The Effect of Disclosure/Non-disclosure on the Well-Being of HIV-Positive Pregnant African Women in Gauteng Province, South Africa

by

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The Effect of Disclosure/Non-disclosure on the Well-being of HIV-Positive Pregnant African Women in Gauteng Province, South Africa

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I further declare that I have not previously submitted this work, or part of it, for examination at UNISA for another qualification or at any other higher education institution.

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SIGNITURE DATE

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Summary

This study aimed to explore the experiences of HIV-positive pregnant African women in the province of Gauteng, South Africa, and the perceived effect of their HIV-positive status disclosure/non-disclosure on well-being. Data were gathered through in-depth semi-structured interviews and were analysed according to the interpretative phenomenological analysis methodology. The findings of this study showed that in most cases disclosure was made to the male partner and female family members. The main reasons for disclosure to a partner were honesty and to allow the partner to make informed health decisions. The reasons for disclosure to family members were motivated by the need for support. Appropriate support provided by the family, or a partner, had a positive effect on a woman's well-being. Women who did not disclose their status felt increased levels of anxiety due to the possibility of unintentional disclosure. Well-being was defined by participants and included physical well-being and happiness.

Keywords

Gauteng, HIV, HIV-positive status disclosure, HIV-positive status non-disclosure, interpretative phenomenological analysis, pregnant African women, qualitative research, social support, South Africa, well-being

Isifinyezo

Lolu cwaningo luhlose ukuhlola okubandakanya okwabesifazane base-Afrika abakhulelwe abane sandulela nculazi esifundazweni sase-Gauteng, eNingizimu Afrika, kanye nomphumela ocatshangwayo wokudalulwa/nokungavezi isimo sabo sokuba ne- sandulela nculazi enhlalakahleni. Ulwazi yaqoqwa ngezingxoxiswano ezijulile ezihlelwe nokwe nxenye futhi yahlaziywa ngokuvumelana nendlela yokuhlaziya ye-phenomenological. Okutholwe kulolu cwaningo kubonise ukuthi ezimweni eziningi abasefazane badalule kumlingani wesilisa kanye namalungu omndeni wabo. Izizathu eziyinhloso zokudalula kumlingani kwakuwukwethembeka kanye nokuvumela umlingani ukuthi enze izinqumo zezempilo enolwazi. Izizathu zokudalula kumalunga omndeni zazigqugquzelwa isidingo sokusekelwa. Ukusekelwa okufanele okunikezwa umndeni, noma umlingani, kwaba nomphumela omuhle enhlalakahleni yowesifazane. Abesifazane abangasidalulanga isimo sabo bazizwe benyukelwa amazinga okukhathazeka ngenxa yokuthi kungenzeka badalule bengahlosile. Abahlanganyeli ocwaningweni, noma engxoxweni, banikeza ezabo izincazelo ezisho ukuthi inhlalakahle yayihlanganisa ukuphila kahle ngokomzimba nenjabulo.

Igama elisemqoka

Abesifazane abakhulelwe base-Afrika, i-Gauteng, iNingizimu Afrika, i- sandulela nculazi, ucwaningo lwekhwalithi, ukudalulwa kwesimo sesandulela nculazi, ukuhlaziya okuchazayo, ukungadalulwa kwesimo sesandulela nculazi, ukusekelwa komphakathi, inhlalakahle

Opsomming

Hierdie studie het ten doel gehad om die ervarings van MIV-positiewe swanger Afrika-vroue in die provinsie Gauteng, Suid-Afrika, en die waargenome effek van hul MIV-positiewe status openbaarmaking/nie-openbaarmaking, oor hulle welstand. Data is ingesamel deur in-diepte semi-gestruktureerde onderhoude, en is volgens die interpretatiewe fenomenologiese analise metodologie ontleed. Die bevindinge van hierdie studie, het getoon dat in die meeste gevalle openbaarmaking gemaak is aan die manlike lewensmaat en vroulike familielede. Die hoof redes vir openbaarmaking aan 'n vennoot was eerlikheid, en om die vennoot toe te laat om ingeligte gesondheidsbesluite te maak. Die redes vir bekendmaking aan familielede was gemotiveer deur die behoefte aan ondersteuning. Toepaslike ondersteuning verskaf deur die gesin, of 'n lewensmaat, het 'n positiewe uitwerking op 'n vrou se welstand gehad. Vroue wat nie hul status bekend gemaak het nie, voel verhoogde vlakke van angs as gevolg van die moontlikheid van onbedoelde openbaarmaking. Welstand is deur deelnemers gedefinieer, en het fisiese welstand en geluk ingesluit.

Sleutelwoorde

Gauteng, interpretatiewe fenomenologiese analise, kwalitatiewe navorsing, maatskaplike ondersteuning, MIV, MIV-positiewe status openbaarmaking, MIV-positiewe status nie-openbaarmaking, Suid-Afrika, swanger Afrika vroue, welstand

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Chapter 1: Introduction

The purpose of this study was to explore the experiences of Human Immunodeficiency Virus (HIV)-positive pregnant African women attending prenatal care facilities in Gauteng Province, South Africa, and the perceived effect of their HIV-positive status disclosure/non-disclosure on well-being. There is limited research regarding well-being in HIV-positive pregnant African women from a qualitative perspective, which utilised interpretative phenomenological analysis to understand the meaning that HIV-positive pregnant African women ascribe to well-being. Purposive homogenous sampling was chosen for this research comprised of 10 HIV-positive pregnant women who attended a **h**ospital for pre-natal examination.

The intention of this study was to gain an in-depth understanding of what motivates HIV-positive pregnant women to disclose their status to significant others, and the contributing factors of barriers to disclosure. The decision whether to disclose or not to disclose an HIV-positive status is a challenging choice to make. This decision depends on differing life circumstances and a variety of subjective reasons (Brittain et al., 2018; Knettel et al., 2019; Ramlagan et al., 2018; Watt et al., 2018). Therefore, this study investigated self-reported personal reasons and life factors that influenced the decision regarding disclosure/non-disclosure among HIV-positive pregnant women. This study further focused on the different outcomes that followed disclosure/non-disclosure. It was anticipated that understanding the different outcomes of disclosure/non-disclosure would assist in comprehending which outcomes could have a positive or a negative effect on well-being.

Chapter one presents a breakdown of the elements of the study. These elements include: research context, problem statement, research aim objectives and questions, definition of key terms, the significance of the study, theoretical foundation of the study, the research methodology and data analysis.

Research Context

Stats SA (2022) found that South African women are at a higher risk of contracting HIV than South African men. The evidence shows that the majority of women received their HIV diagnosis after they had presented themselves to ante-natal services (Brittain et al., 2017). Women who have been diagnosed with an HIV-positive status during pregnancy are at a higher risk of exposure to psychological challenges (Kotzé et al., 2013; Qin et al., 2019; Rodriguez et al., 2017; Wong et al., 2017). These women have had to come to terms with their positive diagnosis, manage their pregnancy, and decide whether they will disclose their status (Maeri et al., 2016). Women fear disclosing their status to others because of the possibility of stigmatisation, shame, fear of mistreatment and abandonment by a partner (Knettel et al., 2019; Maeri et al., 2016; Naigino et al., 2017; Ramlagan et al., 2018; Walcott et al., 2013).

It has been noted that obstacles to HIV care, safe motherhood and antiretroviral (ARV) medication intake have often been associated with non-disclosure of HIV-positive status (Gourlay et al., 2013; Knettel et al., 2019; Naigino et al., 2017; Ramlagan et al., 2018). Women who choose to hide their diagnosis may put their child at risk of HIV transmission. If there is an increased risk of exposure, women may feel unable to take their ARV medication at the prescribed time. Furthermore, they may not be able to attend required ante-natal clinics (Brittain et al., 2018).

Negative outcomes of non-disclosure can also present themselves as physical and psychological challenges. These challenges can impair a woman’s ability to participate in HIV care (Ashaba et al., 2017; Marais et al., 2018; Naigino et al., 2017; Ramlagan et al., 2018; Walcott et al., 2013), and can have a negative effect on neuro-behavioural functioning, which may lead to the long-term maladjustment of the child (Fredriksen et al., 2017; Peterson et al., 2020). Non-disclosure of an HIV-positive status can protect women from stigmatisation and discrimination, but on the other hand, it can limit women's access to social support which could improve well-being outcomes (Hasan et al., 2012; Katz et al., 2013; Tsai et al., 2013).

A positive effect on well-being after disclosure has been associated with social support. Women who feel supported are less likely to experience psychological distress and are more likely to use active coping strategies, accept a diagnosis, develop resilience, and improve self-esteem (Bhat et al., 2015; Geubbels et al., 2018; Lifson et al., 2020; Knettel et al., 2020; Xiaowen et al., 2018). Women who feel supported are motivated to regularly attend clinical appointments and engage in HIV treatment (Knettel et al., 2019; Kotzé et al., 2013; Naigino et al., 2017; Watt et al., 2018). HIV-positive status disclosure has been associated with the freedom to take medication, and the reduction of anxiety from keeping their status secret. (Watt et al., 2018).

A negative effect on well-being after disclosure has been associated with abandonment by a partner, physical abuse, discrimination or loss of financial support, rejection by friends and family, and being stigmatised by the community (Akatukwasai et al., 2021; Cuca & Rose, 2016; Hampanda Id et al., 2020; Madiba et al., 2021; Ojikutu et al., 2016). A negative consequence of disclosure can lead to emotional distress (Aloyce et al., 2020; Onono et al., 2020; Reyes et al., 2020). Research indicates the importance of well-being for physical health, and has found that positive emotions promote better physical health (Chida & Steptoe, 2008; Feller et al., 2018). Positive well-being is correlated with positive health outcomes, and improved well-being can improve overall physical health (Anton et al., 2015; Howell et al., 2007).

Research has shown a connection between HIV status disclosure and the effect of the disclosure on well-being (Brown et al., 2019; Cook et al., 2015). Disclosure can help women receive improved social support and enhance psychological well-being (Omonaiye et al., 2020; Yeji et al., 2014). However it carries risk of stigmatisation and discrimination and it can have a negative impact on well-being (Cuca & Rose, 2016; Hampanda Id et al., 2020; Maman et al., 2014; Ojikutu et al., 2016). Due to the importance of this subject, there is a need to develop an understanding of well-being and explore what contributes to well-being after disclosure by HIV-positive pregnant women.

Problem Statement

In most cases, a quantitative research approach has been adopted to measure psychological, subjective well-being in HIV patients (Brittain et al., 2017; Đorić, 2020; Hickman et al., 2013; Rzeszutek & Gruszczyńska 2020; Varni et al., 2012). While this method provides a general understanding of how HIV disclosure can affect one's well-being, it does not fully describe well-being nor what this means for a particular population. Well-being measuring tools were developed to measure the population of Western nations, which might not be relevant to non-western countries due to differences in cultural, social and economic influences (Christopher, 1999; Grills et al., 2018; Wilson, 2020). The perceived understanding of well-being does not fit within a universal standard applicable to everyone; instead it is highly subjective and depends on the situation, place, or condition at any particular time (Thin, 2018; Wright & Cropanzano, 2000).

The HIV-positive status disclosure/non-disclosure decision is highly subjective and depends on various personal circumstances (Brittain et al., 2018; Knettel et al., 2019; Ramlagan et al., 2018; Watt et al., 2018). It is important to gain insights from the unique experiences of participants regarding the decision-making process. A qualitative approach will provide a better understanding of what individual aspects act as barriers to disclosure and what motivates women to disclose their HIV-positive status. Disclosure and non-disclosure outcomes can help determine what factors influence well-being outcomes. This study addressed the research gap by examining how well-being is perceived by research participants, the unique factors influencing the decision to disclose/not disclose HIV-positive status, and the elements that comprise well-being after an HIV-positive status disclosure/non-disclosure.

Research Aims and Objectives

Research Aim

The aim of this study was to explore the experiences of HIV-positive pregnant African women attending prenatal care facilities in Gauteng Province, South Africa, and the perceived effect of their HIV-positive status disclosure/non-disclosure on well-being.

Research Objectives

- To explore different reasons and motivators for HIV-positive status disclosure/non-disclosure.
- To compare and analyse the reasons and situations that resulted in positive or negative outcomes after HIV-positive status disclosure/non-disclosure.

- To identify the connection between an HIV-positive status disclosure/non-disclosure and well-being.
- To identify the meaning of well-being as understood by research participants.

Research Questions

1) What factors influence the decision to disclose/not disclose one's HIV-positive status to others?
2) What factors resulted in positive or negative outcomes after HIV-positive status disclosure/non-disclosure?
3) How does an HIV-positive status disclosure/non-disclosure affect well-being?
4) How is well-being defined by the research participant?

Significance of the Study

The current study seeks to contribute to the available literature by investigating the unique experiences of the participants based on self-reported motivators and barriers for HIV-positive status disclosure/non-disclosure.

It is anticipated that the results of this study would contribute to knowledge of the different elements that comprise well-being after an HIV-positive status disclosure/non-disclosure in black HIV-positive pregnant women.

Furthermore, this study will provide a new insight as to how well-being is perceived by black HIV-positive pregnant women.

Theoretical Foundation of the Study

Research Paradigm

A paradigm is the system of beliefs and assumptions employed by researchers to explain how their particular research problem should be understood (Kuhn, 1970). The components of the paradigm are ontology and epistemology, which comprise the assumption aspects of the research (Denzin & Lincoln, 2017). Ontology questions the meaning of reality and the purpose of humans within that reality. Epistemology is the study of knowledge, in particular, our understanding of the world which we live (Crotty, 1998). This study relied on the research paradigm of Interpretivism. Interpretivism relies on the belief that we exist within multiple realities, and that these realities are constantly shifting and changing (Goldkuhl, 2012; Hudson & Ozanne, 1988; Walsham, 1995). These realities should be viewed holistically and individually. We create reality through our behaviour, and our reality receives meaning from the context of our behaviour.

Interpretive ontology is based on relativism and incorporates the principle of multiple realities (Hudson & Ozanne, 1988; Lincoln & Guba, 2013). We interpret reality through our mental construction and our senses. The truth of reality is dependent on the person who is experiencing it for its content and form (Guba & Lincoln, 1994). “It entails that the composition of the world is different because different perceivers see things differently or just because language users from different communities use non-translatable vocabularies or languages which are syntactically different” (Hibberd, 2005, p. 44).

Subjective epistemology means that data acquires meaning from the thought process of the researcher, which is derived from their interactions with the participants (Lincoln & Guba, 2013). The implication is that knowledge is a social construct by the researcher because of their personal experiences with their environment (Berger & Luckmann, 1966; Levers, 2013). The purpose of subjectivism is to understand the subjective experiences of multiple realties. While there is no denial that an outside, objective reality exists, subjective epistemology believes that ‘’universal knowledge of an external reality is not possible beyond individual reflections and interpretations’’ (Levers, 2013). Understanding, and interpretation, of the phenomenon depends on a person perceiving it. The research problem in this study required an understanding of the participants’ interpretation of the meaning of well-being. Well-being can have multiple meanings and realities depending on the person being interviewed, as each person will have their own experiences, interpretations and understandings of what well-being entails. The interpretivist approach to understanding this subject allowed participants to express their knowledge and comprehension of the subject matter.

Theoretical Framework

Consequence theory (Serovich, 2001) and social support theory (Cullen, 1994) have been combined to create a theoretical framework for an understanding of the motives and barriers to HIV-positive status disclosure, and the effects of disclosure on well-being in HIV-positive pregnant women. Consequence theory in the HIV context was developed and applied for the first time by Serovich (2001) who tested consequence theory on 138 HIV-positive men. Serovich was interested in discovering what patterns promote HIV-positive men to disclose their HIV-positive status to their partners, family and friends. According to consequence theory, disclosure occurs after a person has weighed the costs and the rewards of disclosure. If an HIV-positive status disclosure provides more reward than the cost, then the person will choose disclosure. A rewarding outcome can result in social, emotional and physical support from family and friends. If the cost outweighs the reward, then the choice will be made in favour of non-disclosure. Negative outcomes that might follow HIV-positive disclosure are avoidance, abandonment, separation and stigmatisation from others (Qiao et al., 2013). By applying consequence theory to the decision-making process of HIV-positive status disclosure, it will be possible to examine whether the women received the positive support they hoped for that had motivated their decision to disclose. This approach could help to explain why some women disclose their positive status while others do not.

In light of the theory presented above, it is necessary to include social support theory. Social support theory was first proposed by Cullen (1994), and was initially focused on criminals and delinquency. Cullen argued that low levels of community and family support predict higher levels of crime. Supportive societies and interpersonal relationships are two main predictors of decreased crime behaviour. Over the years, this theory has been adapted to other areas of psychology. It can be readily applied to areas where social support could have a valuable role to play (Galvan et al., 2008).

Social support theory hypothesises that social support received by individuals during difficult times can protect them from the negative consequences of life, such as stress and anxiety, and can enhance feelings of personal control, self-worth and overall well-being (Cohen et al., 2000; Galvan et al., 2008). This theory highlights the benefits of social relationships during life-threatening illnesses and traumatic events, where perceived social support helps individuals to deal effectively with life stressors, and leads to positive psychosocial and health outcomes (Mutha et al., 2008). It has been documented that family support and good social networks are essential for well-being in collectivist societies (Brown et al., 2019; Goddard et al., 2020; Wilson, 2020).

Pregnant HIV-positive women who receive appropriate social and partner support after disclosure have been shown to cope better with their HIV-positive diagnosis (Ramlagan et al., 2018). High levels of support from family and partner were associated with lower levels of stress and anxiety (Vyavaharkar et al., 2011), and lower levels of depressive symptoms (Peltzer et al., 2020), increased well-being and quality of life (Cederbaum et al., 2017). Research has found that women who fear stigmatisation and discrimination prefer not to disclose their status and withdraw from their social structures (Brener et al., 2020; Cuca & Rose, 2016; Lingen et al., 2016). A lack of social support increases the likelihood of depression and decreases quality of life (Bekele et al., 2013; Dyer et al., 2012; Yeji et al., 2014). Non-disclosure of HIV-positive status can keep women from receiving the necessary social support needed to improve well-being outcomes; however, disclosure can also lead to, stigmatisation and exclusion from the community (Geubbels et al., 2019; Kotzé et al., 2013). In light of these two theories, it can be seen that consequence theory (Serovich et al., 2000) could have an impact on the decision to disclose or not to disclose one’s HIV-positive status with the expectation of positive benefits. The social support theory (Cullen, 1994) relates to consequence theory in that positive social support after disclosure can lead to improved well-being. Non-disclosure of an HIV-positive status could act as a barrier to receiving support during times when it is needed most.

Research Methodology

Qualitative Research Approach

Qualitative research involves an interpretative, naturalistic approach, which entails studying a subject in its natural setting and interpreting phenomena in terms of their associated meaning (Denzin & Lincoln, 2017). When complex issues require a deeper investigation, the qualitative approach is the appropriate approach to employ (Creswell, 2013). The qualitative approach offers tools for an in-depth examination of the participants' life experiences from their own perspectives (Lyons, 2011). This approach also allows for exploring multiple realities as experienced by the participants in their own unique environments (Smith & Shinebourne, 2012).

The qualitative research approach was selected for this study for several reasons. There is limited literature that examines the effect of disclosure on the well-being of HIV-positive status of pregnant African women within the South African context. Using the qualitative approach would determine a range of potential factors that affect the decision to disclose or not disclose. The qualitative approach of investigation allowed for the voices of black women to be heard regarding their subjective experiences of their HIV status and well-being. A South African study of well-being requires a unique approach to well-being. People ascribe different meanings to what constitutes well-being (Thin, 2018). The qualitative approach allows for the exploration of the phenomenon of disclosure/non-disclosure based on individual views and experiences (Creswell, 2013).

Interpretative Phenomenological Analysis as Research Methodology

Interpretative phenomenological analysis is a research methodology which requires a qualitative approach, with the purpose of providing a detailed insight into how people deal with their meaningful life experiences (Smith et al., 2009). Three major theoretical bases of interpretative phenomenological analysis consist: Phenomenology, Hermeneutics and Ideography. Phenomenology is interested in the lived experiences of subjects, and in exploring these experiences rather than relying on pre-existing theories. Well-being is a phenomenological event (Diener et al., 2003; Wright & Cropanzano, 2000). People are happy when they believe themselves to be so. Through the phenomenological perspective of interpretative phenomenological analysis, this research explored well-being through the participants' experience, their definition of well-being and the factors that influence a good life (Walker & Kaved-ija, 2015).

Hermeneutics is the second central element upon which interpretative phenomenological analysis is based. Hermeneutics is the theory of interpretation (Smith et al., 2009). The importance of hermeneutics in interpretative phenomenological analysis can be seen in analysing and making sense of HIV-positive pregnant women's lived experiences. Experiences are subjective and must therefore be analysed from the subject's perspective. The subject attempts to make sense of their existence while the researcher attempts to understand the subject through their experiences. The researcher must be open to different methods of interpreting the language and words used by the participants. The third pillar of interpretative phenomenological analysis is ideography (Smith et al., 2009). Ideography means exploring the experience of each HIV-positive pregnant woman in detail in order to fully understand her lived experience. The small sample size of participants allowed for a greater inspection of the differences and similarities between the subjects' experiences and in doing so, to develop general claims.

Interpretative phenomenological analysis is used to solve and understand complex topics (Borkoles et al., 2008; Flowers et al., 2011; Smith & Osborn, 2015), such as well-being and psychological distress (Reynolds & Lim, 2007; Rhodesa & Smith, 2010). Interpretative phenomenological analysis research explores in detail how a person makes sense of a life-altering transition or event (Smith et al., 2009). An HIV-positive status diagnosis and pregnancy are both life-changing events in a woman's life. Interpretative phenomenological analysis helps to develop a more holistic understanding of how an individual experiences and interprets life events from their unique perspective. Using interpretative phenomenological analysis allowed for a description of the relationship between disclosure/non-disclosure and well-being, to develop a holistic understanding of motives and barriers behind the disclosure, the emotional experience after disclosure/non-disclosure, and what is well-being from the participants' perspectives. Interpretative phenomenological analysis was the most suitable choice for this study as it permitted an insightful interpretive account of women's mental and emotional experiences through their own words. The participants told their stories which would then be interpreted in order to understand the experience.

Interpretative phenomenological analysis has been successfully employed in health psychology and has been proven relevant within this field of study (Brocki & Wearden, 2006; Smith et al., 2013). However, while it is an effective **methodology,** interpretative phenomenological analysis does have its challenges. The participants of the sample group should have all experienced the phenomenon to be researched and who can articulate their common lived experiences (Creswell, 2013). Locating study participants who have experienced the required phenomenon could be a potential challenge to an interpretative phenomenological analysis study. Interpretative phenomenological analysis seeks to gain an in-depth understanding of a participant's experience, therefore limiting generalisation (Brocki & Wearden, 2006;

Smith et al., 2009). The explorative nature of interpretative phenomenological analysis can be time-consuming in that the open interviews produce large quantities of data that need to be transcribed and analysed.

Research Design

Sampling Method

The purpose of interpretative phenomenological analysis methodology is to find a reasonably homogeneous sample (Smith et al., 2009). The participants of the sample group should all have experienced the phenomenon to be researched and could articulate their common lived experiences (Creswell, 2013). This is why purposive homogenous sampling was chosen for this study. This population sampling shed light on a particular experience (Peat et al., 2019). An idiographic approach of interpretative phenomenological analysis is concerned with understanding a particular phenomenon within specific contexts (Smith et al., 2009). Interpretative phenomenological analysis studies are conducted with small sample sizes. According to previous studies of a similar nature the ideal sample size should be 10-15 participants (Ashaba et al., 2017; Cuca & Rose, 2016; Flowers et al., 2011; Lingen et al., 2016). The final number of participants was determined by data saturation which is when the data has provided enough information, and there are no new emerging themes from data analysis (Denzin & Lincoln, 2017).

Data Analysis

Data were analysed following the interpretative phenomenological analysis data analysis method (Smith et al., 2009). All interviews were transcribed into written text. ATLAS.ti Web (Version 22.2.5) computer software (ATLAS.ti Windows, n.d.) was used to store, organize and analyse the qualitative data. The first stage involved repeat reading to become familiar with the data, and writing the exploratory comments (Smith et al., 2009). Exploratory comments were used to develop emergent themes and to capture key elements of the transcript. The following step involved clustering emergent themes based on their common meanings and links. Themes were clustered in a table of themes made from superordinate themes, themes and subthemes directly linked to the participants' quotes (Langdridge, 2007; Smith & Osborn, 2008).

Each transcript was analysed separately in its own right (Smith et al., 2009). The same process was followed for each transcript before comparing in a table of themes across the cases. The next stage was to compare and examine the table of themes across all the cases and compile a single master table of themes for all cases. The final master table of themes involved superordinate themes, themes and subthemes. Writing up required an analysis of the tabulated data into a narrative and a final statement (Smith & Osborn, 2008). The narrative explored the participants' lived experiences. Themes were expanded and explained while referring to the transcript as evidence for the claims. The strategy of analysis was to take the emerging theme analysis, and through discussion to link the themes with the existing literature.

Definition of Key Terms

- Disclosure: Disclosure of HIV-positive status to someone means unburdening the HIV-positive test results to someone other than medical staff (Hallberg et al., 2019).
- Non-disclosure: The non-disclosure of an HIV-positive status means receiving a positive-for-HIV test result and not sharing it with anyone.
- Social support: Social support in this study refers to the support provided by a person to whom the woman disclosed her HIV-positive status.

- Well-being: Diener et al. (2016) described well-being from a person's subjective experience and believed that people should define well-being from their own perspective. In this study participants ascribed their own meaning of well-being. Furthermore, social support theory was employed to explain disclosure outcomes on well-being (Cullen, 1994). In this study well-being is also associated with the support provided by partner, family and friends.
- Social Support Theory: Support received by individuals during traumatic life events or life-threatening illnesses can act as a buffer against psychological distress (Cohen et al., 2000; Galvan et al., 2008; Lifson et al., 2020; Knettel et al., 2020; Xiaowen et al., 2018). Social support can minimise the stress and anxiety associated with an HIV-positive status diagnosis (Bekele et al., 2013; Cederbaum et al., 2017; Dyer et al., 2012; Mi et al., 2020; Vyavaharkar et al., 2011).
- Consequence Theory: This theory provides a predictor that can influence the decision regarding HIV-positive status disclosure/non-disclosure (Serovich, 2001). According to consequence theory, disclosure occurs after an HIV-positive person has weighed the benefits and consequences of disclosure. If the HIV-positive status disclosure provides more benefit than consequences, then the person will choose in favour of disclosure.
- Instrumental support: This support refers to tangible assistance such a financial support, helping with household chores, babysitting and transportation (Cohen et al., 2000; Cohen & Wills, 1985; Lin et al., 1986; Lin et al., 1999).
- Expressive support: This involves using social relations to build one's self-esteem, seek understanding, outpouring of frustration, receive

encouragement, and motivation, and get emotional support from others (Ang & Malhotra, 2018; Lin et al., 1999).

Summary

Chapter one provided context for the study and further discussed the gap identified in the literature that needed to be investigated. The significance of the study provided a reason as to how this study can contribute to the research field. Two theoretical bases of this study have been discussed: consequence theory (Serovich, 2001) was anticipated to explain why some women disclose their status while others do not, and social support theory (Cohen et al., 2000; Galvan et al., 2008) was intended to help identify well-being outcomes after disclosure/non-disclosure. Further, this chapter discussed the theoretical background of interpretive phenomenological analysis as a form of qualitative inquiry and provided reasoning as to why it was employed to examine participants lived experiences. Research design introduced the sampling method employed for this study and further discussed the reasoning for purposive homogenous sampling. Interpretative phenological analysis follows a specific system during the data analysis process, which was overviewed in the data analysis section.

Overview of the Remaining Chapters

Chapter Two (Literature Review) will discuss literature that is relevant to this subject matter.

Chapter Three (Research Methodology) describes the research methodology, method and design in detail. Furthermore, this chapter discusses trustworthiness of this study, followed by ethical considerations.

Chapter Four (Findings) reports study findings based on themes identified during the interpretative phenomenological analysis process.

Chapter Six (Conclusion) addresses the limitations of this study, study strengths and provides recommendations for future studies. The chapter concludes with my personal reflections.

Chapter 2: Literature Review

This chapter will provide background information by reviewing studies conducted around HIV-positive status disclosure/non-disclosure, pregnancy and well-being. A thematic literature review was conducted. Preference was given to peer-reviewed studies published between 2012 and 2023, with a focus on pregnant women in an HIV-positive context. Older publications, such as books and journals, have been used to enhance the theoretical perspective.

HIV: Symptoms and Effects

The Human Immunodeficiency Virus attacks the white blood cells in the body whose purpose is to combat infections (World Health Organization [WHO] 2023). In doing so, HIV makes a patient vulnerable to diseases that the body would ordinarily be able to combat. HIV is spread through the transfer of bodily fluids from an infected person, including breast milk, blood, vaginal fluid, and semen. The most common methods of transfer are during unprotected sex or sharing hypodermic needles with drug users. HIV infection does not have a cure, but it is treated by antiretroviral therapy (ART), which helps immune system to get stronger in order to fight infections. Engaging in ART reduces the viral count in the body and as such the condition becomes manageable. Regular HIV-treatment engagement has been shown to extend life expectancy of infected persons.

Some early symptoms of HIV include a sore throat, rash, headache, and fever. Some people might not experience those symptoms at an early stage. Without, treatment HIV progresses and can lead to more serious illnesses such as tuberculosis, cancer (lymphomas and Kaposi’s sarcoma), cryptococcal meningitis, and severe bacterial infections (WHO 2023). Despite physical symptoms, HIV-positive people after diagnosis might face some psychological challenges. Reactions such as shock, anger, disbelief, fear of death have been reported as responses to HIV-positive test results (Lingen et al., 2016; Oshosen et al., 2021). Women who were diagnosed during pregnancy reported considering termination of pregnancy, self-harm and suicide (Lingen et al., 2016).

