

**PATTERNS OF DISCLOSURE:
AN INVESTIGATION INTO THE DYNAMICS OF DISCLOSURE
AMONG HIV-POSITIVE WOMEN IN TWO PMTCT SETTINGS IN AN URBAN
CONTEXT, KWAZULU-NATAL, SOUTH AFRICA**

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ABSTRACT

Introduction: Little guidance is given to health professionals over how to deal with HIV disclosure complexities in the biomedical setting. Given the paucity of related research in this context, there is also little consideration of the actual effect of HIV disclosure in a given context. Social constructionist theory is an important contribution to disclosure research because it shifts the focus from a biomedical perspective to one that incorporates an individual's experience with HIV infection in a specific context. The task of this study was to develop substantive theory, with the aim of providing a theoretical framework for public health and health care practitioners to better understand HIV disclosure dynamics in the PMTCT setting.

Methods: This was a qualitative study which explored the experience of disclosure amongst HIV-positive pregnant women in the PMTCT context. Between 5 June – 31 November 2008, a total of 62 participants were recruited from two urban-based PMTCT programmes located within the eThekweni District, KwaZulu-Natal, South Africa.

Results: Participants disclosed to two main groups: sexual partners, and family/others. Structural and relationship network factors shaped transmission risk behaviour, subsequent disclosure behaviour and outcomes. The circumstances which placed participants at risk for HIV acquisition also affected the likelihood of disclosure and health behaviour change. HIV and pregnancy diagnoses often occurred concurrently which profoundly impacted on participant's social identities and disclosure behaviour. Current HIV testing protocols within PMTCT settings often recommend disclosure to sexual partners under the assumption that couples will engage in safer behaviours, yet findings from this study indicate that this assumption should be challenged.

Discussion: The study findings are synthesized in a conceptual model which offers substantive new theory over the concepts and interrelated factors that were identified to shape HIV disclosure and outcomes in the PMTCT context. The model identifies the following domains: 1) social networks and social support; 2) identity; 3) risk behaviour; 4) HIV and pregnancy diagnoses; and 5) HIV disclosure process to partners and others.

Recommendations: Assumed pathways to risk reduction and HIV prevention need to be relooked and reconsidered. The conceptual model provides a proposed framework for future research, intervention design and implementation planning in the PMTCT setting.

DECLARATION

I, Tamaryn Lee Crankshaw, declare that

- (i) The research reported in this dissertation, except where otherwise indicated, is my original work.
- (ii) This dissertation has not been submitted for any degree or examination at any other university.
- (iii) This dissertation does not contain other person's data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
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DEDICATION

This work is dedicated to the strong and inspiring women in my life.

To my mother who always believed this was possible and who taught me to never settle for less.

To Pam Askew, Anne Mackay, Samantha Masters, Eleanor Preston-Whyte and Fiona Scorgie – thank you.

In particular, thanks to my husband, Neal, who continues to challenge all gender preconceptions and who managed our very demanding domestic life in support of my long work hours. I salute you.

To my two beautiful daughters, Michaela and Katherine, be sure to realize your potential and don't let anyone or anything hold you back.

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ACRONYMS AND ABBREVIATIONS

Abbreviation	Definition
AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Treatment
ARV	Antiretroviral
AZT	Zidovudine
CAPRISA	Centre for the AIDS Programme of Research in South Africa
CBM	Communication Boundary Management
CDC	Centers for Disease Control and Prevention
CD4	T-lymphocyte count
DHS	Demographic and Health Survey
DOH	Department of Health
HAART	Highly Active Antiretroviral Treatment
HCP	Health Care Providers
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HPCSA	Health Professions Council of South Africa
KZN	KwaZulu-Natal
MCWH	Maternal, Child and Women's Health
MTCT	Mother-to-Child Transmission
NGO	Non Governmental Organization
NVP	Nevirapine
PCR	Polymerase Chain Reaction
PCRS	Partner Counselling and Referral Services
PMTCT	Prevention of Mother-to-Child Transmission
SA	South Africa
SAMA	South African Medical Association
TAC	Treatment Action Campaign
UNAIDS	Joint United Nations Programme on HIV and AIDS
US	United States
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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CHAPTER 1: INTRODUCTION

1.1 THE GLOBAL PUBLIC HEALTH RESPONSE TO HIV/AIDS

HIV-related behavioural interventions have historically been rooted in the highly individualistic frameworks emanating from the psychological and biomedical traditions, which were amongst the first to formulate a comprehensive response to the HIV and AIDS crisis (Hoosen & Collins, 2004; R. Parker, 2001). The reasoning underlying the early risk reduction efforts simplistically assumed that basic information and advice would be enough to catalyze the required behaviour change (R. Parker, 2001). However, as the HIV epidemic continued unchecked, it became increasingly apparent that the complex social matrix within which the individual was located also strongly shaped risk behaviour (Hoosen et al., 2004; R. Parker, 2001). This resulted in a call for the adoption of a multidimensional approach to all HIV prevention intervention planning (Hoosen et al., 2004; R. Parker, 2001). The proposed multidimensional approach shifted the focus of study from behaviour *per se* to include the socio-cultural setting within which the behaviour occurred (Hoosen et al., 2004; R. Parker, 2001).

Although the broader field of international public health reflects this progress, the recognition of the need for a multidimensional approach is relatively recent and generally not yet filtered into mainstream public health in practice. The original public health intervention models and paradigms in the HIV prevention and treatment arena continue to prevail, particularly in resource-constrained country settings like South Africa. One clear area where these outdated models still predominate is in public health interventions located in the biomedical context. From a public health perspective, risk reduction (i.e. reducing vulnerability to HIV acquisition) and primary prevention (i.e. preventing new cases of HIV acquisition) are vital in curbing the HIV pandemic and HIV disclosure is seen as a critical step towards this end.

1.2 HIV/AIDS AND GENDER IN THE SOUTH AFRICAN CONTEXT

Sub-Saharan Africa is home to 67% of all people living with HIV (UNAIDS, 2009). Of these individuals, women are the worst affected. Sixty percent of all HIV-infected people in sub-Saharan Africa are women. Women are significantly more vulnerable, both biologically and socioeconomically, to acquiring HIV. In a 2008 survey conducted in South Africa, females between the ages of 20 and 24 years were found to be four times more likely to be HIV-infected than males (Shishana, Rehle, Simbayi et al., 2009). Because of female sexual anatomy as well as the presence of prevalent sexually transmitted co-infections, male transmission to females is likely to be three to five times higher than female to male transmission (Strebel, 1995). In addition, there is growing evidence that the routinely under-diagnosed gynecological complaints of bacterial vaginosis and common vaginal yeast infection can, in fact, increase the risk of HIV transmission (Myer, Denny, Telerant et al., 2005; Rebbapragada, Howe, Wachihhi et al., 2008; van de Wijgert, Morrison, Cornelisse et al., 2008).

Southern Africa is at the epicenter of the global HIV pandemic. In the South African 2008 National HIV Prevalence and Syphilis Survey (Department of Health, 2009), at least 29.3% of antenatal attendees were HIV-infected with the highest prevalence occurring in women in the 25 to 34 year age group. KwaZulu-Natal, home to 20% of the South African population, has an extremely high antenatal HIV prevalence of 38.7% (Department of Health, 2009). The HIV prevalence in Ethekwini, the district within which the study was carried out, is 40.3% (Department of Health, 2009).

Gender inequality plays out in pivotal ways in South Africa. More men than women have access to economic opportunity which means that women are often financially reliant on their male partners. In a country where at least 25.3% of the population are unemployed (Statistics South Africa, 2010) this has far reaching effect since financial resource shifts power into the hands of men which allows them to exercise greater choice in relationship matters (Wingood & DiClemente, 1998). Together with deeply rooted patriarchal structures and very high rates of gender-based violence (Dunkle, Jewkes, Brown et al., 2004b; Dunkle, Jewkes,

Brown et al., 2004a; Jewkes & Abrahams, 2002a; Jewkes, Levin & Penn-Kekanaa, 2002b), a woman's ability to exercise autonomy within her sexual relationships is often severely constrained.

1.3 PARTNER NOTIFICATION STRATEGIES

Partner notification is a common component of many public health strategies and is a legal obligation in many countries in the developed world. According to the CDC Partner Counselling and Referral Services (PCRS) Guidelines (CDC, 1998):

“...the provider must assist clients in understanding their responsibility, if their HIV test results are positive, for ensuring that their partners are informed of their possible exposure, and referring those partners to HIV prevention counseling [sic], testing, and other support services.”

In the late 1980's and early 1990's, laws were implemented in the various states within the United States (US) which criminalized failure to disclose one's HIV status to a sexual partner (AIDSMap, 2010). Twenty-three of these states currently have laws in place which can result in a prison sentence if an HIV-infected individual has sexual relations with another without first disclosing his/her status (AIDSMap, 2010). With the United States experiencing a mature HIV epidemic well before sub-Saharan Africa and with considerably more public health expertise at hand, risk reduction and HIV prevention models were predominantly US-based with a US population in mind. In particular, the population to whom these early interventions were targeted were male-to-male sexual relationships since this was where the first cases of HIV-infection were being identified. The HIV epidemic later experienced in sub-Saharan Africa differed completely in character to the localized US epidemic since it was located amongst the general heterosexual population and in a context with vast gender disparities.

In the absence of alternative evidence, the idea of partner notification as a key step to the successful implementation of prevention activities has guided all US government-funded HIV programmes in the developing world and has permeated the mainstream approach to HIV-related

counselling services. Imported directly from the well-resourced US public health repertoire, the emphasis on HIV disclosure is rarely challenged. This has resulted in little critical engagement in terms of how disclosure dynamics *actually* manifests on an interpersonal level in the local South African context.

In 1999, the South African Department of Health published draft regulations relating to communicable diseases and the notification of notifiable medical conditions (The AIDS Law Project and the AIDS Legal Network, 1997). The document specified that if a health care worker diagnosed a person with HIV, the family and/or care-givers should also be notified. The proposed law never proceeded beyond the draft phase and is thus not currently being followed or enforced (The AIDS Law Project and the AIDS Legal Network, 1997). The South African National Policy on HIV Testing Guidelines (Department of Health, 2000), recommends that the party at risk should be informed and this has predominantly provided the general rule of thumb for adult HIV case management in the country's various health care facilities. These guidelines remain uncontested despite revised guidelines issued by WHO (2006) which allows for gendered sensitivities and nuance. In addition, the earlier WHO (1995) and UNAIDS (2000) guidelines were both careful to point out that women and children should be viewed as a particularly vulnerable population who often suffer extremely negative consequences to disclosure, such as abandonment or physical violence. In these cases, disclosure is not considered viable. Similarly, in the 1996 South African Constitution (Section 28)¹ pertaining to children, it specifies that in the case of a mother/child pair, if the decision to disclose to the partner is not in the best interest of the child, then the mother should not disclose her status if she does not wish to.

Partner notification strategies come into effect in the medical context since this is one of the places where people will undergo an HIV test or seek HIV-related care. The Health Professions Council of South Africa (HPCSA) (2002:5) states that:

¹ <http://www.info.gov.za/documents/constitution/index.htm> (Accessed on 26 October 2010).

“Health care practitioners should try to encourage their HIV positive [sic] patients to disclose their status to their sexual partners so as to encourage them to undergo VCT [Voluntary Counselling and Testing] and access treatment if necessary. This is consistent with good clinical practice”.

According to these HPCSA guidelines (2008), should the patient refuse to make the recommended disclosure, the health care provider then needs to make a decision on ethical grounds as to whether or not to reveal their patient’s status to the person at risk. The following steps are recommended (Health Professions Council of South Africa (HPCSA), 2002:5):

9.2.1 Counsel the patient on the importance of disclosing to his or her sexual partner and for taking other measures to prevent HIV transmission.

9.2.2 Provide support to the patient to make the disclosure.

9.3.3 If the patient still refuses to disclose his or her HIV status or refuses to consider other measures to prevent infection, counsel the patient on the health care practitioner’s ethical obligation to disclose such information.

9.3.4 If the patient still refuses, disclose information on the patient’s HIV status to the sexual partner and assist them to undergo VCT and access treatment if necessary.

9.2.5 After disclosure, follow up with the patient and the patient’s partner to see if disclosure has resulted in adverse consequences or violence for the patient, and if so, intervene to assist the patient appropriately.

The South African Medical Association (SAMA) (2006) HIV/AIDS Guidelines reinforce the principle of patient confidentiality (although admit to prevailing ambiguity over the precise bounds of patient confidentiality) and recommend that the patient should generally be consulted about disclosing their HIV status to sexual partners.

South African law provides no clear guidance in respect to disclosure of one’s own or another’s HIV status to another party. There is currently no statute that compels a health care professional (HCP) to disclose a patient’s HIV status to a spouse/sexual partner should the patient refuse

(Professor J. Singh, Head: Bioethics Programme, CAPRISA, *pers comm.*). There is also no legal protection for health care providers should they be sued for disclosing someone else's status, including but not restricted to the person at risk. The legal implications of a breach of confidentiality could result in civil action by the patient on the basis of invasion of privacy or breach of contract (The AIDS Law Project and the AIDS Legal Network, 1997). Alternatively, the health care provider could be sued by the sexual partner for not informing them that they were at risk of HIV (The AIDS Law Project and the AIDS Legal Network, 1997). However, it is unlikely that the courts would award this civil claim, since this would set up the precedent that health care providers be ultimately responsible for informing all sexual partners of all HIV-infected patients (The AIDS Law Project and the AIDS Legal Network, 1997).

Health care providers are left in an unenviable position. The absence of any clear medico-legal direction regarding how to handle HIV-related disclosure in the South African setting poses much uncertainty and ethical tension for health care professionals providing HIV services. While South African health care providers have a variety of different guidelines from which they can draw advice, the burden of decision-making responsibility ultimately rests on their shoulders. Lack of locally derived evidence regarding the application and impact of disclosure in different medical settings amongst different patient populations further complicates the picture.

1.4 THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION (PMTCT) CONTEXT

Close to 90% of the 370 000 children under the age of 15 who are infected with AIDS globally live in sub-Saharan Africa; most of these children acquired the virus during pregnancy (*in utero*), at birth (*peripartum*) or while being breastfed (UNAIDS, 2009). These are all forms of HIV transmission that can be prevented through the prevention of mother-to-child transmission (PMTCT) intervention. In the absence of the PMTCT intervention, approximately 34% children may acquire HIV via vertical transmission by 18 months of age (Bobat, Coovadia, Coutsooudis & Moodley, 1996).

Since the beginning of the 1990's, the South African government's response to HIV and AIDS has been marked by controversy and turmoil (Chigwedere, Seage, Gruskin et al., 2008; van der Vliet, 2001).² The prevention of mother-to-child transmission intervention has been no less fraught (Chigwedere et al., 2008). Despite international evidence demonstrating the effectiveness of the PMTCT intervention, the South African government for years resisted providing PMTCT prophylaxis to HIV-infected women and cloaked this resistance in a "discourse of unaffordability" (Nattrass, 2004:47). It has been estimated that between 2000 and 2005, 35 000 babies acquired HIV through vertical transmission in South Africa because no PMTCT programme was put into place to prevent this (Chigwedere et al., 2008).

In a landmark case in 2001, the Treatment Action Campaign (TAC) took the South African government to the Constitutional Court to legally enforce the implementation of Nevirapine in the public health sector (Minister of Health v Treatment Action Campaign (TAC) 2002). The court ruling stated that the:

"Government is ordered without delay to ... [r]emove the restrictions that prevent nevirapine from being made available for the purpose of reducing the risk of mother-to-child transmission of HIV at public hospitals and clinics that are not research and training sites." (Constitutional Court Judgement in Minister of Health and Others v TAC and Others, 5 July 2002)

As a direct result of this court judgement, a national programme was launched in August 2003 but with no real resolve or accountability. There are, to date, no reliable data on the efficacy and coverage of this intervention (Meyers, Moultrie, Sherman et al., 2006).

In 2004, the Medicines Control Council recommended a dual therapy regimen (Zidovudine and Nevirapine) rather than single dose Nevirapine for prevention of mother-to-child transmission. There was also substantial pressure from health care workers, scientists and activists to update

² Virginia van der Vliet writes a very comprehensive and interesting account of the South African government's original response to HIV/AIDS.

the original regimen since there were serious concerns about Nevirapine-based drug resistance and the dual regimen had also been shown to be more effective in preventing HIV transmission. This recommendation was resisted by the South African Department of Health. In August 2007, the AIDS Law Project based at the University of Witwatersrand, Gauteng, petitioned the Health Minister on behalf of the Southern African HIV/AIDS Clinicians' Society and the Treatment Action Campaign to update the PMTCT treatment regimen in line with international expert recommendations. On 11 February 2008, the South African Department of Health published new guidelines, which at the time of the study formed the current treatment protocols for PMTCT. These guidelines, which had not been updated since 2003, now included dual therapy from 28 weeks for all HIV-infected pregnant women and Nevirapine and Zidovudine prophylaxis for the infant.

In April 2010, the Department of Health issued new comprehensive and progressive National PMTCT guidelines allowing HIV-infected pregnant women with a higher CD4 (<350) to access HAART for life and initiating dual therapy for all pregnant women with a CD4>350 at 14 weeks gestation (Department of Health, 2010).

While PMTCT services are now widely available in the province of KwaZulu-Natal³, many women continue to access antenatal care late in their pregnancy and do not benefit from basic antenatal care or the full potential effects of the PMTCT intervention (KZN PMTCT NGO Stakeholder's Meeting 23/01/09, Nelson R. Mandela Medical School, UKZN, *pers comm.*). Under one half (45%) of pregnant women attended at least four antenatal visits during their pregnancy in 2008 and only 32% of pregnant women accessed antenatal care before 20 weeks gestation (KZN PMTCT NGO Stakeholder's Meeting 23/01/09, Nelson R. Mandela Medical School, UKZN, *pers comm.*). In addition to this, KwaZulu-Natal's PMTCT programme has been crippled by the poor implementation of the dual therapy roll out and by the lack of integration of Maternal, Child and Women's Health (MCWH) services with PMTCT services. The known vertical transmission rate in KwaZulu-Natal is 19% but in all likelihood it is double this figure

³ 97% of KwaZulu-Natal public sector health facilities offered PMTCT services by the beginning of 2009.

(KZN PMTCT NGO Stakeholder's Meeting 23/01/09, Nelson R. Mandela Medical School, UKZN, *pers comm.*).

Historically, the PMTCT programme has had the very immediate focus of prevention of HIV transmission to the child. There has been very little focus on the health and well being of the mother and the long term outcomes of both mother and child. In the 2008 Children and AIDS Third Stocktaking Report, there was a call for a strategic shift from this thinking to include long term improvement of maternal and child survival (UNICEF, 2008). This marked an important move in the way that PMTCT programmes are to be conceptualized and helps shift the focus to the complexities in these women's lives and the obstacles these complexities may pose.

1.5 STATEMENT OF THE PROBLEM

With the focus on the difficulties surrounding the implementation of the PMTCT programme in South Africa, little attention has been paid to the success of strategies aimed at risk reduction or behaviour change. In South Africa, HIV disclosure to partners (and family) receives particular emphasis in the Prevention of Mother-to-Child Transmission (PMTCT) programme, not only for HIV prevention purposes but also to support treatment adherence and infant feeding practices (Department of Health, 2010).

Preliminary findings from unpublished research⁴ in which I was involved, explored the experiences of disclosure amongst HIV-infected women in general. The study findings indicated that additional research needed to be conducted in the PMTCT context since women accessing this programme appeared to experience far greater social complexities as compared to participants who were accessing a general ARV treatment clinic. In addition, the findings revealed that there was strong clinic programme emphasis on the subject of HIV disclosure to one's sexual partner. Partners were a regular topic of conversation in the interviews for this

⁴ Preston-Whyte, E.M. (PI). Partnerships for HIV/AIDS Research in KwaZulu-Natal, Substudy 1: Clinical ethnography: Mothers, Children, Caregivers and Community (E022/03).

group. However, in the general ART clinic responses, partners were not the primary focus either in terms of immediate HIV experiences or future outlook.

The above preliminary findings revealed key thematic areas which needed to be systematically explored and which formed the basis for the dissertation research. It is for this reason that the research focus is specifically on the PMTCT clinic context. The study also sets out to challenge uncritical adherence to outdated public health paradigms, models and frameworks in relation to HIV disclosure in the PMTCT clinic context, which undercut the progress made by the broader field of public health.

1.5.1 RESEARCH QUESTIONS

The primary research question is:

Under what circumstances, how and to whom do HIV-positive pregnant women receiving PMTCT services disclose their status and what are the consequences?

The specific research questions are:

1. What are the factors that influence disclosure amongst HIV-infected pregnant women?
2. What are the factors that influence non-disclosure amongst HIV-infected pregnant women?
3. What are the ways in which HIV-infected pregnant women navigate the disclosure process and to what effect?
4. To whom do HIV-infected pregnant women choose to disclose their HIV status, and:
 - 4.1. What are the reasons for the particular person;
 - 4.2. What are the methods of disclosure to the particular person;
 - 4.3. What are the consequences of disclosure to the particular person?
5. To what extent are HIV-infected pregnant women able to make autonomous decisions within their sexual relationships?
6. What is the relationship between pregnancy and HIV disclosure?

1.6 PURPOSE OF THE RESEARCH

Examining the problem from a social constructionist theoretical perspective, the task of this study is to explore the dynamics of HIV disclosure amongst HIV-infected pregnant women in the urban PMTCT clinical context in Kwazulu-Natal, South Africa.

The specific objective of the study is to generate substantive new theory regarding the dynamics of HIV disclosure in the PMTCT setting with a view to providing recommendations and proposing a conceptual model which encapsulates the critical concepts involved in HIV disclosure in this setting, as well as reflecting the dynamic relationship between the various thematic domains. The conceptual model is intended to provide a proposed framework for elaboration and revision by future research, intervention design and implementation planning in the PMTCT setting.

1.7 ORGANIZATION OF THE REPORT

This dissertation is divided into six chapters.

Chapter one provides an overview of the issues surrounding HIV disclosure and the PMTCT programme in South Africa, both in the public health and medical setting. This chapter also outlines the research questions, main objectives and the purpose of this study.

Chapter two presents the body of knowledge related to HIV disclosure in general and in the PMTCT setting in particular. Furthermore, existing models of HIV disclosure are discussed.

Chapter three provides a description of the study's theoretical and methodological framework. The study design, study population, sampling and analytical methods are further explored in this

chapter. The data management and mechanisms to assure study quality, credibility and trustworthiness, as well as the ethical considerations are also presented.

Chapter four presents the research findings which are organized into three overarching themes. Supporting data are drawn directly from the study transcripts.

Chapter five focuses on the discussion of the study findings, locating these findings in the existing literature and using this existing body of knowledge to help explain the findings.

Chapter six provides recommendations and conclusions based on the study findings. These recommendations are illustrated in a proposed conceptual model as a basis for understanding HIV disclosure dynamics in the PMTCT setting.

CHAPTER 2: LITERATURE REVIEW

The aim of the literature review was to gain a broad overview of the theoretical contribution previously made regarding HIV disclosure in general, and in a PMTCT context specifically. The concept of disclosure, as studied across different disciplines, was explored. Any existing explanatory models used to describe disclosure behaviour were also reviewed.

A systematic literature review was conducted using PubMed and Google Scholar to identify and access relevant articles. A notification alert was set up based on the search criteria. The search terms were as follows: „HIV’ AND „disclosure’ with the following limiters activated: English; core clinical journals; nursing journals; AIDS; all adult 19+. No limiters were set on time periods. Out of 2781 articles found using the above search criteria, 107 were selected for further review.

EndNote 9 was used for reference management and the Harvard referencing style was followed.

This chapter presents the prevailing literature surrounding HIV-related disclosure. Given the broadness of the topic, the literature has been organized around the following core themes. First, an overview of the various descriptions of HIV disclosure is presented, specifically how disclosure has been framed in the literature to date. Second, the main predictors that have been identified as shaping disclosure behaviour are outlined. Third, evidence is summarized regarding the consequences or outcomes of disclosure. Fourth, a synthesis of the rates of disclosure is presented. The literature review is concluded with an overview of the existing models or theories for understanding disclosure.

2.1 FRAMING HIV DISCLOSURE

Comparatively few disclosure-related studies have been conducted in sub-Saharan Africa, home to over two-thirds of people living with HIV and AIDS (Medley, Garcia-Moreno, McGill & Maman, 2004). Studies that have been carried out in African settings tend to reflect the narrow,

clinically-oriented biomedical and behavioural paradigms in which disclosure is viewed unproblematically as a discrete phenomenon. Quantitative methods largely dictate the study designs surrounding disclosure-related research, particularly in the psychological and public health arena (Derlega, Winstead, Greene et al., 2004; Greene & Serovich, 1996; Holt, Court, Vedhara et al., 1998; Maman, Mbwapo, Hogan et al., 2003; Medley et al., 2004; Omarzu, 2000; Serovich, 2001). For most in public health, and for those providing clinical care, a particularly instrumental view of the purpose served by disclosure of HIV serostatus dominates. Within the instrumental view, disclosure enables certain public health gains to be made. Specifically, because partners of the index individual are at direct risk of becoming HIV-infected, there is some urgency about consulting them about the need to be tested and/or bringing them into care. Additionally, gaining access to the partner or family has further implications for ensuring the health of the HIV-infected individual, since it has been found that partners and families have an important role to play in providing support, whether emotional or otherwise, during antiretroviral treatment (Grinstead, Gregorich, Choi et al., 2001; King, Katuntu, Lifshay et al., 2008; Pennebaker, Colder & Sharp, 1990).

Considered in instrumentalist terms, and partly because of choice of methodology, disclosure is generally assigned a dichotomous status: either one has disclosed or one has not. The literature sharing the findings of quantitative research echoes this assumption. However, approaching disclosure from only this dualistic perspective carries serious implications in terms of research, practice and patient experience. The narrow perspective ignores the complex social context in which HIV-infected individuals engage. In a study conducted in the South African setting, Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo (2007) draw attention to the fact that the use of a dichotomous measure for disclosure cannot encapsulate the multiple layering of the issues surrounding the disclosure process. The authors recommend that future studies should pay closer attention to the “broader range of behaviours of HIV disclosure” (Simbayi et al., 2007:33).

In practice, disclosure behaviour is an ongoing, and perhaps more commonly, incremental and iterative journey that is navigated by the majority of HIV-infected individuals within their personal lives (Antelman, 2001; DeMatteo, Goldie, King & Wells, 2002; Holt et al., 1998; MacNeil, Mberesero & Kilonzo, 1999; Norman, Chopra & Kadiyala, 2005; Seidel, Sewpaul &

Dano, 2000; van der Straten, King, Grinstead et al., 1995). While descriptions of disclosure have varied widely (Varga, Sherman & Jones, 2005), a common feature is that disclosure is, more often than not, a deliberate and considered action. Most commonly, disclosure is described as a „selective’ and rational process in which individuals weigh benefits against risks before deciding whether to reveal their serostatus to others (Armistead, Morse, Forehand et al., 1999; Black & Miles, 2002; Hays, McKusick, Pollack et al., 1993; Kalichmann, DiMarco, Austin et al., 2003; Moneyham, Seals, Demi et al., 1996; Serovich, 2001; Serovich, Craft & Yoon, 2007; Simoni, Demas, Mason et al., 2000; Simoni, Mason, Marks et al., 1995; Sowell, Lowenstein, Moneyham et al., 1997; Sowell, Seals, Phillips & Julious, 2003; Stirrat, Remien, Smith et al., 2006; Visser, Neufeld, de Villiers et al., 2008). Sowell et al (1997) found that their study participants based the decision to disclose on three considered criteria: the character of the relationship to the person, the relationship quality and the perceived ability of the person to hold the information confidential.

Disclosure has, perhaps more descriptively, been presented as a strategic behaviour (Almeleh, 2006; Derlega et al., 2004; Greene et al., 1996; Holt et al., 1998; Omarzu, 2000; Petronio, 1991; Serovich, 2001). Black and Miles (2002) present a model that emphasizes the inherently strategic nature of disclosure. These authors discuss a “calculus of disclosure” (Black & Miles, 2002:691) which describes the careful and ordered disclosure process that study participants engaged in when ascertaining to whom, and to what degree, they should disclose. Drawing on the risk-benefit evaluation of disclosure, South African researchers have recently coined the term „strategic disclosure’ (Brandt, 2005; Brandt, Dawes & Bray, 2006; Swartz, Brandt, Dawes et al., 2005) in an effort to describe disclosure communication which preserves “the „private good’ [of]... individual[s]...living with HIV, if at the expense of what service providers and policy makers would term the „public good’ of disclosure” (Brandt, 2005:22). Here, „strategic disclosure’ is a reference to the way in which individuals, in a unique manner, negotiate disclosure (and indeed non-disclosure) within a context of pervasive stigma, in an effort to reduce personal risk and to order the social environment in a way that prioritizes own welfare (Brandt, 2005; Brandt et al., 2006; Swartz et al., 2005). Non disclosure is also considered to be strategic, since it allows individuals to exert some sort of control over the immediate environment through avoiding the anxiety over unknown reactions from others (Holt et al., 1998;

Swartz et al., 2005). Delayed disclosure, that is, disclosure that does not immediately occur but which is later communicated, falls into the description of „strategic disclosure’ since this method allows individuals some measure of control over various disclosures. Niccolai, D'Entremont, Pritchett and Wagner (2006) found delayed disclosure to be prevalent in their study, which helps underline the difficulties individuals encounter with disclosure and the role of the passage of time in terms of facilitating the disclosure process. Above all, disclosure is a “dyadic event” (Serovich, Lim & Mason, 2008:228) since it always occurs between at least two people.

While the above formulations emphasize the deliberate nature of disclosure, the manner in which individuals disclose, in fact, varies widely. Varga et al. (2005) describe direct and indirect/passive ways of voluntarily disclosing: direct disclosure refers to direct, usually verbal, announcements of serostatus to another (Derlega et al., 2004; Greef, Phetlhu, Makoae et al., 2008); indirect disclosure refers to nonverbal or indirect routes of communication (such as hints and innuendoes) to disclose one’s status (King et al., 2008). Suspicion about one’s HIV status can be aroused by sudden behaviour change or clue giving, such as ceasing sexual activity with sex partners, or insisting on condom use with a partner with whom one has generally had unprotected sex. Showing strong interest in HIV-related topics in the media or in conversation is another example of nonverbal disclosures cited in the literature (DeMatteo et al., 2002; Klitzman & Bayer, 2003). In contrast to these voluntary disclosure events, are those in which disclosure is distinctly involuntarily (Greef et al., 2008). This occurs when confidentiality is broken, when one is unable to conceal symptoms known to be AIDS-associated, such as rapid weight loss or shingles, or when one is observed attending an HIV-related treatment facility or any other kind of HIV service setting.

Treatment fits into each of these disclosure systems and scenarios in complex ways. Intentional, active disclosure may have a positive effect on treatment adherence but if the reaction to one’s disclosure is negative it may just as easily result in unanticipated stress or more severe consequences that will compromise medication adherence. Treatment side effects may also present a new set of visible cues those familiar with ARV treatment will be able to identify. One study has reported research participants who were reluctant to take ARVs for fear of this form of disclosure (Klitzman et al., 2003).

Whatever the mode and method of disclosure, it is clear that individual resources and the social and physical environment play a critical role in the different forms of disclosure, which may vary substantially for reasons beyond the individual's control. Not only is disclosure a highly complex and nuanced process, but it is also an emotionally charged act with potentially profound positive or negative consequences.

2.2 PREDICTORS OF HIV DISCLOSURE

The process of disclosure decision-making is determined by multiple factors and social contexts. The most significant predictors of disclosure are the gender of the discloser, the category of intended disclosure recipient (family, sexual partner, friend), and the social and medical contexts of care in which the individual is located. Disease progression and antiretroviral treatment have also been proposed as predictors to disclosure. Predictors of non disclosure include anticipated negative response, absence or presence of social support, age and serodiscordancy between couples.

2.2.1 GENDER AND DISCLOSURE

The tendency of research to approach the study of disclosure as a “series of discrete patient-initiated events ...ask[ing] about the consequences of that event” has been criticized because this approach ignores the broader dimensions to disclosure which have a potentially profound impact on women's lives (Gielen, McDonnell, Burke & O'Campo, 2000:112). These broader dimensions include gender inequities, the socioeconomic milieu, and specific country cultural context. Niccolai et al. (2006) also call for the need to explore sex differences in disclosure. While a large body of disclosure-related work has already been conducted, much of it concerns disclosure amongst same sex, male-to-male relationships and, to a lesser extent, African-American women in a developed world context (Armistead et al., 1999; Derlega et al., 2004; Holt et al., 1998; Ostrom, Serovich, Lim & Mason, 2006). Comparatively fewer studies focus

solely on the disclosure experience of females with a view to differing gendered responses and issues surrounding HIV disclosure (for instances of studies which do focus on women specifically see: Serovich et al. (2007); Siegel, Lekas & Schrimshaw (2005)).

There has been little investigation on the disclosure experience of HIV-infected women in South Africa (Iwelunmor, Zungu & Airhihenbuwa, 2010). Brandt (2005), Doherty, Chopra, Nkonki, Jackson and Greiner (2006), Norman et al. (2005), and Varga et al. (2005) provide examples of South African-based disclosure research. Many women in developing countries are vulnerable on a social, economic and/or physical level and disclosure strategies developed in the first world are often not appropriate, especially considering that disclosure communication is, amongst other issues, intended to mediate sexual risk. Little consideration is given to the gendered nature of sexual relationships and the associated power differentials. Instead, disclosure is simplistically assumed by many public health practitioners and health care professionals to be a strategy to reduce risky sexual behaviour regardless of the gender of the discloser. Negotiation of sexual behavior assumes shared power relations between men and women, which in a developing world context, often does not exist (Hoosen et al., 2004; Strebel & Lindegger, 1998). The implicit assumption underlying disclosure is that the index individual would prioritize her health and engage in associated discussions and behavioural precautions. The assumption is overly simplistic since matters of health are not the only item under scrutiny. Disclosure of HIV status engages an individual in dialogue with another over shared sexual behaviour and practices, the dynamics of which are considerably more complex than any other health-related behaviour (Kelly & Kalichman, 1995). Given this complexity, there in fact exists the likely possibility that the assumed health priorities catalyzed by the act of disclosure are, in fact, subordinated to more immediately relevant relational concerns (Morrill & Noland, 2006). This is especially true in a context characterized by material lack, high rates of unemployment and gender-based violence.

