LINKING LOVE AND HEALTH: SOCIAL NARRATIVES OF SEX, INTIMACY, AND LOVE IN THE CONTEXT OF UNIVERSAL TESTING AND TREATMENT OF HIV/AIDS

By

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Declaration

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This dissertation includes four original manuscripts published (or accepted for publication) in peer-reviewed journals and one unpublished manuscript that has been submitted to a peer-reviewed journal. The development and writing of the five original manuscripts (published and unpublished) were the principal responsibility of myself. The contributions of co-authors towards Manuscript 1 was 65% (primary author) – 35% (co-authors); Manuscript 2 was 70% (primary author) – 30% (co-authors); Manuscript 3 was 58% (primary author) – 42% (co-authors); Manuscript 4 was 63% (primary author) – 37% (co-authors); and Manuscript 5 was 63% (primary author) – 37% (co-authors). A declaration is included in the dissertation indicating the nature and extent of the contributions of co-authors.

Signed:

4 October 2020

Summary

Since the 1990s, HIV prevention efforts have evolved from a primary focus on sexual behavioural change to an increasing focus on treatment-based prevention modalities as scientific evidence about the preventive benefits of antiretroviral treatment (ART) has accumulated. As these new prevention technologies have been tested and implemented worldwide, new knowledge gaps have emerged about how the availability of HIV treatment as prevention (TasP) would fit into sexual experiences and shape relationship dynamics in high HIV burden contexts.

In this thesis I aim to understand how women in South Africa experience sex, intimacy, and health in the context of a changing HIV prevention landscape. As women are disproportionately affected by the disease, the study of their sexual experiences and relationship dynamics in the context of treatment-based prevention is especially urgent. Furthermore, the dynamics of intimacy, care, and emotional connections in relation to sex in Africa remain underexplored. Historically, research on sex in Africa has positioned women as either fetishised or diseased, and the rise of the HIV epidemic did little to redirect this problematic narrative. I challenge these narratives and explore women's conceptualisations of sex, focusing on how intimacy and emotional connections are prioritised.

The study is nested in the HPTN 071 (PopART) HIV prevention trial, a community-randomised trial conducted in South Africa and Zambia from 2012-2018 that aimed to test the effectiveness of TasP at population-level through a strategy called universal test and treat (UTT). We conducted a qualitative cohort study with 89 households (n = ~300 participants, including 180 women) over 18-24 months to describe individual and community experiences of the trial. I analysed data from the cohort to explore women's narratives of their sexual experiences. Working across theoretical constructs (scripting theory, performance theory, normalisation, responsibilisation) and empirical findings, the central emerging theme relates to the ongoing tensions between idealised or expected conceptions of women’s sexual lives and their experienced realities. This is evident in the discord between women’s perception of HIV risk (assigned to ‘transgressive’ others) and how their own intimate relationships are described (trust, fidelity, respect, risk-free). Through focusing on idealised notions of romantic sex, HIV risk is dismissed, and idealised relationship values upheld, even when partners fail to live up to these expectations. An HIV diagnosis, or the possibility of HIV risk, is positioned as challenging to women’s conceptualisations of intimate relationships (safe, trustworthy) and to their conceptualisations of self (as morally ‘good’ women).

As an early study of the effects of UTT on women’s sexual lives, the findings show that readily available HIV testing and treatment has not yet shaped the sexual narratives of women in South Africa. Despite fears related to behavioural disinhibition (where people engage in more risky sex), I did not find demonstrable differences in women’s narratives around their sexual experiences in places where treatment-based prevention strategies were implemented. These findings suggest that public health programmes must be responsive to women’s changing experiences and perceptions of their own HIV risk and consider presenting TasP as a partnered solution.

Opsomming

Sedert die 1990s, soos wetenskaplike bewyse vir die voordele van antiretrovirale behandeling (ART) na vore gekom het, het MIV-voorkomingspogings ontwikkel vanaf ŉ hooffokus op seksuele gedragsverandering na ŉ fokus op behandelingsgebaseerde voorkomingstegnieke. Soos hierdie nuwe voorkomingstegnieke wêreldwyd getoets en geïmplementeer is, het kennisgapings ontstaan oor hoe die beskikbaarheid van behandeling-as-voorkoming (TasP) in seksuele ervarings sou inpas en die dinamika van verhoudings sou vorm in areas met ŉ hoë MIV las.

In hierdie tesis onderneem ek om te verstaan hoe vroue in Suid-Afrika seks, intimiteit, en gesondheid ervaar in die konteks van ŉ veranderende MIV-voorkomingslandskap. Aangesien vroue disproporsioneel geaffekteer word deur die siektetoestand, is die bestudering van hul seksuele ondervindinge en dinamika van hul verhoudings in die konteks van die beskikbaarheid van behandelingsgebaseerde voorkoming veral dringend. Die dinamika van intimiteit, sorg, en emosionele konneksies in verband met seks in Afrika is steeds onbekend. Vroeëre navorsing rakende seks in Afrika het vroue oorwegend as ‘gefetisjeerd’ of ‘besmet’ voorgestel. Die toename van die MIV-epidemie het nie hierdie problematiese narratief help verander nie. Ek bevraagteken hierdie voorstellings en ondersoek vroue se konseptualiserings van seks met ŉ fokus op hoe intimiteit en emosionele konneksies geprioritiseer kan word.

Hierdie ondersoek is deel van die HPTN 071 (PopART) MIV-voorkomingsstudie – ŉ ewekansige gemeenskaps-studie wat in Suid Afrika en Zambië geïmplementeer is vanaf 2012-2018. Die studie het die effektiwiteit van TasP op populasievlak getoets deur middel van ŉ universele toetsing en behandeling (UTT) strategie. As deel van hierdie studie het ons ŉ kwalitatiewe kohortstudie met 89 huishoudings (n = ~300 deelnemers, insluitend 180 vroue) oor ŉ tydperk van 18-24 maande uitgevoer om die ervarings van individue en gemeenskapslede te dokumenteer. Data is ontleed om vroue se narratiewe oor hul seksuele ondervindings te ondersoek. Deur die gebruik van teoretiese konstruksies ('scripting' teorie, 'performance' teorie, normalisering en verantwoordeliking) en empiriese bevindinge, is ŉ sentrale tema geïdentifiseer – die spanning tussen geïdealiseerde of verwagte konseptualisering van vroue se seksuele lewe en die realiteit. Die tema is duidelik in die onenigheid tussen vroue se persepsies van MIV risiko (toegeken aan morele 'oortreders') en hoe hul eie intieme verhoudings beskryf word (vertroue, getrouheid, respek, risiko-vry). Deur te fokus op geïdealiseerde beskrywings van romantiese seks word MIV risiko verwerp en die geïdealiseerde verhoudingswaardes onderhou, selfs wanneer seksuele maats nie aan verwagtinge voldoen nie. ŉ MIV-diagnose, of die moontlikheid van MIV risiko, word posisioneer as uitdagend teenoor intieme verhoudings en vroue se konseptualisering van 'self' (as morele 'goeie' vroue).

Hierdie vroeë studie rakende die effek van UTT op vroue se seksuele lewens wys dat die beskikbaarheid van MIV-toetsing en -behandeling nog nie die seksuele narratiewe van vroue in Suid-Afrika beïnvloed nie. Nieteenstaande vrese rakende gedrags-disinhibering (deelname aan riskante seks), is geen bewys gevind van verskille tussen vroue se narratiewe van seksuele ondervindinge in plekke waar behandelingsgebaseerde voorkomingsstrategieë geïmplementeer is nie. Hierdie bevindinge stel voor dat publieke gesondheidsprogramme moet reageer op vroue se veranderende omstandighede en persepsies van MIV risiko en dat TasP moontlik as ŉ seksuele vennootskapsoplossing aangebied moet word.

Dedication

Thank you to my partner, Daan, for your unwavering belief in me and your unconditional love during this journey. Thank you to Sophia and Frances, who joined us along the way and made it all worthwhile. To my parents, my in-laws, my family, and friends, I am grateful for your continuous support. Thank you to my supervisor Lindsey − for your time, the thought-provoking comments, the cross-continent calls, the opportunities, and for helping me to navigate the hurdles along the way. A special thanks to Graeme, Ginny, and Janet, for reading drafts, for asking the big questions, for pointing me in the right direction, and for your kindness while doing so.

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List of Abbreviations

A B C	Abstain, Be faithful, Condomise
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
BBS	Broad Brush Survey
CD4 count	Cluster of differentiation 4 is a glycoprotein found on the surface of immune cells and is an indication of the robustness of the immune system
CFAT	Couples Functionalist Assessment Tool
CHiPs	Community HIV Care Providers (employed by the HPTN 071 PopART trial)
CHW	Community Health Workers
DTTC	Desmond Tutu TB Centre
DoH	Department of Health (South Africa)
FAS	Foetal Alcohol Syndrome
GBV	Gender-based Violence
GD	Group Discussion
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HPTN	HIV Prevention Trials Network
IPV	Intimate Partner Violence
LMIC	Low- and Middle-Income Countries
MoH	Ministry of Health (Zambia)
MSM	Men who have Sex with Men
PEP	Post-exposure Prophylaxis

PI	Principle Investigator
PLHIV	People Living with HIV
PMTCT	Prevention of mother to child (HIV) transmission
PopART	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
PrEP	Pre-exposure Prophylaxis
RCT	Randomised Controlled Trial
RDP	Reconstruction and Development Plan
TB	Tuberculosis
TasP	(HIV) Treatment as Prevention
TAC	Treatment Action Campaign
UTT	Universal access to (HIV) Testing and Treatment
U = U	Undetectable viral count equals untransmittable HIV
VMMC	Voluntary Medical Male Circumcisions
WHO	World Health Organisation

Chapter 1: Introduction

Since the rise of the global HIV epidemic more than 30 years ago, researchers and public health experts have been working on developing effective means of countering the spread of the virus. In the last decade, two key moments have marked a major shift in approaches to HIV prevention. Firstly, in 2009, drawing on data demonstrating the preventive effects of antiretroviral therapy (ART), Granich and colleagues published a mathematical modelling paper. They projected that increased access to HIV testing and ART for all people living with HIV (PLHIV) could lead to significant reductions in HIV transmission and subsequently, the goal of HIV epidemic control could be reached within five years (Granich et al., 2009). Secondly, in 2011, the results of the first randomised controlled trial (RCT) to test whether ART effectively prevented the transmission of HIV (HPTN 052) were published, demonstrating a 96% reduction in HIV transmission in serodiscordant (mixed HIV status) couples where the partner living with HIV was on effective ART (Cohen et al., 2011). The publication of these results was seen by many in the HIV field as a tipping point as treatment as prevention (or TasP, as the new approach came to be known) presented an effective means to stop transmission and to potentially end the HIV epidemic, a prospect that had seemed unlikely only a few years before (Kalichman, 2013). Additionally, the findings opened up new possibilities for PLHIV to engage in sexual and long-term relationships with HIV negative partners in ways that were not previously possible.

While researchers, public health specialists, and activists embraced the study findings as signals of a new era for HIV prevention (Seale et al., 2011), it was not yet clear how this strategy of TasP could be implemented at scale in the settings most affected by the epidemic – low socio-economic status communities in sub-Saharan Africa. Several community-based HIV prevention trials were thus designed to test a new strategy for treatment-based HIV prevention at the population level (Perriat et al., 2018). Through the strategy referred to as ‘universal test and treat’ (UTT), HIV testing would be made available widely and all people diagnosed with HIV would be offered (and encouraged to access) HIV treatment in order to produce population-wide viral suppression, where the amount of HIV in the blood is reduced to ‘undetectable’ levels (Eisinger et al., 2019). This was expected to produce reductions in HIV incidence, or the number of new HIV infections in a population in a given time period (Hayes et al., 2011).

While the trials focused on population-level HIV incidence as their primary outcomes, they also raised important questions about how this new prevention strategy would impact on sexual behaviour and sexual decision-making for people living in high HIV burden communities (Hayes et al., 2014). In HIV interventions, it is often assumed that people who are familiar with and vulnerable to HIV would readily incorporate biomedical prevention discourse into their daily lives, including in their sex (and love) lives (Adam, 2011). While some researchers highlighted the positive potentials of this new prevention strategy, others hypothesised that the roll-out of increased (or ‘universal’) access to HIV testing and treatment or greater awareness of the potential preventive benefits of ART could lead to sexual disinhibition – or the indiscriminate increase in ‘risky’ sexual behaviour – and thus offset the potential preventive benefits of UTT (Legemate et al., 2017). Researchers were particularly concerned about the potential effects of this new prevention strategy on women, who are disproportionately affected by HIV (Kharsany and Karim, 2016) and often lack control over the use of other HIV prevention methods in sexual relationships (Jewkes and Morrell, 2010). However, at the time, little was known about the real-world implications of the UTT strategy at population level and the impact it would have on sexual behaviour and intimate relationships. In the trials, and with the implementation of increased access to HIV testing and treatment, researchers began to ask whether expanded access to HIV services would impact women’s sexual lives and their intimate narratives.

To attempt to address this gap, this thesis aims to explore women's narratives of intimacy, sex, and health in the context of increased access to HIV testing and treatment in South African communities with a high HIV burden. To this end, the research was embedded within the largest UTT trial, the HPTN 071 (PopART)[1] study, which aimed to test the effectiveness of a combination HIV prevention strategy in a population of more than one million people in South Africa and Zambia (Hayes et al., 2014). The trial presented a unique opportunity to explore women's sexual experiences in some of the first places where UTT was implemented at the population level. Through ethnographically-informed research with a cohort of 89 households living in nine communities in South Africa where the trial was carried out, the project examines if and how women living in study communities incorporate biomedical prevention discourses into their sexual and romantic lives and explores the effects of these discourses in couples and communities.

Through this lens, the thesis contributes to a broader contextual understanding of the dynamics that shape the implementation of increased access to HIV testing and treatment. Furthermore, it offers an analysis of women's experiences of sex and relationships through an exploration of the social constructs of risk perception, health and illness narratives, disclosure, and understandings of sex in the context of the changing prevention scene, including UTT. The findings of this thesis thus expand on the body of literature on women's sexual relationships in Africa. In addition, the findings demonstrate the challenges of incorporating population-wide health interventions into the intimate lives of the communities that they are trying to reach.

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[1] Full title: 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.

1.1 Background and literature overview

In order to locate this PhD project, I provide an overview of the literature relevant to understanding women’s experiences of sex against a changing HIV prevention landscape. Firstly, I provide an outline of the global burden of HIV and the treatment and prevention response, including the development of treatment-based prevention modalities. Next, I describe biomedical prevention modalities and research on sexual relationships. I then give an overview of the portrayal of sex in the African context, highlighting problematic and one-dimensional representations of sex research in the past and the lack of research on emotional connections and intimacy. This is followed by descriptions of women’s experiences of HIV risk, highlighting the nuances of biological and social vulnerabilities experienced by women. Lastly, I describe the epidemic response in South Africa specifically.

The HIV epidemic: Scope, treatment, prevention, and responses

Over the past four decades, more than 75 million people worldwide are estimated to have been infected with HIV and more than 32 million people have died from the disease (UNAIDS, 2020a). Sub-Saharan Africa continues to be the hardest hit region (Dwyer-Lindgren et al., 2019; UNAIDS, 2020a). In South Africa, despite efforts to contain the epidemic, more than 7.9 million people (or approximately 14% of the population) were living with HIV in 2017, making it the country with the largest number of PLHIV in the world (Simbayi et al., 2019). In South Africa, as elsewhere, HIV disproportionately affects women. As of 2017, 33.3% of women between the ages of 25 and 49 (the most affected age group) in the country were estimated to be living with HIV, compared to 19.4% of men (Simbayi et al., 2019). The skewed prevalence has been linked both to biological factors (Chersich and Rees, 2008) and to social vulnerabilities (Mojola and Wamoyi, 2019; Psaros et al., 2018; Roberts et al., 2016). The epidemic in Southern Africa is driven by heterosexual transmission (Kharsany and Karim, 2016), which has shaped not only the way that research on HIV and health is conducted, but also the ways in which research on sex, relationships, and women are framed more broadly (Thomas and Cole, 2009).

As HIV emerged as a global health crisis more than thirty years ago, initial public health efforts to address the epidemic were focused on diagnostics to ensure that health workers were able to identify PLHIV (Kalichman, 2013). In the early stages of the HIV epidemic, information related to HIV/AIDS and prevention was limited. During the early 1980s, health workers struggled to identify the cause of the rapid physical decline of people, mostly young and otherwise healthy men who have sex with men (MSM), who presented with a series of life-threatening symptoms. Aside from establishing that the syndrome was caused by a virus, little else was known about the nature, the mode of transmission, and the possible treatment or prevention methods (Engelmann and Kehr, 2015; Merson et al., 2008). As the epidemic extended to other populations and sexual interaction emerged as the dominant mode of transmission, early prevention efforts focused mostly on intervening in the sexual behaviour of people (Merson et al., 2008).

According to Ross (2010), these HIV prevention interventions that focused on sexual behaviour fell mainly within the following categories: sexual health programmes at community level, sexual health interventions for adolescents, interventions for ‘at risk’ groups (sex workers, MSM, etc.), the promotion of HIV counselling and testing, couples counselling, and active condom promotion. One of the earliest behavioural intervention programmes was the well-known “A, B, C” (Abstain, Be faithful, Condomise) prevention campaign, first implemented at scale during the early 1990s in Uganda (Okware et al., 2005). Other behavioural interventions included programmes such as negotiated safety, which was originally developed for confirmed and mutually disclosed HIV negative men in same-sex relationships (Kippax and Cawford, 1993). Many of these programmes were met with limited success. Catherine Campbell (2003) noted that programmatic failure can be attributed to the lack of involvement of powerful role players in society or the failure to apply appropriate and context specific interventions. However, in the absence of a vaccine or any other biomedical means of preventing HIV transmission, public health specialists had limited options to offer people at risk of contracting the virus.

Parallel to these early efforts to prevent HIV transmission, there was a rapid development in identifying and formulating safe treatment for PLHIV. HIV treatment options evolved and improved and moved away from highly toxic monotherapies (single treatments) towards the administration of a combination of medications known as highly active antiretroviral therapy (HAART) in 1996 (Yeni, 2006). Since the first effective HIV treatment was introduced in the mid-1990s, more than 20 antiretrovirals have been licenced globally (Palmisano and Vella, 2011). The availability of effective treatment has had a drastic effect on the quality of life and life expectancy of PLHIV and of the overall population in highly affected countries. For instance, in South Africa, the probability of a 15-year-old girl dying before the age of 25 was 35 per 1000 in the year 2000, 44 per 1000 in 2004 at the height of the epidemic and before in-country treatment availability, and 17 per 1000 in 2017, after several years of effective HIV treatment availability (Gray et al., 2019).

As treatment availability improved, researchers began to explore if and how ART could be used to prevent HIV transmission (Geffen and Low, 2017). The first successful study of treatment for the purpose of HIV prevention was conducted with pregnant women in the United States and France in 1993. It showed a reduction in the risk of mother-to-child HIV transmission of approximately 67% when the mother living with HIV was on ART (Connor et al., 1994). Although it would take several years, this study paved the way for other treatment-based prevention strategies to develop. Since then, several observational studies have shown that access to ART could prevent the transmission of HIV to sexual partners if PLHIV were virally suppressed (Castilla et al., 2005; Cohen et al., 2011; Cohen and Gay, 2010; Musicco, 1994; Were et al., 2006). The HPTN 052 trial, described above, was conducted in 13 countries with over 1700 (mostly heterosexual) mixed status couples and found a 96% reduction in HIV transmission when the partner living with HIV was on ART and their viral count suppressed (Cohen et al., 2011). In addition to the prevention of mother-to-child transmission efforts (PMTCT) and TasP, the range of available prevention modalities has expanded to include other biomedical prevention approaches such as vaginal microbicides (Mesquita et al., 2019), voluntary medical male circumcision (VMMC) (Gray et al., 2012), and alternative treatment-based prevention modalities including pre- and post-exposure prophylaxis (PrEP and PEP) (Gray et al., 2019).

Recently, and as noted above, a series of RCTs were conducted in Southern Africa to test the impact of the implementation of TasP on HIV incidence at community level through the strategy of UTT (Perriat et al., 2018). UTT and the implementation of the various trials were underpinned by the 90-90-90 treatment targets set by UNAIDS in 2014[2]. According to these targets, if 90% of PLHIV knew their HIV status, and 90% of PLHIV are accessing ART, and 90% of those accessing care are virally suppressed, we will be able to “end the epidemic” (UNAIDS, 2014: 1).

The introduction of these new technologies “inaugurated a shift in global HIV prevention policy towards biomedical approaches” (Keogh, 2017: 64), which allowed for the introduction of a medicalised solution for a health problem where previously none existed and where behaviour change was the only option available. While biomedical technologies are often presented as separate from behavioural interventions, Kalichman (2013: 2) explained that these interventions still “require long-term behaviour change”, be it the

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[2] Updated to propose targets of 95-95-95 (UNAIDS, 2020b).

consistent use of, for instance, the vaginal ring by women not living with HIV or treatment adherence for viral suppression by PLHIV.

Biomedical prevention modalities and sexual relationships

As biomedical HIV prevention modalities evolved over time, researchers have explored how these prevention methods feature in the sexual decision-making practices of people in intimate relationships. Despite the wealth of research on TasP, relatively few researchers have described how TasP features in intimate relationships and the studies that have done so tended to focus more on risk behaviours in relationships than the relationships themselves. Furthermore, much of this work has been done in the context of research with MSM, rather than in heterosexual relationships.

In several contexts, researchers have found that participants were (as of yet) not aware of TasP or did not trust that the modality works. For instance, in a survey in Italy with MSM, PLHIV, and high-risk heterosexual participants, Prati et al. (2016) found that, at the time, most participants were unaware of the benefits of TasP. Researchers from two studies in Canada and New York with MSM shared similar findings (Card et al., 2018; Siegel and Meunier, 2019). In these studies, increased awareness of TasP was associated with condomless sex for some groups. In another survey study with heterosexual serodiscordant couples in Canada, researchers found that women who were virally suppressed and aware of TasP benefits were four times more likely to engage in condomless sex. Although these studies again raised fears of sexual disinhibition, the authors emphasised the importance of safe sex discussions with serodiscordant couples beyond condomless sex to allow for both safe and satisfying sex in relationships (Patterson et al., 2017).

Another mechanism for treatment-based prevention that has been shown to be effective in lower transmission rates is PrEP (Fonner et al., 2016). For PrEP, ART drug regimens are prescribed to HIV negative individuals in order to protect them against HIV acquisition prior to exposure (Koechlin et al., 2017). When used correctly, PrEP has been shown to significantly reduce the risk of transmission during sex between men and women (Baeten et al., 2012) and is also considered a more woman-controlled HIV prevention method than condoms and/or sexual behaviour change-based prevention strategies (Hartmann et al., 2018). Since 2015, the World Health Organisation (WHO) has encouraged the use of PrEP for people who are at higher risk of HIV acquisition, including people in known serodiscordant partnerships (WHO, 2015).

Unlike TasP, there have been numerous studies exploring PrEP and intimate relationships, including in partnerships between men and women in African contexts. For instance, in their study with young women in Cape Town, South Africa, Hartmann et al. (2018) found that participants' romantic feelings and expectations of intimate partnerships influenced their perceptions of risk within their relationships which presented as a challenge to the implementation of PrEP. In the Partners PrEP study with men and women in Uganda, researchers described how serodiscordance was experienced as destabilising for couples. The use of PrEP can thus present as a solution to the tension between preserving relationships and remaining HIV negative (Ware et al., 2012). Some studies, including Willie et al. (2019), have shown that PrEP can be introduced in settings where women are subject to higher HIV risk due to gender-based violence (GBV) as PrEP can be used independent of partner input. However, others, including Roberts et al. (2016) and Braksmajer et al. (2019) from studies in African and North American settings, have shown that GBV also had the potential to reduce women's ability to initiate or adhere to PrEP.

Included under the umbrella of PrEP, other studies explored the efficacy, safety, and acceptability of vaginal microbicide rings (Griffin et al., 2019). In one of the few studies to focus on couple's sexual experiences of using vaginal rings, the MTN-020/ASPIRE dapivirine trial in Malawi, South Africa, Uganda, and Zimbabwe, researchers described the sexual satisfaction and the impact of the ring on relationships for trial participants (Laborde et al., 2018). They found that in order for women to maintain positive relationships, women had to navigate how their partners interacted with the ring and their own sexual satisfaction (Laborde et al., 2018). While PrEP, including vaginal rings, can be positioned as an empowering tool for people who are not living with HIV and for use in serodiscordant relationships, several challenges persist, including relationship expectations, power dynamics, and sexual interactions in intimate relationships.

Overall, there is limited in-depth research that focuses on intimate relationships and how these relationships intersect with biomedical HIV prevention technologies. One notable exception is the edited volume “Cross-cultural perspectives on couples with mixed HIV status” (Persson and Hughes, 2017), which interrogates the concepts of serodiscordance and risk and the role of biomedical prevention modalities in intimate relationships. The editors note that the “conceptualisation [of serodiscordance] through an epidemiological lens of transmission risk does little to deepen our understanding of what [it] actually means to couples in different cultural and epidemiological contexts” (Perssons and Hughes, 2017:4) and argue instead for an analysis of these technologies in the social and sexual lives of people in mixed-status relationships. For instance, in one of the volume’s chapters, Koester et al. (2017) describe how young people with HIV positive partners in the US positioned PrEP as a means to replace discourses of fear and stigma with narratives of hope and empowerment. Similarly, in her ethnographic research on serodiscordant heterosexual couples in Brazil, Hughes (2017) showed how couples contested stigma through the discourse of normalcy and how HIV treatment played a crucial role in ensuring the longevity of those living with HIV. While the authors in the volume engage with the concepts of PrEP, risk, and relationships, they do not engage with how expanded access to HIV treatment, on a population-wide scale, impacts on intimate relationships.

Sex in Africa

Historically, African bodies have frequently been reduced in research and public health policy-making to narrow colonial and racist tropes; depicted as hyper-sexualised, as othered, as fetishised, or as sites of disease (Lewis, 2011). As the HIV epidemic unfolded in Africa as a sexually-transmitted infection affecting mostly heterosexual partnerships, the narrative of 'African sex' as pathologised was revived in global public health platforms (Bujra, 2016; Lewis, 2011). This narrative offered a problematic representation of a homogenous and singular understanding of 'African sex', not acknowledging the various cultures, people, norms, and practices of an entire continent and potentially helped to shape the negative response of some actors in South Africa and elsewhere to early HIV interventions . Mbali (2004: 104) argues that the period of AIDS denialism in South Africa was a legacy of the "constructions of 'the African' as the inherently diseased racial and sexual other in both colonial and post-colonial times." These problematic representations continue to shape the HIV epidemic response in Africa as social determinants are frequently downplayed and diseases and risks highlighted.

Much of early HIV policy referenced work on African fertility by Australian anthropologists, the Caldwells, from the 1980s. In two of their articles, the Caldwells proposed, as summarised by Stillwaggon (2003: 813), that:

> "a religious world view dominates the choices that African people make regarding fertility, that this world view is almost universal in sub-Saharan Africa, that it weakens conjugal bonds in favour of lineage (because of ancestor

> worship), and thus it accounts for high rates of partner change and the consequent higher rates of HIV transmission in the region."

This simplified, narrow, and sweeping framing of sex in African contexts does not engage in the complexity and diversity of experiences of sex, and ultimately, is a barrier to effective and informed prevention efforts.

Research on sex in Africa, especially in the context of HIV, has amplified some of the problematic rhetoric in relation to how Africa is represented in the global arena. In an influential early article, Packard and Epstein (1991) noted the similarities between research on HIV in Africa and other conditions such as tuberculosis (TB) and syphilis, questioning epidemiologists' focus on sexual behaviour while environmental and other social factors were ignored. More recently, Thomas and Cole (2009) have argued that the extensive focus on HIV has reduced understandings of intimacy in Africa to concerns about sex and risk, as interpersonal relations and emotional connections are side-lined. At the same time, Africa continues to be described by policy makers as a 'problem area' in terms of HIV transmission, with Africans often presented as hyper-sexual and sex in Africa as pathologised (Bujra, 2016; Kagaayi and Serwadda, 2016; Reid and Walker, 2005). The lack of attention to the dynamics of intimate relationships, despite the emphasis on sex and risk, is problematic because, as Kalichman has noted, HIV transmission occurs mostly during "intimate acts in private relationships", thus rendering the epidemic a "disease rooted in relationships" (2000: 175).

Many studies on intimate relationships in Africa have focused on issues related to violence and abuse (Meinck et al., 2016), transactional sex (Ranganathan et al., 2017a), and sexual and reproductive health issues (Robinson et al., 2017). However, as Ruark et al. (2017) in their study with couples in Rwanda and eSwatini highlighted, these concerns often coexist with positive experiences of intimacy and love. For couples, complex understandings of intimacy often involve disparate and patriarchal power dynamics, sexual coercion, and love (Ruark, Stern, et al., 2017; Stern et al., 2016). This critique is not meant to suggest that these risk factors do not matter for women, but rather that there are other important dynamics that shape intimate relations which are often not sufficiently explored.

The emergence of the HIV epidemic has also contributed to what has been termed the medicalisation of sex whereby "non-medical problems become defined and treated as medical problems" (Conrad, 1992: 210). When sex is framed around a medical concern, Cacchioni and Tiefer (2012: 308) note that the psychosocial elements, including "sexual enjoyment, well-being, identities, practices, and norms" are neglected. In effect, sex is removed from the intimate sphere of relationships and positioned as a medical problem in need of intervention.

To some extent, more authors have been actively engaging with the complexities of sex in African contexts beyond vulnerabilities and pathologies. Several researchers are acknowledging diverse female sexualities, explorations of (female) sexuality and desire, and challenges to hegemonic representations of sex. See, for instance, volumes edited by Arnfred (2004) and Tamale (2011).

In line with evolving explorations of African sexuality, over time, several researchers have started to recognise the intricacies of intimacy and sexuality and the interaction with HIV in African contexts. The seminal work of Mark Hunter (2002, 2010, 2015), for instance, has highlighted the complexity of sexual networks and the contextual and material underpinnings of sexual relationships in South Africa. Others who have focused on more nuanced understandings of sex in the context of HIV include Swartz et al. (2018), who explored fertility decisions in Khayelitsha and found that young people's decisions around contraceptive use was shaped by gendered ideals, social norms, and relationship aspirations.

Harrison et al. (2008) described how adolescents in a rural setting in South Africa navigate the complexities of idealised love and romance against stigma and secrecy in the context of HIV. More recently, Ruark et al. (2017) did extensive work on intimacy and relationship quality in Rwanda and eSwatini, showing how participants described love (conceptualised through faithfulness, gifts, and quality time) as key to relationships, while managing interpersonal violence, risk, and HIV.

While there is a growing body of literature that offers refined understandings of sex and relationships in Africa, as HIV prevention modalities expand, it is also necessary to continue to explore sex and relationships in changing contexts. Although the over-focus on HIV and risk is problematic, there are some important questions to be answered about how relationships and experiences of intimacy shift in the presence of new biomedical HIV prevention technologies. More than a decade ago, Boyce et al. (2007: 2) argued that "limited conceptualization of human sexuality in HIV and AIDS work constitutes the major barrier to effective HIV prevention". In neglecting the sphere of intimacy and attachment, researchers are, in effect, hindering the implementation of effective HIV prevention methods. As such, it is vital to explore sexual relationships as the HIV prevention era is shifting towards broad treatment-based prevention technologies.

Women and HIV

In the global HIV discourse, women, and young women in particular, have often been positioned as particularly vulnerable to HIV due to both biological and social factors (Jewkes and Morrell, 2010). As a result, numerous initiatives, interventions, and funds have focused specifically on addressing the challenge of HIV prevention for this group. For instance, the recent DREAMS[3] initiative included an investment of approximately $800 million across 15

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[3] DREAMS is an acronym and refers to "Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe" women (Saul et al., 2018).

almost exclusively African countries for the prevention of HIV in vulnerable adolescent girls and young women (Saul et al., 2018). In 2016, the United Nations Political Declaration on Ending AIDS stipulated that policies and health programmes need to focus specifically on addressing the challenges faced by adolescent girls and young women in relation to HIV (UNAIDS, 2019b).

Biologically speaking, the physiological composition of female bodies renders cisgender women more at risk of HIV through vaginal intercourse than men (Chersich and Rees, 2008). Furthermore, contributing social factors play a major part in women's vulnerability to the disease.

Several researchers have highlighted how gender, power dynamics in sexual relationships, and underlying social factors contribute to higher HIV incidence amongst women compared to men. For instance, in their systematic review of studies across global contexts, Li et al. (2014) found a significant correlation between women's experiences of intimate partner violence and HIV incidence. Others, including Jewkes et al. (2009), found that men in South Africa that are perpetrators of intimate partner violence are also more likely to engage in risky behaviour, which in turn affects their (and their partner's) risk of contracting HIV. Stern et al. (2016), in their study on hegemonic masculinities in South Africa, found that experiences of coercive sex were part of many women's understandings of normative sex. All of the authors emphasised that sexual coercion and rape place women in positions of vulnerability. In addition, women's ability to negotiate condom use (and other forms of HIV prevention) are often compromised because of harmful gender norms, as was shown, for example, in the studies of Psaros et al. (2018) with pregnant women in Kwazulu-Natal, South Africa. Similarly Dube et al. (2017) found that women in customary marriage in Johannesburg, South Africa, were unable to negotiate condom use with their partners as they depended on their partners for financial survival, were hesitant to go against their partner's decision of condomless sex, feared separation, and described the act of challenging their partner's decision as socially and culturally unacceptable. In their study on female condom use negotiating in Zambia, Gambir et al. (2019) also highlighted women's limited ability to introduce HIV prevention technologies that are considered to be women-centred (such as female condoms) to their sexual partners.

Although women are more affected by HIV than men generally, HIV risk also differs for women in different stages of their lives (Pathak et al, 2019). While there has been a significant focus in research and programming on HIV risk amongst adolescent girls, women between the ages of 20 and 40 continue to be the most affected by HIV (Simbayi et al 2019). These women − of child-bearing age, sexually active, and often in relationships with varying power dynamics − have diverse experiences of sex, relationships, and power and should also be a central focus of HIV research and programming.

While it is important to acknowledge the biological and social vulnerabilities faced by women, studies have also shown how women have agency in relationships that could be used to circumvent some of these challenges (Jewkes and Morrell, 2012; Ranganathan et al., 2016). For instance, the findings from a gender transformation and livelihood strengthening intervention (the Stepping Stones programme) in South Africa showed that where women were able to develop communication and relationship skills, they were able to take small agentive steps to negotiate power in intimate relationships (Willan et al., 2020). Similarly, there is a need to explore more thoroughly how women interact with their partners as active decision-makers in relation to emotional connections and intimate care, beyond framings of risk, abuse, and violence.

As early as 1994, there were calls for biomedical interventions aimed specifically at redressing women's particular vulnerability and lack of agency in HIV prevention by giving them more control over prevention methods. At the time, Potts (1994: 890) noted that "the most glaring gap in AIDS prevention is the lack of a method a woman can use when she suspects her partner may have … (HIV) infection and she cannot compel him to use a condom." As described above, advances in treatment-based prevention modalities have created increased opportunities for women to access control in protecting themselves against HIV (Baxter and Abdool Karim, 2016), although it was not evident how and if these technologies could be incorporated into women's sexual and love lives.

The HIV epidemic in South Africa

As noted above, South Africa has the highest burden of HIV in the world. One of the factors that has shaped the epidemic in South Africa is the much-criticised denialist response from the President Mbeki-led government in the early 2000s. During this period, the government denied the causal link between HIV and AIDS, and questioned the effectiveness of ART, despite scientific evidence proving the contrary (Mbali, 2004). The South African government's inaction led to increased pressure from civil society, activists (specifically the Treatment Action Campaign – the TAC), and medical practitioners to ensure that PLHIV were given access to treatment in the face of a growing public health crisis (Grebe, 2011). However, it was only after a prolonged legal battle that a Constitutional Court ruling forced government to issue treatment for pregnant mothers living with HIV in 2003, and treatment for people with moderate to severe HIV in 2004 (Fourie and Meyer, 2016). Over time, and as the South African government changed their approach to the epidemic from denialism and deferral to one of acceptance and action, these treatment guidelines changed to allow for more PLHIV to be eligible for treatment (Plazy et al., 2015).

Since this initial dubious response, South Africa has emerged at the forefront of treatment advocacy and availability, serving as an important global advocate for expanded treatment access and producing new science on HIV prevention and treatment. Currently, South Africa has the largest HIV treatment programme in the world with an estimated 4.4 million people accessing care at government health facilities (Simbayi et al., 2019). In 2016, new South African government guidelines were announced that allowed all PLHIV to enrol in ART programmes at public health facilities (Gray et al., 2019). While the treatment programme in South Africa has expanded significantly, HIV incidence remains high, especially amongst women. Recently, Simbayi et al. (2019) found that overall incidence in 2017 in South Africa was 0.48% (95% CI: 0.42–0.54) with more than 230 000 new HIV infections occurring in that year ,which means that the country had one of the highest incidence rates in the world. Women aged 15 to 49, however, were estimated to have accounted for nearly half of these new HIV cases (Simbayi et al., 2019).

While HIV incidence remains high, advances in effective prevention methods have resulted in a steady decrease in the annual number of new cases of HIV over time in South Africa (Simbayi et al., 2019). HIV continues to be transmitted predominantly through sex, and prevention programmes in South Africa, as with other places in the world, are mostly designed to intervene in these intimate acts to stop the spread of HIV transmission.

1.2 Aim and objectives

Undoubtedly, important progress has been made to expand biomedical prevention modalities available to people at risk of acquiring HIV during sexual interactions. However, as Gagnon and Simon (1973) have pointed out, sexual conduct is not embedded simply in biological processes and urges, but also in the social meanings attached to sex and sexuality. Boyce and colleagues (2007: 4) explain:

> “On the one hand, successful prevention strategies must be concerned with the ‘biological acts’ that can transmit HIV, regardless of whether these are explicitly conceived of as sex by the people enacting them. On the other

> hand, successful health interventions require subtle understandings of the interrelated cultural and subjective meanings that frame sexual practice - indeed define what sex is in any given interaction. This is the only way in which attempts to prevent sexual transmission of HIV can hope to intervene in the specificities of sexual risk."

However, very few researchers have explored the implications of treatment-based modalities and the 'subjective meanings' of sex. As universal access to HIV treatment is rolled out, there is a need to explore how the biomedical interventions, targeted at population level, intersects with experiences and expectations of HIV risk in the most intimate of settings.

Set against the changing HIV prevention scene, the aim of this thesis is to investigate women's narratives around intimacy, sex, and health in the context of increased access to HIV testing and treatment. The project is nested within the HPTN 071 (PopART) trial which provided the unique opportunity to explore community interactions with expanded access to testing and treatment and changing messages of treatment-based prevention modalities.

The objectives are:

1. To describe community narratives of women's risk, responsibilities, and vulnerabilities in relation to HIV.
2. To explore how people with increased access to HIV testing describe their understandings of health, responsibility, and HIV.
3. To describe how HIV and health management is located in the personal narratives of people living with HIV.
4. To document how women living with HIV negotiate HIV status disclosure to their intimate partners in the context of increased access to HIV testing and treatment.

5. To describe how women understand sex, risk, and intimacy in the context of UTT.

The first objective contextualises how risk is positioned and understood in the communities where the study takes place. As risk perception is key in determining how receptive individuals are to prevention modalities, descriptions of 'risk' *for* and *by* women are important for locating experiences and perceptions of HIV prevention.

The second objective provides the broader context of UTT and the influence that the implementation of increased access to HIV testing and treatment will have on community settings. Describing community responses and experiences of UTT allows for a contextualised description of the elements that form part of the UTT strategy. I am able to show how the different elements of UTT are interpreted and incorporated into people's everyday lives.

The third objective contributes towards a richer understanding of how people affected by HIV navigate different components of their lives, including health, identity, and privacy. This focus locates 'health' in the context of other concerns, including relationships.

As part of objectives four and five, the descriptions of women's intimate relationships, including the process of HIV status disclosure and descriptions of interpretations of sex, contribute to an understanding of how experiences of health, intimacy, and sex intersect for women in this context of implemented UTT.

1.3 Brief overview of theoretical framing

For the framing of this PhD, I draw on multiple theoretical concepts to build an understanding of women's narrated experiences of sex. As a broad guiding theoretical frame, I employ the dramaturgical metaphor or *performance theory* from the seminal work of Goffman (1959). Goffman used the stage metaphor to describe how social 'actors' (individuals) engage in ‘performances’ (activities conducted in front of others) in order to manage a certain impression of themselves in front of ‘audiences’ (others with whom people interact). This means that social interactions and behaviour (including interactions related to sex) unfold according to socially acceptable or scripted norms.

The development of performance theory also gave rise to several other theoretical frameworks that build on and refine some of the issues raised as part of the stage metaphor. *Sexual scripting theory*, as developed by Gagnon and Simon (Gagnon and Simon, 1973; Simon and Gagnon, 1986, 2003), is based on the principle that sexual conduct entails more than simple biological urges, but is embedded in the social meaning attached to sexuality. The authors also used the stage metaphor to suggest that sexual behaviour is shaped by cultural scenarios (societal norms) and both interpersonal scripts (adapted from cultural norms during interactions between individuals) and intrapsychic scripts (or internalised beliefs and meaning attached to sex). The framework provides the broader outline I use to interpret women’s sexual behaviour and understandings of intimate relationships. I use the frame of sexual scripting, focusing on women’s intrapsychic scripts specifically, to explore narratives of HIV prevention methods generally, and increased access to HIV testing and treatment in particular. These theoretical framings are reviewed in detail in the Manuscripts included as part of this PhD.

Against this theoretical framework, I also unpack constructs that have been employed in HIV specific contexts in my analyses. According to the concept of *normalisation*, an increase in access to HIV treatment will render the disease chronic and no longer exceptional. Notionally, chronic conditions that can be treated, managed, and controlled can be accepted as ‘normal’ and patients can be re-integrated into productive and social life (Roura et al., 2009). I employ the concept of normalisation to understand if and how HIV is accepted as part of the injunctive norm for both PLHIV and in communities with increased access to HIV treatment (See Manuscripts 2 and 3). *Responsibilisation* refers to the neoliberal principles whereby individuals take on the responsibility to become self-governing citizens. In terms of HIV responsibilisation, the concept is connected to HIV stigma and the expectation that individuals should be making the ‘logical’ decision to link to HIV treatment, take care of their own health, and prevent onward transmissions. Those who fail to do so are blamed or stigmatised for failing to be good citizens (see Manuscript 2).

By drawing on the theoretical frameworks of performance theory and the dramaturgical metaphor with HIV specific constructs, I explore women’s experiences and social interactions related to sex in the context of UTT.

1.4 Chapter outline

In the next chapter, I describe the methodological framework for this study, including the context of the study, the trial within which this study is nested, the data collection strategy, sampling and recruitment, training, and ethical considerations. I also provide a detailed reflection on my positionality in the research, including my position in the trial and my positionality with the research participants.

The next chapter, which draws out the findings of the thesis, is structured in the format of five academic articles (manuscripts). All of the manuscripts have been submitted to international journals and have either been accepted for publication or were in the peer review process (at the date of thesis submission). The manuscripts were conceptualised to build on the central argument of this thesis – to show how women describe, understand, and narrate experiences of sex, love, and health in the context of expanded access to HIV treatment.

In Manuscript 1 (*Community narratives about women and HIV risk in 21 high-burden communities in Zambia and South Africa*) I present findings from data collected as part of the formative research conducted prior to the implementation of the HPTN 071 (PopART) trial. From participatory storytelling activities in group discussions, we explored how people living in high HIV-burden communities in South Africa and Zambia engaged with the concepts of 'woman' and 'HIV risk'. In the findings, I show how participant descriptions of risk shift between the archetypal categories of 'good', 'bad', and 'vulnerable'. The manuscript serves to locate community members' perceptions of women and HIV risk and confronted accepted simplified representations of 'risk' from public health narratives. The manuscript was published in the International Journal of Women's Health (2017).