HIV-positive status diagnosis might increase the chance of developing an anxiety disorder, depression, and other mental health conditions (Brandt et al., 2017). After diagnosis, people might fear stigmatisation and discrimination if someone finds out about their diagnosis (Knettel et al., 2019; Marais et al., 2019; Ojikutu et al., 2016). People who experience HIV-related stigma are more likely to develop depression. Negative self-image and difficulty accepting one’s status have been associated with HIV-related stigma (Felker-Kantor et al., 2019). However, increasing awareness of how HIV is transmitted, removing misconceptions about this virus, and educating oneself and others regarding the effectiveness of ARV medications can reduces the stigma associated with this virus (Rael et al., 2017). Furthermore, it has been shown that decreased stigma is associated with viewing this virus as a manageable chronic health condition that can be treated by ARV medication.

HIV Prevalence in South Africa

Stats SA (2022) found that approximately 13,9% of the South African population was HIV-positive, with the total number of people living with HIV in 2022 being approximately 8,45 million. The findings specified that more than 20% of women in the 15 to 49 years age group were HIV-positive, and that women in this age group have a higher likelihood of contracting HIV. Men in the same age group have lower levels of HIV infection and are less likely to be infected when compared with women. Based on the UNAIDS (2022) report on South Africa, the people who are the most vulnerable to HIV exposure are sex workers, transgender people, men who have sex with men, people who inject drugs, and prisoners.

The evidence shows that the majority of women received their HIV diagnosis after they had presented themselves for ante-natal services (Brittain et al., 2017; Marais et al., 2019; Oshosen et al., 2021; Poku et al., 2020; Ramlagan et al., 2018). This is usually the woman's first exposure to ART and HIV care. The treatment is designed to prevent mother-to-child transmission (PMTCT), protect the health of the mother and to optimise the child's health (Psaros et al., 2020). Based on UNAIDS (2022) report approximately 75% of HIV-positive people in South Africa were on ARV treatment. 80% of HIV-positive women aged 15 and older were on ARV treatment. 95% of HIV-positive pregnant women were receiving ARV treatment for PMTCT. As reported by Stats SA (2022) the increased availability of ARV treatment and access to treatment facilities has led to an improvement in life expectancy, even though the levels of HIV infection are slowly increasing.

Disclosure of HIV-Positive Status

Receiving a positive HIV diagnosis during pregnancy can be a challenging experience (Lifson et al., 2020; Mokhele et al., 2019; Oshosen et al., 2021; Ramlagan et al., 2018; Reyes et al., 2020). Most women have described intense negative feelings after learning of their positive status. Emotions such as shock, denial, depression and hopelessness are the most common reactions among HIV-positive pregnant women (Geubbels et al., 2018). After being diagnosed with an HIV-positive status, a pregnant woman is presented with the challenging decision regarding whether or not to disclose her status to others (Maeri et al., 2016; Watt et al., 2018).

The decision regarding HIV-positive status disclosure is already a complex and challenging decision to make and even more challenging during the vulnerable period of pregnancy (Cuca & Rose, 2016; Ogueji, 2021; Omonaiye et al., 2020). Counselling services encourage patients to disclose their positive status (Brittain et al., 2019a). Disclosure could help pregnant women by allowing them access to proper maternity care, improved ARV therapy and regular clinic visits (Hampanda et al., 2020; Ramlagan et al., 2018). HIV-positive status disclosure can help women receive improved social support and to enhance their psychological well-being (Omonaiye et al., 2020; Yeji et al., 2014). The opposite of this is that it carries the risk of rejection by friends and family, being stigmatised by the community, and it can have a negative impact on well-being (Cuca & Rose, 2016; Hampanda et al., 2020; Maman et al., 2014; Ojikutu et al., 2016). The individual circumstances of each patient will influence whether disclosure will have positive or negative outcomes.

Selective Disclosure

HIV-positive pregnant women selectively choose whom they will tell about their HIV-positive status, how they will approach the person, evaluate the possible reaction people might have upon disclosure and what will be the consequences of the disclosure. Women disclose their status to a person whom they think can be trusted with this sensitive information (Doat et al., 2021; Rael et al., 2017; Steenberg, 2020). Controlled and strategic disclosure enables women to limit the negative consequences of disclosure. Selectively sharing their status helps women to receive support and avoid community ostracism, gossip, rejection, and stigmatisation (Rael et al., 2017).

In sub-Saharan African countries, the rates of disclosure to a partner among pregnant women are from 55% to 95% (Abuogi et al., 2020; Geubbels et al., 2018;

Lifson et al., 2020; Matseke et al., 2021; Odiachi et al., 2018; Walcott et al., 2013; Watt et al., 2018). These disclosure rates involving one’s partner are higher than those to family, friends and community members (Knettel et al., 2019). Women who restrict their disclosure to their partner alone seek greater partner support and encouragement during the pregnancy and feel no need for further disclosure to others (Brittain et al., 2018; Makin et al., 2008). Another reason for disclosing only to a partner is when a woman’s choice of disclosure to others is prohibited by their partner (Brittain et al., 2018). A study conducted among HIV-positive pregnant women in South Africa showed that in most cases women disclose their status to their partner, followed by their sister, friend, mother, female cousin, brother, aunt, uncle, other male family members, and lastly, a spiritual leader (Brittain et al., 2018).

Evidence shows that when women do disclose their status to family members, it is most likely to be to a trusted female family member, such as a sister or mother (Hill et al., 2015; Maman et al., 2014). This is because women seek emotional and social support (Lugalla et al., 2012; Ramlagan et al., 2018), and their female family members are seen as being able to give support and trust (Geubbels et al., 2018; Knettel et al., 2019). Disclosure to male family members is less common. Women who seek advice and solidarity may choose to disclose their status to someone whom they know is HIV-positive (Makin et al., 2008; Watt et al., 2018). In this way, women can get emotional support and advice from someone who has experienced what they are going through and who is more likely to keep their status confidential (Prati et al., 2016). A woman’s first reaction when disclosing her status can be a strong determining factor as to whether she will disclose her status to others (Hampanda et al., 2020; Watt et al., 2018). A successful first disclosure can motivate a woman to further disclose her status to friends and family.

Types of Disclosure

The most common methods of disclosure among HIV-positive pregnant women are voluntary self-disclosure and disclosure during the couple's HIV counselling and testing (CHCT) (Abuogi et al., 2020). Despite the evidence of beneficial disclosure outcomes, not all HIV-positive pregnant women find it easy to tell their partner about their positive test results (Odiachi et al., 2018; Ramlagan et al., 2018). In most relationships, women are the first to find out about their HIV-positive status during antenatal care, and as such, they could be blamed for bringing the infection home (Maeri et al., 2016; Poku et al., 2020; Watt et al., 2018). Pregnant women who want to avoid conflict within the relationship may prefer CHCT with mutual disclosure provided by the professional health worker (Abuogi et al., 2020; Walcott et al., 2013; Oshosen et al., 2021). By using this method of disclosure, the pregnant HIV-positive woman does not need to directly disclose her positive status (Bhushan et al., 2019). This is the preferred and safest method of disclosure among some women (Abuogi et al., 2020; Knettel et al., 2020). This kind of disclosure may prevent pregnant women from adverse outcomes such as divorce, abuse and blame. However, CHCT disclosure does still hold the risk of negative consequences, such as separation and abuse (Walcott et al., 2013).

Another type of HIV-positive status disclosure reported in the literature is involuntary disclosure (Hlongwane & Madiba, 2020; Madiba et al., 2021; Rael et al., 2017; Steenberg, 2020). This refers to cases where HIV-positive status is relieved without a person's permission (Brittain et al., 2018). Involuntary disclosure can be caused by different circumstances, such as the women visiting ARV clinics and taking prescribed medication (Hlongwane & Madiba, 2020; Rael et al., 2017; Steenberg, 2020). Women whose status is disclosed without their consent are at risk of experiencing depression and isolation (Fletcher et al., 2016). Distress caused by involuntary disclosure depends upon who disclosed their status and to whom the disclosure was made. Should involuntary disclosure be made to someone who stigmatises people living with HIV, it can cause emotional and psychological distress. Involuntary disclosure takes away a woman’s choice about whether, when, and how to share such sensitive information. Involuntary disclosure can also occur when a person becomes sick and HIV symptoms become visible to others (Rael et al., 2017). Taking ARV pills in front of others can also lead to involuntary disclosure if someone recognises the HIV medication (Hlongwane & Madiba, 2020). Women often avoid taking medication in front of family members and friends and prefer to delay medication doses to a time when they are able to take them alone (Akatukwasai et al., 2021). In order to avoid involuntary disclosure, some people transfer ARV pills into plastic bags, unlabelled pill bottles, or handbags (Muiruri et al., 2020). Self-repackaging pharmacy-issued medication makes HIV medication less noticeable and unidentifiable.

Fear and stress of involuntary disclosure can be a barrier to HIV treatment engagement, attending supportive services and breast feeding (Akatukwasai et al., 2021; Donahue et al., 2012; Lyimo et al., 2014). It is found that involuntary disclosure has been associated with perceived stigma. However, the assumption that involuntary disclosure always leads to negative consequences is not correct. A study conducted in South Africa found that some women prefer involuntary disclosure to family members in order to ease the burden of self-disclosure (Watt et al., 2018). Women who do not have enough courage to disclose their status sometimes place their HIV medications in visible places at home in the hope that family members will recognise the pills. Involuntary disclosure to family members has helped some women receive the necessary support (Lingen et al., 2016; Watt et al., 2018). Studies have shown that there is no definite preferred method of disclosure (Walcott et al., 2013). The individual life circumstances and differences of pregnant women during HIV counselling should be taken into consideration to maximise the beneficial outcomes of disclosure (Brittain et al., 2018; Hallberg et al., 2019).

Reasons for Disclosure

Patterns and predictors of HIV-positive disclosure are dependent on various life circumstances such as socio-economic status, education level, relationship status, personal and interpersonal motivators (Brittain et al., 2018; Cuca & Rose, 2016; Knettel et al., 2019; Loukid et al., 2014; Maeri et al., 2016; Ramlagan et al., 2018; Watt et al., 2018). Studies have found indicators that point to situations when women are more likely to disclose their HIV status. Pregnant women who are motivated to stay healthy for their children and who are engaged in HIV care during pregnancy, might be more inclined to decide in favour of disclosure (Liamputtong, 2013). In this way HIV-positive pregnant women can be open about their need to take prescribed medication, regularly attend a clinic, and get encouragement and emotional support to adhere to their treatment (Hampanda et al., 2020; Mi et al., 2020; Omonaiye et al., 2020; Oshosen et al., 2021). Women who disclose their HIV-positive status often encourage other family members to also disclose their own status. This gives family members the opportunity to support and encourage each other (Watt et al., 2018).

A strong association has been found between disclosure and a woman's education level and relationship status (Brittain et al., 2018). Women who have attained higher levels of education are more likely to tell their partner that they are HIV-positive. The explanation is that educated women are more likely to have a job, and a stable income and are less dependent on their male partner. In this case HIV-positive pregnant women do not fear losing the economic support provided by their partner (Cuca & Rose, 2016). Pregnant HIV-positive women who are in a strong, positive relationship with their husband and family are more likely to disclose their status and receive beneficial family support (Brittain et al., 2018; Damian et al., 2019; Knettel et al., 2019; Loukid et al., 2014; Ramlagan et al., 2018). The Probability of disclosure to a partner is higher among women who are married or cohabiting with their partner. Furthermore, disclosure to a partner is more common when a pregnancy is planned (Brittain et al., 2018)**.** Disclosure of HIV-positive status is motivated by an effort to maintain honesty in the relationship and to protect one's partner (Kotzé et al., 2013; Liamputtong, 2013; Oshosen et al., 2021). Women who are unaware of their partner's HIV status might disclose their status to encourage their partner to get tested (Maeri et al., 2016; Watt et al., 2018). This can help to prevent re-infection or delay the progression of an existing infection, and to increase care-seeking behaviour (Damian et al., 2019; Kotzé et al., 2013; Liamputtong, 2013; Ramlagan et al., 2018). Research conducted in South Africa showed that the time between diagnosis and disclosure to a partner varies by approximately 30 days (Brittain et al., 2018).

To prevent friends and family from learning about their HIV-positive status on their own, women frequently choose to disclose it themselves (Rael et al., 2017). Women who feel that they cannot hide their HIV-positive status due to visible HIV symptoms prefer to tell others before they suspect themselves. Severe side-effects of ARV medications have also been reasons for disclosure among HIV-positive women. Some HIV-positive people have no choice but to reveal their HIV-positive status to their family members after being admitted to hospital (Madiba et al., 2021).

They do not want their families to find out about their status from nurses or doctors. Self-disclosure gives women control over how and when they can share this information with others (Rael et al., 2017). Research shows that choosing the right time is as crucial as finding the right person for the disclosure. Some women prefer to disclose their status after they give birth. When female family members visit to help with a new-born baby, women have the opportunity to disclose their HIV-positive status face-to-face rather than over the phone. Furthermore, some women wait until birth to make sure that the baby is healthy before telling family members (Watt et al., 2018). By the time the baby is born, women are shown to have disclosed their HIV-positive status to at least one person.

Barriers to Disclosure

Some HIV-positive pregnant women, after receiving their HIV-positive status diagnosis, do not feel safe to disclose their status to others (Ashaba et al., 2017; Gourlay et al., 2013; Hallberg et al., 2019). The reasons for keeping one’s diagnosis a secret differ from case to case (Knettel et al., 2019; Naigino et al., 2017; Walcott et al., 2013). Pregnant women who are already in an emotionally stressful situation and need partner support might prefer to keep their test results secret to avoid additional separation anxiety (Ashaba et al., 2017; Fredriksen et al., 2017; Peterson et al., 2020). Fear of a loss of emotional support or a loss of financial support have been identified as major contributors to non-disclosure (Brittain et al., 2018; Hallberg et al., 2019; Walcott et al., 2013). In households where the breadwinner is the male partner, women fear that after disclosure, the husband will withdraw his financial support and leave her without a source of income (Knettel et al., 2019; Longinetti et al., 2014). As a consequence of the Covid-19 pandemic, millions of Black women in South Africa lost their jobs (Brophy et al., 2020). In all likelihood, this has made these women totally dependent on their partners as the family's sole breadwinner. Women in this situation who test HIV-positive are less likely to disclose their HIV-positive status to their partner due to the possibility that their partner may abandon them (Moreira & da Costa, 2020).

Increased attention has been given to Intimate partner violence in the context of HIV-positive status non-disclosure (Abuogi et al., 2020; Aloyce et al., 2020; Damian et al., 2019; Maeri et al., 2016; Matseke et al., 2021). Studies have shown that HIV-positive pregnant women who are subjected to more than two types of violence, such as verbal, emotional or physical, are less likely to disclose to their partner as they fear the possibility of a violent reaction (Bernstein et al., 2016; Maeri et al., 2016; Ramlagan et al., 2018). South Africa had seen increases in gender-based and domestic violence reports due to Covid-19 enforced lockdowns (Joska et al., 2020). Changes in employment status due to the lockdown have led to reduced levels of household income which aggravates the stress and frustration within households (Moreira & Costa, 2020). These changes can increase barriers to HIV-positive status disclosure in pregnant women in order for them to protect themselves and their unborn child from harm (Hampanda et al., 2020).

South African studies have shown that unplanned pregnancies have an impact on the decision-making process regarding disclosure/non-disclosure (Brittain et al., 2018; 2019; Crankshaw et al., 2014; Watt et al., 2018)**.** Women feel that disclosing their HIV-positive status as well as their pregnancy would be too much of a burden on them and their families (Watt et al., 2018). Women who are ashamed of their unplanned pregnancy often fear that disclosing their status will further disappoint their parents. In this regard, women have a fear of double stigmatisation after disclosure. This fear is more prevalent in communities where having a child outside of marriage is frowned upon (Crankshaw et al., 2014)**.** Further fears are related to upsetting the family regarding the child's and mother's health. Women think that their families will be concerned that the mother will die and leave the child to them to raise. In order to protect themselves and their families from this burden, the women do not disclose their status. Research conducted in South Africa with women shortly after an HIV-positive diagnosis and during the prenatal examination found that some women need more time to disclose their status (Ramlagan et al., 2018; Watt et al., 2018). Some women feel that they are not brave enough and emotionally ready to disclose their HIV-positive status, other feel that first they have to accept their own diagnosis before disclosing it to someone (Watt et al., 2018).

A common reason for HIV-positive status non-disclosure is stigma. In collectivist societies, the influence of social connections may inhibit a woman from disclosing her status due to the potential for stigmatisation, or community abandonment, or community isolation (Knettel et al., 2019; Marais et al., 2018; Ojikutu et al., 2016; Walcott et al., 2013). In communities where HIV is still stigmatised HIV-positive pregnant women are the topic of gossip. Some examples of mistreatment from the community and family members are negative labelling, exclusion from household chores as a result of being seen as dangerous and dirty, and stigma being projected onto the whole family, which leads to the entire family being excluded from the community (Geubbels et al., 2019; Kotzé et al., 2013). Families might reject a family member who is HIV-positive to avoid being associated with that person (Madiba et al., 2021). Non-disclosure is often related to a lack of proper information regarding HIV-positive status within the family (Rael et al., 2017). Women often anticipate negative consequences from their disclosure because of HIV-related misconceptions held by their families. Because of the persistent link between HIV and mortality, HIV-positive people believe others would fear and despise them (Steenberg, 2020). Family members who believe that HIV is an untreatable disease transmitted by day-to-day activities would stay away from HIV-infected family member to protect themselves from possible infection (Madiba et al., 2021; Rael et al., 2017).

Well-being

There have been numerous studies that show interest in the exploration of well-being; however, the definition of well-being differs from discipline to discipline and author to author. The important well-being factors differ depending on the individual, their environment and particular life circumstances (Thin, 2018). The reason why there is no precise definition of well-being has been explained by different academics, who have found that there are different dimensions affecting well-being (Diener et al., 2003, 2016; Disabato et al., 2016). Historically well-being has two dimensions: hedonic and eudemonic. The hedonic approach focuses on the experience of positive feelings, low negative effects, pleasant emotions and life satisfaction. The eudemonic approach, on the other hand, highlights the importance of positive psychological functioning, developing one’s potential, personal growth and self-realisation (Ryff, 1989; Ryff & Keyes,1995).

A difference in understanding among theorists as to what plays an important role in well-being has led to the development of different measuring scales of well-being (Ellison, 1983; Warr et al., 1979). However, those measuring scales have been criticised for their positivist approach. Positivist psychology explores human well-being with an individualistic Western cultural influence and minimal societal contribution and assumes that understanding of well-being is universal (Ma & Schoeneman, 1997; Seligman & Csikszentmihalyi, 2000; Tay & Diener, 2011).

People from Western, individualistic societies are oriented towards personal freedom, individual goal achievement and self-growth, and they give preferences to act independently of others (Diener et al., 1995; Veenhoven, 1999). People from non-western collectivist cultures value group goals over personal goals, emphasise group needs over their personal needs and understand the self-concerning others (Ma & Schoeneman, 1997; Tay & Diener, 2011).

It has been documented that in collectivist cultures, personality and culture are interrelated (Diener et al., 2003), and an individual's happiness and life satisfaction is in the happiness of others (Ma & Schoeneman, 1997). Members of collectivist societies are motivated to succeed based on the improved levels of acceptance they will achieve in society, and how their successes will benefit the group. While exploring the meaning of well-being in a South African context and concerning HIV-positive status disclosure, society's influences should be considered. The importance of community regarding a person's well-being is deeply rooted in African philosophy. According to Menkiti (1984) the main difference between a Western man and an African man is that the community defines the person as a person, and the person is not an "isolated static quality of rationality, will, or memory" (p. 172).

The individual African is communal (Gyekye, 2002) and to achieve status, he should participate in communal life and prioritise duties he owes to the community (Menkiti, 1984). In opposition to individualistic cultures, people from collectivist cultures are more likely to receive and value social support (Diener et al., 1995; Tay & Diener, 2011). Persons with a robust social support network are more likely to cope with life stressors by staying motivated during difficult times and being better able to adjust to life's challenges (Bekele et al., 2013; Cederbaum et al., 2017;

Cohen et al., 2000; Dyer et al., 2012; Mi et al., 2020). During life-threatening illnesses, the most relevant support is given by social support, and psychosocial resources, which can act as a buffer against depression and anxiety (Oppong Asante, 2012; Taylor et al., 2000).

Besides the positive influence the community can have on the individual, collectivism does not always lead to positive support and positive well-being outcomes. As a person gives more importance to the opinions of others, it can lead to that person acting to please others and thereby neglecting their own needs and satisfaction, which can limit their freedom to choose a life path (Diener et al., 1995; Veenhoven, 1999). These negative factors of collectivism should be taken in consideration when exploring reasons for non-disclosure of HIV-positive status, social stigma and well-being. Pressure to always fit in with the group can influence an HIV-positive pregnant woman's choice to speak up about her HIV status and prevent her from disclosing (Brittain et al., 2017). Pressure to keep an HIV-positive status secret can have a less negative effect on well-being than exclusion from society. Losing one's community can be compared to losing one's own identity. This is explained by Mbiti (1970) with the phrase ''umuntu ngumuntu ngabantu/-I am,-because we are; and since we are, therefore I am'' (p. 141). Well-being and culture are inter-connected and there cannot be well-being without culture (Wilson, 2020).

According to Diener et al. (2016) each person should define their well-being from their own perspective. Subjective well-being is based on how people evaluate their lives in the present and in the past (Diener et al., 2003). The valuation of one's life can be seen in cognitive states such as satisfaction with life, work and relationships (Diener & , Sapyta, Jeffrey, 2016), how people emotionally react to life events, and the conclusions they reach when they evaluate their existence.

Research showed that people from different countries attribute a different meaning to well-being, which was contrary to Maslow's hierarchy of needs (Maslow, 1954). Maslow's hierarchy of needs states that basic physical survival needs must be satisfied before moving up the pyramid to achieve the highest need for self-actualisation. Once physiological needs are satisfied, a person is motivated to fulfil the next level of needs. Diener and Tay (2011) presented opposite findings regarding Maslow's hierarchy of needs, indicating that people can achieve well-being by fulfilling psychosocial needs even when their lower needs are not met.

Despite psychosocial needs fulfilment, persons with low income can still experience negative well-being (Andersen et al., 2020; Cramm et al., 2012; Diener et al., 1995; Knettel et al., 2020; Mbatha et al., 2020; Tay & Diener, 2011). Material well-being gives a person freedom of action, health care benefits, education, and the ability for self-development (Maslow, 1954). The latest research studies on HIV status disclosure in pregnant women indicate that material well-being is interrelated with personal freedom, and that this has a positive effect on well-being (Grønlie & Dageid, 2017). Women with higher education and income are more likely to use active coping strategies to deal with HIV-related stress and they report a higher quality of life (Kotzé et al., 2013). Higher levels of education and income give HIV-positive women financial independence from their male partner and make disclosure more likely (Longinetti et al., 2014). People from low-income backgrounds are more likely to experience depression, stress, and low levels of subjective well-being (Andersen et al., 2020; Diener et al., 1995). Diener's findings indicate that a person's well-being depends on their personal societal and cultural needs (Tay & Diener, 2011). What contributes to well-being is a complex combination of factors. Attention should be given to the subjective experiences of the well-being of HIV-positive pregnant women after disclosure/non-disclosure.

Pregnancy, HIV-positive Status and Well-being

Pregnancy is a life-changing event when women face numerous challenges that can be associated with negative well-being such as depression, low life satisfaction and anxiety (Fredriksen et al., 2017; Peterson et al., 2020). It has been documented that psychological well-being has an effect on post-partum depression; and women who are experiencing depressive symptoms during pregnancy are at higher risk of developing post-partum depression. Psychological distress during the prenatal period could predict further psychosocial impairment, such as behavioural and emotional problems, cognitive deficits and attachment difficulties in the child's development (Blaney et al., 2004; Stein et al., 2014). Women with poor mental health during the pregnancy are less likely to attend prenatal examinations and more likely to miss clinical appointments (Alhusen et al., 2016).

Pregnant women are already in a heightened risk group for developing psychological distress, including anxiety and depression (Fredriksen et al., 2017; Peltzer et al., 2016; Peterson et al., 2020). Receiving an HIV-positive diagnosis is particularly traumatic during the pregnancy and can further increase the risk of psychological distress (Brittain et al., 2019b; Kapetanovic et al., 2014; Qin et al., 2019; Rodriguez et al., 2018; Tenkorang et al., 2020; Wong et al., 2017). Women are fearful about their own health and whether they will be able to work and support a child (Oshosen et al., 2021; Watt et al., 2018). An additional burden on women is fear regarding their child's health (Ashaba et al., 2017). Women are scared that they will transfer the virus to their unborn child, which could lead to early infant death. Another distressing thought that pregnant women experience after diagnosis is that they will die soon after the child’s birth leaving the child an orphan. In the case of HIV-positive babies, women are worried about how they will manage to take care of an HIV-positive child and what kind of effect ARVs will have on their child’s development.

Women diagnosed as HIV-positive during pregnancy are more likely to experience psychological distress than women who knew about their HIV-positive status before falling pregnant (Knettel et al., 2020; Xiaowen et al., 2018). Studies have shown that some women, after receiving an HIV-positive diagnosis consider terminating their pregnancy (Lingen et al., 2016; Watt et al., 2018). One of the reasons for such consideration is the fear of transferring the virus to their unborn child. Furthermore, when dealing with two life-challenging situations, some women consider terminating the pregnancy to lessen the burden (Watt et al., 2018). These findings highlight the importance of counselling and emotional support after testing HIV-positive. Nurses are providing educational information regarding the virus and medication for the woman’s physical health; however, psychological distress such as suicidal ideation, depression, anxiety, self-blame and feelings of guilt might not be dealt with during counselling (Mbatha et al., 2020; Ogueji, 2021; Oshosen et al., 2021; Tuthill et al., 2017). Pregnant HIV-positive women who do not get the required psychological help after prenatal testing are at higher risk of developing postpartum depression (Mokhele et al., 2019). However, research by Kotze et al. (2013) suggests that high levels of HIV education provided by counsellors help pregnant women to cope with the diagnosis actively and lead to improved physical and psychological well-being.

Disclosure/Non–disclosure Effect on Well-being in Pregnant Women

Much of the literature has shown that HIV-positive pregnant women who do disclose their status have been associated with significantly higher levels of positive outcomes (Abrahams & Jewkes, 2012; Brown et al., 2019; Damian et al., 2019; Hill et al., 2015; Knettel et al., 2019; Madiba & Putsoane, 2020; Ramlagan et al., 2018; Watt et al., 2018). Despite the hesitation and fear of HIV-positive status disclosure, most women generally report positive reactions, support and acceptance**.** A strong positive relationship has been found between male partner involvement during the pregnancy, HIV status disclosure and ART adherence stages, and positive well-being (Brittain et al., 2019a). Disclosure of HIV-positive status to a partner has the effect of stress relief and tends to reduce internalised HIV stigma (Hampanda et al., 2020; Watt et al., 2018)**.**

Family and friends play an important role in the life of the HIV-positive pregnant woman (Hill et al., 2015; Omonaiye et al., 2020). HIV-positive status disclosure to family and friends builds a support foundation which improves motivation for the woman to engage in, and continue, regular clinical attendance, and ART adherence. After disclosure women report feeling loved, being included in social activities, and being treated the same as before their HIV-positive disclosure (Rael et al., 2017). Women are assured that HIV is a manageable condition and that they will live a long, healthy life if they engage in proper HIV treatment. Women often receive advice from family members regarding medication adherence in order to protect their health and the health of their unborn child. Family members also play an active role in reminding women to take medication on time and accompanying them to their clinical appointments (Watt et al., 2018)**.** After disclosure, encouragement by family and friends helps pregnant women to develop resilience and accept their HIV diagnosis (Bhat et al., 2015). High levels of positive social support helps women to use active coping strategies (Kotzé et al., 2013). Women who use active coping with their positive diagnosis show higher levels of self-esteem, lower levels of depression and improved well-being. Social support is often seen as a buffer against psychological distress caused by the HIV diagnosis and HIV-related stress (Lifson et al., 2020; Knettel et al., 2020; Xiaowen et al., 2018).

Situations where social support reduces the effect of positive well-being occur when HIV-related stigma is high in society (Liamputtong, 2013). In communities where HIV is stigmatised, pregnant women make efforts to keep their status a secret from the community while at the same time trying to remain engaged in proper health care (Omonaiye et al., 2020; Watt et al., 2018). Women are fearful that during clinical appointments, someone from the community may identify them as being an HIV-positive patients (Poku et al., 2020). If they are identified, they fear this will lead to judgement and stigmatisation by the community (Watt et al., 2018). To keep their status secret, people often come up with alternative ways to safely engage in HIV treatment (Akatukwasai et al., 2021; Muiruri et al., 2020). It has been found that HIV-positive people find ARV medication packaging eye-catching due to its bulk size, and ratelling noise often attracts unwanted attention (Muiruri et al., 2020)**.** Women try to replace their medications into new containers immediately after collecting them from the local clinic to avoid unintentional disclosure. The fear of taking medications in front of others, and the constant stress of coming up with alternatives to taking medication, add to the anxiety caused by an HIV-positive diagnosis. Furthermore, people often avoid visiting the clinic during rush hour and prefer to attend in later hours to reduce the possibility of being seen by people who know them (Akatukwasai et al., 2021). Keeping away from areas specifically assigned for HIV patients is another method for avoiding stigma and unintentional disclosure. Protecting themselves from discrimination can result in missed appointments and difficulties in taking the prescribed medication when people are around (Omonaiye et al., 2020). The constant stress of involuntary disclosure can lead to negative well-being (Knettel et al., 2020; Peltzer et al., 2020). Stigma and low self-esteem contribute to poor mental health outcomes and can play a role in poor psychological adjustment to a HIV status diagnosis (Hallberg et al., 2019).

A study conducted in South Africa identified the negative outcomes of HIV-positive status disclosure to family members (Madiba et al., 2021). Women reported mistreatment and discrimination after HIV-positive status disclosure. Some women were forced to leave the house, while others reported that family members avoided them for fear of being infected. Furthermore, women did not receive the required physical support when needed. Women felt unsupported, mistreated and rejected by a family members. Disclosure of HIV-positive status to a partner can also have negative consequences for the relationship. Negative reactions to disclosure include rejection, separation, stigmatisation, and blame from a sexual partner (Cama et al., 2020). Disclosure can lead to poor physical and mental health outcomes if a male partner restricts women's access to HIV care due to the partner’s fear of their own HIV status being disclosed (Akatukwasai et al., 2021). Negative outcomes of disclosure include increased stigma, psychological distress, decreased social support, and reduced life satisfaction.

