EXPLORING THE EXPERIENCES OF "TRUST" IN INTIMATE RELATIONSHIPS OF WOMEN LIVING WITH HIV IN THE WESTERN CAPE, SOUTH AFRICA.

BY
Tarshlyn Herandien

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Supervisor: Dr Lario Viljoen
Co-supervisor: Dr Khayaat Fakier

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DECLARATION

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ABSTRACT

The largest HIV burden in South Africa lies with heterosexual people living with HIV. Women comprise of 54% of all people living with HIV (PLHIV) worldwide. In 2021, every two minutes an adolescent or young women was infected with HIV. However, there is currently very little information of how women living with HIV engage in intimate relationships with their partners. Intimacy involves individuals who reciprocates intimate moments and feelings of trust and, emotional and physical closeness towards their partners. Using qualitative data collected between 2012 and 2018 as part of the HPTN 071 (PopART) trial in South Africa, I explore how trust and intimacy is understood and experienced and how a desire for, or aversion towards intimacy in relationships coincide with the management of HIV and antiretroviral therapy (ART). I use a thematic approach to analyse in-depth qualitative data from 12 women, ranging from 17 to 48 years old, who self-disclosed that they were living with HIV. These women also reported experiences of being in intimate heterosexual relationships and had accessed ART.

My findings show that trust is central to the functioning in relationships of women and intersect with women's health-related decision making. Trust is multifaceted in that it may put women at risk of contracting HIV when 'the wrong partners' are trust, similarly, trust may render women vulnerable to experiencing physical, emotional, sexual, and mental trauma when women are in abusive relationships. Simultaneously, trust can be the reason for uptake in ART treatment. While trust is understood to be an important aspect of successful relationships, the desire of women living with HIV to have trusting intimate relationships impacts the management of their illness and treatment. These findings emphasise the significance of the role of understanding intimate relationships in HIV prevention and support interventions for women. It is recommended that health programmes implement HIV interventions which focuses on couples' relationship dynamics to strengthen sexual and emotional intimacy. These interventions can be directed at building stronger foundations of commitment, fidelity, trust, openness, connectedness which assist with HIV prevention and protection of partners.

OPSOMMING

Die grootste MIV-las in Suid-Afrika lê by heteroseksuele mense wat met MIV leef. Vroue bestaan uit 54% van alle mense wat wêreldwyd met MIV (PLHIV) leef. Gedurende 2021 is ‘n adolessent of jong vrou elke tweede minuut met MIV besmet. Daar is egter tans baie min inligting oor hoe vroue wat met MIV leef, intieme verhoudings met hul lewensmaats aangaan. Intimiteit behels individue wat intieme oomblikke en gevoelens van vertroue en emosionele en fisiese nabyheid teenoor hul maats wederkerig maak. Met behulp van kwalitatiewe data wat tussen 2012- 2018 ingesamel was as deel van die HPTN 071 (PopART)-proef in Suid-Afrika, ondersoek ek hoe vertroue en intimiteit verstaan en ervaar word en hoe 'n begeerte na of afkeer van intimiteit in verhoudings saamval met die bestuur van MIV en ART. Ek het 'n tematiese benadering gebruik om twaalf gevalle van vroue, wie se ouderdomme wissel tussen 17 en 48 jaar, ontleed en wie self bekend gemaak het dat hulle met MIV leef. Ek het ook die kwalifiserende deelnemers gekies wat ervarings gerapporteer het om in intieme heteroseksuele verhoudings te wees en tans / voorheen op ART was. My bevindinge toon dat vertroue sentraal staan in die funksionering in verhoudings van vroue en potensieel 'n groot uitwerking op gesondheidsverwante besluitnemings het. Die skending van hierdie oomblikke en gevoelens, verdraai die gemak en veiligheid van verhoudings. Vertroue is veelsydig deurdat dit vroue in gevaar kan stel om MIV op te doen wanneer 'die verkeerde vennote' vertroue het, net so kan vertroue vroue kwesbaar maak om fisiese, emosionele, seksuele en geestelike trauma te ervaar wanneer vroue in beledigende verhoudings is. Terselfdertyd kan vertroue die rede wees vir opname in ART-behandeling. Alhoewel vertroue as 'n belangrike aspek van suksesvolle verhoudings beskou word, beïnvloed die begeerte van vroue wat met MIV leef om vertrouende intieme verhoudings te hê, die bestuur van hul siekte en behandeling.

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I would like to dedicate this thesis to my late father, Clement Herandien and my late grandfather Willem Bosman, who were both my biggest supporters, and would have been so proud to witness the completion of my work.

As challenging as it was to complete this thesis, I felt your presence daily, cheering me on with your encouraging and hard hitting “sayings”.

Daddy: “Nothing worth having comes easy my baby.”

“Just give it your best, and if that’s your best, then it should be good enough”.

Pappa: “There is no such word as “I can’t”. You can. It’s that simple”.

Rest in peace Daddy and Pappa, I miss you so much.

Clement Herandien	(03/03/1963 – 14/12/2020)
Willem Bosman	(01/12/1940 – 25/03/ 2012)

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CHAPTER ONE: INTRODUCTION

1.1 Research problem and background

Despite various extended efforts to end the spread of the Human immunodeficiency Virus (HIV), approximately 38.4 million people worldwide were living with HIV in 2021 (UNAIDS, 2022). Included in this group, approximately 36.7 million were adults (age 15 and above). Women comprised of 54% of all people living with HIV (PLHIV). In 2021, every two minutes a young adolescent or young women was infected with HIV. This group accounted for 49% of the roughly 1.5 million people newly infected with HIV (UNAIDS, 2022). Even though sub-Saharan Africa only accounts for about 11% of the global population, it is home to approximately 25.6 million of the global HIV disease burden (WHO, 2022). In this region, South Africa has the biggest and most high-profile HIV epidemic, with an estimated 8.2 million people living with HIV in 2021 (Statistics of SA, 2022). Since the introduction of a national antiretroviral treatment program (ART) in 2004, ART has been widely used and implemented (Kharsany and Karim, 2016). The epidemiology of the HIV epidemic in South Africa has changed from being classified as high mortality to one in which the illness manifests as a chronic, manageable condition (Kharsany and Karim, 2016). As of 2021, 5.5 million people living with HIV in South Africa were accessing ART in public sector facilities, making the South African programme the largest in the world (UNAIDS, 2022).

In sub-Saharan Africa, HIV is mainly transmitted through heterosexual sex (Kharsany and Karim, 2016; Johnson and Dorrington 2022). The largest HIV burden in South Africa lies with heterosexual people living with HIV. Heterosexual couplings and relationships are thus also the sites of treatment initiation and adherence. A study by Wardhani and Yona (2021) showed how living with HIV and managing ART may have a significant impact on relationships and intimacy. As an example, Gamarel and Golub (2015) study explored how relationship factors such as a desire for intimacy may be a powerful motivator for condom-less sex within primary partnerships and how these unsafe practices are perceived as an expression of commitment, trust, and love. While trust is understood to be an important aspect of successful relationships (Arikewuyo *et al.*, 2021), few studies focus on the desire of PLHIV to have trusting intimate and sexual relationships (Conroy *et al.*, 2016; Wamoyi *et al.*, 2017) and how this impacts on the management of their disease and treatment. Much of the research to date focuses instead on the sexual activity of people living with HIV including the negative aspects for example the difficulty of negotiating condom use between partners (Imo, Odimegwu and de Wet-Billings, 2022; Maharajh and Haffejee, 2021; Gamarel and Golub, 2018) and risky sexual behaviours (Ssemata *et al.*, 2022; Mthembu, Maharaj and Rademeyer, 2019; Okoboi *et al*., 2018). A wide range of studies that explore intimacy, trust, and ART are also focused on disclosure and intimate partner violence (Knox *et al.*, 2010; Rigby and Johnson, 2017; Ruark, *et al.*, 2017). In this study I explore how women living with HIV experience trust in intimate relationships and how using ART features in the meaning and practices of intimacy.

In particular, I describe how trust and intimacy is understood and experienced as physical, emotional, or functional and how a desire for, or aversion towards intimacy in these relationships coincide with the management of HIV and ART. Knowledge gained from this study will contribute to a better conceptualization of ‘trust’ and intimacy, and to improve understandings of how trust intersects with the management of HIV and ART in a high-burden HIV context in South Africa.

1.2 Research context and rationale

Access to HIV testing and ART is important to reduce AIDS-related deaths and to minimize HIV incidence, at a population level (Johnson and Dorrington, 2017). In 2014, The Joint United

Nations Programme on HIV/ AIDS (UNAIDS) launched the 95-95-95 targets (Heath, Levi and Hill, 2021, p. 197). The aim was to achieve a 95% rate in diagnosing all PLHIV, provide ART to 95% of those diagnosed, and to achieve virological suppression for 95% of people on ART by 2030 (Heath, Levi and Hill, 2021, p. 197).

Universal testing and treatment (UTT) have been proposed as an HIV prevention strategy. Accordingly, population-level HIV testing and treatment could reduce HIV incidence, mortality, and was proposed as a way to achieve HIV epidemic control (Havlir *et al.*, 2020). The UTT strategy was tested in the HPTN 071 (PopART) trial, which measured the impact of a combination prevention intervention package on HIV incidence at a community level, and was implemented in Zambia and in the Western Cape province in South Africa (Hayes *et al.*, 2014). As part of a door-to-door HIV prevention intervention, the offer of early initiation of ART was also made available for individuals who tested positive for HIV in some communities, before the changes in the national HIV treatment guidelines to allow for ART for all PLHIV (Hayes *et al.*, 2019).

In South Africa, the PopART trial was implemented in 9 communities in the Western Cape. According to Johnson and Dorrington (2022) by the middle of 2015, high levels of HIV diagnosis were achieved in South Africa, with an estimated 85.5% of HIV-positive adults diagnosed. ART coverage in South Africa in 2015 was 48.6% more than double the ART coverage in 2010 as expressed as a percentage of all HIV-positive people. Additionally, women had significantly higher ART coverage than men. (Johnson and Dorrington, 2022). Coverage for all PLHIV that was diagnosed and on ART differed substantially by province and the percentage of ART patients who were virologically suppressed was 78.4% nationally. Viral suppression rates varied greatly by province, from 69.7% in Limpopo to 85.9% in the Western Cape (Johnson and Dorrington, 2022). My study focuses on the 9 PopART communities situated in the Western Cape province of South Africa.

The PopART study provided a space to acknowledge the treatment experiences of PLHIV in the Western Cape. In this study, I draw on longitudinal qualitative data collected from a cohort of people in the PopART trial (Viljoen *et al.*, 2021) to understand how women living with HIV experience trust in their relationships and how ART treatment features in the meaning and practices of intimacy. In understanding how the women experienced intimacy in their relationship, I am able to demonstrate how trust is an important aspect in relationships; and understand the intended and unintended relation trust has to HIV and ART. Being able to make those connections, I can show how disclosure and intimate partner violence links to trust and understand what possible impediment to ART treatment entail.

In this study, I use social constructionism as a framework for the analysis (Weber and Carter, 2003). Social constructionism is an approach to knowledge and used to describe how social phenomena such as trust develop in social contexts (detailed description in Chapter 2). In this study, I use this approach as a lens to understand women living with HIV’s experiences towards intimacy and ART treatment.

In the section below, I present the research aims and objectives of this study followed by the significance of the study. Thereafter, I provide a description of the key concepts in the study including intimacy, trust, ART treatment, disclosure, and intimate partner violence. Lastly, I provide an overview of the chapters to follow.

1.3 Research aims and objectives

In this study I aim to explore how trust and intimacy is understood and experienced as physical, sexual, and emotional; and how a desire for, or aversion towards intimacy in relationships coincide with the management of HIV and ART. The research objectives for this study are as follow:

1) To describe how women living with HIV experience intimacy in their intimate relationships. *How do women living with HIV describe intimacy in their intimate relationships? How is intimacy affected by an HIV diagnosis? How do women in relationships maintain intimacy in the context of HIV illness?*

2) To explore how women living with HIV manage HIV diagnosis and how ART treatment influences their intimate relationships. *How do women living with HIV describe taking ART? How might a desire for intimacy affect initiation and adherence to ART? How does taking ART affect intimacy in relationships of people living with HIV?*

1.4 Significance of the research

This project contributes to the broader study of trust. It is significant to researchers and institutions as it contributes to understanding the complexity of trust that relates to relationships and ART treatment. Intimate relationships are notable to study as these are spaces where trust is established and how issues such as HIV transmission, HIV status disclosure, HIV treatment adherence, and intimate partner violence (IPV) transpire. Women living with HIV are disproportionately affected by IPV, which is associated with high risk for HIV transmission among women (Ruark, *et al.*, 2017) and is also associated with poor treatment outcomes for the women who are already infected (Fiorentino *et al.*, 2019). Several studies have also shown that women often experience violence as a result of disclosing their HIV status to partners. (Goodwin *et al.*, 2021; Mulrenan *et al.*, 2015; Maeri *et al.*, 2016).

Trust is multifaceted in that it may put women at risk of contracting HIV when ‘the wrong partners’ are trusted (Green *et al.*, 2018); similarly trust may render women vulnerable to experiencing physical, emotional, sexual and mental trauma when women are in abusive relationships (Meskele, Khuzwayo and Taylor, 2021); simultaneously, trust can be the reason for uptake in ART treatment (Sanga *et al.*, 2021), or the reason why some people default on their treatment (Hatcher *et al.*, 2015).

In this study I show how women living with HIV experiences trust, intimate relationships, and HIV treatment. This study is significant as it shows how trust is central to the functioning in relationships and has potentially major effect on health-related decision making. This contributes to the continuous work done by heath researchers to acknowledge ‘trust’ as an essential human value, which influences HIV transmission and treatment.

1.5 Definition of key terminology

In this study I employ the following definitions:

1.5.1 Trust

Trust is commonly defined as “a particular level of the subjective probability with which an agent assesses that another agent or group of agents will perform a particular action” (Gambetta, 1988, p. 217). Rotter (1967, p.439) noted that **“**trust is defined as an expectancy held by an individual or a group that the word, promise, verbal, or written statement of another individual or group can be relied on. For the purpose of this study, I use the concept to denote the confidence in another person and the willingness to be vulnerable (Ma, Schaubroeck and LeBlanc, 2019).

1.5.2 ART treatment

“Antiretroviral therapy (ART) is a treatment which consists of a combination of drugs targeting the human immunodeficiency virus (HIV) life cycle with the aim of stopping HIV replication and preserving or restoring immune function” (Günthard *et al*., 2014, p. 411).

1.5.3 Intimacy

The word intimacy has taken on a sexual connotation, but it includes more than that. It includes sexual, emotional, physical, intellectual, and spiritual connectedness. Intimacy is a form of communication in which partners reveal something personal or private; experience positive emotions about themselves, the other person, and the interaction; and perceive the interaction to have advanced or reflected the partners understanding of one another (Prager and Bhrmester, 1998, p. 436).

1.5.4 Disclosure

Disclosure is defined as the action of revealing personal details that other individuals are not necessarily able to discover in other ways (Tang *et al.*, 2013). It is also argued that any verbal or nonverbal interaction which uncovers something about the self is viewed as disclosure (Masaviru, 2016). In the context of this study, HIV disclosure is defined as sharing one’s HIV positive status with others (Evangeli and Wroe, 2017).

1.5.5 Intimate partner violence (IPV)

“Intimate partner violence is defined as physical violence, sexual violence, stalking, or psychological aggression (including coercive acts) by a current or former intimate partner, whether or not the partner is a spouse” (Miller and McCaw, 2019, p. 850). In this study, IPV is central to understanding women’s experiences of intimacy and trust.

1.6 Overview of chapters

In the next chapter, I introduce social constructionism theory and describe how the concept ‘trust’ has been theorised by authors and defined as a social construct. I then provide an overview of how intimacy in relationships has been studied and how it relates to ART treatment. Following, I describe other relevant issues such as IPV and disclosure which influences ART adherence. I then present how these elements are associated and show the significance of employing social constructionism as theory in this study.

In Chapter 3, I discuss the methodology that was employed in the study. Firstly, I discuss the research design and approach. Secondly, I provide a description of the HPTN 071 (PopART) trial, which my study is nested in. Thirdly, I describe the setting and data source. Thereafter, I elaborate on the participant selection, participant profile and I expand on the data analysis. Lastly, I give a description of my role as a researcher in the data collection process.

In Chapter 4, I use social constructionism theory to understand and describe my key findings. I illustrate patterns of trust in HIV transmission and how it influences intimacy, disclosure, and treatment. I also discuss how trust impacts HIV diagnosis and ART regimen of the women living with HIV. Lastly, I also consider how previous research on trust, intimacy and ART confirms or refute my results.

In the last Chapter, I conclude my findings of the research. Furthermore, I consider the strengths and limitations of my study and the influence it possibly had on my findings. Lastly, I provide recommendations for future research and present closing ideas on the study.

CHAPTER TWO: LITERATURE REVIEW

In this chapter I explore literature related to trust, intimacy, and HIV in heterosexual relationships. Trust is a significant quality in intimate relationships, particularly in relationships where women are living with HIV (Matson *et al.,* 2021). Intimacy involves individuals who reciprocates intimate moments and feelings of trust and, emotional and physical closeness towards their partners (Schroeder *et al.,* 2021). The violation of these moments and feelings, distorts the comfort and safety of relationships (Laborde *et al.*, 2014). The literature in this section contextualise how women experience trust, shaping their partnerships, which in turn influences their experiences of intimacy and wellbeing.

In this study I focus on existing literature on the construction of trust, intimacy, as it intersects with the health of women. I also draw on scholarly research around intimate partner violence, HIV status disclosure, and ART treatment as it impacts women's health, HIV risk and physical safety in relationships.

As noted in the introductory chapter, more than half of HIV patients are women, but a disproportionate number of HIV studies focus on the relationships of men who have sex with men (Curno *et al.,* 2015). As the field of HIV research continues to develop, it is vital to consider acceptable inclusion of female participants (Karim and Dellar, 2014). The under-representation of women's intimacy encounters is problematic as they are the group most affected by HIV. Therefore, this study is valuable as it provides more insight into women's experiences of intimacy and construction of trust in partnerships, as those are spaces where HIV transmission and other relationship challenges occurs.

In this chapter I firstly provide a review of the theoretical framework in this study. I then proceed to describe intimacy literature in relation to partners, trust, and connection. This is followed by a section where I describe safety and disclosure, and its contributions to trust and mistrust in relationships. Lastly, I provide an overview of ART treatment and its implications on intimacy, disclosure and violence, and existing literature of women living with HIV in relationships.

2.1. Trust as a theoretical construct

In this section I present how the term 'trust' has been defined in academic literature. A variety of definitions of trust have been offered, most of them are based upon a rational belief of trust as an expectation in interpersonal relationships. For instance, (Barber, 1983) mentioned three expectations that are crucial for the progression of trust, namely: expectations for social order, expectations for competent role performance and expectations that individuals will position others' interest before their own. In other words, trust refers to different phenomena in different contexts. Sometimes it designates an act, sometimes a reason for such an act, and sometimes a specific state of mind that is regularly associated with such acts or reasons to act (Lahno, 2020).

Subsequently, one of frequently used definitions of trust is the one developed by Rousseau *et al*. (1998, p. 395) which states that "trust is the willingness to be vulnerable under conditions of risk". In Origgi's (2020) conception of trust, she moves away from particular expectations to a comprehensive expectation of the individual for order and stability in the world of social interaction. She notes that,

> "Why we trust, how we trust, and when have we reasons to trust are features of our cognitive, social and emotional life that are highly dependent on how the informational landscape is organized around us through social institutions of knowledge, power relations and systems of acknowledging expertise" (Orggi, 2020, p. 88).

When conceptualising trust, a few theorists have moved towards a more interpersonal definition of trust. As such, Lewis and Weigert (l985a, p. 465) indorses a view of trust as when "members of a system act according to and are secure in the expected futures constituted by the presence of each other".

In Weber and Carter (2003), Lewis and Weigert (1985) suggests three levels of trust: cognitive, emotional, and behavioural. The cognitive element recognises that a person should decide as to whom and when to trust as personal decisions eventually becomes enclosed by the standards of trust which is characterised by a shared cognitive positioning to trust. The emotional element of trust acknowledges the powerful emotions created by trusting, as disruption of trust brings about emotional experiences. The behavioural aspect of trust gives attention to the persons behaviour, which is based on the certainty of others' behaviour even though there is doubt in the interaction (Weber and Carter, 2003). This is relevant to understanding the experience of trust for women living with HIV in relationships in that, it helps to comprehend why women trust specific partners to share emotional and sexual intimacy with. For instance, partners whom women decide to disclose their status to, reasons for engaging in sexual activities, and their decisions for using condoms.

Luhmann (1979) adds the component of risk into a meaning of trust. According to Luhmann (1979, p. 24) "Trust is a gamble, a risky investment", it is impossible to know for sure what the other will do, if it were possible, trust would not be necessary. McGeer and Pettit (2017) explains Luhmann's thoughts of trust as 'reliance'. They demonstrate this reliance in the following scenario:

> "I have been sitting near you in a restaurant and ask you to keep an eye on my computer when I go to the toilet. I am manifestly relying on you not to take off with the computer, and not to let anyone else do so either. And to the extent that I rely on you in this way,

> taking you to be significantly responsive to that reliance - taking you to have the capacity to be moved by my relying on you - I count as putting my trust in you. I have and reveal an attitude of trust in putting myself in your hands - this may be based on how you look or on how you seemed in an earlier exchange of pleasantries and in acting on that attitude I exercise trust: I perform an act of trust" (McGeer and Pettit, 2017, p.27).

