Drawbacks associated with secondary disclosure among family members of the discordant couples: Findings from a qualitative study at a regional hospital in Johannesburg, South Africa

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ABSTRACT

This study explored the drawbacks associated with secondary disclosure among family members of discordant couples at a regional hospital in Johannesburg, South Africa. This was a qualitative study utilising an Interpretative Phenomenological Analysis (IPA) design. A purposive sampling method was used, and participants were recruited using snowball sampling. Data was collected from eight family members of HIV serodiscordant couples using one-on-one semi-structured in-depth interviews, and data was analysed thematically using the IPA framework. The findings indicated that family members of the HIV serodiscordant couples were distressed, and this led participants to show reluctance and opposition to secondary disclosure of the results of discordant couples to other family members. Drawbacks to secondary disclosure stem from being shaped by family differences, family gossip, lack of support, the stigma associated with HIV, and the HIV topics being regarded as a taboo in the family. To minimise disclosure tension and manage stress among family members of discordant couples, HIV programs should be directed at addressing stigma related issues and promote the importance and benefits of secondary disclosure counseling services among discordant couples and family members. This study contributes to our understanding of how discordant couple's family members are negatively affected by secondary disclosure. The study can further contribute to the improvement of policies and guidelines to include discordant families in the planning and implementation of their programs to enhance, strengthen, and promote secondary disclosure, including the comprehensive services of discordant couples and their families.

1. Introduction

Globally, Human Immunodeficiency Virus (HIV) remains a major public health problem and has so far claimed 35 million lives. At the end of 2019, approximately 38 million people were living with HIV, and nearly 1.7 million became newly infected with HIV (UNAIDS 2021). Of all the regions in the world, the African region is the most affected by HIV, with at least 25 million people living with HIV, besides being home to almost two-thirds of the global new HIV

infections (UNAIDS 2021). According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) report, there were about 38.0 million (31.6 ~ 44.5 million) people living with HIV (PLWH) UNAIDS, (2020). The current literature indicates that the prevalence of HIV discordance among married and co-habiting couples in Africa is high, ranging from 3% to 20% in the general population to 20% - 35% within couples in which one partner seeks HIV care services (Crankshaw et al., 2014). There is a growing consensus that HIV prevention research should address couples as a unit of behaviour change and intervention (Crankshaw et al., 2014). In sub-Saharan Africa, HIV-negative members of discordant couples are at extremely high risk of HIV infection with 30% of all new infections occurring in this group of individuals (Chemaitelly & Abu-Raddad, 2013). People and discordant couples living with HIV (PLWHIV) face not only the challenges of living with an incurable disease, but also struggle to make the decision of whether to disclose their status to their partners, families, and friends (Arrey et al., 2015).

Disclosure of HIV-positive status is a phenomenon that has not been fully explored with the scale-up of lifelong HIV treatment for HIV-discordant couples. According to Dessalegn et al. (2019), disclosure of HIV status involves revealing one's HIV-positive status to a sexual partner(s), family members, or others in their social circle. Hult et al. (2012), stipulate that, in addition, once one's status is shared with a particular individual, it cannot be unshared. Given the interpersonal risks associated with HIV disclosure, anxiety about sharing one's status is likely to be the norm, serving to inhibit HIV disclosure. Concerns about other people knowing one's HIV status may be heightened to the extent that very little or no HIV secondary disclosure takes place.

Despite the considerable efforts made in recent decades to improve access to antiretroviral regimens, HIV status disclosure remains central to family members (Spangler et al., 2014). For family members affected by HIV-serodiscordant couples' diagnosis, the challenges remain whether to disclose to other family members (secondary disclosure) or not. The process of secondary disclosure is challenging and can affect others socially, psychologically, and emotionally. Disclosure of HIV-positive status is a phenomenon that has not been fully explored with family members of HIV-discordant couples. Telling other family members can be stressful and bring tension to the family. Some people might feel that they will be rejected, not loved, not supported, or even judged by their families, this might lead family members to ask further questions on HIV related to how one got infected, yet the other partner has no HIV, resulting in more stress, hurt, confusion and disbelief in the existence of serodiscordancy. This study aims to address gaps and explore the drawbacks associated with secondary disclosure among family members of discordant couples at a regional hospital in Johannesburg, South Africa.

2. Theoretical background

This study was guided by the systems theory. According to Rothbaum et al. (2002), systems theory views the family as a complex social system of members who interact and influence each other's behaviours. The main key principle for this theory emphasises the importance of the idea that no part can be understood in isolation from the whole, and therefore, change in one part will inevitably lead to a change in other parts of the system. The systems theory provides a holistic perspective and further provides an opportunity for one to understand the system as a whole and further provides an understanding of relationships that are connected or interrelated to each other. This theory is related to the study because couples and families have personal issues, and therefore, discordant couples are part of the family unit and are related and depend on one another in their families. This also includes the changes that take place in couples,

which are likely to affect other family members. Discordant couples themselves face various challenges in their relationships, and when stressed, sometimes they depend on family members for psychosocial support to alleviate distress to improve their mental health and well-being to improve their quality of life. Research states that the use of psychosocial support under stressful conditions is associated with positive effects on a wide range of social, emotional, physical, and mental health challenges, Taylor and Master (2011). Social support, therefore, can alleviate the negative impact of stressors, especially when it is provided by family members. Therefore, there is evidence of a change in the family system unit, and this includes the diagnosis of discordancy in couples themselves, this further impact on other family members since they are one unit. It is through this theory that when family members work together, they can successfully overcome their challenges, hardships, and choices. Since the diagnosis of discordancy impacted the couples negatively and they have experienced emotional challenges such as secondary disclosure, this - they are not comfortable that other family members be engaged in the diagnosis due to various family differences associated with stigma and discrimination, including poor support system.

Using this theory will assist in looking beyond immediate presenting problems and seeking deeper underlying systemic issues. Employing the system theory will further assist in creating and promoting effective sustainable interventions that can address root causes rather than just symptoms. The interventions can include providing ongoing psychosocial support, reminding couples to continue to support one another, reminding couples to attend the clinic for follow-up appointments, reminding the couples to take medication so that they can strengthen their adherence and compliance with medication, empowering the couples to continue to use a condom to protect another partner from the transmission of HIV infection from one partner to another, engage the couple on newly available safer conception services in healthcare facilities to exercise their fertility desires, etc. Therefore, for family members, this theory offers a lens that allows us to see the dynamic interplay of various elements in discordant couple's lives.