In Manuscript 2 (*Universal HIV testing and treatment and HIV stigma reduction: A comparative thematic analysis of qualitative data*) I explore how increased access to HIV testing and treatment influences conceptualisations of HIV at community level. Using longitudinal qualitative data, I compare people's stigma-related experiences of living in communities receiving the HPTN 071 (PopART) intervention of door-to-door testing and universal access to HIV treatment and 'control' study communities without any interventions. In this manuscript I show that increased availability of HIV testing services (and UTT) influences conceptualisations of HIV as normative, and that there is a shift in community narratives toward individual responsibility. While it does not focus on women's experiences of sex specifically, I have included this manuscript in the thesis as it contributes to understanding how changing access to HIV service impacts social narratives related to health, normalisation, and responsibilisation. These understandings of community-level conceptualisations of HIV provide the framework to understand how public health narratives such as UTT could be abstracted in women's intimate relationships. This manuscript was published in the journal Sociology of Health and Illness (2021).

Manuscript 3 (*"It stays between us": Managing comorbidities and public/private dichotomies in HPTN 071 (PopART) trial communities*) entails the ethnographic account of one woman and her experiences of negotiating health through the dual diagnoses of epilepsy and HIV. With data from 13 other people with comorbidities, I describe how concepts of ‘public’ and ‘private’ shape the management of health conditions. I use layered descriptions of public and private spheres (including social spaces, physical spaces, intersubjective spaces, and the unconscious realm) to describe how people affected by comorbidities have to navigate health and privacy. More broadly, the manuscript illustrates how people affected by HIV negotiate disclosures across various life domains through an in-case and cross-case analysis of people living with comorbid HIV. By acknowledging the position of HIV as private, I am able to build on my understanding of the role of health, treatment, and HIV in the context of intimate relationships. This manuscript has been published in the journal Medical Anthropology: Cross-Cultural Studies in Health and Illness (2020).

In Manuscript 4 (*The act of telling: South African women’s narratives of HIV status disclosure to intimate partners*) I provide a detailed narrative analysis of the disclosure narratives of 15 women living with HIV in three South African communities receiving the HPTN 071 (PopART) UTT intervention. Using Goffman’s dramaturgical metaphor which describes social interactions as ‘performances’ by ‘actors’ (people) guided by ‘scripts’ (anticipated dialogues/interactions), I explore how women living with HIV manage their status disclosure (or decisions not to disclose) to intimate partners in the context of UTT. In this manuscript I demonstrate how intimacies and interpersonal relations that shape decisions around disclosure are not tethered to health-related considerations. The manuscript was published in the journal Women’s Health (2021).

In Manuscript 5 (*Women’s sexual scripting in the context of universal access to antiretroviral treatment*) I explore how the advent of treatment-based HIV prevention modalities unfold for women in intimate heterosexual relationships. Through the lens of sexual scripting, I compare women’s sexual narratives in places where the UTT intervention was available and places where it was not. I show that there are no noticeable differences in the narratives of these two groups and, overall, women's sexual scripts are structured around idealised romantic sex and the well-being of relationships. Risky sex is positioned as belonging to 'others.' HIV and 'prevention' are framed as challenges to scripts. While public health programmes position prevention modalities as part of sexual scripts, this is not normative for many women. This manuscript demonstrates how expanded access to HIV testing and treatment has not yet filtered into intimate relationship narratives or internalised interpretations of HIV and prevention. The manuscript was under peer review in an international journal at the time of thesis submission.

In the concluding chapter to the thesis, I provide an overview of the findings from each of the five manuscripts of this project, describe the key outcomes of this project, reflect on the strengths and limitations of the study, propose recommendations for future interventions, and propose a way forward for future research. In this final chapter, I return to the broader theoretical framing of the thesis to describe how women's sexual experiences can be understood through the framework of sexual scripting. Firstly, by engaging with concepts of risk, normalisation, and responsibilisation, I describe the 'stage' against which women navigate their sexual experience and relate to which extent UTT has been assimilated as part of the broader community narratives. To this end, I trace shifting community narratives of women and HIV risk prior to and after the implementation of the UTT intervention. As part of the interpersonal relationship scripts of women living in high-burden communities in South Africa, I show how people living with HIV and other chronic conditions negotiate the boundaries between different audiences to situate who should be included as part of the intimate private sphere. Similarly, I describe the intricacies of HIV status disclosure performances of women in intimate relationships in trial communities in South Africa and how this relates to UTT. At the most intimate level, intrapsychic scripts, I show how women narrate the meanings of the act of sex in their intimate relationships. I also describe how PLHIV relate to their own HIV diagnosis at this level.

From these findings and through performance theory, I describe how the central emerging theme spanning across analyses and theoretical framings is the ongoing tensions between idealised expectations of women’s sexual lives and their lived realities.

For women in high HIV burden settings, there is a discord between the ways in which HIV risks are described by women and the ways in which women describe their intimate relationships. Women do not describe their own relationships as ‘risky’ as this would challenge their idealised conceptualisations of relationships. HIV presents as a challenge to idealised conceptualisations of intimate relationships as it could signify betrayal and unfaithfulness while ideal relationships are described as risk-free spaces for trust, respect, and fidelity. Additionally, in women’s interpretations of sex, health and risk are not primary concerns and the emotional value of intimate relationships are prioritised.

Secondly, HIV is positioned as a challenge to preferred identities and idealised understandings of intimate relationships. An HIV diagnosis is linked to anticipated stigma which challenges women’s idea of self (as good, respectable, ‘proper’ women), which would align women with other ‘morally transgressive’ women (sex workers, promiscuous women), who are conventionally described as ‘at risk’.

Thirdly, there is a tension between universal access to HIV testing and treatment as a population-level HIV prevention strategy, and the implementation of treatment-based prevention modalities at the intimate (relationship) level. While UTT has the potential to provide ‘umbrella protection’ against HIV at population level if testing, linkage to care, and treatment adherence are achieved, the successful implementation of the strategy still requires participation at the individual and intimate level.

Overall, I demonstrate that despite public health narratives that focus on the normalisation of HIV and the medicalisation of sex in an effort to curb the South African HIV epidemic, HIV prevention more broadly, and treatment-based HIV prevention modalities have not (yet) come to form part of South African women’s sexual scripts, even in communities with high rates of HIV and readily available UTT. Instead, from women’s narratives, conceptualisations of sex and relationships revolve primarily around intimacy. For most women, health (including HIV) is not the primary concern when decisions around sex are made. In order to capitalise on the preventive possibilities of increased access to HIV testing and the universal availability of HIV treatment for all PLHIV, public health programmes should emphasise the potential liberatory power of these new technologies, especially for women. Treatment-based prevention modalities, including the availability of testing and treatment at scale, provide the opportunity for women to take on greater agency in terms of safer sexual decision-making, but only if treatment is accepted and promoted as a means of safeguarding both one’s health and one’s intimate life.

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Chapter 2: Methods and context

In this chapter, I provide a comprehensive description of the research context and methodological approach for this PhD project. In the sections below, I firstly describe the research design of this study. Secondly, I provide an overview of the contextual setting, including the randomised controlled trial in which this PhD study is nested and the communities in South Africa where data were collected. This is followed by a description of the study design, the recruitment and sampling approach employed in this thesis, and the data collection structure. Lastly, I describe the ethical considerations for this project and reflect on my role in the research process.

2.1 Research design

As described in the introductory chapter, the overarching aim of this PhD is to understand how women in South Africa experience sex, intimacy, and health in the context of increased access to HIV testing and treatment.

In this project, I approached my research question from a constructivist world view. Working within the positivist biomedical world, where concepts such as HIV, testing, and treatment are thought to be grounded in ‘objective’ realities (Bonell et al., 2018), I undertook my research from the stance that these terms, in addition to concepts such as sex, intimacy, and health, are socially constructed and part of shifting realities. The approach was suitable as it allowed me to acknowledge the diverse and changing experiences of participants, the agency of women in their sexual experiences, and presented the opportunity for reflection on the complex constructs related to sex and health. Ontologically, this framework supports the notion that multiple realities exist, arising from the various meanings and understandings created by the shared contexts, histories, and beliefs of social beings (Mann and MacLeod, 2015).

In my project, I acknowledge that women construct their understandings of sex and health through a myriad of social experiences and histories. When health services, including increased access to HIV testing and treatment, are introduced, these are not accepted as objective, stable, or uncomplicated 'truths'. Rather, they are incorporated into socially constructed and multi-faceted and shifting realities that impact the ways in which community members engage with biomedical technologies in their everyday lives. These assumptions of socially and shifting realities form the foundation upon which I conducted this study.

I employed an exploratory research design, relying on qualitative data the team and I collected as part of a larger trial (see below). By using participatory, ethnographic data collection methods (Schensul et al., 2012) in community settings, I aimed to address how experiences around health, risk, sex, relationships, and disclosure are part of women's experiences in the context of increased access to HIV testing and treatment. The central findings of this study are presented through five academic manuscripts. The findings draw on data from two qualitative datasets (formative research and a qualitative cohort study) embedded in a community-randomised control trial. By conducting a series of analyses, I was able to address the overall research aim of understanding women's experiences of love, sex, and health in relation to expanded access to HIV testing and treatment.

2.2. Contextual setting

This PhD project is nested within an HIV prevention trial, the HPTN 071 (PopART) study, conducted between 2012 and 2018 in Zambia and South Africa (Hayes et al., 2019). Specifically, I analysed qualitative data we (myself and a team of social scientists – see below) collected prior to the implementation of a community-based intervention (2012 – 2013) and during the implementation of the HIV prevention intervention (2016 – 2018). While qualitative data was collected in both countries, this PhD is focused primarily on the South African context. As such, I draw mainly on data collected in nine communities in the

Western Cape of South Africa during the implementation of the PopART study. In selected components of my analyses, I also draw on some comparative data collected in Zambian communities. In this section, I provide an overview of the trial and locate the study by providing a brief contextual overview of the South African communities where the trial took place. Throughout this thesis, and where relevant, I have included information on the Zambian context.

The HPTN 071 (PopART) trial

The HPTN 071 (PopART) trial was a three-armed community-randomised controlled trial conducted in 12 communities across Zambia and nine communities in the Western Cape Province of South Africa between 2012 and 2018. The aim of the trial was to reduce HIV incidence in communities receiving an HIV prevention intervention. Participating communities were randomly allocated to be in an intervention arm (Arm A or B) or a control arm (Arm C), where standard of care was delivered. The intervention entailed the door-to-door delivery of an HIV prevention package consisting of HIV testing, condom provision, referrals for voluntary medical male circumcision (VMMC) for men who test HIV negative, and referrals to local health facilities for all people who test positive for HIV. Tuberculosis and sexually transmitted infection screening were also included in the package (Hayes et al., 2014). The intervention was delivered by a group of community-based care workers (called Community HIV Care Providers − CHiPs) specifically employed for the purpose of the trial (Floyd et al., 2018). For Arm A communities, all participants who tested positive for HIV were also presented with the opportunity to initiate antiretroviral therapy (ART), while participants in Arm B received HIV treatment according to national guidelines, which was a CD4 count of 350 at the start of the trial but had shifted to be regardless of CD4 count by trial completion. Participants living in Arm C communities received standard of care according to government guidelines, with no additional HIV prevention services (Hayes et al., 2014). All participants in the trial were able to access HIV treatment, although only participants in Arms A and B received home-based services as part of the intervention (see Figure 1 below).

The qualitative component from which the data for this PhD is drawn was embedded within the broader trial. Details of the two qualitative components – the formative research and the qualitative cohort study – are provided in the sections on 'data collection' below.

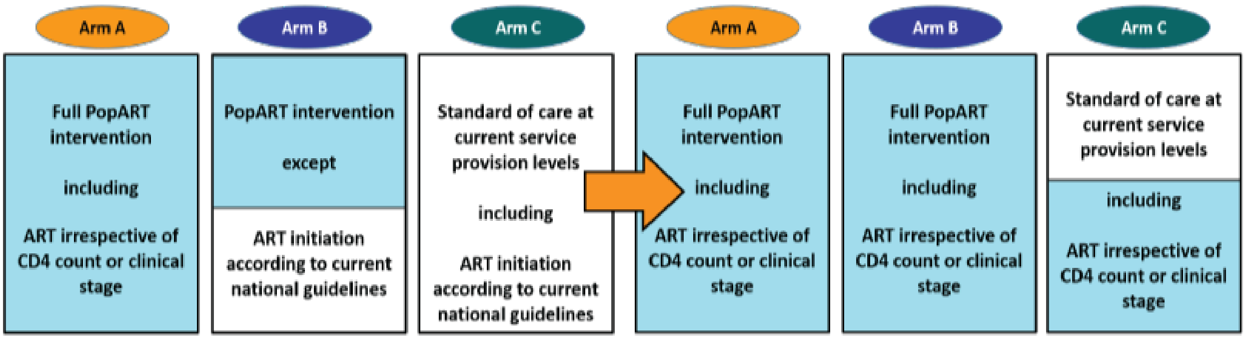

Figure 1. HPTN 071 (PopART) study design reflecting 2016 treatment guideline changes (The HIV Prevention Trials Network, 2019).

Figure 2. HPTN 071 (PopART) study *communities* (Hayes et al., 2019).*Figure 3. HPTN 071 (PopART) study design reflecting 2016 treatment guideline changes (The HIV Prevention Trials Network, 2019).*

The research communities in the HPTN 071 (PopART) trial

The 21 communities – 12 in Zambia and nine in South Africa – were selected for inclusion in the trial in consultation with local health authorities (Department of Health in South Africa and the Ministry of Health in Zambia). The communities were selected based on pre-trial HIV prevalence, the geographic location of each community, available public health facilities, and the availability of research partners to implement the intervention (Hayes et al., 2014). Communities (or clusters) were defined as the respective catchment areas for a given local primary health facility providing ART and were spread across four provinces in Zambia and the Western Cape Province of South Africa (see Figure 2). Communities sharing similar demographics, geographical locations, and HIV prevalence were grouped into triplets and, during a public event, randomly assigned to a trial Arm (Arms A, B, or C) (Hayes et al., 2014).

In South Africa, the triplets are located in the Cape Winelands, in the Cape Metro in Khayelitsha, and in three additional places in the Cape Metro area referred to as the ‘mixed metro’. In Zambia, communities are located across the country in four provinces (Lusaka, Central, Copperbelt, and Southern) along the main road line. All communities included in the trial are urban and peri-urban and predominantly in the lower socio-economic status bracket. To provide a level of anonymity, communities were assigned a code that was used in all reporting structures. Zambian communities were numbered Z1 to Z12, while South African communities were numbered SA13 to SA21. In the section below, I provide a contextual overview of the nine South African communities included in the trial, the focus of this PhD.

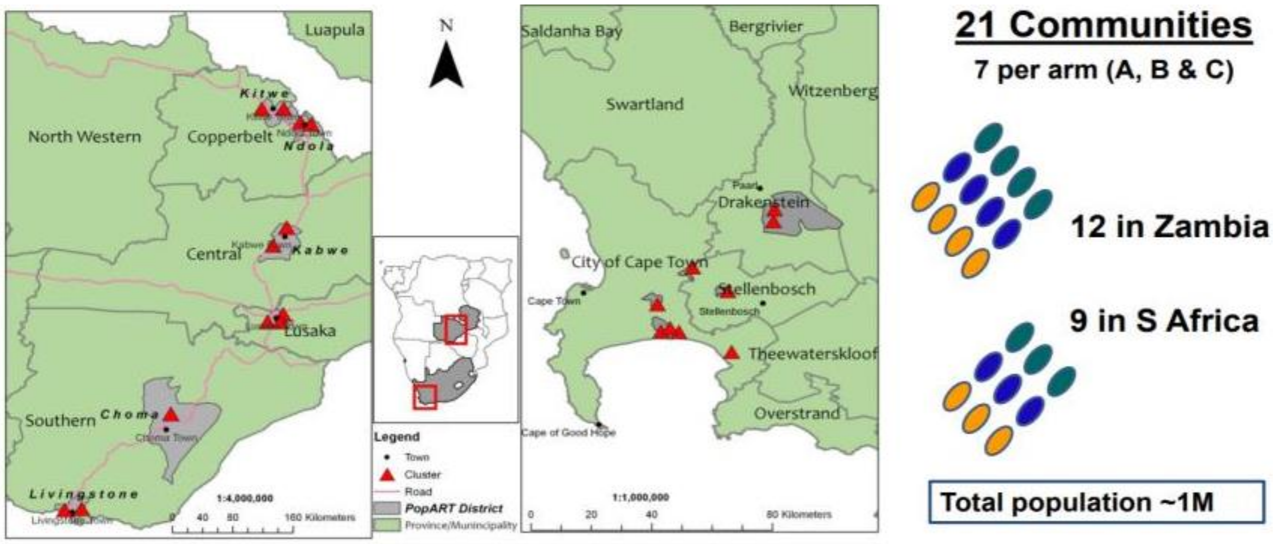

Figure 4. HPTN 071 (PopART) study *communities* (Hayes et al., 2019).

The trial communities in South Africa

The nine South African communities are all within the lower socio-economic status bracket and are densely populated (Bond *et al.*, 2016). In most communities, residents have access to primary and secondary schools, community halls, libraries, markets or shops, and public transport networks. With the exception of the mixed metro triplet, communities grouped in triplets are located in close proximity to each other.

The Khayelitsha triplet

The three Khayelitsha communities, located in the broader Khayelitsha area outside the Cape Town city centre, are similar in size and resource availability and are separated by less than a few blocks. Khayelitsha was established as a township for black[1] South Africans in the 1980s (Cook, 1986). The area has since grown to be the largest settlement in Cape Town (Cook, 1986; Ngxiza, 2012). As in other communities in the trial, housing structures include a combination of formalised brick houses (often built as part of the government's subsidised housing projects under the broader socio-economic framework of the Reconstruction and Development Plan (RDP) (Cameron, 1996)), informal makeshift homes built with corrugated iron sheets and other pieces of loose building materials (generally referred to as shacks), and dwellings (informal or prefabricated) erected in the backyards of formalised housing. Many households lack consistent access to basic services such as running water, sanitation, and electricity or share these services with neighbours (Leeper et al., 2019).

Residents in Khayelitsha are predominantly black and Xhosa-speaking, and many households have strong family ties to the Eastern Cape. The general population in Khayelitsha is young, with approximately 44% of individuals estimated to be between the ages of 15 and 35 years (Statistics South Africa, 2011).[2] Many residents in Khayelitsha struggle to find employment and economic opportunities are scarce. In 2018, the unemployment rate in the larger Cape Metro was estimated at 21% (Statistics South Africa,

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[1] The racial categories black, white, coloured, and Indian are commonly used in South African contexts and are remnants of the system of racial discrimination used during the Apartheid era. While these are social constructs and not essential truths, race continues to be an important predictor of both health and socio-economic status in South Africa (Finchilescu and Tredoux, 2010).

[2] Most recent available data from Statistics South Africa.

2019) and the challenge of youth unemployment is particularly pressing in Khayelitsha (Mjakada, 2019; Pollio, 2020). Residents who are employed work mostly outside of their place of residence in nearby factories, shops, or in the informal market as domestic workers or gardeners, or are self-employed as informal traders or taxi drivers (Bond et al., 2013). Many households also depend on one of the government-subsidised social grants made available to support households in need, including the old age pension grant, the disability grant, the child support grant, and the care dependency grant (Western Cape Government, 2020).

Overall, there are high levels of mobility across Khayelitsha communities, both on a daily basis (when residents commute to work or travel to look for employment) and on a seasonal basis (as many community members in Khayelitsha travel to the Eastern Cape or elsewhere to reunite with family) (see Hoddinott et al. 2018).

Residents in Khayelitsha are subject to significant structural and social challenges, including high levels of crime, violence, substance abuse, gangsterism, and lack of financial opportunities (Bond et al., 2013; Leeper et al., 2019; Maringira and Gibson, 2019; Ngxiza, 2012). Many of these challenges are shaped by historical inequalities based on the racialised system of exclusion during the apartheid era (Ngxiza, 2012). Khayelitsha is also a high HIV burden setting with HIV prevalence estimated at 19% of the adult population across the three communities, prior to the start of the PopART intervention (Hayes et al., 2014). In terms of health service access, most households are located within walking distance of the nearest public health facility. Health facilities in all three Khayelitsha communities have functioning ART services. However, despite access to health services, clients are often subject to other challenges, including long waiting times, clinic congestion, and occasional drug shortages (Bond et al., 2019; Magadzire et al., 2017). Many residents in Khayelitsha also hold strong traditional beliefs and regularly make use of traditional medicines and herbal remedies (Stern et al., 2017).

The mixed metro triplet

In the mixed metro, communities vary in size and are located further apart (approximately 30 kilometres) than communities in the other two South African trial triplets. The demographic profiles within each of the communities in this triplet are also more diverse than in other settings in the trial. The population is a mix of coloured[3], Afrikaans-speaking residents and black, Xhosa-speaking residents. Similar to other trial clusters, these communities are composed of a mix of informal and formal housing structures.

The largest of the three communities has included a large number of migrant labourers from the Eastern Cape Province since the 1960s, and is sometimes described by community members as a gateway community for migrants from the Eastern Cape (Bond et al., 2013). As such, housing structures also include several hostels (or apartment-like buildings with shared amenities) that were originally designed to house migrant men, although they have since been turned into family units. Similar to other settings in the Cape Metro, residents who are employed work mostly outside of the community in both the formal and informal market. The community houses one of the largest clinics in Cape Town, serving an estimated 500 clients per day, where many residents receive ART (Bond et al., 2013).

The smallest of the three communities is located near agricultural land at the periphery of the Northern Suburbs of Cape Town. Residents are mostly black or coloured. Some residents depend on income from employment in the nearby agricultural sector or from other forms of (mostly minimum wage) employment. However, many residents are

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[3] The term 'coloured' refers to a complex category used for people of mixed racial descent or with ancestry from Indonesia or the local Khoisan. As with other racial categories, the label is still used in official and everyday language in South Africa (Posel 2001).

unemployed and depend on the government's social grant system. The community has fewer available amenities when compared to some of the other places in the trial and residents have to travel further in order to reach alternative employment opportunities (Bond et al., 2013).

The third community in the mixed metro triplet is located close to Cape Town International Airport and serves as a central transport hub for the Cape Metro area. As with the other two communities in this triplet, residents are a mix of black, Xhosa-speaking, and coloured, Afrikaans-speaking community members. Although the community has a well-functioning clinic and good infrastructure, instances of violence and taxi-related shootings are often reported (Bond et al., 2013).

Similar to other places in the trial, all three communities in the mixed metro are considered high HIV burden settings and it is estimated that HIV prevalence in the three communities was between 15% and 18% prior to the start of the trial (Hayes et al., 2014).

The Cape Winelands

In the Cape Winelands triplet, communities have expanded over time from a core of formalised housing and facilities to include more informal structures at the periphery (Bond et al., 2013). In terms of demographics, residents in the Cape Winelands are mostly Afrikaans and self-identify as coloured, although there is a growing number of black, Xhosa-speaking community members in two of the respective areas. To some extent, housing is still segregated along racial lines with black residents often living in informal areas with less access to services. Community members in the Cape Winelands are, on average, slightly older when compared to community members in the Cape Metro sites (Bond et al., 2013). Unemployment in the Cape Winelands is estimated at 18% (Statistics South Africa, 2011). In addition to depending on social grants and informal and formal employment, many residents are also employed as seasonal workers on nearby fruit and wine farms (Truyts, 2017).

The largest community in the triplet is older, more established, and slightly more affluent than some of the other places, although the two other Cape Winelands communities also contain pockets of affluence where residents have access to private medical aid and privately-owned formalised housing. Residents in this community are also slightly older and are more likely to have better, more stable employment when compared to other places in the trial. However, gangsterism, shootings, and violent crimes are often reported in the area (Bond et al., 2013).

Like the other trial communities, the communities in the Cape Winelands are subject to social challenges including food insecurity, crime, violence, substance abuse, sexual assault, high rates of foetal alcohol syndrome (FAS), and gangsterism (Bond et al., 2013; Lesch & Casper, 2017; Osaki et al., 2015; Truyts, 2017; Urban et al., 2016).

All three communities have functioning public health facilities providing ART and TB services. However, as with other places in the trial, access to health services were complicated by structural challenges at facilities and long waiting times at public health clinics. In addition, in the Cape Winelands, there are indications that some residents access (Christian) faith-based health care or traditional medicines, in addition to conventional biomedical services. As noted, several more affluent participants were also able to access private medical care (Bond et al., 2013). HIV prevalence at the start of the trial varied between communities and it was estimated that prevalence in the Cape Winelands was between 11% and 12% (Hayes et al., 2014).

2.3. Data collection structure

For this thesis, I draw on two sub-components of qualitative data collection embedded in the HPTN 071 (PopART) trial – formative research prior to the implementation of the trial and a qualitative cohort study during the implementation of the trial. In the section below, I briefly describe the formative research process before describing the qualitative cohort study, the source of most of the data used in this PhD, in greater detail.

Formative research: The Broad Brush Survey (BBS)

Prior to the implementation of the intervention, we conducted formative research in all 21 communities in the trial. The aim was to conduct a rapid analysis to gauge the key features of communities; to explore community perceptions and experiences with HIV prevention, treatment, and care options; and to identify catalysts and barriers to the uptake of the PopART intervention for each of the places. This process was called the Broad Brush Survey (BBS) (Bond et al., 2019). The BBS, conducted between 2012 and 2013, consisted of structured observations, participatory group discussions with community members, and key informant interviews. In total, we conducted 203 observations, 78 group discussions with 604 community participants (including 342 women), and 95 key informant interviews (Bond et al., 2013). One of the manuscripts in this PhD (Manuscript 1) focused on community narratives of women's risk of HIV and is based on data collected as part of the BBS process. A more detailed description of the BBS method is included in Manuscript 1.

The qualitative cohort study

During the implementation of the PopART intervention, we recruited households across all nine communities in South Africa and in four of the communities in Zambia[4] to participate in longitudinal participatory research activities (referred to as the "qualitative cohort study"). Between 2016 and 2018, we completed six thematic data collection modules with 89 households (~300 participants) in South Africa. Across the six modules, we conducted approximately 1000 interviews over the course of the data collection period. Each module

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[4] Fewer communities were included in the qualitative cohort study in Zambia because of logistical issues related to distance from the main site office in Lusaka. As such, three interventions and one of the control communities were included in the qualitative cohort study. In South Africa, all research communities were less than an hour's drive from the site office in the Northern Suburbs of Cape Town and were included in the cohort study.

included a range of data collection activities around thematic ‘domains of life’ (detailed later in this chapter). For this PhD study, I include data from the qualitative cohort study for four of the academic manuscripts (Manuscripts 2 – 5).

In this section, I provide a detailed description of the data collection process, including the 1) ethnographic research framework, 2) participant recruitment, 3) sampling process, 4) data collection and research tools, and 5) the data collection structure, 6) the data collection teams and process of field worker training. I also describe the overarching analytical approach employed for this study. Lastly, I include a summary table describing the methodology for each of the five manuscripts included in this PhD.

Research framework: Participatory ethnographic data collection

Conventional ethnographic research prescribes that researchers should be “living with, learning and speaking the language of, and participating in the cultures of the people being studied” in order to reveal “the social actions, beliefs, values, and norms of markedly different cultures from the viewpoint of an outsider” (Wolf, 2012: 285). This approach, referred to by Clifford Geertz (1998) as ‘deep hanging out’ has usually involved living with participants, becoming part of the community, and spending prolonged time periods (often years) with participants. It is also premised on the assumption that researchers are ‘outsiders’ to the communities being studied. Increasingly, some ethnographers have changed their approach in order to adapt ethnographic research to practical constraints (e.g., safety, travel distance, costs) and professional and personal demands (e.g., short timelines, other professional responsibilities, the need for rapid results). Ethnographic research has evolved to allow for its use in new kinds of settings like online platforms (García-Rapp, 2019; Sade-Beck, 2004), in rapidly changing health environments (such as during the recent COVID-19 pandemic) (Moloney et al., 2020), and in modern urban contexts (Ross, 2015).

In the context of this trial, we adapted the ethnographic approach in order to situate it within the constraints and demands of the larger community-randomised trial and to speak to the different experiences of participants across different study sites, across the trial arms, across communities, and according to different HIV risk profiles of participants. Our adapted method included using a team-based approach, using semi-structured interactive discussion guides, and moving in and out of study communities on a regular basis, as opposed to living on the research site as ethnographers conventionally do. By doing so, we were able to conduct rigorous qualitative work at scale reaching a large number of households (n = ~150), in two countries (Zambia and South Africa) across research communities (n = 13). We had to consider the safety of research team members in South Africa where crime and violence are regularly reported (Fry, 2013; Gokah, 2006). This meant that it was difficult for university employed staff to implement prolonged stays with participants in the communities where the trial was being conducted. However, all staff were familiar with local contexts, fluent in one or more of the languages of the study communities, and several team members lived within adjacent or similar communities. In order to retain the key underpinnings of ethnographic research, we designed fieldwork encounters and guided discussions over an extended period of time with participants, structuring the research to include both targeted, semi-structured conversations with participants as well as informal, social, and extended participatory observations. It was our intention, as Hoey (2014: 2) describes, "to become a participant in the life of the setting while also maintaining the stance of an observer".

Recruitment

In the first phase of recruitment in South Africa, we approached participants during targeted recruitment drives where we walked randomly in different areas of the communities at different times of the day. We would then approach different types of people we encountered in passing (men, women, younger people, older people). Additionally, during community observations in key areas (a separate component of the PopART trial), we approached community members at health facilities, markets, and other busy areas and invited them to participate. We also asked the community health workers (CHiPs) employed by the trial and health workers at facilities to ask some of their clients who were living with HIV if we could contact them. In this initial phase, we had an open sampling strategy and recruited households based on the principles of sampling for diversity (Dattalo, 2010) to include participants of varying ages, genders, housing types, household compositions, socio-economic backgrounds, and locations in the community.

In the second phase of recruitment, we employed a targeted approach to ensure that at least 50% of households included in the cohort had one or more members living with HIV (see Hoddinott *et al.*, 2018) and recruited participants who were more at risk of HIV (including men who have sex with men (MSM), cisgender female sex workers, and transgender people) through snowball sampling (Heckathorn, 2011).We purposefully overrecruited households from communities receiving the intervention (Arms A and B) to ensure that we were able to adequately record participant experiences of the intervention.

Participant selection entailed a process of interactive weekly meetings where researchers would present details on the households they recruited to the rest of the team. Researchers described locations and layout of households, initial impressions of household composition, any disclosed health conditions of household members, details on any participants 'at risk' of being excluded by health services (such as MSM, sex workers, etc.), and general receptiveness of households to engage in long-term research. After these presentations, we would assess if the household should be included in the cohort and we would adjust our targets in terms of which additional households needed to be reached and added to the cohort.

Overall sample from data collection

Of the initial 150 households in South Africa recruited into the cohort, participants from 89 households completed all of the research modules. Nearly 300 individuals (~180 women) participated in discussions. Of these, 61 participants self-disclosed that they were living with HIV and 47 participants revealed that they had initiated ART at least once. Fourteen of the people living with HIV (PLHIV) included in the study were also living with comorbidities.

With each round of fieldwork (defined as the completion of one themed module of data collection), we lost approximately 10% of households to attrition. This was not a particularly surprising rate of attrition considering generally high levels of mobility of households in South African communities (Hoddinott et al., 2018). Many of the families who left the study did so because they moved away over the course of fieldwork. Nearly half of the participants lost to attrition were due to refusals for further participation in the study for other reasons, either explicitly stated or by avoiding calls or missing scheduled field work visits. In Zambia, attrition was much lower as researchers conducted blocks of fieldwork with households over a shorter time span (see details below). In Zambia, a total of 62 participants were recruited and participated in the cohort.

Data collection and research tools

To allow for rich insights into the lives of community members, we designed a set of six themed research modules on the various ‘domains of life’. Each domain included a range of topics and activities to elicit conversations from individuals and extended household members on the particular theme.

1. <u>Household structure and composition</u>: In initial household visits we asked participants to introduce themselves and tell the story of how they came to live in the community. We also drew detailed kinship maps (Leaf, 2006) to establish who the different

members of the family or households were, who was included in extended relations, the ages of participants, and the relations between different family members (see Figure 3). During later discussions, these kinship maps would be revisited and updated as needed.

Figure 7. *Example of kinship map from the qualitative cohort study.*

*Figure 8. Visualising household expenses - activity from the qualitative cohort study.*Figure 9. *Example of kinship map from the qualitative cohort study.*

2. <u>Place and space</u>: Discussions around place and space focused on the places inside and outside the community that were of interest to participants. Over the course of two to three visits, we asked participants to draw a picture or map of ‘the community’ to facilitate these discussions. We asked participants to indicate key infrastructure, including schools, health facilities, and transport routes on their maps and to describe their relationship with their place of residence. We drew an annotated floorplan of the physical household structure with family members to visualise the layout of the household and to determine how spaces were shared (e.g., who slept where, and who lived at home on which days of the week). Where possible, we asked participants if we could walk with them through the community to show us places of significance to

them. Participants completed two timelines – a long-term timeline of how they came to live in this place and notable life events along the way, and a weekly timeline to indicate what a ‘normal’ week entailed for different household members. Lastly, we showed participants printouts of their community, as represented in the PopART trial, in which community boundaries were drawn according to local clinic catchment areas. We asked participants to reflect on and consider how these representations of their communities fit with their own definitions, boundaries, and experiences of their communities.

3. <u>How people ‘get by’:</u> The aim of this module was to assess how households ‘survive’ in terms of financial and other resources. Part of these discussions were to understand how household members spend or prioritise expenses and how decisions around spending are made. After discussions on income sources (formal, informal, illicit) and expenses (routine, recreational, illicit), we asked household members (as a group) to visualise different income sources and expenses by creating a ‘pie chart’ with string to elicit further conversations about household spending (see Figure 4). We also completed a basic socio-economic survey with participants from every household.

Figure 10. Visualising household expenses - activity from the qualitative cohort study.

Figure 11. HPTN 071 (PopART) social science data used in manuscripts in this PhD study.Figure 12. Visualising household expenses - activity from the qualitative cohort study.

4. Love, sex, and romance: Although informed by other modules, data collected during this module represented the core of the data used in this PhD study. For this module, I led in the design of the research tools and I was able to adapt the design of the discussion guide to explicitly address the PhD study objectives. These discussions were timed to ensure that researchers had already developed rapport with participants and that participants were comfortable enough to share intimate details pertaining to their sex lives. We prefaced discussions with participants on the topic of love, sex, and romance by telling participants that discussions on the topic would be on a one-on-one basis with willing participants and reaffirming that confidentiality would be maintained – including between household and family members. We asked participants questions on how sex is talked about in their community and with their friends and partners. Discussions on sex were structured along three parts: an open conversation about community beliefs around sex, a timeline and details of previous relationships, and the intimate and detailed 'story' of participants' most recent sexual encounters. During the first part of the discussion, we probed participants on their general thoughts and experiences of sex (what sex is, what 'good sex' entails, who should not be having sex, when sex is bad, and thoughts on same-sex sexual interactions, etc.).

   In the second part of the interview, we narrowed the focus of the discussion to participants' own experience of sex and asked participants to draw a timeline of their past intimate relationships (both sexual and not) and asked participants to share the story of how each of these relationships unfolded. Where needed, we probed participants on how (amongst other things) each relationship started, if it was sexual, the good/bad things about the relationship, if the relationship involved 'love' or 'romance', if it resulted in pregnancy, if they cohabited, if they ever experienced violence, and (where applicable) how the relationship ended. Lastly, we asked participants to share, in detail, the sequence of how their last sexual interaction happened. We offered participants the opportunity to speak directly to the voice recorder and for the researcher to leave the space, if they preferred. However, fewer than 10 participants made use of this option. After these discussions, we probed participants on HIV prevention methods, and for participants who had disclosed to us that they were living with HIV, how/if they managed HIV disclosure, prevention, and treatment with intimate partners.

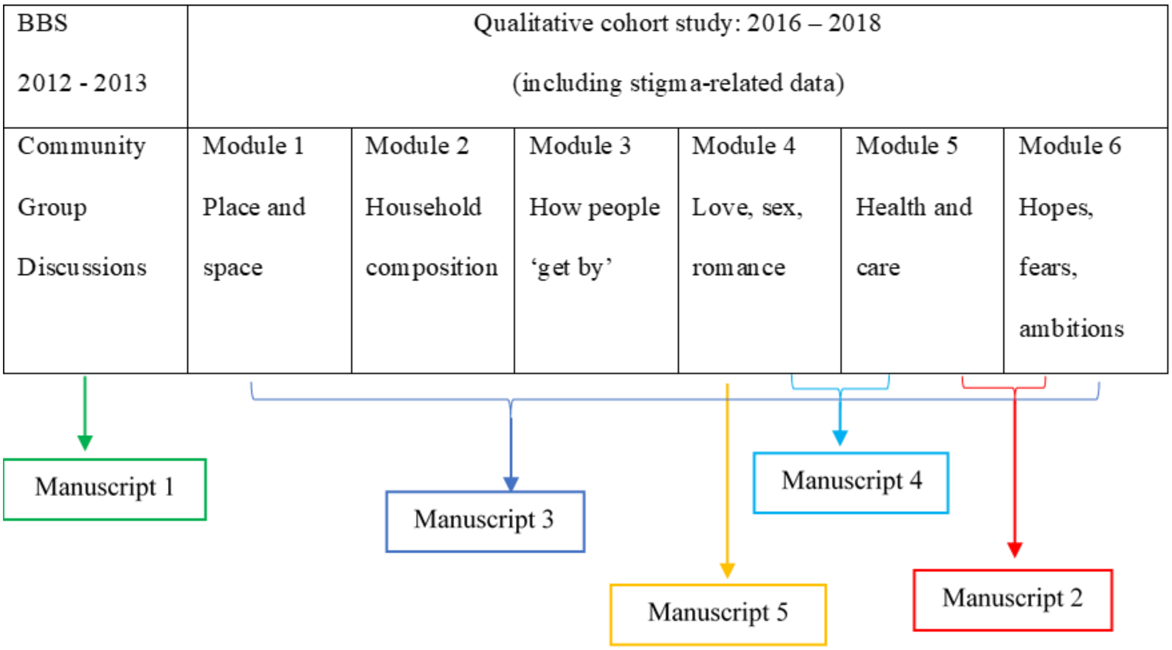
The final part of the discussion entailed the completion of a short Couple Functionality Assessment Tool (CFAT) questionnaire on experiences of relationship quality (see Ruark *et al.*, 2017).

5. Health and care-seeking behaviour: This module focused on exploring individuals' and community members' understandings and experiences of HIV, HIV testing, and treatment. Participants were probed on popular understandings of HIV in the community, including the words used for HIV or treatment, how HIV has affected their community and when they first became aware of HIV in their neighbourhood/area. We asked specific questions about knowledge of HIV prevention modalities and beliefs about treatment. Participants were also asked to reflect on the relative importance of other health concerns in their community compared to HIV. This was followed by a discussion in which researchers familiarised participants with the UNAIDS 90-90-90 HIV care continuum (UNAIDS, 2014), using a visual representation of the continuum. Drawing on their experiences of HIV services access, participants were asked to reflect on the challenges and opportunities around testing, linking to HIV care and treatment, and staying on lifelong treatment. Participants in intervention communities (Arm A and B) were asked to relate the story of what happened if and when the trial community health workers (CHiPs) came to their household.

As far as possible, we also conducted individual interviews with household members to uncover their experiences of HIV testing. Where participants were known to be living with HIV, we completed an additional discussion in which we asked them to share the timeline of their HIV story, including diagnosis, treatment, and disclosures. We also completed a ‘disclosure network’ activity with all people living with HIV to visualise who they have willingly disclosed their status to, who became aware of their status without their consent, and who they wish to disclose to as well. Participants who were part of ‘key populations’ (MSM, cisgender female sex workers, transgender people) were also asked a series of specific questions on their experiences of accessing health services.

6. Hopes, fears, and ambitions: The discussion with participants at our last research visit was framed around a member sense-checking activity. The practice, which has been used in various contexts where data is collected with participants (Locock et al., 2019; Wigfield and Alden, 2018), involved inviting participants “to check, comment on, or approve the researchers’ data or interpretations, i.e. whether they are correct or meaningful from the viewpoint of the informants” (Iivari, 2018: 111). After reviewing information with participants and discussing key thoughts on data collected over the course of the qualitative cohort study, we also asked participants to reflect on their experience of research participation (the topics that were easy/difficult/unexpected or what they learnt over the course of our interactions). During this discussion, we conducted a final confirmatory check of data (kinship map, household map, key household demographics, and updates on health information). Lastly, we asked participants open-ended questions on their hopes, dreams, fears, and aspirations for the future before ending off data collection.

In Figure 5 below, I show how I used the data for each of the outputs in this thesis.



BBS 2012 - 2013	Qualitative cohort study: 2016 – 2018 (including stigma-related data)					
Community Group Discussions	Module 1 Place and space	Module 2 Household composition	Module 3 How people 'get by'	Module 4 Love, sex, romance	Module 5 Health and care	Module 6 Hopes, fears, ambitions

Figure 13. HPTN 071 (PopART) social science data used in manuscripts in this PhD study.

Figure 14. Women's experiences of intimacy and sex across domains.Figure 15. HPTN 071 (PopART) social science data used in manuscripts in this PhD study.

It should be noted that, although the themed research modules are presented as distinct activities above, the modules were designed to be complimentary and to build larger narratives for each household and the individuals in those households through different lenses over a longer period of time. For example, in order to understand women's experiences of HIV status disclosure to intimate partners, data were collated from module 4 (love, sex, and romance) to understand sexual histories, but were informed by module 5 (experiences of health care) and observations of interpersonal power dynamics in households during module 3 (how people 'get by') when they talked about income. Each of the themed research modules provided the opportunity to build on existing knowledge about households or individuals in those households.

Data collection structure

In South Africa, the aim was to visit every household between one and three times per research module and to interact with a household regularly over the course of 18 to 24 months. Researchers regularly 'checked in' with households when they were in the field visiting other participants, phoned, and contacted them via *WhatsApp* (phone messaging service) to keep in contact. In Zambia, communities were geographically spread out and researchers conducted fieldwork in two-week blocks, completing two modules per block. In Zambia, researchers worked with local research assistants in order to keep in contact with participants. Research assistants were tasked with recruitment of participants and maintaining relationships in the gaps between targeted data collection blocks.

Research tools were developed in South Africa during multiple iterations with team members and experts, refined after training workshops, and finalised after a round of testing between researchers. Data collection tools were then adapted by Zambian team members to be context appropriate.

Each discussion lasted between one and three hours, depending on participant availability and willingness to 'hang out'. Researchers were required to take field notes during interactions and write detailed reflective notes on semi-structured activity sheets after each of the discussions. All interactions were audio recorded and, with permission (see section on ethical considerations below), researchers took photos of research activities, the neighbourhood, and the household, as needed.

The research teams: composition and training

In order to collect the large dataset in South Africa, we employed approximately 35 researchers and research assistants with various levels of experience and academic training (high school graduate to graduate students) and from diverse research backgrounds (anthropology, sociology, political science, psychology, etc.). Team members (myself included) were between 22 and 35 years old at the time of data collection. In South Africa, we employed researchers who were first language Afrikaans, Xhosa, and English speakers in order to match community demographics in the trial. Approximately 70% of the research team were women. In Zambia, a smaller team of four core researchers (three men and one woman, all graduate researchers) collected data across the sites with the assistance of four local research assistants (one per community).

To ensure that we collected consistent, detailed, and sufficient data, we conducted interactive training workshops before fieldwork for each of the modules. The workshops were presented by the Social Science Lead (Dr Graeme Hoddinott), the Social Science Advisor (Dr Lindsey Reynolds), and senior researchers in the team (myself included). During these workshops, we discussed the theoretical background for each of the modules and practiced the different components of the discussion guide, allowing time for questions and reflections on anticipated challenges. We encouraged discussions on difficulties and discomforts that researchers might experience – including racism, sexism, homophobia, and power imbalances in research relationships. The discussion guides were adapted after each of the workshops to address concerns raised by the team.

For the module focusing on love, sex, and romance, we anticipated that some team members might find it challenging to conduct in-depth interviews with participants on their love and sex lives. In our research context, these topics are often sensitive for researchers and participants due to cultural, religious, or other personal reasons. We had several sessions where we engaged in open discussions about sex and sexuality and encouraged researchers to practice the discussion guide with a team member they trusted. In order to mitigate potential discomfort that participants might experience, we drew on researchers in our team to match participants, if participants preferred (i.e. men with men, younger women with the youngest of our team members, etc.).

During data collection, we used a team-based approach. Accordingly, we paired researchers who were fluent in the home language of the households that were assigned to them. One team member was primarily responsible for data collection with particular households, but participants interacted with various team members over the data collection period.

