

**Exploring incident HIV in Pregnant Women and Sexual Risk Behaviours and Practices
in Soweto, South Africa**

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DEDICATION

To Sipiwe, Jerry, Mbali and Kenya

I dedicate this work to my mother Sipiwe, who believed in me even when I had lost hope, whose words of encouragement pushed me for greatness. Who was my first and best teacher, very strong in character yet so gentle in spirit. Thank you mama!!

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TABLE OF CONTENTS

DEDICATION:	iii
LIST OF FIGURES AND TABLES:	viii
LIST OF PUBLICATIONS:	ix
SUMMARY OF THE PhD THESIS:	xi
ACKNOWLEDGEMENTS:	xviii
ABBREVIATIONS:	xxii
GLOSSARY:	xxiv
CHAPTER 1: INTRODUCTION	1
1.0.Background:	1
1.1.New infections:	3
1.2.Rational of the study:	3
1.3.Literature Review:	10
1.4. The burden of HIV incidence among stable relationships in Sub Saharan Africa:	10
1.5. The burden of HIV amongst pregnant women in Sub-Saharan Africa (SSA):	11
1.6. The history of prevention and treatment of HIV in South Africa:	15
1.7. Contemporary South Africa:	19
1.8. Social norms as the structural determinants of health:	22
1.9.Vaginal practices, pregnancy HIV:	28
1.10. Disclosure of HIV and pregnancy:	30
CHAPTER 2: PHD STUDY METHODOLOGY:	35
2.1 Study setting:	35
2.2 Study design	37

2.3. Study population	40
2.4. Study Sample:	45
2.5. Trustworthiness:	47
2.6. Talking about sex in pregnancy: Reflections from the field in urban South Africa:	
2.7. Qualitative studies:	49
2.8. Data management and analysis:	80
2.9. Quantitative studies:	82
RESULTS:	87
CHAPTER 3:HIV, Sex, Sexuality and Agency:	87
CHAPTER 4: Personal support and expressions of care for pregnant women in Soweto, South Africa:	104
4.1. Abstract:	104
4.2. Introduction:	105
4.3. Methods:	107
4.4. Results:	109
4.5. Discussion:	115
4.6. Conclusion:	120
CHAPTER 5: Secrets and disclosure among HIV positive pregnant women in Soweto, South Africa:	130
5.1. Abstract:	130
5.2. Introduction:	131
5.3. Methods:	132
5.4. Results:	133
CHAPTER 6: The roles social networks play in supporting women during pregnancy in Soweto, South Africa	145
6.1. Abstract:	145
6.2. Introduction:	146

6.3. Methods:	148
6.4. Results:	152
6.5. Discussion:	158
6.6. Conclusion:	159
7.0. OVERALL DISCUSSION AND CONCLUSION:	165
8.0. REFERENCES:	179
9.0. APPENDICES:	180
Appendix 1: Ethics University of Basel:	180
Appendix 2: Ethics University of the Witwatersrand:	181
Appendix 3: Information Sheet for pregnant women:	182
Appendix 4: Information Sheet for partner:	189
Appendix 5: Consent form for pregnant women:	195
Appendix 6: Consent form for partner:	198
Appendix 7: In-depth Interview Guide for pregnant women:	201
Appendix 8: In-depth Interview Guide for partner:	214
Appendix 9: Baseline Questionnaire for pregnant women:	224
Appendix 10: Observations Checklist:	237
Appendix 11: Curriculum Vitae:	238

LIST OF TABLES

TABLE 1: Stats SA, 2016

TABLE 2: Qualitative study participants and interviews

TABLE 3: Examples of coding

TABLE 4: Demographic characteristics of participants

TABLE 5: Descriptive characteristics of respondents

TABLE 6: Social support amongst pregnant women

TABLE 7: Factors independently associated with family/friend social support in pregnancy

TABLE 8: Factors independently associated with partner support in pregnancy

LIST OF FIGURES

FIGURE 1: Prevalence of HIV among adults globally

FIGURE 2: WHO 2013 Consolidated guidelines on the use of ARV drugs for treating and preventing HIV infection

FIGURE 3: Map of Soweto, showing Chris Hani Baragwanath Hospital

FIGURE 4: Approximate breakdown of spending on HIV Prevention in different areas

LIST OF PUBLICATIONS

Langelihle Mlotshwa, Sonja Merten, Lenore Manderson. 2017. Personal support and expressions of care for pregnant women in Soweto, South Africa: a qualitative study. *Global Health Action*, 10:1

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Langelihle Mlotshwa and Sonja Merten, (Forthcoming) Pregnant, single, and living in Soweto Johannesburg. In *Connected Lives: Families, households, health and care in contemporary South Africa*, N.Mkhwanazi and L.Manderson. Pretoria, SA: HSRC Press.

Langelihle Mlotshwa, Lenore Manderson, Charles Chasela, Sonja Merten (in review) Secrets and disclosure among HIV positive pregnant women in Soweto, South Africa. *AIDS Care*.

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**As long as poverty, injustice and gross inequality persist in our world,
none of us can truly rest**

Nelson Mandela

SUMMARY

HIV infection is an important risk for maternal and neonatal morbidity and mortality, which can, however, be mitigated by timely initiation of antiretroviral therapy (ART) (Sturt 2010, Liotta et al. 2013). Prevention of Mother to Child Transmission (PTMCT) and Anti-Retroviral Therapy (ART) coverage have increased in the last few years, leading to a decrease in maternal mortality in some countries within sub-Saharan Africa, and to a decrease in new infections from 2,4 million to 1,8 million in the region. Still, many women in need of medication do not access ART. In addition to failure to access ART, there may be other continued risks of HIV infection during pregnancy, particularly in low resource settings, for behavioral and biological reasons. There is increased risk of HIV where women have lesions from trauma (from forced sex), intra-vaginal practices, or from herpes reappearing as a result of immunological changes during pregnancy. In sub-Saharan Africa, the high prevalence of HIV infection among pregnant women makes the interaction between HIV and other maternal morbidities an important public health issue. Further HIV/AIDS not only affects the health of individuals but also impacts on households and communities, and on the development and economic growth of nations. The damage caused by HIV/AIDS is unique because it denies young children the opportunity to grow up normally as they may have to take on responsibilities for their parents and have to leave their childhood. The epidemic has found a wealth of opportunities to thrive in the context of constrained and tragic human conditions, fuelled by poverty, abuse, violence, prejudice and ignorance.

Sexuality is lived and practised within the context of local sexual cultures. Different cultures and traditions influence behaviour in particular ways, both normative ways that are accepted and alternative ways that are not accepted by local values and traditions. High risk behaviour is embedded in a wider sexual culture, and extends to and is influenced by economic factors and social structures, in turn shaped by the societies in which individuals live. Gender

inequality and gender based violence lie in the patriarchal nature of societies and the idea of masculinity as dominant, wherein women are subject to the control of men. The behaviours that flow from hegemonic masculinities, as defined by Connell and Messerschmidt (Connell and Messerschmidt, 2005), and subordinate femininities, place women at particular risk of HIV infection. These include intergenerational sex, where women have sex with older men, transactional sex (especially associated with the acquisition of HIV), gender based violence, and substance abuse, especially among women of lower socio-economic status living in crowded, impoverished and constrained circumstances. Masculinity is an important factor in risky behaviours, sexual predatory practices and violence against women in many societies; although in this thesis the focus is primarily on women and their risky behaviours.

Many programs have been introduced to reduce the risk of transmission of HIV, by promoting HIV testing, male circumcision, condom use, and the timely diagnosis and treatment of sexually transmitted infections (STI). There is also a continued need for community mobilization aimed at changing social norms and behaviors within communities. Unfortunately, sexual behaviour during pregnancy and recognizing the extent to which men and women understand the risk of HIV and STI infection in pregnancy is understudied. Little is known about the actual sexual practices of men and women, the social norms surrounding these practices, and reasons for risk-taking during pregnancy. It is unclear whether particular patterns of sexual behaviour are associated with incident HIV during pregnancy, apart from the mediating effect of condom use or cessation of use. More information about sexual cultures and norms during pregnancy and behavioural causal pathways are urgently needed, for example, on reasons for forced sex (if at all) and changes in patterns of sexual partnering (including multiple partnering and transactional sex) by both men and women during part or all of pregnancy, for a range of reasons. The aim of this thesis was to explore and understand

the sexual behaviour of women who acquire HIV during pregnancy, and of their partners, comparing this to the behaviour of women without HIV and their partners.

This PhD was nested in a study entitled “Incident HIV in pregnant women and sexual risk behaviours and practices in urban South Africa,” which in turn was nested within a larger prospective cohort study, the 1st 1000 days study, which followed women and their infants for up to 24 months after delivery at Chris Hani Baragwanath Hospital, in Johannesburg, South Africa. A life history approach was employed to explore in-depth the sexual behaviour of pregnant women and their partners in their local socio-cultural context. All pregnant women attending ANC at Chris Hani Baragwanath Hospital in Johannesburg, South Africa, over 18, who consented, were invited to participate. On agreement, if they had HIV negative antibody test results at the time of their first ANC visit, they were enrolled in the study. A subset of women who became HIV positive during this pregnancy were the cases, thus the sample was stratified for women and their partners, and for acute HIV infection and HIV-negative persons, leading to four subgroups of participants. For each of these subgroups at least 15 persons were envisaged to be interviewed, unless saturation was reached beforehand. A total of 30 women were interviewed, but only three partners.

As part of the methods, in an article entitled Talking about sex in pregnancy: Reflections from the field in urban South Africa published in *Culture, Health and Sexuality*, I explore how qualitative research involves close engagement between researchers and their interlocutors to build relationships of trust, to enable the collection of meaningful information. In doing this, researchers need to tap into a place of privacy that allows for personal talk, as was the aim of this research. The accounts that people provide deal with often deeply troubling issues, partly reflecting the stigma that surrounds HIV, silence within the family around HIV, and the blame attributed to individuals for infection. In South Africa, the challenges of living with HIV, and the threat of HIV within a relationship, is very real because of its high prevalence. This is

complicated by insecurity in relationships. In many circumstances, researchers do not have adequate training to deal with sensitive issues; the content of respondents' accounts of poverty, violence, fear, and distress become overwhelming as they elicit, listen and reflect on them. Women and men struggle to balance risk of infection while maintaining healthy interpersonal and intimate relationships.

Talking about the social meanings of sexuality, HIV infection, and sexual practices is difficult, primarily because these are sensitive and at times embarrassing issues. These issues all affect wellbeing and are complex to address, especially in pregnancy when women may feel vulnerable and need to be cared for as they manage this life changing period. The main conclusions of this work are based on exploring the different behaviours and practices amongst pregnant women and their partners, the latter largely reported on by their partners. These factors potentially influence HIV in pregnancy. In this research and in the published articles, we highlight possible new evidence, as well as evidence that shows little or no change within communities, despite interventions that have been put in place to assist in the prevention of transmission of HIV in pregnancy. The key contribution of this thesis is understanding how there are more complex issues that occur in intimate relationships and HIV: how couples can claim to be close in a relationship but unable to negotiate sex and condom use in pregnancy, the difficulty of honesty in many relationships which contribute to the infection rate in couples. and ultimately what this means to the prevention of mother to child transmission programs. Further this works complements already available literature on sex, pregnancy and HIV.

In **Chapter 3**, I describe the characteristics of all study participants and reflect on some of the important issues they discussed: condom use; men's sexuality before and during pregnancy; testing for HIV and what it means for the couple; abandonment; and male involvement in a society in which traditional beliefs about gender still pertain. This chapter explores all data that has not been published to give a clear overview of all participants.

In **Chapter 4**, in a published article entitled “Personal support and expressions of care for pregnant women in Soweto, South Africa,” I illustrate how important care and support is in relationships but that is often limited from the male partner. Many pregnant women identified their partner as key to support their pregnancy, but he was often not part of the pregnancy for a variety of reasons. This made dealing with the pregnancy bittersweet - the joy of having a child was overshadowed by the frustration women experienced of having to deal with hard times alone. This article discusses policy implications in South Africa in order to improve how pregnant women manage different challenges during pregnancy. Policy reforms in South Africa may need to address social support as important for pregnant women, to manage the emotional and personal as well as economic difficulties that they experience during pregnancy. I recommend the need to build bonds in different social settings with other pregnant women as a way by which help could be provided to deal with challenges -- way for pregnant women to team up and talk about the different challenges they face, and to receive practical support, so reducing anxiety and depression. Such support may be provided by support groups organised at hospitals and clinics, as occurs in the Philani intervention programme in Khayelitsha Cape Town, where women can share personal concerns. On the other hand, women worried that in this context, they could be the subject of gossip. Self-help groups and mentoring programmes for women during pregnancy and after delivery could prove important in such situations. As many women have strong religious affiliations, they may also find support through self-help groups in church settings, with mentorship and encouragement by older women to help them better cope with pregnancy and early infant care.

In **Chapter 5**, I consider disclosure as an important step in establishing support for adherence to the prevention of mother to child transmission (PMTCT) interventions and the negotiation of safer sex practices among couples. Disclosure can improve health outcomes for women and their infants during and after pregnancy by preventing HIV transmission between partners and

re-infection. However, women with HIV have to think through the implications for themselves, their partner and others, fearing that disclosure may lead to violence. Using case studies, I explore the lives of two women from different backgrounds, who after getting infected, needed to make decisions for themselves, their partner and the unborn child. The HIV diagnosis changed their lives in ways they never would have imagined, but they still needed to move on with their lives. Little attention has been given to the challenges of disclosure for women who become positive during pregnancy, when the implications include their need to initiate treatment to prevent parenteral transmission. Step-by-step guidance in pregnancy and after receiving a diagnosis of positive HIV status can assist women to disclose, reducing some of these complexities.

Chapter 6 In this chapter I illustrate the importance of social networks in the context of HIV using quantitative methods. Social support networks play an essential role in the creation, maintenance and promotion of good health, showing positive effects on incidence, prevalence and persistence of diseases and are necessary for strong mental health.

This thesis gives more insight on sexual risk behaviours and practices of both men and women during pregnancy in urban South Africa. Sexuality is lived and practiced within the context of local sexual cultures. Different cultures and traditions influence behaviour in particular ways, whether or not it is considered acceptable by local norms and traditions. In the context of HIV diagnosis, there is further complications as women try to deal with the new HIV infection, and questions of disclosure, support, intimacy, trust, violence and negotiating safer sex spaces for themselves and their partners. The challenges that exist for both women and men in securing and maintaining long-term relationships, and their fear of loss of current partners, complicate their efforts to address issues of HIV risk and sex in pregnancy. There is a lack of an environment to talk about these issues, even within established intimate relationships. Lack of or limited psychosocial support further means that many women and men have few skills to

begin such discussion, and so they remain silent. This silence may affect HIV prevention and access to treatment and counselling programmes. In many instances, men feel that hospital and clinic spaces belong to women as they (men) are supposed to show lack of fear and strength, as they are the protectors of the home. Yet they too suffer from many fears, which makes them react in the many ways they do towards their partners and to researchers when we attempt to speak with them.

In conclusion, this thesis accentuates the need for policy reforms in South Africa and similar contexts to address the importance of sexual risk behaviours and practices, and to provide support in pregnancy to manage the emotional and personal difficulties during and post pregnancy. This may be through support groups organised at hospitals and clinics, where both men and women could share personal concerns, although as noted above, women worried that in this context, they could be the subject of gossip, and men in African cultures do not speak about problems or personal issues bothering them. Self-help groups and mentoring programmes should be an important component for women and men during pregnancy and after delivery. Further research can include more men; in this current study we attempted to do but there was a high refusal rate. Exploring and understanding men can also improve knowledge in understanding sexual risk behaviours and practices in pregnancy.

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Langelihle Mlotshwa

Basel, Switzerland, May, 2021

Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral (drug)
AZT	Azidothymidine
CHW	Community Health Workers
DBS	Dried blood spot
DoH	Department of Health
DSD	Department of Social Development
FAO	Food and Agricultural Organization
FTC	Emtricitabine
GBV	Gender Based Violence
GF	Global Fund
HAART	Highly Active Antiretroviral Treatment
HBC	Home Based Care
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HST	Health Systems Trust
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
MMC	Medical Male Circumcision
MRC	Medical Research Council
MTCT	Mother to Child Transmission
MTEF	Medium Term Strategic Framework
NDoH	National Department of Health
NGO	Non-Governmental Organisation
NHLS	National Health Laboratory Services
NICD	National Institute for Communicable Diseases

NSP	National Strategic Plan
NVP	Nevirapine
PEPFAR	Presidential Emergency Plan for AIDS Relief
PLHA	People Living with HIV and AIDS
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
SANAC	South Africa National AIDS Council
SDG	Sustainable Development Goals
SNSF	Swiss National Science Foundation
SSPH	Swiss School of Public Health
Swiss TPH	Swiss Tropical and Public Health Institute
STI	Sexually Transmitted Infections
TB	Tuberculosis
TDF	Tenofovir
UNAIDS	United Nations Joint Programme on AIDS
USAIDS	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
ZDV	Zidovudine

Glossary

Access to health services: How easy or difficult it is to get to a facility for a service, taking into account affordability, location, time, and ease of approach.

Affordability: The costs incurred by individuals to access a service from direct costs, for example, doctor's fees, travel and medical costs and from indirect costs, such as time lost from work.

Availability of service: This term refers to the delivery (or availability) of services at peripheral level health care units (i.e. primary health care units).

Coverage: The level of interaction between individuals needing the service and the actual service. It ranges from resource allocation to the actual achievement of the desired goal.

Emotional involvement: Psychological association or immersion in the stories that were shared by participants

Health care personnel: Health care providers in different sectors assisting individuals medically, for example, clinics, hospitals

Health care worker: An individual involved in health provision to service users; this excludes health care provider but includes lay counsellors and community caregivers.

HIV-exposed infant: An infant born to an HIV-positive mother and/or having a positive HIV antibody test result using DBS EIA, an HIV-exposed infant who has a positive HIV DNA PCR result.

HIV status unknown: Individuals who do not know their HIV test result or have not taken the test; this includes children and adults.

Infant: A child from birth to 12 months of age.

Intangible support: Care that cannot be seen, that is not material, for example emotional, psychosocial, and perceived or received support and care.

Mother-to-child transmission (MTCT): transmission of HIV from an HIV-positive woman during pregnancy, delivery or breastfeeding to her child.

MTCT rate: The extent to which infants are HIV infected for every HIV positive pregnant woman giving birth.

Partner intimacy: Affection given to a pregnant woman by spouse or partner

Partner Involvement: Proactive partner or spouse in pregnancy, ranging from physical, emotional, and other types of care and support needed by pregnant woman

PMTCT service acceptability: the level in which the Prevention of Mother to Child Transmission service meets the social and cultural needs of the community, which in turn plays an important role in how those in need of the service use it.

Social support: This includes both tangible and intangible care offered by a range of individuals including family, friends, co-workers and others.

Sensitive subjects: Talking about matters that are private and not normally spoken about especially with strangers

Single-parent households: A parent who lives and raises children in a household without the other parent of the children, and who incurs most or all of the costs of living for everybody in that particular household.

Tangible care: Support or maintenance that is physical or material, for example money, shelter, clothing, and food.

Universal access/coverage: This term is defined as at least 90% pregnant women accessing PMTCT.

Uptake of PMTCT services: The use of PMTCT services by pregnant women

Utilisation of health services: The experience of people as receipts of health care services of different types.

CHAPTER 1

Introduction

HIV remains a major health issue globally. Since the epidemic started, about 78 million people have become infected with HIV and 35 million have died from AIDS related illnesses (UNAIDS, 2017d, 2018a). In 2016, it was reported that around 36,7 million people were living with HIV of whom 1,8 million were children, with a global prevalence of 0,8% among the adult population (UNAIDS, 2017d). The vast majority of people living with HIV reside in low- and middle- income countries. An estimated 25,5 million living with HIV and 66% of new HIV infections in 2015 occurred in Sub-Saharan Africa . Of these, 19,4 million people live with HIV in Southern and East Africa; and an estimated 800 000 new infections reported in 2017 globally are in this region (AVERT, 2017a; UNAIDS, 2018a). However, there has been a significant reduction in new HIV infections between 2010 and 2017 in the Sub-Saharan Africa due to the sharp reduction in eastern and southern Africa reporting a 30% decline (UNAIDS, 2018b). The expansion of antiretroviral therapy (ART) coverage has improved resulting in an increase in the number of people living with HIV (PLHIV). South Africa is responsible for a third of all new HIV infection in the Southern Africa region (AVERT, 2017b, 2019). The country has the largest HIV epidemic profile in the world, accounting for about 7,2 million people living with HIV in the year 2017 (AVERT, 2019; UNAIDS, 2017c). The country also has 3,2 million people accessing ART the largest number of HIV positive people in the world on antiretroviral (Nakkazi, 2019).

Every year over 300,000 mothers die from complications of pregnancy and childbirth, and about 830 mother per day with 99% of all maternal deaths occurring in the developing world (WHO, 2015d, 2018c). HIV infection is an important risk for maternal and neonatal morbidity and mortality, which can, however, be mitigated by the timely initiation of ART (Liotta et al., 2013;

Sturt, Dokubo, & Sint, 2010). Some of these deaths (13%) are HIV related (WHO, 2018a, 2018c), and headway is continuously being made in keeping mother and children alive particularly through Prevention of Mother to Child Transmission (PMTCT). PMTCT plays a crucial role in reducing the risk of death from HIV in pregnancy, and preventing transmission of HIV to the foetus or the infant during birth.

PMTCT and Anti-Retroviral Therapy (ART) coverage have increased in the last few years, leading to a decrease in maternal mortality in some countries within sub-Saharan Africa (WHO, 2014) and to a decrease in new infections from 2,4 million to 1,8 million in the region in the adult population (UNAIDS, 2017c). In 2015, 77% of pregnant women globally had access to ART to prevent transmission of HIV to their babies and about 80% reported in 2017 (WHO, 2018d). Yet despite this, many women in need of medication do not (and may not be able to) access ART, especially where need is highest, in particular African countries where many live in poverty. The failure to access ART means there may be other continued risks of HIV infection during pregnancy, particularly in low resource countries, for behavioural and biological reasons (Tang & Nour, 2010). In the absence of any intervention, transmission rates from mother to the unborn child can be high, ranging from 15%-45%; the success of PMTCT interventions means reducing transmission to below 5% (AVERT, 2017a).

HIV/AIDS does not only affect the health of individuals but also impacts on households, communities and the development and economic growth of nations. The damage caused by HIV/AIDS is unique because it denies families, communities and the entire population of their young as well as the most productive people in the society (FAO, 2002, 2003). The epidemic has found a wealth of opportunities to thrive among tragic human conditions fueled by poverty, abuse, violence, prejudice and ignorance (Lyons, 2008). Further social and economic circumstances

contribute to vulnerability to HIV infection, intensifying its impact. Several of the countries most affected continue to also experience high prevalence of other infectious diseases, food insecurity and other problems that enable the epidemic to thrive.

New infections

An estimated 1,8 million people worldwide were newly infected in 2016, a decline from 2,1 million from the previous year (UNAIDS, 2018a). This estimate is inclusive of children (160 000) aged <15years, most of who live in the sub-Saharan Africa region and were infected by their HIV positive mothers during pregnancy, childbirth or breastfeeding (AVERT, 2017a). Younger women are at higher risk of infection than young men, representing 59% of incident HIV in the ages of 15-24, because of biological, social and behavioural factors (Muula, 2008; Nkosana & Rodenthal, 2007; UNAIDS, 2017e). These factors include intergenerational sex; partners culturally allowed to have multiple partners; early marriage some studies have shown this to increase risk; older men who seek out virgin girls as there is a belief in some contexts that virgins cure sexually transmitted diseases; poverty (which may or may not be linked to intergenerational sex); and finally physiological susceptibility to infection than older women due to the lining of the vagina that is thinner, vaginal mucus may be less profuse (Leclerc-Madlala, 2008; Muula, 2008; UNAIDS, 2017e). New infections among adults before 2010 were raising concerns, as they seemed to be increasing; however between 2010 and 2015, the annual numbers of new infections among adults remained static. New infections among children globally reduced by almost half from 2010 to 2016, accounting for a drop from a total of 300 000 to 160 000 respectively. However, researchers have indicated that much more work needs to be done to improve knowledge of HIV/AIDS and HIV testing, particularly among adolescents and young adults (UNAIDS, 2016b, 2017e). With all this progress in the decline of new infections, there is still fear that combating

viral transmission is still not happening quickly enough to meet global targets (UNAIDS, 2017b). Data from different countries show large discrepancies in efforts to slow the spread of new infections, with some countries having achieved a decline of 50% or more in new HIV infections among the adult population over a decade, while in many other countries there has been no measurable progress (UNAIDS, 2017b), South Africa has made good progress in reaching goals as the government sets in to support many HIV programmes in the country.

Behavioural and biological factors in pregnancy play an important role in the spread of HIV (Hahn, Woolf-King, & Muyindike, 2011; Mugo et al., 2011). HIV-negative pregnant women, whose partners are HIV positive, may be more susceptible to HIV transmission as their immune system is compromised in pregnancy (Mbizvo, Msuya, Stray-Pedersen, & Chirenje, 2001). The infection rate increases because of biological factors such as high levels of oestrogen and progesterone (Gray et al., 2005). The hormonal changes that occur during pregnancy which are necessary to support a healthy pregnancy contribute to risk for infection (Robinson & Klein, 2012). The change that occurs in the level of hormonal increase contributes to a shift in immune function during the time of pregnancy, increasing vulnerability to infectious and autoimmune diseases (Robinson & Klein, 2012). In addition, men who have sex with pregnant women have a higher risk of being infected (Mugo et al., 2011; Villar-Loubet, 2013); this was demonstrated in a large multi-centre study in seven African countries between 2004 and 2007, which found an increase in the rate of female-to-male transmission during pregnancy (Mugo et al., 2011). This has been explained as a result of behavioural risk factors: primarily, men seek other sexual partners and if women become less sexually active as their pregnancy progresses (Kilian et al., 1999; Lawoyin & Larsen, 2002; Moodley, Esterhuizen, Pather, & Ngaleka, 2009).

Sexuality is lived and practiced within the context of local sexual cultures (Burchardt, 2011). Different cultures and traditions influence behaviour in particular ways, with a range of behaviours and practices accepted or not by local norms and traditions. High risk behaviour is embedded in a wider sexual culture (Dietrich, Khunwane, Laher, & de Bruyn, 2011), and extends to economic factors and social structures, in turn shaped by the patriarchal societies in which individuals live. Gender inequality, including its expression through gender-based violence, lies in the patriarchal nature of the societies and the idea of a hegemonic masculinity wherein women are subject to the control of men (Jewkes & Morrell, 2010). Research in South Africa, where gender inequality is particularly visible, has revealed that hegemonic masculine ethics are critical to heterosexual performance, boldness and strength (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Jewkes & Morrell, 2010). Further, heterosexual performance is based on being able to control women, which may lead to physical and sexual violence as a way to affirm this authority (Jewkes, Sikweyiya, Morrell, & Dunkle, 2011b). This in its own way continues to place women in vulnerable positions. They are therefore vulnerable to HIV infection particularly if they are pregnant, alone and afraid. Behaviours which may place women at particular risk of HIV infection include intergenerational sex, where women have sex with older men who are more likely than young men to be infected (Muula, 2008); transactional sex whereby women are more likely to be exposed to partners with HIV and to acquiesce to sex without protection; gender-based violence associated both with exposure to men with HIV and to increased risk of infection through physical trauma; and substance abuse, especially among women of lower socio-economic status, which reduces the likelihood of the ability to negotiate protection (Dunkle et al., 2004). Masculinity is an important factor in risky behaviours, sexual predatory practices and violence against women in many societies, including South Africa (Jewkes, Dunkle, Nduna, & Shai, 2010;

Jewkes & Morrell, 2010; Jewkes, Morrell, Hearn, Lundqvist, & Blackbeard, 2015). As noted above, masculinity is hegemonic and rooted in patriarchy, ensuring that men are superior to women (Connell, 1987; Courtenay, 2000; Jewkes et al., 2015; Sikweyiya, Jewkes, & Dunkle, 2014), suggesting that men are supposed to be strong and tough, head of the household and provider. This boldness can be demonstrated through engaging in risky behaviors such as having multiple partners (Jewkes, Sikweyiya, Morrell, & Dunkle, 2011a; Jewkes et al., 2011b; Sikweyiya et al., 2014). However, this boldness should happen without experiencing any consequences such as contracting HIV, which may be viewed or considered as weakness (Lyons, 2008; Skovdal et al., 2011). This understanding means that contracting HIV reflects an insufficient form of masculinity, leading to violence by men if they are questioned about acquiring HIV infection within a relationship (Jewkes et al., 2010).

Effective treatment with antiretroviral drugs can control the virus, so reducing the risk of transmitting the virus to others and ensuring that people with HIV can enjoy healthy lives. Yet even with advances in the scientific understanding of HIV, and years of substantial effort by the global health community, governments and civil society organizations, still many people living with HIV or at risk for HIV do not have access to prevention, care, and treatment. Many programs have been introduced to promote HIV testing and to address other risk factors, including male circumcision, condom use, and the timely diagnosis and treatment of sexually transmitted infections (STI). Continued community mobilization aimed at changing social norms within communities is still needed. Unfortunately, sexual behaviour during pregnancy and recognizing the extent to which men and women understand the risk of HIV and STI infection in pregnancy is understudied. To overcome barriers caused by gender inequality, more information about sexual cultures and norms during pregnancy and behavioural causal pathways are urgently needed, for

example, reasons for increased forced sex and changes in patterns of sexual partnering (including multiple partnering and transactional sex) by both men and women during part or all of pregnancy.

South Africa has one of the largest domestically funded HIV programmes, with about 80% of total costs funded by the government. In the year 2016, South Africa reported 270 000 new HIV infections and around 110 000 AIDS related deaths (UNAIDS, 2018a). Among the 7,1 million people living with HIV, about 56% were accessing antiretroviral therapy (ART), with approximately 45% having suppressed viral load (UNAIDS, 2018b). Among expectant mothers living with HIV >95% were accessing treatment or prophylaxis to prevent transmission of HIV to their infant. Around 20 000 infants were estimated to be newly infected due to mother to child transmission(UNAIDS, 2017b). Although South Africa has successfully rolled-out antiretroviral therapy nationwide, challenges remain in trying to mediate timely access to treatment and care for people living HIV (Church et al., 2017). Some of the strategies that have been put forward to assist in treatment and care are at different levels, that is health service delivery strategies, community based strategies, health system interventions and strengthening research capacity as a way of bridging the gaps that exists in the implementation of prevention of mother to child transmission and HIV (Ngidi, Naidoo, Ncama, Luvuno, & Mashamba-Thompson, 2017).

South Africa has gone beyond trying to address the issue of HIV in the country. The Government has committed itself to action “with confidence, bravery and certainty” in combating the greatest health challenge that the country has experienced and to try to meet the SDGs by 2030 (South African National AIDS Council, 2017). The Government of South Africa has embarked on a careful effort to scale up HIV testing services and strengthen the quality of the HIV testing services within health facilities and non-health facilities (Barker et al., 2007; Naidoo et al., 2017; National Department of Health, 2009, 2010b). Prevention efforts to reduce HIV continue to

include behavioural programmes, for example education around HIV/AIDS and pregnancy, structural interventions such as livelihood training for pregnant women as a way to reduce dependency on their partners, and biomedical interventions which include making ART readily available to all pregnant women in an effort to tailor programmes to be context specific (Ambia & Mandala, 2016; Hart, Iskarpatyoti, Mandal, & Thomas, 2016; UNAIDS, 2010). Reducing HIV incidence over time is important, but for this to occur or results to be seen extensive scale up of combination HIV prevention programmes are needed (Hart et al., 2016; L. F. Johnson et al., 2012). Behavioural programmes needed for prevention include education at different levels for better understanding of the epidemic, which then may be translated to actual results of the reduced incidence of HIV.

Rationale of the study

South Africa has one of the highest number of women infected with HIV/AIDS in the world (National Department of Health, 2017). In 2010 it was estimated that 30,2% of pregnant women attending public health care facilities in South Africa were infected (Barron, Pillay, Doherty, Sherman, Jackson, et al., 2013). Moodley et al. (2011) reported in their study that many pregnant women were infected during the course of their pregnancy and children born to women with incidence HIV were 2,3 times at higher risk of being infected (Moodley et al., 2011). Understanding the risk of HIV acquisition during pregnancy pivots on many behavioural and biological issues. These include among both sero-discordant and sero-concordant couples, fidelity (or not) of both partners during pregnancy, intra-vaginal practices and the implications of this in relation to STIs including HIV, and changes of sexual frequency and its impact on the couple. The way individuals behave cannot be considered in isolation from their socio-cultural and socio-economic context. Complimentary comprehensive information on sexual cultures during

pregnancy is critically needed. This study contributes to identifying individual and structural prevention approaches, including addressing men's sexual behaviour from both the men themselves but also from the perspective of their pregnant partners and socio-cultural norms to clarify the casual chain infection during pregnancy, as a way to better address HIV during pregnancy and strengthen PMTCT programs within South Africa and similar contexts.

Study aim and research objectives

Aim

The aim of the study was to explore and understand the sexual behaviour of women who acquire HIV during pregnancy, and of their partners, comparing this to the behaviour of women without HIV and their partners.

Specific Objectives

- To describe and analyse pregnant women's and their partners' life history, and to identify and understand how socio-economic status and livelihood strategies influence sexual practices, before and during pregnancy.
- To describe and analyse social norms and sexual practices during pregnancy, and the reasons for changes in practices among couples, if any.
- To describe and analyse the impact of receiving a HIV positive diagnosis on a couple's relationship, and the implication of this for livelihoods.
- To describe and analyse pregnant women's and their partners' perceptions of the reasons for the HIV infection.

- To identify and contrast the sexual behaviour of women and their partners who acquire HIV during pregnancy with those of women and their partners without HIV.

LITERATURE REVIEW

The burden of HIV incidence among stable relationships in Sub Saharan Africa (SSA)

Reports show that in Sub-Saharan Africa many adults are in stable marital or cohabiting heterosexual relationships, and HIV prevalence amongst this group is substantial (Chemaitelly, Awad, Shleton, & Abu-Raddad, 2014). Almost two-thirds of total HIV incidence in Sub-Saharan Africa occur among cohabiting or married couples in stable relationships (Chemaitelly, Awad, Shelton, & Abu-Raddad, 2014; Chemaitelly, Cremin, Shelton, Hallett, & Abu-Raddad, 2012). In some studies conducted in the SSA region, authors noted that half of the incidence reported was attributed to HIV transmission from the infected to the uninfected partner in the couple. The attribution of the rest of the HIV was acquired through extra-marital intercourse. Many of these stable couples were mostly found to be HIV discordant (referring to one partner testing HIV negative and the other testing positive) (Baryarama et al., 2007; Bunnell et al., 2008; Guthrie, De Bruyn, & Farquhar, 2007; Lingappa et al., 2008). Accordingly, this means that stable couples constitute a vital target population for HIV prevention efforts, more so in the context of pregnancy within the region. Transmission of HIV within couples can be minimized by interventions such as voluntary HIV counselling and testing (VCT), encouragement of the use of condoms, and antiretroviral therapy (ART) (J. Burton, Darbes, & Operario, 2010; Sweat et al., 2000). This can further protect the unborn child in pregnancy.

The burden of HIV amongst pregnant women in Sub-Saharan Africa (SSA)

HIV continues to be one of the main health and social challenges in Sub-Saharan Africa, although there have been efforts to curb its transmission and its associated morbidity and mortality health outcomes. The region remains the epicentre of the epidemic as a greater number of HIV infections is concentrated there, with Southern African and East African regions most affected with 46% of new cases in this region (AVERT, 2017a; UNAIDS, 2017c). Surveillance stations of HIV prevalence amongst pregnant women attending antenatal clinics were established in the early 1990s in some countries, to assist in better quantifying and observing HIV in sub-Saharan Africa (Eaton et al., 2014). Maternal mortality estimates in recent years are beginning to show a decrease worldwide, although concern is still high for many countries in Sub-Saharan Africa (WHO, 2014), here up to 60% of women are living with HIV (UNAIDS/WHO, 2009). About 1,5 million infections and 1,1 million AIDS related deaths were reported in 2013 (UNAIDS, 2013). Further reports indicating a decline in new infections due to access to ART treatment and behavioural interventions have contributed to this reduction (UNAIDS, 2017a). Still, enormous variations between men and women across the region exist. HIV prevalence varies from 0,4% in Senegal, to 4,7,% in Tanzania, to 18,9,% in South Africa, to 27,2% in Swaziland (UNAIDS, 2017c) (Figure 1). In countries like Swaziland, more than 30% of women are HIV positive, compared to 20% of their male counterparts (UNAIDS, 2018a), while in South Africa prevalence has increased indicating that many people are no longer dying with illnesses relating to HIV (Stats SA, 2017/2018, 2018b). This increase is mainly due to the combined effect of new infections as well as a successfully expanded antiretroviral treatment which assists survival for many people who are living with HIV (Stats SA, 2018b). Further not only in South Africa but in the Southern and Eastern region of Africa Anti-Retroviral Therapy (ART) coverage improved through the years. Coverage in 2010 was reported at 24% and in 2015 was reported at 54% ,reaching a regional total of 10,3

million people (Stats SA, 2018b). A further improvement is still needed for the region to further decrease the infection rates of the epidemic.

Not all pregnant women who are HIV infected are aware of their status, due to lack of antenatal care where routine testing is done; many women in rural areas deliver outside the hospital and have no health care prior to this time (Kongnyuy et al., 2009; van Dillen, Meguid, & van Roosemalen, 2006). Roger et al. (2006) in their study in Southern India reported that some pregnant women do not want HIV testing for fear of stigmatization if the test is positive, and concern that others would ask them why they chose to test (Rogers et al., 2006). Similarly, Mseleku and colleagues (2005) reported that in South Africa, 44% of women refused routine antenatal testing compared to 29% in the overall population (Mseleku, Smith, & Goudozzi, 2005). Although this requirement of routine testing over at least two visits is recommended nationally (DoH, 2010), testing of HIV negative women at follow up antenatal visits is rarely implemented and women often do not attend the number of antenatal visits they are supposed to (Moodley et al., 2009). This means many women can seroconvert without being detected early enough to protect the child. Further, many countries still lack a complete registration system with good attribution of cause of death, thus making it difficult to track patterns of maternal mortality (Say et al., 2014).

According to UNAIDS, there was a decrease in new infection for HIV and other AIDS related deaths within the Sub-Saharan region (UNAIDS, 2017c). This indicates that many countries are moving towards the Sustainable Development Goals (SDGs), although some continue to struggle with new infections. In some instances this is due to the risky behaviour in which many people engage that has increased the incident rates, for example, low and irregular condom use and multiple concurrent sexual partners (Kanda & Mash, 2018; Madiba & Ngwenya, 2017; Manyapelo et al., 2019; UNAIDS, 2016a). For many young people, the challenges of lack

of high quality prevention services such as HIV, sexual and reproductive education and health services, and sexual violence against women and young children seems to have increased (Jewkes & Morrell, 2010; Mazur, Brindis, & Decker, 2018; Odo, Samuel, Mwangi, Nnamani, & Atama, 2018; UNAIDS, 2019).