Research across the globe has found that poverty and patriarchally-based societies are key determinants of intimate partner violence (Jewkes, 2002). In the context of poverty, economic inequality creates unequal power relations between men and women. Men are afforded greater decision-making power, and women have little room for autonomy or negotiation within the relationship. Similarly, patriarchal societies reinforce cultural expectations as to what constitutes

“good womanhood” (Jewkes, 2002:1425). The risk of violent conflict is high if women are perceived to overstep conservative norms surrounding gender roles or are seen to challenge male authority and privileges (Jewkes, 2002). Recourse to financial resource, should this be a possibility for a woman, is one of the main sources of conflict (Jewkes, 2002). In countries where political conflict has historically been resolved through violence, as is the case with South Africa, a normalized view of violence pervades the social context (Jewkes, 2002).

Sexual coercion and gender-based violence have been found to be highly prevalent in South Africa (Dunkle et al., 2004b; Dunkle et al., 2004a; Jewkes et al., 2002a). Maharaj and Munthre (2007) found that 46% of their study participants, who were all young females, had experienced coercion at the time of their first sexual experience. Significantly, it was found that this group of women were also more likely to have a greater number of sexual partners and to have less control over subsequent sexual interactions. These findings support other research conducted in this area (Koenig & Moore, 2000). Dunkle et al. (2004a) found that coerced first intercourse was associated with the increased likelihood of women experiencing physical or sexual partner violence. Additionally, women who have experienced sexual partner violence or who have controlling partners are at significantly increased risk for acquiring HIV infection (Dunkle et al., 2004b). This context of violence needs to be taken into account in the development of interventions for women who are already HIV-infected. That is, an HIV-infected woman may have a predisposing history of and/or be currently experiencing sexual/physical abuse, which must be factored into public health policies encouraging disclosure to intimate partners. Importantly, it has been found that strong social support for women has a potentially protective effect against partner violence (Jewkes, 2002).

2.2.2 DISCLOSURE RECIPIENTS

The nature of the relationship between the discloser and disclosee is a pivotal determinant in the disclosure decision-making process (Derlega et al., 2004; Greene et al., 1996; Petronio, 1991, 2000). Women are most likely to disclose to their sexual partners, mothers, and sisters before others (Armistead et al., 1999; Fekete, Antoni, Duran et al., 2009; Kalichmann et al., 2003).

Disclosure to sexual partners

Disclosure to sexual partners has been described as “conceptually complex” since disclosure can be alternatively viewed as a moral imperative, constructive health behaviour, or legal obligation (Duru, Collins, Ciccarone et al., 2006:498). Given the predominantly sexual mode of HIV transmission in developing countries, there is particular emphasis on disclosure to sexual partners, especially when an HIV-infected person is being counselled by a health care professional (Gielen et al., 2000). The intention behind the counsel is to advise the partner of their inherent risk and to encourage them to also seek health care. While disclosure to one’s greater social network is an inherently emotionally charged act, HIV disclosure to one’s intimate partner embodies difficult dynamics with far-reaching implications (DeMatteo et al., 2002; Derlega et al., 2004; Serovich, 2001). Kalichman and Nachimson (1999) found that females tended to experience more difficulties disclosing to their sexual partners than did males. Despite this, many studies have found that women were most likely to have disclosed their status to spouses or sexual partners than to others (Rice, Comulada, Green et al., 2009; Simoni et al., 1995; Sowell et al., 2003).

The nature of the sexual relationship is an important determinant of disclosure to sex partners (Brou, Djohan, Becquet et al., 2007; Desgrées du Loû, 2005; Duru et al., 2006). The nature of the sexual relationship is independently associated with participant characteristics (Duru et al., 2006). Disclosure is more likely to occur in monogamous sexual relationships (Duru et al., 2006; Klitzman et al., 2003; Marks, Bundek, Richardson et al., 1992; Niccolai, Dorst, Myers & Kissinger, 1999). Women living together with their partners are also more likely to share their HIV test result (Brou et al., 2007; Semrau, Kuhn, Vwalika et al., 2005) although frequency of contact and physical proximity were not associated with disclosure in another study (Serovich et al., 2007). Alternative living arrangements, such as polygamous households, shared households and not living with one’s partner have been found to decrease the likelihood of disclosure (Brou et al., 2007; Semrau et al., 2005). The length of duration of the relationship has also been positively associated with the likelihood of disclosure (Duru et al., 2006).

Concurrent sexual partnerships, which have been suggested to be the key driver in the HIV epidemic in sub-Saharan Africa (Morris & Kretzschmar, 1997), characterize the patterning of many sexual relationships within South Africa (Halperin & Epstein, 2007; Harrison, 2008; Hunter, 2002, 2004; Leclerc-Madlala, 2003; Motsemme, 2007). While female involvement in concurrent partnerships does occur, it is commonly hidden from the censorious public view. Male participation in concurrent relationships, on the other hand, is an often-valourised activity and has increasingly become normalized through discourses of patriarchy and culture and by women themselves. Whomever the initiator, an innate understanding of the socioeconomic context often shapes the expectation of reciprocity inherent within relationships where it is not uncommon for love, desire and attraction to coexist in tandem with substantive and/or consumptive material exchange (Hunter, 2005; Kaufman & Stavrou, 2004; Leclerc-Madlala, 2003; Motsemme, 2007). It is important to note, however, that rather than relationships consisting of merely a series of transactional trade-offs, the material exchange is also considered a visible expression of respect, care and support (Oxlund, 2007).

W. Parker, Makhubele, Ntlabati and Connolly (2007) highlight the hierarchical patterning of sexual partners within concurrent relationships wherein different types of attachments exist in the different relationships. It is common for an individual to have a „primary’ partner in addition to his/her other sexual partners (W. Parker et al., 2007). Often more investment is made to protect the relationship with the „primary’ partner since he/she is regarded as central to „settling down’ in the future (W. Parker et al., 2007). Less expectation of relationship longevity, on the other hand, surrounds conduct with other concurrent partners. That being said, this patterning is dynamic and continually in process where one particular relationship may swap hierarchical status with another at any given time point. Generally, the attachment to primary partners is made publicly visible while concurrent relationships are usually more hidden or discrete, often as a sign of respect and in recognition of the „primary’ partner (W. Parker et al., 2007). Although there are, in practice, high levels of awareness of the presence of other partners within a primary relationship, tacit codes of behaviour regarding the conduct of these concurrent relationships are followed in an effort to maintain the harmony of the „primary’ relationship. It is understood as a sign of respect to not flaunt or parade another partner amongst mutual acquaintances and it is seen as an effort to maintain the other partner’s sense of dignity (W. Parker et al., 2007).

Holding the position of primary partner carries its own form of prestige and relationship security, which means that the dynamics within concurrent partnerships are often highly competitive.

The above patterning of sexual relationships greatly complicates the disclosure process and has hitherto not been adequately acknowledged in disclosure-related research. In a developed country setting, Marks, Richardson & Maldonado (1991) found an inverse relationship between the number of partners and the likelihood of disclosure occurring. In a South African based study, Simbayi et al. (2007) found that disclosure to sexual partners was less likely to occur if the index person reported concurrent sexual partners.

Studies involving male-male sexual relationships have shown that those who disclose their status are more likely to practice safer sex (Kalichman, 1999; Marks et al., 1991). The picture, however, is very different for women operating within hegemonic heterosexual partnerships within a concurrent relationship context. Here, prevention of HIV is only one part of the relationship picture. Other considerations include the strong possibility that condoms could threaten an already established patterning of sexual behaviour and thus the stability of the relationship (Wingood et al., 1998). In addition, condoms could be seen to directly undermine expressions of love, trust and faithfulness between couples (Hirsch, Meneses, Thompson et al., 2007b; W. Parker et al., 2007). These ideals are important to uphold in the milieu of concurrent partnerships. In avoiding using condoms, women potentially deflect any insinuation of infidelity involving themselves and/or their partner (Hirsch et al., 2007b; Wingood et al., 1998). In addition, in a climate of economic lack and where partnerships are consequently highly competitive, women are highly unlikely to insist on condom use.

HIV disclosure to sexual partners has been associated with consistent condom use (Niccolai et al., 1999). Simbayi et al. (2007) found a close association between non disclosure and high risk behaviours, including multiple sexual partners and inconsistent condom use. Desgrées du Loû (2005) questions whether disclosure to a partner actually produces the desired effect of introducing preventative behaviour practices within the relationship. Her research found that condom use did not necessarily follow disclosure, apparently due to the refusal by males to accept the reality of HIV-infection in their female partners. In addition, another study found that

few male partners of female study participants actually tested for HIV themselves (Brou et al., 2007). One of the reasons offered by these authors was that the male partners believed that the partner's status was a proxy marker of their own and therefore saw no need to subject themselves to a test to confirm this. Morrill and Noland (2006) reported a similar phenomenon, where they found that if one partner tested HIV-negative after unsafe sex, the untested partners took the result as an indicator of their own status and did not seek to confirm this. Disclosure most often does not occur when an intimate partner has a known HIV-negative status or where the status of the partner is unknown (Simbayi et al., 2007).

Irrespective, condom use remains problematic with or without disclosure. In research conducted in Cote d'Ivoire, women reported extended post partum abstinence as a strategy to avoid the risk of transmission to sexual partners to whom they had not been able to disclose. In the cases where disclosure had occurred, abstinence was a method employed to overcome the difficult introduction and negotiation of consistent condom use (Desgrées du Loû, 2005).

Desgrées du Loû, Brou, Traore and Djohan (2009) found that women who did not routinely cohabit with their male partner were less likely to communicate with him about sexual risk behaviour whatever their status. Among HIV-infected women, a low level of education of the woman or her partner was associated with less communication regarding sexual risk behaviour (Desgrées du Loû et al., 2009).

Disclosure to non-sexual partners

Simoni et al. (1995) found that sexual partners tended to react more negatively to disclosure than did family and friends, who were generally more supportive. Even so, an individual will carefully negotiate disclosure of his/her HIV status and thus prefer to limit disclosure to a closed social network. Study findings indicate that immediate family members are ranked more favourably than extended family members in terms of disclosing to them (O'Brien, Richardson-Alston, Ayoub et al., 2003; Simoni et al., 1995) but that both immediate and extended family members are prioritized over non-family members (Greef et al., 2008; Greene et al., 1996; Kimberly & Serovich, 1995). In a study conducted by Serovich et al. (2007), the family members who were most often confided in were sisters or mothers. However, disclosure to

family members, as with all forms of disclosure, is situation specific (Bairan, Taylor, Blake et al., 2007).

2.2.3 CONTEXTS OF CARE

It is important to take into account the context of care in which disclosure is encouraged since the context of care influences the likelihood of disclosure occurring. In comparison with studies on disclosure at HIV Counselling and Testing (HCT) sites, the rate of disclosure by women to their sexual partners has been found to be the lowest in the antenatal context (Gaillard, Melis, Mwanyumba et al., 2002; Maman et al., 2003; Maman & Medley, 2004; Medley et al., 2004). However, a more recent review documents high rates of disclosure by HIV-infected pregnant women (Baek & Rutenberg, 2010). Baek and Rutenberg (2010:301) cite the following possible reasons for this increase: “greater HIV awareness, maturation of PMTCT programs, a shift to offering routine HIV testing, and increased services for HIV care.” Regardless, disclosure issues will differ significantly between these locales since women in the antenatal context present for pregnancy-related reasons rather than specifically for HIV testing purposes (Maman et al., 2004).

In a meta-analysis of the reported rates of violence following HIV disclosure, Maman and Medley (2004) found that the highest rates of violence occurred amongst women in the antenatal setting. In particular, the South African studies reviewed tended to most often cite violence as an outcome of disclosure (Maman et al., 2004). However the authors maintain that the findings need to be approached with caution because it was not possible to truly assess risk since the studies reviewed did not report any base rates for violence; did not provide a working definition of violence; and/or differed in measures of severity of violence.

In the antenatal context, HIV-infected women have to simultaneously deal with two important implications of their HIV diagnosis: the risk of transmission to the partner and the risk posed to the unborn child (Desgrées du Loû, 2005). Furthermore, as Rutenberg (USAID/Synergy, 2004) suggests, women accessing Prevention of Mother-to-Child (PMTCT) services generally seem to consider the services as an entry point of care for their infants but not as an entry point of care

for themselves. This is problematic for a number of reasons. Women may not seek out health promoting services such as antiretroviral treatment (ART) for their own health and may miss opportunities to access sexual and reproductive health programmes which may be an integral part of the ART programme. Disclosure is embedded within this context. In Cote d'Ivoire it was found that only 46.2% women in a PMTCT programme disclosed their status to their partners (Brou et al., 2007). Of those who disclosed, the authors identified three critical moments when disclosure would occur to their intimate partners: before delivery of the baby; when sexual activity recommenced post-partum; and at early weaning for the women who breastfed (Brou et al., 2007). Visser et al. (2008) found in their study that women delayed disclosure until after the delivery of their baby.

Since many women are likely to discover their status before their partners, due to the antenatal healthcare encounter (Desgrées du Loû et al., 2009; Groves, Maman, Msomi et al., 2010), current disclosure counsel places the immediate responsibility for dealing with the presence of HIV in the relationship on females. Amongst other complex issues, the unequal burden of responsibility feeds directly into the prevailing stereotype of HIV as a feminized epidemic.

2.2.4 DISCLOSURE, DISEASE PROGRESSION AND ANTIRETROVIRAL THERAPY

According to disease progression theory, illness progression will act as a catalyst to disclosure (Serovich, 2001). However, the findings on the relationship between disease progression and disclosure amongst women are inconsistent (Rice et al., 2009; Rotheram-Borus, Draimin, Reid & Murphy, 1997; Serovich et al., 2007; Simoni et al., 2000; Simoni et al., 1995). While Serovich (2001) and Serovich et al. (2007) report no relationship between disease progression and disclosure, Maman and Medley (2004) found a positive association between disease progression and disclosure. Simoni et al. (2000) also found no association between the stage of illness and disclosure, and no influence of time since diagnosis on the likelihood that disclosure would occur. In her more recent research, Serovich (2007) found that female participants are most likely to disclose within seven years following diagnosis. Women with higher CD4 counts are more likely to disclose (Rice et al., 2009).

The fact that disclosure is actually an open-ended process, and that the consequences of disclosure may change over time, disturbs the basic clinical formula for the supportive effect disclosure is supposed to have on treatment. It may well be that disclosure and treatment are dialectically related, with constant influencing and adjusting in relation to the other. If this is indeed the case, ongoing attention needs to be given to disclosure-related issues, based on an understanding that shifts in treatment efficacy and experiences may accordingly prompt individuals to adjust their disclosure strategies. Should this prove the case, modifications may be needed to clinic-based treatment programmes which often require disclosure to have taken place *before* treatment can begin. It is entirely plausible that treatment may *precede* disclosure (and not the other way round) and in fact act as a „catalyst’ to set disclosure in motion. Excluding individuals from treatment because they have not, or are reluctant to disclose to someone may be inappropriate and even unethical. Clearly, this is an issue that calls for further exploration, since the few studies that have looked at the relationship between disclosure and antiretroviral treatment have revealed complex interconnections and conflicting findings (for example see Klitzman et al. (2004), Nachega, Lehman, Hlatshwayo, Mothopeng, Chaisson and Karstaedt (2005), Skogmar, Shakley, Lans et al., 2006). Nevertheless, the long-term impact of widespread treatment access on the broader disclosure environment is worth considering.

2.2.5 PREDICTORS TO NON DISCLOSURE

Some studies have found that, of the women who disclosed their HIV status, the majority received a positive response from the other (Gaillard et al., 2002; Maman et al., 2003), including sexual partners (King et al., 2008). Importantly, fear of negative outcomes was the biggest barrier to disclosure. The most common reason identified by women who had not disclosed to their partners was the fear of the consequences of a negative reaction. This fear proved to be an enduring barrier to the disclosure process. Anticipated partner reactions have as strong an influence on disclosure behaviour as actual partner reactions (Duru et al., 2006). It has also been found that women either over-anticipate the likelihood of a negative reaction following

disclosure or selectively disclose to ensure that they are not rejected (Cusick & Rhodes, 1999; Siegel et al., 2005).

In their review paper, Maman and Medley (2004) found that, of the studies conducted in the developing world, over 90% reported that the most significant disclosure barrier for women to their sexual partners was the fear of abandonment. Specifically, this fear was rooted in the potential loss of economic support from their partner (Antelman, 2001; Maman et al., 2003; Norman et al., 2005). Against a backdrop of pervasive poverty and high unemployment, loss of economic support has potentially devastating implications to any woman but most especially a woman with a newborn dependant.

Other reported barriers to disclosure, in both developed and developing countries, included the fear of being rejected or discriminated against and an unwillingness to upset family members (Maman et al., 2004). Age may be a barrier to disclosure (Maman et al., 2003). Gaillard (2002) found that women under the age of 22 years were more likely to inform their partner than women over this age. Serodiscordance or unknown status of one's partner has been found to be a barrier to disclosure. Simbayi et al. (2007) found that non disclosure was more likely if participants were unaware of their partner's status or if their partner was HIV-negative. Lack of social support may also be a barrier to disclosure. Studies have found that women who reported higher levels of social support were more likely to disclose (Crosby, Bonney & Odenat, 2005; Kalichmann et al., 2003).

In sub-Saharan African studies, the barriers to disclosure amongst women in an antenatal and perinatal contexts included the fear that disclosing HIV-positive serostatus would: affect the relationship with partners (either a breakdown of the relationship, divorce, abandonment, or being accused of infidelity); influence the relationship with family (either expulsion from the family home, provide cause for family conflict or concern); expose them to violence; or label them, generally, as blameworthy or, specifically, as the source of the infection (Antelman, 2001; Farquhar, Ngacha, Bosire et al., 2000; Kilewo, Massawe, Lyamuya et al., 2001; Ladner, Leroy, Msellati et al., 1996; Sigxaxhe & Matthews, 2000).

2.3 POSITIVE AND NEGATIVE OUTCOMES OF DISCLOSURE

Studies described in the literature report both immediate positive and negative consequences to disclosure. However, many outcomes of disclosure evolve and change over time (Gielen et al., 2000).

Amongst positive outcomes in a developing world context was the relief of the burden of secrecy (Norman et al., 2005), increased social and emotional support (Grinstead et al., 2001; King et al., 2008; Maman et al., 2003; Maman et al., 2004) including support from health care providers (Doull, O'Connor, Jacobson et al., 2006), better mental health (Armistead et al., 1999; Kalichmann et al., 2003) and better overall health and risk reduction (Doull et al., 2006; King et al., 2008). Pennebaker, Colder and Sharp (1990) found that those who had disclosed an HIV-positive status made less visits to health facilities and had better immune functioning than those who did not disclose. The authors viewed disclosure as having a positive effect on an individual's health, reducing stress and promoting psychological well being (Pennebaker et al., 1990). However, as McDowell and Serovich (2007) found more recently, perceived social support was more predicative of mental health than actual social support. That is, perception of support seems to have greater impact on mental wellbeing than the actual number of people available to provide the support.

Negative outcomes included physical abuse (Gaillard et al., 2002; Grinstead et al., 2001; Kilewo et al., 2001; Maman et al., 2003), breakdown/dissolution of a relationship (DeMatteo et al., 2002; Grinstead et al., 2001) and anger or blame being directed towards the disclosing individual (Maman et al., 2003). Other adverse social circumstances following HIV disclosure include economic abandonment, rejection, isolation and/or violence (Gaillard et al., 2002; Maman et al., 2004). In another study, one in five women who disclosed their status to their intimate partner, were abandoned (Simoni et al., 1995). Gielen et al. (2000) found that one quarter of female study participants experienced negative consequences following HIV disclosure, which included

abandonment, rejection and abuse. While disclosure may cause a breakdown in the relationship, Rutenberg (USAID/Synergy, 2004) found that women who did *not* disclose their serostatus were more likely to have experienced the breakup of their marriage than women who had disclosed their status. She was not, however, able to comment on causality.

One Zambian-based study (Semrau et al., 2005) found no increased risk of adverse social events experienced by women who came with their partner for HCT. However, another multi-country study conducted in Tanzania, Kenya and Trinidad (Grinstead et al., 2001) reported that HIV-positive women were most likely to experience a breakdown in, or dissolution of, their relationships should they be in a serodiscordant relationship.

The issue of violence as a consequence of disclosure has been particularly highlighted as a concern in the literature. This issue merits further discussion.

Disclosure and the Risk of Violence

Studies have indicated that violence or verbal abuse does occur following HIV disclosure and that HIV-infected women are most at risk (Gielen et al., 2000; North & Rothenberg, 1993). Overall, however, this may be less than previously assumed and most likely to occur in relationships that had a prior history of violence and abuse (Gielen et al., 2000; Sowell et al., 2003). As Gielen et al. (2000) point out, it is not useful to examine the *specific* instances of violence following disclosure because this does not reveal the role that violence had already played in the lives of women prior to their HIV diagnosis. Because studies have tended to atomize the disclosure event and focus on the seemingly direct consequence of that event, there is no indication of how violence unfolds over time (Gielen et al., 2000). According to Campbell, Rose, Kub and Nedd (1998), violence occurs in escalating cycles. In addition, studies that investigate disclosure-related violence may underestimate women's risk since some high-risk women may not reveal their actual risk at the time of the interview (Koenig et al., 2000).

Gielen et al. (2000) found that a large proportion (67%) of their female study participants had experienced emotional, physical and/or sexual violence. This included violence occurring before disclosure, both before and after disclosure (i.e. an uninterrupted cycle of violence), and

subsequent to disclosure. According to Koenig and Moore (2000), rates of disclosure-related violence lie between 0.5% and 4%. However, this only measures women who have actually disclosed their status and does not take into account those women who do not disclose due to fear of intimidation. These authors highlight that very little is known about the relationship between disclosure and the incidence of violence over time. Gielen et al. (2000) caution that disclosure-associated violence may not occur immediately following disclosure. It is possible that the onset of violent behaviour can be delayed and manifest at a later stage, thereby forming the basis for new behaviour patterns within the relationship (Gielen et al., 2000). It is also possible that the violence was pre-existent. Recent evidence points to the presence of violence in pregnancy in general (Fawole, Hunyinbo & Fawole, 2008; Walsh, 2008).

In a study conducted in Tanzania, HIV-infected women were more likely to report partner violence in their lifetime than were HIV-uninfected women (Maman et al., 2003). The difference in ages between sexual partners and concurrent partnerships also place women at risk for violence. Maman et al. (2003) found that women whose partners were 6 to 15 years older than themselves were almost five times more likely to report the presence of violence within their relationships. In addition, women who reported that their partners were currently involved in concurrent relationships were five times more likely to report violence than were women whose partners were not habitually engaged in concurrent relationships (Maman et al., 2003). Serodiscordancy between couples can also be a determinant for violence. Grinstead et al. (2001) found that HIV-infected female participants who were involved in a serodiscordant relationship were more likely to experience violence.

2.4 RATES OF DISCLOSURE

This section presents a synthesis of the documented rates of disclosure in the prevailing literature. However, studies measuring rates of disclosure are inherently problematic as the underlying assumption is the view of disclosure as a binary event (Gielen et al., 2000). As

Serovich et al. (2007) indicate, rates of disclosure have typically been documented via point prevalence studies rather than longitudinal studies.

Maman and Medley (2004) note that the rates of disclosure in developing countries are lower than those in developed countries. This was expected given the added social complexities and greater dependence on others that individuals in a developing world setting tend to experience (Maman et al., 2004). Other research suggests high rates of disclosure of HIV-infected women to their partners in a developing context (Gielen et al., 2000). However, as Gielen et al. (2000) indicate, little is known about how the delays in disclosure and how this intersects with transmission risk.

The few longitudinal disclosure studies have reported a positive correlation between likelihood of disclosure and amount of time passed since diagnosis of HIV status (Antelman, 2001; MacNeil et al., 1999; Maman et al., 2004; van der Straten et al., 1995). Other studies have found that some individuals took several years to disclose to those closest to them (DeMatteo et al., 2002; Norman et al., 2005). Disclosure rates to partners vary greatly in the literature but partners were more often disclosed to than family or friends.

2.5 EXISTING MODELS OR THEORIES FOR UNDERSTANDING DISCLOSURE

The study of the dynamics involved in self-disclosure has long found a home in multiple disciplines, particularly psychology, communication studies, nursing and, more recently, in the public health field. However, disclosure-related theoretical models remain embedded in the positivist psychological tradition (Hoosen et al., 2004; R. Parker, 2001) or communications frameworks (Petronio, 1991, 2000; Yep, 2000). This section provides an overview of the better known and often cited disclosure models located in these disciplines.

Within the discipline of psychology, Omarzu (2000) suggests a general framework for disclosure decision-making. According to this author (2000:180), the decision to disclose may be

positively influenced by the likelihood of attaining any of five social rewards, namely “social approval, intimacy, relief of distress, social control and identity clarification”. As the individual social goals alter, so too will the content of the disclosure. However, counterbalancing these potential social rewards, is the inherent „subjective risk’ of disclosure which includes “social rejection, betrayal and ... causing discomfort to the listener” (Omarzu, 2000:180). The degree of subjective risk then will have a proportionate moderating influence on the depth⁵ of disclosure (Omarzu, 2000).

Also located in the psychological field, Derlega and colleagues (2004) propose an integrative disclosure decision-making model, looking particularly at disclosure issues in the context of HIV. The integrative model proposes two main factors that influence disclosure decision-making amongst individuals. The first factor takes into account the social environment or context of the individual, while the second factor looks at the “relational, individual and temporal contexts” (Derlega et al., 2004:749) in which the individual is located. As with Omarzu’s notion of „social rewards’, Derlega et al. (2004:750) outline three broad categories of reasons for HIV disclosure or non disclosure which are described as “self-focused”, “other-focused” and “relationship-focused” and which refer to the intended target of disclosure.

In the communications literature, Petronio’s (1991, 2000) theoretical model of communication boundary management (CBM) offers an interesting approach to examining the dialectical nature of disclosure. Her model illustrates how people regulate the flow of non-specific personal information, and manage potential risk to themselves when disclosing on a day to day level (also in Greene, Derlega, Yep and Petronio (2003)). Petronio’s (1991) CBM model theorizes the concept of boundary structures, which act as gatekeepers to the flow of private information. Boundary rules manage these boundary structures by regulating the bi-directional flow of information between individuals. Specifically, this system of rule management consists of “boundary rule formation, boundary rule usage, boundary rule coordination and boundary rule turbulence” (Petronio, 2000:39). In the first instance, Petronio (2000) describes rules as being developed and shaped by culture, individual characteristics and self-esteem. Gender and

⁵ Omarzu (2000) here defines “depth” as the emotionally charged and intimacy levels of disclosure.

motivation are also criteria to be considered in the development of these rules. These criteria form the basis for rule usage which refers to the decision over whether to disclose and to whom, and the depth, breadth and timing of disclosure. Thirdly, coordination is needed when private information is co-owned by another. Here, Petronio (2000) recognizes the role of the recipient in the disclosure process. Lastly, rule turbulence occurs when someone is reluctant to reveal information. Usually this turbulence is brought on by a situational stressor.

Yep (2000) indicates the usefulness of Petronio's model in the HIV context since it concentrates on unsolicited disclosure of information. Given the stigma surrounding HIV, disclosure of HIV-positive serostatus will, in most instances, be unsolicited, especially if it has direct health implications for the recipient, that is, a sexual partner. Most significantly, however, this model does not limit itself to only examining disclosure amongst sexual partners. It can be used as a framework for disclosure in all types of personal relationships.

Disclosure is a complex process that unfolds over time and involves communication of HIV status that must be negotiated between two or more individuals. The communication carries implications not only for the index individual but for the affected and/or potentially infected recipient of this communication. While the above frameworks offer useful theoretical ways of thinking about disclosure, the predominant focus tends to centre on intrapsychic processes with little consideration of the structural and embedded power dynamics within a given social context, all of which may fundamentally influence and shape disclosure behaviour. Disclosure of HIV status is determined by a number of factors, including but not limited to psychological state and communication skills (Visser et al., 2008). Contexts of care, intended disclosure recipient and the structural and relationship context also form part of the picture. The literature generally indicates high rates of disclosure to sexual partners but it is likely that the health care and relationship context will have a mediating influence on the expected outcomes.

The models presented above have contributed significantly to the body of knowledge surrounding HIV disclosure. While these models are often cited in other disclosure-related research as key contributions to the field, they are also limited in terms of the narrow focus on disclosure behaviour *per se*. Little attempt is made to contextualize the models in a broader

public health framework. To the author's knowledge, no HIV disclosure model has been developed or tailored for the PMTCT clinical context or a resource constrained country setting.

2.6 SUMMARY

A review of the relevant literature reveals that HIV disclosure is predominantly viewed in instrumentalist terms and that, largely due to choice in methodology, disclosure continues to be framed as a discrete binary event. A small body of literature acknowledges disclosure behaviour as an ongoing, and perhaps more commonly, incremental and iterative journey that is navigated by the majority of HIV-infected individuals within their personal lives. Disclosure has also been referred to as a strategic behaviour where individuals choose selectively as to who they wish or do not wish to disclose to. Disclosure rates to partners vary greatly in the literature but it appears that partners are more often disclosed to than family or friends.

The process of disclosure decision-making is determined by multiple factors and social contexts. Since disclosure is a dyadic event, the nature of the relationship between the discloser and discloser is a pivotal determinant in the disclosure decision-making process. The context of care needs to be acknowledged in disclosure messaging since the context will likely influence HIV disclosure. Violence as a consequence of disclosure received particular attention. Little effort has been made to look at how violence unfolds over time with or without the intervening disclosure as recent evidence points to the general presence of violence in pregnancy. Various models of disclosure were presented. However, new models of disclosure located in broader contextual frameworks are required.

CHAPTER 3: METHODOLOGY

This chapter presents the theoretical and analytical framework underpinning the research methodology. The study design, study sites and study population are then described, followed by a report of the data collection methods and tools. A discussion of the method for data analysis is also provided. The final sections include a description of how the data were managed and stored, the strategies that were drawn on to ensure quality, credibility and trustworthiness of the data, and the ethical considerations.

3.1 THEORETICAL FRAMEWORK: SOCIAL CONSTRUCTIONIST THEORY

With its roots in postmodernism, social constructionist theory has evolved from a multidisciplinary background. In the early 20th century, the field of sociology contributed to and influenced social constructionist theory, especially those writers interested in symbolic interactionism (Burr, 1995, 2003). The sociological influence is evident in the symbolic interactionist interest in how symbols within language are used to communicate/construct a particular view of the world. Social constructionist theory also bears the strong influence of the post structuralist French philosophers such as Michel Foucault and Jacques Derrida (1976). Foucault's idea of power and discourse and Derrida's notion of deconstructionism remain key elements of the theory. For Foucault, the task of the researcher was to reveal the power relations operating in a given society and the ways in which power was played out or contested (Foucault, 1976). Derrida saw language as a constructive force and argued that through deconstructing texts or discourses, we would be given insight into the how the world becomes represented in a certain way (Burr, 1995, 2003). The mid-20th century marked a crisis in the field of social psychology which became concerned with the dehumanizing effect of the predominantly positivist approach of the discipline (Burr, 1995, 2003). Language started being seen as a "social resource for constructing different accounts of the world and events" (Burr, 2003:14).

Given its multidisciplinary roots, social constructionist theory has been drawn on by a wide array of disciplines, including psychology, sociology, gender studies, anthropology and more recently the field of public health (Brown, 1995; Burr, 1995, 2003; Strebel et al., 1998; Vance, 1991). Because of its multidisciplinary background and application, it is important to point out that social constructionism should be seen as an umbrella rather than a unitary theory (Brown, 1995; Burr, 1995, 2003; Edley, 2001)⁶. This is clearly evident by the presence of many differing definitions or versions of social constructionist theory as represented in the various literatures. That being acknowledged, there are still a core set of social constructionist theoretical elements that are shared by those who work within, and are influenced by, a social constructionist framework (Burr, 1995, 2003). The core elements are outlined below.

All versions of social constructionist theory challenge our everyday assumptions about the world and strongly reject the view that our knowledge of the world is based on objective, empirically-based observation (Burr, 1995, 2003; Edley, 2001; Gergen, 1985; Liebrucks, 2001). According to social constructionist theory, our perception of the world is constructed through our social interactions with other people living in the same society. In this way, social constructionism rejects the essentialist notion that a person ultimately consists of a core set of intrapsychic elements and, instead, embraces the view that an individual is inextricably located in the social realm, where the ways in which the world is viewed and the way in which the individual sees himself and acts are socially produced.

