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The experiences of HIV-serodiscordant couples in Soweto, South Africa

A.H. Mavhandu-Mudzusi[1] **RN, RM, BPsy (Hons), BCur (Hons), Mcur, PhD &**
P.T. Sandy[2] **RMN, BSc (Hons), PGDipED, PGCertED, MSc, PhD**

1 Senior Lecturer, **2** Professor in Public Health, Department of Health Studies, University of South Africa, Pretoria, South Africa.

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Introduction: The study was carried out in a single township in South Africa with a sample size of seven human immunodeficiency virus (HIV)-serodiscordant couples.
Background: South Africa has the highest number of HIV cases in the world, with an estimated 6.4 million of its inhabitants living with this infection. Most people in stable relationships are unaware of the HIV serostatuses of their partners. Many people with an HIV partner are also generally unaware of their own HIV serostatuses. There is a high risk of acquisition of the HIV among couples in HIV-serodiscordant relationships. Yet, there is a dearth of research on HIV-serodiscordant couples.
Aim: To explore the experiences and knowledge of HIV-serodiscordant couples on HIV serodiscordance.
Methods: A qualitative design of interpretative phenomenological analysis was used. Data were collected from seven HIV-serodiscordant couples using a semi-structured interview format. Data were analysed thematically using the principles of interpretative phenomenological analysis.
Results: Three superordinate themes emerged from data analysis: experiences of stress, effects of HIV serodiscordance on couples and knowledge of HIV serodiscordance. The study outcomes were based on retrospective accounts of couples' experiences of HIV serodiscordance. Such accounts are subject to memory bias.
Conclusion: HIV-serodiscordant relationships are riddled with stress. Couples and nurses' knowledge and understanding of the concept of HIV serodiscordance is limited. Such limitation may negatively influence the quality of care and support offered to couples in these relationships.
Implications for nursing and health policy: HIV-serodiscordant couples need to be educated on this phenomenon. Nurses also need to be offered training on how to support and care for couples in these relationships. Such training should be shaped by couples' health-seeking behaviours and cultural norms. Specific guidelines and policy on HIV serodiscordance should be developed to ensure consistency in care provision and enhance uptake of support services.

Keywords: Couples, Experiences, Heterosexual, HIV, HIV Serodiscordant, Serostatus, South Africa

Correspondence address: Dr Peter Thomas Sandy, 6-184 Theo van Wyk, Muckleneuk Ridge, Pretoria 0003, South Africa; Tel: 27-12-429-3361; Fax: 27-12-429-6688; E-mail: sandypt@unisa.ac.za.

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Introduction

This paper reports on the experiences of HIV-serodiscordant couples in Soweto, South Africa. The term HIV-serodiscordant couple relates to a couple in which one partner in a stable sexual relationship is HIV positive and the other is HIV negative (World Health Organisation (WHO) 2012). Significant prevalence levels of this relationship are reported in the literature. Rispel et al. (2009) claim that two-thirds of infected heterosexual couples in the world are HIV serodiscordant. The WHO highlights in one of its publications, 'guidance on HIV counselling and testing', that globally half of people in long-term sexual relationships living with HIV have an HIV-negative partner (WHO 2012). A close examination of data from China indicates that about 75% of couples attending premarital counselling and testing are in HIV-serodiscordant relationships (Dong et al. 2011). A systematic review and meta-analysis study conducted in Africa on this subject confirm these high prevalence levels. Its outcome reveals that about 50% of people with HIV in sub-Saharan African are diagnosed in serodiscordance (Eyawo et al. 2011).

