

# Perceptions of HIV and Fertility Among Adolescents in Soweto, South Africa: Stigma and Social Barriers Continue to Hinder Progress

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**Abstract** The scale up of highly active antiretroviral therapy (HAART) for the treatment of HIV has raised new concerns relating to fertility desires and outcomes. Among these concerns is social stigma surrounding HIV and childbearing. High rates of infection and patterns of high fertility make adolescents a crucial demographic to qualify perceptions of HIV and fertility. We conducted two focus groups ( $n = 11$  males,  $n = 8$  females) with participants ascertained from an HIV adolescent community advisory board in Soweto, South Africa. Adolescents raised concern over re-infection by HIV positive couples attempting to conceive. They also used this concern to justify their attitudes that HIV positive couples should adopt when faced with the desire to have children. Lastly, participants spoke of a need to revise adolescent sexual and reproductive health services to make them more youth-friendly where users could avoid stigma generated by community health-care workers. This study adds to the growing literature that calls for an evaluation of adolescent HIV educational

programs and a healthcare worker intervention that specifically targets stigma surrounding HIV and childbearing.

**Keywords** Adolescents · Stigma · Fertility · HIV · Childbearing

## Introduction

A decade ago, many nations in sub-Saharan Africa afflicted by the HIV/AIDS pandemic were coping with limited access to antiretroviral (ARV) treatment. Since that time, access to ARVs has substantially increased in many parts of sub-Saharan Africa (Joint United Nations Programme on HIV/AIDS 2008). The scale up of highly active antiretroviral therapy (HAART) has raised new issues relating to fertility desires and outcomes (Kaida et al. 2006). This issue lies disproportionately among young women who are at the greatest risk of becoming infected at a time when many contemplate and act upon their fertility desires. In 2007, 12.9% of young South Africans aged 15–19 years were infected with HIV (National Department of Health, South Africa 2008). Childbearing among adolescents in South Africa also remains high. One in three girls have become pregnant by age 20 (Kaufman et al. 2001) and 13–16% of these pregnancies occurred among HIV-infected women (National Department of Health, South Africa 2008).

Medical advances in the prevention and control of mother-to-child transmission of HIV have resulted in a reduction in vertical transmission rates to around 1–2% with HAART (Volmink et al. 2007). Additionally, with appropriate treatment resulting in a non-detectable plasma viral load, there is little to no risk of HIV seroconversion among serodiscordant couples desiring fertility (Barreiro et al. 2006).

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Despite this evidence, research in the United States suggests that high levels of disclosure-related stigma produce an 18.6% decrease in the odds of a woman with HIV choosing to become pregnant (Craft et al. 2007). In South Africa, Myer et al. (2006) showed that childbearing and HIV also remains highly stigmatized, with negative attitudes towards fertility and HIV being significantly associated with not knowing someone who is HIV positive. Among adolescents, however, these attitudes have not yet been fully elucidated. It is thus timely to uncover and qualitatively characterize the attitudes towards HIV and childbearing among the adolescent community.

## Methods

### Study Setting

Soweto is a collection of townships situated southwest of Johannesburg with a population of ~3,000,000 (City of Johannesburg 2008). This study was conducted at the Perinatal HIV Research Unit (PHRU) located at the Chris Hani Baragwanath Hospital in Soweto, a research division of the University of Witwatersrand.

### Eligibility

Participants were recruited through an adolescent community advisory board established at PHRU. Community advisory board members were asked to recruit other members of their peer group who may be interested in participating. Eligibility criteria included aged 16–18 years and residing in Soweto. HIV status was measured by self-report at the time of participant recruitment. Being sexually active was not inclusion criteria for participation in this study. Participants were required to sign a consent form to participate in the study and parental consent was sought for all participants under the age of 18 years. No adolescents or parents refused consent for participation in this study. Ethics approval for this study was given by the Research Ethics Boards of the University of Witwatersrand in Johannesburg and Simon Fraser University in British Columbia, Canada.

### Data Collection

Data was collected by trained facilitators in a meeting room at Chris Hani Baragwanath Hospital, located in the Diepkloof suburb of Soweto. Participants were asked to complete a brief demographic questionnaire that elicited information on age, household demographics and future fertility desires. In total, two focus groups were conducted, one with male participants and the other with female participants.

### Focus Group Discussions

Each focus group discussion lasted ~1.5 hours. The interview guide/moderator's guide for the FGD was semi-structured based on a pre-designed focus group moderator's guide. Eleven males participated in the first focus group while eight females made up the second. Both focus groups were conducted in English with participants invited to respond in the language that they were most comfortable. While the moderator of the focus group spoke only English, a note taker for each focus group, fluent in Zulu and Sotho (local languages of Soweto), assisted the moderator in the translation of some of the discussion.