3. Literature review

3.1. Impact of disclosure

Secondary disclosure of HIV-serodiscordant status remains a concern to many families. Amongst others, these could be related to the protection of the couple's status, the impact, negative concerns, reputation, stigma, rejection, and discrimination are key factors; hence, some family members prefer to choose not to disclose to other family members due to the psychological harm. For those who have already disclosed this to the rest of the family members, this may even provide a great opportunity to strengthen the psychosocial support system and improve and enhance the health of couples to ensure a good quality of life. Baratedi et al. (2014) further asserted that disclosure allows people to be open to social and health initiatives that are aimed at improving their psychological and physical health, such as antiretroviral medication and support groups. Disclosure of one's HIV-positive status is generally a complex undertaking and not a one-step process. The ability to disclose one's HIV status can be related to the degree to which an individual has accepted his or her HIV diagnosis. It is often most difficult to disclose soon after diagnosis when a person is grappling with the initial impact of his or her HIV-positive status. Most studies have examined HIV status disclosure to describe the outcome rather than the process of disclosure (Canadian & Network, 2012). Yaya (2015) noted that the disclosure of one's HIV status, including that of HIV-serodiscordant couples, could result in negative consequences, including loss of support. Many People Living with HIV and AIDS (PLWHA), after disclosing their HIV status, are victims of discrimination, stigmatisation, rejection, and sometimes-violent

reaction (Kyaddondo et al., 2013). Crankshaw et al. (2014), argued that dealing with the unique constellation of relationship complexities among HIV-serodiscordant couples and negotiating HIV disclosure within those relationships was flagged as a particular area of concern by healthcare providers. Thus, healthcare providers may experience personal conflict and ethical difficulties in managing HIV-serodiscordant couple where HIV disclosure has not occurred and will need specific guidance on how to deal with this possibility. Crankshaw et al. (2014) further argued that the breakdown of a relationship, economic abandonment, rejection, intimate partner violence, and isolation are among some of the negative consequences experienced by women living with HIV following HIV disclosure to a male partner of the family.

3.2. Approaches to HIV disclosure

According to Rodkjaer et al. (2011); Arnold et al. (2008); Obermeyer, Baijal, and Pegurri (2011); Hult et al. (2012), there are different approaches to HIV disclosure which include the following 03 categories: disclose to everyone, disclose to no one, and selective and strategic disclosure. Those who disclose to everyone are likely to face more risks of rejection, poor support system, stigma, isolation, and discrimination, but also tend to be more prepared to face negative outcomes; they are reported to have a great and healthy attitude, including good self-esteem. According to Rodkjaer et al. (2011); Arnold et al. (2008) in contrast and comparison to others, maintain that those who prefer to disclose to no one have extreme poor self-acceptance, less access to social support system, show some concerns, and fears and of stigma related challenges, are socially isolated often face the risks of losing their close and personal relationships they have with others as a result of disease-related stress (Arnold et al., 2008; Obermeyer et al., 2011; Rodkjaer et al., 2011). The selective approach to disclosure seems to be a common concern among discordant couples and their family members (Arnold et al., 2008; Hult et al., 2012; Obermeyer et al., 2011; Rodkjaer et al., 2011). Therefore, disclosing and not disclosing are reported to be both ways either way of coping for others, and the decision depends solely on the advantages and disadvantages of disclosure based on the relationship discordant couples have with their family members. Even though these approach categories are helpful in summarizing disclosure experiences, they aren't static. Individuals' disclosure decisions change constantly over time depending on their circumstances. Therefore, generally - individual have their own preferences, and generally, some discordant couples might prefer selective disclosure since they will only disclose to those limited individuals who they deem are likely to have a positive reaction and will provide love and psychosocial support and are thus uncomfortable with the secondary disclosure.

The Rapid Response Service (2013) maintains that for people infected with HIV serodiscordancy; disclosure may be limited in telling someone about their HIV status. Besides, sharing one's HIV status can help one cope with the life stressors so that they can cope well with living with HIV. However, deciding whom to tell can be difficult, threatening, or even more complicated, especially if one does not know how others will respond. While some couples reside with family members and extended family members in the same household, such disclosure may pose a challenge not to share with everyone in the family since some might not be accepting. It is well known that that disclosing one's status is more likely to have an impact on people you tell, it is clear that others may react differently in more negative ways. The Rapid Response Service (2013) further maintains that the common drawbacks to secondary disclosing to other family members include negative experiences with previous disclosures; rejection; lack of a strong social network; feelings of shame and guilt regarding one's HIV status; struggle with HIV+ identity; cultural factors (e.g., homophobia) within one's community; lack of HIV

education and inability to cope with the outcome of the disclosure; and concern about harming or burdening others.

3.3. Stigma and discrimination

While it's known that secondary disclosure of HIV serodiscordant to other family members might be driven by stigma and discrimination, there is need to extend the support to such family groups. Generally, HIV stigma and discrimination is believed to have a significant impact on various aspects of people' lives such as health, the relationship between family members, the well-being couples. High levels of stigma and discrimination continue to undermine positive on HIV related matters responses. Stangl et al. (2019) argue that stigma continue to undermine positive responses and it involves much of negative attitudes, perceptions, judgement, and behaviours often driven by the emotions of ignorance and fear. Whereas discrimination is argued to be involving unfair treatment, violation of laws and policies to some extent and both stigma and discrimination can take many forms, including disparaging attitudes, sub-standard treatment, and denial of treatment, and reduce people's uptake of and retention in the prevention and treatment Joint United Nations Programme on HIV/AIDS (UNAIDS, 2022).