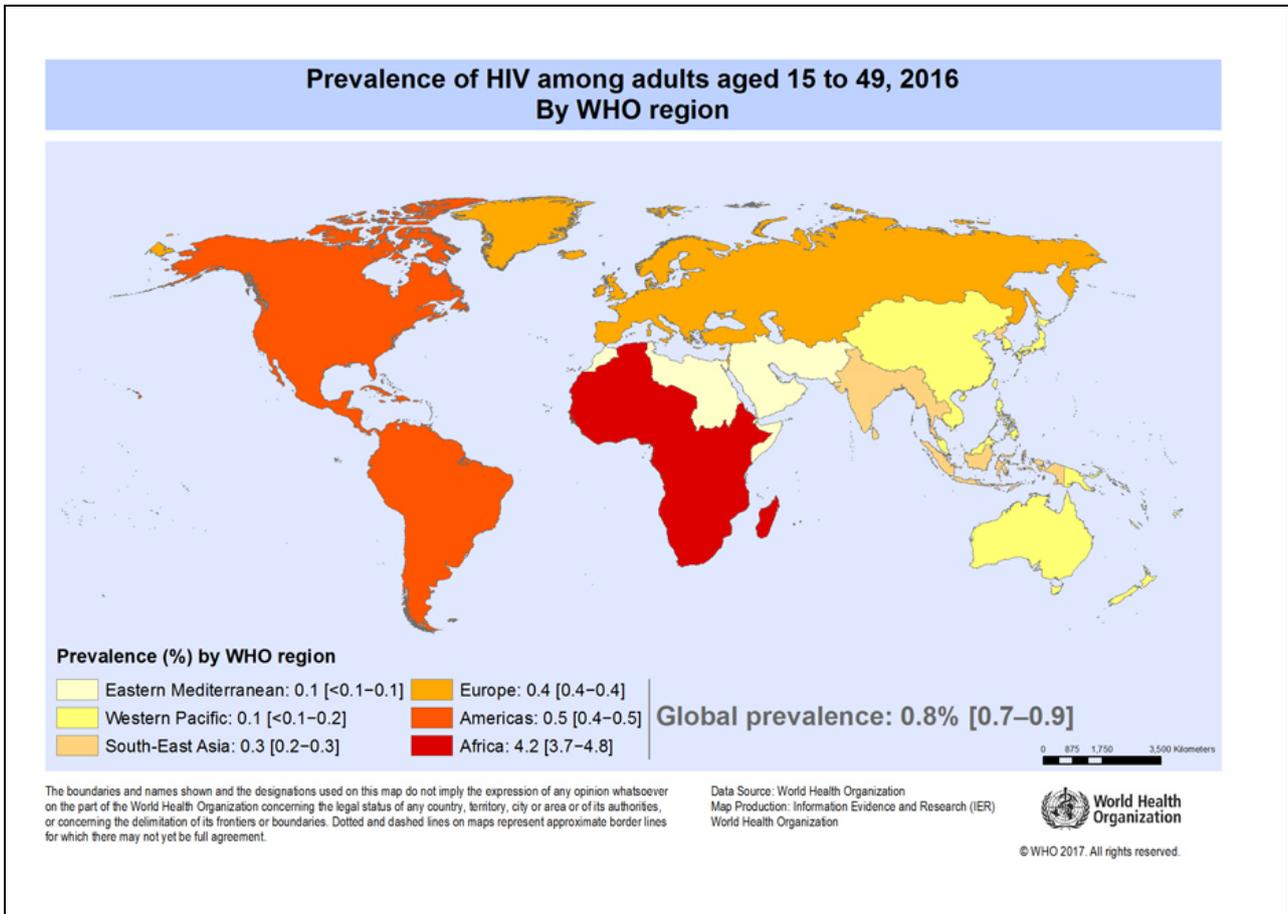


Figure 1 Prevalence of HIV among adults globally

South Africa, like many sub-Saharan countries, has a large population of young women who are at great risk of being infected with HIV (AVERT, 2019; Muula, 2008; WHO, 2019). The high prevalence in this country is because of multiple factors including: poverty, violence against women, cultural practices that promote intergenerational sex, non-condom use, preference for ‘dry’ sexual practices, political factors against HIV, and biological factors such as hormonal

changes affecting the genital tract mucosa or immune system (Abbai, Wand, & Ramjee, 2016; Bradshaw et al., 2008; Gray et al., 2005; Kaul et al., 2011; Moodley et al., 2011; Muula, 2008; Santelli et al., 2013; Wand & Ramjee, 2010). These factors play important roles in the incidence of HIV. Poverty increases the risk of infection as many of the times women feel they have no say in decisions such as condom use as they are financially dependent on their partners (Steinert, Cluver, Torres, & Romero, 2016; Tladi, 2006). Another study reported how sometimes the bread winner of a household may fall sick because of HIV, leading to women in the family resorting to prostitution as a way to make some money to take care of the family, so increasing the risk of infection (Marshall, Shannon, Kerr, Zhang, & Wood, 2010; Shisana, Rice, Zungu, & Zuma, 2010). Further evidence also shows that vulnerability to HIV/AIDS in South Africa is linked to socioeconomic inequality, gender, educational and economic accomplishment (Shisana et al., 2010). In some studies, poorer women have lesser knowledge of HIV/AIDS compared to their wealthier counterparts, and poorer women were more likely to engage in riskier sexual practices with their recent partners (Booyesen & Summerton, 2002; Pascoe et al., 2015; Tladi, 2006).

While some researchers argue that biological factors have played a dominant role in the incidence rate (Gray et al., 2005), others argue that behavioural patterns of both men and women have predominantly contributed to new infections (Lawoyin & Larsen, 2002). It is important to understand the factors that contribute to the incident rates, in order to save the lives of women, men and children. Sexual risk behaviour among populations is influenced by different aspects of life. It is thus important to explore what factors are influencing the incident rates to develop programs that are context specific. For example, Mapingure and colleagues (2010) report on studies in Tanzania and Zimbabwe, which highlight the different factors such as early age of sexual

debut and circumcision respectively as contributing to the increased infection rate in the two countries (Mapingure et al., 2010).

The history of prevention and treatment of HIV in South Africa

South Africa in its early years of democracy from 1994 paid little attention to the HIV epidemic as attention was focused on setting up a new democratic government. However, in this time of transition, civil society created an advisory group or structure known as the Networking HIV/AIDS Community of South Africa (NACOSA) to lobby for and draft a national AIDS plan, which was accepted three months into the term of the new government (McNeil, 2012; Simelela & Venter, 2014). At this point the prevalence rate had risen, and in 1994 it was estimated at about 74 000-120 000 in the total population of South Africa living with HIV (Mabhena, Ndirangu, & Mutevedzi, 2013). In the same year an antenatal survey was conducted for the first time and reported that 0,8% pregnant women were infected with HIV (McNeil, 2012). Unfortunately, four years after independence, South Africa had to undergo a testing period to understand better the impact of the epidemic (Simelela & Venter, 2014). This was in the face of former Minister of health Dr Nkosazana Dlamini Zuma under the presidency of Thabo Mbeki, which was centred on increasing denialism of the causes of the epidemic (Mbali, 2003).

The prevention and response for HIV/AIDS was difficult in the beginning, given that there was limited evidence concerning its transmission and the dynamics that revolved around the epidemic. Therefore strategies were mainly around the provision of condoms, safer sex, and education strategies. These were hindered by stigma, fear, behavioural and other social factors (Simelela & Venter, 2014). Home based care became a response in mitigating the impact of the epidemic HIV/AIDS had caused in communities. This was largely for people who had advanced

AIDS and for children whose parents had died due to HIV/AIDS (Department of Social Development, 2003). Prevention was an important part of the response to HIV/AIDS which followed, through trials and investigating antiretroviral drugs (ARVs). These drugs were mostly delivered to pregnant women and neonates for the prevention of child transmission (PMTCT); however, this was an era of sensitive conflict (Furman, 2016, 2011; Mbali, 2003). Due to this controversial start, the PMTCT program was very slow in the beginning. In 2011 2,7% of HIV exposed babies attending their follow up visits were HIV positive at 4-8 weeks, in comparison to the 30% transmission rate expected with no PMTCT intervention (Barron, Pillay, Doherty, Sherman, Jackson, et al., 2013). South Africa's history has been characterised by delays and lack of political will, with thousands of preventable deaths missed. The denialist period resulted in nothing but a disastrous health policy of the government which ultimately delayed implementation and led to the escalation of the HIV epidemic (Chigwedere, Seage, Gruskin, Lee, & Essex, 2008). The roll out for the national PMTCT programme began in 2002, when the government had been forced to do so by the Constitutional Court after civil society had taken the government to court (Heywood, 2003). Civil society argued that refusing for nevirapine to be provided for PMTCT was a violation of the constitution (Heywood, 2009). The high court ruled that PMTCT programmes nation-wide was an obligation of the state (Simelela & Venter, 2014). Although the Minister of Health (Dr Manto Tshabalala at the time) appealed this ruling directly to the constitutional court, the Health Systems Trust mandated by the Department of Health that nevirapine should be provided immediately and there was no reason for delay. PMTCT was made available in more than 70% of facilities in Gauteng and provision continued to spread throughout the country (Honermann & Heywood, 2012; National Department of Health, 2011; Simelela & Venter, 2014).

The PMTCT program started with the single dose of nevirapine (NVP) at the onset of labour and was then given to the newborn within 72 hours after birth (Burton, Giddy, & Stinson, 2015). The program also included ANC counselling and testing, advice on infant feeding, the provision of infant formula for the individuals who elect not to breastfeed, and antibody testing for infant at 12-18 months (Burton et al., 2015). New guidelines a few years on introduced PCR testing at 6 weeks (Coovadia & Pienaar, 2013; National Department of Health, 2008, 2010a). Providing infant formula proved too costly and encountered problems with distribution, with serious implications such as babies being at risk of developing diarrhea and malnutrition or even death (Ijumba et al., 2013). In 2008, the PMTCT guidelines comprised the inclusion of AZT at 28 weeks with a single dose of NVP at the onset of labour for the pregnant woman with CD4 count < 250 cells/ μ l and introduction of maternal HAART for mothers with CD4 \geq 250 cells/ μ l or with stage IV of the disease (National Department of Health, 2010a). Further a single dose of NVP and 7 days AZT was recommended for infants directly after delivery (National Department of Health, 2008). In 2010 after revising the guidelines to incorporate protocols in line with WHO Option A guideline, AZT was initiated at 14 weeks to expectant mothers with a CD4 count higher have 350 cells/ μ l, with NVP during labour and single dose TDF+ FTC during or directly after delivery. For all women with CD4 count \geq 350 cells/ μ l, maternal HAART was recommended. Infant NVP was given at this point for at least 6 weeks, particularly if not already on HAART or not breastfeeding. For all HIV infected infants immediate initiation of ARV treatment was recommended (National Department of Health, 2010a). In 2013 South Africa improved the PMTCT guidelines in line with the World Health Organization treatment guidelines to further enhance the success of the program (AVERT, 2018; Barron, Pillay, Doherty, Sherman, & Jackson, 2013). At this point initiation of HAART was recommended for all pregnant women taking no account of CD4 count. After

diagnosis and one week after mother stops breastfeeding treatment would be for life (WHO, 2010). “All pregnant and breastfeeding women with HIV should initiate triple ARVs (ART), which should be maintained at least for the duration of mother-to-child transmission risk. Women meeting treatment eligibility criteria should continue lifelong ART” (see fig 2) (WHO, 2010). In 2015 new guidelines were realized by WHO to further improve the PMTCT program, all pregnant women living with HIV would be initiated on lifelong treatment irrespective of CD4 count (WHO, 2015). ART should be initiated in all pregnant and breastfeeding women living with HIV regardless of WHO clinical stage and at any CD4 cell count and continued lifelong” (WHO, 2015a). This approach, called option B+ , was felt to be the most effective particularly in contexts with HIV prevalence and high fertility. Introducing ART among pregnant and breastfeeding women could reduce HIV incidence as well as prevent transmission of HIV in pregnancies which may be current or in the future (WHO, 2015a). Revising these guidelines was undoubtedly important and since then, much improvement has been made with recommendations from WHO as well as local experts. The option B+ resulted in 91% of women receiving ARVs as part of the PMTCT program (WHO, 2015).

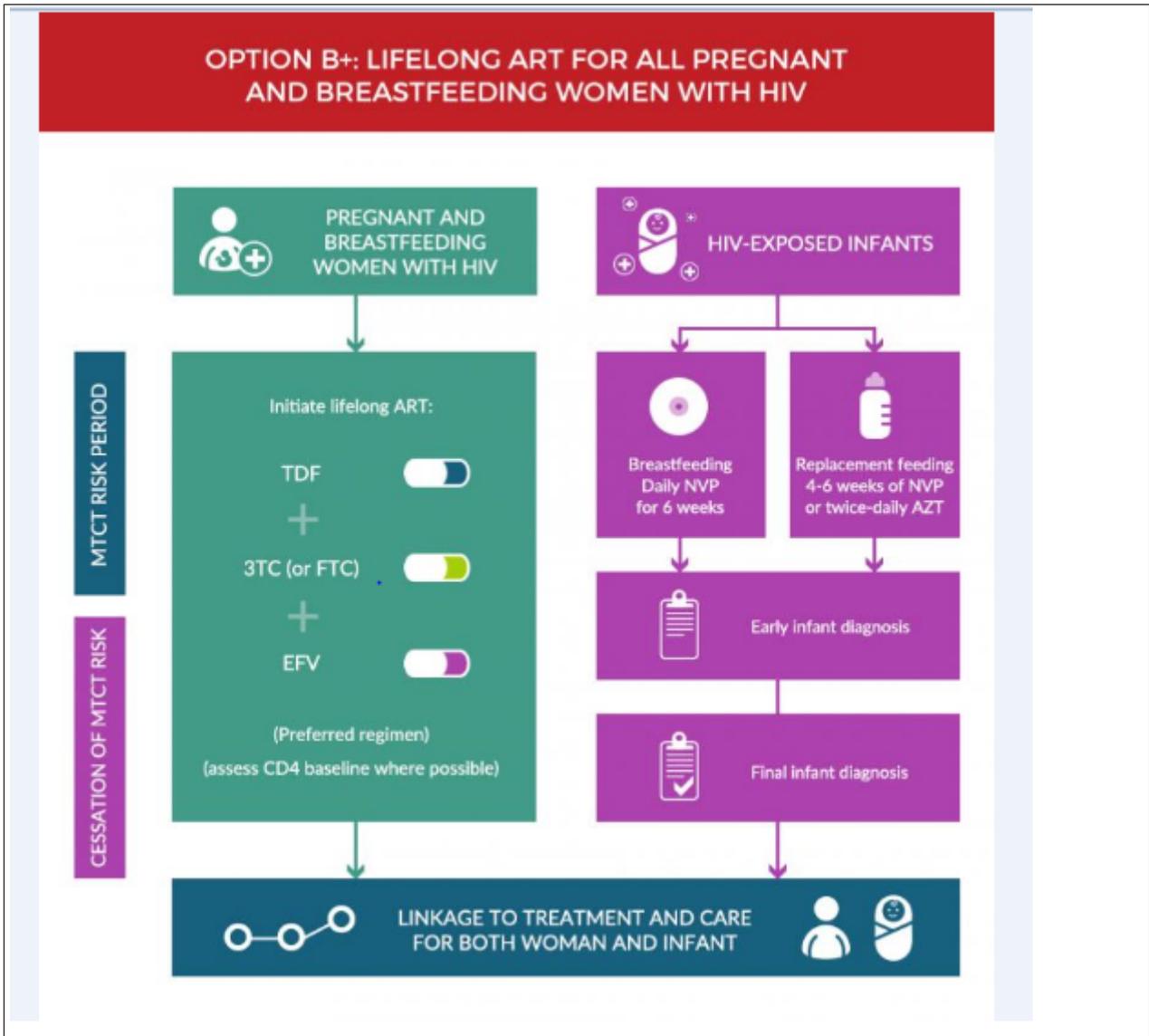


Figure 2 Consolidated guidelines on the use of ARV drugs for treating and preventing HIV infection
Source: WHO 2013

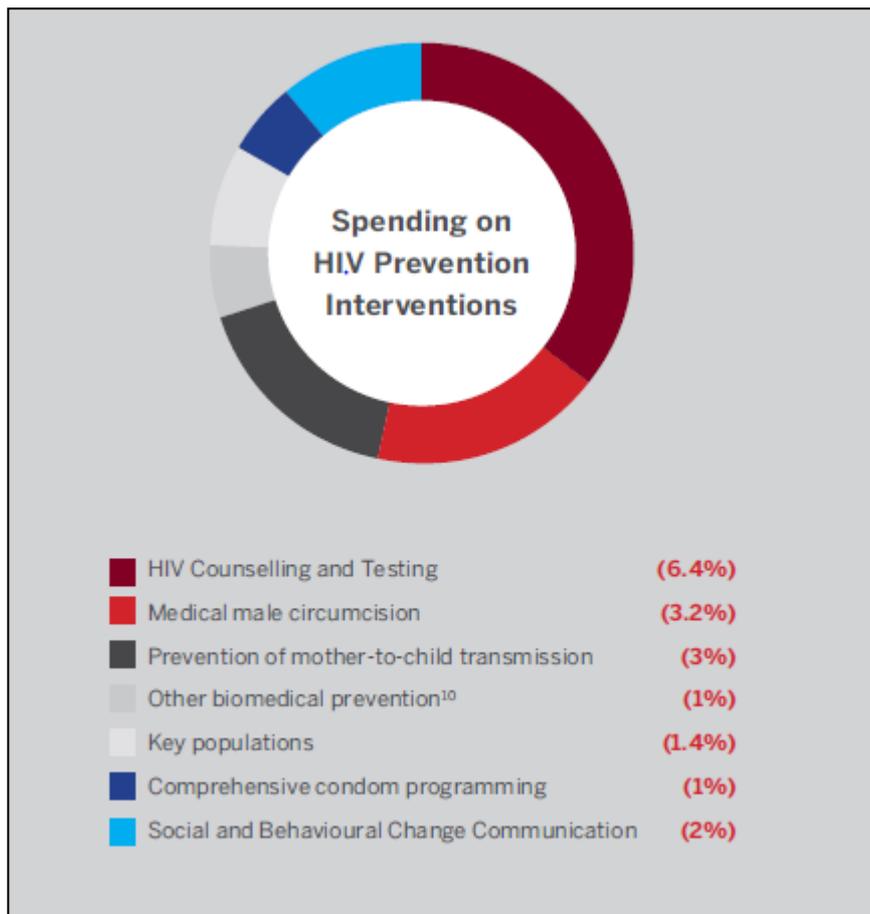
Contemporary South Africa

South Africa has nearly 3.4 million people on ART treatment, the largest treatment programme in the world (Department of Health, 2016). “Test and treat” is a strategy the World Health Organization (WHO) supported by the Department of Health locally, where all HIV infected individuals after being diagnosed receive treatment (WHO, 2016). It is aimed at

eliminating HIV in different countries as it reduces the rate of spreading the HIV virus to other people. Using the test and treat strategy, it is estimated that South Africa can end HIV within 20 years as a public health concern (Department of Health, 2016). In September 2016 South African Minister of Health Aaron Motsoaledi announced that people diagnosed with HIV would be started on treatment immediately. This was after the new policy change which now stated that people living with HIV, were immediately eligible for beginning ART treatment. ART was no longer based on CD4 count but rather infection of the virus (Department of Health, 2016). This has led to a rise in general life expectancy, parents living more productive lives without being afraid to die early and leaving behind young children, and mothers living and giving birth to infants without HIV. Services such as HIV routine counselling and testing for both women and men are readily available, and the encouragement of partners to provide care during pregnancy is always provided at antenatal clinics (Brittain et al., 2015; Brittain et al., 2017; Coovadia & Pienaar, 2013; Department of Health, 2016), although male involvement is lower than expected (Mlotshwa, Manderson, & Merten, 2017). The main idea of these improvements is that utilization rates can be more effective, providing a holistic approach at antenatal care (ANC) and post-natal care (PNC) for all women. These improvements further contribute to maternal health, where major maternal deaths have been reported due to preventable conditions (Coovadia & Pienaar, 2013).

South Africa has committed about R78,2 billion over the 2017/2018- 2019/2020 Medium Term Strategic Framework (MTEF) period for HIV programmes including TB and STI programmes, the total budget of R82,6 billion (US\$) for the three year period (South African National AIDS Council, 2017). South Africa is spending about 21% of total HIV/AIDS resources on prevention efforts, recommended by UNAIDS (South African National AIDS Council, 2017). At this point the key message the government is sending is that all women who want to have children or are

currently expecting, or choose to breastfeed, need to know their HIV status, so that the suitable interventions can be tailored accordingly to different individuals. Those who have been diagnosed need to be put on treatment immediately if not yet on treatment, the sooner treatment starts the better the outcome. “Good adherence is the key to a good result” (South African National AIDS Council, 2017).



*Figure 3 Approximate breakdown of spending on HIV Prevention in different areas
Adapted from SANAC 217/2018 report and Department of Health 2016*

Biological Factors and HIV in pregnancy

The female genital tract is divided into two main compartments, that is, the lower reproductive tract which consist of the ectocervix and vagina (lining of stratified squamous

epithelium) and the upper reproductive tract which consists of the fallopian tubes, endocervix and endometrium (lining of single layer columnar epithelium) (Hickey, Patel, Fahey, & Wira, 2011; Horbul, Schmechel, Miller, Rice, & Southern, 2011; Kaushic, Ferreira, Kafka, & Nazli, 2010). These and other characteristics of the female genital tract increase susceptibility to HIV infection (Reis Machado et al., 2014). In pregnancy, many women remain sexually active; this can be a problem particularly because numerous studies have reported incorrect or inconsistent use of male condoms as a way to prevent HIV infection (Kanda & Mash, 2018; Kaushic et al., 2010; Pilapil et al., 2016; Shih et al., 2011). In many instances women are timid or cannot negotiate condom use with their male partners for reasons such as fear of being left alone, or fear of insinuating infidelity in the relationship (Crosby, DiClemente, Wingood, Rose, & Lang, 2003; Kershaw et al., 2003). This leaves them feeling there is no choice but to have unprotected sex with their partner and they are therefore at a high risk of contracting HIV.

Some studies have suggested that the infection rate during pregnancy increases because of other biological factors such as high levels of oestrogen and progesterone (Gray et al., 2005). The changes of these hormones in and throughout pregnancy affect the genital tract mucosa or immune responses, thus making a pregnant woman more susceptible to infection (Gray et al., 2005). Further HIV-negative pregnant women, who have positive partners, may be more susceptible to HIV transmission as their immune system is compromised in pregnancy (Mbizvo et al., 2001; Mugo et al., 2011; Santelli et al., 2013). In addition, men who have sex with pregnant women have a higher risk of being infected (Mugo et al., 2011; Villar-Loubet, Cook, et al., 2013), as demonstrated in a large multi-centre study in seven African countries between 2004 and 2007 which found an increase in female-to-male transmission rate during pregnancy (Mugo et al., 2011).

Social and cultural norms as structural determinants of health

Society defines the way individuals behave as well as attitudes perceived as right, wrong inappropriate or appropriate. Social norms can be understood as identification that governs the way members of a community live and behave (Mackie, Moneti, Shakya, & Denny, 2015). The only problem that exists in addressing harmful practices that are embedded in culture or society is that they are difficult to change. Education to address this may take long periods of time to understand as well as accept for the obvious reason of the claim to preserve culture. The role of culture has proved to be problematic in the fight against HIV in many instances; for example, issues around patriarchal societies we live in. Multiple partnering can be supported and linked to forefathers and a representation of wealth and a stronger nation in the form of many children. This practice negatively affects the curbing of HIV in the 21st century in the Africa context (Baloyi, 2013; Molofo, 2010). Also gender inequalities which are patriarchal societies have continued to oppress women and contribute to HIV incidence (Molofo, 2010). Cultural practices are learnt, shared, transmitted and valued from generation to generation; these beliefs guide individuals' decision making processes, thinking and action. The gender roles and relations are part of what is constituted in culture. Socialization is what brings these roles and relations to existence where young boys and girls are taught particular roles within society and in relation to each other. An example is in African cultures where the men have always been the wage earners in the home and the women caregivers. This socialization has allowed the belief system that women have certain roles and men have other roles.

Social and cultural factors in pregnancy play an important role in the spread of HIV (Hahn et al., 2011; Mugo et al., 2011). High-risk behaviour is embedded in a wider sexual culture (Dietrich et al., 2011; Lekalakala-Mokgele, 2016), and extends to economic factors and social structures, in turn shaped by the patriarchal societies in which individuals live. Gender inequality

as well as gender based violence lie in the patriarchal nature of the societies and the idea of masculinity, wherein women are subject to the control of men (Jewkes & Morrell, 2010). Behaviours which may place women at particular risk of HIV infection include; intergenerational sex where women have sex with older men who are more likely to be infected with HIV than their age-mates (Lekalakala-Mokgele, 2016; Muula, 2008), transactional sex, gender based violence, and substance abuse, especially among women of lower socio-economic status (Dunkle et al., 2004). Masculinity is an important factor in most of these risky behaviours, and in sexual predatory practices and violence against women in many societies (Jewkes et al., 2010; Jewkes et al., 2011a).

Many programs have been introduced to promote HIV testing, male circumcision, condom use, and the timely diagnosis and treatment of sexually transmitted infections (STI). However, there is also need for community mobilization aimed at changing social norms within communities. Unfortunately, sexual behaviour during pregnancy and recognizing the extent to which men and women understand the risk of HIV and STI infection in pregnancy is understudied. Little is known about the actual sexual practices of both men and women, social norms surrounding these practices, perceptions and reasons for risk-taking during pregnancy. It is also unclear whether a particular pattern of sexual behaviour can be associated with incident HIV during pregnancy, apart from the mediating effect of condom use or cessation of use. To overcome barriers caused by gender inequality, more information about sexual cultures and norms during pregnancy and behavioural causal pathways are urgently needed, for example, reasons for increased forced sex and changes in patterns of sexual partnering (including multiple partnering and transactional sex) by both men and women during part or all of pregnancy.

Cultural norms in every society play an important role in understanding people's lives. These cultural norms sometimes create vulnerability for individuals who may be exposed to the virus

(Lawoyin & Larsen, 2002). Other beliefs, including traditions cultivated by ancestors generations ago, are still part of these societies; this can be seen in some cultures, for example, where it is said to be taboo for women to have sexual intercourse during pregnancy (Lawoyin & Larsen, 2002). Reality is sometimes twisted in these cultures, as men struggle to wait for the wives to give birth so that they can have sex again. Practices like these encourage sexual networking, particularly for men as they seek other women to meet their sexual “needs.” For example, in some cultural settings in Nigeria, there is a strong prohibition against sex for women during pregnancy and while breastfeeding (Esu-Williams et al., 1997), during which time their partners may meet their sexual needs with others. Lawoyin & Larsen (2002) in Nigeria found that sexual networking of men was high during these two periods. Usually the need to fulfill personal needs was an important factor in the occurrence of couple sexual networking, with couples move around to have sex with various other people who were not their regular partners. For men in polygamous relationships, Lawoyin & Larsen (2002) reported less networking when one woman was pregnant or breastfeeding, he could be with the other women in the polygamous relationship. Mapingure and colleagues (2010), however in the Zimbabwean and Tanzanian context reported polygamous relationships being risky relationships as partners were likely to be involved in sexual networking with others, despite having several recognized wives and/or partners (Mapingure et al., 2010). This obviously brings about great problems such as HIV incidence and the challenges to curb infection rates in a society with such practices.

The general utilization of the female condom remains inadequate with both men and women, reporting mixed feeling about its use. Patriarchy and cultural patterns of gender inequality appear influential in diverse study areas (Kavinya, 2013; Obembe, Adebowale, & Odebunmi, 2017; Villar-Loubet, 2013). In Mpumalanga, South Africa, sometimes men resisted the use of female

condoms because of the alleged length of time to insert it, compared with the use of a male condom (Villar-Loubet, 2013), and women found it difficult to negotiate female condom use. Due to women's increased susceptibility to HIV, unwanted pregnancies and STIs particularly prevailing from gender norms and male dominance in decision making with respect to sex, it would be assumed that availability and utilization of the female condom would be ideal (Lekalakala-Mokgele, 2016; Masvawure et al., 2014). A patriarchal society also sometimes lessens the options women have of protecting themselves and their unborn child from HIV. Women are often dependent on men financially, enabling men to dictate to them what to do. In such scenarios, condom use is irregular, and intimate partner violence is high due to power inequity (Jewkes et al., 2010). Women fail to negotiate safer sex methods due to multiple reasons such as violence, financial dependence, fear of being left by their partner (rejection), and the desire for pleasure during sex (Bajunirwe, Bangsber, & Sethi, 2013; Beyeza-Kashesya et al., 2009; Villar-Loubet, 2013). These ideals readily translate into risky behaviour, and women cannot protect themselves and their children.

Religion can also shape the norms and practices of individuals within a society (Zou et al., 2009). Religion provides psychological, social and spiritual resources for people with HIV, as well as for others affected by HIV in many contexts (Lindgren et al., 2013). In a survey in Tanzania, Zou and colleagues (2009) noted that religion played an important role in shaping people's attitudes about HIV and their responses. In the same area, Lemme and colleagues (2013) noted that religion was also associated with HIV infection, with Muslim women having more than double the odds of HIV infection compared to Christian women. However, their explanation was that Muslims lived in high prevalence areas, for example, roadside settlements and urban areas. In addition, it is possible that Muslim women had less access to health promotion information, were less able to negotiate

condom use, and were more likely to be in polygamous relationships (Lemme et al., 2013). Gray (2004), on the other hand, argued that religion may play a positive role in lowering HIV levels through factors such as circumcision, reduced extra sexual affairs due to religion, and reduced alcohol consumption, all of which reduce chances of high sexual risky behaviour (Ruzagira et al., 2011; Lemme et al., 2013; Muula, 2008). This would influence those who adhere faithfully to religious precepts.

Multiple concurrent partners increase risk of infection. Reports on both men and women having many sexual partners as a way to fulfill their sexual or other needs have suggested an increase in multiple partnering (Beyeza-Kashesya et al., 2009; Lawoyin & Larsen, 2002). When the primary partner is away, both men and women may seek out an alternative partner. In scenarios such as these, condom use is not consistently used and therefore alternative partnering is a risk factor in the transmission of STI, including HIV. Condom use declines proportionate to the length of the relationships (Benefo, 2004), and this also means that the longer the duration of the relationship, the higher the chances of infection, as couples begin to reduce condom use as trust begins to manifest in the relationship.

Inter-generational sex – where young women have sex with older men, in most cases for material gain – continues to place women at risk for HIV (Muula, 2008). Inter-generational sex is associated with no or reduced condom use, power imbalances, manipulation, poverty and need for economic survival (Chatterji, Murray, London, & Anglewicz, 2005; Leclerc-Madlala, 2008; Masvawure et al., 2014; Muula, 2008). When women are pregnant and poor, they are vulnerable and may engage in any type of relationship for material gain (Chatterji et al., 2005). In instances where these older men were HIV positive and women already have biological risk factors such as hormonal changes (Gray et al., 2005), women are likely to have an increased HIV incidence. Women interviewed in

a Zimbabwean study explained inter-generational sex in terms of the need for money and gifts; the older sexual partner, because of accumulated assets, was able to provide these for her (Gregson et al., 2002). Masvawure (2010) however has argued that it depends on the particular needs of the different groups, as others want simply a 'flashy' life style. Condoms in these types of relationships are rarely used because men make an economic investment in the relationship, believe younger women are free from HIV, and do not accept that they should protect them from possible infection (Gregson et al., 2002). Many young women are infected this way; ultimately they marry and have children, continuing the spread of HIV. Condoms are rarely used in casual relationships between older men and younger women, putting them at risk at HIV infection; the fact that they are still young with a still maturing vagina mucosa is already a risk factor (Gregson et al., 2002). According to Leclerc-Madlala (2007) a still maturing vaginal wall is easily infected or easily susceptible to trauma during sexual activity, therefore placing women at a higher risk of HIV acquisition than their male counterparts.

Vaginal practices, pregnancy and HIV

Many women in the world clean, tighten, dry or warm their vaginas for difference reasons linked to hygiene, health or sex. These vaginal practices referring to both intravaginal cleansing which is cleaning or washing inside the vagina with fingers or other substances to remove fluids, and intravaginal insertion involving place something inside the vagina, for example, powders, creams or tissue (Martin-Hilber, Hull, Preston-Whyte, & Bagnol, 2009; Martin Hilber et al., 2012). (Alcaide, Rodriguez, Fischl, Jones, & Weiss, 2017) Women who use these practices for sexual intercourse report that it makes sex more enjoyable for the women but mostly the partner, particularly where creams and powders are intended to dry the vaginall wall, so allowing dry sex. Dry sex has been reported in many Sub-Saharan countries, and involves douching and tightening

of the vagina in preparation for sexual intercourse. In Zambia, Zaire, Zimbabwe, Mozambique, Malawi, Botswana, and South Africa, many women are reported to practice some sort of dry sex. They are motivated by different reasons (Halperin, 1999; Martin-Hilber et al., 2009; Martin Hilber et al., 2012; Scorgie et al., 2009; Turner et al., 2010) for example, attracting men and keeping them sexually satisfied (Scorgie et al., 2010; Sandala et al., 1999), and for hygiene, health and wellbeing (Martin-Hilber et al., 2009). The most common methods used for dry sex were vaginal and vulval washing with different substances, including powders, stones, leaves, and herbs inserted inside the vagina for dryness to occur (Martin Hilber et al., 2010; Martin Hilber et al., 2012; Turner et al., 2010). Recently there has been an attempt to better understand the use of these substances and they have been classified into categories: anatomical modification, application of substances to the vulva, intravaginal insertion of substances, oral ingestion of substances, and intravaginal cleansing or douching (Scorgie et al., 2009). Some of these methods can cause inflammation and genital lesions, resulting in increased risk of Sexually Transmitted Infections (STI) including HIV; however Martin-Hilber and colleagues (2010) in their systematic review argued that there was inconclusive statistical evidence about the effect of intra-vaginal practices on women's risk of acquiring HIV infection, while the measures of association showed harm in the practice. Low and colleagues (2011), in their meta-analysis, concluded that women who insert products intended to dry or tighten the vagina, or clean with soap intra-vaginally, are at increased risk of acquiring HIV (Low et al., 2011).

It is sometimes difficult for women of poorer backgrounds who are financially dependent on men to negotiate or refuse dry sex practices for fear of the partner withholding finances and other livelihoods. In a study conducted in Orange Farm, South Africa, it was noted that people who practiced dry sex were predominantly of lower educational status (Breksinka et al., 1999). In

KwaZulu Natal, Smit and colleagues (2011) reported that three quarters of women in their study used such vaginal practices, particularly those engaged in transactional sex (J. Smit et al., 2011). For pregnancy, the results are detrimental to both the mother and the child, because they will be exposed to STIs including HIV, while in some cases women explain doing this as a statement of identity that 'you are a woman' (Hull et al., 2011). Some women claim they are not 'real women' if they do not participate in such practices, and they believe they have to participate as part of their culture.

Disclosure of HIV in pregnancy

HIV-infected individuals suffer discrimination and stigma, and this fuels non-disclosure amongst couples or partners, which then limits pregnant women from seeking and accessing prevention of mother to child transmission services (Visser, Neufeld, de Villiers, Makin, & Fiorsyth, 2008). Disclosure of one's status requires timing and that the individual is ready to tell (Manderson & Davis, 2014; Mlotshwa, Manderson, Chasela, & Merten, 2018; Visser et al., 2008). It unfolds in many ways for the individual to finally tell somebody about his or her status. The battle of telling or not telling somebody includes fighting with emotions and dealing with how people may react to this new information and treat the person after disclosure (Manderson & Davis, 2014). The constant battle of when tell the other, who to tell, whether the person to be told is trustworthy and will keep this secret, and why disclosure is necessary, are constant questions facing the individual who needs to disclose their newfound status (Mlotshwa et al., 2018). In a study conducted in Mpumalanga, some women considered disclosure a good thing, but only if the person with HIV trusted the other person and believed they would not tell other people; women therefore in supportive, loving and trusting relationships would disclose without fearing rejection. Like their male counterparts who thought disclosure was good, for them it was a way to relieve the burden

and stress on themselves (Villar-Loubet et al., 2013). The main problem male participants reiterated in their study was that sometimes women ‘held grudges’ for long periods and would not forgive their partners for what had happened. Further they wanted to tell people outside the couple relationship about personal problems (Villar-Loubet, Bruscantini, et al., 2013). The idea of people thinking that one gets HIV from ‘bad behaviour’ is common in most societies, implying that anyone who gets infected has had multiple sexual partners and so acquired the infection. This type of stigma relating to HIV often makes it difficult for people to disclose their status. Other infected people, after testing positive, struggle to come to terms with the result and therefore resist disclosing to their partner for fear that he or she will leave the relationship (Villa-Loubet et al., 2013). The issue of disclosure is often very complex, putting the partner at risk of infection (Manderson, Davis, Colwell, & Ahlin, 2015). Mlambo and Peltzer (2011) report that disclosure can be a response in prevention behaviours where a partner can seek HIV testing as well. When a partner discloses, there are better options to be taken as a way to protect each other, and the unborn child if the couple is expectant (Mlambo & Peltzer, 2011). Also in situations of stigma and disclosure, HIV infected women may have difficulty asking for information to plan for a pregnancy and to reduce transmission to the partner, and may not seek information on sexual practices in relation to pregnancy.

HIV testing in pregnancy and education

Not all pregnant women who are HIV infected will be aware of their status, due to lack of antenatal care or lack of HIV testing ; many women in rural areas deliver outside the hospital and have no health care prior to this time (Kongnyuy et al., 2009; van Dillen et al., 2006). Roger and colleagues (2006) noted that some pregnant women do not want HIV testing for fear of stigmatization if the test is positive, and concern that others would ask them why they chose to test (Rogers et al., 2006).

For example, Mseleku and colleagues (2005) reported that in South Africa, 44% of women refused routine antenatal testing compared to 29% in the overall population (Mseleku et al., 2005). Although this requirement of routine testing on at least two visits is recommended nationally (DoH, 2010), testing of HIV negative women at follow up antenatal visits is rarely implemented and women often do not attend the number of antenatal visits they are supposed to (Moodley et al, 2009). This means that many women seroconvert without being detected early enough to protect the child. Further, many countries still lack a complete registration system with good attribution of cause of death, thus making difficult to track patterns of maternal mortality (WHO, 2012).