Sub-Saharan Africa has the highest number of HIV and AIDS cases in the world (Kironde & Lukwango 2002). This region, which makes 9% of the world population, carries two-thirds of the total global HIV cases (WHO 2007). Thus, most countries in the sub-Saharan African region have generalized HIV epidemics with a prevalence exceeding 14% (Lingappa et al. 2008). Taking Zimbabwe and South Africa as examples, these states have HIV prevalences of 14.3 and 18%, respectively (Department of Health (DH) 2009). Approximately 85% of such proportions of HIV infections are attributable to heterosexual sexual intercourse in the general population (Zimbabwe National AIDS Council 2005, DH 2009). In other words, HIV is spread primarily in sub-Saharan Africa through heterosexual contact. While this is the case, it is worth noting that approximately 70% of new HIV infections in this region of Africa occur within heterosexual serodiscordant relationships (Celum et al. 2010). Despite this, HIV-serodiscordant relationships including their incidence and prevalence and support services needed for people experiencing the same are under-researched.

Background

South Africa is reported to have the highest number of HIV cases in the world, with about 6.4 million of its inhabitants living with this infection (Shisana et al. 2014). Taking this into account, South Africa is perceived by its Ministry of Health and WHO to have a generalized hyper-endemic HIV epidemic (DH 2009). Generally, countries with HIV-generalized epidemics have significant epidemics among specific populations (WHO 2012). In the case of South Africa, an example of such population is HIV-serodiscordant couples. This population is frequently noted in the literature to be associated with high incidence and prevalence of HIV infection. An examination of data from a survey conducted by Essien (2012) acknowledges this. It reveals that nearly 40% of 2312 couples studied in South Africa were in HIV-serodiscordant relationships. Such a proportion and its growing rate among couples in these relationships are a function of a range of factors.

Most people in stable relationships are usually unaware of the HIV serostatuses of their partners (Loubiere et al. 2009). Added to this, the majority of people with an HIV partner are generally unaware of their own HIV serostatuses (Lurie et al. 2003). Such a lack of awareness increases people's risk or vulnerability to HIV infection. The findings of a range of studies indicate that HIV transmission occurs mainly between serodiscordant partners, particularly in instances where both partners are unaware of each other's serostatus (Kaiser et al. 2011; Malamba et al. 2005). The risk of HIV-positive partners infecting their HIV-negative partners in serodiscordant relationships is approximately 10- to 100-fold higher than the risk of contracting the virus among HIV-seronegative couples (Mujugira et al. 2011). While this rate of transmission justifies the description of HIV serodiscordance as a public health problem, it is one of the factors that enabled the South African government to make prevention and treatment of HIV as one of its top priorities (Joint United Nations Programme on HIV and AIDS (UNAIDS) 2008). Consequently, the South African government developed a National Strategic Plan in 2007 and revised the same in 2011 (South African National AIDS Council (SANAC) 2011).

The primary aims of the National Strategic Plan are to reduce the incidence of HIV infections and to offer effective treatment and support to people already infected with the virus (SANAC 2011). It is worth emphasizing that these aims are achievable if people are aware of their HIV serostatuses. The WHO (2012) agrees with this and states that people who are aware of their HIV serostatuses are more likely to seek treatment and/or engage in protective approaches, such as condom use, than those with no knowledge of their serostatuses. Hence, as part of the National Strategic Plan, the South African government introduced and implemented an HIV Counselling and Testing programme (DH 2009). The rationale for this is not only to improve South Africans' knowledge of HIV and their HIV serostatuses, but also to encourage the use of preventive approaches and access to treatment and support services. Despite this effort, the uptake of this programme remains low, particularly among HIV-serodiscordant couples and HIV-seroconcordant couples (partners with the same HIV test results). Consequently, the South African government, guided by specific national policy guidelines, embarked on a

nationwide awareness campaign and assertive outreach activities in order to increase the utilization of the HIV Counselling and Testing programme (DH 2009). While this effort increased the use of this programme by individuals of the general population, its utilization among couples, including those in HIV-serodiscordant and HIV-concordant relationships, remains low (WHO 2012).

