

“HIV is definitely not the end of the world!?” (woman, 53 (2))



Contextual and cultural factors that might cause differences between the patients' health experience and the professionals' health perception at four Tapologo HIV/AIDS clinics around Rustenburg, South Africa.

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Linda van der Kevie, August, 2009



Abstract

This master thesis is the end result of a wonderful and interesting learning experience during the master program 'social policy and social interventions' at Utrecht University. October 2008, I was offered the opportunity to conduct my master research in South Africa, a topic regarding health care and social science. Needless to say this was an opportunity I passionately embraced, so from February till June I immersed myself in the South African way of life in Rustenburg¹ to conduct this research.

South Africa has to deal with the HIV epidemic. For several years now, HIV has been the number one cause of death. The consequences of this catastrophe are found at a political, economic and societal level in South Africa. The South African Catholic Bishops' Conference (SACBC) is a non-governmental organization which conducts different programmes to fight the consequences of the HIV epidemic. Within this master research, four different HIV clinics of the Tapologo Centre were investigated. The Tapologo Centre is a section of the SACBC.

The following research question will be answered in this study;

1. *What is the prevailing health perception of Tapologo professionals and the health experience of HIV positive patients at the HIV management programmes at four Tapologo clinics around Rustenburg, South Africa?*
2. *How is the health experience of the patients of the four Tapologo influenced by the health perception of the representatives of the three sectors of health care?*

Different influencing parties might influence the patient' health experience through their health perception. These parties are divided in three different sectors of healthcare; the popular sector (family members and fellow patients), the folk sector (traditional healers) and the professional sector (professional nurses). The health perception of these representatives was investigated indirectly via the patients, only the influence of the professional nurses was investigated directly. The empirical data for this research is collected in 23 individual interviews with HIV positive patients, 2 focus group discussions with HIV positive patients and 7 individual interviews with professionals involved with HIV management programmes.

The health experience of HIV positive patients varies from patient to patient. This can be the result of the different aspects of the health experience such as the knowledge of HIV, how a patient encounters his or her status and the cost / benefits of the prescribed ARV regimen. A patient' knowledge is mainly based on the information given by the professional nurses. In some individual cases misconceptions concerning the transmission of the infection or the incurable nature of HIV were found. In the South African context the belief in traditional medicines and traditional healers is still a present factor which has to be taken into account. The Catholic background of the investigated HIV management programmes is, when it comes to condom use, not a major influencing factor at present, in contrary to predictions made in advance.

¹ Rustenburg is located approximately 120 kilometres north west of Pretoria



Physical complaints occur on a daily basis for the interviewed patients. The most common complaint is the loss of energy and strength. Accepting their HIV status still is for some patients difficult task. Nevertheless, some statements made by patients concerning their state of acceptance have to be at least indicated as doubtful. Several patients were using their status to warn and inform others about HIV. Disclosing of one his HIV positive status is a difficult task for a patient due to the still attached stigma on HIV.

Within the research group, the patients indicated that there are more benefits than drawbacks to the ARV treatment. The ARV tablets made them stronger and healthier. Poverty has a major impact on the medicine adherence and the effectiveness of the treatment since ARV medication can only be taken after a proper meal.

Health experience is influenced by the health perception of the representatives of the three health sectors. These representatives can have a negative influence on the health perception for instance through the encouragement of traditional medicines use which can damage the patient' health. Positive influences on the health experience can be the result of caring by a family member and the supply of information by a professional nurse.



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Preface

Wednesday the 6th of May. I am waiting together with my fellow students Mariëlle and Maaïke in a hot and muggy sea container at the Kanana clinic, near Rustenburg in South Africa. I am here to show my support to one of our local translators. She is hesitating about testing herself for HIV and therefore we decide to support her and test together. So here I am, in a country where almost one third of the population is infected with HIV, waiting for a HIV test. The last couple of months I have worked as a nurse at several clinics and assisted many HIV positive patients. I know it is impossible to get HIV from shaking somebody's hand. But during the checking of vital signs check, I came in close contact with HIV positive patients. This occurred on a daily basis. It is my first time working with so many HIV positive people; I just could not help myself wondering, if it was possible to be infected. So I am actually a bit nervous for the outcome of this test, although I know the change of a positive test result is very small.

This experience made me understand the people who are afraid of testing, a little bit better. Honestly speaking, my heart rate was accelerated while waiting for the test results. One stripe appears on a test kit which is similar to a pregnancy test. This means there are no HIV anti bodies in my blood. Belief it or not, I was relieved. My name and date of birth are written down in a book of the Kanana clinic. My negative result sticks out in a long list with names, dates and positive test results. Unfortunately many HIV positive results will follow, probably until the last page of the book.

To make a little contribution in understanding the enormous problem of HIV I went to Rustenburg, South Africa. By interviewing HIV positive patients and professional nurses I have gathered a lot of information about the prevailing health experience of the HIV positive patients and the health perception of the professional nurses. This research would have never been achieved without various helpful people to whom many thanks are indebted.

First of all I would like to thank the patients who agreed to be interviewed and shared their personal stories with me. Therefore I would like to thank them all for being open and inspiring me with their experiences. Some of those stories made me smile, others tore my heart out.

I would like to thank Basetsana Rangoaga and Stephen Blakeman from the Tapologo centre. They provided information about the patients, the clinics and other practical business. Sister Hilda for her interesting insights about the HIV patients of Tapologo. Nthabiseng Moletsani of Tapologo who invited us to join her to the African wedding of her cousin in Soweto. The wedding was a fantastic experience during our period in South Africa. The professional nurses at the investigative clinics for letting us observe and participate with their activities, helping us recruit the patients, and answering all our questions.

I also want to express my appreciation to sister Alison Munro. She is the director of the Southern African Catholic Bishops' Conference (SACBC) and gave us the opportunity to accomplish our research at the Tapologo centre.



Cheerful thoughts go back to our translators, Mmalegae, Kele, Refilwe and Gloria who helped us with interviewing the patients. All the good and interesting conversations we had about our different countries and cultures. Moreover, they prepared traditional and local African food for us, which had the same exotic taste for us as the 'bloemkool'² tasted for them.

Our supervisor in the Netherlands, professor doctor Trudie Knijn for the critical reviews and an interesting visit in South Africa.

My friends and family; Lennart, Edgar, Jessika, Susan, Jaap and my parents for some critical feedback, assistance with transcribing the interviews and encouraging words. Special thanks for my brother-in-law, Wido, for his patience and many hours spending to draft this master thesis '*HIV is definitely not the end of the world!?*'³.

Carrie Bradshaw, Samantha Jones, Charlotte York and Miranda Hobbes for the indispensable distraction after a long day of writing a research proposal, interviewing and transcribing the interviews.

Last but not least, my fellow students in South Africa, Mariëlle and Maaïke. For a shoulder to cry on during the tough moments. But above all, for all the laughs and good conversations, experiences and all the adventures we had together in one of the most beautiful and inspiring countries I have ever been.

Utrecht. August, 2009

Linda van der Kevie

² Cauliflower, a popular vegetable in the Netherlands

³ Quote of a 53 year old woman at Kanana clinic



Chapter 1 Introduction

South Africa faces a HIV epidemic of catastrophic proportions (Martin, 2008). The National Department of Health estimates 28% of the people in this country are infected with Human Immunodeficiency Virus (HIV) (National Department of Health, 2008), which is almost one out of three people. On a population of 48 million a total of almost 13 million people are infected in South Africa. This epidemic has major consequences on the complete population. At economic, political and at all levels of the society, HIV is present (Van Dijk, Van den Dries, Tempelman et al, 2008; Epstein, 2007; Steinberg, 2008).