For many young people, the challenges of lacking high quality prevention services such as HIV, sexual and reproductive education and health services, and sexual violence against women and young children, seems to have increased (WHO, 2011). South Africa, like many sub-Saharan countries, has a large population of young women who are at great risk of being infected with HIV (Muula, 2008). Education is related to the perceptions and knowledge individuals have towards understanding HIV during pregnancy. In a study in Uganda (Chacko et al. 2007), adolescents were asked about condoms and how condoms protect against sexually transmitted infections including HIV; they reiterated that the use of condoms was for couples who were promiscuous, and the use of condoms reflected lack of trust of partner (Chacko et al., 2007). King and colleagues (2012), in their study also in Uganda, reported that people often drew on myths -- such as God protecting people and individuals' blood being strong -- as reasons why they would not get infected. Misinformation actually turns into reality for individuals, and they begin to live and practice what they have conceptualized (Chacko et al., 2007). Shikwane and colleagues (2013), in their study in South Africa, reported that women in the study population had good knowledge on PMTCT when

they were enrolled in ANC. This suggests that attending ANC classes can enhance both men and women's knowledge about their choices about HIV (Shikwane et al., 2013; Nkuoh et al., 2010).

Poverty, violence and HIV

Studies have reported a link between poverty and HIV at both individual and societal levels. Women as reported in studies engage in transactional sex for survival. This type of sexual agreement may involve gifts and services as well as or instead of cash. Smith (2007) argues that this process of extra sexual partners is mainly situated in economic, social and moral contexts. Mutinta and colleagues (2012) reported that sometimes the drive for material gain encourages women to be with men who have money. However, Musvawure (2010) argues that transactional sex is more complex than just trade of money and sex. Drawing on her research in Zimbabwe, she argues that the exchange for different possessions will depend on a number of circumstances, as some women may engage in such behaviour merely for status among peers. In contrast, Charterji and colleagues (2005) reported that many parents engage in transactional sex in order to take care of their children, and to pay for their education and other necessities. For pregnant women, especially where individuals come from poor backgrounds, transactional sex may be considered necessary to fend for their unborn child. Financial independence for women seems to be an important factor for negotiating condom use with partners (Msamanga et al., 2009), while financial dependence means that these women constantly need support from male dominated relationships.

People who abuse alcohol are likely to engage in risky behaviour and also may be involved in gender-based violence. Bujunirwe and colleagues (2013) reported an association with high risk sexual behaviour among patients receiving antiretroviral therapy, confirmed also by a meta-analysis showing the association between alcohol use and high risk sexual behaviour (Shuper et

al., 2009). Pregnant women with partners who abuse alcohol are especially at high risk of HIV infection (Mapingura et al., 2010). Gender-based violence may stem from drunk partners forcing themselves on women, and genital lesions due to forced sex will increase the risk of the transmission of HIV (Jewkes & Penn-Kekana, 2002). Gender based violence in South Africa was included in the Justice, Crime Prevention and Security Cluster reviewing national policy framework for sexual offenses, aiming to bolster prevention of sexual violence by public education and communication (National Department of Health, 2010b; South African National AIDS Council, 2017). Further inter-sectoral planning and combined services delivery for women are needed particularly at the community level, in an attempt to understand better social systems and strengthen service delivery systems. Young people in particular have been hit hard by the harmful use of alcohol and drugs, which continues to destroy families, communities and the society as a whole. All this impacts greatly on HIV arising from risky sexual practices and through exacerbating gender based violence within communities (South African National AIDS Council, 2017).

The future of HIV/AIDS is centered in many respects on the behaviours many young people people adopt or maintain, as well as the contextual factors that affect the different choices that they make (NSP, 2007/2011). Factors such as having many sexual partners, barriers hindering condom negotiation, poverty, alcohol, drugs, violence and others are key in addressing HIV amongst pregnant women.

Chapter 2

METHODOLOGY

The rate at which the population is infected with HIV in South Africa is reported to be declining from 1,9% in 2002 to 0,9% in 2017 (Stats SA, 2017/2018)(STATS SA, 2017). Even so, almost one out of every five women in their reproductive ages (15-49 years) is HIV positive, nearly four times more than their male counterparts (AVERT, 2017a)(AVERT, 2018). Young women in the ages of 15-24 made up 37% of new infections in the country in the year 2016 (South African National Council, 2017).The high prevalence rate contrasts with a prevalence of about 12,8% in the population as a whole, and 19,1% among women aged 15 to 49. Prevalence amongst pregnant women is estimated at about 30%, although in some districts it is estimated at 50% (South African National AIDS Council, 2017). Moodley and colleagues (2011), drawing on a cohort study conducted in KwaZulu Natal between 2005-2007, reported that many pregnant women were infected during the course of their pregnancy, and children born to women with incidence HIV were 2,3 times at higher risk of being infected (Moodley et al., 2011). Dihn and colleagues (2015) found that about 3-4% of pregnant women became HIV positive during pregnancy, accounting for over a quarter of all cases of mother to child transmission (MTCT) of HIV.

Understanding the risk of HIV acquisition during pregnancy pivots on many behavioural and biological issues. These include, among both sero-discordant and sero-concordant couples, fidelity (or not) of both partners during pregnancy, intra-vaginal practices and the implications of this in relation to STIs including HIV, and changes of sexual frequency and its impact on the couple. Sero-discordance refers to only one partner having or acquiring HIV; sero-concordance

refers to both the partners having or acquiring HIV. The way individuals behave cannot be considered in isolation from the socio-cultural and socio-economic context. Complementary comprehensive information on sexual cultures during pregnancy is critical, with important implications for programs for the prevention of mother-to-child transmission of HIV. In this study, I aim to contribute to knowledge identifying individual behaviours and the social context that influence transmission and so are relevant to HIV prevention in pregnancy. This information enlightens structural prevention approaches, including by addressing men's sexual behaviour through the lens and understanding of their partners (the pregnant women) and socio-cultural norms. This information, mostly through the perspective of women, helps to clarify the causal chain of infection during pregnancy.

The First 1000 Days of life Cohort Study (hereafter referred to as S1000 Study) was a prospective pregnancy cohort study conducted at Chris Hani Baragwanath Hospital, Soweto, from 2014 to 2017. The study aimed to enrol over 4000 pregnant women, who were recruited at first presentation to the antenatal clinic and were <14 weeks gestation. The S1000 Study followed women and their infants for up to 24 months after delivery. Chris Hani Baragwanath Hospital, at which 17,000 women give birth each year, is located in Soweto in the southwest of Johannesburg (Chris Hani Baragwanath, 2016). The hospital takes care of referrals from local clinics and smaller hospital for more specialised type of care. Some of the risks and complications which would lead clinic personnel to refer pregnant women to the hospital include multiple miscarriages, severe or persistent nausea and vomiting, persistent vaginal bleeding, cramping, gestational diabetes and hypertension, amongst other complications. Frequent follow up study visits with each woman were scheduled, totalling up to 14 visits of a given woman to the clinic through the study: up to six visits during pregnancy and eight during the first two years of infancy. The S1000 cohort aimed at

addressing the independent and interactive effects of multiple maternal morbidities and factors such as HIV, gestational hypertension, anaemia, obesity, depression on foetal growth (ultrasound 4D scanning), pregnancy outcomes and infant growth, body composition and development. The S1000 platform continues to contribute data to a group of seven countries to assist in understanding foetal growth during pregnancy and delivery outcomes. The cohort study has identified genomic, clinical and environmental risk factors that enhanced understanding of unfavourable health outcomes. The work further looked into psychometrics that has been developed to gather information that are related to childhood illnesses such as diabetes and obesity (The Soweto First 1000 Days Study, S1000; (The INTERBIO-21st Consortium, May 2011,).

Study Design

The data collection for this PhD took place as a component of a longitudinal study of pregnant women participating in The First 1000 DAYS OF LIFE Study. This study was entitled Incident HIV in Pregnant Women and Sexual Risk Behaviours and Practices in Urban South Africa (hereafter referred to as the Pregnancy and HIV Study). Its overall aim was to understand sexual practices of women and their partners during pregnancy and the post-natal period, and to assess the effect of sexual risk behaviour on incidence of HIV infection. The Pregnancy and HIV Study selected women who were HIV negative at entry into the cohort. All pregnant women who had tested negative were again tested for HIV 12 weeks post the initial test, and were retested subsequently at every antenatal visit until delivery. The study used a mixed method research design to comprehensively investigate the sexual practices of women and their partners during pregnancy and the postnatal period, and to assess the effect of sexual risk behaviour and practices on incident HIV infection. Some of the papers that derive from this work and published include Mlotshwa et al. (2017) and Mlotshwa et al. (2018) and also have been included in this thesis.

For this PhD, qualitative research methods were employed to explore sexual behaviour during pregnancy in the local social and cultural context. Repeated in-depth interviews, enabling a life history approach, were employed with those women who agreed to participate, to explore and understand their sexual behaviour, including behaviour that might be protective of infection, and to gain insight into the behaviour of their partner, often (but not always) the father of the expected child. Each woman was encouraged to narrate important life events from her own perspective. The ideal was also to recruit their partners but, as I explain below, this was largely unsuccessful. Over time, a number of the women who were interviewed seroconverted, either because the original test failed to identify that they were already infected, or because of an infection acquired during pregnancy.

A narrative analysis approach to life history was employed. Anthropological studies have shown the importance of a life course perspective to understand sexual relationships as they are constructed over time (Elder, Johnson, & Crosnoe, 2003; N. Johnson, 2009). The advantage of employing a life history approach in this study was that it provided a comprehensive picture of a recently infected woman's view on her relationship history, including with her partner. This was not straightforward. As I discuss further, sensitive issues like sexual practices, sexual risk taking and potentially harmful practices, including labia manipulation and the use of topical agents to dry the vagina, will not necessarily be revealed in a face-to-face interview, unless the interviewer and the respondent are able to establish a strong sense of trust and ease of communication (Corbin & Morse, 2003; Dempsey, Dowling, Larkin, & Murphy, 2016; Elmir, Schmied, Jackson, & Wilkes, 2011; Fahie, 2014; Lee, 1993; McCosker, Barnard, & Gerber, 2001; J. O'Brien, 2010).

In qualitative research, good interview questions need to be open-ended and clear. These questions need to be worded and asked in a way that stimulate replies and that encourage

participants to disclose and discuss their experiences (Patton, 2002). This needs to happen in a way that reflects the fact that the researcher is also mindful of and sensitive towards the feelings of the participants (Dickson-Swift et al., 2007). For example, in this study, the interview began with open questions, asking the participants a preliminary question: “What is your background? Can you tell me a bit about yourself?” Questions such as these encouraged the participant to relax and speak freely about whatever details of her life she felt she would want to share. Then I would gradually move to questions that would elicit further information, following up on events that she deemed to be important life events that she wanted to share -- ranging from her childhood until the time we met.

Collecting sensitive information requires that the participant trust the researcher with the information she shares; this is difficult when there is no prior relationship between the researcher and the participant, as is conventional in much social research. It is thus important that some form of relationship is formed (Ryan and Dundon, 2008). Some authors argue that maintenance of rapport may present a dilemma from the point of view of the researcher. On the one hand, the researcher hopes and is keen for the participants to share information and offer their perspective on the problem under investigation. In soliciting this information, the participant should be put at ease and reassured of confidentiality, the right to withdraw, and so on. Yet on the other hand, at this point, some level of detachment is argued to be necessary from the side of the researcher to ensure objectivity and validity of the findings (Ryan and Dundon, 2008). Anthropologists and other qualitative health researchers argue that this is always an elusive goal, and that sometimes it is difficult to ensure that balance is maintained (Korstjens & Moser, 2018). However the purpose of the inquiry is to develop and improve ideas and understanding about a particular subject (Anney, 2014; Korstjens & Moser, 2018).

Study population and setting



Figure 4. Map of Soweto, showing Chris Hani Baragwanath Hospital
Source: South African Venues

Soweto is a township established in 1931 in southwest Johannesburg largely for black South Africans working in the vicinity; it obtained its name from the first two letters of **South Western Township** to describe the area. Today, it has an estimated population of around 1.3 million (Statistics SA, 2011), and it is one of the largest black populated cities in the country. The Soweto population is divided, according to self-identified census categories, into Black Africans (98,5%), coloured (1%), Indian (0,1%), whites (0,1%) and other (0,2%). Further, the ethnic groups comprise of all thirteen groups, although Zulu, Sotho and Tswana predominate (see Table 3). The township of Soweto is located in Gauteng Province, and is under the municipality of the Johannesburg Metro

Council. There are about 355 351 households in the whole township. Water in some parts of Soweto is still a real problem, with only 55% reporting piped water inside their dwelling and 91% with access to flush toilets connected to a sewage system (Stats SA, 2018a). Some 50,4% of the population is female; 49,6% male. Around 9,3% residents over 20 years have a higher education (referring to college or higher).

Table 1 (Stats SA, 2016)

Ethnic group	Percentage
IsiZulu	37,1%
IsiSotho	15,5%
Tswana	12,9%
TshiVenda	4,5%
XiTsonga	8,9%
English	2,3%
Afrikaans	1,3%
SiSwati	0,7%
IsiNdebele	1,4%
IsiXhosa	8,7%
Sepedi	5,1%
Sign language	0,5%
Other	1,1%

While a diversity of languages is spoken in the township, the most commonly spoken language is isiZulu, followed by seSotho and a mix of local languages, including an urban slang *tsotsitaal*, predominantly spoken by males (Gunner, 2015). *Tsotsitaal* first spread as a criminal language as it had the power of ensuring secrecy and confidentiality and passing messages discretely. More recently in the township, *tsotsitaal* is a variety of languages mixed together commonly spoken in Soweto. In interviews, participants spoke English, seSotho or isiZulu, although they often switched from one language to another; the women's partners we met also mixed languages, but with more *tsotsitaal* and isiZulu in their vocabulary.

The target population for the study was women using antenatal services at Chris Hani Baragwanath Hospital. As noted above, some 17,000 women give birth at the hospital annually, and there are over 350 beds for obstetrics and gynaecology (Chris Hani Baragwanath, 2016). The hospital is an academic teaching and research hospital, which serves about three million people who live within the proximity of about 60km of the hospital; the hospital also provides care to patients who live beyond this radius and wish to access its specialty services (Ayeni et al., 2018). The hospital has facilities for antenatal, intrapartum and postpartum care. Yearly, the hospital terminates about 1 100 pregnancies, has 700 still births, 280 neonatal deaths, and 3500 children born with low birth weights (Chris Hani Baragwanath, 2016). The hospital proclaims that it is the third largest hospital in the world, occupying approximately 233,795m² of land, with 3,400 beds in total and nearly 7000 clinical, administrative and support staff.

According to the South African maternal referral system guidelines, nurses and doctors at primary care clinics should refer patients to hospitals if they are identified as having a high risk pregnancy (e.g. older maternal age, multiple pregnancy), who develop complications in pregnancy, or who have had problems in previous pregnancies. Such referrals may be directly to an academic

tertiary hospital such as Chris Hani Baragwanath, or to a local hospital, for hospital care and diagnostic services which may not be available at the primary care level (Department of Health 2007). These different levels are important for all services to run smoothly, so referral pathways for maternity services need to be followed correctly by all patients in order to be admitted to the hospital as a patient. All pregnant women are tested for HIV/AIDS several times through pregnancy, and if found positive they are referred for counselling, treatment and initiation on ART (Chris Hani Baragwanath, 2016). However, HIV status alone is not grounds for referral, and women with HIV are not regarded as having a high risk pregnancy.

The PMTCT guidelines were developed to ensure the best possible clinical outcomes for people living with HIV (PLHIV), strengthening the integration of services, and promoting a family approach to HIV care. Taking into account the strained health system and limited resources, it is important to give priority to providing antiretroviral therapy to people such as pregnant women to achieve what is desired to combat HIV (National Department of Health, 2015). The PMTCT guidelines state that at an individual's HIV counselling and testing (HCT) sessions, there is a need to evaluate information passed to the participant during their group session to ensure their comprehension and to clarify any questions or concerns. For participants who test positive on a first test, a confirmatory test for HIV should be done. Post-test counselling is mandatory for all participants, within formation including HIV transmission, safe sex, use of condoms, HIV testing for sexual partners, repeat HIV testing, and safe infant feeding and infant prophylaxis (National Department of Health, 2015). In addition, all pregnant women who test HIV negative should be offered repeat tests during pregnancy, labour and breastfeeding. This is essential because, as noted above, around 3-4% of pregnant women in South Africa who initially test negative for HIV become positive during their pregnancy (National Department of Health 2015).

All participants recruited for this study were receiving antenatal care (ANC) at the Chris Hani Baragwanath Hospital, as they had been referred from their local clinics for one or more reasons relating to a risk or complication in their pregnancy (see above). Many of the participants did not attend ANC exclusively at Chris Hani Baragwanath, but were given check-ups once or twice to ensure that any existing or emerging complications were monitored; if no sign of risk developed in the pregnancy, the patient may be referred back to her own local clinic.

After enrolling each participant into the Pregnancy and HIV study, contact details were taken to ensure follow up visits for interviews. Antenatal care clinics were attended every four weeks by each participant at their local clinic or the hospital depending on consultation outcome. All pregnant women attending ANC, who consented and were enrolled during their first ANC visit and who were over 18 years, were invited to participate in the nested Pregnancy and HIV Study. Interviews took place at the research clinic or the home of the participant. The overall aim of the Pregnancy and HIV study was to understand sexual practices of women and their partners during pregnancy and post-natal period and assess the effect of sexual risk behaviour on incidence of HIV infection. The hypothesis of the Pregnancy and HIV Study was that the incidence of HIV in pregnant women increases during pregnancy. The study also asked about the risks associated with the sexual practices of both the pregnant woman and her partners, whether such risks increased during pregnancy, and whether the increased incidence of HIV in pregnant women was directly associated with the increased practice of risky sexual behavior(s). I sought to recruit pregnant women newly diagnosed with HIV infection, and to enrol them as cases in a case control study. Four aged matched controls for each case were selected among women who were HIV negative at the time of a case diagnosis. A total of 1425 participants were enrolled in the Pregnancy and HIV study; among these 104 women (7.3%, slightly lower than national mean) became positive in the course of their pregnancy.

The enrolled women attended study visits every four weeks throughout the course of their pregnancy and received a standard serial finger stick rapid HIV test (NHMed/WFHIV 1/2 HIV Test Devices) at every follow up visit, according to South African guidelines (NDoH, 2009). All women in the cohort were offered routine HIV testing and counselling (HCT) as part of their antenatal care visits. Women who tested positive were referred to care at the hospital, counselled and linked with treatment options as per existing protocols.

Study sample

After diagnosis, fifteen HIV positive women were approached separately for their consent to be interviewed in-depth. The primary partner of these women, who was considered to be the father to the unborn child, although clarified in each interview, was approached separately for an in-depth interview. We acknowledged that not all women would identify primary partners for many reasons, such as abuse from partner, lack of clarity about paternity, separation of the couple, woman's reluctance to refer him for participation for reasons of confidentiality, man's lack of interest in participating, and the man wary for fear that the researcher was biased in favour of the woman. However, all known partners, if this was agreed to by the pregnant woman, were contacted via telephone for recruitment into the study and to participate in an interview. At the same time, another group of women and their partners (15) who tested HIV negative were recruited to be interviewed. The aim of this was to understand social norms linked to changes in sexual practices during pregnancy, to understand pregnant women's and their partners' life context, and for those who seroconverted during pregnancy, their perceptions on the reasons for their HIV infection. I also wished to understand how socio-economic status and livelihood strategies, and the social context in which women were embedded, influenced sexual practices during pregnancy, and to identify differences and similarities of the sexual behaviour of women and their partners, between

those who acquired HIV during pregnancy and those women and their partners without HIV. The sample was therefore stratified for men and women, and for acute HIV infection and HIV-negative persons. This led to four subgroups; for each of these subgroups I aimed to interview at least fifteen persons. However, I expected that realistically, partner referral would be only at 50%, so I estimated that I would be referred to only about seven or eight men per HIV group. However, the referral rate by women and the agreement rate by men were even lower than these expectations. Partners were not forthcoming.

Over the study period, therefore, 15 women were diagnosed with HIV infection during pregnancy and were recruited into the study, and 15 women who were HIV negative were interviewed. As indicated above, it was intended that a total of 15 partners would be recruited for the HIV positive and HIV negative participants. Among women who were negative, five partners refused either directly on the phone or notified their partners that they were not interested in being interviewed; two women were no longer in a relationship with the father of child and the men insisted they had nothing to say about the pregnancy and relationship; and the other five men were booked for several appointments for interviews, but did not honour any of the appointments. Their reasons for not turning up to meet me for an interview included that they were busy and could not make the time; were working very far away; or changed their mind about attending on the morning of the interview and did not answer my phone calls when called. Some said that hospitals were for sick people and they were not sick, and so did not want to come to the hospital. Only three honoured their appointments and these interviews took place.

Of the fifteen women who were HIV positive, three were no longer in a relationship with the father of the child and did not refer us to the men. Four men who we approached to participate in the study refused and reported that they were not comfortable with talking about HIV, sex and

the pregnancy in the interviews; they felt these topics were too personal. Further elaborating, they feared a breach of confidentiality about the private issues they shared with the counsellor or the researcher, even after we had emphasized our ethical obligation and commitment to maintaining confidentiality. Four men did not honour their appointments to be interviewed. Three women had not disclosed their status or felt that too much was at stake if the partner came for interviews: they feared violence or partner with holding economic support for her and her children. One man stated that the woman cleaned for him and firmly denied paternity, insisting he was happily married to someone else. As a result, 30 women and three men were interviewed. All interviews were used for analysis and included in the manuscripts published on this data, as reflected in the articles included in the results section of this thesis.

Trustworthiness

Trustworthiness or the value of truth in qualitative methods and transparency of the conduct of the study are very important to the effectiveness, helpfulness, usefulness and truthfulness of the findings (Cope 2014). Qualitative research helps to explain certain social phenomena. It involves the collection of empirical data in an attempt to describe moments, meanings and experiences in individuals' lives (Mays and Pope, 1995; Renz et al, 2018). The approaches in qualitative research are diverse, and include a variety of philosophical paradigms and methodological approaches such as ethnography, social realism, critical theory, phenomenology, and others (Anney 2014; Blaikie, 2010). Qualitative researchers may engage in rigorous methods of sampling, although often a relatively informal approach may be used. After this, data are collected, analysed and interpreted within a specific context to draw meaning (Hanson et al., 2011). The standards used in quantitative research such as internal validity, objectivity, reliability and generalizability are not suitable to use to reflect the quality of qualitative research (Korstjens and Moser, 2018). Qualitative researchers

thus report trustworthiness, which simply means can the findings be trusted (Korstjens & Moser, 2018; O'Brien, Harris, Beckman, Reed, & Cook, 2014). The quality standard for any qualitative work should include objectivity, credibility, transferability, dependability and confirmability (Shenton, 2004b). These elements of trustworthiness can be confirmed by prolonged engagement in the field of enquiry; the termination of data collection when one reaches saturation; peer debriefing or member check; interpretations shared with colleagues from different cultural groups; thick description which includes an extended description of context and not just the behavior and stories of the participants; and creating an audit trail to allow transparency in describing the research steps from the development of the project until reporting the findings (Korstjens and Moser, 2018). Reflexivity is also an important part of confirming transparency.

I ensured that in collecting data for this study, I was able to illustrate high levels of credibility, dependability, transferability, confirmability and objectivity- the elements of trustworthiness (Shenton, 2004a, 2004b). I ensured credibility by using appropriate data collection methods, and by working with highly trained staff (trained by me), so guaranteeing good quality data collection. I ensured that I collected sufficient detail of context to allow other researchers to be able to understand clearly the researched subject and context. All data collected are the stories of participants. I tried always to be objective to enable the data to speak for itself and to tell the story, and accordingly, while the analysis is my own, I have been careful not to impose on the data my personal conceptions and thoughts.

Qualitative research is useful in collecting and understanding sensitive issues within populations. We are mindful of the distress this might cause those recounting such issues, but often we ignore the stressful and traumatic experiences the researcher encounters while gathering this information. In this study, for example, as already noted, I and my assistants interviewed

participants on sensitive topics, that is, sexuality, HIV infection, and sexual practices. Interviews led to women recounting to me incidents of their partner having multiple relationships, partner violence in the relationship, abuse of alcohol, dealing with an HIV positive diagnosis, and their failure to disclose, even while discussing the importance of disclosure among other issues. Wray and colleagues (2007), reporting on a study of women diagnosed and treated for gynecological cancers, discuss the way in which researcher distress can accumulate in the collection of data, transcribing, and data analysis. The constant re-living of events becomes traumatic, in relation to sensitive issues and to other issues that are highly distressing. When researchers are of the same gender, this may enhance rapport, empathy and communication, but it may also compound the risk of distress, particularly when both the researcher and the respondent might have the same problems (Manderson et al., 2006). This may challenge the validity of the data collected. Being aware of these biases assisted me to detach myself from the issues and to carefully listen to the important stories that the respondents had to tell.

The different experiences of conducting data on a sensitive topic lead to the publication of the article presented below which aimed at interrogating the challenges in researching areas of heightened sensitivity, susceptibility, fragility, and exposure.

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Talking about sex in pregnancy: reflections from the field in urban South Africa

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Abstract

Qualitative research with close engagement in the field allows researchers and participants to build relationships and establish trust, enabling researchers to collect meaningful and sensitive

information. Drawing on findings from a study conducted in an urban setting in South Africa, we discuss the challenges faced when interviewing pregnant women with HIV infection, retaining them in the study, and extending the study to include their partners. We discuss the dynamics of pregnancy and draw lessons from interviews concerned with personal, sensitive issues. The study on which we draw was conducted in Johannesburg, South Africa, and was nested in a larger prospective cohort study of women and their infants, which in turn was part of a case control study. Sensitive topics are difficult and complex, but to ignore these and stay in safe territory is to ignore some of the most pressing questions of our time. It is important that those who conduct interviews are well trained and able to engage empathetically with participants, and that some form of counselling is available for both participants and researchers.

KEYWORDS

South Africa; HIV; qualitative research; reflections; vulnerable groups

Introduction

Qualitative research involves close engagement between researchers and their interlocutors to build relationships of trust, to enable the collection of meaningful information. In any study, however, power relations are always at play, overtly and covertly, and when participants are structurally vulnerable and the subject matter sensitive, these factors raise important ethical questions for researchers. The way a researcher is positioned influences the data collected in terms of both content and quality. The topics discussed may precipitate pain and distress, risking psychological harm (Elmir et al. 2011; Richards and Schwarts 2002) by causing a respondent to relive unpleasant past events (McCosker, Barnard, and Gerber 2001; Taylor and Bradbury-Jones 2011). These vulnerabilities and biases lie at the centre of continuing anthropological discussions

of research ethics; they cannot be resolved through research design and ethics reviews. Further, despite the most rigorous reflection on particular areas of enquiry, there is always the risk of unforeseen outcomes. Yet the lines of enquiry that potentially carry high risk, and expose vulnerability and social exclusion, are precisely the areas where social science research is needed. Hence our interest in interrogating the challenges in researching areas of heightened sensitivity, susceptibility, fragility, and exposure.

In exploring social meanings of sexuality, HIV infection, and sexual practices among pregnant women, researchers often invite participants to speak of personal and private matters, and to address topics that they may rarely discuss on other occasions. Recruitment and participation may be especially challenging when researching sex and intimacy, when establishing relations of trust are critical for even preliminary engagement. This impacts on the capacity of a researcher to pose questions in ways that avoid embarrassment, misconceptions, and distrust. Moreover, the continued retention and involvement of participants needs to occur without making their lives (and those of the researchers) difficult.

Our discussion here is based on research undertaken as a doctoral study that was nested in a larger epidemiological study with women presenting at Chris Hani Baragwanath Hospital, in Soweto, South Africa, where annually 17,000 women give birth (Chris Hani Baragwanath Hospital 2016). Established in 1931, Soweto is a township in southwest Johannesburg. Today it has an estimated population of around 1.3 million, the majority Black (Statistics SA 2011). The hospital claims to be the third largest hospital in the world, with 3,400 beds and nearly 7,000 clinical, administrative, and support staff. In this paper, we reflect on the fieldwork conducted by the first author together with two female research nurses and one male research assistant. We discuss women's experiences of and feelings about their pregnancy, and how this influenced their

relationship with their partner. We draw lessons from interviews on personal and sensitive issues, and discuss the challenges of retaining participants and recruiting their partners.

Methods and context

The research was conducted for a doctoral study and was nested within a larger prospective cohort study of women and their infants. In the larger cohort study, women were recruited at first presentation at the antenatal clinic, with the hope of retaining them in the study for up to 24 months after delivery. This involved them attending the hospital for study purposes at different time points, when the research assistants administered various questionnaires, the research nurses examined them and the growing foetus, and a sonographer performed a foetal ultrasound. The study therefore utilised both quantitative and qualitative methods.

The nested case control study was designed to investigate HIV incidence and to understand the sexual practices of women and their partners during pregnancy and the postnatal period, including assessing factors that might influence HIV infection (where women were HIV negative at first test) or transmission if they were positive and their partner(s) negative. Pregnant women who were newly diagnosed with HIV infection at time of first presentation at the clinic were of interest and were enrolled into the study; they were age-matched with women who had tested negative for HIV when first tested as a component of routine antenatal care. Select women participating in the case control study were recruited to the study we report on here.

While this research architecture made sense to the researchers involved in the superordinate studies, and fitted the questions that they (and we) wanted to explore, the extensive engagement between research staff and participants, and the monitoring associated with this, potentially shaped participants' involvement. For example, although most women enjoyed the physical check-ups

and associated interviews, when they were able to speak about the different challenges they faced (medical or social), the multiple examinations and questionnaires at times agitated and tired them. The fact that the study was in a hospital with nurses and doctors already may also have given researchers particular authority in relation to the participants.

Data for our study were collected between April 2014 and January 2017, using observation and in-depth interviews. Once we had permission to observe participants in the research clinic where some of the interviews would take place, all women from the pregnancy cohort study were potentially candidates to be interviewed. Multiple interviews were conducted with 30 women during and after pregnancy. Of these, 15 were diagnosed as HIV positive, and probably had been infected during pregnancy as they tested negative at time of recruitment. Interviews were conducted with a structured questionnaire in order to learn about sexual risk behaviour and social and behavioural factors associated with risk of HIV infection.

The other 15 women remained HIV negative, to our knowledge. We also interviewed three partners of the pregnant women; most partners rejected any invitation to participate, or agreed but failed to attend appointments. The initial interview with each woman, generally towards the end of the first trimester, provided us with an overview of her life history and enabled the interviewer (Langelihle Mlotshwa) and the participant to begin to establish a relationship of relative trust and ease (Cho and Lee 2014; Johnson and Clark 2003). If a woman was newly diagnosed with HIV, the interview was held at least two weeks after the diagnosis to allow her some time to adjust to this new knowledge. If she was still uncomfortable in speaking with us, we did not proceed with the interview, although some women were interviewed at a later date. A second interview, conducted at the end of the third trimester, focused on the woman's current intimate relationship(s). This interview allowed us to clarify issues that emerged in the first interview,

particularly in relation to sexual behaviour. Final interviews were conducted after delivery to explore further changes in intimate relationships, sexual behaviour, and practices. All interviews were conducted by the first author in one or a mix of the languages predominantly spoken in the study area, in which she is fluent – English, seSotho, or isiZulu – and took between 20 and 96 min; these were transcribed and translated verbatim. All participants were 18 years and above, Black, and attended the antenatal care (ANC) clinic at the Chris Hani Baragwanath Hospital.

Juggling insider/outsider status

Researchers conventionally have outsider status in relation to the people with whom they work. This may be seen as an advantage for heuristic reasons, ensuring ‘objectivity’ from various disciplinary perspectives and providing distance between interviewer and interviewee that might assure study participants of confidentiality. However, outsider status also produces and reflects the power of researchers in relation to study participants (Das 2010). In a formal setting – when encounters take place in an office, a laboratory, or a clinic, for instance – such distance is amplified, as educational, employment, and class distances between researchers and research participants are marked. Our setting was a hospital, and priorities around clinical issues, language skills, and race, and familiarity with medical procedures all reinforced social inequalities. The social relations in such settings are particularly nuanced in South Africa where apartheid, although dismantled in 1994, has a continued legacy. In any setting, however, interactions between researchers and participants require performances of self (Goffman 1959). Ensuring ease of communication and general comfort in conversation between interviewees and researchers is crucial to quality and content; the challenge in talking about sex is that ‘comfort’ can be hard to achieve and sustain, even from one question to another.

As age, class, race, and gender influence interviews in certain directions, they structure social relationships, including those arising within social research (Broom, Hand, and Tovey 2009; Manderson, Bennett, and Andajani-Sutjahjio 2006; Manderson and Davis 2014a, 2014b). These factors contribute to the nature of interactions and flow in conversation between the participants. In this study, the modifying factor was the first author herself. In the same way that gender and age work in different ways to inhibit or open up possibilities to share information (Manderson, Bennett, and Andajani-Sutjahjio 2006), so here personal names, age, skin colour, gender, and language skills helped narrow these gaps. The first author is young, female, married, a mother, and Black. This helped close social distance with the women being interviewed who were all also Black, so assisting her to ask women personal questions about life choices, intimate partners, sexual relations, pregnancy, and infection (and, by implication, fidelity).

In contrast, the social dynamics of interviews, the sensitiveness of the questions, and specific discussions on sexual practices and relationships – including on commitment between partners, communication around sex, HIV diagnosis, violence within the partnership, and multiple partners – made it difficult for us to engage with women's partners. Older men were especially reluctant, but most men refused to be interviewed or failed to attend interviews even when they had agreed to do so. Women considered that their male partners were unwilling to talk about these issues with a person who had already spoken to the woman, for fear of breaches in confidentiality, and that the interviewer would be influenced by the woman's account. Given the difficulties that women reported in talking about sex with their own partners, the personal dynamics that might be disclosed (additional partners, for instance), and men's wariness about the flow of information from interviewer back to the other partner, such reticence was not surprising.

Interviewing men about sex, HIV, and violence can also compromise researchers, with their motivations open to misinterpretation leading to concerns of safety. In this study, we were wary of a woman researcher talking to men about sex, sexuality, and multiple partners, and a few field encounters suggest that this wariness was legitimate. Interviews with men were conducted in a public setting with the researcher travelling with a research assistant, but in a relatively informal and private area of the research clinic. Younger men sometimes took the interview as an opportunity to flirt, and to suggest they meet again outside of the research setting. This created discomfort and forced the researcher to manipulate or divert the conversation.

Despite the usual advantages of personal status, on a few occasions the first author was also an ‘outsider’, not only because she was a researcher, but because of her nationality. Some women would implicitly or explicitly speak negatively of ‘foreign nationals’. The first author is a young Black researcher of Nguni descent, and although she has lived in South Africa for over a decade and had conducted public health research in both rural and urban areas, she was still identified as Zimbabwean. This, sometimes, evoked concern for her safety, particularly when xenophobic discourse was marked and there was intermittent violence against foreign nationals in the study area. However, her ability to speak local languages was a clear advantage, and no hostility was ever directed specifically towards her.

Experiences of forming relationships

Friendship bonds are usually formed between people who are similar to and can relate with each other; this allows for intimate sharing, and sets these relationships apart from others that are instrumental and focused (Tillman 2015). In general, insider status provided the first author with support and acceptance from the women with whom she was working and from others in the study

area. She conducted all interviews, and her personal background and intermittent, sometimes more regular, communication with women between these formal interviews facilitated friendships, influencing how women engaged with her and accepted her into parts of their lives. Living in South Africa for an extended period provided some understanding and appreciation of different aspects of society, and the skills and insights – the cultural and social capital – necessary to interact with the study participants.

In writing of friendship as method, Tillman (2015) has argued that being ‘in the world’ with others, participating in everyday conversations, and taking part in routine activities all help to build these informal bonds. Friendship is a relationship where people receive support, care, and some form of assistance (Tillman 2015); at heart, this is a relationship of open reciprocity. The capacity of the researcher and research participants to share emotions and everyday actions of compassion, generosity, and vulnerability specifically strengthened the relationships such that women reported that they looked forward to attending the research clinic in order to speak of issues that were bothering them. They reported that they felt supported during interviews through the practice of listening and encouragement at times when they felt, for example, overwhelmed by being pregnant or when they were facing other difficulties. Presumptions of common experiences in the world, and personal comfort between the participants (researcher and researched), assisted in breaking down barriers and encouraged women to reflect on intimate and private issues. Participants emphasized the presumed commonality with the interviewer; they expected her to understand different experiences and situations even if this were not so. Often there was no need to encourage women to elaborate; they already felt that they could share these experiences and might find comfort in speaking about them to someone who would understand the situation. In response to probes for further detail or clarification, at times women appeared somewhat surprised.

They trusted the first author enough to talk about matters they might otherwise keep as deeply private; they spoke about how their bond of friendship had grown over the months of working together, and how it reflected or allowed a measure of trust. Friendship allowed participants to share what emerged as ‘deeper stories’ about their lives, with disclosures and reflections that were unanticipated when we planned the study.

The first author was often invited to spend time with women who did not work outside the home. Her visits into the community, and the opportunity to sit in women’s homes and share food with them, helped her gain familiarity with their personal circumstances and the community settings in which they lived. The women often lived in deeply impoverished circumstances, with very few resources. Other women were in paid employment, ranging from domestic work, to sales (often small food stuffs), to clerical work, and many made considerable effort to return to the clinic to meet and participate in an interview. Some women, however, found it difficult to return for appointments, for various reasons: taking children to a clinic, home obligations, or feeling the hospital was too far for them to travel and that, in order to arrive on time, they would have to get up extremely early. Even in this urban area, logistics limited access to care.

But ‘friendship as method’ was not simple. While the approach may be personally rewarding (Lee 1993), leaving researchers feeling that they are doing something worthwhile, researchers may also experience guilt, anger, or frustration in response to their respondents’ narratives, disclosures, or retreats to silence (Hubbard, Backett-Milburn, and Kemmer 2001). Questions of sex, sexual health, and personal safety are often complex, and responses are difficult, particularly when respondents provide accounts of their experiences that are emotionally charged (Elam and Fenton 2010; Mollet 2011). The implications of this became clear. Ethically and personally, as researchers, we may need to detach from participants or establish some distance

from their lives and accounts, but sometimes this was difficult to do. This was a regular theme the first author spoke about in debriefing meetings with the field team and other researchers in the same and similar studies. Sometimes she felt she needed to offer help to participants, but the confines of her engagement with women, as set out in ethics approval, and the limits of her capacity to change matters that impacted their lives, precluded this. Hence, there were frequent contradictions.

HIV, sex, and pregnancy

Our conviction that women would be willing to talk about intimacy, sex, and HIV was confirmed when the first author observed clinic interactions, assisted women to complete questionnaires, and talked with research nurses and assistants. Study staff provided her with information about participants who came to the clinic. Clinic interviews initiated a formal research relationship when women spoke about pregnancy and related issues. Many women indicated that they enjoyed being part of the study; they reported that they learned a lot about their growing baby, not least because of regular routine ultrasounds (and prints to take home). They spoke of how they could protect the baby from infections such as HIV while anxiously awaiting its arrival. Although sometimes women were irritable from hunger and the many questionnaires that needed to be answered in the larger study, women were generally happy to participate and to be interviewed, were easy to engage, and responded openly to most questions.