This low uptake of the HIV Counselling and Testing programme among couples can be attributed to the focus of the DH (2009) policy guidelines on HIV Counselling and Testing. These guidelines concentrate on individual HIV counselling and testing, and not on couples. Thus, the epidemics of HIV-serodiscordant couples are not fully recognized in South Africa, suggesting that knowledge of this population in this region remains limited. Yet, empirical studies on serodiscordant couples in developing countries, including South Africa, are scarce. This study therefore explores the experiences and knowledge of HIV serodiscordance of couples within these relationships of a township in South Africa.

Methods

Design

Taking into account the scarcity of studies on HIV-serodiscordant couples and the limited understanding of their experiences in the continent of Africa, this study utilized a phenomenological methodology (Rispel et al. 2009). This is because these methodologies are suitable for developing understanding of poorly understood phenomena. A close examination of the types of phenomenological methodologies enabled the researchers of this study to opt for interpretative phenomenological analysis (IPA). They utilized this phenomenological approach not only as a methodology, but also as an analytical tool. IPA enables researchers to develop an understanding of people's experiences and meanings of specific phenomena (Smith et al. 2009). IPA stresses that the meanings of phenomenon can be accessed and understood through prolonged researcher–participant interactions and the use of a critical questioning style over what the latter say (Sandy & Shaw 2012). Adopting these approaches can generate comprehensive insights into HIV serodiscordance.

Sampling

The study was conducted in Soweto, a township in South Africa that is predominantly inhabited by black people. Soweto is an overcrowded township with high rates of unemployment, crime, HIV and AIDS. Soweto has a number of HIV Counselling and Testing Centres that offer support services to people living with HIV and AIDS. The researchers conveniently selected one of these centres because it was easily accessible to them. All users were given an information leaflet that contains the aim, benefits and eligibility criteria of the study during their visit to the Centre. Added to this, they were encouraged to contact and express their willingness for participation if they met the study's eligibility criteria (Sandy 2013). A total of seven HIV-serodiscordant couples contacted the researchers and consented to partake in the study.

Inclusion criteria of the study

- heterosexual HIV-serodiscordant couples who have been in stable relationships for at least 6 months,
- heterosexual HIV-serodiscordant couples aged between 18 and 50 years, and
- heterosexual HIV-serodiscordant couples who lived in Soweto and expressed willingness to participate in the study.

Exclusion criteria of the study

- heterosexual HIV-serodiscordant couples who have been in stable relationships for less than 6 months,
- heterosexual HIV-serodiscordant couples aged below 18 years or above 50 years,
- heterosexual HIV-serodiscordant couples who are living outside of Soweto, and
- heterosexual HIV-serodiscordant couples who are not willing to participate in the study.

Data collection

Permission to carry out the study was obtained from the University of South Africa Department of Health's Ethics Committee before data collection. Data were collected between September and December 2013 using a semi-structured interview format with seven HIV-serodiscordant couples in line with the principles of IPA (Smith 2005). An interview schedule was used for data collection (see Table 1 for samples of questions and prompts). To ensure privacy and confidentiality, all interviews were conducted in a designated room in the HIV Counselling and Testing Centre. One of the researchers, an expert in HIV/AIDS counselling and couple therapy, carried out all interviews. This is to ensure that conflicts between partners are effectively and promptly addressed should they arise during interview encounters. Interviews were audio-recorded, and notes were concurrently taken during the process. Interviews lasted from 45 to 60 min. Participants were debriefed at the end of each interview. The rationale for this was to enable participants to discuss their experiences and feelings of being interviewed as HIV-serodiscordant couples. All participants were

Table 1 Interview schedule: sample of questions and prompts

1. Please could you tell me about your experiences of being in an HIV-serodiscordant relationship?
(Prompts. Can you please tell me more about how you felt when you realized that your partner was HIV positive/HIV negative?)
2. What effects does HIV serodiscordancy have on your relationship?
(Prompts. Can you please tell me a little more about what you meant by negative effects on intimate relationship? Why was physical well-being a concern?)
3. What does HIV serodiscordancy mean to you?
(Prompt. Is that so? Where did you get this information?)

given contact details of a psychologist and to contact the same should they need psychological support.