Theoretical Framework

Consequence theory (Serovich et al., 2000) and social support theory (Cullen, 1994) have been combined to create a theoretical framework for an understanding of the motives and barriers to HIV-positive status disclosure, and the effects of disclosure on well-being in HIV-positive pregnant women.

Consequence Theory

Consequence theory provides evidence which shows that people selectively choose to whom they will disclose their HIV-positive status after evaluating the possible reactions and consequences (Serovich, 2001). The decision to disclose a status takes into account issues such as the opportunity to receive social support, a reduction in stress factors and access to required health care (Ashaba et al., 2017; Liamputtong, 2013; Marais et al., 2019; Naigino et al., 2017; Ramlagan et al., 2018; Vyavaharkar et al., 2011; Walcott et al., 2013). Serovich (2008) tested consequence theory among HIV-positive women to document reasons for disclosure/non-disclosure and mental health outcomes. Studies conducted during that period showed that HIV infection rates were increasing among women, and these women were showing increased rates of clinical depression and anxiety. Serovich (2008) believed that disclosure could benefit a woman’s well-being if it were followed by positive outcomes such as social, physical and emotional support. Applying consequence theory could lead to a better understanding of the benefits and risks of disclosure/non-disclosure (Serovich, 2001). If disclosure can benefit the woman and others, then the woman may be more inclined to disclose her status (Serovich et al., 2008). Consequence theory can offer a potential explanation as to what motivates pregnant HIV-positive women to disclose/not disclose their HIV-positive status to others.

Studies have shown that an HIV-positive pregnant woman’s decision to disclose is directly linked to her perceptions of the potential outcomes (Brittain et al., 2018; Geubbels et al., 2018; Hill et al., 2015; Watt et al., 2018). HIV-positive pregnant women who hesitate to disclose often report a fear of negative reactions, however, the outcomes are more often positive (Abrahams & Jewkes, 2012). Most of the literature on this subject has applied the quantitative method (Rodriguez et al., 2017; Stutterheim et al., 2011; Varni et al., 2012) whereas a qualitative approach will allow for the woman’s subjective perspective to be explored and to uncover what factors will act as a reward after disclosure. The benefit of consequence theory is that it will help to understand the motivation for pregnant women to disclose or not to disclose their HIV-positive status. It will also provide clarity as to cost-reward outcomes. Understanding the cost-reward relationship can help in determining what responses will benefit well-being.

Social Support Theory

Social support theory was initially developed to understand criminal behaviour however, over the years it had been adapted to other areas of psychology. This theory shows that social support is an important factor in improving well-being (Cullen, 1994; Galvan et al., 2008). Lin (1986) defines social support as actual or perceived instrumental and expressive support provided by social, and community networks and confiding, and intimate partners. Instrumental support involves physical assistance from others such as financial support, helping with household chores and babysitting (Cohen et al., 2000; Cohen & Wills, 1985; Lin et al., 1986). Expressive support involves using social networks to build one’s self-esteem, receive encouragement and motivation, and get emotional support from others (Ang & Malhotra, 2018). Higher instrumental or expressive support, whether actual or perceived, can minimise stress and anxiety associated with HIV-positive status (Vyavaharkar et al., 2011). Serovich (2008) believed that an important reward of disclosure in HIV-positive women is social support, which could lead to positive well-being. In this regard, social support theory could be the most appropriate theory to apply to understand well-being outcomes after disclosure/non-disclosure in HIV-positive pregnant women.

Disclosure of HIV-positive status can be seen as help-seeking behaviour for an HIV-positive pregnant woman who wants to obtain support from her family and friends (Abrahams & Jewkes, 2012; Kotzé et al., 2013; Lifson et al., 2020; Watt et al., 2018). It has been hypothesised that social support acts as a buffer against HIV-related stigma and negative mental health outcomes (Bekele et al., 2013; Cederbaum et al., 2017; Cohen & Wills, 1985; Dyer et al., 2012; Mi et al., 2020). An HIV-positive person who has a supportive network is more likely to adapt to HIV-related stress and report lower levels of depression and anxiety (Casale et al., 2019). Social support theory can explain positive and negative well-being outcomes after HIV-positive status disclosure in pregnant women. This theory can help explain why some pregnant women receive and benefit from social support after the disclosure, while others do not.

A possible reason for negative well-being outcomes could be inadequate support received after disclosure (Cohen & Wills, 1985). Intimate partners who are only partially involved in the pre-natal or post-partum period are less likely to satisfy a pregnant woman’s supportive requirements (Hill et al., 2015; Peltzer et al., 2016). Behaviour by the male partner that is more controlling than supportive can limit the pregnant woman’s decision and dissuade her from further disclosure to family and friends (Hampanda et al., 2020; Matseke et al., 2021). Furthermore, pregnant women with highly controlling or violent partners are less likely to engage in PMTCT care thereby causing further emotional distress (Aloyce et al., 2020; Onono et al., 2020; Reyes et al., 2020). Family is a primary source of support for most pregnant women and their reaction to disclosure can be a determinant of well-being outcomes (Hill et al., 2015; Mi et al., 2020).

Non-disclosure of HIV-positive status and its effects on well-being can be determined by the community's view of HIV-positive people (Knettel et al., 2019; Marais et al., 2018; Walcott et al., 2013). If HIV stigma is high in the community where the woman lives, she might choose in favour of non-disclosure (Lingen et al., 2016; Loukid et al., 2014; Ojikutu et al., 2016). Women who want to remain a member of the group may choose not to disclose their status, as they will continue having group support under the group's false belief that she is HIV-negative. The group support may not benefit her well-being as an HIV-positive woman, but misdirected support can still be beneficial. Recent research (Mokhele et al., 2019) shows that perceptions of HIV in South Africa are becoming normalised, and this has helped women speak out about their diagnosis and receive support from the community. Social support theory, in combination with consequence theory, will help to explore the differences between positive and negative outcomes after disclosure/non-disclosure. Comparing negative and positive outcomes can help identify the factors which contribute to well-being.

Summary

An HIV-positive status affects more than 13% of the population of South Africa, and women in their reproductive age are at higher risk of contracting HIV (Stats SA, 2022). Regular HIV-treatment engagement makes this virus a manageable health condition; however, its psychological effect on a person is still the subject of research. Literature indicates that more women get tested HIV-positive after they attend their first prenatal check-up (Lifson et al., 2020; Mokhele et al., 2019; Oshosen et al., 2021; Ramlagan et al., 2018; Reyes et al., 2020). Considering that HIV-positive test results can be a traumatic experience, they are even more traumatic during the vulnerable period of pregnancy. The decision whether to disclose or not disclose an HIV-positive status is an additional burden on top of the HIV-positive diagnosis. Chapter two presented the complexity of this decision and further reviewed different reasons for HIV-positive status disclosure and non-disclosure. Literature indicates that women’s decisions regarding disclosure or non-disclosure are based on the potential consequences that can follow the disclosure (Marais et al., 2019; Naigino et al., 2017; Ramlagan et al., 2018). The consequences of the disclosure can further indicate why some women benefit from disclosure while others do not. Social support provided by disclosure recipients can have a positive effect on women’s well-being (Bekele et al., 2013; Cederbaum et al., 2017; Mi et al., 2020). Women who feel stigmatised, discriminated against, and unsupported after disclosure may experience psychological distress.

Chapter 3: Research Methodology

Chapter Three presents the research methodology undertaken for this study. The beginning of the chapter provides philosophical and methodological aspects of the qualitative research approach. Following this, I draw the differences between qualitative and quantitative methodology and explain the rationale for employing the qualitative research approach. This chapter will review the historical background of interpretative phenomenological analysis and provides reasons for choosing this method based on the purpose of this study. Furthermore, I describe the research method and design of this study. Ethical considerations and trustworthiness of this study will be addressed.

Research Paradigm

Understanding the subjective meaning people ascribed to the phenomenon studied is an essential part of the interpretive paradigm (Goldkuhl, 2012). This study is guided by the interpretive paradigm, which holds that knowledge regarding reality is socially constructed by humans (Walsham, 1995). The interpretive paradigm directs that phenomena should be studied from the participants perspective within specific cultural and contextual settings. Furthermore, it is important to conduct the study in a natural setting, where variables are not manipulated or reduced (Hudson & Ozanne, 1988).

Interpretive ontology is based on relativism, which incorporates the idea that knowledge and truth are relative to a place, time, culture, society, and a number of other parameters (Hibberd, 2005). There is no one absolute truth or knowledge because it is relative to a person’s subjective experience at a particular time and place. The world is related to individual perspectives, and people from different communities perceive reality differently. Ontological relativism denies the existence of objective reality and believes in socially contracted multiple realities (Guba, 1992).

This study tended to explore participants' lived experiences from their personal perspective; the epistemological foundation of this study is subjective (Levers, 2013). The principles of subjectivism imply that nothing is purely objective (Denzin & Lincoln, 2005, 2017). Everything perceived by a person is influenced by their cultural, ethnic, and linguistic background. Subjective epistemology is a relationship between the knower and the knowable, and realities depend on their interaction (Lincoln & Guba, 2013). Data attains meaning through the researcher's thought process, and the thought process comes from interacting with the participants.

Qualitative Research Approach

All social science research makes philosophical assumptions about reality (Creswell & Poth, 2018; Hudson & Ozanne, 1988). Qualitative research develops knowledge about social and individual problems through an interpretative philosophical lens. Interpretivists deny the existence of one reality and believe in multiple realities constantly shifting and changing (Lincoln & Guba, 2013). Interpretivism adopts the position that the knowledge of reality is socially constructed through individual and group perceptions (Berger & Luckmann, 1966; Creswell & Poth, 2018; Hudson & Ozanne, 1988; Walsham, 1995). People try to make sense of their world through the categories and theories they develop about reality. The approach of qualitative research and Interpretivism is to understand the subjective meanings that already exist in the social world (Goldkuhl, 2012; Lee, 1991). The understanding of a problem comes to light in the natural settings where participants have experienced the phenomenon being studied (Creswell & Poth, 2018; Denzin &

Lincoln, 2017). The words used by participants are closely linked to the context and place where the problem manifested.

Research participants become the primary source of information (Walsham, 1995) and the researcher is the key instrument (Creswell & Poth, 2018). The investigator engages directly with individuals who have experienced the phenomenon to capture their subjective experiences and beliefs about the problem being studied (Hirschman, 1986; Lee, 1991; Silverman, 2017). Qualitative research adopts multiple ways of data gathering, such as interviews, observations and field notes, ensuring data accuracy and trustworthiness of the study (Creswell & Creswell, 2018; Creswell & Poth, 2018; Lincoln & Guba, 2013). During the qualitative research process, participants guide the research process (Hudson & Ozanne, 1988). The emergent qualitative research design means that the initial research plan might be adjusted after the researcher enters the field (Maxwell et al., 2007). The reason for the adjustment is that the researcher can be flexible, allowing them to gain multiple, complex perspectives from the participants (Creswell & Poth, 2018).

Collected data from the study setting is organised in themes and interpreted by the researcher (Creswell & Creswell, 2018; Hirschman, 1986). The qualitative researcher needs to create a holistic picture of the problem to be studied (Creswell & Poth, 2018). In order to achieve this, the researcher must identify factors and note the multiple perspectives that emerge in creating the holistic picture. The researcher’s purpose is to describe the various interactions that occur in the discovered situation.

One of the research questions to be answered was which factors influence HIV-positive status disclosure/non-disclosure in pregnant women. Decision-making is a complex process influenced by various personal and environmental factors

(Serovich, 2001). Understanding the decision-making process requires gaining an in-depth understanding of the phenomenon from the participants’ perspectives (Silverman, 2017). The qualitative research approach, with its open-ended and semi-structured interviews, allows research participants to discuss their experiences freely (Bernard, 2011; Corbin & Strauss, 2015; Creswell & Creswell, 2018). Furthermore, this approach gives marginalized groups of women a voice and empowers them to share their personal experiences (Creswell & Poth, 2018; Denzin & Lincoln, 2017) regarding the decision-making process, and their experiences of HIV-positive status disclosure/non-disclosure. The qualitative approach also allows for an explanation as to why some women benefit from disclosure and others do not.

The qualitative research approach allows women to define well-being in their own context. The interpretivist tradition of qualitative research does not believe in one objective reality that can be fully understood (Hudson & Ozanne, 1988; Lincoln & Guba, 2013). There are many ways of defining well-being, and each definition can be specific to a particular person. The existing well-being measuring instruments will not be sensitive to personal and cultural differences (Creswell & Poth, 2018). Sharing personal and sensitive information with the researcher requires a trusting relationship (Bernard, 2011). The qualitative research approach gives the opportunity to establish a rapport and an emotional connection between the researcher and participants (Creswell & Poth, 2018). The amount of time spent in the field and face-to-face interactions help to build rapport, which empowers people to disclose their sensitive topics (Atkinson & Delamont, 2011). Establishing a trusting relationship minimises power relations that often occur between the participants and the researcher, which sometimes further marginalises them (Creswell & Poth, 2018). Data gathered in natural settings also minimises the chance of influencing participants' behaviour. Psychologists often use natural settings to learn about and observe particular phenomena. For this study, the natural setting was a hospital where the women learned of their HIV-positive status. Conducting interviews in a familiar environment minimises the chance of behaviour changes in the women involved in the study.

Qualitative Research Approach versus Quantitative Research Approach

The qualitative approach offers tools for an in-depth examination of the participants' life experiences from their subjective perspectives (Lyons, 2011). This study aimed to explore the experiences of HIV-positive pregnant African women, and the perceived effect of their HIV-positive status disclosure/non-disclosure on well-being. The qualitative approach was found to be the best fit when compared with the quantitative approach.

Quantitative research is guided by the positivist paradigm (Lincoln & Guba, 2013), which believes that a single objective reality exists independently of the individual's perception, and this reality can be observed and measured (Creswell & Creswell, 2018; Hudson & Ozanne, 1988). One of the primary differences between qualitative and quantitative research is the inductive and deductive approach (Punch, 2014). Quantitative researchers using the deductive approach enter the study field with objective theories they already hold about the phenomenon (Denzin & Lincoln, 2017). The quantitative research approach tends to prove or disprove their objective theory by examining the relationship between variables in a controlled environment (Creswell & Creswell, 2018; Punch, 2014; Lincoln & Guba, 2013).

Qualitative researchers, on the other hand, are not interested in cause-and-effect relationships (Creswell & Poth, 2018; Punch, 2014). They capture multiple perspectives, developing a complex picture of the problem, building broad themes and then developing a theory based on the gathered information (Maxwell et al., 2007). The quantitative approach provides a general understanding of a phenomenon but does not capture the complex and in-depth understanding of the subject matter (Creswell & Poth, 2018). The quantitative approach reduces peoples' unique subjective experiences to numbers (Bernard, 2011).

For this research, it was important to understand the participants' behaviour and perceptions from their cultural context rather than predict and quantify it, as is usual for the quantitative approach (Hudson & Ozanne, 1988). The positivist paradigm of the qualitative approach has often been criticised from the indigenous perspective for being Western-oriented (Ma & Schoeneman, 1997; Smith, 2012). Measurements developed for Western-individualistic civilisation cannot be universal and made to fit non-Western cultures (Ma & Schoeneman, 1997). The measuring instruments may not be sensitive to cultural, economic, personal and racial differences (Creswell & Poth, 2018).

Interpretative Phenomenological Analysis

The following section presents the historical background of interpretative phenomenological analysis's three major theoretical bases: Phenomenology, Hermeneutics and Ideography (Smith et al., 2009). Each theory is discussed from the historical perspective, as well as how it applies to the interpretative phenomenological analysis methodology. This section also explains the reason behind employing the interpretative phenomenological analysis methodology for this study.

Phenomenology

Phenomenology as a philosophical approach was first presented by Husserl (1964) Phenomenology is a careful examination of the lived experience in its own terms and the ways that these occur (Smith & Osborn, 2015; Smith et al., 2009). Husserl (1970) believed that people see reality from a natural attitude, which means that we see the world from the common beliefs we hold about reality. The world and its experience are relative to a particular person at a particular time (Smith et al., 2009). To understand the world here and now, and the way it appears to a particular person, one should adopt the phenomenological attitude by bracketing the natural attitude (Larkin et al., 2006; Laverty, 2003). Phenomenological attitude allows for watching reality without pre-existing theories and attitudes (Smith & Osborn, 2015). Pure consciousness allows an understanding of pure experiences (Eatough & Smith, 2017; Larkin et al., 2006; Laverty, 2003). This means we should look at the particular human experience without the prejudice and pre-existing theories we may already hold (Smith et al., 2009; Smith & Osborn, 2015).

Later Husserl’s ideas were further developed and adapted by three leading figures in phenomenological philosophy Heidegger, Sartre and Merleau-Ponty (Smith et al., 2009). Their viewpoint is that people are surrounded by objects and relationships, language and culture, projects and concerns. This is a movement away from Husserl’s ideas which leads towards an interpretative position, and focuses on the perspectival directedness of the lived world (Eatough & Smith, 2017; Larkin et al., 2006). The lived world is unique to every person, but it is part of our relationship with others and the world and cannot exist in isolation (Smith et al., 2009).

The phenomenological aspect of interpretative phenomenological analysis as we know it today is based on those three authors who moved away from Husserl’s ideas (Smith et al., 2009). The interpretative phenomenological analysis methodology aims to understand how a person experiences a phenomenon and what meaning they ascribe to it based on their socio-historical background (Eatough & Smith, 2017). Interpretative phenomenological analysis is not interested in the basic description of a phenomenon but rather in the complex meaning ascribed to it by participants. An essential aspect of phenomenological philosophy for psychologists is that it provides them with a volume of data regarding how to explore and comprehend the lived experience (Smith et al., 2009). The interpretative phenomenological analysis researcher engages with participants while trying to make sense of their major life experiences. Meanwhile, the researcher tries to make sense of the participants’ experiences based on their reflections. The dual interpretation of researcher and participant lead to interpretative phenomenological analysis’s second major philosophical aspect, namely hermeneutics.

Hermeneutics

Hermeneutics is often referred to as the theory of interpretation (Smith et al., 2009). Originally this discipline was applied in theology, where it was used to interpret biblical text (Eatough & Smith, 2017). Later hermeneutics was used across other disciplines such as law, history, psychology and the human sciences(Smith, 2007). The prominent theorists who contributed to the devilment of hermeneutics, were Schleiermacher, Heidegger and Gadamer (Smith et al., 2009). For Schleiermacher (1998), interpretation is guided by two aspects, namely grammatical and psychological interpretation. Schleiermacher believed interpretation should represent the objective meaning of the text while also representing the author’s individuality. The text should represent the writer rather than make them irrelevant. The reader should be able to understand the interpretation of a text and also how the author understood and interpreted it. The interpretative phenomenological analysis methodology shares this thought but also claims that the author's interpretation does not mean representing only the researcher's subjective voice over the participant's voice (Smith et al., 2009). The researcher engages in the detailed analysis of the text to give meaning to participants' experiences and to give meaningful insights.

Gadamer and Heidegger share similar beliefs about hermeneutics (Eatough & Smith, 2017; Smith, 2007). For Heidegger (2010), all humans hold a pre-understanding of reality formed by cultural and historical background. A person's understanding and interpretation of the world depends on his or her pre-understanding (Laverty, 2003). One cannot understand the lived world with pure consciousness by putting the pre-understanding aside. The process of interpretation is achieved by the hermeneutic circle (Smith et al., 2009). The hermeneutic circle requires the interpreter to view the sentence as a whole and then analyse each word that comprises the sentence to find the meaning. The total meaning is found in the sentence and from each word used in the sentence. The whole is made up of the parts, and meaning is found in the whole and in the parts that comprise the whole. Hermeneutics shares the idea that people are sense-making creatures and that verbal or non-verbal representation of people's experiences is based on their sense-making processes (Smith et al., 2009). The interpretative phenomenological analysis researcher engages in double hermeneutics, the subject is attempting to make sense of their existence while the researcher is attempting to understand the subject through their experiences.

Ideography

The third pillar of interpretative phenomenological analysis is ideography. Ideography is concerned with understanding the specific and unique experience of a particular person under study (Eatough & Smith, 2017; Smith et al., 2009). Ideography goes against nomothetic psychology (Babbie, 2020). Claiming that most psychological researchers are concerned with making general claims about the population and ignoring the individual psychological experiences of people (Eatough & Smith, 2017; Smith et al., 2009). Ideography engages in the detailed, in-depth analysis of each case. Case-by-case investigation of experienced phenomena means giving a voice to each study participant. It moves to general claims only after each case has been reviewed and analysed to create a holistic picture (Smith & Osborn, 2008).

Interpretative Phenomenological Analysis as Research Methodology

The specific application of interpretative phenomenological analysis lies in life-changing events and their effect on a person's everyday life experience (Smith et al., 2013). As this study aimed to explore the experience of an HIV-positive status diagnosis during pregnancy, interpretative phenomenological analysis was the most suitable methodology. Being diagnosed HIV-positive during pregnancy has a significant effect on a woman's life (Lifson et al., 2020; Mokhele et al., 2019; Oshosen et al., 2021; Ramlagan et al., 2018). This is when everyday life shifts and changes. Using interpretative phenomenological analysis allowed me to engage directly with women who have experienced the phenomenon to be studied. This helped me gain an insider's perspective of unique lived experiences of HIV-positive pregnant women. For this study, the reactions received after HIV-positive status disclosure was one of the crucial aspects to explore. The ideographic approach of interpretative phenomenological analysis allows for an individual analysis of each case (Smith et al., 2009), making it possible to ascertain why some pregnant women benefit as a result of disclosure while others do not. Additionally, detailed information about cost-reward outcomes of the disclosure/non-disclosure can help determine what responses will benefit women’s well-being.

Well-being is a phenomenological event (Diener et al., 2003; Wright & Cropanzano, 2000). The definition of well-being can be personal and depends on their cultural and socio-economic background (Tay & Diener, 2011). Through the phenomenological perspective of interpretative phenomenological analysis, this research explored well-being through the participants’ experience, the participant’s definition of well-being and the factors that define a good life (Walker & Kaved-ija, 2015). Interpretative phenomenological analysis is the best choice as it will allow for an insightful interpretive account of women’s mental and emotional experiences through their own words (Smith et al., 2009). The participants will tell their stories which must then be interpreted to understand the experience. The Interpretation presented to readers will help them to gain meaningful insights of women’s experiences and definitions of well-being specific to their life circumstances. This approach will give a voice to each participant to share their own stories regarding HIV-positive status disclosure/non-disclosure and how it affects their well-being.

Research Method

The following section presents the research method undertaken for this study. The study site and approval received from the hospital is presented. The following section explains the population from which the sample was drawn, followed by sampling techniques and the participant selection process. The sample size section provides information about the total number of participants approached for inclusion in this study and the final number of participants. The research design section begins with the data-gathering procedure specific to the research approach employed. This section also discusses the importance of the pilot study and provides information about the pilot interview undertaken for this study. The data analysis process specific to the interpretative phenomenological analysis methodology is discussed in detail.

Study Site

The Rahima Moosa Mother and Child Hospital (RMMCH), Gynaecology and Obstetrics Department, was selected for this research study. This particular study site was chosen because RMMCH specialises in mother and child treatment and therefore engages with pregnant women, some of whom were HIV-positive, who were the main participants of this study. I believed that at this site, I would be able to engage study participants who have experienced the phenomenon studied and could discuss their lived experience (Creswell & Poth, 2018).

After identifying the study site, it was important to gain access to RMMCH. The first contact was made with the Head of the Department where I intended to conduct my research study. After my research protocol was processed by the relevant Head of Department, my study was further discussed via online meetings. After written approval was granted by the UNISA Ethics Committee, WITS Ethics Committee, National Health Research Database (NHRD), and RMMCH I visited the site to discuss my research study and the process to be followed in gathering data (see Appendices 5 and 7). A particular counsellor who already held the patient information was asked to assist with recruiting study participants. Furthermore, the hospital provided a private room to conduct the research interviews.

Population

The research study population refers to a group from whom the researcher wants to develop knowledge and draw conclusions based on their study interest. (Babbie, 2020; Punch, 2014). The large numbers of population groups makes it impractical to study each person individually. The researcher selects a sample of individuals from a large population from which to collect data. The targeted population for this study was black HIV-positive pregnant women from the ages of 20 to 40 years who had been diagnosed by a doctor as being HIV-positive and were attending RMMCH. The sample was drawn from women who visited the pre-natal department for ante-natal check-ups. The decision regarding the research sample and the sampling techniques were guided by the requirements of interpretative phenomenological analysis (Babbie, 2020; Smith et al., 2009).

This population was selected for a variety of reasons. The first reason is that there is limited research regarding the well-being of HIV-positive pregnant black women from a qualitative perspective. Based on stats SA (2022) ‘’the black African population is in the majority (49,07 million) and constitutes approximately 81% of the total South African population’’, therefore this research focuses on the majority ethnic group of South Africa. Stats SA further states that women in their reproductive age (15 to 49 years) have a higher likelihood of contracting HIV than men in the same age group. The evidence shows that the majority of women received their HIV diagnosis after they had presented themselves for antenatal services (Brittain et al., 2017; Marais et al., 2019; Oshosen et al., 2021; Poku et al., 2020; Ramlagan et al., 2018). Secondly, a particular age group (20 to 40 years) was selected to exclude teenage pregnancies and older than 40 years of age to exclude age-related pregnancy complications. Thirdly, it was important that all women should have been diagnosed as HIV-positive by a doctor to ensure the accuracy of the diagnosis.

Research Sample and Sampling Procedure

This study employed the purposive sampling method to identify potential research participants. Purposive sampling is the principal sampling method used in qualitative research. Purposive sampling entails selecting the research participants, or a research site, purposefully to assist the researcher to understand the research question and the central phenomenon of the study (Creswell & Creswell, 2018). This sampling method employs the non-probability sampling technique (Berndt, 2020; Sharma, 2017). In non-probability sampling, not every individual has an equal chance of being selected for research participation (Creswell & Creswell, 2018), and the selection process depends on the researcher’s decision as to which sample will be included from the population (Tansey, 2007).

Employing the purposive sampling method comes with advantages and disadvantages. This sampling method has been criticised because of its biased approach to participant selection criteria. Purposive sampling relies on the subjective judgement of the researcher (Sharma, 2017). However, the subjective aspect is only a disadvantage when the researcher’s judgement is poorly considered. Another disadvantage of purposive sampling is that it makes it difficult to demonstrate the representativeness of the sample (Berndt, 2020), therefore limiting generalisation. However, qualitative research is not interested in generalising results from the sample to the population but rather in gaining an in-depth understanding of a participant’s lived experience (Brocki & Wearden, 2006; Smith et al., 2009; Wolf et al., 2016).

One of the advantages of purposive sampling is that it is less time-consuming because of the small sample size (Bakkalbasioglu, 2020). The sample does not need to be of such a large size to support prevalence and incidence statements (Ritchie et al., 2014). Furthermore, this method is flexible, as it easily adapts to research changes that might arise during the study process (Tansey, 2007). Purposive sampling allows the use of a wide range of sampling methods for data collection (Ritchie et al., 2014). For example, the homogeneous sampling method allows one to locate a niche sample to obtain specific information about the phenomenon studied. A homogeneous sample helps with the in-depth exploration of the particular phenomenon the researcher wishes to study. Purposive sampling was chosen for this study because purposeful sampling is commonly used in qualitative research for the selection of cases which are information-rich and are related to the phenomenon of interest (Palinkas et al., 2015).

This study identified a group of women for whom the research questions would be relevant (Smith & Osborn, 2008). A particular counsellor who held the patient information was asked to assist with recruiting study participants. This reduced the likelihood of other patients or staff members becoming aware that the study related to HIV-positive women only. The counsellor was asked to approach and refer participants based on the inclusion and exclusion criteria provided.

The criteria for inclusion consisted of the following characteristics:

Participants must be Black women.

Participants must have been diagnosed by a doctor as being HIV-positive during a pre-natal examination.

Participants must be pregnant (12-36 weeks).

Participants must be in the age category 20 to 40 years.

Attending RMMCH: Gynaecology/Obstetrics Department.

Ability to communicate in English.

The criteria for exclusion consisted of the following characteristics:

Women who are a race other than Black.

Women who are not pregnant.

Women younger than 20 or older than 40 years.

Women who are HIV-negative.

Women unable to communicate effectively in English.

After the counsellor identified a potential participant, she discussed the matter in the privacy of the doctor's rooms. The counsellor provided participants with information about the nature of the study to familiarise the participants with the research. Participants who showed interest in the study were asked permission to refer them to me for further discussion. The I provided the participants with the participant information sheet and elaborated on the nature of the study **(**see appendix 1). On the first meeting with participants, the following information was provided:

The purpose and reasons for the study.

The nature of participation in the study.

Voluntary nature of the study.

The potential benefits and negative consequences of participating in the study.

Ensure the confidentiality and anonymity of participant information.

The methods that will be used to maintain the protection of collected information.

Ethical approvals of the study.

The participant and I read through the participant information sheet together, and the participant was allowed to ask research-related questions. Participants were given a copy of the participant information sheet to read independently before making a final decision about participating. After the participants had agreed to participate in the research, a meeting was scheduled to conduct the interviews. Interviews were conducted on the same day as the participants hospital appointment to reduce travelling costs for the participant. Interviews did not interrupt the scheduled appointment and were conducted after the conclusion of the participant's appointment. All interviews were conducted in a private room at the hospital. Before the interview, participants had an opportunity to ask additional questions regarding the study. Once participants made a final decision and agreed to participate in the study, we signed two copies of the participant consent form and permission to audio record the interview (see Appendices 2 and 3). Interviews were conducted in English, considering that fact that English was not the first language of the participants it could influence how the meanings were constructed by research participants (van Nes et al., 2010). However, all participants were able to give rich and detailed information about their experiences. The decision to conduct this study in English was made for various reasons. The cultural and linguistic diversity of the Johannesburg population made the use of interpreters in conducting the study impractical. English is used as a second or third language by the majority of the South African population. If one considers that there are nine indigenous African languages spoken throughout South Africa, and that almost all of those languages are spoken in the greater Johannesburg area, this makes the use of English language the practical solution. Furthermore, conducting the interviews through an interpreter would limit direct engagement with participants. I would work with interpreters' words rather than participants' words. Interviewing through an interpreter would limit non-verbal contact between me and the participant.