Sometimes however women would feel shy and would giggle in reaction to the directness of questions about sex. Lebo, 37 years old and HIV negative, when asked about the frequency with which she had sex with her partner and the positions they used, looked away and giggled and responded in a low voice. Discussions about sex were complicated by the prevalence and ever-

present risk of HIV, and, despite its prevalence, its continued stigmatization (Deacon and Stephney 2007; Deacon, Stephney, and Prosalendis 2005). In South Africa and beyond, HIV infection, AIDS, and stigma associated with behaviours and occupations considered high risk still permeate social life, and persons living with HIV, and those close to them, continue to face considerable discrimination, labelling, name calling, and rumours (Rispel, Cloete, and Metcalf 2015). A number of studies have reported stigma reflecting community fear of people living with HIV, fear of infection, and blame associated with contracting and/or transmitting the virus (Chambers et al. 2015; Rispel, Cloete, and Metcalf 2015; Velloza et al. 2015). HIV determines the stories that people deem to be the most important and recountable. HIV may be central in some people's narratives, but others may evade questions or edit their own accounts of risk and infection. The act of telling can be straightforward or direct, rehearsed, or even staged (Manderson and Davis 2014a, 2014b; Manderson et al. 2015). Consequently, while for certain purposes people may be comfortable discussing sex and HIV status, in other cases they rely on allusion and insinuation. We were attentive to these shifts, and so to the subtle ways in which women responded to questions, opted for silence, withheld information, and told stories relating to sexual behaviours and practices during pregnancy.

Many women, speaking of their HIV status, reflected that infection was no longer a death sentence. Nurses told some women who had seroconverted during pregnancy that they would have to take their treatment until they die, but that otherwise, they could live a 'normal life' like everybody else, if they chose to do so. Women held onto this information and found hope in it, contributing to their capacity to cope with their new status:

The nurses after telling me I had acquired HIV in pregnancy said I can still live a normal life like everybody else. All I had to do was make sure I eat right and take care of myself. I should not think that, because I am now positive, I will die. (Karen, 36, HIV positive)

This news confused others. For example, Lerato (37, HIV positive) asked: ‘Does this mean when the baby is born the HIV will come out also and I will be fine again?’ And Snegugu (21, HIV positive) similarly commented:

I do not really understand what this (HIV) means. At the clinic when I was tested I was just told that I was positive and will have to take this treatment that they gave me. They never explained anything else. (Snegugu, 21, HIV positive).

At this point, the first author would try to explain what it meant to be infected with HIV, in the hope that it would decrease the woman’s anxiety or confusion. Some women reported talking to their partners about HIV and about the need to use condoms when they had sex during pregnancy, but their partners often resisted the use of condoms, as Snegugu explained: ‘Even when I ask him ... he says he does not use them’. Ultimately, women explained, they would give in and have unprotected sex. Women also seemed to believe their partners when they insisted they were HIV negative, leaving women confused about the source of their own infection. Ntsako (32, HIV positive), who had seroconverted, explained:

We are open with each other ... when I found out I was positive I called him and told him. I then asked him if he knew his current status and he said he got tested in February. As we had tested in June the previous year, I asked him what the result was, and he said it was negative. (Ntsako, 32, HIV positive)

During interviews, probes were used to explore women's understandings of their partners' reported negative test results, especially given that they said they had not had sexual relations with others and that they had not accompanied their partners when they said they were tested. Sometimes probing for more information proved difficult, raising ethical questions and risking making participants uncomfortable. In many cases, fear of abandonment influenced women to accept men's accounts, despite flaws of logic: if a woman had been HIV negative prior to and at first test in pregnancy, and had not had new partners subsequently, then she would surely have suspicion that her partner had had other partners and so been infected. Women rejected this proposition. Their willingness to accept men's explanations, and agree to sex without a condom, reflected for us the emphasis that women placed on keeping their partners with them throughout pregnancy, even if the men were unwilling to stay on to help raise the children. Women's fear of being deserted has also been noted in a study on men's 'disengagement' from their families (Makofane 2015; Mazembo, Thomson-de Boor, and Mphaka 2013; Richter, Chikovore, and Makusha 2010), and was reinforced by women's personal experiences. Yet women held on to relationships, even when it was apparent to them that their partner would eventually leave them to manage alone both their pregnancy and HIV infection.

Support, intimacy and risk

Women and men struggle to balance risk of infection while maintaining healthy interpersonal and intimate relationships (Cusick and Rhodes 2000; Rispel, Cloete, and Metcalf 2015). This partly relates to the stigma that surrounds HIV, silence within the family around HIV, and the blame attributed to individuals for infection. In South Africa, the challenges of living with HIV, and the threat of HIV within a relationship, is very real because of its high prevalence. This is complicated by insecurity in relationships, as discussed above (also Mindry et al. 2011);

marriage rates have consistently declined over the past half century (Budlender, Chobokoane, and Simelane 2005; Channon, Hosegood, and McGrath 2016; Hosegood, McGrath, and Moultrie 2009; Hunter 2007; Richter, Chikovore, and Makusha 2010). Tensions around HIV in intimate relationships were very evident. Participants wept, explaining to the researcher the importance of telling the partner(s) about their new positive status but not knowing how to do this. As this was often emotional and overwhelming, trained counsellors were always on standby to talk to these women. But this did not head off the implications of infection: the revelation of newly diagnosed HIV status at times led to gender-based violence, precipitated by arguments about who ‘brought the HIV home’.

Relationships are fragile with or without HIV infection. Busi (27, HIV negative) said that she wanted to trust her partner and to marry the father of her child, and she longed for emotional intimacy. But given her partner’s history of drug misuse and debt, she also saw him as irresponsible and felt emotionally drained by the relationship. He had played no role in caring for their first child, and she doubted that he would act differently towards their second child. She both hoped for his support during her pregnancy and expected none. In the second interview, she mentioned that their relationship had deteriorated and that he was no longer coming to visit her: ‘I do not see him anymore; I cannot remember the last time I even spoke to him. He just makes sure he sometimes visits our older child and that’s that’. She was still hoping that he would change and ‘be a better person’, not for her sake but for their two children. Busi mentioned that participating in the study had given her some support and comfort, as she at least had people with whom to discuss these concerns; she did not have to think about these problems alone and keep them to herself.

For women who had seroconverted, emotional intimacy played a role in the way they coped with their pregnancy and their HIV status. Those who reported partners with whom they had strong

and supportive relationships seemed to cope better with their bodily changes, health status, and the tasks they faced in preparing for the new baby (Mlotshwa, Manderson, and Merten 2017). For others, small things made a difference: a man taking time off from work (or other activities) to accompany his partner to antenatal care (ANC), for instance. Very few women, however, mentioned having a partner willing to accompanying them on ANC visits; most accepted that this was normal and defended their partners' absences:

'He has never been with me for antenatal care, he is never available when I go to antenatal care, he will be at work or doing other things' (Ntsako, 32, HIV positive).

Everyday intimacy was largely demonstrated by sexual relations, and for some women, this was troubled in pregnancy. Some women explained that they did not want to have sex or even to be touched by their partners, either because they were tired, they felt it was 'too much work' to have sex, or they were not interested:

My sex drive has reduced. I don't want to have sex, I just do not feel attracted to men, I actually hate them, I do not want to be around men. They annoy me, especially the father of my child. I don't have sex any more. I do not want to be intimate; I have no interest in it. (Monalisa, 27, HIV positive)

In recounting this, most women turned to the researcher for reassurance that they were acting appropriately – they looked for understanding if not approval. This was always a struggle. As the first author understood it – and as formally inscribed in statements of ethics – a researcher's role is to elicit, listen, and interpret stories, not to give advice and certainly not to offer opinions about whether or not to have sex.

At the same time, some men, either as stated during interviews or as reported by their partners, also felt anxious about having sex for fear that they might hurt the baby or the mother of the child:

To be honest, my sister, it comes that you really want something, your body is telling you that you really want to sleep with her but ever since pregnancy, I ask myself how about if I hurt them, so you just have to leave it like that. She would actually be the one to say, no, we should have sex. I am okay otherwise. I am really afraid. (Themba, 31, HIV status unknown)

Talking about sex was sometimes awkward or embarrassing, but talking with women who were distressed was especially challenging: women's partners had multiple relationships; they were insecure and worried about their relationship; they were anxious about the pregnancy and their capacity to care for a new child; they experienced difficulties in managing their health when HIV positive and in minimising further risks of infection. Asking women to recount their personal histories, and inviting them to share relationship difficulties and sometimes abuse, often left participants and researcher feeling vulnerable. How does a researcher negotiate these moments, when, for instance, she recognises a respondent's tentativeness in speaking of certain private issues, but recognises too their desire to continue to speak? This may be the only time they can do so. Managing these sensitive moments is critical for the ethical engagement of researchers, as much as it is to ensure that results are robust, valid, and reliable.

Detaching from the stories

Increasing attention is being paid to researcher positionality, with emphasis on the importance of researchers acknowledging and describing their own beliefs and biases when

establishing the trustworthiness or validity of their research findings (Berger 2015; Creswell and Miller 2000; Dilley 2000; LeCompte 2010). Ethnographic research involves immersion in the cultural and social context of study participants to ensure understanding of respondents (O'Brien 2010), while clinical research limits this. As the research team conducted observations and interviews, we were often profoundly aware of issues that might influence how participants responded or influenced our interpretation of the data, and we were mindful of what different issues might mean from their perspective.

At the time of the interviews, the first author had recently had a child, and she was conscious of the social support she felt was needed at this time; she was particularly empathetic with abused women and men, and was concerned about the challenges they faced in their daily lives. An example was when she interviewed an ex-boyfriend of one participant, who dismissed their relationship: 'I was not interested in her; I just needed someone to sleep with when I was bored. I would just call her to come over and sleep with her' (Aluwani, 30, unknown HIV status). Initially, she felt angry that women subject to violence appeared not to want to change their situation. With greater insight and empathy, she often felt personal responsibility when women lacked support. We did not always have answers to the questions women posed; neither were we trained clinically or as counsellors. Women in abusive relationships, and those distressed by their HIV positive status and eager to talk about this, were referred for support and practical advice to appropriate professionals. But, as explained above, much of the research was conducted in a hospital setting, and this arguably influenced women to occasionally seek clinical advice from the researcher and research assistants.

Further referring women to others did not necessarily resolve the problem, and the first author was often dismayed and distressed, at times experiencing transferred trauma. Wray,

Markovic, and Manderson (2007) have similarly elaborated on the intensity and stressfulness of research on topics that are inherently emotionally complex – data collection, transcription, and analysis all impact on researchers as they engage with verbal accounts, text, and more directly engaging in the lives of participants.

Trying to separate oneself from subjects of discussion and associated distress can be difficult. Debriefing meetings in the clinic were one way to cope with these challenges, as suggested by others to assist with unexpected or stressful emotional responses in research (Wray, Markovic, and Manderson 2007). The growing acknowledgement that research can harm researchers (Dickson-Swift et al. 2008) sheds an important light on the challenges in collecting and writing up data. When researchers are aware and have insight into their own emotional involvement and vulnerability, their emotions can enhance their research capacity and enrich their findings (Janzen 2016; Mitchell and Irvin 2008).

Conclusion

In exploring sensitive issues in South Africa, Lawhon, Herrick, and Daya (2014) have written of the importance of attending to class, ethnicity, level of education, local and national differences between researchers and participants, and the critical roles these play in research.

This is partly related to the historical exploitation and structural violence experienced by the majority of the population under apartheid, when violent exclusionist policies operated on the basis of gender and race (Coovadia et al. 2009; Lawhon, Herrick, and Daya 2014). Apartheid divided the population spatially, legally, institutionally, socially, and personally; 23 years after its formal end in 1994, these legacies continue to shape social institutions, life chances, and wellbeing despite new reform policies, programmes, and moves towards transformation in health and

education sectors (Khan, Thomas, and Naidoo 2013; Reddy 2004). These initiatives assisted us in conducting fieldwork, and brought meaning to participants' stories.

The women who participated in the study spoke at length of difficulties in initiating discussions about HIV with their partners, addressing its impact on their relationships, and managing how, when, and what information to share with their partners. According to them, having open and intimate discussions about HIV, sex, and pregnancy were difficult, especially if they were diagnosed as HIV positive during their pregnancy when they were sometimes in new relationships. Explanations of how they acquired HIV were often difficult to resolve in these contexts. As we have discussed, for some women, the stakes of such discussions were high and at times seemed to be unbearable – for example, because of the fear of being deserted or physically abused. Women spoke of their desire to belong and to be loved, and they feared that conversations about HIV, sex, and pregnancy would alienate their partner and compromise their relationship. Women sought some counsel from study staff, but researchers have a limited role in this and, for the most part, needed to refer women for further counselling.

Sensitive issues are always difficult and complex. But to ignore these, and stay on safe territory, is to ignore genuinely pressing questions of our time. In many circumstances, researchers do not have adequate training to deal with these sensitive issues; the content of respondents' accounts – poverty, violence, fear, distress – becomes overwhelming to them as they receive them. It is important that those who conduct interviews are well trained and able to engage empathetically with participants, and that some form of counselling is available for interviewers as well as interviewees.

The challenges that exist for women in securing and maintaining long-term relationships, and their fear of loss of current partners, complicate their efforts to address issues of HIV risk and sex in pregnancy. Women often lack an environment to talk about these issues, even within established intimate relationships. Lack of or limited psychosocial support further means that many women have few skills to begin such discussion, and so they remain silent. The silence may further affect HIV prevention and women's access to treatment and counselling programmes.

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* * * *

Data collection

As explained, various participants were interviewed more than once, and this PhD draws on multiple interviews (54) conducted during and after pregnancy between July 2015 and March 2016. Interviews were conducted at a place where the participant, my assistant and I were comfortable; this was usually the hospital but occasionally at the home of the participant. A life history approach was used to understand sexual behavior as contextualized in an individual biography, ie the life experiences and account of their life leading to their current situation were explored, allowing me and my respondents to explore how women navigate sexual relationships during pregnancy and when HIV infection comes to play. A life history approach is a qualitative research method which in detail highlights the respondents' particular experiences and how they interpret this information about their experiences, as well as what they choose to tell as important. In these accounts of their lives, their past life or ongoing life can be included (Rahamah et al., 2008). The intention was to interview each participant up to three times in the study; however some were lost to follow-up, some moved to other cities; or they did not find the time to come back for study visits due to work commitments. Table 2 (pages 77) provides details.

Table 2: Qualitative study participants and interviews

Participants Pseudonym	Number of interviews	Age of participant	Number of children excl current pregnancy	Marital status	Pseudonym of Father of child	Age of child's father	Number of interviews with partner
HIV negative							
Pretty	3	30	1	Single	Mosa	30	1
Hazel	1	33	1	Single	Tshego	unknown	0
Tammy	3	41	2	Married	Bhekifa	46	0
Thembi	2	27	0	Living with partner	Themba	31	1
Rhirandzu	1	32	1	Living with partner	Thuso	39	0
Daisy	2	30	0	Single/not living with partner	Mnqobi	32	0
Ntombi	2	25	1	Living with partner	Mondliwethu	30	0
Rachel	1	27	0	Living with partner	Simphiwe	30	0
Busi	3	27	1	Single	Tshepo	29	0
Tracy	3	32	1	Not living with partner	Kagiso	33	1
Pamela	1	32	1	Living with partner	Thomas	39	0
Lilian	3	38	1	Living with partner	Philani	46	0
Rose	2	34	1	Living with partner	David	41	0
Boniwe	3	39	1	Living with partner	Thokozani	45	0
Lebo	3	37	1	Living with partner	Mbongeni	unknown	0
HIV positive							
Martha	1	28	0	Living with partner	Freddy	40	0
Lerato	2	37	1	Single	Anathi	27	0

Yolanda	2	39	3	Not living with partner	Babongiwe	46	0
Ntsako	2	32	2	Single	Cebisani	unknown	0
Snegugu	1	20	1	Not living with partner	Thobani	25	0
Ellen	1	23	1	Living with partner	Thlali	27	0
Qondisile	1	39	3	Not living with partner	Thabani	46	0
Lindi	1	34	2	Living with partner	Senzo	41	0
Khethiwe	1	30	0	Single	Fezile	38	0
Nokukhanya	1	27	1	Married	Mncedisi	30	0
Joy	1	28	1	Living with partner	Mphiwa	31	0
Dimakatso	1	24	1	Living with partner	Zenzo	27	0
Karen	1	36	1	Living with partner	Zweli	40	0
Nelisiwe	1	22	1	Not living with partner	Sipho	29	0
Monalisa	1	27	1	Living with partner	Charlie	34	0

The use of life histories was chosen as an entry point as it gave respondents the possibility to narrate important life events from their own perspective (DiCicco-Bloom and Crabtree, 2006). In the life histories method, respondents may have a tendency to be selective (Ssali et al., 2015), that is individuals choose what they want to tell and what they perceive as important life events to them, and thus the accuracy of the account is dependent upon events remembered by the participant. Given this, the researcher is challenged to understand the participant's current situation, attitudes and behaviours, and how these may have been influenced by previous situations. In the first interview in this study, the primary aim was to establish rapport with the respondent. For all HIV participants, the first interview was at least two weeks after diagnosis, to allow them to adjust to this new knowledge of HIV infection. This interview was a first step in establishing trust between the researcher and the study participant; in the second and the third interviews, emerging themes related to the main research questions were followed up and consolidated. Once good rapport was established, respondents were able to speak more freely about their relationships, including both emotional issues and sexual practices, which have to be understood in the broader context of a woman's relationships and their expectations of them. The initial interview therefore allowed a general understanding of the person's personal life history, and for the 15 women who had been diagnosed with HIV, their explanations of the reasons for the HIV infection that they were willing to share. A second interview was conducted in the third trimester of pregnancy, with a focus on the current relationship and on sexual behaviour, including if any changes had occurred - in the relationship and specifically in terms of sex - during the last few months. After delivery a final third interview was conducted. This interview focused on the current relationship, on sexual behaviour, and the changes in life the participant was experiencing after delivery.

All interviews were conducted using an interview guide, which contained a few structured questions but mainly open ended questions (see Appendix 7,8). An interview guide identifies important questions, and so serves as a check list so that the researcher does not leave out essential questions while conducting the interview (De Vos et al., 2011); it assists the researcher in guiding the interview without leading the participant. This type of interviewing permits comprehensive and comparable data gathering, ensuring that all main issues are covered. Nonverbal behaviour, expressions and communications were observed during the interview, such as the way participants would relate to neighbours during interviews held at the participants' home, crying, smiling, laughing, and even the change in tone of voice. Sometimes in interviews, things maybe unclear and opinions may change; repeat interviews give an opportunity to clarify these issues and to better understand the participants' story. In addition, questions were adapted depending on the flow of the interview. Adapting these questions also allowed me to obtain personal, sensitive and complex information (De Vos et al., 2011). As part of the interview guide, a checklist was developed (Appendix 10) and this was used to ensure that important content was covered over the three interviews. In order to prevent attrition as far as possible, participants were contacted by phone calls and home visits, enabling me to catch up with each woman, find out how the pregnancy was progressing, and as a way of building rapport. All interviews were conducted by me in one or a mix of the languages predominantly spoken in the study area, in which I am fluent – English, seSotho, isiZulu or tsotsitaal as stated above – and took between 20 and 96 minutes. All participants were 18 years and above, and Black.

Data management and data analysis

As all interviews were audio-recorded, the audio files were stored on password-protected computers, labelled, and saved under the pseudonyms given to the respondent. I transcribed and

translated verbatim all interviews into English. The transcribed narratives obtained from the interviews were coded manually. Coding and analysing the data began after the first interview was conducted, this meant that data collection and analysis were undertaken to allow for iteration. Initially narratives were read and re-read and coded openly for content. This included the coding of text sequences and the writing of memos linked to specific sequences. In a second step, the codes and memos were grouped according to emerging themes by at least two researchers (student and supervisor). The narratives were then re-read fully with the attention to these themes reported in the results. All data were analysed and relevant quotes were included in the results (as written up for publication).

Ethical consideration

Ethical clearance was received from the University of the Witwatersrand Human Research Ethics Committee (Medical) and the University of Basel Research Committee (see Appendix 1,2). At the first meeting, the study was discussed with the woman, and her written informed consent to be interviewed and to be audio-recorded was obtained. All study participants gave informed consent (oral and written) to the researcher. The informed consent clearly stated the purpose of the study, the potential risks of emotional distress for example that could occur, and the possible benefits to them in terms of catharsis --being able release strong or repressed emotions by talking about the bad experiences, talking about a cheating spouse, gender violence or other situations that would have forced them to relive uncomfortable situations. The consent form also made clear their rights to withdraw at any time if they felt they did not want to be part of the study. An appointment was then made with the pregnant woman for the first interview.

All participants gave their written informed consent for all interviews, for their audiotaping, and consent for the publication of quotes from the interviews. In this thesis, participants are referred to by pseudonyms and age only, and identifying information other than study setting has been removed.

Quantitative study

In this study, I additionally used quantitative methods to document social support in pregnancy. This component of the study was nested within the infrastructure of the cohort study, the S1000 days Study (as mentioned above). During the first trimester, pregnant women were recruited and a baseline questionnaire (Appendix 7) was administered in the period of February 2014 and December 2016.

Study setting and design

We analyzed data from a study on Pregnancy and HIV undertaken with pregnant women (N=1043) presenting in their first trimester for antenatal care (ANC) at Chris Hani Baragwanath Hospital, in Soweto, Johannesburg, South Africa. Its overall aim was to understand sexual practices of women and their partners during pregnancy and the post-natal period, and to assess the effect of sexual risk behaviour on incidence of HIV infection. The study in turn was nested in a larger prospective cohort study, the Soweto First 1000 Days Study (S1000), which followed women and their infants for up to 24 months after delivery at Chris Hani Baragwanath Hospital. Data was collected from February 2015-February 2016 using a survey questionnaire on a tablet administered by a research nurse or research assistant. The inclusion criteria for the study were pregnancy, ANC attendance, and consent and enrolment during first ANC visit. Study participants were 18 years or older and were able to give their informed consent. Pregnant women were tested for HIV at every visit until delivery and postnatal. Some women were diagnosed with HIV at their

first ANC visit and others during the course of their pregnancy, while others had been living with HIV infection for different periods.

Measures

Independent variables: Demographic and reproductive health characteristics

Sociodemographic factors such as age, highest level of education attained, marital status, age of partner, and income were examined. Reproductive health characteristic, previous pregnancies, HIV status and time of infection were assessed.

Outcome variable:

Social support networks

Several questions assessed perceived forms of social support in the S1000 study, including: If you had a really big problem and needed help with money, the children, accommodation etc, are there people who could help you? (Nobody, Maybe/unsure, a number of people) (instrumental support); Can you talk to your parents, other family members or friends about any problems you may have? (Nobody, Maybe/unsure, a number of people); Can you talk to your husband or partner about any problems you might have? (Never, sometimes, always) (emotional support; partner communication); Some people think the sisters at the clinic are always helpful, others think only sometimes and some say they are seldom helpful. How do you feel? (Always helpful, Sometimes helpful, Seldom)(External instrumental support).

Additional measures included relationship quality and the social network: Do you feel that the father of your child or your partner makes things harder for you because of the way he acts? (Never, sometimes, always) (Relationship quality); Do you belong to a church group or any other organisation? Likert 5point scale used (yes, no, I don't know, declined) (External support). Do you

have a friend who is also going to have a baby or just had a baby? (yes, no, I don't know, declined) (External emotional support). The questions were adapted from previous validated questionnaires used in the same context (Richter, Norris, Pettifor, Yach, & Cameron, 2007) as well as other similar contexts (Drain et al., 2015). When there was need questions were re-formulated and adapted to suit the South African context.

We asked the respondents to score their agreement on the different statements (items) and then tested the scalability of the items as measures of social support. We performed a Mokken analysis for polytomous items, using STATA 15 command MSP. Mokken models belong to a group of statistical scale analysis called non-parametric item response theory. We used Mokken scale analysis due to its ability to establish the unidimensionality of a scale. (K. Sijtsma & van der Ark, 2017). Mokken scales require three basic assumptions: (1) unidimensionality- one latent variable summarizes the variation in the item score in the questionnaire; (2) local independence- the items measuring the same attribute are statistically independent conditional on the value of the latent trait; (3) monotonicity- the probability of a positive response increases monotonically with increasing values of the latent trait for all items (K. Sijtsma & Molenaar, 1987; K. Sijtsma & van der Ark, 2017). The scale of homogeneity is based on Loevinger's index of homogeneity (Loevinger, 1948; Molenaar & Sijtsma, 1984). Loevinger's coefficient $H < 0,30$ shows poor scalability properties, for $0,30 < H < 0,40$ the scale is weak; for $0,40 < H < 0,50$ shows medium, and for $H > 0,50$ the scale is strong. Mokken scales are estimated using Rho, which is the test-retest reliability coefficient, with $Rho > 0,7$ considered a reliable scale (Gari et al., 2013; Loevinger, 1948; Molenaar & Sijtsma, 1984). Items satisfying the three assumptions of the Mokken analysis can be summed up and individual scores, computed as the rank of the highest endorsed item in this

ordered system, that is it is a sum of positive responses. The sum score is used as an estimate of the level of the latent construct in the outcome variable.

Scales

All the social support variables were included in the Mokken analysis. Two sub-scales were identified: Instrumental support and emotional support by family and friends, which included *If you had a really big problem and needed help with money, the children, accommodation and so on, are there people who could help you?* for instrumental support, and *Can you talk to your parents, other family members or friends about any problems you may have?* for emotional support formed the first sub-scale (H=0.56 and Rho=0.50). ‘Father makes life harder (score inverted)’ and ‘can talk to father of the child’ formed a second sub-scale of support (H=0.45 and Rho=0.53). The finding that the family/friend support scale comprised instrumental support, while partner support did not, this was in line with the findings of the qualitative study (Mlotshwa et al., 2017b). Support by the health staff was included as a separate variable with the question *Some people think the sisters at the clinic are always helpful, others think they are not, what do you think?*. A third scale was identified combining the two items *Do you belong to a church group or any other organisation? How often do you go to meetings?* (H=0,57 and Rho=0,50). We interpreted this scale as a proxy for the membership in a social group of a person.

Mokken scale analysis was also used to create unidimensional wealth scales based on a set of assets. All asset items were included in a single Mokken analysis. Two sub-scales were identified reflecting different dimensions of wealth. The first sub-scale included assets common in rural areas; *animals, land, bicycle*, (H=0.84 and Rho=0,64)(agricultural wealth score), and the second sub-scale included assets more common in urban settings: *scooter, computer, cellphone*,

radio, refrigerator, electricity, vehicle: (H=0,52 and Rho=0,69)(modern goods score). Scores were dichotomized based on medians. Statistical Analysis

We used STATA 15 software to perform all statistical analysis. Means and standard deviations for continuous data and proportions and percentages for categorical data were used to describe demographic characteristics and social support during pregnancy. Logistic regression analysis was used to calculate the crude odds ratio (OR) with 95% confidence intervals for the association between time of HIV infection and social support. We repeated this analysis using the scored scales. In this paper we focus on whether social support networks in pregnancy differed according to time of HIV status of pregnant women. We used first time HIV positive testing during pregnancy as a proxy for infection during pregnancy. Social support was measured at the beginning of the study, while HIV status could change during the pregnancy of the participants. The initial model was then reduced using backward selection, in order to drop the least significant variables. We then continued to successively re-fit the models and applying the same rule, until the remaining variables were statistically significant. In our model relationship quality represented talking to partner or husband about any problem that you may have; external support represented receiving help from nurses, church membership, friend having a baby or just had a baby; wealth represented by modern goods and agricultural assets.

The findings of the study for both the qualitative and quantitative components are presented in the chapters 3,4,5, 6 which follow.

CHAPTER 3

HIV, Sex, Sexuality and Agency

The manuscripts presented in chapter 2,4,5 and 6 reflect only some of the findings in this research. In this chapter, I describe the characteristics of all study participants and reflect on some of the important issues they discussed: condom use; men's sexuality before and during pregnancy; testing for HIV and what it means for the couple; abandonment; and male involvement in a society in which traditional beliefs about gender still pertain. The findings are based on interviews conducted with the pregnant women and a few of their partners, as reported in chapter 2.

Characteristics of participants

The participants' characteristics are represented in Table 3 below. Thirty pregnant women (15 HIV negative and 15 HIV positive women) and three partners (unknown status) were interviewed. From the HIV negative group, four reported that they were single and did not have a partner, four were in a relationship but not living with the partner, four were cohabiting and four were legally married. Amongst the HIV positive group, one reported being single; six were cohabiting and one was married. Seven were in a relationship but not living together, and these women all emphasized the importance of culture and not being allowed to live with a man who has not paid lobola (bridewealth) for the bride: *My boyfriend has his own place where he lives, we do not stay together...this is because he hasn't done anything [referring to paying lobola] at my parent's house. Even though I'm old and do not live with my parents, we still need to follow culture* (Qondisile, 39 HIV positive).

Marriage is common to all cultures as it suggests a central role in procreation (Murdock, 1949 ; Winking, Kaplan, Gurven, & Rucas, 2007). Although some individuals have children out of

wedlock they still emphasize the importance of getting married and being a ‘family’ as in our study. However patterns of marriage and family formation have changed in South Africa in recent years, showing declining rates of marriage for women and increase in cohabitation (Hosegood, McGrath, & Moultrie, 2009; E. Moore & Govender, 2013; Posel, Rudwick, & Casale, 2011). This is anchored in our study as many participants were cohabiting on in relationships but lived separately. Education level for participants varied, and included six (20%) women who had gone to college; the majority of all participants (19, 63%) had attended secondary school. Many of the women (19, 63%) were not from Johannesburg but had come to the city in search of employment opportunities or be with family. The rest (11, 37%) were local Johannesburg residents.

Table 3: Demographic characteristics of participants

Age		Migrants	
20-24	4(13%)	External(outside South Africa)	6(20%)
25-29	6(20%)	Internal(inside South Africa)	13(43%)
30-34	10(33%)		
35-39	7(23%)		
+40	1(3%)		
Marital status		Disclosure to partner(HIV)	
Single	5(17%)	Yes	5(33%)
Not living together	10(33%)	No	10(67%)
Cohabiting	10(33%)		
Married	5(17%)		
Separated	0(0%)		
Education		Religious affiliation	
Primary	6(20%)	Yes	24(80%)
Secondary	19(63%)	No	6(20%)
Tertiary	6(20%)		
Occupation		Planned pregnancy	
No	12(40%)	Yes	6(20%)
Yes	18(60%)	No	24(80%)
Number of children		Experienced violence	
0	5(17%)	Yes	6(20%)
1	21(70%)	No	24(80%)
2	3(10%)		
≥3	2(7%)		

Embracing pregnancy

Most participants reported not having planned the pregnancy, but somehow became pregnant and needed to accept that this was so. Some reported that they had not been using any contraception, but hoped they would not get pregnant; others reported contraceptive failure. In this context, women spoke about embracing the new journey as this was part of life, and such things did happen. Studies have argued that pregnancy while central to the family, societal well-being is a vulnerable time for many women. If not supported adequately this can have negative consequences for the expectant mother and child (Van den Heeve, 2006; Vandervoort, 1999). It is therefore important for women to be able to experience pregnancy in a positive way with their important networks available. Some women reflected that their partners had become anxious, sometimes upset or angry about them falling pregnant: other men went to the extent of wanting them to abort the baby as they were not ready for the child.

It's about how he deals with things. For example if I want to talk about the baby and that I am expecting a child with him, he will be like 'eeyyy, don't talk to me about that; just leave me alone.' And I am like okay, and I also leave him like that. The thing about it is that I cannot force him if he doesn't want to talk to me about it [the baby/ pregnancy]. I just leave him like that (Rachel, 31, HIV negative).

At first we were using condoms, but then we stopped using them. Then I got pregnant, when I aborted I was given an injection that caused me not to have a period for 6 months. And then I was given a card to go to the clinic so I can start family planning. They asked me if I have a child, I said no. They asked me why I used an injection for three months and I told them I didn't know.

Then I just stopped the injection. I got pregnant again and he wanted me to abort again (Martha, 27, HIV positive).

Yes...mmmm, eish how do I put this, sometimes I punish myself for being pregnant because I did not want to be pregnant. I did not want a child, but I have accepted (it) yes, I have accepted (Pretty, 30, HIV negative)

When I found out I was pregnant I wanted to have an abortion because I wasn't ready. I had just gone back to my old relationship with the father of my child. No one knew that we had started dating again, how was I even going to explain that the man who had been doing those bad things to me, I was okay with him now and we were having another child (Busi, 27, HIV negative).

One of the partners explained:

Yes, I told her my son was young and I felt she was trapping me in the relationship. So I suggested to her let's abort the child, please do not keep this child. But she wouldn't hear any of that. She told me it was against her religious beliefs (Mosa, 30, HIV status unknown).

Sex in marriage amongst our study participants was considered a conjugal right, while also they acknowledged that pregnancy had indeed changed sex patterns. One of the partners (man) interviewed reported the difficulty of waiting for your pregnant partner and not having sex with anyone else. This is in line with studies that have reported multiple concurrent partners among males (Adimora et al., 2014; Onoya, Zuma, Zungu, Shisana, & Mehlomakhulu, 2014; Shamu, Abrahams, Temmerman, Shefer, & Zarowsky, 2012), worse off during pregnancy when the partner is unable to have sex more willingly as explained in the study by pregnant women. He reiterated that if as the partner you cannot wait, it was okay to have other sexual partners, but the most important thing to do was practice safe sex. This way you would be protecting your family as they

are the most important amongst the different relationships. He reflected on this, drawing on gender stereotypes to suggest that men have physical needs and that these could be addressed by having multiple partners:

My sister, I don't want to lie to you, sometimes it is difficult for men to stay without sex when the women is pregnant and does not want any sex. If ever one wants to go outside to have those girls that, you know, you are just playing with, the least he should do is protect his family, protect yourself. As guys we know we do these things, so what happens is, there is the love of your life (and) then there are these other ones. These others you know you need to protect yourself because with the true lover you do not wear condoms (Themba, 31, HIV status unknown).

Traditions and practices amongst men

The involvement of men in antenatal care has potential to be used as a tool to protect pregnant women and their infants from preventable infectious diseases such as HIV. In many traditional contexts, gender masculinities confer power to men and they make most of the decisions relating to the health of women (Aluisio et al., 2011; UNICEF, 2007). In the African context, antenatal involvement has been reported to improve acceptance in testing for HIV in women, reduce negative outcomes of disclosure to partners, increase use of condoms, compliance in ART, decrease HIV infection in infants and improve strategies for infant feeding (Aluisio et al., 2011; Farquhar et al., 2004; Mnyani et al., 2016; Oyugi et al., 2017). Some women in the study spoke about their partners as people who do not like the clinic, so they tended to resist the idea of testing for HIV. They reported that men would not go to clinics or hospitals, as they believed this was not a place for them. Similarly in other studies utilization of health services has been low by men and this is often influenced by social construction of masculine identities (None & Stephens, 2008).

These traditional forms of masculinity is likely to be hazardous (Smith, Braunack-Mayer, & Wittert, 2006) to not only their health but their partners too. Cultures, which are dominant, can negatively affect patterns of illness as well as men's behaviors and experience (Seymour-Smith, Wetherell, & Phoenix, 2002; Smith et al., 2006). The belief that patriarchal masculine characteristics, such as self-reliance, independence, superiority and dominance are virtuous may act as a barrier to men appropriately accessing health services (Smith et al., 2006). Women participants also reiterated that when they had to go to the clinic, their partner would be at work so was unable to go to the clinic or hospital. It seemed feasible that the women take a day off, as most (17/30) had daytime jobs, and they were the ones carrying the baby:

I don't know his status, it is not because I do not want to know but you know how it is -- Zulu men and the clinic. It is almost impossible for them to go, you would even say they have fought with the people at the clinic. They just won't go (Nokukhanya, 27, HIV positive).

No, we don't go together [to the clinic or hospital], he will be at work so he can't make it (Tracy, 32, HIV negative).

Yes I have tried to ask him to go with me to the clinic or hospital. He only went once with me the day we confirmed I was pregnant. This was just to confirm that I was really was pregnant, I guess. You know what Zulu men are like, he will tell you that he doesn't go there [referring to hospitals] it's not a place for men...I mean he still wont go and test [for HIV]; he says that is not a place for men (Yolanda, 39, HIV negative).

Although more recently the law in South Africa has given men the right to take paternal paid leave as a way to encourage partners to play their important role in their children's lives (Roodt, 2018).

Preparing for sex

Participants spoke about the different things they did if they were going to sleep with their partners. Some women said they did not need to prepare for sex: if it was supposed to happen, it was a natural process and then it would happen. Others spoke about the importance of preparing for sex, from wearing beautiful lingerie to preparing the vagina to ensure that they please their partners. In line with some studies, strong motivations for different vaginal practices include women's desire to enhance sexual pleasure for their partners and further ensure men's fidelity and practice agency and control in their relationships (Gafos et al., 2010; Martin-Hilber et al., 2009; Scorgie et al., 2009; J. Smit et al., 2011). While vaginal practices were important for some women other women believed they did not need to 'just' please their partners but rather it had to be a mutual feeling of enjoyment, others felt they had to use creams or other substances as long as these do not hurt the vagina:

I think it's fine to do it as long as it does not cause any damage to the vagina as it is a sensitive part of the body. Like I was saying earlier on, I bought some cream when I was going to [name of city] that you put in the vagina so that it would make me dry and moist enough that when we would have sex he would enjoy me. That's the one I bought for him. They say you put it in 30 minutes before you have sex, so yah it would have been great (Hazel, 33, HIV negative).

The partners were interviewed about preparing the vagina for sex and what they thought about these practices that some women mentioned, for example inserting substances and doing different other things for enjoyment. One partner reported against these practices, while the other was indifferent about the practice. For one, the vagina was a sensitive place and nothing needed to be done to it in order to enjoy sex. Sex needed to be about the two people who are having it and that was all that was needed. The other man felt it was the woman's choice to do what she wanted, as long as this practice did not affect him in terms of giving him an STI or other diseases.

No, no, I really do not believe in these things, I just feel that sex is about me touching the person in the right places and making sure she feels me well. Putting things in the vagina, no no no no. If my partner had to do it. I would not have confidence in her. I actually don't think I would want to be with her anymore. No no no that would be too much for me. I would ask myself why, why does she want to do this (Themba, 31, HIV status unknown).

Yes I have heard that women put this pill -- what is it, Panado or Grandpa, one of these headache tablets -- so that the vagina will shrink. Then when you sleep with her she will feel like a virgin ... If she chooses to do this then it's her choice really, as long as it doesn't affect me, like give me an STI or other disease, then she can do it (Mosa, 30, HIV status unknown).

Similarly in a study conducted in Zimbabwe men felt that they enjoy sex anyway and using substances or labia elongation was a waste of time (Pereira & Canavarro, 2009). They felt that it may damage the already sensitive vagina and women should not do it. In the same study others noted that there is a possibility of women who use vaginal substances and labia elongation to be promiscuous and might have many sexual partners (Pereira & Canavarro, 2009). Another study also showed that some men would like these substances to be used as it increased sexual pleasure for them (van den Wijgert et al., 1999).