Since the eighties HIV spreads throughout Southern Africa. South Africa is one of the most affected countries in Sub-Saharan Africa. On account of poverty of the local inhabitants and the passive attitude of the former government in dealing with the HIV outbreak, numerous nongovernmental (NGO's) came into existence. The Southern African Catholic Bishops' Conference (SACBC) is one of these NGO's working in rural and remote areas throughout South Africa. The aim of the SACBC is to provide pastoral and spiritual care to HIV infected people. According to the SACBC prevention through education is the ultimate key in halting the HIV epidemic (Munro, 2006). The SACBC heads the Tapologo Centre in Phokeng⁴, a place of hope, healing and compassion (www.tapologo.com, 5th April, 2009). The prevalence of HIV in the North West province varies between 15, 8% - 19, 2% (WHO, 2005). Out of nine clinics headed by Tapologo, four clinics will take part in our study. Three out of four clinics around Rustenburg are situated in a more original formalized settlement. These clinics are less influenced by the mining industry and contain a higher amount of original Royal Bafokeng tribe members, the original residents of the area around Rustenburg. The fourth clinic is situated in a more recently established squatter camp characterized by a lot of mining influences (paragraph 2.2.2).

According to statistics collected by Tapologo (2004 – 2009, appendix 1) on average, almost one-sixth (16, 8%) of the patients stopped collecting their antiretroviral therapy (ARV's) and thus show program non-adherence.

It is unclear why patients stop collecting their ARV's or do not take them on a regularly basis. This research will explore the cultural and contextual background that contributes to this behaviour of non-adherence. The focus of this research is the prevailing health experience of the patients and the health perception of professionals at HIV clinics around Rustenburg.

According to the literature aspects patients' health experience and the professionals health perception are related to medication adherence (e.g. Epstein, 2007; Helman, 2000; Kalichman, Ramachandran and Catz, 1999; Maratioa, 2007; Munro, Lewin, Swart et al, 2007; Steinberg, 2008 and Vangroenweghe, 1997). Nonetheless, the relationship between programme or medication adherence and health experience will not be investigated as such; the health experience and the health

⁴ Phokeng is located approximately 15 kilometres north west out of Rustenburg



perception itself will be the investigated subject. The health experience of a patient will be unravelled in three aspects; knowledge of health, encountering own health and cost / benefits of the treatment. The health experience might be influenced by the health perception of three different sectors of health care in South Africa. These are the popular sector (family and fellow patients), the folk sector (traditional healers) and the professional sector (nurses of a faith based organization). Each of these representatives has a specific health perception that differs from one another. All these different health perceptions influence the health experience of a HIV positive patient.

The contextual and cultural orientated approach is preferred due to less satisfying results of previous studies by students of Utrecht University in South Africa⁵. These studies were based on social-cognitive models by Fishbein and colleagues and had practical problems in the South African context. These problems were low response, language problems and low level of literacy of the respondents. Cultural bias between the Western based models and the South African culture might also be a difficulty in using these models. The results of these studies were not significant and showed a lack of explanatory power (Briët, Pelt, Greeve et al, 2008; van Dijk et al 2008; van der Lubbe, Schinnij, Tempelman et al, 2008). Therefore this study will use an explorative research method on the cultural and contextual factors that might cause differences between the health perception of the representatives and the health experience of the HIV positive patients.

After this short introduction the following research question will be answered during this study;

- *What is the prevailing health perception of Tapologo professionals and the health experience of HIV positive patients at the HIV management programmes at four Tapologo clinics around Rustenburg, South Africa?*
- *How is the health experience of the patients of the four Tapologo influenced by the health perception of the representatives of the three sectors of health care?*

Several sub questions have been formulated in support of these main research questions. These underlying questions are formulated in paragraph 2.7.1.

1.1 Main research objective

This study is of an explorative nature; the aim is to gain background information for future evaluations of the programme, to strengthen the quality of future questions and questionnaires on these issues and to enrich our perspective and insight in the dual relationship between the assumptions of the HIV/AIDS programmes and of the population at stake.

As stated in the introduction, almost one sixth of the patients quit collecting their ARV's. Some aspects of the patients' health experience and the health perception of professionals are related on medication adherence. By investigating the patients' health experience and the health perception of professionals this relationship can be investigated in the future.

⁵ These studies were performed in Elandsdoorn, close to Pretoria



1.2 Layout of this thesis

An elaborated literature review was the starting point of this research that has been resulted in an overview of the South African contextual situation which is described in chapter two.

This study is based on a theoretical framework as a solid basis for the empirical part of this investigation. This theoretical framework is represented in chapter three. The research methods that have been used in this qualitative research are semi-structured individual interviews and focus group discussions. These methods are discussed in chapter four.

During the empirical study, 23 individual patients, 8 patients within the context of a focus group discussion and 7 professional nurses were interviewed concerning their health experience and health perception. The results of these interviews and focus group discussions are presented in chapter five. Finally a conclusion and recommendations are described in chapter six.



Chapter 2 The HIV in the South African context

Before we can explore the health experience of the patients and the health perception of the representatives of the healthcare sectors we need to review the Human Immunodeficiency Virus (HIV) The specific South African context which is represented in the next paragraph.

2.1 Human Immunodeficiency Virus (HIV)

According to Vangroenweghe (1997) HIV was first discovered in the United States of America in the eighties among homosexual men. From thereon several theories and myths occurred about the origin of HIV. The most plausible theory is the Simian Immunodeficiency Virus (SIV) theory that HIV derives from SIV which shows similarities with HIV. By slaughtering monkeys, a human being might get infected with SIV. Due to colonisation and slavery and eventually globalisation, HIV spreads throughout the world. An alternative hypothesis is HIV originates from the polio vaccinations in Congo in the fifties when millions of people were vaccinated with this vaccine. Nevertheless, the real origin remains so far unclear (Vangroenweghe, 1997; Van Renburg, 2000). There are also myths that HIV is a biological weapon of the US Army. Another myth is that prevention programmes about condoms are strategies of the white people in South Africa in order to influence the number of births of black people. A lot of South Africans believe these theories due to the resistance about the colonisation of the West in South Africa in the past (Vangroenweghe, 1997; Steinberg, 2008).

The Human Immunodeficiency Virus (HIV) is a retrovirus that infects cells of the human immune system. It destroys and impairs the function of the immune system, the so-called CD 4 cells. At the first stage of a HIV infection a person has no symptoms. HIV is transmitted through unprotected sexual intercourse, transfusion of contaminated blood, blood to blood contact by accident or sharing contaminated needles. Infection can also occur between mother and child during pregnancy, birth and breastfeeding (www.who.int, 12 May 2009). A blood test can determine the presence of the HIV. In the first stage of a HIV infection, a person has no symptoms. According to the National Institute of Allergy and Infectious Diseases (NIAID), the first symptoms resemble symptoms like those of the flu, like fever and tiredness (NIAID, 2009). The symptoms can differ individually.

When the infection progresses, the immune system gets more vulnerable and the person becomes more susceptible to opportunistic infections such as tuberculosis or pneumonia. The most advanced stage of HIV is Acquired Immunodeficiency Syndrome (AIDS) and leads eventually to death. This process can take up to 10-15 years to develop AIDS. Nevertheless, antiretroviral drugs (ARV's) can slow down this process by suppressing the viral load (number of HIV in the bloodstream) and improve the CD 4 level. In the Western world nowadays, HIV is seen as a manageable, though serious chronic disease (Moratiao, 2008).

Huge reductions of deaths have been seen because of ARV regimen. Unfortunately ARV's might have, like almost every medicine, side-effects like anaemia or nausea (NIAID, 2009). The ARV treatment is a combination of different medicines to prevent the HIV becoming resistant for these medicines. For the ARV's to be most effective and to prevent resistance (Heyer¹ and Ogunbanjo,



2006) a patient must use the ARV's every day at exactly the same time (NIAID, 2009). This exactness can be a problem for those that use the sun as a clock (Steinberg, 2008). Besides adhering to a strict schedule, a patient must quit smoking and/or consuming alcohol and needs to eat healthy food on a regular basis (Steinberg, 2008; SANAC, 2007 – 2011; Maratinoa, 2007).