When you decide on one course of action over another despite the danger of being let down by someone else's choice, you define the situation as one of trust (Luhmann, 1988). Women living with HIV are also impacted by this "risky" type of trust as they 'rely' on their partners to be faithful in their partnership which in essence could be viewed as an act of trust.

In this study I explore how women living with HIV experience trust in their relationship. Relationships where HIV exists is not only a space for love and commitment with a partner, but it is also a space of reliance, health risks and expectations between partners. This means that women living with HIV in intimate relationships have unique experiences of trust due to specific health challenges.

Weber and Carter (2003) highlights trust as 'an orientation' between oneself and another, whose entity is the relationship. The foundation of trust is the conviction that the other will consider one's viewpoint when making a decision and won't act in a manner that violates the relationship's moral norms (Weber and Carter, 2003). As an orientation, trust entails three things: (1) that it does not exist until it is enacted; (2) that it is an emergent state of the connection; and (3) that it forms the relationship. The trust orientation emerges more readily in some relationships than in others, such as friendships and romantic partnerships. In some, like family interactions, the trust orientation is more structurally anchored (Weber and Carter, 2003). With the interest of trust in intimate relationships and HIV illness, this section turns to the development of the theoretical basis for this study.

In the present study, ‘trust’ is viewed as social construct. According to Luhmann (1979, p.6) "trust occurs within a social constructionist framework of interaction which is influenced by both personality and social system and cannot be exclusively associated with either". Berger and Luckmann (1996) asserts that the dialectical process of externalisation, objectivation, and internalisation leads to the emergence of everyday reality. This suggests that the process of externalisation acknowledges that people are the ones who create the social environment by bringing a private idea, thinking, or action into the public sphere. Objectivation happens when people view these ideas or actions as ‘facts’. During this process, the social structure, and the individual meet as the enactment of roles and the use of language of the objectivated world confronts people in their everyday lives. Therefore, when a person creates his or her "own" perspective on the world through socialization processes, that person is internalizing the objectivated world and personalises it. (Berger and Luckmann, 1996, pp. 36 - 39). For instance, women living with HIV internalise their diagnosis and therefore, they take ART and enact the role of an individual living with the illness.

When it comes to relationships involving two or more people, especially intimate partnerships as opposed to other kinds of connections, trust is an objectivated by-product that helps to increase the relationship's subjective significance. Thus, as an objectivated product, trust arises from the interpersonal encounters between partners and it serves to order these connections by influencing interaction (Berger and Luckmann, 1996; Weber and Carter, 2003). As subjectively meaningful action, trust towards someone is based on the experiences and is supported by value orientation which makes the relationship. Therefore, these subjectively meaningful experiences achieve significance for the self, come to be known as romantic or intimate relationships and so forth, when they are understood to signify a commitment to the other. When a person trusts another, one acts in a specific manner toward that other; likewise, a person also believes one has a particular kind of relationship because of that trust, for instance a romantic relationship which is based upon experiences that an individually meaningful (Weber and Carter, 2003, p. 5). Given the scope of social constructionist perspective, the next section will address intimacy in an attempt to further investigate the role of trust in relationships.

2.2 Intimacy dynamics in trusting relationships

Intimate relationships and specifically the quality of relationships is deeply significant to the health and wellbeing of individuals (Chapola *et al.*, 2021; Laborde *et al.*,2014; Negash *et al.*, 2021; Kleinert *et al.*, 2020). It is broadly acknowledged that intimacy, which is defined as a feeling of closeness and connection between two people, improves the quality of relationships (Schroender *et al.*, 2017). Even though both men and women frequently value the closeness that is part of romantic relationships, the social norm dictates that men are socialised to place more focus on sex whereas women place more emphasis on developing a strong and intimate romantic connection (Towner, Dolcini and Harper, 2015; Schroeder *et al.*, 2017; Hensel *et al.*, 2011). As such, women are found to usually express a desire for more emotional closeness and to feel a sense of intimacy in their relationships, and women want more porous boundaries between partners within intimate relationships (The boundaries between the women's wants and those of others become more permeable in the emotional area). Authors have also found that women put forth more effort to foster emotional connection in their relationships by encouraging conversation and the expression of deep emotions (Hensel *et al.*, 2011; van Lankveld *et al.*, 2018; Umberson, Thomeer and Lodge, 2015). According to studies, women are more prone than men to believe that emotional intimacy is necessary for satisfying sexual encounters and a desire for sex contributes to relationship pressure and conflict, oftentimes jeopardising intimacy. For instance, in their study of intimacy and emotional work in relationships, in Southwestern, United States, Umberson, Thomeer and Lodge (2015) found that women in heterosexual relationships suppressed their own feelings or desires in response to their partner's needs and connected emotional intimacy to sex. In their study, women described efforts to enhance their sexual desire when their partner desired sex more often than they did. These women spoke about feeling guilty when they did not want to be intimate because they believed they should have sex if they loved their partner. This highlighted the connection between emotional intimacy and sex for women. Similarly, Fahs, Swank and Shambe (2019) in their study in Southwestern, United States on negotiating sexual desire discrepancies for women in partnered relationships, found that when women decline sex with their partner, it may have different implications for women than men. The feelings of guilt and shame with refusal of sex, as opposed to flatly declining sex because one is disinterested, reveals a range of gendered emotional labour. In their study, the women who reluctantly had unwanted sex suggests that they wanted to please a partner because they felt it was their duty to engage in sex even if they were not personally interested in it. This showed the role of emotional intimacy in relationships (Fahs, Swank and Shambe, 2019).

Rubin and Campbell (2012, cited in Schroeder *et al.*, 2017) suggests that relationships with higher emotional intimacy have greater physical benefits for partners including greater passion, sexual satisfaction, and commitment. As intimacy includes more than just sexual behaviour, the sexual experience also includes negative and positive expectations of physical sensations, feelings, and understandings of others. (Blume, 2002, p.91). From a social constructionist point of view, all these elements of intimacy are influenced by individuals' relationship context and at the same time the relationship is a context that shapes itself as expectations, meanings, and behaviour are negotiated.

As sexual encounters, fantasies and intentions occur in the context of various overlapping historical and cultural discourses (Blume, 2002) intimacy, such as kissing or touching for an example often have different meaning for people involved. For instance, this research investigates and illustrates how women living with HIV construct trust in relationships in a manner that highlights the differences in intimacy experiences. Individuals may have experiences with their partners which relates to health and other dynamics which also contributes to relationship spaces in which couples' intimacy may have a different meaning (Hensel *et al.*, 2011; Blume, 2002, p.91).

Luhmann (1979) stipulates that trust is only involved when trusting expectations make a difference to practical but meaningful life decision as opposed to hope. Luhmann, (1979, p.40) explains, if a mother leaves her child with a babysitter, a number of hopes are associated with this: that nothing untoward will happen, that girl will be kind to the baby, will not disturb its sleep and so on. Her trust only extends to eventualities which, if they occur, would cause her to regret her decision to go out at all and to leave her child in the care of anybody (Luhmann, 1979). Trust therefore always bears upon a critical alternative, in which the harm resulting from a breach of trust may be greater than the benefit to be gained from the trust proving warranted (Luhmann, 1991). The ways of preparing for relationships of love or more generally for all kinds of personal ties and deepening acquaintanceship can be interpreted as the testing and learning of trust in relationships. (Luhmann, 1979). In the context of this study, women living with HIV have different experiences of trust in their relationships which might be based on their past experience of risks and relationship expectations, which may act as reference to the way they experience emotional and sexual intimacy in their current relationships.

2.3 Trust, intimacy, and HIV

In this study, intimate relationships are intricately linked with HIV. While intimacy in relationships is considered to entail trust, in the forms of closeness and commitment, trust is also associated with risk perception and condom use (Matson *et al.*, 2018; Negash *et al.*, 2021; Goldenberg *et al.*, 2015). For an example, perception of a significant others' behaviour, such as believing their partner has additional partners, influences risk perception and protection behaviours. Matson and colleagues (2018) in their study on the impact of relationship stressors on trust and pro-relationship behaviour within romantic relationships in Baltimore, found that individuals who focused on maintaining trust, had an impact in engagement in protective health behaviours. Similarly, Towner, Dolcini and Harper (2015) showed that gender dynamics interaction in romantic relationships has the potential to influence STI/HIV acquisition risk. It is not unusual for people in exclusive relationships to view safer sex practices as less favourable and unromantic. Studies conducted with students in the USA (Negash *et al.*, 2021; Gamarel and Golub, 2015) and Southern Africa (Hunter, 2002; Aventin *et al.*, 2021) found that the belief that condoms feel unnatural, decreases sexual pleasure, and are a hindrance to sexual intimacy may also limit couples' condom use. Similarly, Patrão and McIntyre (2017) found that in their study on socio-demographic, marital and psychosocial factors associated with condom use among Mozambican women, trust is cited as a primary predictor of condom use. Moreover, it is typically negatively linked to condom use. Similarly, Hunter (2002) found that men will convince women that using a condom represents unfaithfulness and true love symbolises unprotected sex. However, research reveals that trust and sexual health are connected in a more nuanced way. (Fortenberry, 2019). For instance, findings from Matson *et al.* (2018) noted above, found that female participants were at 45% greater risk of contracting STI/ HIV during the period when they stated having a decrease in trust. A decrease in trust is potentially an indicator of relationships that are unsafe. Research have demonstrated that, trust and love are central in defining the meaning of sexual involvements for women across context. In relation to safe sex, researchers have found that women describe love and trust as measures against HIV, and that sex is viewed as 'safe' through its connection with love and trusted partnerships (Corbett *et al.*, 2009; Laborde *et al.*, 2014). In the search for intimacy and a significant relationship, individuals may engage in risky sexual behaviours. For instance, they might base their choices on sex and condom use on implicit risk theories based on personality (Matson *et* *al.*, 2018; Corbett *et al.*, 2009; Negash *et al.*, 2021) or features, such as aspects thinking: "he appears clean," "she's not from the streets," etc. (Corbett *et al.*, 2009, p.3).

In sub-Saharan Africa, consistent use of condoms in relationships is reportedly low (Aventin *et al.*, 2021; Patrão and McIntyre, 2017) and several studies have demonstrated the significance of self-efficacy for protective behaviours among South African women (Maharajh and Haffejee, 2021; Wechsberg *et al.*, 2017; Imo *et al.*, 2022). Condom use, especially in a committed relationships where condoms may not have been used in the past, the suggestion of initiating condom use might cause mistrust and adultery allegations (Aventin *et al.*, 2021; Towner, Dolcini and Harper, 2015; Imo *et al.*, 2022), and the belief that one's spouse is faithful is kept alive through condomless intercourse (Corbett *et al.*, 2009). A review done by Aventin and colleagues (2021) on condom use in South Africa, found 'trust' to be one of the barriers to consistent condom use among individuals. In a study by Ajayi, Omonaiye and Nwogwugwu (2021) in the Eastern Cape, South Africa, young women failed to use condoms constantly because they cite trust their partners to remain faithful in the relationship when explaining why they do not use condoms. The authors found that HIV testing played no role in partnership trust, rather engaging in committed relationships and perceived fidelity of their partner motivated them to engage in condomless sex. For others in their research study, trust could be defined as "blind trust" seeing that trust was implied even though the couple have never tested for HIV (Ajayi, Omonaiye and Nwogwugwu, 2021). In these partnerships, unprotected sex is seen as a sign of trust; disregarding risk of contracting HIV from their partner; and bringing up condoms could be interpreted as showing mistrust. (Ajayi and Okeke, 2019; Fortenberry, 2019).

2.4 Safety in relationships: disclosure and intimate partner violence

For most people, initiating and maintaining intimate relationships is a life-course expectation. While the broad advantages of intimacy in terms of physical, emotional, and psychological health are well known (Schroeder *et al.*, 2017; Negash *et al.*, 2021; van Lankveld *et al.*, 2018), there is value in emphasising these characteristics of intimacy among couples in high-risk context (Mannell *et al.*, 2019; Goodwin *et al.*, 2021; Davis *et al.*, 2021), such as those where there is a risk for HIV transmission (Green *et al.*, 2018).

Researchers have shown that the presence of commitment and trust, which are indicators of close relationships, might alter risk factors (Starks, Gamarel and Johnson 2014). For instance, in a recent study in Rwanda and Uganda by Kyegombe, Stern and Buller (2022) the authors found that romantic jealousy, which arise due to mistrust can be alleviated and reduced, particularly when recognised as a specific trigger of conflict and IPV. The authors also found that strategies such as communication skills and encouraging critical reflections improve trust and faithfulness in relationships (Kyegombe, Stern and Buller, 2022). According to Green et al (2018, p.117) intimacy can be seen as an interpersonal process that includes (1) self-disclosure of feelings and information, (2) responsiveness to a partner regarding his or her self-disclosure needs, which results in (3) increases or reductions in feelings of being understood and cared for. Self-disclosure may be defined as an individual's sharing of sensitive or personal experiences or feelings with others. The degree to which a partner reacts to sensitive information's makes the person who disclosed the information feel understood, cared for, or validated (Green *et al.*, 2018). HIV status disclosure is inextricably linked with this process and ultimately impacts, and is impacted by, intimacy.

The disclosure procedure becomes more complicated within the HIV context, since there is risk involved in disclosing a positive status or because a person questions the consistency of their partner's HIV care management. Studies in Sub-Saharan Africa have demonstrated that disclosure can lead to dialogues about affection, intimacy, safe sex, and trust with partners as well as provide the security of practical support from romantic relationships (Toska *et al.*, 2015). Disclosure can also assist in gaining access to good quality HIV-related health care services (Chen *et al.*, 2021), which reduces morbidity risks (Bella, Aggleton and Slavin, 2016; Green *et al.*, 2018; Sanga *et al.*, 2021). A study conducted by Goodwin et al (2021) for an example, found that PLHIV who disclosed their HIV status to their loved ones received supportive reactions and felt supported, and those who disclosed to partners reportedly increased condom use.

However, if there isn't shared closeness in a relationship, the partner's reaction to HIV status disclosure may cause trust to break down and have an impact on whether the relationship continues post disclosure (Green *et al.*, 2018). Conversely failing to disclose can result in a lack of emotional and physical support, resulting in a poorer health relationship outcome (Sanga *et al.*, 2021) and partners living with HIV who conceal their status may become reinfected themselves, their partners may become infected, and there may be missed opportunities for HIV treatment (Maeri *et al.*, 2016). Studies examining obstacles to HIV disclosure among women living with HIV, found that anticipated stigma and fears of abandonment, rejection, and violence are evident (Goodwin *et al.*, 2021; Maeri *et al.*, 2016; Pashaei *et al.*, 2022).

Intimacy is most clearly demonstrated in scenarios where a person self-discloses their HIV status with the expectation that their significant other will be receptive to the disclosure, and that expectation is validated by the partner's welcoming and supportive behaviour (Green *et al.*, 2018). Disclosure may also reduce the impact of unfavourable situations or experiences in the future, such as a partner's HIV diagnosis and the continued challenges of living with HIV (Bella, Aggleton and Slavin, 2016). However, a relationship with at least one partner living with HIV who exhibits behaviours such as IPV that raise the risk of HIV transmission necessitates an additional level of partner responsiveness and disclosure that may interfere with the couple's ability to maintain the intimacy process (Green *et al.*, 2018).

IPV have been found to have negative effects on women’s health (Davis *et al.*, 2021; Meskele *et al.*, 2021). IPV against women, include physical, sexual, economic or psychological harm by a current or former partner or spouse (Kyegombe, Stern and Buller, 2022, p.1). Literature consistently documents associations between IPV and HIV in South Africa, (Weiss, Peasant and Sullivan, 2017), framing IPV as both a risk factor for and consequence of HIV. In a qualitative exploration of the intersections between jealousy, infidelity, and intimate partner violence, Kyegombe, Stern and Buller (2022) found romantic jealousy was common in many relationships and, in some situations, normalized. A comparative cross-sectional study by Meskele, Khuzwayo and Taylor (2019) in Southern Ethiopia found that in relations where men had control over their partners, women were more likely to experience IPV than women who did not experience such control over their behaviour. Across studies, IPV was found to negatively impact relationship quality and trust, in addition to contributing to women’s increased risk of contracting HIV (Kyegombe, Stern and Buller, 2022; Shamu *et al.*, 2014; Meskele, Khuzwayo and Taylor, 2019). Several studies have also shown when women are in a relationship with partners that suspect infidelity, controlling behaviour may increase, which negatively impacts women’s ability to adhere to ART (Shamu *et al.*, 2014; Bernstein *et al.*, 2016; Fiorentino *et al.*, 2019; Hatcher *et al.*, 2015; Rigby and Johnson, 2017). In this study, I also explore how disclosure and IPV interact with women’s experience of trust in their intimate relationships and their ability to manage their HIV diagnosis.

2.5 Trust and ART treatment

As been shown, trust and intimacy play vital roles in relationships and interacts with HIV transmission dynamics, intimate partner violence, HIV status disclosure, and ART adherence. As lifelong ART use is difficult, and many PLHIV struggle to adhere to treatment regimens (Rencken *et al.*, 2021), in this section I provide an overview of the literature on the interactions between ART treatment adherence in relationships.

South Africa has the largest ART programme in the world (Kim *et al.,* 2021), and coverage of those eligible for ART is improving every year (Osler *et al.*, 2020). Globally, ART has been beneficial in lowering the rate of HIV-AIDS-related deaths, and the treatment has been reported to enhance the quality of life for those who are living with HIV (Wardhani and Yona, 2021). However, ART treatment is effective only if consumed routinely and continuously throughout the individual's life (Wardhani and Yona, 2021; Risher *et al.,* 2016). Understanding the risk behaviours of both those taking ART and those not linking to care are important, especially considering the recommendations to starting early ART as early as possible, to prevent transmission and to offer protection against superinfections (Kim *et al.,* 2021; Wardhani and Yona, 2021). In their study in Indonesia, Wamoyi and colleagues (2017) explores challenges experienced by PLHIV in intimate relationships, including concerns about infecting intimate partners, guilt over enjoying one's sexual activity, HIV-related stigma, and difficulties with sexual communication with intimate primary partners. Such indicators are known to jeopardize attempts to reduce sexual risk and participation in HIV care. The trauma of a person's HIV diagnosis can create a fear of illness, early death, rejection by a partner, and a loss of hope. In addition, in their study the authors found that individuals have a low level of emotional intimacy which the authors noted that could be related to ART side effects. The authors noted that 50% of people on ART treatment can experience side effects such dizziness, nightmares, insomnia, anxiety, and depression which can affect the emotional level of people living with HIV and in turn, impact adherence.

A study conducted by Hickson and Mayers (2020) with young people in a peri-urban township in the Western Cape, South Africa found that, as individuals experience acceptance and support from their partners, they began to feel motivated to learn about ART. Individuals were given a sense of control and power over their condition when they learnt that HIV was a treatable condition, and that adherence would reduce illness and prevent early mortality. As a result, they were able to incorporate living with HIV into their everyday routines (Hickson and Mayer, 2020). At the same time, studies have shown that an HIV diagnosis appeared to alter the sexual and relationship behaviours of many couples, as some chose to abstain, limit the number of partners they have, get married, and/or end a long-term relationship (Wardhani and Yona, 2021). Additionally, high levels of sexual intimacy have been shown to affect ART adherence. Specifically, Wamoyi and colleagues (2017) in their study have found PHIV who already feel sexual intimacy with their partners will try to maintain their physical condition by frequently taking ART to avoid infections and prevent HIV transmission to their intimate partners. Therefore, motivation to preserve sexual intimacy with partners also contributes to higher adherence to ART (Gamarel and Golub, 2015).

2.6 Women living with HIV in intimate relationships

In this study, I investigate the construction of trust in intimate relationships of women living with HIV. Trust, a construct, is influenced by many factors and holds various meanings in relationships (Fortenberry, 2019).

Beyond fidelity, another crucial component of trust for women living with HIV, is emotional and physical vulnerability (Lamborde *et al*., 2014). Emotional vulnerability relates to the risk of entering a relationship and trusting their partners with intimate feelings, such as disclosure, risking rejection or betrayal and/or violence. In addition, emotional vulnerability relates to physical intimacy which contributes to safer sex practice and concerns of transmission (Negash *et al.*,2021). This shows that within primary relationships, women construct trust differently, which consequently, would construct their level of intimacy and relationships differently. Therefore, intimate relationships are key sites where ideas of trust are constructed and performed (Kleinert *et al.*,2020).

In this context, trust, emotional and physical intimacy, violence, disclosure, and fidelity are described and situated within the women's social environment. The patterns of expectations, behaviours, self-protection and cultivation of trust and intimacy are shaped by their relationships and also play a role in HIV diagnosis and treatment. (Lamborde *et al.*,2014). Therefore, it is important to investigate how women living with HIV construct and negotiate trust.

In the following chapter I describe the methods employed to explore women's experiences of trust in their intimate relationship. Thereafter I present the findings of women living with HIV's experience of intimacy, trust, disclosure, intimate partner violence, and discuss how trust impacts an HIV diagnosis.

CHAPTER THREE: METHODOLOGY

3.1 Research design and approach

I applied the social constructionist perspective and chose *'trust'* as the frame through which I examine women's relationships. According to Burr and Dick (2017, p.4) the way in which people generally understand the world, the categories, and concepts humans use, are historically and culturally specific and we construct reality by assigning meaning to objects and experiences to make sense of them. This approach was deemed appropriate as I was able to recognise the different ways the women in my study understood, experienced, and engaged in the topic of trust in relation to intimacy. Additionally, I focused on the management of HIV and how this too influenced trust and intimate relationships. For instance, I looked at what women 'literally' said about intimacy, relationships, ART and HIV, and explored the 'taken for granted' meaning of what they 'say' about these subjects. In turn, I also explored how trust features in these topics.