Consistent condom use in pregnancy

It is recommended that pregnant women at risk for sexually transmitted diseases and their partners use condoms during sex. This is normally difficult as it would insinuate promiscuity and lack of trust in a relationship especially stable relationships (Chemaitelly, Awad, Shelton, et al., 2014; van den Wijgert et al., 1999). While this is so, studies in sub-Saharan Africa show that HIV prevalence is higher in stable relationships (Chemaitelly, Awad, Shelton, et al., 2014; Mtenga et al., 2015).

Women spoke about the difficulty of consistently using condoms as a way to prevent unwanted pregnancies. None of the women spoke about using condoms as a way to prevent sexually transmitted diseases; these issues were raised only after infection, when they reflected that condoms needed to be used to protect the baby from infection. Most did not practice this consistently. Sometimes partners insisted that condoms should not be used as sex was less enjoyable and some women agreed not to use them. As also reflected in other studies in Zimbabwe, Uganda, Tanzania men often reflect to be less willing to use condoms (Mtenga et al., 2015; van den Wijgert et al., 1999). Others spoke about getting drunk, so that they did not even think about using condoms, which many studies reflect the association of alcohol abuse and risky sexual behaviours (Mola et al., 2016; Sales, Brown, Vissman, & DiClemente, 2012). Participants reiterated that partners would ask them why they had to use condoms if they were already pregnant or could not fall pregnant; this was the case particularly with women who had struggled to fall pregnant. Women reported in their narratives that using condoms was a way to prevent unwanted pregnancies. Partners resisted using condoms and sometimes pretended that they had forgotten to buy them, leading to women agreeing to having sex without protection.

We did not plan to get pregnant, it was just on another day where we had gone out and we were drunk. No one was thinking at that time we had sex, we slept without protection and this is how I got pregnant, yah this is what happened. Sometimes we use condoms and sometimes we don't. I do not know why (Nelisiwe, 22, HIV positive).

We did not really plan the pregnancy, it just came ...I would really try and make sure we always have a supply of condoms so that when I would visit his place they were there, or even I would remind him to buy some. But he always had many reasons and excuses for not having them. Sometimes you would find one in the box or none, so that's how we stopped using condoms and

have not used condoms since then. Guys do not like using condoms so this is how I ended up pregnant (Qondisile, 39, HIV positive).

We used to use it [condoms] and then he decided we weren't going to use it anymore, I think that was around December.... Because I would have asked him, "why don't we use condoms?" you know. In all honesty, a lot of men don't like using protection and they will never give you a solid reason... He just said to me, "What are you afraid of? In any case, you are barren, aren't you?" (Khethiwe, 30, HIV positive).

Other women also spoke about never using condoms in their relationship from the beginning of the relationship. This then made it difficult, after testing HIV positive, to raise the issue of using condoms. This would bring up questions that they were not willing or ready to deal with in the relationship.

The first day I met him is the day I had sex with him, we did not use a condom, we still don't use condoms... Maybe now that I know my status we will try using the condoms (Karen, 36, HIV positive).

One of the partners interviewed reported that sometimes society blames it on men, assuming that it is men who do not want to use condoms; they never realise that women could potentially be the cause of inconsistent condom use.

When I think about it, it gets me mad because I asked Pretty if everything was okay and insisted on condoms, but she said no we do not need to use condoms, everything is fine. And I must say because we had been having sex for a while, we began to trust each other. This is why we stopped using condoms (Mosa, 31, HIV status unknown).

In another study condom use was said to be when have sex with a prostitute or side woman and this was mentioned as a prevention strategy. Additionally condom use was disliked saying that they can cause allergic reactions, can burst and also reduce sensation (van den Wijgert et al., 1999; Villar-Loubet, 2013).

Violence in pregnancy

Sexual relationships are largely influenced by norms relating to gender and sexuality within societies. South African men for example are expected to be heterosexual, and thus expected to do ‘manly’ things, in competition with other men (Jewkes & Morrell, 2010). A South African man is expected to be the head of a household as well as a provider, although this is more visible in the masculinity of the older men in contemporary South Africa (Koenig-Visagie & van Eeden, 2013). Men are to be tough or strong, they are supposed to be in control of their environment relating to this includes doing what we once when he wants to (Sikweyiya et al., 2014; Sorrell & Raffaelli, 2005; Wyrod, 2011). Violence in many situations becomes a means of communication and ensuring that the perpetrator retains power in the relationship (Babcock, Waltz, Jacobson, & Gottman, 1993; Minnis et al., 2015). Participants reported that their partners did not like being questioned and did not want to be pressured to answer certain questions. For example, Busi, who had been with her partner for more than eight years, spoke emotionally about how he would beat her if she asked why he was spending so much time away from home. She did not trust him and felt possibly he had other sexual partners, but asking him questions of his whereabouts and who he was with, often incited violence:

When I ask him where have you been, why are you coming home late all the time, he says: ‘Why do you always have to ask too many questions. If I am chilling with the guys that’s it, it’s enough

for you to know. Stop asking so many questions'. If I insist on answers then he beats me....The last time I took pictures of what he had done to me and told him if he did this one last time I would get him arrested (Busi, 27, HIV negative).

Others reported being beaten if they refused to have sex with their partner. Others spoke about forced sex and they would try and fight back. One participant spoke about once being beaten and she ran away because she feared for her life and the baby's life. She took refuge at her mother's house where she knew her partner would not be able to harm her.

He wanted to have sex with me and I did not want, so I refused and then he beat me, he beat me so hard...I was about four months pregnant. This was the first time he was doing this to me. When I saw this I ran away and left him and went to my mother's house (Snegugu, 20, HIV positive).

It is clear that violence by an intimate partner is often expressed by physical, sexual, emotional abusive and controlling behaviours (WHO, 2011). Many of the studies on partner violence during pregnancy measure physical violence although sexual and emotional abuse is also considered harmful. Partner violence during pregnancy has been reported to have fatal outcomes in some instances such as suicide or homicide (Shamu, Abrahams, Temmerman, Musekiwa, & Zarowsky, 2011; Shamu et al., 2012). A review conducted by Shamu and colleagues reported that HIV diagnosis and sero-positivity were positively associated with experiencing Intimate Partner violence (Shamu et al., 2011). This was found in about five of the studies they reviewed and also reflects on our study groups as women who reported not ready to disclose often feared violence.

Understanding HIV infection during pregnancy by women

Finding out that one is HIV can be devastating more especially in pregnancy. There needs to be an approach in care that reduces stigma and discrimination for women ensuring that women are

supported throughout pregnancy and postnatal. In our study some of the women did not understand what it meant to be HIV positive as they explained that the sisters at the clinic did not explain anything to them.

I do not really understand what this (HIV) means. At the clinic when I was tested I was just told that I was positive and will have to take this treatment that they gave me. They never explained anything else. (Snegugu, 21, HIV positive)

Poor knowledge by personnel has been observed in some contexts, studies are being carried out and recommendations have to be shared with health providers, however in a study measuring knowledge, attitudes and practices in sub Saharan Africa only 54,3% of health personnel of the study population participated in the training on guidelines in the PMTCT of HIV (Nkwabong, Nguel, Kamgaing, & Jippe, 2018).

Many women who had found out that they were HIV infected spoke angrily about acquiring HIV. They reiterated how they had not been sleeping around with many partners, and so their infection came as a shock to them. Many also emphasized that as they were now HIV positive, it did not mean they would die. They could live healthy long lives, but this was dependent on eating healthy food and use protection when sleeping with their partners, emphasizing the need to take care of themselves.

It's not a death sentence, I just need to make sure I take care of myself. It means I need to eat well, it means I have to take my treatment well. It also means he has to start taking treatment as well. Further, both of us taking treatment does not mean we need to stop using condoms. We have to use a condom during sex always. We need to avoid risking our lives (Dimakatso, 26, HIV positive).

HIV is like any other disease. As long as you take treatment you will be fine. The most important thing to do is to take treatment (Monalisa, 27, HIV positive).

It is important to be given the correct information, when you have been diagnosed with HIV, more so when pregnant as this also involves the unborn child as well as the partner of the woman. The World Health Organization has guidelines to help pregnant women live a full life with HIV and also protect her partner and unborn child (Siemieniuk et al., 2017). Further countries also have guidelines which are developed from the WHO guidelines (NDoH, 2015). In another study in South Africa participants also began to accept that they were HIV positive and accepted it just as any other chronic illness (Mkwanaenzi, Rochat, & Bland, 2015)

When an individual becomes HIV positive it is very important that they share their new status with someone, this helps ease the burden on them and cope better with the situation. Disclosure is difficult as it may lead to violence, blame and abandonment, but disclosure to partner is still key in issues achieving control of the heterosexual HIV epidemic in the sub Saharan region (Maman, Groves, Reyes, & Moodley, 2016; Roxby et al., 2013; Shamu, Zarowsky, Shefer, Temmerman, & Abrahams, 2014; Visser et al., 2008). Women's ability to safely disclose their HIV positive status to their partner is important for uptake and continued use of prevention of mother to child transmission service (Walcott, Hatcher, Kwena, & Turan, 2013).

Participants seemed not to understand how or from whom they had contracted HIV infection, if they had not been sleeping with people except their partners. Some did mention the possibility that they had been infected by their partner, but they were often unsure of this, and reported partners saying they had been tested before (Mlotshwa et al., 2018). Participants reported the need to disclose their new positive HIV status to protect the baby, their partner and themselves. They felt

the need to tell others close to them about this, in case something happened to them, then their children would have other people willing to care for them. In all this participants also spoke about the difficulty to disclose for various reasons, which was not any different from studies done in other setting (Colombini, James, Ndwiga, Integra team, & Mayhew, 2016; Maman et al., 2016; Shamu et al., 2014). This would open up a difficult conversation of who had possibly brought HIV disease into the house. This would lead to them feeling abandoned, or to violence. Participants did not want to go through this and opted to be silent about the new known status. All women who had not disclosed to their partners reported needing more time to come to terms with the infection first, and then finding ways of telling the partner.

I'm not sure where I could have contracted it and this is what makes it difficult for me to tell him... he said I should go test and if I don't have it, it means he also doesn't have it. He says because it is just difficult for you to go to a hospital and be tested. So, now that I know, I don't know how to tell him. That's why I am avoiding sleeping with him until I get a solution because I take pills for the child and it's not safe for him...My worst fear in telling him about the HIV infection is that maybe he will say I came with the illness (Khethiwe, 30, HIV positive).

Pregnant women who are positive often to not tell their serostatus to their partners, family or friends (Visser et al., 2008). Like in our study, women were likely to tell if they thought you did not talk too much, you would offer them some value in support or you were trust worthy. Women who become HIV positive often spoke about wanting to tell someone in case something happened to them. Lack of disclosure continues to create barriers to preventing sexual transmission to partners and mother to child transmission.

Abandonment in pregnancy

From the study, women did not want to experience pregnancy alone. They felt that the partner needed to play a role in making sure that the child and the expectant mother were okay always, with different things that they needed: money to travel to the clinic, money for food, going with them to antenatal visits, and help them to buy other things they needed or deemed important. Participants also spoke about the need for the partner to be with them emotionally; and while others spoke about other family members and friends who were available, they reported the need of the partner to be always available and focused on this in their narratives.

Well I am supported by the father of my child, he is the only one who really supports me financially and emotionally yes I can say he is the only one He is the one, especially with regards to all my needs, he takes care of me. I really do not have anything so he takes care of everything (Ntombi, 25, HIV negative).

While some women had supportive partners, others reported lack of support, especially emotionally which they felt was very important:

When all this [distancing himself] is going on, you find that if I need anything he will give me the money for it, if I say I need this or that he has no problem, but the emotional side to the relationship is dead. I mean really being in a relationship and there is no emotional attachment. Honestly I don't want to lie; it is disturbing it really is. But such is life, I have no choice, I need to accept it and move on what can I do (Rachel, 27, HIV negative)

Some woman in the study spoke about the fear of leaving the relationship as the partner provided some form of support for her and sometimes her family. Dimakatso, for example, reported anger towards her partner and said that she had wanted to kill him at some point after they had been to the clinic and he had opened up that he had concurrent partners and had sex with them with no

condoms while she was away. She realised however that she needed to calm down and accept the situation, because even though he did all this he still cared for her by ensuring that she had everything she needed. Other women in her situation had been abandoned by their partners and so letting this incident go was a better option for her.

He is the father of my child, I can't leave him. If I leave him where will I go? He takes care of me. When I tell him that there is nothing in the house, he is able to provide. We understand each other. He is always there to make sure everything is available for me. So I was like, let me just let it go. The truth is I don't trust him at all, not anymore, but there is really nothing I can do but stay with him. Also my child needs to grow up with a father (Dimakatso, 26, HIV positive).

Globally, there has been an increasing trend for male involvement in health care delivery. Men in developing countries have to a lesser extent struggled to fit into the role compared to their male counterparts in the developed world (Adeniran et al., 2015). This could be linked to the social norms that exist and how gender roles have been defined. The role of a man is to take care of his family mainly financial and physical. In pregnancy women are often overwhelmed and HIV makes it the more difficult. This means that women although can be in difficult relationships where they are exposed to HIV risk as seen in our study they may fail to leave the relationship as they do not know where else they can go. Women do not want to experience pregnancy alone, they would rather have a present but absent father as demonstrated in our study. Women spoke about knowing that their partners had other partners but as long as he would come home and take care of his duties then that was fine. Similarly with other studies pregnant women desire male partner involvement during antenatal, labour and postnatal care, how partner have not been efficient in meeting these needs (Adeniran et al., 2015).

Chapter 4

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Personal support and expressions of care for pregnant women in Soweto, South Africa

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Abstract

Background: Pregnancy is life changing, making great demands on women to adapt physically, psychologically, and socially. Social relationships and the support that flow from these provide a critical role in managing health problems in pregnancy. Isolation and lack of care, in contrast, may lead women to experience increased distress during this time.

Objective: This study aimed to explore South African women's perception and experience of care and support in pregnancy.

Methods: A life history approach was employed to explore women's experiences of pregnancy and sexual behaviour, with each participant encouraged to narrate important life events from her own perspective. We drew on narrative interviews with 15 pregnant women, conducted between July and October 2015, in which we explored questions regarding pregnancy planning and the provision and receipt of care. A thematic approach was employed to code and analyse the data.

Results: Themes that emerged from the interviews showed that participants gained a sense of stability in their lives when they had support in their pregnancy, especially when dealing with challenging situations. This support came variously from family, friends, and social networks. Overall, those participants who mentioned the most support, and its diversity across different groups, reported a better experience of pregnancy.

Conclusions: Women emphasised the importance of social and emotional support in pregnancy. Understanding women's experiences can assist in making pregnancy less overwhelming, and can add to a woman's ability to deal with different challenges before and after the arrival of the new baby.

KEYWORDS: Care, interventions, masculinity, maternal health, pregnancy, South Africa

Introduction

Pregnancy is life changing, making great demands on women to adapt physically, psychologically, and socially [1]. It is a transition in life which brings many challenges [1,2], and for this reason, the care and support extended to women can impact greatly on their lives and contribute to how they experience the pregnancy [1–4]. Social relationships and support, both formal and informal, play critical roles in managing health and personal problems in pregnancy [5–7]. Reblin and Uchino [2] differentiate between tangible care and support, in the form of money, shelter, clothing, and food, for example; and intangible care and support, including emotional, psychosocial, and perceived or received support. The range of material, contextual, and interpersonal factors that are therefore included reflect the complex phenomena that impact on women [1,2]. These personal, social, and cultural factors vary in different contexts. In South Africa, more than 50% of children are born out of wedlock and grow up in single-parent households, of which two-thirds are headed by women [8–11]. As a result, significant numbers of women carry, give birth to, and care for their infants without the support of the biological father [12]. On learning of their pregnancy, women must negotiate their relationship with the father of the unborn child, with their own family, and with others. In some cases, the social repercussions of an unintended pregnancy may leave a woman with little or no care from those from whom she might have expected support, with impacts on her health and wellbeing [13,14]. Accordingly, many women need to make various

compromises in their own care and in sustaining the household, including in relation to new intimate relationships established when they are pregnant or when the baby is very young [15,16]. At the same time, as we illustrate below, many women invest in the relationship related to their pregnancies, and retain the hope that these men will accept the pregnancy and commit to shared parenting. In South Africa, research on social dimensions of unexpected and unplanned pregnancies has tended to concentrate on women who, despite variation indifferent urban and rural settings, tend to be marginalised [17–21]. The incidence of human immunodeficiency virus (HIV) appears to be higher among young pregnant women than their non-pregnant counterparts [22,23], suggesting an association with the irregular use of protection; communities with high rates of teenage pregnancy also have concomitantly high poverty rates [24,25]. The concurrence of poverty, HIV, and unplanned pregnancy affects older women as well, often leading to a toxic environment of depression and violence [13,14,26]. These combined factors impact on women's capacity, and that of their families, to manage the material as well as social and interpersonal challenges associated with pregnancy. In a study in KwaZulu Natal on social support and pregnancy, women were most likely to disclose their newly diagnosed status as HIV positive when they felt that they could live at home and feel safe and supported [27]. South African women generally attend at least one antenatal visit and give birth with a skilled birth attendant [28], and consequently antenatal care (ANC) is a potentially important point of intervention, hence our focus. In this article, we define care and support received as the material and practical assistance and emotional support given to women throughout pregnancy, primarily through affective ties. The support of the partner plays a crucial role [1,4,29], including in a woman's decision to keep the pregnancy, as described in various studies around Africa [16,21,27,30]. We explore what pregnant women perceive and experience as care and support, with data illustrating the

significance for pregnant women of having a network of people to enable them to cope with different stressors that arise during pregnancy.

Methods

Study design and setting

The study on which we draw was undertaken with women presenting for ANC at Chris Hani Baragwanath Hospital, in Soweto, Johannesburg, South Africa. The study was nested in a larger research project on incident HIV in pregnant women and sexual risk behaviours and practices in urban South Africa (Pregnancy and HIV Study). This, in turn, was nested in a larger prospective cohort study, the Soweto First 1000 Days Study (S1000) [31], which followed women and their infants for up to 24 months after delivery at Chris Hani Baragwanath Hospital. S1000 registers women into the study before or at 20 weeks' gestation, regardless of their HIV infection status, and so includes women who are HIV positive at the time of conception. In contrast, the Pregnancy and HIV Study selected women who were HIV negative at entry. Women were tested for HIV 12 weeks after the initial test and subsequently at each antenatal visit until delivery. Women in the study we report here were recruited from the Pregnancy and HIV Study, and so were all HIV negative at the time of our first interactions. A life history approach was employed with those who agreed to participate, as elaborated below, to explore their experiences of pregnancy and sexual behaviour in pregnancy, with each woman encouraged to narrate important life events from her own perspective [32]. Over time, a number of these women seroconverted, either because the original test failed to identify they were already infected, or because of an infection acquired during pregnancy. In this article, we draw on narrative interviews with 15 pregnant women recruited when they first enrolled into the larger study and were HIV negative. No participants acquired an HIV

infection during the course of our study. This had the advantage of allowing us to focus on tensions around the pregnancy and effective relationships, independent of HIV status.

Data collection

Multiple interviews were conducted during women's pregnancies between July and October 2015, at a place where both the researcher and the participants were comfortable, that is, the hospital or the home of a given participant. An initial interview at the end of the first trimester provided us with a general understanding of the woman's life history and enabled the interviewer (first author) and the participant to establish a relationship of relative trust and comfort [33,34]. A second interview, conducted at the end of the third trimester, helped to clarify issues that emerged in the first interview while focusing on the woman's current intimate relationship(s) and sexual behaviour. Final interviews, not included here, were conducted after delivery to explore changes in sexual behaviour and practices; by this time, two women had HIV seroconverted. All interviews were conducted by the first author in English, seSotho or isiZulu, languages in which she is fluent. Often participants moved between these languages, as is characteristic in the study area. Each interview took between 20 and 96 min, and all were audiotaped, transcribed, and translated verbatim (into English, as needed). All participants were aged 18 years and above. Data analysis

A thematic approach to developing primary codes, subordinate codes, and categories was used to guide the analysis of the data, with interviews analysed inductively [34]. Reflecting one of the strengths of this approach, data collection and analysis occurred simultaneously to inform subsequent data collection [34,35]. Initially, each narrative was read and reread and coded openly for content. With the continued rereading of the narratives, theoretical coding was introduced as a second step, with codes grouped into emerging themes. The emerging themes were developed through analysing their salience within and among interview accounts. Coding was validated by

the coauthors, and, when codes were irregular or inconsistent, consensus was reached after re-analysing the codes. Table A1 in the Appendix provides an example of how these categories were formulated.

Results

Profile of participants

All 15 participants were aged between 25 and 40 years; the majority (12) had completed secondary school and some (four) had then gained post-secondary school qualifications or vocational certificates. Nearly all women (13) reported having a partner at the time of the first interview, although five of these women did not live with their partners. Four were customarily married. Four reported that their partners were known by their families and they were cohabiting, but no formal arrangement had been made for compensation (*inhlawulo*) for the ex-nuptial pregnancy, nor had bride price (*lobola*) been paid. The other two women were not sure how to define their relationships, other than as ‘complicated’. The length of time of the relationship with the genitor of the current pregnancy ranged from less than 1 year to more than 10 years. Almost all participants (14) reported that they had not planned the pregnancy. Only one participant was pregnant for the first time; for 14, the current pregnancy was the second or third; seven reported miscarriage of the previous pregnancy. Four of the participants were mothers to older children, all by a different father. Eight of the participants had migrated to Soweto to marry, to look for employment, or for family reunions, but most had limited family in the area at the time of the interview. Nine women had some paid employment; the rest had no source of independent economic support.

Informal patterns of support and care

Participants reported that they enjoyed a sense of stability in their lives, especially when dealing with challenging situations, through the presence of immediate family, including partner, mother, sister, and/or uncle. At the same time, they differentiated kin as offering different kinds of support and care during their pregnancy, and identified other people who contributed substantially to their well-being. As women illustrated in their narrative accounts, these experiences of care were mainly centred on their partner, then on immediate family members, friends and others from various social networks and organisations. We present these below, in ways that reflect the relative significance of different individuals and relationships, and the variability of families, households, and other support structures in contemporary South Africa [36].

Partner intimacy and involvement About 40% of all households in South Africa are headed by women [12,16,37], reflecting historic patterns of male labour migration, HIV-related mortality, and more recent trends in female migration and family formation outside marriage [12]. Only around one third of South Africans over the age of 20 are registered as married; divorce is common, with the rise of 8.6% from 2012 to 2013 reflecting a continuing trend [38]. Female-headed households are supported by access to different social services and systems of support, for example, income grants and housing, and this provides women with some financial support [16]. Yet despite demographic trends that indicate the prevalence of low marriage rates, short-lived unions, and female-headed households, all participants spoke about the importance of having a supportive male partner during their pregnancy and in the future, and emphasised the value of dual parenting. Many felt that the support from their partner was the most important source of support they could receive, as the two of them ‘needed to be in it together’.

Women emphasised the affective nature of such support, and often reiterated that even if a partner supported the woman financially or in other ways, if he did not show affection or closeness in the relationship, he was considered to be unsupportive:

‘I need support from the father of my child; it is the most important support I need. But I do not get it. This bothers me a lot, even if he is there but he is not giving me the support I feel I deserve [crying] . . . I need him to be there for me, emotionally I need to know that we are in it together . . . The support I received with our first child was good, but now there is none. When I raise it with him, he tells me that I am complaining and I should not be complaining [continues crying].’ (Busi, 27)

Some participants spoke about the possibilities of their partners having other intimate relationships, which they interpreted as indicative of the man’s lack of emotional commitment. However, they also noted that it was not uncommon for men to have outside relationships, and to some extent, this was ‘socially acceptable’. Although women recounted their distress when the men in their lives had relationships with other women, many insisted that they were willing to accommodate this in order to preserve their relationship as primary, for their own sake because of the pregnancy, and so for their future child. At the same time, most women spoke of their fear of HIV; Lillian (38) told her partner simply that if he decided to have extramarital relationships, he needed to use a condom as they were not using a condom in their own relationship. In a country where 29.7% women are HIV positive at entry into ANC [39], their concern that they might become infected was legitimate:

‘Yes, it is possible for him to have [other sexual relationships]. For example I’m sitting with you right now, I am saying he is at work, but it’s possible he is elsewhere doing his own things. I mean you cannot trust someone 100% but what I know is, I told him that if it happens! If it happens, that you [the partner] are seeing someone else outside of our marriage and you are having sex, please use a condom. No one should bring death [through HIV] into this home ever. We know you are

the one as the man who will fail to have self-discipline or self-control, and so if you decide to go out wherever, please use a condom.’ (Lillian, 38)

While this might suggest that women were accommodating, their responses indicated that they were worried and sometimes distressed that their partners might have other sexual partners, and that they may have to deal with HIV in the ‘home’, that is, within their relationship. Women did not want to acquire HIV under any circumstances. In explaining or seeking to understand men’s relationships with them and in relation to other women, participants drew a link between men not wanting the pregnancy and their lack of concern and care for the woman during pregnancy. Unplanned pregnancies, women explained, precipitated men’s disengagement and detachment:

‘I don’t think he is even part of this pregnancy. He is just not interested, there is no support from him . . . I actually think it’s because of the pregnancy, the fact that I got pregnant too soon. Maybe he is not ready for this. However, even when all this is going on, you find that if I need anything he will give me the money for it. If I say I need something, he has no problem with that, but the emotional side to the relationship is dead. I mean really, being in a relationship and there is no emotional attachment, honestly, I don’t want to lie, it is disturbing, it really is.’ (Rachel, 27)

Women who still had a strong emotional attachment with their partner spoke of constraints of the relationship, including with regard to their pregnancy and its course. Some women reflected on the value of visiting the ANC clinic together, but for the most part they accepted that their partner did not understand the importance of a visit to the ANC, was not interested in it, and was not prepared or able to go with them. Women tended to interpret this in the context of a difference in background:

‘I would like to attend ANC with him. It would be really good for us both, so that we experience everything together. But I need to also accept that we come from different backgrounds so the way I take things could be different from him.’ (Rhirandzu, 32)

On the other hand, some participants received extensive support and care from their partners, and they found considerable comfort in having someone on whom they could depend:

‘He treats me well, we have been together for about 10 years now and he respects me. As the woman in his life, I cannot complain really. He loves me and takes care of all my needs. I am really happy. He even takes care of not only his children but my children. I don’t want to lie he is good to me. I know sometimes you will say someone is good then he disappoints you, but he is good to me.’ (Boniwe, 39)

Immediate family involvement

While participants emphasised the importance of support from their partner, strong family support was also considered important, particularly by women whose partner had retreated or gave them limited support. Most of the time the person involved was female kin – a sister or aunt – although uncles were also mentioned as assisting them during their pregnancy. Mostly participants spoke about emotional, physical, and monetary assistance from female support, while male support was mainly linked to financial contributions.

‘Emotionally my mom does this for me [gives me support]. She is there for me even when I start to complain and say, ‘Ahhhhh, my back hurts so much’, she is the one who will calm me down. She will say, ‘no, do not worry, it will all be okay’. So yes my mom.’ (Daisy, 30)

‘My sisters, yes [they are there for me] but there is really nothing much [financially] that they do, they are my friends, so we talk and yah, that’s it. They are the ones I consider my friends. They give me good advice, just talking to them is good.’ (Ntombi, 25)

‘My uncles are those types of people who do not show outward emotion. They are supporting me in other ways, for example money. They are just angry because the father of the child does not want to take responsibility for his actions (the pregnancy); this is what angers them.’ (Hazel, 33).

Support from in-laws Some participants reported having good relationships with their partner’s parents or other family members. Sometimes when the couples were experiencing interpersonal difficulties, members of their partner’s family would call or would ask the participant to come over, so that they could make sure they were fine. In some cases, they would provide the woman with material support as needed, for example, with food to eat.

‘When they [partner’s sister and mother] see I have not visited in a long time they call to check on me . . . they ask me if I need anything and if everything is going on well with the baby.’ (Rachel, 27)

‘Although we are not together with the father of my child . . . his sister is really good to me, she gives me so much support. I don’t know whether it’s because we work together but she’s really good to me.’ (Hazel, 33)

In other cases, however, the relationship between a pregnant woman and her partner’s kin was not warm, and this brought considerable emotional distress to the woman or to the couple. Some participants felt that this lack of concern, acceptance, and affection caused conflict or unsettled their relationship with their partner: ‘What I think the main challenge or problem is just our parents, this is what most the times is hurting our relationship . . .

I think the problem comes with his side of the family, mainly. I don't think they like me, not me as a person but as long as there is anyone involved with their child emotionally they will not be happy about it.' (Ntombi, 25)

Support from friends Not all participants had friends on whom they could depend. However, women who described themselves as single, or who had partners who lived at a distance from them, emphasised the value of regular support from friends:

'My friends are there. I remember the last time I was admitted in hospital they are the ones who made sure they took me to hospital. My partner he was not even there, he works away from home. They called him and told him that he should not worry; if anything needed his attention they would let him know. So I have good friends who are able to take care of me.' (Rhirandzu, 32)

Having a circle of friends on whom they could depend, who were willing to assist them during their pregnancy and beyond it, was critical when women lacked support from their own and/or their partner's families. The care that they received from friends ranged from psychosocial support, being able to talk to someone about issues that were personally challenging and receiving advice on how best to cope with these issues, to transport when going to the hospital or elsewhere:

'Yes, I have friends, we talk about everything if I'm stressed we talk about it all, they come to my house and fetch me and I visit them at their houses and we pray together things like that, they are the only ones who are my support . . . My sister and I we do not talk about personal issues. That is just how our relationship is like.' (Pretty, 30)

The church as a site of support

Those participants who reported having a religious affiliation – the majority – often spoke of how, once pregnant, they had stopped going to church. This was usually not because of ex-nuptial pregnancy, but because it was a long distance to walk or to reach by bus or taxi when they were tired, or because, they said, they had just become lazy. In their stories, they reiterated the importance of this aspect of their life, particularly those who had few or no kin living with them in Johannesburg. The church served as a support structure that, women felt, would be always there to assist them in times of need. Furthermore, although some women had stopped attending services, they still often received some care from church members. In particular, older women often spent time with them during pregnancy and postnatally, advising them about pregnancy, birth, and infant care, but also talking to them about faith and church expectations.

‘At my church you are not supposed to fall pregnant until you have worn your white dress, or without you having been married. . . . So now I am not active in that anymore, until they take me back, that old lady needs to say if I am ready or not. The lady who talks to you and helps you out in pregnancy she needs to say you are ready or not. Now what they have done is assigned a lady in church to look after me through this process of ‘sin’ that I am in, so that after it’s all over I am able to go back to church . . . The thing is according to them the lady helps in the process of becoming okay something like that or me being ready in the eyes of the church that I can go back to doing my normal activities in the church.’ (Daisy, 30)

‘At church they are always there for you, especially the older ladies in the church, who come and check up on you and the baby if you are doing okay. They offer advice that is important, for example they tell us that the baby should be moving when you eat, when you are hungry it is important to have the baby move all the time, they tell us we should rub the tummy with Vaseline

[petroleum jelly] to make sure the baby is always moving. If you do not feel any movement then it's important to go to the doctor immediately.' (Rhirandzu, 32)

Some participants who were unmarried reported that their church disapproved of them being unmarried and pregnant, so they had decided to stay away through embarrassment and to avoid criticism:

'Like right now, because I am not married, I cannot go to church, they say that when you are not married, how can you get pregnant? So I cannot go to church. I cannot wear my church uniform. At church you cannot be seen pregnant when you are not married, but if I was married, it would be okay, there would not be any problems.' (Rachel, 27)

Some further explained that they were protecting their own reputation by not going to church; in this way they would not be judged because they were unmarried and pregnant. These values were often shared by members of participants' families. Family members believed that a man should marry a woman before parenting by paying bride price (lobola), or at least paying damages (inhlawulo) to show their remorse of the 'unintended' pregnancy.

Overall, those participants who mentioned the most support, in terms of numbers, range of supportive actions, and diversity across different groups, reported better experiences of pregnancy. They reflected that they did not need to worry about many things, as they were taken care of by others. This reduced their levels of distress. Women with little support often complained about their relative isolation, and felt hurt and resentful about the absence of care. They reiterated the difficulty of being pregnant and of trying to meet their various material, practical, health, and emotional needs. Participants also mentioned their need for places where they could talk about issues that bothered them, or places that provided them with a safe haven. Many reiterated that the

research clinic fulfilled this function, enabling them to talk about personal and relationship concerns. Women stated that the ‘nurses’ – any staff member of the research clinic – made them feel comfortable, and provided them with an opportunity to talk through and sometimes cry about their problems. They contrasted this with ordinary antenatal clinics, which were crowded and where clinic staff had neither the time to talk confidentially with them nor the willingness to engage with them about social and interpersonal problems.

Discussion

While attention has focused on physical changes and discomfort during pregnancy, far less has been paid to women’s emotional, economic, and social well-being [40], especially in African settings [but see 13,14,30,41, 42]. In women’s narratives, a dominant theme was that pregnant women at times felt vulnerable and emotionally alone, and sometimes were unable to identify what was bothering them or had no one with whom to discuss what was going on in their lives [40,43]. Pregnant women hoped for care that met their personal as well as practical needs, and this might be from a person, a social organisation, a public institution, or a combination of all entities. At the same time, while women emphasised that support came from diverse quarters, they thought that the partner – the biological father – should be present to support and care for them throughout their pregnancy [44]. Some women felt that their partners did not understand what kinds of support and care they needed during pregnancy; they explained this in terms of conventional ideas of masculinity that conflated ideas of what a man is ‘supposed’ to do: take care of everything financially, but not by providing emotional support [45–47]. In South Africa in particular, women characterised masculinity in terms of men being providers in the home or within the relationship [48–51]. A strong masculinist ideology means that a man may be reluctant to show care and concern for a woman in pregnancy, by attending the ANC clinic, for instance, as this could be seen

as weak and a mark of femininity [48]. Yet while many of the women reported a need to have their partner show care by providing for them (housing, cash), they also emphasised their desire for emotional care, for their partner to show his affection for them, including his involvement in and implied commitment to the pregnancy, through his physical presence as much as his financial support. Furthermore, while women spoke of dominant representations of African men's sexuality in relation to multiple partnerships [47,49,50,52], they complied primarily because they felt that this would reduce their risk of being abandoned.

An increasing number of couples are delaying marriage in South Africa, for reasons that include the high costs of marriage, the payment of bride price and rituals associated with it, and the reluctance or inability of men to take care of a family [47,53]. Age at marriage in South Africa is between 25 and 29 years for women and 30 and 34 years for men [53], which is relatively high globally and compared with other countries in Africa. Ex-nuptial childbearing is common, accounting for almost 60% of all births in South Africa, among the highest in the world [45,47]. Furthermore, as noted above, female headed households are becoming increasingly common, with households often constituted of a woman, her children, and grandchildren, and with women's employment and state grants providing the financial resources to meet everyday household expenses. Yet in this current study, pregnant women in relationships were seeking more than material or instrumental support. With limited emotional support, pregnant women often were in strained relationships within and beyond the household, and loneliness and despondency were common for those who feared being left alone to care for the expected baby.

Women with more sources of support, including a reliable and loving partner and siblings, reported less stress than those with less support, replicating the findings of similar studies [31,40,46]. Social organisations like the church also played an important role in the coping strategies of some women.

In some churches, the emphasis on abstinence before marriage meant that some pregnant women felt ashamed and withdrew, and the stigma of pre-marital sex and ex-nuptial pregnancy kept them from this avenue of support and care. Some women described how, after church members found out that they were pregnant, they were required to undergo a period of cleansing, after which they could resume their duties as a member. This sometimes hindered assistance from the church during pregnancy. However, other churches made women feel welcome and congregants shared their everyday concerns.

Financial challenges [44] and marital status [46] were issues that we anticipated from our participants and other studies [14, 41, 54]. Many of the women interviewed had limited sources of income to sustain them, but although they spoke about their need for money, this was not the primary support that they identified they needed from their relationships and in pregnancy. In women's accounts, the need for personal support dominated. When the relationship was not working with the partner, pregnant women identified their need for a safe and confidential space to talk about these challenges. Personal matters were sometimes better and more easily discussed with other people and not with family members, so avoiding the fear of stigma and the risk of disclosure.

Limitations

The study was qualitative and was localised in an urban area in South Africa. Women may have overstated their concerns in the hope that we might speak to their partners with regard to any concerns that they had, as we had sought their approval to also interview the men.

Conclusion

For women throughout pregnancy, social and emotional support was vital. Pregnant women were eager to talk about issues that bothered them, and they seemed to struggle to find spaces where they could talk about these issues. Different people were identified as being available and able to provide of this kind support and care, and most of the time this ensured a smooth or less difficult time through pregnancy. On the other hand, women emphasised the value of a partner who was involved in the pregnancy. However, he was not always available, and in other cases, the relationship with the partner was fragile or tenuous. Policy reforms in South Africa may need to address the importance of social support for pregnant women, to manage the emotional and personal difficulties that they experience during pregnancy [55]. This may be through support groups organised at hospitals and clinics, where women could share personal concerns, although women worried that in this context, they could be the subject of gossip. Self-help groups and mentoring programmes for women during pregnancy as well as after delivery, such as the Philani intervention programme in Khayelitsha Cape Town [56], may be a way for pregnant women to team up and talk about the different challenges they face, and to receive practical support, so reducing anxiety and depression. As many women have strong religious affiliations, they may also find support through self-help groups in church settings, with mentorship and encouragement by older women to help them better cope with pregnancy and early infant care. This may be particularly important for young women who do not have a family or who have a stressful relationship with family members. Understanding these experiences can assist in making a pregnancy less overwhelming, and can contribute to a woman's ability to deal with various practical and relational challenges both before and after the arrival of the new baby.

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Author contributions

LMlo and SM conceived and designed the study. LMlo recruited participants and conducted the interviews, and worked closely with LMan through the iterative phases of interviews, preliminary coding, and new interviews. LMlo, SM, and LMan all contributed to the analysis of the data, the identification of key themes and writing the manuscript, and approved it in its final form.

Disclosure statement

No potential conflict of interest was reported by the authors.

Ethics and consent

We received ethical clearance from the University of the Witwatersrand Human Research Ethics Committee (Medical) and the University of Basel Research Committee. All participants gave their written informed consent for all interviews and for their audiotaping, and consent for the publication of quotes from the interviews. In this article, participants are referred to by pseudonyms and age only, and identifying information other than study setting has been removed.

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Paper context Pregnancy can be overwhelming and life changing, demanding change from women physically, emotionally, psychologically, and socially. This paper is set in an urban African context where many children grow up without their biological fathers. The paper assists in understanding what women perceive as support during pregnancy. Understanding these experiences can add to a woman's ability to deal with different challenges before and after the arrival of the new baby in similar settings.

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Appendix

Table A1. Examples of coding.