Language, and thus discourse, is central to social constructionism because language is regarded as the medium through which we describe and therefore construct (or experience) our sense of self (Burr, 1995, 2003). However, rather than merely *representing* the world, language is seen as a *constructive* force (Burr, 1995, 2003; Edley, 2001). According to a social constructionist viewpoint, we understand ourselves and structure our experiences by drawing on concepts available to us in our discursive culture (Burr, 1995, 2003). Existing within our discursive culture are discourses - “systems of meaning, ways of representing ourselves and our social

⁶ For the purposes of this dissertation, I draw on the sociological concept of social constructionism. This is distinct from the psychological concept, social constructivism.

world, which constitute not only what we think and say, but what we feel and desire and what we do” (Burr, 2003:87). These discourses are drawn on to describe any „object”⁷ and thus reflect that „object’ in a particular way. It is perhaps most helpful to think of discourses as a “frame of reference” or a “conceptual backcloth” against which our experiences and behaviours are understood (Burr, 2003:66). According to social constructionist theory, the types of discourses that we draw on, and that subsequently construct our experiences and view of the world, are dependent on what discourses are culturally available to us at that given time (Burr, 1995). However, given that there are many kinds of discourses operating in a society at any point, a variety of discourses will therefore exist and surround a given „object’. Each of these discourses will construct that „object’ in a particular way and thus offer differing meanings for that „object’. There are power implications in terms of which particular discourse gains prominence for different groups of individuals within that society.

Discourses are simultaneously seen as rooted in and maintained by social structures and practices within a given society (Burr, 1995, 2003). Burr (2003:9) refers to this as the “dynamics of social interaction” – the way in which knowledge is constructed and produced between people through their social practices. Because all individuals are embedded in social life, any construction or description of the world is culturally and historically specific. At the same time, any construction of the world is also seen as a product of the culture and history in which it arose.

Because of the social constructionist interest in the power dynamics at work within a society, Foucault’s theory around this issue has been widely drawn on (Burr, 1995, 2003). According to Foucault (1976), when a particular discourse emerges within a given culture, it becomes available for use by groups within that society to potentially uphold their own particular interests. The type of discourse that is drawn on is the one which produces „knowledge’ (Foucault, 1976)⁸. According to Foucault (1976), knowledge and power operate hand-in-hand. In drawing on particular discourses („knowledge’) and by ignoring others, individuals are able to shape their world in a way that best maintains their interests. Individuals are, in turn, enabled to exercise power over their environment. According to Foucault (1976), power is a productive

⁷ An „object’ can be an event, a person or category of persons.

⁸ „Knowledge’ here refers to a widely accepted or normative view of the world.

force rather than a repressive one because, when exercised, power can produce knowledge. When „knowledge’ is produced we are able to define an „object’ in a way which best supports our interests. In supporting our interests we are able to exert power. Power is seen to be truly effective when this produced knowledge becomes internalized by individuals within that society which results in the self-regulation of behaviour in the *absence* of any physical intervention. Foucault (1976) refers to this as „disciplinary power’.

According to social constructionism, different groups of people hold more power than others within the same society. The „powerful’ groups have a vested interest in maintaining their position. It is in the interest of these groups to uphold the apparent „truth’ of certain discourses by rejecting those discourses which conflict with and thus contest the legitimacy of their „truth’ claims. In this manner, certain ways of understanding the world become normalized within that society and appear as the common sense view of the world. These common sense assumptions (or ideology) cause behaviour to be regulated (Burr, 2003). A key component of social constructionism is the view that various constructions of the world serve to uphold various kinds of social action and social practices (Burr, 2003). The role of the social constructionist, then, is to identify and analyze prevailing discourses with a view to exposing the hidden power relations within them with a view to potentially offering change (Burr 1989).

For Foucault, human sexuality is a key arena in which power relations are played out. Drawing on the „discourse of femininity’, for instance, provides a useful tool in upholding the views of those subscribing to a patriarchal view of the world (Burr, 1995). The „discourse of femininity’ paints a particular picture of women where they are represented as predominantly nurturing and inherently vulnerable.⁹ In this way, the discourse of femininity serves to sustain patriarchal practices where men are seen as the „providers’ and „protectors’ of the world and thus more suited to occupying a prominent space in this world. Consequently, women have no or limited place in worldly affairs and are best suited to staying at home, raising children and being occupied with (and sustained by) purely domestic concerns. Of key interest to those working

⁹ A social constructionist would also be interested in what is not being said. That is, this description could arguably be applied to males but it is not.

within the social constructionist paradigm, would be to reveal how this type of discourse effectively sets up unequal power relations between males and females - with greater freedom and decision-making power being afforded to „men’ while at the same time being strictly regulated for „women’. The idea of female vulnerability versus male protective strength also sets the scene for expectations over a woman’s sexual submission to a man.

Within the context of power relations, it is important to emphasize the dynamic nature of the constructive process because all constructions or „descriptions’ of an object can potentially be disputed by competing discourses that are simultaneously in existence (Burr, 1995, 2003). According to Foucault (1976), where there is power, there is always resistance. While one discourse may have achieved greater dominance over another, there still exists the possibility of the dominant discourse being challenged by other forms of discourses around the same „object’. This view of power and resistance is fundamental to those working within a social constructionist framework because this is where social and personal change can take place (Burr, 1995). Because changes in the nature of society over time create the possibility for particular discourses or „knowledge’ to emerge, understanding the historical context in which these discourses originate is important. In being aware of this context, we are better able to contest the legitimacy of prevailing „knowledge’ (Foucault, 1976). At the same time, tracing the origins of a particular discourse, allows us to uncover hitherto marginalized discourses of those who have been disempowered by this prevailing „knowledge’ and ultimately to give them voice. In opening up a space for their voice to be heard, we are also able to question or contest current knowledge that is upheld as „truth’ (Foucault, 1976).

Since discourse provides the conceptual framework against which people understand and give meaning to their lives, it is also through discourse that our identity is produced (Burr 1989, 2003). Similarly, in the same way that „knowledge’ is a culturally and historically derived product of a society, so too is our identity shaped by these historical and cultural factors (Vance, 1991). Social constructionist theory generally sees the individual as a composite of the subject positions which are taken up in differing discourses. The subject position refers to the way in which an individual positions him/herself within a given discourse. These subject positions determine the scope for acceptable modes of conduct. According to social constructionism,

while some subject positions are always open to change, we will internalise other subject positions which provide us with our basis for identity (Burr, 2003).

It is important to note that while social constructionism sees an individual as having multiple versions of self, the theory still allows for a subjective self or selfhood (Burr, 2003). In this respect, there is no such thing as objectivity because each individual sees the world from their own particular subject position. Social constructionist research is thus necessarily reflexive in that the role and impact of the researcher on the population under study is acknowledged (Burr, 2003). That is, in framing the research questions, the researcher is already influencing the research and the subsequent research interaction is thus seen as a “co-production between themselves and the people they are researching” (Burr, 2003:152).

3.1.1 MICRO AND MACRO SOCIAL CONSTRUCTIONISM

Burr (2003) distinguishes between two broad streams of social constructionist theory: micro and macro social constructionism¹⁰. Micro social constructionism focuses solely on discourse and the analysis thereof. According to those working within this framework, our experience of reality arises solely out of our descriptions of the world (Burr, 2003). In essence, this version of social constructionism takes a very relativist view of the world. There is no attempt to locate discourse within and arising out of the social and material context. In addition, there is little focus on the concept of power and if it is drawn on at all, it is seen as the direct effect of discourse (Burr, 2003).

Macro social constructionism, which includes Foucauldian discourse analysis, holds power as central to its field of enquiry. In uncovering how discourses mask power relations, the concept of ideology – the normative ideas and beliefs about the world – is often drawn on for the purposes of analysis (Burr, 2003). As Burr (1995:87) points out, discourse can be “deployed ideologically, that is in the service of power and in the interests of relatively powerful groups of society”. Ideology is also visible within social practices. For macro social constructionism,

¹⁰ This has also been referred to as „weak’ and „strong’ social constructionism.

language is only part of the picture since language is seen as embedded in and surrounded by the social and material world (Burr, 2003). The material world consists of social structures and social practices which are inextricably bound up with prevailing discourses (Burr, 1995, 2003). The primary outcome, then, of a macro social constructionist analysis is to expose underlying oppressive power relations operating within a society through identification of the discourses operating in support of them and to simultaneously reveal marginalized discourses with a view to bringing about change.

3.1.2 LIMITATIONS OF SOCIAL CONSTRUCTIONIST THEORY

According to Burr (1995, 2003), neither micro nor macro social constructionism look at the ways in which individuals are able to reconstruct themselves and their society. The problem, argues Burr (2003:184), is that traditionally the “individual and society are seen as the two components of a dichotomy”. The idea of agency and subjectivity (personhood) and the relationship between discourse and reality are thus historically problematic areas within social constructionist theory and are either neglected or hotly contested by those working within a social constructionist framework (Burr, 1995, 2003). According to Brown (1995) social constructionism also ignores the social structures within society which provide the context for health and illness. The following section addresses these concerns.

3.1.3 REALISM VERSUS RELATIVISM

There exists no absolute version of „truth’ of the world within a social constructionist framework since what is perceived as reality is historically and culturally bound to that society. This relativistic view, in which everyone’s perspective as to what constitutes reality is equally valid, is an extreme one and has led critical social constructionists to argue for the existence of reality independent of discourse. In an attempt to reframe the debate, Edley (2001) argues that social constructionists do not, in fact, see language as the only reality. According to him, the social constructionist argument is not about whether or not an object or place actually exists, “but that it does so as a socially constructed reality” (Edley, 2001:439). In this respect, a material reality is

recognized by social constructionists – it is just not possible to explain or refer to it without it being socially constructed.

3.1.4 THE PROBLEM OF AGENCY

Problems over subjectivity/agency within social constructionist theory also arise because the theory sees the individual as socially situated and constructed and a product of the discourses in existence within that social context. Rather than a person being presented as a self-contained unit consisting of a core set of intrapsychic elements, social constructionism presents a multifaceted view of an individual who is constituted by social life and maintained or reconstituted through social interaction (Burr, 2003). Historically, social constructionism has largely ignored the idea of ‚agency’ – the capacity for the individual to critically reflect on prevailing discourses and to exercise a varying degree of choice/control over them.

Some attempt has been made to address the problem of agency through discussion of the subject positions that individuals occupy within a given discourse. The subject position determines the structure of power dynamics between the subject (person) in relation to others. The subject position is a dynamic one and thus is always open to contestation (Burr, 1989). However, those individuals who are able to manipulate discourse will do so in a manner that best supports their needs. Burr (1989:138) refers to this process as the “social negotiation of identity” – the way in which people position themselves within prevailing discourses as a means of gaining ‚voice’ in the world. Macro social constructionism, in particular, makes allowance for the individual to be an active participant and user of discourse within the broad social constructionist framework (Burr, 1995, 2003).

3.1.5 SOCIAL CONSTRUCTION OF ILLNESS

Taking into account the limitations of social constructionist theory, Brown (1995) proposes a social constructionist model which incorporates both symbolic interactionist and structuralist approaches. In his description of his model, Brown (1995) distinguishes between the social

constructionism of medical knowledge and the social constructionism of illness since, according to him, while these constructions are interconnected, they are also distinct from one another. Those interested in the social construction of medical knowledge draw predominantly on the structural perspective and are interested in studying knowledge which has been shaped by, and is rooted in, the dominant biomedical paradigm with its associated ethics and moralities (Brown, 1995). The study of the social construction of illness, on the other hand, focuses on the lay experience of illness at intra- and interpersonal levels and thus works from a symbolic interactionist approach (Brown, 1995). Drawing on both social constructionist perspectives, Brown (1995) presents a framework which allows for the social construction of a condition, such as HIV, to be represented not simply as a mere biomedical fact. Rather, this condition “involves a multiplicity of social forces that combine to create and modify the phenomenon ... and that are constantly in flux” (Brown, 1995:37). In particular, this perspective would take into account how HIV and AIDS are viewed by wider social structures and what are the subsequent responses to this view.

3.1.6 SUITABILITY OF SOCIAL CONSTRUCTIONIST THEORY TO THE STUDY OF HIV DISCLOSURE

Social constructionist theory argues that illness cannot be studied in isolation and must be embedded within the social context in which it is being experienced. HIV and AIDS are public health problems as well as social ones. Disclosure of HIV status is a fundamentally social act - it involves communication, accessing social support and sharing of privileged information that is subject to social scrutiny. Social constructionism thus provides a highly useful theoretical framework in which to analyze HIV-related disclosure given the subjectivity of the illness experience as well as the fact that this experience cannot be separated from the politico-socio-cultural context in which the individual is located. There continues to exist a predominantly biomedical discourse surrounding HIV-related disclosure. However, there is little understanding as to what disclosure means to HIV-infected individuals or how the benefits of disclosure are interpreted or realized. The social constructionist emphasis on historical and cultural specificity is important in that it offers an alternative lens to disclosure, from a predominantly westernized,

biomedical perspective to one that incorporates the HIV-infected individual's experience, located in a specific context of health and social world. If we are to make any public health advances in the problems surrounding disclosure of HIV status, we need to work at the interface between the medical, interpersonal and social context.

3.2 STUDY DESIGN

The social constructionist emphasis on historical and cultural specificity is an important contribution to HIV disclosure research because it offers an alternative lens from which to view disclosure behaviour and moves the analytical focus away from solely individual level factors to also incorporate the interpersonal and structural level influences. Those working within a social constructionist framework may validly draw on both qualitative and quantitative methods in their research. Given the complexity of disclosure behavior, however, this particular research employed a qualitative research methodology, since this is best suited to exploring the „subjective reality’ and provides context-rich and locally specific data from the perspective of the individual (Denzin & Lincoln, 1994; Patton, 2002). In qualitative research designs, the focus of interest is not in how representative study participants are of the larger population. Instead, of key importance is the identification of the variation in concepts and, in the process of concept development, the exploration of the incidents that provide explanation for these concepts (Corbin & Strauss, 2008). The social constructionist position also consciously avoids making universalistic truth claims (Burr, 1995, 2003). A topic such as disclosure is well suited to qualitative methodology and multidisciplinary research: its sheer complexity and multiple layering of meanings defy attempts at comprehension through quantitative measures alone. Qualitative methods contextualize a person's experience and provide a richness of textual data in which to examine hitherto unconsidered aspects of the disclosure experience. Social constructionist theory is particularly well suited to qualitative research because the data generated provide a fertile soil for identifying prevailing discourses around a given subject and subsequently revealing power relations at work.

Macro social constructionist theory is the chosen theoretical framework for the purposes of this thesis given the research interest in the gendered power relations inherent in the communication of HIV status amongst intimate partners and the impact of prevailing discourses within the biomedical and social context on HIV disclosure in a Prevention of Mother-to-Child Transmission (PMTCT) setting.

The task of this study was to develop substantive theory around how HIV-infected pregnant women negotiate HIV disclosure, with the aim of providing a theoretical framework for public health and health care practitioners to better understand and interface with clients. In order to achieve this, an examination of the disclosure dynamics and impact of being HIV-positive and pregnant on women's lives was required. Given the aim of concept development with a view to developing substantive theory, this study drew on the most recent version of grounded theory to guide the analysis (Corbin et al., 2008). Grounded theory allows for an emic understanding of the world where the concepts arise from the data and where theory is developed inductively from the data as a whole. In addition, grounded theory is an "action-orientated model" (Strauss & Corbin, 1990:123) which allows the researcher to systematically examine the iterative character of events. Charmaz (1990) provides a social constructionist version of grounded theory which responds to the positivist thread that runs through the earlier work on grounded theory. Here, Charmaz (1990) moves away from the idea of using theoretical categories to shape the data while in the field, preferring to develop conceptual ideas to drive the fieldwork process. Charmaz (1990:1164) also rejects the notion that the "theoretical categories derive from the data and that the research ... [is] unaltered by the observer's presence". According to Charmaz (1990:1165) social constructionist grounded theory "views the process of categorization as dialectical and active, rather than as given in the reality ... [and] assumes an active, not neutral, observer whose decisions shape both process and product through the research." In accordance with this view, the presentation of the research findings is as much a social construction as the social constructions highlighted in the data (Charmaz, 1990).

3.3 STUDY SITES

Study participants were recruited from two different PMTCT sites, Facility 1 and Facility 2, both of which are located within the eThekweni¹¹ Metropolitan District, in the KwaZulu-Natal Province. The PMTCT sites differ from each other in terms of free versus paid for services and were selected in order to include in the study a cross-section of women from differing socioeconomic strata.

Facility 1

Facility 1 was purposively selected because of its involvement with the Demonstration Project¹². The Demonstration Project was established at a number of sites in the eThekweni District with the aim of providing a holistic PMTCT programme focusing on the enrolment of women into PMTCT services, improving PMTCT service delivery, and follow-up and continuing care for women and their infants. Facility 1 was a community health clinic with an antenatal clinic attached (see Table 1). The PMTCT services offered at the time of the study were based on the then current Department of Health PMTCT guidelines (Department of Health, 2008). This clinic primarily refers patients to a large public sector hospital for delivery. Mondays and Wednesdays are clinic days for first time antenatal clients. Tuesday, Thursday and Friday are days for repeat antenatal visits. If a woman tests HIV-positive, she will be given AZT dual therapy while waiting for her CD4 count result. If their CD4 count was less than 200 copies, they would be referred to an ART clinic in order to access HAART for their own health. No clinic fees were charged at this facility

Facility 2

Facility 2 is a state-subsidized district level hospital which serves an urban and peri-urban population. The hospital has had extensive experience in antiretroviral treatment (ART) services for both adults and children. In 2003, the hospital formally joined the KwaZulu-Natal Department of Health Provincial PMTCT programme. In 2004, the PMTCT programme was

¹¹ The main city in the eThekweni District is Durban.

¹² The Demonstration Project: A Holistic Model of Care to Improve Patient Retention and Health Outcomes in Maternal and Child Health Programmes (Reference Number: BF055/07)

expanded and improved as a direct result of funding from the Elizabeth Glaser Pediatric Foundation. At the time of the study, the PMTCT protocols differed from the Department of Health PMTCT guidelines (Department of Health, 2008) in respect of PMTCT prophylaxis (short term HAART versus AZT and NVP dual therapy) and of viral loads being done routinely. PMTCT care was integrated in the antenatal service and part of the package of care. The programme was located within the hospital premises which also had maternity services. HAART for own health and HAART for PMTCT prophylaxis was accessible on-site for all women enrolled in the PMTCT programme. On-site postnatal follow-up clinic services were offered to all mothers and their infants who were part of the PMTCT programme until 18 months postpartum. Antenatal days were on a Monday, Tuesday and Thursday. Wednesday and Friday were postnatal clinic days. Only women accessing the ANC services would have been able to access the PMTCT programme. Antenatal consultations cost R200 per visit at the time of the study. Women who accessed antenatal services at this facility would have been able to afford the Maternity section delivery fees.

The table below provides an overview of the main differences between the two sites. While Facility 1 saw half the number of ANC patients, their HIV prevalence was more than double that of Facility 2.

TABLE 1: Basic patient and HIV statistics in Facility 1 and Facility 2 for the period 1 January 2008 to 31 July 2008

Study site	Facility 1	Facility 2
Average number of ANC attendees per month	68	150
Nature of HIV testing services	HIV Counselling and Testing (HCT)	Provider initiated testing
HIV testing uptake	98%	99%
HIV prevalence	39%	16%

3.4 STUDY POPULATION AND SAMPLING

3.4.1 STUDY POPULATION

All participants were black African females, >18 years old, HIV-infected and accessing PMTCT treatment services in eThekweni, KwaZulu-Natal, South Africa. In the year of the study period (2008), the South African annual HIV and Syphilis Antenatal Sero-Prevalence Survey identified that women between the ages of 15 years and 49 years attended public sector antenatal clinics (Department of Health, 2009). Women located in the age groups of 25-34 years had, for the last three years (2006-2008), displayed the highest rate of HIV infection in comparison to other age groups (Department of Health, 2009). Due to very low numbers of women other than black women accessing care in both PMTCT sites, black African women constituted the whole study population.

3.4.2 SAMPLING STRATEGY AND SIZE

HIV-infected pregnant women were purposively recruited into the study during the course of their clinic visit from 5 June 2008 to the end of November 2008. Interviews were conducted at these women's convenience, either while they were waiting to see a health care provider or afterwards. Interviews were carried out in a private space either in or in the vicinity of the clinic. Clinic counsellors/nurses were asked to introduce the study to potential participants and if they expressed interest in participating in the study, they were introduced to the interviewer. Written informed consent was obtained from all study participants. No participants incurred travel costs because of an interview. Sixty-two semi-structured interviews were conducted between the two PMTCT sites with 31 participants selected from each site. The total sample size was determined once data redundancy and saturation became evident. Saturation was realized when no new information was being presented by subsequent participant interviews and the data was no longer providing material for the development of new codes.

3.5 DATA COLLECTION METHODS AND TOOLS

3.5.1 DATA COLLECTION METHODS

Semi-structured, in-depth interviews were conducted. A predetermined set of open-ended questions were used to introduce the study areas of interest to participants during the interviews. Participants were either asked to elaborate on responses given through interview probes or were asked direct questions to introduce a new topic into the conversation. Broad topic areas included demographic information, discussion over HIV diagnosis, ARV treatment issues, HIV disclosure experiences, and intimate partner issues. As is customary to qualitative research, the interviewer had prior experience in the skill of observing and “noting body language, facial expression and other nonverbal clues to subtle meanings” during interviews (Ulin, 2002:70). These observations were noted in the interview transcripts.

3.5.2 DATA COLLECTION TOOLS

Participants were interviewed with a semi-structured questionnaire which had been translated into isiZulu by one person and back-translated into English by another to check for accuracy (see Appendix 1). With the exception of one interview, all the other interviews were audio-taped.¹³ The interviewer was a black female who spoke fluent isiZulu and English. The same interviewer translated and transcribed the audiotapes. Translation and transcription of the interviews into English was concurrently carried out.

Due to the subjective nature of qualitative work, only one person conducted the interviews in both clinic settings. A first language isiZulu speaking interviewer and not the researcher conducted the interviews. The interviews were all conducted in isiZulu as this was the preferred mode of communication amongst participants. Interviewing participants in their first language allowed them to draw on the full range of expression and vocabulary available within their

¹³ One participant wished to be interviewed but did not want to be tape recorded. The interviewer made notes during the course of the interview which she typed up immediately after the interview had been completed.

language and cultural context. It also avoided disrupting the flow of conversation and train of thought because of language or translation difficulties. Avoiding language difficulties was preferable given the sensitivities surrounding the research topic and the emotionally heightened content of some of the interviews.

3.6 DATA ANALYSIS METHODS

Narrative data were translated and transcribed into English from isiZulu and, through thematic analysis by the principal investigator, collated and coded for themes and sub-themes. Data analysis was an ongoing and dynamic process throughout the data collection phase, so that the analysis guided and optimized the quality of information as it was being collected. Analysis and data collection occurred simultaneously. According to Charmaz (1990), writing and rewriting are also crucial phases of the analytical process. The raw data were initially analyzed as a composite body with the view of identifying overarching themes relating to the study research question. The data were subsequently reanalyzed through a comparison of responses between each Facility described above.

Themes and sub-themes were inductively derived through a coding process as laid out by Corbin and Strauss (2008):

- 1) Open coding/concept identification:** Emerging concepts were sought by disaggregating the data and constantly comparing for similarities and differences. Negative instances of a concept were actively looked for since this “helps the researcher to avoid making premature judgements about the meaning or identification of an item” (Schensul, Schensul & LeCompte, 1999:153). Concept identification refers to identifying the properties (characteristics) and dimensions (variations) of each concept. The concept was then compared with the incident in order to generate a category. Labelling of the categories was carried out. Constant interrogation and asking questions of the data occurred at all stages.

- 2) **Axial coding:** This referred to the process of reformulating the data in new ways by making connections between categories and sub-categories. Corbin and Strauss (2008) provide a paradigm model to facilitate this process:
- a) Elaborating the analysis: Further interviews were analyzed and compared and contrasted to original concepts. Concepts were begun to be related to one another but the initial concept development was checked against incoming data. The conceptual relationships were accepted, modified or rejected with further analysis. Participant experiences were contextualized and included as part of the analysis. Context was viewed from both a micro (immediate set of circumstances) and a macro (structural) level.
 - b) Bringing process into the analysis: Emergent patterns in the data were reviewed and the data were analyzed for process. According to Corbin and Strauss (2008:98), process is “represented by sequences of action/interaction/emotions changing in response to set of circumstances, events, or situations.”
- 3) **Selective coding/integration of the analysis:** As part of the process of theory building, a core category was chosen around which the other categories related and which impelled the theory forward.

Charmaz (1990:1168) recommends line by line coding during the initial coding because this keeps the researcher close to the actual data “rather than lapsing entirely into theoretical flights of fancy which have little connection to the data”. The codes and categories help disaggregate the data and allow questions to be framed around it (Charmaz, 1990). In this way, the codes and categories move from mere description to building up an analysis (Charmaz, 1990). The study findings were prepared for presentation as a set of interrelated concepts encapsulated with an overall unifying conceptual model describing the processes involved in HIV disclosure in a PMTCT context.

3.7 DATA MANAGEMENT AND STORAGE

At no point of the research process were participant names attached to any interview transcript, field note or audiotape. All material remains locked in a secure cabinet, accessible only to the principal investigator. At the beginning of the study, each participant was allocated an anonymous code number for research identification purposes. The code was cross-referenced with participant names on a separate document known only to the interviewer and principal investigator and stored in a locked and secure cabinet. The document carries no identifying links to the research and is not stored with the transcripts and interviews, so as to maintain confidentiality of all participants in the event of unauthorized access. Codes have been used for all participants in the presentation of findings. Any other identifying markers were also removed from the presentation of findings. All related electronic documents have password-only access.

3.8 MECHANISMS TO ASSURE THE STUDY QUALITY, CREDIBILITY AND TRUSTWORTHINESS

The principal investigator is a white, employed female who, at the outset of the research, was working at a research unit based at the hospital in which Facility 2 was located. While not a health care professional by training, much of her activities at that stage involved assisting with monitoring and evaluation, and research activities with health care workers at this hospital. The principal investigator experienced a second pregnancy in the course of the research and gave birth to her second child. She also had direct experience with individuals close to her being diagnosed with HIV and commencing ART. In 2008, she joined the hospital PMTCT programme as the Programme Manager. Her experiences with pregnancy, child birth and being the primary support mechanism for an HIV-positive woman in her immediate circle gave her direct insight into the antenatal and postpartum experience, and immersed her directly in the experiences of the trauma surrounding an HIV diagnosis and the difficulties in the early months of commencing antiretroviral therapy. However, she acknowledges her difference in ethnicity with participants, in addition to her marital and socioeconomic status. While conscious of these

differences and even with practicing reflexivity, the investigator is aware that her middle class and educational background would have had an influence on the analytical process.

An interviewer and not the researcher conducted the interviews in an effort to enhance the quality of the study and to minimize interviewer effects. The interviews were conducted in isiZulu since this was the native language of participants. Given the emotionally laden content of the interview, it was preferable to interview participants in their native language so as to not disrupt the flow of narrative due to difficulties with phraseology and nuances being lost in another language. It was also beneficial to analyze the data directly rather than this being filtered through a translator at the point of the interview.

The interviewer did not represent a figure of authority and/or belong to the medical profession. She was a 58 year old University student, who in the course of her studies had acquired extensive experience in interviewing and fieldwork activities, especially in the field of HIV. She was also previously trained in ethnographic methods. The interviewer was older than the research participants, was a mother herself and matched the participants in terms of sex and ethnicity.

By audio-recording the interviews, the researcher was able to go back to the sound file with the interviewer and check on specific paragraphs or phrases once they had already been translated into English. The principal investigator cannot understand advanced isiZulu and so revisited the original recorded conversations with the interviewer when any questions concerning translation phraseology arose or when any complex concept was presented. As is customary with qualitative work, data analysis was ongoing throughout the data collection process. As such, the researcher had an intimate understanding of the fieldwork progress and was in a position to attend to data quality issues when they arose. The semi-structured questionnaire included repetitive questions which were phrased differently from an earlier one in order to check for consistency of participant response. The interviewer was conversant in both English and isiZulu which allowed participants a choice in their preferred language for the interview. All participants chose isiZulu as their language of choice for their interviews.

As Charmaz (1990:1163) indicates, the “rigor of the grounded theory methods depends upon developing the range of relevant conceptual categories, saturating those categories, [and] explaining the data”. In keeping with grounded theory for analysis, iterative readings of the data in the analysis stage were carried out as well as constant comparisons of emerging concepts and categories. Negative cases were also sought to help refine the analysis process. All these activities were performed in order to increase analysis reliability. Since qualitative research focuses on the analyst’s perspective, it often runs the risk of being wholly subjective. Practicing reflexivity and following systematic procedure throughout the analysis process were both useful strategies to balance this subjectivity. Reflexivity is the “open acknowledgement of the social construction of one’s own account” (Burr, 1995:156). Reflexivity was applied to both the interviewer and the analyst: their shared sympathies and attributes have been stated and reflected upon above. While the interviewer had a set of semi-structured questions, she herself was interpreting the questions in her own way and framing them as such.

Triangulation was also a strategy used to help offset subjectivity on the part of the researcher. The data were triangulated in two ways, methodologically and by using more than one investigator to evaluate the findings (Guion, 2002). As a further measure towards ensuring quality of data, this study provides a clear description of the study context, the data collection and analysis process, as well as a discussion of the personal characteristics of the researcher and disclosure of any bias that she may hold (Mays & Pope, 2000). In this way, it is possible for the readers to make their own decisions about quality of data and whether it is appropriate to transfer the research findings across into another setting. In addition the principal investigator shared a sample of her findings with her thesis supervisor and, again, with a trained anthropologist colleague and compared analytical concepts and categories in order to triangulate analytical findings.

3.9 ETHICAL CONSIDERATIONS

Acceptance of the study for doctoral purposes was granted by the Faculty of Medicine Postgraduate Education Committee (Appendix B), ethical approval by the Biomedical Research Ethics Committee, University of KwaZulu-Natal (Appendix C) and the Institutional Research

Ethics Committee (Appendix D). The researcher had completed two online ethics certification courses as part of the ethical requirements of previous studies she has been involved in (Appendix E).

Three basic ethical principles were adhered to at all times: the principles of respect for persons, beneficence and justice (Patton, 2002). Respect for persons refers to respecting the autonomy of participants and that if autonomy is reduced, recognizing the entitlement to protection. Beneficence refers to doing no harm and to having given consideration to the potential benefits and/or risks that participants may have encountered as a result of the research. The researcher also looked for ways to maximize any possible benefits that the research may embody for research participants while still upholding the principle of justice. When participants presented a problem or had a question regarding their care and/or treatment, the interviewer made sure that they were linked to a nurse or counsellor within the PMTCT department. Since this research dealt with gender issues and since pregnant women are an especially vulnerable population, careful and informed ethical consideration was extended to all research participants. Written informed consent was obtained from all study participants. Of utmost importance was the maintenance of the safety, confidentiality and anonymity of all the participants, both in the data analysis and discussion and dissemination of findings.

This research did not take any coercive measures in the recruitment of participants. Participants were all made aware that their decision of whether to participate in the study would not affect their care. Due to the potentially risky outcome of HIV-related disclosure, there was no compulsion on the researcher's part to influence disclosure or non-disclosure in any manner. Four participants displayed emotional distress during the course of their interview. The interview was immediately suspended, the distress was acknowledged and space and comfort was given as appropriate. Depending on the participant's choice once she had sufficiently recovered, the interview was either recommenced or terminated. In addition, these participants were referred for additional counselling from a predetermined health care provider for professional support.

3.10 SUMMARY

This study drew on a social constructionist theoretical framework. Although an umbrella theory, social constructionism shares common overarching elements. Social constructionist theory argues that an individual's perception of the world is constructed through the individual's social interactions with other people living in the same society. A central interest of the theory lies in the examination of available discourses in a given society since these discourses give clue to the power dynamics operating in that society. The concept of identity is also core to the social constructionist perspective. The two broad streams of social constructionist theory are discussed as well as the limitations of the theory. The study employed a qualitative research study design. All participants were black African females, >18 years old, HIV-positive and accessing PMTCT treatment services in eThekweni, KwaZulu-Natal, South Africa. Sixty-two semi-structured interviews were conducted in two PMTCT sites with 31 participants selected from each site. Drawing on grounded theory as a method for analysis, themes and sub-themes were inductively derived through a step-by-step and iterative coding process. Acceptance of the study for doctoral purposes was granted by the Faculty of Medicine Postgraduate Education Committee, ethical approval was granted by the Biomedical Research Ethics Committee, University of KwaZulu-Natal and the Institutional Research Ethics Committee.

CHAPTER 4: RESULTS

This chapter presents the synthesized findings of the interviews in relation to HIV disclosure, with excerpts drawn directly from the raw data to support thematic claims. The data were organized to answer the overarching research question posed in this thesis:

Under what circumstances, how and to whom do HIV-infected pregnant women receiving Prevention of Mother-to-Child Transmission (PMTCT) services disclose their status and what are the consequences?

The collected raw data were analyzed from a social constructionist theoretical perspective, discussed in Chapter three. In keeping within the social constructionist paradigm, the analysis did not focus on identifying the intrapsychic processes of the participants, as many preceding HIV-related disclosure studies have done. Instead the analysis centered around the socio-historico-cultural context in which the individual was located and looked at the nature of the social interaction that occurred between individuals with a view to identifying the dynamics intrinsic to the HIV disclosure process for HIV-positive pregnant women.

Given the sensitive nature of the material that was discussed, some participants did experience emotional distress during interviews. This is noted in italics in the excerpts below. In these cases, tape recording of the interview was immediately suspended and participants were offered both assistance and the option to terminate the interview. All participants who experienced emotional distress or who had questions of a medical nature were referred to a predetermined counsellor or health care worker for further support and advice.

The study findings are presented as three broad, interrelated themes below. The first section outlines the underlying structural and relational factors influencing sexual risk behaviour as well as HIV disclosure. The second area highlights the concurrency of life changing events (pregnancy and HIV diagnoses) for participants, with particular focus of the impact of these diagnoses on women's identities. The final section reports the specific findings on the HIV

disclosure process and outcomes, looking at disclosure behaviour to sexual partners in the first instance and to family and others in the second.