As expected, during data collection, we often encountered distressing information, including narratives of abuse, assault, violence, and trauma – from participants both as victims and as transgressors. After field visits for all modules, the social science lead researcher and I co-facilitated both individual and team-based debrief sessions. All HPTN 071 (PopART) field staff, including the social science team, also had access to a monthly mentorship session with a trained psychologist and received safety training through Stellenbosch University.

Analytic process

All interactions with participants were audio recorded and transcribed verbatim by the research teams. In transcriptions, we used symbols to indicate hesitations, tone, pauses, interruptions, and changes in volume (Powers, 2005). Researchers added notes throughout transcriptions as needed, for instance, where terms might be ambiguous. Transcriptions were quality checked and then translated. Again, translators added notes and described the meaning of some of the original terms used, as needed. After another round of quality checks, we anonymised transcripts and removed identifying information.

For the analysis for each manuscript, I employed different analytical processes (described in detail in each manuscript), but relied on the overarching frameworks of thematic (Braun and Clarke, 2006) and narrative analysis (Riessman, 2003, 2008). The comprehensive data (verbatim transcriptions, field notes, reflection notes, and visuals) collected as part of the qualitative cohort study allowed the opportunity to analyse not only the broad themes, but also the ways in which identity and illness narratives were narrated and performed by participants over time (Riessman, 2003).

Thematic analysis allows for the "understanding of complexity and context-specific variation" (Riger and Sigurvinsdottir, 2016: 34). Narrative analysis, by contrast, is a means to examine "continual engagement with the discourse as it was delivered, [gaining] entrance to the perspective of the speaker … tracing the transfer of information and experience in a way that deepens our own understandings of what … social life is all about" (Labov, 1997: 396). Through thematic analyses, I was able to collate and analyse across our large dataset and to present comparative findings in terms of women's experiences and show patterns of women's experiences that would not be possible through narrative analysis alone. For this PhD, narrative analysis was also a fitting frame as it enabled me to share the experiences of women and engage with their detailed stories, including the narratives conveyed and the details omitted. In focusing on narratives and not disembodied pieces of quoted text, I was able to better represent women's experiences on the intimate subject of sex.

In the table below, I provide a summary of the data source, sample, and analytic process for each of the manuscripts included in the thesis.

PhD manuscript	Data source	Sample	Analysis process
1. Community narratives about women and HIV risk	PopART Broad Brush Survey: 2012 - 2013. Zambia and South Africa. 21 communities. Community group discussions.	All community group discussion participants: 604 community members (342 women) from 78 group discussions. Groups consisting of: "older women" (aged >35), "younger women" (aged 18–35), "older men" (aged >35), and "younger men" (aged 18–35).	Phase 1: Identifying all textual extracts where "woman" and "risk of HIV" are mentioned in the "wealth, poverty, and risk ranking" activities. Three extracts were independently and inductively coded by the first and second author to establish research themes. Phase 2: A narrative analysis to identify conversational processes through which each of these three categories of "woman and HIV risk" emerged.
2. Universal HIV testing and treatment and HIV stigma reduction: a comparative thematic analysis	Qualitative cohort study: 2016 – 2018. Zambia and South Africa. Research modules: Health and care-seeking behaviour; hope, fears, and ambitions. Data: transcripts, field notes, reflection memos.	All qualitative cohort study participants (Modules 5 and 6): Zambia (n = 60; 32 PLHIV) and South Africa (n = 74 households; 61 PLHIV). Exclusion criteria: health workers.	All extracts where participants, including PLHIV, referred to experiences of accessing HIV related services (or not) were identified. Extracts were coded thematically (Braun and Clarke, 2014) and case examples were presented.
3. Managing comorbidities and public/private dichotomies in HPTN 071 (PopART) trial communities	Qualitative cohort study: 2016 – 2018. South Africa. All research modules. Data: transcripts, field notes, reflection memos.	Data collected with all participants in South Africa who self-disclosed that they were living with HIV and at least one other chronic condition (n=14).	Narrative summaries for 14 identified participants were constructed. A case-by-case comparison of the narratives to identify common and distinct themes across cases were conducted. The narrative of Emily (pseudonym) was identified as resonating with and exemplifying the complexities and tensions experienced by other participants.

			During an in-case analysis, a detailed timeline of Emily's illness narrative was constructed. We present a detailed account of her experiences with supporting data from the 13 other participants.
4. The act of telling: South African women's narratives of HIV status disclosure to intimate partners	Qualitative cohort study: 2016 – 2018. South Africa. All research modules. Data: transcripts, field notes, reflection memos.	All cisgender women living with HIV in the three South African intervention communities receiving early access to ART (Arm A). Fifteen women aged 19 to 45, from twelve households, were included.	A two-phased narrative performative analysis was conducted to explore the life stories and identify the specific 'performances' (moments) of HIV status disclosure of women living with HIV. Phase 1: Data for each of the 15 women were collated to construct a cohesive case description of each participant. Phase 2: A detailed focus on speech sections where participants described the act(s) of disclosing (or deliberately concealing) their HIV status to their sexual partners was created. We identified overarching themes for the various types of performances of (non)disclosure. Through narrative analysis we engaged with several 'lenses' in considering the way that participants construct events, including language, the narrative process, context, and key events.
5. Love, sex, and intimacy: women's sexual scripting and HIV prevention in the context of expanded access to antiretroviral treatment	Qualitative cohort study: 2016 – 2018. South Africa. Research modules: love, sex, and romance. Data: transcripts, field notes, reflection memos.	All (self-reported) sexually active women aged 18-35 who participated in individual discussions on love, sex, and romance. 71 women (Arm A: n = 49; Arm B: n = 9; Arm C: n = 13). PLHIV = 20 (self-reported). Exclusion criteria: Women in same-sex relationships and sex workers.	Two-phased thematic approach. Phase 1: Co-authors identified all extracts with key topic areas including: participant definitions of sex acts, detailed sex act descriptions, HIV prevention strategies, contraceptives, HIV risk perceptions, and interpersonal relationship dynamics. Phase 2: A thematic comparative analysis, as described by Braun and Clark (2014) was conducted. We grouped and compared the sexual scripts of women in intervention communities (Arms A and B) to women in control communities (Arm C).

2.4. Ethical considerations for this project

The HPTN 071 (PopART) trial and all its components received ethical clearance from the London School of Hygiene and Tropical Medicine, the Stellenbosch University research ethics committee (N12/09/056; N12/11/074), and the biomedical research ethics committee at the University of Zambia. I received additional approval from the Stellenbosch University research ethics committee for this PhD project (SOC-2018-8807) – see Appendix A. The approval stipulated that my PhD aim, objectives, and planned analysis processes were wholly within what was consented to by participants in the trial and therefore did not require additional consent. Similarly, my PhD analysis introduced no additional risks to the participants. In addition, I received written permission from the principal investigators (PIs) of the HPTN 071 (PopART) trial to use the data collected during the trial as part of this PhD project.

All participants signed written informed consent forms prior to participation and consent was continually confirmed during follow-up discussions (See Appendix B – consent form). Consent forms were available in Afrikaans, English, and Xhosa in South Africa and in English and the local dialects in Zambia. As stipulated in the consent form, participants were informed that the data collected as part of the PopART study would be stored in a databank so that it could be used for additional analyses (such as this PhD study). Participants were given the opportunity to have their data excluded from the databank while still participating in the primary PopART social science study, although none of the participants indicated that they would prefer to be excluded.

Many of the topics discussed with participants were sensitive (health, HIV, relationships, sexual histories). To ensure that participants were able to discuss these topics with us, we tried to secure private spaces to have selected individual conversations, for instance in the researcher’s car (see Manuscript 3), or we arranged with specific participants to visit them at times when other household members were not at home. Through keeping detailed reflection and field notes, we were able to note when participants shared confidential information that other members of the household were not aware of (for instance, HIV status).

During data processing (transcription and translations), all names and identifying place names were removed from the transcripts. We also used pseudonyms in all presentations and publications of findings to protect participant confidentiality.

Although participants did not receive any cash incentive, South African research staff had discretionary allowances of R80 (approximately 5 USD) per day to spend on expenses shared with participants, for example meals.

2.5. My role in the research process

Employment

During the HPTN 071 (PopART) trial, I was employed as a Social Science Researcher at the Desmond Tutu TB Centre, Stellenbosch University. I was primarily responsible for managing and coordinating the qualitative cohort component of the trial in South Africa. This included contributing to conceptualisation of the cohort, coordinating data collection and data management, contributing to data collection, staff management, analysis, and reporting. I contributed to the drafting of the research tools, leading on the discussion guide for the love, sex, and romance module (the primary thematic area of this PhD). Over the course of the trial, I conducted multiple fieldwork visits, including approximately 20 one-on-one interviews with women during the research module on love, sex and romance, and health and care-seeking behaviour. I often assisted other team members when visiting households and facilitated debrief sessions after fieldwork with multiple team members over time. I contributed to the data processing, including transcriptions and translations from Afrikaans to English.

Co-authorship and collaborations

For the five articles included in this thesis, I led in the conceptualisation, conducted the analyses, wrote the first (and subsequent) drafts, and fulfilled the role of the primary author. However, as data collection for this PhD is nested in the larger trial, manuscripts were often developed with input and support from various senior researchers or PIs who conceptualised the larger HPTN 071 (PopART) trial, as is the convention in large-scale clinical trial research. As with all other outputs related to the trial, all researchers (myself included) offered senior researchers, including the trial PIs, the opportunity to contribute as co-authors with the understanding that they would be expected to offer substantial contributions beyond honorary co-authorship (Kumar, 2018). In addition, junior researchers in the social science team whom I mentored and who contributed to data collection and analysis were also offered the opportunity to co-author selected articles. A note on contributions for each of the articles in this PhD study is included before each of the articles and detailed in Appendix C.

Positionality

During data collection for the qualitative cohort study, I visited multiple households, mostly in the Cape Winelands. As I am Afrikaans-speaking, I was able to conduct interviews with several women in their home language. Whilst we shared a language, the power imbalances that shaped our relationships should be acknowledged. As a middle class, white, Afrikaans woman in South Africa, I am undoubtedly in a position of privilege when compared to the mostly low-income coloured women whom I spoke to. The imbalance is amplified by the lingering injustices of the racialised system of apartheid, which means that housing, education, and job opportunities are still largely structured along racial lines (Tshishonga, 2019). In addition, my position as a researcher from a tertiary institution contributed to this power imbalance. According to Goitom (2019: 197), the imposition of the ‘white gaze’ of the researcher on participants in positions of disadvantage (social, economic, power), is problematic as it reinforces an “atmospheric semblance for texts of authority, … standardizing particular accounts of the world as knowledge and reality, … indicative of gross assumptions about knowledge, who gets to generate it, and who makes claims to it.” While I took steps to build relationships with participants over time, my position as ‘outsider’ was unmistakable. This awareness of my status as outsider was reflected in both subtle and explicit ways during our interactions. For instance, participants would go through additional steps to clean their houses in anticipation of planned visits, would offer the best seating, and would buy treats (cool drinks, chocolates) despite limited means, and would offer apologies for items that they deemed would be socially undesirable, such as broken furniture or appliances.

More subtly, participants would engage in self-policing in the way they shared information about their lives. Beyond social desirability, there was an impetus to appear on par with certain social expectations. For instance, the Jacobs family, described in detail in Manuscript 3 (public/private dichotomies), would hide certain aspects of their life and amplify others to appear respectable in our engagements. They hid their illicit marijuana selling business (explaining that they were selling cigarettes) and the household matriarch would admonish her daughter when she used expletives. When I spoke to the family, they would brush over ‘undesirable’ instances of substance abuse and highlight ‘proper’ behaviour, including church attendance. It was only through extended observations, discussions over longer periods of time, and through reflections with other researchers who had interacted with the household that we were able to construct a more informed account of their lives.

In other instances, the information that participants were willing to share with me differed from the information shared with other researchers. For instance, in one household in the Cape Winelands with a large coloured, Afrikaans-speaking family, the five sisters (all in their twenties) would readily share their stories of going to parties, drinking, and meeting young men with another researcher – a young coloured, Afrikaans-speaking woman. However, during individual interviews, the women did not mention any of these events with me, despite probing. There are other examples where participants would not share their HIV status, or mention the number of previous sexual partners, despite having shared the information with other (non-white) researchers.

However, through repeated interactions over time, I was able to build rapport with many of the women who were able to share meaningful stories about their lives. In addition, in my analyses, I was able to draw on my own (multiple) observations as well as data collected by other researchers who, in some cases, were able to collect data without the additional complexity of racial dynamics.

Keikelame and Swartz (2019) suggest that, in order for better, more ethical research to be conducted among marginalised communities, researchers need to engage in culturally appropriate and respectful research that is both participatory and transformative, with genuine recognition of the assets and knowledge that participants can contribute. In our research, we attempted to incorporate these principles through our regular team workshops, where we engaged with and reflected on the topic of ‘culture’; through our use of iterative and participatory discussions with participants; and through our attempts to centre participants’ own experiences and voices in our outputs.

In exploring the sexual lives of women in high HIV-burden communities, it is also essential to carefully navigate the historical problematics of positionality and to acknowledge significant disparities in power and privilege often present between researchers and participants. Researchers who are external to study communities (such as myself) need to be cognisant of these historically-shaped disparities and to explicitly acknowledge the potential effects of these dynamics both on the data gathered and on the analytic process. Additionally, researchers should be cognisant of the burden of research on the communities in which it is conducted to critically interrogate whether the research will benefit these communities (or other similar communities), and to carefully avoid any form of exploitation (Koen et al., 2017). To address these concerns, our study team has committed to continuous engagement with research communities, open communication with participants with regards to study findings, and acknowledgment of the contribution of participants could make in order to ensure more ethical research. In addition, during regular team workshops, we reflected on data collection and our roles and responsibilities while working in communities.

While I was an outsider in households in South Africa, I had extensive experience working in communities and understood (to some extent) the local context. However, for the data from the Zambian communities, I had no local knowledge and had to lean on the support and interpretation of researchers from the area. For this reason, I focus primarily on the South African dataset and only used selected Zambian data for comparative purposes.

2.6. Conclusion

The context of the HPTN 071 (PopART) trial provided the opportunity to collect rich, detailed, and expansive data on women’s experiences of sex and health in the context of increased access to HIV testing and treatment.

The study setting was unique − both in terms of form and scale. The longitudinal approach to data collection, focusing on the themed domains of life, ensured that I was able to collect detailed narratives from participants over time in the context of increased access to HIV testing and treatment, as it unfolded. I was able to benefit from the richness of the ethnographic process through collaborative and participatory data collection with a team of social scientists. In addition, due to the scope of the PopART trial and the design of the qualitative cohort study, we were able to collect an expansive dataset, comprising of more than 1000 interviews. The methods were particularly valuable to address my research aim as I was able to investigate, in detail, women's experiences of sex, health, and intimacy at a scale that would otherwise not have been possible. The depth and breadth of the data meant that I was able to analyse data at the detailed narrative level, but also, be able to examine broader (thematic) approaches to see patterns of experiences over time.

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Chapter 3: Findings and academic manuscripts

In order to address the aim and objectives of this research project, the findings of this thesis are presented in five academic manuscripts. The manuscripts include the following:

Manuscript 1:	Community narratives about women and HIV risk in 21 high-burden communities in Zambia and South Africa.
Manuscript 2:	Universal HIV testing and treatment and HIV stigma reduction: a comparative thematic analysis of qualitative data from the HPTN 071 (PopART) trial in South Africa and Zambia.
Manuscript 3:	“It stays between us”: Managing comorbidities and public/private dichotomies in HPTN 071 (PopART) trial communities.
Manuscript 4:	The act of telling: South African women’s narratives of HIV status disclosure to intimate partners in the HPTN 071 (PopART) HIV prevention trial.
Manuscript 5:	Women’s sexual scripting in the context of universal access to antiretroviral treatment – findings from the HPTN 071 (PopART) trial in South Africa.

For each manuscript, the referencing style, formatting, and language structure is in accordance with the academic journal where the manuscript has been published or submitted for publication.

Manuscript 1: Community narratives about women and HIV risk in 21 high-burden communities in Zambia and South Africa.

Viljoen, L., Ndubani, R., Bond, V., Seeley, J., Reynolds, L. and Hoddinott, G.

Overview and contribution to dissertation aims

In this manuscript I showcase how community members narrate their understandings of "women" and "HIV risk" in communities in South Africa and Zambia prior to the implementation of the HPTN 071 (PopART) HIV prevention trial. This provides a foundation of sorts for the analyses that follow, which explore if or how conceptions of HIV risk shape women's intimate relationships.

Community responses to HIV prevention initiatives, including universal access to HIV testing and treatment (UTT), are dependent on internalised and shared understandings of HIV risk. Through an analysis of interactive and participatory group discussions conducted with more than 600 community members, I show how community members position and conceptualise HIV risk, specifically women's risk of HIV. From the narrative analysis, three types of archetypal descriptions of women and risk emerged: good women, bad women, and vulnerable women. By describing how community members shift their depictions of women's HIV risk between these categorisations, I demonstrate the fluid positions that women are understood occupy in communities and how 'risk' is neither constant nor stable, but rather subject to lived experiences. The manuscript thus serves to locate women and HIV risk and confront accepted simplified representations of 'risk' present in public health narratives.

Through this analysis, the manuscript contributes to the first objective of the PhD thesis: to describe community narratives of women's risk, responsibilities, and vulnerabilities in relation to HIV. In reference to the dramaturgical metaphor (Goffman, 1959)[1] in scripting theory, as described by Simon and Gagnon (1986)[2], community narratives of women's risk are indicative of the cultural scenarios, or broader social norms, related to women, sex, and HIV. They are thus an important dynamic to understand in order to explore how women's own narratives of intimacy and risk are shaped.

Author contributions

As primary author, I was responsible for the conceptualisation of this manuscript. In addition to contributing to data collection, I led the analysis process, conducted the literature review, and wrote the first (and consecutive) drafts. Co-authors contributed through inputs into the conceptualisation, analysis support, revisions, and detailed comments. A note on co-author contributions is available in Appendix C.

Publication status

The manuscript was peer reviewed and published in 2017 in the 'International Journal of Women's Health'.

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ORIGINAL RESEARCH

Community narratives about women and HIV risk in 21 high-burden communities in Zambia and South Africa

This article was published in the following Dove Press journal:
International Journal of Women's Health

Lario Viljoen[1]
Rhoda Ndubani[2]
Virginia Bond[2,3]
Janet Seeley[3]
Lindsey Reynolds[4,5]
Graeme Hoddinott[1]

On behalf of the HPTN 071 (PopART) Study Team

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Abstract: Public health researchers repeatedly represent women as a group vulnerable to ill health. This has been particularly true in the field of HIV research, where women are disproportionately affected by HIV in terms of disease burden and the social effects of the epidemic. Although women have been the focus of many prevention and treatment programs, structural barriers to implementation of these targeted programs persist. In this article we explore how high HIV-burden communities in South Africa and Zambia engage with the concepts of "woman" and "HIV risk". The data are drawn from participatory storytelling activities completed with 604 participants across 78 group discussions between December 2012 and May 2013. During discussions we found that participants made use of the core archetypal caricatures of "goodness," "badness," and "vulnerability" when describing women's HIV risk. Community members shifted between these categories in their characterizations of women, as they acknowledged the multiple roles women play, internalized different stories about women, and sometimes shifted register in the same stories. Findings suggest that health implementers, in consultation with community members, should consider the multiple positions women occupy and how this impacts the wider community's understandings of women and "risk". This approach of taking on board community understandings of the complexity of HIV risk can inform the design and implementation of HIV prevention and care programs by rendering programs more focused and in-line with community needs.

Keywords: HIV/AIDS, gender, vulnerability, community beliefs

Introduction

In sub-Saharan Africa, the epidemiological distribution of HIV is distinctly gendered. In South Africa, 12.2% of the population is HIV positive, which includes 14.4% of women compared to 9.9% of men.[1] It is estimated that adult women (aged ≥15) account for >3.8 million of the 7 million people living with HIV (PLHIV) in South Africa.[2] In Zambia, where HIV prevalence among adults aged 15–49 is 13%, 15% of all women and 11% of all men are HIV positive.[3] Of the 1.1 million adults affected by HIV in Zambia, ~640,000 (58%) are women.[2] The skewed distribution of HIV between women and men has amplified a long-standing narrative in public health and medicine, and in popular culture that women are a "vulnerable" group, in need of sympathy or support.[4] Social constructions of vulnerability are grounded in part in the disproportionate biological risk, and the epidemiological and social burdens experienced by women.[5–7] The physiological composition of women's bodies makes women biologically more likely to contract HIV through vaginal intercourse than men.[8] This physiological risk is compounded by social risk factors that affect women at higher rates, particularly gender-based violence and rape.[9]

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In this paper, we examine how individuals living in 21 high HIV-burden communities invoke caricatures of "woman" when engaging with ideas of "HIV risk". We explore how people living in these contexts describe women and HIV risk, how HIV is integrated into notions of "womanhood," and how constructions of "womanhood" shift in social narratives. We ground these discussions about women and HIV in lived social contexts in Zambia and South Africa. These understandings have important health implications for developing interventions and the accompanying HIV-messaging. We argue that local (mis)interpretations of women's increased HIV risk can sometimes reinforce underlying narratives about women's inferiority by casting women as lacking the biological and social "wherewithal" to withstand HIV. In contrast, some community narratives explicitly contest such perspectives by highlighting how ongoing gender imbalances in division of labor, care, access, and power perpetuate these epidemiological "vulnerabilities," and must therefore be shifted. In this way, community narratives about women and HIV risk are complex negotiations with broad implications for the experiences of PLHIV and people living in the context of HIV.

Background

The portrayal of women as "vulnerable" to HIV is located in both the biological and social risks of HIV acquisition that many women experience. Firstly, women are physiologically at greater risk of contracting HIV per unprotected vaginal sex act than men.[8] Compounding the increased biological odds is social disempowerment, marginalization, and social risk factors (including risk of violence and assault) that many women face. This disempowerment is illustrated in the UNAIDS Gap Report[10] where adolescent girls and young women are identified as a vulnerable group in part due to the extent of violence against women. For many women in southern Africa, intimate partner violence has become part of their daily realities.[9]

Secondly, and more broadly, social contexts that reflect wider societal gender relations and hierarchical gendered power dynamics[11,12] can limit women's agency and indirectly put them at increased risk of contracting HIV. These contextual factors include the often subordinate or dependent economic status of women which is often affected by men's asserted control over specific sexual domains.[13] Women also often carry disproportionate responsibility for family care, including care of family members affected by HIV, sometimes to the exclusion of their own health priorities.[14]

More distal risks associated with women's social contexts include sex work,[15,16] informal transactional sex,[15,17–19] or survival sex,[20,21] and alcohol and other substance abuse.[22] In addition, women may lack power in sexual negotiations, particularly around issues like negotiating condom use.[23,24] Women also lack control over the sexual lives of their partners outside of their relationships, sometimes even when they are aware of their partner's infidelity.[18] It should be noted that the notion that women bear the bigger burden of HIV in sub-Saharan Africa is not uncontested.[25] However, most researchers argue that the biological and social limitations felt by women in sub-Saharan Africa continue to place women at risk. Therefore, women remain a fundamental concern in terms of HIV prevention, treatment, and care.

Researchers have highlighted that when women's position as subordinate in society is accepted as "normal," women are often less able to negotiate around health, including negotiating condom use, and are at increased risk of gender-based violence.[26] While there are often clear social limitations placed on women, the resilience they show should not be ignored.

When taking these varied experiences of vulnerability and resilience into account, Jewkes and Morrell[27] have argued that femininity is not a singular construct, but rather that there are "multiple femininities" at play in social contexts. As with masculinity,[11,12] there is a hierarchy of femininities. Some femininities (referred to as emphasized femininities[28]) are compliant to patriarchy and the gendered hierarchy, while others are subordinate. Accordingly, while some women are contextually vulnerable to HIV infection and violence, in many other instances women can display significant agency in relationships with men.[27,29] In health literature, however, there has been a tendency to treat women as a homogenous group who are portrayed as victims. Jewkes and Morrell go on to argue that when we use the category of "woman" in an uncritical manner, it diminishes the impact of underlying factors such as women's needs and desires and how they go about achieving them. In turn, these underlying factors potentially influence women's relationships with men and their exposure to HIV risk.[27]

Women as a priority group for HIV programs

Given the uneven distribution of HIV prevalence and risk, women have often been prioritized in prevention and treatment initiatives in southern Africa.[30,31] Many HIV prevention campaigns have focused particularly on the vulnerabilities of women. For example, programs have focused on HIV prevention specifically among female sex workers[32] on female-controlled prevention technologies (as in the MIRA trial[33] in Zimbabwe and South Africa), and reducing rates of gender-based violence (as in the Stepping Stones intervention[34]). Programs have also focused specifically on financial or schooling support initiatives for women as a means of empowerment more broadly to negotiate HIV risk.[14]

Women have often been targeted in prevention and treatment interventions because of their roles as mothers and/or wives. For example, Prevention of Mother to Child Transmission (PMTCT) programs are focused on prescribing antiretroviral therapy to expectant mothers to avoid vertical transmission to unborn babies.[35] In more recent years, PMTCT programs have expanded to retain women on treatment beyond the birth of their babies.[36]

While a large number of programs for the prevention and treatment of HIV are geared toward women, many have met with limited success.[15] Klein et al[37] have identified some early structural barriers that might contribute to the varied success of these targeted initiatives. These include economic underdevelopment, poverty, high rates of mobility and migration, social and political instability, and gender inequalities. Despite an acknowledgment of the importance of structural barriers to HIV prevention among women, few interventions directly address gender-related challenges on the ground, often simply positioning women as "vulnerable," without further exploring implications for effective HIV prevention or treatment interventions. Watts and Seeley have noted that addressing gender inequalities, including gender-based violence, is "not a luxury but a necessity for effective programming, especially in settings where there is a high HIV prevalence among women".[38]

Narratives of risk: dialogical self-theory and positionality

To understand the complexity of community narratives about women, HIV risk and notions of vulnerability, we make use of the dialogical self-theory. In dialogical self-theory, the self is defined as a conversation (dialogue) between different voiced positions.[39] Voiced positions (including experiences of gender) are influenced by various aspects – both internal and shared with others.[40] In this article, these "voices" represent differing views, assumptions, and positions relative to notions of "woman" and "HIV risk" and thus can offer a lens for explicating the complexity of participants' perspectives and experiences. The various "voices" are evident in the discourse of participants. van Dijk[40] noted that discourse is influenced by both "personal and social cognition" which includes "personal memories, knowledge and opinions … [and] those shared with members of the group or culture". Through voicing these positions people "ascribe rights and claim them for [them]selves and place duties on others". This positioning of others implies a person or group being located as "trusted" or "distrusted," "with us" or "against us"[41] or, in this case, to be "at risk," "not at risk," "vulnerable," "good," or "bad." Dialogical self-theory is useful in understanding how community members locate health risks relative to gender as it assists not only in identifying how risk is described, but also identifies the underlying processes behind the allocation of HIV risk.

Our objective is to describe the voiced positions of community members and how they understand HIV risk in relation to the concept of "woman".

Methods and analysis

The findings in this paper are drawn from "Broad Brush Survey" (BBS) research conducted with community members in 21 urban, high HIV prevalence communities (for the HPTN 071 [PopART] trial, communities [or trial clusters] were defined as the catchment area of a selected health care center or clinic[42]) in South Africa and Zambia enrolled into the HIV Prevention Trials Network (HPTN) 071 (PopART) study. The BBS entailed a rapid assessment of communities identified to partake in health interventions. The aim of the BBS was to identify key stakeholders, describe the physical layout of the community, identify health services available, and assess community attitudes toward and knowledge of HIV testing, prevention, and treatment. Research activities included conducting a set of group discussions with community members, individual interviews with key informants, and structured observations in communities and health facilities over a period of 12 days (Bond V et al, PopART Broad Brush Surveys [BBS] Technical report for 3ie: Broad Brush Surveys of HIV Prevention, Treatment and Care in 21 Zambian and South African Communities to prepare for HPTN 071 [PopART], unpublished report, 2013). The approach is explained in detail by Murray et al[43] and Bond et al.[44] This research methodology is based on participatory methods as used by Wallman et al[45] and entails rapid data collection to characterize local community context and visible features for bounded communities across descriptive dimensons.[44] The BBS research was conducted in 21 communities in 2012–2013, prior to the implementation of a community randomized trial of combination HIV prevention (HPTN 071 [PopART]).[42] In Zambia, communities are distributed across four provinces while the South African communities are all in the Western Cape province. For reporting purposes and to ensure anonymity, research clusters are numbered Z1–Z12 in Zambia and SA13–SA21 in South Africa.

Ethical clearance for the research was received from the University of Stellenbosch Health Research Ethics

Committee, the Humanities and Social Sciences Research Ethics Committee at the University of Zambia, and the London School of Hygiene and Tropical Medicine. Permission to conduct the study in health facilities was also granted by the City of Cape Town and the Cape Winelands Provincial Health Research Committee in South Africa and the Ministry of Health and the District Medical Offices in Zambia. Written informed consent was received from all individuals prior to participation in group discussions. Personal identifiers were removed from transcripts prior to analysis and pseudonyms are used throughout this article.

Study participants

A total of 604 community members (342 of them women) participated in 78 group discussions across the 21 sites in South Africa and Zambia.[44] Participants were recruited during a process of systematic community observations and were purposively sampled to represent a wide variety of community views (including age and gender). Participants were recruited into groups consisting of "older women" (aged ≥35), "younger women" (aged 18–35), "older men" (aged ≥35), and "younger men" (aged 18–35). Eligibility criteria included living in the study community and being older than age 18. Discussions were facilitated by a graduate-level researcher and a research assistant in the participants' preferred language (often a mix of English and other local languages).

Data collection

During the BBS process, semi-structured observations, interviews with key informants, and group discussions with various community members were conducted. The analysis presented here is drawn primarily from one activity conducted in the group discussions with supporting contextualization from other data.

The group discussions were structured around various activities, including a "wealth, poverty, and risk ranking" activity. During this activity, participants were given an assortment of 16 character cards (nine of which depicted women) and asked to select cards that represent "the type of people that live in this community" (Figure 1). The images on the character cards were developed as part of a regional anti-stigma education program implemented in Zambia (images developed by Petra Röhr-Rouendaal on behalf of the Academy for Educational Development, International Center for Research on Women and International HIV/AIDS Alliance). Participants were asked to write down their selected character's "story," including descriptions of their income sources, living conditions, families, and health profile in terms of HIV. They then presented the stories to the other participants in the group for discussion.

Data analysis

All discussions were recorded, transcribed verbatim, quality checked, and translated by trained bilingual researchers into English. Photos of the different character cards and descriptions as well as the transcripts were uploaded into ATLAS.ti (version 7.5.10; Scientific Software Development, Berlin, Germany) for analysis by graduate researchers.

The first phase of analysis entailed identifying all textual extracts where "woman" and "risk of HIV" are mentioned in the "wealth, poverty, and risk ranking" activities. Three of the extracts were independently and inductively coded by the first and second authors[46] to establish research themes. Coding discrepancies were reconciled and further coding concluded. Three broad categories of associations between "woman" and "HIV risk" were identified – "good," "bad," and "vulnerable." A narrative analysis was then used to identify conversational processes through which each of these three categories of "woman and HIV risk" emerged.

Findings

Group discussions were held with 158 "older women" (aged ≥35), 166 "younger women" (aged 18–35), 94 "older men" (aged ≥35), and 156 younger men (aged 18–35) (the exact

Figure 1 Character cards depicting women used for wealth, poverty, and risk ranking activity.

Notes: Figures reproduced from Kidd R, Clay S, Chiiya C, editors. *Understanding and challenging HIV stigma: Toolkit for action.* Academy for Educational Development, International Center for Research on Women, and International HIV/AIDS Alliance; 2007. © Illustrations: Petra Röhr-Rouendaal, 2006.[50]

ages of 30 participants [12 men and 18 women] who participated in a "mixed" group discussion are unknown but it was established that they were ≥18 years). We identified three dominant, though not universal, associations between women and HIV risk, which reference archetypal caricatures – "goodness," "badness," and "vulnerability." These characterizations of HIV, women, and risk are illustrative of the narratives of community members and relate to the larger processes related to understanding risk and vulnerability. Further, we found that some participants would shift between these caricatures in describing their perceptions of risk, with the same participant attaching perceived HIV risk to different characteristics at different moments. This finding challenges static explanations of risk, which often assume risk to be consistently attributable to specific characteristics.

We suggest that these shifts in HIV risk perception were premised on three processes: 1) acknowledging the multiple roles women may play; 2) internalizing/personalizing stories about women to fit with lived experiences, and 3) shifting registers in descriptions from what is versus what should be. The archetypal categories of "good," "bad," and "vulnerable" are described in the "The good woman, exempt from HIV risk," "The bad woman, who spreads HIV," and "The vulnerable woman, at risk of HIV although no fault of their own" sections, respectively.

The good woman, exempt from HIV risk

In most group discussions, "good" women, as a theme, were defined by participants by a set of behaviors, some of which are linked to dominant public health narratives of HIV prevention. In particular, it was associated with the "abstinence" and "being faithful" components of HIV prevention messaging. Other characteristics extend beyond biomedical HIV prevention methods and include community involvement, attendance at religious institutions (mostly Christian churches), ability to work through hardship, and willingness to take care of families. The following description by one participant illustrates this caricature about a character card depicting a woman singing and wearing a dress and headscarf:

> She is a member of the church so she's obviously working in the congregation of the church … she is helping people every day [when] they have problems … her family is also very very religious … they go to church and I feel because of their lifestyle, they have a very high standard of living [moral standard] and as far as the HIV … there is no risk for them. They work in the community … they [are] cooking food for the poor and they feed the hungry. [Older woman from South Africa, site SA18, December 21, 2012]

The bad woman, who spreads HIV

The caricatures of "bad" women focus on "risky" (mostly sexual) behavior or putting others at HIV risk. These characterizations often include overtones of moral judgement. This is evident in the following description of a card depicting a female nurse:

> Most of the times why the nurses are at a risk is because most of them do not get married. They are just single women … most of the times they do not have husbands so they have a lot of man friends … they can even snatch [someone's] husband … and start having sex with him. [Older woman from Zambia, site Z2, February 8, 2013]

The vulnerable woman, at risk of HIV although no fault of their own

The third caricature emphasizes that women are at risk because of circumstances beyond their control. Vulnerability is perceived to exist because of physical threats (rape, abusive partners, violence, and physical disability), social threats (economic vulnerability, survival sex), or circumstantial threats (needle prick injuries, accidents). The attitude toward these women is one of sympathy and commiseration.

> There are those lame people (sic). You find that at the house where she stays, there are boys … maybe sometimes she remains alone, they will attack her and take her … remove her from the wheelchair. They go and rape her. When he is done he brings her back and tells her not to tell, she will not tell, she will be quiet. [Older woman from Zambia, site Z10, March 24, 2013)

Shifting narratives of risk

The three caricatures serve as hypothetical extremes in the narratives of "woman" and "HIV risk" presented by participants. In reality, we argue that, for community members, the complexity and multiplicity of women's lived experiences are an ongoing, contesting shifting of position between these extremes. The shifting of community members' understanding happened as different elements of women's experiences were in the foreground of the narrative. The shifting positioning of "woman" and "HIV risk" could, at first glance, appear contradictory or incoherent. However, participants articulated the complexity of women's positioning in relation to HIV risk through three rational processes that maintain narrative coherence.

Referencing the multiple roles women play in the community

During group discussions, participants (men and women) acknowledged that women fulfil multiple roles in communities, some of which might be considered good, bad, or vulnerable, depending on either the circumstances, the audience, or the position of the woman. The way a woman's association with HIV risk is described could therefore change depending on the role she was playing. For example, during a group discussion with young men in Zambia, a participant noted the following about a character identified by the group as a sex worker:

> For this woman to dress like this, then she doesn't love herself because a respectable woman is supposed to dress … in a wrapper [skirt]. [Young man from Zambia, site Z7, March 19, 2013]

With this image of the sex worker as the improper, bad woman established by the group, another participant added the following:

> You find that they are prostitutes (sic), but they have children at home. They say, 'I am going for work', they are just sex workers. Early in the morning they come back home [and] they even buy some bread and small parcels for their children, they have good families, despite that they are sex workers. [Young man from Zambia, site Z7, March 19, 2013]

Through this description there is an acknowledgment that one woman plays multiple roles and the overlapping categories of "good" and "bad" are logically cohesive.

The role of a woman as mother, provider, and wife is also discussed in the following extract from a group discussion with older women in South Africa:

> This lady is "Sarah". She wakes up … to prepare the children to go to school. After she has finished, she cleans the house … She is married and has four kids … She's [at] risk of getting HIV because her husband … is going to the shebeens [taverns] … he can meet some drinking girls there and then he can end up in bed with those drinkers because he's also drunk. [He goes] straight to his wife, as dirty as he is … and then the woman [the wife] can get HIV. [Older woman from South Africa, site SA17, March 26, 2013]

In her role as mother, income provider, and homemaker, her character is described as a "good" woman, capable of earning a living and taking care of her children and her home. However, her other role as wife also places her in the perceived position of "vulnerability".

Internalizing/personalizing stories of women

Related to the referencing of multiple social roles that women play, a second process enabled participants to maintain superficially inconsistent caricatures in descriptions of women. Participants' descriptions of "woman and HIV risk" often blurred the distinction between "a woman" (any woman in their community) and "a particular woman" (such as their mother, sister, or wife). Perceptions and assumptions about "woman and HIV risk" would shift dramatically as the participant changed the referent of their story from "a woman" to "my wife" or "me as a woman" (or vice versa). This blurring between caricatures implies that when the personal history or lived experience of the participant is taken into account, the character is perceived, judged, and presented differently by the participant. In many instances, a community member's narrative would start as a description of an archetypal character, but during the course of the narrative, personal, internalized experiences would transform the description of the character card. For example, one participant named a pregnant woman depicted on a card "Santie" and described her initially as living in adverse conditions and worthy of sympathy:

> She looks like a person who is very poor, [she] seems like [someone] who is raising her child on her own, that doesn't have parents and she, for me it would seem like, I can say, she only visits her friends … that is almost like for her family, because she looks like she no longer has family … it makes me feel bad now … The person seems to me like someone who is suffering, you see. 'Santie' seems to me like someone who suffers, that doesn't work … she has HIV, uhm, HIV/AIDS. [Young woman from South Africa, site SA21, April 10, 2013]

In this case, the description of "Santie" begins as referencing the vulnerability caricature. However, as the narrative develops there is a shift from the sympathetic description of "Santie" to also acknowledging the general "bad" behavior of women witnessed in the community.

> There are people taking care of her baby for the hard times … here in SA21 it happens like that, hey … they make children then leave them with you, just like that. [Young woman from South Africa, site SA21, April 10, 2013]

In this discussion, one participant – a young woman herself – described other young women in her community as actively engaging in sex ("making children") and leaving their children ("just like that") in harder times. Following this general description of women in the community, the same participant shifts her description toward blaming/vilifying

"Santie" for not testing for HIV during pregnancy and passing on the virus to her child:

> She now has the AIDS and … in the end it will be passed onto the baby now … perhaps if she went for her test and she found out … then she [would have] realised she [has] AIDS … As I can see [laughing] she looks like a person who was sleeping around and doesn't know who the child's father is. [Young woman from South Africa, site SA21, April 10, 2013]

In this instance, the shift from "vulnerable" to "bad" is gradual, but purposeful. The participant started with a clear, sympathetic narrative of "Santie," but soon acknowledged her own experiences of women in her community, and fit "Santie" into her experience of young women as "bad" women.

What is versus what should be

Associations between women and HIV risk also shifted markedly along these continuums when participants shifted register between what their understandings of women are or what they understood constituted HIV risk is and what it should be. In the following example, a young man from Zambia initially describes women in the community through the broad lens of expected "badness":

> School girls of nowadays, they do not date their sizes [age group]. They will go for those sugar daddies … every day, every weekend they are out with the teacher or something … even if someone their age tried to propose them they will say, 'What will this one offer me?' … They are just after money … they date men like their parents' age, those elderly men, working class who are stable and married … These school girls are at very high risk of HIV, like in the compounds. [Young man from Zambia, site Z11, January 22, 2013]

However, immediately after this description of the "bad" young women, there is a shift in register from the participant to acknowledge the survival pressures that young women experience:

> You find that where the young girl is coming from things are not good, life is hard. In the end she just thinks, maybe this one will keep me well. [Young man from Zambia, site Z11, January 22, 2013]

In his narrative, there is a self-awareness of the mismatch between moral expectation and circumstantial pressure, which is accounted for by the shift in register. This is also evident in the following example, in which another young man describes a character card depicting a pregnant woman:

> [Zola] has devoted [herself] to be a housewife; she will clean, so that her house is clean … she's not working. She has children. [Young man from South Africa, site SA14, June 3, 2013]

When asked about Zola's risk of HIV, the participant answered:

> On HIV, if I sleep around with other people, you see, I sleep with other people that I don't know … even how they look, you won't see how the person is. Now you just see the person's beauty, you'll see the beauty and sleep with them without a condom. [Young man from South Africa, site SA14, June 3, 2013]

The participant's narrative changes the description of the "good," devoted wife to someone who is potentially the one who passes on HIV to others, including himself. He notes that risks are taken with beautiful strangers and acknowledges that there is more to HIV risk than what could be seen on the surface.

A superficial analysis of participant narratives could point to quite stark, unsophisticated caricatures of women as either "good," "bad," or "vulnerable." However, it is through paying attention to the shifting between such extremes that the complexity of community narratives about women and HIV risk can be explicated. The blurry, contested nature of associations between women and HIV risk is illustrative of the multifaceted, difficult, and tenuous positions that women living in high HIV prevalence contexts occupy.

Discussion

The aim of our research was to characterize the diversity of narratives that are thematically relevant to critically understanding the ways in which people speak about women and HIV risk in looking for patterns in narrative. In this, we found that community members were aware of the ways in which women challenged the positions that they were believed to assume ("good", "bad", "vulnerable") and were able to articulate how HIV risk is a shifting phenomenon.

When shifting through categories of risk, community members often invoked the multiple roles that women play in society. In doing so, they referenced broader gendered power dynamics in society. Further, in their changing descriptions of women and the positions that they could assume, community members in our study either reinforced dominant femininities (for example the "good woman" who completes domestic duties and takes care of her children and husband) or challenged these femininities (where the "bad woman," the sex worker, is also able to provide for her children). Their descriptions of multiple femininities highlight how women can be seen not only to employ different roles, but also to exist in multiple stages of moving between being at risk/not at risk of contracting HIV.

In describing the multiple but simultaneous stages of risk, the concept of dividuality proves useful. Helle-Valle[47] defined dividuality as potential different perspectives that individuals may employ depending on the social context that they find themselves in. The findings demonstrate how individuals shift their perceptions of risk not only based on their understanding of HIV, but also on the context in which they live. The changing context also links to theories of intersectionality, as described by Crenshaw,[48] where the multiple spaces of intersecting vulnerability (such as race and gender) that women occupy are acknowledged. These theories engage with multiple perspectives and viewpoints that individuals can rationally employ at any given point in time.

In addition to addressing broader understandings of the position of women and concepts of risk, our findings also offer important insights for the implementation of public health interventions related to HIV, which must address gender dynamics and power inequalities in order to be effective. Public health prevention and treatment messaging have often focused on women's vulnerability or on their need to avoid "bad" behavior (as in abstinence messaging).

However, our analysis shows that there are positive versions of women that could potentially be drawn on when considering HIV prevention and treatment messaging. The analysis highlights that women are diverse and that many of the positions they occupy are positive. This is also evident in the story of Zola, as told by a young man in South Africa. Zola, although described to be at risk of HIV because of the behavior of her husband, is also seen as a healthy, contributing, member of society. Zola is employed and is the caregiver of her children.

In addition, regardless of how a woman (or person) is cast, this perception can change over time. The analysis shows that community members' perceptions of women are not stagnant in their positions of potential HIV risk, but rather that there is a "shift-ability". This can be seen in the story described by the young man in Zambia of the sex worker (engaging in "bad" behavior) who is also a responsible mother. Messaging that relates only to one aspect of her life (her position as sex worker) and ignores the other (her position as mother) risks stigmatizing certain behaviors and, by extension, certain groups. Health implementers need to consider health messaging beyond the simple casting of a character (or person) into a fixed category of risk.

Lastly, while public health researchers and practitioners categorize risk in certain key populations (defined by WHO[49] as population groups disproportionately affected by HIV; usually limited to men who have sex with men, transgender people, sex workers, and intravenous drug users), we suggest that all women, including those who are not considered part of specific key populations, should also be considered as a special interest group in public health efforts to address the HIV epidemic. This includes broadening the focus of what vulnerability entails, and focusing on positive messaging as well.