Interview text	Codes	Subordinate codes	Categories
I need support from the father of my child; it is the most important support I need. But I do not get it. This bothers me a lot, even if he is there but he is not giving me the support I feel I deserve [crying] ...	Care during pregnancy	Support and affection	Partner intimacy and involvement
Emotionally my mom does this for me [gives me support]. She is there for me even when I start to complain and say, 'Ahhhhh, my back hurts so much', she is the one who will calm me down. She will say, 'no, do not worry, it will all be okay'.	Emotional care by mothers, sisters, aunties	Responsiveness during pregnancy	Immediate family involvement
Although we are not together with the father of my child ... his sister is really good to me, she gives me so much support. I don't know whether it's because we work together but she's really good to me.	External assistance	In-laws' presence	Support from in-laws
Now there is this thing that when you fall pregnant without going through the right path you get cut off from the congregation. You get cut off such that even when you pray in church the person next to you should not hear you, even when you sing he or she should not hear you.	Church and how they assist during pregnancy	External groups caring	Social organisation

Table 3: Examples of coding

CHAPTER 4

In review *AIDS Care* (in review)

Secrets and disclosure among HIV positive pregnant women in Soweto, South Africa

Langelihle Mlotshwa, Lenore Manderson, Charles Chasela, Sonja Merten

Abstract

Disclosure plays an important role in supporting adherence to prevention of mother to child transmission (PMTCT) interventions and the negotiation of safer sex practices among couples. In addition, disclosure is a necessary step in involving partners in care during pregnancy and after delivery, partner testing for HIV, and supporting women's adherence to recommended infant feeding practices. In an on-going case control study, in-depth interviews were conducted with pregnant women who seroconverted during their current pregnancy, and were attending the Antenatal Care Clinic at Chris Hani Baragwanath Hospital, Soweto, South Africa. Drawing on their narrative accounts, we explore their understandings of and challenges faced in the disclosure of HIV. Telling others of one's HIV status is a complicated process for the infected person and those to whom she might disclose. Partners can provide women with encouragement and support, but men's involvement in antenatal care is still very low and is not possible without disclosure. Women who become positive during pregnancy face particular difficulties in disclosing their status. Their desire for emotional and economic support in pregnancy, and their fear that this will be withdrawn, complicates their willingness to disclose.

Keywords: Disclosure, fear, HIV, pregnancy, PMTCT, South Africa

Introduction

Disclosure is considered an important step in establishing support for adherence to the prevention of mother to child transmission (PMTCT) interventions and the negotiation of safer sex practices among couples. It is an essential first step in partner testing for HIV, is arguably critical to the involvement of partners in care during pregnancy and after delivery, and is important if women are to receive support to follow recommended infant feeding practices (Curran, Baeten, Coates, Kurth, Mugo, & Celum, 2012; Walcott, Hatcher, Kwena & Turan, 2013). Studies in sub-Saharan African have reported HIV disclosure as associated with positive outcomes including improved mental health, reduced stigma, and increased social support, safer sex behaviours, increased understanding from partners, increased trust, and improved uptake of HIV treatment (Maman, van Rooyen & Groves, 2014; Maeri et al., 2016). Paradoxically negative social outcomes, including stigma, discrimination, blame and violence, have also been reported amongst couples disclosing HIV status (Maeri et al., 2016; Visser, Neufeld, de Villiers, Makin & Forsyth, 2008).

The timing and process of disclosure is complex, however, and is influenced by individual psychology of both the person disclosing and his or her perception of the other person's psychology, and by assessments of what is acceptable within society in relation to economic, cultural, religious and political systems (Manderson and Davis 2014a, Manderson, Davis, Colwell & Ahlin, 2015). Where disclosure is unplanned or unintentional, it may have especially problematic consequences, and this too contributes to wariness (Manderson and Davis 2014b; Hardon and Posel 2012). Visser and colleagues (2008), in exploring this issue among 293 pregnant women, found that disclosure was complex and difficult. A decade later, we explore disclosure in an urban

setting in an attempt to see if HIV disclosure among pregnant women has improved through the years or if different challenges have risen. In this article, we describe the challenges faced by pregnant women in deciding whether or not to disclose their new HIV status, and in association with this, consider the extent to which women hide their HIV status from significant others, including family members, friends and, most importantly, their intimate partner(s).

Methods

The study on which we draw was a sub-study of a case control study, which in turn was nested within a larger prospective cohort study (the S1000 days study) of women and their infants at Chris Hani Baragwanath Hospital, Soweto, South Africa (The INTERBIO-21st Consortium, 2011), where 17,000 women give birth each year (Chris Hani Baragwanath, 2016). Women were 18 years and over, were recruited at first presentation at the antenatal clinic (ANC) of the hospital, and were followed up through to 24 months after delivery. The cohort study registered women before or at 20 weeks' gestation, regardless of their HIV infection status. For this present study, a life history approach was employed to explore women's different experiences in pregnancy, living with secrets, understandings of disclosure, how HIV status affected their lives in any way. Interviews aimed at encouraging women to narrate important life events were carried out between July 2015 – January 2017 at a place where both the researcher and the participant were comfortable, that is, at the hospital or at the home of the participant. Interviews were held at least two weeks after diagnosis of HIV to allow women some time to adjust to this new knowledge. All interviews were conducted by the first author in one or a mix of the languages predominantly spoken in the study area and in which she is fluent (English, seSotho or isiZulu); these were transcribed verbatim and translated into English.

Data collection and analysis occurred simultaneously as a way to guide subsequent data collection. Interviews were analysed inductively drawing on participants' stories. Initially all narratives were read, re-read and coded openly for content. With the continued re-reading of the narratives, a phase of theoretical coding followed as a second step, when codes were grouped into emerging themes, and emerging themes were developed by analysing their salience within and across interviews. If any codes were irregular or inconsistent, consensus was reached by the researchers following review of analysis. Coding was validated by the co-authors.

Below, we present two case studies, which represent the common themes illustrated by the 15 women who were diagnosed as HIV positive during their pregnancy. Participants are referred to by pseudonyms.

Didi

Didi was 36 years old and pregnant with her second child when she learnt she was HIV positive. She was from Lesotho, and had lived there until she was about 28 years. She was first pregnant at the age of 17 when she was still in high school. On learning of her pregnancy, her parents were angry, and insisted she leave school and work to support the child. The father of her child promised he would marry her and so she moved in with him, confident that he would pay the bride price (*lobola*) to her family. Shortly after, however, he died, and like many of her compatriots (Khonje 2015), in 2009 she decided to move to Johannesburg. From 2011-14, she was in a relationship with a man called Nathi, but this ended when he found out she had been unfaithful. Although she justified this by saying she wanted money from the other relationship when she did not have paid work, she acknowledged that she had wronged him. Two years later they met again, began to chat on WhatsApp, and began to see each other. Immediately they started talking about starting a family

and they stopped using condoms. A few months later, Didi found out she was pregnant and was very excited.

Didi was not diagnosed with HIV on first testing at the ANC, but a few months later, she found out that her HIV status had changed. She was furious.

I started asking questions about how this could have happened. I blamed myself for it. The problem is, you think you know someone very well and then this happens, this is when you realize you can't trust anyone (sighs). I was angry with him, because I had not slept with anyone else besides him. He could also see that I was angry but he never asked why I was angry. I didn't care, I didn't care about him or anything; I was just angry.

Didi insisted that she would never trust Nathi again, but cared only that "he gave me money for my survival for going to the hospital and getting all I needed. I did not care whether he was having other relationships or not." Didi had never imagined she might get HIV, but she explained that through counselling provided at the hospital, she had come to the view that HIV was like "any other chronic condition. I just need to take my treatment well and I will be fine." Didi had told a sister living in Johannesburg that she was HIV positive, and she planned to tell her mother and younger sister when she next went to Lesotho. But she had not yet told Nathi.

I am afraid. I do not know where to start. We have had sex once and we did not use a condom. I mean, what would be the reason for using the condom when we have gone for months without using condoms. I feel so guilty because I always think that he could start on treatment... maybe I will be saving his life, but the truth is, I don't know where to start and so I am quiet (tears). The truth is I don't trust him, but with time I will have to tell him also... This can save his life.

Many women in our study encountered similar experiences. Many struggled, often because they did not know how they had been infected, insisting that they had not had sexual encounters with people other than their regular partner, and were unaware of and rejected the possibility that their partner might be infected and might have been responsible for their infection. Disclosure was difficult for some women, too, because they did not trust anyone enough.

Martha

Martha was 28 years old, an immigrant from Maputo, Mozambique, who had moved to Johannesburg in 2012. She met John, a married man, and became pregnant. John already had children and insisted that Martha have an abortion. The second time she conceived, there were complications with the pregnancy and foetal development, and Martha again opted for a termination. When she was recruited into the study, she was pregnant for a third time, this time with twins. John maintained that the pregnancy could not be his, as he had no family history of twins. He beat her, berated her, and sometimes did not buy food. But Martha did not have paid work, and John was her only source of support.

Martha explained that the pregnancy was “planned,” to the extent that she and John had discussed having children in the future and they had stopped using condoms. Martha felt that even if he asked, she would not have another abortion. She believed this pregnancy was a gift from God.

Martha explained that sometimes she tried to avoid sex, but John would force himself on her. She suspected that he was sleeping with other people while travelling away from Johannesburg, but she did not use condoms with him when he returned. Martha said that she had “indirectly” told him about her HIV status, by encouraging him to test and asking him what would happen if they found out that she was HIV positive. He was calm in response, almost as if he did

not mind; he simply said: “I am okay, I work for white people, they test us often so I know I am okay.” This response puzzled her, so she asked him how then she would be HIV positive and him negative, because she was only sleeping with him. He explained to her that people can acquire HIV in different ways and sex was not the only way.

Martha felt she could not tell anyone else about her new status, for fear of gossip. She did not have many friends, and her lack of support from her partner, and her HIV status, lead her to sometimes have suicidal thoughts. Despite John’s infidelity and his violence towards her, she was determined to stay with him, as long as he would accept the children and take care of them.

Telling the secret

Years on since the first difficulties around encourage people to test, disclose and seek treatment for HIV, the complexities of disclosure are still relevant and need to be addressed. The stigma that people can experience when their HIV status is disclosed can hinder the effectiveness of HIV prevention programs (Deacon, Stephney &Prosalandis, 2005; Deacon and Stephney 2007, Chambers, Rueda, Baker, Wilson, Deutsch, Raeifar& Rourke, 2015), but disclosure can be daunting (Manderson and Davis 2014a). Telling someone of their status, women reported, gave permission to “the world to start talking,” and fear of gossip had a profound effect on women’s willingness to disclose. As illustrated above, women also found it confronting to think about how they had been infected, given that they had been tested before the pregnancy and during their first antenatal clinic visit, when the results were negative. Women reported that they found issues of trust difficult, further complicating their decisions about who and when to tell (see also Visser et al., 2008).

Choosing to disclose is difficult both because of fear of the implications of their diagnosis and because of the ways in which moral values are questioned of individuals who acquire HIV. Although disclosure is associated with support that might help women adjust to their infection status and its associated management (Shikwane, Villar-Loubet Weiss, Peltzer, & Jones, 2013; Villar-Loubet, Bruscantini, Shikwane, Weiss, Peltzer, & Jones 2013). Women who in other ways were disadvantaged especially feared that disclosure might lead to the withdrawal of support, violence, abuse and abandonment (Varga, Sherman, & Jones, 2005, Brandt, Dawes, & Bray, 2006, Visser et al., 2008), and this affected whether, when and who they choose to tell. Some women indicated that they were ready to disclose to their partner and close family, but others still needed time to plan this. Further, whether or not the pregnancy was intended, and although termination is legal up to 20 weeks in South Africa (McQuoid-Mason, 2010), women felt they had few options other than to continue the pregnancy and to keep the baby. Women seemed not to think abortion was an option, reflecting continued negative social norms related to abortion (Rohrs, 2017). The challenge of contracting HIV during pregnancy, and its association with multiple concurrent partners, was something women needed to address, but for them, this was preferable to abortion.

As in other studies, most women reported that they did speak with their partners about HIV/AIDS, sex and disclosure (Peltzer, Mlambo, Phaswana-Mafuya, & Ladzani, 2010; Peltzer & Mlambo, 2013), but they did so often indirectly, and this did not translate to them requesting the use of a condom during sex. Despite fear of HIV transmission and reinfection, women argued that condom use would seem illogical for a woman who was pregnant already, and when they and their partners had not used condoms for years. Consequently, they avoided suggesting condoms to avoid being questioned by their partners, because this would imply their own or their partner's infidelity (Shikwane et al., 2013; Villar-Loubet et al., 2013). In a study conducted in Mpumalanga, South

Africa on HIV disclosure and sexual negotiation, men reacted strongly to women suggesting condom use during pregnancy, leading to accusations, lack of trust, and misunderstandings (Villar-Loubet et al., 2013).

Conclusion

Disclosure can improve health outcomes for women and their infants during and after pregnancy by preventing HIV transmission between partners and re-infection. However, women with HIV have to think through the implications for themselves, their partner and others, as disclosure may lead to violence. Little attention has been given to the challenges of disclosure for women who become positive during pregnancy, when the implications include their need to initiate treatment to prevent parenteral transmission. Women's desire for personal support in pregnancy is both emotional and economic (Mlotshwa, Manderson, & Merten, 2017), and their fear that this will be withdrawn complicates disclosure. Many women were afraid of physical, sexual or psychological violence (Watts 2000), and so they needed to manage their relationships in ways to avoid harm and to ensure a healthy pregnancy. Women's fear of the timing and process of telling, its consequences, and the implications of their status for others, all need to be addressed by health professionals during counseling sessions.

Step-by-step guidance in pregnancy and after receiving a diagnosis of positive HIV status can assist women to disclose, reducing some of these complexities. In this way, women are less likely to feel alone and less distressed (Schlebusch and Govender, 2015; WHO, 2016). Partners can provide women with encouragement and support throughout pregnancy, including in taking ARVs, but men's involvement in ANC is still very low and is not possible without disclosure.

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CHAPTER 6

In review BMC Public Health (in Review)

The roles social networks play in supporting women during pregnancy in Soweto, South Africa

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Abstract

Social support networks can provide benefits for the wellbeing of pregnant women, which is relevant in a country with a high HIV prevalence. In this study we investigated the prevalence of different forms of social support among pregnant women, We hypothesized that instrumental and emotional social support were dependent on the women's HIV status, on household wealth, and on the degree of social participation. We analyzed data from a study on Pregnancy and HIV undertaken with pregnant women (N=1043) presenting in their first trimester for antenatal care (ANC) at Chris Hani Baragwanath Hospital, in Soweto, Johannesburg, South Africa. Associations were examined using multivariable logistic regression. Our study findings show that social support networks differed according to HIV status, wealth, having a partner, previous pregnancy and tertiary education. . Partner and family/friend support were positively associated (OR=2.6395% CI=1.92 3.59), however church membership was associated with less partner support (OR=0.53 95%CI=0.4 0.7) and less family/friend support (OR=0.65 95%CI=0.47 0.9). Women who had a friend with a baby (OR=0.85 95%CI=0.64 1.14) were also less often reporting partner support and women receiving support from nurses (OR=0.76 95%CI=0.59 0.99) were less likely having family/friend support. Being HIV positive prior to the baseline (OR=0.56 95%CI=0.36 0.88) was associated with less family/friend support. Reforms in policy are needed to address the importance

of social support for pregnant women, as a way to manage the emotional and personal difficulties experienced.

Keywords

Social support South Africa Pregnancy Social Networks HIV/AIDS

Introduction

Social support networks can provide benefits for the wellbeing of pregnant women, which is relevant in a country with a high HIV prevalence (McKee, Cunningham, Jankowski, & Zayas, 2001; L. Mlotshwa, L. Manderson, & S. Merten, 2017a). Social support networks play an essential role in the creation, maintenance and promotion of good health, showing positive effects on incidence, prevalence and persistence of diseases and are necessary for strong mental health (Harandi, Taghinasab, & Nayeri, 2017; Vandervoort, 1999).

Social support networks are the web of social ties that surrounds an individual at any given time, offering a network of family and friends that one can turn to in times of need (Berkman, 1984). These networks can provide emotional and instrumental support, potentially mitigating the stress women may experience during pregnancy. Emotional support can be understood as relationships that make the individual feel appreciated, valued and loved, while instrumental support can be the more tangible support available, for example money, clothes and shelter (Orr, 2004; Reblin & Uchino, 2008). Evidently social support plays a positive role in pregnancy, providing physical and psychological benefits for women who have to deal with stressful events (Uchino, 2006). But sometimes, women are forced to go through pregnancy without support, which may impact negatively on their health and well-being (Mlotshwa et al., 2017a; Swartz, Colvin, & Harrison, 2016). Mental stresses can inhibit a woman's ability to carry out their usual

roles, adding further stress upon the already difficult situation (Gjerdingen, Froberg, & Fontaine, 1991).

Globally it is expected that mental disorders, primarily maternal depression during pregnancy affect an average of 10% of expectant mothers and 13% of women who have just given birth (WHO, 2018b). In developing countries this is even higher, around 15,6% and 19,8% (WHO, 2015b). Additionally 9-21% of women experience anxiety, depression, stress, low self-esteem, feelings of inadequacy and lack of confidence when trying to strike a balance between social expectations and the day-to-day reality of pregnancy (McLeish & Redshaw, 2017).

In South Africa it is estimated that about 1 in every 3 women will experience mental illness during or after their pregnancy (PMHP, 2013). The concurrence of poverty, migration, domestic violence or gender based violence, extreme stress, emergency or conflict situations, HIV infections and unplanned pregnancy often leads to a toxic environment which may ultimately lead to mental distress (WHO, 2015b).

In South Africa formal marriage is not the rule, with only one quarter of adults aged 18years and over being married (Hosegood et al., 2009; E. Moore & Govender, 2013; Stats SA, 2018a). Further 46% of pregnancies within the low-income range of households earning less than ZAR 5000 (US\$ 357) occur in female headed homes. Around half (53%) of these women are single, 26% married, and 19% cohabiting (Van den Heeve, 2006). Often, low income and limited commitment of the partner coincide. Emotional distress, which may result from this situation, can lead to an increase in pregnancy and birth complications, poor neonatal status and low birth weight (Orr, 2004).

The lack of social support both emotional and instrumental has been reported to have negative effects on pregnancy outcomes (Da Costa, Larouche, Dritsa, & Brender, 2000; Elsenbruch et al., 2006) In this study we investigated the prevalence of different forms of social support among pregnant women, We hypothesized that instrumental and emotional social support were dependent on the women's HIV status, on household wealth, and on the degree of social participation.

Methods

Study setting and design

We analyzed data from a study on Pregnancy and HIV undertaken with pregnant women (N=1043) presenting in their first trimester for antenatal care (ANC) at Chris Hani Baragwanath Hospital, in Soweto, Johannesburg, South Africa. Its overall aim was to understand sexual practices of women and their partners during pregnancy and the post-natal period, and to assess the effect of sexual risk behaviour on incidence of HIV infection. The study in turn was nested in a larger prospective cohort study, the Soweto First 1000 Days Study (S1000), which followed women and their infants for up to 24 months after delivery at Chris Hani Baragwanath Hospital. Data was collected from February 2015-February 2016 using a survey questionnaire on a tablet administered by a research nurse or research assistant. The inclusion criteria for the study were pregnancy, ANC attendance, and consent and enrolment during first ANC visit. Study participants were 18 years or older and were able to give their informed consent. Pregnant women were tested for HIV at every visit until delivery and postnatal. Some women were diagnosed with HIV at their first ANC visit and others during the course of their pregnancy, while others had been living with HIV infection for different periods.

Measures

Independent variables: Demographic and reproductive health characteristics

Sociodemographic factors such as age, highest level of education attained, marital status, age of partner, and income were examined. Reproductive health characteristic, previous pregnancies, HIV status and time of infection were assessed.

Outcome variable:

Social support networks

Several questions assessed perceived forms of social support in the S1000 study, including: If you had a really big problem and needed help with money, the children, accommodation etc, are there people who could help you? (Nobody, Maybe/unsure, a number of people) (instrumental support); Can you talk to your parents, other family members or friends about any problems you may have? (Nobody, Maybe/unsure, a number of people); Can you talk to your husband or partner about any problems you might have? (Never, sometimes, always) (emotional support; partner communication); Some people think the sisters at the clinic are always helpful, others think only sometimes and some say they are seldom helpful. How do you feel? (Always helpful, Sometimes helpful, Seldom)(External instrumental support).

Additional measures included relationship quality and the social network: Do you feel that the father of your child or your partner makes things harder for you because of the way he acts? (Never, sometimes, always) (Relationship quality); Do you belong to a church group or any other organisation? Likert 5point scale used (yes, no, I don't know, declined) (External support). Do you have a friend who is also going to have a baby or just had a baby? (yes, no, I don't know, declined) (External emotional support).The questions were adapted from previous validated questionnaires

used in the same context (Richter et al., 2007) as well as other similar contexts (Drain et al., 2015). When there was need questions were re-formulated and adapted to suit the South African context.

We asked the respondents to score their agreement on the different statements (items) and then tested the scalability of the items as measures of social support. We performed a Mokken analysis for polytomous items, using STATA 15 command MSP. Mokken models belong to a group of statistical scale analysis called non-parametric item response theory. We used Mokken scale analysis due to its ability to establish the unidimensionality of a scale. (K. Sijtsma & van der Ark, 2017). Mokken scales require three basic assumptions: (1) unidimensionality- one latent variable summarizes the variation in the item score in the questionnaire; (2) local independence- the items measuring the same attribute are statistically independent conditional on the value of the latent trait; (3) monotonicity- the probability of a positive response increases monotonically with increasing values of the latent trait for all items (K. Sijtsma & Molenaar, 1987; K. Sijtsma & van der Ark, 2017). The scale of homogeneity is based on Loevinger's index of homogeneity (Loevinger, 1948; Molenaar & Sijtsma, 1984). Loevingers coefficient $H < 0,30$ shows poor scalability properties, for $0,30 < H < 0,40$ the scale is weak; for $0,40 < H < 0,50$ shows medium, and for $H > 0,50$ the scale is strong. Mokken scales are estimated using Rho, which is the test-retest reliability coefficient, with $Rho > 0,7$ considered a reliable scale (Gari et al., 2013; Loevinger, 1948; Molenaar & Sijtsma, 1984). Items satisfying the three assumptions of the Mokken analysis can be summed up and individual scores, computed as the rank of the highest endorsed item in this ordered system, that is it is a sum of positive responses. The sum score is used as an estimate of the level of the latent construct in the outcome variable.

Scales

All the social support variables were included in the Mokken analysis. Two sub-scales were identified: Instrumental support and emotional support by family and friends, which included *If you had a really big problem and needed help with money, the children, accommodation and so on, are there people who could help you?* for instrumental support, and *Can you talk to your parents, other family members or friends about any problems you may have?* for emotional support formed the first sub-scale (H=0.56 and Rho=0.50). ‘Father makes life harder (score inverted)’ and ‘can talk to father of the child’ formed a second sub-scale of support (H=0.45 and Rho=0.53). The finding that the family/friend support scale comprised instrumental support, while partner support did not, this was in line with the findings of the qualitative study (Mlotshwa et al., 2017b). Support by the health staff was included as a separate variable with the question *Some people think the sisters at the clinic are always helpful, others think they are not, what do you think?* A third scale was identified combining the two items *Do you belong to a church group or any other organisation? How often do you go to meetings?* (H=0,57 and Rho=0,50). We interpreted this scale as a proxy for the membership in a social group of a person.

Mokken scale analysis was also used to create unidimensional wealth scales based on a set of assets. All asset items were included in a single Mokken analysis. Two sub-scales were identified reflecting different dimensions of wealth. The first sub-scale included assets common in rural areas; *animals, land, bicycle*, (H=0.84 and Rho=0,64)(agricultural wealth score), and the second sub-scale included assets more common in urban settings: *scooter, computer, cellphone, radio, refrigerator, electricity, vehicle*: (H=0,52 and Rho=0,69)(modern goods score). Scores were dichotomized based on medians. *Statistical Analysis*

We used STATA 15 software to perform all statistical analysis. Means and standard deviations for continuous data and proportions and percentages for categorical data were used to

describe demographic characteristics and social support during pregnancy. Logistic regression analysis was used to calculate the crude odds ratio (OR) with 95% confidence intervals for the association between time of HIV infection and social support. We repeated this analysis using the scored scales. In this paper we focus on whether social support networks in pregnancy differed according to time of HIV status of pregnant women. We used first time HIV positive testing during pregnancy as a proxy for infection during pregnancy. Social support was measured at the beginning of the study, while HIV status could change during the pregnancy of the participants. The initial model was then reduced using backward selection, in order to drop the least significant variables. We then continued to successively re-fit the models and applying the same rule, until the remaining variables were statistically significant. In our model relationship quality represented talking to partner or husband about any problem that you may have; external support represented receiving help from nurses, church membership, friend having a baby or just had a baby; wealth represented by modern goods and agricultural assets.

Results

A total of 1043 participants responded to the interview questionnaire. Table 1 summarizes the characteristics of the respondents, as well as the number of women who were tested positive before the current pregnancy (11.3%)(HIV positive prior to baseline), those who were first time tested HIV positive at the first antenatal care visit in their current pregnancy (5.85%) (first-time HIV positive at baseline), and the remaining 82.84% representing the HIV negative pregnant women. Mean age of women per the reported HIV category was 29 for the HIV negative, 29.3 for the HIV positive before baseline, and 28.9 for first-time HIV positive at baseline. Mean education in years in the same HIV categories was 18.0; 11.7; 11.9 respectively; the age group 25-34 reported most of the HIV infections in the study (52.54%). Participants already living with HIV were less

likely having a tertiary education (12.82%) and less likely having a white collar job (13.6%), respectively (Table 1). Many of the participants reported having a number of people they could ask assistance such as money, or help with the children (78.18%). This was less common among women living with HIV already prior to the baseline (70.8%). Only very few reported having nobody they could ask for assistance (3.64%). Women who were living with HIV prior to the baseline were more likely to feel that sometimes their partners made their life harder. In contrast, HIV positive pregnant women were more likely to be church members (Table 2).

Table 1
Descriptive characteristics of respondents

Variable	Negative (N=864)		Positive, diagnosed before first antenatal care visit (N=118)		Positive, diagnosed at first antenatal care visit or during pregnancy (N=61)		Total (N=1043)		Chi2 p-value
	N	(%)	N	%	N	%	N	%	
Age									
18-24	235	(27.20%)	25	(21.19%)	16	(26.23%)	276	(26.46%)	
25-34	447	(51.74%)	71	(60.17%)	30	(49.18%)	548	(52.54%)	
35+	182	(21.06%)	22	(18.64%)	15	(24.59%)	219	(21.00%)	0.461
Tertiary Education									
NO	612	(71.88%)	102	(87.18%)	49	(75.00%)	763	(73.79%)	
YES	240	(28.12%)	15	(12.82%)	16	(25.00%)	271	(26.21%)	0.001
Marriage									
NO	522	(60.77%)	66	(71.00%)	36	(59.02%)	624	(60.12%)	
YES	225	(26.19%)	27	(29.00%)	16	(26.23%)	268	(25.82%)	
Not disclosed	112	(13.04%)	25	(21.20%)	9	(14.75%)	142	(14.07%)	0.237
Employment									
White collar									
NO	648	(76.33%)	95	(86.40%)	43	(72.88%)	786	(77.21%)	
YES	201	(23.67%)	15	(13.60%)	16	(27.12%)	232	(22.79%)	0.034

Previous Pregnancies					
None	161 (18.70%)	18 (15.90%)	9 (14.75%)	188 (18.09%)	
1	320 (37.17%)	47 (41.60%)	12 (19.67%)	379 (36.48%)	
2	213 (24.74%)	34 (30.10%)	23 (37.70%)	270 (27.60%)	
3+	115 (13.36%)	14 (12.40%)	13 (21.31%)	142 (14.50%)	0.066

Table 2
Social support amongst pregnant women

Variable		Negative (N=864)	HIV positive, before baseline (N=118)	HIV positive, first-time diagnosed at baseline (N=61)	Total (N=1043)	P - value
If you had a really big problem and needed help with money, the children, etc. Is there anyone to ask?	Nobody	24 (2.88%)	5 (4.42%)	2 (3.64%)	31 (3.09%)	0.012
	Maybe/unsure	110 (13.19%)	28 (24.78%)	10 (18.18%)	148 (14.77%)	
	A number of people	700 (83.93%)	80 (70.8%)	43 (78.18%)	823 (82.14%)	
Can you talk to your parents, other family members or friends about any problem?	Nobody	27 (3.24%)	4 (3.54%)	6 (10.91%)	37 (3.69%)	0.001
	Maybe/unsure	133 (15.95%)	32 (28.32%)	6 (10.91%)	171 (17.07%)	
	A number of people	674 (80.82%)	77 (68.14%)	43 (78.18%)	794 (79.24%)	
Can you talk to your husband or partner about any problems you might have?	Never	35 (4.17%)	7 (6.19%)	4 (7.14%)	46 (4.56%)	0.293
	Sometimes	267 (31.82%)	40 (35.4%)	13 (23.21%)	320 (31.75%)	
	Always	537 (64%)	66 (58.41%)	39 (69.64%)	642 (63.69%)	
Do you feel that the father of your child or your partner makes things harder?	Never	410 (49.16%)	44 (38.94%)	31 (56.36%)	485 (48.4%)	0.047
	Sometimes	363 (43.53%)	64 (56.64%)	19 (34.55%)	446 (44.51%)	
	Always	61 (7.31%)	5 (4.42%)	5 (9.09%)	71 (7.09%)	

Some people think the sisters at the clinic are always helpful, others think they are not, what do you think?	Always helpful	500 (59.74%)	82 (71.93%)	33 (58.93%)	615 (61.07%)	0.051
	Sometimes helpful	302 (36.08%)	28 (24.56%)	23 (41.07%)	353 (35.05%)	
	Seldom	35 (4.18%)	4 (3.51%)	0 (0%)	39 (3.87%)	
Do you belong to a church group or any other organization?	No	359 (45.27%)	34 (30.36%)	17 (32.08%)	410 (42.8%)	0.003
	Yes	434 (54.73%)	78 (69.64%)	36 (67.92%)	548 (57.2%)	
How often do you go to meetings?	Once a week	163 (21.17%)	14 (13.46%)	8 (16.67%)	185 (20.07%)	0.171
	Once a month	181 (23.51%)	20 (19.23%)	10 (20.83%)	211 (22.89%)	
	Irregularly	426 (55.32%)	70 (67.31%)	30 (62.5%)	526 (57.05%)	
Do you have a friend who is also going to have a baby or just had a baby?	No	468 (56.32%)	64 (58.18%)	32 (57.14%)	564 (56.57%)	0.939
	Yes	363 (43.68%)	46 (41.82%)	24 (42.86%)	433 (43.43%)	

In table 3a and b we separately present the crude odds ratios associated with family /friends support and partner support. In the univariable analysis, having a whitecollar job (OR=1.44 95%CI=1.00 2.07) and having partner support (OR=2.57 95%CI=1.89 3.51) were positively associated with family and friend support. Being HIV positive at baseline (OR=0.51 95%CI=0.34 0.78), church membership (OR=0.52 95%CI=0.39 0.7), and receiving help from nurses (OR=0.75 95%CI=0.59 0.95) was negatively associated with family and friend support.

Having had previous pregnancies (OR=1.14 95%CI=1.02 1.28), a tertiary education (OR=1.5 95%CI=1.13 1.98), being wealthy (OR=7.71 95%CI=4.22 14.08), and having friend/family support (OR=2.57 95%CI=1.89 3.51) was associated with more partner support; women with partner support were less likely having church support (OR=0.47 95%CI=0.36 0.61) or a friend with a baby (OR=0.86 95%CI=0.67 1.11).

In the adjusted model younger women had more partner support; Women with more previous pregnancies (OR=0.85 95% CI=0.74 0.97): reported less support by family/friends, but more partner support (OR=1.22 95% CI=1.05 1.41). Marital status did not play a role.

Women with tertiary education (OR=0.63 95% CI=0.44 0.92) had less family support, but if they were wealthy (OR=10.59 95% CI=4.98 22.53), they had more partner support (association may be both ways). Women with a white collar job (OR=1.5 95%CI=1 2.25) were also more likely to have family/friend support. Women with more agricultural assets (OR=0.44 95%CI=0.26 0.74) reported less partner support. Partner and family/friend support were positively associated (OR=2.63 95% CI=1.92 3.59), however church membership was associated with less partner support (OR=0.53 95%CI=0.4 0.7) and less family/friend support (OR=0.65 95%CI=0.47 0.9). Women who had a friend with a baby (OR=0.85 95%CI=0.64 1.14) were also less often reporting partner support and women receiving support from nurses (OR=0.76 95%CI=0.59 0.99) were less likely having family/friend support. Being HIV positive prior to the baseline (OR=0.56 95%CI=0.36 0.88) was associated with less family/friend support.

Table 3**a) Factors independently associated with family/friend social support in pregnancy**

Variable	Unadjusted odds Ratio [95% CI]	P value	Adjusted odds Ratio[95% CI]	P value
Age (+ 1 year)	1.00 [0.98 1.02]	0.905		
Married (vs. unmarried)	1.00 [0.99 1.00]	0.908		
Previous pregnancies (+1)	0.93 [0.82 1.06]	0.283	0.85 [0.74 0.97]	0.020
Education				
Only primary education	0.74 [0.31 1.73]	0.482		
Tertiary education	0.94 [0.68 1.29]	0.698	0.63 [0.44 0.92]	0.015
Employment				
Employment white collar	1.44[1.00 2.07]	0.048	1.5 [1 2.25]	0.049
Wealth				
Modern goods score, top quintile	2.14 [1.15 3.98]	0.017		
Agricultural assets > median	1.09 [0.70 1.71]	0.701		
HIV status				
+ prior to baseline (vs. HIV neg.)	0.51 [0.34 0.78]	0.002	0.56 [0.36 0.88]	0.013
+ first-time at baseline (vs. neg.)	0.77 [0.42 1.41]	0.393	0.78 [0.41 1.5]	0.460
Relationship quality				
Partner support	2.57 [1.89 3.51]	<0.001	2.63 [1.92 3.59]	<0.001
External support				
Receives help from nurse	0.75 [0.59 0.95]	0.019	0.76 [0.59 0.99]	0.039
Church membership	0.52 [0.39 0.7]	<0.001	0.65 [0.47 0.9]	0.009
Has a friend with a baby	0.98 [0.73 1.3]	0.865		

Statistical significance p<0.05.

b) Factors independently associated with partner support in pregnancy

Variable	Unadjusted odds Ratio [95% CI]	P value	Adjusted odds Ratio[95% CI]	P value
Age (+ 1 year)	1.00 [0.98 1.02]	0.843	0.97 [0.95 1.00]	0.036
Married (vs. unmarried)	1.00 [0.99 1.00]	0.236	1.00 [0.99 1.00]	0.319
Previous pregnancies (+1)	1.14 [1.02 1.28]	0.019	1.22 [1.05 1.41]	0.010
Education				
Only primary education	0.74 [0.33 1.7]	0.484		
Tertiary education	1.5 [1.13 1.98]	0.005	1.38 [0.98 1.94]	0.062
Employment				
Employment white collar	1.27[0.94 1.71]	0.118	0.80 [0.55 1.15]	0.229
Wealth				
Modern goods score, top quintile	7.71 [4.22 14.08]	<0.001	10.59 [4.98 22.53]	<0.001
Agricultural assets > median	0.91 [0.61 1.34]	0.623	0.44 [0.26 0.74]	0.002
HIV status				
+ prior to baseline (vs. HIV neg.)	0.65 [0.43 0.99]	0.043	0.77 [0.48 1.25]	0.294
+ first-time at baseline (vs. neg.)	1.20 [0.7 2.06]	0.512	1.32 [0.72 2.44]	0.370
Family/friend support				
Support by family/friends	2.57 [1.89 3.51]	<0.001	2.45 [1.74 3.46]	<0.001
External support				
Receives help from nurse	0.68 [0.55 0.86]	<0.001	0.63 [0.49 0.81]	<0.001
Church membership	0.47 [0.36 0.61]	<0.001	0.53 [0.4 0.7]	<0.001
Has a friend with a baby	0.86 [0.67 1.11]	0.25	0.85 [0.64 1.14]	0.278

Discussion

Our study findings show that social support networks differed according to HIV status, wealth, having a partner, previous pregnancy and tertiary education. During pregnancy, expectant mothers may experience psychological worries, such as thinking they will not be able to handle the upcoming circumstances with the new baby and other duties (Biaggi, Conroy, Pawlby, & Pariante, 2016; Gjerdingen et al., 1991). These stressors can have a negative impact on pregnant women, and even more so in the context of HIV.

Sometimes experiencing pregnancy alone can be a stressor, too. The presence of a partner in some studies has been reported to have a positive effect on pregnancy outcomes (Stapleton et al., 2012). In our study at least 64% of pregnant women reported always being able to talk to the husband or partner about any problems they might have. Furthermore, pregnant women who seroconverted and became HIV positive during pregnancy still reported that they could talk to their husband or partner (65%). Similarly, another study reported good satisfaction with the marital relationship even after HIV diagnosis (Hill, Maman, Groves, & Moodley, 2015; Pereira & Canavarro, 2009).

We also noted that church membership was associated with less partner support and less family/friend support, suggesting that pregnant women turn to the church once their emotional support deteriorates. Other studies also showed that pregnant women found solace in the church environment (Sorenson, Grindstaff, & Turner, 1995). Church or religion provides direct or indirect support to the expectant mothers, usually from the older women within the church (Mlotshwa et al., 2017b). Religion represents a potential source of culture or institutional support, which assist pregnant women through pregnancy and the post-natal phase. However in a study conducted in California authors reported that religion was not associated with reduced perceived stress and was

in fact associated with increased perceived stress among pregnant women (Mann, Mannan, Quiñones, & Palmer, 2010). But also during the qualitative phase of this study some women suggested not going back to church during pregnancy as they feared negative repercussions especially if they were not married (Mlotshwa et al., 2017b).

Family support is an important resource for pregnant women around the globe (Abdollahpour, Ramenzani, & Khosravi, 2015; Fernández & Newby, 2010; Haobijam, Sharma, & David, 2010; Hill et al., 2015; James, Van Rooyen, & Strumpher, 2012; Mlotshwa et al., 2017b) ensuring that the well-being of pregnant women is maintained throughout the antenatal and postnatal phase. While having a job and a partner were positively associated with family support, at least three in four women with an HIV infection were able to speak to many people if they had a problem. Similarly in a study of young people in KwaZulu Natal participants reported that even after disclosure their family was still supportive (Hill et al., 2015). Our findings also show that wealth was significantly associated with partner social support meaning the more wealth accumulated amongst pregnant women the more social support they reported from the partner. Socio demographic factors such as marital was not associated with social support, while other studies have reported a positive effect with social support (Glazer, Elgar, Goel, & Holzapfel, 2004; Woldetensay et al., 2018).

Conclusion

Social support networks play a critical role in pregnancy as a way to assist the expectant mothers to cope with the many changes that occur in her life. Lack of social support creates a significant risk factor for maternal well-being particularly in pregnancy leading to mental health problems and adverse effects on pregnancy outcomes. This needs to be managed well in an attempt to curb the vulnerability of expectant mothers. This study was conducted in an urban South African

context were many children are raised by single parents, or raised without their biological fathers. Understanding the challenges that come with experiencing lack of social support in pregnancy can assist in making pregnancy less overwhelming, and ultimately contribute to the ability to deal with various practical and relational challenges that exist before and after the baby.

