Master thesis

'You cannot eat a sweet with a paper on it'

Sexual autonomy, gender inequality and HIV

Case study at four HIV clinics in the North-West province in South Africa

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Mariëlle, T.W.G Lunenburg, August, 2009

Abstract

With this thesis I conclude the master programme: 'Social Policy and Social Interventions' that I followed at Utrecht University. Between January and June 2009 I lived in South Africa to observe the lives of HIV infected patients. Approximately 28 % of the 48 million citizens in South Africa is infected with the Human Immunodeficiency Virus (HIV) (National Department of Health, 2008), which amounts a total of approximately 13 million inhabitants. The Southern African Catholic Bishops' Conference (SACBC) offers Antiretroviral Therapies (ART's) to extend the life span of the patients and to reduce the spreading of the HIV virus. This research has been completed with the cooperation of the Tapologo centre in Phokeng (near by Rustenburg), funded by the SACBC. The HIV infection rate of people around Rustenburg has reached large proportions; approximately 15.8 % – 19.2 % of its inhabitants is infected (World Health Organization, 2005). This research has been undertaken at the clinics Kanana, Tlaseng, Chaneng and Freedom Park. Three of the four clinics are established within the traditions of the original Tswana culture and one clinic, Freedom Park, is an informal settlement. At these four clinics almost 17,03 % of the 424 women and 182 men, who started the ART's had stopped participation between 2004 and 2009. The reason why those patients withdrew from ART's is unclear. Also a lot of people in this area, who may have been infected, do not have themselves tested in order to establish their HIV status and could not be persuaded to follow ART's. This qualitative research explores the cultural and contextual factor gender inequality associated with this non-adherence. It will focus on the sexual autonomy of black HIV infected black men and women from the perspective of gender inequality. The sexual autonomy of HIV infected patients will be distinguished in four aspects: instrumental sexual autonomy, emotional sexual autonomy, gender roles and the influence of significant others (main informants). This study will focus on what kind of limitations and opportunities HIV infected men and women experience in their social environment with regards to their gender role and sexual autonomy. The main research question in this research is: *What are the perceptions of the HIV patients in Rustenburg South Africa, through the perspective of gender inequality about their sexual autonomy?* To answer this question 27 patients, 11 caregivers, 4 professional nurses, 1 track controller, 1 chemist, 1 supervisor Home Based Care and 1 supervisor Nursing participated in focus group discussions (FGD's) and in-depth interviews.

The basic assumption, on which the theory is founded, states that sexual autonomy results from gender inequality via the ascribed gender roles, that in turn are constructed by the perceptions of the main informants. The views of the main informants can influence the sexual autonomy of the patients in both positive and negative ways. The findings confirm this basic assumption.

Poverty plays an important role when it comes to the instrumental sexual autonomy of the mostly female patients. Being financially and socially dependent on men puts women in an inferior position within a relationship, which decreases the ability of female patients to insist on condom use and monogamy, which in their turn decreases the ability to protect their own sexual health. Emotional sexual autonomy decreases within traditional gender roles, violence and not so supportive social relations. Patients who have emotional sexual autonomy disclose their status to their partners and

insist on monogamy and condom use. Patients know that they need to use a condom, for the sake of their own and their partner's health, but at the same time they do not condomize.

The results show that sexual autonomy (both instrumental and emotional) is shaped by diverse cultural and contextual factors, such as: gender inequality, cultural norms about gender roles, poverty and (non)supportive social relations.

Kin relations play a major role when it comes to gender roles. People in the community are more and more aware that HIV really exists but they are the ones who discriminate and stigmatize HIV patients. Peers are the ones who empower the patients to engage in safe sexual intercourse. The church and the media play an important role as a source about safe sexual behaviour and its relation to HIV. The healthcare workers at the Tapologo clinics they educate patients about a healthy sex life: being faithful, having one partner and using condoms. However, they do not have a consistent policy on condoms, which may therefore confuse for the patients.

Prologue

"Difficult to rhyme the words
Which come and go in this place
The longer we watch
The better we see
That this fruit salad tastes like rubbish
A few kilometres further
Big white villas without HIV"

Preface

On 31 January 2009 Linda van der Kevie, Maaike Hootsen and I arrived in Rustenburg South Africa. We were unaware that we would go back to Holland in June 2009 with much more than a big suitcase of clothes. When I open my suitcase now, I see a lot of sad and complicated stories of patients and healthcare workers, who are struggling with the daily misery of this HIV epidemic. I really admire and respect the people that I have met. Even without material possessions I take for granted, they coloured my days during my stay in South Africa. It really surprised me that they were so open during the in-depth interviews and focus group discussions (FGD's) and that they wanted to share their stories with me. I am truly grateful for that. Indeed the only thing that came to my mind in the last weeks, when my motivation was down to finish this master thesis, was the faces of all those wonderful people. Sometimes I was overwhelmed when a 45 year old female patient thanked me at the end of the conversation with a big hug because this was the first time in her life she was able to speak so openly about her problems.

The first months of our stay in Rustenburg we did volunteer work at some Tapologo clinics. With her nursing background Linda helped by taking the vital signs of the patients and Maaike and I did some administrative work. During this volunteer work we were faced with the reality of this HIV epidemic. You can read many books with stories and theories but if you want to get a complete picture of the problematic situation you need to be in the field, right there with the people who are suffering. This confirmed the importance of research about HIV and cultural and contextual factors.

First of all I want to express my appreciation to Sister Alison Munro of the Southern African Catholic Bishops' Conference (SACBC) for giving us the opportunity to carry out our research at the Tapologo centre in Phokeng. Furthermore, I want to thank our supervisors Basetsana and Stephen for their assistance, support and confidence during our research. And not forgetting the other healthcare workers at the Tapologo centre who helped us. A special thanks to Hilda because of her insights and enthusiasm and our interpreters Kele, Mmalegae, Gloria and Refilwe for their translations during the in-depth interviews and FGD's. I believe we would not have any data without you guys! And Mmalegae, I am still proud that you did that HIV test with us at the Kanana clinic, even though we were nervous too. I am also grateful that I have met my great new friend Nthabiseng. Nthabiseng, thank you for all the nice moments, especially allowing us to attend your cousin's wedding, the delicious African meals you prepared for us and for just being you!

Additionally, I would like to thank my supervisor Trudie Knijn for her feedback, patience and assistance. Furthermore, I want to express my appreciation to Rosey Lea and Lindsay Vermeer for reviewing this master thesis. Moreover, the support of my family, boyfriend, friends and fellow students was really valuable. And last but not least, I am grateful that I was one of the 'terror three', who were often going to the 'we do not go there area'; drinking Milo milkshakes or Windhoek; wearing 'grefo clothes'; trying to drive in the blue Mazda at the left side of the road; watching 'Sex and the city'; trying

to dance as well as the black South Africans; joining home visits of the patients; climbing mountains; consoling each other after receiving feedback; preparing salads with lots of feta; switching the master bedroom; going out at the weekends to discover the country; watching Kobus around the house etcetera…etcetera…

Utrecht, August 2009
Mariëlle T.W.G. Lunenburg

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List of abbreviations

ABC:	Abstain, Be faithful, use Condoms, Delay sexual activity
AIDS:	Acquired Immune Deficiency Syndrome
ART:	Antiretroviral Therapies
HBC:	Home-Based Care
HIV:	Human Immunodeficiency Virus
IPU:	In-Patient Unit
FGD:	Focus Group Discussion
NGO:	Non Governmental Organisation
SACBC:	Southern African Catholic Bishops' Conference
STD:	Sexually Transmitted Disease
STI:	Sexually Transmitted Infection
VCT:	Voluntary Counselling and Testing

Chapter 1: HIV epidemic a social problem

"Some wanted children, some wanted money, some wanted property, some wanted power, but all we ended up with is AIDS" (quotation in: Epstein, 2007: p. 253).

1.1 Definition of a problem

South Africa is one of the countries, which has to handle a large proportion of people infected by the Human Immunodeficiency Virus (HIV). Approximately 28 % of the 48 million citizens is infected with the virus (National Department of Health, 2008), which means a total of approximately 13 million inhabitants. Finally this HIV infection will become the Acquired Immune Deficiency Syndrome (AIDS). This HIV epidemic therefore has social, political, economic and demographic consequences for the whole South African society (Van Dijk, Van den Dries, Tempelman and Vermeer, 2008).
Today, HIV can be treated as a chronic disease with Antiretroviral Therapies (ART's). An ART programme includes antiretroviral drugs, counselling and support services for HIV positive individuals. It is important for infected persons to be tested and to follow the ART's the rest of their lives as it reduces the spreading of the HIV virus and can extend the life span of a patient.

Various Non Governmental Organizations (NGO's) provide ART's in the battle against the HIV epidemic. The Southern African Catholic Bishops' Conference (SACBC) offers ART's, tries to fight the gender inequality and wants to empower women in Southern Africa. The AIDS office of the SACBC, which is based in Pretoria, has got more than 150 HIV treatment programmes in South Africa, Botswana and Swaziland (SACBC, 2009). The target group of the AIDS office is the black population in Southern Africa. This religious-based organization is focusing special attention on women and children.

This research has been realized with the cooperation of the Tapologo centre, a place of hope, healing and compassion in Phokeng (near by Rustenburg), funded by the SACBC. The HIV infection rate of people around Rustenburg has reached large proportions; approximately 15.8 % – 19.2 % of its inhabitants is infected (World Health Organization, 2005).

A lot of mineworkers employed by the platinum mines live in and around Rustenburg. Rustenburg is typically inflicted with major poverty, high rates of HIV infections and a lack of family – and community life (Waal, 2008). Consequently there is a lack of social support for HIV positive individuals. The Tapologo centre has got nine HIV clinics with ART's around Rustenburg. Tapologo started with ART's in March 2004 (Waal, 2008). At these nine clinics 697 men and 1504 women are on ART's. This research has been undertaken at the clinics Kanana, Tlaseng, Chaneng and Freedom Park. Three of the four clinics are established within the traditions of the original Tswana culture and one clinic, Freedom Park, is an informal settlement. At these four clinics almost 17,03 % of the 424 women and 182 men, who started the ART's had stopped participation between 2004 and 2009 (Appendix 1). The reason why those patients withdrew from ART's is unclear. Also a lot of people in this area, who may have been infected, do not have themselves tested in order to establish their HIV

status and could not be persuaded to follow ART's. This qualitative research explores cultural and contextual factors associated with this non-adherence.
Most studies on HIV focused on prevention and adherence to HIV treatment programmes, from the view of individual attitudes, as indicated in some earlier research studies from the University Utrecht[1]. The aim of cognitive studies based upon theoretical models of sexual behaviour related to HIV is to reduce the risks, spread and consequences of HIV infections by changing the behaviour of individuals (Parker, 2001). Unfortunately these studies show less satisfactory results because of practical problems such as low response, language barriers and a low level of literacy of the respondents (Van Dijk et al., 2008; Van der Lubbe, Schinnij, Tempelman and Vermeer, 2008). This study will therefore investigate cultural and contextual factors related to HIV behaviour in an explorative way. It will focus on the sexual autonomy of black HIV infected men and women from the perspective of gender inequality. Both men and women will be investigated because both are victims of the HIV epidemic. The sexual autonomy of HIV infected patients will be distinguished in four aspects: instrumental sexual autonomy, emotional sexual autonomy, gender roles and the influence of significant others (main informants).

The SACBC wants to cooperate in this research in order to find out how gender inequality related to HIV manifests itself at the four clinics of Tapologo. According to Sr. Munro (2008: p. 371), the director of the SACBC,

"AIDS has shown us that we actually know very little of how people behave sexually with one another and, despite knowledge and information of the potential dangers, why they take the kind of risks they take".

The results of this research, in this specific context, can be used for further investigation into gender inequality, sexual autonomy, HIV and medication adherence. Ultimately the results of this study may help to evaluate the HIV treatment programmes of the SACBC in the future. Further investigation and evaluation may also lead to the improvement of HIV programmes in Rustenburg. This improvement may eventually encourage adherence to the ART's and may therefore assist in the fight against the HIV epidemic.

1.2 Purpose

This qualitative research will not offer a causal empirically-based explanation of the relationship between gender inequality and medication adherence to ART's. Instead, it will explore the cultural and contextual background of gender inequality related to HIV in Rustenburg. Fundamental to this research is the sexual autonomy of HIV infected people in view of the gender inequality within the South African context. The aim of this study is to gain more insight in the sexual autonomy of HIV positive individuals. Literature shows that sexual autonomy to be an important quality for HIV positive individuals to enable them to protect their own sexual health and to reduce the sexual transmission of the HIV virus.

[1] In Elandsdoorn.

Historical patterns of sexual behaviour caused a wide extend of the HIV virus (Epstein, 2007). Colonisation and Apartheid have lead to an unequal social and economic situation in South Africa (Albertyn, 2003), which has made a lot of black people even more susceptible to the HIV virus. The context in which infected people make decisions related to sexuality will be studied. People's abilities to protect themselves against the negative impacts of unprotected sexual behaviour are influenced by structural factors (Campbell and MacPhail, 2002). This study will focus on what kind of limitations and opportunities HIV infected men and women experience in their social environment with regards to their gender role and sexual autonomy. Having this stated the next main research question will be answered during this research:

What are the perceptions of the HIV patients in Rustenburg South Africa, through the perspective of gender inequality about their sexual autonomy?

Diverse sub questions are formulated in paragraph 4.2.1 to assist answering the main research question. The main research objectives during this study are both male and female patients and the healthcare workers at the Tapologo clinics. The influences of the other main informants (kin relations, partners and peers) are investigated through questioning the patients.

1.3 Outline of this master thesis

A description of the Southern Africa cultural and contextual situation is the root of this research, which is stated in chapter two. In chapter three the theoretical framework is described, which forms the basis of the empirical part of this study. Chapter four shows the research design of this qualitative research. In total 27 patients, 11 caregivers, 4 professional nurses, 1 track controller, 1 chemist, 1 supervisor Home Based Care and 1 supervisor Nursing participated in focus group discussions (FGD's) and in-depth interviews. The results of the empirical part are presented in chapter five. This research will be finished with a conclusion in chapter six. This conclusion includes a discussion, a reflection on this study and recommendations.

Chapter 2: Sexual autonomy and gender inequality within the Southern African context

"Gender inequality is one of the root causes of the spread of HIV infection" (quotation in Albertyn, 2003: p. 601).

This chapter shows the cultural and contextual situation in which behaviour of HIV infected men and women takes place, i.e. factors which influence gender inequality and sexual autonomy in South Africa.

