Psychosocial- and disclosure-related challenges among HIV-serodiscordant couples: an interpretative phenomenological analysis study [version 1; peer review: awaiting peer review]

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Abstract

\textbf{Background:} Serodiscordant refers to a couple where one has human immunodeficiency virus (HIV), and the other partner is HIV negative. HIV-serodiscordancy often results in diverse psychological and emotional challenges. Evidence demonstrates that the dynamics of living in an HIV-serodiscordant relationship are often stressful. This study explored the psychosocial- and disclosure-related challenges faced by couples in HIV-serodiscordant relationships in South Africa.

\textbf{Methods:} An interpretative phenomenological analysis (IPA) design was followed. A total of 13 HIV-serodiscordant partners were purposively sampled. Data were collected through individual face-to-face interviews and analysed using the IPA framework.

\textbf{Results:} The findings indicated that HIV-serodiscordant couples experienced diverse psychosocial challenges such as shock, sadness, hurt, denial and disbelief. Participants also experienced challenges such as selective disclosure and fear of further disclosure.

\textbf{Conclusions:} The findings have implications for public health and are critical in programming and designing couple-based HIV care interventions. Couples in HIV-serodiscordant relationships would benefit more from differentiated, client-centred psychosocial support. To contribute to the HIV epidemic control and reduction of new HIV infections, specific interventions such as couples counselling, disclosure counselling, support groups, health education and safer conception risk reduction strategies need to be implemented.
Keywords
HIV-serodiscordant couples, serodiscordancy, psychosocial, disclosure, challenges

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Introduction

Serodiscordant couples are a major source of human immunodeficiency virus (HIV) transmission in the sub-Saharan Africa region and evidence estimates their contribution to be about 30% of all new infections occurring in this region (Chihana, Ellman, Poulet, Garone, Ortuno, Wanjala, Masiku, Etard, Davies & Maman, 2021). HIV serodiscordancy often results in diverse psychological and emotional challenges. Evidence demonstrates that the dynamics of living in an HIV-serodiscordant relationship are often stressful (Martins, Canavarro & Pereira, 2021). HIV-serodiscordant couples experience psychological, social and sexual challenges. The challenges determine decision-making in all aspects of the couple’s lives. Challenges such as disease acquisition, transfer of HIV to the uninfected partner and fertility decisions are all sources of conflict (Mendelsohn, Calzavara, Daftary, Mitra, Bidutti, Allman & Myers, 2015).

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2019), in 2018, 37.9 million people were living with HIV (PLHIV) worldwide, 1.7 million had new HIV infections with 61% of these being in sub-Saharan Africa and there were 770,000 AIDS-related deaths globally. According to (Statistics SA, 2021), South Africa has been reported to have the highest HIV epidemic in the world compared to other countries, and a total of approximately 7.7 million people are living with HIV in the continent. The prevalence of HIV among the general population has been reported to as high as 20.4%. Thus, such prevalence is also higher in the following population groups e.g., people who inject themselves with drugs, transgender women, men who have sex with men and sex workers.

Men living in a serodiscordant relationship often have reproductive goals that can increase the HIV-transmission risk to their partners (Mathenjwa, Khidir, Milford, Mosery, Greener, Pratt, O’Neil, Harrison, Bangsberg, Safren & Smit, 2022). Transmission of HIV may be reduced by earlier initiation of antiretroviral therapy (ART), medical male circumcision and the use of Pre-Exposure Prophylaxis (PrEP). However, for these strategies to be effectively implemented, couples counselling that is tailored to the needs of this group is of paramount importance. Additionally, the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2019) indicates that the effective expansion of PrEP provision requires attracting people who are at high risk of HIV infection, serodiscordant couples being one example, and supporting its proper use and adherence.

Serodiscordant couples experience diverse psychological challenges resulting in shock, sadness, hurt, denial and disbelief. Their relationship also revolves around challenges related to trust between partners, communication issues, HIV-related stigma, HIV risk perceptions, partner support and decision-making processes between relationships (Larki, Latifnejad-Roudsari, Bahri & Moghri, 2020). Challenges may lead to an impaired ability to maintain therapeutic marriage relationships.