UNAIDS (2021) stipulated that HIV-related stigma and discrimination refer to a range of stigmatizing experiences, including gossip mongers between individuals and family members, poor psychosocial support, avoidance behaviours, social rejection, gossip, and verbal abuse. Although this mostly have an impact on discordant couples as partners, there is limited data relating to secondary disclosure to family members of discordant couples. To overcome the challenges of secondary disclosure, it is necessary to strengthen and promote HIV interventions; the importance of social and environmental context within family relationships and behaviours should be discussed, and acknowledge HIV-related stigma and marginalization of certain populations due to race, gender, and sexual orientation, as stigma influences the likelihood of disclosure.

4. Objective of the study

The objective of the study was to explored the drawbacks associated with secondary disclosure among family members of the discordant couples at a regional hospital in Johannesburg, South Africa.

5. Methods

The study adopted a qualitative approach, and eight in-depth interviews were held with family members of discordant couples between Oct-Dec 2017. All interviews were conducted face-to-face for 30 - 45 minutes at their homes in a private room to maintain confidentiality and privacy. During the interviews, an unstructured interview guide was adopted, and all participants were asked open-ended questions about their experiences of HIV-discordant couples secondary disclosure to family members. To get more information, probing skills were implemented so that participants were able to express and share more information and to ensure the researcher understood their experiences.

5.1. Study setting

According to Butler, Wilson, and Abrahamson (2022), the study setting refers to the physical, social, or experimental place within which the study is conducted. The setting for this research was a public hospital providing services to diverse community members presenting healthcare challenges. This is a referral hospital from other local community healthcare clinics facing limited service provision and resources.

5.2. Population and sampling

According to Rahman et al. (2022), a study target population is a group of people or items about which researchers must make broad generalisations. Polit and Beck (2016) state that a population refers to the entire set of individuals or objects that have the same common characteristics. The study population included family members who reside with and providing support to discordant couples. All participants met the inclusion criteria and were recruited using a non-probability sampling, and the snowball technique method.

5.3. Sampling and sampling size

Sampling aims to produce a reasonable representative selections of population elements. The researcher adopted a non-probability sampling to recruit participants to take part in the study. In non-probability samples, elements are selected by non-probability methods. Therefore, there is no way to estimate the probability that each element has of being included in a non-probability sample, and every element usually does not have a chance for inclusion, Polit and Beck (2012). Qualitative researchers select cases gradually, with the specific content of a case determining whether it is chosen.

For the purpose of this research, the researcher used a snowball technique. De Vos et al. (2002) maintain that snowballing involves approaching a single case that is involved in the phenomenon to be investigated, to gain information on other similar persons. In turn, this person is requested to identify further people who could make up his sample. It is, therefore, advisable to ask for at least five names instead of one so that the researcher can maintain the chain. A snowball technique was appropriate because, according to Polit and Beck (2012), the participants are selected through referrals from either participant, also called network sampling. Furthermore, this technique is excellent for those cases where the researcher is investigating a relatively unknown phenomenon (De Vos et al., 2002). In this instance, HIV serodiscordant couples were informed about the inclusion criteria so that they can only nominate at least one family member whom they have disclosed their diagnosis. The following inclusion and exclusion criteria were observed for all participants who were enrolled in the study:

Inclusion criteria

- 18 years and older.
- HIV serodiscordant couple have disclosed their status/diagnosis to them.
- Residing with at least one partner of the HIV-discordant couple/ with both partners of the HIV-discordant.
- Willing to take part in the study.
- Willing to sign an informed consent form and have it audio recorded.

Exclusion criteria

- Less than 18 years of age.
- No knowledge of being informed about discordant couples in the family.
- Not residing with any partner of the HIV-discordant couples.

6. Data collection

Polit and Beck (2012) define data collection as the process of gathering information to address a research problem. It is a precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions, or hypotheses of the study (Burns &

Groves, 2011). The researcher developed a semi-structured interview guide that was divided into two sections: section A, section A contained participants' demographics, and section B had open-ended questions to solicit data from participants. The guide was piloted by interviewing one participant to identify the gaps for the better improvement of gathering rich data using probing skills. In this process, the supervisor was engaged for further intention and management of refining the data collection tool. The targeted sample size was between 08 and 10 ten counselors, and family members of the HIV serodiscordant couples. However, this was determined by data saturation. According to Polit and Beck (2012), qualitative researchers sampling decisions are guided by data saturation, which occurs when themes and categories in the data become repetitive and redundant, such that no new information can be gleaned by further data collection. Mason (2010) further stipulates that, the concept of data saturation is the most determining factor for sample size in qualitative research.

7. Ethical measures

Prior to data collection, approval was obtained from the University South Africa (UNISA), Department of Health's Ethics Committee. Helen Joseph hospital also provided permission for the study to be conducted. The UNISA ethics reference number is HSHDC 608/2017. All participants provided voluntary written informed consent prior to data collection. Confidentiality and anonymity of participants were respected throughout the research process.

8. Data analysis

The researcher adopted a thematic analysis. According to Braun and Clarke (2021), thematic analysis is defined as a heterogeneous approach and an overarching term under which there are a variety of thematic approaches to data analysis. This process provided the researcher with the support to assist in identifying and analysing the drawbacks associated with secondary disclosure among family members of the discordant couples since the thematic analysis is flexible, especially for a lot of data collected from participants. The researcher managed to transcribe data within 48 hours after collecting data and was able to identify themes. Each transcript was double-checked against the audio tapes to minimise errors as possible. The researcher followed Poland's (1995) guide of three categories of errors, as quoted in Polit and Beck (2012). Furthermore, Polit and Beck (2012), continue to say that this will allow the researcher to develop, and code open ended responses and categories, transform responses to fixed categories in a post hoc fashion so that tabulations can be made. For all data collected, the researcher ensured that the stored data tapes were kept carefully, and labelled them with an identification code number, the date of the data collected, and the anonymous name or identification number of data collection. The importance of confidentiality was observed as well as anonymity. To address the trustworthiness of the data collected, the researcher was able to contact participants to verify their descriptive experiences. Data collected was further used to check for any misunderstanding, misinterpretation, or perhaps ambiguity.

9. Trustworthiness

Trustworthiness is defined as the degree of confidence in data, interpretation, and methods used to ensure the quality of a study (Polit & Beck, 2014). Maher et al. (2018) assets that trustworthiness is a more suited criterion for assessing qualitative research. The researcher suggests that in ensuring the rigor or validity of the proposed research study, the focus should be based on trustworthiness. Polit and Beck (2014) stipulates that trustworthiness or rigor of a study refers to the degree of confidence in data, interpretation, and methods used to ensure the quality of a study.