2.1 Social, economic and political situation

The dream and hope of many in the new democracy in South Africa was a society with equality between black and white and men and women. Although gender equality is an important part of democracy, in daily life not much gender equality has been realised (Albertyn, 2003). Nelson Mandela said, during his presidential years, that South Africa only would be free until all women are emancipated from all forms of domination. And yet many black South African women remain dominated by or dependent on their men. The current culture in the South African society is based on a *hegemonic masculinity* (Morrell, 1998), i.e. a lot of men play the leading role and many women are in a disempowered position. Men dominate and have power in the private sphere such as sexuality, the community, the family and in the labour market (Albertyn, 2003). The differences between men and women in South Africa are mostly based on unequal social economic status, educational levels, traditional family structures (polygamy), religion and knowledge about health issues. This has resulted in unequal social and sexual relations (Seidman, 1993; Klasen, 1997; Vangroenweghe, 1997; Whelan, 1999; MacPhail and Campbell, 2001; Albertyn, 2003; Van Dijk et al., 2008).

During Apartheid, migrant labour policies made men and women leave their families for labour which consequently destroyed the social structure of many communities and families. Often both parents were absent for long periods (Albertyn, 2003), which had a major impact on the social and economic relationships between men and women (Vangroenweghe, 1997). Men lived in male-only hostels, which enforced further fragmentation of the existing traditional African pattern of multiple partnerships (Helman, 2000). The decimated social structure resulted in marital breakdown, female-headed households (Seidman, 1993) and both men and women leaving their communities to look for an income and social security (Albertyn, 2003).

Apartheid not only destroyed the black communities' social structure, it also caused social and economic exclusion (Albertyn, 2003). The effects of this social and economic exclusion were impoverishment, unequal access to education, healthcare, transport, employment, social grants and other resources for black South Africans.

Today many black South Africans are unemployed, have a simple job or live on a government benefit (Steinberg, 2008). Poverty, a lack of hygienic and suitable living conditions increases the HIV epidemic among the black population.

According to Klasen (1997) many women in South Africa suffer from a higher degree of poverty than men, because there are more unemployed women and they have less access to different kinds of social and economic services (Klasen, 1997). Most women need to take care of their children and feel responsible for them. They wait at home and hope their men send their wages back home (Murray, 1981).

Poverty is also one of the driving forces for many women to have sex in exchange for basic needs such as food, clothes, shelter and housing (Van Dijk et al., 2008). According to Wood, Maforah & Jewkes (1998) some young women in South Africa have sexual intercourse with men in exchange for gifts, clothes and money. Many women engage in short- and long-term sexual relationships or become a commercial sex-worker in order to meet their basic requirements. This makes those women more vulnerable to contracting HIV and sexually transmitted diseases (STD's). Another reason that women are more vulnerable for the HIV virus is the biological transmission of the virus. The transmission from men to women is from two to four times higher than from women to men (Van Dijk et al., 2008). Compared to men, women have sexual intercourse at a younger age, which causes a higher possibility of infection. And women do suffer more often from STD's, which again increases their risk of infection (Albertyn, 2003).

2.2 Sexual behaviour, gender inequality and sexual autonomy

In the African's view of the world 'sex' and 'getting children' are related to immortality and status (Van Dijk et al., 2008); many children means personal immortality and helping hands on the land or in the household. Witchcraft, God, ancestors, spirits of death people and other superstitions are playing a major part in the life of black South Africans (Van Dijk et al., 2008). A lot of South Africans believe that white people are trying to reduce the number of births with condoms because of the aftermath of the colonisation and Apartheid (Vangroenweghe, 1997). These perceptions and practices prevent both men and women from using condoms, practicing monogamy (Van Dijk et al., 2008) and sexual abstinence which make the control of HIV more complicated. Both black men and women are living in a world in which the African traditional way of life still prevails. These perspectives on sexuality and daily life have a major influence on the sexual behaviour of HIV patients.

Another primary factor that influences the sexual behaviour of black South Africans is gender inequality. Gender inequality is one of the reasons for a lack of female sexual autonomy. According to traditional African beliefs, men are the head of a household and women need to respect and accept the decisions of their men (Steinberg, 2008). In many cultures it is common that men decide when, where and how to have sexual intercourse with their female partners (Kaleeba, 2003). This might lead to STD's, pregnancy and HIV. Most men want and can have sex for pleasure without wearing a condom. Many women are only allowed to have sex as a mean of procreation. This means that women in general have less opportunity than men to make their own choices when it comes to their own sexual behaviour.

Hoosen and Collins (2004) found that a lot of women could not insist on condom use because of threats of abandonment. If women depend on their men financially to cover their basic needs, they have little room for negotiation. If a man wants to negotiate about having sex with a condom he

probably prefers safe sexual intercourse. Most of the time it causes a woman a bad reputation when she wants to negotiate about having sex with a condom (Holland, Ramazanoglu, Scott, Sharpe et al., 1990) or some men may think that she does not trust or respect her sexual partner(s). And although both men and women in South Africa often have coexisting sexual relationships, such behaviour does not increase women's status; on the contrary, polygamy undermines her position (Hoosen et al., 2004). When a man has multiple partners, this is perceived as being fruitful and rich (Van Dijk et al., 2008), he is justified because he has a greater biological need for sexual intercourse. Indeed, polygamy is a main cause of the rapid spread of the HIV virus because it connects people in a sexual network (Epstein, 2007).

In addition to women's dependence, several authors point to psychical and mental violence during sexual intercourse (Wood et al., 1998; Albertyn, 2003). Kalichman, Simbayi, Kaufman, Cain et al. (2005) found out that 40 % of their sample group of women in Cape Town had been sexually assaulted. During those sexual assaults alcohol and drugs seem to be common components. Wood et al. (1998) found out that their respondents, a group of sexually active women in South Africa, confirmed that to 'be quiet' and to 'tolerate' seemed to be the best solutions during sexual intercourse. 'Being punished' was perceived by most women a sign of love. According to Wood et al. (1998) there are women who have to 'undress', 'lie on the bed' and 'open their legs' to meet the needs of their partner(s). Those men can see struggling or refusal as a sign that a woman has got other sexual partners, so she can be punished or verbally intimidated. Another example comes from Hoosen and colleagues (2004), they found out that some married women in KwaZulu-Natal, were not able to reject sexual intercourse because it is said to be part of their gender role. The findings of Wood et al. (1998) also say that a lot of men do not prepare women to have sex; dry sex is a common element during sexual intercourse. This can be seen as a form of violence. Therefore gender inequality is still present in South Africa; the power balance in gender relationships is asymmetric, which deprives a lot of women of sexual autonomy and as a consequence, the ability to protect themselves against HIV/AIDS by testing and adhering to ART's.

In summary: both men and women are influenced by diverse cultural and contextual factors which decrease the possibility for especially women to protect their own sexual health.

Chapter 3: Theoretical framework

This theoretical framework clarifies the sexual autonomy of HIV infected persons. The sexual autonomy of HIV infected persons is constructed by the prevailing gender inequality in South Africa.

3.1 Definitions and theoretical assumption

People having sexual autonomy are capable of controlling their sexual health. The South African context in which HIV individuals make decisions about their sexuality is constrained by the structural factor gender inequality (Campbell et al., 2002). Gender inequality causes both South African men and women to make diverse decisions about their sexual health.

Sexuality in this study is understood as:

"not only sexual practices, but also what people know and believe about sex, particularly what they think is natural, proper and desirable. Sexuality also includes people's sexual identities in all their cultural and historical variety. This assumes that while sexuality cannot be divorced from the body, it is also socially constructed (Turner, 1984 in Holland et al., 1990). The negotiation of desires and practices occurs in social contexts in which power is embedded. [….] significant in the negotiation of safer sex in heterosexual encounters is the power which men can exercise over women" (Holland et al., 1990: p. 339).

Gender inequality can be described as:

"the power that men have over women, and how this is differentially constructed, reinforced and reinvented through cultural norms about gender and sexuality" (Albertyn, 2003: p. 596).

These definitions emphasize the importance of gender (in) equality in relation to having sexual autonomy. A structural factor can deliver limitations and opportunities for action. Also cultural habits form conditions for gender inequality and gender inequality form limitations and opportunities for sexual autonomy.

Having stated that gender inequality results from both structural factors and cultural habits, this study focuses on the way gender inequality constructs sexual autonomy of HIV positive black South Africans. The theoretical assumption of this study is that sexual autonomy results from gender inequality via the ascribed gender roles, that in turn are constructed by the perceptions of significant others (main informants). The next paragraphs explain these relations.

3.2 Sexual autonomy

Intimate relationships in South Africa are often characterized by unequal decision making, a minimum of bilateral communication concerning sexual topics and a lack of preparation before sexual

intercourse (Varga, 2003). As we have seen before; power relations and social contexts play a major role in sexual behaviour of individuals (Holland et al., 1990). When it comes to sexual intercourse, women act passive. According to Sanchez, Kiefer and Ybarra (2006) one of the reasons for women to show submissive sexual behaviour is because they associate their gender role with submission. Submissive sexual behaviour decreases the sexual autonomy of an individual.

According to Albertyn (2000) a lot of women are powerless within intimate sexual relationships; they are less able to refuse sex or claim safe sex. Having sexual autonomy for people is not only related to having freedom in making choices about procreation and sexuality but also being free of physical and emotional violence (Albertyn, 2000).

Related to HIV is having sexual autonomy the ability an individual has got to protect his own sexual health. Sexual autonomy can be described as: *"having a sense of control and feeling unburdened by external pressures"* (Sanchez et al., 2006: p. 514). Both infected men and women try to hide their HIV status because they might fear stigmatization, discrimination and exclusion by their (sexual) partner(s), friends and families when they disclose their status (Nachega, Stein, Lehman, Hlatshwayo et al., 2004). This might influence condom use of both men and women. Because of their illness, HIV positive people are not always capable of fulfilling their daily duties in the household or at work. This makes it even more difficult for them to have access to their basic needs (Albertyn, 2000) and, especially for men to support their families financially. Also psychosocial antecedents play a role in the life of an infected person (DiClemente, Crittende, Rose, Sales et al., 2008) such as low self-esteem, self-efficacy, self-awareness, and self-image problems (Vermeer and Tempelman, 2008), which might influence the possibility to protect someone's sexual health.

Following the theory of McBride (1990) autonomy can be divided in two different distinct types of autonomy; instrumental and emotional. *Instrumental autonomy* is defined by McBride (1990: p. 22) as: *"the ability to act upon the world, carry on activities, cope with problems and take action to meet one's needs"*. Instrumental autonomy exists if women do not depend on men in the economic domain (McBride, 1990). Emotional autonomy can be defined as: *"the freedom from pressing needs for approval and reassurance"* (McBride, 1990: p. 22). Expressing anger or other emotions can be difficult and women who do not have emotional autonomy easily put the blame on themselves, instead of seeking their own needs (McBride, 1990). In this research sexual autonomy will be distinguished between instrumental and emotional sexual autonomy. As previously established, women and specifically women in South Africa, are neither instrumentally nor emotionally autonomous particularly when it relates comes to sexuality.

3.2.1 Instrumental sexual autonomy

Instrumental sexual autonomy is defined here as economic and social independence concerning sexuality. As in many other countries, in South Africa women are economically, socially and financially dependent on men, which involves having sexual intercourse in exchange for basic needs (Albertyn, 2003). If men lose interest, women and their children may lose their basic daily life provisions. This creates a double bind situation, because if a woman is infected, her husband or boyfriend may leave

her. Men prefer flesh-to-flesh sex without a condom. So both using and not using condoms bears the risk of being abandoned.

Furthermore, people have sex because of procreation (related to immortality and status) (Van Dijk et al., 2008), as a source of payment, a form of prestige, for pleasure, as a way to survive (Vangroenweghe, 1997) and for romance related to love. When sex is more closely connected to means of survival due to the social and economic structure it is more instrumental. According to Albertyn (2003) this is more often so in South Africa than in most Western societies. In South Africa a real emotional connection between a man and a woman and their sex life seems to be sporadic (Vangroenweghe, 1997). Many women are financially and socially maintained by their men. Some women see sex as a part of their household responsibilities or as a duty to care for their partners (Bonthuys, 2006).

3.2.2 Emotional sexual autonomy

Emotional sexual autonomy is defined here as the freedom of expressing feelings and emotions related to sexuality. Having fun during sex is an important feature for people, as well as receiving and expressing trust, building their self-esteem and relieving the pressure of daily life (Marais, 2005). The motivations for women in South Africa to be sexual active are more material (instrumental sexual autonomy) and emotional, while for men these motivations are based on physically desire and social status in the community (Varga, 2003). For both men and women sex should lead to intimacy, personal satisfaction and the expression of passion (Fritz, 2004). Emotional sexual autonomy, based on the autonomy definition of McBride (1990), includes the freedom to express own needs to sex partner(s), instead of only meeting the needs of the other one. When we focus on HIV individuals on ART's, having sexual intercourse with a condom and monogamy are important for HIV patients to take care of their sexual health. When it comes to sexuality in Africa, men are often in the position to decide about sex (Kaleeba, 2003), while most women are coerced into meeting the needs of men (Wood et al., 1998). In such a system a woman's own sexual desire is less important. Many women need to please their men and live under pressure to have sexual intercourse (Holland et al., 1990). Different authors (Hoosen et al., 2004; Bonthuys, 2006) say that sex for women is like a duty, or a form of self-sacrifice. Talking about sex with male partners, but also with other women, is still a taboo. If women agree into having sexual intercourses because they are scared that their male partners will lose interest or use violence against them (Wood et al., 1998), it is difficult to claim condom use or monogamy. It might lead to sexual violence; verbal intimidation or physical in the form of rape, dry sex, or punishment (Wood, 1998; Kalichman et al., 2005). Bowleg, Belgrave and Reisen (2000) associate HIV protective strategies like condom use with sexual self-efficacy. Self-efficacy can be seen as the patient's own belief in his ability to make autonomous choices according to his own sexual health.

3.2.3 Gender roles

Sexuality relates to gender role stereotyping prescribing 'appropriate' rules on how men and women need to behave according to social standards in the society in which they live (Bussey and Bandura, 1999). Gender roles in this study are the social positions men and women occupy in the society in

which they live. The shared rules and values, on which gender roles are based, include what is proper behaviour for men and women according to their own sex type (Bussey et al., 1999). *"Gender conceptions and role behaviour are the products of a broad network of social influences operating both familiarly and in the many societal systems encountered in everyday life"* (Bussey et al., 1999: p. 676). Gender roles are constructed by a complex mix of human experiences which are formed by structural factors, like gender inequality.

Gender roles create an asymmetric power balance between men and women especially when it comes to sexuality and multiple partnerships in South Africa. According to traditional African values, men are, with their task to financially support their household and partners (Bonthuys, 2006), head of the family (Steinberg, 2008). Women are often the ones who are responsible for child rearing and housekeeping (Durik, Hyde, Marks, Roy et al., 2006). They need to respect and accept the decisions of their men. The cultural practice 'bride wealth' also called 'lobola', which men need to pay to the family of the brides, provokes that after marriage a man owns a woman (Albertyn, 2000). These traditional gender roles include personality and emotion differences ascribed to each sex (Durik et al., 2006).