To gain an understanding as to how women experience trust, I employed an exploratory approach. I explore the phenomena accurately through narrative-type descriptions, using qualitative methods that was collected as part of a larger HIV prevention trial[1]. The purposeful use of qualitative approach allowed me gain insight into what it is like to be a women woman living with HIV and experiencing trust in the context in which they live, as the qualitative approach allows for more descriptive and conceptual data (Creswell and Creswell, 2018).

According to Mosera and Korsjens (2018) qualitative research investigates phenomena, typically in an in-depth, holistic manner through the collection of rich narrative information using a flexible research design, which allows us to interpret social problems in terms of the meaning people give them. Therefore, this research method provides an opportunity for a much more significant evaluation of the topic of trust.

3.2 Context: The HPTN071 (PopART) trial

In this project, I draw on data collected as part of the HPTN 071[1] (PopART) HIV prevention trial (Fig 1). The study was a three-armed community cluster randomised trial that measured the impact of a combination prevention intervention package on population level HIV incidence in South Africa and Zambia (Hayes *et al.*, 2014). A cluster is the catchment population of a government primary health care facility which provides ART services to the population in the community (Hayes *et al.*, 2014). The HPTN 071 (PopART) study was conducted between 2012- 2018 and took place in 21 communities, 12 across Zambia and 9 in the Western Cape of South Africa (Hayes *et al.*, 2019).

The participating communities were randomly assigned to one of three study arms – Arm A and B (intervention arms) or Arm C (control arm). Arms A and B received HIV combination prevention package which was provided at household level (Hayes *et al.*, 2019). Participants from Arm A were also eligible for ART irrespective of their CD4 count, while individuals in Arm B received treatment as per national guidelines. Arm C obtained standard of care (Hayes *et al.*, 2014). In 2016, the national HIV treatment guidelines in South Africa changed and all PLHIV were eligible for treatment, irrespective what their CD4 count was, which meant treatment was made available to all PLHIV in all communities (Hayes *et al.*, 2019). In figure 1 below, I provide an overview of the trial design.

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[1] Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART): A cluster-randomized trial of the impact of a combination prevention package on population-level HIV incidence in Zambia and South Africa.

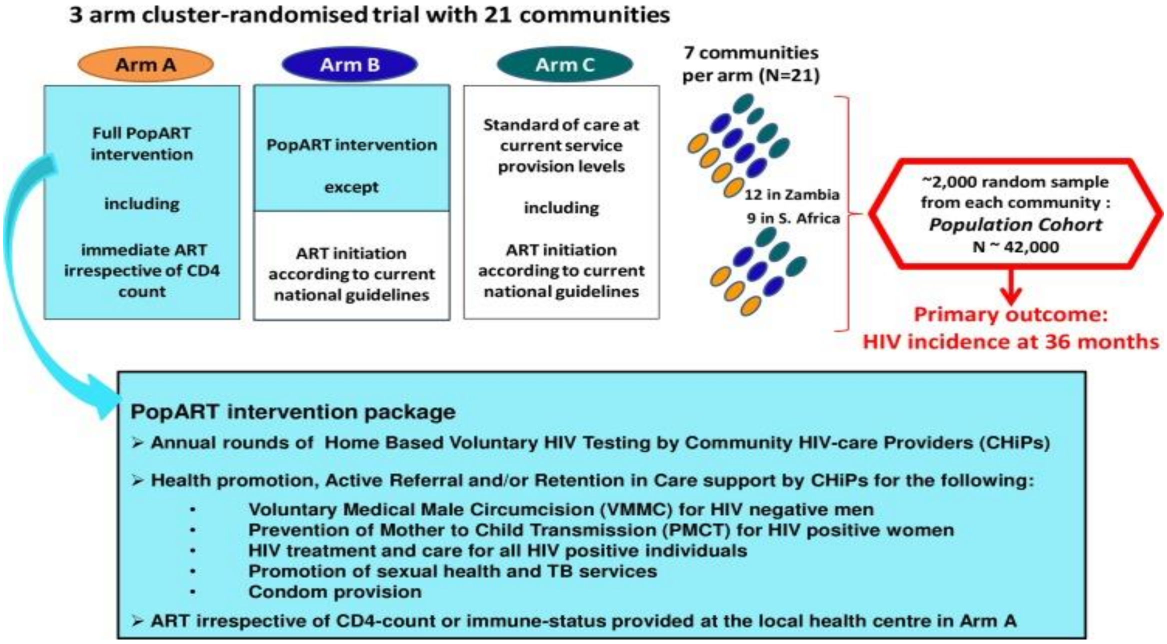

Figure 1. Overview of the HPTN 071 (PopART) trial design (Hayes et al., 2017).

As part of the trial, a cohort of participants were recruited to participate in a series of longitudinal interviews in order to contextualise the trial findings (Viljoen *et al.*, 2021).

3.3 Setting

The figure below (Fig 2) maps the locations of the communities (clusters) that took part in the trial in the Copperbelt, Central, Lusaka and Southern provinces of Zambia and the Western Cape province of South Africa. (Hayes *et al.*, 2019). In my study I focus on nine South African intervention communities located in the Cape Metro, the Cape Winelands and in the Mixed Metro in the Western Cape province. By 2022, it is estimated that approximately 11,9% of South Africa’s population live in the Western Cape (Statistics of South Africa, 2022). In 2017 the Western Cape had the lowest provincial HIV prevalence estimates among people of reproductive age at 12.5% (Simbayi *et al.*, 2019). Women, however, continue to bear a disproportionate burden of the HIV epidemic, where close to one in four of South African women aged 15- 49 are estimated to be living with HIV (Statistics of South Africa, 2022). Research has shown that people who stay in informal districts of the country continue to carry an increased risk of contracting HIV, with higher HIV incidence reported in these areas when compared to other districts (Palanee- Phillips, *et al.*, 2022). Higher incidence is associated with partial access to effective HIV prevention and treatment approaches progressively in informal districts as well as the explicit impact on HIV incidence trajectories in these areas (Simbayi, *et al.*, 2019; Palanee- Phillips, *et al.*, 2022). The data used in this analysis was collected from areas in these communities in the Western Cape province.

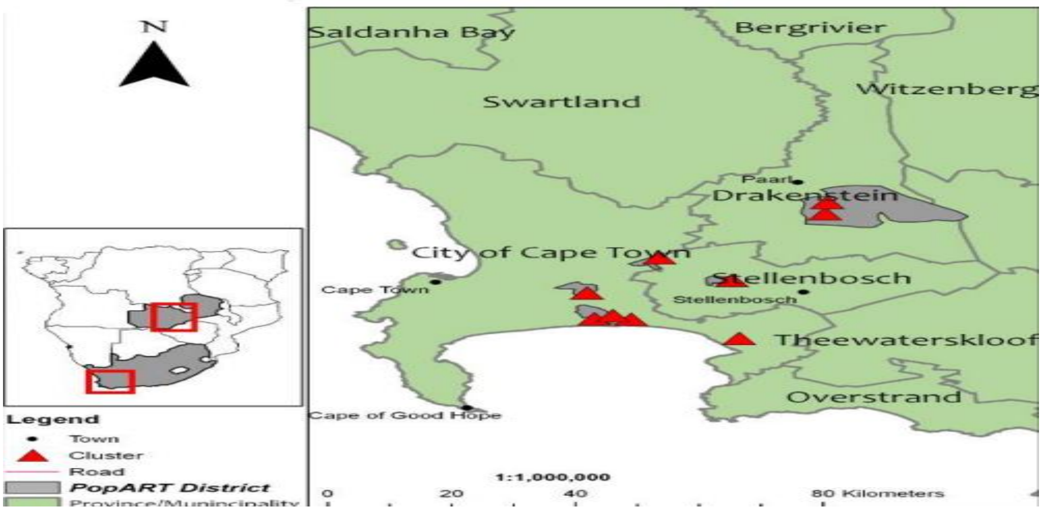

Figure 2. Map showing location of study communities (Hayes *et al.*, 2014).

3.4 Data source

In this study I conduct a secondary analysis of qualitative data collected in the HPTN 071 (PopART) trial. The qualitative data was collected by a team of trained team Social Science researchers, including myself. We used ethnographic research principles and data collection involved participatory semi-structured interviews, questionnaires, as well as interactive activities conducted over regular, multiple contacts with participants. Depending on the subject, some of the discussions took place in a group (household) setting while others were one-on-one. We included 87 households in South Africa and interacted with more than 200 individuals (Viljoen *et al.*, 2021).

The discussions were divided into modules and focused on topics such as: household and family structures; place, space and movement; how they get by (revenue and expenditures), love, sex and romance; understandings and experiences of the intervention or HIV prevention services; and hopes, fears and ambitions (Viljoen *et al.,* 2021). My project focused primarily on the interviews and activities that focused on love, sex, and relationships and data were collected as interviews. The interviews were done in Afrikaans, English and isiXhosa, depending on the preferred language of the participant. During data collection, all interviews were recorded, photos were taken, and observational and reflective notes were made during the process. We transcribed the recorded interviews verbatim, double-checked them for accuracy, and then translated them into English. I was involved in all of these steps – from data collection to data processing, interacting with more than 20 families participating in the cohort over a period of 18 – 24 months.

3.5 Selection of participants

In my research analysis I include 12 purposefully selected cases of women who self-disclosed that they were living with HIV from the qualitative cohort nested in the HPTN 071 (PopART) trial in South Africa. The ages of these women range from 17 - 48. I employed a purposive sampling strategy specifically, critical case sampling. Purposeful sampling is a "technique widely used in qualitative research for the identification and selection of information-rich cases for the most effective use of limited resources" (Patton, 2002, cited in Palinkas, *et al.*, 2015, p. 2). I included cisgender women who reported that they were living with HIV and were currently (at the time of the interview) or previously had been on ART. I also selected the eligible participants who reported experiences of being in intimate heterosexual relationships. Sampling is important interpretive research because many qualitative studies involve analytic generalisations which are applied to a wider theory based on how selected cases fit with general constructs (Omona,2013). The cases for my study were included in the analysis because they provided rich information on their experiences of trust, intimacy, and how ART treatment featured in their lives.

3. 6 Data analysis

3.6.1 Narrative analysis

I adopted a narrative analysis approach to analyse the data. A narrative analysis “elicits and analyses stories in order to understand people, cultures, and societies” (Wolgemuth and Agosto, 2019, p. 1). The women in my study were asked to share stories about their experience of intimacy and relationships, and at another interaction, about their experiences living with HIV and accessing ART. These narratives were employed as a way in which the participants create meaning to their lives through their life experiences. According to Riesmann (2005) narratives can be linked to a whole life story, gathered from the interviews, observations, and documents.

The interviews with the women were a pathway for me as the researcher to gain insight to their lives as they directed me through their stories. Therefore, through analysing the stories, I was able to identify what the women considered to be of value by noticing what information they share and how they relay their experiences of intimacy and their treatment regimen. According to Polkinghorne (1995) researchers can use model reasoning to generate illustrations of themes that carry across stories whereby researchers gather descriptions of occurrences and assemble them into a story and use a plot line. This also allows the researcher to group participants experiences in an organized thematic thread. The themes that emerged from the narratives that the women shared, were thematically analysed.

3.6.2 Thematic analysis

For this study, I include 12 verbatim transcriptions of 12 in-depth interviews, along with supplementary field notes. As I was involved in the transcription process, it allowed me to have a clearer interpretation of the interviews, which assisted the analysis process. I used a hybrid approach which incorporated both deductive and inductive thematic coding to analyse the transcripts (Swain, 2018). This process involved producing pre-empirical codes that emerged from the research aims, research questions, and individual questions asked in the interviews, resulting in a series of post-empirical codes that were created from an examination of data (Swain, 2018). In turn, this allowed me to get familiar with the data and code patterns that developed from the dataset (Braun and Clarke, 2012).

I selected thematic analysis as it allowed me to identify the overall themes my project aims to explore trust, intimate relationships, and ART (Kiger and Varpio, 2020) By using Atlas.ti. a computer software programme, I could organise the data, and identify patterns present across interviews focusing on the theme of trust (Nowell., *et al*., 2017).

I employed the framework produced by Braun and Clarke (2006) and conducted analysis in six phases namely: i) familiarizing oneself with your data, ii) generating initial codes, iii) searching for themes, iv) reviewing themes, v) defining and naming themes, and vi) producing the report.

3.6.2.1 Familiarizing oneself with the data

The first phase as indicated by Braun and Clarke (2006) is about engrossing oneself in the data. I was able to follow this process through transcribing the audio recorded interviews, reading and rereading the transcripts which has already been transcribed; and made notes of the of patterns which emerged from the text (Braun and Clarke, 2012; Maguire and Delahunt, 2017).

3.6.2.2 Generating codes

The themes identified during the first step were then grouped in categories which included descriptions of participants demographic information; intimate relationships; disclosure, as well as accounts of ART treatment. The table below was used to record the codes and summarise participants responses.

Table 1: Summary demonstrating participant codes

Pseudonym	Age	Intimate relationship	Disclosure	Adherence
Participant name	Age of the participant at the time of the interview	Are they married, in a relationship, cohabitating, or single.	Have they disclosed their HIV status to intimate partners or others	Are they currently on ART/or treatment interrupted

3.6.2.3 Searching for themes

This step involved codes that was generated from my research aims and research question. (Swain, 2018). In this phase, I sorted the codes into themes. I reviewed the sections in the coded categories and extracted quotes that I could assess in terms of my research focus. These excerpts are selected as illustrative key points or arguments identified in the analysis. Additionally, I coded many possible themes as for as many potential themes as achievable that might be useful at a later stage and to ensure that context was not lost (Braun and Clarke, 2006). The themes I identified are presented in table 2 below.

Table 2: Post-empirical codes

Post-empirical codes
Description of relationship Physical intimacy Sexual intimacy Emotional intimacy Intimate partner violence (IPV)

HIV status disclosure
ART
HIV diagnosis
Condom use
Married
Single
Dating
Children
Post exposure prophylaxis (PEP)
Mother-to-child transmission (PMTCT)

Themes were analytically grouped and created based on similar quotes that were noticed in all the interviews. I identified themes within each participants narratives and thereafter I considered the relationship between themes and sub-themes. This process assisted with selecting relevant themes that showed women’s experiences of intimate relationships and ART (Braun and Clarke, 2006).

3.6.2.4 Reviewing themes

During this phase, quotes were extracted from the transcripts to support the analysis (Swain, 2018). I was able to identify how the themes were related and which themes needed to be divided into separate and smaller sub-themes. For instance, the sub-theme ‘intimate relationships’ was further divided into three smaller sub-themes consisting of emotional intimacy, physical intimacy, and sexual intimacy (Braun and Clarke, 2012). At this point I added, combined, and separated themes and also re-read the entire data set to re-examine themes, re-code data that fall under themes that had been created (Kiger and Varpio, 2020).

After this process I had a thorough overview of how all the various themes were connected and how they fit into this study.

3.6.2.5 Defining and naming themes

Braun and Clarke (2006) indicated that the next phase of analysis begins when the researcher has an adequate thematic layout of the data. At this phase, I identified the main themes intimate relationships, HIV diagnosis, disclosure, adherence/ managing ART treatment, and intimate partner violence (IPV). I considered how the themes linked to the primary aim of this study and how I was relaying the data in relation to the research question. During this process I took note of all the themes and sub-themes as they gave different meanings, and how in the final analysis it would give the reader a sense of what the data was about (Kiger and Varpio, 2020). Fig 4 below is a final thematic map that illustrates the relationship between themes.

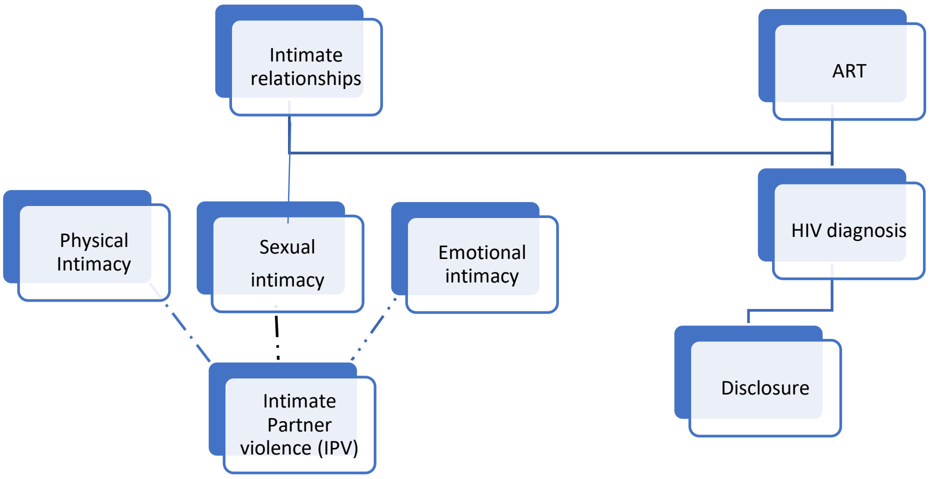

Figure 3: Thematic map illustrating the relationship between themes.

3.6.2.6 Producing the report

According to Braun and Clarke (2006), the next phase involves the final analysis and write-up of the report. All tables and summaries were also written up to provide a continued description and analysis of the participants' biographic data and relationship information to provide a holistic overview of their lived reality. The aim was to provide a rich description of the data regarding the lived reality of my participants, including their experience of trust, intimacy, and ART. In this study I provide a detailed description of evidence of the themes within the data through the examples or extracts to capture the essence of participant stories (Maguire and Delahunt, 2017; Braun and Clarke, 2012).

3.7 The role of the researcher in the data collection process

According to Braun and Clarke (2013) thematic analysis declares that no analysis can proceed with non-existence and that the researcher's background, histories, assumptions, values, distinctiveness perspectives may all impact the data collection and analysis process. The researcher's analysis and interpretations may have characteristic such as their understanding of theories, knowledge, and perceptions and/or reference systems. Even though a complete interruption of researcher influences is never possible nor enviable, the researcher is informed to make a conscious effort to become aware of their biases and previous knowledge (Moser and Korstjens, 2018).

3.7.1. Trustworthiness

Researchers use the trustworthiness to illustrate their analysis of qualitative data is legitimate. In qualitative research, the most widely accepted criteria to achieve trustworthiness is i) credibility, ii) transferability, iii) dependability, and iv) confirmability to parallel the conventional quantitative assessment criteria of validity and reliability (Nowell *et al.,* 2017). I describe these elements as it pertains to my study in the section below.

3.7.2 Credibility

Credibility concludes whether the research findings display plausible data drawn from the respondent's original information and is an accurate interpretation of the participants' original views (Nowell *et al.,* 2017). Methods to ensure credibility involves activities such as prolonged engagement, persistent observation, triangulation, and member checking (Mosers and Korstjens, 2018). I employed three out of the four strategies (prolonged engagement; persistent observation and triangulation) based on Lincoln and Guba (1985) criteria in (Moser and Korsjens, 2018).

I use secondary data from a larger study (HPTN071- PopART), but I was one of the researchers that conducted interviews with participants, to collect data. During the data collection phase, I had extended interviews with participants over a long period of time (18 – 24 months) which sometimes lasted close to three hours on one day; at times I would see participants twice a week (depending how discussions progressed), and the data collection process lasted for months in the field. During the interview process, some the of participants would carry on with their daily tasks such as house chores, making food, doing their hair, or even having visitors during the interviews and still felt comfortable engaging in the discussions. Through the prolonged engagement phase, I invested time to become familiar with the setting and context; to test for misinformation; to build trust and to collect rich data (Moser and Korstjens, 2018). After doing fieldwork, I would also reflect on the discussions I had with the participants and jot down anything that I have observed while conducting interviews that might be worthy to report. For instance, I would make a note of the participants body language or note if the participant was in a different mood compared to my last visit (and include reasons if I could) or note specific things that the participant said that I would want to follow up on. We also had extended debrief sessions to reflect with other researchers on our experiences in the field. Through persistent observation I could identify characteristics and elements that are most relevant to the study and which I could pay attention to in detail (Nowell *et al.,* 2017).

I achieved triangulation by using various data sources such as collecting data in different times (collecting data different time of the day/week/month) spaces, (collecting data in their setting) tools (interviews, observation) and persons (collecting data from different individuals) (Moser and Korstjens, 2018). Additionally, I analysed the interviews which was transcribed verbatim, translated as well as quality checked to guarantee accuracy of the data.

3.7.3 Transferability

Transferability refers to the manner which the occurrence or findings described in one study are suitable or useful to theory, practice, and future research (Moon *et al.*, 2016). According to Nowell *et al.* (2017, p.3) “the researcher cannot know the sites that may wish to transfer the findings, however, the researcher is responsible for providing thick descriptions, so that those who seek to transfer the findings to their own site can judge transferability”.

To address transferability, I provided a “thick description” by not only explaining the behaviour and experiences of participants, but providing detailed accounts of the sampling process, the respondents involved as well as the setting in which the study was conducted to ensure that the information is more meaningful to an outsider (Korstjens and Moser, 2018). I describe the various methods I utilised in the study in detail in the section above.

3.7.4 Dependability

Dependability references the consistency and reliability of the research findings and the extent to which the research processes are written up, which allows outside individuals to follow, audit, and critique the research process (Moon *et al.*, 2016, p.2).

To illustrate dependability, I attached various documents in the Appendix to show that the steps in the research study can be followed (Moon *et al.*, 2016). I include the two discussion guides that were used to collect the data I analysed (see Appendix A and B) and shown a structure illustrating the development of themes (see section 3.5.2.5). In addition, the data I used, verbatim transcripts, and fieldwork notes, anonymised, and could be made available (under strict ethical considerations and study permission procedures) should it be requested by the reader.