Study limitations

Participants were recruited from public spaces (at the clinic, library, public transport hubs, and shopping areas) and there is a likelihood that community members who do not frequent these spaces are under-represented and should be further researched. However, through the analysis, we included representation of a variety of group discussions from various communities across countries to ensure that we were able to represent the processes at play in understanding women and HIV risk.

Our analysis shows the processes through which community members in these study communities understand HIV risk. We have not proven that these processes are exhaustive, universal, or equally applicable in all contexts. Instead, they provide a useful starting point for considering how to escape narrow caricatures of associations between women and HIV risk. The illustrative quotations presented here are thus purposively selected to explicate the diversity and complexity of perceptions about women and HIV risk in real-world talk.

Conclusion

In summary, our analysis has shown that, in consultation with affected communities, a wider understanding of the lived experiences of women and the various potential stages of being at risk/not being at risk of HIV could be beneficial for the implementation of efficient HIV prevention programs.

Our participants described the multiple positions that women occupy not as contradictory, but rather as an accurate reflection of the multifaceted realities of women in communities with high HIV prevalence. Further, this paper has shown that community members' perception of being "at risk" is not a static position and that women, and community understandings of women, go through multiple shifts.

Our analysis has implications for understanding how perceptions of HIV risk can influence the perceived and real position of women and how these positions shift. Interventions that target specific groups of at-risk women will not be sufficient to reduce women's risk of HIV acquisition, as shown in the intervention studies focusing only on sex workers, female-controlled prevention technologies, gender-based violence, or financial and schooling support.[15,32] Focusing only on the contexts where women are perceived to be most at risk could potentially mean missing out on women who might be at risk at a different time. Instead, health implementers would benefit from taking into consideration the multiple positions women employ in different contexts (including positions of power, or positions perceived to be devoid of risk) as well as how the wider community's understandings of women and "risk" might shift when designing and implementing HIV prevention and care programs. This can be achieved through more active consultation with various local community groups with discussions that extend beyond simply defining HIV risk but aim to explore the everyday roles and realities of men and women.

Author contributions

All authors contributed toward data analysis, drafting and critically revising the paper, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

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Disclosure

The authors report no conflicts of interest in this work.

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Manuscript 2: Universal HIV testing and treatment and HIV stigma reduction: a comparative thematic analysis of qualitative data from the HPTN 071 (PopART) trial in South Africa and Zambia.

Viljoen, L., Bond, V. A., Reynolds, L., Mubekapi-Musadaidzwa, C., Baloyi, D., Ndubani, R., Stangl, A., Seeley, J., Pliakas, T., Bock, P., Fidler, S., Hayes, R., Ayles, H., Hargreaves, J. R., and Hoddinott, G.

Overview and contribution to dissertation aims

In this manuscript I explore how expanded access to HIV testing and treatment in the HPTN 071 (PopART) trial communities influenced community members' descriptions and conceptualisation of HIV. The analysis includes data from 150 households participating in the nested qualitative cohort study in South Africa and Zambia. The exploratory analysis entails a comparative thematic assessment of the experiences of households in communities receiving the community based UTT intervention and those who lived in communities receiving standard of care. The findings show that there were no marked differences in how people described or conceptualised HIV between households receiving the intervention and those who did not. However, the implementation of increased HIV services, including household HIV testing services and increased access to treatment, impacted the visibility of people living with HIV in household and community spaces. In addition, there was some semblance of 'normalisation' of HIV as part of community narratives in intervention communities, although an HIV diagnosis was still positioned as an exceptional event. Lastly, in light of increased service access, community members from intervention sites emphasised the (moral) responsibility of people living with HIV to take up HIV services that thought to be readily accessible.

This manuscript contributes towards the second objective of the PhD: to describe the broader context of UTT as it is implemented in community settings. Through this manuscript, I am able to show how the different elements of UTT are interpreted and incorporated into people's everyday lives. As with the first manuscript in this thesis, this manuscript helps us to understand the broader cultural scenarios against which women make decisions around sex and relationships in the context of a rapidly changing HIV landscape.

Author contributions

As primary author of this manuscript, I was involved in the design of the data collection tools and the implementation of data collection. I was responsible for the conceptualisation of the manuscript and I led the analytic process. I wrote the first and consecutive drafts. Co-authors provided support in terms of analysis and data collection (DB, RN), and conceptualisation (VB, GH, LR). All co-authors provided manuscript review and comments. The principal investigators of the PopART trial (PB, SF, RH, HA) also provided input and reviewed the manuscript, and thus are also named as co-authors (as per the publication agreements of the trial). A note on co-author contributions is available in Appendix C.

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Universal HIV testing and treatment and HIV stigma reduction: a comparative thematic analysis of qualitative data from the HPTN 071 (PopART) trial in South Africa and Zambia

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Abstract Despite continued development of effective HIV treatment, expanded access to care and advances in prevention modalities, HIV-related stigma persists. We examine how, in the context of a universal HIV-testing and treatment trial in South Africa and Zambia, increased availability of HIV services influenced conceptualisations of HIV. Using qualitative data, we explore people's stigma- related experiences of living in 'intervention' and 'control' study communities. We conducted exploratory data analysis from a qualitative cohort of 150 households in 13 study communities, collected between 2016 and 2018. We found that increased availability of HIV-testing services influenced conceptualisations of HIV as normative (non-exceptional) and the visibility of people living with HIV (PLHIV) in household and community spaces impacted opportunities for stigma. There was a shift in community narratives towards individual responsibility to take up (assumingly) widely available service – for PLHIV to take care of their own health and to prevent onward transmission. Based on empirical data, we show that, despite a growing acceptance of HIV-related testing services, anticipated stigma persists through the mechanism of shifting responsibilisation. To mitigate the responsibilisation of PLHIV, heath implementers need to adapt anti-stigma messaging and especially focus on anticipated stigma.

Keywords: universal test and treat, sub-Saharan Africa, stigma, responsibilisation, normalisation

Introduction

Over half of the 37.9 million people living with HIV worldwide are in southern and eastern Africa (UNAIDS 2019). The past 30 years have seen improvements in effective treatment (Boswell *et al.* 2018), expanded access to HIV care (WHO 2015) and advances in prevention modalities, including HIV treatment as a form of prevention (Cohen *et al.* 2016). However, HIV-related stigma, one aspect of the social landscape of HIV, persists (Maughan-Brown *et al.* 2018).

Stigma is linked to people's anxieties, including the fear of disease and death, and moral concerns about sex or sexuality (Shefer *et al.* 2002). Physical (symptoms/side effects) and social (sex, morality, identity) markers of HIV are highly stigmatised (Persson 2013). People affected by HIV may be part of marginalised communities (WHO 2017) who are blamed, or held responsible, for their diagnosis and their perceived moral transgressions (Shen *et al.* 2019). Historically, the progression of HIV infection made an HIV diagnosis difficult to hide due to physical symptoms. As antiretroviral therapy (ART) became available, the side effects of treatment became stigmatised markers (Persson 2013). New treatment regimens have fewer side effects, but many PLHIV are fearful of being seen accessing HIV treatment, or being identified as living with HIV (Bond *et al.* 2019). As treatment becomes widely available, and ART is posited as an HIV prevention modality, PLHIV are increasingly held responsible for accessing care and preventing onward transmission (Carrasco *et al.* 2017).

HIV 'stigma' is sometimes misconstrued as a proxy for all social experiences of disease (Bonnington *et al.* 2017) and may be changing alongside the evolving HIV treatment landscape (Mall *et al.* 2013). As more HIV services become available, researchers have theorised that stigma in communities may either decrease (Squire 2010), or increase (Chan and Tsai 2016, Roura *et al.* 2009a). Others have argued that even in an era of 'universal' testing and treatment (UTT) (Chan *et al.* 2015), stigma continues to contribute to morbidity (Bonnington *et al.* 2017) and creates service access inequalities (Hatzenbuehler *et al.* 2013). There is limited information on how communities respond to increasingly available HIV services and the impact on stigma.

HIV stigma has been associated with how people access HIV health services, including delaying diagnosis (Treves-Kagan *et al.* 2016) and treatment initiation (Sayles *et al.* 2009), inhibiting use of prevention tools (UNAIDS 2017), limiting status disclosure (Katz *et al.* 2013), complicating adherence (Rueda *et al.* 2016) and poorer health outcomes overall (Peitzmeier *et al.* 2015).

Researchers, policy makers and activists present the 'normalisation' of HIV, or the re-conceptualising of the infection as a chronic condition, as a way to counter the othering of PLHIV (Moyer and Hardon 2014, Roura *et al.* 2009a). By contrast, fears of involuntary disclosure and being marked as living with HIV ('being visible'), and being held responsible for HIV acquisition, treatment and transmission are part of evolving stigma dynamics (Beckmann 2013).

We analysed people's experiences of HIV-related stigma in the context of a community-randomised controlled HIV prevention trial, HPTN 071 (PopART) (Hayes *et al*. 2014) in Zambia and South Africa (Hayes *et al*. 2014). The interventions included door-to-door HIV testing and treatment for PLHIV regardless of CD4 count. The trial was the largest study investigating the impact of UTT, prior to World Health Organisation (WHO) changes in guidelines promoting HIV treatment for all PLHIV. Community HIV care providers (CHiPs) provided the in-home intervention. Being visited at home through the trial intervention introduced new routes to service access that intersected with social processes of stigma. The trial showed a significant reduction in population level HIV incidence amongst communities receiving the household testing intervention. However, quantitative analyses of the effect of the study intervention showed no impact on HIV stigma levels (Stangl *et al*. 2020). We used qualitative data to explore study community members' stigma-related experiences. Specifically, we examined how increased availability of HIV services in intervention communities influenced conceptualisations of HIV as normative (or no longer exceptional), how the visibility of PLHIV in household and community spaces impacted stigma, and how greater opportunity for service access influenced narratives of PLHIV's responsibility for their own health.

Theoretical background

Link and Phelan (2001: 377) defined stigma as 'elements of labelling, stereotyping, separation, status loss and discrimination' that co-occur with 'enabling power situations'. Maluwa *et al*. (2001: 6) noted that stigma is not a naturally occurring (or static) phenomenon, but rather a process of devaluation created in social contexts by individuals and communities. We employ the concepts of normalisation, visibility and responsibilisation to understand how stigma is either amplified or mitigated in the context of increased access to HIV services, specifically in Zambia and South Africa.

Normalisation and exceptionalism

At a global scale, HIV/AIDS was historically treated as an exceptional condition in need of an exceptional response (Hardon and Moyer 2014), due to medical uncertainty surrounding the virus, the physical deterioration of affected patients, and the lack of effective treatment (de Cock and Johnson 1998). However, in the late 1980s, there were calls from researchers in the global north for a shift in focus towards quality of life and long-term survival of patients by managing HIV as a chronic condition (McGrath *et al*. 2014). Notionally, chronic conditions that can be treated, managed and controlled can be 'normalised', with patients accepted and 're-integrated into productive and social life' (Roura *et al*. 2009b: 2) and as 'self-regulating, healthy citizens' (Squire 2010: 408).

In order to position HIV as 'normal', health specialists across contexts promoted the implementation of HIV testing as part of routine care (Johnson 2019, Wise 2008). Early on in the epidemic and in the absence of effective HIV treatment, health providers emphasised the importance of (exceptional) lengthy and detailed pre-test counselling for groups that were considered to be 'high risk' (Bassett *et al*. 2007, Johnson 2019). Over time, routine HIV testing was increasingly introduced as part of government programmes to all adults (including in

Zambia in Africa) in order to improve case findings, and potentially, to reduce stigma, and to position the act as non-exceptional (Mall *et al*. 2013).

However, it is the roll-out of ART programmes across contexts that was expected to further the process of normalisation (Persson 2013). For instance, Squire (2010:407) noted that, in the UK, as more people became eligible for treatment, taking on the role of a 'regular, unremarkable citizens' would be increasingly possible. McGrath *et al*. (2014:305), however, noted that 'the transition [of HIV] to a manageable chronic disease has not unfolded at the same rate or in the same way in all populations'. The shift of HIV to a chronic condition is linked to stable access to HIV care, and was, at least historically, therefore more difficult to achieve in Low and Middle Income Countries (LMIC) and/or marginal populations where structural and social constraints undermine access to services.

As treatment became more readily available in LMIC, activists also anticipated that through the re-conceptualising of HIV as a manageable condition, stigma would decrease and disclosure and HIV testing could increase (Roura *et al*. 2009a). This echoes sentiments from research in the UK where normalisation is presented as a means to counter HIV stigma by positioning the illness as a 'regularised part of biological and social life' (Squire 2010: 410).

However, PLHIV and communities affected by HIV have continued to be positioned as outside of the injunctive norm and treated as exceptional. The causal link between more effective biomedical responses and social normalisation of illness remains unclear (Moyer and Hardon 2014). From research in Australia, Persson (2013) questions whether bodies that have historically been positioned as dangerous and contagious can be reimagined as non-infectious and harmless through the introduction of biomedical interventions, such as treatment as prevention. The same questions persist in southern Africa, where African bodies have repeatedly been presented as either hypersexualised or problematic (Reid and Walker 2005). The implementation of UTT is dependent on the roll-out and uptake of HIV testing and treatment at scale. Little is known about the extent to which these increased services will become part of 'normalised' community narratives.

Visibility

Historically, both the literal and metaphorical 'visibility' of HIV has shaped social responses to the epidemic. Goffman (1963) categorised stigmatising conditions in terms of either 'discredited' or 'discreditable' identities. Conditions that are linked to discredited identities are visible through stigmatising markers, whereby the 'inferior status' of the person cannot be hidden. As the stigmatising condition is public, the affected person is tasked with developing coping strategies for when they experience discrimination. Brouwer (1998: 1233) in his research on HIV/AIDS and visibility in the USA, for instance, explained that affected persons have to confront the challenge of 'assuaging the discomfort that [a] visible stigma compels in others'. Discreditable identities, alternatively, are conditions that can be hidden from others and persons affected must manage 'when, how, and to whom' hidden conditions are disclosed. Similarly, Steward *et al*. (2008) from HIV research in India noted that, persons with discreditable conditions may try to maintain the boundaries, keeping their discreditable status from becoming a discredited identity.

Early on in the epidemic, the absence of any treatment meant that HIV was especially physically visible to others (Sitas and Newton 2000) and patients were easily identifiable (Persson 2013). As combination therapy became available across the globe, it became increasingly rare for PLHIV to present with the physical symptoms reflecting advanced stages of AIDS, positioning the condition, potentially, as no longer discrediting, but rather as discreditable.

However, initiating HIV treatment meant that some PLHIV became visible in other, often unexpected ways. Many PLHIV experienced visible symptoms related to the side effects of treatment, including lipodystrophy (visible redistribution of body fat). In addition, when people took the (often large number of) tablets into their homes, the medication acted as a potential visible indicator of living with the illness, especially in households in African contexts where privacy was not always possible (Horter *et al.* 2017). Across contexts, many PLHIV continue to hide their medication for fear of involuntary disclosure. In respective studies, Kalichman *et al*. (2019a) and Mackworth-Young *et al.* (2020) for instance, noted that many PLHIV in southern Africa hide their treatment as a strategy to avoid identification and stigma. In addition, although HIV testing and treatment has become common-place in most African contexts, people remain wary of inadvertent status disclosure and its social consequences (Pai *et al.* 2013) HIV services are still not geared towards maintaining confidentiality and clients often note their fears of 'being seen'(Bond *et al.* 2019). However, it is not visibility itself, but rather the social implications of being associated with HIV that is the concern. Treichler (2002: 261) noted that HIV is 'an epidemic of signification' and that a positive diagnosis is a 'nexus where multiple meanings, stories, and discourses intersect and overlap, reinforce, and subvert one another'. Often, these meanings are inscribed with stigmatising connotations, including associations with moral transgressions. Across the world, these notions are informed by the negative attitudes that people hold towards those that are thought to be more responsible for HIV transmission, notably, men who have sex with men, people who inject drugs, sex workers, people who are seen as 'promiscuous', African sexualities in general and, more recently, PLHIV who are not on treatment (Bond *et al.* 2016, Persson 2013).

Responsibilisation

The notion of responsibilisation, derived from the Foucauldian analysis of governmentality and power, has been incorporated into understandings of HIV management, and specifically, HIV self-management. According to Foucault (1991), 'governmentality' is the ways in which power or governance can be exercised through the making and maintaining of subjects and through managing responsibility-taking of these subjects. Through subjects that are self-governing, the state is able to shift the responsibility of governance onto citizens. In this way, responsibilised citizens are no longer obedient dependent subjects, but rather are themselves producing government ends (Foucault 1977, 1991). Authority is self-imposed, rather than the externally enforced agent of the state (Rangel and Adam 2014).

HIV treatment was initially either unavailable or difficult to access. In South Africa, for instance, after 2004, ART was made available in the public health system (National Department of Health 2004). Through activism, treatment access was positioned not only as a human right, but as the responsibility of the state (Robins 2006). Thereafter, ART in South Africa, as in many other contexts, became available, but administered by specialised doctors. At the time, the process of initiating treatment was highly regulated and adherence closely monitored (Koenig *et al*. 2006). Patients had very little opportunity for agency or control over their treatment journey. Over time, the WHO advocated for more PLHIV to be able to access ART. To meet the demand of initiation and managing more patients on treatment programmes, treatment initiation in Africa (and beyond) shifted from the responsibility of specialised doctors to trained nurses (Crowley and Mayers 2015). In many places, including South Africa and Zambia, HIV treatment distribution moved from health facilities to off-site adherence clubs (Campion 2015) and even in-home delivery of treatment in some instances (Wringe *et al*. 2010). In line with global trends, PLHIV in Africa have been encouraged to engage with treatment as active citizens – autonomous care users rather than passive recipients of health services (Newman *et al.* 2015, Robins 2006).

The process of responsibilisation is posited against the theoretical notion of the 'logic of choice' (Mol 2008). Accordingly, the supposition is, if persons have access to HIV testing, they will do 'the right thing' to 'know their status' (Wallace *et al*. 2011). Similarly, if PLHIV are provided with sufficient information and effective treatment, they would be 'good citizens' who avoid transmission, access treatment and take care of their own health (Rangel and Adam 2014). In this way, complex issues are reduced to matters of choice, where 'technologies and information are treated as neutral aids to making the right decisions' (Beckmann 2013). People who 'choose' not to make the 'logical' decision to test, access treatment or prevent transmission are therefore blamed because of these 'irresponsible acts' (Bond *et al*. 2016). Researchers in the USA have noted that PLHIV are often subject to intersecting vulnerabilities – including stigma, economic and social burdens – and positioning clients as responsibilised citizens potentially compound existing inequalities (McSwiggin 2017). This is also reflected in the experience of many people in sub-Saharan Africa affected by HIV.

Stigma and the HIV landscape in Zambia and South Africa

As HIV prevalence in adults in Zambia (11,3%) and South Africa (20,4%) remains high (UNAIDS 2018a, 2018b), efforts to address stigma have been prioritised by many health specialists.

Since the early 2000s, ART has become increasingly available in Zambia and South Africa and HIV testing has become part of the routine public health care. Over time, and as both countries adopted changing WHO guidelines, more people became eligible for HIV treatment (Hayes *et al*. 2019). As in other contexts, increased available to ART in Zambia and South Africa was expected to aid in the normalisation of HIV (Persson 2013) and at a time when the HIV prevalence ranges from between 10-30% in many communities in sub-Saharan Africa (Grobler *et al*. 2017, HSRC 2018), living in a family affected by HIV is becoming descriptively normative.

With more people accessing HIV testing and treatment, aspects related to the visibility of HIV is being balanced on multiple platforms. In addition to the possibility of ART as visible marker of an HIV diagnosis in the privacy of the home (Horter *et al*. 2017, Kalichman *et al*. 2019b), in both Zambia and South Africa, the spatial organisation of health services in facilities have been identified as an avenue for signifying HIV status and as a risk for PLHIV to be recognised as living with the illness (Bond *et al*. 2019).

The notion of responsibilised citizens in the Zambian and South African context is particularly pertinent at this stage, as ART is increasingly positioned as a viable HIV prevention strategy (Hayes *et al*. 2019). The potential exists for increased pressure on PLHIV to be positioned as responsibilised citizens who know their status, adhere to treatment, and by doing so, carry the responsibility of preventing onward transmission.

We employ the constructs of normalisation, visibility and responsibilisation in Zambian and South African communities where universal access to HIV testing was rolled out prior to the adoption of the strategy on a global scale.

Methods

Setting

The HPTN 071 (PopART) cluster randomised three-armed controlled trial, implemented in South Africa and Zambia from 2013 to 2018, included 21 study communities (9 in South Africa, 12 in Zambia). All 21 communities were classified as urban areas and located relatively close to district towns. Most of the sites were porous with high levels of mobility (see Co-author 2016 and Co-author 2018). Housing consisted of a mix of 'informal' and 'formal' housing across communities. Sites were defined around public health facility catchment areas with households located in close proximity to facilities. HIV prevalence at baseline (2013) varied across communities. In one triplet of trial communities in South Africa, HIV prevalence varied between 3% and 12% while others ranged from 19% to 35%. In Zambia, prevalence across the 12 communities ranged from 16% to 26%.

The trial intervention package included door-to-door HIV-testing services and early access to ART (Hayes *et al*. 2014). A study-specific cadre of approximately 740 CHiPs (recruited from and mostly resident in the study communities) were employed to implement the HIV prevention package in the 14 intervention communities. The 7 control communities received the standard of care and no additional testing or treatment services (Hayes *et al*. 2019).

As part of an ancillary study on stigma (Hargreaves *et al*. 2016), we included a longitudinal qualitative cohort, conducted in 13 of the study communities (see Hoddinott *et al*. 2018).

Study design and sampling

The qualitative cohort included 150 households in 9 intervention and four control communities. Through an open sampling strategy we recruited households based on the principles of sampling for diversity (Dattalo 2010) to include participants of varying ages, genders, housing types, household composition and locations in the community. At least 50% of households included one or more PLHIV (Co-author 2018). In South Africa, we analysed data from 74 households (with 61 PLHIV) and 60 households (with 32 PLHIV) in Zambia.

Data collection

We collected data between 2016 and 2018 and interacted with each household ~5-12 times[1] over the course of 12–24 months. Field teams facilitated more than 1000 interviews and group discussions, informed by the ethnographic research principle of repeated interactions and 'deep hanging out' (Geertz 1998). We employed participatory methods such as household map drawings, kinship maps and timeline activities to elicit conversation. We recorded interviews and collected detailed field notes.

Data analysis

We undertook an exploratory analysis employing a reflexive approach in order to contribute to theory-generation. We included routine, structured written reflections by data collectors and a targeted review of all primary data. All recordings were transcribed verbatim, anonymised and translated into English.

We made use of a two-phased coding approach. Firstly, we identified all extracts where participants, including PLHIV, referred to experiences of accessing HIV-related services or not. During the second phase, four of the co-authors coded these extracts thematically, informed by the analytic objectives (Braun and Clarke 2006). Themes were cross-checked and confirmed between coders. We present the findings as case examples. All interpretations of data were discussed with the in-country teams.

Ethical considerations

Approval was provided by the London School of Hygiene and Tropical Medicine, University of Zambia, and Stellenbosch University research ethics committees. All participants signed written informed consent. We use pseudonyms throughout to protect participant confidentiality.

Findings

HIV at community level: exceptional or the new norm?

The implementation of the HPTN 071 (PopART) HIV prevention package delivered at household level introduced new forms of interaction between community members and the health system. CHiPs scheduled annual household visits with community members and offered multiple opportunities to test for HIV in home (Hayes *et al*. 2014). Many community members in both Zambia and South Africa reported that they tested more often, or whenever they encountered the CHiPs in their neighbourhood. The continued presence of the CHiPs meant that some participants described testing with the CHiPs as routine. For example, Mapalo (26), from a Zambian intervention community, described testing with the CHiPs as ordinary, and even as a way of assisting the CHiPs to 'do their jobs'. He described how he was 'impressed with their efforts' and he 'wanted to give time to the people who have made an effort to come and visit [him] at home'.

For others, testing with the CHiPs was relayed in a matter-of-fact way. Eva (49) lived in another Zambian intervention community. She told the story of her HIV test with the CHiPs:

> They just came as you have come … I asked them to come in and they sat where you are sitting. They explained that they are going around testing people. They asked me if they could test me, and I said they could test me. And then they tested me.

Tracy (35) from a South African intervention community, described testing with the CHiPs as ordinary, and even as a convenient distraction:

> Tracy: I do it [HIV test] just here in the road. I just say, I am sitting here, I am going nowhere. Come, do it just here.
> Researcher: Do they just walk in here then you say; 'It's time?'
> Tracy: No, I keep on bothering them in the road, I am very [serious] about my testing. I just call them: Hey! Come, come! I want to see what's going on (laughing).

By contrast, HIV testing outside of the intervention communities was mostly available at health facilities, or intermittently, at mobile testing sites during targeted drives. Many participants described testing at public health facilities as either burdensome, or once-off experiences incorporated into other health services, including antenatal care, family planning or chronic care. Thandi (35), from South Africa, jokingly recounted how provider-initiated HIV testing was experienced as mandatory at the local health facilities. She explained: 'there, we are tested by force (laughing). They don't beg [keep asking] us there [like the CHiPs do]'.

Alex (48), from a Zambian control community, described the taxing experience of testing for HIV at government facilities:

> "You really need to come early. You find that you just brush your teeth before eating anything, [and] rush to the clinic … Sometimes you will find few people and at times a lot, it differs … You find that you are coming out of this place [clinic] at 14, 15 or even 16 hours [two, three of four o'clock]. Sometimes [we] quit because of queuing and spending a lot of time there".

HIV testing with the CHiPs was described as mundane when compared to the effort of accessing HIV testing at health facilities. Routine, in-home HIV testing can be seen as a mechanism of normalisation, where testing is a way to render HIV as non-exceptional. This could pave the way for positioning an HIV diagnosis as normalised or as a 'regularised part of biological and social life' (Squire 2010: 410) and as a way to counter different forms of stigma.

While the testing process was described as ordinary, a closer examination of participant responses to a potential HIV-positive diagnosis, revealed a different narrative. Tracy, who was receptive to the intervention and even enthusiastic about testing, described how she would respond if she were to test positive:

> What comes to mind? For me, I am not actually afraid, but everyone else, other people will think, geez, she has HIV! . . .I told myself, if I must have it, then I will throw myself under a train. I won't still be able to live with such an illness (exhales loudly). I won't be able to live with it, really (pause). I wouldn't (pause). It will just have to be the end of my life (pause). I would mention it to my family and then I would tell them but (pause, reconsiders) I can't, I am too. . . (pause). I would probably die quick (pause), because I stress too much (laughs).

Although Tracy does not report ever having experienced stigma related to HIV, she anticipates a severe reaction. Turan *et al*. (2017: 284) describe this as anticipated stigma or the 'expectation of repercussions in the future; these are beliefs by PLHIV that others will treat them negatively due to their HIV status'. Eva, whom in the excerpt above described how she tested with the CHiPs who knocked on her door, relayed how when she received her positive test results: 'I was just afraid, like, you are feeling guilty'. For Eva, the normalisation of testing did not counter her initial feelings of fear or guilt.

For Tracy, Eva and others in our cohort, the act of testing for HIV was positioned as 'ordinary' and acceptable, but a (potential) positive diagnosis was still viewed as life altering. The acceptability of regular household HIV testing did not necessarily translate into normalisation of HIV.

Despite the acceptance of HIV testing, the high prevalence of HIV, the daily occurrence of HIV across settings and the labelling of HIV as 'normal' by some local residents in both Zambia and South Africa, this did not translate into normalisation per se. An HIV-positive diagnosis in these settings was still accompanied by life adjustments (Seeley *et al*. 2019) and by 'social peril' (Alonzo and Reynolds 1995) if relationships were strained and/or individuals or sub-populations were otherwise marginalised (de Wet 2019).

In Zambia, health workers explained that HIV is 'normal' or 'similar to malaria'. Brenda (25), from a Zambian community explained:

> These days they have stopped [using derogatory terms] . . . Now it is just like Malaria. They don't laugh at each other these days . . . you just have to adhere to the medication . . . and your body will be healthy.

While increased services meant HIV was, for some, more 'normal', for many participants, an HIV diagnosis was still considered a life-altering event, associated with anticipated stigma.

The visibility of HIV and HIV services

The CHiPs conducted more than 150,000 annual door-to-door HIV tests over the three-year intervention period and numerous household follow-up visits. The CHiPs, wearing their recognisable uniforms, served as a visible reminder of the ongoing trial with a focus on HIV prevention.

In the intervention, HIV-testing services were provided in the private sphere of the home and participants were effectively able to avoid public health facilities. Participants frequently expressed similar fears over the perceived lack of confidentiality and concerns of being recognised when accessing HIV-related services at public health facilities. In control communities, there were few HIV-testing or -treatment options outside of public health facilities. In Zambia, Naomi mentioned PLHIV avoiding accessing HIV treatment at her local clinic: 'they do not want others to be seeing them when going to collect the [HIV] drugs. When they are seriously sick [they] go to the clinic. That is when they accept [it]'.

Peter (27), also from Zambia, noted: 'a lot of people recognise [us] and when they do, they might be laughing at me. If it is woman, they might think that men won't be asking them out and if it is a man, women will not be accepting their proposals because they will know he is sick'. The implication is that being identified, or visibly living with HIV, renders a person potentially less desirable to potential intimate partners.

Many participants presented testing with the intervention health workers as a welcome alternative. Joy (36, South Africa, living with HIV), explained her preference for door-to-door testing:

> People are reluctant to leave houses and go to the clinics for testing, or to go to that particular tent [mobile testing] . . . They are shy to be seen. People will know that 'here is so and so, he has entered that tent' . . . At the clinics, it's because of eyes (being seen/watched), so they are wary of people.

In-home HIV testing, however, meant that HIV became a topic of discussion in intervention households, even if only for the duration of the annual CHiPs' visits. While the household presented a potentially 'safe' environment when compared to public health facilities, the experiences of participants showed that challenges with confidentially and visibility persist. The CHiPs were supposed to find a private space to offer HIV testing in participant homes but in most communities, the physical layout of (often informal) houses with many residents meant that it was difficult to do (Viljoen *et al*. 2020). While privacy could be negotiated, even in crowded spaces, the ability to do so was predicated on relations between household members. Strained relations made it harder to create the desired privacy. Although in-home testing was for many participants a better alternative than the explicit visibility of public health facilities, for some participants, the door-to-door service was described as a threatening experience and as an invasion into the intimate privacy of the home. Brenda (25), a Zambian woman living with HIV, explained that taking an HIV test at home meant that there would be unwanted HIV-status disclosure:

> Your parents, and everyone, or your neighbours will be there. And when they [CHiPs] tell you the results, everyone will get to know [your status]. It is automatic that the people around will be forced to hear those results.

The CHiPs and their services were at times met with distrust. Many participants, especially in South Africa, questioned the confidentiality of the CHiPs and the quality of their services. The familiarity of the CHiPs, as fellow community members, added another layer of complexity. Ramona (28), from South Africa, explained:

> Ramona: God, there's one of them wearing that red shirts [referring to a CHiP walking past]. Oh damn. That's a vile woman. She is Paul's sister. She lives up here in the newly built area. She thinks the world of herself.
> Researcher: Have you ever tested by them?
> Ramona: Yes, the first time. I just want [to say], if we knew you and we are comfortable with you, then we won't allow you to come test us.

The underlying concern Ramona described was related to the expectations that, if she were to test positive for HIV, her status would not be confidential, but would be shared in the community by the CHiPs. Again, the fear of HIV visibility is related to anticipated stigma, or the expected social repercussions of living with HIV, rather than actual experiences of stigma.

Building on counselling approaches in similar sub-Saharan contexts, the in-home intervention was explicitly designed to encourage household counselling, couples counselling and disclosure within a household unit. For household members to test together for HIV with the CHiPS, they needed to provide verbal consent. However, the CHiPs' imposed position in the private sphere of the home meant that, in times of unexpected positive diagnoses, the CHiPs were experienced as unwelcome, or even threatening, despite the process of consent. It was the anticipated consequences of the unwanted disclosure that affected people; potential social shame, blame and concerns over losing standing in the community. Katryn (45), from South Africa, reflected on her experience testing positive for HIV with the CHiPs and the unintended consequences of the interaction:

> Researcher: Why did you tell Harris [your son] first?
> Katryn: (pause) He heard.
> Researcher: They gave your results, in front of your child?
> Katryn: Hmm [yes], in front of everyone.
> Researcher: That was the first time you knew [about your status]?
> Katryn: Yes.
> Researcher: How did you feel that they said it in front of everyone?
> Katryn: They are outside people - I actually felt a bit hurt.
> Researcher: Because you didn't have control over it?
> Katryn: You understand.

The story of the unwanted disclosure of Katryn's HIV status in front of her children, however, does not end at this point. Despite being initially upset, Katryn explained that the unexpected positive diagnosis and ensuing disclosure meant that she was able to access both physical and emotional support and care from her family. Katryn went on to access HIV treatment outside of national guidelines and regularly went to the clinic to check her health.

The in-home intervention presented the opportunity to avoid public health facilities and the associated visibility. However, for some, it produced a different type of visibility in the intimate, domestic space and an increase in anticipated stigma. For others, facilitated disclosure through the CHiPs enabled access to social support and care.

Responsibilisation: Individual blame vs collaborative support

The HPTN 071 (PopART) intervention introduced a dramatic increase in HIV service availability (Hayes *et al.* 2019). The CHiPs were also tasked with distributing the message about the availability of HIV testing and treatment. However, in our discussion with participants, we observed potential subtle narrative shifts. Some participants suggested that, beyond the *availability* of services, community members have the *responsibility* to make use of these now readily available testing or treatment services. Thandi (35, intervention community, South Africa), for instance, told us:

> A person is a killer of his/her own self with HIV. HIV doesn't kill anyone, it kills someone who wants to die. A person would stop taking treatment. A person who stays with [the PLHIV] should then rush them to the clinic… That's what HIV [positive] people do. That is why prevalence is rising high and not decreasing - they [PLHIV] don't take the treatment.

Thandi described how PLHIV were not taking responsibility for their own health. People who were not on (supposedly easily accessible) treatment and who did not engage with the 'logical choice' (Mol 2008) of accessing care, were not only held responsible, but blamed for their deteriorating health and HIV transmission. These sentiments of 'taking care of yourself' (Bond *et al*. 2016) were also echoed in the response from Buhle (65, intervention community, South Africa): 'Someone who doesn't take his treatment doesn't have time for his own life [doesn't know the value of life]'.

Ben (48), living with HIV in a Zambian intervention community, also described people who did not make use of the HIV services:

> Some of them just want to waste their lives, because they have failed to understand what getting tested is all about. They are too ashamed... getting tested does not mean that you are going to die. [...] Some people have a low thinking capacity. If a doctor advises you properly on an issue, you have to follow what the doctor tells you.

Shame, or being ashamed, is a key aspect of stigma (Scambler 2006). Ben shamed people who did not test or access ART by describing them as 'wasting their lives'. Responsibilisation, or the expectation that people should be self-governing citizens (Foucault 1991) who take care of their own health, was emphasised. PLHIV were not only expected to take on the logical responsibility of taking care of their own health, but also the moral responsibility of curbing transmission (Bond *et al*. 2016). The neoliberal move towards individualism positions those who did not take up personal responsibility for accessing and services related to good health (such as testing and treatment) as social transgressors (Brown and Baker 2012).

Responsibilisation is one way through which blame can be shifted towards those who do not access HIV services (Newman *et al*. 2015). However, we also found that, for some, responsibilisation could be employed to ensure positive health outcomes. Responsibilisation positioned individuals as autonomous empowered citizens and was used by some PLHIV to assert agency in their own health. Several participants related how HIV testing was a method of self-care. Theo, (intervention community, Zambia), for instance, explained: 'It is very important for me to test for HIV ... I would like to know how to take care of myself based on my status'.

For others, responsibilisation translated as a collaborative, communal effort and 'the responsibility to take care of each other, for each other, or because of each other'. Ben (48), who was diagnosed with HIV with his wife, explained their decision of initiating HIV treatment:

> I convinced my wife that what had befallen us was not good, but since our children are still young, we should go to the clinic ... [and] started medication ... [We] started asking each other questions as to how we could have contracted the virus, but we realised that the more we asked questions, the more worried sick we became. For the sake of our children ... we decided to come to the clinic.

Several community members had either not heard of or did not 'trust' the notion of HIV treatment as a form of prevention. Clifford (48), despite articulating how ART works in the body, did not translate this working of ART as a way to prevent transmission:

> ART ... makes someone regain their strength and then they work in such a way that they make the virus dormant so that the cells can work the way they should. [But] he has a virus. Even if he is on ART, he can still infect another person.

In both Zambia and South Africa, participants were still processing the message of HIV treatment as a form of prevention and most participants were either unfamiliar with or had misconceptions of the prevention capabilities of ART. It is not yet clear how UTT, and the normalising of treatment as a form of HIV prevention might impact HIV stigma in future. From our data, there are indications that responsibilisation for accessing HIV services (including testing and treatment) can lead to shaming, and othering those who are deemed devious – who choose not to access HIV services or adhere to treatment.

Discussion

By using the concepts of normalisation, HIV visibility and responsibilisation, we have shown how changes to HIV services influenced stigma in complex and nuanced ways. The annual delivery of HIV testing in the private sphere of the home by the CHiPs meant that there was a growing acceptance of HIV-related services – and that HIV (or testing at least) was normalised, which reduced the stigma associated with testing. However, while HIV testing might have been accepted as the norm, many participants still feared the social repercussions of being diagnosed with HIV. Alongside this, there are a growing set of responsibilities expected of those who test positive, the failure to comply with which can lead to new forms of stigma.

People from all trial communities (intervention and control) reiterated their fears of being identified or suspected of living with HIV when accessing HIV services. For some, concerns of 'being seen' were confined to the duration of accessing services at public health facilities. Participants in intervention communities welcomed the new in-home intervention. This meant that certain HIV services (such as testing), moved away from the public gaze, and into the private sphere of the household. However, participants now became vulnerable to other types of unwarranted disclosure, including to household members. Many participants were wary of the CHiPs, as fellow community members, and their ability to maintain confidentiality. Anticipated stigma remained a concern for people within and outside of the intervention communities. In intervention communities, many participants were able to exchange potential public disclosure at health facilities with the intimacy of in-home testing and some participants were able to use it as a way to garner support and care for their HIV diagnosis.

As HIV testing became more common, and messaging around testing and treatment increased, new dynamics emerged around responsibilisation. People who did not access the increasingly available services were described as deviant, irresponsible, or careless. Most participants were not aware of how HIV treatment can be employed as a form of prevention. Different forms of responsibilisation might shape stigma once the messaging around treatment as prevention becomes the norm.

As a strength, our data set included detailed, longitudinal, ethnographic data. We were able to compare across conditions (intervention and control), and communities. Through a robust analysis of the large dataset, we were able to show the ways in which stigma is amplified or mitigated in communities. Although we provide a detailed description of the dynamics at play at household level, we have not used quantification of these dynamics to prove statistically significant trends.

Previous research has suggested that increased access to HIV services will lead to a decrease in HIV-related stigma (Roura *et al.* 2009b). We found that, although community members were more accepting of HIV testing and are, in some cases, better able to navigate disclosure, anticipated stigma and blaming of PLHIV remain pervasive concerns. Some aspects of HIV testing remain exceptional and stigmatised and require specific interventions.

In this manuscript, we have built on the theoretical concepts of normalisation, visibility and responsibilisation as they pertain to HIV stigma. Up to this point, few authors have explored the implications of expanded access to HIV testing in terms of 'normalisation'. By drawing on empirical data we describe how increased access to testing and the shifting of health services into the private sphere of the home impacts HIV-related stigma. We found that, despite the acceptance of increased HIV services (and testing specifically) as 'normal', HIV normalisation was constrained by other social relationships, rendering the possibility of a diagnosis as potentially life altering. In addition, while some of the concerns of being identified at public facilities were alleviated, the visibility of HIV and a positive diagnosis are subject to different but still challenging conditions, even when delivered at scale and in home.

More telling, the neoliberal positioned expectation of personal responsibility for accessing readily attainable testing options was presented in the narratives of participants in both Zambia and South Africa. These narratives of responsibilisation are potentially born from the historic demand for individual rights, including HIV treatment, in a post-apartheid South Africa. In Zambia, the emphasis on responsibility stems partly from the religious moral code found in many communities (Bond *et al.* 2016). In both countries, however, participants positioned accessing HIV treatment either as a personal responsibility (as a way of taking care of one's own health) (Newman *et al.* 2007) and/or as an expectation of others, who, if they refuse to take up the opportunity, risks being shunned by the community.

However, despite these shifts, there are still uncertainties in terms of how universal access to treatment impacts HIV-related stigma. At this stage, community members in our cohort were unaware, uncertain, or wary of the mechanics of HIV treatment as a form of prevention. To counter anticipated stigma and the responsibilisation of PLHIV, heath implementers need to incorporate messaging focusing on anticipated stigma, countering blame narratives. While this research provides the groundwork for understanding changes in stigma, more research is needed to understand these changes on a granular level as HIV treatment is increasingly becoming the norm.

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Data availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Note

1 Due to large traveling distances, fieldwork in Zambian were structured around 6-week 'blocks'. In South Africa, researchers were located closer to field sites and shorter, more frequent visits were possible. The number of interactions with households varied as researchers were responsive to participant needs, preferences and availability, and the time required for discussions with larger households.

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Manuscript 3: “It stays between us”: Managing comorbidities and public/private dichotomies in the HPTN 071 (PopART) trial communities.

Viljoen, L., Myburgh, H., Reynolds, L.

Overview and contribution to dissertation aims

In this manuscript, written with two other researchers from the HPTN 071 social science team, we provide a detailed ethnographic account of how health conditions are managed by people in resource constrained settings in South Africa. By exploring how comorbidities (including HIV) are located along public and private spheres, the manuscript illustrates how people navigate disclosure, privacy, and health. The boundaries between public and private spheres are evident across different domains of life: social spaces (intimate household/family vs others), physical spaces, interpersonal spaces (self vs others), and the unconscious realm (understandings of ‘self’). This manuscript draws on data collected as part of the HPTN 071 (PopART) qualitative cohort study in South African communities and present the central narrative of Elsie, a young woman affected by both HIV and epilepsy. The in-case analysis is supported by data we collected from 13 other participants also affected by comorbidities (TB, diabetes, hypertension). Through this detailed analysis, we highlight the complex challenges that people with comorbidities face in managing, negotiating, and redrawing the boundaries between the different public and private spheres of their lives. We also demonstrate how people living in contexts of precarity often lack control over the management of these boundaries and must reconcile themselves to an increasingly constrained private sphere.

This manuscript contributes to the broader thesis objective of describing how HIV and health management are located in the personal narratives of people living with HIV. Through this objective, I offer a richer understanding of how people affected by HIV navigate different components of their lives, including health, identity, and privacy. The detailed description included in this manuscript locates 'health' in the context of other concerns, including interpersonal relationships. This manuscript also draws on performance theory (Goffman, 1959)[1] and serves to show how different elements related to health are 'performed' in order to maintain the boundaries related to public and private spheres. These performances (at the interpersonal and unconscious/intrapsychic level) are integral to understanding how interventions such as universal access to HIV testing and treatment are incorporated in the lives of women.

Author contributions

As primary author of this manuscript, I was involved in the design of the data collection tools and the implementation of data collection. Together with co-author HM, we spent many hours collecting data with the central participant in this manuscript, Elsie, and her family. I describe our interactions in detail in this manuscript. The authorship team also spent time workshopping the paper's analysis and key findings, especially around the central narrative. I led the analysis process, conducted the literature review, and wrote the first and consecutive drafts, with extensive input from my co-authors. A note on co-author contributions is available in Appendix C.

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"It Stays Between Us": Managing Comorbidities and Public/Private Dichotomies in HPTN071 (POPART) Trial Communities

Lario Viljoen[a,b], Hanlie Myburgh[a,c], and Lindsey Reynolds On behalf of the HPTN 071 (PopART) team[d]

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ABSTRACT

In contexts of scarcity, managing comorbidities is a complex process, shaped by divergent understandings of causes, prognoses, and social meanings of illness. Drawing on research with one young South African woman living with HIV and epilepsy, and 13 other people with comorbidities, we describe how concepts of "public" and "private" shape the management of co-morbid conditions. Despite narratives of HIV "normalization," participants labored to keep their HIV status private, while sharing other illness experiences more publicly. We challenge simple dichotomies between public and private spheres and emphasize the need for more fluid understandings of how people negotiate social space.