For this research, the researcher will apply the following four criteria: credibility, dependability, transferability, and conformability will be assessed. According to the researcher, credibility should be the primary concern while ensuring the rigor or validity of the planned research study. For credibility, the researcher will adopt credibility by using member checking to ensure she is on the right track. Maher et al. (2018) continue to elaborate that there are many strategies to address credibility that include "prolonged engagement" and member checks. Dependability ensures the process is described in sufficient detail to facilitate another researcher to repeat the work. Conformability is comparable to objectivity in quantitative studies. The researcher will use an audit trail to determine the dependability of the findings. To ensure transferability, the researcher will compare the findings with the literature through thick descriptions. According to Andrew, Richards, and Hemphill (2017), transferability is addressed by providing a detailed account of the study context and through rich description in the presentation of results. The collected data will then be transferred to the researcher to be able to present the results of the context. To assess conformability, the researcher will use self-reflexivity to check for any personal beliefs and experiences relating to the topic that could be viewed as prejudicial.

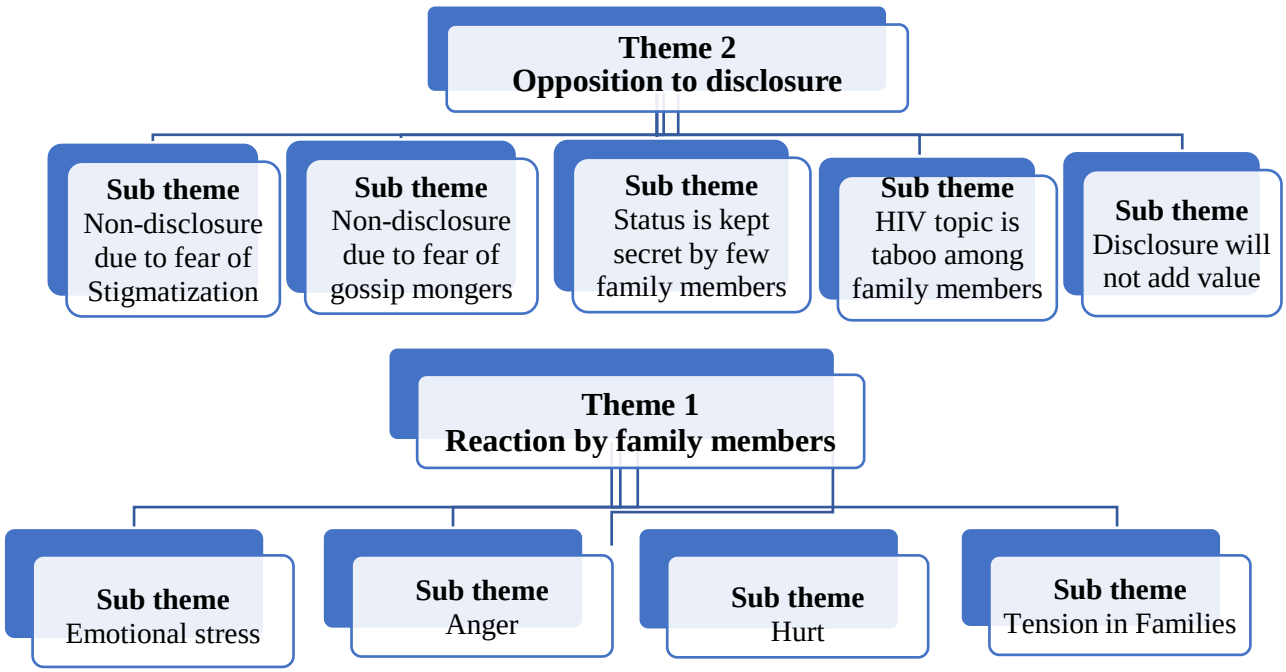
10. Results

10.1. Participants' characteristics

A total of eight participants took part in the study. All participants were family members of HIV serodiscordant couples, and they met all the inclusion and exclusion criteria for the study. Their ages ranged between 29 and 76 years old, and all were females. They were related to the discordant couples and had a healthy, strong relationship with them. Amongst the family members, a total of four (4) participants were mothers/parents of the discordant couples, two (2) were sisters, and another two (2) were cousins of the discordant couples. The employment data suggested the following: four (4) were employed, three (3) were unemployed, and only one (1) was reported to be a pensioner. All participants were South Africans.

Figure 1

Summary of Results



10.2. Theme 1: Reaction of family members

The discovery of by family members that a family member is in an HIV serodiscordant relationship is characterised by various emotions such as emotional stress, anger, hurt, and tension in families. It seems to be normal to feel emotionally challenged when one discovers other people's HIV status. This was also the same with the family members of HIV-discordant couples. The family of the HIV-negative partner has been seen to harbor anger towards the HIV-positive partner, especially if that partner had initially concealed their HIV status. Some members of the family even wished that the couple would separate upon discovering the HIV status of the infected partner. Family members upon discovering that one of their own is HIV positive, revealed that this brings a great amount of stress. Some of those interviewed indicated that they endured lengthy periods of emotional stress, wondering why this dreadful disease had infected their relative. Family members endure ongoing stress as they try to find ways of dealing with the disease in the family.

Emotional stress

Emotional stress was one of the emotions shared by family members. They felt knowing the status by themselves was sufficient and no other members as there was no need for them to know. This is because other family members would bring additional stress to them, and this might affect the life of discordant couples and them, therefore, keeping such to them was beneficial. This is supported by the below quote:

"That will also add more stress to me. No, I do not want other family members to know, and it ends there" (Family member 5).

Not only did this bring some emotional stress, but some family members were angry as well and shown some additional stress. Family member 2 said:

Anger

"I sometimes feel angry at her because, but I try to cool down and tell her that I am your child and you are my mom, please respect me" (Family member 2).