In the study of Bowleg et al. (2000) gender roles play a major role when it comes to sexual self-efficacy. The authors associate a more traditional gender role with lower sexual self-efficacy and a more modern gender role with higher sexual self-efficacy for women; they think that a modern gender role leads to more protective sexual behaviour of an individual.

In the literature there are a lot of analysis of gender stereotyping. This stereotyping is the result of what people hear and see, associated with someone's gender role. In many works of literature in the South African HIV context men are seen as more intelligent, superior (Hoosen et al. (2004), dominant and aggressive and women are seen as docile, dutiful and faithful (Wood et al., 1998; MacPhail et al, 2001; Albertyn, 2003; Steinberg, 2008).

Gender roles are important for understanding why people act like they do (Durik et al., 2006) and understand the social construction of sexual intercourses of HIV infected persons. In this research the analysis of gender role stereotyping will be used as a strategy to study the sexual autonomy of HIV positive individuals.

3.2.4 Main informants and their influence on sexual health of HIV patients

When it comes to sexual autonomy it is important that the social environment encourages the HIV positive individual to protect his own sexual health, which may entail motivating the patient to adhere to ART's.

The social environment of HIV patients that may influence sexual autonomy of HIV positive individuals consists of a network of kin relations, partner(s), friends and the ART provider (Heyer and Ogunbanjo, 2006). Fellow patients[2] (peers) may also influence the sexual behaviour and health of HIV positive individuals. Pressure from peers and intimate partners seem to be a push factor to engage in unprotected sex, which is often seen as a symbol of commitment and trust (Varga, 2003). Other influences from the informal social environment can be discrimination, exclusion and stigmatization of

[2] Others who are dealing with the same problems.

the patient (Marcus, 2008; Vermeer et al., 2008; Munro, Lewin, Swart and Volmink, 2007; Rutlegde, 2006). Besides the informal social environment[3], the patient also might be influenced by the formal social environment, which is the ART provider (Marais, 2005). The social environment of the patient in this research is called the 'main informants'. The main informants educate, share experiences and influence the patients' attitudes towards sexual health. It is essential for the adherence of the patient to the ART's that the social environment of the patient is supporting and stimulating the patient (Heyer et al., 2006). Adherence to ART's might increase having sexual autonomy for HIV positive individuals, which makes people more able to control their sexual health.

Informal main informants

In this research the social network of the patients is divided into two groups, the formal and informal social environment. The informal environment exists of the kin relations, partner(s), friends and fellow patients.

Kin relations

Family members are important when it comes to supporting the patient to adhere to ART's (Heyer et al., 2006). In particular, those relatives who are already HIV positive and follow the ART's can encourage the patient to remain in the programme (Helman, 2000). These relatives can also give the HIV positive individual information about protective sexual behaviour, which might influence the sexual autonomy of the patient in a positive way. Often family members share the same values when it comes to the perception of good (sexual) health (Helman, 2000). Family members can influence the sexual autonomy both negatively and positively. A positive influence occurs if the relatives stimulate the HIV positive individual to adhere to the ART's, to accomplish protective sexual behaviour and to strive for sexual autonomy. A negative influence occurs if kin relations stigmatize the HIV positive individual when he discloses his status to his family, accentuates gender inequality and blame mainly women for getting infected.

Partner(s)

Intimate partners play an important role when it comes to protective or unprotective sexual behaviour (Varga, 2003). Most of the time individuals engage in unprotected sexual behaviour because they trust their partner(s) or are committed to them (Varga, 2003). Another reason to engage in unprotected sexual behaviour or to show non-adherence to ART's is the fear of stigmatization and exclusion by their intimate partner(s) (Nachega et al., 2004). Especially in the South African context this stigmatization can have, mainly for women, major consequences to their financial and social circumstances. When HIV positive individuals engage in a relationship based on more traditional gender roles both men and women might be less capable of managing their own sexual health.

[3] Kin relations, partner(s), friends and fellow patients.

Friends and fellow patients (peers)

Peers influence the development of the self-efficacy of individuals (Bussey et al., 1999). In this research this means that peers can influence the beliefs of an individual and his ability to choose freely when it comes to his own sexual health. Not only can someone's self-efficacy be influenced but friends can also encourage risky or protective sexual behaviour (Varga, 2003). According to Heyer et al. (2006) it is important for a HIV positive individual to disclose his status to family, friends and peers to receive support to adhere to ART's. Friends often have common interests and shared values, i.e. friends and fellow patients might have shared values about sexual health. When it comes to fellow patients, they are dealing with the same struggles as the HIV positive individual (Helman, 2000). This can result in stimulating HIV positive individuals in disclosing their status to their partners and family, using condoms and seeking out more modern gender roles.

Formal main informants

The ART provider is distinguished as the formal environment of the HIV positive individual. According to Heyer et al. (2006) it is essential for patients to have a supportive relationship with the healthcare provider because this can encourage adherence to ART's. Because of the complex, cultural situation it is important for a healthcare provider to provide a holistic approach to HIV prevention and care (Albertyn, 2000). Open clear communication, routine counselling and encouragement, involving and stimulating the patients are important when it comes to adherence to ART's (Heyer et al., 2006). Also important is the perception of the healthcare provider about what good sexual health is. Healthcare providers who act judgmental about specific behavior ensure some infected people stay away from the healthcare system (Chesney, 2003). Some NGO's have a theological mission when it comes to providing ART's. According to Hasso (2005) religion can cause reflexivity of how men and women 'need to behave'. But if the professional or voluntary support promotes abstinence as a good strategy in overcoming HIV, and at the same time people in poor communities have many more and dispersed sexual intercourse, this strategy is deemed to fail.

Different forms of help and healthcare workers

HIV management programmes offer different forms of help to assist patients in the fight against HIV, such as: support groups, Voluntary Counselling and Testing (VCT), Home-based care (HBC) and ART programmes (Wagemakers, 2006). To maintain these different forms of practices help HIV management programmes have different healthcare workers, like: caregivers, counsellors and professional nurses, who assist, support and educate patients for the duration of their medical regimes. During support groups caregivers, counsellors, nurses and fellow patients can (spiritually) support the patient. Fellow patients can share their experiences and discuss their problems. The purpose of VCT is to test, educate and counsel people who attend on a voluntary basis and want to know more about HIV and sexual health (Wagemakers, 2006). HBC can be an element of the ART programme. During HBC caregivers visit patients at home to give social support to the patients and control and help the patients with the use of their medication (Wagemakers, 2006). However some

caregivers, often HIV positive themselves, have a lack of knowledge of HIV to counsel patients about a good sexual health (Marais, 2005).

ART programmes include education and counselling about good (sexual) health, medical practices and the provision of antiretroviral drugs. Mainly counsellors and professional nurses have the knowledge and authority to counsel and educate patients and establish medical practices. Counselling is an important feature in the fight against HIV but it is possibly the most neglected form of help (Marais, 2005). If counselling is neglected this is insufficient because counselling can lead to realisation of safe sexual behaviour. Interactions with health care workers who counsel, support and encourage patients can have a moral boost and energizing effect on patients (Marais, 2005). These healthcare workers can also stimulate the patient to practice protective sexual behaviour and follow the ART's. A trusting relationship between healthcare workers and patients is therefore important.
In order to reduce HIV infections, the aims of prevention programmes are sexual and moral behaviour changes (Van Dijk et al., 2008). A strategy of HIV prevention is educating people about using condoms. Maybe some women have the knowledge about using a condom but they do not have the opportunity to discuss condom use (Kaleeba, 2003), especially not women with traditional gender roles. Or patients might not have the ability to buy condoms. In this case the HIV prevention does not produce the essential results.

Another important element in HIV health programmes in the field of sexuality is the equal access for both men and women to condoms[4], gels and creams that can reduce the transmission of sexual transmitted infections (STI's), information about safe-sex practices and reproductive health services (Albertyn, 2000). Counselling patients to use condoms and not providing them, can deliver conflicting information, so that patients do not know what to do or what to believe.

When it comes to HIV prevention and care it is important for a patient that his social environment encourages him to adhere to ART's and to maintain sexual autonomy and protective sexual behaviour.

3.3 Assumptions

Based on the theoretical framework we assume that women experience more resistance and power from their social environment. Through the perspective of gender inequality we assume that women are less sexual autonomous and are less able to make free decisions about their sex lives and to protect their own sexual health than men. Men are mainly the ones who decide when, where and how to have sex (Kaleeba, 2003). These power relations in sexual behaviour is embedded in gendered cultural role norms (Albertyn, 2003) and can be confirmed or challenged by the main informants of the patient.

[4] As well male as female condoms.

Chapter 4: Research design

4.1 Sexual autonomy model

The outlined information brings us to the following model that provides a framework for the exploration of sexual autonomy of HIV infected patients. Within this model the South African context, the aspects of sexual autonomy and the influences of the main informants (+/-) on the sexual autonomy of HIV positive individuals are important.

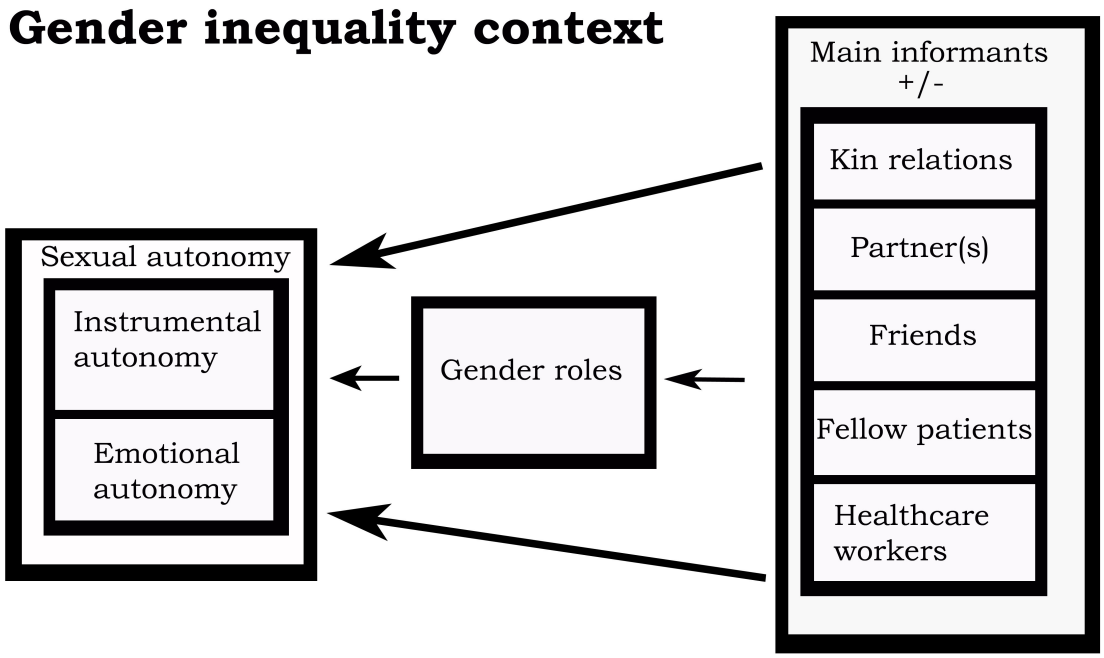

Figure 1. Construction of sexual autonomy

People's sexual autonomy is influenced by gender roles and the gender roles in their turn are provided by information and attitudes of the main informants. The sexual autonomy of a HIV positive individual can be influenced by the social environment of the patient. To investigate the sexual autonomy of HIV positive individuals it is important to know how the main informants influence the attitudes positively or negatively towards sexual autonomy and actions concerning sexual behavior of HIV positive individuals. To analyze sexual autonomy we explore *who of the main informants is telling what* and *who of the main informants is doing what*. Main informants can deliver opposite information to the patient. This information and barriers can cause this patient to struggle and make him decide not to protect his own sexual health.

Having autonomous sexuality is assumed here to be related to reducing the rate of HIV infections as well as to adherence to ART's.

4.2 Research questions

The previous information leads to the following main research question:
What are the perceptions of the HIV patients in Rustenburg South Africa, through the perspective of gender inequality about their sexual autonomy?

4.2.1 Sub questions

The main research question leads to the next sub questions:

1. How does the sexual autonomy of the HIV infected patients look like, structured per aspect?
    - Instrumental sexual autonomy
    - Emotional sexual autonomy
    - Gender roles
2. How is a HIV infection related to the sexual autonomy of a HIV patient?
    2.1 What strategies are used by the HIV patients, to protect their sexual health?
3. Which constrains and opportunities formed by the main informants, influence the sexual autonomy of HIV patients?
    3.1. Who of the main informants is telling what to the HIV patients about sexual autonomy?
    3.2. Who of the main informants is doing what for the HIV patients when it comes to sexual autonomy?
    3.3 Which constrains and opportunities, formed by the main informants contradict the sexual autonomy of HIV patients?

The sub questions one till three form answers, these answers assist in formulating an answer to the main research question and to reject or adopt the assumptions.

4.3 Research method

4.3.1 Type of research

The aim of qualitative research is to describe, interpret and explain human beliefs and behaviour (Boeije, 2005). The basis of this study is explorative, interpretative and qualitative. The scientific knowledge about sexual autonomy of HIV infected patients in South Africa shows a lack of knowledge about sexual autonomy in the specific context in which this study takes place in Rustenburg South Africa. Also, the relationship between sexual autonomy and the perceptions of the main informants is not yet clearly examined. Figure 1 shows that this research tries to investigate how the main informants influence the sexual autonomy of HIV patients, either directly from main informants to patients or via the gender roles.

Interpretative qualitative research is characterized by assumptions about the social reality (Boeije, 2006). According to Fay (1996) everybody has his own conceptual framework wherein he

sees the social reality. So there are differences between and within societies about appropriate heterosexual manners (Helman, 2000). This case study explores which perceptions HIV positive individuals in South Africa have about their own specific social reality; sexual autonomy related to HIV. It is important to understand sexual autonomy of HIV patients related to their own traditional culture, their own geographical, ideological and specific context. Gender roles are used to understand the social construction of sexual autonomy. Another research object is the main informants of the HIV patients because we assume that their perceptions about sexual autonomy and gender roles influence the perceptions of the HIV patients. We investigate the influences and perceptions of the main informants through questioning the research population. We did not question these main informants as such, information on their perceptions are collected among the patients. In addition we questioned the healthcare workers. Outlining the basic notions of beliefs and principles of HIV positive individuals can lead to an understanding about how sexual autonomy manifests itself in Rustenburg South Africa, an area with a high HIV prevalence.