4.1 PARTICIPANT CHARACTERISTICS

All participants interviewed were black African women between the ages of 18-36 years. The median and mean age of the total sample was 26 years (see Table 2). The median age for participants in Facility 1 was 25 (range 18-34) while the median age for participants in Facility 2 was 27 (range 19-36). There were differences in participant demographics between the facilities which is to be expected given the paid for versus free services. Slightly more participants accessing PMTCT services in Facility 2 were employed than in Facility 1. No women were currently married in Facility 1. Six women were married in Facility 2 with one woman widowed in Facility 2. Most participants were single.

TABLE 2: Characteristics of HIV-positive pregnant women who attended the Prevention of Mother-to-Child Transmission programme in Facility 1 and Facility 2

Age (N=62)		
Median age	26 years	(range 18-36)
Facility 1 (n=31): Median age	25 years	(range 18-34)
Facility 2 (n=31): Median age	27 years	(range 19-36)
Employment status (N=62)		
Employed	33	53%
Facility 1 (n=31): Employed	14	45%
Facility 2 (n=31): Employed	19	61%
Marital status (N=62)		
Married	6	10%
Facility 1 (n=31),	0	0%
Facility 2 (n=31),	6	19%

Single	55	89%
Facility 1 (n=31)	30	97%
Facility 2 (n=31),	25	81%
Widowed	1	2%
Facility 1 (n=31)	1	3%
Facility 2 (n=31)	0	0%

There were differences in living arrangements with partners between participants from the two facilities. Nearly half of the participants accessing services at Facility 2 lived with their partners (at least 14 (45%) participants reported living consistently with their partners) which could perhaps account for them being able to afford/access the paid-for service. In contrast, only three participants accessing services in Facility 1 lived consistently with their partners with the majority (n=21; 68%) of participants reporting that they did not live with their partners. While partner age data were not consistently reported, the age gap between participants and their partners appeared generally higher in Facility 2 (6 years) than in those from Facility 1 (2 years). The median age of partners in Facility 1 was 27 years (range 18-42, missing data n=6). The median age of partners in Facility 2 was 33 years (range 21-72, missing data n=7). Despite the above stated differences there was no substantial difference in the core issues identified. Participant voices and experiences from each facility were similar across themes. While the study ID, age, employment and marital status of each participant is noted in the excerpts drawn from the raw data, there is little direct comparison between participants from the differing facilities in the analysis. This was a deliberate decision since the analytical focus was on the core subjectivities and experiences across the range of participants who were all HIV-positive and pregnant.

4.2 STRUCTURAL AND RELATIONAL FACTORS UNDERLYING TRANSMISSION RISK BEHAVIOUR

Structural and relationship factors were identified as two inter-related themes which fundamentally shaped transmission risk behaviour and subsequent disclosure behaviour and outcomes. Fluid household structures and the burden of HIV on households and on household members' lives very specifically formed part of the broad socio-cultural and historical (structural) influences. Relationship factors included: the lack of involvement of parents; prior experience with violence and intimidation; mutual distrust within sexual relationships; concurrent partnerships; and gendered power imbalances. All these factors characterized the relationship of many participants and formed part of the relationship context within which the women operated and responded to their HIV diagnosis.

4.2.1 STRUCTURAL CONTEXT

Household Structures

The majority of participants lived in households characterized by constant in and out migrations. Many participants did not live with their partners or parents on a consistent basis, if at all. This household patterning formed part of the structural context which influenced disclosure behaviour.

Households, as described by participants, were fluid in composition with immediate family members, including parents, dispersed or entirely absent. Most participants referred to having two homes - a 'family' home in the outlying, rural area, which was visited on an *ad hoc* basis as well as a convenience-based, urban household for day-to-day living. The composition of the urban household was complex and dynamic, consisting of a variety of extended family and sometimes non-family members, as the need arose. The households adjusted and changed in response to socioeconomic circumstances. Often a death in the family necessitated alternative arrangements for surviving children, who were added to an established household. Alternatively, a death of a family member could cause a current residence to be claimed by another part of the

family with the original members having to find other accommodation. Family disagreements or household conflict caused participants to relocate, as well as current sexual relationships, where women may be living wholly or partly with their partners. At the time of the study, at least half of all participants did not live on a day-to-day basis with their partners. Some lived in different provinces to one another and saw each other on a very infrequent basis, sometimes as little as once a month. Losing employment and pregnancy were also reasons for participants moving between households.

Financial resources were generally very constrained, particularly for participants accessing Facility 1, the public sector study site. Those who did manage to generate an income were in the minority, relative to the total number of household occupants. Many in the household relied on this income and there was the general expectation that those who were employed were responsible for contributing to the household upkeep. For example, one participant previously lived in another province and avoided coming home too often because she was expected to purchase groceries for the household at each visit (22 years old, single, unemployed, FA15).

HIV within the Family Context

Many participants had had immediate experience with HIV through one or more family members either being HIV-positive or having passed away from an AIDS-related illness.

“From my family, three are HIV positive and they come to this hospital... it is my two sisters and my cousin.” (29 year old, single, employed, FB10)

“We used to be five but now we are three. The other two died. One died in 2006 of AIDS and another one died last year in February. He shot himself.” (31 years old, single, unemployed, FA27)

4.2.2 RELATIONAL CONTEXT

Absence of Parental Support

Many participants indicated the lack of involvement of one or both of their biological parents in their lives. A 34 year old woman (FA24), for example, last saw her mother in 1978, at which point she “simply disappeared”. She also had never known her father but had been told that he was now deceased.

With low levels of parental support and high levels of morbidity and mortality within the family, many participants had been compelled to shoulder the primary burden of responsibility for their family’s welfare from a very young age. The following woman did not know the whereabouts of her mother who had unexpectedly left home. Her father was also unknown to her and she had been too afraid to ask about him while living with her mother. At the time of the interview, this woman was supporting her younger sibling and a young relative following the multiple deaths of her own mother, father and cousin:

“I was living with my mother while she was employed. When she stopped working she left me with my father’s family and disappeared. Later her cousin decided to take me. ... [When my father passed away] it was in 1999. I was still living with his family. I only came to live with my mother’s cousin in 2006 because I had finished my Matric in 2005. This year, my mother’s cousin passed away in July. ...She was HIV-positive. So I am now left with her daughter who is thirteen years old. When she got married, she got twins and a boy. When she died, her husband took the twins and the boy and went back to his family, leaving the thirteen year old because she was not his child.” (21 years old, single, unemployed, FA22)

In particular, participants’ biological fathers were often absent or unknown to them. It was, however, common for participants to be familiar with or even live with half-siblings born from other relationships of one/both of their parents. One of the reasons given as to why fathers were often absent was that they were involved in relationships with other women.

“He disappeared into thin air. I understand he is somewhere in [a City]. He left when my brother who comes after me was only two years old. He tried to communicate with us but still he didn’t come back. He has got another wife who lives in the rural area. They have two children. The older one visits us now and then.” (27 years old, single, employed, FA25)

This was not true of all fathers. Some had taken on the responsibility of providing a home for their children, in the absence of their mother/s. As a 23 year old, unemployed woman explained, these situations could generate conflict over parental loyalties, where children felt they had to choose between parents. This participant was torn between wanting to connect with her mother to draw on her support during pregnancy but feeling the need to remain loyal to her father who had (and still was) providing a home and financially supporting her and her sibling.

“Ja, that might happen [that one day I might communicate with my mother] but I can’t really say how I feel about her because there are times when I feel I really need her, like now that I am pregnant. When you are a girl at home, you need a mother. Like now I am pregnant and I need her. This is my first child and I have no clue as to what happens when you get a baby. ... I feel I cannot have a relationship with my mother because this would mean I am against my father. So there is this conflict that I have to live with.” (23 years old, single, unemployed, FB01)

Others, however, had no desire to reconnect with one or either parent, and spoke instead about their emotional and physical distance from them. This distance had implications for the way disclosure of HIV status to parents was handled:

“I live with my grandmother, my grandfather and my aunt. ... They are the people I grew up with. I never lived with my mother. When she comes back from overseas she goes to her house where she lives with her husband and my younger siblings. I am the only one she got before she got married to the father of my siblings. ... I know my aunt will tell her [about my HIV status], if she hasn’t already. Then it will be up to her if she wants to

talk about it with me. If she doesn't mention it, I will also not say anything. She is not really part of my life. So whether she knows or not is not important for me.” (21 years old, single, employed, FB22)

Another participant had fallen pregnant at 15 years of age and had dropped out of school because she received no assistance from her mother in the rearing of her child. She went on to have two additional children, both of whom were born HIV-positive. A further child died at birth. This participant was pregnant for the fifth time at the time of the interview. She was also unemployed.

“... I passed standard seven but I couldn't continue after I had a small child and she was sick all the time and I had to sleep with her in hospital. My mother would refuse when I asked her to be with the child in hospital. She was not even employed at that time. She would also go around gossiping about me with her friends. That is when I decided to go and live with my granny. She welcomed me and I even felt free to tell her that the child had tested HIV-positive. She comforted me and said I should not worry because everyone has a date when they will pass on whether they have this virus or not. I decided not to tell my cousins and my younger sister because they might go around telling other kids in the community. ... I have not told my parents, especially my mother as she gets drunk most of the time.” (22 years old, single, unemployed, FA33)

Intimate Sexual Relationship Dynamics

Pre-existing sexual relationship dynamics strongly mediated disclosure behaviour and disclosure outcomes. The themes of gender-based violence, concurrent sexual partnerships, simultaneous pregnancies, relationship expectations and prior risk behaviour were all factors that directly related to disclosure decision-making and outcomes.

Gender-based violence

Some participants had previously experienced sexual and/or physical violence. One woman spoke of a previously violent partner:

“He used to assault me and he was also an alcoholic. When he came home he would just start being violent.” (29 years old, single, unemployed, FA18)

Another 30 year old woman, told us about her experience with sexual violence while she was still at school. She was raped on her way home from a night time waitressing job. In the excerpt below she tells us how she never returned for her HIV test results after the incident because finding out that she was HIV-positive in addition to having been sexually violated was too much for her to bear:

“...I was afraid. I preferred not to know because that would destroy me. Being raped by an HIV-positive person is very mean and destructive.” (30 years old, single, employed, FB28)

Experiences with violence greatly constrained many women’s autonomy and played into subsequent disclosure decision-making processes. Having no paternal support to negotiate her interests on her behalf, the following participant believed she had very little bargaining power within the relationship and would not risk displeasing her partner for fear of physical abuse.

“... I told him when I came here at the clinic I did the test but I will only get the results when I come back again. I then asked him to come with me so that we can have a blood test together. He then became violent and started shouting at me. He then said I must stop pestering him. If I know that I am positive I must go and stop bothering him. He then said he knows he doesn’t have HIV. He is the kind of a person that will make you the guilty one, not him. Even if I have caught him with a woman, he will turn the whole thing around and make me guilty. He also has this attitude that he is a man and cannot be controlled by a woman. He can shout for the whole week. In any case, I try to be calm because he supports me. ... The problem is that I am afraid of him. He knows I come from a broken family. He knows I don’t have a father and all that. That is why I am saying it would be easy for him to do anything he feels like doing to me...” (31 years old, single, unemployed, FA27)

Concurrent Sexual Partnerships

There was a high awareness amongst study participants of their partners being engaged in concurrent relationships but the desire to challenge this was often subordinated by immediate and very real material concerns.¹⁴ One woman was aware that her partner was married and that he had another long term girlfriend in addition to herself. She told us that it was enough that her partner continued to support her through her HIV experience and pregnancy and that he was intending on finding a house for her to stay. That is, there were both emotional and financial considerations to losing a partner during pregnancy. Given the high rates of unemployment amongst the study participants, it was often enough that their partners were providing materially for them, despite manifold relationship problems. Another participant (21 years old, single, unemployed, FA21) reported that her partner never referred to the future in terms of her and the child but that she was “grateful” for the times when he came to see her and for when he, on occasion, gave her some money for her expenses.

Many other participants revealed a deep dissatisfaction with these relationship arrangements but attempts to address this were cause for much contention, usually resulting in the relationship being terminated or the issue being dropped in the interests of relationship harmony and longevity. The age of the partner also often factored into this power dynamic. A 27 year old employed woman told us that other women in her 36 year old partner’s life were a constant source of tension in their relationship.

“...whenever I go to his house I can see that a woman has been around. When I ask him we start quarrelling. I am not sure whether it is because I am younger than him or what. He doesn’t respect me.” (27 years old, single, employed, FB25)

A 26 year old, unemployed woman had been in a four-year relationship with her 42 year old partner but continued to find it difficult to address the issue of concurrent relationships, largely because of the threat of aggression:

¹⁴ This study did not explore to what extent women were involved in their own concurrent relationships since this was not the main focus of enquiry. The likelihood was high based on findings from a previous unpublished study in this area.

“Once I start talking about his relationships he loses his temper and says I don’t want us to live peacefully in the house. I end up not saying anything.” (26 years old, single, unemployed, FB06)

A 28 year employed woman (FB17) broke off her relationship with her younger partner because of his numerous affairs with other women. She told us she “could not stand it”. Some women had no direct evidence that their partners were involved with other women but many felt that it was inevitable especially if they lived some distance from their respective partners and only saw them infrequently.

“Though I am not sure, but I always tell myself he has got another girlfriend. We are too far apart for him not to have another relationship.” (25 years old, single, employed, FA01)

Some participants did not view concurrent partners as inherently problematic. A 20 year old woman (FA02) was aware that her partner was involved with another woman when she first met him. A 23 year old student (FA7) knew her partner had a girlfriend who was 5 months pregnant at the time when she met him. A 26 year old unemployed woman (FB30) had given birth to two children by a man who she already knew was married. His wife, who had since deceased, and children had previously lived in a rural area while he had lived in an urban area together with the study participant.

Simultaneous pregnancies

Sometimes partners’ hitherto concealed concurrent relationships were revealed through simultaneous pregnancies. Several participants were pregnant at the same time as their partner’s concurrent girlfriend/spouse. A 23 year old woman (FB16) only discovered the presence of partner’s concurrent relationship when the woman came to see him with their newborn. The participant was pregnant at the time. A 36 year old employed woman (FB26), also pregnant, left her partner because he impregnated another woman while they were together. A 21 year old participant involved with a 34 year old man also experienced a simultaneous pregnancy with her

partner's girlfriend. She had assumed he was still involved with one of his partners when she started dating him, although this was only confirmed once they were already in a relationship. She describes how she felt when she discovered his other relationship:

"I was deeply hurt. In fact I dumped him. I wasn't aware that I was already pregnant I told him [that I was pregnant] and then he started visiting me again and the relationship continued because I wanted his support. [When I told him I was pregnant] he was really shocked. He didn't expect it. To crown it all his other partner was also pregnant." (21 years old, single, unemployed, FA21)

Another participant, aged 24 years, no longer wished to compete with the other women in her partner's life nor with the constant unknown as to where her partner's affections may lie at a given point, and chose to raise her child alone.

"I have come to a stage where I am too tired to keep talking to him [about the many women in his life]. I have asked him to leave me. ... He once said he is going to include the child in his medical aid and I refused. I told him I don't need his help. I have my own medical aid. I didn't want him to do that because my future with him is very bleak. I don't want to phone him in future and find that he does not answer my calls. ... I am going to raise my child alone... When I told him I wanted another child he might not have been in favour of that and he didn't tell me. Now it is clear he is not prepared to be a good father. ... He has three children from different women and two are not born yet." (24 year old, single, employed, FB14)

As highlighted above, male partners often had other children born to other women in both prior and concurrent relationships.

Relationship Expectations

Many participants voiced very high levels of distrust in terms of their partner's relationship intentions and had low expectations of the future outcome of the relationship itself. A 29 year old woman (FA29) had tested positive in 2003 and had had significant time to come to terms

with her status, yet she refused to disclose to her partner. Earlier in the interview she told us that she “didn’t feel like telling him”. However, her uncertainties over their relationship future clearly influenced her disclosure decision-making:

“The thing is we also have our ups and downs. I am not sure about our future. So I don’t see the need to tell him something so confidential.” (29 years old, single, employed part time, FA29)

Another participant also displayed distrust regarding her partner’s intentions towards her:

“When he deceives me he says he wishes one day we get married but I don’t believe that because men always say that.” (23 years old, single, student, FA07)

The reality of sharing one’s partner with another woman and/or being involved in one’s own concurrent relationship had a large role to play in relationship distrust dynamics.

Many participants presented the gendered construct of a „man’ whose promises were to be viewed with deep suspicion and who was characterized as someone who, despite assurances to the contrary, could change his position at any time without prior warning. The below quotes also illustrate how many women were not in a position of power in terms of determining the future of their relationships.

“I am hoping to continue with my partner as long as he loves me. At the same time I cannot be sure of my future because men change all the time. They are not trustworthy.” (28 years old, single, unknown employment, FA14)

“I can’t be sure because men change all the time.” (34 years old, single, employed, FA24)

In examining the data for other reasons underlying this deep-rooted distrust of male partners, it seemed that past bad relationships very much set the scene for cautiousness in current ones. This had direct implications for the likelihood of disclosure occurring. A 26 year old, employed

woman had been involved with her partner for over a year. She stated that she would not reveal her HIV status to him even if she were to become engaged him:

“I don’t trust him. My first child’s father disappointed me a lot. So I am not prepared to trust any man that I come across. I was careless even to get pregnant. ... I am afraid. I don’t know how he will react. I don’t trust him at the moment and I am not sure how much he loves me. Maybe I don’t know him very well.” (26 years old, single, employed, FA20)

The issue of trust, however, was a complex one. One 28 year old woman (FA14) did not trust her partner’s intentions but told us that she was “hoping to continue with [her] partner as long as he loves [her]”. She was HIV-negative during her first two pregnancies and had only tested positive in this third pregnancy. Her partner later revealed that knew he was positive but hadn’t told her. Yet she still saw a future with him, should he wish it. She had a standard eight education, was unemployed and thus entirely reliant on others for material support.

Prior Risk Behaviour

Most participants revealed that they had previously not used condoms consistently within their sexual relationships, if at all. Various factors fed into this high risk behaviour. The data consistently highlighted that decision-making power around condom use was in the hands of the male partner. In particular, decisions surrounding condoms rested strongly on men’s willingness to use them. This was an especially fraught issue for participants who were in relationships with older men – as was the case for most women in the study. Asked to reflect back on past high risk behaviour, some women believed that they had not had control over the situation and often were at a loss as to why they had not used condoms. Prevailing constructions of masculinity and gendered norms clearly factored into this dynamic.

“Sometimes men are what they are, and at times they end up like they are controlling a person. This is what I feel when it comes to using condoms, especially when a person is much older than you... At times I felt I was not in control of the situation but at the same time it was being stupid from my side. That’s all I can say. I was counselled here and I

knew everything. The best way to put it is that I was being stupid.” (27 years old, single, employed, FB25)

One woman explained how her partner refused to use condoms and that since he was “a man”, she felt unable to force him to do so, and in fact had to “give in to his demands” (36 years old, single, employed, FB26).

Others reported that they did not insist on condoms because they wanted to avoid unwanted conflict with their partners and thereby risk ending the relationship.

“... When my child’s father passed away, whenever I had a relationship I had this fear that I was going to lose him again. I had a problem knowing what men expected of me. I wanted to keep the relationship. That is why I gave in when he said he didn’t have any condoms. I thought if I refused he would lose interest in me. Another thing men always say is that when you keep pressurizing them to use a condom they say it means you are the one that are HIV-positive. Why do you insist on using a condom! They don’t understand that you are also trying to protect yourself. Some even point it out that you insist on using a condom because you don’t trust them, you think they are HIV-positive and the argument will start. So whenever you meet him you are reminded of what he has said about condom usage. That is why I ended up not using any condom with some of my partners. I didn’t want to lose them.” (29 years old, single, employed, FB24)

The issue of trust between partners also influenced the likelihood of condoms being used by couples. Some women did not insist on using condoms because they genuinely trusted their partners to be faithful to them.

“Early in the relationship we used to use it [a condom] but as time went on, we began to trust each other as we lived together. Also I never thought he would have another relationship while I was with him. I only discovered that very late. I noticed that he likes women.” (31 years old, single, unemployed, FA27)

Others did not press the condom issue to avoid appearing distrustful of their partner.

“When we started our relationship, I asked him if he knew his status because it would be a big risk to have sex without a condom. He then said it meant I didn’t trust him. So it happened by mistake that we had unprotected sex and I got unwanted pregnancy and most of all HIV.” (34 year old, single, employed, FA24)

The unequal gender power dynamics within relationships that contributed to risk behaviour, as outlined above, continued to form part of the relationship and HIV disclosure behaviour dynamics.

4.3 CONCURRENT LIFE CHANGING EVENTS

Many participants were diagnosed with HIV and unintended pregnancy concurrently, which had a profound impact on participant’s identities and on subsequent disclosure behaviour. This section highlights the interplay of the conditions of HIV and pregnancy on each other and the shifting realities and identities of participants as a result of their concurrent diagnoses. Stigma was also evoked in multiple ways. There was stigma attached to being HIV-positive, having an unintended pregnancy and being both pregnant and HIV-positive. Internalized and externalized stigma was reported by participants. The timing of the two diagnoses and the stigma attached to these conditions strongly influenced decision-making over disclosure of pregnancy and actual disclosure of HIV.

4.3.1 CONCURRENT DIAGNOSIS: THE INTERPLAY OF PREGNANCY AND HIV

Two clear ‘diagnosis events’ emerged from the participant narratives: 1) being HIV-positive, and 2) being pregnant. Each impacted on the other and on disclosure in critical ways as well as on participants’ sexual and family relationships. The two diagnoses may have been discovered simultaneously or separately from one another, although were in most cases closely related. The

fact that most pregnancies were unplanned meant that participants had to come to terms with pregnancy and its implications, as well as adjust to their HIV diagnosis and its impact on their lives and their unborn infants. Two diagnoses also meant two levels of communication or disclosure to another person, in addition to having to deal with the ramifications of an HIV diagnosis and an unplanned pregnancy. Cultural observances attached to pregnancy out of wedlock were folded into these complexities.

HIV Diagnosis

Most participants had only recently been diagnosed with HIV. The majority of participants had discovered their status as a direct result of an antenatal clinic encounter, with over half of the study participants having learned their HIV status in 2008, the same year that we interviewed them. It is important to note that the condition of pregnancy, together with the availability of HIV services offered at the antenatal clinics, influenced the decision for these women to test. A 29 year old married woman told us that if it were not for her pregnancy, she may have avoided going for an HIV test altogether.

“I had ups and downs with my husband. He wasn’t faithful to me and even before I became pregnant, I had already suspected I might be positive because my husband had other relationships. Though I tested negative the first time but I kept telling myself this time I could be positive but I could not let myself do the test. I was only compelled to do it when I was pregnant. ... I am not sure if I would [have tested if I was not pregnant]. I don’t think I would. At times it is difficult to face reality. You feel better if you keep it in suspense.” (29 years old, married, employed, FB27)

Unintended Pregnancies

At least two thirds of the participants had had a previous pregnancy and very few current pregnancies had been planned. Because most pregnancies were unintended, participants were not only dealing with the implications of their HIV status to their unborn child and themselves, they were also confused about their feelings regarding being pregnant.

“I am still trying to deal with my emotions right now. To tell you the truth I can’t tell you how I feel right now... Well I have made peace with the HIV. I am specifically talking about the pregnancy because, I mean, it wasn’t planned, you know.” (28 year old, single, employed, FB04)

Having an unplanned pregnancy posed considerable disruption to participants’ lives. Some women had dropped out of school and others had resigned from their current places of employment due to their pregnancy. This had a direct effect on how they responded to their pregnancy, some feeling positive about it, and others being dismayed over the unforeseen nature of the event. In addition to this, while both parents-to-be may not have planned the pregnancy nor wished for a child, it was understood that the woman was primarily responsible for supporting and raising the child, with or without financial commitment from the biological father. Care-giving activities, as evidenced by earlier children, usually fell to the mother of the child or a close female relative. A 22 year old, unemployed woman shared her profound dismay at having fallen pregnant for the second time and the ramifications of this on her academic future:

“This child I am carrying is a big mistake. I don’t know how it happened because I was on a pill. ...I don’t know what I should do now because when I asked for an abortion, the nurses said it was too late. I want to ask the nurses today what happens if a mother does not want the child. My partner said he wants nothing to do with this pregnancy. As it is I asked him to buy some clothes for the child and he refused. ... My grandmother said if I get pregnant again she won’t pay for my education.” (22 years old, single, unemployed, FA30)

A 36 year old employed woman did not want to have a baby for other reasons altogether.

“Naturally I don’t like children...I think it is because we grew up watching our father having relationships with women who already had kids. He would fall in love with a woman and bring her together with her children to our house. On top of that he would

make this woman pregnant and he would love this woman's children more than us." (36 years old, single, employed, FB26)

Announcement of unintended pregnancy was also often unwelcome news for the imminent grandparents since they frequently took on the responsibility of being the child's primary caregiver. In addition to her own feelings of shock at her unintended pregnancy, an 18 year old scholar recounted how her mother reacted when informed of the pregnancy. She had not disclosed her HIV status at the time of the interview.

"Eish, she shouted at me. She was only short of beating me up. She said I had disappointed her. She cried a lot." (18 years old, single, scholar, FA26)

Although it was the case for the majority of participants, not all pregnancies were unintended. A 24 year old employed woman was 18 years old when her first child was born. This child was being raised by her grandmother. Because of this, the participant felt she had missed the experience of motherhood and wanted to have another child in order to go through the mothering experience herself.

Pregnancy also had a direct impact on sexual relationships. All participants were pregnant at the time of their interviews yet one tenth were no longer involved and/or in contact with the biological father-to-be. This was sometimes due to a general relationship breakdown but was also because of many partner's unwillingness to take responsibility for the unborn child. A 31 year old, employed woman had been in a relationship with her partner for three and half years, but this ended the day she informed him of her pregnancy. He reportedly asked her to terminate the pregnancy. When she refused, he informed her via email the next day that the relationship was over. At the time of the interview, she had had no further contact with him. Another woman was abandoned by her partner eight months into her pregnancy.

While pregnancy caused some participants' relationships to disintegrate, for other women, it was reason for greater display of commitment from their partners. Although one woman's (FB03)

partner was already married, he continued to show support to her on announcement of her pregnancy.

“At the moment everything is fine. I always think getting pregnant by him was a blessing because he gives me support. He gives me that support because I am pregnant and it is his child. He hopes that the child will not be infected. I also don’t think he would dump me eventually. He supports me in every way possible.” (36 years old, single, employed, FB03)

Some study participants referred to the expected cultural observations and practices attached to becoming pregnant. For example, the customary practice of the father of the child presenting himself to the woman’s family with a view to introducing himself and arranging to pay ‘damages’ for the extra-marital pregnancy.¹⁵ The partner of an 18 year-old woman had already paid damages for the pregnancy, yet she had doubts about the longevity of the relationship:

“He does talk about that [marriage] but I can’t rely on that because men are not trustworthy. He can say it now just because I am pregnant. He might find another woman at any time.” (18 years old, single, scholar, FA6)

The pre-existing gender power imbalances were exacerbated by women’s inherent material vulnerability during pregnancy, where partners held much of the bargaining power. A 30 year old, unemployed woman believed that her partner was the one who had infected her. However, she occupied a passive role in determining the future of their relationship. Her decision was strongly influenced by her awareness of her vulnerable state of being pregnant with no apparent income of her own to support herself or her child.

¹⁵ According to customary law (Harrison 2008, Hunter 2006), the biological father is not entitled to claim custody of the child if he has not paid damages (*inhlawulo*) in the form of livestock or, more commonly, financial remuneration. If marriage between the parents does occur, the payment from the damages forms part of the *lobola* (bride wealth). It is important to note, however, that payment of damages by a man does not necessarily signal intention to marry the mother of his child

“It came to my mind when we tested positive that he might leave me, but when we talked about it and he said we must continue our relationship, I was relieved. ... It would be very difficult for me [if he left the relationship] because I was pregnant and unemployed. It would mean I would have to raise my child single handedly. It is not a good thing to be dumped with a child.” (30 years old, single, unemployed, FB13)

Impact of Concurrent Events on HIV Disclosure

There were two broad categories of disclosure for participants: communication over their HIV status and communication over their pregnancy. Being HIV-positive and pregnant had implications for the woman’s health and for the health of her unborn child. Disclosure of HIV status therefore could communicate risk to the sexual partner, raise concerns over the woman’s health, and raise questions about the risk posed to the foetus. Pregnancy impacted HIV-related disclosure in a number of key ways. Often the pregnancies and the need to maintain their relationships in the time of pregnancy, rather than HIV, were of immediate concern to participants. A 34 year old employed woman was engaged to get married to her partner yet had withheld her status because she was unwilling to jeopardize their relationship future, especially as she was about to have a baby. Despite the imminent marriage, she was not convinced that he would not leave her should she disclose to him and although she recognized that withholding her status may constitute a betrayal, she decided to wait until the baby was born.

“I am not ready to tell him because since I am pregnant, anything can happen. What I told myself was that I have to put this baby first, for now, and then deal with the other things afterwards.” (34 years old, single, employed, FB15)

A 25 year old employed woman (FB23) reported that she was going to wait to see what her baby’s HIV status was before she disclosed to her mother in order to spare her mother the inevitable worry over the health of the infant. A 22 year old unemployed woman encountered different levels of complexity in disclosing her HIV status. She did not want to compromise her partner’s excitement over the pregnancy by disclosing her HIV status to him and did not want to “disappoint” her mother further by revealing her status so closely following her announcement of

her unintended pregnancy. This participant also feared the stigma attached to falling pregnant by mistake, in addition to the stigma in acquiring HIV:

“...I have been a bad girl by falling pregnant and now to tell her I am HIV-positive, it will be too much for her.” (22 years old, single, unemployed, FB21)

Varying levels of HIV disclosure were evident within the pregnancy dynamic. A 21 year old employed woman had disclosed her HIV status to her partner but chose to withhold from him her concerns regarding the potential HIV transmission to the child.

“I haven’t told my partner about the chances of the child being infected already. ...I think he will be very worried. I won’t tell him about this.” (21 years old, single, employed, FB22)

A 20 year old woman described some of the known expectations surrounding the announcement of an unintended pregnancy but felt she had no such precedent for disclosure of her HIV status. She found herself in a „double disclosure bind’; how to deal with the stigma surrounding her pregnancy and how to go about disclosing her HIV status and then dealing with the associated stigma.

“You see the problem is where I come from. I come from a very traditional community. Even this pregnancy will be a big issue when I go back home because I will be expected to introduce my boyfriend to my parents and the whole community should be invited to come and see him. So since I am pregnant, I haven’t told anybody except my mother. It would be even worse to tell them I am HIV-positive.” (20 years old, single, employed part-time, FA02)

The complexities around unintended pregnancy and being diagnosed with HIV were not the only considerations for some participants in the disclosure decision-making process. One woman felt that she could not tell her family about her HIV status since they had not endorsed her relationship with her partner and her unintended pregnancy was already viewed as a disgrace.

“Nobody knows at home. At the moment it is me and my partner that are aware that I am HIV positive. I really don’t feel I can tell them at the moment. ...The reason for that is that they were not in favour of me having a relationship with my boyfriend. I had spent a very long time after I separated with my previous boyfriend. So when I eventually found myself a boyfriend, I quickly got pregnant. So it would be a disaster for them to hear that I am now HIV-positive.” (36 years old, single, employed, FB03)

4.3.2 SHIFTING REALITIES, NEW IDENTITIES AND DISCLOSURE

A key theme which emerged was that being diagnosed with HIV (and invariably pregnancy to some degree) had a profound effect on these women’s established social identities and often marked a period of profound introspection regarding this new, often contested, identity. Some had accepted and made peace with their HIV diagnosis but the majority of women were still grappling with the implications of HIV on their lives. Dealing with this new identity was central to disclosure decision-making activities where the *perceived* costs versus benefits to disclosure, relative to the self, had to be weighed up. The index pregnancy was an additional consideration. Once a decision was made to disclose to someone, the *actual* costs and/or benefits would form the outcome. Feedback as an outcome of HIV disclosure greatly impacted on some participant’s identities and this influenced the likelihood of further HIV disclosure. This section highlights how shifting realities and new identities marked a crisis point in participant’s pre-existing identity structures, the various stages of identity incorporation that participants went through and the impact of HIV-stigma on identity and disclosure.

Identities in Crisis

Most women were forced to confront their statuses directly, at least for the duration of their pregnancies. Due to the tendency for their pregnancy and HIV diagnosis to be concurrent, participants had little time to adjust to their pregnancies and to assimilate their HIV status in terms of the impact on their own lives as well as for their current pregnancy.

“What made it worse was that I first discovered that I was pregnant and then later HIV-positive. It was like putting salt in an open wound.” (21 year old, single, student, FB29)

A 28 year old woman was so traumatized by the discovery of an earlier pregnancy, at the same time as learning she was HIV-positive, that she terminated the pregnancy.