The emotions continued to escalate, and while some were angry and worried, some shown some emotions of hurt too, and family members said:

Hurt

"This has hurt us so much; this has hurt us so much because she has children, and we were worried what we are going to say to her children" (Family member 7).

"We were worried that our mom would die at that time. This brought so much hurt and worries and we had no answers at the time. It was scary." (Family member 8).

Tension in families

The discovery that a family member is in an HIV discordant relationship has also resulted in tension in families. The resulting anger from family members, especially those of the HIV-negative partner, has resulted in blame and anger, which culminates in tension among the family members. The quotes that have been taken from the respondents which indicate the existence of tension are listed below:

"We have tension in the family at the moment, we don't support each other, and we have children out of wedlock, too much competition amongst each other" (Family member 1).

While some family members were aware of the tension, they felt that communication could improve the situation and improve relationships in the families. This is what participant 4 said:

"Families must also learn to talk a lot and maintain open communication all the time to reduce tension" (Family member 4).

Some family members noted that tension not only brings challenges but also some additional emotions. It was evident that some tension resulted in anger as a result that some of the partner who were HIV infected failed to disclose their status to their partners in their families. This is supported by the quote from family member 7:

"I was also angry with my sister partner for not telling her that he was HIV infected, I was angry at him for so long but ended up relating well alter on" (Family member 7).

10.3. Theme 2: Opposition to disclosure

The bulk of the family members also indicated that they did not want anyone to know about the HIV serodiscordance of their family members/relatives. The respondents indicated they were protective of their families as they feared that people would gossip, stigmatise the couple and even insult those affected. The concealing of the HIV statuses of HIV serodiscordant couples has been done because the issue of stigma has not changed much in our society. Other people have used the HIV statuses of people to insult them. The concealing of HIV statuses of serodiscordant couples can therefore be viewed as a way of protecting these couples from other relatives who might spread this and from neighbours who might be insensitive.

Non-disclosure due to fear of stigmatisation

Family members support the non-disclosure of HIV statues of serodiscordant couples because they are afraid that the couple may be exposed to stigmatisation in the family and community. Stigmatisation of HIV-positive people is something that is gradually declining, but it is still very much a reality in African society. Some of the quotes that reveal that fear of stigma is the reason for non-disclosure are listed below:

"I know with my knowledge that people who don't have HIV stigmatise those with HIV and still believe those infected will infect them" (Family member 3).

"Families must embrace such couples, support them, advise them and not stigmatise them" (Family member 4).

"Also, families must stop stigmatising and discriminating discordant couples. They must know that these couples are like any other person, they are like them too and they need love and support them like anyone" (Family member 6).

Non-disclosure due to fear of gossip mongers

The family members of HIV serodiscordant couples do not want a lot of people in the family to know of this situation because they fear that this will result in a lot of gossip. They fear that this gossip may end up destabilising the couples and impact the health of the couples, especially that of the HIV-positive individual in the relationship. The quotes that indicate that non-disclosure is being done to avoid fueling the rumour mill are listed below:

"There are too much gossip in the family" (Family member 1).

"Yooo… I cannot say much about family, sometimes you cannot trust family. Even when you tell the family about your status, they want people to know, they go tell the world" (Family member 2).

"I don't think we can inform them because we are scared of stigma, lack of support, too many talks and gossip" (Family member 5).

Status is kept secret by a few families' members

The HIV status of serodiscordant couples is a closely guarded family secret by the few family members who know. The few who know about the HIV statuses of the serodiscordant couples seem to have sworn that they would never tell anyone, and they have various personal reasons why they chose to take this route. It therefore emerged that family members prefer that this information be kept among fewer family members as possible. The quotes that reveal that most of those interviews prefer secrecy around the HIV statuses of serodiscordant couples are listed below:

"The family right now do not know about NN HIV status and her partner. It is only me" (Family member 1).

Issues of trusting members were seen as a challenge hence some family members preferred the status to themselves. This is supported by:

"So, when my mom told me about her status she was also not well, her husband was supportive, and I understood and promised to support her too. We decided to keep it amongst us because we do not trust the family" (Family member 2).

The decision to keep the HIV status private and confidential was also based on the request made by the infected patient, who had to request the family member not to share their status further with anyone. So, some family members had to respect such requests and decisions made by their infected family members: This is supported by the following statement:

"We kept it a secret because my sister does not want people to know about it. At home, they also do not know much about it except me and my father" (Family member 3).

"No other people know about my infected daughter HIV status, so we are fine for us to know that, and I don't want the rest of the family to know" (Family member 5).

HIV topic is taboo among family members

Even though more is known about HIV/AIDS in our communities when compared to twenty years back, the topic of HIV/AIDS remains taboo. Few families still do not feel comfortable discussing it. The family members of the serodiscordant couples reflect that they are not comfortable discussing anything linked to HIV, let alone reveal the status of one of their relatives in serodiscordant couples. Some of the quotes that indicate that HI- related topics are treated as taboo by most respondents are listed below:

"I don't talk about their HIV status to both of them…At the moment, I don't touch that subject of discordant anymore hey especially when I am with them" (Family member 3).

"The family do not know about their HIV status. We do not even talk about it at all" (Family member 1).

Disclosure will not add value

The family members also believe that disclosing to other family members is not necessarily going to help with anything. Most of those that were interviewed indicated that they felt disclosure is more likely to increase gossip as well as result in the affected serodiscordant couples being stigmatised by family members and the community. It can therefore be concluded

that some of those that choose to keep the HIV serodiscordance a secret does so out of the belief that it would not add any value if that were known by others. The quotes that indicate this belief among some of the respondents are listed below:

"We will not get the support of the rest of the family members. We have too many fights and poor support here. So, that will be a problem and it is therefore better for the rest of the family members not to know out status" (Family member 1).

"Why must they know? Why should they know? No, I do not want them to know, I do not want them to know at all" (Family member 5).