Sample Size

Interpretative phenomenological analysis studies are conducted with small sample sizes as each case requires in-depth exploration (Smith et al., 2009; Langdridge, 2007). Interpretative phenomenological analysis is an idiographic approach concerned with understanding certain phenomena within a particular context (Smith et al., 2009). The purpose of the idiographic approach is to gain an in-depth understanding of each case individually. This research was concerned with understanding the individual, unique experiences of each HIV-positive pregnant woman. According to previous studies of a similar nature, the ideal sample size was 10-15 participants (Ashaba et al., 2017; Cuca & Rose, 2016; Flowers et al., 2011; Lingen et al., 2016). Initially, 31 potential participants were engaged in the study from whom 10 (30%) women aged 26 to 40 **years** agreed to participate in this study. All the potential participants who were approached to participate in this study had been diagnosed HIV positive on a date prior to the research commencing. The final number of participants was determined by data saturation. After 10 interviews the data reached saturation point, and the **I** terminated engagement with potential participants.

Research Design

Pilot Study

It has been suggested that new researchers should conduct pilot interviews to improve their interview skills and gain appropriate field experience for further data gathering (Creswell & Poth, 2018; Smith, 2009). The pilot interview is conducted by the researcher to evaluate their research questions or to change or modify the approach if needed (Howitt, 2016). In addition, a pilot study prepares the researcher to avoid unexpected problems that may arise during the data-gathering process. The pilot interview indicates the approximate time needed for each interview (Creswell & Poth, 2018).

After conducting the pilot interview, I engaged my supervisor to review the first interview. During the review process, suggestions were made regarding adding or modifying questions in the interview schedule. The suggestion was made to rephrase some of the questions to improve the quality of the research interview. English was not the first participants' first language, and it was important to rephrase and simplify some of the questions. Suggestions were made about prompts and probes to clarify and gain more information about the subject matter.

Data Collection

The qualitative researcher engages in a series of activities and employs appropriate methods to gather data in order to answer the research questions (Creswell, 2013; Howitt, 2016). Data collection tools include interviews or observation, structured and semi-structured in depth-interviews (Rogers & Willing, 2017). During the data collection phase, the researcher is guided by ethical considerations (Creswell, 2013). Different qualitative approaches employ specific steps to collect the data appropriate to that approach (Babbie, 2020). An interpretative phenomenological analysis interview aims to explore within the participant's lifeworld and allow the participant to recount their life experiences (Smith et al., 2009). For this reason, in-depth, open-ended, one-on-one, semi-structured interviews were employed for this study.

An In-depth interview is a qualitative data collection technique (Creswell & Poth, 2018; Seidman, 2005). This method is best suited to explore the participants' subjective experience of the phenomena to be studied (Smith et al., 2009). It offers the researcher a first-person, detailed view of the participants' lifeworld (Denzin & Lincoln, 2017; Rogers & Willing, 2017). The in-depth interview is the most suitable method for exploring sensitive topics (Smith et al., 2009), and HIV-positive status disclosure/non-disclosure is a sensitive subject; therefore in-depth interviews were the most suitable method for exploring this topic.

Interviews began after signing the relevant documents. I reminded participants that they had a right to stop and pause the interview, and they also had the right not to answer certain questions. I asked participants demographic-related questions such as age, relationship status, employment, etc. I made sure that the participant was ready and felt comfortable to start the interview process before asking research questions. This helped establish rapport between the participant and I. An important step for qualitative and interpretative phenomenological analysis researchers is to develop rapport with the participants (Creswell & Poth, 2018; Smith et al., 2009). One-on-one interviews allowed for a rapport to be developed between the researcher and the participants, giving participants the space to think and speak freely and be heard. Developing rapport helped access participants' stories which would otherwise not be accessible to me. An HIV diagnosis is a sensitive topic and sometimes secretive. Therefore, gaining trust and establishing rapport with the participants was crucial for successful data gathering.

All interviews were guided by a semi-structured, interview schedule (Smith & Osborn, 2008). Questions were developed in following the interpretative phenomenological analysis methodology (see Appendix 4). The opening question for each interview was related to the definition of well-being: How would you explain the term well-being? After participants had shared their subjective definition of well-being, I focused on the participant’s experience regarding their HIV-positive diagnosis and disclosure/non-disclosure patterns. Semi-structured interviews helped to address important questions related to this study but not inhibiting the possibility that new questions may arise (Smith et al., 2009; Bernard, 2011). Interview questions partly flowed from new relevant information that arose during the interview. The questions were not asked in a particular order from the interview schedule; instead, I allowed the questions to flow based on the direction of the discussion. Therefore, each interview was somehow different from another and was based on the unique experiences of each participant. Semi-structured, in-depth interviews allowed this research to explore new, unexpected, research-related matters. As stated by Smith et al. (2009), new unexpected themes can be the most valuable part of the interview process, as they arise without prompting and participants are giving the researcher information which carries particular importance to them.

During the interview process I used probes and prompts in order to clarify the information and motivate participants to give more detailed information to learn more about their experience of HIV-positive status disclosure/non-disclosure (Langdridge, 2007; Rossman & Rallis, 2017). To motivate participant and extend the information given, probes such as, can you tell me more about it, were used. In cases where I was not sure if I understood participants correctly, I requested clarification, for example, you said that people don’t take medications because they are scared?

In-depth, semi-structured interviews are conducted using open-ended questions (Babbie, 2020; Bernard, 2011; Seidman, 2005). It has been suggested that when exploring the participant’s experience in small sample sizes, the appropriate approach is to employ open-ended questions (Silverman, 2017). Open-ended questions lead to an in-depth understanding of reasons and barriers for HIV-positive status disclosure/non-disclosure and the elements that comprise well-being after HIV-positive status disclosure/non-disclosure. Examples of open-ended questions used for this study were, what influenced your decision to disclose or not to disclose your HIV-positive status; what effect did disclosure or non-disclosure have on your well-being? Furthermore, it helped to examine how research participants perceived well-being. Open-ended questions are non-directional and non-judgemental which helps the narrative to emerge (Creswell & Poth, 2018). Considering that each participant had their own reasons and barriers to disclosure, open-ended questions helped to document the different viewpoints and stories of participants. The use of open-ended questions did not restrict participants as to how they view specific phenomena (Creswell, 2013). Open-ended questions allowed for the collection of information while maintaining an open agenda.

The qualitative research approach, allowed study participants to freely discuss their experiences (Bernard, 2011; Corbin & Strauss, 2015; Creswell & Creswell, 2018). Furthermore, this approach gave marginalized groups of women a voice and empowered them to share their personal experiences (Denzin & Lincoln, 2017) regarding the decision-making process and their experiences of HIV disclosure/non-disclosure. To ensure the data accuracy field notes were taken during the interview after obtaining permission from the research participants. Field notes were based on observations of the research setting, which allowed me to see and record the participants’ activities and the context of these activities (Phillippi & Lauderdale, 2018). Field notes were used to capture non-verbal cues and as a back-up in case my recording equipment failed to record. Field notes provided extra data to contextualise the interview material (Smith et al., 2009). In-depth, semi-structured open-ended interviews allowed the exploration of multiple realities as experienced by the participants in their own unique environments (Smith & Shinebourne, 2012).

Data Analysis

Data analysis in the qualitative approach requires the researcher to prepare and organise the data to start the data analysis process (Creswell & Poth, 2018). This process involves transcribing the interviews to written text, followed by coding the transcript and developing the final themes. The final stage of data analysis involves presenting and interpreting the data (Smith et al., 2013). Different qualitative approaches follow specific steps in the analysis of the data. Data in this study were analysed following the ground-up approach by allowing the narrative to emerge from a close examination of the data. Interpretative phenomenological analysis adopts the ground-up approach which requires an investigation of participants' lived experiences through their personal perceptions rather than testing pre-developed theories and hypotheses (Smith et al., 2009). The following section will discuss the data analysis procedures undertaken for this study. The section will begin with the transcribing of interviews followed by steps of data analysis specific to the interpretative phenomenological analysis methodology.

Transcribing Interviews

The data analysis process began with transcribing audio-taped interviews verbatim. This allows the researcher to engage closely with the data. Verbatim transcription carries importance in interpretative phenomenological analysis research by giving a voice to research participants and allowing the readers to verify the interpretation made by the researcher (Smith et al., 2009). Taking ethical issues into consideration, any information that could identify the participants was removed. A unique number, rather than a name, was assigned to each participant's transcript.

Reading the Transcript. Following the interpretative phenomenological analysis data analysis procedure, the first stage was reading and re-reading the interviews. The first stage of reading involved listening to the audio-recorded interview while reading the transcript to create a holistic picture (Smith et al., 2009). To become familiar with the participant's world from their interviews, the transcripts were read several times (Creswell & Poth, 2018). To ensure that participants became the main focus of my analysis, I recorded my ideas and preconceptions in a notebook, and by doing so, this helped to bracket off my idea while actively engaging with the data and entering the participant's life world. Rapid reading of the transcript helped to gain new insights (Smith et al., 2009; Smith & Osborn, 2008).

Initial Noting. The next stage involved note-taking like free-textual analysis (Smith & Osborn, 2008). This process involved reading the transcripts while writing the exploratory comments (Smith et al., 2009). There are no strict rules in assigning comments to the data, however one should stay closely engaged with the data and keep an open mind to avoid commenting only on expected information. This stage was used to become familiar with the data and identify specific aspects of participants' experiences, and how they speak about a particular issue.

Exploratory comments during this stage involved summaries, ideas, key concepts, associations and connections that accrued during the reading process (Creswell & Poth, 2018; Smith et al., 2009; Langdridge, 2007). The aim was to produce a comprehensive and detailed set of notes and comments on the transcriptions (Smith & Osborn, 2008). Exploratory comments have been linked to significant statements made by the respondents. This connection was critical to deeply engage with participant experiences and data analysis. As the transcripts were read, re-read and commented on, more comments were added.

Developing Emergent Themes. Following the note-making, I returned to the interview transcripts to capture and develop the emergent themes. Initial notes were used to develop emergent themes and capture key elements of the transcript. The main task was to work with the initial notes rather than the interview transcripts (Smith & Osborn, 2008). The exploratory comments were tightly linked with the original transcript, thereby reflecting the source material (Smith et al., 2009). Exploratory comments were turned into meaningful statements reflecting theoretically relevant concerns (Langdridge, 2007).

Identifying emergent themes reduced a large amount of data and initial comments to manageable parts (Smith et al., 2009). As the focus was on specific sections of the transcript, the data analysis was influenced by the entirety of the transcript. This is referred as the hermeneutic cycle in interpretative phenomenological analysis (Langdridge, 2007). By capturing key elements of the interviews, transcripts were interpreted in relation to the whole text, and the whole was interpreted in relation to its constituent parts (Smith et al., 2009; Smith et al., 2013). While initial notes were less structured and open, emergent themes reflected my interpretation and descriptions of the participants' words. Emergent themes were listed in their original chronological order.

Superordinate Themes. During this process some of the emergent themes were clustered based on their common meaning, and were linked to the developing superordinate themes (Smith et al., 2009). A superordinate theme usually applies to each participant within a group but is characterised in different ways on a case-by-case basis. Some of the emergent themes developed in the previous stage were broken up into separate themes. Themes that did not provide expansive evidence or did not fit with the emergent themes were removed. The main themes were categorised into subthemes which gave extra meaning to the superordinate themes (Langdridge, 2007).

Themes were clustered in a table of themes. Each theme was ascribed an appropriate name and linked to a particular quote from the participants. This stage involved reviewing the table of themes several times and returning to the original text to re-evaluate the importance of the themes. Each transcript was analysed separately in its own right. The same process was followed for each transcript before comparing themes across the cases (Smith et al., 2009; Smith & Osborn, 2008). On completing this stage, each participant had a table of themes comprising superordinate themes, themes and subthemes directly linked to the participant's quotes. The next stage was to compare the table of themes across all the cases. The process required looking for diverging and converging themes across the cases (Smith & Osborn, 2008). This involved moving from case to case, reworking themes, and removing some of the themes which were not relevant for the majority of cases (Langdridge, 2007). The decision regarding removing some themes was based on interpretative phenomenological analysis guidelines. Smith and Osborn (2008) state that during this stage, some themes that do not fit with emerging themes or are rich in evidence within the transcript are removed. Once all transcripts were analysed, the master themes for all cases emerged (Smith & Osborn, 2008; Spiers & Riley, 2019). This final table of themes created a framework for the write-up stage.

Writing Up. The final stage involved writing up results to represent the findings of the research study (Smith et al., 2009). Writing up required analysis and interpretation of the tabulated data into a narrative and a final statement (Smith & Osborn, 2008). I engaged in interpretation to make sense of the data and represent the meaning (Smith et al., 2009). The interpretation stage required a critical mindset to distinguish what meaningful themes emerged from the data analysis.

Interpretative phenomenological analysis is the result of the interaction between the participant and researcher. While capturing the participants' lived experience, the researcher ascribes meaning and interpretation to the experience (Bloomberg & Volpe, 2019). Themes were expanded and explained while referring to the transcript as evidence for the claims (Smith & Osborn, 2008). The strategy of analysis was to take the emerging theme analysis, and through discussion to link the themes with the existing literature (Langdridge, 2007).

Ethical Considerations

Research involving HIV-positive pregnant women required strong ethical considerations because of the participants' vulnerable condition and the nature of the study. My ethical considerations in conducting this study are set out below.

Respect for Persons: Autonomy and Protecting those with Diminished Autonomy

Research participants must take a part in a study voluntarily without any undue influence, and their rights, autonomy and dignity should be respected (Principles of Research Ethics, n.d.). In terms of the rules every individual has the mental capacity to think for themselves and to decide their course of action. Individuals should not be prevented from pursuing their goals unless these goals are harmful to society. A person who is not of sound mind and full mental capacity should be protected from harmful influenced of society. All participants who volunteered for this study were adults with full mental capacity and who were in their sound and sober senses. Participants were recruited by a hospital counsellor who informed participants about the study. This type of study could raise power-risk issues with regard to the researcher, the participants and the study site (Creswell & Poth, 2018). The counsellor explained to participants that the researcher has no vested interest in the hospital and the woman’s decision to participate in the study is purely voluntary. Their decision either way would not affect their treatment.

Beneficence and Non-maleficence

Research involving human participants carries the risk of potential harm to the participants. This harm could be psychological, physical, legal, and socio-economic (Principles of Research Ethics, n.d.). The researcher should weigh the potential risk and benefits of the study. The researcher should attempt to minimise the possible risk of harm to participants and maximise the benefits of the research.

This research involved direct data gathering from human participants. As my research sample group consisted of a vulnerable sector of the population, I took the following steps to protect and minimise the harm that might occur during the research: Disclosure of HIV-positive status is a sensitive subject. My research questions could have been interpreted as being insensitive to some participants. I explained to all participants that if they feel uncomfortable about a specific research question, they had the right not to answer the question. To protect the women from psychological distress, if the interview caused emotional or psychological distress, the participant had the right to pause, postpone or withdraw from the interview. There were no negative consequences for participants who wanted to withdraw from the study. If it became evident that a participant suffered from psychological distress, I would stop the interview and refer the participant for counselling to a social worker provided by RMMCH. Even though all participants were informed of the availability of counselling services if required, none requested professional help during or after the interview.

During the Covid-19 pandemic, extra measures were taken to protect research participants and me. Before each hospital visit, I underwent a Covid-19 screening at the hospital entrance. Before interviews, I sanitised all surfaces that the patient and I may have come into contact with, such as tables, chairs, writing instruments, and recording devices. I provided additional masks to all participants. During the interview process, an appropriate minimum distance was maintained. Fortunately, lockdown restrictions did not prevent face-to-face data collection. Participants were informed of the potential benefits of the study, and any potential risks they may be exposed to.

Informed Consent

Potential participants should be provided with all the appropriate information regarding the nature of the study in an understandable language to make an informed decision whether or not to participate in the study (Principles of Research Ethics, n.d.). Information given to participants should include: The right of the participant to withdraw from study any time; risk and benefits of the study; and study procedure. Participants should have a clear understanding that their participation is voluntary and they should not feel under duress to take part in the research study.

I provided each participant with the information sheet and discussed each of the criteria with them. The information sheet contained the following information: The purpose and nature of the study; the reason why they were being invited to participate in the study; potential risks and benefits to the participant; voluntary aspect of participation; protection of identity and anonymity; data protection; information about ethical and hospital approval of the study. It was clear that participation is purely voluntary, with no negative consequences for refusing to participate in the study. Withdrawal at any time would also have no negative consequences, and the participant could withdraw at any stage. The participant information sheet allowed the participants to peruse all the relevant information and then make an informed choice as to whether they were willing to participate in the study. All participants were presented with the consent form as well as giving permission to record the interview. Two copies of the forms were signed by me and the participants; one copy was given to each participant. I started the interview only after obtaining their signed permission.

Confidentiality and Data Protection

Participants' rights regarding anonymity and confidentiality of the information should be respected and maintained (Principles of Research Ethics, n.d.). Participant data that has been gathered must be secured and stored to prevent unauthorised access**.** To ensure confidentiality and to minimise the possibility of the women being identified, several measures were taken. Each participant was assigned a unique number instead of their name. The recordings of the interviews were placed on a flash drive stick and immediately deleted from the recording device. The flash drive was stored in a safe, protected by a code lock. My PC is password secured. The transcript and the participant's data were encrypted with an encryption program. After five years, the flash drive will be formatted, and the files stored on the computer will be electronically shredded, and any paper trail will be shredded. The person involved in the co-coding was subject to confidentiality requirements. To maintain confidentiality, data were only shared when I ensured that it did not identify the participants' identity or any other information that may indicate the identity of the participants.

Integrity

Research should be designed to uphold integrity, and should be assured of both transparency and quality (Principles of Research Ethics, n.d.). My research study was undertaken after being granted National Health Research Database, UNISA and WITS Ethics Committee clearance. I obtained permission to conduct my research at RMMCH from the CEO of the hospital and from the Head of Obstetrics/Gynaecology Department and from the Department of Paediatric and Child health. To maintain academic honesty, I cited and referenced all sources used in my study. Information collected will only be used for this particular research project.

Conflict of Interest

As I was an independent researcher and am not affiliated with any institution or organisation pursuing of this research. I have no personal benefit to gain in conducting this research. As such, there is no conflict of interest in conducting this research.

Trustworthiness of the Study

Trustworthiness is an essential element in any qualitative research study. In order to establish trustworthiness in this study, I employed the following strategies to ensure the quality of the study: credibility, dependability, confirmability and transferability (Creswell & Poth, 2018; Lincoln & Guba, 2013). One technique to achieve credibility of the qualitative study is to employ member checking. Member checking involves bringing the interpretations and conclusions of the study back to the participants to check for accuracy. However, this technique has been criticised by interpretative phenomenological analysis researchers because the participant is not viewing the data in the context that it was collected, and it places the participant in control of an important part of the research, and the risk that the participant may want to change their story (McGaha & D’urso, 2019).

Instead of member checking as a means of achieving credibility, the peer debriefing method is preferred (Lincoln & Guba, 2013). The truth of the study was obtained by using the strategy of credibility and the criteria of peer debriefing to establish confidence in the findings and interpretation of my research study. According to Lincoln and Guba (2013), this is one way of keeping the researcher honest and free from bias. The independent co-coder, who is an expert in qualitative research and was not part of my study, was asked to examine my interviews and provide data analysis (see Appendix 8). The co-coder signed a confidentiality form and will not be permitted to divulge any information from the study. After the data were independently analysed by me and then by the coder, a meeting was set to discuss and compare similarities and differences between our data analysis. During the discussion, the coder and I agreed that our final table of themes, superordinate themes, and subthemes were matching.

To ensure dependability (Lincoln & Guba, 2013) I used the mini-audit (Smith et al., 2009). A mini-audit was conducted by the research supervisor and included reviewing the interview transcripts, field notes, final table of themes, superordinate themes, subthemes and interpretation. The supervisor validated the transcript and the approach. Triangulation was chosen as the preferred method for confirmability (Lincoln & Guba, 2013). Triangulation of methods uses multiple forms of data collection to ensure data accuracy, and determine if different data sources provide different information. My research study used two types of data collection: interviews and field notes.

Transferability is the degree to which the study’s results can be transferred to other contexts or subjects (Lincoln & Guba, 2013). The difficulty of transferability when used with an interpretative phenomenological analysis based study lies in the small sample size and the fact that the data gathered is based on an individual’s unique personal experiences, thereby limiting generalisation (Smith et al., 2009; Krefting, 1991). The interpretative phenomenological analysis methodology explores the range of experiences rather than the median experience. If we accept the assumption that there is more than a single reality, then the notion of reliability is no longer as relevant. This leads to the possibility that different researchers will likely achieve different results due to their study participants having different experiences. However, to achieve transferability in this study, I have provided a comprehensive description of the entire research process, which will allow other researchers follow similar steps. I have explained the reasons for employing the qualitative approach, interpretative phenomenological analysis and specific methods used for this research. Furthermore, I have described the data collection process. The reader is free to determine if my research findings apply to their context.

Summary

This study intended to explore the experiences of HIV-positive pregnant African women, and the perceived effect of their HIV-positive status disclosure/non-disclosure on well-being. In this research, a qualitative approach and interpretative phenomenological analysis were chosen to gain detailed insights into how an individual experiences and interprets life events from their unique perspective (Smith & Osborn, 2008; Smith et al., 2009). Chapter 3 discussed how the qualitative approach would help achieve the study's aims and answer the research questions. Furthermore, two research approaches, qualitative and quantitative, were compared to emphasise why the qualitative approach was the preferred approach to guide this study. Three pillars of the research paradigm that guides the research process have been discussed. Fieldwork was described by providing detailed information about the study site, research sample, participant selection process, and qualitative tools employed to gather the data. I have discussed the importance of the pilot study. Data collection and data analysis procedures were discussed. In concluding this chapter, I addressed ethical considerations and how I achieved the trustworthiness of this research study. The next chapter will present the findings of the study.

Chapter 4: Findings

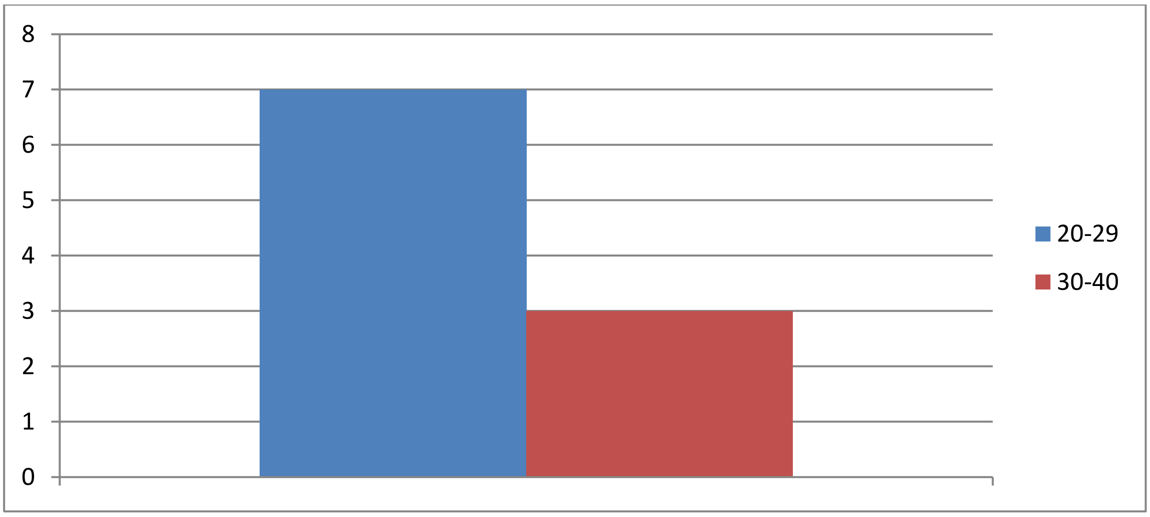
Chapter four presents the key findings obtained through in-depth interviews with 10 participants. The chapter will begin with participant biographical data followed by a brief overview of superordinate themes. Thereafter will be presented findings obtained from interpretative phenomenological analysis data analysis. Each superordinate theme will be presented in a diagram along with their accompanying definitions.

Biographical Data

This section presents the research participants' biographical data. The information includes age, relationship status, gestation period, employment, and education.

Figure 1

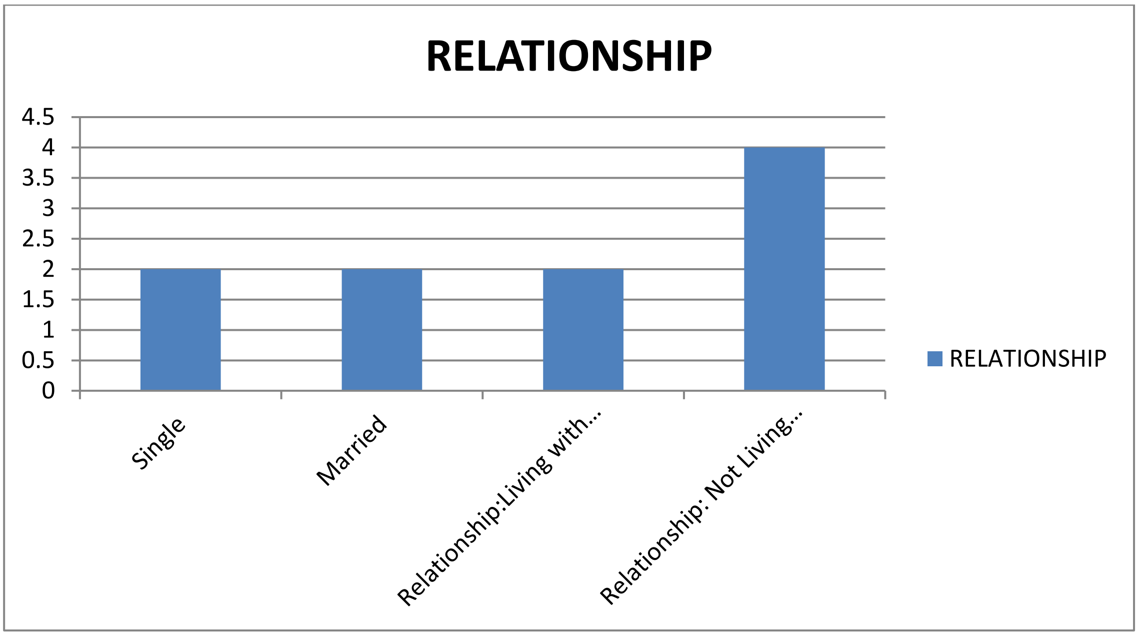
Age of Participants



Participants at the time of being interviewed were between the ages of 26 and 40 even though the age criterion was in the age range of 20 to 40 years. No women under age of 26 participated. The youngest participants were 26 years of age (*n*= 3) and the oldest participant was 40 years of age (*n*=1). The mean age of the participants was 30 years of age.

Figure 2

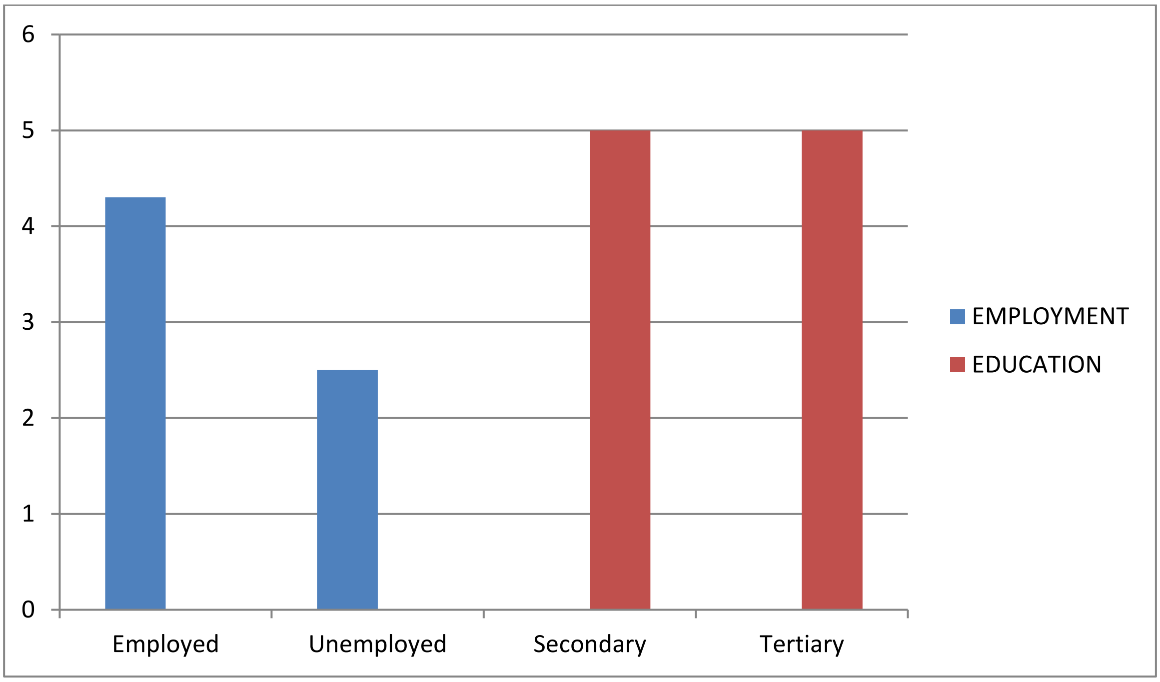
Relationship Status



Two of the participants were married while another two stated that they are single. A further two of the participants stated that they are living with their partner, while four other participants stated that they are not living with a partner.