After receiving HIV-serodiscordant results, couples are shocked and stressed. Shock and stress occur out of the fear of the risk of the increased spread of HIV. Seronegative partners in a serodiscordant relationship are at higher risk of HIV transmission in comparison with the negative serodiscordant one (Mavhandu-Mudzusi, Lelaka & Sandy, 2014). Living within an HIV-serodiscordant relationship has been recognised as a stressful experience for both HIV-infected and HIV-uninfected partners (Martins et al., 2021). Shock and stress are manifested by sadness, hurt, denial and disbelief. Evidence has demonstrated that living in an HIV-serodiscordant relationship results in diverse psychological and emotional challenges (Kumwenda, Corbett, Choko, Chikovore, Kaswaswa, Mwapasa, Sambakunsi, Gutteberg, Gordon, Munthali & Desmond, 2019; Martins et al., 2021). Additionally, the non-disclosure by such partners makes it difficult for the family members to provide additional social support to the couple (Dessalegn, Hailemichael, Shewa-Amare, Sawleshwarkar, Lodebo, Amberbir & Hillman, 2019; Siegel, Meunier & Lekas, 2018). According to Mashaphu (2018), a significant challenge when it comes to infected individuals disclosing their status, is mainly due to the fear of stigma or the feeling of guilt after contracting the virus. Mashaphu (2018) also reported on instances of intimate partner violence among couples in HIV serodiscordancy. Additionally, the HIV seronegative spouses of People Living with HIV AIDS suffered from instances of stigma (Siegel, Meunier & Lekas, 2018). The study explored the psychosocial- and disclosure-related challenges faced by couples in HIV-serodiscordant relationships in South Africa.

Methods

An interpretative phenomenological approach was chosen as an appropriate design for this study. The design is praised for its ability to delve deeply into the participants’ lived experiences (Qutoshi, 2018; Creswell & Creswell, 2018). The design was used to explore and describe the psychosocial- and disclosure-related challenges as “lived experiences” of HIV-serodiscordant couples from the point of view of those who have lived it (Qutoshi, 2018; Ellis, 2016). The approach was chosen to understand the event at a deeper level of consciousness; to help explore our own nature as researchers and to bring transformation at a personal level (Qutoshi, 2018, Smith & Osborn, 2015; Creswell & Creswell, 2018). The researchers selected this approach as the best to explore and describe the psychosocial- and disclosure-related challenges of the HIV-serodiscordant couples as experienced by them. This study followed the COREQ checklist (Lelaka, 2022).
Ethical clearance
Ethical approval of the study was received from the Ethics Committee of University of South Africa (HSHDC/608/2017) on 15/02/2017. Permission to conduct the research study was also received from the Department of Health Gauteng Province and the Chief Executive Officer (CEO) of the hospital. Written informed consent was sought before the interviews were conducted, participants were informed prior about the upcoming study that would take place. Confidentiality and anonymity were ensured through the use of pseudo names and age ranges, instead of exact ages. The hospital name was also not mentioned to protect the hospital’s identity. Ethical principles such as voluntary participation, withdrawal, respect for autonomy, privacy, confidentiality, justice and informed consent were adhered to (Babbie, 2020; Polit & Beck, 2021).

Setting
The research was conducted in an urban public regional hospital situated in South Africa under the Johannesburg district and is affiliated to the University of Witwatersrand. The hospital is a level three institution and offers diverse healthcare services to adolescent children and adults. The hospital collaborates closely with various non-governmental organisations (NGO) both within the hospital and those outside the hospital. It also has specialised clinics that treat mostly patients presenting with tuberculosis (TB)-related and HIV-related diseases. The hospital as such, provides diverse and comprehensive healthcare services to in-patients and out-patients including discordant couples.

Sampling and recruitment
The population for the study was all HIV-serodiscordant couples receiving their treatment at an HIV unit within the regional specialist hospital in Gauteng. A purposively selected study sample comprising of 13 participants, who were in an HIV-serodiscordant relationship at the study site, were recruited with the assistance of the facility counsellor. The researchers received the participants who met the inclusion criteria from the facility counsellor. Both the HIV negative and positive participants took part in the study. All the study participants were interviewed in the counselling room. A total sample size of 13 participants were interviewed and was deemed adequate as supported by Alase (2017) who indicated that in interpretative phenomenological analysis (IPA), two to 25 participants could suffice. Additionally, Kvale (2018) asserted that a sample of six participants or more could be adequate for an interpretative phenomenological design. However, the sample size for this study was determined by data saturation. Data saturation was reached at the stage where no new data emerged and there was redundancy of data already collected (Polit & Beck, 2021).