11. Discussions

11.1. Reaction of family members

Rapid Response Service (2014) maintain that secondary disclosure is something that every person living with HIV experiences and struggles with. The process is more complex and fraught with mixed emotions for couples diagnosed with discordancy, and the outcomes can be unpredictable and difficult to handle for most family members. Although some might have disclosed this to only one family member, some family members are not aware of such a diagnosis. There are difficulties related to secondary disclosure, which might pose detrimental impacts on the discordant couples since they might face additional distress, tension in the family, lack of support, criticism, stigma, or even face some daily gossip from other family members. The Rapid Response Service (2013) further stipulates that the people infected with HIV, disclosure may be limited in telling someone about their HIV status. Besides, sharing one's HIV status can help one cope with the life stressors so that they can cope well with living with HIV. However, deciding whom to tell can be difficult, threatening, or even more complicated, especially if one does not know how others will respond. While some couples reside with family members and extended family members in the same household, such disclosure may pose a challenge not to share with everyone in the family since some might not be accepting. It is well known that disclosing one's status is more likely to have an impact on people you tell, but it's clear that others may react differently and in more negative ways. It is for such reason that educational counseling on disclosure support with family and significant others be extended, enhanced, and strengthened by healthcare providers and not only limited to discordant couples.

The study explored the drawbacks associated with secondary disclosure among family members of discordant couples. The findings suggested two (2) themes that emerged and their related sub-themes namely, 1) reaction by family members, and 2) opposition to disclosure. Overall, the discovery of HIV statuses in serodiscordant couples resulted in a range of reactions, which ranged from emotional distress, anger, hurt, and tension among family members. The family members felt stressed and afraid that the HIV-negative partner would eventually become positive. The relatives of the HIV-negative partner in the serodiscordant couple were stressed because they somehow felt the negative partner was taking an unnecessary risk and was eventually going to become negative. The bulk of the anger would, therefore, be directed at the HIV-positive partner, who would be accused of having lived a reckless life that was now endangering their daughter or son. The anger, stress, and hurt also emanated from failure to accept that HIV had infected one of their own, and it took time to accept this situation. Experiencing hurt was attested by Van Dyk (2008) who stated that family members of people with HIV often experience some pain, hurt, and shock because they feel they might lose their loved ones to some chronic illness and eventually to death. Rizza et al. (2012) also added that

amongst other emotional responses, such as shock was one of the reported emotional responses after family members or loved ones share or disclose their HIV status with them.

In the event that the family members were related to the HIV positive partner, the family members were stressed that one of their own had contracted a disease that had no cure. Tshoma (2014) also highlights that family members of serodiscordant couples who carry the burden of care suffer the most in terms of anxiety, depression, and social malfunctioning than the patients themselves. Eventually, most of the family members decided to accept the situation and support the serodiscordant couple even though this did not take place in a short space of time. In some instances, the revelation of the HIV statuses in the serodiscordant couple ignited tensions among families. These tensions impacted the level of support the couple could obtain from both their families. The tension also meant that some family members would have taken time to accept. However, the study revealed that the reactions of anger, stress, and hurt were not permanent. It was something that happened upon finding out, but it would eventually disappear with time in most cases.

11.2. Opposition to disclosure

While secondary disclosure might challenge some family members to respond and provide high quality social support, stronger family cohesion and relationships, reduce anxiety and depression, and promote improvements in physical health, this may strengthen the relationship couples have with their family members. Regardless, secondary disclosure is encouraged by most researchers and healthcare providers due to the positive benefits this might have. Most of the family members of serodiscordant couples were opposed to the disclosure of HIV statuses of couples. In a study by Arrey et al. (2015), all participants reported selective disclosure to a variety of people including general practitioners, intimate partners, children, selected family members. Concealing the HIV statuses of the couples was mostly viewed as a way of protecting the couple from negative impacts of gossip, stigmatisation and in some cases from insults from other family members.

HIV stigma and discrimination is believed to have a significant impact on various aspects of people' lives such as health, the relationship between family members, and the well-being of discordant couples. High levels of stigma and discrimination continue to undermine positive responses to HIV related matters responses. According to the UNAIDS (2021), HIV-related stigma and discrimination refers to a range of stigmatizing experiences including gossip mongers between individual and family members, poor psychosocial support, avoidance behaviours, social rejection, gossip, and verbal abuse. Stangl et al. (2019) argue that stigma continues to undermine positive responses and it involves much of negative attitudes, perceptions, judgement, and behaviours often driven by the emotions of ignorance and fear. Whereas discrimination is argued to be involving unfair treatment, violation of laws and policies to some extent and both stigma and discrimination can take many forms, including disparaging attitudes, sub-standard treatment, and denial of treatment, and reduce people's uptake of and retention in prevention and treatment (UNAIDS 2022). This is also what Mbonu, van den Borne, and De Vries (2009) asserted that stigma enhances secrecy and denial and these are catalysts of HIV transmission. According to Mbonu et al. (2009), in some cases the family members of the people living with HIV are stigmatised as well. This may explain why family members choose to conceal the HIV statuses of their children or relatives in serodiscordant relationships as is the case in this particular study. The family members choose to remain silent in order to avoid rejection from society.

The opposition to disclosure was found amongst almost all the family members who participated in the study. This, in a way, indicated that issues regarding stigma and negative perceptions of people living with HIV had not changed as much as HIV experts, researchers and government had envisaged. The knowledge of HIV statuses of the serodiscordant couples was kept among a select few family members who became guardians of the secret as they feared that if more had knowledge, it would lend to neighbours and the community. In some instances, the HIV-positive partner in the serodiscordant relationship would emphasise to family members not to disclose to anyone. Despite the advances in the knowledge of partners' status, partners at times fear disclosing their HIV status because they are not yet ready to divulge the information and are uncertain of spousal family support and understanding (Baratedi et al., 2014).

It was also discovered that issues regarding HIV and AIDS were seldom discussed, especially in families of serodiscordant couples. The topic of HIV was treated more like a taboo. The family members were not comfortable discussing anything related to HIV, especially when they were sitting with the couple. This just goes to show that the perceptions regarding HIV/AIDS have not changed a lot, and more work still needs to be done by government and other organisations to ensure that people freely discuss HIV-related issues. Kwan (2014) argued that taboo and stigma were some of the primary barriers to accessing information, testing, and treatment. The fact that family members prefer not to discuss issues related to HIV & AIDS implies that information is not being shared among the family members, and this may impact HIV frequent testing especially by HIV-negative partners and other family members. Hearing one's status from other family members may be associated with negative emotions. In some family members, topics related to HIV are not freely and openly discussed as they bring shame and embarrassment to them. Culture and norms play an important role and contribute negatively to those infected and affected by discordancy. Cultural norms specific to different family members and across different communities may dictate different responsibilities related to disclosure. Clearly, this is related to what participants had to do by refusing to tell some family members about their serodiscordancy diagnosis. This is also supported by Flowers and Davis (2013), who asserts that also in Asian communities, the norm of collectivism dictates that disclosure of one's discordant status added in families, therefore in most families, disclosure is not recommended and supported because it might cause emotional damage and division in families due to various reasons.