3.7.5 Confirmability

Confirmability is related to determining that the researcher's interpretations and findings are clearly extracted from the data, requiring the researcher to demonstrate how conclusions and interpretations have been reached (Nowell *et al.,* 2017, p. 3). According to Moser and Korstjens (2018) the researcher should link the inter-subjectivity of the data and the interpretation should not be based on the researchers own bias and viewpoints but should be grounded in the data (Moser and Korstjens, 2018, p. 122). During interviews, when sensitive topics was discussed and possible feelings of uncomfortably arise for the participants. They were given the option to be alone in a room with the recorder on and answer the questions alone without the researcher present. Also, during interviews some findings were overwhelming, and we as researchers had debriefing sessions and monthly training to assist us during sensitive interviews.

According to Moser and Korstjens, "as a qualitative researcher, you have to acknowledge the importance of being self-aware and reflexive about your own role in the process of collecting, analysing and interpreting the data, and in the pre-conceived assumptions, you bring to your research" (2018, p. 123).

3.8 Ethical consideration

In conducting this research, I abided by the guidelines that were set out by the International Sociological Association (ISA). The Departmental Ethics Committee and the Health Research Ethics Committee (HREC) of Stellenbosch University provided ethical approval for the HPTN 071 (PopART) trial (HREC: N12/11/074) as well as for this research study (S19/10/209) (see Appendix D). Additionally, since I am using secondary data in the context of the HPTN 071 (PopART) trial permission to use data for the use of this research project was granted by the principal investigators of the larger trial (see attached Appendix E). All participants in the study signed written informed consent documents (See Appendix C) and consent was repeatedly confirmed during the data collection process.

An informed consent process was followed with all participants in the PopART trial during which researchers explained: what the research is about, why the participant has been invited to participate, that the participant has the right to refuse to participate in the research and could withdraw their participation at any stage, that there are no benefits to taking part in the study, possible risks involved, who will have access to the information they provide, where the data would be stored, the contact details if participants had queries, and how the research would be reported on to ensure the anonymity of the research participants. Participants were also asked if the data collected could be stored and used for future analysis (such as this study). To protect the privacy of the participants, the interviews took place in a space of the participants' choosing. Audio recordings of interviews and field notes taken during interviews were submitted to the data team at the Desmond Tutu TB Centre. Electronic and soft copy data were stored on a password protected computer and hard copy data and consent forms were separately stored in locked cabinets in the Centre's data office. The data required for my project comprise anonymised transcripts of interviews.

CHAPTER FOUR: FINDINGS AND DISCUSSION

In this chapter I present the findings of 12 cases of women living with HIV, illustrating how trust plays a role in HIV transmission and how it shapes women's experience of intimacy in their relationships. This section will also examine how trust intersects with women's HIV disclosure process (or lack thereof) to their partners and the support they receive for managing their illness and treatment. The chapter begins with a summary of demographics, fundamental partnerships, and HIV illness characteristics of the participants.

Following the tabled summary, I present a diagram (Fig 5) illustrating the themes identified in the data. Lastly, I describe the themes with illustrative quotes. This section expands on themes on women's experiences of physical, sexual, and emotional intimacy, their understanding of trust and betrayal in their relationships, safety in relationships, including the threat of IPV, HIV diagnosis and disclosure and the challenge to trust, and HIV, ART, and support in relationships.

4.1 Participant demographics, fundamental partnership, and HIV illness characteristics.

For this study, I include data from 12 women living with HIV. Key information on each of these women are illustrated in Table 3 below. In the table, I have included the participants self-reported age, relationship status, and treatment at the time of the interview. Pseudonyms are used to ensure that their identity of participants are protected.

Table 3: Demographics, relationship status, and treatment status of women living with HIV

Pseudonyms	*Age*	*Relationship status*	*Self-reported ART adherence*
Sisanda	48	Single[2]	Yes[3]
Samantha	28	In a relationship	Yes
Rona	35	In a relationship	Yes
Adele	23	Single	Undisclosed
Nomsa	42	In a relationship	Yes
Brie	39	In a relationship	Yes
Zinzi	35	Married	Yes
Des	26	In a relationship	Yes
Lilly	31	In a relationship	Yes
Jacky	44	Married	Yes
Thandi	27	In a relationship	Yes
Kolisa	17	Single	Yes

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[2] At the time of the interview, some of the participants were not in a relationship, i.e., single but reported that they had previously been in a relationship or married and reported on those relationships during interviews.

[3] Some of the participants reported initiating ART through PMTCT (Prevention of mother to child transmission) while another reported initiating ART through PEP (Post exposure prophylaxis).

All the women included in this analysis reported having been "in love" and in intimate relationships at least once in their lives, and they reflect on these relationships during the interview. As shown in Table 4, the 12 PLHIV included in the study were, between the ages 17 to 48 years.

Amongst the 12 women, two were married; 7 reported being in a relationship, of which 3 of these women were previously married but dating someone else at the time of the interviews; and three reported being single. These relationships ranged in length between five months and 10 years. During the interviews, the participants described their relationship and 11 indicated that they have children and 6 reported a history of physical and emotional abuse from their partners (current and/or previous). This included hitting, slapping, stabbing, being kept hostage, verbal abuse, threats, jealousy, and controlling behaviour.

At the time of the interviews, 11 women self-disclosed to previously/currently being on ART treatment. 3 of which stated that they defaulted on their treatment. 4 others reported experiencing side effects of ART, which was described to have an influence on the women's experiences of intimacy. In the next section, I describe the themes which was discovered in the study and structured below in congruence with the findings.

4.2 Constituting themes

The following diagram (figure 4) presents the themes that emerged during the analysis. I include the central finding to women's experiences of intimate relationships and show how 1) trust, or lack of trust, interrelates with their experience of intimacy (2) trust, betrayal, and fidelity impacts relationships, (3) safety, including IPV which influences their intimate relationships (4) an HIV diagnosis presents a challenge to understandings of trust in relationships, (5) and how trust also (often subconsciously) informs their decisions around disclosing and managing/ asking and receiving support their HIV illness.

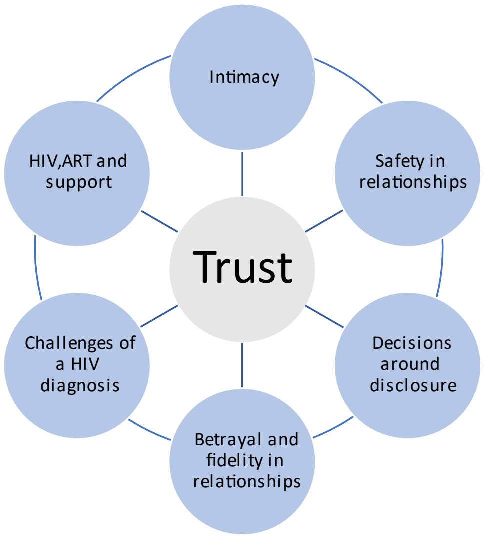

Figure 4. Organised themes of findings

As a part of the analysis, I can describe how trust is a vital component, as it affects various intimate and health aspects in relationships. The themes shown in the diagram above are discussed in detail below with illustrative quotes.

4.3 Understanding intimacy in relation to trust in relationships

Trust and intimacy are connected. Being vulnerable to experience intimacy could be difficult if there is a lack trust between partners and/or spouses (Schroeder *et al.*, 2017). In this section I describe women's experiences of sexual and emotional intimacy. This section demonstrates how trust impacts sexual encounters and how the desire for emotional intimacy contributes to relationship pressure and conflict, oftentimes jeopardising sexual intimacy.

4.3.1 Sexual intimacy is more than just sex, it is trust.

Physical intimacy is viewed as “sensual proximity or touching, being in someone’s personal space, holding hands, hugging, kissing, petting and other sexual activity” (Muniruzzaman, 2017, p. 2). For participants in this study, physical intimacy is experienced in different ways. This definition of physical intimacy is converged with sexual intimacy as experienced by women in this study. For many, they described a lack of physical intimacy in their relationships but experienced some characteristics thereof such as touch and kissing when engaging in sexual intimacy. All the women reported sexual intimacy which generally referred to penile penetration of the vagina, anus or mouth (McKinney, 2010). However, women’s experiences of intimacy varied. Some enjoyed being touch, kissed, caressed, and having sex with their partners, a few women wanted more of these elements of intimacy, while others described how they avoided intercourse. This section focuses on the sexual acts in relationships and shows how sexual and physical intimacy is complicated by other dynamics including trust.

Lilly, a 31-year-old from the Cape Winelands who had been diagnosed with HIV in 2012, was in a relationship with Sam (30). They were neighbours and started dating after Lilly and her ex-partner separated. Her family thinks Sam is a drug dealer and have reservations about their relationship. Regardless of her family’s stance on their relationship, Lilly is optimistic about her future with Sam and looks forward to getting married to him. Sam has been in prison until recently. He often tries to have sex with her and find ways to get her aroused. According to Lilly, he never forces her to engage in sexual activity like her previous boyfriend did. Lilly described how she does not really enjoy having sex, but she tolerates it. Lilly objected to sexual intercourse when she perceived it to be a mechanical act. She referred to discomfort when they engaged in sexual activity too often. She says:

> A machine, you work on a lot, I am not a machine. Don't work on me! I don't like that. And sometimes then having a lot of sex the whole time, hurts my vagina, he chafes and so on. It tears me and it is sore.

> And I don't like it. Oh no! I don't like a lot of sex. I can only ... Once is enough ... It's too much for me (Lilly, 31 years old).

Lilly resist when her partner tries to change her behaviour during intercourse.

> ... and styles [sexual position], no. Now the last time, he said to me, 'Gosh you always just lie straight like a bride [implying reticence]'. He said it to me straight Can't we... '[And] I said. Look here, don't come here with that idea' ... Then I also said to him. No. You can say what you want. Not me. I won't do what you ask of me!

Lilly is able to tell her partner what she finds acceptable in their sexual engagement. This could indicate that she feels secure in her relationship and trusts that her partner would respect her decisions when it pertains to sexual intimacy. She further suggests that she is not averse to having intercourse when her partner makes the effort to persuade her by making jokes and allowing her the prerogative to deny or accept his overtures. Lilly also reports an event where her partner tried being intimate with her. He asks:

> 'What's the matter with you now?' He was touching me. I said, 'Nothing! You can hear I said I am going to sleep now. Nothing else [is the matter]'. So, he said, 'don't be like that. Geez!' Then he put his hand over me and I was like, 'no ... we are going to sleep.' And now he's playing with my breasts. Then I said, 'no. How can I lie and you're playing? Can't you stop?' Then he said, 'just a little piece, just like a little piece or just ... like in front then it's done'. I said, 'you're [not] going to stop until you get some, hey?' And then he laughed but said, 'maybe you don't feel like it. If you don't feel like it, then we should leave it'. Then I said, 'no hu-uh, you started it already.' I said, 'first start we can finish it.' Then he asked if we were going to play tennis or rugby or what? Then I said, 'just choose a sport if you want to play a sport, but like a normal sex.' But he wanted to know which 'sport' we are going to do, if it's going to be cricket soccer tennis or what. [I said] 'let's just finish so that we can go sleep. Please, I just want to sleep because I am not into it.' And then we had sex with each other and so.

Even though Lilly has her boundaries as to what she and her partner can do sexually, it seems that her partner can find innovate ways to get her to engage in sex. He also creates trust by giving her the assurance that they do not have to proceed with intercourse if she does not want to. Although she initially resists, his approach allowed her to feel safe which led to her to feel comfortable and have sex. When trust is high, then intimacy is high. In other words, when emotional needs get met in a relationship, you trust your partner and better able to connect sexually.

Jacky, a 44-year-old mother of three who also resides in the Cape Winelands got married to her first husband, Jarred at the age of 22. After the birth of their first child, Jarred went to prison. Not too long after Jacky and Jarred welcomed their second child, Jarred was stabbed to death. She met someone else and conceived a son with him. Years later, Jacky met Chris (35) and they got married. Her current husband, Chris resembles similar characteristics to Jarred and also went to prison. Jacky describes her relationship with Chris as tumultuous, but always loving. Chris betrayed her as he moved in with another woman and her family, admitting that he would have sex with this new partner. However, from time to time, he would return to Jacky, and they would have sex. This was difficult for Jacky as she then questioned her relationship with her husband and displayed feelings of hesitation and mistrust. Similarly, to Lilly, Jacky reports her hesitation when describing one sexual interaction with her husband. She says:

> I told him [that] I didn’t feel I [should] lay in his arms but okay. Then I laid on his chest. He kissed me in my neck ... on my mouth... and I didn’t want to kiss him back. Almost like, why must I do it? I don’t know it anymore. But okay, I told myself on the inside, it is my husband! (Jacky, 44 years old).

Here, Jacky is referring to how she does not know how it feels to kiss and be intimate with her husband anymore because he has a separate life with another woman which impacts her emotional connection to him. Jacky also expresses her hesitation to be intimate with Chris and had to remind herself that he was her husband, and it was okay to have sex with him. Jacky, in a sense felt that even though Chris has a girlfriend, she is ‘his’ wife and she is allowed to share intimacy with him. In comparison to Lilly’s experience of high trust resulting in high intimacy, Jacky's experience is the opposite. As a result of Chris's betrayal, the trust is broken, which influences the change in her emotional and sexual connection with him. Jacky further explains:

> He kissed me by my groin. He told me he missed me a lot and he'll never be able to have sex with someone the way he does with me. He knows I love him. Wait, I'm his wife and I love him. So, I felt ... it's my husband... Let it [hesitation/resistance] go.

Even though Jacky and Chris are married, there is a trust gap in their relationship which doesn't allow intimacy to occur frequently. Jacky feels hurt by Chris's action which causes tension in the love she feels for him and the betrayal. This makes receiving affirmation that he misses her more significant in the fact she was then fully able to "let go" of the hurt and broken trust. Chris stating that he would not experience intimacy the same way with anyone else, and the longing for intimacy makes Jacky trust their interaction and be comfortable to have sex. Even though she expressed apprehensiveness at first, according to Jacky, she wanted to continue having sex and share closeness with her partner.

Separately, and in a seemingly contradictory move, Jacky rekindled her relationship with her high school boyfriend Simon, who is currently married. Jacky longs to be intimate with a partner but is conscious about her HIV status and possible transmission. She has not disclosed her status to him, and he wants to be sexually intimate without using a condom. Jacky states:

> My status played [a role]. I wanted it [sex] but I had my periods. If I didn't have my period, I would have asked him for a condom because he had one in the car. [And then] he said, "[w]ith you I don't want a condom" [a]nd I said, 'No!' (Jacky, 44 years old).

As she forms a new relationship with Simon, she has not disclosed her status, indicating that she does not trust to disclose that information. But by refusing to have unprotected sex, or sex on her menstruation cycle shows that there is a form of connection, and she wants to protect his health and secure their relationship by having safe sex. Similarly, Thandi (27) who is in a sero-discordant relationship for five years mentioned that she is cautious about infecting her partner. As such they try to abstain from having intercourse until Thandi's viral load is low. She mentions how she decided to postpone sex with her partner and says:

> *I decided we must not focus on sex, you know. [We must] just love each other, sex we will do it after I get better" (Thandi, 27 years old).*

Ensuring her partner's health in a sero-discordant relationship is an important element of their emotional intimacy.

Brie is 39 years of age and stays in the Southern Suburbs of Cape Town, in the Western Cape. At the age of 18, she gave birth to her daughter, fathered by a previous love interest. After a few years, she met Mpho, and they were married for 7 years. They did, however not have any children together. Due to Brie's infidelity, the couple ended their relationship. During the interviews, she mentioned that they did not have an open and trusting relationship as they hid things from each other. She is currently in a relationship for two years with a Umi (42) who is a foreign national. According to Brie, their relationship is a 'bit rocky'. She also states that he is rude and has kicked her out of the house a few times. Brie and Umi have not been sharing a bed for three months and according to her, Umi does not show any compassion and love towards her. However, she is willing to stay with him because she does not want to "go look for mister better" and knows what she is "gaining" (financial support) from their relationship and "accepts" it. Brie describes sexual intercourse with her partner as uncaring and almost mechanical. She says:

> So, this one, he's like that guy [who] doesn't care about kissing or what. [Just] sex, and then it's finished, you see? And huh that is [the] thing after finishing having sex, you wipe him, or he wipes you. He doesn't care, you see? Things like that (Brie, 39 years old).

It seems that even though Brie has sex with her partner, she makes references that he does not care to kiss her. For her, sexual intimacy includes comfort and foreplay or displays of caring, which shows the comfortable, caressing aspect of physical intimacy and characteristics of trust.

Des, a 26-year-old women, is dating Siya (29) for two years. During the interview, she reflected on her relationship with her former boyfriend, Buhle, whom she dated on and off for seven years. Des and Buhle have two children together, but both of her children are in foster care. Des still has a sexual relationship with Buhle, who is reportedly living with HIV. According to Des, he and he does not want to use protection. According to Des, Buhle says they are soulmates, and he does not mind if she infects him.

Sex with Siya is described as pleasurable, and Des described how she fully participated in sexual intercourse when he ensures that she is comfortable. She says:

> He started tickling me, started kissing my neck, things like that. And then he throws himself on top of me, then he lays on top of me and looks at me in my face and then he kisses me. And then he says words like, he loves me and things like that. Now I also say, I love you and he start to feel [touch] and make me also … rev up [getting aroused] And then I also feel in the mood. Then, we [had] sex (Des, 26 years old).

Des's partner makes her feel comfortable and caresses her before they become intimate. She further explains how Siya negotiates sexual intimacy. She says:

> I wasn't even interested in sex. He says we don't really talk; we don't say to each other when we have to do it. We write it for each other on the phone [text message]. He's laying right here beside me, or he's writing it here on top of my leg. We don't [talk about] it. I've asked him many times why not, and he says it's the way to become intimate with me, because if he's going to tell me, 'My dear let's do this', then I'll probably feel down. And he doesn't want that he wants to touch me completely with his romantic hands and body.

Here, it's also noted how Des and her partner considered emotional intimacy and sexual intimacy to be inextricably linked and might be reluctant to engage in intercourse if it was explicitly asked for or if she or her partner was not in the mood.

Zinzi is 35 years old. She resides in the Mixed Metro area in the Western Cape with her husband Sipho (36), and her family. She has two children, one from a previous relationship and a baby with her husband. Sipho has been unfaithful to her in the past and she has also admitted to having sexual relations with another man for financial reasons. Even though they have experienced distrust in their relationship, Zinzi still has her ideologies about relationships and feels that love and romance is important. She mentions that Sipho does not give her enough affection and that she would like to experience the physical aspects of relationships. She says:

> The problem is I don't become comfortable when oral sex is done to me. I can do it to my husband, I don't mind. It turns me off, it's a turn off for me yoh, when he touches me, for something. I like being loved just being touched, I like cuddling, not being touched because you want something. I think like no, I'm not open enough, that is why I didn't enjoy ... because I was supposed to really talk about it I'm not open enough the way I see it (Zinzi 35 years old).

Zinzi wants physical intimacy from her partner and does not want him to show affection only for the purpose of sex. Zinzi mentions not enjoying sex because she is not open, which could mean that she does not feel connected to communicate with her partner, and because the emotional intimacy is lacking in her relationship, it influences her sexual intimacy with Sipho.

Zinzi being apprehensive in engaging in sex could also be a result of low trust in their relationship as a cause of other aspects in their relationship. As seen with Des and Thandi, their partners can negotiate sex in their relationships. Similarly, Sipho would assist Zinzi with chores in the house and this would be an indication to her that he wants to be intimate. She mentions:

> I know that okay, tonight is the night, but we start during the day. He assists me with many things in the house and not just leave me. Then we will have sex (Zinzi 35 years old).

When Sipho responds with gestures such as helping her with household duties, Zinzi is more receptive to having sex.

Rona 35-year-old was diagnosed with HIV in 2009. She has two children. She gave birth to her eldest daughter at the age of 14 with her childhood boyfriend Joe, who was 17 at the time. She describes her relationship with him as “close” and views him “as a brother”. She has been dating Mike (45) for 14 years and they share a son together. Her relationship with Mike seems dysfunctional as Rona outlines their relationship to be filled with jealousy, disrespect, and abuse but she also describes characteristics of a loving relationship. Rona is having an affair with Tom whom she met at the nearby shebeen and indicates that she is “happy, he’s [referring to Tom] a good guy [and] he’s not scared about me [w]hen we walk [in] the street he’s not … scared” [not afraid/shy to be seen out in public with her]. At the time of the interview, she does not elaborate much about this relationship, other than that Tom is also in a relationship and that she would like to keep the relationship hidden from Mike.

In contrast to Zinzi not feeling comfortable with different kinds of sex, Rona indicates that she has had “all kinds of sex” and finds it “romantic” if Mike performs oral sex on her, because “not all guys do that”. Regardless of her sexual experience, she feels that men should be gentle with women and handle them softly. She says, “men should not be rough because it hurts our bodies”. Rona also mentions that she and her partner would not have sex thrice a week if she is tired, and that he would always have condoms. This could imply that she and her partner are intimate regularly. The fact that Rona’s partner always uses condoms could indicate that there is a level of respect for each other as they are concerned about additional infections. It seems that Rona could also inform her partner when they could be intimate. She says:

> If feel I want sex, then a man can get [it] if I’m wanting. But if I’m not in the mood, then I am not (Rona 35 years old).

Here, it could be noted that Rona can communicate with her partner as to when or how frequently they can be intimate and negotiate with her partner the sexual activities she is comfortable with. This could indicate openness and vulnerability in their relationship.

The findings on physical and sexual intimacy illustrates that intimacy between the respondents and their partners include much more beyond the physical act of sexual intercourse. An additional factor which the participants refer to is emotional intimacy.