2.2 Contextual situation South Africa

Health perception in South Africa requires specific understanding of the South African situation and their view on the world. The former Apartheid era is a historic event, which even nowadays influences the HIV epidemic. The platinum mines around Rustenburg are a specific contextual factor in this South African area. A faith based organization such as the SACBC might give contradicting information about condom use.

2.2.1 The former Apartheid era

In 1948 the Nationalist Party won the elections and the apartheid state erected causing systematically discrimination against the black majority of South Africans. Low skilled labour was reserved for the black population and 3, 5 million people were forcefully relocated by the state between 1960 and 1982. Relevant services such as healthcare, housing and education were differentially provided (Burman, 1996; Benatar, 2004; Helman, 2000). The former apartheid regime still causes differences in standards of living and this will last well into the twenty-first century (Burman, 1996). Ntsoakae (2003) has an interesting view on the relation between the Apartheid era and the HIV epidemic. Ntsoakae hypothesises HIV might also be related to the Apartheid era. Due to the forced removals and resettlements without for instance appropriate sanitary facilities, black people were exposed to these immunosuppressant conditions and were therefore more vulnerable to HIV.

Important is to admit that a healthy immune system does not protect people if they come in contact with the virus. However, when a weak person gets in contact with HIV, the period before AIDS will develop is much shorter than a person with a proper functioning immune system. There is no doubt that HIV, when not treated, will kill and this partly explains why HIV kills much more quickly in Africa than in the Western world. Eventually, Ntsoakae (2003) distinguishes this hypothesis by not stating poverty causes HIV, but poverty fuels and derives the epidemic. This statement points out how the former Apartheid still occurs in the daily life of black South Africans living with HIV and influences their health experience in a context with poor medical services.

2.2.2 Mining influences

The largest sources of platinum in the world are found around Rustenburg. This attracts a high number of migrant labourers from different parts of South Africa and the surrounding countries (Epstein, 2007; Helman, 2000; Vangroenweghe, 1997; de Waal, 2008). The mineworkers live in single sex-hostels which are built close to the mine shafts. Women have set up informal settlements close to the gates and work as prostitutes to make a living. All together, shack settlements have grown around the hostels and accommodate poor, desperate and uprooted people. This context of poor and hopelessness might influence the health experience of patients. There is also a lack of community and



personal resources (de Waal, 2006) that influences the health experience of people living here. An example of the lack of community resources is the lack of sufficient medical services and therefore people rely on traditional healers (paragraph 3.3.4).

2.2.3 Faith based projects

The Southern African Catholic Bishops' Conference (SACBC) is a faith based organization that plays a major part in fighting the South African HIV/AIDS epidemic. The SACBC runs over a hundred programmes throughout South Africa, like ARV roll-out in poor resourced areas (UNAIDS, 2006). These programmes are based on a Catholic background and the health perception of representatives of these programmes is based on these Catholic influences. This religious background might influence the health experience of patients who visit their clinics. An important statement of the Catholic Church is the rejecting position towards condoms. The SACBC preaches ABCD; Abstinence, Be faithful, be Careful, or your in Danger (Munro, 2008). This disposition is in major contrast to the motto of UNAIDS (2004), which is a joined United Nations (UN) program on HIV/AIDS. Their ABC means Abstinence, Be faithful and Condom use. These different dispositions can influence the health experience of a patient by giving contradicting information.



Chapter 3 The greatest wealth is health⁶

The title of this chapter is a well known proverb. In this theoretical framework, the health experience of a patient will be theoretically clarified. The health perception of the representatives, which is for instance a professional nurse at a HIV management program (paragraph 3.4.4), might influence the health experience of a patient. This will be subsequently depicted in the following paragraphs.

3.1 Health perception and health experience

It is commonly accepted that people's health is an expression of the interaction between genetic, biological, psychological and social factors (Gilbert and Walker, 2002). 'A large number of empirical studies have demonstrated that a person's own appraisal of her/his general health is a powerful predictor of future morbidity and mortality' (Eriksson, Unden and Elofsson (2001, 526). Therefore the health experience of a patient is a key factor in the fight against HIV in South Africa.

The statements of Gilbert et al (2002) and Erikson et al (2001) lead to the following conclusion. There is a relationship between the health perception (appraisal) and the health experience (the ability to continue one's existence). This relationship is the most important focus of this thesis.

Perception is defined by Gibson (1979, in Norman 2002, 85); 'Perceiving is an achievement of the individual, not an appearance in the theatre of his consciousness. It is a keeping-in-touch with the world, an experiencing of things rather than a having of experiences. It involves awareness-of instead of just awareness. It may be awareness of something in the environment or something in the observer or both at once, but there is no content of awareness independent of that of which one is aware'. In this research, a perception will be defined as follows; being aware and connected with the business that matters. In this case it is the situation of the patients and their disease HIV. The interesting part of health perception in the South African context⁷ is the presence of different perceptions. Each of these perceptions influence the health experience of a patient to a different extend. There are three different healthcare sectors with their own perceptions. These sectors are the popular sector (family members and fellow patients), the folk sector (traditional healers) and the professional sector (professional nurses). HIV positive patients are confronted with these different sectors and this research investigated how these different perceptions influence the patient his health experience.

Before discussing the healthcare sectors, the health experience will be unravelled in three different aspects; knowledge of health, encountering own health and the costs and benefits of treatment.

3.2 Aspects of a patients' health experience

The experience of a person of his own health is in this research is composed by three aspects; the knowledge of a patients, how a patient encounters his own health and the costs and benefits of following a treatment. These aspects are stated to be relevant aspects of a patient' health experience.

⁶ Publius Vergilius Maro 'Virgil' a Roman poet author who lived from 70 BC – 19 BC (Petry, 2001).

⁷ In each and every context different perceptions do occur. Nevertheless, in the South African context the belief in traditional healers still have a huge influence on the health experience of South African people.



For this research cultural and contextual factors belonging to the black South African people make up will be integrated within the research method.

3.2.1 Knowledge of health

Knowledge about health is crucial in fighting the HIV epidemic (UNAIDS, 2000). Knowledge of HIV infection is a requirement to initiate ARV therapy. Increased knowledge is urgently required to serve new imperatives, such as the provision of specific services for people living with HIV, for their care, treatment and support (WHO, 2001).

Knowledge is defined as 'factual and interpretive information leading to understanding or useful for taking informed action' (Finnegan and Viswanath, 1997 in Pequegnat, Bauman, Bray et al, 2001). Knowledge contains a broad spectrum of items that can influence a person's health perception in regard to his or her illness. With regard to HIV/AIDS, the distinction between curing and caring is rather crucial. Curing is a medical term for attempting to regain one's health. Since a cure for HIV is still not available, and maybe will never be possible, HIV/AIDS patients do not have a perspective anymore on ever living without the virus (Epstein, 2007). Their only option therefore is to receive good care, existing in getting adequate information and knowledge, being supported in adherence and in additional needs (social care, income and health costs). Religious and secular forms of symbolic healing may be able to 'heal' (care) for the patient even if they cannot cure the disease (Helman, 2000; Munro, 2008).

Health experience might contain biased knowledge and false information; the spread of several myths throughout South Africa might have a negative influence on the health experience (Heyer¹ and Ogunbanjo, 2006). Steinberg (2008) describes some myths, for example that white people have a cure for AIDS but holding it back from the black people. Another myth is the common South African belief that traditional medicine can cure HIV (Moratioa, 2007). A patient acting from this biased knowledge can affect his wellbeing in two different ways. Firstly, there is a possibility that patients combine traditional medicine and western ARV treatment, which can lead to high toxicity levels and virus resistance (Hoffman, Rockstroh and Kamps, 2005 in Maratioa, 2007). Secondly, illiteracy about the treatment can lead to an interruption of the ARV's (Rowe, Makhubela, Hargraeves et al, 2005 in Maratioa, 2007). Helman (2000), Lazarus (2006), Maratioa (2007) and SANAC (2007 – 2011) confirm the common belief in traditional medicine in South Africa (paragraph 3.3.2).