12. Conclusions and recommendations

HIV status affects not only the individual but also his or her family. In some cases, non-disclosure and secondary disclosure is a way to avoid stigma, discrimination and embarrassing the larger family. In the context of couples, families, and the community at large, disclosure and secondary disclosure are thought to be important for public health purposes in terms of preventing the spread of HIV from one partner to another in discordant couples. Despite residing with family members in the same households, the relationships that discordant couples have with their family members differ, and this might determine the possibility of disclosure to them or not. When discordant couples intend to disclose their discordancy status, it is vital they consider the importance of their relationships with their family members by assessing the type and quality of the relationship they have with them, their attitude and characteristics of relationships, the likelihood of acceptance and confidentiality which must pose a challenge for some. Since the disclosure of discordant results has an impact on families, they experienced some emotional reactions post disclosure of couples and thus brought them tensions in a various ways such as

stress, anger and hurt. The emotional reaction was further accompanied by the tension in families, which made them not get along. Since couples disclosed to only one family member, there was some strong emotion related to the opposition to disclosure, which was evident due to stigma and discrimination, gossip mongers, family prefers to keep the status a secret. Since the HIV status is seen as a taboo and not many family members are open to talking about it, family members preferred to keep the status private as disclosure could not add value.

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References

[Name of authors] (Year): Psychosocial factors associated with disclosure of HIV positive serostatus: Understanding the influence of depression and social support. *Journal of HIV/AIDS & Social Services, 7*(1), 83-98. https://doi.org/10.1080/15381500802093258

Andrew, K., Richards, R., & Hemphill, M. A. (2017). A practical guide to collaborative qualitative data analysis. *Human Kinetics Journals, 37*(2), 225-231. https://doi.org/10.1123/jtpe.2017-0084

Arnold, E. M., Rice, E., Flannery, D., & Rotheram-Borus, M. J. (2008). HIV disclosure among adults living with HIV. *AIDS Care, 20*(1), 80-92.

Arrey, A. E., Bilsen, J., Lacor, P., & Deschepper, R. (2015). It's my secret: Fear of disclosure among sub-Saharan African migrant women living with HIV/AIDS in Belgium. *PloS One, 10*(3), Article e0119653. https://doi.org/10.1371/journal.pone.0119653

Baratedi, W. M., Thupayagale-Tshweneagae, G., & Ganga-Limando, M. (2014). Experiences of the HIV serostatus disclosure in serodiscordant couples in three urban areas in Botswana. *Life Science Journal, 11*(11), 961-965.

Braun, V., & Clarke, V. (2021). The ebbs and flows of qualitative research: Time, change and the slow wheel of interpretation. In B. C. Clift, J. Gore, S. Gustafsson, S. Bekker & I. S. Costas Batlle (Eds.), *Temporality in qualitative inquiry: Theories, methods, and practices*. Routledge.

Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide*. Sage. https://doi.org/10.1007/978-3-319-69909-7_3470-2

Burns, N., & Grove, S. K. (2011). *Understanding nursing research: Building an evidence based practice* (5th Ed.). Saunders.

Butler, C., Wilson, P., & Abrahamson, V. (2022). Optimum models of hospice at home for end-of-life care. National institute for health care research NO. 10:24 England.

Canadian, H. I. V., & Network, A. L. (2012). HIV disclosure to sexual partners.

Carpenter, L. M., Kamali, A., Ruberantwari, A., Malamba, S. S., & Whitworth, J. A. (1999). Rates of HIV-1 transmission within marriage in rural Uganda in relation to the HIV sero-status of the partners. *AIDS (London, England), 13*(9), 1083-1089. https://doi.org/10.1097/00002030-199906180-00012

Caughlin, J. P., Bute, J. J., Donovan-Kicken, E., Kosenko, K. A., Ramey, M. E., & Brashers, D. E. (2009). Do message features influence reactions to HIV disclo-sures? A multiple-goals perspec-tive. *Health Communication 24*(3), 270-283.

Chemaitelly, H., & Abu-Raddad, L. J. (2013). External infections contribute minimally to HIV incidence among HIV sero-discordant couples in sub-Saharan Africa. *Sexually transmitted infections*, *89*(2), 138-141. https://doi.org/10.1136/sextrans-2012-050651.

Crankshaw, T. L., Mindry, D., Munthree, C., Letsoalo, T., & Maharaj, P. (2014). Challenges with couples, serodiscordance and HIV disclosure: Healthcare provider perspectives on delivering safer conception services for HIV-affected couples, South Africa. *Journal of the International AIDS Society*, *17*(1), Article 18832. https://doi.org/10.7448/IAS.17.1.18832

De Vos, A. S., Strydom, H., Fouche, C. S. L., & Delport. (2002). *Research at grass roots: For the social sciences and human service professions* (2nd ed.). Van Schaik.