Inclusion criteria
The researchers used own judgement in selecting those participants that met the inclusion criteria as follows: heterosexual HIV-serodiscordant couples who have been in stable relationships for at least six months, disclosed their HIV status to either a partner or a family member, aged 18 years old and above, living in Soweto and willing to participate in the study (Polit & Beck, 2021).

Exclusion criteria
The study excluded heterosexual HIV-serodiscordant couples who had been in stable relationships for less than six months, aged below 18 years old, living outside of Soweto, those who had not disclosed their HIV status and those not willing to participate in the study.

Data collection
The researchers developed a semi-structured interview guide for the study and data collection was conducted from October 2017 to December 2018. The guide had several questions that were framed to explore the psychosocial- and disclosure-related challenges experienced by HIV-serodiscordant couples. The development of the interview guide was based on a literature review and the aim of the study guided the questions. The guide can be found as Extended data (Lelaka, 2022).

The pilot process was helpful since it enabled the researchers to check the feasibility of the approach before embarking on the interviews with the rest of the participants (Brink, van der Walt & van Rensburg, 2012; Babbie, 2020; Ellis, 2016). The researchers were, therefore, able to revise the data collection tool in relation to the demographic section as well as the probes to get more in-depth answers. The data collection tool was initially piloted on two participants and refined post-interview; the data obtained during these sessions was not included in the findings of the study, to prevent contamination of the study results. The purpose of the study was explained and written informed consent was obtained from study participants before proceeding with the data collection and audio-recording of the sessions.

The semi-structured interview guide questions comprised of one central question posed as: “May you describe the challenges of being in an HIV serodiscordancy relationship?”. Other questions were comprised of open-ended questions.
with follow-up questions for further clarification (Creswell & Creswell, 2018). Probes followed as directed by what the participants said. The semi-structured interview was chosen for facilitation of rapport, which is vital when the phenomenon of the study is a sensitive matter such as HIV serodiscordancy (DeJonckheere & Vaughn, 2019; De Vos, Strydom, Fouche & Delport, 2016). The guide gave flexibility of coverage and allowed the participants to introduce an issue that the researchers had not thought of. The researchers were directed by the participants on the flow of questions, as the questions were not sequentially followed. The semi-structured interview guide was a good instrument as it allowed the researchers to explore novel areas to get rich data. Participants could tell their stories. An audio tape recorder was used to record all interviews, as consented to by participants deidentified, and stored safely for privacy and confidentiality purposes. Field notes were used to capture notes on physical expressions and gestures (De Vos, Strydom, Fouche & Delport, 2016). Data were collected through in-depth face-to-face interviews in the hospital private counselling rooms. The duration of each interview was about 30 to 45 minutes, and the sessions were conducted in English, Sesotho, or Zulu, depending on the participants’ preferences.

Data analysis
Analysis of data was done immediately following data collection. The recorded data were transcribed verbatim. The researchers first bracketed their personal experiences related to HIV serodiscordancy to avoid interjecting personal experiences into the lived experiences of the research participants. The four researchers analysed the transcripts independently using an IPA framework (Smith & Osborn, 2015; Alase, 2017). No software was utilised, however, line by line coding analysis was adopted to understand the narratives reported by participants. One experienced researcher was a co-coder who assisted code further with the interview transcripts. For coding to be successful, transcripts were read, this was followed by listening to the audios several times to verify participants interviews. The researcher adopted the following steps by Smith and Osborn (2015): (1) the first step was reading and re-reading transcripts; (2) taking notes to develop themes, taking and developing emergent themes; (3) clustering of the themes; (4) drafting a table of themes, subthemes and other categories identified from the data; (5) checking and identifying the similar related themes; and (6) compiling a single master list composed of the themes and sub-themes. Following this process, all researchers discussed the list of themes and subthemes that emerged from the transcripts and finally agreed to develop a finalised master table describing themes and subthemes. All the subthemes were supported by the excepts from the transcripts of participants (Smith & Osborn, 2015; Creswell & Creswell, 2018).