KEYWORDS
South Africa; comorbidities; HIV; public/private

On a cool spring day in the Cape Winelands of South Africa, we (LV and HM) huddled in the cramped makeshift bedroom that 23-year-old Elsie Jacobs shared with her partner and another couple. Our knees almost touched as we sat opposite Elsie on the tired mattresses of the neatly made beds. As she had on numerous occasions, Elsie freely recounted her experiences of living with and managing her epilepsy diagnosis. She pointed to the tablets displayed on her bedside table, saying: "I take my medication. I look after my health. I can't put it behind my back [neglect it]." She explained how her family and small community were essential to managing her symptoms. When we gently probed about her other illness, HIV, she glanced nervously at the doorway, where blankets created an uncertain barrier against the wind and curious neighbors. Looking down, she continued quietly:

> I don't like to put my mind on it. Sometimes I just sit and think, I don't talk. They [neighbors] like asking questions. I just say that I am thinking about the things I did last night (laughing). Then they won't know what I am really thinking about.[1]

An estimated 7.9 million people live with HIV (PLHIV) in South Africa (Simbayi et al. 2019), many of whom also manage comorbid conditions. Due to the legacy of apartheid and ongoing socioeconomic inequalities, the burden of disease and the delivery of health services continue to be distributed unevenly (Clark and Worger 2016; Coovadia et al. 2009). Apartheid in South Africa enforced the categorizing, ranking and segregating of persons by race, with privilege and freedom allocated in line with these categories (Clark and Worger 2016). Nonwhite people experienced inferior access to health care and significantly worse health outcomes than whites (Andersson and Marks 1988). Many of these inequalities persist, and black and colored[2] South Africans are disproportionately affected by medical conditions (National Department of Health 2019; Simbayi et al. 2019). For instance, while 16.6% of

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Media teaser: People living with comorbid-HIV navigate public/private spaces on multiple levels to manage their health conditions in discreet ways black South Africans and 5.3% of colored people are living with HIV, only 1.1% of whites are affected (Simbayi et al. 2019).

The South African government rolled out its national antiretroviral treatment (ART) program in 2004 to provide free treatment for the largely poor, marginalized population most affected by the disease. By 2019, 4.7 million people were accessing ART in public sector facilities (Simbayi et al. 2019). These advances in ART access have gone hand in hand with efforts to normalize the highly stigmatized disease, to increase uptake of testing and treatment, and to reconfigure HIV into a chronic, manageable illness (Moyer and Hardon 2014).

While advances in treatment access have been transformative of the experiences of PLHIV, there has been a concomitant rise in chronic conditions as lifespans increase. One study in peri-urban communities in South Africa found that of all clients accessing ART, 19.3% were also accessing treatment for another chronic condition, including hypertension (77%), tuberculosis (TB) (24%) and diabetes (17%) (Oni et al. 2015).

Patients with multiple morbidities often have increased needs for healthcare services, experience greater reductions in quality of life, and have poorer health outcomes in general (van Heerden et al. 2017). Care for chronic illness is further complicated by challenges such as resource constraints, social instability, and high levels of mobility (Hoddinott et al. 2018).

HIV illness management is of particular concern for public health specialists because of the transmissibility of the virus and the socio-economic impacts of infection (LeVasseur et al. 2014). The public health attention given to other conditions varies, although there has been an increasing concern with chronic illness in Africa (Oni et al. 2015). Moreover, people's experiences of comorbidities do not always resonate with the priorities of public health systems or with donor policies (Bosire et al. 2018). People's illness interpretations and care access are shaped by lived experiences, relationship dynamics, household settings, and community contexts. In addition to the physical burden of living with comorbidities, people with chronic conditions are also often subjected to intersecting stigmas associated with HIV, TB, epilepsy, and other comorbidities, which impact how people access care or disclose their conditions (Elafros et al. 2018; Maughan-Brown et al. 2018).

Further to navigating medical care, people with multiple morbidities negotiate their conditions as "public" – suitable to be publicly shared – or "private" – requiring private containment. This distinction relates to a broader tension between public and private spheres, referred to as one of the "grand dichotomies" in social and political life (Bobbio 1989) and often deployed as a strategy to divide the "social universe in a comprehensive and sharply demarcated way" (Weintraub 1997: 1).

In South Africa, public/private distinctions are also informed by cultural practices, historical systems, and socio-economic factors. In his critical analysis of privacy and culture in African settings, Makulilo (2016) noted that scholars generally portray "African" cultures as valuing communalism and interdependence as opposed to individualism and independence (see Adams et al. 2012; Eaton and Louw 2000). This dominant view assumes, he explains, "that Africans exist in collectives: family, kinship or other types of groups," and that "the individual in Africa has no space to claim for privacy as he or she is overburdened by the group's interests" (Makulilo 2016: 96). However, people's desires and experiences are more complex than this often-simplistic portrayal of collectivist "culture." Nonetheless, individuals must negotiate cultural, historic, and contextual factors that shape and constrain their ability to navigate boundaries between public and private spheres while managing their health.

We draw on Ariés (1960), Jacobs (1961), Goffman (1959), and Butt and Langdridge (2003) to explore four dimensions of the public/private divide along which people living with comorbidities organize illness, including in social spaces, physical spaces, intersubjective spaces, and the unconscious realm. We engage with these dimensions to understand how people with comorbidities continually negotiate the boundaries between public and private spaces in contexts of fluidity and constraint.

This article is centered on the story of Elsie, a young woman living with HIV and epilepsy. To contextualize her experience, we also draw on data collected with 13 other people living with comorbid

HIV in the Western Cape Province of South Africa. We explore how participants positioned their illnesses as public or private.

Despite public health narratives about "normalizing" HIV as a chronic condition, and a public health mandate that encourages people to disclose their status publicly, participants repeatedly positioned HIV in the private sphere, cementing the imagined position of an HIV diagnosis as private. By presenting the case of Elsie and others, we show how this desired private space was emotionally and practically difficult for many participants to maintain in precarious social and physical spaces. Our findings challenge simple dichotomies between public and private spheres and argue for a more fluid understanding of how people living in contexts of constraint negotiate public and private spaces.

Methods: collaborative research in community contexts

For this analysis, we draw on qualitative data collected as part of the social science component of an HIV prevention trial (HPTN 071/PopART) conducted in nine South African and 12 Zambian communities from 2013 to 2018 (see Hayes et al. 2019). The three-arm cluster randomized controlled trial was implemented to determine whether an HIV prevention intervention – regular household HIV testing with immediate access to ART – could reduce community-level HIV incidence. For the social science component of the trial, we recruited 89 households across the South African study communities (all located in Western Cape Province) to explore the varied lives of people and to contextualize trial outcomes over time (Hoddinott et al. 2018).

Using a cohort study design, we purposively sampled households to ensure diversity across trial arms and in age, gender, household structure, and distance to local health facility. At least half of all households included one or more members who self-reported living with HIV.

Data collection involved multiple interactions with households over a period of 18 months between 2016 and 2018 and was informed by the ethnographic approach of "deep hanging out" (Geertz 1998) in the homes and communities of participants. Teams of two researchers were assigned to households, including at least one researcher who was fluent in the household's home language. Teams conducted participatory research activities framed around six themed modules with each household. Modules focused on the following: household composition; mobility; how people "get by;" love, sex, and romance; experiences of accessing care; and hopes, ambitions and fears (see Hoddinott et al. 2018). While the research was designed to explore life experiences more broadly, discussions of health were often HIV-focused as the data were collected in the context of an HIV prevention trial. To counter this narrow focus, we conducted several discussions to engage with conceptions and experiences of health more generally. Further, the depth and range of topics covered in relation to participants' lives gave us insight into how they positioned health and illness more generally.

Aside from routine employee turnover, we endeavored to maintain continuity in the researchers assigned to households. Through the team-based approach, we had the benefit of having insight from multiple researchers over time, but it also presented challenges to ensuring consistency and quality of data collected. We addressed this through continuous interactive workshops, standardized discussion guides, and debriefings. The team approach also added new complexities in that participants often revealed information selectively to different team members. By entering their homes for research purposes, different team members imposed new "audiences" (Goffman 1959) for which participants performed and negotiated their own boundaries of what was to be shared or kept private.

Depending on the topic, discussions were conducted either on a one-on-one basis or with groups of household members. We assured participants throughout that information shared on an individual basis would not be shared with other household members. Discussions also took place in a space of the participant's choosing. All discussions were conducted in local vernacular (Afrikaans, Xhosa, or English) and audio recorded, and researchers compiled detailed field notes and semi-structured reflection notes.[3]

Researchers interacted with each household on multiple occasions (at least 10 times) for between one and four hours per visit. Team members also maintained continuous contact with households outside of regular field visits by "stopping by" when visiting other households in the vicinity, calling participants, and sending text messages. This approach allowed many meaningful relationships to develop between researchers and participants over time. The intensity of the interactions allowed researchers to observe household members *in situ*, noting changes in household composition and witnessing exchanges between household members and neighbors (Hoddinott et al. 2018). Participatory research activities (e.g. co-created kinship maps, community maps, illness timelines) also facilitated richer discussions with participants.

Informed consent was practiced as a continuous process, with participants providing written consent at recruitment and reconfirming consent over the course of the study. Additional household members who became known to researchers over time were also invited to participate and subsequently consented. For the analysis on comorbidities presented here, we included data collected with all participants from the cohort who self-disclosed that they were living with HIV and at least one other chronic condition (n = 14). We conducted a narrative analysis (Riessman 2003) of all data (transcripts, field notes, reflection notes). We reviewed available data for each participant and wrote narrative summaries, drawing out themes related to community context, household structure and relationships, illness experiences, and disclosures. We conducted a case-by-case comparison of the participant narratives to identify common and distinct themes across cases. We shared these interpretations with the social science team and expert reviewers as a sense checking mechanism. During cross-case analysis, we identified the narrative of Elsie and the ways in which she managed her comorbidities as resonating with and exemplifying the complexities and tensions experienced by other participants affected by comorbidities. During the in-case analysis, we constructed a detailed timeline of her illness narrative, comparing reflections of the more than 20 hours of engagements we had with the family, exploring our understandings of her health experience against the frame of the public/private dichotomy. In presenting Elsie's case, we weave together an argument how different individuals negotiate private/public divides in managing illness in contexts of constraint. All names are pseudonyms.

Elsie Jacobs: living out in the open

Our team first came to know of Elsie's HIV status during a recruitment interview with her mother, Bettie, the matriarch of the Jacobs family. The discussion took place inside the university vehicle parked down the street, a space Bettie suggested as her preferred location for our discussion. It was often difficult to find a quiet space for private conversations in the bustling informal community of Vineridge, a small, densely populated area located in the Cape Winelands region of South Africa. In opting to have the interview in the car, Bettie situated the topic of the discussion in the realm of the private, not to be overheard or shared publicly. Outside the stillness of the vehicle, the noises of the community could be heard and seen – people socializing, cooking on open fires, and recycling glass (a common form of informal labor in the area). In this place, as we came to understand over the course of our fieldwork, everyday activities are often performed in the open. Life is, as Ogden (1996: 169) describes, "both 'domestic' and intensively public." Maintaining the boundaries of private and public knowledge often required complex negotiations between residents.

In this first encounter, Bettie casually described her life in Vineridge and her family's history. When the conversation veered to the topic of health, Bettie began to speak, without prompting, about her daughter Elsie who had contracted HIV from a boyfriend that she "wasn't open about." Her voice cracked, but she continued, "I look after her. I keep it [Elsie's HIV status] to myself. It stays between us, between her father and me. We don't let her feel that she has the sick [HIV]."

When we (LV and HM) met Elsie for the first time a few weeks later, she easily leapt into discussion about her epilepsy, a condition her mother had not mentioned. She had been diagnosed as a teenager, she told us, and often endured unpredictable seizures publicly. It was another six months before Elsie subtly disclosed her HIV status to us, pointing to the word "HIV" on a household survey we were completing with her and Bettie. After this quiet acknowledgment of her positive status, Elsie continued to slowly unveil additional details of her HIV diagnosis, although always out of earshot of neighbors and extended household members. During these initial exchanges, we became acutely aware of a tension in the Jacobs's ordering of daily existence in which certain aspects of their lives and Elsie's health were selectively positioned as either private – hidden and managed within the close family – or public – openly shared with the collective and wider community.

The four dimensions of the public/private divide

As our encounters with the Jacobs family highlight, disclosures about health are not simple, once-off events. Instead, they are layered exchanges in which individuals selectively reveal particular elements of their illness narratives over time (Kleinman 1988). As we will show, for residents in Vineridge and other communities, managing what is revealed and to whom, and deciding who is included in collective processes of care, required intricate and calculated decisions across multiple dimensions of the public/private divide.

These dimensions included, firstly, the divide between social spaces – or the divide between domesticity and sociability. In this distinction, Ariés (1960) understands the family or the household (as a unit) as part of private life, where care, support and privacy are maintained. By contrast, public life is understood to include others who fall outside of the family unit. Secondly, Jacobs (1961) describes a divide between physical spaces, i.e., public, shared spaces, and spaces limited in terms of allowed audiences. Divides in physical spaces refer, for instance, to the intimacy of household structures, or public communal spaces, such as the spaces where socializing or shared work takes place. Thirdly, Goffman (1959) defines the public/private distinction as between the intersubjective (others) and the individual (self), where some social behaviors take place under the gaze of other people (in public) and other behaviors take place in relative isolation (the private). Lastly, Butt and Langdridge (2003) expand on a fourth dimension relating to the private sphere, i.e., the realm of the unconscious. In this dimension individuals go through a series of complex processes to reconcile their self-conceptions with their social experiences. In this way, the public (interactions with others) and the private (self-theory) interact, enabling individuals to come to an understanding of "self."

While these public/private divides are useful for framing illness experiences, we show how the neat dichotomies these theorists propose come apart in the fluidity inherent to people's daily lives. We describe how individuals living in contexts of constraint negotiate both physical and social boundaries to locate their diagnoses, how these boundaries are tested and renegotiated, and how participants adapt when boundaries are difficult to maintain.

Sociability and the family space

When Bettie introduced us to Elsie for the first time, the pair invited us to sit in the narrow space between their front door and their neighbor's house. We were drawing a floorplan of their home as part of a discussion on household structure when Elsie greeted a young man walking by. Bettie explained that he lived in a makeshift room attached to their house. Assuming that he was part of their family, we suggested they invite him to join the discussion. Both women quickly brushed off this request, explaining that he was not part of the "family," he "just stayed there." If we wanted to talk to "the family," Bettie said, we needed to talk to her or to Elsie. Over time, we came to understand that there was a clear demarcation between those who "just lived" in the home and those who were part of (or allowed to speak on behalf of) the "family." The Jacobs often added temporary rooms to their home to accommodate friends or extended family in times of need. Extended relatives, unofficial foster children, and acquaintances who lived in these rooms for differing lengths of time were not "family."

As Ariés (1960) theorized, people actively create boundaries between the public (the community, others, outsiders) and the private (family, us, insiders) in organizing their social world. The complex social arrangements of insiders and outsiders can be seen in the construction of the concept of "family" for Elsie and others in our cohort. Although members of their broader extended household (which included 10–12 residents at any given time) often shared food and domestic chores, Elsie included only herself, her mother (Bettie), her father (Ben), two brothers, and her boyfriend of the past seven years, Jake, in her family. These six people formed the core of the family. Various other household members shared in selected household knowledge. Only some household members knew that the family sold small quantities of marijuana for extra income, and none of Bettie's children knew that Ben had previously been incarcerated. Only the core family knew the most private details of the Jacobs's lives, including that Elsie was living with HIV. For Elsie, the intimate family was the *appropriate* (private) space for HIV-status disclosure and health support. By contrast, she understood her epilepsy diagnosis to be a more comfortably public matter, which she shared openly with her extended social circle.

On more than one occasion Elsie fetched her epilepsy medication to show it to us. The repeated display emphasized how Elsie viewed epilepsy as part of her accepted public persona – one that she was not afraid to share beyond her intimate family. We came to understand that the distribution of care is not limited by the visibility of the condition but is shaped by the social meanings of illness. Different chronic conditions are experienced differently by those affected and some chronic conditions (often including HIV) are considered to *belong* in the private sphere. These conditions are often disclosed to and cared for by close family members only. Other conditions are considered more acceptable to publicly reveal, and to ask for and expect support from the wider community.

Fezeka (32), from the Cape Metro area, managed her conditions in ways similar to Elsie. She disclosed her dual diagnoses (HIV and TB) to her siblings and her mother. Although she maintained to us that she did not have a close relationship with them, she emphasized the importance of family and considered this closed group her most trusted form of social support. Fezeka explained that only her family would be able to support her when it came to the intimacies of illness.

In contrast, when Josephine (34) from the Cape Winelands found out she was living with HIV, she told only her grandmother, who kept her secret for five years, until Josephine was ready to share her status with others in her family. Josephine describes herself as involved with "the wrong things," including drugs and alcohol, which resulted in a strained relationship with her mother, stepfather, and siblings, whom she lived with. The immediate family had long been aware that Josephine had been diagnosed with TB, but not HIV. When Josephine decided it was time to share her HIV status, her boundaries between the public and the private shifted to include her immediate family into her private sphere.

These conceptualizations of the family as part of the private sphere fits with Ariés (1960) understanding of the public/private divide. He positions the family and domesticity as the realm of "the private" while civil society, or sociability, is considered to be "the public." The private realm is not the realm of isolated individuality, as others have theorized (Goffman 1959), but of intimate collectivity, "constituted by particular ties of attachment, affection, and obligation." In contrast to the experiences of our participants, Ariès' conceptualization of the family is tied more closely to the boundary of the household. In our context, the divide between the family and "others" is complex as household composition was fluid and changing, and understandings of "family" and kinship were not universal or fixed. For example, Agnes (45) was being treated for HIV and high blood pressure and did not want her brother to know about her HIV diagnosis. She explained: "He is my brother, my own blood brother, but my family are my children," indicating a distinction even amongst blood relatives. The fluid and changing nature of families have been described extensively by new kinship studies scholars (Carsten 2004; Reynolds 2015). Carsten (2004: 149), for instance, defines "family" as the broader social unit where "belonging" extends beyond the limits of birth or blood relations, and is rather defined by time and endurance. We found this definition useful in understanding how participants delineated who were "insiders" or part of the private sphere, and who were "outsiders" or part of the public sphere. In our research, we allowed participants to decide who was included in their family. We came to understand "family" as a group of people who are intimately connected, which could include neighbors and close friends. We continually checked with key household members to come to a common understanding of the "family," and to identify the members of households in our cohort.

Drawing the line between public and private spaces

As described in the introductory vignette, it was difficult for Elsie (as for many other participants) to keep her HIV status hidden. In Elsie's neighborhood, homes stand in close proximity to each other with no more than 1.5 meters between them, and "walls" were rarely more than blankets, corrugated iron, or hardboard sheets. Neighbors were close enough to inadvertently turn intimate conversations into shared knowledge. Individuals needed to be vigilant and manage their physical spaces carefully to establish boundaries between the private (the physical home, the "family," the self), and the public (shared space, outsiders, or "others"). Life in this context challenges the public/private boundary, as theorized by Jacobs (1961), in that even the physical divide between spaces becomes permeable.

Lack of steady employment, income and resources meant that the Jacobs family and their neighbors from Vineridge have had to make do with repurposed materials to construct homes, while participants from other neighborhoods had access to formalized housing. For many participants, housing structures, even formalized housing, were in close proximity to neighbors and offered little in terms of physical private space. Household structures accommodated several residents and rooms were often shared with multiple others. In addition to the limited privacy *within* households, the physical layout of housing in resource-constrained communities also lends little privacy *between* households (Ogden 1996).

Because the boundaries between the public and the private are constantly being constructed, they are neither stable nor impermeable. At any given moment, people make decisions on whether a person should be included as part of their private or public realm. Through these choices, individuals are constantly crafting the boundaries of public and private spheres (Kilian 1998). Yet, the physical layout of households, communities and shared spaces often limits individuals' ability to conceal elements of life, including health conditions. How people construct the public/private divide is thus determined by both social bounds and physical space (Kilian 1998; Wolfe 1997).

Different housing types presented diverse challenges in managing comorbidities and maintaining privacy. As in the Jacobs's house, Jasper (34), a former gang member diagnosed with TB and HIV, shared with his father an informal structure without windows, flooring, electricity or running water. While the Jacobs' house had several add-on rooms, Jasper and his father's one-room house was nestled in a densely populated corner of their community. There was little protection against the wet, cold Cape Town winters or the scorching heat in the summer months. There was also limited opportunity for Jasper or his father to establish privacy for themselves.

Even with formalized housing, some participants still found it challenging to maintain boundaries between personal and shared spaces. Cynthia and Charlie, both living with HIV, stayed in a two-bedroom government subsidized brick house. To secure an income, the couple compromised their privacy by leasing the second bedroom. They did not disclose their HIV statuses to their tenants, which meant that they often could not discuss their health at home. Similarly, Aviwe, a former police officer, lived in a one room brick house with his wife, son, and daughter. The couple were both living with HIV and did not disclose to their two teenaged children (who Aviwe believed to be HIV negative), explaining that it was a private, adult issue. To create some semblance of boundaries, the family used wall drapes to separate the adult sleeping space from that of the children. Aviwe complained about the lack of physical privacy, as it compromised intimacy with his wife.

The constrictions on private spaces also extended to health settings. When Mark, a Mozambican national living in the Cape Metro, found out that he was living with HIV, he voluntarily disclosed to his live-in girlfriend, Lita, but not to his brother who lived in the same building. When he went to the clinic to access treatment and saw his brother in the queue for ART, both men's statuses were inadvertently revealed. For Aviwe, Cynthia, Charlie, and others, the public/private divide is complicated by the physical constraints they experience.

The intersubjective and the self

In addition to the divide between the family (as a private unit) and those outside of the family (the public), the public/private divide is reinforced through a distinction between intersubjective "others" as the public sphere and the "self" as the private sphere. Goffman's (1959) use of the dramaturgical metaphor is useful in this regard. Public encounters, as "staged performances" are "rarely natural or spontaneous" (Wolfe 1997: 184). Instead, it is in the private space of individuals' own minds, or "backstage," where people retreat to their "true selves" in anticipation of future public performances. Participants' public performances, such as when Elsie spoke of her diagnoses, are used to gauge the reaction of audiences and to assess what is acceptable to make public. Throughout our interactions, Elsie and her mother were set on presenting a specific appropriate image when we were with them. In a few instances in which slippages in appearance (or performance) occurred, such as swearing or expressing anger at community members, Elsie and her mother were quick to correct themselves. These corrections seemed to be about more than composure, but about the maintenance of the family's *ordentlikheid* (Afrikaans for decency/respectability) in front of outsiders like us. Afrikaans-speaking members of our cohort often raised the concept of *ordentlikheid* in their descriptions of expected and proper behavior and social interactions, including sex. In her explanation of *ordentlikheid*, Teppo (2015: 287) describes it as intertwined with concepts of morality, social and spatial boundaries, and forms of belonging. To be *ordentlik*, people are expected to adhere to, or appear to adhere to, abstract and unwritten normative practices in how they act and speak, or perform, in public spaces. However, *ordentlikheid* is more than just good manners; it is understood to be part of individual and collective identity, and to powerfully shape how individuals portray themselves to select audiences. For example, Elsie referred to a "socially acceptable" or *ordentlike* narrative of how she contracted the virus. In this version, she became HIV positive through cuts on her hands (from recycling) while helping an elderly, sickly neighbor (an often-repeated narrative).

Other cultural groups in South Africa have similar, often gendered, notions of respectability. In Xhosa- and Zulu-speaking communities, the concept of *ukuhlonipha* similarly creates clear "proscriptions in terms of action, space and language" (Herbert 1990: 457). The rules of *ukuhlonipha* also dictate the use of appropriate language in social circumstances (Ogden 1996). Both *ordentlikheid* and *ukuhlonipha* imply preconceived notions of appropriate public performance or persona. These personae can be "compromised" by the diagnosis of a chronic condition. Treichler (2002: 261) pointed out that chronic illnesses, including HIV, are conditions of signification: in addition to the weight of mortality that is still associated with a positive diagnosis, HIV is a "nexus where multiple meanings, stories, and discourses intersect and overlap, reinforce, and subvert one another" and that beyond the biomedical implications of the illness, it is "an epidemic of signification." Illnesses can have social meanings which relate (negatively) to respectability (Bond 2010). However, all conditions are not "equal" as beliefs about the public/private status of health conditions are also informed by the moral interpretations of illness acquisition, their prognoses, and the possibility of disease transmission (Bosire et al. 2018). Participants actively decide which conditions should be kept within the private domain and which conditions are "appropriately" within the public domain. These decisions are based in part on reinforced social experiences. Simmel's (1906: 441) description of secrecy illustrates how the shift between public and private spheres can happen. He explained that "in all relationships … there develops … intensity and shading in the degree in which each unit reveals himself to the other through word and deed."

In asserting if a condition *should* be shared, participants "tested" the potential consequences of disclosing. Lesley, an openly gender fluid woman from the Cape Winelands, revealed that she did not disclose her HIV status openly as this would confirm community preconceptions that someone who is gay, transgender, and a former drug user is likely to be HIV positive. She explained that when people at work had "open conversations about HIV" she might give her opinion and correct them, but would not "give too much" so that they think, "why are you so well read in this topic?." This strategy of engaging in the topic of HIV, testing the reactions of their audience but without "letting on" that they knew more than others, was employed by many other participants, including Elsie.

Lesley also engaged in subtle, partial disclosures. She purposefully left her HIV medication open. When her mother enquired about the pills, Lesley explained that they were "nothing, they're just for my back." While she went through extraordinary steps to hide her HIV treatment from other household members (removing pill container labels, carefully emptying the pills onto her bed to avoid noise), Lesley chose not to hide her tablets from her mother. This limited disclosure created an unspoken "don't ask, don't tell" agreement between Lesley and her mother, in which neither of them explicitly acknowledged Lesley's HIV status but which allowed Lesley to gauge what her mother's reaction would be *if* Lesley were to openly disclose. Despite high levels of reported stigma associated with the disease (Murray et al. 2013), her TB diagnosis was openly shared and Lesley involved her wider social networks for support.

Partial disclosures also extended to the researchers. Across our cohort, many participants shared details about their health, including their HIV status, with us, even during initial recruitment visits. Others took time, or "tested the waters," to determine reactions to selective disclosures before allowing us into their private sphere, where they felt comfortable to disclose health concerns.

The public/private, the affective and the unconscious

The house was unusually quiet when we met for one of our final discussions with Elsie, as most of the household members were out and Bettie had gone to visit her sister. In contrast to her usually upbeat demeanor, Elsie somberly described her shock upon being diagnosed with HIV and how she had considered suicide. After a moment of silence, she explained with renewed vigor, "actually, I don't put my attention on the HIV … My thoughts are more on the epilepsy because it doesn't feel like I really have it [HIV]." Despite these words, she often alluded to spending time thinking about HIV.

Over time, Elsie, with Bettie's help, found ways to distance herself from her HIV status by downplaying the severity of her own illness. She distanced herself from others who were living with HIV by emphasizing her difference from them because she did not have "deep" HIV. Elsie explained that her doctors had agreed that she likely did not contract HIV through sex, and this was why her HIV was not as severe. Robins (2006) and others have described an HIV diagnosis as a transformative event, inducting individuals into a new collective and shifting their sense of self. In her narrative, Elsie avoided claiming any identification with this broader collective and resisted what she found to be negative associations linked to her HIV status. There was a clear disjuncture between the image that Elsie held of a person with HIV – someone who is sexually promiscuous and not "proper" – and her self-image as an *ordentlike* woman from a good family. This sentiment was most obvious when Elsie reflected on her *onbeskofdigheid* (rudeness), as she described it, when she was younger – consuming too much alcohol and engaging in fights. In one discussion, she considered out loud whether her HIV might be the (moral) consequence of her "bad" behavior in her youth.

Bond's research with PLHIV in Zambia revealed that while a lack of disclosure "can be dangerous and even tragically fatal, it also allows individuals living with HIV room for maneuver and the possibility of defining their identity separate from their disease" (2010: 6). Although Elsie shared her status with a few individuals in her private sphere, she still (partly) disavowed her HIV diagnosis in her interactions with others and at the level of her own unconscious. Even to the small group of people aware of her status, Elsie was able to shape the image of her condition and her identity by presenting herself as proper and different to other PLHIV.

Across our cohort, people diagnosed with multiple conditions described the various iterations they go through in their daily lives to reconcile their conditions with their identity, and to assert what should be kept private or made public. However, beyond simply "keeping it secret" (in the realm of the unconscious), individuals go through complex processes to reconcile their self-conceptions (or self-theory) with their diagnoses. The dimension of the unconscious, conventionally excluded from theoretical understandings of the public/private, contributes to a more nuanced understanding of the ordering of social life.

In exploring expressions of sexuality, Butt and Langdridge (2003: 479–480) describe how "the public reaches into the private sphere, producing a self-theory, and how (perhaps unconscious) self-deception is practiced in order to maintain this theory." They theorize that individuals go through a process of acting (pre-reflective) in the world, and retreat to reflect on their acts. From previous interactions, and with the aid of internalized language acquired from previous social interactions, individuals either reconcile their pre-reflective engagements with their (morally informed) self-theory, or disavow their acts if they did not resonate with their self-theory. In this way, public interactions impact the most intimate conceptualization of the private sphere. This production of self-theory resonated with the experiences of participants in coming to terms with their dual diagnoses.

Over time, participants in our cohort compared the impact of different morbidities on their lives. Perhaps surprisingly, many presented their other chronic conditions (TB, diabetes, high blood pressure) as "worse" than HIV, with a more profound impact on their lives in terms of pain, anxiety, or discomfort. By contrast, HIV was often superficially presented as an unwelcome aside to their everyday experiences. In the quiet moments during intimate discussions, however, participants hinted that HIV had a significant presence in their most private of spheres.

While several participants downplayed the visibility and the impact of HIV in their lives, concerns about their diagnoses remained (mostly) unspoken but ubiquitous. In reflecting on their HIV diagnoses, participants reconciled or disavowed (through suppressing thoughts of) their HIV diagnoses in efforts to confirm their self-theories – their sense of what characterizes them (Butt and Langdridge 2003). As an example, Cynthia, who described herself as an alcoholic, was diagnosed with HIV and TB and lived with her partner Charlie, also diagnosed with HIV. We often left Cynthia's house without having had any discussions with her because she was unwilling or unable to participate. When we did talk, she made no secret that her life with Charlie was less than desirable; she described it as a "shit life." In these already difficult circumstances, Cynthia revealed that she tries to keep her thoughts away from HIV: "I take it as it is, I don't focus on the illness [HIV]. I try to shift my thoughts to other things." In dealing with her diagnosis, she preferred to keep her thoughts private: "I keep it all to myself. I just want to be alone. I lock my door and put the music on loud."

Jasper, a former gang member introduced earlier, expressed thoughts on his HIV and TB diagnoses that contradicted what he revealed in moments when he vented more freely. He had endured long periods of TB-related hospitalization. During one visit, we found him to be extremely frail, so much so that we feared that he might pass away soon. After another four-day stay in hospital, he explained that he was angry over his TB diagnosis and had stopped caring about himself. His concerned family phoned the ambulance. He continued to explain that "TB took over his body" and that "HIV wasn't that bad." In a later sullen moment, however, he reflected: "I *skel* [shout/admonish] often. I don't want to blame the disease [HIV] the entire time, but to me it just feels like everything is just fucked up. My life is fucked up … I don't want anyone around me." Elaborating, he added: "They can tell you that you can live normal, but you can never be normal." While Jasper would describe TB as consuming his entire body, he believed his HIV diagnosis separated him from those who are "normal." Dealing with the anguish of his diagnosis was an intensely private affair that Jasper did not readily share with others.

Some participants, however, embraced their HIV-positive status as part of their identity. When Nceba (48), a Xhosa woman from the Cape Metro, found out that she was living with HIV, she disclosed her status widely and joined the Treatment Action Campaign (an activist group instrumental in making treatment available for PLHIV in South Africa) (Friedman and Mottiar 2005). She believed that her diagnosis should be widely and publicly revealed to facilitate access to care and cement her place in the community as a care provider to newly diagnosed patients.

Elsie's and others' choice not to dwell on their HIV diagnoses represented a form of disavowal and a decision to avoid any self-examination (see Butt and Langridge 2003: 487). Participants created a moralistic self-image of themselves that allowed them to retain a sense of self-respect and virtue. As much as participants positioned HIV as "not as important" as their other conditions, it was an unavoidable unconscious presence. Bond noted that HIV is hard to conceptualize as "a 'manageable' chronic illness because it is weighted by such extraordinary baggage" (2010: 9). Because of this moral "baggage," HIV is experienced as different from other chronic illnesses. To manage this, PLHIV often position their diagnosis as private – even from themselves.

Elsie's (and others') challenge in coming to terms with the diagnosis and the conviction that HIV *should* be private is in part informed by her interpretation of what an HIV-positive status signifies. To Elsie and others, HIV is still considered a disease of promiscuity and moral transgressions (Leibowich 1985: 5). The implication is that when people reveal that they are living with HIV, they are also potentially revealing other aspects of the "self." This public engagement in the world informs how individuals reflect on and make meaning of comorbidities, including the repeated positioning of HIV as a condition that should be kept private.

Conclusion

Across the four dimensions, the public sphere has been understood to be an "outside" or "other" domain – as shared spaces, sociable "others," outside the intimate family, or outside of the unconscious "self." The private sphere, by contrast, is understood to be part of the "intimate" domain – personal spaces, the individual, the limited family, and understandings of "self." We have shown how people living with chronic illnesses in precarious social contexts and constrained physical spaces often find it challenging to maintain boundaries between these spheres. When managing their health conditions, Elsie and other participants repeatedly attempted to position HIV as a condition that *should* be private, reinforcing the idea that HIV *is* a private affliction. Faced with the potential risk of the collapse of the boundary between private and public spaces, participants continuously had to (re)draw and negotiate the line between these spheres, across domains. For instance, although participants often made a distinction between family "insiders" and other "outsiders" whom they entrusted with illness support, the boundary of the "family" was porous and shifting, forcing participants to renegotiate who was privy to their multiple diagnoses. Participants also described their challenges maintaining privacy in physical spaces where homes were temporary or flimsy and shared spaces encroached on areas that people would prefer to keep private. In addition, performances of health and illness in intersubjective spaces and unconscious understandings of illness were complicated when both physical and social spaces were constrained.

In a public healthcare system that is resource-constrained, there is little space to negotiate around people's private lives or personal boundaries. Physical space at public health facilities in South Africa, as elsewhere, is not designed to facilitate the desired private boundaries and health providers are often not attuned to the complexities of how different people manage their illnesses. The recent national shift toward integrated care, where HIV care and treatment are aligned with other care options at public health facilities (Njuguna et al. 2018), is aimed at decreasing stigma and making care more accessible and cost effective. Grouping conditions together for public healthcare, however, does not resolve the tensions that individuals living with comorbidities experience in managing the different social implications of their illnesses.

The repeated challenges in maintaining preferred boundaries between public and private spaces powerfully illustrate the lack of control that people experience over the boundaries between these spheres. Our analysis illustrates that they must reconcile themselves with an increasingly constrained private sphere. Perhaps, one might suggest, the private sphere is a space of privilege that a limited few can claim for themselves or maintain.

Notes

1. A condensed version of Elsie's story is described elsewhere (Viljoen et al. 2020).
2. South Africa has done away with racial classification for the purpose of legislated discrimination for people of color. However, commonly used categories – white (for European), black African (for African decent), and

colored (a complex category used for people of mixed racial descent or with ancestry from Indonesia or Khoisan) are still used in official and everyday language (Posel 2001).

3. While authors LV and HM were involved in data collection for Afrikaans-speaking participants, we relied on Xhosa-speaking researchers for collection with Xhosa-speaking participants.

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Manuscript 4: The act of telling: South African women's narratives of HIV status disclosure to intimate partners in the HPTN 071 (PopART) HIV prevention trial.

Viljoen, L., Wademan, D. T., Hoddinott, G., Bond, V. A., Seeley, J., Bock, P., Fidler, S., and Reynolds, L.

Overview and contribution to dissertation aims

HIV status disclosure has been shown to facilitate the negotiation of HIV prevention methods (such as condom use) in intimate relationships and to ensure that people living with HIV (PLHIV) are able to secure treatment adherence support from others. As described in previous chapters, recent research has shown that viral suppression through antiretroviral therapy (ART) adherence offers protection against HIV transmission. It has been suggested that this shift to treatment as prevention can ease the process of disclosure for people in intimate relationships. In this article, I explore how women living with HIV manage status disclosure to intimate partners in communities in the HPTN 071 (PopART) trial where universal access to HIV testing and treatment was made available. I present an analysis of the disclosure narratives of 15 women living with HIV in three South African communities. The analysis is guided by Goffman's dramaturgical metaphor (1959)[1] which describes social interactions as 'performances' by 'actors' (people) guided by 'scripts' (anticipated dialogues/interactions). In this context, I show how disclosure is rarely framed around health concerns but is instead shaped by women's understandings of the nature and stability of their relationships and their concerns with personal (and relationship) preservation.

This paper contributes towards the 4th objective of the thesis – to describe how women living with HIV negotiate HIV status disclosure to their intimate partners in the context of increased access to HIV testing and treatment. Public health experts position

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disclosure as a primary mechanism for HIV treatment linkage and adherence and as a central determinant of sexual behaviours and risk-taking. Through status disclosure and adherence support, HIV treatment can be incorporated into the relationship scripts of couples to negotiate safe sex. This manuscript serves to describe how women's disclosure unfolds in the context of UTT.

Author contributions

As primary author of this manuscript, I was involved in the design of the data collection tools and the implementation of data collection with several of the participants. I led the analysis process, conducted the literature review, and wrote the first and consecutive drafts. Author DW was involved with the analysis. Authors GH and LR supported the conceptualisation of the manuscript and provided detailed comments and revisions on drafts. Authors VB, SF, PB, and JS provided comments and feedback on drafts of this manuscripts. A note on co-author contributions is available in Appendix C.

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The act of telling: South African women's narratives of HIV status disclosure to intimate partners in the HPTN 071 (PopART) HIV prevention trial

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Abstract

Background: Public health programming often frames HIV status disclosure as a means to negotiate condom- and abstinence-based prevention or to involve intimate partners in HIV care to garner treatment adherence support. HIV treatment can be used to ensure viral suppression and prevent onward transmission, which provides strong evidence to encourage disclosure. The ideological shift towards HIV treatment as prevention is expected to facilitate disclosure.
Purpose: There is a lack of research on how the scale-up of universal HIV testing and treatment influences disclosure practices in high burden settings. In this manuscript, we aim to address this gap.
Methods: To this end, we conducted a two-phased narrative performative analysis of the disclosure scripts of 15 women living with HIV in three communities of Western Cape, South Africa where the HPTN 071 (PopART) HIV prevention trial implemented a universal HIV testing and treatment model as part of the intervention. The women were part of a larger cohort nested in the trial. We use Goffman's dramaturgical metaphor, which understands social interactions as 'performances' by 'actors' (people) guided by 'scripts' (anticipated dialogues/interactions), to explore how women living with HIV manage their status disclosure.
Conclusion: We describe how these women perform HIV status disclosure (or deliberate non-disclosure) to retain, reaffirm or redefine existing social scripts with partners. Their performances reveal priorities other than those imagined by public health programmes driving HIV disclosure (or non-disclosure): establishing trust, resenting betrayal and ensuring self-preservation while simultaneously (re)constructing self-identity. None of the women engaged with the concept of treatment as prevention in their disclosure narratives, either to facilitate disclosure or to 'justify' non-disclosure. HIV prevention, in general, and treatment adherence support were rarely mentioned as a reason for disclosure. To date, there has been a missed opportunity to ease and support disclosure in health programmes by tapping into existing social scripts, impeding potential patient and public health benefits of universal HIV testing and treatment.

Keywords
disclosure, HIV, performance, relationships, universal HIV testing and treatment

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Introduction

In South Africa, voluntary status disclosure is framed as an individual and social good in HIV prevention and treatment programmes and is often encouraged by health workers as an important first step after diagnosis.[1,2] Status disclosure to intimate sexual partners is usually positioned by health implementers as a way to either negotiate condom- or abstinence-based methods to prevent onward HIV transmission[3,4] or to ensure antiretroviral therapy (ART) adherence support.[5,6]

Globally, there have been efforts to scale-up access to ART (WHO 2018)[7] as ART holds both individual's health benefits[8] and has the ability to prevent onward HIV transmission when people living with HIV (PLHIV) are virally suppressed.[9] Health providers often position HIV status disclosure as a catalyst for treatment access and adherence through increased social support and as a means to prevent transmission when sexual partners are able to make informed decisions around safe sex.[1,2,5] With the established health benefits of ART and the ability to prevent onward transmission, the diverging reasons for disclosure are brought closer together. Evidence from health settings in South Africa has shown that the message of treatment as a means of preventing HIV transmission has not being explicitly advocated, and authors have noted that it will be difficult to implement and will require appropriate resources at every step in the HIV care continuum.[10,11] In addition, research from trial settings has shown that despite ART availability to all PLHIV, ART coverage is undermined by suboptimal linkage to care.[12,13] We suggest that messages of HIV treatment as a form of prevention might ease and facilitate more disclosure among PLHIV in intimate relationships and encourage linkage to care. However, there is a lack of empirical data on how, or if, the offer of universal access to testing and treatment (UTT) and messages surrounding treatment as prevention are filtering into the disclosure practices of people in high burden settings. To understand the motivations behind and pathways of HIV disclosure in the context of UTT, we conducted a performative analysis[14] of the narratives of women living with HIV in South Africa, the country with the most PLHIV.[15]

For PLHIV, a positive diagnosis has both biological and social implications. HIV has been described as 'an epidemic of signification'[16] that has to be managed 'both clinically and socially'.[17] The historical association of HIV with sex, promiscuity and death[18] means that it is a highly stigmatized condition[19,20] and that for many PLHIV, their diagnosis is positioned as a private condition.[17,21,22] As is the case for other chronic illnesses, the act of disclosure (or deliberate non-disclosure) often means more than just revealing health information, but rather, signifies the performance of broader underlying interpersonal processes and the reconciling of self and identity,[23] where 'self' can be understood as the sense of who one is in relation to others.[24] The aim of this article is to explore how women living with HIV negotiate disclosure (or non-disclosure) of their HIV status with their sexual partners through social scripts and performances.

HIV status disclosure: health and social consequences

Studies have found that HIV status disclosure is associated with an increased likelihood of ART initiation and adherence,[5,25] increased social support[26] and safer sexual practices among intimate partners.[27,28] As a result, status disclosure is generally regarded as an important part of HIV treatment adherence and is actively promoted in many settings.[2] As HIV is transmitted mainly through sex in South Africa,[29] researchers need to focus on whether individuals decide to disclose in sexual relationships, or not. HIV status disclosure in intimate sexual relationships is subject to various dynamics, including perceived relationship quality and type, decisions around childbearing, knowledge of others who have disclosed their status, HIV knowledge and individuals' self-esteem.[27,30,31]

Disclosure is further complicated by associations with enacted stigma,[32] while non-disclosure is associated with internalized and anticipated stigma.[33] Intertwined with these factors are broader social processes, including gender roles and power dynamics.[34,35] For example, fears around intimate partner violence[17] render disclosure problematic. Abdool Karim et al.[36] found that lower rates of HIV status disclosure by women to their sexual partners are 'suggestive of significant gender-power imbalance within couples . . . [highlighting the] fear of enacted stigma and gender-based violence as significant barriers to disclosure'. Against this background, we explore how South African women in heterosexual relationships 'perform' HIV status disclosure (or non-disclosure).

Performance and disclosure

According to Goffman,[37] social interactions between people, including health status disclosures, are similar to theatrical performances. Goffman employs stage metaphors of actors and audiences (participants in social interactions); roles and scripts (anticipated dialogues and interactions); the front stage (where persons 'do' performances for others) and the backstage (where individuals retreat from their public, social performances) to understand how persons operate and sustain accepted/normative social interactions or scenarios. Goffman highlights how performances are key in constructing and maintaining self-identity. Building on Goffman's work, Brissett and Edgley[38] noted that the self is 'established by its activity and the activity of others with respect to it . . . [and] selves are outcomes, not antecedents, of human interaction'.

Performances, in addition to being mechanisms of maintaining accepted social scripts, are thus instrumental in constructing identity. Goffman noted that people are constantly negotiating impression management whereby, to preserve positive self-identities, individuals attempt to shape favourable impressions of themselves and avoid embarrassment or social discomfort.