“I was confused. There were so many things happening at the same time. ...Like testing positive and getting pregnant. Everything was just overwhelming...” (28 years old, single, employed, FB04)

A 22 year old woman (FA30) also told us that she tried to have her pregnancy terminated but was told that the foetus was too far along in gestation for her to be allowed this procedure. Another 22 year old unemployed woman revealed her bewilderment in how to deal with her concurrent diagnoses:

“I have got a lot at the moment that is going through my mind. I am the one that has a problem and it is not an easy type of a problem to tell. I am still in a very confused state of mind.” (22 years old, single, unemployed, FB21)

An HIV diagnosis, without pregnancy considerations, was also deeply upsetting to many women. Some participants touched painfully on the concept that they had brought their HIV status upon themselves because of previous ‘bad’ behaviour and so feared disclosing to others. In theory, disclosure for this group of women would not only reveal their health status but could invite unsolicited comment over their past behaviour which some participants themselves already greatly regretted. A 26 year old very starkly sums up how she feels about herself in regards to her status:

“[To be HIV positive] means I am empty. I am ‘f.....up’. I mean that my life is empty. What else can I do when I am HIV-positive?” (26 years old, single, employed, FA20)

Being diagnosed HIV-positive gave many women cause to take stock of their lives and often marked the beginning of a shift in how they fundamentally viewed themselves. Many participants perceived themselves as „different’ to how they had been prior to knowing their status. This could relate to the above feelings of hopelessness and anger at oneself but also could relate to having to take care of their health through healthy living and eating:

“I know that I have to change the way I have been living, like now I have to live a healthy life. I also feel I am now different. I am no longer the same person that I used to be. Now I have to keep it in my mind that I am positive and that I can no longer take things for granted, like having sex without a condom, because I will be infected again. My life has really changed. I must also be careful what kind of food I eat because if I am not careful I will get sick.” (21 year old, single, student, FB29)

“I mean my life is not going to be the same again. So that is why I am saying,,as normal as it can get’ if that makes any sense. It is not going to be normal again. ... Because my health has changed. I am going to be having to deal with drinking ARV tablets which the normal person would not have such complications or problems to deal with, you understand. So I now have different kinds of challenges than your normal folk on the street.” (28 years old, single, employed, FB04)

Participants often revealed deep-seated inner conflict and trauma in their responses to questions concerning their perceptions of their HIV status. At face value, a 32 year old employed woman (FB09) responded off-handedly over her feelings related to her HIV status. However, on closer reading of her interview, nothing that she did concerning her status was casual. She and her partner had stopped having sex for the duration of her pregnancy so that they didn’t “endanger” the child. They didn’t even risk using condoms due to a previous incident where one had come off during sexual activity. According to the participant, “sex is taboo”. The participant was also on ARVs and was concerned that she had not come to PMTCT early enough in her pregnancy in order for them to have the most effect. This woman, in fact, was taking her status very seriously despite what she initially claimed. It also appeared as if this participant could not truly engage

her mind with her status for fear that she would lose herself. She told us: “if I start crying now, it will always eat me up”.

Another woman told us that she did not take her status seriously yet she also revealed that she felt angered whenever she thought about her status. She communicated her dislike of her antiretroviral treatment, because despite her apparent nonchalance over her status, the medication represented a physical reminder of an HIV status she would have preferred to forget:

“Maybe you will say I am weird. I just don’t take it seriously ... being HIV-positive is not so much of a problem for me. It was only when I started taking treatment that I cursed the day I got the virus. When I was holding the tablets in my hand it was like I was holding the devil himself. I felt like not taking them at all and I was really not going to take them if I was not pregnant. ... They are a constant reminder of your status. You cannot forget that you are HIV-positive.” (29 years old, single, employed, FB10)

A few interviews had to be suspended due to emotional breakdowns when women recounted the time when they tested positive for HIV. It was very clear that some women were very far from accepting their HIV diagnosis:

“Oooh! I really don’t know what to say. First of all, when [the clinic nurse] told me, what I told myself was that, “O.K. if I have got it, then I have got it”, but the minute I was alone at home, I started crying endlessly and asking “why me, why me?” I have been with one boyfriend all this time and I never cheated on him and then this thing happens. I was really shocked and angry. [*Participant is crying*] ... Ja, I am o.k., it’s just that I haven’t accepted it.” (25 year old, single, employed, FB23)

Another woman told us that her partner had previously known that he was HIV-positive but had withheld this from her. It was only after she announced her pregnancy that he revealed this knowledge in the interests of protecting the unborn child. What he could not express in time to protect his partner, he was able to convey only once she fell pregnant:

“We used to use [the condom] but on this particular day he decided not to use it. ... He had it on. I am not sure when he removed it. I only realized after we had had sex that he had removed it. ... I was so angry that I started crying hysterically. I told him by using a condom I was protecting myself from falling pregnant and getting HIV. I was also not on any contraception. I was really mad at him for being so careless. ... [When I told him I was pregnant] he was not happy because our first child is still very young.” (*She started crying hysterically. She could not continue with the interview*) (28 years old, single, unemployed, FA14)

The excerpt above highlights the far reaching hurt and betrayal that occurred between couples in terms of HIV by withholding one's status and knowingly exposing that partner to risk. The withholding of critical information can be seen as an irrevocable betrayal on a very intimate level to the trust between couples. This participant's description brings into stark relief her experience of betrayal on multiple levels. She stated that she tested negative with her first child (also a child of the current partner) but with this second pregnancy had tested positive. She revealed that she suspected that her partner had had other sexual relationships during the times she went to stay at her family's home. Being interviewed about these issues proved how fragile her apparent composure was. At the outset of the interview, this participant confidently told us that she has accepted her status and appeared composed. However, as the interview progressed, she became distraught and was clearly far from accepting any aspect of her situation.

Being diagnosed with HIV almost always brought the spectre of past relationships into the current one - this was most visible in serodiscordant relationships. Testing positive for HIV could also point to a potentially concealed infidelity on either side and therefore also constitute an additional betrayal of trust between the couple. Not only had a partner strayed outside the relationship bounds but also potentially brought HIV into the index relationship as a result of these infidelities. As highlighted earlier, some women, as an expression of trust in their partner's presumed fidelity, did not use condoms to protect themselves from HIV. These women experienced dual fold betrayal on a very intimate and visceral level.

“I was very angry with my partner [when I tested positive] because I knew I hadn’t cheated on him. I asked him what he did in my absence. I was very angry and I shouted at him. I told him I was negative when I tested with my first child. Now I am positive. I blamed him for it.” (25 year old, single, unemployed, FA13)

Identity Incorporation Process

Participants, throughout the interviews, clearly demonstrated that they were at different stages of coming to terms with their status. These stages were broadly characterized by states of denial, anger, bargaining, depression, and finally acceptance.¹⁶ Not all participants went through each of the above stages and not necessarily in the same order but, on the whole, did experience one or more of these states after their respective HIV diagnosis. As participants cycled through the different stages of assimilation of their diagnoses, this fed into their evolving new identities which in turn influenced the disclosure process. Similarly, the various responses to their disclosure fed back into their evolving identities which in turn fed into how they responded to their diagnoses. A 34 year old unemployed woman shared her very raw truth in terms of her HIV diagnosis and highlights the unpredictable oscillation between the different stages in coming to terms with her diagnosis:

“It is a bad experience and I would not wish it on anyone else. On the other hand I have to accept it and learn to live with it because the fact is it is in my blood and will not go away. It is one of the diseases that make you feel helpless because no matter how much you resent it, it will always be in your blood. So the best option is just to accept it and live with it.” (34 years old, single, unemployed, FA17)

A 30 year old unemployed woman linked her HIV diagnosis with imminent death. A 36 year old woman could not accept her HIV status on first time testing. She felt that there had to have been a mistake with her results and it was only after she returned for her CD4 results that her status became a reality for her.

¹⁶ These stages are based on the Kübler-Ross model of grief.

“So we kept telling ourselves that when I see my blood results I would find I tested negative. So when I came back for my results, that was the hardest day for me. I was really very shocked. Everything changed and I looked at my health situation differently.” (36 years old, single, employed, FB03)

On the whole, accepting one’s diagnosis took time for the majority of participants, even those who had known their status prior to falling pregnant:

“...it has taken me a very long time to accept that I am living with this disease. It took me years.” (27 years old, single, employed, FB25)

Making peace with their personal role in the risk behaviour leading up to their diagnosis was something that only very few women could acknowledge. A 21 year old student tried to come to terms with her one reported unprotected sexual encounter which resulted in both HIV acquisition and pregnancy.

“I think though, acceptance is the best way to deal with HIV. Not accepting your status will only make matters worse. I only had sex with this guy once and we didn’t use a condom. I had never had sex before that. I never thought anything could happen. It was the first time and I got pregnant and I got HIV as well. Whenever I think of that day I feel angry with myself, because I am to blame. I can’t go around blaming other people when I am the one that put myself in all this trouble.” (21 years old, single, student, FB29)

A 26 year old employed woman viewed her diagnosis as a positive event since it gave her pause to reassess and redefine her prior social identity and associated behaviour:

“Last year I was telling myself that I was just a normal person, that I didn’t have HIV. Now I have HIV and I think it is good that I know because I have changed my life around, unlike a person who does not know her/his status.” (26 years old, single, employed, FA11)

Another participant reassesses her priorities, shifting focus from defining herself in terms of her relationship with men to her relationship with herself and her coming child.

“I am in a new place now where I have to focus and know what I want. There is no more time to do whatever I wanted to do. I have to stay healthy. In fact for me it is like a new challenge in my life and it is the hardest battle that I have to fight, a very hard battle, and I am trying to come to terms with it and fully understand it. So even if my boyfriend leaves me, I will never have another relationship. It will not be worth it. The relationship I will have will be between me and my child. So I will just have to focus on my life.” (25 years old, single, employed, FA09)

The Role of Stigma on Identity and Disclosure

The theme of stigma emerged when participant's expressed their fears around being viewed differently by others (external stigma) and when participant's internalized feelings of shame at being diagnosed with HIV (internal stigma). Both forms of stigma (internal and external) influenced HIV disclosure. There were also multiple levels of stigma related to these communications: stigma attached to an unintended pregnancy, stigma in acquiring HIV and the stigma surrounding being an HIV-positive, pregnant woman.

Many participants revealed deeply internalized stigma and this impacted strongly on their ability to accept their status and by extension, engage with the process of disclosure. A 30 year old unemployed woman had known about her HIV infection for three years prior to this interview yet continued to view her condition in the following light:

“HIV is not like other diseases. It is a shameful disease and when you tell other people about your status they judge you as someone who has been sleeping around. There are many reasons why I will not tell anyone. I wish I didn't have this virus. It is not easy to disclose something that everybody would not like to have, something that everybody is talking badly about. As I told you, when I got my results I thought of death and also of my unborn child. HIV is not an easy illness to live with. You can't go around telling

people, no matter how close they are to you. Maybe if I was dying I would tell them, but I just don't see myself telling anyone, and I will not.”(30 years old, single, unemployed, FB13)

Many women expressed anger at having acquired HIV. This anger was either directed inward at themselves or outward towards a clearly identifiable individual who was viewed as the culprit for transmission. A 26 year old recalled her experience of testing positive for HIV and reveals deep feelings of regret over her past behaviour:

“What can I say, I was expecting it, because I also have had quite a number of relationships and out of these relationships, I can't say I must blame so and so because I don't know how I contracted the virus along the way. I know that I have had unprotected sex many times. [You have unprotected sex even if you know you might contract HIV because] first of all, when you meet a guy and listen to him talk, you begin to trust him and not think he might be positive. Secondly it is carelessness. I have been careless in most of my relationships and from that I got HIV. So as long as people don't protect themselves from HIV, they will be infected all the time. People have to learn to love themselves and not be fools like me.” (26 years old, single, employed, FA20)

A 23 year old student blamed her condition on another's “loose character” drawing on the commonly evoked theme of dubious morals and sexual licentiousness in relation to HIV acquisition.

“... I am convinced he infected me because his girlfriend had a very loose character. I have only had sex with my previous partner and him. I was negative when I tested with my first child and now I tested positive. My previous boyfriend was negative and he was well behaved.” (23 years old, single, student, FA07)

Closely related to the theme of HIV being linked to „shameful' behaviour, were expressions of disappointment by women in themselves in having acquired the virus. A 27 year old, employed woman encapsulates this view:

“At times I see myself as a failure and ask myself, “Why me?” Why was I careless in so much that I contracted this disease whereas there are people who have reached fifty to sixty years and they are not positive! Sometimes I even doubt if I will live up to that age. At times I keep blaming myself. I was careless. My mother used to talk to me about everything, and she made it a point that I was protected from this disease. She even took me to boarding school. She said she wanted me to have a life she didn’t even have and I disappointed her. So I think of myself as a dismal failure.” (27 years old, single, employed, FB25)

Some women spoke about living a different life, a „clean’ life. This theme is directly linked to the theme of HIV being allied with sexual licentiousness/shameful behaviour. „Clean living’ by direct contrast requires „self control’. The notion of „being in control’ was often juxtaposed with „being out of control’ and that having one’s life out of control was what had led up to their HIV acquisition. Being diagnosed with HIV, then, brought that life back under control or into perspective. A 30 year old woman tells us:

“For me, being HIV-positive means that life is in my hands now. I am in control of my life. If I want to live longer I have to live positively. So I am in control of my life.” (30 years old, single, employed, FB28)

In an effort to preserve their original social identities and not have others look at them differently, many women preferred to strictly limit their disclosure and some, not to disclose at all. A 23 year old student refuses to disclose to her family on the following grounds:

“I want to remain the same sister they know without HIV.” (23 years old, single, student, FA07)

Many women feared that they would be stigmatized if knowledge of their status was widely known. When asked about her feelings of HIV disclosure, a 21 year old unemployed woman confided:

“Ay, I am afraid. I don’t want people to point fingers at me. The way I always hear people talking about HIV-positive people is not good. They are not educated about it yet. That is why I am afraid. Even my own aunt does not say good things about HIV-positive people. Whenever she sees someone that has gone thin, she says bad things. Never mind the community.” (21 years old, single, unemployed, FA21)

However, maintaining secrecy over one’s HIV status also was a burden.

“Stigma is still there in our communities. I think that is why many people prefer not to know their status because they are afraid of the communities they live in. When you are HIV-positive it is like people are aware you are positive. I don’t know, and all the time you have to be cautious how you talk, in case you give yourself away and people will start talking about you...” [*begins to cry*] (21 years old, single, student, FB29)

A 27 year old employed woman sought to escape the censorious gaze of others who knew of or perhaps suspected her HIV status due to her altered appearance, all of which had a marked effect on her ability to accept herself. It appeared that the expressed or unexpressed views of others over her HIV status had a strong role to play in the reconstruction of her new identity:

“I wish I could be away from the people I grew up with and go somewhere where I can start a new life and live the life I want to live. I want to live with people who don’t know my status. As I have said to you, maybe some of the people in the community have started talking about me. ...I used to have a very smooth skin but since I had chicken pox, now I have all these black marks on my face and body. I also swell at times and my life just becomes a mess. People look at all this and this makes me feel they are suspecting I am positive. So I want to be somewhere where I can get a job and start loving myself again and bring my children up in a good environment. Just that.” (27 year old, single, employed, FB25)

Experiences of HIV-related stigma proved a barrier to HIV disclosure. Some participants had had previous experience of being stigmatized and this, in turn, influenced their decision not to disclose to others.

4.4 HIV DISCLOSURE PROCESS

The preceding sections have highlighted the broad overarching and intersecting influences on disclosure behaviour. This section deals specifically with two main groups of individuals to whom participants in a PMTCT context disclosed to: sexual partners, and family/others. The issues involved in disclosure to family members and others within participants' social networks overlapped with that of intimate partners to a certain extent. Pregnancy, the general recentness of the HIV diagnosis and the overlap of these two conditions formed the main shared obstacle for disclosure to both groups of individuals. Previous bad experiences with disclosure also greatly influenced decisions to disclose in the present, as did socioeconomic concerns and disclosure recipient cues – although different iterations of these two themes occurred for each category. Three main elements to the HIV disclosure behaviour were identified for each group of individuals: 1) Disclosure decision-making; 2) The disclosure process; and 3) Disclosure outcomes/consequences.

4.4.1 PANDORA'S BOX¹⁷: HIV DISCLOSURE TO SEXUAL PARTNERS

Decision-making activities regarding HIV disclosure to intimate partners occurred in the context of a highly complex web of pre-existing and non HIV-related relationship dynamics. This has been discussed in preceding sections. Disclosure of HIV often tipped the balance to these other sensitive relationship complexities and played out against prevailing gender inequality and structural vulnerability. Factors such as an unknown HIV status of one's partner, pregnancy and past and present sexual relationships all influenced HIV-related disclosure to sexual partners.

¹⁷ With its origins in Greek mythology, the opening of Pandora's box is an idiom used to refer to something that can lead to unanticipated and often irrevocable consequences.

Disclosure to sexual partners often had unexpected consequences for study participants. Particular disclosure outcomes for sexual partners were identified: partner proxy testing, partner silences, deliberate high risk behaviour and persistent condom negotiation difficulties. The concept of blame and betrayal were two threads that ran throughout the negotiation of HIV-status within sexual relationships.

Disclosure decision-making to sexual partners

The message that came through very clearly from participants was that disclosure to a sexual partner was not a matter of simply informing him about her HIV status. Disclosure of HIV posed direct and profound implications for the partner given the sexual route of transmission. The participant interviews highlighted the highly complex and sensitive nature of disclosure to others in general but particularly in the context of intimate relationships. A 24 year old employed woman discusses her views on the topic:

“It depends on the situation in which you are in. This is a delicate matter and it can cost you your relationship. I think it is good to tell your immediate family members because they are the ones that will help you when you need help, but telling your partner is a tricky business because you don’t know how he will react. That is why I am keeping my mouth shut.” (34 years old, single, employed, FA24)

There were also very real pragmatic concerns in disclosing to one’s partner. A 28 year old employed woman suspected that her partner was HIV-positive but had deliberately concealed his status from her. This was the participant’s first pregnancy and first time to test. She admitted that she would have left him had she discovered he was HIV-positive. In recognizing this truth in herself, she expected the same of him. In this participant’s view, it was not in her best interests to be honest about her status. Allied to this was her wish to avoid being blamed for “bringing” HIV into the relationship. This participant had not disclosed her status to her partner at the time of her interview.

“I don’t want to spoil our relationship, because if I leave him, where will I go? People are sick out there. I might as well stay put. ...I have been in relationships where I was

desperate to be a wife. I was well behaved and did everything a man wanted, but they never talked about marriage. Now I have met this man. I only met him towards the end of last year and he is already paying *lobola* for us to get married. He is different from all the healthy men I have met. He is honest with me. When I leave him here I know he will not have sex with anybody else. He will wait for me to come back. I know of men who cannot sleep without a woman next to them. I know of men who don't come back home when they have got their salary. That is why I am saying I am satisfied with things as they are." (28 years old, single, employed, FA08)

A 34 year old woman revealed how her own feelings of responsibility over acquiring HIV and potentially transmitting the virus proved an obstacle to her disclosing to her partner:

"...I could not blame him. I know a lot about HIV and it wasn't something that was new to me. I know that there is always stigma attached to it, but going around asking where I could have got it from was not going to help me at the end of the day. So I just told myself it was going to be difficult because if I went to him and said „this is the story, and you infected me.’ What if he didn't and it is the other way round?" (34 years old, single, employed, FB15)

The Disclosure Process

Most participants did disclose their status to their partners. Given the sensitivities involved in communicating their HIV status, participants often found indirect or strategic ways of telling their partners, and indeed others, about their HIV status. This could involve „testing the waters’ to try ascertain how their disclosure would be received prior to deciding to disclose.

"I was afraid. I didn't know how he would react. Before I told him I kept introducing the topic, when we were just talking in general. I wanted to see how much he understood about HIV and how he would react when I eventually told him. When I was satisfied with his answers, I told him." (26 year old, single, employed, FA11)

“... Another biggest worry was how to tell my present partner. I wasn’t even sure whether to tell him I tested positive. Though I have been with him for quite some time, but I wasn’t sure how he would react. So I introduced the topic by telling him about someone he knew that looked HIV-positive. I just kept talking about other people, trying to feel how he perceived HIV-positive people. Eventually I was convinced that he wasn’t really afraid of HIV as it were.” (29 year old, single, employed, FB24)

The next two participants share their own particular situational strategies in disclosing to their partners.

“I was taking my iron tablets that morning and when he saw me he said, „Oh you are already on ARVs?’ I said that was not the case. ... We always joke about that when one of us takes any medication. We say „Oh you are on ARVs’. So when he said this statement I told him that I only take ARVs at seven in the morning and seven in the evening. He thought I was still joking like we used to do until I showed him the tablets. I then told him I tested HIV-positive. There was dead silence and he did not say anything. Then he asked if I was telling the truth and I said, yes. He then started to cry.” (30 year old, married, employed, FB11)

“We started dating last year. After dumping that one, I was alone for quite some time because I was just fed up with men. I met this one last year in January. When he asked me to be his girlfriend I just said it would be impossible. At first it was difficult to tell him because we were not in a relationship yet and I didn’t know him from a bar of soap. So when he pressurized me one day I just decided to tell him it would be impossible to have an affair with him and I took out a piece of paper and wrote, „HIV, impossible’ and I gave him that piece of paper. I was afraid to tell him verbally. I just started crying and tears rolled down my cheeks. I was so afraid that after I had disclosed my status to him he would go out and tell the rest of the community that I am HIV-positive.” (28 years old, single, employed, FB17)

Some participants were not able to disclose their status to their partners, either because of personal fears or views on the matter or because they had not yet found a way to communicate their status. Non-disclosure did create difficulties for participants with regard to the stress involved in maintaining their secret, but most particularly in the area of negotiating condoms.

“It really breaks me [to be in a situation that he doesn’t know my status and he is pushing me to test]. It has come to a point where I don’t know what to do. For instance we have to use a condom now but now how will I explain this. He will ask me why all of a sudden. That is why I was saying maybe it will be easy if he does his own test and I do mine separately.” (29 years old, single, employed, FB10)

The “Pandora box” effect was the very reason why a 31 year old employed woman refused to disclose her status to her partner. Like other participants, she strongly suspected her partner already knew his status but did not want to be blamed by him for introducing the presence of HIV into their relationship. Interestingly, this participant’s partner also seemed to be warning her not to open “Pandora’s box”.

“I think he already knows his status. That is why he has behaved in this way. It is wise for me just to keep quiet. He can even go on and say he told me that should he ever become sick, I would be to blame, and yet he has never shown me his results.” (31 years old, single, employed, FB20)

Disclosure Outcomes

Anger and Blame

Partner reactions to HIV disclosure tended to be linked with their own HIV status. That is, if the partner was similarly HIV-positive, the couple dealt with their shared positive status as a unit. However, if a partner was HIV-uninfected or had not yet ascertained or revealed his status, misunderstanding, blame and isolation for the woman often arose. The following is a summary of a field note documenting the interviewer’s conversation with a 19 year old unemployed woman who did not want to be tape-recorded:

“...the participant’s husband blamed her for infecting him because he has always tested negative and told her his previous partner was also negative. He is now avoiding having sex with her because he does not want to use a condom. She finds it extremely difficult to know what is going on in his head. She feels he is going to leave her and start a relationship with someone who is not HIV-positive. Once in a while they have sex and they use a condom but she feels her husband is slowly drifting away. She has already started taking ARVs but does not see herself continuing taking them for the rest of her life because she does not like the look on her husband’s face when he sees her taking tablets. She says she can see he is very upset and angry, though he does not verbalise it. When I asked her why she does not make time and just talk about her condition, she said she feels restricted. His being negative makes it very difficult for her to keep raising the subject. She feels she is in it alone ...” (19 years old, single, unemployed, FB12)

Blame casting, anger and/or feelings of guilt on one or both sides were common outcomes of disclosure, particularly when one partner wished to create distance in terms of personal liability in acquiring HIV.

“[When he came back from testing] he was mad at me. He went on and on shouting, saying I let him down. I put him in trouble by not telling him to use a condom. He went on and on shouting. It came to a point when I suggested that we stop this relationship and he said I wanted to leave him because he was now infected and would be sick any moment. ... He doesn’t stop. Each time he sees me he reminds me that I infected him and I have put his life at stake. He is going to be sick and die. He also says what makes it worse is that he is unemployed.” (29 year old, single, unemployed, FA18)

As has been reported of male partners, some women deliberately withheld their HIV status in an attempt to avoid blame. A 29 year old woman had been abandoned by her former partner when she disclosed her status to him which caused her to withhold her status from her subsequent partner until they had already begun a sexual relationship. Despite her knowingly subjecting him to the risk of HIV, this woman did not reflect overt remorse at her interview and instead suggested the likelihood that he was already HIV-positive when they first met. Either way, it

was clear that the timing surrounding disclosure was extremely important because revelation of HIV status at a particular point in time could precipitate much blame casting and anger.

“He was mad at me and became very violent. He asked me why I didn’t tell him from the beginning. His family was also very angry with me when he told them I had disclosed my status after we had had sex. My question to him was how could he be so sure that I infected him and yet he had been in prison before. How would he be sure that he didn’t contract the virus from prison? I also suspected he was already positive when we had sex. So I was not the only one to blame here. He also did not know his status.” (29 year old, single, unemployed, FA18)

Some participants were strongly suspicious that their partners were already aware of their own status because of their lack of reaction when they had disclosed to them. However, few were willing to challenge their partners about this because of their own feelings of culpability in acquiring HIV.

“He just took it lightly and said this is common and most of the people are dying from it. He didn’t show any shock. I felt like he knew about it even before I told him. In any case I didn’t want to probe him further because at that time I felt I was the culprit who came with this thing.” (28 years old, single, unemployed, FB17)

Silences

Other passive forms of behaviour following disclosure were identified from the data. While some partners had an emotionally heightened response to disclosure, others retreated into deeply non-communicative silences which participants struggled to break through. It appeared as if these men were unwilling to engage with the issue of HIV at all, despite being made aware of their partner’s status.

“I told him I tested positive. I asked him to also go for a test because it was obvious he also had the virus. I am telling you he kept quiet. He didn’t say a word. ... When I ask

him to go for a test, he would just say, „mmm’ and that would be all. He won’t go.” (24 year old, single, employed, FB14)

“He just doesn’t want to talk about it. It was like he doesn’t have anything to say (*akanalutho*).” (30 years old, single, employed, FB28)

A 20 year old, unemployed woman took her cue from her partner’s silence and after her initial disclosure chose not to raise the topic of her status again. In her view, this approach was in the best interests of their relationship.

“He said nothing. Not a word. I would have expected him maybe to say I infected him or something. He just kept quiet and looked at me... and I prefer not to say anything either... and everything is just going smoothly.” (20 years old, single, unemployed, FA05)

In addition to falling silent over the topic of HIV, some partners informed respective participants that they were to maintain a similar silence and to not talk to others about their HIV status. While some participants could break out of this silence, others were not willing to go against their partner’s stated desire.

“He just said I was joking. He said there was no such thing. ... He doesn’t want to talk about my status all the time. He doesn’t want other people to know. So it is just between me and him.” (23 year old, single, student, FA07)

Reciprocal disclosure

Finding out and disclosing one’s status to one’s partner could also precipitate a reciprocal disclosure, albeit of a previously known status, and therefore also constitute an irrevocable betrayal within the relationship dynamic.

“He only told me when I informed him I had tested positive ... he wasn’t shocked because he knew he was HIV-positive. He just said he didn’t know how to let me know.

... When [I] told him [I] tested positive ... well, he had to comfort me because I am the only one that was ignorant about the fact that he was HIV-positive. ... When [I] discovered that [I was] HIV-positive I didn't even want to look at him. I wished we could part ways. I just lost interest and love in him. ... I felt bad because all along he knew he was HIV-positive. He should have told me even before I became pregnant.” (23 years old, single, unemployed, FB01)

Disclosure to a partner did not always precipitate a reciprocal disclosure. The following 23 year old woman had disclosed to her partner when she first met him, yet he continued to remain silent over his known positive status.

“That is the first thing that I told him when he was still dating me. I told him I could not have a serious relationship with him because I was HIV-positive. He said there was no problem with that. There were lots of ways by which we could protect ourselves. He said he understood what I was saying but all the same he wanted us to start a relationship. When we started this relationship, I was already on training for ARVs and he was aware of that. So by this time I knew how they looked like. I was surprised one day when I saw them in his bag. All the time he had been hiding them from me. So when we started living together, I saw them. When I confronted him, he said he was afraid to tell me he was also HIV-positive. ... He said he had been using them for three years.” (23 years old, single, employed, FB16)

Relationship breakdown

Relationship breakdown often followed women's disclosure of HIV status to partners. However, it was very difficult to isolate what in particular caused the breakdown since HIV was not the only cause for contention within many relationships. Concurrency, gender power imbalances, and pregnancy, as well as HIV, all fed into the relationship complexities. In the context of concurrent relationships, maintaining the role of primary partner was often hotly contested amongst the women who shared a man's attentions. Shifting allegiances between concurrent partners also rendered many relationships vulnerable and unstable, even without HIV disclosure. A 24 year old unemployed woman tried to explain why she thinks her partner left her.

“There are so many things. I can’t just say he left me because I told him I was HIV-positive. There are many other reasons. For instance he has got a child from another woman and apparently he went back to her. ... I cannot say what happened, because we didn’t quarrel. It was only after a week, when I had been away, when I came back his family told me he went to stay with his other woman with whom he has a child. So we didn’t stop the relationship as such. He just vanished. He tried to come back about two months back and we quarrelled. I told him that his other woman phones me and says all sorts of nasty things. What annoyed me most is that when I saw him two months back, I told him he must buy everything for the child because I am about to deliver. This woman phoned and said I must stop bothering her man. I am a nuisance. So I realized that whatever I say to him, he goes back and repeats it to his woman. So we quarrelled. ... He said he was going to handle the situation, but then after that he stopped phoning me and if I called him he would say he would come and never came. I ended up giving up. I no longer try to call him.” (24 years old, single, unemployed, FA04)

Another woman no longer was in a relationship with the father of her unborn child because he had also returned to his other relationship.

“...we don’t see each other anymore. When I phone him, he would say I am disturbing him. He is spending time with his child’s mother. Even my aunt could see that I had a problem. She asked me and I told her everything. She wasn’t even aware that I am pregnant. She then suggested that I stop calling this guy because each time I phoned him, he would say nasty things that would hurt me. If I asked for something he would say I was disturbing him. He was with his family, meaning this woman and his child.” (21 years old, single, unemployed, FA21)

Some women, on the other hand, identified HIV as the direct catalyst for the relationship breakdown. The 20 year old participant below still saw a future with her partner despite being aware that he was involved with at least one other woman, but her disclosure of HIV status tipped the relationship balance and he no longer „found’ time to be with her.

“Since I told him I was positive he started dragging his feet. He doesn’t see me anymore. ... There is nothing that we discuss about our future and I don’t think he is interested in spending his future with me. [The fact that he has another woman and a child] that I have no problem with. I can live with his other woman. The biggest problem is that he is not interested in me anymore. I thought we would have a future.” (29 years old, single, employed part-time, FA02)

Proxy Testing

HIV disclosure to a partner did not necessarily prompt a partner to ascertain his own HIV status. Of those partners who were disclosed to, at least half refused to undergo an HIV test. This is concerning since of those partners who did agree to test, the majority were HIV-positive (n=11/15). Many of the partners who did not seek out an HIV test for themselves reportedly chose to use participants’ HIV-positive status as proxy for their own. In these cases, HIV disclosure to partners caused them to immediately assume that they were similarly HIV-positive without confirming this for a fact with an actual HIV test.

“He says it is obvious he is also positive. Recently he said we must both go and check our CD4 count because he knows already he must be positive. He doesn’t see the reason of undergoing a test.” (21 years old, single, employed, FB22)

A 23 year old woman, who was a previous PMTCT patient, was involved with a 38 year old man. He refused to test at the time of her first pregnancy, two years prior to her current pregnancy. He had not yet tested at the time of the interview.

”My partner has not tested [because] the only thing he keeps saying is that because I am positive it means he is also positive. ... He tells himself he is also positive. He doesn’t have to go further and test.” (23 years old, single, unemployed, FB19)

This behaviour could, in fact, discourage disclosure to one’s partner as explained by a 25 year old woman below. She refused to disclose to her boyfriend because she felt he wanted to use her

status as a proxy for his own. The implication was that he did not want to know her status for her sake, but rather to ascertain if he was at risk of testing positive. In refusing to disclose her status to her partner, this woman was refusing to allow her partner to abdicate his personal responsibility for ascertaining his own status through his own test. It also speaks to the continued fears surrounding having an HIV test and discovering one's status.

“What I didn't like about him, he was always pushing me to go for a test as if he wanted to know his status from my results. When I asked him to go and test, he kept saying I must go and test because I am pregnant. That is why I didn't tell him.
... I think he is afraid. He knows he might test positive but he is reluctant to go. So my pregnancy gave him the scope of saying I must test so that he can know whether he is positive or not. That is why I don't want to tell him. He must go and find out for himself.” (25 years old, single, employed, FA01)

Deliberate exposure

Two participants described a situation where their partners deliberately did not protect themselves from HIV after they had been disclosed to. The one partner willingly traded his (assumed) uninfected status as a means to express his devotion to his partner. He maintained that he was HIV-negative at the time of the unprotected sex but apparently subsequently seroconverted after just one sexual act with his partner.

“Shame I don't know how to tell you this. When I met him he was negative and he wanted us to start a relationship knowing well that I was positive ... he said he wanted me to know that he can die for me because he loved me so much. He wanted us to have unprotected sex. I said to him there were very few people who would risk their lives by doing that. He said he wanted me to infect him. He said he had been through a lot of relationships and all the women let him down. He said he sensed I was a good woman and I knew what I wanted in life. I then said to him that was not the way to show that he loved me, by infecting himself like that. He said there was no other way. He wanted us to have unprotected sex right away. As it is he has paid *lobola* for me already. He went to my parents last year in September. ... I told him that was not the way to show me that

he loved me by having unprotected sex with me. I said he should protect himself. He just said, „I want to be with you in this.’ So I had no other means of convincing him. We ended up having sex just like that.” (28 years old, single, employed, FB17)

The next partner also knowingly had unprotected sex, both through his desire to conceive a child and, perhaps, as an expression of solidarity with his partner.

“At first I didn’t tell him. I only told him towards the end of the year. He was quite shocked but then he said he loved me a lot and he would not let this prevent him from having a relationship with me. He tested long ago before we even met, and he told me he tested negative. So after we had been in this relationship he started talking about having a child and when I reminded him of my status, he said he was willing to be infected. ... He said he does not mind being infected by me... What I get from this is that whatever I am experiencing, he wants to experience. I really can’t explain this, but this is how he put it... [he understood the consequences of acquiring HIV]. He was well educated about HIV.” (21 years old, single, employed, FB22)

4.4.2 THE DISCLOSURE PARADOX: HIV DISCLOSURE TO FAMILY MEMBERS AND OTHERS

Acceptance of one’s own HIV status also did not automatically translate into willingness of participants to disclose their status to others. That is, they may have made peace with themselves over their status, yet they could not bring themselves to verbalize this status for a number of reasons already discussed. In general, HIV in the abstract appeared easier for participants to deal with than actually verbalizing it and making the condition a concrete reality.