Data analysis

The audio-recorded interviews were transcribed verbatim into textual materials, which were manually and independently analysed by three researchers using Smith's (2005) IPA approach to analysis that consists of a number of stages. The first stage involved reading and rereading transcripts, followed by note making and development of emergent themes. Similar themes were grouped, and this led to the development of superordinate themes. For each transcript, a master table of themes was formed. The master table of themes consisted of superordinate themes, sub-themes and associated quotes to illustrate where in the transcripts the themes could be found (Sandy 2013). The master table of themes of each transcript was compared and similarities were examined. The outcome of this was a single master list of themes for all the transcripts (interviews). It is important to note that analysis proceeded in parallel with the interviews and was conducted iteratively throughout the interview period until category saturation was achieved (Sandy 2013).

Results

Three superordinate themes emerged from the data analysis: experiences of stress, effects of HIV serodiscordance on couples and knowledge of HIV serodiscordance. Each of these themes is made up of sub-themes indicated in bold italics. Excerpts from participants' transcripts are used to support the discussions of themes. The initials 'PM' (positive male), 'PF' (positive female), 'NF' (negative female) and 'NM' (negative male) are used in this paper to indicate the HIV serostatuses and gender of participants.

Experiences of stress

This theme relates to feelings of stress in HIV-serodiscordant relationships. Participants frequently talked about their personal experiences of stress. This was particularly the case for those who became aware of their HIV-positive statuses while in a relationship, an outcome revealed in the extant literature (Bunnel et al. 2005).

> Being informed that I had the deadly virus, HIV, made me to feel worried about my health and that of my partner who was HIV-negative. I was also worried about how he would perceive me. (PF)

These expressed worries were mostly associated with feelings of embarrassment, as participants often considered being HIV positive as an outcome of sexual intercourse outside relationships. It was therefore not surprising for most participants to describe ***feelings of guilt and embarrassment*** as normal reactions in HIV-serodiscordant relationships.

> I often accused her of cheating on me. But she was HIV-negative and I had the virus. Knowing this made me to frequently feel embarrassed, guilty and distressed. I now feel more stressed than when we started our relationship. (PM)

According to some participants, these experiences can give rise to a state of high emotional arousal, a finding noted in Sandy (2013). They reiterated few times that a state of high emotional arousal is usually associated with a range of emotional responses. Such responses may include feelings of self-hatred, being blamed and self-blame. Some participants reported to have experienced these feelings. A minority of them emphasized that ***blaming oneself*** indicates acceptance of 'wrong doing', which in this case relates to being infected with HIV, attributable to engagement in sexual activity outside relationships.

> I blamed and hated myself for having sexual relationships with other men from the moment a nurse revealed my HIV-positive status. ***Being blamed*** by my partner reinforced my feelings of 'wrong doing' and ***self-hatred***. (PF)

Participants claimed that these feelings can be tormenting for anyone, and they can even be more tormenting for couples in HIV-serodiscordant relationships. So, some participants spoke

of strategies they adopted to alleviate their distress. Examples of these include thoughts of opting out of their relationships and abstaining from sexual activities.

HIV serodiscordance: effects on couples

This theme relates to the impact of HIV serodiscordance on couples and their relationships. Most participants believed that serodiscordant relationships, such as those related to HIV, are often associated with ***fear and concern***. Some participants who were HIV positive expressed concerns at the possibility of transmitting the HIV infection to their negative partners. For these participants, they coped with these anxieties by attempts to ***terminate their relationships*** and/or ***abstain from intimate sexual activities***.

> I wanted to protect him from being infected with the virus. I told him we better breakup because I'm positive and I suggested he get a negative partner. (PF)

A minority of participants was of the view that HIV-negative partners are usually not worried about being infected with HIV. They went on to say that their focus was in the main to ***maintain their relationships*** and ***promote the physical well-being*** of their HIV-positive partners. Taking these issues into account, participants emphasized that HIV-negative partners are generally not concerned about having unprotected sexual intercourse with partners living with the virus.