4.3.2 Women's experiences of emotional intimacy.

Emotional intimacy is widely understood to allow connection, trust, and vulnerability within romantic relationships, and is considered a key characteristic of healthy relationships (van de Rijt and Buskens, 2006). Without emotional intimacy, other forms of intimacies – physical and/or sexual – are often disrupted. Umberson, Thomeer and Lodge (2015) found that when women in long term relationships can communicate openly and effectively with their partners, emotions of closeness, and sexual desire for their partners, are increased.

This section focuses on how emotional closeness and trust affects sexual intimacy in relationships. In my analysis, women sought, but seldom experienced, emotional intimacy in their current and/or previous relationships. Past and/or ongoing infidelity, violence, and substance abuse impacted negatively on the quality of relationships of my participants.

For example, Kolisa, who is 17 years old and was born with HIV has been sexually active with boys but has never disclosed her HIV status to them. At the time of the interview, she and Julius (19) has ended their relationship, but she reflected on their relationship while participating in discussions. According to Kolisa, her relationship with Julius was very playful, and caring. They would treat each other on dates, and he would buy her gifts. But later in the relationship she found out he was cheating on her, and they broke up. Kolisa describes feeling connected to her partner and links emotional intimacy with sex. She says:

> When you [are] doing it [having sex] with a person you don't love you won't feel it, or you won't be in the mood of this thing you [are] doing. You must feel this person is doing this thing [having sex]. You

> must love him. You must have a feeling here on your body when you make love, like you are melting (Kolisa 17 years old).

It seems that for Kolisa, to be sexual intimate, she has to have an emotional connection to her partner and trust him otherwise she would not enjoy having sexual intercourse.

Lilly (31) who was described above, also mentions concerns about transmission and would want to use condoms when being intimate with her partner Sam. She says:

> We are not going clean [without condoms], so safety yes. When it comes to intercourse, we [have] sex now and then. I say to him: condoms! He is not going to be like 'yes', but I still say 'no'. He gets tired of using condoms all the time (Lilly 31 years old).

Lilly is also well informed about additional infections, and she insists on using protection with Sam. During the interview, Lilly also expressed fear of her partner leaving her because she always insists on using condoms. Lilly also mentioned her concerns that due to her positive diagnosis; she is afraid Sam might leave her for another woman to have sex with her without a condom. But other than her fear of Sam being with someone else, Lilly also reported experiencing openness with her partner. According to Lilly, when she has family troubles, or concerns about her diagnosis she can confide in Sam, and he would be supportive. She says,

> I [tell] him everything. We sat and talked first. I opened up to him. We share everything with each other. As friends, we help each other.

Lilly does not only see Sam as her partner but refers to having a friendship as well. She indicates that she does not have other friends that she trusts disclosing her HIV status to him, and that Sam was very understanding. Lilly says that he accepted her status and discussed ways to manage infection.

In contrast to Lilly (31), Zinzi (35), who is married to Sipho, describes a lack of emotional intimacy with her husband. She explains,

> [I understand emotional intimacy] as caring for me, like you see, when you have painful thing then someone is able to ask that 'are you alright? How was your day?' It's things like that you see, those things. It's small things that [your partner does that make] you think you are not valuable, it's [what] makes you to be in love, to be enough like kissing someone when he comes from work and when he is going [to work]. It doesn't happen in my house (Zinzi 35 years old).

Zinzi connects emotional intimacy with physical intimacy. For her, to feel cared and loved for, she would want her partner to acknowledge her emotions and show interest in the small things in their relationship.

The discourse on emotional intimacy shows that when trust is present, in turn emotional closeness is greater and when this occurs, other forms of intimacy is enhanced. However, if mistrust features, it may hinder intimacy in relationships.

The findings reflect the results from Rhodes and Cusick (2000) which indicates that intimacy, is an important aspect in relationships that are perceived as trusting, loving, and secure which also influences transmission risk. As seen in the data, when women experience trust and attributes thereof with their partners, sexual and physical intimacy is easier for them to engage in. Similarly, Schroeder *et al.* (2017) notes that relationships that have an increase in intimacy experience great passion, sexual satisfaction, and stronger commitment. When women are comfortable, able to communicate their concerns, negotiate and compromise on sexual intercourse with their partners, their encounter was more satisfying. When the women reported dissatisfaction with their physical and sexual intimacy, it caused tension in their relationship as some women craved emotional intimacy in their relationship. This may indicate that satisfied intimacy is important in relationships as it may lead to connectedness with partners. This matches findings from other authors (Gamarel and Golub, 2018; Fahs, Swank and Shambe, 2019; van Lankveld *et al.*, 2018) who noted that sexual intimacy consists of trust and vulnerability with a significant other and closeness is coupled with other forms of intimacy.

Intimacy is vital to share feelings with a partner, as some individuals tend to feel lonely and isolated irrespective how satisfying their sex life might be. The more a couple experience physical and emotional intimacy, the more fulfilling their sexual intimacy becomes.

The findings also show that women can negotiate condom use with their partners, which plays a role in how women protect themselves and their partners against HIV infections and reinfections. In contrast to other studies which indicates that condom use amongst couples may raise questions about partners commitment to monogamy and generates feelings of distrust between partners (Aventin *et al.*, 2021), this study reflects that the motivation to engage in safer sex practices is not solely dependent on the individual, but also dependent on the shared concerns and beliefs of couples. These findings are similar to those by Chapola *et al.* (2021) which found that for women living with HIV in relationships with partners also living with HIV, the main reported reason for condom use was concerns that their viral load would increase if they had unprotected sex.

Women in this study also observed their and/or their partner’s support as indication of a loving, caring and committed relationship. For instance, one woman (Thandi) explained that she and her partner could openly talk about abstinence to prevent transmission. Another woman (Zinzi) explained how her husband does not ask about her well-being and take interest in her health and described his actions making her feel unappreciated and not loved. Partner involvement is seen as a form of trust in intimate relationships, absence of a partner’s support signifies a lack of love in that relationship. According to Chapola *et al.* (2021) partner support is shown to have a positive effect on women’s health management. Therefore, it is evident that trust influences how couples engage in intimacy in relationships, and in turn these relationships act as a product where these women draw on many influences that shapes the outcome of their relationship and well-being.

4.4 Understanding trust and betrayal/ fidelity in relationships

The following section explores how women expresses their feelings of trust in partnerships once they experienced betrayal. The connection between trust and betrayal acts as a basis for how they act and construct their ideas of intimacy in their relationship.

Infidelity was common amongst the participants where eight of the twelve participants reported their partners being unfaithful and two indicated that they were unfaithful in their relationships. For some of the participants, when cheated on, trust becomes the hinge on which their continued relationship with their long-time partners rotates. After experiencing infidelity in their marriages, Nomsa (42), Sisanda (48) and Jacky (44) continued their relationships with their intimate partners, but also entered relationships with other men. However, the betrayal in their relationship continues to affect their perceptions of relationships with their husbands and/or their new partners.

Nomsa is 42 years of age and resides in Khayelitsha, Western Cape with her family. She was married to Joseph (47), and they have 2 children together. At the time of the interview, Nomsa and Joseph was separated and she was in a partnership with another man. Nonetheless, she referred to her relationship with her former husband a lot and mentioned that she would possibly ‘take him back’. Joseph was in the military which resulted in him being away from home often. During their marriage, Joseph was unfaithful multiple times which led to their separation. As a result of his infidelity, Nomsa does not trust him. She says:

> You’re no longer interested like before because you know this love we are making...I’m sharing it with somebody else. So, there’s nothing to be excited about because [there is] somebody else also. It’s like, uh you will see that there is someone in this relationship [her husband having an affair]. You will have that hope that maybe this year he’s [going to] change. Then each and every month or year you got that hope [that he would stop cheating], you are giving hope, but your emotions drop (Nomsa 42 years old).

She connects trust with sexual intimacy and because she does not trust Joseph, she cannot have sexual intercourse with him, even though she hoped that their relationship would change. Due to Joseph's constant infidelity, her desire for emotional and sexual intimacy with him starts to minimise.

Nomsa reflects on a previous sexual encounter when they were still married and says:

> Oral [sex] my husband did it, he liked [it] but the relationship was already a mess. So, I didn't enjoy it. [Sex is] something I want now but when I was in marriage, uh it was a kind of a need. There was that pressure of him counting the weeks, the days [and] the months. So, you've got that mentality of being a wife. You have to have sex whether you like it or not. [But] it's not straight forward. Look, you trust someone right, let alone the fact that you didn't trust him, but you kind of trust him in a way. Then you find out that. No, this person doesn't give it a try so he can change right.

Nomsa felt that she was obligated to be sexually intimate with her husband because they were married, but they did not share enough emotional intimacy for her to see that he cares and wants to work on their marriage. This is also an indication that if trust is not present, all forms of intimacy may be compromised.

Nomsa has also been dating Henry for five years and according to her, the relationship is unfulfilling. When they are together, things are awkward between them and therefore refers to their relationship as "casual" and "not serious". She explains:

> I'm coming from the marriage so even the age now, I'm getting old so I can't go on with [a] causal relationship so somewhere somehow [I] must have a steady relationship. Even if it means I'll get back [with] my husband (Nomsa 42 years old).

Nomsa's narrative suggests that she desires the stability that comes with being married. It also reveals that she may be reluctant to have a causal relationship because she is older and might have concerns whether dating casually would be socially acceptable or emotionally fulfilling.

As mentioned above, Jacky (44) and Chris (35) are married, and he cohabit with his girlfriend most of the time. Jacky no longer experiences a connection with her husband but still yearns for one. She reflects on a previous incident with him, where her attempt at intimacy with him was rejected. She says:

> We lay and we play, and we talk. We were alone here. And I sat on top of him. Nothing [He has not reacted to her wanting to be intimate]. I can't describe it. It was heart-breaking for me. I was crying inside, and I asked the Lord to take that away! That feeling that I still have deep within. [But I] care, it's part of providing because who is going to provide for [him]. I tried my best, tried to like, buying him [things] and loving him like a wife should. I'll come from work and make food, everything is right, you know. But it was just not enough (Jacky 44 years old).

Jacky feels isolated in her relationship and wants intimacy in her marriage. She is vulnerable and wants to feel wanted, loved, cared for and be a provider. As such, Jacky does good gestures to show her love and appreciation, but those feelings are not reciprocated. With being rejected emotionally and not trusting her partner with her feelings, she withdraws herself from the relationship.

Jacky evaluates her connection with her spouse and identifies that she does not 'just' want sexual intimacy 'without' emotional intimacy. She says:

> I think but why must I still have sex with this man? The feeling isn't there anymore, but I still love him, now [how] do I describe that? I told him, "You are abusing me not physically but emotionally, so it's a grudge that I'm building up in myself. Why am I still allowing it?

Jacky realises that she wants more out her relationship and in turn, trades her feelings of 'emotional connection' to 'emotional abuse'. Due to her love and affection being rejected, she seeks intimacy elsewhere and rekindles a relationship with her childhood boyfriend.

She says, he tells her things like "You are what I'm looking for in a woman". Reflecting on what has been said, she asks:

> Why must I hear that from another man? I want to hear it from my own husband. That satisfaction, that safety. I don't know how I can describe it for you, but I really wanted that in him [husband] (Jacky44 years old).

Jacky continues to reflect on her current relationship and says:

> I feel touched by him [boyfriend]. I feel safe with him and. I trust him.

Jacky reiterates that she wants intimacy in a relationship, where she feels safe and loved, and by experiencing those feelings makes her trust her partner. But being in a relationship makes her question why her husband could not appreciate and love her the way her boyfriend does.

Most women reported to wanting to have loving relationships with their partners and if they were not connecting with their partners, they would find intimacy with others.

Similarly, to Jacky, Sisanda (48) experienced betrayal in her marriage. At the time of the interview, Sisanda was not in a relationship but has reflected on her past relationships and reported on those experiences. Sisanda was 13 when she met her first love at school, she fell pregnant at 16 and they got married. Her husband James began drinking, was unfaithful and abusive, which lead to their separation. Years later, Sisanda met another man, Zinko (33) whom she describes as "the right one" and "no one like him". According to Sisanda, Zinko treated her well and they had trust in their relationship. She was expecting Zinko's child but sadly he passed away before she could tell him that she was pregnant. Years after Zinko's death, she briefly dated Thando. He had similar characteristics to her first husband which resulted in their breakup For Sisanda, trust and openness is important in a relationship. She says:

> A person should be open with your partner, because if you are not open you would create tension in your relationship and have fear (Sisanda 48 years old).

Sisanda caught her former husband James being unfaithful to her, which broke her trust and resulted in them drifting apart. She says,

> I trusted him very much. I thought I knew him, and it turned out I didn't know him. [After he cheated] I never trusted him anymore though. Do you understand? No one was saying the right things for me and even himself, if he speaks, he just throws the words the way he feels like throwing you see. Trust...it got lost like that.

Sisanda expresses that trust was broken between her and James and they would say hurtful to each other, which caused intimacy to be lost. In contrast, Sisanda further explains that she shared great intimacy with Zinko and that they had good communication and understanding. She reiterates:

> The thing is to be open; you see. As a person you mustn't have things that...you cannot share to your boyfriend you see. Those are the other things that makes your relationship to be tense. Sometimes because you have got things that you have in your heart. This thing we are hiding we would put everything on the table and solve it at that moment. No matter how bad it is, no matter how it is. It's ours together, it is not for someone else. We don't want a third person [outside influence] we are going to solve it together you see (Sisanda 48 years old).

When applying social constructionist perspectives to this research, it is evident that "trust is a gamble, and a risky investment" (Luhmann (1979, p. 24) for women living with HIV in relationships. For instance, women in this study takes 'risks' as they 'rely' on their significant other to be faithful in their relationship which in turn is a representation of 'trust' which in essence is a 'gamble'. Social constructionism helps to interpret how women experience trust on a cognitive, emotional and behavioural level. Particularly with regards to decisions around whom and when women disclose their HIV status, their feelings of trust and betrayal in their relationships, and how women engage in intimacy. As the findings illustrate, the participants have experienced infidelity in their marriage. Through infidelity trust was broken which had an influence on the women's perception and experiences of intimacy. For participants, having sex is connected to emotional closeness and they did not want to experience sexual intimacy without the emotional connection. When they do not experience closeness with their partners, this leads to feeling rejected and alone. As such, they tend to seek connections with other individuals. These findings are in agreement with those of other studies who also found that sexual intimacy influences emotional discrepancies in relationships, especially for those who wants more connectedness with their partner (Gamarel and Golub, 2018) and if closeness is not mutual, trust and communication may be broken which may affects couples' relationship status (Green *et al.*, 2018). Jacky (44), Nomsa (42) and Sisanda (48) have all found other partners, who they trust and share stronger intimacy with.

Trust and intimacy play an important role in long term relationships, it may 'make or break' a union. Other than intimacy, safety, and intimate partner violence (IPV) also influences trust in relationships.

4.5 Safety and violence in relationships

In this section I describe participants experience of safety in their relationships. Intimacy in relationships is by definition a sensitive matter, and even more so in relationships where one partner is living with HIV. Women who are diagnosed with HIV are at higher risk of experiencing violence in their relationships.

Many of the participants reported physical, emotional, and verbal abuse in their relationship. Most of the respondents retaliated by returning the assaults and reported staying in the relationship for years. Some were able to break away from their abusive relationships while others tried and worked it out because they expressed that they loved their partner, regardless of abuse.

Sisanda (48) experienced emotional as well as physical abuse from James. According to Sisanda, when James is drunk, he would threaten her with a knife, and she realised that she would either get hurt or die and nobody would support her. Sisanda constantly had to deal with violence on her own and she described how she thought she would be seen as if she was "in the wrong". She describes one instance:

> One day I was working night shift. [When I came home] I found him sleeping with a girl. We argued and fought, and it was that thing, I am telling you that I got beaten up instead of getting help on this thing [attack/ violence]. So, what he is doing is right? [She means because she was beaten and nobody helped stop the fight, that his infidelity is seen as appropriate], is it right? if you are tired of me, why don't you say so? You, see? I decided I must get out of that relationship. I stayed on my own (Sisanda 48 years old).

Sisanda suggests that because she was assaulted when she objected to his cheating and nobody stopped the assault, James's infidelity was deemed socially acceptable. She recognised that her relationship was abusive and decided to withdraw herself from the relationship. Similarly, Rona (35) reported being in an abusive relationship with Mike for years. She, however, tried to leave the relationship and find a better companion. She described the mutual abuse in the relationship:

> No, what love? You get tired of the love because other guys want to see you then you have a scratch in your face (Rona 35 years old).

Rona has been physically abused in her relationships, but also indicates that she used to retaliate. She explains:

> I used to [hit] him. I didn't allow myself to be hit.

Rona says when she went to the shebeen she would come home and "look for trouble", then physically hit her boyfriend first and "throw him down" on the ground and they would get violent. Rona also mentions a previous altercation where her partner hit her and gave her a black eye because she rejected his marriage proposal. In the interview she pointed out scars and described how he pulled her hair from her scalp. Rona's relationship was violent, and it seems like, for many women, abuse was the norm. Experiences of abuse in intimate relationships can have long term affects such as physical and mental health consequences for the women (Meskele, Khuzwayo and Taylor, 2021). Abuse is also highly emotionally charged; it raises questions of trust and loyalty which may later affect sexual connection.

Des (26) experienced violence throughout her life and explained that the reason for her children being in foster care is because she wants different life for them. She says:

> I want them to have a better life ... better than my life. I don't want them to grow up the same way that I did. Like I grew up among this swearing and the fighting and the scolding and stuff like that. My dad assaulted my mom [and] my mom time and again stabbed my dad (Des 26 years old).

Des has also experienced abuse in her relationship with her children's father Buhle. Their relationship is very unstable as he has been unfaithful to her a few times, but she reported that she was still involved with him. She explained their violent relationship:

> Well, the first time that me and him started dating we were like a normal couple. And [then] he started getting aggressive. Jealous of any person that would talk to me...man or woman. He would ask, "Are you talking [to] other men?" [And] then he started to hit me. Like the day before yesterday he choked me. He doesn't choke me to give me a fright. He chokes me into a fit [seizure] on the ground! He doesn't want me to [be] happy. He wants me to sit at home and watch him.

Des mentions that when she was pregnant, she had to go to a safe house until she was due to give birth because she was afraid that he would hurt her. Des mentioned that she is not in love with Buhle anymore, but she is afraid of him. She says:

> I must go sleep worried every night. What am I going to hear tonight. Am I going to get hit? Am I going to get scolded?

Des however, continues to say that she is planning revenge and states:

> I am really going to burn him with boiling water! He is going to think I am making coffee then I am not making coffee. He will still sit then he won't be sitting anymore. I am going to do it, because it is the

> second time that he choked me like that. He hits me [until I am] unconscious, or he kicks me. I am tired! I am going to burn him. I am that [spiteful]. I will burn that shack (Des 26 years old).

Des's relationship can be described as unhealthy, abusive, and controlling. Even though Des mentions she does not love her former partner anymore, they still have relations. Both Des and Buhle are violent towards each other. She comes from an environment of abuse and is afraid that if she ends her relationship with Buhle, the violence may lead to critical injuries or death.

Similarly, Lilly (31) was in a mutually abusive relationship with her previous partner. She describes a physical fight that occurred between her and her former partner when she found out he was cheating on her. She explains:

> He wanted to put his hands on me, hit [me] and so on. Then I hit him back [and] then I ran to the knife drawer, and I said, till here and no further! I was still pregnant when he [hit] me the first time.

When Lilly saw her former boyfriend talking to another girl with his hand around her waist, she confronted the two of them and wanted to assault the girl.

> I went home and went to fetch a knife. Uhm I am going to start a stabbing here now. And [the girl] went to fetch her mother ... but she didn't come outside. I would have stabbed her (Lilly 31 years old).

Lilly reported violent incidents with her former boyfriend which she has not experienced with her current partner. Despite the violence with her former boyfriend, she still described it as the one time that she was in love. Romantic jealousy and violence are commonly, and in some instances normalised. However, romantic jealousy negatively impacts the quality of trust in intimate relationships and leads to significant risk factors for women to experience violence.

Similar to Lilly, Jacky (44) described being physical and emotionally abused by her first husband, Jarred. According to Jacky, he was unfaithful in their marriage and only allowed her to be outside of the house to see her family. Other times he would lock her inside of the house and be gone for the whole weekend. Jacky said she stayed with him because she loved him and had children with him. Even though Jacky experienced abuse from Jarred, she still considers him to be her 'biggest love'. However, women have different experiences and ideas of love. Therefore, for some women, abuse is acceptable in their relationships.

According to Rigby and Johnson (2017), men who are more at risk of having HIV are more likely to exhibit violent behaviour. The authors imply that transmission is more likely to occur in relationships where violence is present. Intimate partner violence often escalates in relationships where there is infidelity and frequent disagreements. However, the majority of women in my study selected to stay in their abusive relationship because they stated that they loved their partners, even though trust, commitment, compassion and characteristics of emotional intimacy may have decreased or disappeared. According to Davis *et al*. (2021) traumas may interact with women's experiences of IPV and women who experience abuse, may also experience attachment insecurities, which is seen in my study. Furthermore, there are similarities to the findings presented by Campbella, and colleagues (2008) who found that physical abuse is the most extreme form of IPV. The data in my study suggests that while some of the women feared the men and had stopped trusting them, they still perceived these men as their "biggest loves". Research from South Africa indicates that love is constructed in diverse ways and for some, love can coexist with violence, and love may condone male dominance and IPV (Ruark *et al.*, 2017). Moreover, women may see violence from trusted male partners as normalised (Stern, Buikema, and Cooper, 2016). The co-existence of such contradictory emotions may explain the reluctance of some of the women to leave their partners, even when subjected to emotional and physical abuse.