4.3.2 Population

The population of this research consists of HIV infected patients and healthcare workers of the Tapologo centre in Rustenburg South Africa. This research has been completed at four Tapologo clinics; Kanana, Chaneng, Tlaseng and Freedom Park. These clinics were selected on basis of their specific features and location. Kanana, Chaneng and Tlaseng are based in a more original Tswana culture and Freedom Park is characterized by a mingling of people because of the mining influences. This may create different experiences for patients and healthcare workers because of the different contexts. The patients at the four clinics are all black South Africans from different tribes, like Tswana, Xhosa, Sotho's, etcetera. In total 16 female patients, 7 male patients, 3 caregivers, 1 track controller, 1 chemist, 1 supervisor Home based Care and 1 supervisor nursing were interviewed. Additionally, 4 female patients, 8 caregivers and 4 professional nurses participated in 4 FGD's. Both male and female patients aged 15[5] and over were questioned. Appendix 2 shows an overview of age, gender and research method per patient per clinic. The patients go to the Tapologo clinics every month or week to gather their antiretroviral drugs and to join the support groups, talk with fellow patients or visit the counsellors or the professional nurses. Three out of twenty-seven patients are not yet taking the antiretroviral drugs. They are only taking the boosting pills. Most of the patients are religious and believe in God. The majority of the patients live with their relatives or when they have a partner they sometimes live with their partner. It also appears that patients live alone. None of the interviewed patients stopped in between with their treatment and only five patients had a STD, like drop or pimples in the past.

One of the reasons to interview the healthcare workers too, was to have a broad view of the sexual autonomy of the HIV infected patients in Rustenburg. The information about the other main informants, such as relatives, friends and partners, ere collected by interviewing the patients. The healthcare workers were selected during the research period according job position and experience.

[5] Age cohort, in whom women start to be sexual active and get infected with the HIV virus, is between 15 and 24 in South Africa (Marcus, 2008).

The caregivers were living in the same community as the patients. Most caregivers, the track controller and the chemist were also HIV positive so they felt connected with the patients.

Mining influences

Our study was held in an area where mostly male labour (im)migrants work in the platinum mines in Rustenburg in the North-West province in South Africa. These men migrated to Rustenburg to find employment in the mines. A lot of people from outside the borders[6] and other provinces within South Africa are living permanently or temporary in formal or informal settlements. All these different cultures together create a mingling of many different people, which generates a breakdown of traditional social structures and norms. Approximately 400 000 people live in the Rustenburg Municipal Area. Nearly 240 000 people live on non-tribal land and roughly 100 000 persons stay on the tribal land, which belongs to the Royal Bafokeng Nation, a homeland of the Bafokeng people. Out of this total, nearly 20 000 people stay in mining hostels close to the mines (Municipality of Rustenburg, 2009). The mineworkers in Rustenburg live with or without their wife's in squatter camps near the mines. There are also mineworkers who live in hostels or unofficial settlements, near the mines, where female sex workers offer their sexual services to earn some money (Waal, 2008). If no condoms are used, migrant workers who go back home might infect their wives and/or other sexual partners with HIV (Helman, 2000). Therefore migrant labour in the mining area plays an important role in the distribution of HIV/AIDS among black South Africans.

Catholic Church

Another specific contextual aspect of the Tapologo clinics is the influences of the Catholic Church. The Tapologo centre is funded by the SACBC AIDS office. The theological mission of the SACBC around the HIV epidemic is to care for the poor[7], fight against the gender inequality and educate about moral perceptions and a 'healthy' life to decrease transmission of the virus (Munro, 2008). In addition to HIV provision, the SACBC tries to educate people about sexual health during their antiretroviral programmes. This education is based on the views of the Catholic Church. People on treatment need to know that they can infect someone else and can themselves be re-infected by others and that it is better not to have more than one partner at the same time. The HIV epidemic confronts the Catholic Church with topics in which it prefers not to get involved voluntarily, like condom use, sexual abuse, prostitution, polygamy and sex before marriage. According to Munro (2008) teaching patients about contraception and providing condoms does not belong to messages about preventing the disease. The Catholic bishops in Southern Africa say that to 'abstain' and 'being faithful' are the best solutions to overcome HIV. The C that in the regular ABC programmes of NGO's means 'use Condoms' and for the Catholics is transformed into 'be Careful'. The Catholics, like all other NGO's tend to influence the sexual behaviour of the patients in order to conquer the disease. However, the question is whether this religiously inspired condemnation of the distribution and use of condoms will prevent the spreading of HIV/AIDS.

[6] From Mozambique, Lesotho, Swaziland etcetera.

[7] Especially women and children.

4.3.3 Data collection

Because of the complexity of the subject, triangulation of different research methods has been used. To gather information about how sexual autonomy of HIV patients manifests itself at the four Tapologo clinics the following methods were used: half structured in-depth interviews (including vignettes) (appendix 3), FGD's (appendix 4), a literature review, statistics of Tapologo (appendix 1), and observations. The validity and reliability will be warranted by using half structured in-depth interviews, so the possibility of accidental errors is minimal. A benefit of half-structured in-depth interviews is that participants have got the opportunity to introduce their own topics. We decided to have face to face in-depth interviews with patients and healthcare workers so they could give their individual opinions and speak freely about their experiences.

The vignettes are originally a marketing strategy to investigate people's judgement about specific aspects ('t Hart, Boeije and Hox, 2005). The vignettes provide a more indirect way of questioning (Finch, 1987). Vignettes are: *"short stories about hypothetical characters in specified circumstances, to whose situation the interviewee is invited to respond"* (Finch, 1987: p. 105). The vignettes in this research are short and simple and include different aspects about sexual autonomy. These vignettes helped to analyse the norms and ideas on sexual autonomy of HIV patients.

According to MacPhail et al. (2001) FGD's are a good method to move away from the point of view that sexual behaviour is caused by individual decisions. Therefore, different FGD's are organized, with a group of women and with Tapologo employees. During the FGD's the research population could discuss sexual autonomy of HIV patients. In this study the researcher joined the life of the research population as much as possible by assisting the healthcare workers, joining support groups and home visits and talking to patients. So the research population became familiar and trusted the researcher, this was important because of the sensitive subject. To collect information from the research population, local interpreters helped during the interviews and FGD's. The interpreters were instructed, so they could understand the meaning of the questions. They were also instructed that they needed to translate the messages as objectively as possible. During this research interpreters were needed because the majority of the patients could not speak understandable English. To warrant the validity of this research all participants are introduced to a standard introduction, so they all got the same instructions and information about the aim of this research.

4.3.4 Data analysis

The interviews and FGD's are tape recorded. The data has been analysed in MaxQDA by patterns and regularities of the behaviour and perceptions of the research population. The different aspects of sexual autonomy have been developed to help analyse the perceptions of the research population and to answer the sub questions. Also analysis of gender role stereotyping are used to study the behaviour of the HIV positive patients. After answering the sub questions an answer is given to the main research question. After finishing this research the findings of this research will be shared with the Tapologo centre, the SACBC and Utrecht University.

4.4 Societal relevance

"It is not only an urgent public health priority that they be properly informed. Access to accurate public health information is also a human right" (quotation in Epstein, 2007: p. 255).

The number of people with a HIV infection is still growing. And not everyone who is infected shows adherence to ART's. This does not immediately lead to the satisfactory results of the SACBC programmes. A HIV infection is a matter of life and death. The societal relevance of this research is to assist against the cloud burst that is HIV.

Research on sexuality in the perspective of gender inequality related to HIV in this specific context is relevant in several ways. Firstly, it is relevant to the citizens of South Africa, because the fight against HIV/AIDS can only be successful if the relationship between men and women will change (Vangroenweghe, 1997). Understanding the perspectives of the complexity of gender relations and sexuality is fundamental in the transfer and control of the HIV virus (Vangroenweghe, 1997). Secondly, it is also relevant for the SACBC, because understanding the situation at the Tapologo clinics is a starting point for further research that eventually can help to create specific adequate HIV programmes in that area.

4.5 Theoretical relevance

Earlier research done by University Utrecht, in Elandsdoorn, has mostly been focused on preventing and adherence to treatment programmes of patients, from the perspective of individual attitudes. The aim of cognitive studies based upon theoretical models of sexual behaviour, knowledge, attitudes and beliefs about sexuality, related to HIV is to reduce the risks, spreading and consequences of HIV infections by changing the behaviour of individuals (Parker, 2001). An example of a study based upon a cognitive model is the study of Van Dijk et al. (2008). These researchers used the Planned Behaviour model of Ajzen (1991). This model shows that individual behaviour is influenced by the factors; attitudes and norms towards the behaviour, perceived behaviour control and intention (Van Dijk et al., 2008: p. 179). After the data analysis of their research Van Dijk et al. (2008) found a relationship between intention and the use of condoms and between intention and sexual abstinence of infected black South Africans. These results did not explain the realization of this intention. Another example is the evaluation of an Aids Awareness Programme done by Van der Lubbe et al. (2008). They concluded that the intention for using a condom is influenced in a different way for boys than for girls. Unfortunately, the investigators do not outline the details of this intention. There is a lack of empirical data as well as theoretical reflection on how sexual autonomy manifests itself among infected black South Africans. This study investigates what kind of obstacles and possibilities affected black South Africans' experience of their sexuality in the discourse of gender inequality and HIV at the Tapologo clinics.

4.6 Interdisciplinary embedding

Because human behaviour is constrained by different kind of factors (Parker, Mars, Ransome and Stanworth, 2003), an interdisciplinary approach will be used for this research. First of all this research

has a sociological point of view. Sociology investigates social structures and human activity in a society with a systematic approach. Sociologists look at different levels to understand human action. For example: the social economic situation in a society or the interaction between two social actors (Parker et al., 2003). The second approach is anthropology. Anthropology helps to understand the traditional culture, like the South African world view (Van Dijk et al., 2008) and the contextual situation of this research based on the gender inequality, mining industry, and the large number of persons infected with HIV and the influences of the Catholic Church. To understand the instrumental and emotional sexual autonomy, a psychological perspective is useful. With the combined approaches the complexity of the problem can be revealed and analysed in an interdisciplinary way.

Chapter 5: The secondary position

Results on case study

This chapter presents the results of this qualitative research. It will become clear how the sexual autonomy of HIV positive individuals at the four Tapologo clinics looks like, which constrains and opportunities formed by the main informants influence the sexual autonomy of HIV positive individuals. The perspectives of both patients and healthcare workers as well as the sometimes opposite perspectives from both sexes will be presented in this chapter.

Sub question one will be answered in paragraph 5.1. The answer to sub question two is described in paragraph 5.1, 5.2 and 5.3. Sub question three is outlined in paragraph 5.2. And the answer to the main research question is presented in paragraph 5.4. Paragraph 5.5 shows an extra note about *why people do not go to the clinic*, which does not appear in the research questions, but which is relevant in relation to this study.

As we have seen in the theoretical framework this research is about HIV positive individuals, this empirical part also presents experiences of HIV positive individuals.

5.1 The sexual autonomy of HIV infected patients

The first sub question was: *How does the sexual autonomy of the HIV infected patients look like, structured per aspect, instrumental sexual autonomy, emotional sexual autonomy and gender roles?* The answer on this sub question is structured per aspect of sexual autonomy. This paragraph also answers the second sub question: *How is a HIV infection related to the sexual autonomy of a HIV patient?*

5.1.1 No joy without annoy

Perspectives of instrumental sexual autonomy

Poverty plays an important role in instrumental sexual autonomy. Black men and women try to find work in the platinum mining industry. Instead of finding decent work, women depend on financial support from men to survive. "*The only job that is available here at Freedom Park for a woman is to live with a man. It has to be man after man, man after man. That is the job.* Y*ou have to live with a man, so that you can survive. A man has to provide for you, buy clothes, food and also maintain your children back home"* (56 year old female patient, Freedom Park). In exchange for daily provision women have sex with men. Not only women need to be financial maintenance, for both male and female patients this is quite common. The majority of the patients at the four Tapologo clinics are living under the level of poverty and are undereducated[8]. Both men and women are often unemployed and depend financially on a government grant, their kin relations or partners. Sometimes a patient gets food parcels from the clinic, has a temporary job, and women get maintenance from their (ex) partners for their children. Most of the time these wages and incomes are not sufficient to buy basic needs, like: (healthy) food, electricity and clothes. The drugs Tapologo is providing need to be taken with (healthy)

[8] Most patients only finished primary school. The highest level of education was grade 11 accomplished by a female patient of the Kanana clinic.

food, but from time to time patients do not have enough money to buy food. It results in patients who are not taking their treatment (properly). Patients can get a disability grant from the South African government because of their HIV infection. When the CD4count[9] of patients is higher than 200, their disability grants will be cut off by the South African government. This results in patients who are not taking their treatment properly on purpose, because otherwise they do not have an income. These patients forget their own health. This cutting of the grants causes also major problems for the sexual health. *"Cutting grants is another source of spreading HIV. Positive women still need money and food and everything. And the only way they can get it, is through a man, is to sleep with a man. Sleeping around. (…) They are spreading HIV now. And if they only had a source of income, only had the grant to provide for themselves, they would not need to spread the virus by trying to sleep around for money"* (36 year old female patient, Freedom Park). This patient pretends with 'sleeping around' female patients who have sex in exchange with several men. This sex in exchange increases the ability for women to have protective sexual intercourse. "*All we want is the money, so it depends on the man what he wants, if he does not want to use a condom there is no way you can say no, because you really need the money. So you just keep quiet and let him do whatever he wants to do for the sake of money (…) whatever he wants; protected or unprotected sex, as long as you are getting money and you are going to buy food"* (39 year old female patient, Freedom Park). If women have sex with several men in exchange and these men do not want to use condoms, this is maintaining the HIV virus. When male partners lose interest, the female partner has no one to depend on, resulting in women who start looking for one partner after that another, which continues the circle of spreading the HIV virus. Being independent and educated is important for both men and women to take care of themselves. Other strategies for women to survive are: trying to sell soda at the corner of the street, doing the laundry for other people in the neighbourhood, selling clothes or brewing African beer. Women do not only have sexual intercourse with men for basic needs but also in exchange for luxury. There was a female patient who said she has sexual intercourse with a guy only so he can buy her airtime.

Patients are worried about their own situation.*"Even though you know, this sex is killing us, it is causing diseases, you still have this sex because of hunger and making money. And then again why did god created sex, when it is now killing us?"* (36 year old female patient, Freedom Park). This female patient knows that sleeping around is not good for her own health but her contextual situation leads to her having a lack of instrumental sexual autonomy. Female patients with a partner, mention during the conversations, that they are scared to lose their partners. They think sex is an important feature to prevent their partners going out with another woman. They want to keep their partners interested for various reasons, like: fear of losing their lovers, fear of losing their daily provision and fear of getting (re)infected with HIV and STD's. One of the reasons for female patients to have fear of getting (re)infected is if no condoms are used. Maybe their partners sleep outside the house and come back home again and (re)infect them. Female patient have sex for material reasons and do not have a choice in whether or not they have sexual intercourse with men. They do not only need to maintain

[9] HIV detects the immune system of a person. A healthy person has got a CD4count between 500 and 1500. The CD4count is an indicator for the stage of HIV (Soa AIDS Nederland, 2009).

their own lives, but most of the time the lives of their children too. *"When he comes back from his work in the mines anytime, he wants to have sex with you. And then the woman does not have a say, you just have to obey what he is saying to you, because he is the one who is providing everything for you"* (Caregiver, Freedom Park).