3.2.2 Encountering own health

The way HIV is encountered in South Africa was investigated by Feitsma, Koen, Pienaar et al (2007) in the Potchefstroom District. This district is in the same province as Rustenburg. Encountering acceptance, disclosure and feeling strong are very important for the investigated participants. People feel strong after disclosing their status. Accepting themselves is a key statement and talking about their status with family members and fellow patients made them feel free. This implies a person who is disclosing and accepting his or her status has a stronger capability to deal with HIV. People with HIV can encounter poverty, stigmatization, stress and loneliness.



HIV patients encounter physical problems, such as headache, fatigue and weakness. These physical problems that a patient encounters can influence the daily life of these persons, for instance patients are unable to work because of these symptoms (Peltzer and Phaswana-Mafuya, 2008).

3.2.3 Costs and benefits of treatment

Benefits of ARV treatment for a HIV positive patient is, at least in a Western environment like the United States of America, the transition from a lethal disease to a manageable, though serious chronic illness (Thrasher, Golin, Earp et al (2006). To achieve this transition, a nearly perfect medication adherence is necessary, up to ninety-five percent of the time (Moratioa, 2007; Heyer¹ and Ogunbanjo, 2006; Heyer² and Ogunbanjo, 2006). Costs (disadvantages) of ARV are, together with many other factors like social stigma or lack of knowledge are a reason for a patient not to adhere. Disadvantages are for instance the discouragement of the use of alcohol or smoking while using ARV's (Moratioa, 2007), while these are habits of some patients.

Pill burden and regimen complexity or side effects occur daily for the rest of the life of a HIV positive person (Heyer² and Ogunbanjo, 2006). A complex and strict medication regime influences a patient in deciding to stop the treatment (Heyer¹ et al, 2006). This can happen by implicating the HIV regime might be too complex and too much of a burden for a patient. Ultimately the benefits of the treatment are no match for the costs of the treatment and a patient stops. The benefits of the treatment are in this case not enough compared to the costs. A solution for this problem might be negotiating about the patient's lifestyle so he or she understands the importance of the ARV regime (Maratioa, 2007).

Ignorance of the lifelong nature of ARV's might be seen as a disadvantage of the treatment. Within the health experience of a patient feeling better on ARV's might be mixed up with being cured. A patient decides to stop the treatment with negative consequences, like falling ill on opportunistic infections (Maratioa, 2007). Sustaining on a rigorous treatment like ARV's is difficult for people (Wynsberghe, Nobuck and Corolla, 1995 in Maratioa, 2007).

3.3 Sectors of health care

People who are suffering from physical discomfort such as HIV have a number of different ways of seeking help or helping themselves with self-medication like pain relieving drugs. The decision depends from personal preference and cultural and contextual factors. One might ask advice from a family member, visit a folk healer or consult a doctor. All these different steps can be followed or a different combination might occur. In urbanized societies many pathways of diagnosing and treating ill health are offered like a well developed health care system (Helman, 2000).

In the South African context these facilities are not always available or affordable. In South Africa, counting an average of 0.77 doctors per thousand inhabitants and these doctors of whom the majority work in the cities. In the Western world this is 3.09 per thousand inhabitants (Helman, 2000). Therefore, patients in rural areas often (have to) rely on family members and traditional healers (Sangoma's).

In each society three different sectors of health care can be distinguished, the popular, the folk and the professional sector (Helman, 2000). Each sector characterises itself in treating and explaining



ill health and in defining who is the healer and who is the patient depends on these sectors. These three sectors might influence the health experience of a patient to a more or lesser extent or in a combination of the three sectors. Each sector has specific representatives like family and fellow patients, a traditional healer or medical professionals.

3.3.1 Popular sector

The *popular sector* is a non-professional and non-specialist realm of society. In this sector ill health will be firstly recognized and defined. People might use self-treatment based on lay beliefs, self medication or advice of a family member. Another possibility is to consult fellow patients with the same symptoms or complaints. A family member or fellow patient who is HIV positive and using ARV's might be a suitable source of information (Helman, 2000).

In this sector the main area of health care is the family. It is estimated that up to ninety percent of health care takes place within this segment, mostly provided by women (Helman, 2000).

This sector also includes a set of dispositions about health maintenance, which differs between cultural groups. Healthcare in this sector means that both patient and healer share similar assumptions about health and sickness and therefore misunderstandings between the two are relatively rare (Helman, 2000).

In Southern Africa the cleansing ritual is a disposition about health maintenance. This ritual is performed after the death of a husband, wife or a miscarriage. When not performed, the soul of a loved one cannot enter the ancestral spiritual world (Liddell, Barrett and Bydawell, 2005). Several traditional medicines must be used during this cleansing period. This might cause all sorts of problems like for instance a patient is on ARV's since traditional medicines (see the following paragraph) and ARV's do not combine (Maratioa, 2007).

3.3.2 Folk sector

The *folk sector* is especially large in rural areas. Assured individuals are specialized in forms of healing that are either sacred or secular, or a combination. These healers are not part of the official health care structure but work between the popular sector and the professional sector. Within this sector a wide variation of typologies are found like herbalists, purely secular healers or bone-setters.

The folk sector exists in the traditional African worldview and based on an anthropocentric ontology. This means a human being is inseparably connected to the cosmos and that everything like God, spirits and nature is connected to mankind. 'Without a thorough knowledge of these three cosmic orders, the psychological and social dimensions of AIDS in Africa cannot be fully understood and appreciated' (van Dijk, 2001, 2). This cosmos exists at three levels: the macro, meso and micro cosmos. The *macro*-cosmos is the highest level and contains God, ancestors and the spirits of people who passed away. God is seen as the designer and a supreme creator in a traditional religious structure. The spirits of ancestors influence daily life in Africa as they protect from bad luck or illness. Within this belief structure, people can also be punished by sending misfortune or illness. This might happen when prescribed rituals are neglected (van Dijk, 2001; Steinberg, 2008).

The *meso* cosmos is a universe where spirits, witches and sorcerers live. Some forms of illness are ascribed to this level as an incident of ancestor-caused illness. It is a common belief that HIV is



caused by witchcraft, especially among poor and uneducated people. The *micro* cosmos represents the social and collective daily life in Africa (Van Dijk, 2001). In this cosmos illness is caused by germs. The distinction between different levels of cosmos gives an insight in how African people may experience a disease like HIV (Van Dijk, 2001). These various views on illness is likely to have a major influence on patients health perceptions, for instance the believe HIV is caused by witchcraft.

In the South African context, the WHO estimates that over eighty percent of the population in rural areas seeks advice and treatment from a traditional healer before visiting a medical doctor (Richter, 2003). The belief in traditional healers is a cultural aspect that is based on the African worldview. Those who do seek formal health care (in the professional sector) often continue to visit a traditional healer (www.amref.org, 12 May, 2009).

Traditional medicine (*muthi*) is defined by the WHO as 'health practices, approaches, knowledge and beliefs incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques and exercises, applied singularly or in combination to treat, diagnose and prevent illnesses or maintaining well-being' (WHO in Richter, 2003, 6). The definition for African traditional medicine is the following: 'the sum total of all knowledge and practices, whether explicable or not, used in diagnoses, prevention and elimination of physical, mental or social imbalance, and relying exclusively on practical experience and observation handed down from generation to generation, whether verbally or in writing (WHO in Richter, 2003, 7).