However, some women may decide to leave their abusive partners and find another partner. The harmful consequences of IPV among women living with HIV, have shown to have effects on women's mental, emotional, and sexual health, which increases their risks for additional infections (Mannel *et al.*, 2019; Rigby and Johnson, 2017; Meskele *et al.*, 2021). In many cases, IPV is also the consequence of HIV disclosure (Fiorentino *et al.*, 2019; Mulrenan *et al.,* 2015) and therefore, intimacy and trust also becomes challenging.

4.6 HIV diagnosis and the challenge to trust and disclosure

In the following section I describe how women became aware of their HIV positive status. In this section I also explain how participants experienced disclosure to their partners and close networks. Furthermore, it has been suggested that disclosure of HIV status to specific individuals can assist a person to come to terms with a positive HIV diagnosis (Bella, Aggleton and Slavin, 2016). Careful disclosure can facilitate conversation with partners about affection, intimacy, and safe sex, provide emotional relief and practical support from significant others and close networks, and make it easier to receive HIV-related health care treatment (Sanga *et al.,* 2021; Bella, Aggleton and Slavin, 2016).

Most participants reported that they found out they were living with HIV when they were pregnant and went for antenatal care. Sisanda (48) indicated that she was not certain how she acquired HIV and Brie (39) described herself as ‘careless’ in her sexual practices prior to her diagnosis. Jacky (44) reported receiving her diagnosis during the PopART household HIV testing intervention. While she consented to testing for HIV with her family, she says that she received her positive results in front of her adult children which was embarrassing and hurtful. She continued to say that both her and her husband Chris (35) was tested on one of the days when he was with her and not with his girlfriend. Jacky was tested twice for confirmation. She explains the event:

> Chris came back from the room then they told him: “But Mr have AIDS”. Then I told them, I have my period, can’t it now be that? I told her [community health worker] it’s probably my period and then they tested again. And then it was the same [results] again. My children stood here, and they told him [Chris] his results and my daughter asked me: “Is it so?” And then…I didn’t have words anymore (Jacky 44 years old).

Jacky not being able to respond to her daughter after receiving her results and requesting to be tested indicates that she was in disbelief about her results. The results also lead to the realisation that her partner was unfaithful and/or was not truthful about his HIV status and transmitted the disease to her. Her trust in her partner was affected and the consequences of his actions lead to broader embarrassment and health risks.

Similarly, Lilly (31) also learnt about her HIV status through testing with health worker. Lilly was five months pregnant when she went to the government clinic because she described experiencing her vagina itching and burning when urinating. This was when she discovered that she had syphilis. Her first reaction was not to suspect her partner of being unfaithful, but that to explain that she did not use public toilets and therefore could not have picked it up from there. Only after thinking it through did she conclude that her partner was cheating on her. She described how he had sexual relations with other women and says:

> He came back with that [condition, likely STD] without maybe washing himself or something. And then he wants to [have sex] with me, with that same thing [penis] that he just used with that other person. He comes to me, and I am pregnant! (Lilly 31 years old).

Lilly confronted her former partner about her infection and reiterated what the healthcare worker told her. She explains:

> I showed him my box [medication], the pink and white [medication] that you push up into your vagina. They explained to me the first time you will be healed but if you switch over to uh HIV you will get sicker if you keep on like this [if she continues having unsafe sex] because you're coming here the whole time. I was there for the second time [that she went to the clinic because of symptoms].

Later, Lilly went to the clinic again for prenatal care, she was tested and diagnosed with HIV.

Rona (35) found out that she was living with HIV in 2009. She does not specifically say where she might have contracted HIV but mentions her partner “messes around a lot” with girls and he was the one to tell her to go to the clinic. Rona explains that she was itching and had rashes and according to her:

> It felt like something is eating me from the inside [in] my blood [they tested me] and asked me if, I was sure. Then I said, No problem because it's part of life. I won't cry, it won't hurt me. It's part of life, what happened happens. Really! And the results came. [it was positive] I started to smile [and] I say thank God, I [wasn't] even shocked. I smiled. Now I can eat my pills (Rona 35 years old).

Rona was aware of her partners infidelity and when he told her to go to the clinic, she was both mentally and emotionally prepared for an HIV positive diagnosis. Therefore, her experience of betrayal in her relationship allowed her to not be surprised about the additional betrayal of learning about her HIV status.

Des (26) reports different conflicting scenarios of how she was diagnosed with HIV. She first explains that she took her former partner to the clinic in November of 2015 because he was not well. According to Des, she did not "want to live with a man who gets sick out of the blue." After a rapid test at the clinic, the health workers revealed his HIV positive status in front of her. She says:

> So, it is there that I said the same day that they also [have to] test me. They tested me and said I also have the virus. I looked at him and cried. I stood up, walked out, and left him just there [at the clinic] (Des 26 years old).

In another discussion, Des described how, in 2015, she tested negative for HIV after she gave birth. However, she then continues to say that in December of 2016 she overdosed on medication [suicide attempt] and was admitted to the hospital. She was then tested and diagnosed with HIV. By Des reporting different variations of her diagnosis experiences, could indicate her difficulties in accepting her status and the accompanying disclosure narrative. She was not expecting to receive the same HIV diagnosis as her partner, Buhle, and thought he could have a different illness. His silence about his diagnosis could be viewed as betrayal in their relationship. When male partners do not disclose their HIV status but lead their female partners to find out about the transmission of HIV through testing, it raises further questions about trust in relationships.

In contrast, Nomsa (42) mentions that she suspects that her husband infected her with HIV knowingly. According to Nomsa, Joseph found out he was living with HIV when he tested positive at work. He would get tested regularly as he was in the military. Nomsa explains that she went to the clinic and tested positive. She says:

> I heard over the radio right, so I went to the clinic. There was a container [prefabricated testing site] there, so I did a voluntary testing there and the results were positive (Nomsa, 42 years old).

Nomsa confronted her husband and he admitted that he knew he was living with HIV, but he did not know how to tell her.

In 1990 Sisanda (48) found out she was living with HIV and started treatment in 1999. According to her, she is not certain how she acquired HIV. She says:

> I am not sure where I could say I got it from. I don't want to lie and say, I got it from [my son's] father [James] or from [my daughter's] father [Zinko, who has passed away]. No, I don't know, I don't know when and what time I could say I got it. Or maybe it was long in my body or because of my strong immune system or it didn't show itself at that time. (Sisanda 42 years old).

It could be assumed that she knew that James transmitted HIV to her, but she does not explicitly want to acknowledge it. She makes references that she could've had the virus, but it may have just been undetected. Sisanda also revealed that when she had shingles, Zinko (33) went with her to the clinic for support. According to Sisanda, after waiting three months her result for HIV came back positive as HIV test results took much longer in the early years of the epidemic. Sisanda informed Zinko about her HIV positive status and according to her, he refused to get tested himself and she explains what he said:

> [Zinko said] No! I won’t have your HIV, you better stay with it.

The fact that Zinko refused to test, could indicate that he was fearful for the outcome and/ or was aware of his positive status and did not want to disclose. His refusal possibly also created doubt and distrust and therefore Sisanda was uncertain as to who transmitted HIV to her. Alternatively, Sisanda revealed that her former husband, James, remarried, and his wife then passed away from AIDS. Moreover, this pattern of women being diagnosed with HIV in a healthcare setting with their partners, who have not disclosed their status still raises questions about the level of trust, vulnerably, commitment and openness existing in intimate relationships.

Trust influences fidelity, betrayal, disclosure and ultimately impacts an HIV diagnosis, in the sense that women have to go for an HIV test which raises questions of unfaithfulness and mistrust. For many women, receiving an HIV diagnosis was a shocking and hurtful experience. Furthermore, the women’s reactions suggested that they found out about their partners (often suspected) betrayals and affairs through HIV testing. According to Maeri *et al.* (2016), men are concerned about the consequences of their infidelity being exposed, thus, they do not easily disclose their HIV status. Moreover, the majority of the participants in this study was diagnosed with HIV in the presence of their partner or their partners urged them to go to the clinic for HIV tests. For instance, Nomsa’s husband was unfaithful, kept his HIV status from her but encouraged her to go to the clinic where she was diagnosed with HIV. Furthermore, HIV testing could imply that the partners either entrust their results to be the same as their partner or use testing as a method of disclosure. These findings are similar to the study by Crowell and Emmers-Sommer (2001) study, where they found that the longer a person was in a committed trusting relationship and viewed their relationship as ‘safe’, the less likely the individual feel that they are vulnerable to HIV. The findings also relate to those of Mindry *et al.* (2011) who found that men often depended on female partners to test as a manner of determining their own

HIV status. People have diverse experiences of disclosure and often, couples feel that they can openly reveal their HIV status, and other times revealing an HIV discussion with a partner alone can be dangerous (Mindry *et al.*, 2011).

Furthermore, disclosure is described as stressful, people living with HIV would maintain control over the disclosure of their HIV status – who they can trust with this information and under what circumstances information is shared (Bella, Aggleton and Slavin, 2016).

After the women were diagnosed with HIV, most experienced fear of disclosing because it may have negative impacts such as rejection, isolation, or even avoidance. As such, similarly to their male partners, they also chosen specific people to disclose to. Generally, the women in this study revealed their HIV positive status to at least one other person other than their partners. At the time of the interview, most of the participants reflected on their steady relationships. Five of the women were not in the same relationship in which they became aware of their HIV status and had to manage disclosure with their new partners, whereas two of the participants were still in relationships with the same partners. Four of the women indicated that they did not disclose to their partners but have shared their information with close family members and friends. This again raises the question as to what the participants relationships are like, what their relationships signify when they disclose to their partners or not, and what their reasons for disclosure are.

Some of the participants felt it was an important decision to disclose their status. They explained that disclosure was important because they had experienced ‘not knowing’ their significant others’ status. Some women reported to verbally disclosing their status, whereas others would not explicitly verbalise their diagnosis to family and friends but would leave hints such as openly displaying their ART medication. Others would not disclose at all.

Brie (39) mentioned that even though she was not sure how she acquired HIV, she had a suspicion that her former husband, Mpho has transmitted HIV to her. According to Brie, she has not gone for testing until he mentioned her "showing funny signs" and had to "get checked out". She describes him having shingles in 2006 and then years later she had boils and was diagnoses with HIV in 2015. Brie however states that Mpho never disclosed his status, even though she revealed hers to him. Brie has not disclosed to her current partner Umi. According to Brie, his behaviour causes her to distrust his potential reaction to such news. She says:

> My reasons for me not wanting him to know is that I see that he is also rude! Like it's about three times now throwing me out of the house, so you see. I also told myself that, no, there's no need to show who I am. Let me just keep it this way and then continue the way we are. We're in love [and] everything is nice. And the way things are happening now I don't want to tell him. Let's just keep it this way. If we are already using condoms, we are right on that side because I don't know what will happen in the end (Brie 39 years old).

Brie is afraid of how her status might affect her boyfriend and their relationship and she does not want to disrupt their relationship by disclosing her positive status. She also feels that using condoms is a safe method of protection, both as a form of avoiding disclosure and protecting her partner and herself from infections. During the interview, Brie said that she does not experience love and compassion with Umi (42) and only with him for financial reasons. Brie being uncertain what would happen in her relationship which could be interpreted as an ending to her relationship. Therefore, it could be assumed that condoms are more prominent in her relationship due to infidelity, lack of trust, nondisclosure and as a form of protection.

Similarly, Sisanda (48) also states that an individual should disclose their status. However, she contradicts herself and mentions people not disclosing in general, due to fear of being 'dumped' (partners ending the relationship). Sisanda only indicates disclosing to her boyfriend. She however makes references about community and disclosure and says:

> Even here in the community it's not easy to disclose. People around here don't disclose. It's the main thing they don't even bother to disclose so I don't think they use protection. They don't even care (Sisansda 48 years old).

Sisanda also indicates that fear could have an influence regarding disclosure, she says:

> What can I say you want to be like another person I don't know because I see it [as] complicated when a person for example discloses, he will get dumped, there are many things that people think of, they don't think about their lives they think of someone else. Even though a person knows the situation they are into, you, see? They ignore their situation. Like preferably for me, a person should disclose you see. To think telling a person that I am HIV positive, take it or leave it. You see, not being honest with a person, you see that's not love.

Here Sisanda points out that people don't use protection and frames their actions of no protection and nondisclosure as not 'caring'. In contrast, she references fear of disclosure but also mentioning people should accept her positive status if she discloses because dishonesty is not love. Therefore, Sisanda's thought could also be highlighted as 'caring' as she considers disclosure as an act of 'love'/ respect.

As Sisanda (48) points out, that people are afraid of disclosing, Kolisa (17) expresses the same concerns. Kolisa's family knows that she is living with HIV, and she has only disclosed to one school friend. Kolisa has stopped her ART treatment and lost weight. Her friend was concerned about her and Kolisa disclosed to her. However, Kolisa did not disclose to Julius, who was her boyfriend at the time. She described how she was on her menstruation cycle and her partner wanted to be sexually intimate without protection. She was not comfortable having sex without protection and lied to her Julius and said she has not gone for family planning. Kolisa reiterates:

> I never used a condom when I first slept with him because I didn't know what to say why I wanted protection because he trusted me. I also trusted him. But then now I deceived him I said that I don't inject the needle [referring to the contraceptive injection] so we must use condom then he agreed (Kolisa 17 years old).

Kolisa was afraid of disclosing her status and therefore withheld her HIV status information from him. She also lied about being on contraceptives for them to use a condom as a form of protecting him from possible transmission. This decision of Kolisa could also be viewed as trust that they both have in the relationship, which Kolisa does not want to disrupt.

Similarly, to Brie's (39) experience, Rona (35) told her boyfriend Mike (45) her boyfriend about her HIV status but according to her, he has not disclosed. However, she has not disclosed her status to her other informal partner. According to Rona, disclosure is not easy, she says:

> I didn't tell him yet because it's not easy to tell someone. You must think before you do. If you tell someone about something. Sometimes you will get hurt (Rona 39 years old).

Rona has not disclosed her status to her other informal partner as their relationship is still new and there is no foundation of trust.

Similarly, Jacky (44) also struggles with disclosure to a new partner. She says:

> I don't want [him] to know because I don't know what his response will be, and I can already think for myself what he will think of me now (Jacky 44 years old).

Jacky mentions that Simon, her former boyfriend whom she is dating again, gets tested at work. Simon has requested to have unprotected sex with her. She is afraid of being intimate with him and possibly transmit HIV to him, therefore, she is apprehensive of disclosing. She says:

> I don't want to [be intimate] then he'll know it's me. You know, that's why I said I am a bit careful to tell him. Do you understand? Would you still want to talk with me? Would you want to come to me? All those questions are still a question mark. And not a small one, a big one, so I don't think I am going to tell him. But I want to, but I don't know how (Jacky 44 years old).

Here Jacky demonstrates fear of rejection and thinking of the possibilities of HIV transmission. Questioning her position leads to doubt which influences her decisions of disclosure. Similar to Rona's (39) experience, trust still needs to be built with a new partner before Jacky can be open and comfortable to disclose.

Findings in this study are similar to findings from other studies which showed that most women fear rejection and do not want to cause disruption in their relationship, therefore, they refrain from disclosing (Rhodes and Cusick, 2000).Women tend to disclose their status more easily with steady partners who they have been in long term relationships than to those who they have dated for a short period or have casual encounters with. As seen in the data, most of the women learnt about their status from testing at a clinic with or because of their partners. Thus, disclosure may also motivate PLHIV to seek treatment. Moreover, barriers to HIV disclosure among women living with HIV is anticipated by fear of abandonment, stigma, and violence, conversely the failure to disclose can lead to a lack of moral, financial and physical support as seen in the study (Sanga *et al.*, 2021; Maeri *et al.*, 2016; Goodwin *et al.*, 2021; Toska *et al.*, 2015). Hence, trust should feature in long-term committed relationships for women to feel comfortable to disclose, however, non-disclosure could indicate mistrust.

4.7 HIV, ART and support

In the following section I will discuss women's experiences of taking ART. In this section I explores how ART treatment is used in intimate relationships as protection from transmissions and the support women receive for adhering to treatment.

At the time, most women were adherent to taking ART and initiated treatment through the National Prevention of Mother to Child Programme (PTMTC). In this programme, women are able to access to ART to prevent passing on the virus to their child through birth or breast feeding.

Rona (35), Sisanda (48) and Nomsa (42) have experience having side effects of ART such as weight gain/ loss and being physically sick. Others have stopped their treatment and only Jacky (44) reported that she thought she is healed from HIV and takes her treatment as precaution.

Rona (35) was diagnosed with HIV in 2009 and initiated ART through the PTMTC programme. Rona is currently still on ART, and says that if people take their treatment, both their intimate partners and themselves are protected from transmission. She reiterates:

> Because you eat it [consume ART treatment], If I don't use it [take ART treatment] and we don't use it [use protection] it's [their health] not protected (Rona 35 years old).

Lilly (31) indicated that she started ART between 2012- 2014. She first initiated ART through PTMTC. But it is not clear if she is adherent with her treatment. She mentions*:*

> After [my son] was born I didn't go to the clinic again [for] myself just with him now, because I didn't really believe that I was sick (Lilly 31 years old).

She also mentioned that it was challenging for her to be on ART as well as TB treatment as the time of consumption is different. However, Lilly being in denial and not trusting to disclose her status to others, conversely influences the level of emotional support she receives. Thus, disclosure and acceptance have an influence in adherence.

Kolisa (17) receives support from her family who encourages her to stay on treatment. When Kolisa was dating Julius, she stopped her treatment as she feared him finding out about her HIV status and rejecting her. The pause in adherence caused Kolisa to have symptoms such as rashes. Thereafter, her family supports her and monitors her treatment in-take. Having a family member as her treatment supporter raises questions of partner support and how exclusion of support affects the emotional aspect of intimate relationships.

Sisanda (48) started treatment in 1999 and takes her treatment every day. She had initiated ART through PTMTC, although her baby was born with HIV. Sisanda constantly made negative references to taking treatment. She says:

> This annoying thing of eating pills (Sisanda 48 years old).

Apart from the physical side effects such as dizziness, weight gain, nausea, etc. that women have reported, a few women have described that ART treatment influences their intimacy, specifically their sexual intimacy. Rona (35) and Lilly (31) stated that taking ART decreases their desire to be sexually intimate. Whereas Des (26) indicates that ART treatment increases her desire to have sexual intercourse.

According to Lilly (31) Lilly feels that sex is not something that she is interested in, this was not her previous experience before her diagnosis. Even though she mentions engaging in sex at times, her sexual drive has changed. Therefore, Lilly makes the connection that her ART treatment affects her libido. She says:

> Through these pills and things that I use. Hey! I don't know if it's the pills or the things, but it takes away that thing, that feeling for sex. It takes it away piece by piece it falls away (Lilly 31 years old).

In contrast, Des's reports ART treatment having a positive effect on her sexual drive. She says:

> To me, it seems just after I've drank my pill [ART] when I'm with him funny things happen with me. I drink my pill, and we have sex. [And] I can't get enough of him (Des 26 years old).

Des indicates that prior to being on ART, her sexual drive was not extreme. However, being on ART treatment currently has increased her libido which she refers to as "a booster". This section has demonstrated that ART treatment has different effects on women which impacts their experiences of intimacy differently. Furthermore, this section revealed that trust and support influences women's adherence to treatment.

According to Arrivillaga (2011), adherence to ART treatment is central to managing HIV. ART adherence impacts immune function and lowers viral load, which prevents transmission. Arrivillaga (2011) suggests that 95% adherence to treatment is necessary for the viral load to be suppressed and control attributes of the virus. Most women in this study who self-reported taking ART described adherence to treatment and reported side effects of the treatment. A few participants have shared that the treatment has influenced their sexual desires and behaviours. Moreover, this may have impact in sexual relationships as a decrease in desire of intimacy may hinder the level of trust in relationships; and possibly emerge factors of distrust and betrayal. However, Ortiz (2007) states that the sexual desire of many women living with HIV weakens due to fatigue, muscle aches, pains, paraesthesia, and depression. Therefore, ART treatment may have a negative effect on women's physical and emotional health, which in turn has an impact on the overall experiences of intimacy in relationships.

4.8 Discussion

HIV transmission primarily occurs through heterosexual intercourse in sub-Saharan Africa (Johnson and Dorrington 2022). Heterosexual women living with HIV in South Africa bear the majority of the HIV burden. Women in relationships are thus also the sites of ART treatment initiation and adherence as treatment may have a significant impact on intimacy. In African context, the representations of women and their intimate relationships are grounded in violence, infidelity concepts, and disease (Medie, 2019; Olaore and Agwu, 2020; Hunter, 2010). Even though there are widespread narratives supporting women's sexual independence, various challenges and generalised underlying assumptions continue to exist in the African context, mostly ignoring the subtleties of trust in intimacy in relationships (Birnie-Porter and Lydon, 2013).

The onset of the HIV epidemic added more complexity to how women's experiences of intimacy is portrayed in the African context. Women, and their experience of trust and intimacy (physical, emotional, sexual, desire, and/or aversion) are frequently reduced to descriptions that focus on their place along a continuum of risk due to the unequal and gendered distribution of HIV in Africa (Viljoen *et al.*, 2021). African women are commonly portrayed in public health discourses as vulnerable (victims of physical/ psychological/ sexual abuse or inability to provide consent to sexual activities), without adequate consideration for the subtleties of women's sexual, physical, and emotional experiences (Scully, 2009). Although there has been various research done on the experiences of African women, fairly little is known about how trust and intimacy are conceptualised outside of these risk-based frames.