Reforms in policy are needed to address the importance of social support for pregnant women, as a way to manage the emotional and personal difficulties experienced. This is even more important in instances where people are living with HIV or become infected during pregnancy. Different programs in clinics, organizations should be aware of the relative importance of pregnancy-connected distresses over HIV-related or non-related HIV issues amongst the pregnant population. As many women have strong religious affiliations in the South African context (Schoeman, 2016), they may also find support through self-help groups in church settings, with mentorship and encouragement by older women to help them better cope with pregnancy and early infant care. There is a need for safe spaces for psychosocial counselling services in pregnancy, as way to mitigate negative effects of the lack of social support on maternal and child health. Engaging family members and friends is critical in ensuring social support for this vulnerable population group. Support groups are essential as they allow people to talk about their problems through a non-judgmental environment. In low resource areas mental illness and related disorders are often overlooked. Integrating counselling or screening in routine antenatal procedures would allow early detection of psychological distress in many cases.

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Author contributions

LMlo, SM, CC, and SN conceived and designed the study. LMlo worked closely with LMan in recruiting participants and coordinating data collection activities. LMlo, SM, CC, SN supervised the implementation of the research activities. All authors read and approved the final manuscript.

Disclosure statement

No potential conflict of interest was reported by the authors.

Ethics and consent

We received ethical clearance from the University of the Witwatersrand Human Research Ethics Committee (Medical) and the University of Basel Research Committee. All participants gave their written informed consent for all interviews and for their audiotaping, and consent for the publication of quotes from the interviews.

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CHAPTER 7

Discussion

The main aim of this work was to describe and analyse incident HIV, sexual risk behaviours, and practices in pregnancy among women living in urban Soweto, South Africa. In this thesis, I offer an understanding of the dynamics that exist in being pregnant and living with HIV infection, HIV vulnerability in relationships, social norms and sexual practices during pregnancy, and the reasons for changes in practices among couples if any changes do occur. I explore social meanings of sexuality, HIV and sexual practices among pregnant women. Additional concepts that are also explored include family, gender, power relations, trust, intimacy, vulnerability and the quality or value of relationships. These aspects were mainly explored during the qualitative phase of the study. I also investigate whether and how social support changes when an HIV infection occurs during pregnancy; this was part of the quantitative analysis.

Sexuality amongst men and women

In all societies, sexual relationships are guided by norms related to gender and sexuality (Heslop & Banda, 2013). The way in which people are socialized contributes a great deal to their decision-making processes including in relation to sexuality. Socialization is the process by which norms and ideologies of a society are internalized (Little, 2018). Socialization involves learning and teaching, a means by which social and cultural continuity is attained (Birhan & Zewdie, 2018). For example, participants in this study spoke about social support from family and other networks, and this influenced the different decisions they made throughout their pregnancy and postnatally. Understandings of family and heritage also connected the unborn child with ancestors mostly from the paternal side, who were believed to take part in the life of the unborn child. While Soweto is

urban, mothers still considered it important that children learn their culture. Women alluded to the fact that they were unable to teach their sons what was expected of them within their culture, to the extent that this was sex specific and socialisation from father to son; and emphasised that this was important for the child's development and identity. Women who were no longer with the father of the child spoke about the need to connect the child with his/her people through patrilineage connections. From birth, individuals come to understand societal norms and expectations, to accept societal beliefs, and be aware of and respect social values (Little, 2018). Further gender socialization involves learning behaviour that is considered culturally correct or appropriate for a particular sex (Raselekoane, Morwe, & Mulaudzi, 2017). Interactions with social groups like family and peers provide guidelines to how people are expected to behave within society; schools, the workplace, and media communication reinforce some cultural norms and values by mirroring what is conventionally perceived to be the right or wrong behaviour. This means families can have positive engagement with pregnant women or couples to ensure that they do what is right and possibly best for a good healthy pregnancy. Some women alluded to the fact that religion did not allow them to practice certain traditional rituals that they would have done if they were still in their original rural homes. However, in a township like Soweto, different cultural groups from across South Africa and beyond come together and co-exist within the same community, resulting in overlaps in beliefs and practices through religion and interactions among people. In various social interactions, individuals still try to uphold their own cultural beliefs as a way to retain their identity (Heere et al., 2015; Sheldon & Serpe, 1994). These beliefs form the basis of their views on everything, including who they will have relationships with, getting pregnant, what is done during pregnancy, and what is done after pregnancy.

South Africa is a rapidly changing society, where unequal power relations and gender inequality are being challenged, with expectations of changes in the social constructions of masculinity. There is growing acknowledgment that this change will have benefits for everyone, but this requires efforts from both women and men. However, historically labour migration forced the separation of families, with men staying away from their families for long periods of time as a result of laws that instituted (coercive) measures while encouraging labour migration (R. Smit, 2001). Labour migration resulted in rural poverty with massive numbers of families separated and living in dense settlements largely without adult males (Clark, Collinson, Kahn, Drullinger, & Tollman, 2007). Socially constructed gender roles defined the father as the wage earner and mothers as caregivers. This limited women's agency regarding decision making towards child care and her own reproductive health (Yamine et al., 2015). Labour migration also resulted in multiple sexual partners and possibly unsafe sex practices (Dzomba, Tomita, Govender, & Tanser, 2018; Lurie, Harrison, Wilkinson, & Abdool Karim, 1997). In our study, just below half of the participants (13/30) had moved to Johannesburg in search of jobs or their parents were part of the labour migrant system of the Apartheid era. Many of the participants were not married but rather, were cohabiting with the child's father, or had had a child with a boyfriend who was living elsewhere. About 47% of South African households are female headed, with women going to work and looking after the children (Stats SA, 2018c), while the father is absent (Madhavan, Richter, & Norris, 2014). The lack of the child's or children's father within a household has become the norm within South African communities, although women still report the desire to be married and settle with a partner as in our study.

Many women globally still face discrimination in the societies in which they live, and this is often related to entrenched patriarchy. Men who live in patriarchal communities are often

identified as the decision makers in all aspects of day to day living (Bhatta, 2013). South Africa is no different. At the end of Apartheid South Africa, women were guaranteed freedoms that they had not previously enjoyed (Hodes, 2015). This freedom might have been expected to translate into agency in all aspects of life, with positive impacts for women, including the ability to negotiate sex with partners, negotiate condom use, and so have positive outcomes in preventing unintended pregnancy and decreasing their risk of acquiring HIV. However, in the current study, many women reported that even during pregnancy they had to adhere to the wants of their partners. This included in relation to sex negotiations because women regarded sex as a man's right, and feared that if she did not comply, her partner would have sexual relationships with other women outside their union. Many study participants spoke of the inevitability of their partner having extramarital partners, because "that is what men do." Women considered it to be "cultural" for men have many sexual partners and felt that there was nothing they could do to change this. Thus women suggested that "all you need to do is ask him (partner) to use condoms while he is out there, as we (in our relationship) don't use condom."

The role of social norms for health system responses to HIV infection

Due to these patriarchal ideas, male involvement in PMTCT is difficult. Men see health seeking behaviours in sexual reproductive health as a woman's task and generally had nothing to do with this (Matseke et al., 2017). The antenatal clinic has been defined as a space for women, and the organization of the antenatal clinic activities are primarily female oriented (Matseke et al., 2017; Reece, Hollub, Nangami, & Lane, 2010; UNAIDS, 2011; WHO, 2012). Unsurprisingly, men consider that antenatal clinics fall outside of their area, as reflected in our study. Some men refused to come to interviews held at the hospital as they considered that there was no reason for them to be there, and felt that clinics and hospitals were for women. Men also feared stigmatization

by other men, as other men would consider their attendance at an antenatal clinic with their pregnant partner as abnormal.

Patriarchy is entrenched in South Africa. Women felt it was necessary to have a man, and explained this in terms of knowing who you belonged to and being called by his name. This gave many women esteem and worth. Masculinity is associated with dominance, assertiveness and aggression. The patriarchal unit has been identified as a significant risk factor for intimate partner violence (Jewkes & Penn-Kekana, 2002; Sathiparsad, Taylor, & Dlamini, 2008). Although women spoke about the need for their partners to pay damages (*inhlawulo*) for impregnating them before marriage and ultimately paying the bride price (*lobola*), many women were cohabiting and had been doing so for a long period of time. Kyalo (2012) elaborates that in the African context, marriage is a transfer of the legal rights to a woman, from her kin to her partner or husband. The partner gains rights to his wife's labour, her sexuality, her cooking and offspring, and to any reparations for any harm done to her by others (Kyalo, 2012; Posel et al., 2011). The man's responsibility is to provide economic sustenance for the household, while women play the domestic role. However, men who have migrated from rural households to urban areas have experienced difficulties in getting employment, while there has been increased female participation in the labour market, changing the quality of the relationship between the woman and her partner (E. Moore & Govender, 2013; H. Moore, 1996) and giving the women some sort of agency in her decision making.

As in our study, some women contended that marriage is still an important institution that needs to be valued, although it is often difficult to attain. Attitudes and norms regarding marriage in South Africa, including the strength of the marital bond, have weakened following decades of labour migration and apartheid-era policies which, is already discussed above, did not permit

young couples and their families to be together (Jones, 1999; E. Moore & Govender, 2013; Murray & Ramphela, 1995). Women and men built up separate support networks, including turning to rely on support from parents and siblings, in an attempt to manage during this difficult period of separation (Murray & Ramphela, 1995). With separation difficulties and learning to fend for the family, there is some suggestion that black South African women were opting out of marriage and choosing the more reliable and stronger bond of parents and other filial bonds (E. Moore & Govender, 2013). Women were choosing to stay single to escape inadequate providers, heavy drinkers and intimate partner violence, adding to a perception that marriage was no longer a prerequisite for having children (Kaufman, de Wet, & Stadler, 2000; E. Moore & Govender, 2013). Evidence also points to men negotiating and entering marriage late; scholars have documented that men experienced a lot of financial difficulties in paying the bride price and being able to meet expectations to support a family; these factors discouraged some men from getting married (E. Moore & Govender, 2013; Posel et al., 2011).

Women's concerns in these unions included the lack of ability to negotiate condom use, and lack of control over their partner having multiple concurrent sexual relationships. This perpetuates spaces of vulnerability for pregnant women, especially for those who are financially dependent on partners. While this is so, the majority of women in our study did not report financial dependence on the partner – that is, they did not speak directly about economic support from the father of the child. Instead, they spoke about how the need for emotional support from him.

Sexual health: violence, education and empowerment for women

Violence against women in South Africa is huge, despite laws meant to protect women (Jewkes et al., 2010). Patriarchal attitudes are a catalyst for this problem, legitimizing violence and inculcating in men the acceptability of such behavior (Jewkes et al., 2011b). Due to gender

inequality, there is difficulty in allowing women to make choices about their lives, for example, the choice of wanting to be pregnant or not, and the choice to have sex or not (Morrell, Jewkes, & Lindegger, 2012). This means that pregnant women may be unable to enjoy pregnancy, as it can be a difficult time in their lives.

HIV infection rates among married women, or women in stable cohabiting relationships, is significantly higher than among single women, and over 80% of new infections in the Sub-Saharan region occur in stable relationships through heterosexual transmission (Chemaitelly, Awad, Shleton, et al., 2014; Madiba & Ngwenya, 2017). This poses serious challenges of new HIV infections occurring in this population, as about 23,2% black South Africans are in marital relationships, and the risk is critical in the context of pregnancy because of the possibility of parenteral infection. The risk is increased when women are unable to negotiate condom use or refuse unprotected sex, both of which may be seen as questioning male authority (Madiba & Ngwenya, 2017). The power imbalances that exist relating to sexuality increase women's vulnerability to HIV infection, as negotiation for safer sex or refusal of sex may lead to violence (Madiba & Ngwenya, 2017; Mkandawire-Valhmu et al., 2013; Mtenga et al., 2015). In the context of pregnancy, therefore HIV is complex, especially because of gendered power dynamics. In our study, some women were unable to disclose HIV infection when they were diagnosed, despite that they knew their current partner had infected them. Women spoke about the anger they felt, but there was nothing they could do about it because they had already been infected. Some spoke about the lack of remorse from their partner, despite that they were carrying their child. Women spoke about having unprotected sex with their partners, even after knowing their HIV status, because it would be difficult to explain why they would need to use a condom when they had not used a condom for months and were already pregnant, or had ceased to use condoms from the beginning

of their relationship. Women explained that men felt they were at liberty to have multiple partners, and that men felt free to make a decision to have other partners or not. Even after women follow the ABC -- remaining abstinent until marriage, being faithful to a single partner, and using condoms -- they could still be vulnerable to HIV from their partners because of a near universal sexual double standard that allows men to have extramarital sex (Burman, Aphane, & Delobelle, 2015; Murphy, Greene, Mihailovic, & Olupot-Olupot, 2006). Pregnant women reiterate their need for care and support in our study -- the need to have a good pregnancy, feel appreciated and loved. The ideal pregnancy would have the partner, family, friends and religious groups part of the pregnancy, expressing their different forms of care and support, which ranged from emotional support to instrumental support. There was also a need for women to receive some form of care from hospitals and clinics, as they emphasised this was where they received medications and check-ups to see if the baby was growing well. Although many studies have centred on physical changes and discomfort in pregnancy, less attention has been paid to womens' emotional, economic and social wellbeing (Collins & Feeney, 2000), particularly in African settings (Brittain et al., 2017). In women's narratives, a dominant theme was that pregnant women at times felt vulnerable and emotionally alone, and sometimes were unable to identify what was bothering them and had no one with whom to discuss what was going on in their lives (Mlotshwa et al., 2017b). Pregnant women hoped for care that met their personal as well as practical needs, and this might be from a person, a social organisation, a public institution, or a combination of all entities (Mlotshwa et al., 2017b). Pregnant women differentiated kin as rendering diverse support and care, and also rendered this according to their own personal needs during their pregnancy. Similarly, in other studies social support has improved the experience of pregnancy for many women, including

those who find themselves with unplanned pregnancies (Anglely, Divney, Magriples, & Kershaw, 2015; Garipey, Lundsberg, Miller, Stanwood, & Yonkers, 2016).

Men globally seem to disengage during pregnancy and the postnatal period. The World Health Organization acknowledges that the quality of evidence about male partner attendance at antenatal care is currently low (WHO, 2015c). Few men accompany their pregnant partners to antenatal visits or even want to receive an HIV test from the clinic (WHO, 2015c). This phase in a couple's life has been understood to be for women and therefore should not involve the partner. This is more evident in African societies where a man is understood to be available for financial support but not for emotional and physical support (Brittain et al., 2015; Mlotshwa et al., 2017b). In addition to their reluctance to attend antenatal clinics with their pregnant partners, as described above, expectant fathers were reluctant to be interviewed and came up with different reasons for their unavailability, ranging from being at work, to busy schedules, to clinic facilities belonging to women. In addition, they argued that they would feel uncomfortable being questioned about pregnancy when in fact they were not the ones pregnant. However, as a way to improve treatment and reduce the stigma of pregnant women who are infected with HIV, it has been argued that methods that involve male sexual partners are important in improving health outcomes for women. (Brittain et al., 2015; Nesane, Maputle, & Shilubane, 2016; WHO, 2015c). PMTCT programmes, authors have argued, should be developed and implemented with partners at their centre to assist couples cope with the new changes that come with pregnancy and new HIV status for women, and that engaging with couples would impact positively on the health of the mother and child (Brittain et al., 2015; Mohlala, Gregson, & Boily, 2012).

Many researchers have found also that pregnant women consider pregnancy a shared responsibility, and would like partners to be supportive. This support might include helping at

home, looking after children, consistently asking about the pregnancy, providing money so that the woman can go to the clinic, assisting her with care, especially when the pregnancy is at an advanced stage, and going with her to the clinic to support her in antenatal sessions (Brittain et al., 2015; Davis et al., 2018; Mlotshwa et al., 2017b). Some studies have shown that when the partner shows support during pregnancy or is involved in the pregnancy, it makes it easier for disclosure of HIV to occur (Mohlala et al., 2012), and men may then be involved in collecting ARVs for their pregnant partner, so ensuring that medication is taken on time and other important aspects of care for the partner (Brittain et al., 2015).

Conclusion

The Southern African region -- South Africa, Botswana, Swaziland, Namibia, Malawi, Mozambique, Lesotho, and Zimbabwe -- is the epicentre of HIV, with the highest burden of the disease globally. Women, especially young women and adolescent girls, are reporting the highest HIV incidence of women of all ages, and their rates are higher than their male counterparts. This is attributed to complex behavioural factors such as multiple partners and inconsistent condom use; social factors such as gender inequality and poverty; structural factors such as policies, practices, environment and context that directly or indirectly affect individual's options; and biological factors such as vaginal vulnerability, especially among young women and in the context of forced sex, which makes transmission higher in women than in men. Further, the risk of contracting HIV increases two to four fold during pregnancy, because of hormonal changes, behavioural factors including higher frequency of unprotected sex, and biological factors during pregnancy (Harrison, Colvin, Kuo, Swartz, & Lurie, 2015; Mugo et al., 2011). As HIV is complex, various contextual factors need to be assessed and incorporated into comprehensive combination interventions, for example structural and behavioural interventions -- increasing education on condom use, while also empowering women through education to ensure that they are able to make their own decisions relating to their reproductive health. There is also a need for data relating to the effectiveness of these combination prevention interventions during pregnancy and possibly post-natally, to ensure that these programs are working for the people they are intended for, that is, that they are context specific. Community level interventions for maternal and child health have recently been conducted in South Africa to evaluate the effectiveness of these programmes (Mkwanzani et al., 2015), and to determine how best these interventions can be improved. Educating women and communities on pregnancy, HIV related issues including stigma and giving

support to such women, is important. For pregnant women who become HIV positive in pregnancy, emotional support is especially necessary to help them accept their newly diagnosed status, to disclose their status, and to participate in a PMTCT program, although the opposite was true in our study, it showed that support was less when the woman was HIV positive.

Men are active transmitters of HIV, but they are not included as active agents in prevention. Policy reforms in South Africa need to prioritise involving men in pregnancy as a way to improve health outcomes for both mother and child. Male involvement throughout pregnancy and the postnatal period remains limited, with many barriers and the lack of an enabling environment which would successfully draw them into antenatal care. Men also need to formally be part of child rearing. Many of the worries which women raised as occurring during pregnancy were related to the questions: who cares for the child once it is born; if the partner is not available, will he come at a later stage to claim the child; is this more likely if the baby is a boy? A description of the legal situation in policy documents (Department of Social Development, 2017) needs to be more effective in practical situations -- child grants and eligibility – and the involvement of the biological father in the child's life. Additionally in some countries, as a matter of policy, pregnant women are not treated or checked if the partner is not present (Peneva & Maluka, 2018), and this has had negative outcomes for mother and child. There is a need to unite communities to support men and boys and to challenge them to demonstrate leadership through their own behaviour. Men at all levels need to be mobilized as leaders nationally, provincially, within districts, within communities and within the household. The broader community and faith-based leaders need to work with educators, employers, and health professionals to challenge violence and oppression. There is a need to encourage men to live healthy, productive lives that support and honour women and girls.

The common barriers in the fight against HIV include the way other community members react towards the involvement of men in care during pregnancy and birth, reflecting conventional and dated views on how men ought to behave and the things they are supposed to do or not do. Lack of knowledge or understanding of maternal health has negative impact on interventions. Programmes of building community consciousness through community education and awareness of the benefits of fathers participating in pregnancy and postnatal health services are urgently needed. Health system related barriers, which include unavailability of clinic spaces suitable for men, particularly first time fathers who may be very uneasy, for example the fear of how to care for both mother and child financially, emotionally, physically and other fears. The training and supervision of antenatal care nurses and auxiliary nurses on how to treat people who come to ANC not only pregnant women but also family members who are involved in the support and care of pregnant women is integral. Further education about HIV, voluntary counselling and testing, and PMTCT education for couples, are needed in these safe spaces.

The success of PMTCT and ART interventions to eradicate HIV requires the scale-up of HIV/AIDS programmes that are sufficiently funded to realize the goal of ending the AIDS epidemic by 2030 (Granich et al., 2015). Further the 90-90-90 targets, which aim to have 90% of people living with HIV knowing their status, 90% of those with HIV being initiated on ART, and 90% of these people who are receiving treatment achieving viral load suppression -- are dependent on the success of all HIV interventions (UNAIDS, 2017b). To achieve these targets, a coordinated global scale up of prevention programmes is needed. Given also that family is a central point in encouraging women's initiation of antenatal care, the development of programs that encourage open dialogue between young women and parents or guardians earlier in pregnancy is important, and this could be a way to reduce sexual risk behaviours.

Pregnancy, sex, intimacy and HIV are sensitive issues and are always difficult to speak about, but to ignore these issues, and stay on safe territory, is to ignore genuinely pressing questions of our time. In many circumstances, counsellors, researchers, nurses and other personnel do not have adequate training to deal with these sensitive issues, and the content of respondents' accounts – poverty, violence, fear, distress – becomes overwhelming. It is important that those who involved with such work be well trained and able to engage empathetically with patients, and that some form of counselling is available for those in this work. This is because consistently dealing with these issues can be draining and strenuous to all parties involved, to speak about violence, risk and relive possible events that caused pain cannot be easy.

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APPENDIX 1: Ethics University of Basel

Ethikkommission Nordwest- und Zentralschweiz EKNZ

Präsident
Prof. André P. Perruchoud
Vizepräsidenten
Prof. Gregor Schubiger
Dr. Marco Schärer

Dr. S. Merten
Swiss Topical- and Public Health-Institute
Socinstrasse 57
4002 Basel

Basel, 16th June 2014

EKNZ: 2014-091

Incident HIV Pregnant Women and Sexual Risk Behaviors and Practices in Urban South Africa

Dear Dr. Merten

On the occasion of its meeting (02/04/2014), the Ethics Committee of Northwestern and Central Switzerland EKNZ checked the research project "*Incident HIV Pregnant Women and Sexual Risk Behaviors and Practices in Urban South Africa*".

This research project was evaluated according to the ICH-GCP (International-Conference on Harmonisation - Good Clinical Practice) guidelines. It conforms to the conditions that have to be met for research studies in Switzerland, namely:

- scientific validity and relevance of the research project and of the results that are to be expected;
- favourable benefit-risk ratio;
- consent of the study subjects;
- protection of the private sphere and confidentiality;
- professional qualification of the Swiss research scientists involved in the project;
- Definitions of the qualifications that are required of the other research scientists involved.

Whether the project can be accepted from ethical points of view depends on the local circumstances, which could not be assessed. In particular, the present statement does not consider the following points:

- procedure and documentation for recruitment of the study subjects, especially the information sheets and consent forms written in the local language;
- the adequacy of the local infrastructure (material, premises, personnel etc.) with regard to the best possible protection of the study subjects;
- Professional qualification of the non-Swiss research personnel.

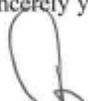
The points listed above should be assessed by the responsible ethical research committee(s) of the place(s) where the project is carried out.

./.

Geschäftsführerin: Frau Irene Oberli, Hebelstrasse 53, 4056 Basel, Telefon 061 268 13 50, Fax 061 268 13 51, ekuz@bs.ch, www.eknz.ch

The Ethics Committee of Northwestern and Central Switzerland acknowledges the revised Documents (according to the list of Attachments - Version 1.1 vom 07. Mai 2014).

Sincerely yours

A handwritten signature in black ink, appearing to be 'A. P. Perruchoud', written over a thin horizontal line.

Prof. A. P. Perruchoud
President of the EKNZ

APPENDIX 2: Ethics University of the Witwatersrand



HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M140110

NAME: Dr Charles Chasela
(Principal Investigator)

DEPARTMENT: School of Public Health
Medical School

PROJECT TITLE: Incident HIV in Pregnant Women and Sexual
Risk Behaviours and Practices in Urban
South Africa

DATE CONSIDERED: 31/01/2014

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR:

APPROVED BY: 

Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 25/04/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS
To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 3

Information sheet for pregnant women



INCIDENCE HIV AND SEXUAL BEHAVIOUR STUDY

INFORMATION SHEET (Pregnant women)

Hello, my name is LangelihleMlotshwa, I am a Researcher in the School of Public Health and the Developmental Pathways Health Research Unit (DPHRU), Chris-Hani Baragwaneth, University of Witwatersrand. Together with other colleagues from the Swiss School of Public Health at the University of Basel we will be conducting a research study to investigate sexual behavior during pregnancy and its relation with HIV infection.

What is the purpose of this study?

You are being asked to take part in this research study because:

- you are pregnant
- you are part of the S1000 study

Before you decide if you want to join this study, we want you to know about the study. We will explain the study to you. You are free to ask questions at any time. If you decide to join, we will ask you to sign or mark this consent form (in front of a witness, if needed). You will be offered a copy to keep.

The primary goal of the study is to develop more effective HIV prevention services for pregnant women, their partners and their children. This study is part of the S1000 study, in which you are participating. Before you decide to participate, we would like you to understand why the research is being done, and what it would involve for you and your partner.

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason and at any time.

Deciding not to be in the study or leaving the study before it is done will not affect your relationship with the researcher, your health care provider, or the DPHRU and the University of Witwatersrand

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist, any questions you have about this study at any time.

What is involved in the study?

If you agree to take part in this study, we will collect the following research data:

- Blood samples from finger pricks to perform HIV tests periodically when you come for the S1000 study visits.
- Note that, regardless of the results, we will not disclose the results of your test results to anyone including your partner/spouse.
- *If you are found to be HIV positive:*
 - No more HIV tests will be performed to you but we will take a few drops of blood to keep, using a filter paper, for additional tests to study the timing of your infection (when did you get infected) and the strain of the virus you are infected with.
 - You will be asked a series of questions related to yourself and your sexual practices before and during your pregnancy.
 - You will be referred to the ART clinic in the Chris-Hani Baragwaneth hospital to start the treatment.

- We will ask for your permission to contact your spouse/partner. If your spouse/partner agrees, we will ask them for an HIV test. Regardless of the results, we will not disclose the results of his test to you neither yours to your partner/spouse.
- All procedures will be conducted by trained researchers and counselors.

If you are found to be HIV negative:

- Periodic HIV tests will be performed to you at each S1000 study visits until the day of your delivery.
- You will be asked a series of questions related to yourself and your sexual practices before and during your pregnancy.
- We will seek permission to contact your spouse/partner if there is need for possible involvement.. If your spouse/partner agrees, we will ask them for an HIV test. Regardless of the results, we will not disclose the results of his test to you neither yours to your partner/spouse.
- All procedures will be conducted by trained researchers and counselors.

Below are details of the procedures:

Procedures

Self-administered questionnaires

At each visit in our offices, you will be asked to fill in a 10 minute questionnaire. It will include questions about your current and past sexual and hygiene practices, whether you know if your partner(s) have been previously tested for HIV infection and, if so, whether you know what the result of the test was. You may also be asked to participate in a second, similar interview 4 weeks after the first interview. If you are uncomfortable about answering any of the questions you need not answer them. If you refuse to answer a question, you will not be penalized or lose any benefits to which you may be entitled. If you agree to the first interview, you may still refuse to participate in the second interview for any reason.

Blood taking and HIV testing

At each visit in our offices, a counsellor will perform a 10-15 minute HIV pre-test and prevention counseling session followed by the performance of an HIV antibody rapid test. This test will require a specimen from droplets of blood obtained by finger prick. When infected with HIV, the body

produces proteins called antibodies. This test is looking for those antibodies. This is not a test for AIDS. Only a doctor can make this diagnosis.

We will tell you the results of the HIV the same day they are performed.

- If you receive a Negative test result it means that you are not HIV Positive at this time. However, since it takes time for antibodies to develop, we will take another test in the next visit
- If you receive a Preliminary positive test result it means that there is a very good possibility that you are infected with HIV. It also means that we would need to perform another finger prick for a second test. This is the best way to make sure that the information given to you is accurate. You will receive the result of the second test in about 20 minutes.
- If the result of the second test is positive it means you are infected with HIV. You will be referred to hospital doctor to be informed for antiretroviral treatment and prevention of HIV transmission to your child.
- If the result of the second test is negative it means that the result is unclear and that there is need to have a third confirmatory test. You will be referred for another confirmatory test using a technique called ELISA. The final result will be given to you by the same professional who administered the test at the hospital and will include a post-test counselling session that includes information on the meaning of the result and, if appropriate, how to access services for follow-up care.

The results from the blood tests will be absolutely confidential; this means a code will be used instead of your name. We will tell you the results of your blood tests and explain them in detail so that you can understand what they mean. If the results indicate there is any health concern we will assist in referring you to the appropriate doctors.

Collection of dry blood spots (DBS)

At each visit few drops of blood from a finger prick during HIV testing will be collected using a filter paper. If in subsequent tests you are found positive using regular HIV tests, we will test the dry blood spots to assess exactly when you were HIV infected and what type of HIV it is, how HIV is transmitted including if the HIV is resistant to anti-HIV drugs and how the body responds to HIV. Unused dry blood samples will be stored with your permission using a separate consent form. Further research using the stored dry blood spots will be with the permission of the ethics committee. There will be no names on the blood filter papers, only a special number.

Interviewer-administered questionnaire

If you receive an HIV positive test result you will be invited for a 30 minute interview that will be conducted at your place by the trained counsellor assigned to you in the study. If you are found HIV negative you may also be asked to complete the same interview. If you prefer the interview could take place at the research unit or another place of your choice transport expenses will be reimbursed to you. This interview will include questions about your current and past living situations, education level and sources of income, family relationships, past and current sexual behaviour, use of intimate hygiene products, and domestic violence. If you are uncomfortable about answering any of the questions you need not answer them. If you refuse to answer a question, you will not be penalized or lose any benefits to which you may be entitled.

Qualitative interviews

Regardless of the result of your HIV test you may be invited for a second interview with a research assistant working in our study. This will be an open question interview where you will be invited to talk more in-depth about sexual behaviour. The aim is to clarify the socio-cultural and socio-economic context of sexual behavior. Specifically, we will aim to understand sexual behavior during pregnancy of women and their partners who acquire HIV during pregnancy, and to compare with women and partners without HIV.

Research studies are designed to obtain new knowledge that may help other people in the future. You may not receive any direct benefit from being in this research study. There also may be risks to being in this research. Below there is a list of the potential benefits and/or risks of participating in this study.

What are the possible benefits of this study?

Research is designed to benefit society by gaining new knowledge. This study may or may not be of direct benefit to you. The results of the study will be shared with you and with the medical staff providing your antenatal care at this clinic and may help them know more about what care you need. If you are found HIV positive they will give you the opportunity to immediately start antiretroviral treatment which will allow caring for your own health and your baby by increasing the chances to prevent the transmission of HIV to your baby (mother-to-child transmission).

What are the possible risks or discomforts involved with study screening?

Taking blood from you may cause slight pain, swelling, and bruising at the place where the blood is taken. Drawing blood can also cause fainting or infection, but this is rare. In this study, some hospital and study staff will know that you have HIV. The study doctors and staff will protect information about you and your participation in these tests to the best of their ability. On your study records, a code will be used instead of your name. Only the study staff will know this code. Study staff will make every possible effort to be sure that others do not learn your HIV status. However, sometimes if you receive special treatments or attend a special clinic, it may make others wonder if you have HIV.

Will it cost you anything to be in this study?

The screening procedures, physical examinations and blood tests will be done free - at no cost to you

Records of your participation in this research: What about confidentiality?

You have the right to privacy. The principal investigator will keep information about your participation in locked files. Your blood samples, results from the blood tests and the information you provide in the questionnaires, will be labelled with a code to ensure your privacy. This means that your personal information will be removed so that no one will be able to link any of the sampled or results to you personally.

- Ethical approval: This study protocol has been submitted to the University of the Witwatersrand's, Human Research Ethics Committee (HREC), and written approval has been granted by that committee.
- Publication of the results of the research: The results of this research may appear in scientific publications without identifying you in any way.

Your questions:

The investigator listed on the first page of this form is available to answer your questions about this research. You may contact the investigator at any time on the following number (011) 717-2312. If you require any further information or have any questions/complaints about the study

please contact the Human Research Ethics Committee of the University of the Witwatersrand on (011) 717-1234 or anisa.keshav@wits.ac.za

YOU WILL HAVE A COPY OF THIS INFORMATION SHEET TO KEEP

If you are happy to take part in the study please read and sign the attached consent form and contact us to confirm your participation.

Your signature on the consent form certifies the following:

- You have read the information provided in this consent form
- You have received answers to all of your questions.
- You have freely decided to participate in this research.
- You understand that you are not giving up any of your legal rights.

APPENDIX 4

Information sheet Partner



INCIDENCE HIV AND SEXUAL BEHAVIOUR STUDY

INFORMATION SHEET (Partner)

Hello, my name is Langelihle Mlotshwa I am a Researcher in the School of Public Health and the Developmental Pathways Health Research Unit (DPHRU), Chris-Hani Baragwaneth, University of Witwatersrand. Together with other colleagues from the Swiss School of Public Health at the University of Basel we will be conducting a research study to investigate sexual behavior during pregnancy and its relation with HIV infection.

What is the purpose of this study?

You are being asked to take part in this research study because:

- you are the partner of a pregnant woman recruited in our study

Before you decide if you want to join this study, we want you to know about the study. We will explain the study to you. You are free to ask questions at any time. If you decide to join, we will ask you to sign or mark this consent form (in front of a witness, if needed). You will be offered a copy to keep.

The primary goal of the study is to develop more effective HIV prevention services for pregnant women, their partners and their children. This study is part of the S1000 study, in which your

partner is participating. Before you decide to participate, we would like you to understand why the research is being done, and what it would involve for you as a partner.

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason and at any time.

Deciding not to be in the study or leaving the study before it is done will not affect your relationship with the researcher, your health care provider, or the DPHRU and the University of Witwatersrand

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist, any questions you have about this study at any time.

What is involved in the study?

If you agree to take part in this study, we will collect the following research data:

- Blood samples from finger pricks to perform one HIV test when you come for the research study visit. Note that, regardless of the results, we will not disclose the results of your test results to anyone including your partner/spouse.
- Regardless of the results of the HIV test, you will be asked a series of questions related to yourself and your sexual practices before and during the pregnancy of your partner.
- *If you are found to be HIV positive:*
 - No more HIV tests will be performed to you but we will take a few drops of blood to keep, using a filter paper, for additional tests to study the timing of your infection (when did you get infected) and the strain of the virus you are infected with.
 - You will be referred to the ART clinic in the Chris-Hani Baragwaneth hospital to start the treatment.
 - All procedures will be conducted by trained researchers and counselors.

Below are details of the procedures:

Procedures

Blood taking and HIV testing

At each visit in our offices, a counsellor will perform a 10-15 minute HIV pre-test and prevention counseling session followed by the performance of an HIV antibody rapid test. This test will require a specimen from droplets of blood obtained by finger prick. When infected with HIV, the body produces proteins called antibodies. This test is looking for those antibodies. This is not a test for AIDS. Only a doctor can make this diagnosis.

We will tell you the results of the HIV the same day they are performed.

- If you receive a Negative test result it means that you are not HIV Positive at this time. However, since it takes time for antibodies to develop, we will take another test in the next visit
- If you receive a Preliminary positive test result it means that there is a very good possibility that you are infected with HIV. It also means that we would need to perform another finger prick for a second test. This is the best way to make sure that the information given to you is accurate. You will receive the result of the second test in about 20 minutes.
- If the result of the second test is positive it means you are infected with HIV. You will be referred to hospital doctor to be informed for antiretroviral treatment and prevention of HIV transmission to your child.
- If the result of the second test is negative it means that the result is unclear and that there is need to have a third confirmatory test. You will be referred for another confirmatory test using a technique called ELISA. The final result will be given to you by the same professional who administered the test at the hospital and will include a post-test counselling session that includes information on the meaning of the result and, if appropriate, how to access services for follow-up care.

The results from the blood tests will be absolutely confidential; this means a code will be used instead of your name. We will tell you the results of your blood tests and explain them in detail so that you can understand what they mean. If the results indicate there is any health concern we will assist in referring you to the appropriate doctors.

Collection of dry blood spots (DBS)

If you are found HIV positive we will also collect a few drops of blood from a finger prick using a filter paper. The dry blood samples will be used to assess exactly when you were HIV infected and what type of HIV it is how HIV is transmitted including if the HIV is resistant to anti-HIV drugs and how the body responds to HIV. Unused dry blood samples will be stored with your permission using a separate consent form. Further research using the stored dry blood spots will be with the permission of the ethics committee.

Interviewer-administered questionnaire

Regardless of the results of your HIV test you will be invited for a 30 minute interview that will be conducted at your place by a trained counsellor working in our study. If you prefer the interview could take place at the research unit or another place of your choice transport expenses will be reimbursed to you. This interview will include questions about your current and past living situations, education level and sources of income, family relationships, past and current sexual behaviour, use of intimate hygiene products, and domestic violence. If you are uncomfortable about answering any of the questions you need not answer them. If you refuse to answer a question, you will not be penalized or lose any benefits to which you may be entitled.

Qualitative interviews

Regardless of the result of your HIV test you may be invited for a second interview with a research assistant working in our study. This will be an open question interview where you will be invited to talk more in-depth about sexual behaviour. The aim is to clarify the socio-cultural and socio-economic context of sexual behavior. Specifically, we will aim to understand sexual behavior during pregnancy of women and their partners who acquire HIV during pregnancy, and to compare with women and partners without HIV.

Research studies are designed to obtain new knowledge that may help other people in the future. You may not receive any direct benefit from being in this research study. There also may be risks to being in this research. Below there is a list of the potential benefits and/or risks of participating in this study.

What are the possible benefits of this study?

Research is designed to benefit society by gaining new knowledge. This study may or may not be of direct benefit to you. The results of the study will be shared with you and with the medical staff providing your antenatal care at this clinic and may help them know more about what care you need. If you are found HIV positive they will give you the opportunity to immediately start antiretroviral treatment which will allow caring for your own health and your baby by increasing the chances to prevent the transmission of HIV to your baby (mother-to-child transmission).

What are the possible risks or discomforts involved with study screening?

Taking blood from you may cause slight pain, swelling, and bruising at the place where the blood is taken. Drawing blood can also cause fainting or infection, but this is rare. In this study, some hospital and study staff will know that you have HIV. The study doctors and staff will protect information about you and your participation in these tests to the best of their ability. On your study records, a code will be used instead of your name. Only the study staff will know this code. Study staff will make every possible effort to be sure that others do not learn your HIV status. However, sometimes if you receive special treatments or attend a special clinic, it may make others wonder if you have HIV.

Will it cost you anything to be in this study?

The screening procedures, physical examinations and blood tests will be done free - at no cost to you

Records of your participation in this research: What about confidentiality?

You have the right to privacy. The principal investigator will keep information about your participation in locked files. Your blood samples, results from the blood tests and the information you provide in the questionnaires, will be labelled with a code to ensure your privacy. This means that your personal information will be removed so that no one will be able to link any of the sampled or results to you personally.