> I felt that there was no need to use condoms. If I became HIV-positive, it would be fine. We have never used condoms. We avoided it even before we got married. So why should we start now? (NF)

While some participants considered such disregard of the risk of being infected with HIV as a function of maintaining intimacy in relationships, others attributed it to limited knowledge of HIV serodiscordancy.

Knowledge of HIV serodiscordancy

This theme relates to participants' understanding of HIV serodiscordance and factors influencing the same. Some participants explicitly expressed ***limited understanding*** of this phenomenon.

> I do have some understanding. So, I would like to know more, particularly what causes one person to be positive and the other negative. One nurse told me that our cells are not the same. The explanations were unclear. I got confused. (NF)

Limited understanding of HIV serodiscordance was compounded by explanations and terminologies used by nurses.

> The nurse told me that I was not positive because my blood type was zero. Her blood type was different from mine. She also said that the receptors on my CD4 cells were unique. This was why I was not HIV-positive. I did not understand her. (NM)

Most participants were of the opinion that nurses do not generally understand what HIV serodiscordance is, its causes and specific support which individuals within this relationship need. Most participants emphasized that healthcare workers, including nurses, frequently use terminologies that distorted their understanding of serodiscordance. ***Appropriate use of terminologies*** is critical for enhancing understanding of explanations provided to users of services. Limited understanding of HIV serodiscordance, some participants asserted, increases the risk of HIV infection of negative partners.

> I know why they use terms they do not seem to understand. They are ***not properly trained***. Some of the nurses, healthcare workers are not even trained. In fact one told me that there are no ***specific guidelines*** for them to use to support us. (NF)

Discussion

This study has explored a very important but neglected area of healthcare practice: experiences of couples in HIV-serodiscordant relationships. It is noted in this paper and extant literature that there is stress in relationships, but this is particularly the case in HIV serodiscordance (Bunnel et al. 2005). This assertion is a function of a common assumption that people are usually infected with HIV through sexual intercourse outside their formal relationships, a view echoed by Bunnel et al. (2005). It was therefore not surprising for participants of this study to frequently describe feelings of guilt, embarrassment and self-hatred as common emotional reactions of couples in HIV-serodiscordant relationships. HIV-positive partners usually experience these emotions. Associated with these emotions were feelings of self-blame and an indication of acceptance of wrongdoing, which in this instance was related to engagement in sexual activities outside formal relationships.

Participants claimed that experiencing the mixture or cocktail of emotions thus far can lead to an unbearable overwhelming emotional state, a view also acknowledged by Sandy (2013). This was particularly noted to be the case for HIV-seropositive partners during interviews. HIV-seropositive partners are therefore more likely to adopt strategies, like terminating relationships and abstaining from sexual intercourse to alleviate their tormenting emotions. Underpinning these strategies are HIV-positive individuals' intentions to prevent the transmission of HIV to their negative partners. But noting that sexual intercourse is an important facet of any loving relationship, its

absence may lead to feelings of frustration and resentment (Bunnel et al. 2005). Prolonged exposure to these feelings may therefore negatively affect the quality of relationships.

HIV-negative partners tend to expend more energy on building and maintaining relationships with their partners. In addition to this, they also focus their attention on promoting the physical health of their HIV-positive partners, and are less concerned about the risk of contracting HIV. This is because, according to participants of this study, they are willing to have unprotected sexual intercourse with their HIV-positive partners. Some participants also attributed the willingness to engage in unprotected sexual intercourse to limited knowledge of HIV serodiscordance.