In relation to health conditions, Bury[23] noted that illness, especially a chronic illness, can be understood as a 'biological disruption', as it upends the structures of everyday life. By carefully crafting how, when and to whom they disclose their status, people with chronic illnesses create 'bounded impressions' or 'scripts' of themselves through which they attempt to regulate others' reception of the information and maintain a positive identity.[39] Interactions are, therefore, structured around actors' mutual understandings of the accepted 'scripts' for social scenarios. When people disclose their illness status, it is feasible that they want to convey a certain message (or performance) and hold the expectation that their partner will adhere to an anticipated script or react in predictable ways.[39]

The public health 'script' for HIV status disclosure has focused mainly on the so-called 'logico-scientific reasoning' approach, whereby inferences are made from pragmatic empirical evidence as opposed to an intuitive narratives approach, where subjective experiences form the basis of knowledge.[40] Accordingly, HIV status disclosure is framed as a means of transferring knowledge of a diagnosis to make informed, and by implication, better future (sexual) health decisions. However, research has shown that HIV status disclosure has repercussions for intimate partners that PLHIV consider when deciding if, why and how to share their status. HIV status disclosure is related to the anticipated reactions from significant others[41] and has been linked to strengthening identity and intimate relationships,[42] while non-disclosure has been linked to fear, mistrust and anticipated stigma.[35,41] We explore how HIV status disclosure is framed by women in South Africa at this stage of the HIV epidemic where treatment is available for all PLHIV.

Methods

Context

The data for this analysis were drawn from the social science component of a cluster-randomized HIV prevention trial referred to as HPTN 071 (or PopART).[43] Through a cadre of community-based health workers, community members were offered door-to-door testing and a package of HIV prevention interventions consisting of condoms, STI screenings, referrals for medical male circumcision, and, in communities randomized to receive the full intervention, early access to ART to PLHIV (ART regardless of CD4 count). The aim of the trial was to measure the impact of universal access to HIV testing and treatment on HIV incidence. The trial was conducted in 9 communities in the Western Cape Province of South Africa and 12 communities across Zambia. This analysis is based on the data we collected with 89 households participating in a longitudinal qualitative cohort study nested in the 9 trial communities in South Africa. Households were recruited through referrals by community health workers and during structured community observations.

We conducted bimonthly household visits over an 18-month period between 2016 and 2018. Researchers worked in pairs, usually a man and a woman, with at least one researcher fluent in the participants' home language. We used participatory research methods and completed thematized discussion guides arranged by modules with family members, either as one-on-one interviews or as group discussions, depending on the topic and household structure. Modules focused on household composition; income and expenditure; love, sex and romance; health access; and hopes, dreams and fears. Households were recruited to ensure diversity across age, gender, composition and HIV status (including participants who self-reported as living with or not living with HIV).[21]

Sample

For this analysis, we included all cisgender women living with HIV in the three South African intervention communities receiving early access to ART and who participated in the qualitative cohort (n = 15) (Transgender women were excluded from the analysis as they have unique, intersecting experiences of HIV risk, status disclosure and relationship dynamics.[44]).

Analysis

The analysis was informed by performance theory[14,37] and by the broader life narratives of each of the 15 women included in this study. A narrative performative analysis entails a focused analysis of the accounts and self-narrations of life events, 'both as constructions and claims of identity'.[45] We conducted a two-phased narrative performative analysis to explore the broader life stories and identify the specific performances (moments) of HIV status disclosure of each participant. In phase one, we collated data collected across all research modules for each of the 15 women to construct a cohesive case description of each participant, including their kinship maps, housing arrangements, economic prospects, romantic relationships, illness narratives and health access history. Data included verbatim translated transcripts of in-depth interviews, field notes, photos and detailed reflective notes. Second, we focused on the specific speech sections where participants described the act(s) of disclosing (or deliberately concealing) their HIV

Table 1. Pseudonyms and demographic description of participants.

Pseudonym	Age	Language	Romantic partnership
Cynthia	33	Afrikaans	Steady relationship with Peter.
Lana	28	Afrikaans	New relationship with Simon.
Asanda	42	Xhosa	Divorced.
Chantelle	31	Afrikaans	New relationship with long-term friend, Bradley.
Ntombi	40	Xhosa	Steady relationship with Chikhu; casual relationship with Esihle.
Millie	45	Afrikaans	Married to James.
Mara	21	Xhosa	Steady relationship with Zonke.
Cebisa (daughter of Nosipho)	19	Xhosa	Single, previous relationship with Xola.
Nosipho (mother of Cebisa)	48	Xhosa	Divorced.
Rebecca	26	Xhosa	Previous relationship with Danny.
Abby (lives with Stella)	20	Afrikaans	Several casual sexual partners.
Tina (lives with Stella)	21	Xhosa	Long-term relationship, Ben.
Stella (lives with Tina, Abby)	35	Xhosa	Long-term partner, Thando.
Fezeka	45	Xhosa	Long-term partner, Fuzile.
Dora	30	Afrikaans	On/off relationship with Hector.

status to their sexual partners. We then identified overarching themes[46] for the various types of performances of (non) disclosure. Through narrative analysis, we engage with several 'lenses' in considering the way that participants construct events, including language (word choices), the narrative process (sentence structures), context (in which events take place) and moments (identifying key events).[47]

From the analyses, we describe key 'moments of disclosure' narrated by participants during the extended course of data collection. We present these disclosure narratives with supporting longitudinal data from each participant where they described their intimate sexual relationships in detail.

Approval was provided by the London School of Hygiene and Tropical Medicine Ethics Committee, Stellenbosch University Research Ethics Committee, and the Bio-medical Research Ethics Committee at the University of Zambia (N12/09/056; N12/11/074). All participants signed written informed consent and continually reconfirmed over time. Pseudonyms are used throughout for reporting purposes.

Findings

In our findings, we present data from 15 women aged 19–45years, from 12 households. In terms of demographic representation, nine of the women were Black African, Xhosa-speaking, and six women were coloured, Afrikaans-speaking community members (see Table 1).(During the apartheid era in South Africa, persons were ranked and segregated by race with privilege and freedom allocated in line with these categories. Other researchers have noted that 'although the notion of racial groups is now legal history, it is not always possible to gauge the effects of past discriminatory practices . . . without referring to race. For this reason, (we) use the terms "black African" and "coloured". . . where pertinent to the data analysis'.[48])

We found that, for several women, disclosure (or deliberate non-disclosure) served a purpose beyond relaying biomedical information to inform sexual practices or for accessing HIV treatment support. Disclosure narratives were constructed according to broader scripts specifically performed to convince the audience or co-actors (intimate partner in this case) of the woman's intentions or position. We grouped these performances into three categories: cementing relationships, betrayal, and anger, and ensuring self-preservation.

Cementing relationships: disclosure as affirmation of intimacy

For several women, HIV disclosure was positioned as a productive next step towards affirming their intimate relationship with their sexual partners. Dora (aged 30 years) was diagnosed by the PopART intervention team in 2015 and, with the support of her close-knit family, initiated early treatment (outside of national guidelines, which at the time required a CD4 count of less than 500 for eligibility) soon thereafter. When we spoke to her, Dora was in an on-again, off-again relationship with her neighbour, Hector (55). Dora described how Hector made her feel special and that he took good care of her: 'he does everything for me . . . he is a good person'. For Dora, the act of disclosure was positioned around the intention of 'being honest' with her partner, and in so doing, cementing their relationship.

During one of our discussions with Dora she described how, on seeing PopART community health workers (CHWs) who conduct door-to-door HIV testing in her neighbourhood, she preemptively engaged in a performance to assess Hector's reaction to the possibility that she might need health support. In this prelude, Dora positioned herself as vulnerable and in need of care. In her account, Hector's initial response to potentially distressing news assured her of his preservation of their relational script casting him as supportive partner which led to her disclosing her HIV status later that day:

> [Hector] asked me, 'how's it going?' And, 'are you okay?' Then I said, 'no, give me another hug'. Then [Hector] said, 'it's going to be fine'. And then he asked, 'what's it about?' I said, 'I'm going to talk with you later' [pause] and then later I told him.

Although the preliminary conversation gave Dora sufficient confidence that Hector would react supportively to her HIV status disclosure, the excerpt below illustrates just how tenuous the moment of disclosure can be,

Researcher	What did he say?
Dora	He was upset and so on. Then I told him, if he's not happy with me, then he must say 'no'. I'll take my things and leave, I'll move [end the relationship]. Then he said, 'no, it's good' I told him, and I was honest with him. And then he also said now [disclosed his HIV-positive status].
Researcher	He also told you about himself [his HIV status]? [Dora nods] And how did you feel that he didn't tell you about it earlier?
Dora	I wasn't angry. Now if I was negative, then I would've been angry. But because I'm now already positive [it is okay]. We sat and spoke now [pause, exhales] and after that time, then everything was okay again.

When asked why she had disclosed, Dora explained to us that they were 'at that stage of their relationship', indicating that, for her, status disclosure was expected when a relationship had reached a certain level of seriousness. Dora's status disclosure was thus a carefully constructed performance, guided by the intention to strengthen their bond. When it seemed that Hector might be going 'off-script' and not reciprocating her investment in the relationship, Dora threatened to end the relationship. However, with Hector's acceptance and unexpected co-disclosure of also being HIV-positive, the status of their relationship was reaffirmed. In addition, through Dora's disclosure, she cast herself in the positive framing of an 'honest' partner. In this disclosure dance, the parties co-constructed a script that championed their relationship above whatever social and health-related issues that come with living with HIV. To note, according to her account, at no point during their mutual disclosure did Dora, or Hector, mention the health-related aspects of HIV (treatment and transmission) or benefits of having disclosed (adherence support).

While HIV disclosure is often carefully planned and scripted, as indicated above, reactions from partners that do not adhere to expected scripts are disruptive and threaten the discloser's identity and relationship with their partner. Lana (aged 28 years), for instance, went through careful measures to conceal her HIV status from others, including hiding her ART in the ceiling of the home she shared with her group of friends. She was diagnosed with HIV by the PopART intervention CHWs in 2015. During our interview in 2016, Lana was in a new relationship with one of the men in her social group, Simon (aged 28 years). Lana told us that she had told Simon about her diagnosis because 'I always trusted him, see, I could talk to him. Other people close to me aren't like that'. However, when asked about Simon's reaction, Lana described the following:

Researcher	What did he say [about your status]?
Lana	[extended pause] It is another story.
Researcher	When did you tell him?
Lana	When the two of us tested.
Researcher	Were you and Simon together when you tested? [Lana nods] And so you tested positive [Lana nods] And he? [Lana nods]. So, you were positive already? [Lana nods] So you tested again with Simon?
Lana	Yes, but then Simon was positive already [knew his status prior to this test].
Researcher	Oh, he also knew? [Lana nods] And so what did he say– [Lana interrupts]
Lana	–I did not know.
Researcher	What happened then?
Lana	Because I did not know about him [pause]. I just told him, but [pause, hesitant] I did not know about him [pause], and he is not one who freaks out [overreacts]. He is just calm, but I have not [pause, reconsiders]. He did not tell me about himself [exhales loudly, sounds reproachful].
Researcher	And was he ugly [mean/rude] towards you?
Lana	No, he [pause] he knew about himself.
Researcher	He told you he knew already [about his own status]?
Lana	No, he did not tell me. I found out at the clinic [inaudible]. I was getting angry, because I told him about me [my status] but he has not told me about himself [his status].

Lana described how she used the opportunity of retesting for HIV with the CHWs to inadvertently 'reveal' her status to Simon. When she tested positive, Lana explained, she told Simon that she had known she was living with HIV for a few months. Lana wanted to disclose to Simon because she thought of him as kind and trustworthy. Since Lana viewed Simon as supportive, she expected that her disclosure would be met with acceptance, even though he tested positive. Lana cast both herself and Simon as trustworthy. However, according to Lana, she inadvertently found out at the clinic that Simon had long been aware of his positive status, leaving her feeling betrayed. In this instance, the 'disclosure script' unfolded positively, and as expected, however the broader 'relational script' appears to have been fractured by Simon's decision not to disclose his status earlier on in their relationship. While status disclosure presented a challenge to our participants' relational scripts, it also revealed an opportunity to cement relationships especially when both partners were living with HIV. However, the disclosure process was, ultimately, influenced by the partner's HIV status and their willingness reciprocates disclosure.

For others, like Chantelle (aged 31 years), HIV status disclosure was described as an affirmation of trust in her long-term childhood friend, neighbour and eventual boyfriend, Bradley (aged 27 years). Prior to her relationship with Bradley, Chantelle had been in several abusive relationships and had struggled with substance use. She described her disclosure to Bradley:

> Before the two of us were bound [had sex], I already opened up to him. He is my friend and I sat with him. We share everything with each other, as friends. We help each other . . . I opened up to him. I told him what I'd been through. I spoke to him about myself, that I have HIV so he would know, as a friend. I don't have other friends. But I didn't know how he is going to be [react] and how he's going to speak to me. Is he going to be upstairs [looking down on] towards me? Many *tjommies* [buddies] . . . when they hear that a friend is HIV-positive, then they move their company [friendship] away.

As in the previous disclosure narratives, Chantelle described the angst and uncertainty she felt about disclosing to Bradley. Unlike with other participants, Bradley maintained Chantelle's script and turned the conversation towards a discussion on HIV transmission and safe sex. Chantelle explained,

> Bradley said, 'it's not about being contagious. You just have to know how to avoid it [HIV transmission]. You won't have clean [condom-less] sex, [you need to know what to do] if you have cuts'. Furthermore, the two of us, we understand each other. He understands me and I understand him. He accepts what I have been through.

Maintaining a script of trust and understanding and managing Chantelle's identity in their larger social group led Bradley to procure condoms without raising suspicions of Chantelle's HIV status. Together, the couple engaged in a wider social script:

> Bradley goes to the clinic, or he asks his friends [for condoms]. Then they want to know, why he's asking for condoms. Then he says, 'it's for CD discs, to clean them'. [laughing] He tells them . . . you get the oil from the condoms and you rub it on [the cd]. He [tells them]: you can put it on your skin too. 'I need those things [condoms] for that [cleaning CDs, skin lotion], not for women [sex], I mean, do you know me?'

For Chantelle, her status disclosure was meant to cement her relationship with Bradley. When Bradley also engaged in an elaborate act to conceal Chantelle's HIV status from their friends, we see how the couples' script bleeds into a wider script they both ascribe to in their social group. In this wider social script implied by Bradley's rhetorical adage ('I mean, do you know me?'), safe sex (and HIV by implication) is positioned as outside of the norm for their group. Although the initial disclosure led to a discussion on safe sex practices, the logico-scientific information served to carve out a script both parties could ascribe to – one where HIV is not part of their socially performed personas – rather than being the centre around which other scripts revolve. It is important to note that neither Chantelle nor Bradley were aware of ART as a form of HIV prevention, despite living in a community where universal access to ART and door-to-door HIV testing was available.

Betrayal and anger

For other women, the act of disclosure was the aftermath of an unanticipated HIV-positive diagnosis. For these women, disclosure was part of a process of confrontation and acknowledgement of physical and emotional betrayal by their partners. In the moment of an unexpected HIV diagnosis, existing relational scripts came undone. This follows Bury's observations that an unexpected illness diagnosis 'brings individuals, their families, and wider social networks face to face with the character of their relationships'.[23] By disclosing their HIV status, some participants articulated a break in trust and disruption in their relationships, while others used the opportunity to force their partners to acknowledge infidelity and disclose their own HIV-positive status in an attempt to stitch the threads of their relationships together. Where the preexisting script was irreversibly spoilt, the women had to reevaluate their relationships and create new scripts based on new self-identities and impressions of their partners, shaped by the unwelcome introduction of HIV into their relationship.

Millie (aged 45 years) had been married to James (aged 47 years) for several years. She described her relationship with James as tumultuous – with James often drinking too much alcohol, taking drugs and disappearing for days at a time. However, Millie also describes herself as being deeply in love, and, every time James returned home, she would allow him to stay. Millie explained that she had unexpectedly tested positive for HIV during a routine household visit by the PopART intervention CHWs. James was out at the time, but her three children (from her previous marriage) were at home. The diagnosis was especially difficult for Millie, she explained because she was deeply religious. After reflecting on her diagnosis, she suggested that it must have been God who sent the CHWs so that she could become aware of her status and start medication. However, it was difficult for her to reconcile the romantic and emotional bonds she shared with James, with the realization that he had betrayed her and that he had been unfaithful. She recounted how she confronted James about her HIV status, conveying her anger, betrayal and shock:

Millie	It was tense [emphasis]. He walked out, then he came back the night again.
Researcher	Did he then get in bed? [Millie confirms]. How did you feel that time? No anger, no emotions?
Millie	Maybe.
Researcher	We– [Millie interrupts]
Millie	–maybe in my insides, sore, heartbroken and such things. [Whispering] I didn't expect something like that, that it would happen. It also came back to me. Okay so maybe that was what [he] wanted to talk to me about. [He] said there is something that [he] wanted to tell me, but [he] didn't know how I would accept it.
Researcher	So he had already wanted to tell you something? Do you think he knew about it [his positive status]?
Millie	Maybe. Yes, but he never talked about it . . . I said to him, 'you gave it to me'. I said, I just said, 'ok, fine it is how it is'.

She continued to explain her shock and disappointment and how disclosure led to exposing other issues in the relationship:

> I wasn't expecting it you know. But, as the time passes [you think], why would someone you love, you really love [stops mid-sentence]. That's why I was saying, if he loves me, why would he hurt me in this way, you know? I told him, 'tell me, if you feel you don't want to be with me, because, I can talk to you openly about how I feel'. But he said I won't understand him because we won't be speaking the same language. So, I asked him, 'just tell me if you don't want to be in my life anymore, [if you] can't take this'. He didn't want to talk. He said I won't understand him. I said, 'so what does this mean? Where does this end? So, you think this must go on and on and on and I must just be at ease with you coming and going?'

Millie description shows how the preexisting scripts where the couple was cast as committed, loyal and loving, had been ruined by James. Despite this, she attempted to recreate a new script in which she will no longer 'be at ease with [James] coming and going'. Although Millie positions herself as subject to James' choice to take the lead in ending the relationship (to tell her if *he* doesn't want to be with her), she also sketches new boundaries in which their relationship must exist. In Millie and James' relationship, the act of disclosure was not associated with accessing treatment support or supporting other health-related decisions, but rather, the conversation was used as a way for Millie to recast a script in which underlying issues in their relationship would be averted and in which trust could, perhaps, be reestablished.

Rebecca (aged 26 years) is a shy woman who lives in a small informal home with 10 other extended family members and friends. When she was in high school, she had a sexual relationship with a taxi driver in his late 20s. Although occurring long after the relationship ended, she confronted him after being diagnosed with HIV:

> He was a man driving a taxi, I was still a school child. I used to go to him just for sex, then come back here at home again. When I was breaking up with him, he called. I didn't know that I was sick, he called saying, 'do you know that you are sick?' But I never took that serious. I was still dumb; I didn't ask him. So, after years I just fell sick. I had TB and my mind came back to that first guy that I used to date. I called him back. Of course, when I called him, I insulted him, told him that he is cruel for not telling me that he is sick, for not putting on a condom and so on. For not wanting to go to a clinic [to test], you see. So, he said that he doesn't know about that, and I told him that he should stop denying it.

In telling Rebecca that she is 'sick', the taxi driver engaged in a nonchalant disclosure performance. For Rebecca, the former boyfriend is the target of her anger, but the betrayal she experienced at her diagnosis appeared to be directed towards herself. That is, she appears to rebuke herself for being naïve and 'dumb'. By confronting the taxi driver, Rebecca appears to be recreating a script and identity in which she is wiser and regains agency, up to where she is able to reprimand the older man to 'stop denying' that he has HIV. Rebecca's act of disclosure conveyed several intentions. While Millie and Rebecca's anger towards their intimate partner was partly related to the impact of acquiring an incurable condition, it was the implicit betrayal that was being relayed. For these women, an HIV diagnosis signified that their partner was either dishonest or deceitful and the act of disclosure was a means to elicit a confession or to highlight other shortcomings in the relationship.

Ensuring self-preservation

For some women, not disclosing their HIV status to their intimate partner was a calculated decision. To conceal their HIV status, these women presented particular performances, aimed at maintaining the boundaries of privacy (or the dramaturgical backstage). For instance, Cebisa (aged 19 years), who became HIV-positive through vertical transmission, chose not to disclose her status to her boyfriend as an act of self-preservation. She described to us how she had been on HIV treatment 'her entire life', but only started questioning her mother about the medication when she was about 12 years old. Her mother was her main source of health support, as both her brothers were HIV negative – one born before her mother contracted HIV and the other after treatment for pregnant women became available. Cebisa has disclosed her HIV status to only one close friend, whom she describes as caring and loyal. She conceals her treatment and her diagnosis from everyone else. Cebisa spoke about her first serious boyfriend, Xola, whom she met in school when she was 16 and he was 18. She explained her feelings towards him:

Cebisa	Yho! [Exclamation]. The problem is, I loved him very much
Researcher	What is it you loved about him?
Cebisa	Yho! Even him, the way he was [Cebisa smiling], the way he was speaking, everything about him I loved it [laughs]. He was a right/good person [smiling].

Cebisa explained that she had a sexual relationship with Xola, and how she negotiated condom use without revealing her status:

Researcher	So sometimes you would use protection sometimes you would not use a protection?
Cebisa	No, I never used it when I first slept [had sex] with him [brief pause], because I didn't know what to say. I wanted protection for him because he trusted me. I also trusted him but then now I deceived him. I said that I don't inject the needle [contraceptive injection]. So [inhales loudly], we must use condoms, then he agreed.
Researcher	So then would he agree to have a condom? [Cebisa nods] You were on [family] planning at the time?
Cebisa	Yes, I was on [family] planning

Cebisa explained that she cared for her partner, and to protect him, she orchestrated the scene where condom use was presented as a way of preventing pregnancy, not HIV transmission. For Cebisa, condom use for pregnancy prevention, despite already using another form of pregnancy prevention (Depo-Provera injection), was a more acceptable scripted performance than revealing that she was living with HIV. This alternative script is exemplified by Cebisa's admitting to 'deceiving' Xola. Her non-disclosure is purposefully orchestrated as self-preservation, in addition to the perceived preservation of the relationship:

Researcher	Do you ever say, look this is what is happening and disclose [your status]?
Cebisa	No never. [I] don't do that thing, I have never done it [disclosed].
Researcher	Why?
Cebisa	No, yho [exclamation, laughing]
Researcher	Why Cebisa?
Cebisa	No.
Researcher	Why, [are] you afraid?
Cebisa	Yes, I'm afraid.
Researcher	What are you afraid [of]? That he would dump you? He would beat you?
Cebisa	Yes, I'm afraid [of] those things, maybe he dumps me.

The couple dated for 2 years, but Cebisa ended the relationship after she heard that he had 'cheated on her'. Somewhat ironically, Cebisa explained that trust in relationships is very important to her and that you cannot have two girls from the same school dating the same boy.

Ntombi (aged 40 years) became sick in 2014 and was diagnosed with HIV at the clinic. She started on ART in 2015 as part of the PopART trial, prior to the changes in HIV treatment national guidelines. When asked why she decided to access ART, she explained that she did not want to 'be behind' and continued: 'I wanted to know where I stand. I must know myself'. When we spoke to Ntombi, she was in a relationship and living with Chikhu. The couple shared Chikhu's house, and Ntombi ran a small business selling alcohol from their home. Although Ntombi was fond of Chikhu, she complained that he no longer satisfied her sexually, and that she had another casual partner (Esihle) that she met at a tavern. Neither of these men were aware of Ntombi's HIV status. When asked why she did not want to disclose to Chikhu, Ntombi explained:

Ntombi	My reasons for me not wanting him to know is that, I see that he is rude. And he is as rude as he is proud. He is proud. Too much. He is full of himself. And he doesn't take nonsense, you see? When a person loves, [they] will be there. Even if it means to die with you. But him, no.
Researcher	This guy?
Ntombi	Yes. It is about three times now, [he was] throwing me out of the house. I also told myself that no, there's no need to show him who I am. Let me just keep it this way and continue the way we are. Because then from the very start when I met him, we used a condom. And he doesn't take a risk. If it's not there, it's not there, simple [meaning, no sex without a condom].

Ntombi emphasizes that she hides her true self from Chikhu. Ntombi's internal script of what it means 'to love someone', to 'be there even if it means to die with you', has been violated on at least three occasions by Chikhu, without her disclosing her HIV status. As such, she performs according to alternative script both to conceal 'who she is' and to protect herself from a potentially 'rude' reaction from Chikhu. Ntombi described her relationship with Esihle as casual, although she did start having more serious feelings towards him at one stage. She told us that she enjoyed his company, and they were having sex, but, when we last spoke to her, she did not foresee a long-term relationship. Ntombi employed several metaphors to explain why she did not disclose her status to him:

> When you see it's too windy, you leave. So, before you do that thing, you have to see first that it is okay. If I pour sugar, how sweet will this sugar taste? I realised, okay fine. We are in love. Everything is nice the way things are happening. 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.

Ntombi provided three reasons for her non-disclosure: disclosure might be disruptive for the relationship (cause wind/turbulence); if she discloses, the consequences are unknown (adding sugar will alter the taste); and as they were already using condoms, there was no need to disclose. For Ntombi, fear of the unknown consequences of disclosure was presented as the reason for non-disclosure. Non-disclosure is also seen as a justifiable performance ('on the right side') as she insists on using condoms. In addition, Ntombi also appears to be relatively powerless in her relationship with Chikhu, on whom she relies for a place to stay and run her shop. She does not foresee any possibility of creating a script in which Chikhu reacts in a supportive way following disclosure. An unsure future with Esihle meant that Ntombi decided not to disclose her status to him either. However, it appears Ntombi is fully aware of the risks of HIV and has managed to both refrain from unprotected sex and maintain a script in which her HIV status goes unquestioned by her partners.

Discussion and conclusion

We found that HIV status disclosure (and deliberate non-disclosure) is part of a carefully scripted performance, where the end product is not the sharing of biomedical information but rather to communicate underlying social intentions and to affirm social- and self-identities. Some women disclosed their HIV status to convey their trust in their partners and to cement their relationships. In preparing for disclosing, these women anticipated certain positive (scripted) reactions from their partners – acceptance, support and understanding. However, as we show, partner performances were at times discordant with women's expectations, leading to tension in relationships. For others, disclosure was in reaction to receiving an (mostly unanticipated) HIV-positive diagnosis. For these women, disclosure was instrumental in conveying anger and betrayal. More than blaming their partners for transmitting a sexual infection, these women wanted to express their anger/anguish because of the breakdown of the relationship and the partner's assumed sexual transgressions. Other women participated in different performances to avoid telling their partners about their HIV status, either as a form of self-preservation or for the preservation of the relationship. Performances included engaging in more acceptable social scripts and acts, such as condoms for pregnancy prevention, rather than HIV prevention. In disclosing, women engaged in (re)constructing their identities as PLHIV in intimate relationships – either as good/honest partners strengthening relationships; as betrayed partners reevaluating relationships or as women who were claiming agency and ensuring self-preservation. HIV prevention, in general, and treatment adherence support overall, was rarely mentioned as a reason for disclosure – and never as the primary driver for HIV disclosure. At the time of our research, the message of HIV treatment as form of prevention had not yet filtered down into the intimate disclosure narratives of women who had access of treatment regardless of CD4 count. It is plausible that scale-up of UTT has, to date, missed an opportunity to support disclosure thereby impeding the potential patient and public health benefits of this approach.

Similar to other research focusing on HIV disclosure practices, we highlight that the process of revealing one's HIV status is simultaneously a test of intimate relationships and a reconciling of self-identity.[42] Bury noted that acquiring an illness diagnosis, and in effect, decisions around disclosure are 'disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved'.[23] We suggest that, in selected (non-)disclosures, women living with HIV try to maintain their relationship scripts with the intention of avoiding further disruptions to their lives. Wekesa and Coast[49] noted that 'incorporating HIV . . . into one's identity also involves multiple phases of identity transition, including diagnosis, (non-)disclosure, positive living and attempts at repair and normalcy'. Others have suggested that considerations of disclosure are driven by potential social gains in support or evasion of negative reactions.[41] In highlighting the complexities of disclosure, it is worth noting that, while public health messaging might be focused on HIV prevention and treatment adherence, HIV is not a standalone condition but is often nested in the complexities of intimate relationships.[50]

By drawing on rich longitudinal data set, we were able to support accounts of disclosure with additional longitudinal data on intimate relationships.(For a detailed description of the data collection process, see Viljoen, Myburgh, and Reynolds (2020)[21]). As an additional strength, the analyses were informed by the experiences of the primary authors who were involved in the conceptualization, design and data collection of the project and received input from an experienced multi-disciplinary research team familiar with the HIV landscape in South Africa.

As a limiting factor, we were only able to analyze the disclosure narratives presented to us by participants. As such, we present an analysis of the retelling of women's performances, rather than the disclosure performance itself. Participants could also have viewed the researchers as another type of audience, where retelling their disclosure stories allowed them to 'construct themselves and others as particular kinds of moral agents'.[51] However, through longitudinal data collection, we are able to supplement once-off narratives of disclosure with broader and repeated life narratives and in doing so, present comprehensive and informed accounts.

We have shown that HIV status disclosure happens in context of tensions and overlapping priorities, such as relationship dynamics and identity formation. In addition, there are apparent competing disclosure principles: public health systems are focused on treatment adherence and transmission prevention while women living with HIV are focused on the dynamics of interpersonal relationships. In addition to other stresses in high-burden, low-resource communities, PLHIV often have challenges in preserving confidentiality, as the decisions around disclosure are complicated by a lack of private spaces.[21] It is in these spaces where effective HIV counselling could be instrumental in facilitating disclosure processes by simultaneously providing interpersonal relationship support and engaging couples in the personal and public health benefits of ART adherence.

Author contributions

L.V., G.H. and L.J.R. contributed in conceptualization; L.V. contributed in data curation; L.V., D.T.W. and G.H. contributed in formal analysis; L.V. wrote the original draft; D.T.W., G.H., V.A.B., J.S., P.B., S.F. and L.J.R. reviewed and edited the article; D.T.W. validated the article; V.A.B. investigated the article; P.B. and S.F. contributed in funding acquisition; L.J.R. supervised the article.

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Manuscript 5: Women's sexual scripting in the context of universal access to antiretroviral treatment – findings from the HPTN 071 (PopART) trial in South Africa.

Viljoen, L., Hoddinott, Malunga, S., Vanqa, N., Mhlakwaphalwa, T., Marthinus, A., Mcimeli, K., Bond, V. A., Seeley, J., Bock, P., Hayes, R., and Reynolds, L.

Overview and contribution to dissertation aims

The availability of treatment-based HIV prevention modalities offers new ways for people in intimate relationships to negotiate 'safe sex'. In this manuscript, I explore how women conceptualise and narrate their sexual relationships and explore how HIV risk and prevention fit into these narratives. Using the theory of sexual scripting, as proposed by Simon and Gagnon (1986)[1], I compare women's sexual narratives in South African communities where universal access to HIV testing and treatment (UTT) was available through the HPTN 071 (PopART) trial to communities that didn't receive this intervention. I show that across these communities, women's sexual scripts are structured around idealised romantic sex and the wellbeing of intimate sexual relationships. Risky sex is described as belonging to morally transgressive 'others.' While public health programmes position prevention modalities as part of sexual scripts, this is not normative for many women. This manuscript demonstrates how expanded access to HIV testing and treatment has not yet filtered into women's narratives about their intimate relationships or internalised interpretations of HIV and prevention. As HIV prevention appears to be difficult for women to internalise in their sexual scripts, I argue that in order to capitalise on the preventative capabilities of treatment-based prevention strategies, HIV prevention interventions should frame treatment-based prevention modalities

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[1] Simon, W. & Gagnon, J.H. 1986. Sexual scripts: Permanence and change. *Archives of Sexual Behavior*. 15(2):97–120.

as a means to protect and maintain relationships, rather than simply as a way to preserve health.

This manuscript aims to address objective five of the thesis: to describe how women understand sex, risk, and intimacy in the context of UTT. In the manuscript, I show how women in South African communities narrate their understandings of the meaning of sex, including women who have access to increased HIV testing and treatment. By exploring women's intrapsychic scripts (internalised meanings attached to sex), I explore when and how HIV prevention modalities intersect with the most intimate understandings of the act of sex.

Author contributions

For this manuscript, I designed the tools used for data collection and participated in several of the data collection activities with women. I led in the conceptualisation, analysis process, and literature review. I wrote the first and consecutive drafts. Authors SM, NV, TM, AM, and KM assisted with data analysis. Authors GH and LR provided conceptualisation support and provided detailed comments on drafts. Authors GB, JS, PB, and RH provided input on drafts and revisions. A note on co-author contributions is available in Appendix C.

Publication status

The manuscript was under peer review in an international journal at the time of PhD submission.

Women's sexual scripting in the context of universal access to antiretroviral treatment – findings from the HPTN 071 (PopART) trial in South Africa

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Abstract

Background

HIV treatment-based prevention modalities present new opportunities for women to make decisions around sex, intimacy, and prevention. The Universal test and treat (UTT) strategy, where all people with HIV can access treatment, has the potential to change the ways in which sex is understood and HIV prevention incorporated into sexual relationships. We use the frame of sexual scripting to explore how women attribute meaning to sex relative to UTT in an HIV prevention trial setting. Exploring women's sexual narratives, we aimed to understand how HIV prevention feature in the sexual scripts for women who had access to UTT (prior to guideline changes), compared to places without widespread access to HIV testing and immediate access to treatment.

Methods

We employed a two-phased thematic analysis to explore longitudinal qualitative data collected from 71 women (18 – 35 years old) between 2016 – 2018 as part of an HIV prevention trial in the Western Cape Province, South Africa. Fifty-eight participants were from intervention communities while 13 lived in control communities without access to UTT. Twenty participants self-disclosed that they were living with HIV.

Results

We found no narrative differences between women who had access to UTT and those who did not. In their scripts, women idealised romantic sex, positioned sex as 'about relationships', and described risky sex as 'other'. 'HIV' and 'prevention' were largely absent from women's thinking about sex.

Conclusion

These findings suggest that HIV-negative women did not include their partners' use of antiretroviral therapy in sexual partnership choices. For these women, UTT's prevention

benefits are passive – reducing the aggregate risk of onward transmission – and not because of active participation in treatment as prevention.

Introduction

More than 20 percent of the 37 million people living with HIV (PLHIV) worldwide reside in South Africa, where there are reportedly nearly 8 million cases of HIV (Simbayi et al., 2019; UNAIDS, 2019a). In this sub-Saharan African country, HIV transmission occurs mainly through heterosexual sex and women are disproportionately affected − prevalence among people aged 15 to 49 years is estimated at 26% for women compared to 15% for men (Kharsany and Karim, 2016; Simbayi et al., 2019).

Globally, HIV prevention strategies have predominantly been targeted at disrupting transmission through behavioural interventions, including abstinence and condom use (Merson et al., 2008). The range of prevention modalities has expanded over the past 20 years to include a number of biomedical approaches, such as vaginal microbicides, medical male circumcision, and HIV treatment-based prevention approaches. Treatment-based prevention modalities include the use of antiretroviral therapy (ART) for the prevention of mother to child transmission (PMTCT), pre- and post-exposure prophylaxis (PrEP and PEP), and ‘treatment as prevention’ (TasP) (Gray et al., 2019). The TasP approach is based on evidence from several studies that have shown that PLHIV are unlikely to transmit HIV to their sexual partners if they are on virally suppressed through effective treatment (UNAIDS, 2018). TasP has been operationalised on a wider scale through a strategy known as universal test and treat (UTT). Widespread HIV testing is made available through UTT, and immediate ART initiation is offered and encouraged for all PLHIV. This is done in order to achieve both clinical benefits for PLHIV and (through community-wide viral suppression) reduced risk of infection for others (Granich et al., 2009; Hayes et al., 2019). Some researchers have posited, however, that the implementation of UTT could lead to ‘sexual disinhibition’, whereby people are more likely to take greater risks in their sexual lives (Shafer et al., 2014), although evidence to support this argument is lacking (Legemate et al., 2017). Others have shown that

UTT messaging has not yet had wide resonance or uptake locally in Africa (VA Bond et al., 2016; Iwuji et al., 2016), which is in stark contrast with the U=U movement[1] in Europe and North America (Averitt et al., 2018).

Decisions around sex are complicated by gender roles, relationship dynamics, and child-bearing intentions (Swartz et al., 2018). One approach to interpret sexual behaviour that helps us to consider sexual decision-making is sexual scripting. Sexual scripting is described as the accepted sexual norms that are supported, internalised, and endorsed by individuals through the processes of socialisation (Simon and Gagnon, 1986).

We explored and compared the sexual scripts of young women (aged 18 to 35) living in communities in the Western Cape Province of South Africa where the HPTN071 (PopART) HIV prevention trial offering UTT was implemented (Hayes et al., 2014). We focussed on intrapsychic scripts – or women's "personal sexual cultures" (Whittier and Simon, 2001) – to show how meaning is attributed to sex relative to UTT. We aimed to understand the opportunities and barriers to including TasP in women's sexual behaviour choice-making in this high HIV-burden and generalised epidemic setting.

Young women, sex, and HIV prevention

To contextualise our findings, we provide an overview of representations of women in HIV research in Africa. As HIV took hold of the continent from the 1990s, an expanding body of work developed with a focus on sex and how it fuelled the epidemic (Friedland and Klein, 1987). In the early years, Packard and Epstein (1991) documented important similarities between research on HIV, tuberculosis, and syphilis, showing how the 'unhealthy behaviours' of Africans were often deployed as a central explanatory framework, while environmental, social, and structural factors were overlooked. Thirty years later, the framing

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[1] The U = U (undetectable equals untransmittable) campaign was designed to raise awareness and to promote the definitive evidence of the preventative properties of ART (UNAIDS, 2018).

of Africa as a ‘problem area’ and Africans as hypersexual continues to shape how HIV is researched (Kagaayi and Serwadda, 2016; Reid and Walker, 2005). Thomas and Cole (2009) describe how this extensive focus on HIV transmission in research in/on Africa has reduced understandings of intimacy in Africa to a concern with sex and risk, while emotional connections have been side-lined.

Young women are often included as priority groups in HIV research because they are described as particularly vulnerable to HIV due to both biological and social determinants (Ackermann and De Klerk, 2002; Higgins et al., 2010; Mojola and Wamoyi, 2019). In the public health discourse, African women’s sexual behaviour continues to be framed around one-dimensional concerns such as violence and abuse (Meinck et al., 2016), transactional sex (Ranganathan et al., 2017a), and reproductive issues (Robinson et al., 2017), with limited focus on intimacy, interpersonal connections, pleasure, or the internalised understandings of sex. However, as Ruark (2017) notes, in southern Africa, these issues often coexist with, rather than oppose, intimacy and love in relationships. Disparate patriarchal power dynamics, gender inequality, violence, male dominance, and sexual coercion are often part of complex understandings of intimacy and sex (Ruark, Stern, et al., 2017; Stern et al., 2016).

With the roll-out of extended testing initiatives and treatment-based prevention modalities on a wider scale through the strategy of UTT, there has been speculation about the potential effects of these prevention technologies on women’s understandings of (safe) sex and their sexual behaviours. Fears of sexual disinhibition have resurfaced (Shafer et al., 2014), while others have posited that UTT might lead to the normalisation of HIV where ART is incorporated into routine dialogues on sex – in communities and between intimate partners (de Wet, 2019). Through sexual scripting, we explored women’s narratives about sex and investigated how prevention modalities featured in these scripts.

Sexual scripting and HIV

Sexual scripting is a framework where the metaphor of 'scripts' is used to understand the mutually shared conventions that guide individuals in their engagements with sexual interactions (Dworkin et al., 2007; Gagnon and Simon, 1973). Individuals are responsive to each other's cues in these exchanges, and react according to broader accepted social or cultural norms and expectations (Ortiz-Torres et al., 2003).

According to Simon and Gagnon (Simon and Gagnon, 1986), scripts develop through the interactions between three distinct spheres of human experience: cultural scenarios, interpersonal scripts, and intrapsychic scripts. Cultural scenarios are socially determined normative expectations and provide the guidelines by which sexual interactions are expected to take place. These scenarios determine, for instance, the appropriate time, place and form of sexual expression (Gilmore et al., 1996). Individuals employ sexual scripts to align their behaviours with cultural scenarios. Interpersonal scripts evolve when pairs or groups adapt generic normative scripts from ongoing experiences and interactions with each other.

At the most intimate level, the intrapsychic script is the mechanism whereby individuals attach and internalise 'meaning' to sexual behaviour as they interact with the social world over their life course (Whittier and Simon, 2001). It is at this level where motivational elements are located that allow individuals to commit to a particular sequence of events (Dworkin et al., 2007: 270).

Wiederman (2005: 497) suggests that scripts are used to interpret "what is considered normative within a culture … providing directions for how to feel, think, and behave in particular situations". Sexual behaviour is a process that entails the acceptance of a socially defined performance and the development of personal meaning attached to this performance.

Researchers have employed scripting to interpret sexual behaviour in relation to HIV in Africa, in which include studies on concurrent sexual relationships (Leclerc-Madlala, 2009), with young people (Maticka-Tyndale et al., 2005; Singleton et al., 2019), and with heterosexual couples in trial settings (Duby et al., 2016). Scripting has also been used to understand sexual behaviour amongst vulnerable women (Bowleg et al., 2004; Dworkin et al., 2007; Hill and Andrews, 2017; Ortiz-Torres et al., 2003). With the evolving HIV prevention landscape, scripting can be employed as a means to understand if and how prevention modalities are incorporated into sexual narratives. Through intrapsychic scripts specifically, we can explore how internalised interpretations of sex can shape (and are shaped by) HIV prevention methods.

Researchers have acknowledged the role of gendered scripts in determining sexual behaviour and access to HIV prevention modalities (Dworkin et al., 2007). For instance, in their study amongst African-American women in Washington DC, Bowleg *et al*. (2004) found that, as part of accepted sexual scripts, men generally had more control than women in relationships – both in terms of sexual activity and condom use. In these accepted scripts, where women lack control, women’s risk of HIV may be indirectly or directly increased. Similarly, in their study on urban women in the USA, Ortiz-Torres *et al*. (Ortiz-Torres et al., 2003) concluded that most women's narratives continued to endorse the traditional gender script of men as initiators of sexual encounters and women as submissive partners, while in South Africa, Duby *et al*. (2016) described how the interpersonal scripts of women tended to overemphasise the satisfaction of male partners.

While some studies focused on HIV prevention in sexual scripts (Dworkin et al., 2007; Maticka-Tyndale, 1991), less attention has been paid to how women’s conceptualisations of HIV risk shape their sexual scripts (Viljoen et al., 2017). In our analysis below, we explore young women’s sexual narratives to understand how HIV prevention feature in intrapsychic sexual scripts in the context of UTT, when compared to places without widespread access to HIV testing and immediate access to treatment.

Methods

We analysed data collected as part of the HPTN 071 (PopART) trial conducted in South Africa and Zambia. This three-armed community randomised trial was aimed at assessing if the implementation of community-based HIV prevention intervention would reduce HIV incidence at a population level (Hayes et al., 2014). In the intervention arms (Arms A and B), communities received door-to-door HIV testing, referrals for medical male circumcision, condom distribution, TB and STI screening, and referrals to local health facilities for treatment for PLHIV. Control communities (Arm C) received health services according to standard of care. In South Africa, the trial was implemented in nine peri-urban communities in the Western Cape Province. As part of the intervention, people living in Arm A communities received UTT from the start of the trial. Changes in national treatment guidelines in South Africa allowing all PLHIV to access HIV treatment effectively meant people living in Arm B communities also received UTT from 2016. Approximately 2000 individuals per community were randomly selected for cohort follow up to measure the primary trial outcome. The trial results showed an overall reduction of ~20% in HIV incidence in intervention arms compared to control communities (Hayes et al., 2019).

As part of the trial, we conducted longitudinal research with a cohort of 89 households (~290 individuals) in the South African sites over 18 months between 2016 and 2018. We conducted a series of interactive and ethnographically informed interviews structured around ‘domains of life’, focussed on: household composition; place, space and movement; how people ‘get by’; love, sex, and romance; healthcare behaviour; and hopes, fears and ambitions (Hoddinott et al., 2018).