It appears that not only women struggle with this situation. *"What can I do if she does not want to have sex, if she does not have the feelings? What can I do? Am I suppose to leave her in the house and go, while she uses my money, uses everything, food and everything, it is mine. What must I do?"* (37 year old male patient, Kanana). His girlfriend was resisted having sexual intercourse with him. It looks like he does not know if he wants his girlfriend to move out of his house or not. In the interview he hinted that he loves his girlfriend, but still he did not know what to do: his girlfriend is not giving him what she is supposed to give. In the interview he told us that his girlfriend's attitude makes him angry sometimes. There is a similarity between the perceptions of the male and female patients; it seems to be for both sexes quite normal that men provide material items to women in exchange for sexual intercourse. Female patients do have strategies to receive money from their partners. This indicates that perhaps women, because of their social economic status, do not have a choice on whether to have sexual intercourse to acquire their daily provision, but they do find strategies around this sexual intercourse, to receive what they want. *"If it is towards the end of the month and you are still refusing sex, but then you agree to have sex with him, he is definitely giving you his money"* (42 year old female patient, Freedom Park). Although if female patients refuse sex, men may think women are cheating, sleeping around and being disrespectful to their male partners. These beliefs are rather common in Rustenburg. As we have seen is having a man for female patients important. Not only for financial reasons, but social dependence also plays a role in the life of these women:

"I[10]: do you want to have a man or not?
R[11]: I want to have it.
I: why?
R: that is life to have a man. If you got a man, you do have a reputation. You become to have a reputation.
I: I do not understand. What do you mean with a reputation?
R: if you have a man you have a reputation. I am saying this because when you do not have a man people keep on talking about you: "that one, she does not have a man she is always alone", things like that. They are chatting about you. Once you have got a man, it is something like a status thing."
(34 year old female patient, Kanana)

As this patient indicates, having a male partner is important to increase a woman's social status. This paragraph shows us that female patients in Rustenburg do have sexual intercourse with male partners to survive economically and socially. Women who are dependent on men to survive are placed in an

[10] Interviewer.

[11] Respondent.

inferior position within a relationship. This aspect tells that female patients in Rustenburg have sex with their partners out of necessity.

5.1.2 He is not made of wood

Perspectives of emotional sexual autonomy

The aspect instrumental sexual autonomy pretends that when it comes to sexual intercourse, a real emotional connection between a man and a woman is sporadic. Although it often occurs that a material motivation drives female patients to have sex, it does not mean that other motivations do not exist. According to patients sex is a thing for both sexes. For those patients who think sex involves both men and women, bilateral communication about what both partners prefer during sexual intercourse seems to be important. *"I think listening is the way. Because if I insist all the time I do not think it is right. We must talk first, we must be sure that what we are going to do is right for both of us. No psychological problem later or whatever. (...) We have to communicate in a way that (…) what we do is right for the both of us"* (38 year old male patient, Chaneng). Communication about sex is important, but on the other hand not all patients have the ability to communicate about sex issues with their partners. In general it appears that talking about sex is still a taboo subject. Patients just keep those things for themselves because discussing sex topics with their partners is just no option. Female patients mention that when they want to talk about sex with their male partner, their partners become angry. Talking with partners about sex is not always necessary; if people know their lover for long, one already knows what the opposite party is thinking about sex related topics.

If patients do talk about sex, this is mainly with their partners, peers or sometimes with a relative. Patients, who talk about sex topics with their partners, discuss diverse things, like: what they are going to do during sexual intercourse, what they both prefer in bed, condom use and their HIV status. Communication between partners might be important, but pleasing both their own needs and the needs of their partners, appears to be essential in a relationship. The idea is that it is necessary for female patients to satisfy the needs of their male partners. Female patients pointed out diverse reasons for that: *"I admire my partner", "If I am in love with a guy it is my task to please the guy and not to disappoint him when he wants sex", "because we are in a relationship together", "I always have sex with him because I have chosen to be with him", "should I refuse, it starts creating problems, like maybe he thinks that I am cheating", "I do not want him to go and look for sex elsewhere"*, but also the idea is that sex is a duty when you have a male partner. Both female patients and healthcare workers mention that men take the initiative to have sexual intercourse. One professional nurse pointed out an extreme situation of a female patient:

"I: who is the leader in bed? Who decides when, where and why to have sex? Is it the woman or the man?
R: the man! (…) He comes back from drinking: "heeee. Even if the woman is cooking or what; come to the bedroom".
I: and then?

R: whether you have those feelings or not. I do not mean myself. I mean about a patient that told me. (…) There was one woman, shame, who came in and said: "heeee, I want a social worker". "For what?", I asked. "No it is enough", she said. "Enough is enough". She was plus minus one year and four months married to that guy. This woman said: "during the day anytime he comes in, he wants sex. The night, I spent sleepless nights, I am sure that man is sick. So I can not tolerate it any longer". I referred her to the social worker. I could not allow that, because she said if that man came in, perhaps he is working on night duty and came in, in the morning. He took her to the bedroom; sex. Once she was doing washing or cooking, once she woke up; to the bedroom. Before he went to work (…); to the bedroom and when he was off, not on night duty, the whole night a sleepless night and then (…) she felt exhausted. That woman felt very exhausted, no minute rest, whether she was having a visitor or not. He will go: "heee, you legs up to the bedroom". (…) That means that woman she was giving out that sex without no feelings. She will not have feelings. She is against it. Once she was cooking, she needed to leave the pots and go there, while you do not have the feelings, but it is just a matter of must. That is why she reported and said: "I am thinking of divorcing". (…) That demand comes from the man. (…) She could not say no."
(Professional nurse, Chaneng)

For female patients it is not always common to express their own sexual desire. One of the reasons for that is that female patients do not dare to ask their partners to please their needs. For both male and female patients the sexual desire of the men appears to be more important than the sexual desire of the women. When a male partner finishes satisfying his own needs, the sex is over. Although, there are also female patients who demand men to satisfy their requests and have a say when it comes to sex with their partners. *"He needs to satisfy my needs as much as he satisfies his needs"* (34 year old female patient, Kanana). *"If I do not feel to have sex, I will not do that. (…) The guys were always accepting it when I did not want to have sex. And if they do not accept it, then they should leave. (…) I am telling him straight that I am not in the mood for sex. And he definitely has to understand"* (42 year old female patient, Freedom Park). When female patients disagree with having sex, because they do not feel like having sex or they want to use a condom and their partner disagrees, this can result in sexual violence or in female patients who just agree because they do not want to make their partners angry. If female patients do not want to have sexual intercourse with their male partners they figure out diverse strategies to escape of this coercion, like sleeping with clothes on in bed or sleeping on the floor. The next fragments show the perspectives of healthcare workers about sexual violence in Rustenburg:

"One female patient came and she was just beaten by her boyfriend, very badly. And then we asked "Why?" and she said: "he was forcing me to have sex with him". But the woman was not in the mood of having it by that time. So the guy was forcing her to have sex with him and when she was struggling he started to beat her. (…) It happens more often here, especially in these squatter camps. Because it is just like: I just met you. I do not know you. I come from that country. It is just like we only made sex for pleasure. (…) Like, to have sex, I do not have really deep feelings for love with you, to (…) release

our feelings. (…) That is why I do not care whether I will insult you or hurt you or whatever. I can not sympathize with you, because I do not know you. We only met just for our pleasure."
(Track controller Tapologo centre)

"Most of our patients normally say to us, that their husbands do not want to use condoms when they have sex. And then as a result, that they force themselves to have sex without a condom."
(Supervisor Home based care)

Male partners do not always accept that their female partners are HIV positive. When they need to have sexual intercourse with a condom this can lead to confrontations. The next fragment shows the story of a female patient and her boyfriend:

"R: now he gives me a lot of problems. And I do not know why. I am not happy. Two months ago he did not want to use condoms anymore. (…) then he forced me to use nothing. Now, it appears he is HIV positive. (…) He was forcing me to sleep without a condom by taking the gun and then he told me: "I love you and I never want to lose you". (…)
I: why did he want to sleep without a condom?
R: I do not know, you know men are very difficult, I do not know why.
I: what do you mean with very difficult?
R: you know, I sat down with him and told him about my status, he accepted that for a short period. After that period he did not accepted it anymore (…) that he should use a condom. It was after 5 months, in January, he said: "I am tired of using condoms". (…)
I: and how was the forcing going? (…) Was it by words when he threatened you with the gun?
R: no he sat down with me and he was nicely first. And then I disagreed. And after that (…) my boyfriend told me if I do not want to sleep with him, he was going to kill me. (…)
I: he was nice but he told you that he wanted to kill you?
R: he was nice, he did not beat me. He was not hush. He told me nicely: "when we are going to separate I am going to kill you because I love you". (…) My boyfriend did not want to hurt me because he knew that I am infected."
(30 year old female patient, Chaneng)

This patient thinks she is lucky that her boyfriend did not swear at her. In the beginning of the fragment she shows her discomfort with his action, but later on it looks like she finds it quite normal. The boyfriend loves the female patient and it looks like his love gives him justification to threaten her with a gun. According to patients and healthcare workers sexual violence among condom use and other sex related topics still prevails, various reasons for that are: *"men feel that they own you", "because both men and women drink too much alcohol or use drugs", "partners do not believe that patients are sick and need to use a condom"* or *"patients refuse to have sexual intercourse without a condom"*. Patients do not talk easily about these fights with the healthcare workers, which makes it sometimes difficult for healthcare workers to sympathize with these patients.

Another form of sexual violence which still appears is dry sex. Both healthcare workers and women give diverse reasons for that: *"he does not care about your feelings, so it would not matter that you are wet or dry". "we only have dry sex, he only prepares himself", "he is always saying that he is craving for sex no matter if I am wet or not", "when a man comes in from were he is coming from and he wants to have sex, they are going to have sex", "men think foreplay is just a silly thing", "when you want to have foreplay, a man might see that as a struggle, so he thinks that you do not want to have sex", "most black men do not have time for fore play", "foreplay only happens when the love is new, but after a couple of weeks when he is used to you, he does not do that anymore", "men are just chicken, up and go, up and go", "because the woman is already a sleep"*, etcetera. This sexual violence obstructs the sexual autonomy of female patients and the opportunity to negotiate about condom use and within that the opportunity to protect their own sexual health.

5.1.3 The position of the sexes

Perspectives of gender roles

"In general it is culturally gender inequality. Especially when you go to Freedom Park you will find a woman actually subordinate to her man. Yes, that is how it is. The man is always the head of the figure. (…) If he says you need to cook, you need to cook. (…) And if you go to the clinic because you are not feeling well, you have to ask permission of your husband or ask for money. You are depending of this man for everything: for shelter and security reasons and women, we comply on to this because women need their security. In Freedom Park it is worse because this are mainly people who are coming from outside and these women do not have anywhere to go. And if this man says you are sick, get out of my koekoe (shack). They must go out, but where to go? Because they are from outside the border. So that is how it is culturally with the roles of men and women. We are situated down there" (with her hands she represents that men are higher situated than women).
(Supervisor Nursing, Tapologo centre)

In general the man is the head of the family and as such the breadwinner. He needs to look after his wife and children. The man needs to provide shelter, the facilities in the household, money to buy food, clothes and education for the children. It is his duty to maintain his wife or girlfriend and the children. The tasks of the woman are to take care for the husband, preparing food, cleaning the house, dishes, doing the washing, ironing, bare children, look after the father and mother in law, make sure the husband and children look nice, educate the children and satisfy her husband and children. Women need to be submissive, respectful to their partner and need to tolerate everything a husband does. The traditional gender role in which the man is the provider and the woman is the caregiver of the family is rather common. The next fragment emphasizes the position of the two sexes within a marriage:

"There is a say in Tswana that says: a man is an axe, he must be borrowed around. An axe as in chopping. A man is that, you can borrow your labour to that one and that one and that one, meaning that a man can go and sleep there and there and there. (…) And if you attend our weddings, even the

songs are like; as a woman you are not suppose to ask your husband where he comes from if he comes home very late. Honestly, do not ask your husband where he has been. Month end, do not ask your husband for a pay slip, if your husband is having an affair there, do not go and fetch your husband there. (…) In a way I think men are really allowed to have more partners."
(Supervisor Nursing, Tapologo centre)

As this supervisor is saying, men in the Tswana culture have more permission than women to have more than one partner. If a woman has more than one partner this might ruin her reputation. So when it comes to polygamy gender inequality still exists. Although more often patients have just one partner, polygamy still appears. If women have more than one partner the reason for that is more material: when one partner is not satisfying their material needs, they take a second or a third partner. When a female patient has her own income she starts having a relationship with just one man. Guys more often have more partners to satisfy their sexual desire and because this is culturally tolerated. *"He had lots of women, he used to change women like changing underwear. He was better in changing women then in changing his underwear. Even today after we are not together he is still doing it"* (42 year old female patient, Freedom Park). Men think they have the right to have another relationship because of providing material items, women just need to agree with that, just like the Tswana song expresses. If female patients depend on their male partners, they might continue an unfaithfulness relationship, because they do not have another choice.

If there are problems in the marriage, husband and wife need to ask advice of their uncles and aunts, so they can help to resolve issues. Compared with a Western marriage an African marriage seems to be more a matter for the whole family, instead of only an arrangement between two people. To marry a woman a man needs to pay 'lobola' to the family of the bride in exchange for the bride. A man can pay lobola in the form of cattle or money. Some female patients mention during the conversation that they were not much good anymore because they were HIV infected, i.e. their lobola was not so high anymore. With paying the lobola a man might think he owns the woman. Patients did not talk about this topic, but some healthcare workers did. *"When they marry a woman they are saying they own you (…) I take out lobola, and you are my property. I play the guitar and then you dance, if you do not want to dance I will take a stick and I will hit you"* (Professional nurse, Kanana). *"They believe, they give out lobola to their wife's family for the wife to come in and bare children. Many many children. So the condom prevents pregnancy, why should they use a condom (…) According to their culture, a woman is there for washing and cleaning and sex. That is why she was bought in"* (Professional nurse, Chaneng). With the lobola, the black population maintains the gender inequality. The lobola mechanism pretends that the man is superior to the woman. A woman is not free in protecting her own health if she needs to ask permission from her partner to go to the HIV clinic.