Generally speaking, traditional healers are divided into two categories:

- Firstly a traditional healers serves the role of diviner-diagnostician (or diviner-mediums) and diagnoses usually through spiritual means.
- Secondly, the healers (herbalists) who choose and apply relevant remedies for diagnoses made by the diviner (Richter, 2003).

Most traditional healers share the basic cultural values and world view of the communities that they live in. This worldview (paragraph 2.2.1) also includes the origin, significance and treatment of diseases. It is a South African holistic approach, information will be gathered by the social background of the patient together with details of the sickness before making a diagnose (Helman, 2000).

Since the seventies, traditional healers can join the Traditional Healer Organization (THO), which counts 25.000 members. The South African Traditional Healer Health Care Group is another umbrella body which focuses especially on Voluntary Testing and Counselling (VCT) on HIV (Richter, 2003). This is the first step in making this sector controllable and comprehensible. Nevertheless, it is estimated 70.000 traditional healers perform their traditional practices in South Africa (www.factnet.org, 13 May, 2009), and only one bit over a third is member or the THO. This means that many traditional healers work on their own without supervision.

3.3.3 Professional sector

'The *professional sector* is the organized, legally sanctioned healing profession, such as modern Western scientific medicine, also known as allopathy or biomedicine' (Helman, 2000, 58). Not only



physicians are included, also paramedical professionals, like nurses. Medicines and treatments are scientifically approved. In South Africa fifty-nine percent of the doctor's work in the private sector decreasing the already low number of doctors available for the population (see paragraph 3.2). Basic health care is free of charge in South Africa. Eighty percent of the population relies on this public sector, which is under-resourced and over-used. For those who can afford private health care (eighteen percent of the population), highly specialized health services are available (Reagon, Irlam and Levin, 2003; www.southafrica.info.co.za, 13 May 2009).

Within this sector, professionals who perform medicine form a group apart with their own rules, values, concepts, theories of sickness and behaviour. A profession is (Foster and Anderson 1978 in Helman, 2000, 61); 'based on, or organized around, a body of specialized knowledge (the content) not easily acquired and that, in the hands of qualified practitioners, meets the needs of, or serves clients'. There is a collegial organization, which maintains control over the field of expertise. Nurses are registered by the South African Nursing Council (www.sanc.co.za, 12 May 2009) and will be representatives of this sector within this research.

3.4 Health perception of influencing representative of the three sectors of health care

The three different sectors of health care discussed in paragraph 3.3 have different representatives who might influence the health perception of a HIV infected person. For each sector representatives will be defined in the following paragraphs. Also possible positive and negative influencing factors or issues will be discussed.

Each representative finds him or herself in a structure of rules and constrains (Giddens, 1984). For instance a nurse needs to follow the professional rules within a faith based organization. Within this structure a nurse is able to handle and operate as an agent and has the opportunity to make his or her own choices. Acting autonomous is possible within these rules and regulations (Giddens, 1984).

3.4.1 Family members

A family member in the South African context is not only a member of the nuclear family, but also aunts, cousins or grandmothers (Murray, 1980; Siqwana-Nduluo, 1998). Within the popular sector different health perceptions exists, which might be differently interpreted through family members. In a Southern African family, countless experiences of illness are integrated in the social framework of family life (Dilger, 2006).

The family members have both positive and negative influences on a patient's health perception. The major part of health care is provided within a family in a setting of shared values (Helman, 2000; Siqwana-Nduluo, 1998). This might be a positive influence on the health experience of a patient. When a family member is sick he knows his family members might take care and inform him or her. Negative influences are a family who impede health care (Helman, 2000). This might be very reasonable according to the stigma attached to HIV (Vermeer and Tempelman, 2006). Nevertheless, this stigma is not within the scope of this research, it is a reason for family members to deny a family member who is HIV infected (Ashforth, 2002). Hypothetically speaking this might have an influence on other kin relatives when it comes to a HIV infected member of the family. Therefore the health experience of a patient can be influenced through the health perception of a family member.



3.4.2 Fellow patients

Fellow patients are representatives of the popular sector and might have an influence on a patient's health experience since they share the same illness (Helman, 2000; Thoits, 1995). Fellow patients meet each other when visiting a health facility and share their knowledge, encountering of health and the costs and benefits of the followed treatment. Positive aspects are patients who encourage and comfort each other. Negative influences on a patients' health experience can also happen in a manner By sharing negative experiences concerning certain medicines for instance.

3.4.3 Traditional healers

'The World Health Organization (WHO) defines traditional healers as those recognized in their communities as skilled and knowledgeable in the use of indigenous medications (like herbal, substances) and therapies (such as acupuncture) that are considered alternative or complementary in Western health care' (Giarelli and Jacobs, 2003, 40). Traditional medicine is still commonly accepted throughout South Africa (Helman, 2000; Lazarus, 2006; Maratiao, 2007; SANAC, 2007 – 2011)

A positive aspect of folk healing is the explanation of ill health in a wider, more familiar and cultural terms (Helman, 2000). The social, psychological and spiritual aspects of a patients' life are also included. This holistic view might, on the other hand, cause disadvantages for a patient.

- First the uses of traditional medicines are based on experience of the traditional healer and the combination might differ from time to time. This might have harmful consequences for a patient, like toxic levels in the blood (Maratiao, 2007).
- Second, a traditional healer might tell a HIV patient he or she is being guilty of an offence, like for instance not obeying the ancestors. Contrary, a traditional healer might be convinced to cure HIV. This contradicting information has a major influence on the health perception of a patient. This can result in quitting the ARV's and starting to use muthi⁸ (Ashforth, 2005).

3.4.4 Professionals from HIV-management programmes

HIV management programmes supply several different care providers to assist HIV patients with medical services, like a counsellor, a home based care worker or a professional nurse. A professional nurse is the care provider when it comes to knowledge of health, how to encounter health and the cost and benefits of a treatment. A professional nurse also trains and educates counsellors and home based care workers and is the representative of the professional sector within this research.

A professional nurse can fulfil interpersonal needs of a HIV positive patient, like advice and prescribe medication and provide support (Feitsma et al, 2007). According to the South African Nursing Counsel (SANC) nurses who care for HIV and AIDS patients need to operate in a certain way. This is a confidential, non-judgemental, emphatic, caring and protecting way of caring. Discriminating and violating of confidentiality is strictly forbidden (www.sanc.co.za, 14 May 2009).

These regulatory requirements are positive influences on the health experience of patients who can talk in a private and trustful atmosphere. Also, the scientific based and clinically proven

⁸ Traditional medicines

medicine is an advantage for the patient. At the same time this is a disadvantage when not approaching a patient in a holistic manner (Helman, 2000). A negative influence might be the faith based background of the nurses. The Catholic nurse faces issues like condom use, sexual relationships outside marriage, multiple partners, prostitution and casual relationships (Munro, 2006) that form a basis for her health perception. In order to handle these issues a Catholic nurse might react in a judgemental way and will thereby influence on the health experience of a patient.

3.5 Research design

Within this research it is important to keep the South African context connected to the health experience of patients in mind, jointly with the aspects of this health experience and the health perception of the representatives of the sectors of healthcare. All together, within this research the subject is the health experience of a patient in South Africa and the influencing health perception of the representatives who might influence this health experience. The following scheme is a simplified model which is the basic framework of this research.