Figure 3

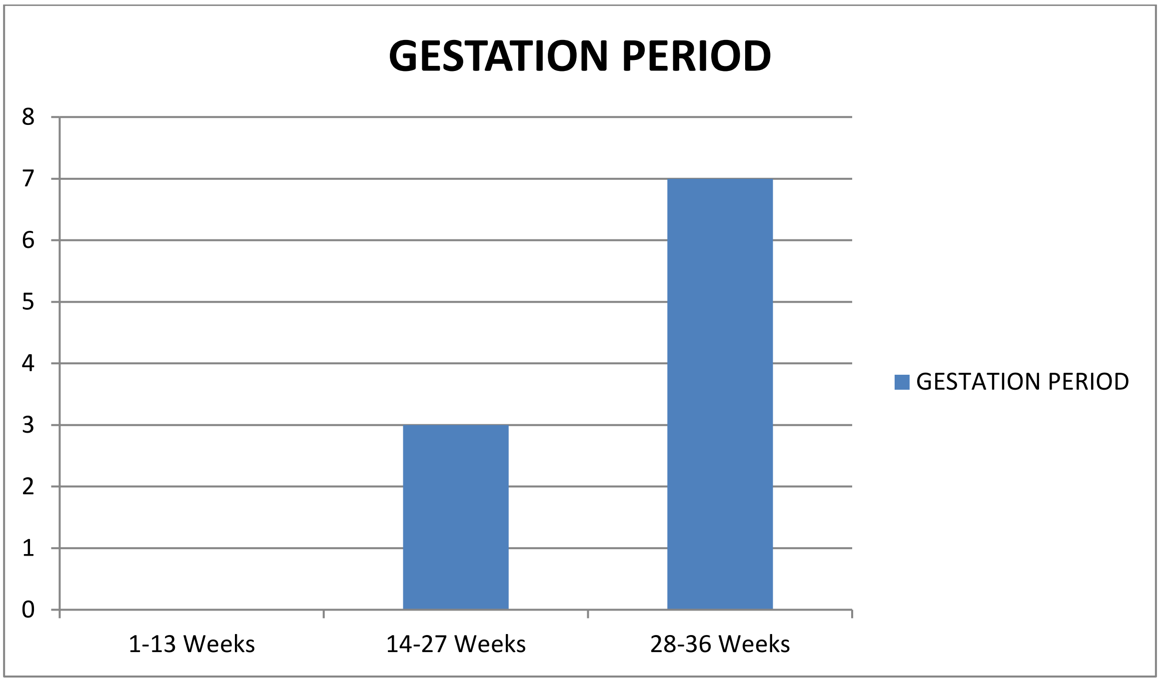
Employment Status and Education Level



Eight participants were employed, two participants were not working. Half the participants (*n*=5) had obtained their matric certificate, while the other had post-school education.

Figure 4

Gestation Period of Participants



This study invited participation of women in all three trimesters of their pregnancy. At the time of being interviewed three participants were in their second trimester of pregnancy (14-27 weeks), while the other participants were in their third trimester of pregnancy (28-36 weeks). The earliest gestation period reported in this study was 24 weeks, with the latest being 36 weeks.

Overview of Superordinate Themes, Themes and Subthemes

Table 1

Overview of Superordinate Themes

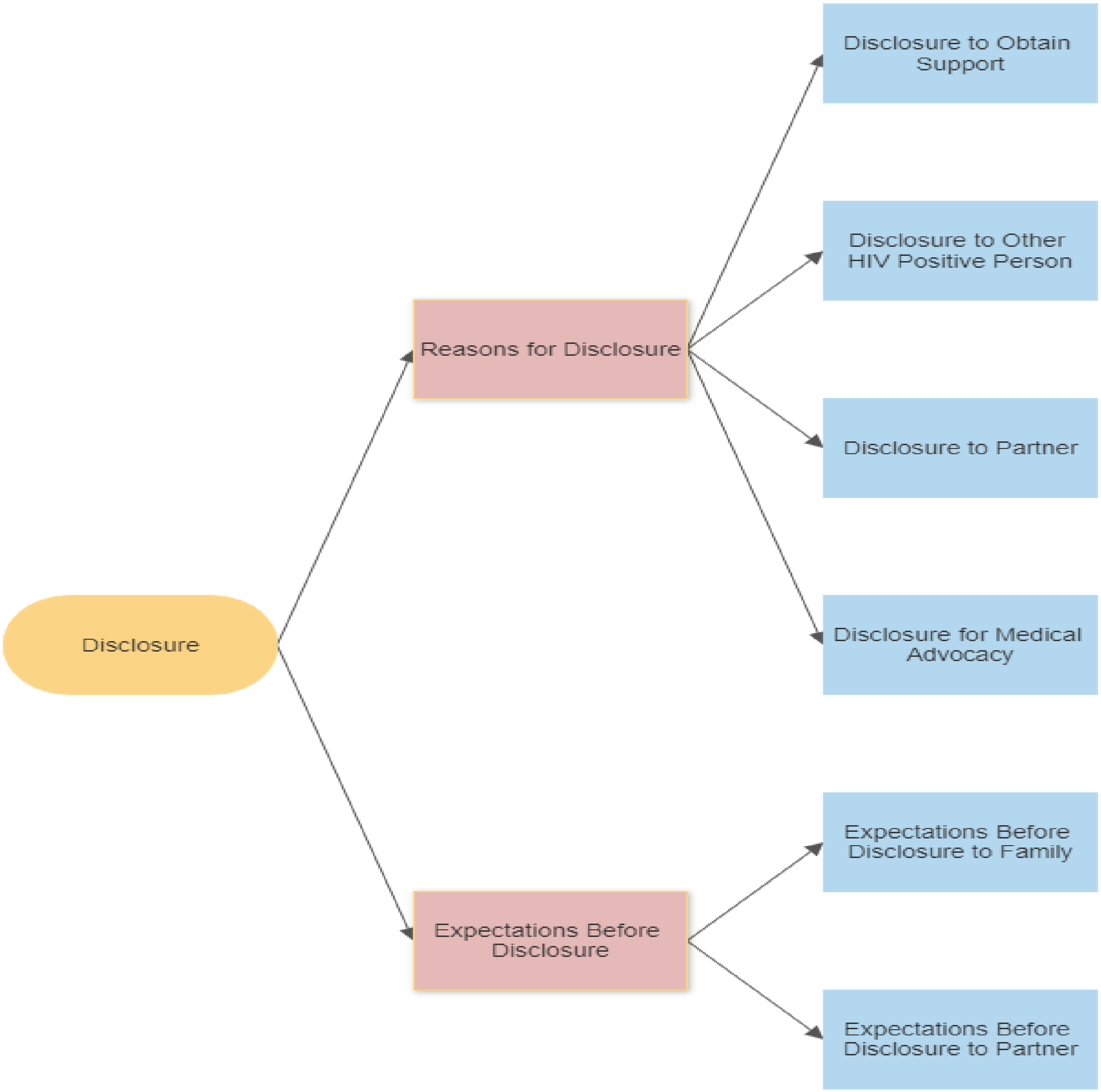
Superordinate Theme	**Overview**
Disclosure	This theme was created to house all findings related to disclosure, which included participants' reasons for disclosure and their expectations before disclosure.
Non-disclosure	This theme houses all findings about the participants’ reasons for nondisclosure. This theme presents personal reasons for non-disclosure as well as the impact that society and communal values have on participants' decisions not to disclose. This includes conversations on stigma and the causes of stigma.
Effect on Well-being after disclosure/non-disclosure	This theme houses findings on the outcomes of disclosure/non-disclosure and its effect on participants’ well-being.
Definition of Well-being	This theme houses findings how participants identify and define well-being.

The result section presents the superordinate themes: Disclosure, Non-disclosure, Effect on well-being after disclosure/non-disclosure, and Definition of well-being. Each category will be explained and linked to participants’ responses.

Disclosure

Figure 5

Superordinate Theme Disclosure



This superordinate theme addresses the reasons for disclosure of HIV-positive status among HIV-positive pregnant women. Reasons for disclosure were divided into two themes. The first theme to be presented are the reasons why women disclosed their HIV-positive status. The second theme addresses the expectations before disclosure of HIV-positive status.

Reasons for Disclosure

This superordinate theme discusses the concerning HIV-positive status disclosure in pregnant women. This theme involves the different reasons why some women decided to disclose their HIV-positive status to others and whom.

Disclosure to Obtain Support. This subtheme was created to understand the motivations for HIV-positive status disclosure. These participants shared their positive status with others because they had the need for support. Eight of the ten participants decided to confide in someone with whom they could share their diagnosis, and who could provide the needed support. They believed that it could positively affect their physical and mental health. One woman described her reason for disclosure to her sister, saying that:

> *Mostly when I sit alone and I don’t have anyone to talk to I am thinking about my status, baby and everything. … Because I am overthinking some things … It can be too much pressure on the baby, and my blood pressure is not very good for the baby so I needed to find a person whom I can talk to and trust. … I thought I would get depressed if I would not talk about it. … Even at work, I would be sitting alone away from other people* (Participant 7).

Women who felt they would not be able to deal with the diagnosis alone disclosed their status to receive encouragement. Sharing one’s feelings with someone was believed to help them to better deal with the negative emotions caused by the diagnosis. A participant shared her feelings regarding HIV-positive status diagnosis, saying that:

> *There is no one, I was feeling lonely, lonely, and eish, I thought she [the mother] is the only one who will make me calm down [sic]. … Because she is the person who is close to me, I tell her all my problems* (Participant 9).

Women selectively chose close family members to whom they could entrust their secret and receive understanding and support. Being confident that family members can keep the diagnosis secret and provide support was also a motivator for one woman to disclose her HIV-positive status:

> *"At least your family can keep your secret and give you support"* (Participant 8).

As described by participants, this journey is hard to walk alone. They needed motivation and encouragement from the people close to them. The disclosure choice was based on who would be sympathetic towards them and who could provide adequate support. Eight of the ten women disclosed their status to their female family members, such as the mother and sister. Only two of these eight women participants reported disclosure to their male family members, such as their brother and father. The disclosure was motivated by a close relationship and confidence:

> *"In my darkest hours they [parents], will be there for me"* (Participant 10).

It must be noted that disclosure by eight of the women was voluntary disclosure. Only one woman reported involuntary disclosure:

> *"My grandmother just knew because she saw my medications; she found out by herself, yeah.*
>
> *She just convinced me to take care of myself and told me that it is not the end of life"* (Participant 4)

These findings showed that women disclosed their status to close family members. The disclosure was motivated to obtain support. Furthermore, trusted family members were seen as the ones who would keep their diagnosis secret.

Disclosed Status to Other HIV-Positive Person. Four participants decided to disclose their status to a friend or family member who had already been diagnosed HIV-positive, as they thought these individuals would be more understanding and supportive. Findings showed disclosure was only made to HIV-positive female family members and friends. None of the participants reported disclosing their positive status to HIV-positive males. Disclosures of an HIV-positive person were based on different reasons. For two participants, sharing their status with an HIV-positive person was seen as a shared secret. Both of them knew the other’s secret and had a mutual responsibility to keep the secret safe. In this regard, a participant shared the reason for disclosing to her sister:

> *She told me that she tested positive. That is why I decided to tell her. … I could see that she got encouraged; she felt better after I told her that, I am positive. … I am keeping her secret, and she is keeping my secret. No one can tell anyone’s secret* (Participant 6).

A shared secret and having a trusted HIV-positive friend was also a reason for disclosure for another participant. She stated that one should be conscious as to whom they are disclosing their status to as not every friend can be trusted to keep their personal information safe. She believed that a friend who had been diagnosed positive would be the one who can be trusted, relate to her diagnosis and give her informational support. She discussed her motivation for disclosure to her friend, saying:

> *I have one friend, who I trust and I even told her. … She was sick, so she needed my help so I tried to help her … she was … open to me. … When I found out my status, I also told her. ... She was giving me advice, do not worry my friend she said, we are not going to die … let's just take care of ourselves* (Participant 8).

Disclosure to an HIV-positive person was perceived as giving and receiving support. These women were seen as being the ones who could relate to their situation and show more empathy towards them. Another reason for disclosure to an HIV-positive female family member was having a close relationship and the example they set for the participant as an HIV-positive woman. Women who were open about their status and living a happy life were motivators for disclosure. One respondent shared her reasons for disclosure saying:

> *"I only told my sister, who is … my strength, my support. … My sister is also HIV-positive … she is healthy, she is fine, she is happy … She told everyone about her status"* (Participant 1).

Similar circumstances for disclosure were reported by another participant who disclosed her status to her cousin with whom she had a close and trusting relationship. She said:

> *"She is open about her status, so it was easy for me to tell her ... she can relate"* (Participant 2).

This subtheme showed that women were more likely to disclose their status to HIV-positive people. Disclosure to HIV-positive people was based on close relationship with the participant and the example that person had set for participants by living a happy life. Furthermore, women were sure that a person diagnosed HIV-positive would be more conscious of keeping their status a secret.

Disclosure to friends was also motivated to receive informational support such as advice.

HIV-Positive Status Disclosure to Partner. This subtheme entails information with regard to reasons for HIV-positive status disclosure to a partner. Nine out of ten participants disclosed their status to their partners. Disclosure to a partner was motivated by a desire to maintain honesty and transparency in the relationship, to protect the partner from infection and adopt safe sexual behaviour. Women who did not know their partner's HIV status disclosed to them to encourage their partner to get tested. Not telling their partner could lead to poor health outcomes and put their partner's health at risk. In order to protect their partner from infection, if their partner is HIV-negative, women disclosed their status to promote condom use and adopt safe sexual behaviour. One of the participants spoke about her reason for disclosure to her partner:

> *He also has to know, and there is a baby coming; if our relationship continued, he had to test and find out about his status, and if we were going to continue to have sexual interaction, he needed to protect himself, actually to protect ourselves, use protection and everything* (Participant 2).

Six out of ten participants said they wanted their partners to make informed health decisions based on their HIV-positive status:

> *"I told my partner to be honest … to let him know what I know, so it is best to try and look after your health as well"* (Participant 3).

Women felt that this was the right decision and it would lead to their partner also getting tested so they could start treatment on time. Other motivators for disclosure were to protecting one's health and the health of their child. Three out of ten participants who were motivated to engage in proper HIV care to protect their own health and their child's health, made a decision in favour of disclosure:

> *I have to drink my medication on time, so if I did not tell him, it would be a problem … I am pregnant; I have to protect my child. … So, the day you find out about it, just tell him so you can set yourself free* (Participant 8).

Tree participants reported that they could not hide their medications from their partners, as hiding their status and medication could lead to missed medication adherence. Furthermore, keeping their status and medication secret would put additional stress on them.

> *"I have to drink my medications at the same time … I want to be free; I do not want to be scared"* (Participant 5).

Two women who tested HIV-negative before their relationship and felt strongly that their partner had infected them, were also motivated to disclose. For one woman, disclosure was to confront her partner about infidelity:

> *Last time when I checked I was negative … when I found out I was pregnant they tested me… positive. … I told him that I think you are the one who brought it, because you are cheating and I am not cheating* (Participant 9).

It must be noted that all other participants disclosed their status to their partners. Only one participant stated that she did not disclose her status to her partner. Partner's Infidelity was one of the reasons for non-disclosure.

Disclosure for Medical Advocacy. This subtheme refers to the reasons why some women decided to disclose their status based on their health concerns. Five participants were afraid that if something happened to them because of having HIV virus no one would know why. In case of disclosure, they were sure they would get appropriate support if something went wrong with their health. One of the participants said:

> *Because I know that when something wrong happens to me, she will be the person to tell, you know this diseases they make you faint [sic]; maybe she can be there, the person who can tell the health workers when they giving me a medication that I am HIV-positive [sic]* (Participant 4).

A similar reason was reported by another participant who said:

> *"If I wake up sick tomorrow, I know there is somebody who knows why I am sick. … If anything happens to me there is someone who knew what was going on with me [sic]"* (Participant 5).

Three women felt that if they got sick, they would have supporting people who would inform others about their medical history if necessary. Fear of sudden death was also a reason for disclosure. A participant feared that if she died without her family knowing about her HIV-positive status, someone could be blamed for it. Letting her sister know about her status made her feel that there would be no confusion if she died.

> *So, if you die unexpectedly people will say … someone killed her, so I did not want them to think like that; at least if I die today, they will know why. She will know that her sister was HIV-positive and they have to accept it; they do not need to fight with anyone and just accept it [sic]. That is the reason why I felt I need to tell her* (Participant 8).

This subtheme discussed reasons for disclosure. Women felt it was the right decision to tell some family members about their diagnosis. Having health-related concerns led them to disclose. This way, they could be sure that there will always be someone who knows their status in case of a medical emergency.

Expectations Before Disclosure

This theme reflects participants' expectations and concerns before disclosing their HIV-positive status to their family and partner.

Expectations Before Disclosing to Family Members. Women reported that before disclosing their HIV-positive status, they held some concerns about the possible reactions that could be made due to their disclosure. Four participants thought they would receive negative responses from family members, while other four were sure that their disclosure would be followed by understanding and support. One of the participants described her expectations before disclosure, saying:

> *"I thought my mother would be worried about me and stressed as to how I am going to deal with it" (*Participant 2).

Telling someone about an HIV-positive diagnosis could be stressful for both parties. Despite those worries, they still decided to disclose their status. One woman said:

> *"They were very understandable [sic] about it, but I did expect the worst. … That also helped me feel comfortable around them"* (Participant 3).

Four women reported that their anticipated negative reactions did not meet reality. Fear of mistreatment, avoidance and stigmatisation was an expected reaction for another participant. She was worried about the possible negative reaction that could follow her disclosure to her sister. However, those fears did not materialise. One participant said:

> *I was worried also the first time… you know some people when they find out you are like this, they will ignore you, they will say eish she is HIV just leave her ... but she did not do that, she gave me support* (Participant 8).

The four women who were sure that disclosure would be followed by understanding and support also did not report negative expectations. They were sure that the person they chose would be the one who would comfort them in difficult times. One participant spoke about her positive expectations saying:

> *"With my parents I did not have any expectations, because my parents always say to me whatever happens to you, we are there for you"* (Participant 10).

Participants reported two types of expectations, four feared that the reaction upon disclosure would be negative, while others four were sure that they would receive positive reactions. Despite negative expectations, women disclosed their HIV-positive status to family members.

Expectations Before Disclosing to Partner. This subtheme continues the discussion regarding disclosure expectations and captures the participants' expectations held before disclosing to their partners. Expectations will be compared with the actual reaction of the partner. Five of the participants dicussed their negative expectations before HIV-positove status disclosure. Despite fear and difficulty of disclosure, participants disclosed their status to their partners or husbands. These findings showed that none of the negative expectations materialised in real life. This participant described her fears of disclosure and how it really turned out:

> *I thought he will dump me or fight with me, but when I told him he was so cool about it, he was so calm, he did not fight with me, he did not shout. Then he told me that he will go and test* (Participant 9).

Similar expectations were reported by another participant who said:

> *"Maybe not talking to me, maybe leaving me, that [sic] what I was thinking about but nothing changes"* (Participant 4).

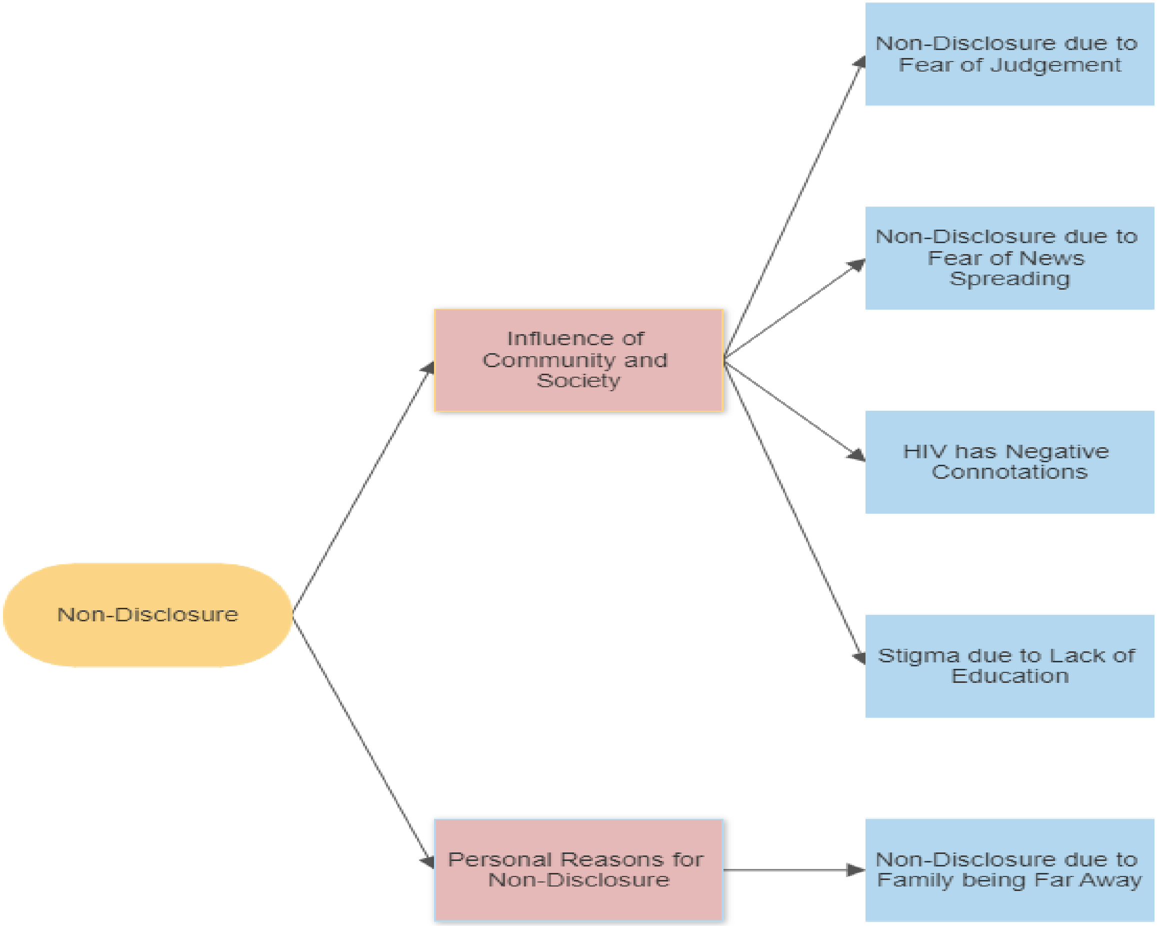
One participant expected her partner to be furious and blame her for infidelity; she said that his reaction was in fact the opposite of what she was expecting. She said:

> *I thought he will be angry, like furious. I was expecting him to tell me something like, we are going to talk about baby, like we will go do some paternity test … but I got a different reaction because he was very calm* (Participant 7).

Non-disclosure

Figure 6

Superordinate Theme Non-disclosure



This section discusses the reasons for non-disclosure of HIV-positive status among HIV-positive pregnant women. Superordinate theme non-disclosure was divided into two themes. The first is the societal and communal values that affect decisions not to disclose. The second theme addresses the personal reasons for non-disclosure.

Influence of Community and Society

This theme indicates why some women do not feel comfortable sharing their diagnosis with others. These women stated that their decision for non-disclosure was motivated by the influence of their community and society. Stigma within the community was a barrier for HIV-positive status disclosure.

Non-disclosure due to Fear of Judgement. Nine women reported the fear of judgement as a common reason for non-disclosure of HIV-positive status. Five of the nine participants stated that society believes HIV is only spread by sleeping around or having many sexual partners. Thus, they are reluctant to share their statuses as others would make negative inferences about their character and behaviour. An HIV-positive status is often subject to stigmatisation and discrimination. Participants were concerned about the judgemental and negative comments they heard from others about HIV-positive people. Awareness of how people treat or speak about a person's seropositive status led to non-disclosure of HIV-positive status. Community, friends and family have been the ones who stigmatised HIV and made participants hesitant to disclose. One of the participants said:

> *I have to now come out and say, oh by the way I am positive, no it is not going to work that way. It does influence because in the conversations that we have, you can hear that these people … like to stay far away from [HIV] positive people* (Participant 3).

Avoiding potential mistreatment and judgement leads to non-disclosure among other participants. One participant said:

> *"They will take me otherwise [sic] … they will judge me. … Sometimes, when we talk about HIV-positive, I can hear their words, this and that, so that is why I decided to shut up.*" (Participant 9).

A common reason given by five participants for non-disclosure was a fear of negative labelling. A major stigmatisation of HIV-positive people is that HIV is directly linked to multiple sexual partners. Participants were concerned that their HIV-positive status would automatically present them in a negative light to the community. To avoid the additional stress of negative labelling, they decided to keep their HIV-positive status a secret. One of the participants described prejudices held by her community, saying:

> *"From the location I am come from [sic], I think what comes in people's mind when someone says HIV-positive is … she slept all around with many man [sic], that why she or he is like that"* (Participant 5).

Additionally, this participant said that being HIV-positive means a person went against cultural norms and religious rules. Having sexual interactions with men and falling pregnant outside of marriage adds to the negative perceptions of HIV-positive women.

Stigma, such as making moral judgements about HIV-positive people, and believing that only a certain type of woman has it, was the most common reason for non-disclosure. In communities where HIV is highly stigmatised, it made women feel that they cannot do anything to change these perceptions; therefore, they preferred to keep their status hidden. This participant spoke about community influences in connection with non-disclosure. The participant said:

> *If I tell a person that I only slept with one partner, got pregnant and then I went for a check-up and I found out that I am HIV [sic], they still won't believe me. … They will be like, oh she been with 1, 2, 3* (Participant 7).

It must be noted that none of the participants directly experienced stigmatisation or discrimination. However, to avoid potential negative assumptions, name-calling and negative labelling, the nine participants decided not to disclose their status to a person they did not fully trust.

Non-disclosure due to Fear of News Spreading. Six participants stated that they had decided not to disclose their statuses because they feared that others would not keep the news to themselves. The fear of the spread of gossip in some communities makes some participants not want to disclose their status. Women believed that they needed to be cautious about whom they trusted with their secrets. To protect themselves from unintentional disclosure, women decided not to disclose their status to certain people. One participant shared her reason for non-disclosure with her mother, saying:

> *"She is not secretive … she will just tell everyone in my family. If I will tell her she will tell it to [sic] whole family, my other sisters … and they are also as judgemental as her" (Participant 1).*

Another participant echoed a similar response. She was afraid to disclose her status to her friend, saying:

> *"When I tell my friend I am HIV-positive it is between me and my friend and not for their friends, no, what happens if you tell your friend, is that it will travel that I am HIV-positive"* (Participant 9).

Two women believed that HIV-positive status makes a good topic for gossip and rumour. To avoid being negatively discussed and gossiped about, they decided to keep their status secret from people they did not fully trust. As one woman said:

> *"If I do disclose, they will have a topic about me. … I am not ready for that drama"* (Participant 10).

A similar reason was reported by another participant who said that people would not keep her status secret which would lead to:

> *"Gossip at work … like my status, the way she is, they just talk, like nasty things, like … you don't know how you got infection [sic]"* (Participant 7).

Three participants did not want their status to be known by family members. They feared that family members would not keep their status secret which would lead to judgement. Other three participants did not want their status to be known to a broader group of people, such as friends, community members and colleagues. Women who feared entrusting this sensitive topic to others due to fear of involuntary disclosure decided to keep their status secret.

HIV has Negative Connotations. Four participants stated that HIV has negative connotations in society, for example, that the individual will die young. This prejudice was based on people passing away from AIDS in their families or their communities. A participant reported that her family holds stigmatising views on HIV, which had a strong influence on her decision about disclosing. This stigma was directly related to a family death caused by this virus. She said:

> *Stigma around, like at home, around my community and in my family, it is caused by [sic]. I lost my brother due to this virus in the first years [sic]. So, I think this is a reason why there is so much stigma around this virus* (Participant 1).

To avoid involuntary disclosure, this participant avoided visiting the local clinic where her relative worked as a nurse. Having a family and community who stigmatised HIV-positive status made the coping process harder.

The participant’s first thought, and what she believed her family would think, as well as the community, is that being HIV-positive is equal to a death sentence. The participant referred to community perceptions associating HIV with death:

> *“I think that is the thing that is still on our mind. When you are HIV-positive you can die earlier. … It comes from that [sic] people… we knew… people used to pass away mostly from HIV long time ago”* (Participant 5).

They stated that they did not want to be seen as a dying person. People in their community still hold a prejudice that:

> *“HIV does not have a medication” (*Participant 9).

The social context surrounding HIV diagnosis had an impact on how women experienced their HIV-positive diagnosis, and this effected their decision of non-disclosure of their HIV-positive status.

Stigma due to Lack of Education. Four women believed that the biggest contribution to stigma and discrimination is a lack of education about HIV. Understanding the nature of this virus is still low among some communities, and there are misconceptions as to how the virus is transmitted. One of the participants said that she believes that stigmatisation and discrimination are caused by:

> *“I think the way this HIV thing came at first, the first time when it came the communication was not right. ... That is why people can discriminate’’ (Participant 4).*

A similar reason was echoed by another participant who believed that stigma held by society is based on:

“People are not well educated about HIV” (Participant 2).

Even though much has changed after the first appearance of HIV, such as effective treatment, social perceptions about the virus are still negative. Negative connotations are deeply rooted in a lack of information and awareness. This has led to the judging and stigmatisation of HIV-positive women. People believe that this virus can infect only certain ‘type’ of women. As one participant described misconceptions about this virus is based on:

> *They do not have enough information about it. … There are different ways of getting HIV, and they should not focus on one thing, like sex, or maybe she was sleeping with different people. … I would tell yes, if like [sic] there is improvement in education … but now the way … people are talking about HIV, nah (Participant 7).*

Personal Reason for Non-disclosure

This theme discusses the personal reasons for HIV-positive status disclosure. These participants reported that distance was a hindrance for HIV-positive status disclosure. Furthermore, the distance factor gave them the opportunity to come to terms with their HIV-positive diagnosis before having to disclose it to their family.

Non-disclosure due to Family being Far Away. Participants’ decision not to disclose their HIV-positive status to family members was related to long distance. Four participants were unable to visit their home town after diagnosis. Participants who were thinking about disclosure reported that disclosure is not a topic for a phone conversation but instead something be discussed in person. Disclosing to family members about HIV-positive diagnosis is something that participants preferred to do face-to-face. Participants reported they were looking for the right time and the right place to make their disclosure. After visiting family, they would have a chance to decide if they wanted to disclose. As one of the participants reported, she had not disclosed to her family yet:

> *"Because here I am living alone and parents, siblings, relatives are far away, so I cannot just tell them by the phone"* (Participant 4).

Another participant echoed the response of a previous participant, saying that she was not able to visit her family in another province after diagnosis:

> *I cannot tell them over the phone. … maybe they are little bit far from us because since I found out I never met my them [the family]. … I think when I am close to them, it will give me a chance to decide if I am going to tell them or not* (Participant 5).