In addition to discourse regarding women's intimacy, HIV treatment-based prevention programmes have assisted women with choices they make in relation to their intimate relationships. By implementing the approach of treatment as prevention (TasP) through strategy of universal access to HIV testing and treatment (UTT), which was tested in the HPTN 071 trial, women are able to construct new ideas of intimacy and be in control of their own health. Women would either have access to new areas of universal "safe sex" under the protection of population-wide viral suppression or would be able to access more tools to help avoid transmission to their partners (Viljoen *et al.*, 2021; Iwuji *et al.*, 2020). Although, as the findings of the HPTN 071 (PopART) and subsequent UTT trials in sub-Saharan Africa became known, the results were underwhelming, with the UTT intervention proving marginally more effective in some contexts than others (Iwuji *et al.*, 2020). Similarly, the results of the HPTN 071 (PopART) trial in Zambia and South Africa, described throughout this thesis, were not as expected. When comparing communities receiving the household preventive package and UTT (Arm A) with those getting standard of care, the trial's data revealed no reduction in incidence (Arm C) (Hayes *et al.*, 2019). An overall reduction in HIV incidence of 20% was seen when Arms A and B results were coupled with results from the control areas (Viljoen *et al.*, 2021;

Hayes *et al.*, 2019). Collectively, the trials amply demonstrated the UTT strategy's shortcomings in preventing HIV transmission in real-world settings (Viljoen *et al.*, 2021).

In this thesis, I present women’s narratives of their experiences of trust in their relationships, and how an HIV diagnosis interacts with practices of intimacy. I demonstrate how women deal concerns HIV disclosure, transmission, violence, emotional and sexual intimacy in the context of HIV. The findings shows that trust is central to the functioning in relationships of women and has potentially major effect on health-related decision making. Women’s narratives are guided by their own constructions of intimacy and relationships, and their experiences are often shaped by idealised conceptualisation of trust. Many women develop narratives and an awareness of risk because of the interaction between "what is" (abusive relationships, betrayal, HIV risk or exposure) and "what should be" (romantic sex, trust, safe partnerships). Regardless of the level of trust experienced in relationships, women also expressed that they often felt that it was their duty to have intercourse with their husbands. Therefore, when women in my study described their intimate experiences, trust, connection, pleasure, disclosure, HIV prevention, concerns of transmission, and ART treatment influences the women’s engagement sexual activities.

In the final chapter, I summarise the findings of my research and provide recommendations for future studies.

CHAPTER FIVE: CONCLUSION

In this chapter I summarise the significant themes and reflect on the implications of these findings. I also discuss the strengths and limitations of the study and provide recommendations for future studies.

5.1 Overview of findings

In this thesis I employ social constructionist theory as a lens to explore women's experiences of trust in their intimate relationships. Social constructionism provided the framework to understand the perception and expectations of women, trust, and intimacy in Southern Africa, as well as the interpersonal experiences and internalised meanings attached to intimacy for women in this study. Additionally, I integrated the connected constructs of sexual and emotional intimacy, disclosure, risk, violence, adherence, and ART to make sense of women's experiences of heath in the context of intimate relationships.

In this section, I provide a summary of key findings across the 12 cases of women and highlight how the construct of trust identified throughout this thesis intersect in women's experiences of intimacy and relationships dynamics in relation to HIV prevention and ART treatment.

Understanding intimacy in relation to trust in relationships

In my study, I have found that trust influences women's experiences of intimacy. The data revealed that characteristics such as vulnerability, risk, faithfulness, commitment, and openness, are attached to trust and is used to interpret/making sense of intimate relationships. For instance, when women conveyed that they trusted and felt emotionally connected to their partners, they were more inclined to engage in physical and sexual intimacy. However, when women lacked trust and relayed that they experienced minimal feelings of connectedness, they were reluctant in their sexual engagement. Moreover, I found that when women acknowledged their HIV diagnosis, they were able to understand HIV risk in their own lives as well as their partners. In doing so, they were able to describe condom use in their sexual practices to prevent HIV transmission to new or existing partners not living with HIV and avoided acquiring additional infections from their partners diagnosed with HIV. In comparison, women in this study relayed how they used condoms as prevention primarily for transmission, compared to other studies which found condom use in relationships to be related to infidelity – which is understandable as the women in this study were already living with HIV (Aventin *et al.*, 2021; Negash *et al.*, 2021). Women's narratives, therefore, demonstrated characteristics of trust in their sexual engagement and honest expectations of risks with the indirect pressure of living with HIV. These perceptions of risk for women living with HIV influences how they engage in intimacy.

Understanding trust and betrayal in relationships

The findings from this thesis show that when women experience trust and emotional closeness in their relationship, forms of intimacy are enhanced but if betrayal occurs, it causes a rupture in the partnership. As noted in the findings chapter, partners' infidelity was a common experience among many of the participants. Many women developed narratives of awareness of HIV diagnosis as a cause of betrayal, and their trust was shaped by their experiences. For instance, the experience of betrayal violated women's trust and perception of intimacy which often impacted their level of sexual desire for their partners. The women's construction of what a trusting relationship should be, which was described as characteristics of safety, faithfulness, loving and caring, was filtered by what the relationship is, which was unsafe, unfaithfulness, and betrayal which tarnished these core assumptions in which their relationships were placed. Therefore, the construction of trust and perceived faithfulness in women's relationships, influences their experiences of intimacy which in turn influences perceived risk and HIV prevention.

Safety in relationships: disclosure and intimate partner violence

In this study, the findings suggests that many women experienced emotional, verbal, mental, sexual or/and physical abuse from their current or previous partner. Participants gave various reasons as to why they stayed in their abusive relationship which included reasons of having a lack of support from family and friends, lack of financial support, fear of retaliation, love, and trusting that their partners would change. Despite these barriers, majority of the women in the study left their abusive partners after numerous attempts and years of violence. From those who were able to escape their abusive relationships, few entered new abusive relationships. Additionally, some factors that intersects with violence in these women's partnerships was the influence of alcohol, previous exposure to violence, early age of marriage, infidelity, and acceptance or normalised beliefs around partner abuse. Thus, women have different experiences and constructions of trust and love in relationships. These constructions ultimately shapes women's experiences of intimacy, and contributes to the meaning they attach to violence, influencing their decisions of either staying or leaving their abusive partners.

Apart from experiencing violence in relationships, the findings show that women endured the challenge of being diagnosed with HIV and trusting partners to disclose their HIV status. The data revealed that most women learnt about their diagnosis when they were pregnant while receiving antenatal care. This suggests that women entered their relationship with the constructed expectation of their partners being trustworthy, committed, faithful and honest and, as far as they were aware, free of HIV. The study found that women living with HIV who entered a new partnership, and have not disclosed their HIV status, faced challenges of trusting their partner to disclose their HIV status. However, women who were in long term relationships and/or married, and who suggested acquiring HIV from their partners, were able to disclose their HIV status to their partners.

This shows that the action of HIV disclosure was not for health- related intension, but rather for confirmation of their partners untrustworthiness and/or the cause of infection. Women living with were aware of HIV transmission, and many would initiate safer sex (condoms) while still concealing their HIV diagnosis to avoid rejection. Moreover, participants who have disclosed their HIV status to their partners experienced feelings of relief and self-empowerment. Women disclosed their HIV status to individuals they trusted and had long-term relationship with.

Trust and ART

The findings showed that most women in this study were adherent to ART treatment. This involves taking ART medication, which is important to both manage their health and prevent the onward transmission. Women in this study often experienced side effects of the treatment, and some women expressed that ART influenced their libido. This suggests that ART adherence may impact women's intimate relationships and their experiences of intimacy.

As literature shows, in South Africa, women are most vulnerable to acquire HIV through intimate relationships (Kharsany and Karim, 2016). In this context, women experience various barriers to adherence. Additionally, women adhere to treatment not only to prolong their lives; but also, to protect themselves from additional infections and to prevent transmission to others. Women acquire knowledge about ART treatment and their diagnosis through their trusting intimate relationships. Taking that into consideration this research chose to observe intimate relationships from the perspective of women living with HIV, recognising them as people who 'create' their own meaning in their social processes that exist within their relationships.

This research has demonstrated that trust is a social construct which impacts the connected constructions of intimacy, IPV, disclosure, HIV prevention and treatment. Firstly, trust is constructed differently for women living with HIV. Secondly, these constructions are different in relation to women's intimate relationships, and experiences of intimacy, disclosure, and violence. Thirdly, these factors additionally influence treatment adherence. Women's ideas of love, romance and intimacy is influenced by trust and impacts how act in their relationships. Therefore, the risks they take when engaging in intimate activities may influence their physical, mental, emotional, and sexual health.

5.2 Strengths and limitations

The primary strength of this research is that I draw on the extensive PopART social science database and was able to use in-depth data that were appropriate for my research. The data allowed me to conduct a thorough analysis on women living with HIV and their experiences of intimacy and ART treatment. The data I used was gathered by skilled social scientist (myself included) with a range of experience and backgrounds, which lessened the limits of data gathered from the viewpoint of a one researcher.

The findings from this study were generated by using interviewing, ethnographic observations, and activity-filled interactive conversations (Creswell, 2014). Observations assisted in the analysis as I was able to view behaviour and interactions that serves to address the research question, instead of just relying on the participants statements (Rudestam and Newton, 2015).

In addition, I am a woman and can speak Afrikaans, which is the home language of many participants. Being able to speak the language and interview woman allowed a more in-depth discussion and comprehensive understanding. Additionally, during data collection, I participated in the activities. By being a woman researcher and allowing the women participants to ask me questions about my experience of love and romance gave insight as to how these women thought about relationships The interview sessions gave me the chance to delve further into what I noticed during the sessions. For instance, finding out how the women's experiences of love, sex, and romance fits into what is known about HIV risk, prevention, and treatment.

The data were gathered by sampling to ensure diversity and made use of a variety of data sources, including verbatim transcripts, fieldwork notes, and recordings. As a result, the data's quality reinforced my ability to conduct a thorough analysis for my study, which is essential for qualitative research.

There is currently insufficient research on women's experience of ART treatment and intimacy in relationships (Hareru *et al.*, 2022; Ruark *et al.*, 2017; Namiba *et al.*, 2022; Orza *et al.*, 2017; Yoo *et al.*, 2014). Accordingly, my study addresses a gap in that I did not only explore the experiences of trust in intimate relationships for women living with HIV in the Western Cape, but I also addressed how using ART features in the meaning and practices of intimacy, specifically in the context of 'universal test and treat'.

There are, however, some limitations. The small sample size in my study may have limited the potential to transfer the findings to other communities, even if it was adequate for a qualitative study. Moreover, the study was aimed only at households situated in PopART intervention districts. We still do not know how women from other areas may maintain intimate relationships in the context of HIV illness. As an additional limitation, participants might've been reluctant talk about their romantic relationships with male researcher also involved in the PopART trial. Furthermore, I was not a member of the group that established the larger PopART study's methodology, including the sample and research questions used to gather data. The study's findings came from a retrospective review of secondary data that was acquired for a different objective. However, I took part in the data collection and actively contributed to the transcription and translation of audio recorded interviews.

Furthermore, I examined data which included translated transcripts from Afrikaans or IsiXhosa to English and that the translation procedure may have resulted in the loss of some of the data's complexity or deeper meaning. However, transcripts were verbatim, and quality checked throughout. In addition, with the assistance of other colleagues, I was able to revert when unsure of a specific transcript. In addition, background information was included in the transcripts along with a verbatim translation, which minimised errors.

5.3 Recommendations for service delivery for women living with HIV

The finding of this thesis offers information that can be incorporated into HIV programmes in practice. In this section, I make recommendations on how the results may be applied to future HIV programme initiatives for women in sub-Saharan Africa.

Trust in intimate relationships of women living with HIV is rarely recognised in research. My results show that trust is of fundamental importance to women’s experiences of intimacy, sexual relationships, HIV transmission, HIV status disclosure and IPV. These factors play a significant role in HIV prevention and support interventions for women and should be recognised when interventions or programmes are designed. Researchers should continue evaluating trust in relationships. Interventions could implement HIV programmes which focuses on couples’ relationship dynamics to strengthen sexual and emotional intimacy. These interventions can be directed at building stronger foundations of commitment, fidelity, trust, openness, connectedness which assist with HIV prevention and protection of partners. Additionally, supportive approaches for women could be implemented to learn new skills specifically tailored to learn how to cope with the experiences of IPV as well as how to protect themselves or escape in violent relationships. Furthermore, interventions could address strategies for safe disclosure skills which could reduce HIV risks. These interventions could be community based, or accessible and being contextually aware as many of these women live in communities with little or few resources. Distribution of information could be provided in spaces where women are often found – such as clinics.

5.4 Concluding thoughts and the way forward

In many countries around the world, including South Africa, the adoption of HIV therapy for all PLHIV has changed from a hypothetical situation to public health policy, even though HIV trials such as HPTN 071 did not have the outcome that was intended. Since the nationwide ART programme was implemented in 2004, all HIV diagnosed individuals, regardless of their CD4 count were eligible to use ART. The treatment was also made available as prevention for people at risk of acquiring HIV infections (as postexposure prophylaxis [PEP] or preexposure prophylaxis [PrEP]) (Günthard *et al*., 2014). However, to ensure that women can make informed decisions around HIV management, further studies need to consider how relationship subtleties such as trust, emotional connectedness, fidelity, and commitment affects women's sexual experiences in future years. This is important to support women in HIV programmes which could assist with the impact of ART adherence.

Trust in relationships is crucial. We need to acknowledge it and offer women the needed support as we try and curb the HIV epidemic.

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APPENDICES

Appendix A: Excerpt from discussion guide – Module 3

Qualitative Cohort

Discussion Guide- Module 3

Purpose: *The HPTN 071 (PopART) qualitative cohort enables us to contextualise the experiences of people living with HIV (PLHIV) or people living in the context of HIV in relation to scaled-up ART access regardless of CD4 count. In South Africa, this transition means moving from approximately three million PLHIV on ART to approximately six million PLHIV eligible for ART. Scaling up ART uptake will require significant shifts in both how HIV-related services are delivered (in health facilities and in community spaces) and client testing, treatment initiation, and adherence patterns. These patterns are interrelated with intrapersonal, interpersonal and social contexts, which shape, for example, individual life course trajectories, patterns of disclosure, and gendered power dynamics. Central to these intrapersonal contexts is the formation of intimate relationships. Module 3 builds on initial interactions with families in the qualitative cohort and explores the intimate lives of participants. In it, we aim to continue to build relationships with families and to understand intimate, sexual and/or romantic relationships. It includes activities to be completed with families in the cohort. The guide should be used flexibly with each family over the course of several interactions with them. It is to be used alongside the ARF and RIDD.*

Objectives:

- *To continue building your relationship with participants.*
- *To understand how community members conceptualise notions of relationships, romance, sex and love*
- *To understand and contextualise intimate partner relationships in the cohort*
- *To understand the sexual/romantic/intimate life narratives of participants*
- *To explore issues related to gender and sexuality within the context of HIV*
- *To explore how decisions are made around sex and how 'health' (including HIV prevention, HIV treatment, reproductive intentions, healthcare) features in these decisions*

Form of data recording: *(1) Audio-recording of* **all talk** *from "Preamble" to "Closing". (2) Notes of key points per topic area handwritten by the facilitator into the ARF. (3) Still photographs of relevant images.*

<u>Expected time needed per use:</u> *3-4 hours*

Preamble (**to be read by facilitator at the start of each encounter**): Today is the (**insert date [day xxth Xxx xxxx**]) and it is (**insert time XX:XX**) and we are in (**insert site**). This is a discussion with (**insert participant name(s)**) in the qualitative cohort. Thank you for your time. May I remind you that we are audio recording this discussion and ask that you speak loud and clear? As the facilitator I will also be taking some notes. Do you have any questions before we begin?

Activity/Topic area 1 *– Structured discussion*

Topic area 2- *Personal discussions about sexual relationships (one on one)*

1. **To get us started I'd like to talk about some of the words for sex that people in this community use.**
2. **If you were to describe sex to someone who didn't know what sex was, or how it happened, what would you say?**
3. **Where did you find out about sex? Who taught you how to have sex?**
4. **What kinds of messages/information were given to you about sex as you grew up?**
5. **What is love/being in love?**
6. **Have you ever been in love? Tell me your story about the times in your life when you were 'in love' and the people that you were 'in love' with. In our discussion we would like to get an overall view of the relationships you have had in your life, for instance, starting with the first time you were in a serious relationship, or the first time you introduced someone to your parents/family up to now, ending with your most recent relationship.**
7. **Can you tell me about your last/current partner/relationship?**
8. **We know that part of being in a sexual relationship sometimes involves being pregnant or having children.**
9. [*If the participant indicated that they have never had sex]* **Why are you not having sex?**
10. **What is the most romantic thing you've ever done for someone? What is the most romantic thing that someone has done for you?**
11. **Have you had good sex? 12. Can you tell us of in an instance where you feel that you avoided sex, love and romance?**
13. **Was there ever a time when you have had sex with someone when one of you didn't want to have sex?**
14. **How open are you about talking about sex with your partner?**
15. **Who do you think should or should not have sex? Who should people not be having sex with?**

Topic area 3 – Understanding sex

1. **How many times a month do you have sex?**

2. **Have you had sex with men or women or both?**
3. **When you had sex for the first time, what were your main reasons?**
4. **When you have sex now, what are your main reasons?**
5. **If you had to estimate, how many people have you had sex with in your life – remember that there is a general trend to be shy/boastful about this number. Please take the time to really count as best you can.**
6. **Please describe a typical 'sexual encounter' in your life. When describing these stories begin by saying either how they identify a new sex partner (e.g.) going to a bar and meeting someone. For others the story might begin with the things you do to get each other 'in the mood'.**
7. **Please describe your most recent 'sexual encounter'. Please describe a step by step account of all the intimate interactions you had in this sex.**
8. **Describe the most recent time in your life that you have been in more than one sexual relationship at the same time.**
9. **What does sex mean to you in your life?** ***Activity 4*** **-** Questionnaire

The final activity that we will do with you is a short survey. We will not share the information with the other members of your household or with your partner. When you have completed the survey we will store your papers in sealed envelope. If you have any questions during the survey you can ask me any time. **Complete Questionnaire**

Thank you for taking the time to talk about your life in such detail. We appreciate that this is a sensitive topic. We will not share your information with anyone in your family. Is there anything else that you would like to talk about? <u>Is there anything else you wanted to tell me that you were not comfortable telling me before or anything else you wanted to tell in a different way into the recorder?</u>

Appendix B: Excerpt from discussion guide – Module 4

Qualitative Cohort

Discussion Guide - Module 4

Purpose: *The HPTN 071 (PopART) qualitative cohort enables us to contextualise the experiences of people living with HIV (PLHIV) or people living in the context of HIV in relation to scaled-up ART access regardless of CD4 count. In South Africa, this transition means moving from approximately three million PLHIV on ART to approximately six million PLHIV eligible for ART. Scaling up ART uptake will require significant shifts in both how HIV-related services are delivered (in health facilities and in community spaces) and client testing, treatment initiation, and adherence patterns. These patterns are interrelated with intrapersonal, interpersonal and social contexts, which shape, for example, individual life course trajectories, patterns of disclosure, and gendered power dynamics. As we begin to prepare for closing with our cohort, we want to be sure that we have covered essential topics related to the HIV care continuum and patterns of uptake with all our families. As such, in Module 4 we will talk about each step along the HIV care continuum, i.e., testing, linking to care, and remaining on ART. We will do this to explain patterns of uptake for various types of individuals, families, and communities. We aim to describe motivators and challenges to uptake at each step of the HIV care continuum, as well as the social processes that may include or exclude certain types of individuals. The lessons that we learn will help inform the national scale up of the HIV programme to offer universal access to ART.*

The goal of the discussion guide is to help facilitate discussion about key topic areas. It includes 5 discrete activities to be completed with families in the cohort. The guide should be used flexibly with each family over the course of one or two interactions with them. It is to be used alongside the ARF and RIDD.

Objectives:

- *To begin to prepare for the closure of the qualitative cohort*
- *To assess understandings of HIV, HIV testing, and treatment*
- *To explore community members' perceptions and experiences of the PopART intervention (the household and clinic interventions)*
- *To explore the unique experiences of people living with HIV as they navigate the HIV care continuum*

<u>Form of data recording:</u> *(1) Audio-recording of **all talk** from "Preamble" to "Closing". (2) Notes of key points per topic area handwritten by the facilitator into the ARF. (3) Still photographs of relevant images.*

<u>Expected time needed per use:</u> *3-4 hours*

Topic area 2 – Popular understandings of HIV in the community

First, we would like to talk about general understandings of HIV in your community.