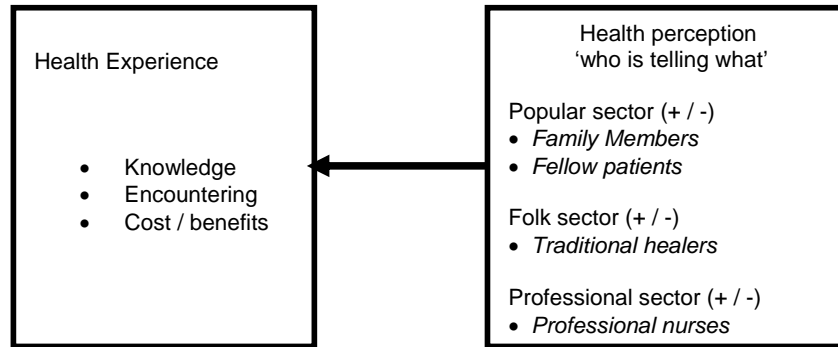


Figure 1; schematically framework health experience and health perception

This model shows in a simplified way that the health perception of a HIV positive patient can be influenced ('who is telling what'), in a positive or a negative manner, by one or more of the representatives of the three health sectors. This might be influencing the health perception of a patient. This model will function as a guideline within this research due to the explorative character of this research.

Aforementioned representatives, according to the literature review, are the main informants when it comes to the health perception of a patient. These representatives form a broad guideline for this research. Due to the explorative character of this research other representatives than the three health sectors will be included during the analysis of the data.



3.6 Main research question

To investigate the relationship between the patient's health experience and the health perception of the representatives, the following research questions are formulated:

1. *What is the prevailing health perception of Tapologo professionals and the health experience of HIV positive patients at the HIV management programmes at four Tapologo clinics around Rustenburg, South Africa?*
2. *How is the health experience of the patients of the four Tapologo influenced by the health perception of the representatives of the three sectors of health care?*

3.6.1 Sub questions

To answer the main research questions four sub questions are formulated. The first sub question investigates the aspects of the health experience of the patient and by which representative this experience is influenced. Sub question two addresses the difference between the health experience of a patient and the health perception of a professional nurse and will be answered via sub question one. Of the representatives, only the professional nurse will be directly questioned. The influence of other representatives will be investigated through questioning the patients and the professional nurses.

1. What is the prevailing health experience of HIV positive patients at the Tapologo clinics around Rustenburg, South Africa and which of the representatives' (table 1) health perception influences their health experience?

1.1 Knowledge of health

- What does a patient know about HIV?
- What tells a representative, according to a patient, about HIV?
- How does this information influence the health experience of a patient?

1.2 Encountering own health

- How does a patient encounter his own health being HIV positive?
- What does a representative tell, according to a patient, about encountering HIV?
- Which of the representatives influence and help the patient to encounter HIV and how?

1.3 Cost / benefits

- Is the regime of the ARV treatment worthy to be followed according to a patient?
- What does a representative tell, according to a patient, about the cost/benefits of the ARV regime?

* Representatives

- o Popular sector
 - Family members
 - Fellow patients
- o Folk sector
 - Traditional healer
- o Professional sector
 - Professional nurse



Chapter 4 Method and relevance

This qualitative research describes the contextual and cultural factors that might influence the health experience of a HIV positive patient. Both cultural and contextual factors are important in describing and understanding the complex HIV epidemic in South Africa. Due to this qualitative approach, no hypotheses were formulated.

Qualitative research describes behaviour, experiences, and outcomes of the involved (Boeije, 2005). Through this kind of research the health experience of HIV positive patients can be explored and interpreted in a way that is close to the natural environment of people under study ('t Hart, Boeije and Hox, 2005). Through in-dept interviews with patients and professionals an insight is given in the health experience of the patients and the health perception of representatives of the different sectors of health care. This insight is from an insider perspective which is formed through the cultural and contextual situation and can be used in the future to evaluate the HIV management programs of Tapologo.

A disadvantage of a qualitative research method is the reliability of this study. The reliability is improved through semi-structured interviews (paragraph 3.1.1). Nevertheless, sometimes it is necessary to interrogate more thoroughly on one or two situations, for instance interviewing a patient which used to work as a traditional healer. However, this improves the validity of the results (Boeije, 2005). The external validity of this research is limited due to the specific setting of data collection. It is difficult to generalise the outcomes of this research to other situations. Since this not the aim of this research, the insider perspective of the investigated participants was the overall goal. Another strategy to improve the validity is the use of different research methods. Besides interviewing patients and professionals, focus group discussions are used, together with observations at stake.

4.1 Data collection

Via Tapologo Centre we received information about the nine different clinics they head up for. We visited eight clinics⁹ and selected four different clinics (paragraph 3.2). To get familiar with the professionals and the patients I worked as a nurse at each of the four clinics and my fellow students were assisting with administration tasks. Eventually we started with our research. Besides these observations we started with in-dept interviews and focus group discussions were held among patients. Out of the representatives, only the professional nurses of all four clinics were interviewed, together with the Tapologo head nurse, the home based care manager and a Tapologo employee. An overview of the interviewed patients is given on the next page.

While interviewing the patients, local translators were assisting by translating the questions and answers. Local translators were trained to translate the answers of the patients in English. These translators were able to speak several local languages like Tswana, Xhosa and Zulu. Training and instructions were given to emphasize the importance of translating literally and in an objective manner. The translators were necessary since only a few patients speak 'South African' English which was not understandable.

⁹ The ninth clinic was due to logistic reasons not suitable to investigate



| Gender | Number of patients |
|--------|--------------------|
| F | 25 |
| M | 6 |
| Total | 31 |

Table 1; number of patients¹⁰

| Age | Number of patients |
|---------|--------------------|
| 20 – 29 | 5 |
| 30 – 39 | 12 |
| 40 – 49 | 9 |
| 50 – 59 | 5 |
| Total | 31 |

Table 3; age of patients

| Months | No. of HIV infected | On ARV's since (number of patients) |
|---------|---------------------|-------------------------------------|
| 0 – 6 | 1 | 11 |
| 6 – 12 | 3 | 2 |
| 12 – 24 | 8 | 7 |
| 24 – 36 | 3 | 2 |
| 36 – 48 | 8 | 4 |
| > 48 | 8 | 5 |
| Total | 31 | 31 |

Table 2; period of HIV infection

| Male focus group | Age | HIV infected since; |
|------------------|-----|---------------------|
| Participant 1 | 36 | 2005 |
| Participant 2 | 35 | 2006 |
| Participant 3 | 51 | 2008 |
| Participant 4 | 50 | 2008 |

Table 4 & 5; male and female focus group

| Female focus group | Age | HIV infected since; |
|--------------------|-----|---------------------|
| Participant 1 | 27 | 2008 |
| Participant 2 | 34 | 2006 |
| Participant 3 | 37 | 2007 |
| Participant 4 | 26 | 2009 |

4.1.1 In-dept interviews

In-dept interviews are used to provide an insight perspective in the health experience of the patients and the health perception of the representatives of the health sectors. The HIV positive patients were interviewed about their health experience. The professional nurses were interviewed about the patients' health experience and their own health perception.

The population of this research is recruited from the HIV infected patients who visit the Tapologo clinics Kanana, Chaneng, Tlaseng and Freedom Park which are located around Rustenburg. These patients visit the clinics to collect their ARV's on a monthly basis and consultate a professional nurse. These patients were asked to participate in this research. Every professional nurses working at the clinics under study was interviewed together with the professional head nurse, the home based care manager and a Tapologo employee responsible for drug-control.

The selection was complete randomly since the patients were free to choose, whether or not to participate within this research. Both men and women were questioned, though the ratio between male and female was not 1:1 at all. This is partly due to the fact the majority of males is treated for HIV at clinics associated with the mining business. Another reason why males are underrepresented is their fear of testing and facing their HIV status. However, this reason is not within the scope of this research. In total, twenty three patients are interviewed individually, eight (other) patients participated in two focus groups, a male and a female group (see table 4 & 5).