Reflexive statement
The researcher who collected data at the time of the study was a PhD student with interest in doing research to explore serodiscordant couples. The researchers have knowledge of the study location, however – only one researcher (PhD student) used to work at the study location a few years ago as a social worker and was able to access the setting easily since she was familiar with the place. This enabled the researcher to establish a safe, healthy, and professional rapport with participants. However, the researcher did not have any relationship with participants as they did not know each other at the time of the study.

While collecting data, in addition to observing research ethics, the researcher also respected social work principles to accept participants for whom they are, understand where they come from and what they are going through. This enabled the researcher to have an open mind and allowed participants to freely share their experiences but ensured she needed to be fair, not impose any personal beliefs, bias, nor allow prejudice or negative perceptions while collecting and analysing data with the team. The narratives of participants were accepted as they shared their own experiences and the researcher was challenged to observe that discordant couples indeed experience a lot of challenges and need further support like other people experiencing HIV challenges. All authors who took part in this paper have research experience and PhD qualification.

Results
Sociodemographic characteristics
A total of 13 participants aged 30 to 62 years old who met the inclusion criteria participated in the study (see Table 1). Out of the 13 participants, nine were female and the remaining four were male. With reference to the HIV status, seven female and two male participants were HIV positive. The marital status revealed that the majority (nine) of participants were unmarried with only four being married. Table 1 below presents the demographic data of the study participants.

Table 2 below presents the themes, subthemes and related excepts from the participants of the study.

Reaction to HIV serodiscordancy
Following the data analysis, two superordinate themes emerged: reactions to HIV serodiscordancy and disclosure issues. Reactions to serodiscordancy emerged as emotional and psychological reactions. Three sub-themes on the emotional
| Pseudonym | Age range in years | Sex   | Marital status | Number of children | HIV status | Duration of relationship in years | Length of diagnosis in years | Level of education | Employment status |
|-----------|--------------------|-------|----------------|-------------------|------------|-----------------------------------|-----------------------------|-------------------|------------------|
| Lindiwe   | 60–65              | Female| Married        | 3                 | Positive   | 11 Years                          | 8                           | Grade 11          | Unemployed       |
| Khethiwe  | 30–35              | Female| Unmarried      | 2                 | Positive   | 9 Years                           | 10                          | College certificate| Employed         |
| Winnie    | 30–35              | Female| Unmarried      | 1                 | Positive   | 2 Years                           | 8                           | College certificate| Employed         |
| Nomzamo   | 36–40              | Female| Married        | 2                 | Positive   | 8 Years                           | 5                           | Grade 11          | Unemployed       |
| Lerato    | 36–40              | Female| Unmarried      | 0                 | Negative   | 4 Years                           | 2                           | College certificate| Employed         |
| Bheki     | 51–55              | Male  | Unmarried      | 5                 | Negative   | 6 Years                           | 2                           | Grade 12          | Self-employed    |
| Nkhane    | 46–50              | Male  | Married        | 2                 | Positive   | 2 Years                           | 4                           | Grade 12          | Employed         |
| Khumbu    | 30–35              | Female| Unmarried      | 1                 | Positive   | 4 Years                           | 3                           | College certificate| Self-employed    |
| Dudu      | 30–35              | Female| Unmarried      | 1                 | Positive   | 4 Years                           | 6                           | Grade 12          | Unemployed       |
| Dumisani  | 30–35              | Male  | Unmarried      | 0                 | Negative   | 2 Years                           | 6                           | Grade 12          | Self-employed    |
| Keneiwe   | 40–45              | Female| Married        | 2                 | Positive   | 9 Years                           | 11                          | Grade 12          | Employed         |
| Refilwe   | 40–45              | Female| Unmarried      | 1                 | Negative   | 4 Years                           | 4                           | Grade 12          | Self-employed    |
| Solly     | 40–45              | Male  | Unmarried      | 2                 | Positive   | 8 Years                           | 6                           | Honours           | Employed         |

HIV, human immunodeficiency virus.
Table 2. Superordinate themes, themes and sub-themes.