Disclosure decision-making dynamics

In addition to the above overarching contextual influences, the following specific factors were all identified as issues that fed directly into the disclosure decision making process to family: the

need to retain original identities, anticipated personal impact to another, health of disclosee, shielding of the disclosure recipient, socioeconomic concerns, and other people's cues.

The below 31 year old did not want to be scrutinized by her family and singled out, thereby reminding her of her own status. Folded into this multilayered complexity, was the very possible fact that the disclosure of her status was not something that people close to her wanted to hear.

"I will leave that up to my parents to tell [my brothers]. Maybe I will also tell them one day. The problem is that I know them. This will create a rift between us. I know they will think that I am now sick and going to die and all that... Even though they are [educated about HIV]... it takes time for people to really understand the issue when they are directly faced with it. ...I am still living at home. It would be better if I had my own place where I could be at peace with myself and not have people looking at me and thinking about my status." (31 years old, single, employed, FB20)

Some participants believed that disclosure of HIV status would negatively impact the health of the person being told and that, by not disclosing, they were preserving the other person's health.

"I haven't [told my mother]. Her health is very fragile. I know this can affect her a lot. She has high blood pressure." (24 years old, single, employed, FB14)

It was believed that the emotional shock to the disclosure would irrevocably set back the other's physical or mental health.

"I am so afraid to tell [my mother]. ...She is epileptic and I am afraid that if I tell her such a thing, she might collapse." (34 years old, single, unemployed, FA17)

Closely linked with not wishing to compromise a family member's health through disclosure of HIV status, was the reality that many families in the South African context had already had immediate experience with HIV and had often experienced deaths in the family as a result. This fact placed an extra burden on some participants because they chose to assume responsibility for

shielding family members, particularly mothers, from the knowledge that another member was similarly infected.

“Almost all my sisters were positive. Some have passed away. Those who passed away had also told us they were positive. My other sister is still alive. ... You know, I always feel she cannot take the pain of looking at all of us living with this virus. She watched my other sisters dying with HIV. I don’t think she can be strong enough to watch me living with this disease. I just feel for her.” (25 years old, single, employed, FA01)

Despite HIV being present in this participant’s household she still could not tell her mother in order to avoid compounding her pain. The following participants interviewed from another clinic echo the same concern.

“You know in this family, as I have told you, three of us are infected. When I think of myself, being the fourth person that makes me feel reluctant to even tell my mother.” (29 years old, single, employed, FB10)

“I won’t tell lies, I haven’t told anybody. I feel I am not ready to tell anybody. Another thing is that I have a sister that has been positive for nine years now and she didn’t tell anybody at home for a very long time. Only my mother knew her status, but she didn’t tell us because she asked her not to tell us. She only disclosed her status recently to the family. I feel I have to protect my mother. She already has a burden of knowing my sister’s status and knowing that she has another HIV-positive daughter would be too much for her to bear.” (29 years old, married, employed, FB27)

Even without HIV in the family, there was a manifest desire to protect the family unit from what the following 30 year old viewed as painful news:

“... No one likes living with HIV. It is a sad case if you have contracted it. I am protecting my family. I want them to be at peace and I want us to be the same family that

we have been. I don't want them to see me as a person living with HIV." (30 years old, single, unemployed, FB13)

Within tenuous socioeconomic contexts, disclosure of HIV was viewed as an announcement of imminent illness and even death, thereby posing a real threat to the financial security of the household, by either adding further burden on an already struggling household or by affecting the capacity of the breadwinner to provide.

"I didn't tell all of them. I only phoned one of them and said she should tell the others. I told her as I am pregnant I had to be tested for HIV and the results were positive. Ey, she felt extremely bad because as it is we don't have parents and I am the only breadwinner at home. Right now I am in the process of building our home. So they have high hopes since I am now employed. It was a blow to them to find that I am now HIV-positive." (29 years old, single, employed, FB24)

The following 24 year old woman offered two reasons as to why she would not disclose to her mother: 1) the participant was the sole financial contributor of the household, and 2) to protect her mother's health.

"Ha! I can never tell her. At home I am the sole breadwinner and if I tell her, her blood pressure will rise enormously. I will never tell her." (24 years old, single, employed, FB14)

HIV disclosure messaging assumes a willing recipient in the person being disclosed to. However, some participants were „warned off” disclosing their status by the intended recipient. The below participant had drawn on a variety of different methods of disclosing to her mother with little apparent success.

"... She is always saying to us we mustn't tell her when we are sick because she will die. I always say it is advisable for her to know when one of us is suffering from any terminal disease. She just says we must just go and get treatment and get well. So she is the main

person that should know my status but I am finding it difficult to let her know because of what she keeps saying. I don't think it is good for my own mother not to know that I am HIV-positive. It worries me.” (28 years old, single, employed, FB17)

It appeared, however, that her mother may have been aware of her daughter's status but did not want to be confronted with it directly.

“She knows that at 6.00 my phone rings in the morning and in the evening. She even alerts me to it and I tell her that it is reminding me to take my treatment. She doesn't even ask me what that treatment is for. I have tried all means to put my tablets where she can see them but she does not say anything. At times I leave empty containers where she can see them but still she pretends she does not see them. I am not sure whether she is aware and is avoiding talking about the subject, I don't know. ... At times when we are just having a conversation, I try to bring in the subject of HIV and AIDS and she just ignores me as if I haven't said anything.” (28 years old, single, employed, FB17)

For many participants, their HIV status was a closely guarded secret and their views over disclosure were complex and often contradictory. That is, it often appeared that participants did not have a problem with the concept of disclosure *per se* and could ascribe direct benefits to the process. But when applied to their personal context, many participants did not view disclosure as an experience they were willing to embrace. The following 26 year old employed woman encapsulated this view:

“I think it is a good thing [to disclose your status] because by telling other people, you are encouraging them to also know their status so that they can protect themselves from being infected.” (26 years old, single, employed, FA20)

However, later in the interview, the interviewer asked how she felt about disclosing her status to other people:

“... personally I am not ready. It depends who you are. To do that you have to be brave. Right now I cannot even tell my boyfriend.” (26 years old, single, employed, FA20)

Yet another participant echoed this sentiment.

“Well, I feel, disclosing your status to other people does not mean it is the end of the world. God meant it to be like that. Though I am not talking about myself here, because I am not ready to tell other people...” (29 years old, married, employed, FB27)

The following participant perhaps gave some clue behind this reluctance to disclose.

“I think it is a good thing but I don’t think people are ready to deal with HIV-positive people. Even my own mother does not think she can be able to deal with me when I have an illness that is caused by HIV. I also hear my friends, when we are just talking about HIV, saying they would ridicule someone who is HIV positive. I don’t think that is a good thing. That is why most people do not want to disclose their status. So what I can say is that I am not ready to tell other people for that reason.” (28 year old, single, unemployed, FA14)

Disclosure process

Participants tended to disclose selectively to those close to them or to immediate family. In particular, participants most often disclosed to partners, friends, mothers, sisters, and/or aunts. Male kin, namely, brothers, fathers and/or uncles were rarely disclosed to. Many participants reported that they did not have any friends but, if they did, preferred not to disclose to them for fear of becoming a victim of gossip.

Above all, HIV disclosure was a process that was carefully and *strategically* navigated by the majority of participants. Despite the availability of antiretrovirals and health care support mechanisms, there remained significant fear over revealing their status to another.

“The thing is I still want to get used to the idea that I am going to live with the virus for the rest of my life. It is not an easy thing to do. ... The problem is that [my mother] suffers from high blood pressure and she becomes very sensitive when you tell her bad things that are happening in your life. That is why I don’t want to tell her at the moment. I will see as time goes on whether I will tell her or not.” (26 years old, single, unemployed, FB06)

As was the case with intimate partners, participants were often strategic in the communication process. An example of this is highlighted in the excerpt below where a 28 year old woman told us she chose to first prepare her mother prior to her disclosure through a process of educating her over HIV and thereby allaying some her mother’s unfounded fears.

“I am planning to tell her but at the moment I am afraid because even when we discuss HIV, she seems to be very afraid of it. I always try to introduce the subject and I tell her that HIV is not so bad as long as one looks after one’s self. I want to keep talking about it until I am sure that she understands what HIV is all about. Then I will tell her about my own status.” (28 years old, single, unemployed, FA14)

Other participants were still not able to disclose their status to one or more family members. The following 28 year old told us that because HIV was a common disease of the day, she need not worry unduly over her HIV status. Yet despite this argument, she was not willing to disclose because she feared others would be afraid of her assumed imminent death.

“I am not sick. I am the one who should look after myself. Telling other people won’t help me because they won’t go and buy tablets for me. They will be afraid of me and think I am going to die. That is when I will have a problem.” (28 years old, single, employed, FA8)

As long as her health remained and in order to avoid being made a point of reference by others, this woman did not see good reason to disclose her status. A 26 year old woman echoed the above participant’s fears, as well as demonstrating the desire to shield her family from the news.

“I am afraid that they are going to think that I am going to die. They will be hurt.” (26 years old, single, employed, FA11)

Closely allied to the fear of being perceived differently, was the interplay of the states of sickness versus health. That is, participants often stated that while they were not showing symptoms of AIDS, there was no reason to feel different to anyone else and by extension strove to preserve their social persona prior to their diagnosis. If their bodies started to show symptoms of illness, they were at risk of being labelled ‘HIV-positive’. However, as long as they could maintain their original physical appearance, some participants preferred to defer disclosure indefinitely.

“...I am just telling myself that as long as I am still healthy, I am not going to tell anyone. It will be different when I start getting sick and all that. People will want to know what is wrong with me. Then I will tell them.” (22 years old, single, unemployed, FA15)

“I see myself as just an ordinary person who is not different from other people. As far as I am concerned I am still one of them. Nothing has changed. My life has only changed because I know that I am HIV-positive but at the same time life goes on as normal. I am not sick and nobody can point a finger at me and say I am HIV-positive. So for me being HIV-positive does not mean anything so far. I know that if I get treatment and I adhere to it, I will be fine.” (26 years old, single, unemployed, FB30)

For some, it appeared that only a physical manifestation of the virus would precipitate them to engage with their status and move forward with disclosure. The underlying assumption seemed to be that unless one fell ill, one could continue to deny one’s condition to others, and perhaps oneself. A 25 year old woman underlined this point with the comment:

“...the moment I see someone who is also positive...” (25 years old, single, employed, FA01)

To “see” someone else as “positive” means that a person’s symptoms are AIDS defining and therefore clearly indicate the person’s status. As suggested by a 22 year old woman below, the sight of other HIV-positive individuals with manifest AIDS symptoms could cause participants to reflect on their own status. The following 22 year old also had two HIV-positive children:

“Though it doesn’t affect me much but at times I feel bad when I see sick people at the clinic. I become concerned that one day it will be me. It does affect me at times and I cannot forget that I am HIV positive. Also I always look at my children and I think of my own situation. They are a constant reminder of the disease.” (22 years old, single, employment status unknown, FA33)

The above data suggested that some individuals may avoid interacting with the reality of their HIV status until they fell ill, at which point action would be required. This point is supported by the partner reactions to disclosure and their avoidance of HIV testing.

In general, non disclosure did cause difficulties for participants due to the complex webs of secrecy and deflections of suspicion that participants had to engage in. As these women’s stories got more complex and with the passing of time, it proved increasingly difficult for them to extricate themselves from their original narrative without appearing to have been deceptive, even if they had subsequently decided to reveal their status.

“... when I am coming here I tell lies and say to the principal I am going to fetch my treatment for diabetes. I can’t say anything else. He is also diabetic and he knows how it feels like when you don’t have tablets. The worst thing is that I have no clue as to how you feel when you are diabetic. When he asks me about my sugar situation I just say, „Ey, the levels are too high principal!’ One day he asked me to show him the treatment I am using and I just said the tablets I am taking are tiny. He suggested that I must buy this equipment where a diabetic patient has to keep checking the sugar levels. So I am doing this so that he can allow me to come here every month.” (28 years old, single, employed, FB17)

Keeping one's status a secret when medication was involved also proved stressful.

“It is really difficult, especially at home. As it is I can't keep hiding my medication from my family members. That is my main problem. I have to keep watching where my bag is and that no one comes near it. Naturally I never have to keep checking where my bag is or who is touching it, but now I have to do that.” (36 years old, single, employed, FB03)

However, the passing of time and the correct permutation of circumstances was what many women needed in order to come to terms with and to communicate this status to others.

Disclosure outcomes

For women who were able to disclose, clear benefits of disclosure to family members were identified.

“I told my whole family. They all know. I thought it would be best for me if I told them because it eases the pain for me. They are all by my side. If I didn't tell them I wouldn't be feeling well.” (24 years old, single, unemployed, FB18)

“I am saying it is good to disclose your status to some people because after you have told a person, you feel good inside. You feel like you have lessened the load that has been inside you.” (21 year old student, single, student, FB29)

4.5 SUMMARY

The results were organized into three broad overarching themes. The first section identified the underlying structural and relational factors influencing sexual risk behaviour as well as HIV disclosure. Fluid household structures and the burden of HIV on households and on household members' lives very specifically formed part of the broad socio-cultural and historical (structural) influences. Relationship factors included the lack of involvement of parents; prior

experience with violence and intimidation; mutual distrust within sexual relationships; concurrent partnerships; and gendered power imbalances. The second section highlighted that many participants were diagnosed with (predominantly) unintended pregnancy and HIV concurrently. This had a profound impact on many women's identities. The interplay of the conditions of HIV and pregnancy on one another and the shifting realities of participants as a result of their concurrent diagnoses was described. Stigma was also evoked in multiple ways. The final section reported the specific findings on the HIV disclosure process and outcomes. This section dealt specifically with two main groups of individuals to whom participants in a PMTCT context disclosed to: sexual partners, and family/others. Three main elements to the HIV disclosure behaviour were identified: 1) disclosure decision-making; 2) the disclosure process; and 3) disclosure outcomes/consequences. The issues involved in disclosure to family members and others within participants' social networks overlapped with that of intimate partners to a certain extent.

CHAPTER 5: DISCUSSION

The study set out to examine under what circumstances, how and to whom did HIV-positive pregnant women in the PMTCT context disclose their HIV status and what were the consequences. The study findings challenge prevailing public health assumptions around HIV disclosure in the PMTCT context. From a public health perspective, risk reduction and primary prevention are vital in curbing the HIV epidemic and HIV disclosure is seen as a critical step towards this end. While the end goal is not in dispute, this study found that the assumptions underlying the means to this end are fundamentally flawed. Assumed pathways to risk reduction and HIV prevention need to be carefully relooked and reconsidered.

Drawing on social constructionist theory, the focus on HIV disclosure was deliberately shifted from the traditional westernized, biomedical approach which views the individual in isolation, to one that incorporated the individual's experience of HIV infection and located this experience in a specific health and social context. Studying HIV disclosure in this manner allowed an examination of the unfolding gender dynamics as well as the structural factors that had a role in shaping the sexual and social behaviour of participants. The complex social and relational landscape which emerged had a direct impact and influence on HIV- related disclosure.

Three overarching themes were presented in the results section: 1) Structural and relational factors, 2) Concurrent life changing events and 3) the HIV disclosure process. A discussion of these findings within the broad thematic areas follows.

5.1 STRUCTURAL AND RELATIONAL FACTORS: SOCIAL NETWORKS AND SOCIAL SUPPORT

Health care professionals providing HIV-related care often interact with their patients from the point of their HIV diagnosis with little or no examination of a patient's past which may have put them at risk for HIV in the first place. It is important that this personal history is, in fact,

considered since the circumstances or events which placed participants at risk for HIV acquisition will also affect their capacity or likelihood to disclose this status.

Many participants were situated within dynamic household structures, with household members (including participants) regularly moving between households and provinces. It is important to note that the Westernised concept of the nuclear family system and disclosure preconceptions surrounding this formulation did not apply in the study context. Households were not necessarily the „contained’ units evidenced in nuclear household structures composed of immediate family members of biological descent. The predominant patterning of households consisted of extended family kinships that were often shaped by economic, as well as relationship considerations. This type of household composition is very characteristic of urban black households in South Africa, the character and roots of which has been well documented by others (Hosegood, McGrath & Moultrie, 2009; Russell, 2004). Therefore, assumptions surrounding disclosure to „family’ household members need to be carefully examined.

Participants indicated responsibility in care giving activities and/or provision of income to others in their household. The data revealed that financial resources were generally very constrained for participants, particularly those who accessed the public sector facility, Facility 1. Women accessing this facility were also less likely to be living with their sexual partners and were therefore less likely to be directly benefitting from the primary resources that a partner could provide. PMTCT-related counselling logically presupposes the presence of a sexual partner and it is to this partner that disclosure and subsequent prevention activities are predominantly directed. However, long standing anthropological research has shown that parents and siblings have often represented a more dependable and stable source of emotional, financial and material support than spouses or partners (Niehaus, 1994; Preston-Whyte, 1978, 1988). Hosegood et al. (2009:282) argue that this has caused a realignment of “social structures and support ... around the stronger and more enduring parental and filial bonds.” By disclosing to the partner, the prevention function of disclosure may theoretically be achieved but the support function is less likely to be realized.

In a country context with high unemployment rates (Statistics South Africa, 2010), there was a general expectation that those household members who were fortunate enough to be earning some kind of income would financially support the others residing in that household. Given the realities of the very high HIV prevalence in the study district catchment area (Department of Health, 2009), participants reported high levels of AIDS-related illness and mortality within their households which clearly added to the household burden by further stretching already limited financial and human resources. Many households included other HIV-positive family members and it was not uncommon for households to have suffered multiple losses of family members due to AIDS-defining illnesses. Against the backdrop of the struggle to care for severely ill inhabitants with AIDS-defining illnesses and in the face of losing the earning capacity of that family member in his/her prime, it is unsurprising that some participants were reluctant to further burden family or household with news of their own HIV-positive status.

The relational context played out against the above structural backdrop. Many participants revealed a lack of physical and/or emotional connection with one or both biological parents. Many participants had never lived with nor knew their biological fathers. Some participants had a distinct lack of maternal support in their lives and had, by Western standards, at a young age stepped into this role for other household inhabitants. Many of the participant's children did not reside with either biological parent, having been fostered in other households. This practice of fostering of children is a distinctive feature of black South African households and is also largely in response to economic concerns (Russell, 2004). According to the 2003 South African Demographic and Health Survey (Department of Health, MEASURE DHS & ORC Macro, 2003), 21.1% of households had foster children¹⁸ residing in them and only 33.7% of children lived with both parents. As Russell (2004:43) suggests, although the child would usually have a clearly established kinship identity based on the agnatic principle, this fostering out of children “whether as a cause of consequence...[has the effect of] neutralising ... the emotional relationship between parents and their biological children”. The practice of foster childhood in the historico-cultural context sheds light on participant's childhood backgrounds and perhaps

¹⁸ A foster child is described as an individual <15 years with no biological parents residing in the same house.

provides some indication as to why many participants, in their adulthood, had limited physical and emotional attachment with one or both parents.

Most participants were not married and at least half the study participants did not live with their intimate partners on a day-to-day basis. This can, in part, be attributed to the declining rates of marriage over time in South Africa (Hosegood et al., 2009). Hosegood et al. (2009), using demographic surveillance data in rural KZN between 2000-2006, found that most married men lived in the same household as their wives but that only one third of unmarried male partners were part of their partner's household. This was especially the case for younger couples (Hosegood et al., 2009).

If cohabitation is understood as “an indicator of social connectedness” (Hosegood et al., 2009:294), the study findings disturb the traditional formulae of the sexual partner (and to a lesser extent immediate family members) forming the basis for household social support through the act of disclosure. Participants often did not reside with these groups of individuals. Many women, in fact, gave little evidence of strong social support in their lives. The literature has demonstrated that social support and participation in social relationships will positively influence HIV disclosure (Bairan et al., 2007; Crosby et al., 2005; Kalichman, DiMarco, Austin et al., 2003). Additionally, social networks can powerfully influence behaviour. If research on disclosure is to make headway it needs to refocus on the relationship and network dynamics rather than, as traditionally has been the case, on the disclosing individual (Rice et al., 2009). It is critical for further research to examine the nature of the social support networks and the concept of social capital¹⁹ in relation to HIV-positive pregnant women *prior* to identifying disclosure recipients. Information on social support networks and social capital would also shed light over the ways in which HIV disclosure behaviour and outcomes manifest.

Sexual risk behaviour and relationship patterning is an important factor to consider in HIV disclosure messaging. That is, current disclosure recommendations largely ignore predisposing

¹⁹ Social capital is defined as “the direct value (in cash, kin, reputation, „distinction’, or other tangibles and intangibles) that persons may derive from social structures, roles and networks” (Thornton 2009:417).

sexual risk factors and are premised on assumed patterns of behaviour within relationships which were not supported by the study data. The data revealed that many participants engaged in high risk behaviour prior to their HIV diagnosis. HIV disclosure is assumed to mediate sexual risk behavior. However, this public health assumption overwhelmingly ignores the sheer complexity of sexual behaviour. Emotional attachment, low education, immediacy of the moment, lack of parental involvement, attaining and maintaining social capital, and the fact that sexual connections often allow individuals to transcend social realities are all plausible conditions in which high risk behaviour may occur (Thornton, 2009). It is also highly possible that these women had entered a high risk situation (and may continue to do so) and had simply not known how to manage it (Gafos, 2010). Gender-based violence, as evidenced in the study findings, also offers explanation for high risk behaviours. Studies have shown that between 10-20% of women in a South African context had experienced coerced first sexual intercourse (Dunkle et al., 2004a) and that this category of women are more likely to exhibit increased sexual risk behaviour (Maharaj et al., 2007).

The theme of concurrent sexual partnerships rose repeatedly in the study data. Concurrent partnerships are a relationship reality for many black South Africans (Halperin et al., 2007; Harrison, 2008; Hunter, 2002, 2004; Leclerc-Madlala, 2003; Motsemme, 2007). However, the dynamics of HIV disclosure have hitherto not been considered in a society where relationship concurrency is the norm and where relatively long term concurrent relationships may co-exist. In a setting with concentrated sexual networks involving concurrent sexual partnerships, relationship dynamics are complicated and play out in very specific and fundamental ways. Quina, Harlow, Marokoff, Burkholder and Deiter (2000) found that women involved in multiple partnerships with at least one risky partner displayed the most risky behaviour of all the women involved in their study. Women with high risk partners have been found to be at risk of poverty, lack of education, partner violence and lack of power in relationships (Gómez & Marín, 1996; Wingood et al., 1998). All of this has implications for the likelihood and the success of HIV disclosure and disclosure outcomes.

There are direct consequences to the concurrent patterning of relationships since the movement between partners invariably sets up precarious relationship dynamics in which the status quo

needs to be carefully preserved. These dynamics are further skewed by gender imbalances especially in the case where the male partner is engaged in the multiple relationships allowing him to exercise greater choice in available partners. In light of the inherent instability of these sexual relationships, female participation in their own concurrent relationships can arguably be seen as a strategy to minimize the social and economic impact of one relationship abruptly or unexpectedly ending (O'Sullivan, Harrison, Morrell et al., 2006; Thornton, 2009). With concurrent relationships being the norm, there is likely to be the omnipresent awareness that dissension within the relationship would give one's partner cause to end the relationship with very little provocation. Some participants were pregnant at the same time as their partner's concurrent girlfriends. Given that their partners had concurrently established other similarly „committed' relationships, women were perhaps unlikely to presume a high level of partner commitment within their relationships.

The findings highlighted that participant's relationships were often characterized by little trust, mutual suspicion, secrecy, silence and little expectation of permanency. Similar attitudes were found in another study amongst men which highlighted denigrating and negative attitudes towards women as sexual partners (Ragnarsson, Townsend, Ektrom et al., 2010). These authors suggested that this derision, in fact, promoted power imbalances within sexual relationships. Key to the study findings were the high levels of distrust that participants voiced over their partner's relationship intentions. Women revealed low expectations in terms of the long term future of their relationships. This can partly be explained by the commonly presented view that the relationship longevity was at the discretion of the strongly gendered „man'. Certainly, the divided attentions of the male partner due to simultaneous relationships and simultaneous partner pregnancy would strongly undermine feelings of trust. According to Meyer-Weitz (2005), low trust amongst sexual partners is a sign of low levels of social capital. Disclosure of HIV would then pose strong threat to already scant existing social resources.

Despite voicing a marked lack of trust in their partners' relationship intentions, women described experiencing feelings of profound betrayal by their partners on disclosing their HIV status to them. Some women discovered that their partner, in fact, had been aware of his own HIV-positive status prior to her own diagnosis and so knowingly exposed her to risk. Some

participants became aware that their partners had been engaged in a concealed infidelity. Women were both trying to come to terms with the shock of their own diagnosis as well as with the knowledge that their partners had betrayed their trust on different levels. The same level of concealment was true for some participants. One woman chose to withhold her HIV status from her partner until she was married and the baby had been born. This raises the question of the likelihood of disclosure ever occurring. It would, in theory, prove increasingly difficult to disclose the longer one concealed one's status. That is, it would be difficult to communicate one's HIV status without running the risk of revealing prior concealment of this status, creating an awareness of the breach in trust between the couple, especially if condoms had not been consistently used. Lack of trust in partner's intentions also influenced the likelihood of HIV disclosure occurring since there was little apparent benefit for many participants to disclose to their partners. The issue of trust between couples is a key component in dyadic models of behavioural change. This is further discussed in Chapter six in the presentation of the conceptual model emanating from the study.

In an attempt to move towards a deeper understanding of the relationship and risk behaviour dynamics within the context of concurrent partnerships, it is useful to draw on Thornton's (2009) theoretical framework for concurrent sexual networks. Thornton (2009) frames sexual networks as social structures which are actively fostered in an attempt to maximize social capital. For those who have very little social support, increasing one's social capital will be a priority (Thornton, 2009). These 'networks of social capital' are often not visible to those who participate in them: "Sexual secrecy, issues of respect (*hlonipha*), decorum and possibly stigma may also account for this lack of transparency" (Thornton, 2009:415). Thornton (2009) suggests that there often exists good reason for individuals to practice high risk sexual behaviour especially if it brings tangible benefit to many parts of an individual's life.

As Jewkes and Morrell (2010:6) argue, women who need to maintain or increase their social status will be required to adhere to prevailing social norms where "successful womanhood is based on being desirable to men". Having many sexual partners may also be an expression of manhood for men (Ragnarsson et al., 2010). Risk of HIV infection is not, in these instances, the key consideration. Rather the risk to their social relationships and, by extension, their overall

wellbeing is of paramount concern (Thornton, 2009). These complexities do not simply disappear with an HIV diagnosis and are not necessarily meaningfully changed on disclosure of this diagnosis. If sex is seen as critical to the success of a relationship (Jewkes, Morrell & N.Christofides, 2009), everything about HIV - the episodes of ill health, the necessity for condoms or abstinence, and the advisability or the ability to bear a child, disturbs this picture. Sexual activities come under scrutiny and are strongly regulated by external forces in the form of health care providers. Thornton (2009) points out the intrinsic difficulties in talking about matters of sex in Southern African society and argues that it is the very silence and secrecy over the nature of the sexual networks that makes them such a valuable form of social capital. HIV disclosure may disrupt expectations surrounding appropriate social behaviour within a given context by bringing to the surface issues regarding sexual behaviour.

Concurrent relationships were identified as a high risk behaviour that women engaged in before and after their HIV diagnosis. Lack of condom use within these relationships greatly heightened the risk. The study particularly explored reasons behind the general lack of condom use amongst women with their partners. The fact that participants often struggled to find answers to this question, reflexively blaming themselves or recounting that they „just found [themselves] having sex’ and not using a condom, demonstrates the deeply entrenched gendered norms and expectations related to sexual behaviour. It can be argued that this partly demonstrates, as Jewkes and Morrell (2010) suggest, that women were active participants in the process that constructs, performs and reproduces the principles of hegemonic masculinity. Certainly, in being an integral part of this process, women may often not consider the full implications to themselves until the point at which the question is posed to them. It was only at that particular point of the interview, or perhaps at the point of receiving one’s HIV diagnosis, that the space for introspection was provided for some women to move towards understanding of their role in their risk behaviour. It is questionable, however, how much agency these women, in fact, had to implement safer sexual practices. It has been observed in chronically ill people that “during the specific past, ill people may not have perceived themselves as having control of events or their lives. However, when compared to the present, the past now looks *as if* it had been controllable” (Charmaz, 2002:312). Meyer-Weitz (2005) offers an alternative perspective where she describes the failure to implement safer sexual practices as a fatalism borne from the social, cultural and

historical contexts. According to Meyer-Weitz (2005:76), these contexts have created a situation of “learned helplessness” where “efforts to control stressful life-events are continuously unsuccessful and when intolerable situations remain unchanged”. Meyer-Weitz, Latka, Fielding, Kruger and Churchyard (2009) argue that this fatalistic sentiment needs to be considered in any intervention planning.

Certainly, against the multiple partnership dynamic, preserving the “fiction of fidelity” (Hirsch et al., 2007b:986) may be prioritized over the need for safer sex. Because many participants had only recently been diagnosed with HIV, the study was not able to meaningfully explore condom use following disclosure. Other research findings indicate that HIV-positive women, 18 months postpartum, were not significantly more likely to systematically use condoms compared to HIV-negative women (Desgrées du Loû et al., 2009). The impact of the structural and relationship factors on condom use, even after disclosure, needs to be explored in future research.

Asking a woman to disclose her HIV status to her sexual partner is not simply a request to tell another about her serostatus. Disclosure of HIV, by implication, raises the issue of past sexual relationships which have no place in the present. There also involves the risk of exposing concurrent, secret relationships which are better concealed than revealed. Sometimes, HIV disclosure involves acknowledgement of an already known but concealed status and therefore entails dealing with the implications of having knowingly exposed the partner to risk. The complex power dynamics and realities in terms of participant’s sexual relationships challenge the inherent assumption about the ‘stable dyad’ to whom PMTCT-related counselling is directed. Thornton’s (2009) structural explanation for concurrent sexual networks also offers some clue as to what may be at stake in disclosing an HIV status to sexual partners. In this context, disclosure to a partner may be perceived to, or may actually, threaten an individual’s accumulated social capital.

The emphasis on reaching the male partner through the female counterpart receiving antenatal care likewise carries assumptions about the permanency of sexual relationships. Recent locally relevant research has shown that sexual relationships which have resulted in the birth of a child do not commonly resolve into stable unions between parents (W. Parker et al., 2007). This was

certainly reflected in the current study findings. The expectations surrounding relationship permanency has direct implications for the likelihood and success of disclosure. Some participants indicated very little anticipation of commitment from their partners and had low expectations of their relationship future. Relationship dissolution has been associated with concurrent relationships and with partners who do not cohabit (Desgrées du Loû et al., 2009). Many study participants met these criteria which placed them at high risk for relationship breakdown – with very little provocation. Interestingly, women accessing Facility 2 services tended to disclose more to their partners than those accessing Facility 1 services. Women from Facility 2 more often cohabited with their partners than those in Facility 1.

The socio-cultural construction of sexuality in a specific social context should be core to any HIV-related intervention planning. An appreciation of the gender context also furthers understanding of HIV disclosure dynamics since this forms the backdrop against which sexual relationships are played out. Working within a social constructionist framework, Jewkes and Morrell (2010:4) argue the need to view sexual behavior through a gender identity lens as “a way of reflecting on the emotional and material context within which sexual behaviours are enacted”. Social constructionism is well suited to examining the power relations occurring on the social and interpersonal level. Viewing the power dynamics and resistance to this power is fundamental because it is precisely at this point that social and personal change can take place. Relationship power and gender dynamics play a key structural role in constraining women’s ability to minimize sexual risk behaviour (Amaro & Raj, 2000). Interpersonal power within relationships therefore becomes a critical area of focus on any issue that touches on sexuality (Quina et al., 2000). Where women were more likely to be employed and cohabiting or married, in Facility 2, and thus in a stronger socioeconomic position, they were also generally involved with older men who had their own access to economic resource. In Facility 1, fewer women were employed and were cohabiting with their partners but their partners were also closer in age to them and were often not well employed, if at all. For each group, gender power relations were skewed in favour of men. In a patriarchally-based society, decision-making power is in the hands of men, especially older men and those with access to economic resource. For women who had greatly constrained socioeconomic situations, as with those accessing Facility 1, any kind of male support would be desirable and thus cause unequal power within relationships. Importantly,

entrenched ideas about modes of conduct, which initially had a role to play in sexual risk behaviour, will likely continue to be present throughout the disclosure process and directly feed into disclosure outcomes.

5.2 CONCURRENT LIFE CHANGING EVENTS

Two clear „diagnosis events’ emerged from the participant narratives: 1) being HIV-positive, and 2) being pregnant. Each impacted on the other and on disclosure in critical ways as well as on participants’ sexual and family relationships. Of key importance in the findings was that HIV diagnosis was most often directly connected with a recent pregnancy diagnosis due to the antenatal health care encounter. Most participants had, in the same year of their pregnancy discovered their HIV status for the first time ever.