These outlined examples are characteristics of traditional gender roles. On the other hand some patients acknowledge that there are also modern gender roles in Rustenburg, i.e. men and women are more equal. A man who also has to undertake household duties whilst his female partner earns the money. *"It is 50/50. When I am at work and he is off, he must look after the children (…) and he must also cook"* (30 year old female patient, Chaneng). Although, there are some patients who

acknowledge more modern gender roles, the traditional gender roles are quite common in Rustenburg and within that the gender inequality maintains. In such a context where women do have less power than men, negotiating monogamy and condom use is difficult.

5.2 Who is telling what and who is doing what?

Perspectives of main informants

The third sub question was: *Which constrains and opportunities formed by the main informants, influence the sexual autonomy of HIV patients?* Sub question three includes the questions:

- *Who of the main informants is telling what to the HIV patients about sexual autonomy?*
- *Who of the main informants is doing what for the HIV patients when it comes to sexual autonomy?*
- *Which constrains and opportunities, formed by the main informants contradict the sexual autonomy of HIV patients?*

The answer on this sub question is given per main informant. Only the Tapologo employees are questioned, the perspectives and actions of the other main informants we know by questioning the patients. This paragraph is also answering the second sub question: *How is a HIV infection related to the sexual autonomy of a HIV patient?*

5.2.1 Informal main informants

Kin relations and community

When a man and a woman want to get married both families sit the groom and the bride down to tell them what they can expect in marriage. Uncles and aunts, who are already married, are allowed to tell the couple how they need to behave. Only married ones are authorized, because of their experience of marriage. The roles of both men and women in marriage become clear during this meeting. Also in their upbringing the social positions of the two sexes are visible. *"I think when we were brought up our parents actually (…) are the ones who promote gender inequality. If you grow up together even as twins a boy and a girl. A girl will be told: go and clean up the dishes and clean the kitchen. A boy will be told: pick up the papers outside or water the garden. You know the roles are not played around. There are roles that are mainly for girls; doing the washing it will be for the girl. And that boy can sit there for days. (…) So I think with our parents it is the education of roles in the house"* (Supervisor Nursing, Tapologo centre). Parents teach their children that boys and girls are not equal. Parents might also have a say in the choice of partner of their children. Both parents of the girl and the boy sit down together and discuss if there is a possibility for their children to get married together. *"In Lesotho when you are a young girl maybe living in a poor family and there is a man out there who is working and has got money. They would organize for you and that man that you will be together, without knowing each other. Without telling you and without telling the guy. They just take you to the man's*

place then you will be a man and a woman living together. So that is what also happens to me. I did not have a choice. (…) For me being with a man was not nice. (…) And when it comes to sex I did not want to have sex but I did not have a choice. And it is difficult for you to go back home maybe tomorrow morning because you are asking yourself questions: what is my mother or my granny going to say when I come back? What am I going to say, where have I been? So that is when you end up with a man" (51 year old female patient, Freedom Park). When parents arrange a marriage the sex for both men and women is not always voluntarily. This means that both men and women do not have emotional sexual autonomy in deciding with whom they want to have sexual intercourse. As this patient says she had no choice when it came to sex, because sex belongs to marriage and otherwise she and her family did not have enough money to survive easily. On the other hand there are patients, with a partner, who have a say to decide with whom they want to have a relationship.

When it comes to a HIV infection relatives are often the ones with whom patients can speak openly about their HIV status. A male patient called his HIV status his family secret. He does not want to tell it to people in the community, because they make fun of patients, discriminate or gossip about them. The community is more and more aware that HIV is a sexual transmitted disease, but it still appears that people have the wrong knowledge[12] and associate HIV with sleeping around. People think that a HIV patient is reckless and does not follow the correct way of living, like being faithful to a partner. It appears that people associate condom use with cheating and being infected, which makes the use of condoms difficult. People in the community need to be educated more about HIV and AIDS. There are also relatives who are not giving the patients social support[13], because they feel ashamed for their infected relative, they are scared that they will also get infected or they feel it as a burden to take care for their kin relation. These kin relations do not accept their HIV positive family member. This makes that HIV patients do not dare to speak openly about protective sexual behaviour within their family and within the community. On the other hand there are people in the community who are taking the disease like any other disease, know they can spread the virus by sexual intercourse, and understand that the disease can affect anyone.

It appears that patients educate their relatives about HIV, adherence to ART's and condom use. A female patient told us that she instructed her fifteen year old daughter how to use condoms, because she did not want her daughter to suffer from the same thing she did. Another female patient organised with her partner, who was negative and accepted her status, a feast for both their families to tell their relatives about her status and to educate about HIV. Although communication is important within families, people do not often communicate open about sex related topics with their relatives.

[12] They have traditional beliefs about HIV, like: being bewitched or not being cleansed after the dead of a partner. This subject is excluded in this research but Linda van der Kevie attends to this subject in her master thesis *'HIV is definitely not the end of the world!?'*.

[13] Social support is not the subject of this master thesis, Maaike Hootsen attends to this subject in her master thesis *'Blood is definitely thicker than water! but 'sshht…what will the neighbours say!??'*.

Partner(s)

Patients who tell their partners about their status and condom use have diverse reasons for that: feeling responsible for spreading the HIV virus, because of the health[14] of both patient and partner, because of loving a partner or because the patient just wants to be open to a partner. On the other hand there are also patients who do not disclose their status to their partners and do not speak open about condom use, because of: fear of being deserted, stigmatized and discriminated by a partner. It appears that male patients are scared that their partners will undermine them and female patients are scared of losing their daily provision or being punished by a male partner. Partners of HIV patients do not always believe that their lover is infected. They say that their partner looks healthy. Female patients have experienced rejection from men after disclosing their status. This decreased their self-esteem and trust in relationships and their goodwill towards condom use. After those experiences they just wanted to stay alone, because they think nobody wants to have a relationship with a HIV infected person. *"Every time somebody asks to have a relationship with me, before I agree with a relationship or the conversation, the first thing I do is; I have to tell you this, I am HIV positive and that is where the conversation ends. Then they thank me for telling the truth"* (42 year old female patient, Freedom Park). These men do not want to get involved with a HIV positive person. Partners even go into denial, i.e. that they do not want to know that their lover is HIV positive; they stigmatize their partner's status. Male partners become angry when they find out that their wife goes to the Tapologo clinic, this mainly ends in a dispute. A male patient told us that since his status became known his girlfriend does not want to have sex with him anymore, because she is afraid of getting the virus. On the other hand there are also partners who support their lover. Both patients and healthcare workers mention that most of the time women are more supportive in a relationship than men and are more willing to use condoms. A female patient mentions that after her partner found out she was HIV positive they were separated for a while but after that he realised he loved her so much that they started seeing each other again. It also appears that patients do not know if their partner is also HIV positive, because they do not dare to speak openly about HIV. Relationships sometimes end when one of the partners does not want to use condoms. Female patients say that their male partners did not want to follow the ART's and did not want to use condoms, this made them stressful and angry so they decided to quit the relationship. Other women mention that their partners did not want to use condoms, this resulted in them not having sex with their partners anymore and eventually these relationships ended because their male partners were no longer faithful.

Friends and fellow patients (peers)

It appears that fellow patients became friends with each other because they are dealing with the same problems. Peers talk about relationships and sex. They chat about condom use, having one partner and being faithful. When patients talk about sex with their peers they think it is easier to advise their peer to also go to the Tapologo clinics. Female patients also talk about other problems with their peers, like what to do when a man does not want to use a condom. It looks like they advise and empower each other when it comes to men and condom use, which can increase their sexual

[14] Infection and re-infection

autonomy. A female patient mentions that a fellow patient sometimes gives her money, so she does not have to have sexual intercourse with men anymore to survive. This data shows that peers have positive influences on the sexual health of patients.

Religion

Religion seems to be important for the Tapologo patients. It turns out to be that most patients are Christian. Patients who attend the Zion Christian Church, let their religion lead their sex life. *"According to my church there are some days where by we are not allowed to have sex and there are days that we have to do our things that we need to do from the church. So I am only going to sleep with my wife when it is the time for us to have sex. (…) On these specific days you need to have sex and on these specific days you do not need to have sex, according to our church. (…) The reason being that my wife should be free to put on the church uniform (specific clothes they both man and woman need to wear when they go to church). So according to our church we do not have to have sex the day (Saturday and Tuesday) before we go to church. That is the church law. (…) On the other days we have sex"* (48 year old male patient, Kanana). Patients also talk about sex and relationships with people at the church or their priest. Those people give them advice on how they need to behave. In church they advise people to use condoms and not to have more than one partner. Unfortunately we do not know if these churches also provide condoms to the patients.

The media

During the in-depth interviews patients also mention the media as an important source of information about HIV/AIDS and condom use. More often people state to listen to the radio than to watch the television. This might be because people do not all have a television because of a lack of financial resources. Some patients also inform us about adverts in town which promote condom use. A female patient tells that every Saturday morning at eleven o'clock she sits down her children to let them listen to a radio programme telling about HIV and AIDS.

5.2.2 Formal main informants

Tapologo clinics

"The rules are saying that if you are HIV positive you have to use a condom. The nurses are telling that" (45 year old male patient, Chaneng). Educating and convincing patients about a healthy sex life are important at the Tapologo clinics, this happens during the VCT's, support groups, home visits and during the monthly/weekly consultations with the professional nurses or doctor. Patients experience it as a nice thing to talk about how they can protect themselves with healthcare workers. Patients need to change their life style because the 'goes around, sleep around' way of living, which according to the professional nurses often appears, is not the correct way of living. A healthy sex life is: having one sex partner and using condoms when you are not married. This last aspect is dangerous when both husband and wife are HIV infected. Although, healthcare workers educate all patients (married or not)

about using a condom, abstinence and STI's/STD's. Though, it still appears that patients have the wrong notions about condom use.

The Catholic worldview might have lead to a negative attitude towards condomizing. Luckily that is out of order at the Tapologo clinics. One supervisor tells during the in-depth-interview that providing condoms is actually not allowed for a Catholic organization. Although, her own opinion is that to refer condoms is as good as providing them, i.e. she has no problems with providing condoms. Also Bishop Dowling[15] has no negative notion among condoms. Though, these persons do not have a negative attitude towards condom use there is no consistent condom policy at Tapologo. Patients get condoms for free at the community clinic and they pay for them at the shop or chemist. From time to time one of the healthcare workers will bring a box with condoms from the community clinic or the Phokeng clinic. Healthcare workers only provide them when patients explicitly ask for them. Sometimes boxes with condoms stand in the corner, without attending patients taking them. *"I have never seen them here. (…) I always take them when I see them at public places"* (39 year old male patient, Kanana). Patients do not always know that they can ask the healthcare workers for condoms. Some patients do not dare to ask for condoms. It also appears that the Tapologo clinics do not always have condoms when patients need them. Referring to condoms is not the same as providing them. If Tapologo provides condoms arbitrarily, this might be confusing for patients. Several patients do also not have the ability to buy condoms because of a shortage of money. Patients who use the free condoms from the community clinic complain about the quality. The free 'Choice' condoms do burst often and are more tighter than condoms from the chemist. Female patients also complain about skin eruption after using those free condoms, they did not experience that with the condoms of the chemist. When we discussed this topic with healthcare workers they did not all know the policy around providing condoms. It appears that the knowledge about HIV and sex of caregivers is also not always sufficient. *"We always ask patients; if you say you have only got one partner how did you then got HIV?"* (Caregiver, Freedom Park). Having one partner does not mean that you cannot get infected. A partner might be unfaithful or maybe the patient is already positive for a while without knowing his status. Healthcare workers are more sympathetic with women than with men. If male partners are negative and female partners positive, healthcare workers still think that these male partners are the 'carrier' of the disease and brought the virus into the house. According to Soa AIDS Nederland (Personal communication, retrieved on 17th of July 2009) this is only possible when the male partner takes his medication, because then the viral load[16] drops to an extent that the HIV test cannot detect the virus anymore. These male partners were not using medication, so theoretically it is not possible that these men pass the disease to their female partners.

According to Albertyn (2000) HIV management programmes need to provide female condoms, this increases the ability for women to protect themselves. Healthcare workers have an opinion on this subject. *"I do not think that the female condom is working for the women. Firstly, it is not easy to put on that condom, that female condom for women to use it. Well people will say if you do not want to*

[15] Bishop of the Catholic Diocese in Rustenburg. Bishop Dowling is closely involved with the activities of Tapologo.

[16] The viral load is an indicator for the quantity of virus cells in someone's blood (Soa AIDS Nederland, 2009).

have sex with this man, why are you not doing it and he is forcing you to have sex with him, why do you not use a condom. (…) It is not as easy to put it on as the male condom, it is not easy. Secondly, I can go to the government clinics and I will not find a female condom. Where are the patients suppose to get them? (…) The female condom is not as easily available as the male condom" (Supervisor nursing, Tapologo centre). *"If the man does not want to use a condom, patients can use a female condom without the man is seeing it. Because the female condoms you can put them in an hour before you have sex with a man and it is unknowable"* (Caregiver, Freedom Park). This caregiver forgets that patients do not always schedule their sexual intercourse, so they cannot always put a female condom on an hour before they have sexual intercourse. As the supervisor says the female condom is not an easy thing to put on. This supervisor has a true-to-nature idea about how female patients are dealing with this problem. A caregiver mentions that you can not get pregnant when you are using a condom. She forgets that condoms can also break. When it comes to abstinence professional nurses and supervisors have realistic thoughts, they mention that abstaining is not the solution for overcoming HIV. They say that it is impossible for anyone to abstain. The perceptions among providing condoms are exceptional for a Catholic organisation, although the inconsistent policy may confuse patients.

5.3 The condom issue

Strategies to protect their sexual health

This paragraph gives an answer to the second sub question: *How is a HIV infection related to the sexual autonomy of a HIV patient?* Sub question two includes the question: *What strategies are used by the HIV patients, to protect their sexual health?*

There is a belief in the African culture that when you are married, you should not use condoms. This because you are husband and wife and that means that it is your task to produce children. In general African men do not like condoms and they do not want to use them. Female patients call men stubborn when it comes to condom use. Women are more willing to use them, but sometimes women do not have the ability to engage in condom use. Statements of our respondents about why people do not condomize: *"men just want to have flesh-to-flesh sex", "men say that using condoms is just a waist of time", "men are to rush", "some guys will say condoms make them sick", "condoms will damage the kidney's", "men cannot sleep with you with a condom because otherwise they cannot give you money", "I do not feel sex like I use to", "you cannot eat a banana like that, first you must peal the skin off", "you cannot eat a sweet with a paper on it", "condoms have worms, they are making them ill", "people associated condoms with sleeping around and being unfaithful", "people associated condom use with HIV", "HIV comes from condoms"* or *"a condom is not comfortable"*. Healthcare workers say that men have too many excuses for not using condoms. On the other hand women also have excuses for not using a condom, perhaps because they are afraid of their male partners. Healthcare workers do not believe their patients when they tell them that they are using condoms. *"We are not sure they are doing it. Because the HIV and pregnancy statistics are just going up, so that shows us*

that they are not doing it" (Track controller, Tapologo centre). Patients still complain about STD's and this is weird when they say they are using condoms.

