.7** For some HIV+ people, an HIV diagnosis changes their thoughts, attitudes, and behaviors about sex, while for other HIV+ people, an HIV diagnosis has no effect at all. How if at all, do you think having HIV has affected or not affected your sex life?
- IF FEELINGS CHANGED:*
PROBE for
- Desire to have sex
 - Having sex while HIV-infected
 - Frequency of having sex
 - Pleasure in the sexual act (enjoy it more or less)
 - Need to have safer sex., e.g., abstinence, limit partners, use condoms
- 1.8** Since you learned you are HIV+, how have you dealt with telling or not telling your sexual partner that you want to have safer sex?
- IF have told partner/s: Why? How?*
IF haven't told partner/s: Why not?
PROBE for
- Does it depend on the kind of partner you are with?
 - What kind of partners do you tell? How?
 - Think of a situation when you told a sexual partner you wanted to have safer sex.
 - What did you say or do?
 - What did your partner say or do?
 - When in the course of being together, did this happen?
 - Now, think of a situation when you did NOT tell a sexual partner you wanted to have safer sex.
- 1.9** What do people in your community think about HIV+ persons having sex?
- PROBE for:**
- What have you heard?
 - Has this had any effect on what you think, feel, or do?
- 1.10** If you would like to have sex with someone and still keep yourself safe from new infections, what do you do?
- PROBE for** Male and female condom use, monogamy, not having sex
- 1.11** What happens when *you want* safer sex and your partner does not?

 What happens when your *partner wants* safer sex and you don't?
- PROBE for** what your partners likely reaction is/would be if you were to refuse?
PROBE for reasons for this type of reaction

- 2.1 I know we may have covered this already – but if there are some aspects we haven't could you elaborate: how important is it to you to have/not have (more) children?
- PROBE for:**
- What are some of the reasons that you feel this way?
- 2.2 Once again, I know we may have covered this already – but if there are some aspects we haven't could you elaborate: what effect, if any, does your HIV status have on your desire to have/not have (more) children?
- PROBE for** participant's feelings prior to being diagnosed HIV+ compared with what feelings are now
- IF FEELINGS CHANGED:*
- PROBE for** how is this affected by:
- How you currently feel physically and emotionally?
 - Do you know our partner's status? What is it? Is the change in your desire to have children because of your partner's status?
 - The chances of your infant becoming infected with HIV?
 - The level of support available to you?
- And then PROBE for** would it make any difference if:
- Your partner was Positive and you were Negative?
 - [You/your partner] already [have/has] children?
 - [You/your partner] already have had a child who is infected with HIV or who has died of AIDS?
 - [You/your partner] [have/has] experienced the death of someone who has died of AIDS?
- 2.3 How important is it to your partner to have/not have (more) children?
- PROBE for:**
- What are some of the reasons that you feel this way?
 - [Has this had/would this have] any effect on what you think, feel, or do?
 - What are some of the reasons that you think your partner feels this way?
- 2.4 What effect, if any, does your HIV status have on your partner's desire to have/not have (more) children? [Linked to earlier discussion – 2.2]
- 2.5 How important is it to your family and/or your partner's family for you to have/not to have (more) children?
- PROBE for:**
- [Has this had/would this have] any effect on what you think, feel, or do?
- 2.6 What do people in your community think about HIV+ persons having children? [might come up with question about HIV+ people having sex – refer back]
- PROBE for:**
- What have you heard
 - Would this have any effect on what you think, feel, or do?
- 2.7 There is a program at the health services in your community that you can join when you are pregnant to very much reduce the risks (to about 2 out of 100 women) transmitting the virus to a baby. This is called prevention of mother to child transmission or PMTCT. If you could access this program would your feelings or what [you do/intend to do] be affected by being able to access this?
- [Interviewer: you may note that it is part of Mother and*
- PROBE for**
- Are you aware of and know what PMTCT is?
- [note for interviewer: find out what this is called in the clinic]*

Children services]

- 2.8 There is a program that is available at the health services in your community that when you become weak or ill from HIV, you can take certain medicines that don't cure HIV, but improve your immune system so that you become well again. These medicines are called antiretroviral treatment (ARVs) Would your feelings or what you do/intend to do about having a child/more children be affected by you being on this ARV treatment?
- 2.9 Who, if anyone, would you seek advice or support from in making decisions about having (more) children?
- 2.10 Many women discover that they are HIV+ when they become pregnant. In these cases, what do you think they should do about continuing or not with this pregnancy?

PROBE for

- Are you aware of and know what ARV treatment is?
- Would your feelings change regarding having (another) child if you were on ARV treatment or treatment were available?

