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# The Experiences of HIV-serodiscordant Couples at the Perinatal HIV Research Unit in Soweto, South Africa

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**ABSTRACT** The incidence of HIV-sero-discordancy among heterosexual couples is estimated between 30 to 50%. This poses great risk to increased spread of HIV as seronegative partners in a sero-discordant relationship have higher risk of HIV infection compared to negative serocordant couples. This paper reports on the experiences of HIV sero-discordant couples at the Perinatal HIV Research unit in Gauteng Province, South Africa. A qualitative approach was adopted, underpinned by interpretative phenomenological analysis. Data were collected using semi-structured interviews of seven couples (N=14). The data were thematically analysed using interpretative phenomenological analysis framework.Three superordinate themes emerged as the experiences of couples after receiving HIV sero-discordant diagnosis namely: psychosomatic responses to HIV serodiscordant results, Impact of serodiscordancy on the couples' relationship and support for serodiscordant couples.The main source of the negative experiences were mainly indicating inadequate information and counselling offered to serodiscordant couples after receiving serodiscordant diagnosis. The findings of this study have both practice and policy development implications. Recommendations have been put forward for development of contextual relevant HIV Serodiscordant Couple Counselling and Support guidelines focusing on enhancing knowledge and skills of health care professionals responsible for counselling and supporting HIV sero-discordant couples.

## INTRODUCTION

The term Human Immunodeficiency Virus (HIV)-serodiscordant refers to a sexual relationship in which one partner is HIV positive and the other partner is HIV negative (World Health Organisation (WHO) 2012). The prevalence of HIV sero-discordance relationship differs from place to place. Rispel et al. (2009) indicted that an estimated two-thirds of infected heterosexual couples have been classified as HIV sero-discordance. De Walque (2007) reported that approximately half of people with HIV who are in stable relationships have HIV-negative partners, implying that they are in a sero-discordant relationship. A study conducted in South Africa by Essien (2012) indicated that among couples tested, 37% had discordant HIV results confirming the earlier studies by Rispel et al. (2009). A study conducted in India on HIV transmission amongst HIV-serodiscordant couples reported the 1.2% HIV infection rate per year among HIV-seronegative partners. The authors concluded that higher rates of condom use, lower rates of STIs and higher CD4 counts among the Indian HIV sero-discordant couples might account for those lower rates. This picture depicting low incident rate of HIV infection in a sero-discordant relationship is completely different to what is happening in Africa, especially in Sub-Saharan Africa where the incidence of HIV infection is 10 to 100 fold higher in serodiscordant couples than in the relationships where both partners seronegative (Mujugira et al. 2011). In South Africa, the infection rate of negative partner in serodiscordant couples is reported to be ranging from 10 to 20% per year higher than of those who are in sero-negative relationship.

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Rizza et al. (2012) indicated that serodiscordant couples experience a variety of emotions following the diagnosis of HIV sero-discordant results. The emotional reactions mentioned include shock, denial, depression, loneliness and feelings of loss, uncertainty, grief and sadness. To some individuals engaged in serodiscordant relationship, these reactions may persist and even lead to behavioural challenges such as alcoholism, poor communication, cessation of sexual activities and even separation or divorce to avert facing the situation (Cichocki 2007). Same findings were also documented by Floyd and Crampin (2008) indicating that discordance can threaten the couples' s relationship to an extent of separation.

These reactions may also be worsened by lack of counselling as counselling is defined as a structured conversation aimed at facilitating a client's quality of life in the face of adversity. Bunnell et al. (2005) reported that some reactions such as denial and behavioural challenges highlighted in the previous paragraphs are the results of misunderstanding of HIV sero-discordancy. A study in Abidjan among HIV positive women showed that their male partners did not seek HIV testing assuming that if the wife has tested for HIV, the results obtained automaticaly reflect their sero-status (Brou et al. 2005).This confirms earlier documentation by WHO (2012) stating that the concept of 'HIV sero-discordancy is poorly understood in most communities despite its high prevalence. Lack of understanding of HIV serodiscordancy and inadequate counselling may contribute to continuous increase in the infection rate of HIV seronegative partners in this type of relationship. This increase will defeat the South African government's goal of Zero new HIV infection by 2015 (South African National Aids Council 2011). This paper presents the experiences of HIV sero-discordancy amongst heterosexual couples at a Perinatal HIV Research Unit in Gauteng Province, South Africa.