The interviews were semi-structured and this strategy provided an opportunity for a patient or a professional to tell their own story (Baarda, De Goede and Van Der Meer, (2007). The structure of the interviews is based on the theoretical framework. Different categories are divided and the operationalized questions are conducted out of these categories. The semi-structured strategy prevents random errors and will improve the reliability of the observations ('t Hart et al, 2005). These interviews are replenished with observations and participation at the Tapologo clinics. I as the

¹⁰ The eight focus group participants are included



research instrument myself and tried to learn about the habits and the behaviours of the investigated people. Therefore I joined the daily life of the investigated people and did not change their daily routine ('t Hart et al, 2005). The objective is to describe how it works in the local context, the prevailing opinions that occur and therefore my participation and observations were useful ('t Hart et al, 2005). Interview questions will restrain topics like the sub questions mentioned above.

Since the explorative aim of this research it can be valued as a case study. A case study investigates a phenomenon in the natural context using several methods like observation, participating and interviewing (Boeije, 2005).

During the interview, it occurred that the patient revealed his or her misconceptions about HIV. These patients were referred to the professional nurse in order to receive the right information at the end of the interview. The professional nurse was not informed about the lacking knowledge of the specific patient to protect the confidentially character of the interview.

4.1.2 Focus groups discussions (FGD's)

'Focus groups are a microcosm of 'thinking society', capable of revealing the processes whereby social norms are collectively shaped through debate and argument' (Lunt and Livingstone, 1996 in MacPhaila and Campbell, 2001: 1618). This research strategy is developed based on the fact that many consumer decisions are made in a social context as an result of discussions with others. For investigating public attitudes and experiences of disease this is a proper research method. Participants are a typically homogeneous group who were asked to reflect on the questions posed by the interviewer. It might occur that participants react on other people's opinions with their own opinion and this can provide useful information.

Eventually a focus group discussion will not lead to generalized statements, in contrary to research methods with limited responses (Robinson, 1999). "Group discussions can generate more critical comments than interviews" (Watts and Ebbutt, 1987 in Robinson, 1999; 906). Therefore this method will enhance our perspective on the health experience of the patients and the health perception of the professional nurses.

The patients who participated in the male focus group had several discussions with each other, which resulted in the gathering of more information in comparison to an individual interview. The disadvantages of focus groups are the different response times between the participants and the possible collective agreement on certain topics (Robinson, 1999).

4.2 Data analysis

The interviews and focus group meetings were recorded and transcribed. To increase the reliability of the analyses of the data, a qualitative software program like MAXQDA must be used (Boeije, 2005). The collected data from the patients as well the professionals is labelled in this program and these labels are based on the research design in paragraph 3.5. Other relevant information is also labelled and used in representing the results of this research in chapter five. During the data collecting, the data was analysed and this analysis was used during further data collection. This method is considered to improve the reliability and validity of the research ('t Hart et al, 2005).



The interview questions and the data analysis were performed from the patient his point of view. The professional nurses were questioned about the health experience of the patient. Opinions of patients were propounded to the professional nurses to clarify some insights of the patents health experience. Subsequently, the information given by a professional nurse is his or her health perception.

4.3 Scientific and societal relevance

This research can be relevant for developing social scientific theories on contextual and cultural embeddings of health experience and health perception. Research by previous students from Utrecht University using models by Ajzen (1991 in Van Dijk et al, 2008) have let to less satisfying results in the South African cultural en contextual situation. For example, research by van Dijk et al (2008) found some significant relationships between intention and behaviour. This is replenished by Briët, van Pelt, Greeve et al (2008) in researching intentions to voluntary counselling and testing (VCT). They found a significant relation between knowledge and VCT. Nevertheless, this relationship has statistical problems like scaling and therefore some relations are actually not significant. Only the positive attitude towards VCT and the intention for VCT were demonstrated (Briët et al, 2008). Yet, how this intention is shaped remains unclear.

Therefore this research investigates the cultural and contextual factors that influence the health experience of black South African HIV/AIDS patients. These factors can be used in the future to improve questionnaires and research approaches about these issues. This research steps aside of Western orientated models such as the theory of planned behaviour by Ajzen (1991 in Van Dijk et al, 2008) and focuses on the cultural and contextual factors of the health experience.

On societal level the spread of HIV and deaths as a result of AIDS must be decreased. The impact of the HIV epidemic is huge and appears on a political and economical level throughout South Africa (Arndt and Lewis, 2001; Tempelman and Vermeer, 2008). The sheer numbers of HIV positive people in South Africa show the extensiveness of this problem. Seventy percent of all the people living with AIDS in the world, live in Africa (van Dijk, 2001) and more than fifty percent of all deaths in South Africa are due to HIV/AIDS (WHO, 2006).

The department of health in South Africa estimates that 28% of the South African people are infected by HIV (National Department of Health, 2008), consequently, nearly one out of three persons. The following quote by Epstein (2007) gives us an insight in the persons behind those numbers; 'Everybody is affected by HIV/AIDS. Everyone has a friend, a sister, someone who is sick or dead because of AIDS' (Epstein, 2007, 21). Thus not only the HIV positive African people are affected, their family, friends and children are affected as well. Families fall apart, children of twelve take care of their brothers and sisters because their parents died (Tempelman and Vermeer, 2008). Therefore the epidemic must be fought for all the South Africans who are affected by this disease.



4.4 Interdisciplinary social science accountability

The interdisciplinary character of this research becomes comprehensible by the several disciplines that are used during this investigation. The aspects of the health experience and the health perception will be approached by several disciplines.

First of all the sociological approach will be used to analyse how people react, interact and deal with the social world and structures around them. In this case the African world view is structured through contextual factors, such as the mining industry and the spread of HIV and this influences the choices patients make at the Tapologo clinics.

'Medical anthropology is about how people in different cultures and social groups explain the causes of ill health, the type of treatments they believe in and to whom they turn to if they get ill' (Helman, 2000, 1). Medical anthropology will be used to explain how patients react on and deal with a disease like HIV and the treatment like ARV's or traditional medicine.

Psychological insights will be used to understand the feelings and coping mechanisms of the patients (Gilbert et al, 2002 in Gilbert et al, 2003).



Chapter 5 Research findings

The results of the interviews with the patients and the professionals are described following the sub questions as represented in paragraph 3.6.1. Firstly the questions are answered through the patients' point of view. This point of view is the health experience of the HIV positive patient. The aspects of the health perception are knowledge of patients, encountering own health and the cost and benefits of the treatment. These aspects structure this chapter in the first three paragraphs.

Individual interviews and the two focus group discussions with patients provide answers for first two sub questions. Subsequently the influences of the representatives will be described which where derived from the individual interviews with the patients and professionals. These representatives in this context are family members, fellow patients, traditional healer and professional nurses. Out of the last group of representatives, only the professional nurses have been interviewed. The influences of other representatives where derived from the individual interviews with via the patients. This chapter will end with an answer to the main research question.

The fragments are literally drawn from the interviews. Only editorial adjustments were made to improve the readability and some parts are not represented, considering these fragments as not relevant.

5.1 Knowledge of patients

The analysis of the interviews with the patients is divided in several sub topics to improve the readability. These sub topics are based on the theoretical framework represented in chapter three. A patient' knowledge contains information concerning HIV infection, the use of muthi's, the incurable character of HIV and the use of condoms. The fist sub topic to be discussed is the patients' knowledge about the way a HIV infection is sustained. These are the scientific approved ways of infection, but in the South African context other ways of HIV infection are believed, for example the cleansing ritual and other individual misconceptions. Further more, today's' common, hence declining belief in traditional medicine are part of someone's knowledge about HIV. The distinction between caring and curing cannot always be made and some patients have an interesting view on the use of condoms.

5.1.1 'HIV positive by running around'

The knowledge of patients about HIV infection is versatile. Some are very well informed, others are abreast of the proper information. HIV infection identifies several potential possibilities. Unprotected sexual intercourse and blood to blood contact are the most acquaintance and scientific approved possibilities. In the South African context a disease like HIV can be seen in a different way, contrary to the scientific approach. These different perspectives can result in an ambivalent situation.