The majority of participants were currently experiencing unintended pregnancies with many of these women conceiving fairly early in their relationships. The study findings indicated that many participants simultaneously had to grapple with the cultural, social and personal implications of their unintended (and often unwanted) pregnancy in addition to assimilating the shock of their HIV diagnosis. Their HIV diagnosis had immediate ramifications for their own health, that of their unborn child and to their sexual partnerships and social network. In addition, in the process of assimilating their HIV diagnosis, many women had to acknowledge and come to terms with the factors or events that led up to their diagnosis, such as prior high risk sexual behaviour and contemplation of their own role in these sexual encounters. Testing HIV-positive gave rise to confusion surrounding how they acquired HIV, uncertainty as to how to deal with a pregnancy and ultimately a baby with or without a partner (depending on his willingness to be involved) and, despite this, still accomplish personal life aspirations. Other research has found that HIV-positive pregnant women required time to come to terms with their status before they could give thought to disclosure (Visser et al., 2008). The study findings are strongly suggestive of this as well. Some participants were reluctant to reveal their HIV status while pregnant for fear of compromising their partner’s happiness over the pregnancy, preferring instead to

postpone this until delivery of the baby. Waiting until after delivery of the baby before disclosing has also been found in other research (Visser et al. 2008). An appreciation of and insight into the individual perspective must inform and shape public health messaging surrounding HIV disclosure in order for disclosure to be contextually relevant and ultimately effective in terms of outcomes. Previous studies have found the quality and consistency of topics covered during post test HIV counselling in antenatal setting in sub-Saharan Africa to be lacking (Baek, Creek, Jones et al., 2009; Chopra, Doherty, Jackson & Ashworth, 2005; Delva, Mutunga, Quaghebeur & Temmerman, 2006)

The findings highlighting the interplay between pregnancy and HIV are consistent with other research in this area and demonstrate the complex decision-making that an HIV-positive woman is required to undergo in a very short space of time before her baby is born (Doull et al., 2006; Visser et al., 2008). Despite this, current disclosure counsel reflects little consideration as to the personal implications of this concurrent diagnosis on a woman's life and the effect this has on HIV-related communication efforts within the context of their relationships.

Most of the participants were not first time mothers and had experienced prior, usually, unintended pregnancies. The 1998 SADHS found that 61% all first pregnancies and 46% of all second pregnancies were unintended (Department of Health, Medical Research Council & ORC Macro, 1998).²⁰ In HIV-positive women in the South African setting, an estimated 84% of all pregnancies are unintended (Rochat, Richter, Doll et al., 2006). Research has also shown that half of all black women in South Africa have had a child by the age of 21 years, and most of these births occur out of marriage (Jewkes et al., 2009). A recent study looking at HIV risk behaviour amongst youth in the KwaZulu-Natal context documents high levels of unintended pregnancy despite the participant's stated desire to prevent them (Harrison & O'Sullivan, 2010). The desire to prevent pregnancy has been found to be overlaid with little attempt to actually prevent this happening through condom use and contraceptive methods (Wood & Jewkes, 2006). The study data lends further support to these findings.

²⁰ There were data quality issues with the fertility section of the SADHS 2003 which is why I have reported the earlier DHS figures. However, the 2003 SADHS report similar unintended pregnancy trends as the 1998 SADHS.

There exists other very complex gendered and structural dynamics at play during pregnancy, even without factoring HIV into the calculus. Early ethnographies amongst isiZulu speaking individuals, the largest group of people in KwaZulu-Natal, have highlighted the importance placed on having a child (Krige, 1936; Ngubane, 1977). Within a patriarchal context, a woman is seen as fulfilling her expected biological imperative by falling pregnant and bearing children. In all matters concerning sex, she must subdue to the demands of the „man’ who demonstrates his power through physical strength and his virility (Ngubane, 1977). Fathering children is also evidence of masculinity (Morrell, 2006). However, as Ngubane (1977) points out, it is here that we meet with a paradox since the man is ultimately dependant on the woman to be fecund. In this context, infertility would therefore be viewed much more seriously than extra-marital pregnancy and demonstrating one’s fertility would likely be more important than preventing conception (Hosegood et al., 2009; Wood et al., 2006).

Pregnancy can also lend weight to relationship commitment expectations. According to Jewkes et al. (2009), acknowledged pregnancies may strengthen ties in the context of concurrent relationships. These authors found that couples who had children together would often have long term contact and attachment relative to the norm. In this light, disclosure of HIV may ultimately undermine all the benefit the pregnancy has brought to the relationship cohesion.

The study findings underscore the far reaching cultural, social, personal and economic consequences for women with unintended pregnancies. In conservative rural communities, pregnancy is considered shameful when the man has not yet been introduced to the woman’s family and, by extension, the community within which her family are living. This view permeates, to varying degrees, in black urban communities. Women must carefully navigate this transgression in addition to dealing with family-related cultural expectations of „damages’ (*inhlawulo*) due to them by her partner for impregnating her. Some participants revealed that their partners were reluctant to admit paternity of the pregnancy and some were no longer still in their relationship. This finding is consistent with other research in this area and appears, in part, to be related to the payment of damages (Harrison et al., 2010).

With high rates of unemployment, women were little able to afford compromising their job security or discontinuing their studies by falling pregnant but this was the reality for some participants. Other research has also documented these findings (Harrison et al., 2010). Many study participants were deeply dismayed at having fallen pregnant with some expressing the desire to terminate their pregnancy. Having HIV often factored into these decisions, greatly compounding participants' pregnancy-related anxieties and hindering attempts to come to terms with these pregnancies. This dismay was compounded by a sense of having disappointed, or incurring the disapproval of, a close family member, usually the person on whose shoulder's the care giving responsibility may fall.

Of key importance in the findings was the impact of these concurrent diagnoses on HIV disclosure. For women experiencing unintended pregnancies, they had to negotiate dual disclosure: communication of pregnancy and communication of HIV infection. Even if a pregnancy was unintended, it may still have strengthened participant's relationships for all the reasons already stated. However, disclosure of HIV posed enormous threat to the relationship since it involved communication of direct risk to the partner and threw question over the risk to the baby. For this reason, HIV was often subordinated to pregnancy concerns where the need to maintain the relationship in the time of pregnancy outweighed the need to communicate to the partner his own risk. Some women wanted to first ascertain that their infants were born HIV-negative before revealing their own status. In the first instance, perhaps addressing their own very immediate anxieties over the well being of their infant and secondly, to help mediate the shock to the father of the infant when disclosure did occur. In earlier unpublished research by the study author, women in the PMTCT setting were more successful in implementing sexual risk reduction activities during pregnancy than prior to their pregnancy by abstaining from sexual intercourse or insisting on condom use to prevent sexually transmitted infections that may pose risk to the foetus. While not actually disclosing their status, this group of women achieved the same ends as intended through disclosure. This perhaps offers an ethical alternative in lieu of disclosing immediately and rather delaying disclosure until after the pregnancy. Interestingly, Marks and Crepaz (2001) found that disclosure did not necessarily reduce unsafe sex and of those who did not disclose, 73% actually engaged in safer sex.

Another key theme which emerged was that being diagnosed with HIV (and pregnancy to a degree) had a profound effect on the women's established social identities and often marked a period of intense introspection regarding this new, often contested, identity. Some had accepted and made peace with their HIV diagnosis but the majority of women were still grappling with the implications of HIV on their lives. Dealing with this new identity was central to disclosure decision-making activities where the *perceived* costs versus benefits to disclosure, relative to the self, had to be weighed up. The index pregnancy was an additional consideration. Once a decision was made to disclose to someone, the *actual* costs and/or benefits would form the outcome. This is reflected in the conceptual model proposed in Chapter six. Feedback as an outcome of HIV disclosure also greatly impacted on many participants' identities and this influenced the likelihood of further HIV disclosure. The concept of identity, also represented in the conceptual model in Chapter 6, is seen as the central link between an individual's available social networks and social support and that individual's risk behaviour, all of which feeds into disclosure behaviour. The issue of identity is elaborated further below.

Women accessing the PMTCT programme arguably take on two new identities: HIV-positive and impending motherhood. According to identity theory, there exists the self (the person) and the multiple social identities of which the self is composed (Baumgartner, 2007; Serpe, 1987). The notion of identity and the concept of agency - the extent to which individuals are actively involved in exercising power and bringing about effects in their lives - lie at the heart of social constructionist theory. Individuals are engaged in a continual process of constructing, reconstructing, enacting and reproducing their identities and these identities are simultaneously being shaped by social interactions and social structures. According to Serpe (1987), social structures greatly impact an individual's ability to exercise „choice'. Here, he conceptualizes „choice' as “reflecting constraints which operate on any given set of identities” (Serpe, 1987:46).

Serious chronic illness, like HIV, causes a disruption of identity and disruption of relationships (Baumgartner, 2007; Charmaz, 1994, 2002) and raises questions over self, identity and moral status (Charmaz, 2002). An individual's experience of illness is a central determinant to the disclosure of this condition and therefore merits critical attention. The study findings revealed that being diagnosed HIV-positive gave many women cause to take stock of their lives and often

marked the beginning of a shift in how they fundamentally viewed themselves. Many were deeply shocked or angered by their HIV diagnosis and while some admitted to not paying enough attention to HIV prevention, others had been exposed to risk outside of their control which had been traumatic for them. An HIV diagnosis during pregnancy may also precipitate feelings of being out of control. According to Charmaz (2002:307), while in the chaos of the diagnosis “once-anchored identities become mobile and so do the selves imbedded in those identities”. Female bodies in the PMTCT setting have also temporarily lost control – pregnancy reshapes the body and follows biological imperatives often at the expense of the body. An HIV diagnosis indicates her blood carries an indelible and harmful virus which takes its own multilevel toll. She is likely to be on antiretroviral prophylaxis and may be experiencing side effects out of her control. Intimate partners are also exercising independent choice about continuing or discontinuing relationships. One very specific area that an HIV-positive pregnant woman may assert control is the extent to which she shares her knowledge of HIV status.

As the data highlighted, participant’s identity shift, from a prior social identity to the new HIV identity, could manifest in various ways. Participants spoke of „living a new life’, of reasserting control over the direction of their lives, and of desiring a fresh start. Interestingly, Lynch, Brouard and Visser (2010) described the same type of „transformative’ discourse amongst HIV-positive men who reported moderating their sexual behaviour on being diagnosed. For the purposes of the study under discussion, it is not possible to know whether this „transformative’ discourse fed into long term behavioural change given that the study design was not longitudinal. It needs to be taken into account that participant’s HIV identity is also likely to be at odds with the social identity required to attain and maintain their positions and their sexual partnerships (Baumgartner & David, 2009). HIV clearly threatens to disrupt sexual behaviour norms which are pivotal to maintaining masculine and feminine gender identities. As Charmaz (2002:308) highlights, people with chronic illness may “partition their experience [since] expectation of continuity of self and self-presentation outweigh illness and suffering”. It was beyond the scope of the study to ascertain how women dealt with their statuses after their pregnancies but this is potentially a critical area for investigation. Further research into the degree of permanency of transformative discourse would also be valuable in view of behavioural interventions intended to mediate high risk behaviour.

Study participants revealed substantial emotional hurt, confusion, feelings of blame and betrayal on discovering their status and were at different stages of coming to terms with their status. Baumgartner (2007) offers a useful framework for addressing the incorporation of an HIV identity which begins with the HIV diagnosis. According to this author, the initial reaction of an HIV diagnosis may be shock, fear, denial, sadness and even fatalism. However, individuals are “jarred” out of this initial reaction when a ‘turning point’ occurs which helps them start to come to terms with their diagnosis (Baumgartner, 2007:922). Importantly, a medical intervention is identified as one such turning point (Baumgartner, 2007). Many study participants had only recently discovered their HIV status through their antenatal care encounter and had to quickly engage with this diagnosis in terms of the implications of this on the pregnancy and the merit of commencing ARV prophylaxis in the best interests of the infant’s health outcomes. Given these dynamics, the PMTCT intervention arguably functions simultaneously as both the diagnosis and the turning point for many HIV-positive pregnant women since it forces women to deal with the medical urgencies related to her pregnancy as a result of her diagnosis. The passing of time is a key factor in the integration process (Baumgartner, 2007; Baumgartner et al., 2009). The implications of this are that HIV-positive pregnant women may not achieve integration of their HIV identity prior to accessing antiretrovirals or having their baby.

According to Baumgartner and David (2009:1735), the HIV identity will be central for a time, especially if there has been “the onset of an HIV health-related scare [which] increase[s] the salience of the HIV identity”.²¹ Certainly being pregnant with an HIV diagnosis will cause a re-evaluation and shift in the salience of other identities where this identity is prioritized over previously central identities. Once the infant has been born, other identities, like work, scholar, spouse may reassert themselves to take central place. Importantly, Baumgartner and David (2009) conceptualize disclosure as interwoven throughout the integration process. In her earlier work, Baumgartner (2007) suggests that disclosure indicates the levels of incorporation of an

²¹ According to Serpe (1987), the more likely an identity will be called on the higher its salience.

HIV identity. However, stigma is also viewed as something that critically constrains the process of incorporation of HIV into one's identity (Baumgartner et al., 2009).

For HIV-positive individuals and, indeed, the greater population living in South Africa, HIV infection remains a deeply social and value laden disease and continues to be highly stigmatised. Greef et al. (2008:312) define stigma as “a broad and multidimensional concept whose essence centers on the issue of deviance”. Insufficient attention has been paid to the internal dimensions of HIV stigma in related research. The concept of ‘deviance’ may be so pervasive that the individual who is experiencing the stigmatized condition may accept this discrediting attribute and internalize it leading to feelings of shame and low self worth (Goffman, 1963 (1986)). This relates to the notion of a spoiled identity (Goffman, 1963 (1986)). Edwin Cameron, a Supreme Court Judge and an HIV-positive person himself, speaks about the internal dimensions of stigma and the deeply rooted identity issues in relation to acquiring HIV:

“...the fear, self-disablement, feelings of contamination, self-rejection and self loathing experienced by people with HIV, and those who fear they have HIV...”

4 May 2006, University of KwaZulu-Natal, Durban.

The dissonance between the HIV-positive identity and that of impending motherhood, may give rise to different levels of external stigma: stigma related to HIV and stigma related to being HIV-positive and pregnant. There is the additional potential stigma surrounding unintended pregnancy. Disclosure of HIV can no longer be simplistically viewed in this setting since the disclosing individual will need to take into account these different levels of stigma and the implications thereof as they come to terms with their diagnosis and navigate the disclosure process.

The comments made by study participants regarding their beliefs of promiscuity and immorality as the cause of HIV-infection underlines the stigma attached to being diagnosed with HIV. These pervasive society level value judgements were internalized by some participants who voiced high levels of self-recrimination and regret over past behavior which they believed led to them acquiring HIV. Recent research points to the presence of post-traumatic stress disorder in HIV-positive individuals as a result of their exposure to various HIV-related events, including

HIV diagnosis, treatment, and HIV disclosure (Theuninck, Lake & Gibson, 2010). It is worthwhile to note that these findings may be suggestive of signs of depression and need to be factored into counselling sessions since pregnant women are already at risk for post partum depression and HIV-positive women have been found at risk for antenatal depression (Rochat et al., 2006). Importantly, unintended pregnancy and unstable household income, and not HIV diagnosis, were the factors associated with the antenatal depression (Rochat et al., 2006).

HIV disclosure may be reflective of a more integrated HIV identity (Baumgartner, 2007). However, HIV disclosure is rarely studied in terms of the process of adapting to an HIV diagnosis (Rotheram-Borus et al., 1997). If disclosure has a direct feedback effect on identity as Arnold, Rice, Flannery and Rotheram-Borus (2008) suggest, it is not surprising that some individuals may avoid disclosing their HIV status in order to avoid this feedback. Hypothetically then, by not disclosing, it can be argued that the individual is able to reject or avoid internalizing the reality of their condition. It is also entirely possible that disclosure feedback may construct an unwanted or contested identity. Importantly, the disclosure literature often does not examine disclosure as a *reflection* of identity (Arnold et al., 2008) and future research examining how disclosure fits into an individual's social identity may further uncover the dynamics of the disclosure process. Based on the study findings, it is argued that both identity and disclosure are closely bound but that a third element, the nature of the relationship, will also impact on whether and/or how disclosure will occur. It is therefore imperative to examine relationship dynamics in any disclosure context.

5.3 HIV DISCLOSURE DYNAMICS AND OUTCOMES

Filtering participant responses through a gender identity lens advances our understanding of some of the possible reasons underlying the perceptions and behaviours of women in the study context. It also forces us to consider the likely (limited) possibilities and scope for disclosure behaviour to occur within heavily gendered identity bounds. Viewing participant responses through a gender identity lens helps highlight the highly conflicting issues these women had to

weigh up in relation to their HIV diagnosis. Some immediate considerations include concerns over their infant's health and their own health and their deeply personal and visceral response to being diagnosed with a stigmatised and life threatening disease. Added to this are a variety of key sexual partner considerations: addressing the need to protect themselves and/or the foetus from further infection in the face of entrenched gendered norms; expectations in regards to sexual behaviour; and the material concern over irrevocably alienating one's partner in a climate of real economic constraint. Women's decision making power was often highly regulated by their partners with the result that women experienced high levels of internal conflict as to how to handle the implications of their status.

Many participants revealed a very contradictory response to the concept of HIV disclosure. That is, their initial responses indicated that they did not have a problem with disclosure *per se*. When applied, however, to their own situation on further questioning, it became evident that disclosure was not an experience that they were yet ready to apply to themselves. They saw benefit in disclosure but just did not see any benefit in terms of themselves. This finding offers strong caution to quantitative study designs which may question subjects over their attitudes to disclosure. The overwhelmingly positive response over the concept of disclosure in the abstract may not, in fact, accurately capture the reality.

Three main elements to the HIV disclosure behaviour were identified in the study findings: 1) disclosure decision-making; 2) the disclosure process; and 3) disclosure outcomes/consequences. Pregnancy, the general recentness of the HIV diagnosis and the overlap of these two conditions were the main obstacles to disclosure to both partners and to family. Previous bad experiences with disclosure also greatly influenced decisions to disclose, as did socioeconomic concerns and disclosure recipient cues - although different iterations of these two themes occurred for each category of disclosure recipient. No participant made the decision to disclose to everyone. Some did not disclose at all but most disclosed selectively which as Arnold (2008) suggests, is the most complex manifestation of the disclosure process.

Participants disclosed mainly to partners, mothers, sisters and then to others. These findings are consistent with the literature (Armistead et al., 1999; Fekete et al., 2009; Kalichman et al., 2003).

The majority of participants disclosed to their partners which lends further support to similar research findings (Rice et al., 2009; Simoni et al., 1995; Sowell et al., 2003). However, the literature rarely unpacks the dynamics inherent in HIV disclosure behaviour between sexual partners and the effect of these dynamics on the disclosure process and outcomes. Instead, the literature tends to focus on more tangible outcomes such as abandonment, rejection and violence at predetermined time points. The idea that the nature of the relationship is an important determinant in disclosure needs to be further expanded. The fact that at least 61% of participants disclosed to their partners suggests a trend that disclosure may occur *despite* the nature of the sexual relationship. However, the effect of disclosure was mitigated *because* of the nature of the relationship.

Disclosure-related research has been criticized for focusing on particular disclosure recipients, namely sexual partners versus family and others, without looking at the disclosure process as a whole (Rice et al., 2009). Barain et al. (2007) argue that these two categories need to be addressed separately because disclosure is fundamentally embedded within social relationship contexts. The study findings support this view but indicate that there is also some overlap in disclosure issues between sexual partners and family. This is reflected in the conceptual model emanating from the study presented in Chapter six.

The study identified that there were many reasons for women to disclose to their partners: anger, blame, needing support and being counseled to do so in an effort to reduce risk were some of the main motivations. The literature predominantly highlights the strategic nature of disclosure (Arnold et al., 2008). However, the study also underlined that, with sexual partners, disclosure may not be strategic at all. Participants sometimes disclosed their status to their partners out of anger at finding out their HIV status, usually because they felt the partner was directly responsible for their condition. The study findings also suggested that in order to avoid blame, some women chose not to disclose to their partners. Studies have shown that “blame is a critical concept in disclosure” since the person who tests first is often held to be responsible for the HIV infection (King et al., 2008:242; Maman, Mbwapbo, Hogan et al., 2001). The study findings highlighted that blame casting, anger and/or feelings of guilt on one or both sides was a common outcome of disclosure, particularly when one partner wished to create distance in terms of personal liability in acquiring HIV. As highlighted in the results, partner reactions to HIV

disclosure tended to be linked with their own HIV status. If a partner was similarly HIV-positive, the couple dealt with their shared positive status as a unit. However, if a partner was HIV-negative or had not yet ascertained or revealed his status, there were high possibilities for misunderstanding, blame or isolation to occur. Interestingly, Crepaz and Marks (2003) found that disclosure was less common if the HIV status of the partner was unknown.

HIV disclosure to sexual partners is currently viewed as a health promotion intervention in public health programmes. The purpose of disclosure in the PMTCT setting is to encourage dialogue over condom use and birth delivery options, to persuade the man to test and for the woman to access emotional and treatment-related support. One of the fundamental assumptions around disclosure to sexual partners is that knowledge of HIV status will mediate sexual risk behaviour. This assumption was not supported by the study findings.

Rather than facilitating communication, the study findings revealed the silencing effect of disclosure on some partners and on further HIV-related discussion both within and outside the relationship. Visser et al. (2008) report partner's lack of reaction and indifference on disclosure. Lynch et al. (2009:23) found in a South African-based study with HIV-positive men that "wellness colludes with silence". That is, men could retain their performance of idealized masculinity only while they were still „well'. These findings throw question as to the extent that participants and partners meaningfully engaged with the presence of HIV within their relationships. Some participant responses suggested that silences over HIV within the relationship, in fact, preserved the relationship status quo through conflict avoidance. Additionally, although HIV may be an unvoiced reality in the relationship already, participants may have feared actually voicing this reality and making HIV something that had to be dealt with. In these cases, it may have been better not to verbalize the presence of HIV and to avoid relationship disharmony. Good communication between sexual partners is central to the success of any risk reduction intervention. Crepaz and Marks (2003) reported that amongst serodiscordant couples, those who disclosed their HIV status and those who discussed the need for safer sex with their partner were significantly more likely to practice safe sex than those who only disclosed. If good communication did not pre-exist disclosure, it is unlikely that disclosure would substantially alter this dynamic between couples.

Finding out and disclosing one's status to one's partner could also precipitate a reciprocal disclosure. Some partners revealed that they had previously known that they were HIV-positive but had concealed it up to the point of the women's disclosure. This constituted an irrevocable betrayal within the relationship dynamic and, again underlines the highly charged nature of HIV disclosure. The fact that disclosure did not always precipitate a reciprocal disclosure highlights the difficulties involved in revealing one's HIV status.

As shown in numerous other studies, relationship breakdown did occur following disclosure to partners. However, as indicated in Chapter 4, it was difficult to determine the precise cause of the relationship breakdown since HIV was not the only basis for contention within many relationships. Shifting allegiances between concurrent partners and unwanted pregnancy also rendered many relationships vulnerable and unstable, even without HIV disclosure. Future disclosure-related studies need to more carefully trace the cause of relationship breakdown following disclosure before ascribing it reflexively to the communication itself.

HIV disclosure to an intimate partner rests on the assumption that once a partner becomes aware of the other's HIV-positive status, he/she will be motivated to ascertain his/her own status. The findings indicate that this was, in fact, often not the case in the study setting. Only half of the partners who had been disclosed to sought out an HIV test. The feelings of loss of control amongst participants can perhaps be extended to the partner's reactions. According to Lynch et al. (2009:20-21), HIV disturbs "normative constructions of men being in control" and that a man's disclosure of his status is to acknowledge that he has a condition out of his control. This condition, left to run its own course, will ultimately physically diminish his control over his vital bodily processes and his capacity to function as the „provider'. Fitzgerald, Collumbien and Hosegood (2010) found that the threat of the loss of their strongly gendered „provider identity' underlay male participant's reluctance to test. It is, therefore, possible that the „male identity' will predominate even if the partner is made aware of the woman's status. Further research with men and within dyads is clearly required.

In terms of the study findings, many male partners preferred to rely on their female partner's status as proxy for their own, assuming they were similarly HIV-positive without verifying if this was indeed the case. This may have been due to misunderstandings over the concept of serodiscordancy or it may, in fact, have been easier to deal with HIV on an abstract level than cement this reality with an actual test. King et al. (2008) found misconceptions surrounding HIV serodiscordance in their study where HIV-positive individuals assumed their untested partners were also HIV-positive. Recent evidence has shown that men's risk of HIV acquisition is doubled if their partner is pregnant (Mugo, Heffron, Donnell et al., 2010). It is therefore imperative for partners to test so as to minimize risk of acquisition if they are, in fact, HIV-negative. For those men who tested HIV-positive, this would be the first step in the pathway to antiretroviral treatment care. Without an HIV-positive test result, none of these men would be able to undergo a CD4 count, without which they could not access antiretrovirals for their own health, if needed.

An unexpected research finding as an outcome to disclosure, was the deliberate exposure of partners to known risk of HIV-infection as an expression of their commitment. As Thornton (2009:417-8) suggests, it is "precisely because of the risks involved, [that] sexual liaisons...may be felt to be 'more serious' and therefore more valuable than other kinds of social relationships." While Thornton (2009) theorizes within the general context of concurrent sexual relationships, his explanation of sexual risk can be equally applied to the study findings. That is, the partner's exposure to known HIV risk functioned to cement his particular relationship and, by extension, his social network. The first participant's (FB17) feedback suggests that her partner had been disappointed by his past sexual relationships. By deliberately exposing himself to infection, he was (perhaps genuinely) expressing his attachment to his partner as well as ensuring her investment in the relationship. In terms of the second partner who deliberately exposed himself (FB22), it seemed that his desire for a child with the participant surpassed his desire to protect himself from infection. That being said, neither participant reported that they had seen the actual results of their partner's negative status. It was arguably in the relationships' best interest for the two women to take it on trust that their partners were HIV-negative since they too faced an uncertain future navigating their sexual relationships knowing they were HIV-positive. While

having a child may also add to an individual's social capital, this was outside of the study focus and is a subject for further research.

The study findings also revealed very particular disclosure issues in terms of family members. The family context needs to be carefully considered (DeMatteo et al., 2002). Some participants reported that while they had accepted their status, they were concerned that another may not be ready to hear about this status or able to make the same peace with it. This provides an alternative perspective to disclosure and demonstrates that disclosure is an activity with shared emotional ramifications for the discloser and the disclosure recipient (Fekete et al., 2009). Some women refused to disclose for fear of disappointing a family member, causing them shock or suffering, or distressing them to the point that it would negatively affect that person's health. Serovich (2001) found that disclosure was influenced by the anticipated impact of that disclosure. It must be kept in mind that many lay people in South Africa still associate HIV-infection with illness and ultimately death, in large part due to an overburdened and inadequate public health care system, which was only mobilized to deliver widespread treatment very late in the HIV epidemic. With families experiencing high rates of AIDS mortality amongst family members, some women may have wished to protect their already emotionally vulnerable loved ones from the news that they too are HIV-positive. In households where finances were constrained, women may not have wanted to add to family concerns about the perceived impact of losing a breadwinner. In these instances, while participants still retained their health and therefore did not fear involuntary disclosure through experiencing AIDS-related symptoms, some chose not to disclose. Participants may also have wished to avoid the feedback mechanism of disclosure and to maintain their family role identity (Arnold et al., 2008). Although some reported that they had accepted their status, sharing this status with others and viewing themselves through another's eyes would arguably make an individual *feel* different. An HIV status may remain an abstract concept until it is verbalized, and having others around one become aware of this status could cement this reality and make it less easily ignored.

The findings regarding disclosure being seen to be harmful to another's mental and/or physical well-being merits further study. In this light, disclosure cannot be viewed as simply an issue of getting over one's own fear of revealing one's status. Further research is recommended which

looks into whether there is a generalized fear of compromising another's health through relaying bad news.

HIV disclosure is often directly associated with HIV stigma in related research which means that HIV disclosure is usually studied in relation to stigma. However, this study identified other reasons, besides stigma, why participants chose not to disclose. Participant responses underlined the inherent stress involved in concealing their status because of the need to provide fictional reasons for their modified sexual behaviour or to explain clinic visits unrelated to antenatal care. Participants also expressed feelings of relief after disclosing their status. However, the findings clearly reveal that the move from disclosure decision-making to actual disclosure of status was a complex, fraught and sensitive process.

5.4 STRENGTHS AND LIMITATIONS OF THE STUDY

This study has several important strengths. Employing qualitative methodology allowed for an exploratory and critical approach to investigating the topic of disclosure amongst HIV-positive pregnant women. The methodology is best suited for exploring the complexities involved in HIV disclosure and allows for a specific understanding of pregnancy and relationship contexts and dynamics in relation to HIV disclosure. Consideration of the interconnected contexts of relationships, pregnancy, socioeconomic vulnerabilities and personal response to these in relation to HIV disclosure greatly strengthened this study. Social constructionist theory removes the focus of study away from the intrapsychic processes of an individual and instead is interested in the socio-historico-cultural context in which an individual is located and the nature of the social interaction that occurs between individuals. The study included a purposive sample of HIV-positive pregnant, black African women accessing PMTCT services in two different sites.

There were also several limitations to the study. Due to the nature of qualitative research and the fact that study comprised of a unique sample of women: HIV-positive, black, >18 years, pregnant and attending ANC services, the findings from this study are not generalizable. In

addition, the concepts of reliability and validity cannot be applied to the findings. However, according to Burr (1995:158), these concepts are not appropriate measures of the quality of social constructionist work since “all knowledge is provisional and contestable, and accounts are local and historically/culturally specific”. Certainly, the results are transferable to other PMTCT contexts. This was a cross sectional study which meant that disclosure decision-making and behavior could not be examined over time. In addition, women were recruited within a PMTCT clinical setting which may have influenced their responses. Although desirable, it was often not feasible to conduct a follow up interview with participants. Many participants were reluctant to be re-interviewed after their initial one. It was not clear if they were unwilling to reopen the sensitive topic of their HIV status, if they were genuinely rushed or tired, or if they perceived that they would be pushed to disclose their status despite reassurances to the contrary.

Despite thorough training and quality measures, the fact that the interviewer was older than study participants may have influenced participant responses in terms of social desirability bias. In addition, despite practicing reflexivity, the researcher acknowledges that she brings her own perspective to the interpretation of the results. Having recently experienced pregnancy, being parent to two young children and being a woman herself, meant that her sympathies would have been naturally aligned with study participants. However, being educated, employed and White, also would have distanced her from some the social and culturally-related experiences that study participants underwent and which underpinned their relationships and responses.

Not including men in the sample is a clear limitation given the dyadic nature of HIV disclosure. All male involvement/behaviour was reported by participants and thus filtered through their own perceptual lens. The direct perspective of men is important in future research amongst dyads.

5.5 SUMMARY

This discussion highlighted that the circumstances or events which placed participants at risk for HIV acquisition would also affect their capacity or likelihood to disclose this status and to effect change. Participants revealed low levels of social support but indicated responsibility in care

giving activities and/or provision of income to others in their household. Household structures did not conform to the standard westernised nuclear family system. Most participants were not married and did not cohabit with their partners on a day-to-day basis. The complex social and relationship dynamics during pregnancy were highlighted. The concurrency of HIV and pregnancy diagnoses underlined the complex decision-making activities in which participants had to engage. Current disclosure recommendations are premised on assumed patterns of behaviour within relationships which were not supported by the study data. Concurrent sexual relationships complicate HIV disclosure dynamics. HIV disclosure may disrupt expectations surrounding appropriate social behaviour within a given context. Deeply entrenched gendered norms and expectations related to sexual behaviour were identified. An individual's experience of illness is a central determinant to the disclosure of this condition and merits critical attention. The impact of HIV and pregnancy on identity is an important component for future disclosure-related research. Some disclosure outcomes ran counter to public health promotion assumptions. Fears around disclosing to family members was highlighted as an area for further research.

CHAPTER 6: THEORETICAL CONTRIBUTION

This study has shown the need to move away from the biomedical model of HIV disclosure towards a more contextually and gender-appropriate one. The study findings highlight that various public health assumptions underpinning the concept of HIV disclosure in the PMTCT setting are fundamentally flawed. Prevailing assumptions that individuals will prioritize their health once aware of risk do not allow for the likely possibility that health concerns may be subordinate to very real contextual and relational issues. The assumptions arise out of the persistently „blinkered’ focus on individual level models of behaviour change which wholly ignore the advances made by the broader field of public health, that have established the influence of the context within which individuals are located on behaviour (Albarracin, Rothman, Di Clemente & del Rio, 2010a). In this light, it is perhaps not surprising that, decades into the HIV epidemic, HIV disclosure issues and difficulties in implementation of risk reduction strategies continue to endure.

In a very recent special issue supplement of *AIDS and Behavior*, there was a call to integrate theory across the individual, interpersonal and structural levels in order to provide frameworks to explore behaviour at different levels of analysis (Albarracin et al., 2010a). The editors of the supplement were critical of the current research gap in understanding the role of the intervening interpersonal and structural factors on health behaviour change (Albarracin et al., 2010a). In one of the papers within this supplement, it was stated that prevailing risk reduction strategies in the United States focus on individual-level models of health behaviour, where the primary area of interest centres on intra-psychic processes and predictors of behaviour change (Karney, Hops, Redding et al., 2010). In addition, the strategies, which have been tested in a specific country context, are often imported directly into other country settings, especially in those which receive US-based funds to support flagging public health systems. Little consideration, in general, is given to the application of these strategies across differing populations and contexts, the effects of which may “backfire, have null effects on behavior [sic], or result in unstable outcomes over time” (Albarracin, Tannenbaum, Glasman & Rothman, 2010b:Epub ahead of print).

The task of this study was to explore the dynamics of HIV disclosure amongst HIV-positive pregnant black African women in an urban PMTCT context in South Africa and to develop substantive new theory. Given the sheer complexity of the issues needing to be taken into consideration, this study proposes a conceptual model (Figure 1) encapsulating the critical concepts involved in HIV disclosure in this setting, as well as reflecting the dynamic relationship between the various thematic domains. The conceptual model provides a proposed framework for elaboration and revision by future research, intervention design and implementation planning in the South African urban PMTCT setting. The proposed model also offers a contribution to meet the gap identified by Albarracin et al. (2010).