| Superordinate theme         | Themes                      | Sub-themes               |
|-----------------------------|----------------------------|--------------------------|
| Reactions to HIV serodiscordancy | Emotional reactions         | Shock                    |
|                             |                            | Sadness                  |
|                             |                            | Hurt                     |
|                             | Psychological reactions    | Denial                   |
|                             |                            | Disbelief                |
| Disclosure issues           | Challenges related to disclosure | Selective disclosure    |
|                             |                            | Fear of further disclosure|

HIV, human immunodeficiency virus.

reactions and two sub-themes on the psychological reactions emerged. Disclosure-related challenges emerged as selective disclosure and fear of further disclosure. Table 2 provides the summary of the superordinate themes, themes and sub-themes.

**Emotional reactions**

Participants reported having reacted differently to the news and the reactions, such as feelings of shock and sadness, were evident in their partners. In nearly all the circumstances, interviewed couples expressed how shocked they were after receiving the news of their status for the first time. This is supported by the following excerpts:

**Shock**

“I was shocked. I felt like dying. This was although I had symptoms that were pointing to that result”. (Nomzamo)

Related to this, another participant had this to say:

“This has affected me so much as I was shocked when I found out about my status”. (Dumisani)

The HIV diagnosis shocked not only the infected but also the affected partners, as shown in the following extract:

“This had scared and shocked my partner too. We were not open about it. I guess we were both embarrassed and too scared to talk about it. But we took things very slowly. I thought of my children so much during the first few weeks. Then after 2 to 3 months, things were much better between my partner and I. We were able to talk freely about HIV, and she was there to support me”. (Dudu)

**Sadness**

In addition to the shock, the participants further admitted that the discovering of their status was a turning point in their relationships. The participants indicated that they felt disturbed and saddened by the apparent betrayal. The extracts illustrate that:

“My partner did not tell me as I had to find out by myself, and that disturbed me so much and I was hurt”. (Lerato)

Other participants recall how they took longer to become composed enough to deliver news of their status to their respective partners:

“After discovering that I was HIV positive, I felt so sad and pained, it took long for me to compose myself and eventually disclose the test results to my partner”. (Khumbu)

Participants experienced different reactions after finding out the HIV diagnosis and felt hurt after the discovery.

**Hurt**

Hurt was also one of the identified emotional experiences highlighted by participants following the HIV test results associated with blame apportioning. A reaction of hurt on hearing about HIV-serodiscordant diagnosis was displayed by participants. This is supported by the following excerpt:
“How was it possible that the results would come out differently for both of us? I believed I was the innocent party”. (Dumisani)

It was evident that participants reacted differently upon receiving the HIV results after testing, as some were in denial of their HIV status despite being given the test results by healthcare providers.

Psychological reactions

Participants reacted with denial and disbelief when they first discovered that they were in a serodiscordant relationship.

Denial

Some participants reported that their partners reacted with denial to their HIV status results. Regardless of the results, there were still some challenges related to accepting HIV discordant results by some couples. Some participants’ partners stayed in denial as shown by the excerpt below:

“He thinks it is not true even though he is HIV negative”. (Keneilwe)

Disbelief

HIV positive participants and their partners found themselves in disbelief after receiving their results. Some went to the extent of insisting on having retests. The following extracts show that:

“I could not believe it and was saddened and very stressed about the results. I had to go for a retest”. (Dumisani)

Despite witnessing their partners taking medication daily as evidence that they are infected with HIV, some participants were still in denial and disbelief. This is shown in the following extract:

“I told my partner about my HIV status when I was six months into the current relationship. I tried to explain to him, but he does not believe me even though he could see that I am taking medication. Even now, he does not believe that I am HIV infected. You see, some people are ignorant”. (Khumbu)

“My partner was in disbelief and surprised at the beginning that I have HIV, and he doesn’t have it since we met one year ago”. (Winnie)

The findings from this study emerged as disclosure and psychosocial challenges experienced by HIV-serodiscordant couples.

Disclosure-related challenges

Participants disclosed their HIV status to their preferred and trusted family members. However, not all family members were aware of their HIV status, as they did not inform other family members due to personal reasons. A significant number of interviewed individuals from the couples had not disclosed their status to close family members and relatives at all. Participants had selective disclosure as well as a fear of further disclosure, which was influenced by the stigma attached to the phenomenon.