- **When people talk about HIV, they do not always use the word HIV or AIDS.**
- **What other words come to mind if someone talks about/you think about HIV?**
- **How does HIV affect your community? Has this changed over time?**
- **What are some of the health concerns that worry you most?**
- **For you, how do you see HIV compared to other illnesses like cancer? What about HIV compared to TB? What about HIV compared to diabetes? Has this changed over time?**
- **Tell me what you have heard or know about each of the following**
    - Prevention of mother-to-child transmission (PMTCT)
    - Pre-exposure prophylaxis (PreP) / post-exposure prophylaxis (PEP)
    - Treatment as prevention (TasP) or universal test and treat (UTT)
- **We've been working in this community over the last couple years and some of the things that we think have changed over time is the way that people think about HIV, and the way people think about sex after being diagnosed with HIV. What do you think?**
- **We think that having ARVs available for everyone at the clinic will change the way that people think about living with HIV. What do you think?**
- **As you know, in South Africa, HIV is transmitted mainly through sex. How do you think the availability of HIV treatment has changed how you and others think about sex and HIV?**

Activity/Topic area 4 – HIV testing and acceptability of home-based HIV services

- **As we said earlier, to get to our 90-90-90 (show the sketch), our first aim is to get 90% of people to get to know their HIV status. Why do you think some people would be in the group that do not know their status? How do you think we can get to the 90%?**
- **If you think about testing, where do you think is the best place to test, and why?**
- **Tell me about the people in the maroon shirts (CHiPs) walking around in the community.**
- **What works and does not work about the services that they offer?**
- **Are these door-to-door HIV services, services that people in your community need?**
- **Are these services something that you personally or your family need or find useful?**
- **Have the CHiPs ever been to your house/knocked on your door?**

If yes (CHiPs HAVE BEEN to their house/knocked on their door),

- **How did they explain what they were doing? What information did they give you?**
- **Did you make use of any of the services they offer? Which services did you use?**
- **What feelings did the experience with the CHiPs leave you with?**
- **This is the last year that there will be door-to-door testing as the study is nearing completion. What do you think will happen next year after the CHiPs have gone?**
- **Have you ever tested at the clinic or somewhere else? How is testing with the CHiPs different to testing at the clinic or other places?**

If no (HAVE NOT used CHiPs service)

- **Please tell me about the time that you avoided or declined the CHiPs service.**
    - **What helped your decision not to allow the CHiPs into your home?**
    - **Have you ever tested for HIV? Where did you go to test? Why do you prefer this place?**
- **Are there any health services that you *would* want to receive at home?**
- **What do you think are some of the *challenges* to offering HIV services in the home? What do you think is *good* about offering home-based services**

Activity/Topic area 5: Exploring community members' understanding and experiences of linking to ART and remaining in care

- **What do you know about treatment for HIV? How do people get treated for HIV?**
- **There are many factors that influence a person's decision to go to the clinic to access HIV treatment or not.**
    - **What about this community could make it challenging for a person who has HIV to go to the clinic to get treatment? What could make it easy?**
    - **What have you heard/do you know about HIV services at the clinic that could make it challenging for a person who has HIV to go there to start treatment?** If
- **In what ways are people excluded from accessing health services?**
- **One of the roles of the CHiPs is also to help people to access treatment at the clinic (for HIV, TB, STIs, MMC). Have you heard anything about this? The last 90% is about keeping 90% of the people who start treatment on effective treatment. Treatment for HIV is lifelong. If a person with HIV takes their treatment every day they can lead a long, healthy, normal life. Taking treatment also makes it less likely that HIV can be passed on to others.**
- **What kinds of things do you think shapes whether people are or aren't able to stay on treatment?**
- **Have you ever supported someone living with HIV?**
- **In your community, what kind of support do you think a person who is taking ART will need to stay on treatment?**

- **What have you heard about people who are taking ART and live in this community?**
- **What do you think are some the challenges of taking ART every day?**
- **<u>People living with HIV – Extended DG for individual interviews</u>**

- **(TESTING) Please tell me about when you first tested positive for HIV**

- **(DISCLOSURE) Have you shared your status with anyone?**
  - **Please tell me about the first time that someone learned that you were positive.**
- **(MANAGING HIV) What are some of the challenges of staying healthy – including using ART and other ways of managing HIV?**
  It is a fact that many people find it challenging to go onto any kind of lifelong treatment. Tell me about some of the challenges you have experienced with taking ARVs every day.
- **(LINKING TO CARE/STARTING ART) Please tell me about the first time that you went to the clinic after testing positive.**
  - **Were you initiated on treatment then?**
  - **When did you go to the clinic again?**
- **Tell me about when you started on ART**
  - **How did it happen that you started treatment?**
  - **What role did your (health condition) play in starting or not starting ART?**
  - **How did your health worker know that you were ready to start ART**
  - **What was it like to start ART?**
  - **Imagine that you are the health worker who initiated you on ART, please show me how (role play) this was explained to you.**
  - **Please explain to me starting ART at a specific CD4 count.**
  - **If you had to tell someone who was living with HIV who was starting treatment at a high CD4 count, how would you explain changes in the treatment guidelines?**
  - **We think that maybe if people are on ART, it might influence how they make decisions around sex.**
- **(ART INTERRUPTIONS) Since you started using ART was there a time when you stopped taking it, even if just for a short while?**
  - **Have you ever stopped (defaulted) your ARVs**
  - **What do you think about starting treatment again?**
  - **Tell me about what it was like restarting your treatment?**

- **What regimen of treatment are you on now? What do you feel you need to be able to stay on treatment?**

Appendix C: Informed consent

PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT FORM

Title of Research Study:	**Population Effects of Antiretroviral Therapy to Reduce HIV Transmission (PopART): A cluster-randomized trial of the impact of a combination prevention package on population-level HIV incidence in Zambia and South Africa**
Protocol #:	HPTN 071, Version 1.0, 26 October 2012 DAIDS ID: 11865
Sponsor:	National Institute of Allergy and Infectious Diseases National Institute of Mental Health (U.S. National Institutes of Health) Office of the United States Global AIDS Coordinator Bill and Melinda Gates Foundation
Investigator of Record:	**Professor Nulda Beyers**

Research Site Address (es):

Site: Delft South Clinic **Address: Cr Main Rd & Boyce St**	**Site: Bloekombos Clinic** **Address: Sam Nokasela Avenue**	**Site: Ikwhezi clinic** **Address: Simon Street Nomzame**
Site: Town 2 Clinic (outreach) **Address: c/o Zibonele and Manyano Street**	**Site: Kuyasa Clinic** **Address: Ntlazana Street, Khayelitsha**	**Site: Luvuyo Clinic** **Address: Hlela Road, Makaza**

Site: Dalevale Clinic (outreach) **Address: Symphony Avenue,**	**Site: Cloetesville Clinic** **Address: Tennant Street**	**Site: Wellington Clinic (outreach)** **Address: Wellington Municipality**

Daytime telephone number(s): **021 983 9114**

24-hour contact number(s): **083 572 1470**

Introduction to the forms

Please ask the researcher staff to explain any words or procedures that you do not understand clearly, both in this information form, and throughout your interaction with them.

The purpose of this form is to give you information about the research study you are being asked to join. By signing this form, you are giving permission to the researchers to use the information you share with them as research data. The form describes the purpose, procedures, benefits, and risks of the research study so that you can know why the researchers are doing this research, why you are being invited to participate, and what this participation will mean. You should take part in the study only if you want to do so. You may choose not to join the research project or withdraw from this study at any time. Choosing not to take part in this research will not in any way affect the health care or benefits that you or your family will receive. Please read this Informed Consent Form for Social Science Participants and ask as many questions as needed. You should not sign this form if you have any questions that the researchers have not been able to answer in a way that you understand.

This study is being funded by the U.S. National Institutes of Health, the Office of the United States Global AIDS Coordinator, and the Bill and Melinda Gates Foundation.

There are several key points that you should be aware of before signing the consent form. These key points have been separated into sections under **bold headings** below; the first of these sections about your participation being *voluntary*.

Your participation is voluntary

You *do not have to* be part of this study. This means that being part of the study is your free choice, not because you feel pressure to participate. If you decide not to participate now, you are welcome to inform the researcher of this immediately. You are also welcome to not participate in particular parts of the study as we go, either by keeping silent, or indicating to the researcher to skip that section as you go. After completing the data collection with you, you also have the opportunity to tell the researcher that you would like to withdraw your participation from the study and your contribution will be excluded from scientific analysis. If you do decide not to participate, to skip some sections, or to withdraw your data contribution this will *not* influence the care you are entitled to at health facilities. Your choice to participate or not is your choice, and we respect that. From our side, we also make the commitment to protect the information about your choice to participate or not safe (see section on "**participant confidentiality and privacy**" below).

Purpose of the Research (what is this about?)

The research you are being asked to participate in is one part of a larger study. The larger study is called HPTN 071 (PopART). It is evaluating whether a program to try to reduce HIV infection in a community like yours works or not. This HPTN 071 (PopART) study is being done in 21 communities in total, including 9 communities in South Africa (all in the Western Cape), and 12 other communities in Zambia. It is estimated that about 600,000 adults are included in this research. If you would like more information about the HPTN 071 (PopART) evaluation, please ask the researcher who can also supply you with a study fact sheet.

Part of this bigger study called HPTN 071 (PopART) is what we as the researchers call the social science component. This social science component is the part of the study that helps us to understand the experiences of people implementing the research, living in the study communities, or who are important in other ways. The social science component aims to give detailed, real, contextual explanations of how and why things happen as they do to complement the larger evaluation of 'if' the intervention works or not. Typically, most of this social science component involves spending time with people, observing their daily lives, and listening to their stories. Broadly, there are three aims to the social science components of HPTN 071 (PopART); (1) telling the story of the study and the intervention it is evaluating, (2) explaining peoples' choices to take-up offers of HIV counseling and testing and ante-retroviral therapy or not, and (3) describing the social context of life in the study communities (for example, how and why things like unemployment is important to the story of health). More information on why the social science research team would like you to participate is included in the section on "**participant eligibility – why am I being asked to participate**" below.

Participant eligibility – why am I being asked to participate

As part of the social science components of HPTN 071 (PopART), it is of utmost importance that the everyday lives of community members in the study communities are described; especially in relation to the way health issues (including HIV) intersect with wider social issues and contextual experiences. You are being invited to participate because you live in one of these study communities. We believe that you have valuable information to share about your life and the lives of people living in your community and we would be very grateful if you share this with us.

What will happen during this study?

The social science field team would like to spend time with you as representatives of people living in the HPTN 071 (PopART) study communities. In order to properly understand your lives (it is our assumption that everyone lives complex, complicated, and interesting lives) we would like to spend a significant portion of time with you; at your homes, in the places you go to during the day and evening, and anywhere else you think that would help us to clearly understand your life. For most participants, we will spend at least a week worth of interactions with them at the beginning (not quite living with them, but definitely visiting for a while), then call again to see how things are about a month later, and at least one in-person follow-up visit about 6 months later. During this time, the research team will ask you questions and may ask you to do some activities (like ranking of alternatives). The research team will make notes of what they see and hear and will also keep records like audio recordings and photographs of relevant parts of their observations. You are being invited to participate in all of these interactions. The research team would also like you to refer us to other people that are your significant others, or otherwise important to understanding your life that we can have discussions with during the time spent with you.

What are the possible risks or discomforts?

There is a risk that some of the questions we ask may be uncomfortable and may make you feel worried or embarrassed. If any of the questions make you feel upset, the interviewer may go to another question or stop the discussion. The researchers may ask questions or ask for more detail in your answers than would be normal if you are having a discussion with friends or in another social context. The researchers are not doing this because they are nosy or trying to judge you. Rather, it is done to remain true to your real experiences and opinions. If you feel the need for follow-up counseling services, please indicate this to the research staff, and you will be referred to appropriate services. Thank you in advance for your honesty and candor as the real value to this research is telling such stories truthfully.

There is also a risk that being seen with us might lead other people to make assumptions about you. As part of the HPTN 071 (PopART) study, we have tried to make it common knowledge about why we are in the community (to learn about HIV prevention). However, some few people might still make wrong assumptions. Please inform us if you ever feel that this is the case and we can make alternate arrangements, for example finding a private or neutral venue to meet.

What are the potential benefits?

This is a research study, not a service delivery programme. You will not receive any direct benefit from being part of this study, other than the opportunity to share your experiences with us. The aim of the research is to produce information that will benefit people living in this place, in Africa, and across the world.

Are there any alternatives to participation?

The research study is an opportunity for us to learn from you, not the other way round. If you decide not to participate in this study, but would like to receive more information about public health concerns like HIV, or you would like to access HIV tests and other services, please visit your local health facility.

Participant confidentiality and privacy

Confidentiality means we as the research team will protect your identity and take steps to make sure that your story, the opinions that you express, and other identifying images or recordings are separated from your identity as a person. We do this so that someone else cannot read one of our reports or see our presentations and know ‘ah, it was *you* who said that’. We keep this confidentiality in everything that we do and in a number of ways. For example, when we save the data or recordings we do not save it with your name, we save it with a unique study number. And, if in a story that you tell us, you use your own name, we change your name to a fake name when we report on that story. And, if we see you again after this, we will not mention that we had already interacted with you as a research participant, we will pretend that we had not met you. We also store all the data in a safe and secure way, so only study staff can have access to it. All your personal information (name, address, phone number) will be protected by the research staff. This information will not be used in any publication of information about this study.

To protect your privacy, when you wish it, the researcher will meet with you in a private area where others cannot overhear conversations with you.

There are some people who may review the records of your data. They do this to check that we the researchers are treating you in the correct way and otherwise adhering to guidelines for good scientific practice. The people who may review your records include: Stellenbosch University Health Research Ethics Committee, local regulatory agencies, US National Institutes of Health (NIH), study staff, and study monitors. Institutional Review Boards (IRBs) or Ethics Committees (ECs) are committees that watch over the safety and rights of research participants.

There are some things that if you told us them we would be legally obliged to report this to the relevant authorities. For example, if we observe child abuse, we would need to report this to the Ethics Committee immediately and this matter will be referred to appropriate services.

Long term storage of the data and inclusion in a social science databank

If you sign the consent document, you are agreeing to allow the researchers to use the information you share with them to answer the questions described above. Hard copies of the data will be stored in secure, lockable cabinets and soft copies on secure, password-protected computer platforms. The data will be stored for a minimum of 7 years and destroyed after 7 years or after study completion.

You are *also* agreeing to allow researchers to store your data for analysis in other ways and to answer other relevant research questions. All data stored in this way will be treated as confidential as described in the section above on "**participant confidentiality and privacy**". We ask to store the data and use the data in this way for four reasons:

(a) To reduce the burden on research communities because multiple researchers do not have to 'keep coming back' asking very similar questions
(b) Enable researchers to understand patterns over much longer time scale than is usually possible because we will have contributions like this from multiple research studies
(c) Offer opportunities to students to analyse real data that it would usually be too logistically challenging for them to collect and thus improve social science training
(d) Help ensure that all such social science research is conducted with the same rigor and at the same high standard

Every new study or analysis that wants to use the data you contribute will still need to receive approval to do this from an appropriate ethics review committee, and there are strict controls in place as to who may access such stored data and for what purpose.

If you ***DO NOT*** want your data to be included in this databank, please indicate this to the research staff now and they will show you how to indicate this on the consent form when you sign consent. Otherwise, it will be assumed that you are happy for the data to be included as described.

What happens if I am injured by participating in this study?

It is very unlikely that you could be injured as a result of participating in this study. Nothing that we will be asking of you should place you at risk for injury (we are just talking with you and spending time with you). However, if you are injured while participating in this study, immediate treatment is more important than the research study. To be clear though, this care will be the normal care available from the local Department of Health facilities. Participation in this study does not give you access to any extra care or support. There is no program for compensation either through this institution (University of Stellenbosch) or the United States NIH. At the same time, you will not be giving up any of your legal rights to care by signing this Informed Consent Form for Social Science Participants.

What are some reasons why the researchers may decide to withdraw your participation in the study?

You may be withdrawn from the study without your consent for the following reasons:

- The research study, or this part of the study, is stopped or cancelled
- The study staff feels that completing the study or this part of the study would be harmful to you or others
- The scientific goals for the research have already been met and continuing would be of no further scientific benefit
- If you as participant would not be able to, or would be unwilling to participate in the study in such a way that is in accordance with the needed study procedures

Persons to Contact for Problems or Questions

If you have any questions about your participation in this research study, your rights as a research participant, or if you feel that you have experienced a research-related injury, contact:

1. Dr Peter Bock, Co-Principal Investigator, Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, University of Stellenbosch. Telephone: 021 9389062. Email: peterb@sun.ac.za

2. Principal Investigator: Nulda Beyers, Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, University of Stellenbosch. Telephone: 021 938 9114. Email:nb@sun.ac.za

If you have any questions or concerns about your rights as a research participant or want to discuss a problem, get information or offer input, you may contact:

1. Independent Review Board/Ethics Committee: Mr Franklin Weber, HREC coordinator, Health Research Committee 1, Stellenbosch University Health Research Ethics Committee, Tygerberg Campus. Telephone: 021 938 9657.

HPTN 071 (PopART) – Social Science Component

- I have been given sufficient time to consider whether to take part in this study.
- My taking part in this research study is voluntary. I may decide not to take part or to withdraw from the research study at any time without penalty or loss of benefits or treatment to which I am entitled.
- The research study may be stopped at any time without my consent.
- I have had an opportunity to ask the researcher questions about this research study. My questions so far have been answered to my satisfaction.
- I have been told what participation would mean in terms of what may be asked of me and how long this may take; including that the research may take pictures and make audio and recordings.
- I have been informed of the procedures that may be performed during the research study.
- I have been told what the possible risks and benefits are from taking part in this research study. I may not benefit if I take part in this research study.
- I do not give up my legal rights by signing this form.
- I have been told that before any study related procedures are performed, I will be asked to voluntarily sign this Informed Consent Form for Social Science Participants.
- I have been told that unless I indicate otherwise below, the data I contribute to this study will be stored in a databank for future social scientific analysis and research.
- I will receive a signed and dated copy of this Informed Consent Form for Social Science Participants.

If you have either read or have heard the information in this Informed Consent Form for Social Science Participants, if all of your questions have been answered, and if you agree to take part in the study, please print and sign and your name and write the date on the line below.

I voluntarily agree to take part in this research study.

________________________________	________________________________
Participant’s Name and Surname (print)	Participant’s Signature

____

Date

I, the participant, indicate my preference that the data I contribute be *EXCLUDED* from the social science databank (that is, the data I contribute will only be used for the HPTN 071 (PopART) study and *NOT* other research) by signing again here: (otherwise leave blank) ________________________________

I certify that the information provided was given in a language that was understandable to the participant.

________________________________ ________________________________

Study Staff Name and Surname (print) Study Staff Signature

____

Date

(*as appropriate*) I certify on behalf of the participant that they take part in this study voluntarily.

________________________________ ________________________________

Witness' Name and Surname (print) Witness' Signature

____

We work at the Desmond Tutu TB Centre, Paediatric Department, Stellenbosch University and part of our work is to do research, train students, raise awareness and give talks and presentations on TB, HIV and other health concerns in communities. The photos and recordings we make are part of the research process, which we can analyse to better understand health issues from the perspective of community members. We also give presentations to fundraise for research and want to put up work related pictures in our offices. Photographs and quotations are also very useful to illustrate our reports as it helps to explain our findings to funders and others.

It is our practice when using photos or making recordings during research and training, to obtain your signed permission before including photos or anonymous quotations of you/your business/ your organization/ your home or child. No names or surnames will be used. The photos will not be used for media publications.

Hereby I ______________________________________ give permission that the photo/s taken/recordings made today in which I/ my business/ my organization/ my home/ my child appear, may be used for the following purposes:

- ○ Providing contextual detail to qualitative research
- ○ Training of and raising awareness under students
- ○ Talks and presentations by staff from the Desmond Tutu TB Centre and other researchers
- ○ To put up in the Desmond Tutu TB Centre
- ○ Presentations to fundraise for TB research from corporate businesses
- ○ To illustrate reports written by the Desmond Tutu TB Centre
- ○ To be included as part of a social science database on ‘health in context’ in southern Africa

Signed at ____ (city/suburb/community) on ____________________________(date).

____________________________ ____________________________

Signature of representative Signature of recorder

____________________________ ____________________________

Name and surname of representative Name and surname of recorder

Stellenbosch
UNIVERSITY
IYUNIVESITHI
UNIVERSITEIT
forward together
sonke siya phambili
saam vorentoe

Appendix D: HREC ethics approval letter

Approval Letter

Progress Report

23/08/2022

Project ID: 11711

Ethics Reference No: S19/10/209

Project Title: Exploring intimacy and the usage of antiretroviral treatment (ART) in heterosexual relationships of individuals living with HIV.

Dear Miss TL Herandien

We refer to your request for an extension/annual renewal of ethics approval received 05/07/2022.

The Health Research Ethics Committee reviewed and approved the annual progress report through an expedited review process.

The approval of this project is extended for a further year.

Approval date: 23 August 2022

Expiry date: 22 August 2023

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your Project Id 11711 and ethics reference number S19/10/209 on any documents or correspondence with the HREC concerning your research protocol.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Yours sincerely,

Melody Shana
Coordinator: Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number: REC-130408-012 (HREC1)·REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number: IRB0005240 (HREC1)·IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006).Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix E: Permission letter for use of data

DESMOND TUTU tb CENTRE · SENTRUM · IZIKO
UNIVERSITY | STELLENBOSCH | UNIVERSITEIT
Every breath counts

30 September 2019

Dear Dr Barsdorf

Re: Clarification of how qualitative data will be analysed to meet protocol objectives as approved HREC Ref: N12/11/074 – Master's student sub-analysis

The protocol states that mixed qualitative data will be used to describe the HIV landscape in study communities. The purpose of this description is to inform interpretation of study outcomes. A key dynamic is how people living with HIV experience the study intervention components relevant to their choices around sex. Preliminary analysis of the data indicates that these people's experiences of intimacy are important to our planned interpretation. This letter serves to update HREC that we have enlisted a Master's student – Tarshlyn Herandien – to complete an in-depth analysis of the existing data on this topic. Tarshlyn is a long-time staff member of the project and was herself part of some of the data collection. She will be co-supervised by one of the senior social scientists at the DTTC who was also a key part of the project team. This study has been discussed with the PopART leadership and the PIs are very supportive of Tarshlyn's project. This letter supports Tarshlyn's proposal for review of a nested sub-analysis.

Yours sincerely,

Dr Peter Bock

Co-Principal Investigator

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jou kennisvennoot • your knowledge partner

Desmond Tutu TB Sentrum □ Centre □ Iziko