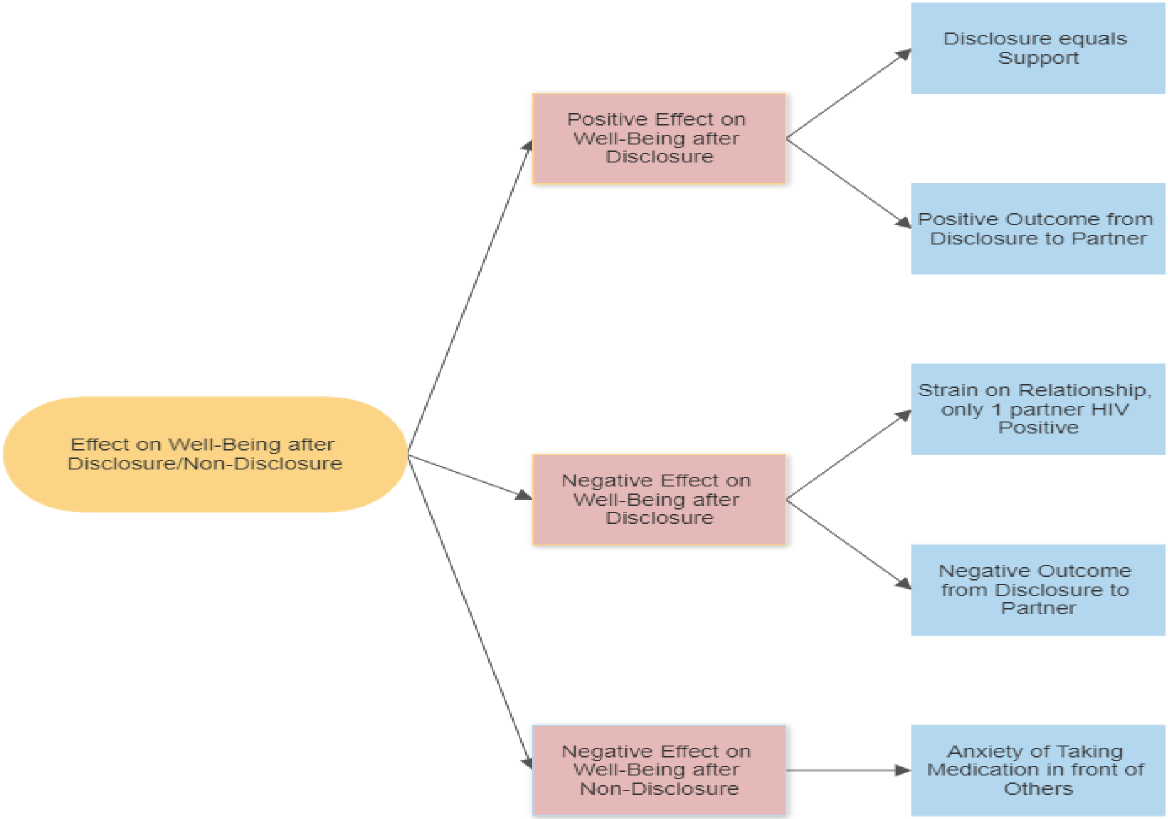
Delivering such news could be emotionally stressful for both sides. In the time before visiting their families, they could emotionally prepare to disclose. When they would be with their family, it would give them a chance to make a final decision regarding disclosure. As one of the participants reported, she would make a final decision when she would visit her family, but for now:

> *"I just want to keep it to myself for now. Then when the time comes, I will tell them, because since [HIV-positive diagnosis] I was not able to go home. … I will tell them, maybe, I am not sure"* (Participant 6).

Effect on Well-being after Disclosure/Non-disclosure of HIV-Positive Status

Figure 7

Superordinate Theme Effect on Well-being after Disclosure/Non-disclosure of HIV-Positive Status



This superordinate theme discusses what constitutes a positive or a negative effect on well-being after HIV-positive status disclosure/non-disclosure. This superordinate theme houses themes: a combination of positive and negative effects on well-being after disclosure and negative effect on well-being after non-disclosure. Each theme is divided into subthemes. The following section presents findings regarding to positive effects followed by a negative effect on well-being after disclosure/non-disclosure.

Positive Effect on Well-being after Disclosure

This theme presents finding regarding positive outcomes after HIV-positive status disclosure in pregnant women.

Disclosure Equals Support. Disclosure often resulted in increased support and concern from loved ones. Social support provided by family and friends had a positive effect on women's well-being. Findings showed that the two most common types of support obtained after HIV-positive status disclosure were instrumental support and expressive support. Instrumental support was associated with financial support, material goods, transport services and physical assistance. Expressive support, the most common type of support, was associated with emotional support, receiving motivation and encouragement. Less common support was informational support, provided mainly through friends, and spiritual support, provided by a family member. Nine women who disclosed their status to family or friends reported positive outcomes. One of the participants described support obtained after disclosure to a family member and said:

> *It is overwhelming, because I actually received so much support. … Like emotional support, physical support, if I needed to go to clinic, they were offering me [to take me to the clinic], they ask me what I need, do I need any extra stuff. With my other cousins, do you need to take these kinds of vitamins? We can buy them for you. … it is easier like this rather than if I was doing it alone, if I was going this journey alone. …I have people around me who support me (Participant 2).*

Support provided by family members promoted ARV adherence and contributed to physical well-being. Family members played an active role in reminding women to take their medication on time and ensure they do not miss the adherence. One woman reported that her sister:

> *"… Is reminding me of my medications … she is so supportive" (Participant 1).*

Another participant noted that her grandmother:

> *"Ensures that I drink my medications … she is always helpful"* (Participant 3).

Women felt comfortable taking medication around family members and were not under pressure to keep their medication hidden.

The disclosure was reported as bringing peace to their mind, and the support they received helped in accepting the diagnosis. Assuring HIV-positive women that they will live a long and healthy life was a significant factor in reducing the anxiety caused by diagnosis. One participant described emotional, instrumental and spiritual support provided by her sister after disclosure:

> *Most of the time when I talk to her it will be like counselling, we will pray together, and I will be fine. She checks on me. Now I am fine, I am recovering. Like emotionally, we talk about and she says that, you are not the only one with HIV, you are not the first, as long as you take your medications you will be fine … She offers to come with me for check-ups* (Participant 7).

Positive Outcome from Disclosing to Partner. As with the previous theme, disclosure outcomes resulted in two types of support, expressive and instrumental. Three women reported support and encouragement after disclosure to their partner. After being prepared for the negative reactions, women reported feeling relieved and happy with how their partner reacted to their disclosure. Their fears were based on the commonly held belief that disclosure would lead to separation.

> *I did not think I will take it as easy … he is the one who made me to take it so easy, normally he encouraged me. … He did not treat me the way I heard from my friends. …He told me that you are still the same. … I felt encouraged like ok I will take it as easy as he is taking it* (Participant 6).

The support provided by partners was based on the assurance that they would go on this path together and that positive status would not affect their relationship. Motivating and supportive words from partners acted as a bulwark against the stress caused by diagnosis. The partner's willingness to get tested for HIV was also seen as a positive response to the disclosure. Women found that their partner engaging in HIV care was an important part of their support. One of the respondents described support obtained from her partner:

> *He told me … Do not worry everything will be fine … if we will follow the instructions, we are going to live long [sic] … We always talk, he always gives me an advice how to take care of myself and how to take care of ourself, and that is very important for me, and that cannot stress me. … When time comes to drink your medication, they remind you … if you have someone on your side everything goes perfect* (Participant 8).

As with family members, male partners supported women in taking their medications and encouraged them to stay engaged in HIV care. Taking care of women's emotional and physical well-being was an outcome of HIV-positive status disclosure. One participant described her partner's support as:

> *"He is there for me, he makes sure that I am okay, emotionally well-being, physically well-being, eating correct food"* (Participant 5).

Negative Effect on Well-being After Disclosure

This theme presents two subthemes regarding negative outcomes after HIV-positive status disclosure in pregnant women. The subthemes are: strain on the relationship of only one partner being HIV-positive, and negative outcomes from disclosure to partner.

Strain on the Relationship of Only one Partner being HIV-Positive. This subtheme houses all findings concerned with the effects of only one person in a relationship being HIV-positive and the impact that has on the participants and their relationships. Four women reported their partner's being tested negative. Two out of four participants feared that they would be the ones who would be blamed for bringing this virus into the home. One of the participants whose partner tested negative said:

> *Because he … is negative … that is the most stressful part about our relationship. … I thought, did I bring this disease in the house? Because you are the one who is positive … you are the one who caused this … that was going in [sic] my mind* (Participant 5).

One woman reported being anxious about the possibility that her partner would abandon her. A participant described her feelings as:

> *"I did not feel comfortable, I was very scared. I thought maybe he will leave me? … I do believe him that he really loves me ... because since I got tested nothing went wrong, everything is the same"* (Participant 8).

Being diagnosed HIV-positive is already a stressful situation, and a partner receiving an HIV-negative test result is an additional burden for women. Despite the stress of mixed test results, the encouragement and understanding received from their partner made women believe that their relationship was built on trust and support. However, not all the participants experienced support from their HIV-negative partner. One of the women who disclosed her status to her partner to encourage him to get tested and take safety measures reported that he left the relationship. She reported mixed feelings regarding his negative status, saying

> *I do not know actually how I feel … but I am happy he is negative, because I feel like with his mentality, he was not going to deal the way I have dealt with it. … He should just get educated about it, yeah and get more knowledge about the virus* (Participant 2).

Negative Outcomes from Disclosure to Partner. These women reported being unsatisfied with their male partner's support after disclosure. Avoidance of engaging in an honest and open discussion about HIV-positive status was seen as unsupportive behaviour by the male partner. Avoiding getting tested for HIV made three women question the source of the virus. Women who were open and honest about their diagnosis were waiting for their partner to take safety measures and also get tested. One of the participants spoke about her unmet expectations regarding her partner's support:

> *He said he will go and check his status. But he did not. …I did not keep it secret, because he is my partner. …I thought he will support me, we will support each other, but for now he does not want to talk about that* (Participant 9).

Another participant reported similar issues, she wanted to engage in open discussion but:

> *He ignores it, like he just brushes it off. … He will actually block me … he will just avoid that question and never gives me a direct answer and he never tells me that he will go and test now* (Participant 7).

Unsatisfying reactions were related to unmet emotional support. Five women expected their partners to be more emotionally involved after disclosure. They wanted their partners to make sure they were coping with the diagnosis, ask HIV-related questions and show more empathy towards them. Two out of five women reported their partners only being involved with the pregnancy part of their health but not showing interest in their HIV treatment. One of the participants who reported her partner being supportive mentioned that support should go along with the talk. She experienced mixed feelings about his support. She said that her partner's support:

> *Was not satisfying for me. … If we could talk about it … I want him to ask me questions. … That is the thing that concerns me every time. … He will ask about baby part but not about HIV* (Participant 5).

In addition, a partner's overly calm reaction to disclosure was seen as a suspicious reaction making women question if their partner already knew about his own HIV-positive diagnosis that he kept hidden. One participant shared her experience regarding her partner's reaction and avoidance behaviour to test and discuss HIV-positive status. She said:

> *What makes it emotionally hard for me is that … he said to me, I do understand, it is fine … he is talking as if it is something he knew before and he doesn't mind. … The only questions he asks me is: how was the hospital, what did they say about the baby? But he will never talk about HIV!*
> *I ask him why don't you talk about it? He just says to me, I do not want to think about negative things.* (Participant 10).

Nine participants disclosed their status to their partners. Five participants felt they were not supported by their partners, such as not openly speaking about HIV-positive status or not getting tested. One participant reported full satisfaction with her partner’s support. Two participants reported that the support provided by a partner was only partially satisfying. One participant reported separation after HIV-positive status disclosure.

Negative Outcome from Non-disclosure

This theme discusses findings regarding negative outcomes after disclosure and its effect on women’s well-being.

Anxiety of Taking Medications in Front of Others. The constant stress of hiding medications and HIV-positive status added unnecessary stress for women. Five participants believed that drinking medications would make people realise that they are HIV-positive. Two women out of the five reported avoiding family visits and social outings to keep their status hidden and being able to drink their medications on time. Participants saw social engagements and family visitations as barrier to their treatment adherence. As one of the participants reported:

> *If friends, they will go out and I go with them, and I need to take my pills, how can I take it in front of them, it is secret. … They will take me otherwise. … all of them will know that I am positive, even at my workplace, so I don’t want that* (Participant 9).

A similar reason was reported by a participant who said that stigma in her family makes her avoid visiting family, where her HIV-positive status could lead to judgement and stigmatisation. She said:

> *I will feel good if stigma ends especially in my environment; I hardly go home … I am afraid when I go home, I do not drink medications, I will feel happy if my whole family knows and understand my situation* (Participant 1).

The possibility that workplaces and friends would find out their status puts a mental strain on the participants. Someone seeing the name of the medication could lead to unintentional disclosure followed by judgement. Anticipated anxiety was caused by the impending birth when they and their child have to take medications at the hospital in front of family and others. As one participant said:

> *“My only problem of how I am going to explain to those who will ask me about [child’s] medications. … These days, you can google anything … that scares me” (Participant 3).*

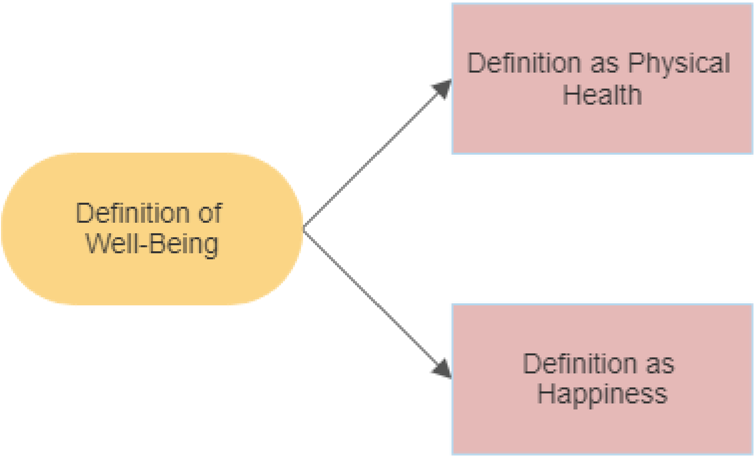
Two participants believed that stigmatisation of HIV-positive status is a factor in non-disclosure and non-adherence to medication regimes among HIV-positive people. Women believe that HIV is so stigmatised in their communities that people avoid taking medications, which is why so many people die. This creates a vicious cycle. Not taking medication leads to death, and HIV gets stigmatised because of death. One of the participants spoke about how societal beliefs affect the non-disclosure decision:

> *People who are HIV-positive, are treated differently, they give them their own class. I found it unfair, so that is why, you found most people die because they are scared to open up. …. You have to take medication all the time and you working somewhere and you did not tell them about your status. … so, you are worried that they will end up finding out. … because I am HIV-positive, people act funny like you wake up dead* (Participant 10).

Definition of Well-being

Figure 8

Superordinate Theme Definition of Well-being



This superordinate theme discusses how participants identified the meaning of well-being. In this section, two themes are discussed. The first is the definition of well-being as physical health, followed by the definition of well-being as happiness.

Definition of Well-being as Physical Health

Six participants described well-being as being physical health. The meaning of physically healthy for each participant was specific to each case. For two participants, physical health was associated with healthy habits such as a balanced healthy diet and exercise and physical activity. A participant described physical health as:

> *"Like to check your body, when you are not feeling well, you need to go to the hospital to eat healthy food"* (Participant 4).

Physical well-being was associated with taking care of their body, and maintaining a healthy quality of life. For three participants, physical well-being was directly linked to regular screenings for common health conditions, and monitoring vital signs and viral load. Getting tested and taking prevention measures to reduce the risk of HIV transmission was an important part of the physical well-being for one participant.

> *Eat healthy ... do exercise. … But right now, what I understand for me to understand more about my well-being is to get tested not just for HIV, but tested for the most of the disease. … like to get tested for like a HIV, cancer. … To take care of myself, using protection, every time* (Participant 5).

The findings showed that women prioritised their physical health and identified it as a vital part of their well-being. Good physical health could also promote better mental well-being outcomes. The influence of physical health on mental health outcomes was discussed by one participant who said:

> *I would say it is about my health. … My immune system, umm my vitals. … For me to be well, I feel like I cannot be anymore that kind of 100% well, like 100% healthy, now I believe in medicine like forever. … I do not expect my health to be 100%. That strikes me that I will never be 100% healthy* (Participant 7).

Taking good care of their health could also positively affect their maternal health and promote better psychological and physical well-being outcomes. Raising awareness about one’s health was related to taking safety measures and engaging in proper health care. For these women, well-being was equivalent to good physical health. For some women, it involved regular check-ups and for others practising healthy habits such as diet and physical activities.

Definition of Well-being as Happiness

The second subtheme that emerged during the data analysis process was the definition of well-being as happiness. Five participants understood well-being as being happy and stress-free. However, participants ascribed different meanings to happiness and a stress-free life. For two participants, happiness was directly linked to a stress-free life. Being mentally free from worry was a priority for well-being and happiness. One of the participants' who identified well-being as happiness stated:

> *"When I feel good, I do not have any stress, when I am free and happy. ... I am stressed when I think about something that bothers me"* (Participant 9).

Another participant also spoke about happiness and stress-free life saying:

> *I know my status; I am just happy. I am happy because the day I learned that I am HIV-positive, I was scared, and I was very stressed. … I told myself, there is nothing I can do. I just accepted it, because it already happened (*Participant 8).

Accepting one's diagnosis was also related to happiness for another participant who said:

> *"I have been the happiest person. …I accepted my diagnosis"* (Participant 3).

Being free from stress and accepting one's diagnosis was not the only definition of well-being among the participants. Three participants described happiness as financial security. Financial security is a vital factor of well-being and happiness for employed as well as for unemployed women. Financial security and employment were believed to satisfy personal needs and the family's needs. Furthermore, receiving financial support from a partner was an important part of a stress-free life and a happy relationship. A participant described well-being as financial security, which results in the family being happy. She said:

> *If I am working it means I can help my family and my kids, so if they are happy I will feel happy as well, if I am not doing anything I will feel worse. ... But I do not stress too much because I have his [partner's] support.* (Participant 8).

Financial support was also an essential part of a happy relationship for another participant who said:

> *"Like to be in good relationship, to be always happy in my relationship … I am having some challenges in my relationship, financially, and all this stuff*" (Participant 6).

Participants believed that financial difficulties put some strain on their relationship. Having a good relationship with one's partner who would financially contribute to the family was the definition of happiness.

For another participant, financial security was believed to bring a sense of freedom in life choices and relief from shame and stigma. A stable job with a good income could help a woman to maintain a good quality of life, feel independent from others and improve well-being outcomes. She described her happiness as follows:

> *I will be happy. … If I will have a stable job, to pay me well. So, I can be able to maintain my ... needs. …If I just can [sic] finish my studies and just live well, comfortable, so I won't even care about anyone's comments or anyone's feelings and opinions. … I will be able to maintain my lifestyle and just live however I want to live … without feeling any shame or stigma around me, I won't even care (*Participant 1).

Findings showed that two women shared the same meaning of well-being and identified it as stress free life while other three described well-being as financial security. Accepting ones HIV-positive diagnosis was also described as happiness for two participants. Evidence showed five women identified well-being as physical health, while four women stated well-being as happiness, and one woman identified with both physical health and happiness as well-being.

Summary

This chapter presented the key findings and four superordinate themes that emerged during the data analysis process. Superordinate themes were composed of themes and subthemes separately presented and reported. The findings of this study identified reasons and predictors of HIV-positive status disclosure/non-disclosure. Disclosure of HIV-positive status to family members or an HIV-positive person was motivated by the hope that these people would provide adequate support and keep the woman's status confidential. Women who wanted to protect their partner's health and maintain honesty in the relationship disclosed their status. Disclosure to a partner was also believed to help the pregnant woman engage in HIV care and freely take her medications. Hiding one's status could negatively impact the child and the mothers' health. Despite a fear of negative outcomes, women disclosed their status to family members or a partner.

Positive outcomes of disclosure were the expressive and instrumental support provided by family, a partner and friends. Negative outcomes were related to a partner's HIV-negative status, as well as a partner's avoidant behaviour to get tested for HIV and engage in open discussion about the virus. A barrier to disclosure was the fear that others would not keep the woman's diagnosis secret, which could lead to involuntary disclosure and judgement. Women who felt that stigma was high in their family or community reported a fear of taking medications or engaging in HIV care. The stigma was based on a lack of information and education about the nature of HIV. Women who have not visited their families and were not emotionally ready to disclose also reported those reasons as barriers to disclosure. Furthermore, findings of this study identified subjective meaning ascribed to well-being by HIV-positive pregnant women. Physical well-being was related to healthy habits and medical screenings for health conditions. Happiness was related to accepting the HIV-positive diagnosis, living a stress-free life, and having financial support and freedom.

Chapter 5: Discussion and Interpretation of Research Findings

This chapter will discuss and interpret the findings of this research study. Each superordinate theme will be discussed separately in order to link them with the existing literature and compare similarities and differences. The superordinate themes to be discussed are:

- Disclosure
- Non-disclosure
- Effect of Well-being after Disclosure/non-disclosure
- Well-being Definition

Disclosure

This superordinate theme combined the reasons for disclosure and expectations before disclosure. This superordinate theme is linked to the research questions, what factors influence the decision to disclose/not disclose one's HIV-positive status to others, and to consequence theory (Serovich et al., 2008). Findings showed that the motivation to disclose was connected with the need to obtain support, get help in case of a medical emergency, and protect one's health and the health of one's partner. Expectations before disclosure address the theoretical framework of consequence theory to help understand why some women disclose their status and others do not (Serovich et al., 2008).

In the limited period of time from diagnosis until the birth of the child, black HIV-positive pregnant women faced an important decision whether or not to disclose their HIV-positive status. Nine participants in this study reported disclosing their status to a male partner. The reasons for disclosure were honesty and to allow the partner to make informed health decisions based on the woman's HIV-positive status, and in addition to promote safe behaviour between the couple, such as engaging in safe sex and using protection. Women who were unaware of their partner’s HIV status disclosed their own status in order to motivate their partner to get tested. This would also help both parties take preventative measures and engage in proper HIV treatment. Common patterns were found in other research where disclosure to male partners was most common among HIV-positive women (Brown et al., 2019; Knettel et al., 2019; Maeri et al., 2016; Naigino et al., 2017). These researchers found that reasons for HIV-positive status disclosure were to maintain honesty in the relationship, to protect one’s partner, to encourage the partner to get tested and to increase care-seeking behaviour (Damian et al., 2019; Kotzé et al., 2013; Oshosen et al., 2021). These findings are similar to this study’s findings regarding why women tended to disclose to their male partners.

As found in other literature, black HIV-positive pregnant women in this study who were motivated to engage in ART for the protection of their health and the health of their unborn child decided in favour of disclosure (Mkandawire et al., 2022; Omonaiye et al., 2020; Psaros et al., 2020; Ramlagan et al., 2018). Hiding their status and medication regime from a partner could lead to missed medication adherence, thereby increasing the chance of mother-to-child transmission. The disclosure was motivated by the desire to protect the unborn child’s health (Lytvyn et al., 2017; Mkandawire et al., 2022). The women in this study believed that hiding medication would lead to involuntary disclosure and cause negative reactions, such as anger, from the partner. To avoid the extra stress of involuntary disclosure and hiding one’s status, women decided to disclose their status to family members and partner from whom they would not be able to hide their medications. The decision to disclose an HIV-positive status can be motivated by personal reasons as well as counselling services, which encourage patients to disclose their HIV-positive so that they can regularly visit the clinic and effectively engage in ART (Brittain et al., 2019a; Hampanda et al., 2020; Ramlagan et al., 2018).

Disclosure can be a challenging decision, and not every woman feels safe disclosing their status (Maeri et al., 2016; Watt et al., 2018). Predictors of HIV-positive status disclosure/non-disclosure is explained by consequence theory (Serovich, 2001). Consequence theory argues that HIV-positive women only disclose their status if the reward outweighs the cost. If disclosure would be followed by negative outcomes such as avoidance, separation, stigmatisation and abandonment, then women are less likely to disclose their status (Qiao et al., 2013). This theory was not supported by the participants in this study, as women disclosed their status despite their concerns about possible negative reactions.

In this study, the common expectations before disclosure were fear of separation, divorce, disharmony in the relationship, and abandonment by their partner. Black HIV-positive pregnant women also feared being blamed for bringing the infection into the home and being accused of infidelity. Despite those fears, the women disclosed their status to their partners. Possible explanations for disclosure among these women have been suggested by other studies. A woman’s decision to disclose is directly linked to her perceptions of the potential outcomes (Brittain et al., 2018; Geubbels et al., 2018; Hill et al., 2015; Watt et al., 2018). Potential outcomes for women from this study could be honesty, and stress relief through not having to hide their medications and status from their partner. The fear of separation and blame did not outweigh the urge to protect one’s health, and the health of the partner, to engage in proper HIV health care, and PMTCT.

Previous research documented patterns and predictors of HIV-positive status disclosure to a partner. Findings showed that women with higher education and a good income were more likely to disclose their status to their partner (Brittain et al., 2018). Women who were dependent on their partners were less likely to disclose as they feared the possibility of losing economic support from their partner (Hallberg et al., 2019; Kinuthia et al., 2018; Ngonzi et al., 2019). However, the findings of this study do not support the findings in the literature. Women from this study disclosed their status to their partner regardless of their education level or financial status. None of the women reported the fear of losing financial support from their partner. This could be related to the fact that most of the participants were employed and somewhat financially independent (see Figure 3). Furthermore, previous research documented that women who were married and had a strong, positive relationship with their husbands were more likely to disclose their HIV-positive status (Brittain et al., 2018; Knettel et al., 2019; Mosisa et al., 2022; Ramlagan et al., 2018). As shown in Figure 2, only two participants were married, relationship status was not a factor in making the decision whether or not to disclose a status among the participants of this study.

Consequence theory (Serovich, 2001) was, however, partially supported in this study regarding disclosure to close family members and HIV-positive persons in order to obtain support. Only four women reported concerns before disclosure to female family members. These concerns were related to upsetting the person and receiving negative reactions. Despite these concerns, they did disclose their status. This can be explained by the close and trusted relationship between the family members. Women reported that female family members were the ones they trusted to keep their diagnosis secret and to provide support and understanding during stressful times.

Receiving an HIV-positive diagnosis is a traumatic event and can increase the risk of psychological distress (Brittain et al., 2019b; Kotzé et al., 2013; Qin et al., 2019; Tenkorang et al., 2020). Black HIV-positive pregnant women in this study believed that disclosure to a close and trusted person could positively affect their physical and mental health and help them better to adjust to their diagnosis. As found by other research HIV-positive people intentionally disclose their status to chosen people to receive support and minimise the negative outcomes (Hlongwane & Madiba, 2020). As described by study participants, this journey is hard to walk alone. They needed motivation and encouragement from people close to them and who were aware of their health condition. In this way, they were sure that there would always be someone who knew their status in case of a medical emergency and would support them to stay positive during the hard times. Other research has made similar findings that women disclose their HIV-positive status to family members so that they can inform medical stuff about their health condition should there be a medical emergency (Madiba et al., 2021). In this study eight women voluntarily disclosed their status to female family members, such as a mother or a sister. Two out of the eight participants also reported disclosing to a male family member. Female family members are seen as those who can be most trusted and who can provide adequate support; these findings are supported by previous research (Geubbels et al., 2018; Knettel et al., 2019; Madiba et al., 2021; Ramlagan et al., 2018).

Black HIV-positive pregnant women in this study who sought emotional and informational support, disclosed their status to female family members and friends who were also HIV-positive. An HIV-positive friend or family member was seen as someone who could relate to their diagnosis and provide advice from their own personal experience. For some participants, sharing their status with an HIV-positive person was also viewed as a shared secret. Literature showed that women who seek advice and solidarity might choose to disclose their status to someone whom they know is HIV-positive (Watt et al., 2018). In this way women can get emotional support and advice from a person who has experienced what they are going through and is more likely to keep her status confidential (Prati et al., 2016; Watt et al., 2018). A study conducted in South Africa showed that disclosure of positive status to an HIV-positive friend becomes a shared secret and strengthens the bond of the friendship (Steenberg, 2020).

This section discussed the reasons for disclosure and addressed consequence theory (Serovich, 2001) to understand what prompts the decision to disclose. Reasons for disclosure to a partner were motivated by a need to maintain honesty in the relationship and protect the partner from infection. The disclosure was also motivated by the need to engage in proper HIV care to promote healthy outcomes. The findings of this study did not support consequence theory concerning disclosure to a partner. Despite the fear of adverse reactions, women disclosed their status to their partner. Close and trusted relationships were a predictor and a reason for disclosure to close family members. The HIV-positive status of a family member or friend was also a reason for disclosure and to get informational support and solidarity.

Non-disclosure

This section continues addressing the research question, what factors influence the decision to disclose/not disclose one's HIV-positive status to others? This superordinate theme focuses on factors that influence the decision regarding the non-disclosure of HIV-positive status. Some participants reported personal reasons for non-disclosure, such as being far away from family and not being emotionally ready to disclose. Other participants reported that their decision for non-disclosure was influenced by the community's and society's perceptions regarding HIV-positive status. Common reasons given for non-disclosure were fear of judgement, rumour mongering, and stigmatisation, which supports consequence theory (Serovich, 2001).

Societal perceptions of an HIV-positive status among the community played a significant role in the decision of HIV-positive status non-disclosure in this study. Findings showed that HIV has a negative association among communities. The most common reason for non-disclosure given by participants referred to a fear of judgement. Black HIV-positive pregnant women stated that society believes that HIV is only spread by sleeping around or having many sexual partners. Women found this prejudice unfair. They reported that people would not understand that this virus could be present in long-term relationships where they have been faithful to their partner. Their HIV-positive status would automatically make people assume that a woman was careless of her health by engaging in irresponsible sexual behaviour. Similar associations were found by other researchers stating that HIV/AIDS is stigmatised because It is often associated with prostitution and drug use, where the infected person is blamed for not looking after their health and allowing themselves to become infected (Cuca & Rose, 2016). A study conducted in Cape Town, South

Africa, found that people believe HIV/AIDS is a punishment for having many sexual partners, and HIV-positive people have only themselves to blame for being infected (Machemedze, 2023). HIV-positive people are often judged by society as being socially immoral, such as by being blamed for engaging in risky sexual behaviour and spreading the virus. Women often refuse to share their diagnosis with close family members because, in the eyes of their family, they might be perceived as prostitutes (Doat et al., 2021)**.** Women in this study who were dealing with pregnancy and HIV-positive status diagnosis selectively chose people who were less likely to give an adverse reaction to the disclosure.