Selective disclosure

When asked about how they view disclosing their HIV status to other people later, most couples promised that they would do so in due time, while others vowed to keep it a secret. Couples’ account that from their understanding of their family members, a message of living with HIV or being married to a person with HIV would not be well received. Just as much as wide shock, disbelief and denial would be expected, there is also a real chance that family members may seek to break the relationships. Furthermore, signs of social stigma were greatly feared by couples who have chosen not to disclose their status. Society around interviewed couples seems to possess a negative opinion, especially since the understanding of HIV-serodiscordant couples is limited. A general social view, today, suggests that if two individuals are sexually involved with each other and one is positive, then the negative one is going to contract the virus as well. Worse still, couples feared workplace stigma arising from disclosure, as workmates begin to look at them differently and probably become reluctant to associate with them. The responses quoted below show selective disclosure:
“I am not comfortable about it; I think it is better if it’s only my parent and sister only who know that. I am scared; I am also scared of the stigma. I can’t do that. We kept this a secret for many years; my sister as well has not told anyone. Even my mom’s status, other family members don’t know about it”. (Khumbu)

“They do not know at all; it’s only my mom that knows. We decided to keep it between us as a couple”. (Khethiwe)

While some have felt comfortable to disclose to friends and neighbours, some participants, unfortunately, were not comfortable to share their status and did not disclose it, specifically to their children. Dudu supports this:

“My few friends and neighbours know, but my children do not know at all”. (Dudu)

When asked about their reasons for selective disclosure, couples had this to say on why they only allow a select few to know their status:

“Truth is that the other ones are talkative: I do not know how they will take it, but for now my mom and sister know, but people talk too much like I said, I do not want them to know. I do not think they know much about discordant, and I believe they do not understand it so much, I do not think they believe me as well. I told my friend who is my neighbour one day about my HIV status, I also told her that my partner is HIV negative, and she went to tell other people about that”. (Nomzamo)

“From his family, nobody knows only from my family. And from my family, it’s only my mom who knows as the rest don’t know anything. If my family knows they will look at her with bad eyes and treat her badly. So, I don’t want them to know as they will stigmatise her, so I don’t want them to know. It fine for me not to know”. (Khethiwe)

In other instances, HIV positive partners delayed or completely withheld disclosure of their status from their partners. One HIV negative female participant attested to the following quote:

“When he got the results, he thought I would dump him and was scared to attend at the government clinic because he didn’t want people to see him due to stigma and discrimination”. (Lindiwe)

Fear of further disclosure

After finding the bravery to at least disclose to select family members, participants indicated that they found it difficult to disclose to other family members.

“No one knows about my HIV status from the family, and I do not want them to know so far. It’s only from my partner’s side”. (Dumisani)

“Part of me does not care if others know, but also part of me does not want. I do not want them to treat me differently, and I am scared they will be hurt. I know my family; they will get hurt. My partner does not want people to know; he does not want that at all”. (Keneilwe)

Participants showed that they felt more comfortable with those family members they had already disclosed to and could not see any other reason to disclose to other family members as shown below:

“Those who know about my HIV status are fine. I do not want others to know”. (Nomzamo)

Participants as couples were completely aware of the serodiscordancy status and had accepted their conditions as couples. They experienced challenges when trying to explain serodiscordancy to friends, family and other people. Participants expressed their challenges of disclosure in the following quotes:

“I need to go through this process and explain to people how it is so, which is difficult for me. I struggle to explain as I do not have the right answers, I do not have the right words to explain when they ask me how and why so, it is difficult really”. (Winnie)

The limited understanding may be a key to explain the likely stigma arising from disclosure, thus the decision to keep quiet as Partner Nine recollects:

“From my experience, people are still ignorant. They do not know anything related to that (serodiscordancy); they do not even know much about general HIV, and they do not know other ways of how one can contract it. They think that even when one uses my cup, they can still get it (HIV)”. (Dudu)
Dynamics of living in an HIV-serodiscordant relationship are often stressful (Martins et al., 2021). The following themes emerged from the study: shock, sadness, hurt, denial and disbelief. This study found that couples reacted with shock on receipt of the HIV positive results for the infected partner. The common thread across studies on HIV serodiscordancy is that, for many couples, the HIV positive diagnosis is stressful, and feelings of shock, hopelessness and fear emerge (Yang, Lewis & Wojnar, 2016). The related findings by Kumwenda, Corbett, Choko, Chikovore, Kaswaswa, Mwapasa, Sambakunsi, Gutteberg, Gordon, Munthali and Desmond (2019) found that the couples reacted with shock on learning that they were in an HIV-serodiscordant relationship. However, the same author highlighted the fact that although there were a few who had developed coping mechanisms, because they already knew from the symptoms, usually, the immediate response was one of immense distress. This was also the finding of this study where some participants already had suspicions about being HIV positive because of the symptoms they had. It also emerged that being aware of the HIV symptoms did not cushion the individual against the shock.

Another adverse psychological effect after getting an HIV positive result was hurt. This concurs with study findings in Malawi, where these feelings of hurt included crying and blaming oneself (Kasenga, Hurtig, & Emmelin, 2010). Meanwhile, Kumwenda, Corbett, Choko, Chikovore, Kaswaswa, Mwapasa, Sambakunsi, Gutteberg, Gordon, Munthali and Desmond (2019) found that the feelings of hurt also included blame directed at the infected partner, especially if the partner had a previous record of infidelity. These feelings were often accompanied by feelings of betrayal by the partner who was being blamed for introducing HIV into the relationship. Similarly, in this study, the uninfected partners felt not only hurt, but betrayed as well. This study also found that the couples reacted to knowing the dire affliction of their HIV status with sadness. Similar findings were established by Thapa and Yang (2018) in Cambodia, where couples reported feeling sad due to the HIV serodiscordancy. The sadness in women often bordered on anxiety disorders (Darak, Pawar, Phadke, & Kulkarni, 2021). Other findings noted that sadness was accompanied by fear of social disgrace and depression (Pence et al., 2012; Simms et al., 2011).

In some instances, partners reacted with disbelief of the HIV test results, particularly where one partner was HIV negative and the other was HIV positive. Reconciling the apparent contradictions was difficult. Similar findings were noted in a study in Uganda by King et al., (2012) and in South Africa by Rispel (2011). Both studies reported shock and disbelief concerning the HIV serodiscordancy. The findings of this study showed that some participants reacted with denial to the serodiscordancy. Denial was also associated with fear. A study in Ethiopia by Jibat, Nigussie, & Tesfaye (2014) noted that serodiscordant relationships were characterised by disbelief, denial and fear of HIV transmission, leading to a shift in patterns of sexuality and emotional intimacy. This was despite the fact that the HIV tests were conducted in their presence. Whilst in our study, fear was associated with contracting or spreading HIV, in other studies, fear in serodiscordant couples was linked to intimate partner violence, stigma and discrimination, rejection and loss of intimacy (Maeri et al., 2016; Nannozi et al., 2017). Some studies have shown that the denial about HIV positive diagnosis in serodiscordant couple acts as a barrier to antiretroviral or PrEP initiations (Patel, Anand, Stanford-Moore, Wakhungu, Bukusi, Baeten, Brown, 2016). Evidence has shown that HIV-serodiscordant relationships are challenging and result in unique stressors that negatively affect the mental well-being of these couples (Lua, Mustapha, Abdullah & Abdul Rahman, 2014; Jibat, Nigussie, & Tesfaye 2014). According to Ondenge et al. (2018), HIV-discordant couples can also experience non-specific psychological distress after discovering their HIV positive status or that of their partner. A study in India by Darak et al. (2021) found that women in HIV-serodiscordant relationships experienced anxiety disorders and suicidal ideations, following the disclosure of the HIV status of their husbands.

Disclosure-related challenges
Disclosure remains a dilemma in most serodiscordant couples. Participants of this study indicated different ways of disclosing and not disclosing their serodiscordancy to other people. It was indicated that participants either disclose to their partner only, some family members or chose not to disclose at all. A pattern followed for disclosing differed with individual couples. Some of the couples chose to disclose their status to select people. Others chose some family members over others, for reasons ranging from fear of being stigmatised to fear of being discriminated against. Some participants chose not to disclose as a way of avoiding the stigmatisation. Others even voiced that out of the two families from which the couples came, one family would have members who were disclosed to and some to whom disclosure had not been made. Participants even agreed to the fact that the stigma around serodiscordancy is still rife, as most people were still in shock of whether a condition such as serodiscordancy exists. There was also fear of talkative family members who would then let the status of the couple reach others outside the circle of confidentiality.