Discussions were held with either groups or individual household members, depending on the topic and participant availability. Participants were recruited during community observations, targeted recruitment drives, and through referrals from health workers. Households were recruited through targeted recruitment drives and through snowball sampling for at risk populations (e.g., sex workers, men who have sex with men). We purposively sampled households across trial arms to ensure diversity in terms of age, gender, household structure and location within the community (Dattalo, 2010). We recruited households from all 9 South African study communities and ensured that at least half of all households had one or more member who self-reported living with HIV. To document intervention implementation, we overrecruited households from intervention communities, ~4:1 intervention:control. We worked in teams and were paired to ensure a good 'fit' (language, age or gender compatibility) with participants (Viljoen, Myburgh, Reynolds, et al., 2020).

Discussions were designed to be more than one-off conversations. We embraced the principle of 'deep hanging out' where researchers use participatory observations to immerse themselves in the social experience of participants at an informal level over extended time periods (Geertz, 1998). We had multiple (7 – 12) interactions with households, spending between one and three hours per discussion with participants.

Discussions on sex were structured along three parts: an open conversation about community beliefs around sex; a timeline and details of previous relationships; and the intimate and detailed 'story' of participants' most recent sexual encounters. We probed participants experiences related to HIV (prevention and disclosure) only after the open-ended discussion. These conversations took place after more than six months of regular rapport-building. To make it easier to describe intimate acts, participants were given the option to speak directly to the audio recorder while the researcher stepped away, although very few participants (<10) opted to do so.

Reliable, accurate and consistent data on sexual behaviour is notoriously difficult to collect due to the social desirability and the (still) taboo nature of the topic (Mitchell et al., 2007). To ensure that researchers were comfortable facilitating open and inclusive discussions on the topic, we conducted workshops and practiced several iterations of the open-ended discussion guides. Researchers were trained on appropriate and ethical responses when encountering reports of violence, abuse, drug use, and unsafe sex in discordant relationships in the field. After discussions, researchers were instructed to provide accurate health information and, where needed, to refer participants to appropriate support structures (like social services). Interviews were conducted in English or another local language (Afrikaans, Xhosa). All discussions were recorded, transcribed verbatim, translated to English and anonymised.

For this analysis, we included data from all women aged 18 to35 years-old (given younger women's higher HIV risk) who participated in individual discussions for the research module on love, sex, and romance, and who self-reported that they had sex in the past 12 months. We excluded women who self-disclosed that they currently engage in sex work and women who are health workers, as these groups had different experiences of sexual relationships or health knowledge that deserve separate analyses. From the 89 households, the sample included 71 women (with 20 self-disclosed PLHIV), including 58 in intervention communities (Arm A, n = 49; Arm B, n = 9) and 13 in control communities. All 71 women included in the analysis reported that they had sex in the previous 12 months.

We employed a two-phased thematic approach for the analysis. In phase one, co-authors (LV, SM, TM, KM, AM, NV) identified all extracts with key topic areas, which include: participant definitions of 'sex acts'; detailed sex act descriptions; HIV prevention strategies; contraceptives; HIV risk perceptions; and relationship dynamics. In phase two, we conducted a thematic comparative analysis, as described by Braun and Clark (2006) to group and compare the sexual scripts of women in intervention communities to women in control communities. Our analysis focused in particular on women's intrapsychic sexual scripts.

The HPTN 071 (PopART) trial received ethical clearance from the London School of Hygiene and Tropical Medicine and the Stellenbosch University research ethics committee. All participants signed written informed consent prior to participation and ongoing consent was confirmed during follow-up discussions.

Findings

In this analysis of the narratives of the 71 women participating in discussions, we found no noticeable differences in the sexual scripts of women by trial arm. For most women (including those living with HIV and not), HIV remained largely unacknowledged in their described sexual experiences. When asked about ‘prevention’, women referred almost exclusively to contraceptive methods and researchers had to probe to elicit responses specifically related to HIV, with HIV prevention descriptions limited to condom use. When the team asked about biomedical prevention modalities, including TasP, no participants reported hearing of these options before. All participants in intervention communities had received the door-to-door testing services but did not relate this to TasP, but rather as expanded access to HIV testing.

More broadly, we identified three dominant framings of women’s intrapsychic sexual scripts: 1) the idealisation of romantic sex; 2) the conceptualisation of sex as being about relationships; and 3) the positioning of risky sex as ‘other.’ HIV and ‘prevention’ were framed as challenges to normative sexual scripts. Finally, we demonstrate specific points of disjuncture in women’s intrapsychic scripts, where women had to manage the imposition of HIV, including risk perceptions, in the ‘meanings’ they attached to sex.

Sexual scripts and the silence around HIV

We found that spontaneous references to HIV and risk were mostly absent in the narratives of women, especially for women who were not living with HIV. Women’s descriptions of their sexual interactions with their intimate partners seldom included HIV prevention methods.

When probed on ‘protection’ during sex, women readily referred to contraceptive methods, including the Depo-Provera injection, contraceptive implants, or occasionally the “pulling out” method, rather than HIV prevention. Pregnancy prevention was framed as women’s responsibility with few men reportedly engaging with their partners on birth control.

Nita[2] (20, Arm B), had been diagnosed with HIV a few months prior to our discussion. She had a casual relationship with her partner, whose HIV status was unknown to us. Nita told us that she ‘sometimes’ used protection. When we asked why, she explained:

Nita	It is when I think that my contraceptive [injection] is finished [needs to be replaced].
Researcher	Then what does [your partner] say when you are taking [condoms] out?
Nita	I give it to him and he doesn’t say anything, I tell him that I don’t have contraceptives, and I don’t want a baby.

While Nita did occasionally incorporate condoms as part of her sexual interaction, it was not for the purpose of HIV prevention for her partner. When probed about HIV prevention specifically, descriptions of biomedical modalities were wholly absent in the women taking part in this study’s narratives. None of the participants mentioned treatment-based options as HIV prevention options. After we described the potential of ART as a means to viral load suppression and to prevent onwards HIV transmission, none of the women indicated that they had heard of this message. This despite the participants living in communities where HIV testing and referral for ART had been offered door-to-door and annually for each of the preceding two to three years. When we described the concept of TasP to Zinhle (19, HIV

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[2] Pseudonyms are used throughout

negative, Arm B), she had several questions on viral suppression. She told us she had never used condoms with her boyfriend of the past four years, Robert, and expanded:

> My boyfriend is positive, but we tested, three times, I'm negative … We went to the clinic last month … because I saw that he was sick. I told him, 'Baby, you are taking treatment and you are hiding [things] from me'. He told me, 'Baby I'm [HIV] positive'. 'Okay fine', I said to him, 'let's go to the clinic' … I was negative, he was positive.

Zinhle explained that she anticipated that she would receive a positive HIV test because she had had sex with Robert who was positive – she assumed transmission was automatic and immediate. Her confusion about her repeated HIV negative test results illustrated that, while the couple used no other form of prevention, they were unaware of the potential of HIV treatment as an effective prevention strategy. Although Zinhle was concerned with Robert's physical health, she did not frame this concern as connected to their sexual script.

Chantelle (31, Arm A), who was living with HIV, was also in a sero-discordant relationship and had disclosed her status to her long-term friend and then partner, Kyle. When asked explicitly about HIV prevention, she reported that she always insisted on using condoms, but that they had recently started discussing having children together. Although Chantelle had heard that it was possible to become pregnant without transmitting HIV to her partner, she was unsure of what they should do to make this happen:

> He asked me if maybe, [we could] have a baby. I said that when the time comes the two of us need to go to the clinic … He also wants to know how [it works]. I don't know either … We have to go to the clinic and find out

> about condoms and so on. I don't know, because when a child gets made, then the condom has to be gone! I can't give him an answer.

Most women reported occasional condom use during sex, while few told our research team that they insisted on consistent condom use with intimate partners. A few women also presented HIV testing, including proxy testing[3] as a way to mitigate HIV risk without taking other steps to counter potential HIV transmission, which might have jeopardised the continuation of the relationship. Regular testing was seen as a protective measure, one that many women welcomed. Landi (33, Arm A) who was in a long-term relationship with her partner, Timo, declared that she was HIV negative. When we enquired about Timo's status, she explained:

> He is too, because the two of us, how can I say, if I test myself, obviously the two of us sleep together. If we have sex tonight, he climaxes, the two of us both [climax]. I will get that ailment [HIV] from him and he will get the ailment from me … He doesn't test himself, but I do it. If I go again to get myself tested and they say I have the illness [HIV], obviously who does it come from?

Rosalie (33, HIV negative, Arm A) told us that she tested with her partner every month. When asked why they tested so often, she explained, "because, around here, a person doesn't know … We share toilets [communal ablutions]. Things like infections and stuff can come". She also described that she was not worried about her partner "messing around", because "he made a promise to me and I need to trust him". For Rosalie, HIV risk is not located in the

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[3] Where a sexual partner's HIV test result is adopted or assumed as one's own without confirmation through testing oneself.

domain of her intimate relationship. As part of her intrapsychic script, or the 'motivational elements' (Dworkin et al., 2007: 270) attached to sex, she, like many other women, emphasised the need for 'trust' and an unfaithful partner associated with HIV risk was not considered an option. Rosalie rather deems her relationship as a safe and appropriate space for sex and blames, perhaps as a deflection, communal ablutions as the potential source of HIV. Interestingly, we found that the same participants (like Rosalie) would, in other conversations, readily describe accurate HIV prevention knowledge, but not in their narratives about sex.

Women's intrapsychic scripts

While HIV did not feature in the way that most participants constructed their intrapsychic scripts, internalised framings around sex were constructed along the following: 1) the idealisation of romantic sex; 2) sex as being about relationships; 3) and risky sex as 'other'.

1. The idealisation of romantic sex

Many women defined the act of sex as synonymous with love, trust, respect, and care. This is consistent with romanticised normative scripts described by researchers in other contexts (Morris, 2020; Papp et al., 2016). However, for most of our participants, as with many women in Southern Africa, experiences with intimate partners are often removed from these idealised scenarios, as violence, betrayal and distrust were frequently experienced. Despite these tensions, idealised concepts of sex formed an integral part of the intrapsychic scripts of participants.

Carli (31, HIV negative, Arm C) had been in a relationship with her partner, Ronaldo, for approximately six years. In her descriptions of how sex during the early stages of their relationship, Carli employed normative and even stereotypical imagery of romantic sex:

> We were very in love. When I got home in the evenings, the roses were scattered on the bed with the red nighty [lingerie] and the chocolates! … And there's champagne! … [Ronaldo] and I were hungry for each other! They [friends] said … it looks like I can't wait to get home so I can jump [claps hands for emphasis] on him or he wants to kiss me!

Both Carli and Ronaldo adhered to normative romanticised scripts of sex, and idealised conceptions of sex were also reflected in Carli's description of the act:

> [Sex is] not supposed to be with anyone. And the person with who you're doing it has to respect you. Sex isn't just for sex. You should know the person and don't just let him, like "shoot a card" [make a move].

Despite these conceptualisations of sex as respectful and intimate, Carli's recent experiences were not aligned with these ideals and she acknowledges that there are discrepancies between her internalised expectation and her lived reality. She explained:

> Look, I don't experience it, like I would tell you "it's fantastic" [claps hands] or "nice" or "I enjoyed it". To me … it's a matter of, I have to. It must happen because otherwise I'm going to be bothered for the entire night …You see it's not the right reasons anymore, to be intimate.

For Carli, sex with Ronaldo was no longer for the 'proper reason' of intimacy, but rather a task that needed to be done to avoid being 'bothered' by her insistent partner. Carli also described how the relationship became violent: “He hit me a lot, he’s very aggressive, violent, he has probably tried several times to kill me.”

Similarly, Rosalie (33, HIV negative, Arm A) who emphasised the importance of trust in her relationships in the section above, had been with her boyfriend, James (35, HIV negative), for a few weeks when we also met him. They were both regular methamphetamine users. Rosalie would often explain to us that sex and romance was an important part of her life and that she prioritised what she called her weekly ‘mommy’s night’, or date night, where the couple would be intimate. She explained:

> If we have sex, I say we make love, or we share each other … Others say ‘fuck’, but that isn’t what you should call it. Because if you really love someone, and you are going to have sex, then you two are sharing each other … You can’t just say you are going to ‘mount’ her; you must say that you are going to make love. [Otherwise] you think nothing of her.

Rosalie describes sex as an act beyond the physical. She emphasised intimacy and suggested that a lack of respectful sex indicates a disregard for your partner. However, while Rosalie prioritised intimacy, her understanding of sex and pleasure was also framed around the needs of her male partner. When asked how important sex is in her life, Rosalie said:

> It is very important to satisfy your guy because that is what a man needs. If you can’t satisfy your man, he is going to have a look around to find what he wants. If your guy wants sex, you should never refuse him. You owe him that.

For Rosalie, her intrapsychic sex script was framed around the idealisation of romance, but also the gendered utilitarian function of sex as a means to sustain her relationship.

2. *Sex as about relationships*

We found that sexual narratives were not concerned with the physical health and wellbeing of bodies, but rather about the wellbeing of perceived intimate relationships. Even when an HIV diagnosis was revealed, for many women the primary concern was the interpersonal implications. For instance, Mara (21, LHIV, Arm A) and her boyfriend, Zonke (22), opted to test together for HIV with a team of community health workers at Mara's house. The couple had been together for a few months and, according to Mara, trusted each other. While Mara received a positive result, her boyfriend tested negative. The unexpected diagnosis meant that the couple had to renegotiate their sexual relationship. Mara explained that she thought she should end the relationship because she feared infecting her partner. Zonke, however, insisted that the relationship should continue. After using condoms once after the positive test result, Zonke told Mara that they should stop using condoms and return to their normal routine of condomless sex.

Since Mara's diagnosis, she briefly linked to treatment but had since stopped taking ART. When asked about this decision, she replied: "When I'm drinking pills, it's as if my love would be low on Zonke. Maybe he would be embarrassed". Mara infers that taking treatment would lower her libido, which could make Zonke feel less desirable and possibly less masculine, leading to embarrassment on his part. The couple briefly considered the implications of Mara's HIV diagnosis on the future of their relationship and potentially Zonke's health. However, they soon reverted to established sexual scripts, where condoms did not form part of their sexual interaction. Mara's concerns about HIV and treatment were not framed around health (her own or Zonke's), but rather about the implications for her sexual relationship with her partner.

3. *Locating risk in the 'other'*

When women were asked specifically about HIV, risk was presented as fluid, context-specific, and mostly relevant to 'others', often those who were believed to be involved in 'morally transgressive' behaviours. 'Others' included sex workers and their clients, men who have sex with men, and teenage girls, who were described as easily persuaded to have unprotected sex with older men. While most participants described how they had been sexually active as teenagers and almost half had had children while still in their teens, there was a dissociation between participants' behaviour and their beliefs about risky 'others'. Again, intrapsychic scripts and the internalised meaning of sex (appropriate, desired, and acceptable) were in conflict with lived experience.

Cherise (31, HIV negative, Arm A), who had an unplanned pregnancy in her twenties, noted that with "the teenage pregnancies the HIV comes in, because the men make them dumb, they can easily be manipulated." She added, "every person has his own life and what he does with his life is his business, but if you are begging to get sick, then you should just go to the sex workers."

Carli (31, HIV negative, Arm C) who, as described in the section above, was in a contentious relationship with Ronaldo, did not consider her relationship 'risky'. This was despite describing how her partner cheated on her and how she contracted an STI. In her account, she described the other woman as dirty, locating sexual risk as 'other':

Researcher	Have you guys ever used condoms?

Carli	Never during our entire relationship. In the six years we have been together we've never used condoms.
Researcher	Do you think he used condoms with other partners?
Carli	I've asked him about that many times. He says yes, but I don't know. Because the one time when he also had a girl [cheated] and then after a while, he came back. Then we … got together [had sex], then I picked up that thing [STI]. It was almost like the girl was dirty. You see my lower body [vagina] itched very much and burned. I went to get pills, then they [health workers] said the girl was dirty. That's why she gave him that filthy disease.

Carli, and other women, positioned HIV risk as belonging to morally transgressive 'others'. HIV was placed as belonging outside of accepted intrapsychic scripts, where women understood themselves to engage only in proper and respectable sex (Ross, 2005), and where an association with HIV would cast doubt on the perceptions that they have of themselves (Viljoen, Myburgh and Reynolds, 2020).

Various participant used observations to reaffirm the position of being 'safe' in their relationships. When Viv (28, HIV negative, Arm A) described how she made decisions around sex with her partner, Trevor, she assumed that he was HIV negative because he carried condoms, although she had never used condoms with him. The assumption was that he used condoms with 'other' women, and that, because they had a trusting relationship, HIV risk was minimal. She explained: "[We] always had clean [condomless] sex. But I trusted him, and he trusted me. He should know I wouldn't go to another guy." In her explanation, Viv does not consider the possibility that Trevor might be unfaithful.

Points of disjuncture in intrapsychic scripts

In the extracts above, we have shown how HIV prevention, is largely absent in women's sexual scripts. Most women positioned HIV prevention methods as difficult to incorporate into preferred sexual scripts – much like intimate partner violence or unfaithfulness. When HIV and risk is considered, it was positioned as 'in tension with' or as an imposition to accepted intrapsychic scripts.

When prompted to discuss HIV prevention, Rosalie (33, HIV negative, Arm A) had fluid descriptions of her perceived HIV risk. When she was in her teens, Rosalie engaged in sex work, although she rarely spoke about it and did not disclose her past to James. When asked for a timeline of sexual partners, she excluded clients from this period of her life. Her time selling sex was seemingly omitted from her understanding of sex. She also readily stated that she had never used condoms during sex. She considered her stable relationships as safe sexual spaces, and was therefore concerned when her previous partner cheated on her:

Researcher	Earlier you said that you were worried about HIV. When was this?
Rosalie	It was the time my children's father was messing around [cheating] … I had myself tested and I stayed clean [negative].
Researcher	Have you ever used condoms?
Rosalie	No, never. I am not one for condoms … [reconsiders] I mean, previously, when I was on the street [sex work], then it was important to use them.

Rosalie was aware of the protection offered by condom use during transactional sex. However, her intrapsychic understanding of sex with her trusted intimate partner was markedly different from the script related to sex work. Sex with James was, as described above, romantic (‘mommy’s night’, ‘making love’), condomless, and by association, risk free, while sex work was risky and thus required protection.

Others experienced a shift in their perceptions of risk when unexpectedly confronted by a partner living with HIV. Lihle’s (32, HIV negative, Arm A) partner, Nhlobo, had recently disclosed his HIV status to her. The information forced her to reconsider her perceptions of sex, risk, and the relationship:

Lihle	Last week he told me about his status. I was like, I don’t know if I must continue with that [relationship] or not.
Researcher	Have you had sex with him?
Lihle	Not yet. I’m scared. What if we make a mistake, or the condom will break and then I’ll be at higher risk of getting it [HIV]. I’m not sure … because he’s so decent and quiet.

Nhlobo’s revelation prompted Lihle to go for an HIV test, which she had not done in more than two years:

> As soon as I heard his status, I ran [to get] mine … I’m still fine [negative]. But now it seems like I’m taking a risk here with my life. This person is older than me, [he] achieved more things in his life … I’m still confused ... Sometimes I’ll say ‘No, it’s not a problem’. But now it’s practical … I used to tell myself, I’ll [use] condoms. It was a theory [hypothetical] that time, now it’s practical. I have a lot of negative thoughts in my mind … There is risk and then it’s a responsibility. What if we have sex? Then all the time, I must be careful.

Her partner's revelation meant that Lihle had to reassess her own level of risk, and her potential acceptance of being in a sero-discordant relationship. The act of sex that was safe in one context, was repositioned as risky in another. For Lihle, this moment of rupture, where she is confronted with a reality that challenges her accepted understanding of the meaning of sex meant that she had to rewrite her sexual script – either accepting and including sex with a partner living with HIV as an option, or rejecting a partner based on an HIV positive status and the associated risk.

Discussion

In our findings, we show that HIV generally does not feature in the sexual scripts of women living in high HIV burden settings in the Western Cape Province of South Africa. In their descriptions of sex, most women in our study maintained normative and idealised romantic intrapsychic scripts, and described sex as intimate, respectful, and an act that transcended physical attachment. Women maintained these scripts even when experiencing violence, assault, and unfaithful partners. Continued coherence of a preferred sexual script in an established partnership would be prioritised over physical health, including the prevention of HIV transmission in confirmed sero-discordant relationships. For many women, sex was internalised as a way of sustaining relationships and to ensure that partners were satisfied.

HIV prevention was positioned outside of intrapsychic scripts about sex, and HIV risk assigned to transgressive 'others'. When women were confronted with the possibility of HIV exposure in their partnerships they managed this – by adjusting their scripts – in three ways: (1) dismissing the seriousness of the risk and focussing on other aspects of the relationship, (2) questioning the viability of the sexual relationship since it did not meet their idealised expectations – although this was limited to their talk about the relationship and we did not find any women to have actioned this talk by ending their relationship; (3) relabelling and making exceptions for some sex acts within relationships.

We compared the patterns of intrapsychic scripts by arm but observed no qualitative difference. Further, when explicitly probed on HIV prevention methods, participants only mentioned condom use while treatment-based prevention methods and UTT as a strategy were not acknowledged by any participants, even in communities where UTT was being actively promoted through the PopART trial. Simon and Gagnon noted that for sexual scripts to change, motivation and opportunities are key (Simon and Gagnon, 1986). These were lacking in the scripts of women in our study. The complexity of internalised sexual meanings, objects, and practices (Whittier and Simon, 2001) do not currently allow for easy inclusion of prevention as part of the accepted scripts of women in our study context.

In other parts of the world, the U = U narrative promoted by activists and endorsed by UNAIDS, has gained traction and has been embraced by PLHIV communities as a liberating and hopeful message that frees intimate relationships from the fear of risk of HIV transmission (Averitt et al., 2018; UNAIDS, 2018). From our findings, we show that this message has not yet filtered through to people in communities most affected by the epidemic. Researchers in other settings have found that the implementation of TasP as an effective HIV prevention method in sero-discordant relationships is dependent on partner dynamics such as status disclosure, safety negotiation, and adherence support, and requires the acceptance of prevention as part of relationship scripts [47]. Our findings suggest that even in the context of UTT, TasP remains dependent on these relationship dynamics. For women in sero-discordant relationships to capitalise on the benefits of TasP by supporting their partners to be on ART will most likely require specific intervention and support, most likely delivered to couples. Since HIV prevention is difficult for women to internalise as part of sexual scripts, such interventions would need to frame TasP as a means to protect and maintain relationships, rather than as an integral part of the meaning of sex. These efforts would, however, not necessarily benefit women who are in vulnerable relationships. In their study on PrEP and women in South Africa, Hartmann et al. [55] suggested that when PrEP is framed in a positive and empowering way that avoids linking it to relationship risk, it may ultimately encourage greater uptake. Similarly, we propose that prevention modalities, including PrEP and TasP, should be made available and supported, but should be framed as an intervention to promote relationship well-being, not about preventing onward transmission of HIV.

The aggregate reduction in viral burden from UTT is likely to benefit women not living with HIV, but only if men are actively engaged in care and virally suppressed. As it currently stands, men in South Africa are underrepresented in the 'care cascade' and are less likely to know their status or be virally suppressed through treatment (Simbayi et al., 2019). Without support structures in place for men, UTT as a truly 'universal' mode of HIV prevention that benefits women as well will be difficult to utilise.

One of the main strengths of this analysis is that it is based on a large, diverse sample of more than 70 young women. Further, the longitudinal approach enabled researchers to develop rapport with participants over time which ensured that deeper, detailed discussions on the sensitive topics of sex and HIV could be conducted. The open-ended ethnographic approach allowed for participants to tell their stories without interruption, which allowed for a better understanding of women's intrapsychic scripts. The diverse team involved in the rigorous analytic process ensured that the data was accurately interpreted. However, the possibility of sampling bias exists, as we overrecruited people from key populations and more women from intervention communities were included in the cohort. We also acknowledge that women's experiences of sex are diverse and that, specifically in South Africa, cultural contexts are not homogenous across communities. Findings may thus not be transferrable to all communities in the region or in South Africa.

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Chapter 4: Discussion and conclusion

4.1. A moment of (potential) change

Over the last century, understandings of women and the ways in which they experience sex have gone through remarkable changes. In the West, representations of women's sex have evolved from descriptions of women as passive recipients of (marital) sex who engage in the act as part of 'wifely duties' (including social reproduction) to an era marked by the sexual revolution, the acceptance and celebration of pleasurable sex for women, and increased access, availability, and acceptability of birth control (Chiappori and Oreffice, 2008; Montagu, 1999; Rowland, 2020). In African settings, however, these changing narratives have often been overlooked as representations of women and sex have instead been grounded in racist and colonialist abstractions, where women are presented as exotic, fetishised, or diseased (Bujra, 2016; Hunter, 2007; Lewis, 2011). Despite global narratives celebrating women's sexual liberation, many of these problematic and simplified underpinnings persist in African settings, leaving the nuances of intimacy and emotional connection relatively ignored or unexplored (Thomas and Cole, 2009).

The emergence of the HIV epidemic further complicated representations of women's experiences of sex in the African context. The disproportionate and gendered distribution of HIV in Africa has meant that women (and the sex they are having) have often been reduced to descriptions that focus on their position along a continuum of risk (Reid and Walker, 2005; Thomas and Cole, 2009). In public health narratives, women on the continent are frequently described either as vulnerable (victims of sexual abuse/assault or powerless partners in consensual sex) or as transgressors (sex workers, participants in transactional sex, 'promiscuous' women with multiple sexual partners), with little acknowledgement of the complexities of women's sexual experiences (Ranganathan et al., 2017b; Tsampiras, 2019).

Despite a myriad of studies on women in Africa, relatively little is known about how sex and intimacy is conceptualised beyond these framings of risk.

In addition to shaping the discourse around women and sex, HIV prevention programmes have actively aimed to intervene in women's decisions around sex. The earlier "A, B, C" (Abstinence, Be faithful, Condomise) behavioural intervention model described in the first chapter, for instance, was designed to alter sexual behaviour to be safe from HIV transmission. However, women rarely had control over the "B" or "C" elements of the model as fidelity of (male) sexual partners and condom use were often difficult for women to negotiate (Psaros et al., 2018). Until recently, available HIV prevention modalities did not afford women with many options to control HIV transmission in sexual acts (Potts, 1994). The introduction of treatment-based prevention modalities presented a moment of potential change in the prevention narrative. Treatment as prevention (TasP), implemented through the strategy of universal access to HIV testing and treatment (UTT), could potentially reposition women as the drivers of their own health and as liberated sexual citizens. Through TasP and UTT, women would either have access to additional tools to prevent transmission to their partners, or access to a new space of universal 'safe sex' under the umbrella of population-wide viral suppression (Baxter and Abdool Karim, 2016; Eaton et al., 2014; Hayes et al., 2011; Koester et al., 2017).

Through these new mechanisms, the UTT approach was expected to eventually "turn off the tap" of new infections (Maurice, 2014) and achieve HIV epidemic control[1]. However, as the results of the HPTN 071 (PopART) and other UTT trials in sub-Saharan Africa became available, the outcomes were more variable, with the UTT intervention proving marginally more successful in some contexts than others (Baral et al., 2019). Across settings, the UTT

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[1] Epidemic control is reached when the number of new HIV infections are fewer than the number of deaths among HIV positive individuals (PEPFAR, 2020).

trial outcomes did not have the significant impacts on HIV incidence predicted by modellers (Baral et al., 2019). Neither the ANRS 12249 TasP cluster-randomised trial implemented in KwaZulu-Natal, South Africa, nor the SEARCH study implemented in Kenya and Uganda observed significant differences in HIV incidence in communities that received increased HIV testing and immediate access to ART compared to places that received standard of care (Baral et al., 2019; Iwuji et al., 2018).

Similarly, the outcomes of the HPTN 071 (PopART) trial in Zambia and South Africa, described throughout this thesis, were not as expected. The trial findings showed no reduction in incidence when comparing communities receiving the household prevention package and UTT (Arm A) with standard of care (Arm C). When results from all the intervention sites (Arms A and B) were combined, an overall reduction in HIV incidence of 20% was observed when compared to control communities (Hayes et al., 2019). HIV testing targets were reached across trials, while linkage to care and associated viral suppression were more challenging to achieve in some settings. Collectively, the trials clearly showed that there were limitations as to how the UTT strategy could be used to prevent HIV transmission in real-world settings (Brault et al., 2019).

The unexpected findings from the trials raised several questions relevant to the sexual behaviour of individuals. Brault et al. (2019) have noted that although it is well-known that people with multiple concurrent sexual partnerships contribute disproportionately to onward transmission of HIV, it is difficult to model how these partnerships impact HIV incidence in sub-Saharan settings and how they might have impacted the effect of UTT in the absence of viral suppression. The unexpected trial results also raised questions as to whether changes in sexual behaviour may have undermined the impact of increased viral suppression on HIV incidence in communities receiving UTT. As the lead researchers from the HPTN 071 (PopART) trial suggested in their reflection on possible reasons for the surprising trial results, it is possible that "wide-scale ART delivery in [Arm] A may have led to sexual disinhibition or de-emphasis of primary prevention" (Hayes et al., 2019: 215), thus explaining the lack of significant difference in incidence between Arm A (intervention) and Arm C (control) communities. As women are most affected by HIV in the trials' study communities, their sexual experiences are especially relevant to explore in trying to find an answer to this question.

In this thesis, I present women's narratives about how sex and relationships are experienced in their everyday (intimate) lives in southern Africa. I demonstrate the ways in which women navigate complex issues of health, HIV, relationships, sex, and intimacy against a landscape of changing HIV service delivery and prevention options. The findings show that although the implementation of broad community-based HIV prevention programmes impacts how HIV is conceptualised (normalised and responsibilised) at the community level, women's own narratives about their intimate experiences of sex and relationships seem to be relatively unaffected by these programmes. Rather, women's narratives are guided by other internalised meanings of sex. Specifically, despite lived realties that challenge these idealised abstractions, women's experiences are shaped by idealised conceptualisations of sex, relationships, and 'self'. For many women, the disjuncture between 'what is' (abusive relationships, betrayal, HIV risk or exposure) and 'what should be' (romantic sex, trust, safe partnerships), produces narratives not acknowledging risk. As such, when women in this study described their sexual relationships, HIV prevention and health overall did not feature as the primary concern when women made decisions around sex.

As an early study of the effects of messaging around the availability of UTT on the sexual lives and decision-making of women in South Africa, I found that these messages do not shape the sexual scripts of women. The findings suggest that the introduction of new HIV technologies (such as UTT) had not measurably impacted the ways in which women conceptualised sex, risk, and intimate narratives at the time when the data was collected.

While the longitudinal study design involving interviewing participants multiple times over a period of 18 months, it is, however, possible that it might not have been enough time for messaging around UTT to 'settle' on community and intimate levels. For interventions and technologies to be incorporated into accepted everyday speak, or for knowledge translation to occur, either more time or drastically different messaging platforms would perhaps be needed (Santesso and Tugwell, 2006). In addition, even though the trial was focused on the implementation of UTT, observations conducted of encounters between community members and the community health workers implementing the intervention suggest that, in practice, more emphasis was placed on the uptake of HIV services (testing and treatment) than the communication regarding the messaging of treatment as prevention. This interactions would have been the first (and for many the only) opportunity to date where the message of TasP and UTT could be relayed.

In recent years, TasP messaging has culminated in the powerful tagline, U = U (undetectable viral load equals untransmittable HIV), which has been promoted by activists, public health specialists, and medical practitioners alike (Prevention Action Campaign, 2018). While the U = U message and the broader messaging around treatment-based prevention modalities have been embraced as liberating and hopeful on international platforms (Averitt et al., 2018), these messages have failed to filter down to people living in the sub-Saharan communities most affected by the epidemic. In addition, despite health implementers' fears of sexual disinhibition as a result of the introduction of treatment-based prevention technologies, my thesis demonstrates no evidence that this was a concern. At the time of this study, both the hopeful message of TasP from activists and the fears of sexual disinhibition from health implementers were absent from the sexual realities of women.

4.2. Overview of findings

In this thesis I employ several theoretical constructs to explore women's experiences of sex, intimacy, and relationships. These constructs provide the framework to understand broader community perceptions and expectations of women and sex in southern Africa and the interpersonal experiences and internalised meanings attached to sex for women in this study. I engage with the connected constructs of risk, normalisation, responsibilisation, disclosure, relationships, and internalised meanings of sex to trace women's contextual experiences of health, sex, and intimacy in the context of UTT.

In this section, I provide a synopsis of key findings across the five manuscripts and highlight how the constructs identified throughout this thesis intersect in women's experiences of sex in an evolving HIV prevention landscape. The intersecting experiences are presented across three domains, as adapted from Simon and Gagnon's (1986) model: community level experiences representing cultural scenarios, interpersonal experiences, and intrapsychic, or internalised scripts. Figure 6 below shows how all three domains are interrelated and impact on women's experiences of sex.

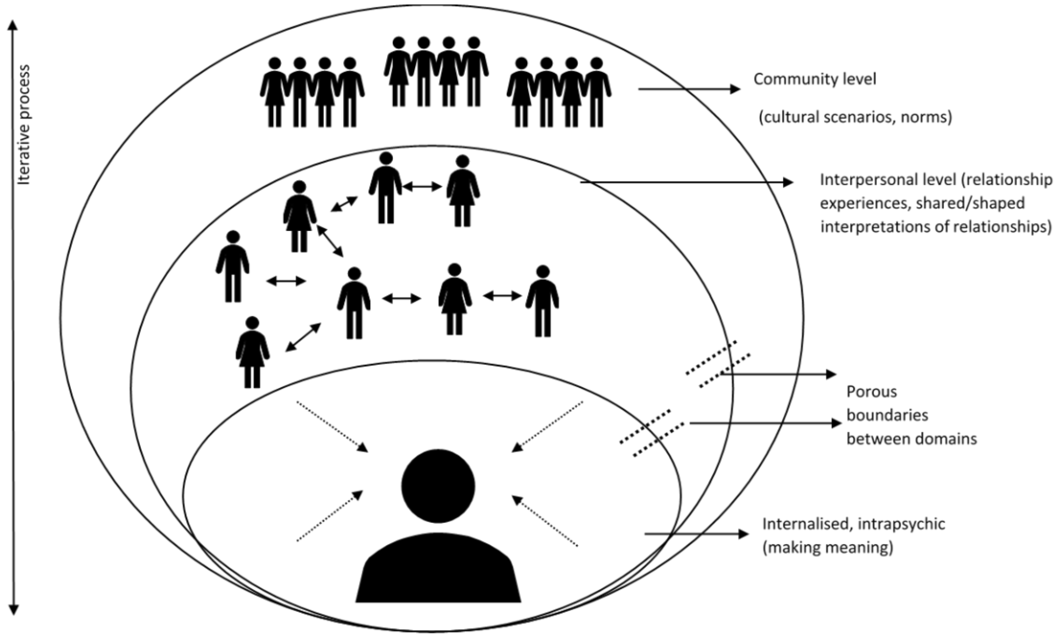

Figure 16. Women's experiences of intimacy and sex across domains.

Community-level insights into women and sex in the context of universal access to HIV testing and treatment

The study findings reveal that conceptualisations of women's HIV risk at community level are not stable constructs but instead are responsive to contextual understandings and lived experiences. Data from group discussions in Zambia and South Africa prior to the implementation of the PopART trial showed how community members categorised 'women' and 'HIV risk'. Using the lens of dialogical self-theory (Hermans, 2008), where the 'self' is imagined as a conversation between different voiced positions, I show how community narratives shifted as they described the ways in which women were at risk of HIV. In their narratives, participants would adapt their descriptions of women to acknowledge that women take on multiple roles that place them at risk of acquiring HIV in different ways. Participants also internalised and applied conceptualisations of HIV risk in their own lives (or the women in their lives) and, in doing so, were able to describe how women's household, economic, or relational circumstances circumscribed their ability to avoid HIV risk. This rendered participants more sympathetic to the real-life risk experienced by women. Participant narratives thus contrasted moral expectations of risk with the circumstantial pressures of lived realities. Community members recognised the multi-faceted nature of women's lives and that risk (and 'risky behaviour') is not stable. These indications of shifting risk perception set the stage against which the UTT intervention was implemented and the normative environment against which women experience sex and intimacy.

This acknowledgement of the nuances of women's risk reveals the contextual complexity of the 'cultural scenarios,' to use Simon and Gagnons's (1986) term, against which universal access to testing and treatment was implemented. These scenarios (or stages) are shaped by decades of HIV messaging, often with moralising undertones, community norms of sexuality, and gendered understandings of women’s roles (Bond et al., 2016; Winskell et al., 2020).

In addition to fluid risk perceptions, during the implementation of the trial, increased access to HIV testing and treatment services shaped community responses and anticipations of behaviour related to HIV. While HIV and HIV services were positioned as ‘normative’ in the narratives of South African and Zambian community members in the PopART trial, individual responses still showed that an HIV positive diagnosis (or the anticipation of a positive diagnosis) was experienced as a disruptive event. A shift in community narratives towards individual responsibility for PLHIV to take up services that are perceived to be more easily attainable with the implementation of the UTT strategy, creates the space for blame for those who do not take up services. Community members across trial sites voiced the expectation that individuals should take up treatment to “take care of their own health” and to know their status so that they are able to prevent onward transmission.

Importantly, notions of treatment as prevention were not part of either the normalisation or responsibilisation of HIV in this context as most people had either not heard of or are wary of the prevention capabilities of treatment. From the data there were indications that UTT as an HIV prevention strategy was not part of the broader cultural scenarios against which women made decisions around sex and relationships. The hope that increased access to HIV services, including access to testing and treatment, would facilitate the normalisation of HIV was slow to realise. From these observations, it is evident that the broader social and normative contexts in which decisions around sex and relationships remained relatively unchanged by the intervention and that new narratives shaped by changing HIV prevention modalities were yet to be incorporated. It is possible that these changes might still come as people newly diagnosed and initiated on treatment during the course of the study may not yet have shifted their narratives. On an individual level, learning one's diagnosis is the first step along a trajectory and that living with HIV, for many, comes with a later stage of acceptance (or normalisation).

Women's interpersonal experiences and intrapsychic scripts in the context of universal access to HIV testing and treatment

The findings of this thesis have shown that women living with HIV in South African trial communities navigate the process of status disclosure to intimate sexual partners through performances and 'interpersonal scripts' (Simon and Gagnon, 1986). More broadly, PLHIV living in conditions of precarity have to consider how to negotiate disclosures of health conditions and how to best manage boundaries between 'private' and 'public' audiences, including intimate partners (Ariès, 1960; Butt and Langdridge, 2003; Goffman, 1959; Jacobs, 1961). At the interpersonal level, the process of revealing one's HIV status is shaped both by shared understanding(s) of illnesses and 'the audience' (or social others), as is demonstrated in Manuscript 3 through the narrative of Elsie.

The processes of HIV status disclosure also show how dynamics related to UTT are reflected (or not) in the interpersonal scripts of women. Women employ different performances (or interpersonal scripts) to communicate their status to their partners. Status disclosure has been shown to facilitate HIV treatment access and adherence (Stirratt et al., 2006). In the context of UTT, disclosure is thus often positioned as a step towards initiating treatment, both for personal health and well-being and for the associated benefits of treatment-based prevention (Eaton et al., 2014). Emerging literature from the Southern African region, however, has questioned this assumption and highlighted the complexities of HIV status disclosure. For instance, the study by Toska et al. (2015) in South Africa found that while knowing one's own status was associated with safer sex, knowing the status of a partner and disclosure to partners were not. Others, like, Mackworth-Young et al. (2017,

2020) describe how young women in Zambia are often discouraged to disclose their HIV status by concerned health workers or caregivers in an effort to avoid stigma and blame.

In this study, I found that women in study communities did not position the act of disclosure for the health-related intentions imagined by some public health specialists. Rather, using the dramaturgical metaphor (Goffman, 1959), the findings show that disclosure performances are related to the reassessment of relationships – either as affirmation of intimacy and trust or to convey betrayal. When women in the study deliberately concealed their status, they did so to ensure self-preservation or the status quo of the relationship. Participants did not engage with ‘treatment as prevention’ when considering disclosure, either to facilitate disclosure as part of a prevention strategy, or to ‘justify’ non-disclosure for ‘risk-free’ sex. HIV prevention, in general, and treatment adherence support were rarely mentioned as a reason for disclosure by women in my study. While I describe the various types of disclosure narratives of women in our cohort, I acknowledge that relationship types and quality also influence the ways in which disclosure unfolds. The women described in Manuscript 4 were mostly in established or long-term relationships which means that other interpersonal dynamics (relationship security, long-term stability) are folded into these disclosure narratives. Women in other types of relationships (casual, once-off sexual encounters) are likely to consider and engage in different disclosure processes. In this study, women’s disclosure narratives were shaped by interpersonal dynamics and relationships well-being. However, and unexpectedly, safe conception and childbearing desires did not emerge as a reason for disclosure during our discussions. To some extent, this is again indicative of how consideration of prevention and the preventative capabilities of HIV treatment are not yet incorporated in narratives. However, in broader narratives related to relationships and well-being, women often spoke about their desires to have children. As has been found in other studies (Smith, 2004; Swartz et al., 2018), childbearing was often described as a way of cementing relationships.

These complex dynamics of disclosure and other relationship dynamics highlighted in this research, suggest that there is little evidence to show that UTT and TasP are part of the interpersonal or intimate scripts of women in community settings in Africa where UTT was made available. As explained by Simon and Gagnon (1986), at the most intimate level, intrapsychic scripts (or the backstage) are the spaces where identity and meaning are shaped. Throughout this project, I have shown that HIV is repeatedly presented as a challenge both to identity formation and to understandings of acts of sex and intimacy. In terms of identity formation, individuals go through complex processes to reconcile their self-conceptions (or self-theory) with their HIV diagnoses, as HIV is associated with negative and stigmatising connotations bestowed on morally transgressive ‘others’ that is incongruent with women’s descriptions of themselves as decent, proper, or good women.

The findings on women’s intrapsychic scripts and their intimate understandings of sex demonstrated how internalised understandings of consensual, heterosexual sex are presented as separate from conceptualisation of HIV and risk. Sex and intimate relationships are conceptualised along romanticised ideals, describing the act as respectful, loving, and intimate, despite often experiencing violence and betrayal from intimate partners. At the time of data collection, there were no differences between sex-descriptions of women in the study who had access to UTT and those who did not, indicating that messaging on treatment as prevention is slow to reach these communities and be incorporated into sexual scripts, even in the context of the PopART intervention actively promoting UTT. Women described consensual sex as being about relationships. Sexual narratives were not concerned with the physical health and well-being of bodies, but rather about the well-being of perceived intimate relationships.

Despite narratives where sex acts could be considered ‘high risk,’ participants described risky sex as a distant concern only relevant to ‘others’, (see also Viljoen et al., 2016). In most cases, HIV prevention does not fit into the descriptions of sex from women participating in the trial, and it is presented as a challenge to accepted conceptualisations of the act. These findings suggest that, overall, women do not engage with treatment-based prevention modalities in their partnership choices. In these early stages, behavioural disinhibition, as feared by public health specialists, was not evident in the PopART context.

The ideal vs reality: Discord, disjuncture, tensions, and the question of UTT

The theoretical constructs and frameworks employed throughout this thesis (dialogical-self-theory, normalisation, responsibilisation, public/private dichotomies, performance theory, and scripting theory) provide the foundation to understand how women’s experiences of sex can be understood in a changing HIV prevention landscape. Working across these theoretical constructs and the findings presented in this thesis, one central theme emerged as spanning across analyses and theoretical framings. From the analyses, it is evident that there are ongoing tensions between idealised or expected ‘scenarios’ of women’s sexual lives and their lived realities.

There is discord between women’s perception of HIV risk and the ways in which they describe their own intimate relationships, which, in turn, impacts women’s experiences of sex. Appropriate risk perceptions are integral to the successful implementation of prevention strategies as community members are less likely to use prevention methods if they consider themselves or their relationships risk-free. From my analyses I show that, for women in high-burden settings in South Africa, HIV risk perceptions are unstable and shift as individuals acknowledge different realities, including situational pressures or the multiple roles that women fulfil in society. This was evident in community narratives of risk, in women’s disclosure narratives, and in women’s descriptions of their intimate relationships. This is shown in the ways in which community members narrate risk in Manuscript 1, for instance, where there are expectations of one-dimensional ‘bad’ women engaging in risky behaviour, but community members acknowledge that women play multiple nuanced roles in society which would render them vulnerable to HIV.