### FGD Question Content

FGD questions addressed primarily attitudes of adolescents towards HIV and childbearing. General attitudes towards fertility and HIV were assessed with the following questions:

- Can you tell me your thoughts about having children in the future?
- Who encourages you to have children?
- How does your community feel about adolescents who fall pregnant?
- What does your community think about people who are HIV positive?
- How might you think pregnancy would be different if you were HIV positive?
- How would someone access information on pregnancy and HIV in Soweto?

Perceptions of HIV and childbearing were further explored by stimulating discussion with the following two scenarios written in plain language to ensure comprehension among adolescent participants:

#### *Scenario 1*

A 17-year-old girl who knows she is HIV positive sees a doctor because she thinks she might be pregnant. She is not currently taking medication for HIV. The doctor confirms the girl is pregnant. She is worried about her health and the health of her baby and seeks counseling to help understand her concerns.

#### *Scenario 2*

A 25-year-old woman and her husband want to have a child. They are both HIV positive but have both been taking treatment for 3 years and both feel very healthy. Their community and family know they are both HIV positive and the couple has also heard there is treatment to

prevent the woman from passing the virus to her unborn baby. However, they are still very concerned about the health of their unborn child and what the community may think about them falling pregnant.

### Data Analysis

Each FGD was audio recorded and transcribed verbatim. Where a local language was used, the discussion was translated into English. Transcripts were analyzed for key qualitative themes using the analytical formula of grounded theory (Corbin et al. 2008; Walker and Myrick 2006). Each of the three thematic categories presented in our results were drawn out of transcript analysis. From these themes, we generated a common code system, which was revised several times as coding proceeded. This coding system was used to identify key quotes from each transcript. Quotes below are presented verbatim and are identified with their study ID number.

### Results

Table 1 shows demographic characteristics of the male and female focus group participants. Eleven males participated in the first focus group and eight females in the second. The

**Table 1** Demographic characteristics of focus group participants

	Males (focus group 1)		Females (focus group 2)		Total
	<i>n</i>	%	<i>n</i>	%	
Total number of participants	11		8		19
Age					
16	4	36	0	0	4
17	5	45	4	50	9
18	2	18	4	50	6
Median number of household members	8, IQR <sup>a</sup> : [5.5,10]		5.5, IQR <sup>a</sup> : [5,6.5]		
Number of household members pregnant					
0	7	64	7	88	7
1	3	27	1	13	4
Missing	1	9	0	0	1
Number of household members with HIV					
0	8	73	4	50	12
1	0	0	0	0	0
2	0	0	2	25	2
3	1	9	0	0	1
4	0	0	1	13	1
Missing	2	18	1	13	2
“Would you like to have a child?”					
Yes now	0	0	0	0	0
Yes in the future	10	91	4	50	14
Never	0	0	2	25	2
Undecided	0	0	2	25	2
Missing	1	9	0	0	1

<sup>a</sup> IQR, Interquartile range

median number of household members per participant was seven. In total, four participants (21%) reported that a member of their household was currently pregnant and another four participants (21%) reported having household members who have disclosed a positive HIV status. The vast majority of participants expressed the desire to have children in the future. Two participants (11%) expressed a desire to never have children while two other participants (11%) were undecided at the time of questionnaire completion. All study participants self-reported as HIV negative.

### Community Attitudes Towards Childbearing

Participants were asked about how their community feels about having children. Participants believed that having a child is a crucial part of life. As one female participant stated:

“I think it’s about having future generations...just continuing the generation and knowing that there is another person leaving your legacy behind.” [ID No.: F02, 17-year-old female]

Most participants agreed that while “accidents” can sometimes happen, the choice to have a child is almost always made by the mother. However, one participant

added that some girls in Soweto are not always given the choice to have children. In South Africa, all women who have children under 6 years of age are entitled to a child care grant, the “Child Support Grant”. She explained:

“There’s girls that have babies for grants sake. There are some places where poverty is very high. Now if there is girls in the house and the mother is really struggling to take care of the rest of kids...she will tell the girl to go make a baby and then she will get the grant and that grant will be used for stuff in the house.” [ID No.: F05, 18-year-old female]

Speculation is rife in South Africa about the association between teenage pregnancy and the Child Support Grant. Research undertaken in 2006, by the Department of Social Development failed to show any link between teenage pregnancy and uptake of the Child Support Grant. Both male and female participants agreed that having a child as a teenager would be both unacceptable by the community and not consistent with personal values.