Dessalegn, N. G., Hailemichael, R. G., Shewa-amare, A., Sawleshwarkar, S., Lodebo, B., Amberbir, A., & Hillman, R. J. (2019). HIV Disclosure: HIV-positive status disclosure to sexual partners among individuals receiving HIV care in Addis Ababa, Ethiopia. *PloS One, 14*(2), Article e0211967. https://doi.org/10.1371/journal.pone.0211967

Flowers, P., Davis, M. D. (2013). Understanding the biopsychosocial aspects of HIV disclosure among HIV-positive gay men in Scotland. *Journal of Health Psychology May, 18*(5), 711-724. https://doi.org/10.1177/1359105312454037

Hirsch Allen, A. J., Forrest, J. I., Kanters, S., O'Brien, N., Salters, K. A., McCandless, L., Montaner, J. S., & Hogg, R. S. (2014). Factors associated with disclosure of HIV status among a cohort of individuals on antiretroviral therapy in British Columbia, Canada. *AIDS and Behavior, 18*(6), 1014-1026. https://doi.org/10.1007/s10461-013-0623-9

Hult, J. R., Wrubel, J., Bränström, R., Acree, M., & Moskowitz, J. T. (2012). Disclosure and nondisclosure among people newly diagnosed with HIV: An analysis from a stress and coping perspective. *AIDS Patient Care and STDs*, *26*(3), 181-190. https://doi.org/10.1089/apc.2011.0282.d

Kwan, M. P. (2014). *Geographies of health, disease and well-being: Recent advances in theory and method*. Routledge.

Kyaddondo, D., Wanyenze, R. K., Kinsman, J., & Hardon, A. (2013). Disclosure of HIV status between parents and children in Uganda in the context of greater access to treatment. *Journal of Social Aspects of HIV/AIDS Research Alliance, 10*(Suppl 1), S37-S45. https://doi.org/10.1080/02664763.2012.755323

Maher, C., Hadfield, M., Hutchings, M., & de Eyto, A. (2018). Ensuring rigor in qualitative data analysis: A design research approach to coding combining nvivo with traditional material methods. *International Journal of Qualitative Methods, 17*, 1-13.

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung/Forum Qualitative Social Research, 11*(3), Article 8.

Mbonu, N. C., van den Borne, B., & De Vries, N. K. (2009). Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review. *Journal of Tropical Medicine, 2009*, Article 145891. https://doi.org/10.1155/2009/145891

Murphy, D. A., Armistead, L., Marelich, W. D., Payne, D. L., Herbeck, D. M. (2011). Pilot trial of a disclosure intervention for HIV+ mothers: The TRACK program. *Journal of Consulting and Clinical Psychology, 79*(2), 203-214.

Obermeyer, C. M., Baijal, P., Pegurri, E. (2011). Facilitating HIV disclosure across diverse settings: A Review. *Am Jounal Public Health, 101*(6), 1011-1023.

Polit, D. F., & Beck, C. T. (2012). *Nursing research: generating and assessing evidence for nursing practice* (8th ed.). JB Lippincott Williams and Wilkins.

Polit, D. F., & Beck, C. T. (2014). *Essentials of nursing research: Appraising evidence for nursing practice* (8th ed.). Wolters Kluwer/Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2016). *Nursing research: Generating and assessing evidence for nursing practice*. Wolters Kluwer.

Rahman, M., Tabash, M. I., Salamzadeh, A., Abduli, S., & Rahaman, M. S. (2022). Sampling techniques (probability) for quantitative social science researchers: Conceptual guidelines with examples. *SEEU Review, 17*(1), 41-51.

Rapid Response Service. (2013). Rapid Response: Disclosure of HIV-Positive Status. Toronto, ON: Ontario HIV Treatment Network: March 2013. Updated November 2014. [Link]

Rizza, A., Kaplan, V., Senn, O., Rosemann, T., Bhend, H., & Tandjung, R. (2012). *Age- and gender-related prevalence of multimorbidity in primary care: The Swiss Fire Project*. BioMed Central Ltd.

Rodkjaer, L., Sodemann, M., Ostergaard, L., & Lomborg, K. (2011). Disclosure decisions: HIV-positive personscoping with disease-related stressors. *Qualitative Health Research, 21*(9), 1249-1259.

Rothbaum, F., Rosen, K., Ujiie, T., & Uchida, N. (2002). Family systems theory, attachment theory, and culture. *Family Process, 41*(3), 328-350. https://doi.org/10.1111/j.1545-5300.2002.41305.x

Spangler, S. A., Onono, M., Bukusi, E. A., Cohen, C. R., & Turan, J. M. (2014). HIV-positive status disclosure and use of essential PMTCT and maternal health services in rural Kenya. *Journal of Acquired Immune Deficiency Syndromes (1999), 67*(Suppl 4), S235-S242. https://doi.org/10.1097/QAI.0000000000000376

Stangl, A. L., Earnshaw, V. A., Logie, C. H., van Brakel, W., C Simbayi, L., Barré, I., & Dovidio, J. F. (2019). The health stigma and discrimination framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine, 17*(1), Article 31. https://doi.org/10.1186/s12916-019-1271-3

Taylor, S. E., & Master, S. L. (2011). Social responses to stress: The tend-and-befriend model. *The Handbook of Stress Science: Biology, Psychology, and Health*, *101*(109), 101-109.

Tshoma, R. L. (2014). *Factors contributing to the mechanisms of sero-doscordant relationships*. North-West University.

UNAIDS. (2020). *Global HIV & AIDS statistics - 2020 fact sheet*. Unaids. https://www.unaids.org/en/resources/fact-sheet

UNAIDS. (2021) *Global HIV & AIDS statistics - 2021 fact sheet*. Unaids. https://www.unaids.org/en/resources/fact-sheet

UNAIDS. (2021). *Global partnership*. Unaids. https://www.unaids.org/en/topic/global-partnership-discrimination

UNAIDS. (2021). *HIV and sigma and discrimination: Human rights FACTSHEET series*. Unaids. https://www.unaids.org/en/resources/documents/2021/07-hiv-human-rights-factsheet-stigma-discrmination

UNAIDS. (2022). *Stigma and discrimination*. Unaids. https://www.unaids.org/en/keywords/stigma-and-discrimination

Van Dyk, A. (2008). *HIV/AIDS care and counselling: A multi-disciplinary approach* (4th ed.). Pearson Education.

Yaya, I., Saka, B., Landon, D. E., Patchali, P. M., Patassi, A. A., Aboubakari, A., Makawa, M., D'ri, M. K., Senanou, S., Lamboni, B., Idrissou, D., Salaka, K. T., & Pitche, P. (2015). HIV status disclosure to sexual partners, among people living with HIV and AIDS on antiretroviral therapy at Sokode Regional Hospital, Togo. *PLoS On 10*(2), Article e0118157. https://doi.org/10.1371/journal.pone.0118157