The manner at which explanations are offered and the use of technical terms may deter people's understanding of phenomenon, which in this case relates HIV serodiscordance. Some participants of this study agreed with this, as they explicitly claimed to be confused by explanations provided by nurses on the causes of HIV serodiscordance. The questions now arise: are causes of HIV serodiscordance difficult to explain or are nurses not knowledgeable about the causes of this phenomenon? The latter is more likely the case. It is evident from this study and outcomes of related studies that healthcare professionals and nurses' understanding of the concept of HIV serodiscordance and its causes is generally poor (WHO 2012). The limited knowledge and understanding of HIV serodiscordance noted in this study is attributable to lack of or limited training nurses received. Taking this limitation into account, it would be expected that explanations and approaches to care that this professional group adopts when working with this user group may be inconsistent and inadequate. Apparently, this is the case, as most couples of this study reported during interviews that they felt confused by nurses' explanations of the causes of HIV serodiscordance. This is probably a factor that contributed to the limited uptake of the HIV Counselling and Testing programme.

Implications for nursing and health policy

During interviews, some participants expressed limited knowledge of HIV serodiscordance and desire to learn more about this phenomenon. They also emphasized that nurses were also generally not knowledgeable about HIV serodiscordance, and yet they continue to offer support to people in these relationships. Such limitations may negatively influence couples' help-seeking behaviours and the quality of care and support offered to them. Thus, couples in HIV-serodiscordant relationships need to be educated about this phenomenon, including its causes and available support and treatment services. With regard to nurses, they also need to be trained on how to effectively support couples in these relationships. But such training should be shaped by couples' health-seeking behaviours and cultural norms, and where applicable for couples to act as co-facilitators.

Participants reported limited uptake of the HIV Counselling and Testing programme. In addition to limitation of knowledge, the absence of a specific national policy or guidelines to offer guidance on how to support couples in HIV-serodiscordant relationships was also a factor that hindered couples' utilization of the HIV Counselling and Testing programme. The inappropriate use of terminologies could also be attributed to the lack of guidelines or policy on support and care provision for HIV-serodiscordant couples. Acknowledging this, there is a need to develop guidelines or policy to address HIV-epidemic profiles of South Africa with an emphasis on HIV serodiscordance. Couples and HIV testing and counselling should be integrated in the policy or guidelines. It is critical for such inclusion to be guided by couples' health-seeking behaviours and cultural norms, as these are factors that may influence their acceptability, practicability and uptake of services.

Limitations

The authors are aware of some of the limitations of this study. It was conducted in a single township (Soweto) in South Africa with a sample size of seven HIV-serodiscordant couples. Participants in this township are probably different from other couples in other townships in the context of their experiences and understanding of HIV serodiscordance. Involving other couples in other townships as data sources would have enriched the findings of the study with different perspectives of HIV serodiscordance. In addition to this, participants might only share experiences that are favourable in order to avoid negative judgement by the researchers and their partners. In response to this, the researchers assured confidentiality to all participants as well as adopted a non-judgemental approach during interviews. Findings may have relevance for other serodiscordant couples in South Africa. This is because they offer insights for understanding the concept of HIV serodiscordance, including support, care and treatment needs of couples in these relationships.

Conclusion

It is noted in this study that HIV-serodiscordant relationships are riddled with experiences of stress, which participants expressed using a range of emotions. Examples of these were feelings of guilt, self-hatred, self-blame and embarrassment. These emotional reactions were attributable to HIV-positive partners' quest to protect their negative partners from contracting the virus. They were also a function of negative partners' intentions or willingness to maintain relationships as well as to

promote the physical well-being of their positive partners. These differential intentions or perspectives may cause emotional conflicts that may ultimately increase the stress levels in these relationships.

Nurses' knowledge of HIV-serodiscordant relationships was reported here to be limited. The absence of guidelines or policy on HIV serodiscordance, together with limited knowledge and understanding of these relationships, contributed to inconsistency and inadequate care provision reported by participants. Thus, understanding the concept of HIV serodiscordance is important, as it ensures the provision of the most appropriate care and support to couples in these relationships. Hence, further research is needed in this area of practice.

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Author contributions

AHM: Conception of study area, conception of design, data collection, data analysis, interpretation and drafting of manuscript. PTS: Conception of design, data collection, analysis, drafting of manuscript and critical revision for intellectual content.

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