- Ethical approval: This study protocol has been submitted to the University of the Witwatersrand's, Human Research Ethics Committee (HREC), and written approval has been granted by that committee.
- Publication of the results of the research: The results of this research may appear in scientific publications without identifying you in any way.

Your questions:

The investigator listed on the first page of this form is available to answer your questions about this research. You may contact the investigator at any time on the following number (011) 717-2312. If you require any further information or have any questions/complaints about the study

please contact the Human Research Ethics Committee of the University of the Witwatersrand on (011) 717-1234 or anisa.keshav@wits.ac.za

YOU WILL HAVE A COPY OF THIS INFORMATION SHEET TO KEEP

If you are happy to take part in the study please read and sign the attached consent form and contact us to confirm your participation.

Your signature on the consent form certifies the following:

- You have read the information provided in this consent form
- You have received answers to all of your questions.
- You have freely decided to participate in this research.
- You understand that you are not giving up any of your legal rights.

APPENDIX 5



Questionnaire ID: _____

CONSENT SHEET (Pregnant

women)

I agree to myself being a participant in the study. The goals and methods of the study are clear to me.

I understand that the study will involve interviews, blood taking and HIV testing. All the details and purposes of this study have been explained to me. I understand that I have the right to refuse to participate in the study at any time.

I agree to participation in the study on the condition that:

1. I can withdraw voluntarily from the study at any time and that no adverse consequences will follow on withdrawal from the study.
2. I have the right not to answer any or all questions posed in the interviews and not to participate in any or all of the procedures / assessments.
3. The University of the Witwatersrand's Human Research Ethics committee has approved the study protocol and procedures.
4. All results will be treated with the strictest confidentiality.

5. Only group results, and not my individual results, will be published in scientific journals and in the media.

6. The study scientific team are committed to treating participants with respect and privacy through interviews conducted in private and follow-up counselling available on request.

7. I will receive a referral note to a health service if any result is out of the normal range or a problem is detected during the course of the study.

8. I give permission to contact my spouse/partner should there be need for possible involvement:

Yes No

Study Title :	Incident HIV in Pregnant Women and Sexual Risk Behaviors and Practices in Urban South Africa
Place of Study:	Johannesburg
Study Participant:	
Name and Signature:	_____ _____
Date of Birth:	___ / ___ / _____ <input type="checkbox"/> male <input type="checkbox"/> female
Study participant who cannot read or write:	
Name and Signature:	_____ THUMB Print _____
Date of Birth:	___ / ___ / _____ <input type="checkbox"/> male <input type="checkbox"/> female
Witness of Study participant (for participants who can't read or write):	

Name and Signature:

Date of Birth:

___ / ___ / ___

male

female

**Name and Signature of person
who has conducted the
information/consent
Date/Time**

APPENDIX 6



CONSENT SHEET (Partner)

I agree to myself being a participant in the study. The goals and methods of the study are clear to me.

I understand that the study will involve interviews, blood taking and HIV testing. All the details and purposes of this study have been explained to me. I understand that I have the right to refuse to participate in the study at any time.

I agree to participation in the study on the condition that:

1. I can withdraw voluntarily from the study at any time and that no adverse consequences will follow on withdrawal from the study.
2. I have the right not to answer any or all questions posed in the interviews and not to participate in any or all of the procedures / assessments.
3. The University of the Witwatersrand's Human Research Ethics committee has approved the study protocol and procedures.
4. All results will be treated with the strictest confidentiality.

5. Only group results, and not my individual results, will be published in scientific journals and in the media.

6. The study scientific team are committed to treating participants with respect and privacy through interviews conducted in private and follow-up counselling available on request.

7. I will receive a referral note to a health service if any result is out of the normal range or a problem is detected during the course of the study.

Study Title :	Incident HIV in Pregnant Women and Sexual Risk Behaviors and Practices in Urban South Africa
Place of Study:	Johannesburg
Study Participant:	
Name and Signature:	_____
Date of Birth:	___ / ___ / _____ <input type="checkbox"/> male <input type="checkbox"/> female
Study participant who cannot read or write:	
Name and Signature:	_____ THUMB Print _____
Date of Birth:	___ / ___ / _____ <input type="checkbox"/> male <input type="checkbox"/> female
Witness of Study participant (for participants who can't read or write):	
Name and Signature:	_____
	___ / ___ / _____

Date of Birth:	<input type="checkbox"/> male <input type="checkbox"/> female
Name and Signature of person who has conducted the information/consent Date/Time	

APPENDIX 7

Interview guide for pregnant women

Thank you for meeting with me today and allowing me to talk to you. My name is LangelihleMlotshwa. I am a Researcher at Swiss Tropical and Public Health Institute, the University of Basel, and the School of Public Health and the Developmental Pathways Health Research Unit (DPHRU), Chris Hani Baragwanath Hospital, University of the Witwatersrand.

What is the purpose of this study?

You are being asked to take part in this research study because:

- you are pregnant
- you are part of the S1000 study
- you are part of the incident study

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason and at any time.

You can also decide to leave the study before it is completed. This will not affect your relationship with the researcher, your health care provider, or the DPHRU and the University of Witwatersrand

I am providing some details about this study below. It is important that you understand this information so that you can make an informed choice about being in this study. You will be given a copy of this consent form. You can ask the researcher named above, or staff members who may assist, any questions you have about this study at any time.

As you are part of the study named above (S1000 study), this component of the study allows a more in-depth conversation about sexual behavior during pregnancy as you may remember our discussion in our first interview with you. This component of the study forms part of my studies at the University of Basel, Switzerland.

Are you happy with me to continue?

I am interested in asking you some questions about your current pregnancy, sexual behaviour during pregnancy and other issues about the way you live with others including the father of your child. First of all, may I ask you a few background questions?

THEN GO TO NEXT PAGE

Basic demographic

1. Tell me about yourself (background) (probe 2-13)	
2. Age	
3. Education (clarify level of education)	
4. Are you married or living with your partner....if Yes →5	
5. Length of time with current partner (How long have you been together)	
6. i. Who else do you live with? (household) ii. Number of children	
7. Age at which had first child i. alive, died, abortions	
8. Where do the children live? i. Do all the children live together	
9. Who lives with children?	
10. Where do you work (occupation)?	

11. What is the household income for your family?	
12. Religious affiliation	
13. Do you come from this area (Soweto) (Migration) i. How long have you lived here.	

Now I would like to talk to you about **pregnancy**, is that okay?

1. When did you find out you were pregnant after conception?

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2. Did you plan your pregnancy?

a. Yes go to 5 No go to 4

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3. Were you on any contraception? (What?)

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4. Any complications during this pregnancy? Previous ones (if applicable)?

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5. Has your health been good throughout this pregnancy?

- a. Physical and psychological? health problems (would they mention eg any mental health problems? What about saying Physical health problems? What about stress?

6. Does your partner/father of your child ever go to ANC with you? (probe)

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7. Can you tell me about the sources of support in your pregnancy? (Probe)

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Now I would like to talk to you about your **sexual behaviour**, is that okay? These first questions are general, about sex before you were pregnant.

1. Can you tell me a bit about partners?

Probe: number, concurrent or sequential, long standing or not, frequency of contact

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2. Before you were pregnant would you do anything to prepare for sex ? Now that you are pregnant do you do anything?

Probe:

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3. What if your partner wants sex and you don't, what happens then?

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4. If you do not want to have sex with your partner, are you able to tell him this? Then what happens?

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5. Do you take any drugs or alcohol? What about your partner/father of child?

Probe: Too much? A lot? What do you mean? Does this affect your lives in anyway?

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6. Have you been physically abused due to drugs or alcohol? What about others in your household?

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7. Have you or anyone else within the household been beaten or physically abused for any other reason?

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8. Have you ever had forced sex?

Probe: Are there times or occasions when this might occur? (e.g. Drinking?

Arguments?Drugs?

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The next questions are about **pregnancy and sexual behaviour**: is that okay?

9. Do you think pregnancy has affected your sexual behavior?

Probe: Change in sex positions? Change in sex frequency?

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10. Any cultural and religious beliefs that have affected this?

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11. Do you do anything to your vagina before sex now? What do you use? Why do you do it?

- a. Probe: Do you think it changes sex between partners? How many times do you do it? Changes in frequency, changes in substances in pregnancy and before pregnancy

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12. Do you think your spouse/partners' sexual behaviour is the same now you are pregnant?

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13. Does he have other sexual partners you know about? Probe: Does he go out a lot and spend time away from home? Did he do this before you were pregnant, or only now?

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14. Have you ever discussed getting tested for HIV together, seeing that you are pregnant?

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15. Do you know the HIV status of the father of the child?

Probe: Check current partner

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16. Do you know the HIV statuses of other people you have had sex with?

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For HIV negative women only:

1. What do you consider as safe sex? Do you practice safe sex?

Probe: with everyone? Condom use?

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2. Is your partner circumcised?

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3. Are other people you have sexual relations with circumcised?

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4. Do you think that if your spouse/partner were to have other sexual relationships, he would practice safe sex?

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This is the end of our interview. Is there anything you would like to talk about before I go?

Please do not forget we will meet again soon. I will keep in contact with you by phoning you if you are okay with this kind of arrangement.

HIV negative women interview ends here

For HIV positive women:

Now I would like to talk to you about **sex behaviours, pregnancy and HIV**, is that okay?

1. What do you understand about HIV infection?

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2. How do you think you got infected?

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3. What do you understand by disclosure?

a. Telling about your status?

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4. Have you told your status to your partner/father of child, or to anyone else?

Probe: Who? Context?

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5. Knowing your status, how has that affected your relationship with your partner/spouse?

Probe: Sex? Other?

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6. What to you understand about being HIV infected and being pregnant?

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7. Do you use condoms now that you know your HIV status?

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8. Other than condoms, has your sexual behavior changed?

Probe: Are you able to talk to your partner/father of child about this?

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9. Talked about sex and pregnancy with partner/father of child (negotiating sex in the relationship)? Him using condom?

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10. Have you talked to anyone about sex during pregnancy, or HIV and pregnancy, in ANC or anywhere else?

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11. In general, how has having HIV affected your lives and your household?

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Thank you for your time. This is the end of our interview. Is there anything you would like to talk about before I go. Please do not forget we will meet again soon. I will keep in contact with you by phoning you if you are okay with this kind of arrangement.

APPENDIX 8

Interview guide for Partner

Thank you for meeting with me today and allowing me to talk to you. My name is LangelihleMlotshwa. I am a Researcher at Swiss Tropical and Public Health Institute, the University of Basel, and the School of Public Health and the Developmental Pathways Health Research Unit (DPHRU), Chris Hani Baragwanath Hospital, University of the Witwatersrand.

What is the purpose of this study?

You are being asked to take part in this research study because:

- Your partner/spouse is pregnant
- Your partner/spouse is part of the S1000 study
- Your partner/spouse is part of the pregnancy and HIV study

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason and at any time.

You can also decide to leave the study before it is completed. This will not affect your relationship with the researcher, your health care provider, or the DPHRU and the University of Witwatersrand

I am providing some details about this study below. It is important that you understand this information so that you can make an informed choice about being in this study. You will be given a copy of this consent form. You can ask the researcher named above, or staff members who may assist, any questions you have about this study at any time.

As your partner/spouse is part of the study named above (S1000 study), this component of the study allows a more in-depth conversation about sexual behavior during her pregnancy. This component of the study forms part of my studies at the University of Basel, Switzerland.

Are you happy with me to continue?

I am interested in asking you some questions about your partner/spouse's current pregnancy, sexual behaviour during pregnancy and other issues about the way you live with others including the father of your child. First of all, may I ask you a few background questions?

THEN GO TO NEXT PAGE

Basic demographic

14. What is your background? Tell me about yourself ...	
15. Age	
16. Education	
17. Married or not married (or other)	
18. Length of time with spouse/current partner	
19. Who do you live with?	
20. How many children do you have	
21. Age at which had first child	
22. Who lives with children	
23. Where you work (occupation)	
24. Household income	
25. Religious affiliation	
26. Perceived health status	
27. Migration	
28. Where do you live now	

Now I would like to talk to you about **pregnancy**?

8. Did you plan this pregnancy with your spouse/partner?

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9. When did you find out that your spouse/partner was pregnant?

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10. Was your partner on any contraception? (What?)

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11. Has your partner/spouse had any complications during this pregnancy? Previous ones (if applicable)?

12. Have you ever been to ANC with your partner/spouse? (probe)

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Now I would like to talk to you about **sex**, is that okay?

1. Can you tell me a bit about partners?

Probe: number, concurrent or sequential, long standing or not, frequency of contact

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2. Do you like your spouse/partner to do anything to herself before you have sex (vaginal practice)? Why?

Probe: Do you think it changes sex between partners/spouse? How many times do you do it?

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3. What if your partner wants sex and you don't, what happens then? What if you want sex and your partner does not, what happens then?

.....

.....

.....

.....

4. Do you take any drugs or alcohol? What about your partner/spouse?

Probe: Too much? A lot? What do you mean? Does this affect your lives in anyway?

.....

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.....
The next questions are about **pregnancy and sex**: is that okay?

13. Do you think your spouse/partner being pregnant has affected your sexual behavior?

Probe: Change in sex positions? Change in sex frequency?

.....
.....
.....
.....

14. Any cultural and religious beliefs that have affected this?

.....
.....
.....
.....

15. Do you think your spouse/partners' sexual behaviour is the same now that she is pregnant?

.....
.....
.....
.....

16. Have you ever discussed getting tested for HIV together, seeing that she is pregnant?

.....
.....
.....
.....

17. Do you know the status of your spouse/partner?

Probe: Check current partner

.....
.....
.....
.....

18. Do you know the statuses of other people you have had sex with?

.....
.....
.....
.....

For HIV negative men only:

5. What do you consider as safe sex? Do you practice safe sex?

Probe: with everyone?

.....
.....
.....
.....

6. What do you think about circumcision?

.....

.....

.....

.....

7. Do you think that if your spouse/partner were to have other sexual relationships, she would practice safe sex?

.....

.....

.....

.....

This is the end of our interview. Is there anything you would like to talk about before I go?

Please do not forget we will meet again soon. I will keep in contact with you by phoning you if you are okay with this kind of arrangement.

HIV negative men interview ends HERE

For HIV positive men:

Now I would like to talk to you about sex, pregnancy and HIV, is that okay?

12. What do you understand about HIV infection?

.....

.....

.....

.....

13. How do you think you got infected?

.....

.....

.....

.....

14. What do you understand by disclosure?

.....

.....

.....

.....

15. Have you disclosed your status to your spouse/partner, or to anyone else?

Probe: Who? Context?

.....

.....

.....

.....

16. Knowing your status, how has that affected your relationship with your partner/spouse?

Probe: Sex? Other?

.....

.....

.....

.....

17. Do you use condoms now that your HIV status is known?

.....

.....

.....

.....

18. Other than condoms, has your sexual behavior changed?

Probe: Are you able to talk to your spouse/partner about this?

.....

.....

.....

.....

19. What to you understand about being HIV infected and your partner/partner being pregnant?

.....

.....

.....

.....

20. Have you talked to anyone about sex during pregnancy, or HIV and pregnancy?

Probe: Anywhere?

.....

.....

.....

.....

21. Have you talked about sex and pregnancy with spouse (negotiating sex in the relationship)?

.....

.....

.....

.....

22. In general, how has having HIV affected your lives and your household?

.....

.....

.....

.....

Thank you for your time. This is the end of our interview. Is there anything you would like to talk about before I go. Please do not forget we will meet again soon. I will keep in contact with you by phoning you if you are okay with this kind of arrangement.

APPENDIX 9

Questionnaire ID: _____

Baseline questionnaire – Pregnant Women

	QUESTION	Coding categories	Skip
Socio-economic Characteristics			
1-	Are you living with a partner	0 no 1 yes 98 I don't know 99 Declined	
2	How many days of the week do you spend at the provided address	Number _____	
3	Age in years	Number _____	
4	Is the woman aged 18 or over?	5 no 6 yes 98 I don't know 99 Declined	
7	Marital status	1 Married formal 2 Married, with other ceremony 3 Married, but living separate 4 Cohabiting 5 Widowed 6 Divorced 98 I don't know 99 Declined	
8	Total years of formal education		
9	Highest level of education attended	1 No school attended 2 Primary	

		<p>3 Secondary</p> <p>4 Professional/technical training</p> <p>98 I don't know</p> <p>99 Declined</p>	
10	Which of the following best describes her occupational status?	<p>1 managerial/professional/technical</p> <p>2 clerical support/ service or sales</p> <p>3 housework</p> <p>4 student</p> <p>5 skilled manual work</p> <p>6 unskilled manual work</p> <p>7 other _____</p> <p>98 I don't know</p> <p>99 Declined</p>	
11	Fathers age	Number _____	
12	Does the woman's household have or own any of the following?	<p>Electricity? 1 Bicycle? 2 Radio? 3 Motor Cycle? 4 Television? 5 Car/Truck/Tractor? 6 Refrigerator? 7 do they own their own home? 8 cellphone? 9 microwave? 10 personal computer? 11 Washing Machine? 12 Farm Animals? 13 Landline Telephone? 14 MNET/DSTV Satellite? 15 Internet Access? 16 Agricultural Land? 17 DVD player? 18</p>	
13	Main fuel used for cooking woman's household	<p>1 Electricity</p> <p>2 Wood</p> <p>3 Liquid Propane</p> <p>4 Shrubs/Grass</p>	

		<p>5 Natural Gas</p> <p>6 Animal Dung</p> <p>7Bio-Gas</p> <p>8 Kerosene</p> <p>9 no cooking</p> <p>10 charcoal</p> <p>11 other</p>	
14	Main source of drinking water in the woman's household	<p>1 bottled water</p> <p>2 public tap</p> <p>3 piped water into dwelling</p> <p>4 tanker truck/cart with small tank</p> <p>5 piped water into yrad/plot</p> <p>6 unprotected dug well</p> <p>7 protected dug well</p> <p>8 unprotected spring</p> <p>9 protected spring</p> <p>10 surface water</p> <p>11 rainwater</p> <p>12 other</p>	
15	Type of toilet facility in the woman's household flush to piped sewer system	<p>1 ventilated improved pit latrine</p> <p>2 flush to septic tank</p> <p>3 no facilities or bush or field</p> <p>4 traditional pit toilet</p> <p>5 other</p> <p>98 I don't know</p> <p>99 Declined</p>	

16	Is the toilet facility shared with other households	1 yes 2 no 98 I don't know 99 Declined	
17	Main flooring material in the woman's household	1 earth/sand/mud 2 ceramic tiles 4 wood planks 5 cement 6 finished wood 7 carpet 8 vinyl/linoleum 9 other 98 I don't know 99 Declined	
18	Main Wall material in the woman's household	1 no walls 2 prefab 3 plastic or cupboards 4 bare brick or cement block 5 mud 6 plastic finished 7 mud and cement 8 corrugated iron/zinc 9 other 98 I don't know 99 Declined	
0	Section B: Current pregnancy		

1	Height	Number_____	
2	Weight (at this visit)	Number_____	
3	Has she had a syphilis test?	1 yes 2 no 98 I don't know 99 Declined	
4	If yes, was the result positive?	1 yes 2 no 98 I don't know 99 Declined	
5	If positive, was treatment given?	1yes 2 no 98 I don't know 99 Declined	
6	Haemoglobin level or haematocrit	Number_____	
0	Section 3. Various characteristics		
1	Was the pregnancy conceived with fertility treatment?	1yes 2no 98 I don't know 99 declined	
2	Has she ever been diagnosed or treated for diabetes?	1yes 2no 98I don't know 99 declined	
3	Has she ever been tested for HIV?	1yes 2no 98 I don't know 99 declined	
4	When did you test?	0-During this pregnancy 1-9 months ago 2-more than 9 months ago	

		99 Declined 98 I don't remember 98	
5	Have you been initiated for ART?	1Yes 2No 97 I don't know 99 Declined	
6	When where you initiated?	Date_____	
7	Do you sometimes find it difficult to take your treatment?	1Often 2Sometimes 3Not at all 99Declined 98I don't know/remember	
8	Reason for this?	_____	
9	Has she ever been diagnosed with or treated for tuberculosis?	1yes 2no 98 don't know 99declined	
10	Has she ever been diagnosed with or treated for anaemia?	1yes 2no 98 I don't know 99 declined	
	Has she ever been diagnosed with or treated for mental depression?	yes 1 no 0 I don't know 98 declined 99	
	Section 4. Gyn. and obstetric history		
	Has she had regular (24-32 day) menstrual cycles in the three months prior to this pregnancy?	yes 1 no 0 I don't know 98 declined 99	
	What is the average length of her menstrual cycle?	Number _____	

	Has she used hormonal contraceptives or been breastfeeding in the two month prior to this pregnancy?	yes 1 no 0 I don't know 98 declined 99	
	Is the first day of the last menstrual period (LMP) known?	yes 1 no 0 I don't know 98 declined 99	
	if yes, date:	Date _____	
	Was she certain of the date of her LMP? yes 1 no 0 I don't know 98 declined 99		
	Number of previous pregnancies, excluding this one	Number _____	
	Date of last delivery, miscarriage or termination	Date _____	
	Number of previous miscarriages	Number _____	
	Number of previous terminations	Number _____	
	Number of previous births	Number _____	
	Section 5. Current pregnancy		
	During this pregnancy, has she been diagnosed with or treated for HIV	yes 1 no 0 I don't know 98 declined 99	
	If yes when was treatment initiated?	Date _____	
	During this pregnancy, has she been diagnosed with or treated for any genital tract or sexually transmitted infection?	yes 1 no 0 I don't know 98 declined 99	
	Was this pregnancy planned?	No 0 Yes 1 I don't know 97 Declined 99	

	Was this a wanted pregnancy?	No 0 Yes 1 I don't know 97 Declined 99	
	Did you consider terminating the pregnancy at some point?	No 0 Yes 1 I don't know 97 99 Declined	
	Does the father of the baby know about the pregnancy	No 0 Yes 1 I don't know 97 Declined 99	
	Section 7. Social Support questions from the Antenatal		
	1.1. If you had a really big problem and needed help with money, the children, accommodation and so on, are there people who could help you?	Nobody 1 Maybe / unsure 2 A number of people 3	
	1.2. In order for us to be able to understand your particular circumstances better, we would like to know how much help and support you feel you get from your family and friends	Nobody 1 Maybe / unsure 2 A number of people 3	
	1.3. Can you talk to your parents, other family members or friends about any problems you may have?	Nobody 1 Maybe / unsure 2 A number of people 3	
	1.4. Can you talk to your husband or partner about any problems you might have?	Never 1 Sometimes 2 Always 3	
	1.5. Some people think the sisters at the clinic are always helpful, others think	Always helpful 1 Sometimes helpful 2	

	only sometimes and some say they are seldom helpful. How do you feel?	Seldom 3	
	1.6.Do you feel that the father of your child or your partner makes things harder for you because of the way he acts?	Never 1 Sometimes 2 Always 3	
	1.7.Do you belong to a church group or any other organisation?	yes 1 no 2 I don't know 98 declined 99	
	1.8.How often do you go to meetings?	Once a week 1 Once a month 2 Irregularly 3	
	1.9.Do you have a friend who is also going to have a baby or has just had a baby?	yes 1 no 2 I don't know 98 declined 99	
	If YES, how often do you see her?	Once a week 1 Once a month 2 Irregularly 3	
	Section 8: Revised Life Orientation Test		
	In uncertain times, I usually expect the best	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	It's easy for me to relax	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	If something can go wrong, it will.	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	I'm always optimistic about my future.	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	I enjoy my friends a lot.	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	It's important for me to keep busy.	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	I hardly ever expect things to go my way.	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	I don't get upset too easily.	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	

	I rarely count on good things happening to me.	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	Overall, I expect more good things to happen to me than bad.	strongly disagree 0 disagree 1 neutral 2 agree 3 strongly agree 4	
	Section 9: Spielberger State Anxiety Scale		
	I feel calm disagree 1 neutral 2 agree 3 strongly agree 4 9.2. I am tense disagree 1 neutral 2 agree 3 strongly agree 4 9.3. I feel upset disagree 1 neutral 2 agree 3 strongly agree 4 9.4. I am relaxed disagree 1 neutral 2 agree 3 strongly agree 4 9.5. I feel content disagree 1 neutral 2 agree 3 strongly agree 4 9.6. I am worried disagree 1 neutral 2 agree 3 strongly agree 4		
	Section 10: Antenatal Stress Questionnaire		
	During the last 6 months have you or a member of your close family been in real danger of being killed, in one of the following ways?	1By criminals 2By police, army or other 'officials' 3During political activities 4 This has not happened at all	
	During the last 6 months did you witness a violent crime (e.g. murder, robbery, assault, rape)?	1yes 2no	
	During the last 6 months have you found that you are in so much debt that you don't know how you will repay the money?	1yes 2no	
	During the last 6 months have you or your close family ever had too little money for basics, such as food, rent, and clothes?	1yes 2no	

	Have you or one of your close family not been able to find a job for more than 6 months? yes 1 no 2	1yes 2no	
	During the last 6 months have you or anyone in your close family been seriously ill? yes 1 no 2	1yes 2 no	
	During the last 6 months did any member of your close family die?	1yes 2 no	
	Is there anyone in your close family with a serious disability (e.g. epilepsy, mental retardation, deafness, blindness, mental illness)?	1yes 2 no	
	Is there anyone in your close family who has a problem with drugs or alcohol?	1yes 2 no	
	During the last 6 months have you had a break-up with your husband or partner? yes 1 no 2 2.0 During the last 6 months has your husband or partner hit or beaten you?	1yes 2 no	
	During the last 6 months have you had any serious fight or alienation from members of your family or your close neighbours?	1yes 2 no	
	During the last 6 months have you or any member of your close family been arrested, had to go to court or consulted a lawyer on a non-routine matter?	1yes 2 no	
	During the last 6 months have you given help (money, accommodation etc.) to close family or friends in need?	1yes 2 no	
	During the last 6 months have you been separated unwillingly from any of your children (excluding holidays)?	1yes 2 no	
	During the last 6 months have you experienced any problems with your other children (such as schools closing,	1yes 2no	

	failure at school, problem behaviour, drugs, etc.)?	3 No other	
	1.0. If YES, specify problem_____	_____	
	Section 11:Edinburgh Depression Scale (EPDS)		
	1.0. I have been able to laugh and see the funny side of things.4	1As much as I always could 2Not quite so much now 3Definitely not so much now 4 Not at all	
	1.2. I have looked forward with enjoyment to things.	1As much as I ever did 2Rather less than I used to 4Definitely less than I used to 4Hardly at all	
	1.3. I have blamed myself unnecessarily when things went wrong.	1Yes, most of the time 2Yes, some of the time 3Not very often 4 No, never	
	1.4. I have been anxious or worried for no good reason.	1No, not at all 2Hardly ever 3Yes, sometimes 4 Yes, very often	
	1.5. I have felt scared or panicky for not very good reason.	1Yes, quite a lot 2Yes, sometimes 3 No, not much 4No, not at all	
	1.6. Things have been getting on top of me.	1Yes, most of the time I haven't been able to cope at all 2Yes, sometimes I haven't been coping as well as usual	

		3No, most of the time I have coped quite well 4 No, I have been coping as well as ever	
	1.7. I have been so unhappy that I have had difficulty sleeping.	1Yes, most of the time 2Yes, sometimes 3Not very often 4 No, not at all	
	1.8. I have felt sad or miserable.	1Yes, most of the time 2Yes, quite often 3Not very often 4 No, not at all	
	1.9. I have been so unhappy that I have been crying.	1Yes, most of the time 2Yes, quite often 3Only occasionally 4 No, never	
	2.0. The thought of harming myself has occurred to me.	1Yes, quite often 2Sometimes 3Hardly ever 4 Never	

You have finished the questionnaire.

Do you now have any comments or questions yourself?

Comments respondent: _____

Thank you very much for your time and collaboration

Name and signature of the interviewer	
--	--

APPENDIX 10

Observation checklist

- ✓ Relationship status (is it still the same or changed)
- ✓ Where do you live (is it still the same or it has changed)
- ✓ Who do you live with (is it still the same or it has changed)
- ✓ Support(all types)
- ✓ Occupation
- ✓ Partner behavior
- ✓ Partner sexual behaviour
- ✓ Women sexual behaviour
- ✓ Condom use

HIV positive

- ✓ Disclosure – to whom
- ✓ Condom use
- ✓ Support (all types)

APPENDIX 11

27 BRYANBROOK ESTATE CNR MAIN & WITKOPPEN • PAUSHOF • 2191
PHONE +27 73 968 9232 • E-MAIL mlotshwaL@gmail.com

LANGELIHLE MLOTSHWA

OBJECTIVE

To find a challenging position in the public health or social science sphere to meet my experiences, competencies, skills, capabilities, as well as education.

MARITAL STATUS

Married

SEX

Female

DATE OF BIRTH

01 April 1986

LANGUAGES

English, IsiNdebele, Shona, IsiZulu, SiSwati

HOBBIES

Watching sports, listening to music and being a facilitator

PROFESSIONAL EXPERIENCE

Nov 2018-date **International Journal for Public Health Editorial Assistant Consultant**

1. Provide technical support for IJPH editors
2. Screen and submit all articles to editors
3. Screen and submit articles to reviewers
4. Provide feedback to authors with regard to articles
5. Provide technical support on the special issue for the journal
6. Participate in meetings with different stakeholders
7. Collaborate with the Swiss School of Public Health team and Swiss Tropical Public Health Institute team, to participate actively in internal meetings
8. Provide monthly activity reports and time sheets
9. Provide all correspondence for activities for the journal

Sep 2018-Mar2019

United Nations Development Programme (UNDP) National Consultant on Key Populations

1. To determine a programmatic and capacity gaps in Key Population (MSM)- legal gaps and advocacy opportunities for comprehensive HIV programming
2. To standardise the implementation of Paralegal services for Key Populations-(MSM);
3. To produce a National Paralegal Training and Service manual for MsM and MsM Implementing Partners

Jan 2018 and Dec 2018

Public Health Specialist Consultant

Swiss Tropical and Public Health Institute (SwissTPH)

Project: MIACSA – Maternal Immunization and Antenatal Care

service delivery Situation Analysis Project 2016-2018

1. Provide technical support analysis to project partners
2. Provide a desk review of all countries included in the MIACSA project
3. Train local assistants in data collection
4. Contribute to analysis and reporting
5. Participate in meetings with different stakeholders
6. Collaborate with the SwissTPH team and participate actively in internal meetings
7. Provide monthly activity reports and time sheets

Feb 2014-date

Researcher/PhD fellow

Swiss Tropical Health Institute (Swiss TPH)

Basel, Switzerland

Title of project: Exploring incident HIV in Pregnant Women and Sexual Risk Behaviours and Practices in Urban South Africa

1. Maintain smooth running of study
2. Provide leadership, coordination and guidance on different components of the study
3. Clear understanding of qualitative and quantitative research methods
4. Prepare and plan qualitative and quantitative interview
5. Participate in preparing, developing and reviewing qualitative and quantitative tool for data collection.
6. Participate in putting the project strategies in short and long term goals.
7. Support the implementation of study activities
8. Participate and ensuring proper training of research nurse and counsellor before engaging with participants.

9. Coordinate quality checks throughout the study to maintain high levels of quality standard of data.
10. Monitor and evaluate project as it moves to different levels.
11. Assisting in management of budgets
12. Report writing
13. Writing Standard Operating Procedure for the study.
14. Participate in planning and presenting at dissemination meetings
15. Deliver presentation at conferences
16. Tutor some Master courses

June 2011- May 2017

: **Consultant Bushbuckridge coordinator**

Global Health, Organization for Tropical Studies (OTS),
Mpumalanga, South Africa

1. Establish relationships with all home based care stakeholders.
2. Establish relationships with traditional healers association within the community.
3. Prepare and plan field visits for students within the community.
4. Lecture students in pre-university level
5. Establish quality control standards and procedure, ensuring smooth running of the programme.

March 2013-Dec 2013:

Research Reviewer

Centre for Health Policy,
University of the Witwatersrand,
School of Public Health, Johannesburg, South Africa

Title of Review: Health system interventions for improving maternal health and for reducing maternal health inequities in low- and middle- income countries: a two-stage mixed methods research synthesis.

1. Using EPPI Reviewer to download and upload articles for Mascot-Wotro systematic review project
2. Using end not to upload pdf articles for the systematic review
3. Using different electronic search engines to search for articles for the systematic review
4. Coding of articles
5. Screening abstracts for review
6. Screening articles for review
7. Writing articles for publication

February 2010-2012

:Junior Researcher

Rural and AIDS Development Action Research program,

University of the Witwatersrand, School of Public Health,
Mpumalanga, South Africa

Title of project: Care in the home study (home based care and community health workers)

1. Establish and maintain relationships with communities as well as home based care stakeholders.
2. Clear understanding of qualitative and quantitative research methods
3. Prepare and plan qualitative and quantitative interviews.
4. Participate in preparing, developing and reviewing qualitative and quantitative tool for data collection.
5. Participate in putting the project strategies in short and long goals.
6. Managing and monitoring research assistants.
7. Participate and ensuring proper training of research assistants before engaging with collection of data.
8. Coordinate quality checks throughout the study to maintain High levels of quality standard of data.
9. Monitor and evaluate project as it moves to different levels.
10. Report writing to global funders
11. Participate in planning and presenting at dissemination meetings
12. Deliver presentation at conferences
13. Lecturing 3rd year medical students engaging in the rural health block in Bushbuckridge
14. Participating in writing articles for publication

February 2009- December 2009 :Sociology Tutor
University of the Witwatersrand, Sociology
Department, Johannesburg, South Africa

1. Tutor student
2. Mark scripts for first year students
3. Invigilate tests and exams
4. Administrative responsibilities

April 2008- December 2008 :Student Assistant

North West University, Sociology Department
Mafikeng, South Africa

1. Tutor students

2. Invigilate tests and exams
3. Mark tests scripts
4. Administrative work

PROFESSIONAL QUALIFICATIONS

February 2014- Date : PhD Epidemiology

University of Basel, Switzerland

Training:

- Health Systems
- Academic writing in Health Sciences
- Culture epidemiology and practices
- The psychosocial and health consequences of forced migration
- Introduction to computing & biostatistics
- Biostatistics for Health Research
- Essentials in Health Research Methodology

December 2012

:University of the Witwatersrand, South Africa

Master in Public Health, Rural Health

1st year

Health and Society

Health measurement

Rural health care context

Approaches to Population Health

Designing Effective Public Health Programs

Management of health and health services

2nd year

Research Methods

Research Monitoring and Evaluation

Development of rural Services and Strategies

Quality Improvement in Rural Health Care

The Health of Rural people- Epidemiology and Burden of disease

3rd year

Research topic: Exploring the role of training and support received by community health workers on their experiences of providing home based care in rural South Africa, Bushbuckridge.

December 2009

:University of the Witwatersrand, South Africa
Bachelor of Arts (Honours) Development Sociology
Advanced Social Research
Sociology of Health and illness
Social Transition
Development as Ideology and Practice
HIV/AIDS in Context

December 2008

:Northwest University
Bachelor of Social Science (Cum Laude)
Majors: Psychology and Sociology
Minors: Social Work and Development Studies
Ancillaries: Population Studies, English, Research Methods,

KNOWLEDGE AND SKILLS

- Coordination of multidisciplinary teams
- Excellent oral and written communication skills
- Self-motivated, ability to work independently
- Good interpersonal skills, thus work effectively in a multidisciplinary
- Knowledge of HIV/AIDS care and treatment
- Knowledge in community based work or programs
- Knowledge in working with government from sub district level to prov level
- MS Word
- MS Excel
- Power point
- Epi info
- End Note
- EPPI reviewer
- STATA (beginner)

OTHER ACHIEVEMENTS

Tutorial certificate

Feb to May 2009

Witwatersrand University: Faculty of Humanities

Senior Bursor/ Tutor Development:

Secretary (NWUPS)

June 2008-Dec 2008

Founder and secretary of North West Psychology Association

CONFERENCES ATTENDED

University of the Western Cape, Cape Town

Community health worker Symposium,

June 2012

Durban, KwaZulu Natal

South Africa and Netherlands Research Programme on Alternatives in Development (SANPAD)

Policy briefs

May 2012

Bushbuckridge, Mpumalanga

Care in the home conference

June 2012

Johannesburg, South Africa

Health wellbeing and Families of care workshop April 2015

Anthropology Museum, University of the Witwatersrand, East Campus – Braamfontein

Bern Switzerland

Annual Conference of the Swiss Ethnological Society. SEG

November 2015

Kigali Rwanda

International Conference on Family Planning (ICFP)

November 2018

PUBLICATIONS

Mapping maternal health research in low- middle (LMIC) income countries (policy brief) (2014)

Matthew Chersich, Duane Blaauw, Francisco Becerra, AsharDhana, Mari Dumbaugh, Josephine Kavanagh, Elinor, Kern, LangelihleMlotshwa, SipiweThwala, Emily Vargas, Loveday Penn-Kekana

Exploring the perceptions and experiences of community health workers using role identity theory (2015)

LangelihleMlotshwa, Bronwyn Harris, Helen Schneider and MosaMoshabela

Local and foreign authorship of maternal health interventional research in low- and middle-income countries: systematic mapping of publications 2000–2012 (2016)

Matthew F. ChersichEmail author, Duane Blaauw, Mari Dumbaugh, Loveday Penn-Kekana, AsharDhana, SphiweThwala, Leon Bijlmakers, Emily Vargas, Elinor Kern, Francisco Becerra-Posada, Josephine Kavanagh, PriyaMannava, **LangelihleMlotshwa**, Victor Becerril-Montekio, Katharine Footman and Helen Rees

Mapping of research on maternal health interventions in low- and middle-income countries: a review of 2292 publications between 2000 and 2012 (2016)

Matthew Chersich, Duane Blaauw, Mari Dumbaugh, Loveday Penn-Kekana, SphiweThwala, Leon Bijlmakers, Emily Vargas, Elinor Kern, Josephine Kavanagh, AsharDhana, Francisco Becerra-Posada, **LangelihleMlotshwa**, Victor Becerril-Montekio, PriyaMannava, Stanley Luchters, Minh Duc Pham, AnaydaGerardaPortela, and Helen Rees

Personal support and expressions of care for pregnant women in Soweto, South Africa: a qualitative study (2017)

LangelihleMlotshwa, Sonja Merten, Lenore Manderson

Talking about sex in pregnancy: Reflections from the field in urban South Africa (2017)

LangelihleMlotshwa, Lenore Manderson, Charles Chasela Sonja Merten

Pregnant, single, and living in Soweto Johannesburg

Mlotshwa L Merten S (book chapter, in review)

Secrets and disclosure among HIV positive pregnant women in Soweto, South Africa

LangelihleMlotshwa Lenore Manderson, Charles Chasela, Sonja Merten (In review)

The roles social networks play in supporting women during pregnancy in Soweto, South Africa (in review)

Langelihle Mlotshwa Shane Norris Lenore Manderson Charles Chasela Sonja Merten

References

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Switzerland
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Medical Anthropologist
Brown University/ University of the Witwatersrand
USA/South Africa/Australia
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