6.1 CONCEPTUAL MODEL

The study's conceptual model offers substantive new theory about the concepts and interrelationship of factors that shape HIV disclosure behaviour and outcomes in the PMTCT context. Within the proposed model, HIV disclosure is viewed as one of several interrelated concepts. The model deliberately avoids focusing on and thereby isolating the disclosure process, in an attempt to contextualize disclosure within the broader structural and relational dynamics revealed in the study. These interrelated concepts both influence and are influenced by HIV disclosure. The interrelationship has direct implications for intervention design.

All aspects of the proposed model are embedded in the overarching structural context which was identified as a critical consideration in the study. The major components of the model are based on the major themes arising out of the study and include the following domains: 1) social networks and social support; 2) identity; 3) risk behaviour; 4) HIV and pregnancy diagnoses; and 5) the HIV disclosure process. All categories in the proposed model are linked, with some categories having bidirectional influences. This is indicated by the use of arrows.

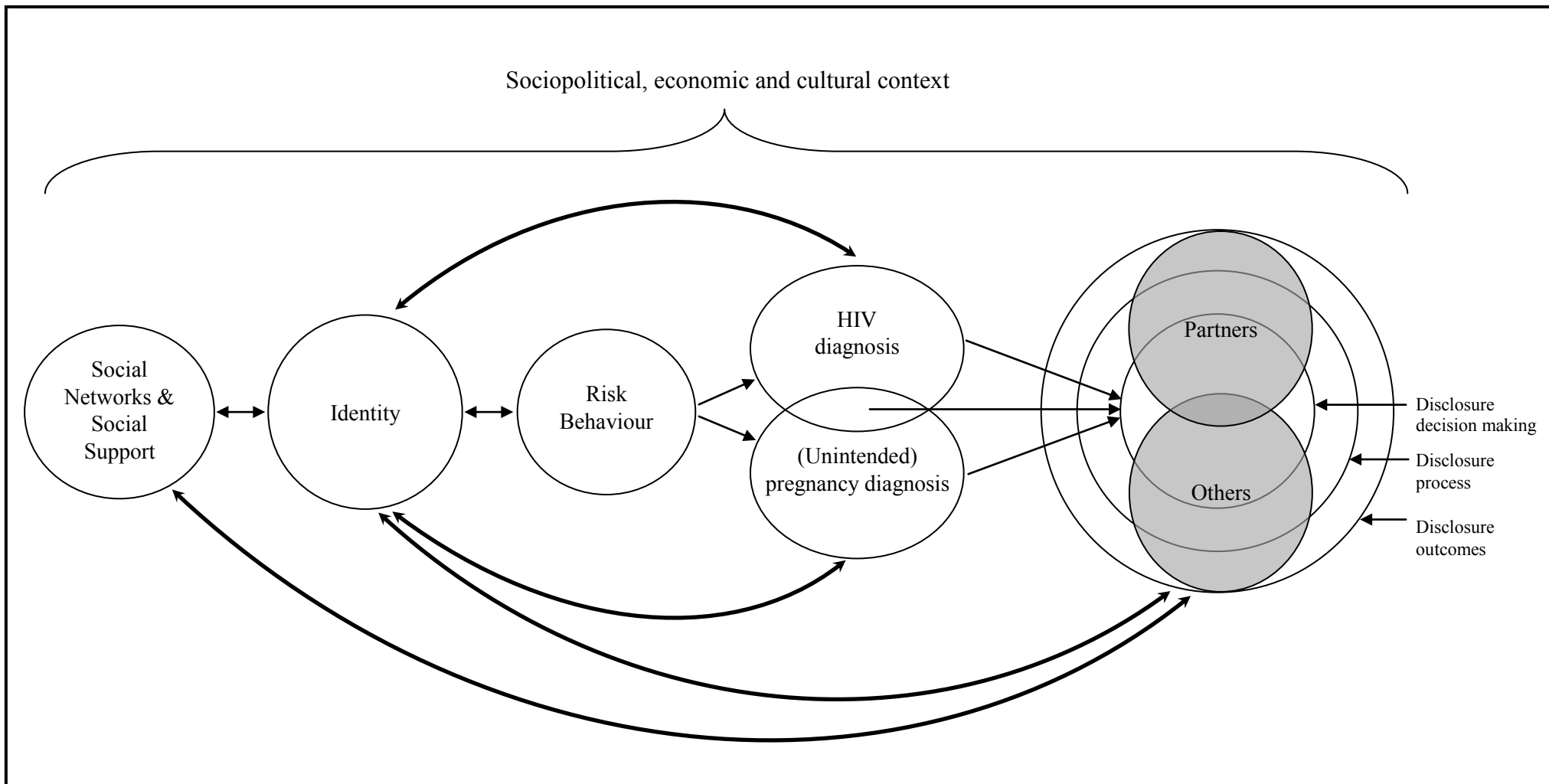


FIGURE 1: Conceptual Model of the Dynamics of HIV Disclosure in the PMTCT Setting

The structural context consists of the overarching sociopolitical, economic and cultural context within which women participate. Economic and social constraints and cultural behavioural norms all form part of this context and are recognized as greatly influencing risk behaviour. This is supported by Latkin et al. (2010), who argue that structural level factors provide incentive or disincentive for sexual risk behaviour to occur. The concept of gender starts at the structural level and influences all other domains of the conceptual model.

Embedded within this overarching structural context is the broad relational context identified in the study. The relational context is reflected by the domain representing social networks and social support. The two concepts have been incorporated into one domain in the model since social support is derived from whatever resources are available and accessible within the social network of a given individual. For the purposes of the model, these broad social networks include sexual as well as non sexual relationships. Thornton's (2009) idea of sexual networks posing or representing a source of social capital for individuals is also an underlying assumption in this domain.

Latkin and colleagues (2010) distinguish between macro, meso and micro level structures of influence. Here, the overarching sociopolitical, cultural and economic context and broad social institutions is considered to form macro level structures; the meso and micro level structures incorporate broad and immediate social networks (Latkin et al., 2010). Social norms and expectations are found at each of these structural levels but have a unidirectional level of influence on lower structural levels respectively (Latkin et al., 2010). This framework usefully refines and elaborates the conceptualization of the proposed model.

Johnson, Redding, DiClemente, Mustanski, Dodge, Sheeran, et al. (2010) offer a network analytical framework for risk reduction intervention design which includes dyads, families, peers, and communities. The network approach considers how individuals manage their environmental stressors by accessing or sharing resources with a view to ascertaining how this impacts on their HIV risk. According to this model, network behavioural norms can directly influence an individual's behaviour despite an individual's internal resources or thoughts to the contrary (Johnson et al., 2010). Of particular interest to this framework, is the suggestion that

individuals deal with their environments by placing value on resources that meet their most immediate and pressing need (Johnson et al., 2010). This view offers some explanation as to reasons underlying high risk behaviour as highlighted by the study findings and supports the inclusion of the social network domain within the study conceptual model.

According to the proposed model, the social context is seen to directly impact on a person's social identity since one's sense of identity vested in one's social and sexual networks. The presence or absence of social support resources will strongly shape identity structures which will feed into risk behaviour. In addition, as a given identity increases or decreases in salience, this will affect the nature and structure of the social networks and types of social support available. There is, therefore, a bidirectional flow of influence between social networks and identity.

The overarching structural context, the relational and social context and one's sense of identity are all viewed as influences on sexual risk behaviour. Critically, the model illustrates that risk behaviour will continue to be influenced by these same factors, as well as other factors, even *after* HIV disclosure has occurred.

The conceptual model illustrates how high risk behaviour led to an often unintended pregnancy diagnosis, an HIV diagnosis and, at the area of overlap, an HIV-related pregnancy diagnosis. It is at this area of overlap that participants will access PMTCT services. An HIV diagnosis and a pregnancy diagnosis, viewed together or separately, are here argued to catalyze a major shift in a women's prior identity. Each diagnosis also has a direct impact on disclosure behaviour and outcomes. The pregnancy and HIV diagnoses are placed at the same stage of the model because in an antenatal and PMTCT setting they are predominantly concurrently diagnosed. The general recentness and concurrent nature of these diagnoses has strong implications for new identity incorporation and disclosure behaviour.

Embedded within the overarching structural context, the most salient aspects of the evolving identity structure involve the pregnancy and HIV diagnosis. The evolving identity is subject to continuous feedback and assimilation where the individual moves between the implication of her two diagnoses and the overlap of these diagnoses, as well as the disclosure process. As she

moves between these domains, the new aspects to identity continue to undergo the process of integration. Part of the identity integration process manifests when participants begin to consider previously unconsidered aspects of their behaviour and ultimately those aspects of identity that propelled this behaviour. To what extent this self examination continued beyond the interview setting or whether HIV diagnosis and pregnancy proved only a brief island of contemplation and participants, for often good reason, lapsed back into previous social identities is a subject for further intervention research.

Disclosure shapes identity, both in terms of self-perception and in terms of the impact of another's perceived view of that person. In addition, identity shapes disclosure. Individuals who once took their personal and social identities for granted may now "need to reclaim or revise them" (Baumgartner et al., 2009:1741). The study findings identify this as a critical time for specialized counselling support to be offered to women – not only in assisting them in becoming aware of their role in their risk behaviour and/or relationships, but helping them come to terms with this role and looking at what they realistically can address in terms of secondary HIV prevention. In the context of severe gender imbalances and normative expectations surrounding sexual conduct, the notion of choice and the structural factors that may constrain an individual's ability to affect choice is a key consideration in any behavioural intervention research. It also underlines the importance of paying attention to the socio-cultural context in an identity transition such as one catalyzed by an HIV diagnosis since this context may not be supportive of the new identity.

The complexity of the disclosure process has been conceptualized in a model which incorporates the two main spheres of social relationships: sexual and non sexual (Bairan et al., 2007). The study findings very clearly indicate that, while there is some overlap in issues that caused difficulties in disclosing, these two relationship categories need to be separately addressed; fundamentally different issues between the two relationship types were predominantly experienced.

HIV disclosure is considered a key behavioural intervention strategy in the PMTCT programme which means that the PMTCT health care context may influence the likelihood that disclosure

will occur. Based on the proposed model, this intervention would only occur from the point of diagnosis. The proposed model demonstrates that this intervention, in isolation, ignores all the preceding domains. Albarracin et al.'s (2010a) argument that interventions must pay attention to processes at all levels of analysis supports the study findings and conceptual model.

Beginning with the innermost circle and working outward, the model proposes that the heart of disclosure behaviour involves disclosure decision-making activity; the process of weighing up the *perceived* costs versus benefits of disclosing to another.

If a decision to disclose is made, the individual will determine the mode and methods of communication which may involve „testing the waters’ or going about it in another strategic manner or outright communicating her HIV status. The model allows for the possibility of involuntarily disclosure, where disclosure decision-making does not precede the disclosure process. For instance, a woman’s antiretrovirals may be discovered by a partner/family member or she may experience an illness with AIDS associated symptoms which she cannot hide. This is a direct communication of her HIV status with direct outcomes regardless of any decisions made.

In terms of voluntary disclosure, the model reflects the dynamism of disclosure behaviour by also allowing for the situation where a woman may decide not to disclose to anyone and to not move to the next level, but leaving the opportunity for this to change at any time. In these cases, feedback may continue between the diagnoses level, the identity level and social network level until the point at which the individual can move towards the process of disclosing her status.

The outermost circle represents HIV disclosure outcomes, the *actual* costs or benefits following HIV disclosure. This could include acquiring support, on the one extreme, or being abandoned, on the other. Each outcome will feed back into identity, social networks and social support dynamics or processes, which in turn will influence subsequent disclosure behaviour.

The study findings highlighted that the hoped for risk reduction activity as a result of the intervention was often not achieved amongst couples. Karney and colleagues’ (2010) dyadic analytical approach to HIV-prevention provides a useful explanatory framework for these

findings. These authors (2010) identify six elements within dyadic relationships which may influence HIV transmission: trust, intimacy, relationship satisfaction, good communication, relationship commitment, and power differentials. The research findings indicate a partial or complete lack of these relationship elements for women participating in the study. The study findings also give clue as to the underlying cause of this lack; an effect of the dynamics of concurrent sexual relationships. Certainly, these relationship elements would be hard to achieve in the context of competitive concurrent partnerships, especially in a climate of economic lack with the associated power asymmetries. The study findings highlighting the lack of trust between partners find support in other South African-based research as discussed in Chapter five. This is highly important. In their review of the three HIV prevention frameworks presented in the AIDS and Behavior special supplement, Albarracin et al. (2010b:Epub ahead of publication) highlight that all three frameworks “emphasize trust as a moderator of the impact of the social context on behavior [sic]” and call for closer focus on the concept of trust in multilevel HIV prevention interventions. According to Karney et al. (2010), if relationships are based on trust, couples will be more likely to allow themselves to be influenced by their partner since it would be assumed that that partner had their best interest in mind.

Although HIV-prevention interventions have included couples-based strategies, these interventions overlook the nature of the relationship between partners (Karney et al., 2010). Karney and colleagues (2010:Epub ahead of publication) argue that the behavioural outcomes of any couple’s based intervention, will depend on the relationship context of both dyad members and suggest that “people within a relationship may choose to act based on how they think and feel about their partner and relationship, independent of their direct thoughts and feelings about the behavior [sic].” The central premise here is that risk reduction is a coordinated effort and influenced by the *nature* of the relationship and by each member of the dyad. This framework allows for individual attributes as well as structural and relational influences on behaviour since these factors will directly or indirectly impact on the dyadic ability to successfully coordinate risk reduction activities (Karney et al., 2010). According to these authors, a dyadic model does not require the presence of a partner. It provides a way to measure the impact of the partner effect if they do exist (Karney et al., 2010).

Johnson et al.'s (2010) argument that it is critical to look at the quality of the relationship between couples before selecting an HIV prevention strategy lend further support to the study findings which indicate little likelihood of change in behaviour following disclosure. Determining who the higher power partner is, in a given setting, is important since this is the person who ideally should be targeted in couples-based interventions (Karney et al., 2010). This may shift between couples according to medical care setting. That is, it is possible that pregnancy may temporarily shift the power balance between genders depending on the value placed on pregnancy in a given socio-cultural setting. Interventions need to be tailored to specific populations and need to take the relationship between partners in a dyad into account (Karney et al., 2010). Karney et al. (2010:Epub ahead of publication) urge future research to “identify the minimal level of relationship functioning necessary for a dyad to benefit from relationship-focused HIV-prevention strategies.”

Johnson et al.'s (2010) network approach also sheds light on the difficulties many study participants had with disclosure to family members given the resource constraints within family networks. For instance, applying the above analytical model to the decision not to disclose because one was a breadwinner presents this decision as entirely rational given the severe economic constraints. The most pressing need perhaps is *not* to be forced to deal with the HIV status within the family network since this will threaten a highly valued resource. Further research looking at dyadic and network models of intervention are clearly recommended.

6.2 CONCLUDING REMARKS

The process of HIV disclosure is not a universal concept. It is deeply affected by the structural context and the health care context. Given women's often rapid transition into the PMTCT programme, they may require some time to come to terms with the initial shock of their diagnosis. The tendency for the HIV diagnoses to be concurrent with an often unintended pregnancy is cause for further stress. Leeway needs to be given in these cases for disclosure to be delayed so as not to cause increased stress and risk, on many levels, for an HIV-positive

pregnant woman. Delaying disclosure will not be a comfortable position for many health care professionals who may feel ethically obliged to inform the partner at risk. However, these concerns need to be balanced against an understanding that there are many intervening structural and contextual issues that may derail the expected outcomes of disclosure in particular relationship contexts. What women could not negotiate with their sexual partners before they knew about their status is not necessarily going to change with disclosure. Alternative strategies need to be drawn on. Making the partner part of the PMTCT programme intervention by ensuring that the partner comes in for his own HIV test and using this as a platform for disclosure, other than merely counselling the woman to disclose, may need to be considered given the reported shifts in identity for women and the documented identity shifts for men. This would certainly address the study finding that men tended to use their partner's status as a proxy marker rather than ascertaining their own. Comprehensive and informed post test counseling relating to vertical and horizontal risk reduction, far beyond what is currently offered by lay counsellors, should also be carried out in this setting.

Health care professionals need to take patient cues into account. Even with overarching structural and contextual constraints, women must be seen as active agents in navigating their lives and their relationships. HIV is only one part of the consideration. Other considerations include losing one's partner and all that he represents at the time when support for a HIV-positive pregnant woman is most critical. Women accessing PMTCT services will know best what kind of communication will be tolerated within their relationship context. Actively formulating disclosure strategies (if disclosure is appropriate) with the involvement of the patient may more likely lead to desired outcomes. Public health interventions may need to focus on more than just behaviour change. The redefinition of identities as a conscious process may well be what is required.

On a methodological note, there is an urgent need to incorporate a more comprehensive view of the concept of disclosure in the public health repertoire. It is critical to study disclosure within the social contexts of HIV-positive individuals and to perform grounded and gender-based analyses within any research study. Future studies must avoid framing disclosure as a

dichotomous event. The core issue of identity and HIV and the feedback mechanism of HIV disclosure on an individual's identity need to be acknowledged.

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APPENDIX A

SEMI-STRUCTURED QUESTIONNAIRE

Clinic:	Code ID:
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A. BACKGROUND

1. Age
2. In what area do you currently live (Explore multiple residences)?
3. Ascertain current relationship status (ie. single, married, common-in-law, etc).
4. Can you list all the people in the household in which you live most of the time and tell me who they are in relation to you?
5. Can you list all the people in this household who are financially responsible for the needs of the household?
6. Ascertain obstetric history including paternity/ies.
7. Level of education completed.
8. How do you currently occupy your day? (employed/student/at home, etc)

B. HIV TESTING AND ANTIRETROVIRAL TREATMENT

1. What made you decide to come to this particular clinic for antenatal care?
2. Can you tell me about the first time you found out you were HIV+? (*Explore: Where did she test, when (month/year), what motivated her to test, what result was she expecting, how she felt*)
3. At that time, how important was it to you to discover how you were HIV infected? How important is it to you now?
4. Are you currently on antiretroviral treatment?
 - a. If so, when did you start?
 - b. If not, have you been told that you will be starting sometime?
 - i. If yes, when?

C: DISCLOSURE

Use disclosure diagram to capture dynamics and as a point of discussion)

1. Have you talked about your HIV status to anyone at all? If so, please could you help me fill this diagram out (attached) by showing who you have disclosed to and what is your relationship with them. (Probe: who was the first person spoken to, how soon after the diagnosis, who else they spoke to, why these particular people, feelings experiences?)
(Note: only discuss the first 5 people)
2. Did anyone encourage you to disclose your status to another eg a nurse, counsellor, family member, etc.? (If so, explore how person felt, circumstances surrounding this interaction)
3. Have you ever asked someone else to disclose your HIV status to another person on your behalf? Could you tell me a little about this please *(Explore: Who was this person, why did they choose this particular person)*
4. Has anyone ever disclosed your status to someone else without your permission? If so, could you tell me a little about *this (Explore the circumstances and the consequences)*
5. Who are the people that you most talk about your HIV status? *(Explore: intensity, frequency. Explore other forms of emotional support)*

D: PARTNER ISSUES

I would like to turn to the issue of partners and to talk a little about your relationship with the father of your child or the main person who you are currently involved with.

1. Would you mind sharing with me a little bit about your current relationship with the father of your baby? *(Explore whether he plays a big role in her life or if she is thinking of taking a break from him/ is she aware of any other women in his life, explore to what extent he is in her life or if she has formed/ is forming a new relationship, how often does she see him?).*
2. Have you been able to talk to your current partner *(person based on outcome of above discussion)* about your HIV+ yet? *(Explore answer, reasons why or why not, what occurred, how she approached the issue with him, what did she fear, what was his reaction, is she aware of his status? Is there more than one partner?)*
3. Could you share with me how much your partner expects to know things that happen in your life, what you do and who you choose to talk to? *(Explore whether these are only*

important events, all events, some events, etc, to what extent is she free to make her own decisions, did she have to check if it was okay first with her partner before she disclosed to other people?)

4. (If applicable) Has being HIV+ changed your relationships in any way compared to before you discovered your status? *(Explore change in both their emotional and sexual relationship,*
5. Would you mind sharing with me the type of issues, if any, you talk to your partner regarding your HIV status?
6. Could you share with me your hopes for the future in terms of your relationship and/or more having more children. *(Explore whether she or her partner want to have another child? What are her plans for the relationship, for her life, etc.)*

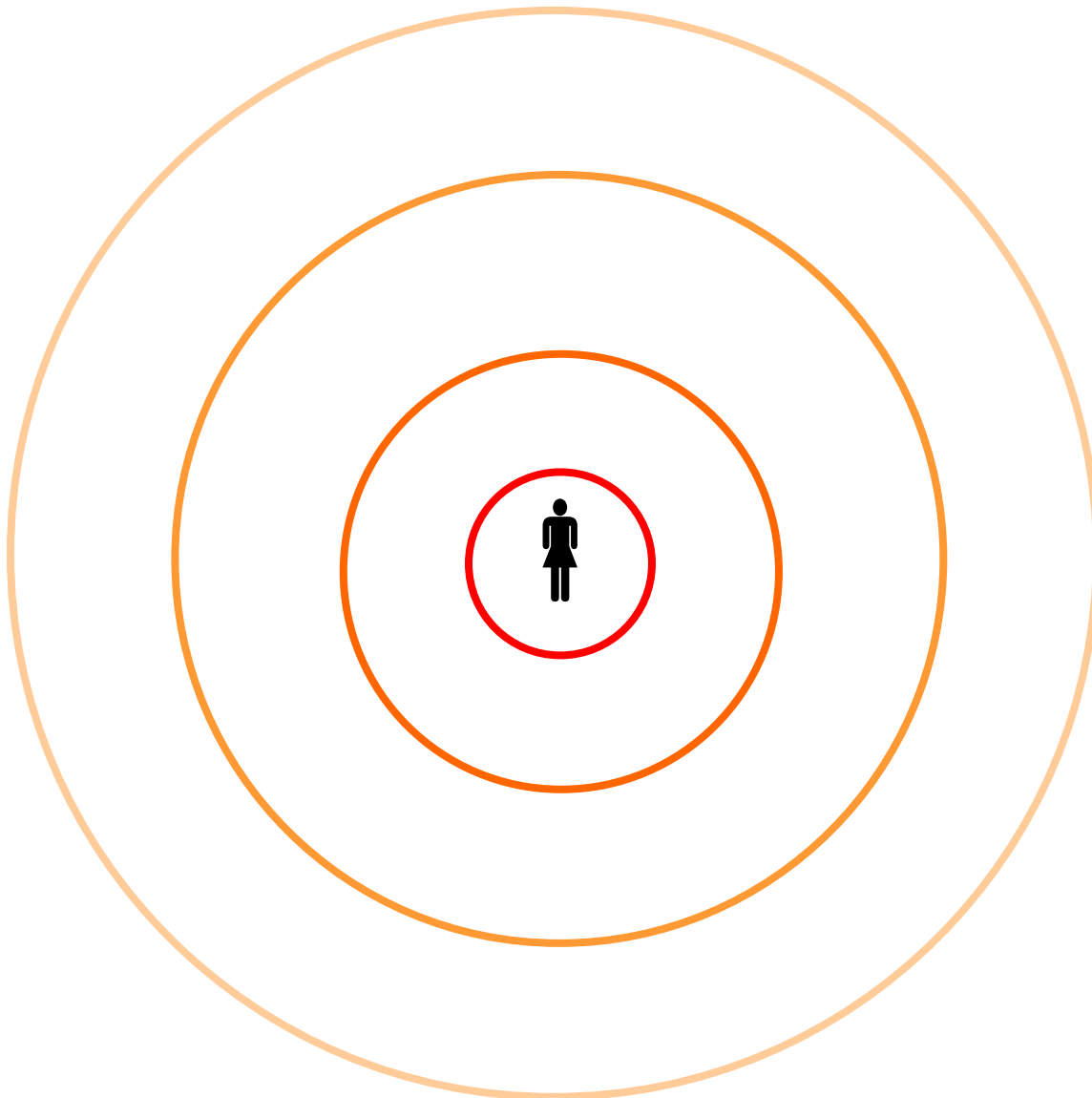
I have been asking you so many questions, is there anything you would like to ask me?

Thank you very much for your time.

Disclosure Diagram

Imagine that you were in the centre of this picture and that the circles around you represent the different people in your life. The circles closest to you represent those people who are closest to you and who play an important emotionally supportive role in your life. As the each circle gets bigger and further away this represent people that are less and less close to you and who play less of an important role in your life.

1. Keeping in mind what the circles represent, please can you show all the people in your household on this diagram.
2. Now, please could you circle, if any, the people that you have drawn here who you have disclosed to.
3. With another colour pen, please can you draw any other person in your life who you have disclosed to but who is not a member of your household. Put them on this circle grid as well and indicate your relationship to them.



APPENDIX B

13 November 2007

Dr A Voce
Public Health Medicine
NRMSM



PROTOCOL: Patterns of Disclosure: An Investigation of the Dynamics of Disclosure amongst HIV+ Women in Two PMTCT Settings in an Urban Context. T Crankshaw, PHD, Public Health, Student number 941310734

Protocol number : PG021/07

Dear Dr Voce

The Postgraduate Education Committee ratified the approval of the abovementioned study on the 13th November 2007.

Please note :

- the Postgraduate Education Committee must review any changes made to this study.
- the study may not begin without the approval of the Biomedical Research Ethics Committee. (The Ethics application form is available on the LAN. (V:) /User/Staff/General/Ethics)

May I take this opportunity to wish the student every success with the study.

Yours sincerely

A handwritten signature in black ink, likely belonging to Professor P Moodley.

PROFESSOR P MOODLEY
Chair : Postgraduate Education Committee
c.c T. Crankshaw

**Nelson R Mandela School of Medicine, Faculty of Health Sciences,
Continuing Professional Development (CPD)**

Postal Address: Private Bag 7, Conaella 4013, South Africa

APPENDIX C



UNIVERSITY OF
KWAZULU-NATAL

Research Office
BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office
Room N40 - Govan Mbeki Building
University Road, WESTVILLE CAMPUS
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769/1074 - Fax: 27 31 2604609
Email: ngwenyap@ukzn.ac.za - Website: www.ukzn.ac.za

05 June 2008

Mrs T Crankshaw
School of Family Medicine - Department of Public Health Medicine
Centre for HIV/AIDS Networking (HIVAN)
PO Box 37587
Overport
4067

Dear Mrs Crankshaw

PROTOCOL: Patterns of Disclosure: An Investigation of the Dynamics of Disclosure amongst HIV+ Women in Two PMTCT Settings in an Urban Context. Dept of Public Health Medicine.(HIVAN) Mrs.Tamaryn Crankshaw. BE014/08

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your response received 23 April 2008 to queries raised on 08 April 2008. The study is given full ethics approval and may begin as at today's date: **05 June 2008**.

You are requested to revise a minor change in the Informed Consent sheet as "This study has been reviewed and approved by the UKZN Biomedical Research Ethics Committee"

This approval is valid for one year from **05 June 2008**. To ensure continuous approval, an application for recertification should be submitted a couple of months before the expiry date. In addition, when consent is a requirement, the consent process will need to be repeated annually.

I take this opportunity to wish you everything of the best with your study. Please send the Biomedical Research Ethics Committee a copy of your report once completed.

The sub-committee's decision will be RATIFIED at a full sitting of the Biomedical Research Ethics Committee meeting to be held on **08 July 2008**.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'D Wassenaar'.

PROFESSOR D WASSENAAR
Chair: Biomedical Research Ethics Committee



**UNIVERSITY OF
KWAZULU-NATAL**

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
Website: <http://research.ukzn.ac.za/ResearchEthics11415.aspx>

08 May 2009

Mrs T Crankshaw
School of Family Medicine - Department of Public Health Medicine
Centre for HIV/AIDS Networking (HIVAN)
PO Box 37587
Overport
4067

Dear Mrs Crankshaw

PROTOCOL: Patterns of Disclosure: An Investigation of the Dynamics of Disclosure amongst HIV+ Women in Two PMTCT Settings in an Urban Context. Dept of Public Health Medicine.(HIVAN) Mrs. Tamaryn Crankshaw. BE014/08

RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved: 05 June 2009
Expiration of Ethical Approval: 04 June 2010

I wish to advise you that your application for Recertification dated 06 April 2009 for the above protocol has been noted and approved by a sub-committee of the Biomedical Research Ethics Committee (BREC) for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

The approval will be ratified by a full sitting of the Committee at a meeting to be held on **09 June 2009**.

Yours sincerely

Ms D Ramnarain
Senior Administrator: Biomedical Research Ethics



BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
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Email: BREC@ukzn.ac.za
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15 July 2010

Mrs T Crankshaw
School of Family Medicine - Department of Public Health Medicine
Centre for HIV/AIDS Networking (HIVAN)
PO Box 37587
Overport
4067

Dear Mrs Crankshaw

PROTOCOL: Patterns of Disclosure: An Investigation of the Dynamics of Disclosure amongst HIV+ Women in Two PMTCT Settings in an Urban Context.
Dept of Public Health Medicine.(HIVAN) Mrs. Tamaryn Crankshaw. BE014/08

RECERTIFICATION APPLICATION APPROVAL NOTICE

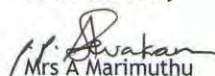
Approved: 05 June 2010
Expiration of Ethical Approval: 04 June 2011

I wish to advise you that your application for Recertification dated 04 June 2010 for the above protocol has been noted and approved by a sub-committee of the Biomedical Research Ethics Committee (BREC) for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

The approval will be ratified by a full sitting of the Committee at a meeting to be held on **10 August 2010**

Yours sincerely


Mrs A Marimuthu

Senior Administrator: Biomedical Research Ethics

APPENDIX D



28 McCord Road,
Overport,
Durban 4001,
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Overport 4067 KZN,
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P.B.O. No : 18/11/13/4121
Fundraising Authority : 06 600386 000 9

Medical Superintendent : Dr Helga Holst
Financial Director : J E Carroll
Senior Nursing Service Manager : Mrs Z E Mageba

MCCORD RESEARCH ETHICS COMMITTEE

CLEARANCE CERTIFICATE

STUDY NUMBER: **261007/5.1 tc**

PROJECT TITLE: **Patterns of disclosure: An Investigation of the Dynamics of Disclosure amongst HIV+ Women in Two PMTCT Settings in an Urban Context**

INVESTIGATOR (S): T Crankshaw, J Giddy, E van Wyk, S Reid, A Voce

MREC DATE APPROVED: **26 October 2007**

DECISION OF COMMITTEE: **Approved**

DATE: **14 November 2007**

Prof E Preston Whyte
Chair: McCord Research Ethics Committee

APPENDIX E

CITI Course in The Protection of Human Research Subjects

Tuesday, February 15, 2005

CITI Course Completion Record for Tamaryn Crankshaw

To whom it may concern:

On 2/15/2005, *Tamaryn Crankshaw* (username=tamarync) completed all *CITI Program* requirements for the *Basic CITI Course in The Protection of Human Research Subjects*.

Learner Institution: *University of North Carolina at Chapel Hill*

Learner Group: *Group 2*

Learner Group Description: ***Social and Behavioral Research:** Studies on sociological, psychological, anthropological or educational phenomena that typically involve direct contact with subjects. Does not include drug or device studies.*

Contact Information:

UNC Affiliation: Non - Affiliated

UNC PID: 0000

Department: Centre for HIV/AIDS Networking

Which course do you plan to take?: Social & Behavioral Investigator Course Only

Role in human subjects research: Site Coordinator

Mailing Address:

Email: tamarync@hivan.org.za

Office Phone: 27312685811

Home Phone:

The Required Modules for <i>Group 2</i> are:	Date completed
Introduction	02/10/05
History and Ethical Principles - SBR	02/10/05
Defining Research with Human Subjects - SBR	02/10/05
The Regulations and The Social and Behavioral Sciences - SBR	02/15/05
Assessing Risk in Social and Behavioral Sciences - SBR	02/15/05
Informed Consent - SBR	02/14/05
Privacy and Confidentiality - SBR	02/15/05
Records-Based Research	02/15/05
Research With Protected Populations - Vulnerable Subjects: An Overview	02/15/05
Group Harms: Research With Culturally or Medically Vulnerable Groups	02/15/05
Workers as Research Subjects-A Vulnerable Population	02/15/05

Conflicts of Interest in Research Involving Human Subjects	02/15/05
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HIPAA and Research at UNC- Chapel Hill	02/15/05
--	----------

Additional optional modules completed:	Date completed
---	-----------------------

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Course Coordinator



Human Participant Prote... x

file:///H:/PhD_1/ethics/Human%20Participant%20Protections%20Education%20for%20Research%20Teams.htm

NATIONAL CANCER INSTITUTE National Cancer Institute
U.S. National Institutes of Health | www.cancer.gov

Search GO

Cancer Topics Clinical Trials Cancer Statistics Research & Funding News About NCI

 
Human Participant Protections Education for Research Teams
Completion Certificate

This is to certify that

Tamaryn Crankshaw

has completed the **Human Participants Protection Education for Research Teams** online course, sponsored by the National Institutes of Health (NIH), on 02/04/2005.

This course included the following:

- key historical events and current issues that impact guidelines and legislation on human participant protection in research.
- ethical principles and guidelines that should assist in resolving the ethical issues inherent in the conduct of research with human participants.
- the use of key ethical principles and federal regulations to protect human participants at various stages in the research process.
- a description of guidelines for the protection of special populations in research.
- a definition of informed consent and components necessary for a valid consent.
- a description of the role of the IRB in the research process.
- the roles, responsibilities, and interactions of federal agencies, institutions, and researchers in conducting research with human participants.

National Institutes of Health

09:38 AM
2010/11/06