Participats also noted that disclosure may predispose them to being treated differently by those who knew their HIV status. A number of participants were not comfortable to disclose their status to certain members, even if they were family,
as they could further disclose to other people. Most participants wanted to keep their status undisclosed, whilst some were saying they could disclose and were not concerned about the consequences. The participants in this study believed that stigma is the main reason for not disclosing their status. Selective disclosure of HIV-serodiscordant status to family, friends and community members is not unique to this study. Similar findings were established in studies on serodiscordant couples in South Africa, Tanzania and the Ukraine (Rispel et al., 2015). Non-disclosure of such partners can lead some family members to not know the status of such couples, denying them additional social support (Dessalegn et al., 2019). However, there is a significant challenge when it comes to infected individuals disclosing their status, mainly due to the fear of stigma or the feeling of guilt after contracting the virus. Some individuals even failed to disclose their status to their partners, who in turn would find out through other means with the resultant fallout including fights, feelings of anger and regret. However, disclosure challenges do not end here; uninfected partners in the relationship often find it hard to disclose to their own families for fear that their family members would become hostile towards the infected partner for “bringing the disease into the house”.

Upon disclosing to a select few confidants, fear of further disclosure was common as couples were unsure of the possible reactions, including fear of stigma and discrimination. Norman, Chopra and Kadiyala (2007) assert that people living with HIV find it daunting to disclose their status, for reasons ranging from fear of disclosing a secret to fear of rejection and breaking up of relationships. Other reasons, as noted by Daftary, Padayatchi and Padilla (2007), are fear of losing economic support, blame, abandonment, physical and emotional abuse, discrimination and disruption of family relationships. Mashaphu (2018) reported on intimate partner violence among couples with HIV serodiscordancy and disclosing the discordancy results to a partner as predisposing to family or sexual violence.

Limitations

Only one public hospital HIV unit was the setting for this study and, therefore, the results cannot be generalised to the whole Gauteng Province or all the provinces of South Africa. The topic of the study is a sensitive matter and could have caused emotional harm to the participants, however, all participants were given the contact number of a psychologist and social worker in case they needed further counselling following the interviews. Further research could be done focusing on counsellors, HIV-serodiscordant couples and their family members.

Conclusions and recommendations

This paper has explored the psychosocial- and disclosure-related challenges of being in an HIV-serodiscordant relationship. What emerged from this study was how HIV-serodiscordant couples experienced adverse psychological feelings of fear, sadness, disbelief and hurt on discovering that they were in a serodiscordant relationship, including disclosure challenges. Our findings suggest that couples in serodiscordant relationships would benefit more from differentiated, client-centred psychosocial support, directed at the management of dynamic challenges in such relationships and disclosure counselling. It is recommended that the HIV-serodiscordant couple go through extensive on-going counselling to improve their mental well-being and strengthen their resilience.

Data availability

Underlying data

The underlying data cannot be provided as the authors have an existing agreement with participants that their responses/data will not be shared without their consent. Due to the privacy, confidentiality, sensitivity and nature of the study on HIV, data cannot be openly shared with the public and the researcher did not receive consent from participants to do so. For more information on the research study, the researcher can be reached at lelakatshidi@gmail.com/lekalcm@unisa.ac.za.

Extended data

Figshare: INTERVIEW GUIDE FOR HIV-SERODISCORDANT COUPLES.docx. https://doi.org/10.6084/m9.figshare.21437943 (Lelaka, 2022).

Reporting guidelines

Figshare: COREQ checklist for ‘Psychosocial- and disclosure-related challenges among HIV-serodiscordant couples: an interpretative phenomenological analysis study’. https://doi.org/10.6084/m9.figshare.21408489 (Lelaka, 2022).

Data are available under the terms of the Creative Commons Zero “No rights reserved” data waiver (CC0 1.0 Public domain dedication).
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