## METHODOLOGY

### Design

As limited studies have been conducted regarding the experiences of HIV sero-discordant couples (Rispel et al. 2009), the researchers opted to use an interpretative phenomenological analysis (IPA framework as both a methodology and as a tool for data analysis. This Framework was chosen as the researchers were not focusing only on exploring the participants 'experiences, but also offering expert interpretation of those experiences" (Smith 2009).

### Sampling

The study was conducted at a Perinatal HIV Research Unit in Gauteng Province, of South Africa.The Perinatal Research Unit serves members of one of the largest townships with a population of over one million people. Majority of the population in that township are black South Africans from all over South Africa and also migrants from other African states. Consequently, the greatest challenge of this township is overcrowding, informal settlements, poor sanitation, high prevalence rates of unemployment, crime and HIV and Tuberculosis (TB). The Perinatal HIV Research Unit is one of the leading research centres in South Africa which is deeply involved in HIV related research and clinical activities. Ethical clearance for conducting the study was obtained from all relevant organisations. To recruit the participants of this study, the couples visiting The Perinatal Research Unit for HIV related services were given information leaflets containing the study aim, inclusion criteria, means of adherence to ethical issues emphasising confidentiality and the benefits of participating in the study.Those who were willing to participate were requested to complete a consent form and make appointments for interviews. A total of 7 heterosexual HIV-serodiscordant couples, aged from 18-to 50 years who were in a relationship for more than six months participated on the study. This sample size was determined by category saturation.

### Data Collection

All participants signed an informed consent form before collection of data. Semi-structured interviews were conducted between September and December 2013 using interview schedule designed in with IPA guidelines (Smith 2005). The interview schedule included prompts and open questions to enable participants to freely discuss issues relating to living in HIV-serodiscordant relationships.Though participants came as a couple, individual interviews were conducted. This was done based on researcher's previous experience of interviewing the participants

as couples and realised their reluctance to freely and openly share their experiences. Interviews were conducted by one of the researchers who is an expert in couple HIV counselling and testing. All interviews were conducted in the Perinatal HIV Research Unit's counselling centre for HIV to ensure confidentiality. Audio-recording was done to ensure capturing of participants' responses. Field notes were also taken to document other cues that were not audio recordable such as emotions and body language. Each interview lasted for about 45 to 60 minutes. At the end of each interview, some time was spent debriefing participants. They were encouraged to talk about their experiences of the interviews and their feelings of being interviewed about their life in HIV- serodiscordant relationships. Each participant was given the contact details of a psychologist working in the PHRU in case they needed further counselling and assistance.

### Data Analysis

All interviews were transcribed verbatim and transcripts were analysed manually and independently by all the researchers following steps for IPA approach as described by Smith (2005). The steps included: (1) Reading and re-reading of a transcript, (2) Note making and development of emergent themes, (3) Clustering of emerging themes into superordinate themes, (4) Formation of master table of themes consisting of superordinate themes, sub-themes and associated quotes to illustrate where in the transcripts the themes could be found. (The above steps were followed for each transcript). (5) Comparing of and examining similarities of the master tables of themes of each transcript and finally (6) Compiling of a single master list of themes for all the transcripts.Three superordinate themes containing a number of sub-themes emerged from this process of analysis.

## RESULTS

Three super-ordinate themes that emerged from the data analysis were (1) Psychosomatic responses to HIV serodiscordant results, (2) Impact of serodiscordancy on couples' relationship and (3) Support for serodiscordant couples. These superordinate themes contained a number of sub-themes which are illustrated in bold. Extracts from participants' narratives written in italics are used to support the discussions of identified themes. The initials "MP" (seropositive male), "FP" (seropositive female), "FN" (seronegative female) and "MN" (seronegative male) are used in this paper to indicate the HIV-serostatus and gender of participants.

### Psychosomatic Responses to HIV Serodiscordant Results

This theme relates to the responses of serodiscordant couples immediately after receiving HIV-serodiscordant results. The responses were mainly psychological but end up affecting the physical functioning.Those responses were reported by majority of participants regardless of their HIV status. The frequently reported psychological response was denial of the HIV-serodiscordant results which were expressed by most participants regardless of their own HIV-serostatus.

*Immediately when the nurse told us that my wife is HIV positive and I am HIV negative, I completely denied that knowing that I married her being a virgin. If it was me, yes, that would be understandable because I had several sexual relationships before marrying her (MN).*

Though some participants expressed denial, to some participants, the results brought intense fear and panic which was based on the assumptions that being diagnosed as HIV positive is a one way ticket to the grave. Other participants verbalised that their fear was related to knowledge of a relative or someone who died of HIV and AIDS related conditions. The experience of fear was expressed by both seronegative and seropositive partners where seropositive individuals were afraid of what will happen to themselves whereas, for the positive once it was related to feeling for the partner.