PROBE for reasons you would seek advice/support from this person(s)

PROBE for:

- Under what particular circumstances, if any do you think HIV+ women who are pregnant should discontinue their pregnancy?
- Under what particular circumstances, if any, do you think HIV+ women should continue with their pregnancy?

SECTION 3: PROVISION AND INTEGRATION OF REPRODUCTIVE AND SEXUAL HEALTH AND HIV CARE SERVICES

The next set of questions is about how you feel about the sexual and reproductive health and HIV care services. These are services that cover needs for preventing pregnancy (contraception), terminating pregnancy, sexually transmitted infections prevention and treatment, screening for cancers that affect the reproductive system (e.g. prevention of cancer of cervix) etc.

- .1 As an HIV+ woman what do you feel are your most important sexual and reproductive health needs?

By this I mean needs such as preventing pregnancy (contraception), terminating pregnancy, sexually transmitted infections prevention and treatment, screening for cancers that affect the reproductive system (e.g. prevention of cancer of cervix) etc.

- .2 Where would you go to (if anywhere) to seek help for these needs?

- .2 If you have been to seek HIV care, how common is it that a provider/counselor will discuss sexual issues and reproductive health issues with you?

[For interviewer: If the person has not gone to seek HIV care skip this question an go on to question 3.3]

In what ways, if any, are your needs different from uninfected women who use reproductive health services? For example, do you think your needs for contraception are different? If you should become pregnant? Condom needs? Needs for TOP services; needs for PAP smears (check that know what this is

PROBE for

- Is this being done routinely or not?
- If discussed: What issues have you/they discussed? Do you feel that issues of sexual and reproductive health are being adequately discussed?
- What factors may make these discussions difficult?

- What factors could help facilitate these discussions?
- Reproductive intentions; contraceptive needs; dual protection/method use; EC; TOP; sterilization; cervical cancer screening

[NOTE: the following question is to pursue any issues not exhausted in 3.2]
What are the major challenges you face in obtaining sexual and reproductive health services?

PROBE for: If services provision not fully integrated, what challenges do you face – [explain 'integration' in understandable terms]

- In HIV care?
- In S&R health care?

.4 How would you feel about reproductive services being provided where you receive/would receive your HIV care?

PROBE for:

- What would you see as some of the benefits for each?
- What would be some of the drawbacks for each?
- Which way of provision would you prefer?
- What improvements or additions would you recommend to improve services for sexual and reproductive health? -
- Types of services, regularity in providing services, tailoring information to the needs of HIV+ women, accessibility of services, more S&RH-friendly policies

SECTION 4. HIV+ WOMEN, PREGNANCY AND PARENTING. Now for some questions about pregnancy and parenting among HIV+ women.

4. If you very much wanted a child and a doctor or nurse told you that you could reduce the risk of passing on HIV to your partner, or your partner could limit the risk of passing the virus on to you by, for example, only having sex without a condom for 2-3 days in a month– this would be only during the time of the month when a women is most likely to become pregnant/most fertile – how would you/your partner feel about doing this?

4. If you wanted a child, rather than bearing you own child, how would you feel about:

Fostering a child

caring for a relative's child

Formally adopting a child

PROBE for:

- What may be some personal, social and/or cultural and barriers to this?
- What may be some personal, social and/or cultural and barriers to this?
- What may be some personal, social and/or cultural and barriers to this?
-

This is the end of our interview. Thank you so much for sharing your ideas with me. Do you have any questions, or is there anything that you would like to add?

[ALLOW ADEQUATE TIME FOR RESPONSE]

There is a possibility that I may contact you to interview you again in a few months time. If you have further thoughts about any of the issues we discussed today, please call Dr. Diane Cooper, the South African Principal Investigator of the study, at 021-406 6528.

University of Cape Town

APPENDIX 2

Client interview information and consent form

Purpose of Study

You are being asked to participate in research about reproductive and sexual health services for HIV-positive women and men. The purpose of this study is to understand how best to improve the quality of reproductive health services for HIV+ women and men within the HIV care system. The University of Cape Town School of Public Health and Family Medicine and the Population Council in the United States are working together to carry out this study. You are being asked to participate because you were part of the ACASI study.

Alternatives to Study Participation and Rights of Participants

Your participation in this study is completely voluntary. You do not have to take part in this research if you do not wish to do so. You can also decide to stop participating, or refuse to answer any question, at any time. Not participating in the study or withdrawing from the study, will not affect the care or services you receive at this health facility in any way.