Having a sexual relationship and falling pregnant outside of marriage was also seen as going against cultural expectations and religious rules, according to one participant in this study. Society has its own expectations of how a person should lead a ‘good’ life. Going against those rules can lead to negative perceptions of HIV-positive women. In cultures where pre-marital sexual intercourse is prohibited, falling pregnant outside of marriage and contracting HIV can contribute to double stigmatisation (Gurmu & Etana, 2015).

Even though none of the black HIV-positive pregnant women in this study directly experienced discrimination from others, they were aware of the meaning their community ascribed to HIV-positive status which led to an internalisation of the stigma. Internal stigma accrues when an HIV-positive person applies the negative associations and stereotypes of an HIV-positive status to themselves (Pantelic et al., 2015). Internalised stigma has often been associated with shame and guilt, as a barrier for HIV-positive status disclosure and treatment engagement (Darlington & Hutson, 2017; Katz et al., 2013; Tsai et al., 2013). Internalised stigma also has a negative effect on psychological well-being (Brener et al., 2020).

Black HIV-positive pregnant women in this study believed that an HIV-positive status makes a good topic for gossip and rumour. To avoid being negatively discussed and gossiped about, they decided to keep their status secret from people they do not trust. They believed that not everyone could keep their status secret, and it would quickly spread among family, friends, workplace and the community. This fear was especially common among the women who believed HIV is highly stigmatised by their family, friends and community. Research conducted in collectivist societies found that social connections may inhibit a woman from disclosing her status due to the potential for stigmatisation, community abandonment, or community isolation (Knettel et al., 2019; Marais et al., 2019; Walcott et al., 2013; Ojikutu et al., 2016). In communities where HIV is still stigmatised, HIV-positive pregnant women are the topic of gossip. Women are very mindful when sharing an HIV-positive diagnosis with others. The selection of the person to whom they will disclose their status relies on that person being trustworthy and that the person can keep their HIV-positive diagnosis secret (Madiba et al., 2021). Trusting sensitive information to the wrong person might lead to the spread of this news within the community, further leading to gossip and discrimination (Camlin et al., 2020; Doat et al., 2021). People create rumours about how one got infected, further spreading false information among others, which tarnishes an HIV-positive person’s reputation (Akatukwasai et al., 2021; Duby et al., 2020; Madiba et al., 2021). In line with previous research conducted in South Africa, the findings of this study have shown that non-disclosure of HIV-positive status is associated with a fear of gossip and rumour mongering (Duby et al., 2020; Madiba et al., 2021; Steenberg, 2020).

Another assumption that HIV-positive status has within the community is that HIV is a death sentence. This has contributed to the stigmatisation of HIV-positive people and played a role in the decision not to disclose by some women in this study. Having family or community members who passed away from this virus made people fear it and that it would lead to an early death. Similar findings were reported by other research where HIV itself was not as stigmatised as taking medication for HIV. Antiretroviral therapy was associated with the late stages of AIDS and death (Zuch & Lurie, 2012). This could explain why some participants did not want their family or friends to find out about their medication. Discovered medication adherence would lead to involuntary HIV-positive status disclosure and, as a result, stigmatisation. A study conducted in South Africa found that there is still a misconception that HIV is a death sentence (Steenberg, 2020). This misconception is based on a lack of proper information regarding effective ARV treatment. Furthermore, the unsubstantiated fears that people have regarding possible infection of HIV from everyday items and general interaction makes them less likely to willingly engage with HIV-positive people. Fear of premature death is often experienced by HIV-positive people after receiving their test result. This leaves them feeling depressed with the possibility that they may not have enough time accomplish their life goals (Steenberg, 2020).

Black HIV-positive pregnant women in this study believed the biggest contribution to stigma and discrimination is a lack of education about HIV. Information as to the nature of this virus is still low among some communities, and there is a lack of education as to how HIV is transmitted. Negative connotations are based on a lack of information and awareness. This has led to the judgement and stigmatisation of HIV-positive women. Research has shown that proper information and education about HIV/AIDS decreases stigmatisation (Gurmu & Etana, 2015). Socio-cultural context should be taken into consideration when addressing awareness of the stigma among the community. Increased awareness about this virus can help reduce discrimination of HIV-positive people (Darlington & Hutson, 2017) .

Fear of stigma, discrimination and rumour mongering were not the only reported reasons for non-disclosure in this study. Personal reasons for non-disclosure were distance as well as not being emotionally ready to disclose. Some Black HIV-positive pregnant participants were not able to visit their home town after diagnosis, and they reported that disclosure is not a topic for a phone conversation but rather an issue that requires face-to-face discussion. Finding the right place, time and words to reveal their diagnosis to family members were important aspects of the planned disclosure. Participants reported distance from family as a barrier to disclosure, and they also noted they did not have enough courage for disclosure and preferred to keep their status to themselves. Only after visiting their family would, they make a final decision regarding disclosure.

Black HIV-positive pregnant women needed more time before making the final decision. They preferred to delay disclosure before visiting their families. The time before visiting family can be seen as an adjustment period during which they can come to terms with the diagnosis. Similar findings were documented by research conducted shortly after HIV-positive diagnosis and during the prenatal examination. These studies found that some women needed more time to disclose their status. Non-disclosure of status is due to not being emotionally ready, not being brave enough and needing more time to come to terms with the positive diagnosis (Abuogi et al., 2020; Ramlagan et al., 2018; Watt et al., 2018). It should be noted that the findings of this study regarding physical distance as a barrier to disclosure have not been linked to other literature.

A significant factor in the non-disclosure decision among participants in this study was the fear of judgement, stigmatisation and discrimination. Stigma within the community led women to believe that others would react negatively to their diagnosis leading to internalised stigma (Brener et al., 2020). Stigma can negatively affect a woman’s psychological well-being and can be a predictor of poor health outcomes (Parcesepe et al., 2018; Rasoolinajad et al., 2018; Rendina et al., 2019).

Effect on Well-being after Disclosure/Non-disclosure of HIV-Positive Status

This superordinate theme is linked to the research question, how does an HIV-positive status disclosure/non-disclosure affect well-being, and what factors result positive and negative outcomes after HIV-positive status disclosure/non-disclosure? Furthermore, this superordinate theme is aligned with social support theory (Cullen, 1994). It was believed that social support theory would facilitate an understanding of well-being outcomes after disclosure/non-disclosure in HIV-positive pregnant women. Social support theory argues that supportive societies and interpersonal relationships lead to improved well-being (Lin et al., 1986). It is argued that social support can lessen the stress and anxiety related to HIV diagnosis and lead to enhanced psychological and physical well-being (West et al., 2019; Xiaowen et al., 2018). Serovich (2008) believed that an important reward of disclosure in HIV-positive women is social support, which could lead to positive well-being. Taking Serovich’s idea into consideration, disclosure could lead to positive outcomes if it is followed by social support. Theories and research suggest that people from collectivist cultures are more likely to value and benefit from social support during stressful times (Diener et al., 1995; Tay & Diener, 2011).

Black HIV-positive pregnant women in the current study who initially disclosed their status to obtain support predicted an outcome which would positively affect their well-being. The findings in this study showed that disclosure followed by support, had a positive effect on the physical and mental well-being of the participants. The two most common types of support received after HIV-positive status disclosure were instrumental support and expressive support. Support provided by family members and partners promoted ARV adherence and contributed to physical well-being. Family members and partners played an active role in reminding women to take their medication on time. Some women reported that female family members offered transportation, physical assistance during the check-ups and financial support to buy material goods. It has been argued that instrumental or expressive support, can minimise stress and anxiety associated with HIV-positive status and acts as buffer against negative mental health outcomes (Brittain et al., 2017; Cederbaum et al., 2017; Mi et al., 2020). Literature, thus, supports the findings of this research study and emphasises the importance of support obtained after disclosure.

A support network helped the black HIV-positive pregnant women accept their diagnosis. Ensuring women that they are not the only ones with this virus and that they will live a long and healthy life by engaging in HIV care was the biggest factor against anxiety caused by the diagnosis. A partner who recognised the woman’s emotional state and supported her feelings helped her cope better with the diagnosis. Staying emotionally strong together and engaging in open dialogue about the HIV-positive diagnosis influenced better mental and physical well-being. Mental well-being was related to HIV-positive status acceptance and reduced stress. Disclosure relieved the stress of unintentional disclosure and made women feel comfortable taking medication in front of people to whom they are close. Other authors have stated that keeping one’s status secret adds unnecessary stress for the woman, and in order to relieve this stress, the woman makes a decision in favour of disclosure (Kisigo et al., 2020; Rich et al., 2022; Watt et al., 2018). Women who disclose their status can be open about their needs to engage in HIV treatment and get emotional support (Hampanda et al., 2020; Mi et al., 2020; Omonaiye et al., 2020; Oshosen et al., 2021).

Black HIV-positive pregnant women who felt that they needed more informational support from someone who could relate to their situation disclosed their status to HIV-positive friends or family members. HIV-positive status disclosure to HIV-positive persons should be taken into consideration to promote well-being outcomes. The findings indicate that women benefit from disclosure to an HIV-positive person who can provide adequate emotional and informational support. A study conducted in England among black HIV-positive pregnant women showed that peer support from HIV-positive mentor mothers had a positive influence on the women’s emotional and physical well-being (McLeish & Redshaw, 2016). Specially trained volunteer mothers helped women to obtain necessary information in order to promote healthy outcomes and PMTCT (McLeish & Redshaw, 2016). Informational support was as important as emotional and practical support for the women in this study.

Proper informational and emotional support could also benefit couples in serodiscordant relationship. Serodiscordant couple is a couple where one person has tested HIV-negative and the other has tested HIV-positive (Muessig & Cohen, 2014). Having a partner test for HIV and being found negative was reported as the most stressful and emotionally hard part of the relationship by two participants. Being diagnosed HIV-positive is already a stressful situation, and the partner receiving a HIV-negative test results was an additional burden for women. Women in serodiscordant relationships reported a fear of being blamed for bringing the infection into the home, which could lead to separation.

Studies have shown that in South Africa, 51% of couples are in a serodiscordant relationship. This raises the risk of HIV transmission and puts a strain on the relationship (Mashaphu & Burns, 2017). Women in a serodiscordant relationship might benefit from special couples counselling. A study conducted in South Africa among serodiscordant couples indicated that support for these couples is critical for a better quality of life and treatment outcomes (Lelaka et al., 2022). Furthermore, the unique needs of serodiscordant couples are not addressed in treatment programmes. It is believed that these couples would benefit from a client-oriented interaction which will address their unique needs.

An unfavourable outcome of disclosure was related to a partner's unknown HIV status, avoidance behaviour and unmet expectations regarding emotional support. Inadequate support was related to a partner's avoidance of being tested or engaging in an open discussion about the HIV-positive diagnosis. Not receiving negative reactions such as anger and separation did not automatically lead to positive outcomes, however avoidance of getting tested and engaging in an honest and open discussion about HIV-positive status was seen as unsupportive behaviour from a partner. Black HIV-positive pregnant women reported their partners only being involved in the pregnancy but not showing interest in their HIV treatment. An overly calm reaction and avoidance made women question if their partner already knew about his positive diagnosis. Not taking the woman's feelings seriously made the woman feel that they are not being supported by their partner. Previous research has shown that inadequate support received from a partner could be a reason for negative well-being outcomes (Knettel et al., 2017; Peltzer et al., 2018; Tuthill et al., 2021).

The findings of this study revealed that a partner getting tested for HIV-positive status and emotionally engaging in an open discussion about their HIV-positive status were the best support reported by five black HIV-positive pregnant women. Emotional and practical support provided by the partner helps women to cope with their HIV diagnosis, and motivates them to stay engaged in HIV treatment (Hampanda et al., 2020; Peltzer et al., 2016; Watt et al., 2018)**,** and to further disclose her status to others (Ramlagan et al., 2018). Findings of this study supported social support theory (Cullen, 1994; Lin et al., 1986) and showed that women benefit from disclosure when it is followed by adequate support from their partners.

Negative outcomes after non-disclosure were also identified among the participants. Negative factors of collectivism should be considered when exploring the reasons for non-disclosure of HIV-positive status, social stigma and well-being (Brittain et al., 2017; Diener et al., 1995; Veenhoven, 1999). Women in this study who stated that stigma around their community and family was high reported non-disclosure of HIV-positive status. Black HIV-positive pregnant women in this study who did not disclose their status to family and friends reported avoidance of family visits and social outings fearing that someone would see them taking their medication. They were anxious that regular clinical attendance and medication adherence would cause suspicion among colleagues, friends and family. In order to freely take medications, women preferred to avoid situations where they would not be able to take medications freely and on time.

Giving a child medication and taking medication after birth also caused anticipated anxiety in women who did not disclose their status. According to studies, women fearful of stigmatisation might prefer to keep their diagnosis secret and withdraw from their social circle (Brener et al., 2020; Cuca & Rose, 2016; Lingen et al., 2016; Yeji et al., 2014). Considering that the family is a primary source of support for most pregnant women, stigma within the family can be a determinant of well-being outcomes and disclosure decisions (Hill et al., 2015; Mi et al., 2020). Keeping an HIV-positive status secret can be a stressful factor in the pregnant woman's life; however, disclosure also carries the possibility of discrimination and stigmatisation from others. Exclusion from society can be more harmful than keeping an HIV-positive status in secret. Loss of once community in collectivist cultures is similar to losing one's own identity (Wilson, 2020).

This study identified the in majority of cases disclosure to a partner was made safely and without negative reactions. This could be related to the fact that these women were less likely to experience adverse events such as Intimate partner violence, because they knew it was unlikely that their partner would react with violence, and they would be more likely to obtain support (Kennedy et al., 2015). Furthermore, women who successfully disclosed their status were more inclined to participate in this study. There is no clear cut method for safe disclosure, and the unique circumstances of each woman should be taken into consideration, such as the couple's relationship and the woman's preference as to where and how to disclose her status (Walcott et al., 2013). What can be beneficial for one woman could be inappropriate for another. The findings of this study showed that safe disclosure was related to a trusting relationship where the women were most likely to obtain support.

Well-being Definition

This superordinate theme is aligned with the research question, how is well-being defined by the research participant? Women ascribed their own meaning to well-being which included well-being as being physically healthy and as happiness; each will be discussed in this section. Six black HIV-positive pregnant women who identified well-being as being physically healthy stated that they wanted to be conscious of and take good care of their health. Physical well-being was identified as comprising a balanced diet and regular physical activity, regular check-ups for common health conditions, and monitoring viral load and vital signs. The reasons women identified well-being from a physical health perspective could be related to their different circumstances. The important factors of well-being differ depending on the individual, their environment and their particular life circumstances (Thin, 2018). Life factors that made women want to prioritise their health could be related to their pregnancy as well as HIV-positive status.

Black HIV-positive pregnant women who emphasised the importance of healthy habits could be related to doctors' recommendations and their own beliefs on improving better health outcomes for themselves and their child (Grenier et al., 2021). During pregnancy, physical activity and a healthy diet are recommended in order to decrease the chance of obesity which could negatively affect the mother's and child's health, and could lead to pregnancy complications. The definition of well-being as physical health and the motivation to disclose overlapped among some participants in this study. Participants who believed that healthy behaviour directly affects their health and the health of their child emphasised the importance of using protection and taking their medications daily. Engaging in proper HIV treatment could be related to the desire of women to give birth to an HIV-negative child, protect their partner from infection and not allow the virus to progress to AIDS (Lytvyn et al., 2017; Young et al., 2014).

Black HIV-positive pregnant women in this study stated that it is important to increase disease awareness by being screened for common health conditions. Health check-ups are an important part of early disease detection and increase the chances of effective treatment (Labeit et al., 2013). The relationship between physical health and well-being is interrelated and influences one upon the other (Howell et al., 2007; Diener et al., 2017). Good physical health promotes well-being outcomes and vice versa (Park et al., 2016). Life satisfaction, positive emotions, and life purpose have been associated with good health. A negative state of mind and stress had a negative impact on physical health (Diener et al., 2017). Physical health can promote better mental health outcomes and help women adjust to life stressors.

Another definition that participants ascribed to well-being were happiness. For five participants, happiness was associated with a stress-free life, acceptance of HIV-positive diagnosis, and financial security. Financial security was an important factor of well-being and happiness for employed and unemployed women. Financial security and employment can satisfy personal needs and the family’s needs. In this study financial security was believed to bring a sense of freedom in life choices and relief from shame and stigma. Having a stable job with a good income could help women to maintain a good quality of life, continue their education feel independent from others and improve their well-being outcomes.

It has been stated that material well-being is interrelated with personal freedom, and this has a positive effect on well-being (Grønlie & Dageid, 2017). Material well-being gives a person freedom of action, health care benefits, education and the ability for self-development (Diener et al., 1995; Maslow, 1954). For one participant in this study, financial support provided by her partner reduced the stress of unemployment, while for another a financially unsupportive partner increased the worry and put a strain on the relationship. Financial support from a husband or partner would have a positive impact on woman's happiness and well-being. These findings indicate that financial security provided by the woman or her partner would contribute to their happiness leading to a stress-free life and improved well-being.

A further definition ascribed to happiness was a positive psychological adjustment to an HIV-positive status. Accepting one's diagnosis was reported as a definition of happiness therefore contributing to well-being outcomes. Research has found that HIV-positive status acceptance improves emotional well-being (Liamputtong et al., 2012) and reduces HIV-related stigma (Oppong Asante, 2012). Acceptance of one's illness reduces psychological distress caused by an HIV-positive diagnosis (Ogueji, 2021).

Summary

This chapter discussed the main findings of this study. Each superordinate theme was discussed separately and linked to the existing literature to draw similarities and differences. The consequence theory (Serovich, 2001) was only partially supported in relation to disclosure to family members and was not supported in the case of disclosure to a partner. However, consequence theory was fully supported in relation to non-disclosure. Social support theory (Cullen, 1994), in combination with literature, showed that expressive and instrumental support could be beneficial for an HIV-positive pregnant woman's well-being. Support that met the black HIV-positive pregnant women's expectations, and satisfied their needs, was reported as appropriate support.

The effects of non-disclosure on well-being are that the women felt increased levels of anxiety due to the possibility of involuntary disclosure. Following a medication regime and regular clinical visits could expose their HIV-positive status to others. Fear of involuntary disclosure was based on communities’ negative perceptions about HIV-positive women. Furthermore, this chapter discussed the subjective meaning women ascribed to well-being. Some women identified well-being as physical health, while others stated that well-being is happiness. Definition of well-being overlapped with the reasons for disclosure. Women who felt that disclosure would benefit their health, the health of the child, and their partner reported disclosing their status.

Chapter 6: Conclusion

This study determined the importance of social support in the life of newly diagnosed HIV-positive pregnant African women. Disclosure of an HIV-positive status was made when it could be of benefit to the pregnant woman's health and her partner's health. As a means of coping with the adverse emotions caused by the HIV-positive diagnosis women disclosed their status to family members to obtain emotional support. Disclosure to an HIV-positive person was motivated by the potential benefit of informational support. Appropriate support was reported as support that met the woman's expectations and needs. An unfavourable outcome of disclosure was avoidance behaviour by the partner and the woman's unmet expectations regarding emotional support. This study showed that a partner who was willing to be tested for HIV would help the HIV-positive woman cope better with her own status.

Stigma within the community and the family had a significant impact on a woman's well-being and acted as a barrier to disclosure. Geographical distance from family members was another reason for non-disclosure, but this can be viewed as delayed disclosure. The research question, how is well-being defined by the research participant, is addressed subjectively by the participants. It can be seen that physical, emotional, and financial well-being are important to HIV-positive pregnant women, and a strong support network helps them to bear the weight of an HIV-positive status.

Limitations

Context and Settings

As the recruitment of participants was facilitated through the RMMCH, this study does not and cannot capture the experience of women who visit other healthcare facilities. Furthermore, the context and setting must be taken into consideration. Qualitative research is conducted in settings where participants experience the phenomenon (Creswell & Poth, 2018). We cannot separate participants' answers from the place where they said it. Conducting research in other settings outside of the hospital might influence on respondents' responses, leading to different results.

Participant Criteria

Other limitations of this study that need to be addressed are the participant's age, and disclosure patterns. This study tended to invite women from the age category of 20 to 40 years. However, women in their early 20's did not participate in this study. As such, this study only captured the experiences of women aged 26 to 40 years. One of the reasons for this could be that they are not emotionally ready to speak about their HIV-positive status diagnosis (Abuogi et al., 2020; Ramlagan et al., 2018; Watt et al., 2018).

From the beginning of the research study, I had the assumption that women who did not disclose their status were less likely to participate in this study. All the women who participated in this study disclosed their HIV-positive status to at least one person. As such, this study did not capture the experiences of women, who did not disclose their status to anyone. Those women might need more time to come to terms with their positive diagnosis (Abuogi et al., 2020; Ramlagan et al., 2018; Watt et al., 2018).

Language

My sample size comprised of black women whose home language was not English. Considering language influences, language could influence how the meanings were constructed by research participants (van Nes et al., 2010). Fortunately, all participants were fluent in English and were able to give rich and detailed information about their experiences. Language did not limit their ability to describe and communicate their experiences of HIV-positive status diagnosis.

Study Strengths

This study had a number of strengths. As reported by Stats SA (Stats SA, 2022), HIV prevalence in South Africa is highest among women of reproductive age, this research sheds light on how these women experience an HIV-positive diagnosis and what challenges they face after the diagnosis. Employing a qualitative research approach led to an in-depth exploration of the cost and reward outcomes of disclosure. I believe that understanding those issues could make a meaningful contribution to literature. Findings of this study showed that HIV-positive status is still stigmatised among people. HIV-positive status is a sensitive topic, and not every woman feels safe speaking about it. I believe that face-to-face interviews helped me to develop rapport with participants and explore their unique experiences. Furthermore, semi-structured interviews helped to address important questions and did not limit the possibility of unexpected themes arising. New themes made a meaningful contribution to this research study.

Recommendations

Further research is needed to identify what constitutes and contributes to the “safe disclosure” of an HIV-positive statuses. Research around safe disclosure have identified that there is no straightforward method for safe disclosure. The unique circumstances of each woman should be considered, such as the couple’s relationship and the woman’s preference as to where and how to disclose her status (Kennedy et al., 2015; Walcott et al., 2013). Qualitative research is needed to capture women’s unique experiences and preferences for safe disclosure. This can help counsellors to promote safe disclosure to improve well-being outcomes. This study identified that well-being was defined by black HIV-positive pregnant women as physical health and happiness, future research should investigate how disclosure/non-disclosure can have an effect on happiness and physical health.

The findings of this study and study conducted in South Africa among serodiscordant couples, indicate that support for these couples is critical for a better quality of life and treatment outcomes (Lelaka et al., 2022). More research is needed among South African serodiscordant couples. This could help to gain insight into the experiences and challenges these couples might face. This can further help to develop client-oriented interaction which could address their unique needs. This study only captured the experiences of women from age 26-40. Future research should investigate the experiences of younger and older women who are HIV-positive. Comparisons could help to draw differences and similarities between the age groups.

When addressing an HIV-positive pregnant woman’s depression and anxiety, HIV-related stigma, as well as internalised stigma, should be taken into consideration to effectively target psychological distress (Knettel et al., 2020). More research is needed to investigate how internal stigma affects women’s physical and mental health outcomes. Connections between social support and stigma should be given more attention. It has been stated that social support could have the effect of diminished positive well-being when HIV-related stigma is high in society (Liamputtong, 2013). Quantitative researchers should investigate the links between social support and stigma concerning well-being outcomes. Internalised stigma should be given attention in counselling services to help women better adjust to their diagnosis and improve their physical and psychological well-being.

Researcher’s Personal Reflection

Supervisor

I had the chance to meet with my supervisor a few times during the research process. During these meetings, I had the opportunity to discuss different issues and aspects of my research. At our first meeting, we discussed how I could choose the appropriate research approach. After giving me practical advice regarding what literature to read, I was able to determine that interpretative phenomenological analysis methodology with the qualitative approach was the best fit for my research. The first draft I sent to my supervisor consisted of research questions, aims, objectives and approach. On drafts, she gave me feedback which made me critically evaluate my work and make changes where necessary. Being guided by a supervisor who is an experienced researcher greatly assisted the development of my research skills and abilities.

The Research Process

Before embarking on this research, I had had very little interaction with HIV-positive people. By engaging in this research, I was given some insight into the world of HIV-positive African women. As can be seen from this research HIV-positive pregnant women have more challenges to overcome in order to live a happy and healthy life. What this study has shown me is that a close family connection can provide a solid support network to help these women overcome life’s difficulties, and that honesty in a relationship is invaluable.

Research Challenges

The first major obstacle to overcome before conducting fieldwork was to be granted approval by the various government and academic oversight bodies. The “gatekeepers” have stringent control systems to ensure ethical and legal compliance.

While it is understandable why these measures exist, they do create bureaucratic hurdles in gaining the required approval. However, having gone through this process, I understand how this process works and how to obtain the required approval.

My preconceived idea before conducting this research was that there would be challenges in finding willing participants to participate in this study. However, finding willing participants who fit within the study parameters, and who were willing to volunteer for this study, proved to be more challenging than I had expected. From my interactions with potential participants, they informed me that due to the sensitive nature of the subject matter they were less likely to participate in a study.

Research Skills

A major facet of the interpretative phenomenological analysis methodology is that the researcher should allow the participant to tell their story without interruption or suggestion from the researcher. As such, this required me to develop my listening skills and allow the participants the freedom to tell their stories. The starting point for every researcher is to gather data; however, data without meaning has no value. The research process helped to refine my ability to extract information and meaning from the gathered data. This study required interaction between the participants and me through face-to-face interviews. The success of a research interview is assisted by a good rapport between the interviewee and the interviewer. The rapport developed with participants helped to create a more relaxed environment where the participant could feel calm and relaxed, and be free to tell their stories.

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Appendix 1

Participant Information Sheet

The Effect of Disclosure/Non-disclosure on the Well-Being of HIV-Positive Pregnant African Women in Gauteng Province, South Africa

Date ________________

Dear Prospective Participant

I am conducting my research under the supervision of Ms. Hester-Louise Henderson, a lecturer in the Department of Psychology, towards a MA degree at the University of South Africa. We are inviting you to participate in a study entitled The Effect of HIV-Positive Status Disclosure/Non-disclosure on the Well-being of HIV-Positive Pregnant African Women in Gauteng Province, South Africa.

What is the Purpose of The Study?

I am conducting this research in fulfilment of my Master's degree study at the University of South Africa. With this research I am exploring the experiences of HIV-positive pregnant women attending prenatal care facilities in South Africa, and the relationship between their HIV-positive status disclosure/non-disclosure and well-being.

Why are you Being Invited to Participate?

You have been invited to participate in this study as you meet the following conditions for the research study which are:

- The participant is pregnant.
- The participant has been diagnosed HIV-positive during their current pregnancy.

- The participant is attending Rahima Moosa Mother and Child Hospital Obstetrics/Gynaecology Department.
- The participant can communicate in English.

I have obtained permission to conduct my research at Rahima Moosa Mother and Child Hospital from the CEO of the hospital and from Head of Obstetrics/Gynaecology Department and from the Department of Paediatric and Child health.

I have asked the Obstetrics/Gynaecology Department doctors to inform potential participants about my research study. You were informed of the study by your doctor and you have shown interest in participating in the study. If you agree to participate you will be asked to give written permission to the doctor to allow them to pass your contact details on to me. When I have your contact details, I will contact you to discuss the research study and to arrange an interview. Doctors have been asked to engage approximately 15 patients who would potentially be interested in participating in the study.

What is the Nature of your Participation in this Study?

If you agree to participate in this research study you will be invited for a one-on-one interview with me, the researcher. The interview will be conducted in a dedicated room at Rahima Moosa Mother and Child Hospital, where your identity and the nature of the interview will remain private and confidential.

Before the interview we will read through the participant consent form, and if you have any questions, I will answer these questions. You will be asked to sign the consent form in order to proceed with the research interview. I will ask your permission to audio tape the interview. The interview is expected to last approximately an hour. The aim of the questions is to provide me with information about your experiences regarding the motives and barriers of HIV-positive status disclosure/non-disclosure and its effects on your well-being.

Examples of question you can expect to be asked:

- How would you define/describe well-being?
- What influenced your decision to disclose or not to disclose your HIV-positive status?
- What effect did disclosure/non-disclosure have on your well-being?

Can You Withdraw from this Study Even After you have Agreed to Participate?

Participation in this study is voluntary and you are under no obligation to consent to participate. If you do decide to take part you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason, there are no negative consequences if you decide to stop and withdraw from the interviews.

What are the Potential Benefits of Participating in this Study?

This research will not be of direct benefit to you. However, this research will contribute to the understanding of well-being as perceived by HIV-positive pregnant women in South Africa, and this information can be used by counsellors. Research findings will help counsellors to develop effective strategies for safe HIV-positive status disclosure by pregnant women, in a manner which will maximize well-being outcomes

The results of this study will help to direct efforts to issues which should be addressed with regards to HIV counselling in South Africa.

Are there any Negative Consequences for you if you Participate in the Research Project?

I am fully aware that speaking about personal experiences regarding HIV-positive status may be distressing or uncomfortable for some participants. To protect you from psychological distress during the interview you can tell me if you feel distressed in any way and I will stop the interview. After the interview has stopped you will be given the option to reschedule the interview, or to pause the interview, or to withdraw from the interview.

There will be no negative consequences for you if you want to withdraw from the study. If it is evident that you have experienced severe psychological/emotional distress as a consequence of the interview I will refer you to a counsellor for debriefing. Counselling services are available from: Ms Thakgalo Mohlala, ART Social worker at Empilweni Clinic (011 470 9421).