#### Attitudes Towards HIV and Fertility

Two major themes emerged with regards to HIV and fertility in response to the scenarios. First, participants’ primary concern with couples having children who are HIV positive was their risk of re-infection as illustrated by the following quotes from a male participant:

“They should be very worried because they are going to re-infect each other with this virus and then they will leave the treatment unable to work and they will give themselves the risk of getting more sick.” [ID No.: M02, 18-year-old male]

Secondly, participants also expressed that adoption would be a much better option for this couple than trying to have a child. The following quote by a male participant highlights the feelings of most focus group members in response to the second scenario:

“I think what is best for them is to adopt a baby because when they will have a newborn baby, what if after four years they are going to die and then the baby will still be a child.” [ID No.: M10, 17-year-old male]

Adoption was further supported by many participants’ fears that the couple would re-infect each other. Another male participant defended the position of the group by saying:

“I think it is right to adopt because they have HIV and AIDS and to my opinion they must adopt because they should think that the more they have unprotected

sex the more they reach AIDS through re-infection” [ID No.: M01, 16-year-old male]

Re-infection or “superinfection” is a common topic amongst HIV infected adults in Soweto. There is a belief that if someone has unprotected sex with another HIV infected individual, one can get re-infected or “superinfected” with a different viral strain that can render ARV treatment ineffective.

#### Barriers to Accessing Services on HIV and Fertility

Participants unanimously agreed that Soweto lacks youth-friendly services and public clinic nurses generate much of the stigma surrounding the issue of HIV and fertility. One participant noted:

“In Soweto, we have a youth clinic that is situated in Kliptown called Kygana Motsha and it is a place that I have been going a lot. The services are very good and they do not judge you. I prefer to go there for my information than any other public clinic where there is everyone there because the nurse might as well tell me in front of everyone, you are HIV positive and dying, you have AIDS, you can’t have children. Just go home and sleep, you don’t need children.” [ID No.: F06, 18-year-old female]

Another female participant added:

“Nurses in Soweto do not treat you like human beings. They stigmatize you and by the time you leave there you just have a different mindset. If you came happy because you are wanting to find information on being HIV positive and wanting to have a child, the nurse will come there, and maybe she pretends to be your mother so she gives you this long lecture on how you are not supposed to have children.” [ID No.: F04, 17-year-old female]

Participants expressed their desire for more youth friendly services where they can receive advice from people their own age who will not judge them for their behaviours. One participant’s final comment in the focus group stated:

“What I feel, is that Soweto needs more clinics like Kygana Motsha where there are teens who are speaking to people they feel are at their level. I mean if you go to the community clinic, I don’t want to speak to old ladies about my problems because then she speaks to me like she is my mother...So if that would be implemented then more things would change in Gauteng as a whole or maybe even worldwide.” [ID No.: F04, 17-year-old female]

## Discussion

This study qualitatively reports the perceptions of adolescents who regard themselves as HIV negative, on fertility and HIV, who reside in a country where more than one in ten adults is HIV infected (National Department of Health, South Africa 2008). To the best of our knowledge, this is the first study to report these perceptions, specifically among adolescents. Our study adds to the growing body of literature on HIV and fertility. We present three key themes of importance to the field of fertility and HIV. First, participants in both FGDs perceived unprotected sex among HIV positive couples as a serious threat to the progression of their disease. The threat of re-infection was stated as the most important reason why HIV positive couples should not try to conceive. This level of concern about a process called HIV superinfection is perplexing. Although, the scientific community appears to have reached little consensus on this topic (Smith et al. 2005), recent literature may suggest that HIV superinfection is more common than once thought. Piantadosi et al. (2007) detected seven cases of HIV superinfection in a cohort of 36 high-risk Kenyan women. However, regardless of a true prevalence of HIV superinfection, the authors suggest that this data has far greater implications for vaccine development than for individual disease management. This would suggest that the issue of HIV superinfection needs to be redressed among Sowetan youth in light of the fact that HIV superinfection is still not of enough concern to justify an abstention of conception among HIV positive couples.

Secondly, adolescents in both focus groups felt adoption would be a much better option for an HIV positive couple wanting to have a child. Participants also often used re-infection as support for adoption. Members of each focus group also supported their attitudes of adoption by saying parents would not want to have kids when they are ill. However, Ezeanolue et al. (2006) quantitatively assessed sexual knowledge, behaviours and fertility intentions of adolescents with perinatally acquired HIV in the United States. Among the 50 participants who were aware of their HIV diagnosis, 70% expressed intent to have children. The authors concluded that fertility intentions were highest among those adolescents who perceived the risk of mother-to-child transmission as low. This suggests that with more education on the fertility options of HIV positive women, attitudes towards childbearing with HIV may change.