The condom issue is really difficult in Rustenburg, even the prostitutes in Freedom Park and in town charge more for not using a condom and less for using one. Not only condom use was a mentioned strategy to protect the sexual health of the patients, also abstinence seems to be a common good for both male and female patients. Reasons for abstinence are: the patient needs to concentrate on his treatment or they just do not want to have sex. When we asked patients, who abstain, if they will ever have sex in the future again, they said they want to and they will condomize then. Another strategy to protect their sexual health is having one partner since their status became known.

5.4 Sexual autonomy and HIV in Rustenburg South Africa

Answer to the main research question

Following the data analysis and the answers to the sub questions, we can answer the main research question: *What are the perceptions of the HIV patients in Rustenburg South Africa, through the perspective of gender inequality about their sexual autonomy?* A summary of the answers given in paragraph 5.1, 5.2 and 5.3 assist in answering this main research question.

This chapter showed diverse mechanisms which appear in Rustenburg South Africa, and which in their turn influence both the instrumental and emotional sexual autonomy of HIV infected persons. Instrumental sexual autonomy is hard to gain in conditions of poverty and traditional gender roles. Being financially and socially dependent on men puts women in an inferior position within a relationship, which decreases the ability of female patients to insist on condom use and monogamy, which in their turn decreases the ability to protect their own sexual health. Patients who have more instrumental sexual autonomy, mostly men, but also some women do have the ability insist on using condoms.

If sex is a thing for both partners bilateral communication seems to be essential to ensure that both partners enjoy sexual intercourse. If patients talk about sex it is more often with partners and peers than with relatives. Patients are not always able to talk about sex issues with their partners, because sex is still a taboo subject. It is required that female patients satisfy the needs of their male partners. Reasons for that are: love, security, it is part of a relationship or to avoid making men angry. It appears that women are more supportive in a HIV relationship than men. If men do not want to use a condom they force their female partners to have sexual intercourse without a condom. This leads to confrontations and it decreases the emotional sexual autonomy of female patients. Emotional sexual autonomy decreases within the confines of traditional gender roles, violence and not so supportive social relations. Patients who have emotional sexual autonomy disclose their status to their partners and insist on monogamy and condom use.

It looks like gender inequality is culturally-based. When it comes to gender roles these are already established in childhood. Girls learn to be a caregiver and boys to be the provider of the family. Men are the head of the family, which places women in an inferior position. Women need to

respect their men and need to ask permission to go to the HIV clinic. It seems to be that men are culturally allowed to have more than one partner; this also appears in a traditional Tswana song which people sing during weddings. Before marriage uncles and aunts tell the bride and groom how they need to behave in a marriage. Traditional gender roles may cause female patients to stay in an unfaithful relationship, and if men do not condomize the chance of re-infection is highly probable. The subordinate position, in which women find themselves, decreases the instrumental and emotional sexual autonomy of female patients.

Patients know that they need to use a condom, for the sake of their own and their partner's health, but at the same time they do not use condoms. A belief in the African culture says that if you are husband and wife you should not use condoms because it is your duty to produce children. African men do not want to use condoms; they do not like them. Women are more willing to use them, but sometimes women, if they have a lack of instrumental and emotional sexual autonomy, they are not able to protect their own sexual health. Healthcare workers say that both men and women have too many excuses for not using condoms. Besides condom use, is abstinence also stated as a strategy for patients to protect their sexual health. Reasons to abstain are: patients want to concentrate on their treatment and they simply do not want to have sexual intercourse. Healthcare workers do not believe patients when they tell them that they use condoms because patients still complain about STD's. When it comes to the main informants they influence the sexual autonomy of the HIV patients both positively and negatively. Kin relations play a major role when it comes to gender roles. More traditional gender roles seem to have a negative influence on the instrumental sexual autonomy of women and the emotional sexual autonomy of both male and female patients. Relatives are often the ones who care for the patient. People in the community are more and more aware that HIV really exists but they continue to discriminate and stigmatize HIV patients. Patients find it easier to talk about sex issues with their peers (friends and fellow patients). Their peers empower the patients to engage in safe sexual intercourse. The church and the media also play an important role as a source of information about safe sexual behaviour and its relation to HIV. The healthcare workers at the Tapologo clinics educate patients on a healthy sex lifestyle: being faithful, having one partner and using condoms. However, they do not have a consistent policy on condoms, which may confuse patients. Healthcare workers do not always understand the reality of circumstances in which patients find themselves. Sometimes healthcare workers provide wrong information. This might have influences on the self-efficacy of patients to protect their own sexual health. The following model based on figure 1, shows in summary the influences of the main informants on the sexual autonomy of HIV infected patients in Rustenburg.

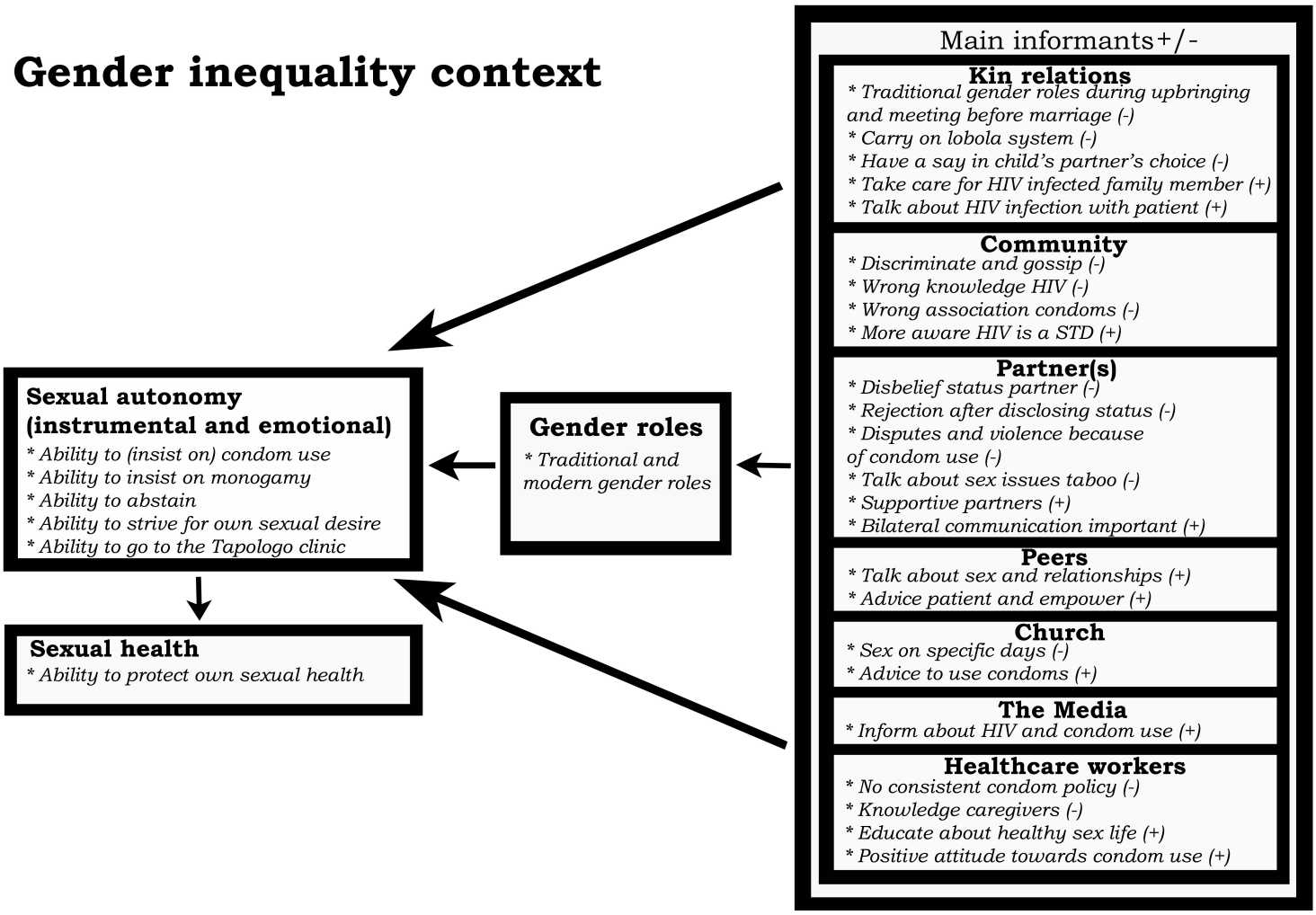

Figure 2. Construction of sexual autonomy in Rustenburg South Africa

5.5 Note: Why people do not go to the clinic

Because we assume that having sexual autonomy is related to reducing the rate of HIV infections as well as to adhere to ART's, we asked the respondents during the in-depth interviews and FGD's why they think people do not test and not follow ART's. Patients mention that people feel ashamed to come out and test, because then people in the community will chat about them, discriminate or stigmatize them. People hide their status because they do not want to be recognized as someone who is HIV positive, reasons for that are: people say that you are going to die or that you are cursed[17].

Men are seen as more stubborn to go to the clinic. They do not go because they more often than women worry about their reputation. This results in men who come in very late and are too ill to increase their condition. The supervisor Nursing tells us that men do die more often in the In-patient Unit (IPU) than women. Another reason why men do not come to the Tapologo clinics is because of the trading hours, men are working at the mines when the Tapologo clinics are open. There are also men who go to the clinics of the Impala platinum mine. Tapologo collaborates with the Impala platinum mine in Freedom Park. Some people are also going to the community clinics because of the trading hours of Tapologo. Specific reasons why women do not come to the Tapologo clinics are: because they need to ask permission at their partners and they are scared of their male partners.

The introduction shows a number of male and female patients: 424 women and 182 men who started the ART's between 2004 and 2009. This number might contradict the gender inequality which is described in this master thesis. The reasons why more women than men attend the Tapologo clinics are: 1. women feel responsible for their children, so they want to be in good condition to take care for their infants and 2. women more often than men utilize the healthcare services. For example: because they companion their children at the clinic when they are sick, women suffer more often from STD's so they go to the clinic or when women are pregnant they visit the health centre for check ups. When these women visit the healthcare system healthcare workers might draw attention to them to test and eventually to follow the ART's.

[17] This subject is excluded in this research but Linda van der Kevie attends to this subject in her master thesis *'HIV is definitely not the end of the world!?'*.

Chapter 6: Conclusion

6.1 Discussion

This paragraph presents how the empirical part (chapter five) is related to the theoretical framework (chapter three), which formed the basis of this study. Holland et al. (1990) state that sexual behaviour is socially constructed by the social context in which people live. This study confirms this statement. The results show that sexual autonomy (both instrumental and emotional) is shaped by diverse cultural and contextual factors, such as: gender inequality, cultural norms about gender roles, poverty and (non)supportive social relations. The basic assumption, on which the theory is founded, states that sexual autonomy results from gender inequality via the ascribed gender roles, that in turn are constructed by the perceptions of the main informants. The perceptions of the main informants can influence the sexual autonomy of the patients both positively and negatively. The findings confirm this basic assumption.

Varga (2003) stated that intimate relationships are characterized by unequal decision making. The results prove this because traditional gender roles in Rustenburg ensure that women find themselves in an inferior position within intimate relationships. These traditional gender roles maintain the gender inequality. According to Albertyn (2003) women are less able to refuse sex or engage in safe sex. This assumption is confirmed by both patients and healthcare workers. The research findings provide an extensive view of the mechanisms which occur in Rustenburg on this subject. A remarkable result, which was not stated in the literature is that women do have room to invent strategies to receive money from their male partners when they lack instrumental sexual autonomy. On the other hand there are also women in Rustenburg who are vocal about protecting their sexual health. These women do have emotional sexual autonomy. Another interesting finding is that men also experience resistance from their social environment to have emotional sexual autonomy, for example: when their parents have a say in their choice of partner.

According to Varga (2003) partners and peers play an important role in encouraging patients to engage in unprotected sexual behaviour, this is because they trust their partners or are committed to them. Our findings show that it is true that partners play an important role in engaging in unsafe sexual behaviour, but the reasons for that are different in our research. The main motives for our patients to engage in unsafe sex are: fear of losing daily provision, fear of being deserted or of being punished by a partner. The differences between the reasons might be related to the diverse contexts of the studies. The study of Varga (2003) was not focused on HIV positive individuals but on adolescents in KwaZulu-Natal. Our findings also show that peers do have a positive influence on the sexual behaviour of patients; they share experiences, advise each other and therefore empower each other. This also differs from the results of Varga (2003). Our different findings may be caused by the differences in network of adolescents and HIV positive individuals. Conceivably when patients choose to engage in testing and following ART's they create their own social network, which is supportive and encouraging. Another observation of Varga (2003) was a lack of bilateral communication concerning sexual topics. However, our findings confirm that talking about sex is still a taboo subject; they also

show that for those patients who think sex involves both men and women, bilateral communication is relatively important.

According to Heyer et al. (2006) the social environment of the patients consists of a network of kin relations, partners, friends and the ART provider. The explorative nature of this research made it possible to gather information about other main informants, such as the church and the media. These main informants seem to be an important source of information about HIV/AIDS and condom use. Although we found some differences between our results and the literature, we can state that the outline of the theoretical framework and data are equal.

6.2 Reflection on this study

This paragraph discusses some limitations of our study. Firstly, our study was completed at four different clinics, each with their own specific context. This may have created different experiences for both patients and healthcare workers in relation to the sexual autonomy of HIV patients. We have not investigated the differences between these four clinics, which may be an omission. We assume that the structure of social relations is different in Freedom Park compared with the more original based clinics, because of the squatter camp character (people who come from other provinces in South Africa and outside the border who leave their families and seek for labour in the mines). This may have consequences for the support HIV positive individuals receive from their social environment (possibly other main informants), which in turn might have an influence on the sexual autonomy of HIV positive individuals. We do not assume that labour (im)migrants do not attend the other clinics. The accommodation at the founding communities is permanent. This may also influence the motivations of female patients in Freedom Park on having sexual intercourse with men.

Secondly, when we arrived at the research location we discovered that the majority of the patients could not speak (understandable) English. We solved this problem by using interpreters. Using interpreters during the data collection, might have influenced the data. Another thing which might have influenced the data is the selection of the patients. The selection procedure did not happen a-select but on a voluntary basis in exchange for a small fee. It could be that patients only wanted to participate because of this payment. This could have a negative influence on the representativeness of the external validity of our data.