*Thinking that she is going to be very ill and die soon make me feels so anxious and nervous. I have seen people dying of AIDS. They just shrink in few months and die. I really did not want to see her undergoing that process (MN).*

According to some participants, receiving HIV-serodiscordant results did not only affectthem psychologically, but also presented in physical symptoms.

*After the nurse told us about the results, I immediately suffer from continuous diarrhea. This was accompanied by inability to swallow anything, my throat was just blocked but I was not even feeling hungry for the whole week (FP)*

The impactof receiving HIV-serodiscordant-diagnosis did not only affect the individuals but it also affected the relationship of those couples.

**Impact of Serodiscordancy on Couples' Relationship**

This theme relates to the impact of receiving serodiscordant results on the sexual and social relationship of the couples involved in such relationships. According to participants, some seronegative partners, especially females seems to be less concerned about the seropositive status of their male partners as one indicated that she had continued to have sexual intercourse with her partner as they use to do

*For me there is nothing which have changed, He is still my husband and we are continuing to have sex without using a condom. If he infect me it will still be fine. Why should I punish him knowing that he never liked condoms? (FN)*

According to some participants, though the seronegative partners were willing to engage in sexual relationship, it seems as if there was reduced sexual desire on the seropositive male partner as indicated by the following excerpt:

*The sex part of it is tough as he could not get an erection no matter what I do. I just told myself that this is due to the treatments which he was given at the clinic. When he complete taking his treatment, he will be alright again and we shall continue having sex. (FN)*

Though HIV-serodiscordant status seems-not to deter some negative partners from wanting to engage in sexual intercourse, to some participants, especially the seronegative males, serodiscordancy had negatively affected their sexual life.

*Since the day we were told by the nurse that she is HIV- positive and I am HIV negative, I started to be afraid of having sex with her.I always make excuses or come back very late, pretending to be drunk. I cannot even get an erection (MN).*

According to majority of participants, ccompromised sexual lives of serodiscordant couples also affect other social aspects of the relationship such as communication.

*We use to communicate well with each other, but since the day we were told about our HIV status, he become very aggressive and angry for no apparent reasons and always tells me to leave his house.Most of the time when he is around I keep quiet to avoid unnecessary conflicts (FN).*

Majority of participants mentioned that strained communication and sexual relationship were threatening the sustainability of the whole relationship.

*The way we are living these days is like we are strangers to one another, "no sex, and no communication," I sometimes do not see the value of staying with him. I am just afraid that people will think that I am leaving him to die alone (FN).*

Some participants relate the difficulties they experienced as HIV-serodiscordant to inadequate support.

**Support for Serodiscordant Couples**

This theme relates to the counselling and information provided by healthcare professionalto ensure that serodiscordant couples understand their situation and also be empowered with strategies of coping in those relationships. Most of the participants indicated that they received *inadequate information* from the nurses after being given their HIV-serodiscordant results.

*A nurse, who gave us the results, told us that nothing has changed, except that now we know each other's status. She further told us that there are other people who are also serodiscordant but living normal lives and that some of them have HIV negative children (FP).*

A number of participants were of the opinion that they received inadequate counselling from the nurses who seems to have limited time to spend with the individuals in serodiscordance relationships. Some were of the view that if they were properly counseled and well informed about the causes of serodiscordancy and how to live positively in such a relationship would have made their lives better.

*The sister (nurse) at the clinic did not tell us what to do. When we go to the clinic, she just takes blood or tells me about my CD4 viral load results. She is always busy and there is always a queue of people waiting for her outside the clinic (MP).*

Inadequate information coupled with inadequate counselling offered by nurses to the individuals in serodiscordant relationships according to the results of this study seem to be the

core of all the negative experiences encountered by individuals in such a relationship.