Lastly, participants highlighted their concern that progress surrounding fertility and HIV continues to be hindered by attitudes of community healthcare workers. The issue of healthcare worker stigma requires further research and discussion within the South African context and appears to be a requisite for overcoming community stigma surrounding HIV and fertility. In a 2006 Nigerian

study by Sadob et al. (2006) only 77% of nurses surveyed correctly identified breastfeeding as a mode of HIV transmission. A second study in a Madagascar context, demonstrated that only 9% of healthcare workers were aware of HIV transmission through breastfeeding and 73% were unaware of interventions to prevent mother-to-child transmission (Hentgen et al. 2002). These data corroborate our study's qualitative description of healthcare worker stigma towards HIV and fertility and call for direct healthcare worker interventions that target the knowledge, attitudes and practices of community healthcare workers.

Participants also spoke about their desire for more youth-friendly sexual health services. Particularly, participants expressed concerns for services that may eliminate the stigma that their HIV positive peers may face when they try to access information on HIV and fertility from community clinics. Kipp et al. (2007) highlighted this barrier in Uganda where sexual and reproductive health services were not adequately tailored for young people. These authors called for a redress of programs, which target healthcare worker attitudes in addition to increasing the confidentiality and privacy of clinic users.

## Limitations

Members of a local Sowetan community advisory board on HIV were asked to be participants in this study, which perhaps added an additional filter of information to this study. Convenience sampling from this population was used to gain valuable insight from youth who have pre-existing knowledge of the services and social climate surrounding HIV and fertility. The adolescents of this study were only able to comment on their perceptions of HIV and fertility because they had a background on the subject and perhaps youth selected at random from the community may not have been able to provide as much insight into the topic. Additionally, access to the adolescent population at large was not possible without the avenues and connections that take time to appropriately establish.

Additionally, although this study only qualitatively evaluated the perceptions of adolescents from two focus group discussions, we were able to provide a thick, narrative description. In this study, the authors are confident that data saturation was reached to adequately describe issues relating to the important topic of adolescents, HIV and fertility perceptions with the number of participants available for study. This evidence can be used to support future quantitative and qualitative studies that acknowledge the stigma and social barriers hindering the progress of issues relating to HIV and fertility.

Our study also asked adolescent participants to self-report their HIV status. While all participants reported their status as negative, this may not be a reflection of their true

HIV status. Testing rates in South Africa among adolescents remain low. In 2004, only 11% of HIV positive young men and 19% of positive women reported knowing their status (Pettifor et al. 2005). It is also well documented that many social barriers continue to delay young people from seeking voluntary counseling and testing (VCT) (MacPhail et al. 2008). However, while participants' actual status may not be concordant with their reported status, this was expected to have minimal influence on their perceptions of HIV and fertility. Participants who believe their status to be negative would thus share their attitudes from an HIV negative lens. We recognize that response bias is always a possibility. In an attempt to minimize the influence of response bias, participants were assured by both the moderator and the translator, that there were no right or wrong answers and that their experiences and attitudes would not be judged by any member of the research team.

Lastly, we failed to ascertain data from our participants on sexual activity and behaviour. Particularly, characteristics on sexual activity and choice of contraception would be of use to further qualify the relationship between HIV and fertility stigma and sexual behaviour. In 2004, Simbayi et al. (2004), reported that in a multi-stage cluster sample of 2,430 South African adolescents, the median age of sexual debut was 16.5 years and with very little variation by sex. These data indicate that it was safe for our study to assume that in two focus groups of 19 adolescents aged 16–18 years, a number of participants would have sexual experience, which may contribute to an exploratory analysis of the stigma surrounding fertility and HIV. We were not able to explore issues relating to sexual behaviours in the current study however, future research should incorporate this important topic into the research agenda. Additionally, to avoid overlap with other studies currently being conducted at PHRU specifically exploring sexual behaviour and HIV in the same age demographic, we chose to explore only attitudes on fertility in the context of HIV.

## Conclusions

Adolescents are of critical importance for sexual health interventions worldwide and in South Africa particularly. This age group not only represents the most under-served and under-researched of populations, but also a demographic that is most at risk of receiving inaccurate HIV education and reproductive advice. A lack of researcher integrated adolescent social networks and strict ethical guidelines may unintentionally be silencing young people who most need to have a voice in sexual and reproductive health research (Flicker and Guta 2008). Additionally consolidating existing HIV services for adolescents with existing sexual and reproductive health services will ease

the recruitment and access to adolescents for future research. It is imperative that this age demographic receives evidence-based knowledge and interventions that are tailored to meet the needs of adolescents. The qualitative data in this study suggests a need for reviewing the current practices of HIV education in Soweto that includes an update and consensus of existing knowledge on HIV superinfection prevalence and the success of ARV therapies in reducing virus transmission (Gay and Cohen 2008). Finally, this study also supports the importance of health-care worker interventions to increase capacity in this group and to help minimize HIV stigma in relation to fertility. This may include youth-friendly sexual and reproductive health services that include peer support and healthcare workers trained specifically to work with an adolescent population.

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