During the Covid-19 pandemic extra measures must be taken to protect you and I from infection. Before the interview I will make sure that I do not have any symptoms of Covid-19. Before each interview I will measure your and my temperature. All surfaces of the interview room will be sanitised before and after the interview. We will both wear a mask and face shield to minimise the risk of Covid-19 infection. I will provide both the mask and face shield for you to wear. During the interview process appropriate minimum distance will be maintained.

Will the Information that you Convey to the Researcher and your Identity be Kept Confidential?

To protect your identity and maintain anonymity your name will not be recorded and no one will be able to connect you to the answers you give. Instead of your name I will use a number or a pseudonym. To ensure quality of my findings an external coder and my supervisor will have access to your data. To maintain confidentiality before sharing your answers with the coder or the supervisor I will make sure to remove any information which can identify you. The external coder and supervisor will both be asked to sign a confidentiality form.

How will the Researcher Protect the Security of Data?

The following methods will be used to maintain the protection of processed information so that third parties do not have access to this information. Methods to protect data:

- The recordings of the interviews will be placed on a flash drive/memory stick. This data will be deleted immediately from the phone and tablet. The flash drive will be stored in a safe protected by a code.
- My PC will be password secured. The transcript and the participant's data will be encrypted with an encryption program. The file can only be viewed by input of the correct password.
- After 5 years when the information is no longer needed, the flash drive will be formatted, and the files stored on the computer will be electronically shredded, and any paper trail will be shredded.
- Persons involved in the co-coding and mini audit process will be subject to confidentiality requirements.

Will you Receive Payment or any Incentives for Participating in this Study?

Participating in this research study is on a voluntary basis and there is no payment involved for exchange of information.

Has the Study Received Ethics Approval?

This study has received written approval from the Research Ethics Review Committee of the University of South Africa, the Human Research Ethics Committee

(Medical) of the University of the Witwatersrand and the National Health Research Database.

How will you be Informed of the Findings/Results of the Research?

If you would like to be informed of the final research findings, please contact Tinatin Gvilia on 071 542 5894 or 64083519@mylife.unisa.ac.za

Should you have concerns about the way in which the research has been conducted, you may contact: Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

You are also free to contact the Department of Psychology (UNISA) on 012 429-8088. Alternatively contact: Professor MA Antwi Health Research Ethics Committee Chairperson at the University of South Africa: antwima@unisa.ac.za

Thank you for taking the time to read this information sheet.

Tinatin Gvilia

Appendix 2

Consent to Participate in this Study

The Effect of Disclosure/Non-disclosure on the Well-Being of HIV-Positive Pregnant African Women in Gauteng Province, South Africa

I, __________________ (participant name), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to participate in the study.

I understand that my participation is voluntary and that I am free to withdraw at any time without penalty.

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I have received a signed copy of the informed consent agreement.

Researcher’s signature ______________________ Date ____________________

Name of Participant: ____

Date: ____

Place:____

Signature or mark ____

Witnessed by:

Name of Witness: ____

Signature: ____

Date :____

Principal Investigator: Tinatin Gvilia. Telephone no 0715425894; E-mail: 64083519@mylife.unisa.ac.za

Supervisor: Hester-Louse Henderson. Telephone no 0124298214; E-mail hendeh@unisa.ac.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Department of Psychology (UNISA) on 012 429-8088. Alternatively contact: Professor MA Antwi

Health Research Ethics Committee Chairperson at the University of South Africa : E-mail antwima@unisa.ac.za

Appendix 3

Consent Form for Audio Recording

WITS UNIVERSITY

Project Title

The Effect of Disclosure/Non-disclosure on the Well-Being of HIV-Positive Pregnant African Women in Gauteng Province South Africa

I hereby consent to audio recording of the interview.

I understand that:

- The recording will be stored in a secure location (a locked in a safe protected by a code) with restricted access to the researcher.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research

- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: ____

Date: ____

Place: ____

Signature or mark ____

Witnessed by:

Name of Witness: ____

Signature: ____

Date: ____

Appendix 4

Interview Schedule

Well-being

- How would you define/describe well-being? /What do you understand by well-being? /How would you explain the term well-being?
- What factors do you associate with well-being?
- What effect has your positive status had on your well-being?

Disclosure/Non-disclosure

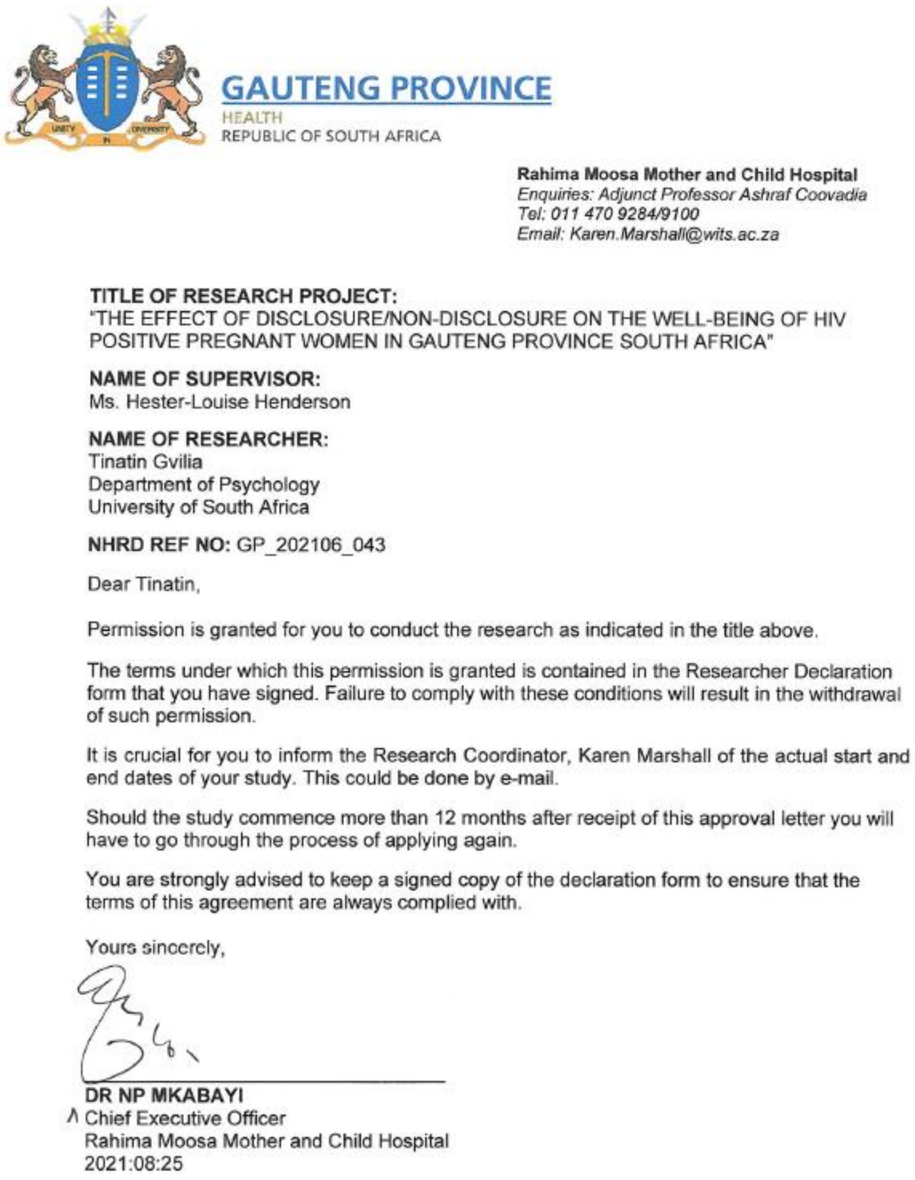
- What were your feelings when you found out you are HIV-positive?
- What influenced your decision to disclose or not to disclose your HIV-positive status?
- What factors affect the decision regarding to whom to disclose your status?
- Before disclosure was there an expectation as to the other person's reaction? What was the expectation?
- How do communal values influence your decision to disclose/not disclose?

Outcomes

- Tell me your experience of disclosure/non-disclosure?
- What was the reaction of the person to whom you disclosed your HIV-positive status?
- In what way did your expectations meet reality after disclosure/non-disclosure?
- Were the expectations of perceived support met with reality?
- What effect did disclosure/non-disclosure have on your well-being?
- How would you compare your description of well-being to your life?

Appendix 5

Permission to Conduct Research



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Rahima Moosa Mother and Child Hospital
Enquiries: Adjunct Professor Ashraf Coovadia
Tel: 011 470 9284/9100
Email: Karen.Marshall@wits.ac.za

TITLE OF RESEARCH PROJECT:
"THE EFFECT OF DISCLOSURE/NON-DISCLOSURE ON THE WELL-BEING OF HIV POSITIVE PREGNANT WOMEN IN GAUTENG PROVINCE SOUTH AFRICA"

NAME OF SUPERVISOR:
Ms. Hester-Louise Henderson

NAME OF RESEARCHER:
Tinatin Gvilia
Department of Psychology
University of South Africa

NHRD REF NO: GP_202106_043

Dear Tinatin,

Permission is granted for you to conduct the research as indicated in the title above.

The terms under which this permission is granted is contained in the Researcher Declaration form that you have signed. Failure to comply with these conditions will result in the withdrawal of such permission.

It is crucial for you to inform the Research Coordinator, Karen Marshall of the actual start and end dates of your study. This could be done by e-mail.

Should the study commence more than 12 months after receipt of this approval letter you will have to go through the process of applying again.

You are strongly advised to keep a signed copy of the declaration form to ensure that the terms of this agreement are always complied with.

Yours sincerely,

DR NP MKABAYI
Chief Executive Officer
Rahima Moosa Mother and Child Hospital
2021:08:25

Empilweni Services and Research Unit
Rahima Moosa Mother and Child Hospital, JHB

South Africa (Private Bag X20 Newclare 2112) • Tel: +27(0)11 470 9421 Cel: +27 (0)82 687 3633 Fax: +27(0)86 553 5046 •
E-mail:karltechnau@gmail.com

2nd August 2021

Dear Ms Gvilia

Re: ***The Effect of Disclosure/Non-disclosure on the Well-Being of HIV-Positive Pregnant African Women in Gauteng Province South Africa***

Thanks for approaching us regarding your study. We would like to support your work as it is in line with our work and we consider it to be important and potentially a useful addition to the body of knowledge in the field of HIV, maternal health and vertical transmission prevention of HIV.

You have our support to conduct your study once you have received Ethics permission from WITS HREC. Regarding the practicalities of your work we would like to suggest the following: Since the timing of your study implementation is likely to fall outside of a COVID-19 wave of infections and since your interaction with clients requires responsiveness and presence with regard to any psychological needs that may emerge we urge you to conduct the process face to face, albeit with necessary procautions in place. Weather permitting interviews could be conducted outside, otherwise in a well ventilated room.

Support services available include: Ms Thakgalo Mohlala, ART Social worker at Empilweni clinic (011 470 9421) who you may refer to should any patient require further support or care.

Yours faithfully

Karl Technau, MBBCh, Dip HIV Man, DCH, MSc (Med), PhD

Associate Professor, Deputy Director Empilweni Services and Research Unit (ESRU)
Department of Paediatrics and Child Health, University of The Witwatersrand (Wits)
Rahima Moosa Mother and Child Hospital

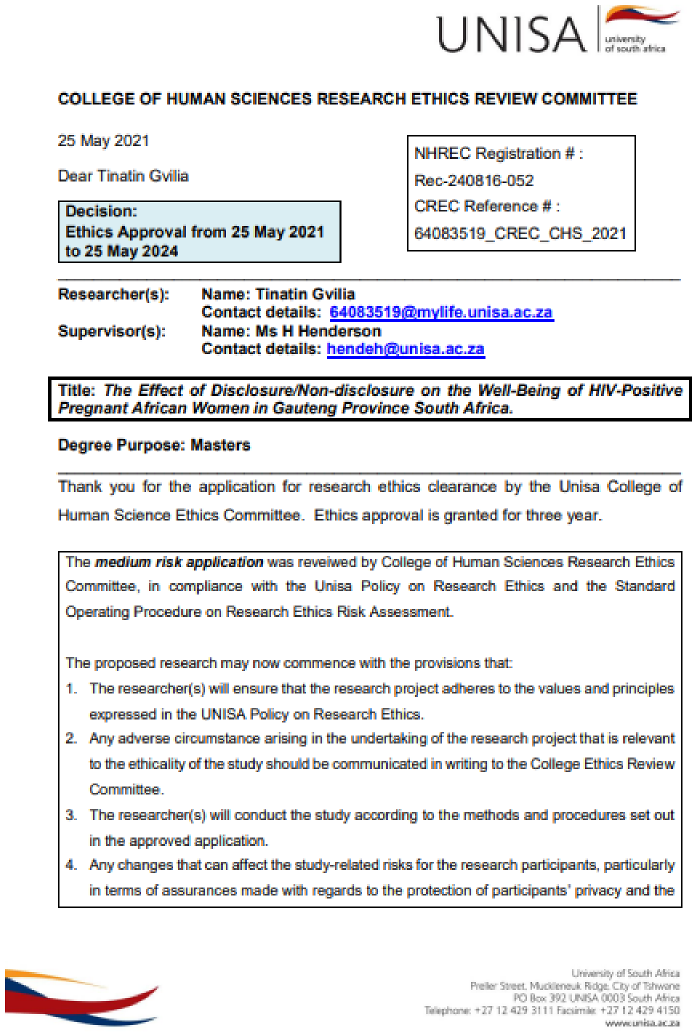
Tel : +27 11 470 9421
Mobile : +27 82 687 3633
Email : Karl-gunter.technau@wits.ac.za

Amy Wise, MBBCh, FCOG, MMed, Dip HIV Man, Cert MFM

Senior Lecturer, Department of Obstetrics and Gynaecology, University of The Witwatersrand (Wits)
Acting HOD, Dept of O&G, Rahima Moosa Mother and Child Hospital
Tel : +27 11 470 9090 **Mobile** : +27 73 152 7513
Email : amy.wise@wits.ac.za

Appendix 6

UNISA Ethics Committee Clearance Certificate



UNISA university of south africa

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

25 May 2021

Dear Tinatin Gvilia

Decision:
Ethics Approval from 25 May 2021 to 25 May 2024

NHREC Registration # :
Rec-240816-052
CREC Reference # :
64083519_CREC_CHS_2021

Researcher(s): **Name: Tinatin Gvilia**
Contact details: 64083519@mylife.unisa.ac.za

Supervisor(s): **Name: Ms H Henderson**
Contact details: hendeh@unisa.ac.za

Title: ***The Effect of Disclosure/Non-disclosure on the Well-Being of HIV-Positive Pregnant African Women in Gauteng Province South Africa.***

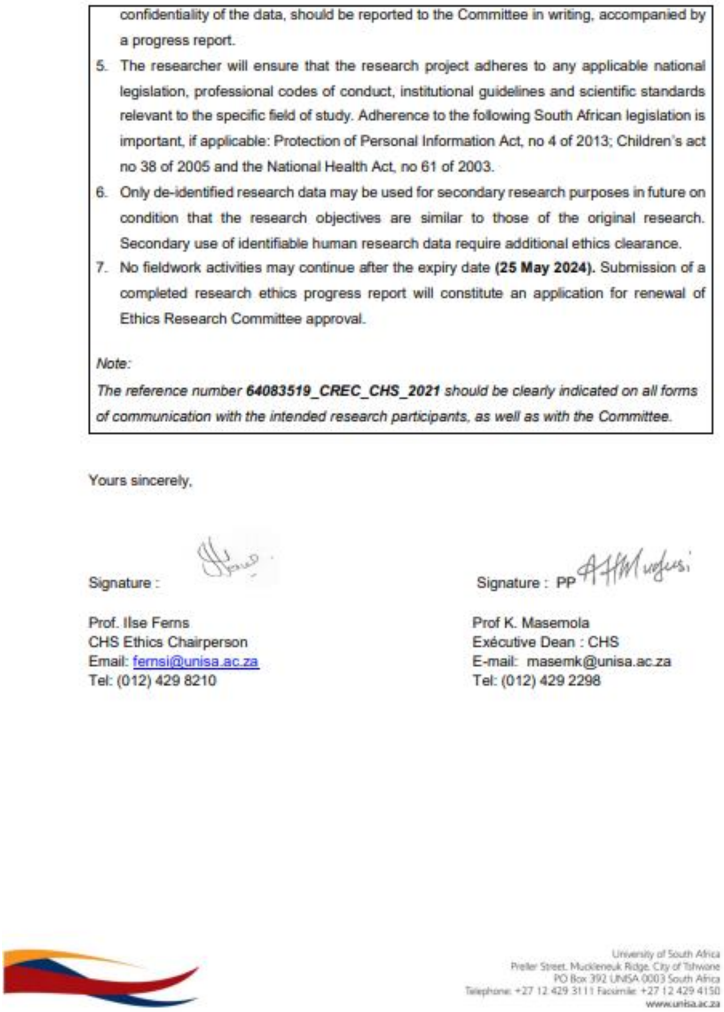
Degree Purpose: Masters

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for three year.

The ***medium risk application*** was reveiwed by College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the



confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.

5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
7. No fieldwork activities may continue after the expiry date **(25 May 2024).** Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

*The reference number **64083519_CREC_CHS_2021** should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signature :

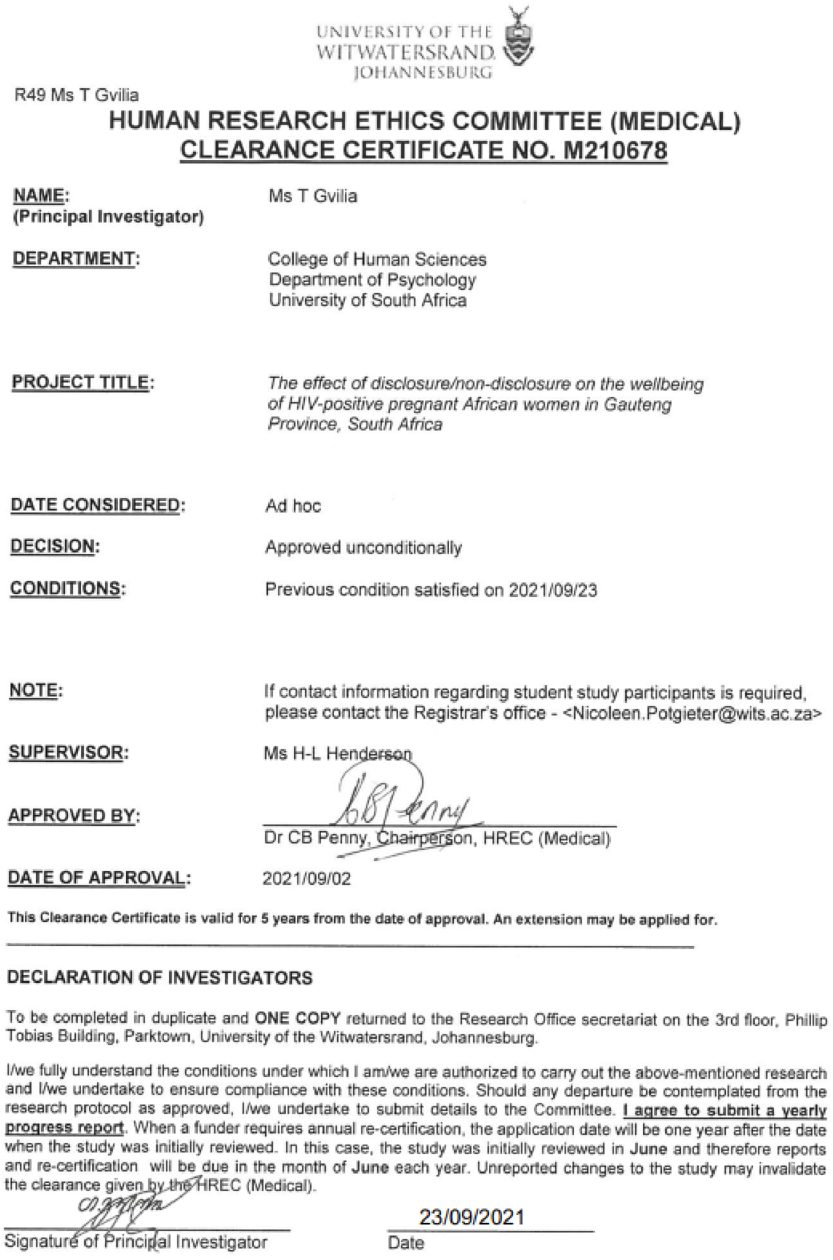
Prof. Ilse Ferns
CHS Ethics Chairperson
Email: fernsi@unisa.ac.za
Tel: (012) 429 8210

Signature : PP

Prof K. Masemola
Exécutive Dean : CHS
E-mail: masemk@unisa.ac.za
Tel: (012) 429 2298

Appendix 7

WITS Ethics Committee Clearance Certificate



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

R49 Ms T Gvilia

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M210678

NAME: **(Principal Investigator)**	Ms T Gvilia
DEPARTMENT:	College of Human Sciences Department of Psychology University of South Africa
PROJECT TITLE:	*The effect of disclosure/non-disclosure on the wellbeing of HIV-positive pregnant African women in Gauteng Province, South Africa*
DATE CONSIDERED:	Ad hoc
DECISION:	Approved unconditionally
CONDITIONS:	Previous condition satisfied on 2021/09/23
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Ms H-L Henderson
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2021/09/02

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

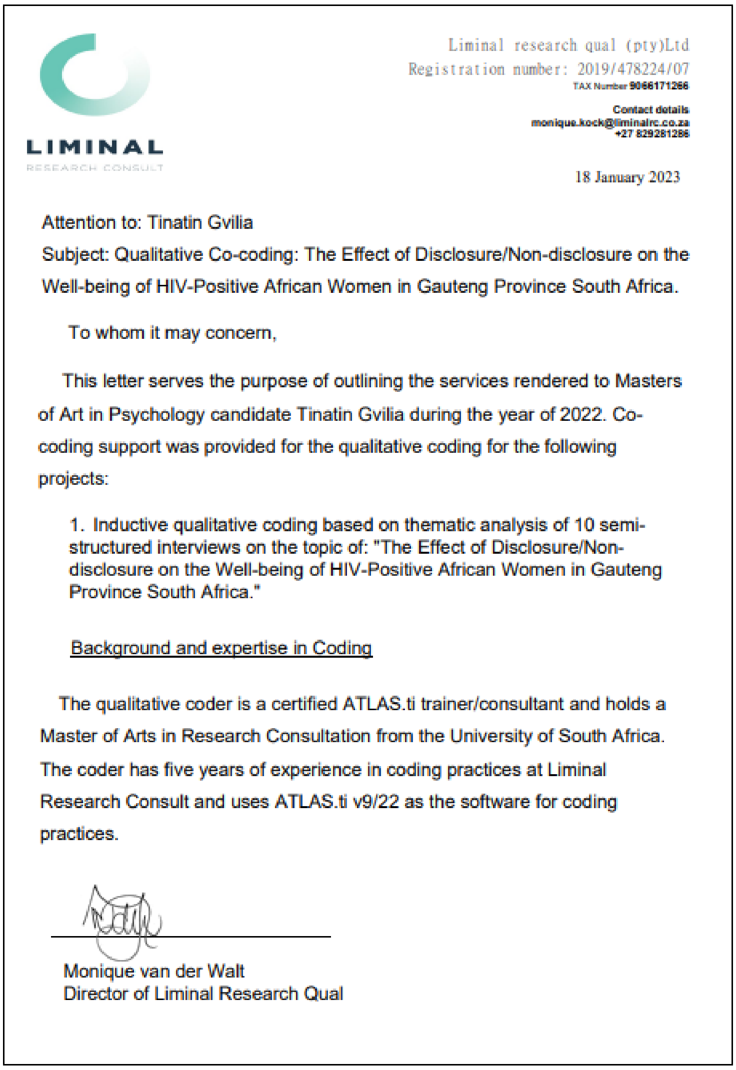
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **June** and therefore reports and re-certification will be due in the month of **June** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

23/09/2021
Date

Appendix 8

Declaration of Independent Coder



LIMINAL
RESEARCH CONSULT

Liminal research qual (pty)Ltd
Registration number: 2019/478224/07
TAX Number 9066171266

Contact details
monique.kock@liminalrc.co.za
+27 829281286

18 January 2023

Attention to: Tinatin Gvilia

Subject: Qualitative Co-coding: The Effect of Disclosure/Non-disclosure on the Well-being of HIV-Positive African Women in Gauteng Province South Africa.

To whom it may concern,

This letter serves the purpose of outlining the services rendered to Masters of Art in Psychology candidate Tinatin Gvilia during the year of 2022. Co-coding support was provided for the qualitative coding for the following projects:

1. Inductive qualitative coding based on thematic analysis of 10 semi-structured interviews on the topic of: "The Effect of Disclosure/Non-disclosure on the Well-being of HIV-Positive African Women in Gauteng Province South Africa."

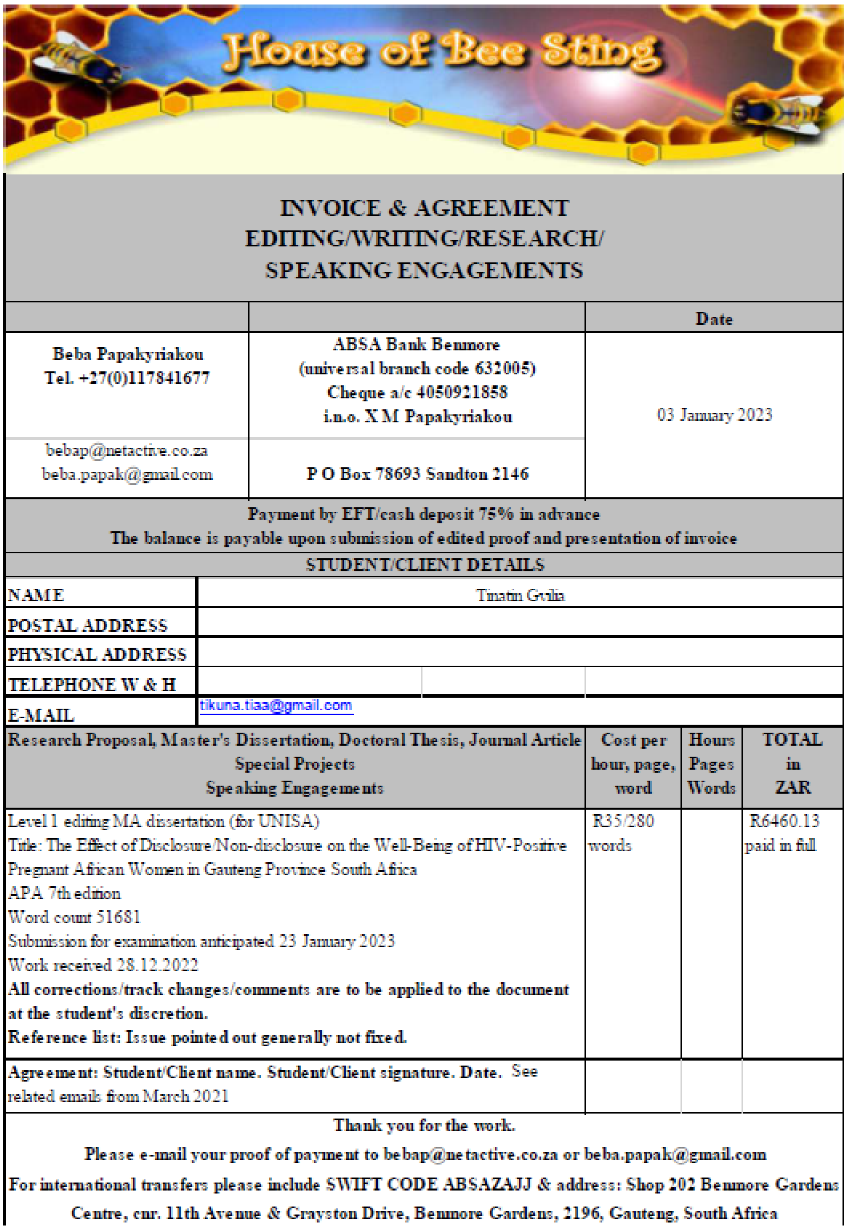
Background and expertise in Coding

The qualitative coder is a certified ATLAS.ti trainer/consultant and holds a Master of Arts in Research Consultation from the University of South Africa. The coder has five years of experience in coding practices at Liminal Research Consult and uses ATLAS.ti v9/22 as the software for coding practices.

Monique van der Walt
Director of Liminal Research Qual

Appendix 9

Editing



House of Bee Sting

INVOICE & AGREEMENT
EDITING/WRITING/RESEARCH/
SPEAKING ENGAGEMENTS

		Date
Beba Papakyriakou **Tel. +27(0)117841677**	**ABSA Bank Benmore** **(universal branch code 632005)** **Cheque a/c 4050921858** **i.n.o. X M Papakyriakou**	03 January 2023
bebap@netactive.co.za beba.papak@gmail.com	**P O Box 78693 Sandton 2146**	

Payment by EFT/cash deposit 75% in advance
The balance is payable upon submission of edited proof and presentation of invoice

STUDENT/CLIENT DETAILS

NAME	Tinatin Gvilia
POSTAL ADDRESS	
PHYSICAL ADDRESS	
TELEPHONE W & H	
E-MAIL	tikuna.tiaa@gmail.com

Research Proposal, Master's Dissertation, Doctoral Thesis, Journal Article Special Projects Speaking Engagements	**Cost per hour, page, word**	**Hours Pages Words**	**TOTAL in ZAR**
Level 1 editing MA dissertation (for UNISA) Title: The Effect of Disclosure/Non-disclosure on the Well-Being of HIV-Positive Pregnant African Women in Gauteng Province South Africa APA 7th edition Word count 51681 Submission for examination anticipated 23 January 2023 Work received 28.12.2022 **All corrections/track changes/comments are to be applied to the document at the student's discretion.** **Reference list: Issue pointed out generally not fixed.**	R35/280 words		R6460.13 paid in full
Agreement: Student/Client name. Student/Client signature. Date. See related emails from March 2021			

Thank you for the work.

Please e-mail your proof of payment to bebap@netactive.co.za or beba.papak@gmail.com

For international transfers please include SWIFT CODE ABSAZAJJ & address: Shop 202 Benmore Gardens Centre, cnr. 11th Avenue & Grayston Drive, Benmore Gardens, 2196, Gauteng, South Africa