Study Procedures

We are conducting interviews about sexual and reproductive health with HIV+ women. If you agree to participate in this research study, you will be asked to participate in a one-hour interview. The interview will cover a range of topics about reproductive and sexual health, including attitudes about pregnancy, use of family planning methods, sexual relationships, sexual practices, condom use, disclosure of HIV status, and children and other family members. This interview will be confidential. Your name will not appear on the interview. The interview will be conducted in your preferred language by a trained interviewer in a private room here at the Uluntu Centre.

Tape recording of interview

You will be asked to allow the interviewer to tape record the interview so that the study staff can make sure that they understand what is being said. We will listen to the tape(s) and type what you said during the interview. After we finish writing out what you said on the tape (s), the tape(s) will be erased. Information from the tapes may be presented at professional meetings or in written articles, in which case no names or other things that could personally identify you will be used. The interview will be confidential; it will be identified only by an assigned number, and your name will not appear on the tapes and interview. No one, except the researchers at the University of Cape Town School of Public Health, will have access to the audio-tape(s) and interview. Tape recording the interview is a requirement for study participation. You can decide to withdraw your consent to be tape recorded at any time, and tapes can be erased either during or after the interview.

Risks

There are no physical risks related to this study. There is a slight risk that you may share some personal or confidential information by chance or that you may feel uncomfortable about talking about some of the topics. However, you may refuse to answer any question or not take part in a portion of the questionnaire if you feel the question(s) are personal or if you feel uncomfortable. There also is a potential risk of violation of confidentiality. We follow strict procedures for protecting confidentiality, and all study information and material will be kept confidential.

Benefits

There will be no direct benefit to you as a result of your study participation. However, your feedback will help us to improve the quality of reproductive health services to HIV-positive women and men attending HIV care clinics.

Compensation

You will receive R 50 for your time for completing this interview.

Confidentiality

All study staff will be told not to discuss any identifying information that they learn about you. All study information or material will be identified only by a participant number and will be kept confidential in a file in a locked drawer at the University of Cape Town School of Public Health and Family Medicine. No one, except the researchers at the University of Cape Town School of Public Health and Family Medicine will have access to the interview data. This information also will be available only to the researchers at these institutions as part of routine checks, to ensure that this study is being conducted in a professional way that protects your rights.

The data file from the interview will be sent by e-mail between South Africa and New York without your name and anything else that may identify you. Study results will be reported only in summary form so that no individual participant can be identified.

If you have any questions about this study or study procedures you may ask those now or later. If there is anything that is unclear or you need further information; we shall be pleased to provide it. If you wish to ask questions later you can contact Dr. Diane Cooper, whose telephone number and other details are listed below.

The University of Cape Town's Research Ethics Committee has approved recruitment for this study. The Research Ethics Committee oversees the protection of people participating in research studies.

If you have any questions about your rights as a research participant, or any complaints, you can call the Project Office or University of Cape Town's Research Ethics Committee. Contact people and numbers are: Dr. Diane Cooper, Senior Researcher, University of Cape Town School of Public Health and Family Medicine: Telephone: 27-21-406 6528; Fax: 27-21-406 6788; e-mail: Diane.Cooper@uct.ac.za; Professor. M. Blockman, Chairperson, University of Cape Town's Research Ethics Committee, Telephone: 27-21-406 6496; Fax: 27-21-406 6411.

Documentation of Consent

I voluntarily agree to participate in the research study described above.

(Print Name)

(Date)

(Signature)

I have discussed the proposed research with this participant, and, in my opinion, this participant understands the benefits, risks and alternatives (including non-participation) and is capable of freely consenting to participate in this research.

(Print Name of Person Obtaining Consent)

(Signature of Person Obtaining Consent)

(Date)

University of Cape Town

APPENDIX 3

Socio-demographic characteristics of participants*

Characteristic	Participants (n=14) n (%)
<i>Mean age (standard deviation)</i>	28.58 (9.67)
<i>Median age</i>	28
<i>Age range (years)</i>	20-56
<i>Age Group</i>	
<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)
<i>Highest grade obtained</i>	
≤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)
<i>Employment status</i>	
Employed	5 (41.67)
Unemployed	7 (58.33)
<i>Marital status</i>	
Married	2 (16.67)
Not married	10 (83.33)
<i>Partner status</i>	
No partner	3 (25.00)
Lives with partner	3 (25.00)
Partner not cohabiting	6 (50.00)
<i>Contraceptive use</i>	
Currently on contraceptives	10 (83.33)
Currently not on contraceptives	2 (16.67)
<i>ARV treatment</i>	
Currently taking ARVs	0 (0.00)
Currently not taking ARVs	12 (100.00)
<i>Number of living children</i>	
0	3 (25.00)
1	3 (25.00)
2	4 (33.33)
> 2	2 (16.67)

*Socio-demographic data is unavailable for two of the participants