## DISCUSSION

This study explored the experiences of heterosexual couples after receiving HIV serodiscordant results. All the participants in this study were couples from one of the townships in South Africa with high prevalence of HIV. The prevalence of serodiscordancy was estimated to 37% (Essien 2012). A range of experiences were presented by these study participants. The experiences reported include psychological responses, mainly denial which was verbalised by majority of participants regardless of their HIV serostatus.Denial was also identified by Rizza et al. (2012) as one of the reactions that can manifest following the diagnosis of HIV serodiscordant status. Denial in this situation was expected as most of people are of the opinion that if individuals were engaging in unprotected sexual relationship for a specific duration, which in this study it was more than six months; those people are bound to have similar HIV results. In reality, this is not always the case as there are several factors which contribute to HIV transmission or contraction. The incident were one participant mention the virginity of her sexual partner may indicate lack of knowledge of transmission of HIV infection from mother to child which is still very high in some African Countries including some (WHO 2014) . Studies indicate that children who get HIV infection from their mother before, during or after delivery can live with the HIV even beyond the age of 15 years without knowing their HIV status. This means that it will not be surprising to see a person married being a virgin but already being HIV positive (De Walque 2007,WHO 2012).

The other emotion reported by some participants in this study was intense fear and panic, same was reported by Rizza et al. (2012) . The fear of participants was based on the assumptions that being diagnosed as HIV positive means that a person is not going to live for a longer time. This assumption indicates lack of accurate information by participants regarding HIV and AIDS. This may also indicate that participants were not offered adequate information regarding the meanings of HIV results, and also on what should need to be done to live positively based on the different outcomes of those results.

Added to these psychological responses, this study showed that some participants were also experienced physical symptoms which were mainly gastrointestinal such as inability to swallow, diarrhoea and the absence of hunger despite not eating anything for up to a week. The reality is that these symptoms were not the results of any organic matter but of results intense psychological stress, thus they were considered psychosomatic conditions by the researchers of these studies.

The serodiscordance diagnosis did not only affect the psychological and gastrointestinal tract but it had a tremendous impact on the relationship of serodiscordant couples. It was evident in this studies that females try by all means want to maintain the relationship with their partners even to the state of predisposing their life to HIV infection. Some participants even tolerated staying in abusive relationship for the sake of maintaining the relationship and, also averting being accused of leaving the partner to die alone by the partners' relatives and friends. Same results were females in serodiscordant relationship try to maintain the relationship and also carrying for the physical health of the spouse was documented by Cichocki (2007).

On the other hand, results of this study indicated that males in serodiscordant relationship regardless of their own status try by all means to get out of the relationship. This was shown by one participant who mentioned that her partner is hypersensitive to any type of communication and always tells her to leave his house. The other evident was self-report by a negative male partner who attempted everything to avoid sexual contact with her seropositive partner to such an extent of coming back late pretending to be drunk. Same was reported in literature that the couple may become overly cautious to the extent of completely stopping any sexual contact (Cichocki 2007). Issues of being always pretending to be drunk may end up leading to real alcoholism which was reported as the most common condition on people who are in serodiscordant relationship. This aversion of sexual contact may lead to separation as highlighted in this. Same findings were documented by Floyd and Crampin (2008).

According to this study results, lack of adequate explanation of serodiscordancy by health care professionals to individuals in this type of

relationships contribute to their lack of understanding of serodiscordancy. It was also explicitly reported by the participants in this study that the challenges they are facing in HIV-serodiscordant relationship is compounded mainly by lack of counselling which make them neither to understand each other nor knowing what to do to handle their situation. This allegation may not be denied considering Van Dyk (2008)'s definition of counseling.

### Measures to Ensure Study Trustworthiness

The researchers adopted Guba and Lincoln's framework of trustworthiness as described in Polit and Beck (2012). The framework focuses on five criteria namely credibility, dependability, confirmability, transferability and authenticity. Dependability was enhanced in this study by the use of an interview schedule, audio-recording the entire interview process, and coding data independently by all the researchers. To ensure confirmability, individually developed master list of themes where compared and discussed, and all researchers agreed on the outcome of their analysis before finally compiling a single master list of themes. Member checking was conducted through requesting some participants to check transcripts and final master list of themes to ensure authenticity and credibility of data. To ensure transferability, the researchers provided thick description of methodology.

## CONCLUSION

This study explored the experiences of heterosexual couples after receiving HIV serodiscordant results. Three superordinate themes emerged as the experiences this couples namely, psychosomatic responses to HIV serodiscordant results, impact of serodiscordancy on couples' relationship and support for couples on those relationships. The main sources of the negative experiences for the HIV-serodiscordant couples were mainly indicative of inadequate information and counselling offered to serodiscordant couples after receiving this type of diagnosis. The findings of this study have both practice and policy development implications.

## RECOMMENDATIONS

Based on the findings of this study, the researchers recommend development of contextual relevant HIV Serodiscordant Couple Counselling and Support Guidelines focusing on enhancing knowledge and skills of health care professional responsible for counselling and supporting HIV-serodiscordant couples.

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