Thirdly, the number of participants is insufficient to provide a representative picture of the social reality in which the sexual autonomy of HIV infected patients in Rustenburg South Africa occurs.

Fourthly, before starting with the data collection the vignette method seemed to look a good way of questioning patients indirectly about the sensitive topics related to sexual autonomy. However, during the data collection it appeared that some vignettes were too subjective, which could have led to the provision of socially acceptable answers. During the data collection the researchers became aware of this problem, which resulted in some vignettes being omitted for consideration. Socially acceptable answers were also given when we asked patients if they use condoms. Patients told us at the beginning of the in-depth interviews that they were always using condoms, after further questioning they admitted that they did not always condomize.

6.3 Recommendations

6.3.1 Further research

This research has given a broad view of the sexual autonomy of HIV infected patients in Rustenburg South Africa. However, further research is necessary to increase the sexual autonomy of patients and to assist in the fight against HIV. This research can be a basis for other researchers. For example, it may be used to investigate a specific aspect of sexual autonomy in more detail. Such as to what extent do female patients need to ask permission from their male partners to go to the clinic? This research question might lead to more insight into why people withdraw from ART's. To date, we have only questioned patients who do adhere to ART's. Another question could be: to what extent exist arranged marriages and to what extent do arranged marriages influence the sexual health of a patient? Because of the explorative nature of this research we have only had a minor discussion on these topics slightly, but it might be interesting to gain more detailed information on these subjects.

In this research we have only questioned patients and healthcare workers, for a more complete picture of the sexual autonomy of HIV infected patients, it would also be useful to question the other main informants of the patients.

Another issue that is key to the sexual autonomy of HIV infected patients is poverty. A crucial way in which alleviate the influence of poverty on the sexual health of people might be through education and improved awareness of HIV. It may be interesting for researchers to investigate which methods are most effective to make people more aware of HIV and its consequences on their sexual health.

Another interesting subject for further research might be an evaluation of the ART programmes at the Tapologo clinics. With an evaluation of their programmes Tapologo will be able to distinguish which parts of their ART programmes may be improved.

The last interesting subject for further research might be related to the knowledge of HIV positive patients. It appears that patients know that they need to use a condom, but do not always do so, because of the prevailing contextual circumstances in which they are placed. The data showed that patients do not talk easily about disputes about the use of condoms with healthcare workers, which results in healthcare workers who do not sympathize easily with these patients. According to Albertyn (2000) a holistic approach to HIV prevention and care is important, so maybe it is a good idea to create (more) possibilities in the ART programmes for patients to talk about these issues. A research question related to this subject might be about how Tapologo can facilitate this in their ART programmes.

6.3.2 What can Tapologo do?

Firstly, we recommend the removal of the practical limitations which influence the sexual health of patients in a negative way. Tapologo has got a positive attitude towards condom use, but it has no consistent condom policy. Because of a lack of financial resources patients cannot always buy condoms. We advise Tapologo to provide both male and female condoms in a structured way at all clinics. We advise on the distribution of female condoms because this might increase the likelihood of

women using female condoms. Secondly, we advise that all healthcare workers receive instruction on Tapologo's condom policy. It appears that healthcare workers do not know what the policy is. When they talk to patients about this policy they might influence the sexual autonomy of patients in a negative way. It appears that patients do not know that Tapologo provides condoms arbitrarily. If Tapologo wants to encourage patients to use condoms, Tapologo needs to communicate this frequently to patients. It is important to communicate this often because of the low level of education of the patients. This condom policy does not decrease the gender inequality of patients' circumstances but it decreases the practical limitations to be able to use condoms. Thirdly, we suggest Tapologo to educate caregivers about HIV, sexuality and condom use, because it appears that caregivers have wrong conceptions about these topics. If these caregivers educate patients this might have a negative influence on the sexual autonomy and health of patients. If caregivers have a low education level we advise re-education of caregivers on regular basis. Fourthly, we propose Tapologo creates the opportunity for patients to report complains on the behaviour of healthcare workers, for example via a confidential counsellor. Some patients told us that there are healthcare workers who do not treat the patients well, like professional nurses who threaten patients with not giving their antiretroviral drugs when they do not clean the clinics. This behaviour might lead to patients not coming to the clinics anymore, which can have major consequences for patients (sexual) health. Fifthly, we suggest Tapologo to do more on promoting awareness of HIV and protective sexual behaviour. Not only at the clinics but also at the communities because it still appears that patients and the people in the communities have the wrong notions on HIV, sexuality and condom use.

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Appendix 1: Tapologo statistics 2004 - 2009

FREEDOM PARK							
	2004	2005	2006	2007	2008	2009	Total
Started ART	36	96	51	34	30	6	253
Resume ART	0	6	6	11	4	0	27
Transfer in on ART	0	0	0	2	2	0	4
Death on ART	4	14	12	10	4	1	45
Stopped ART	2	20	14	10	14	0	60
Transfer out	0	1	5	4	7	1	18

KANANA							
	2004	2005	2006	2007	2008	2009	Total
Started ART	13	37	53	60	119	18	300
Resume ART	0	4	3	4	3	4	18
Transfer in on ART	0	1	0	5	2	1	9
Death on ART	0	7	10	17	14	3	51
Stopped ART	0	3	5	10	18	9	45
Transfer out	0	0	1	3	7	1	12

CHANENG							
	2004	2005	2006	2007	2008	2009	Total
Started ART	25	81	43	73	79	16	317
Resume ART	0	0	5	1	11	2	19
Transfer in on ART	0	2	0	2	6	3	13
Death on ART	4	20	13	23	15	1	76
Stopped ART	0	8	5	4	21	7	45
Transfer out	0	0	6	4	4	4	18

TLASENG							
	2004	2005	2006	2007	2008	2009	Total
Started ART	4	26	28	42	90	14	204
Resume ART	0	0	1	3	2	2	8
Transfer in on ART	0	1	0	5	6	0	12
Death on ART	3	4	8	11	19	1	46
Stopped ART	0	0	6	6	15	4	31
Transfer out	0	0	0	2	0	0	2

TAPOLOGO CURRENT PATIENTS ON ART PER CLINIC AND GENDER		
	MEN	WOMEN
Chaneng	59	119
Freedom Park	14	86
Kanana	71	135
Tlaseng	38	84
Total	182	424

Appendix 2: Overview of age, gender and research method per clinic

FREEDOM PARK		
Gender	**Research method**	**Age**
Female patient	In-depth Interview	41
Female patient	In-depth Interview	42
Female patient	In-depth Interview	46
Female patient	In-depth Interview	51
Female patient	In-depth Interview	53
Female patient	In-depth Interview	56
Female patient	FGD	36
Female patient	FGD	37
Female patient	FGD	39
Female patient	FGD	42

KANANA		
Gender	**Research method**	**Age**
Female patient	In-depth Interview	34
Female patient	In-depth Interview	36
Female patient	In-depth Interview	37
Female patient	In-depth Interview	51
Male patient	In-depth Interview	37
Male patient	In-depth Interview	39
Male patient	In-depth Interview	48

CHANENG		
Gender	**Research method**	**Age**
Female patient	In-depth Interview	30
Female patient	In-depth Interview	39
Male patient	In-depth Interview	39
Male patient	In-depth Interview	39

TLASENG		
Gender	**Research method**	**Age**
Female patient	In-depth Interview	26
Female patient	In-depth Interview	29
Female patient	In-depth Interview	35
Female patient	In-depth Interview	41
Male patient	In-depth Interview	45
Male patient	In-depth Interview	54

Appendix 3: Questionnaire in-depth interview

Questionnaire patients

Introduction:
Thank you very much that you want to cooperate with my research. I am praised to meet you. My name is Mariëlle Lunenburg, I am from the Netherlands and I am doing research for Tapologo. My subjects are gender, sex and HIV. First of all I want to tell you that everything you say is completely safe with me. This research is confidential and anonymous, so your name will not be used in any reports of this research. So you can speak free if you want. If you do not like to answer a question, it is ok, just say it. There are no wrong or right answers. I will tape the conversation, just because I can not write so fast. This interview takes about 45 minutes. Thank you for your cooperation.

Background information

- Gender
- Date of birth
- Level of education
- HIV infected since
- On ART's since
- STD's
- Stopped in between/resumed the ART's
- Religion
- Attend support group
- Job
- Study
- Marriage
- Number of sex partners
- Number of sex partners husband/wife (difference and why?)
- HIV status sex partners

Family structure

- How does the family structure in which you live in look like? (Children)
- Who in the family is responsible for child-rearing, preparing food and care for other members of the family?
- Who in the family is responsible for an income?

Being HIV infected

- What do you know about HIV?
- In which way has Tapologo changed your knowledge about HIV?
- Are you open about your status (who knows your status)? Why you are open/ why not? (! partners!)
- (How did your family and partners react on your status?)
- How do you feel about being HIV positive?
- In which way HIV changed your life?
- In which way HIV changed your relationships with your partner(s)? (problems/misunderstanding)
- In which way HIV changed your sex life?

Sexual autonomy

Instrumental sexual autonomy

- For what kind of reasons do you have sex? (propagation (related to immortality and status), as a source of payment, as a form of prestige, for pleasure, as a way to survive (as well as social as economical).

Vignettes
Imagine yourself:

You and your partner have two young children. You are HIV positive. Your partner does not know that you are HIV positive. When it comes to sexual intercourse: do you use a condom or not? Do you tell your partner about your status? Explain me what you would do and why?

If your partner wants to make love without a condom and you refuse to make love without a condom? What will happen? Who is winning and why?

If you want to make love without a condom and your partner refuses to make love without a condom. What will happen? Who is winning and why?

Women
Your partner wants to have sex with you. You do not want to have sex. But your partner's craving for sex is very big. What do you do? Do you meet the needs of your partner? Does your partner leave you if you do not want to have sex? Explain me what would happen and why?

Men

You want to have sex with your partner. Your partner does not want to have sex. But your craving for sex is very big. What do you do? Do you leave your partner or not? Explain me what you would do and why?

Emotional sexual autonomy

Vignettes

Imagine yourself:

Women

During sex you want that your partner also pleases your needs. Do you ask your partner to please your needs? Explain me what would you do?

A man, with whom you slept a few weeks ago, tells to your friends that you had sex with him. You did not have sex with a condom. Where do you worry more about, about your reputation or the fact that you did not have sex with a condom? Explain me your reaction.

Men

During sex your partners wants to be pleased according to her needs. Your partner asks you to please her needs. What is your reaction? Explain me what would you do?

Women

- Can you talk about sex with your partners?
- Have you ever been forced by a partner because of sex? Can you tell me about that? (Condom use issue?).
- Have you ever been verbal intimidated by your partner during sex? Can you tell me about that?
- Have you ever been psychical punished by your partner during sex? Can you tell me about that?
- Does your husband prepare you to have sex or do you have dry sex?

Men

- Can you talk about sex with your partners?
- Do you prepare your partner to have sex or do you have dry sex?

Gender roles

- What is the role of a woman/man during sex?/ How does a good woman/man needs to behave during sex?

- What is the role of a woman/man in general?/ How does a good woman/man needs to behave? (Tasks in the household, family, relationship).
- Who is the leader in bed? Who decides when, where and why to have sexual intercourse?
- (In case patient does not have a partner) Do you want to have a partner? Why?

Main informants

- What do people in the community know and belief about HIV?
- With whom do you talk about your HIV status?
- To whom do you go if you do not feel well about your status?
- With whom do you talk about you relationship?
- With whom do you talk about sex?
- Who is telling you what to do according to sex? (abstinence, condom use)
- Who is telling you that you need to use a condom?
- Where do you get condoms?

Adherence

- Why do people not go to the clinic to test or follow the ART's?
- Is there a difference between why men and women not go to test or follow the ART's?

Questionnaire healthcare workers

Background information

- What is your function? What do you do on a working day?
- How is it to work with HIV infected people?

Being HIV infected

- What do patients at this clinic know about HIV?
- Why are people not open about their status to the community?
- Is their a difference between how women and men react on their HIV status?
- What kind of changes are there in the life of a patient?
- What kind of changes are there in the relationship of the patient?
- What kind of changes are there in the sex life of the patient?

Sexual autonomy

Instrumental sexual autonomy

- For what kind of reasons do men/women have sex?

Emotional sexual autonomy

- Who decides to use a condom?
- Do all patients use a condom or do you know examples who does not?
- Are all patients open about their status to their partner(s), why or why not? Examples?
- Do you know patients (females) who have been forced/verbally intimidated/physical punished by a partner because of sex (maybe condom issue)?

Gender roles

- What is the role of a good woman/man during sex? How does a good woman/man needs to behave? And in general (tasks)?
- Who is the leader in bed is that the woman or the man? Why? Examples
- Who decides when, where and why to have sex?

Adherence

- Why do people not go to the clinic to test and to follow the treatment?
- Is there a difference between why men and women not go to the clinic?

Appendix 4: Questionnaire FGD

Questionnaire patients

Being HIV infected

- Is their a difference between how women and men are dealing with their HIV status?
- Why are people not open about their status to the community?

Sexual autonomy

- For what kind of reasons do men/women have sex?

Gender roles

- Who is the leader in bed is that the woman or the man? Why? Examples
- Who decides when, where and why to have sex?
- What is the role of a good woman/man during sex? How does a good woman need to behave during sex? And in general (tasks)?

Main informants

- When it comes to sex who is telling you guys how to behave?
- Who is telling you guys that you should use a condom?
- Where do you get condoms?

Adherence

- Why do people not go to the clinic to test and to follow the treatment?
- Is there a difference between why men and women not go to the clinic?

Questionnaire healthcare workers

Being HIV infected

- Why are patients not open about their status to their partners? Difference between women and men?
- What kind of changes are their in the relationship of the patients?
- What kind of changes are their in the sex life of the patients?

Sexual autonomy

- For what kind of reasons do males and females patients have sex?
- Are both men and women equal in having multiple partners? Is there a difference between the four clinics?
- Do men and women both have an equal say when they want to use a condom?
- Why do not all patients use condoms?

Gender roles

- Who decides when, where and why to have sex? Is it the man or the woman? Why?
- What is the role of a good woman/man in a relationship? How does a good woman/man needs to behave?
- What is the role of a good woman/man during sex? How does a good woman/man needs to behave during sex?

Main informants

- According to Tapologo how does a woman/man needs to behave in a relationship?
- According to Tapologo how does a woman/man needs to behave according to sex? What do you tell the patients?
- According to traditional African values how does a woman/man needs to behave in a relationship?
- According to traditional African values how does a woman/man needs to behave according to sex?
- (What kind of things do you do to empower women?)
- Why do you not provide condoms at all clinics?

Adherence

- Are both women and men autonomous in making the decision that they want to go to the clinic to test and follow the treatment?
- Is there a difference between why men and women not come to the clinic to test and follow the treatment?