Similar to observations from a previous study (see Viljoen et al., 2016), the findings show that intimate relationships that fit the profile of ‘high risk’ relationships, as per public health understandings (non-monogamous relationships, condomless sex, violent), are not necessarily labelled as risky by the women in those relationships. In Manuscripts 4 and 5, for instance, when women in the study describe their interactions with their sexual partners on an interpersonal level, expectations of ‘ideal relationships’ are upheld (including trust, fidelity respect), even in the face of contradictory experiences. When partners fail to live up to these ideals, it creates internal and relationship turmoil for women, which results in either disavowal, or eventual acceptance.

The disjuncture between reality and expectation means that even when women are subjected to risk factors such as unfaithful or violent partners, they rarely perceive themselves to be vulnerable to HIV. This is shown in Manuscript 5, where women’s narratives about their perceptions and experiences of sex highlight the disjuncture between ideal and romanticised versions of sex and sexual relationships and lived experience that often involve violence and betrayal. Romantic idealised conceptualisations of sex and relationships mean that women distance themselves from the possibility of ‘risk’ as the acknowledgement thereof would jeopardise internalised conceptualisation of relationships (loving, trusting spaces of intimacy).

This tension between the ideal and lived experiences is also evident in the way in which women in the study described themselves. To position themselves as vulnerable to

HIV would cast doubt on women's conceptualisations of self (good, moral, respectable women) and would align them with other 'morally transgressive' women (sex workers, promiscuous women) who are described as 'at risk'. In the absence of an acceptance of risk as part of relationship narratives, women are unlikely to engage in HIV prevention strategies.

In their narratives, women also described their own actions and values in accordance with moral ideals of 'good women'. However, in women's descriptions of HIV, there was often a disavowal of their own positive diagnosis and a lack of discussion on HIV overall. HIV was instead positioned as belonging to transgressive others and is (at least initially) irreconcilable with conceptualisations of self as this would force them to reconsider their identity. Across the findings, when women became aware of their own positive HIV status, it was, for many, difficult to reconciliate their perceptions of what it means to be a person living with HIV and who they perceived themselves to be, as described in the case of Elsie in Manuscript 3. In addition to confronting the possible betrayal of sexual partners and having to re-evaluate intimate relationships, women in the study had to realign their perceptions of self as a person who is living with HIV, including the health and social implications of a positive diagnosis (Bond, 2010).

In high-burden contexts, women are frequently confronted by HIV messaging, and even more so in the context of an HIV prevention trial. Even as HIV becomes somewhat more accepted as 'normal in the community', participants in the study presented a potential diagnosis as a disruptive and exceptional event and as a challenge for self-identity.

Lastly, my findings reveal a tension between universal access to HIV testing and treatment as a population-level HIV prevention strategy, and the implementation of treatment-based prevention modalities at the intimate (relationship) level. While the widespread implementation of UTT has the potential ability to provide 'umbrella protection' against HIV at population-level if widespread testing is implemented, access to care facilitated, and viral suppression maintained, the successful implementation of the strategy still requires participation at the individual and intimate level. There are still major gaps in understanding how to structure public health programmes and the messaging around these programmes to adequately address the needs of individuals and to ensure that appropriate and meaningful health messages are distributed.

The tensions between ideals and lived experiences have consequences for how intimacies, relationships, and sex are experienced and understood by women in South Africa, and more so in the context of HIV prevention. In HIV prevention programmes, this disconnect can mean that ‘at risk’ women do not take up HIV prevention methods that they do not identify with.

The roll-out of other health interventions at community level, including family planning programmes, have highlighted some of the challenges of implementing large scale interventions aimed at addressing sexual behaviour and well-being. In a global survey in 77 countries, less than 53% of women who reported a desire for family planning were accessing ‘modern’ birth control technologies (Ewerling et al., 2018). Researchers in the Democratic Republic of the Congo have found that challenges to the implementation of large-scale programmes include tensions with local cultural norms favouring high fertility, insufficient health infrastructure and service delivery, and economic constraints (Kwete et al., 2018); Jacobstein (2018) highlighted concerns with limited infrastructure in sun-Saharan African with the implementation of the contraceptive implant. Similarly, implementing HIV prevention technologies that may challenge or disrupt established relationship, gender, or sexual norms or put a strain on local health services might face difficulties in being acceptance amongst communities and in the practical application and rollout. In order to implement programmes, it is essential to address these issues directly. Studies in low-and middle-income countries have repeatedly shown that interventions that integrate activities that actively address gender norms and dynamics have a positive impact on family planning implementation, although these are often difficult to implement (Mandal et al., 2017).

The analyses in this thesis and the expansion on the conceptualisation of the ways in which sex is experienced and internalised by women in Africa, provide a valuable way of interpreting women's sexual behaviour in the context of HIV prevention services, including UTT. The analyses can guide health programmes in offering more suitable ways of presenting HIV prevention technologies, including helping women to maintain physical health and relationship well-being, without compromising on relationship ideals.

4.3. Strengths and limitations

In this project, I draw on data collected as part of one of the largest community-based HIV prevention trials ever conducted. The HPTN 071 (PopART) presented one of the first opportunities to explore how the implementation of UTT, at scale, would impact the lives of participants at individual, interpersonal, household, and community levels (Hayes et al., 2014). Since the start of the trial, as per WHO guidelines, expanded access to HIV treatment for all PLHIV has been widely encouraged and 96% of all lower-middle income countries have committed to adopting treatment for all by the end of 2020 (WHO, 2019). The manuscripts included in this thesis were designed both to inform the broader HPTN 071 (PopART) trial results and to complement the quantitative elements of the study by exploring in-depth the nuanced realities of communities and participants in the study.

As part of the PopART trial, I facilitated the design of research tools and actively participated in data collection. For the analyses conducted in the manuscripts that make up this PhD thesis, I draw on the large set of data we collected (n= ~1000 interviews) with multiple households (n = 89 in South Africa) over an extended time period (18 – 24 months).

The ethnographic and participatory nature of the data collection (described in Chapter 2) meant that the data were rich and comprehensive. The inclusion of audio recordings, detailed verbatim transcriptions, and extensive field notes and reflective memos ensured that I was able to analyse both what was said and also what was left “unsaid” by participants (Todorova, 2007). Repeated engagements with participants, multiple data sources, and careful debrief sessions with the data collection teams to reflect on findings and iterate methodologies, ensured that the data was detailed and expansive and allowed for the triangulation of data (Flick, 2004).

Another strength is that the analyses presented in this project across the manuscripts are theoretically grounded. I draw on and expand on established performance theory, as developed by Goffman (1959), and scripting theory, as proposed by Simon and Gagnon (1986). However, I also draw on the theoretical constructs dialogical self-theory (Hermans, 2008), the public/private dichotomy (Bobbio, 1989), normalisation (de Wet, 2019; Persson, 2013; Squire, 2010), and neoliberal responsibilisation (Beckmann, 2013) to understand the complexities of women’s experiences and contextualise the findings.

The comprehensive data collection activities allow for transferability of findings to other similar contexts within the region. Tracy and Hinrichs (2017: 7) have noted that findings can be more transferable to other settings when researchers conduct an “in-depth, situated analysis of contexts, rhetorical situations, and embodied experiences … [that] extends or problematizes current theoretical assumptions …[and] that help explain social life in unique ways”. By offering detailed descriptions that are theoretically grounded, the insights gained from this study are relevant to the delivery of HIV prevention services to women in southern Africa. However, as with other research, context matters. When findings from one HIV prevention initiative are implemented in another setting without considering local context, the outcomes can be disastrous. For instance, the “A, B, C” HIV prevention initiative was hailed as successful in Uganda but failed to reach the same impact when implemented in Botswana (Okware et al., 2005). Researchers suggested that the failure of programme implementers in Botswana to involve local religious leaders and the lack of considering local customs meant that the programme was met with antipathy (Allen and Heald, 2004). Rather than using the findings of this PhD project to "predict, generalise, and control future interactions" (Tracy and Hinrichs, 2017: 7), researchers need to carefully consider established customs, historical context, and the trajectory of the epidemic in a given place.

One limitation to extrapolation from the findings is the nature of the research question. Research on the topic of sex is notoriously difficult to conduct because of the taboos, sensitivities, and privacy concerns that surround the topic (Mitchell et al., 2007). Other researchers have reflected on how difficult it is to elicit "true" answers about sexual experiences and have revealed the influence of social desirability bias[2] on what people report (Kelly et al., 2013; van de Mortel, 2008). In addition, HIV continues to be a stigmatised condition, which adds another layer of complexity. While enacted HIV stigma has decreased across contexts (Chan and Tsai, 2016), an HIV diagnosis still carries negative associations and individuals are often blamed for their diagnosis and their assumed moral transgressions (Shen et al., 2019). However, I mitigate this limitation by noting the study design which catered for extended conversations with participants and intensive rapport building over time and ensured that data collection teams were carefully trained and prepared. I have also made my extrapolations necessarily circumspect.

This project benefited from being situated within a broader HIV prevention trial in terms of the availability of the large data set and the resources made available in working in

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[2] Social desirability bias refers to the desire of participants to provide answers that are viewed as socially favourable rather than an accurate reflection of experiences or perceptions (Stuart and Grimes, 2009).

this setting (as explained above). However, there were also important limitations involved with conducting a nested study in this context. Firstly, while doing data collection, we (the social science team) were automatically associated with the trial through our required uniforms and through our formal introductions. As such, all discussions took place against this framing, meaning that participants would likely be inclined to structure their responses bearing the trial in mind. In managing the challenge of engaging with participants beyond an HIV-framing, we would regularly emphasise to participants that we are interested in their lives in general, not only their experience of the trial, and guide discussions accordingly.

Through the analyses, I present the experiences of women in the context of UTT. There is obviously a lack of representation of the "other half" of these heterosexual relationships – the experiences of men. It has been well-documented across contexts that while women are more likely to be affected by HIV, men are less likely to engage in care (Fleming et al., 2016; Sharma et al., 2017). As such, we need more information on the experiences of men. One suggestion is for future studies to include a similar exploration of men's narratives and experiences of sex, disclosure, gender dynamics, and HIV treatment in the context of evolving prevention modalities. Other groups that are not represented in this project and who were excluded from the analyses are women who have sex with women, cisgender female sex workers, and health workers. Women who have sex with women and female sex workers were excluded due to their differential experiences of sex and HIV risk. For instance, Coetzee, Jewkes, and Gray (2017) found that sex workers in South Africa had multiple clients, had inconsistent condom use, and were at higher risk for HIV than women not engaging in sex work. Health workers, alternatively, were excluded because they can be expected to have better access to information on novel HIV prevention modalities such as treatment-based prevention, although research has shown that this is not necessarily the case (Lippman et al., 2020). Analysis of the experiences of these groups thus falls outside the scope of this study. The narratives around sex and intimacy for people who fit within these groups also merit further careful study.

4.4. Recommendations for delivering HIV services for women

The findings of this thesis provide insights into the practical application of community-based HIV prevention programmes. In this section, I provide suggestions on how the findings might be translated to inform future HIV programmes for women in sub-Saharan Africa.

One key issue with many HIV prevention programmes is the framing of HIV risk around stagnant conceptualisations of ‘at-risk’ individuals. However, HIV risk is not homogenous. The study findings indicate that women’s experiences and perceptions of HIV risk are fluctuating, as women address situational pressures (e.g., maintaining intimate relationships, ensuring economic survival) and shifting social contexts. Similarly, Brault et al. (2019, S108) note that the shortcomings of models predicting the impact of UTT on HIV incidence were due to the failure to anticipate the “heterogeneity of risk”. Public health programmes must be responsive to women’s changing experiences of HIV risk, including providing support to women who appear to be, on average, ‘low risk’ and avoiding reifying women who often experience high risk as ‘high risk women’.

Health programmes, including UTT, is increasingly being rolled out as standard of care across contexts (WHO, 2019). However, as the study findings show, even in a trial context where the message of treatment of prevention was intended to be actively promoted and HIV services dramatically increased, community members had limited knowledge of (or limited trust in) the prevention capabilities of UTT. While the PopART-employed CHiPs were responsible for implementing the door-to-door intervention, and by implication, the health message of UTT, most community members were still unaware of treatment as prevention as a prevention modality and the incorporation of TasP into intrapsychic and interpersonal scripts was thus unlikely. The potential reasons for this lack of knowledge are twofold. Firstly, the primary aim of the CHiPs was to promote HIV testing and linkage to care, while health message promotion (including UTT) was potentially positioned as a secondary concern. Secondly, community members were tasked with accessing HIV care at health facilities where, as Mubekapi-Musadaidzwa et al. (2021) found, there were no radical changes in the ways in which health workers promoted treatment access, despite changes to South African national guidelines to allow all PLHIV access to ART.

The findings from this thesis highlight the complexities in the implementation of an intervention consisting of both biomedical and behavioural components and how these elements interact and impact the lives of community members. While the PopART intervention did result in a reduction in HIV incidence (Hayes et al., 2019), the findings from this thesis also show that incorporating new narratives of HIV prevention as part of accepted cultural norms is difficult to achieve. In many ways, the introduction of TasP contradicts the accepted and standing narratives of the assumption that treatment is for making you feel ‘less sick’, not for prevention, and that ART should therefor only be taken by those who are feeling ill (see Bond et al., 2016). This means that in addition to spending resources to link PLHIV to care and treatment, health programmes need to invest in time and effort to adapt the messaging around accepted scripts around HIV treatment and prevention.

Additionally, even for those community members who were aware of TasP, there is the question as to what extent people would focus on individual as opposed to community benefits. As such, intrapsychic and sexual scripts would not necessarily be influenced by the TasP or UTT narrative as taking treatment ‘for the benefits of others’ and not for their ‘own health’ would not necessarily offer a compelling argument to access and adhere to treatment.

In order for women to access the health and prevention benefits of HIV treatment for all, health implementers would need to actively engage in more intensive programmes to effectively inform communities of changes in treatment guidelines and the mechanisms of TasP. These findings suggest that a more active facility-based and media campaign might be necessary to disseminate the message of the preventive benefits of HIV treatment more widely. Previous HIV prevention approaches (most notably the “A, B, C” approach mentioned above) have been extensively promoted through massive public education campaigns, and have thus become part of the accepted language around HIV (Levine and Ross, 2008). Newer biomedical approaches to HIV prevention have not received nearly the same investment in public education or media campaigns. The message of U = U, which was gaining traction in other contexts as the PopART trial was drawing to a close, is positioned as one way in which the ‘treatment as prevention’ message can be disseminated and incorporated into narratives of sex and prevention. Based on study findings that show that those with effective viral suppression do not transmit HIV (Averitt et al., 2018; UNAIDS, 2018), it frames viral suppression through treatment as a way of ensuring safe sex. However, the spaces where the U = U message has been more actively embraced are mostly in contexts where sex-positive messaging has been more actively accepted. At the time of this study, the general idea of treatment as prevention and the U=U message were not yet accepted as common knowledge in sub-Saharan Africa. In future, the language of U = U, which is centred around sexual liberation, individual choice and, to some extent, personal responsibilisation, could have the potential to transform sexual narratives. If the message is embraced, PLHIV, and communities in general, could reconceptualise treatment as a means to ensure safe sex in partnerships and to secure broader community protection.

Even if UTT and U = U messaging were to be accepted, other factors related to interpersonal relationships still need to be considered. For instance, for women who mainly have sex with men and who are not living with HIV, the protective benefits of UTT can only be reached if their sexual partners (men) are reached by UTT. As such, there may be a greater need to engage (some) women with their partners in HIV counselling and support programmes. In addition, the training (and follow-up training) content for health workers should be more attuned to and willing to engage with the needs of communities being served, specifically the relationships dynamics and sexual priorities of their clients.

As UTT programmes are rolled out and community members are made aware of the dual treatment and prevention benefits of ART, health programme implementers need to be responsive to anticipated stigma and evolving conceptualisations of HIV service uptake as the ‘moral responsibility’ of PLHIV. Similar to pregnancy prevention, HIV has repeatedly been positioned by both community members and public health specialists as women’s responsibility. In addition to the risk of HIV prevention becoming the responsibility of PLHIV, prevention might again be positioned (in community narratives and between women and their partners) as women’s responsibility. This positioning is problematic as it again contributes to unequal labour and the burden of care in households. It is therefore important that the strategy of TasP is presented as a ‘dual’ or partnered solution for people in intimate relationships.

The successful implementation of treatment-based prevention modalities will require dedicated and sex-positive couples counselling and improved adherence support for PLHIV. The findings indicate that HIV (as a health issue) is positioned as outside of sex and intimate relationships for women. Other types of counselling support are therefore needed, including improved communication support and relationship counselling to address concerns like infidelity, trust, and sexual satisfaction for both men and women. It is only when men and women receive the necessary support that community-based programmes, such as UTT, can be rolled out and women (who are disproportionately affected by HIV) will be able to benefit equally from the programmes.

The efficacy of HIV treatment as prevention has been proven and accepted. However, the strategy to implement UTT at scale has not been as effective as anticipated. UTT, in its current form, is not the silver bullet for the HIV prevention efforts and will not be the singular catalyst to end HIV. For communities to maximise on the benefits of UTT, researchers will need to explore how other prevention modalities, in conjunction with appropriate stigma-reduction programmes, TasP awareness campaigns, and couples counselling can best be incorporated into programmes.

4.5. Concluding thoughts and the way forward

Since the conceptualisation of this PhD project nearly five years ago, the implementation of HIV treatment for all PLHIV has shifted from a hypothetical scenario to public health policy in many places in the world, including South Africa. As one of the first studies of women's sexual lives in the context of UTT, this study presents an early indication of how UTT may impact community narratives and the sexual narratives of women in high HIV burden settings. While the implementation of UTT did not bring the 'moment of change' many researchers and activists had hoped for, the study findings suggest that it also did not result in sexual disinhibition as feared by other public health specialists. It also did not result in any major changes in people's sexual life narratives. As UTT becomes the norm, future studies will need to investigate how these changes in treatment availability impact women's experiences of sex in the long term. This is especially relevant if HIV prevention information is to evolve to include more comprehensive messaging on the benefits of TasP.

This study also relates to the broader findings of the PopART study including the unexpected findings of the reduction of HIV in some communities and not others (Hayes et al., 2019) and the experiences of community members where the trial was implemented. For example, early analyses of the quantitative findings of the trial (not yet published) also suggest show that sexual disinhibition was not evident in HPTN 071 (PopART) trial communities receiving the UTT intervention. The findings from this qualitative study complement these quantitative findings by providing a more nuanced understanding of concepts of HIV risk, sexual behaviour, disclosure, and relationship dynamics, which are often defined in more reductive terms in the analysis of quantitative data. The findings from this qualitative study can assist in widening the categories of risk beyond binary descriptions often used in quantitative surveys to help identify individuals who are at different stages of risk and to have more meaningful engagement with communities affected by HIV.

Further, in order for communities to capitalise on the benefits of UTT, the successful implementation of the strategy will require engagement with and participation of community members at the individual and intimate level. Additional research is needed to understand how to structure public health programmes and messaging on UTT and TasP to involve women in intimate relationships, including those women who do not fit high risk criteria conventionally described in public health narratives.

As public health campaigns are increasingly promoted through social media platforms (Taggart et al., 2015), there is potential for messaging around UTT to be distributed using these platforms. In this study, social media did not emerge as a dominant theme although most participants had access to some form of social technology (Mixit, WhatsApp messaging, Facebook). Consequently, there is also the opportunity for future studies on the influence of media on the ways in which women view their options, their health, and their relationships.

Importantly, current research on women and sex in Africa has been slow to engage with conceptualisations beyond risk and vulnerability. While there is a growing number of researchers who are starting to acknowledge the importance of intimacy, love, partnership dynamics, and emotional connections in relation to health research, there is still much we do not know about how women in Africa conceptualise and make decisions around sex.

Researchers in other contexts, including the US and Europe, have explored some of the complexities of intimacy and sexual behaviour. For instance, women’s sexual pleasure has been described in research in other contexts, but there are notable gaps in research in Africa, especially as it pertains to high HIV burden settings Findings from microbicide trials have shown that, in addition to gender and power dynamics, considerations of sexual pleasure are pivotal in shaping sexual behaviour when HIV prevention methods (such as vaginal microbicides and vaginal rings) are used (Van Der Straten et al., 2012; Woodsong and Alleman, 2008). There is a need to further explore the role of sexual pleasure in the context of evolving HIV prevention modalities to provide a more well-rounded and comprehensive understanding of women’s experiences of sex and HIV.

In addition, research has shown that women in different stages of their lives experience sex and HIV risk in divergent ways (Pathak et al., 2019). While this study looked at the experiences of adult women in the cohort, there is also a need to do a comparative analysis of the scripts of women in different age groups as this would allow researchers and health implementers to respond appropriately to the varying needs and experiences of women.

This thesis presents findings from multiple and rich engagements with women over time. However, while we were able to have meaningful engagements with women over an extended time period, 18 months might not have been long enough to observe changes in values and core sexual narratives. As such, I would suggest that even more research be conducted, if possible, in the same areas, to explore the long-term influence of changes in HIV guidelines.

In addition to understanding women’s experiences of sex and intimacy in the context of UTT, there is an equally pressing research imperative to explore men’s experiences.

Arguably, their experiences of sex and intimacy are subject to other normative expectations of masculinity. As such, we need to explore how men conceptualise UTT, sex, and intimacy. It would also be valuable to explore relational and community-level dynamics that cut across gender in order to provide better support and care for men and women.

More research is needed to explore if and how women are able to take up the liberating message of UTT for their own physical wellbeing and for the protection of their sexual partners. As available HIV prevention technologies expand, there is a need to explore how these modalities can be incorporated into women's understandings of physical well-being with minimal disruptions to experiences of intimacy and relationships.

In order to facilitate the end of the epidemic, HIV interventions need to be better suited to address heterogeneity in the needs and expectations of women's intimate relationships and would need to be adapted to respond to women's complex understandings of intimacy and meaningful sex. More qualitative research is needed to understand how best to engage with women in meaningful ways. Further studies are needed to understand how to provide responsive and customised care to women that do not disrupt women's relationship ideals.

In southern Africa, women have been integral to the response to the epidemic – leading in activism efforts, providing care for others affected by HIV, and in their active engagement in prevention and treatment services. Women are more affected by HIV and, in Africa, the face of the epidemic is decidedly feminine. As we go forward to find effective ways to curb the epidemic, it is essential that we find ways to better serve and support women – as clients, as caregivers, and as people seeking, using, and enjoying sex.

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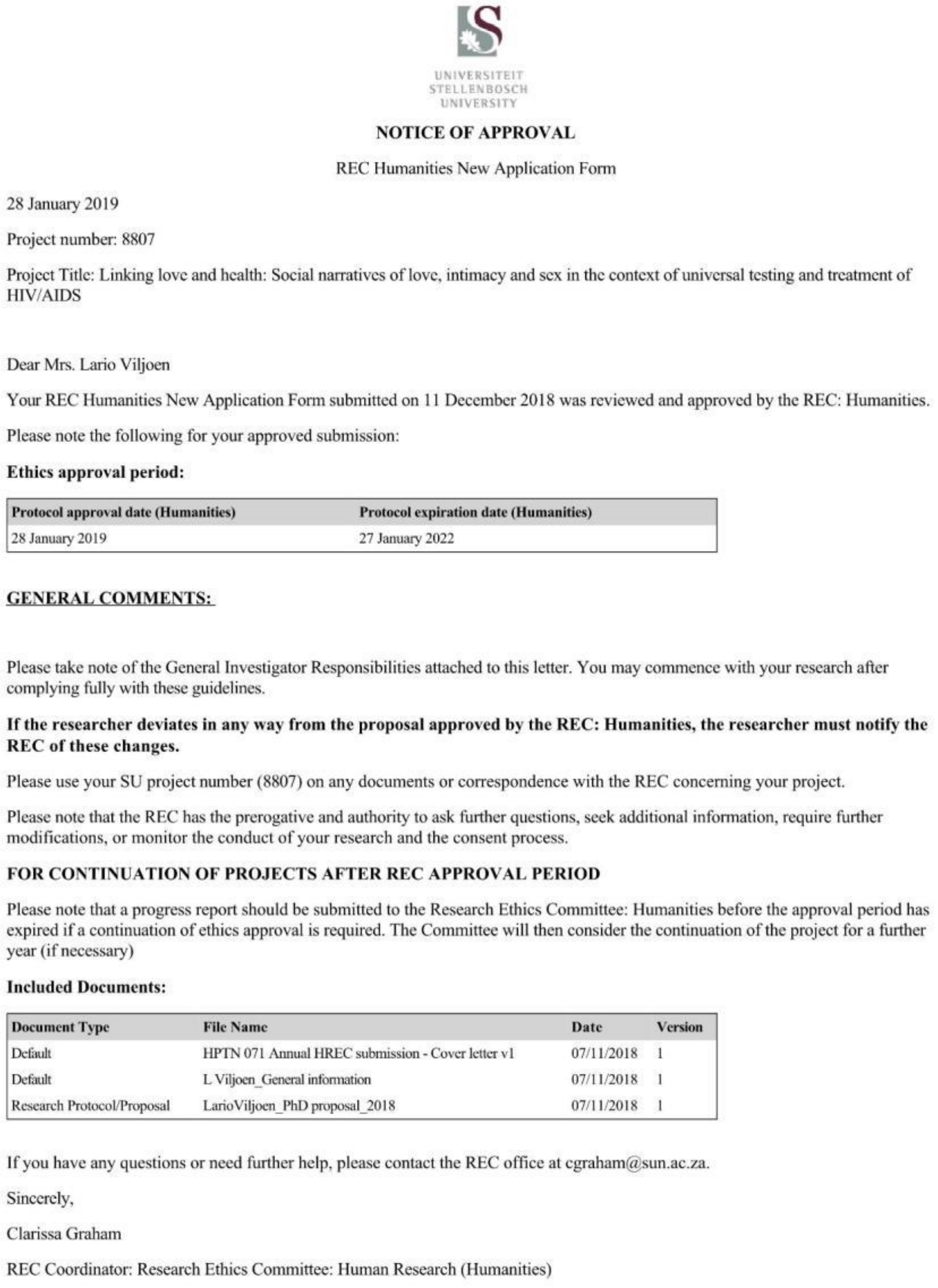
Appendix A: Ethics Approval



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

NOTICE OF APPROVAL

REC Humanities New Application Form

28 January 2019

Project number: 8807

Project Title: Linking love and health: Social narratives of love, intimacy and sex in the context of universal testing and treatment of HIV/AIDS

Dear Mrs. Lario Viljoen

Your REC Humanities New Application Form submitted on 11 December 2018 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
28 January 2019	27 January 2022

GENERAL COMMENTS:

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (8807) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Default	HPTN 071 Annual HREC submission - Cover letter v1	07/11/2018	1
Default	L Viljoen_General information	07/11/2018	1
Research Protocol/Proposal	LarioViljoen_PhD proposal_2018	07/11/2018	1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

Appendix B: Informed Consent Document

INFORMED CONSENT FORM – SOCIAL SCIENCE PARTICIPANTS

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.

PARTICIPANT'S STATEMENT OF CONSENT_Activities 28, 30, & 31

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.

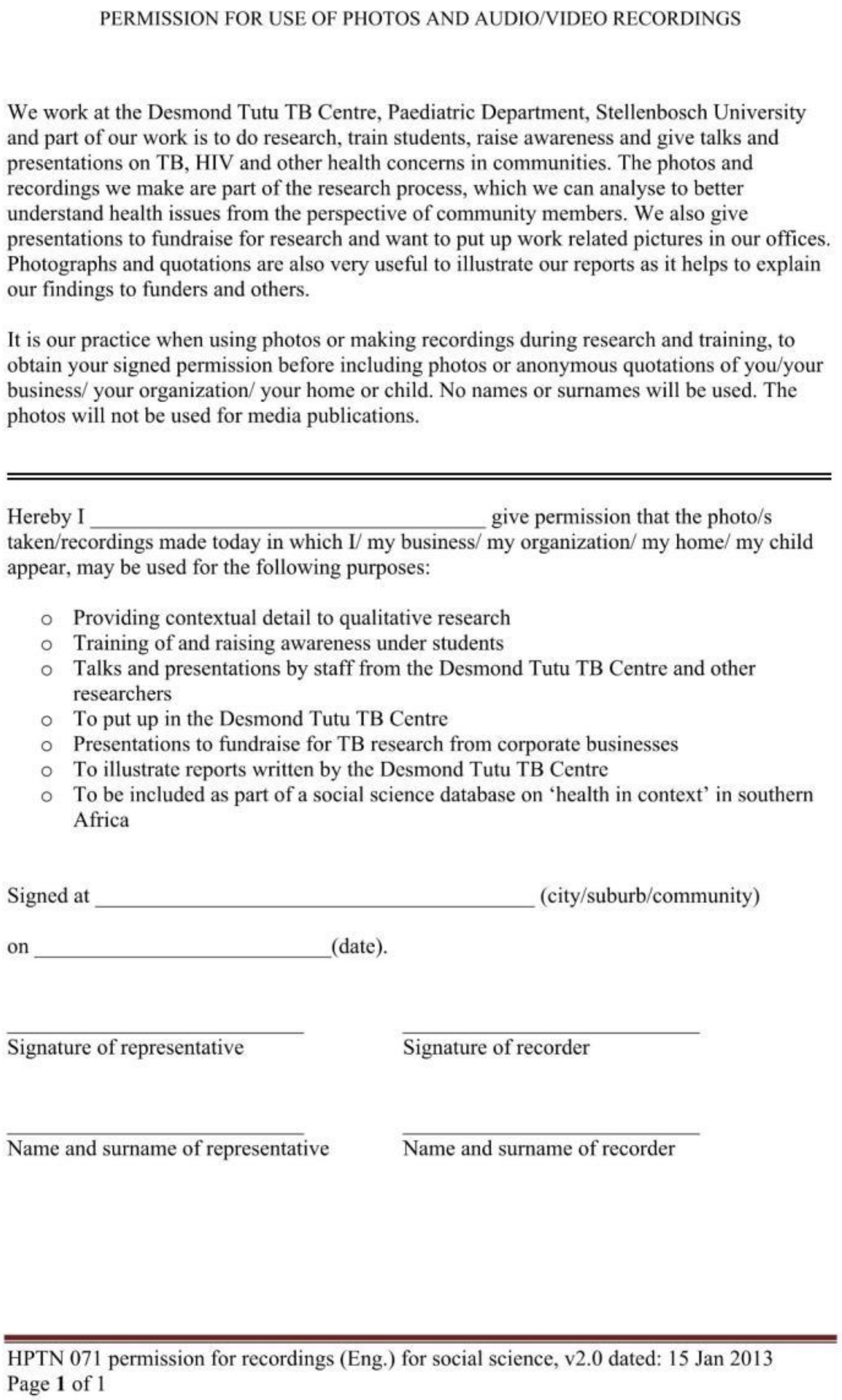
____________________________ Study Staff Name and Surname (print)	____________________________ Study Staff Signature

____
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

____
Date



PERMISSION FOR USE OF PHOTOS AND AUDIO/VIDEO RECORDINGS

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

HPTN 071 permission for recordings (Eng.) for social science, v2.0 dated: 15 Jan 2013
Page **1** of 1

Appendix C: Authorship contributions

Declaration by the candidate:

With regards to Manuscript 1-5, the nature and scope of my contribution were as follows:

Manuscript	**Pages**	**Nature of contribution**	**Extent of contribution (%)**
1. Community narratives about women and HIV risk in 21 high-burden communities in Zambia and South Africa.	83 - 94	Data collection, conceptualisation, analysis, drafting (1st, 2nd and final)	65%
2. Universal HIV testing and treatment and HIV stigma reduction: a comparative thematic analysis of qualitative data from the HPTN 071 (PopART) trial in South Africa and Zambia.	95 – 115	Data collection design; data collection; manuscript conceptualisation; manuscript writing - including background, literature review, findings, and discussion (1st, 2nd, and final draft)	58%
3. "It stays between us": Managing comorbidities and public/private dichotomies in the HPTN 071 (PopART) trial communities.	116 - 132	Data collection design; data collection; manuscript conceptualisation; manuscript writing - including background, literature review, findings, and discussion (1st, 2nd, and final draft)	70%
4. The act of telling: South African women's narratives of HIV status disclosure to intimate partners in the HPTN 071 (PopART) HIV prevention trial.	133 - 146	Data collection design; data collection; manuscript conceptualisation; manuscript writing - including background, literature review, findings, and discussion (1st, 2nd, and final draft)	63%
5. Women's sexual scripting in the context of universal access to antiretroviral treatment – findings from the HPTN 071 (PopART) trial in South Africa.	147 - 182	Data collection design; data collection; manuscript conceptualisation; manuscript writing - including background, literature review, findings, and discussion (1st, 2nd, and final draft)	63%

Manuscript 1: **Community narratives about women and HIV risk in 21 high-burden communities in Zambia and South Africa.**

The following co-authors have contributed to Manuscript 1 on pages 83 – 94 of this dissertation:

Name	**e-mail address**	**Nature of contribution**	**Extent of contribution (%)**
Rhoda Ndubani	rhoda@zambart.org.za	Data collection, Analysis support (Zambia), draft review	8%
Virginia Bond	gbond@zambart.org.zm	Study design, expert review; comments and draft review	5%
Janet Seeley	Janet.Seeley@LSHTM.ac.uk	Technical advisor; comments and draft review	5%
Lindsey Reynolds	lreynolds@sun.ac.za	Technical advisor; conceptualisation support; detailed review	8%
Graeme Hoddinott	graemeh@sun.ac.za	Data collection; Conceptualisation support	9%

Signature of candidate: Declaration with signature in possession of candidate and supervisor. Date: 6 October 2020

Declaration by co-authors:

The undersigned hereby confirm that

1. the declaration above accurately reflects the nature and extent of the contributions of the candidate and the co-authors to Manuscript 1, pages 83 – 94
2. no other authors contributed to Manuscript 1, pages 83 – 94, besides those specified above, and
3. potential conflicts of interest have been revealed to all interested parties and that the necessary arrangements have been made to use the material in Manuscript 1, pages 83 – 94.

Name	**Signature**	**Institutional Affiliation**	**Date**
Rhoda Ndubani	Declaration with signature in possession of candidate and supervisor.	Zambart, School of Public Health, University of Zambia.	06/10/2020
Virginia Bond	Declaration with signature in possession of candidate and supervisor.	Zambart, School of Public Health, University of Zambia; Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Janet Seeley	Declaration with signature in possession of candidate and supervisor.	Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Lindsey Reynolds	Declaration with signature in possession of candidate and supervisor.	Department of Sociology and Social Anthropology, Stellenbosch University.	06/10/2020
Graeme Hoddinott	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020

Manuscript 2: Universal HIV testing and treatment and HIV stigma reduction: a comparative thematic analysis of qualitative data from the HPTN 071 (PopART) trial in South Africa and Zambia.

The following co-authors have contributed to Manuscript 2 on pages 95 – 115 of this dissertation:

Name	e-mail address	Nature of contribution	Extent of contribution (%)
Virginia Bond	gbond@zambart.org.zm	Data collection, analysis support, writing support, review	7%
Lindsey Reynolds	lreynolds@sun.ac.za	Conceptualisation support; comments and draft review	5%
Anne Stangl	alstangl@gmail.com	Comments and draft review	2%
Dzunisani Baloyi	dbaloyi@sun.ac.za	Analysis support	2%
Rhoda Ndubani	rhoda@zambart.org.za	Analysis support (Zambia), draft review	2%
Constance Mubekapi-Musadaidzwa	cmubekapi@gmail.com	Analysis support, draft review	2%
Janet Seeley	Janet.Seeley@LSHTM.ac.uk	Technical advisor; comments and draft review	3%
Triantafyllos Pliakas	Triantafyllos.Pliakas@lshtm.ac.uk	Comments and draft review Draft review	2%
Peter Bock	peterb@sun.ac.za	Trial design (PI); comments and draft review	2%
Sarah Fidler	s.fidler@imperial.ac.uk	Trial design (PI); comments and draft review	2%
Richard Hayes	Richard.Hayes@lshtm.ac.uk	Trial design (PI); comments and draft review	2%
Helen Ayles	Helen@zambart.org.zm	Trial design (PI); comments and draft review	2%
James Hargreaves	James.Hargreaves@lshtm.ac.uk	Study design; comments and draft review	2%
Graeme Hoddinott	graemeh@sun.ac.za	Conceptualisation support; analysis support; comments and draft review	7%

Signature of candidate: Declaration with signature in possession of candidate and supervisor. Date: 6 October 2020

Declaration by co-authors:

The undersigned hereby confirm that

1. the declaration above accurately reflects the nature and extent of the contributions of the candidate and the co-authors to Manuscript 2, pages 95 – 115
2. no other authors contributed to Manuscript 2, pages 95 – 115, besides those specified above, and
3. potential conflicts of interest have been revealed to all interested parties and that the necessary arrangements have been made to use the material in Manuscript 2, pages 95 – 115.

Name	**Signature**	**Institutional Affiliation**	**Date**
Virginia Bond	Declaration with signature in possession of candidate and supervisor.	Zambart, School of Public Health, University of Zambia; Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Lindsey Reynolds	Declaration with signature in possession of candidate and supervisor.	Department of Sociology and Social Anthropology, Stellenbosch University.	06/10/2020
Anne Stangl	Declaration with signature in possession of candidate and supervisor.	International Center for Research on Women; Hera Solutions.	06/10/2020
Dzunisani Baloyi	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Rhoda Ndubani	Declaration with signature in possession of candidate and supervisor.	Zambart, School of Public Health, University of Zambia.	06/10/2020
Constance Mubekapi-Musadaidzwa	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Janet Seeley	Declaration with signature in possession of candidate and supervisor.	Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Triantafyllos Pliakas	Declaration with signature in possession of candidate and supervisor.	Department of Public Health, Environments and Society, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Peter Bock	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Sarah Fidler	Declaration with signature in possession of candidate and supervisor.	Imperial College NIHR BRC, Department of Infectious Disease, Imperial College London.	06/10/2020
Richard Hayes	Declaration with signature in possession of candidate and supervisor.	Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Public Health, London School of Hygiene and Tropical Medicine.	06/10/2020
Helen Ayles	Declaration with signature in possession of candidate and supervisor.	Zambart, School of Public Health, University of Zambia; Department of Public Health, Environments and Society, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
James Hargreaves	Declaration with signature in possession of candidate and supervisor.	Department of Public Health, Environments and Society, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Graeme Hoddinott	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020

Manuscript 3: “It stays between us”: Managing comorbidities and public/private dichotomies in the HPTN 071 (PopART) trial communities.

The following co-authors have contributed to Manuscript 3 on pages 116 – 132 of this dissertation:

Name	**e-mail address**	**Nature of contribution**	**Extent of contribution (%)**
Hanlie Myburgh	hmyburgh@sun.ac.za	Data collection, analysis support, writing support, review	15%
Lindsey Reynolds	lreynolds@sun.ac.za	Analysis support, review	15%

Signature of candidate: Declaration with signature in possession of candidate and supervisor. Date: 6 October 2020

Declaration by co-authors:

The undersigned hereby confirm that

1. the declaration above accurately reflects the nature and extent of the contributions of the candidate and the co-authors to Manuscript 3, pages 116 – 132.
2. no other authors contributed to Manuscript 3, pages 116 – 132, besides those specified above, and
3. potential conflicts of interest have been revealed to all interested parties and that the necessary arrangements have been made to use the material in Manuscript 3, pages 116 – 132.

Name	**Signature**	**Institutional affiliation**	**Date**
Hanlie Myburgh	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Lindsey Reynolds	Declaration with signature in possession of candidate and supervisor.	Department of Sociology and Social Anthropology, Stellenbosch University.	06/10/2020

Manuscript 4: The act of telling: South African women's narratives of HIV status disclosure to intimate partners in the HPTN 071 (PopART) HIV prevention trial.

The following co-authors have contributed to Manuscript 4 on pages 133 – 146 of this dissertation:

Name	**e-mail address**	**Nature of contribution**	**Extent of contribution (%)**
Dillon Wademan	dtwademan@sun.ac.za	Analysis support; comments and draft review	8%
Graeme Hoddinott	graemeh@sun.ac.za	Conceptualisation support; analysis support; comments and draft review	7%
Virginia Bond	gbond@zambart.org.zm	Data collection, analysis support, writing support, review	4%
Janet Seeley	Janet.Seeley@LSHTM.ac.uk	Technical advisor; comments and draft review	4%
Peter Bock	peterb@sun.ac.za	Trial design (PI); comments and draft review	3%
Sarah Fidler	s.fidler@imperial.ac.uk	Trial design (PI); comments and draft review	3%
Lindsey Reynolds	lreynolds@sun.ac.za	Conceptualisation support; comments and draft review	8%

Signature of candidate: Declaration with signature in possession of candidate and supervisor. Date: 6 October 2020

Declaration by co-authors:

The undersigned hereby confirm that

1. the declaration above accurately reflects the nature and extent of the contributions of the candidate and the co-authors to Manuscript 4, pages 133 – 146.
2. no other authors contributed to Manuscript 4, pages 133 – 146, besides those specified above, and
3. potential conflicts of interest have been revealed to all interested parties and that the necessary arrangements have been made to use the material in Manuscript 4, pages 133 – 146.

Name	**Signature**	**Institutional Affiliation**	**Date**
Dillon Wademan	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Graeme Hoddinott	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020

Virginia Bond	Declaration with signature in possession of candidate and supervisor.	Zambart, School of Public Health, University of Zambia; Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Janet Seeley	Declaration with signature in possession of candidate and supervisor.	Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Peter Bock	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Sarah Fidler	Declaration with signature in possession of candidate and supervisor.	Imperial College NIHR BRC, Department of Infectious Disease, Imperial College London.	06/10/2020
Lindsey Reynolds	Declaration with signature in possession of candidate and supervisor.	Department of Sociology and Social Anthropology, Stellenbosch University.	06/10/2020

Manuscript 5: Women's sexual scripting in the context of universal access to antiretroviral treatment – findings from the HPTN 071 (PopART) trial in South Africa.

The following co-authors have contributed to Manuscript 5 on pages 147 – 1182 of this dissertation:

Name	e-mail address	Nature of contribution	Extent of contribution (%)
Graeme Hoddinott	graemeh@sun.ac.za	Conceptualisation support; analysis support; comments and draft review	8%
Samantha Malunga	samanthamalunga@gmail.com	Analysis support; comments and review	4%
Nosivuyile Vanqa	nvanqa@sun.ac.za	Analysis support	4%
Tembeka Mhlakwaphalwa	tmhlakwaphalwa@sun.ac.za	Analysis support	3%
Arlene Marthinus	amarthinus@sun.ac.za	Analysis support	3%
Khanyisa Mcimeli	kmcimeli@sun.ac.za	Analysis support	3%
Virginia Bond	gbond@zambart.org.zm	Study design; comments and review	3%
Janet Seeley	Janet.Seeley@LSHTM.ac.uk	Technical advisor; comments and review	3%
Peter Bock	peterb@sun.ac.za	Trial design (PI); comments and review	3%
Richard Hayes	Richard.Hayes@lshtm.ac.uk	Trial design (PI); comments and review	3%
Lindsey Reynolds	lreynolds@sun.ac.za	Conceptualisation support; comments and draft review	8%

Signature of candidate: Declaration with signature in possession of candidate and supervisor. Date: 6 October 2020

Declaration by co-authors:

The undersigned hereby confirm that

1. the declaration above accurately reflects the nature and extent of the contributions of the candidate and the co-authors to Manuscript 5, pages 147 – 182.
2. no other authors contributed to Manuscript 5, pages 147 – 182. besides those specified above, and
3. potential conflicts of interest have been revealed to all interested parties and that the necessary arrangements have been made to use the material in Manuscript 5, pages 147 – 182

Name	**Signature**	**Institutional Affiliation**	**Date**
Graeme Hoddinott	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Samantha Malunga	Declaration with signature in possession of candidate and supervisor.	AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town.	06/10/2020
Nosivuyile Vanqa	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Tembeka Mhlakwaphalwa	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Arlene Marthinus	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Khanyisa Mcimeli	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Virginia Bond	Declaration with signature in possession of candidate and supervisor.	Zambart, School of Public Health, University of Zambia; Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Janet Seeley	Declaration with signature in possession of candidate and supervisor.	Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine.	06/10/2020
Peter Bock	Declaration with signature in possession of candidate and supervisor.	Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University.	06/10/2020
Richard Hayes	Declaration with signature in possession of candidate and supervisor.	Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Public Health, London School of Hygiene and Tropical Medicine.	06/10/2020
Lindsey Reynolds	Declaration with signature in possession of candidate and supervisor.	Department of Sociology and Social Anthropology, Stellenbosch University.	06/10/2020