The questioned HIV positive patients are well posted on the subject HIV. Most patients know HIV is a chronic, degenerative disease; *"There is no cure for HIV but the ARV's can help you decrease the virus in your body"* (woman, 41 (6)). *"You have to control your HIV, do not let it control you. You have to be the one to take over, do not let HIV take over your life"* (woman, 43 (11)). Nevertheless, for



a few patients there are some vagueness's about curing HIV, this will be reviewed later on in this paragraph.

Unprotected sexual intercourse is the main cause of infection; *"I only know if you are sleeping with a boyfriend or a man without protection you can get HIV"* (woman, 41 (8)). Though, HIV is in most cases associated with sex and especially with having multiple partners ('running or sleeping around').

"HIV is a STD¹¹ due to having more than one sexual partner". (woman, 29 (4)).

"I understand that HIV is an existing virus, and HIV is a STD due to having more than one sexual partner". (woman, 29 (4)).

"You will only get infected if you sleep around with different partners" (woman, 36 (22)).

In the female focus group discussion all participants agreed HIV is only possible when a person has several sexual partners. Having only one partner cannot cause HIV according to these women; L¹²: *"If you only have one partner than you cannot get HIV?" Every participants in female focus group; "No"* (Female FGD, 5th of May, 2009).

Blood to blood contact is another way of becoming infected and almost every patient uses the same example about a (car) accident; *"You also can have it through accidents if you are not HIV, if you are HIV negative and I am HIV positive and maybe I am trying to help you without using gloves and maybe our blood contaminated and you will get HIV"* (woman, 28 (16)).

"Through car accidents or maybe if your blood, when you have a scratch, and than your blood becomes infected" (woman, 35 (20)).

It is unlikely that the interviewed patients were infected through childbirth, since the youngest patient was born in the beginning of the eighties. In this period HIV was first discovered in the United States. As a result infection through childbirth was excluded from this research. References to the car accident were made in most of the interviews, however, there are patients who mention childbirth, sharing needles, washing a HIV positive person without gloves and the cleansing ritual (paragraph 5.1.1.1) as other ways of contracting HIV.

The belief in witchcraft is decreasing according to all patients *"I do not believe in this witchcraft. Even though there are people who say it is. How can having sexual intercourse with a male and a female having sexual intercourse be witchcraft?"* (woman, 29, (4)). Probably due to education given at the clinics they do not believe HIV is caused by witchcraft.

Representatives about HIV infection

Knowledge among family members concerning the transferral of a HIV infection result in several misconceptions; *"If I am the one who prepared the food she [the patient' sister] would not eat"*

¹¹ Sexual Transmitted Disease

¹² L (Linda); the question that has been asked during the interview



(woman, 38 (10)). These misconceptions manifest themselves not only among family members but also within the community; *"There are some people who like now would not be able to touch a HIV positive person. They say when they touch the person, they will be HIV infected"* (woman, 32 (18)). Family members still belief HIV is witchcraft; *"They are just saying they are bewitched. My sister in law who passed away last year. She had al the signs of HIV but she says it is witchcraft"* (woman, 42, (19)). These different ways of in comprehensions might infect the acceptance process of a patient and keep the stigma attached to HIV alive (paragraph 5.2.2).

In some cases a family member encourages a patient to avoid infection; *"She [her younger sister] encourage me always to have safe sex (...)"* (woman, 34 (13)). Only one patient talked with her boyfriend (also a fellow patient) how they got infected; *P: "Usually we talk about how we got infected. He asked me and then I asked him. Than he usually tells me how he got infected and I tell him but I do not know how I got infected"* (woman, 28 (15)).

Two of the interviewed patients used to work as a traditional healer in Freedom Park. These patients are aware a person can get infected with HIV after unsafe sex or through blood to blood contact; *"When it is the time to have sex and you are a lady you don not know he is sick. You just ignore and do not use a condom. And that is the time you can be infected". (...). "The traditional healers used to wash other peoples bodies. And by that time the other person has a scratch or has something to do with blood and that it can affect the traditional healers. Because they do not use gloves. (woman, 53 (7)). "You get infected with HIV through blood and it [HIV] does not want to people have sex without a condom¹³"* (woman, 49 (12)). For these traditional healers it is common to refer a patient to the clinic when they suspect HIV contrary to other traditional healers who still try to treat HIV positive patients with their muti's.

Other traditional healers influence the health experience of a HIV positive patient by saying they are being bewitched or poisoned and need traditional medicine to solve this problem. This happened more often in the past; *"In the older days, yes because there are those, there are this traditional healer who will tell HIV positive people someone like your mother in law is bewitching you. It is witchcraft and so on"* (professional nurse Freedom Park clinic, 11th of May, 2009). However, this is still happening, also due to the fact traditional healers want to earn money by selling their medicines; *"Because they do it for gain"* (professional nurse Chaneng clinic, 4th of May, 2009).

According to the professional nurse at Tlaseng clinic (8th of May, 2009) knowledge on manners of infection are still lacking; *"It is only transmitted by sexual, I mean relation with them. They are not more able if we try to educate them that that is not the only way. Because they [the patients] neglect the other things, I mean using your bare hands when are tending to blood and any fluid that is from the... because they think that "I do not have a boyfriend and I do not have a husband, that means I am safe." And yet they are not".* This quote implies still a lot of patients are not completely aware of the different ways of becoming infected with HIV and this consists with the misconceptions of patients in paragraph 5.1.1.

¹³ This woman means HIV cannot spread when people use a condom



Mentioned misconceptions about HIV infection are still very common, especially among relatives of patients who are not educated by the clinic; *"We find that their relatives intent they are not there even when we visit them. They do not know how to touch their food or their dishes and their blood. They do not know, some of them, that how does it spread. They do not know. But we keep on"* (professional nurse Tlaseng clinic, 8th of May, 2009). According to the professional nurse at Kanana clinic (7th of May, 2009) they must invalidate the belief HIV is only caused by having more than one partner; *"They think when you are HIV positive, they think, you have been going around, you have too many girlfriends. Even if you have one girlfriend, you can still get it. Because not only transmitted through sex you know there are quite a number of issues can transmit that. But now the bottom line is that, the majority is that people associate it with sex. O, these people would say he is running around and running around. So you take out that perception, just put it there (puts symbolically something in the corner of his office)"*.

The professional nurses are the most important and biggest influencing factor towards the patients' knowledge about infection. The nurses educate the patients about HIV infection, based on his or her own professional training. The information given by the nurses is similar to the information given, by for instance, the World Health Organization about HIV. Controversy, obscurity does occur when talking about caring and curing (paragraph 5.1.3). However, family members, fellow patients and traditional healers also influence the health experience of a patient about HIV infection.

5.1.1.1 Cleansing ritual

The cleansing ritual and is a South African ceremony that must be performed after the death of a husband or after a miscarriage. Traditional medicines should be taken to clean the blood (see paragraph 2.3.1). Besides the problems this ritual might give because traditional medicines are used while a patient is using ARV's, some patients believe you can become HIV infected after the death of a loved one; *P; "Like for instance you are a women and your husband dies and than you just do not take the right medicine, herbal medicine like the whole test will be done traditionally"*

L: "So if your husband dies, than you have to take some traditional herbals for a year right?"

P: "Yes".

L; "So you got HIV because you did not take the right herbals".

P: "Yes" (women, 42 (19)).

The focus group with the female patients (5th of May, 2009) showed another example of the cleansing story. However, these women all agreed on contracting HIV when a loved one dies. They do mention that if a person is HIV positive and there was not death of a husband, this person becomes infected via sexual intercourse or a car accident.

L: "What do your ladies know about HIV?"

(Participant 1, woman, 27): "It is unclesaned blood. The fact that your blood is dirty" [the others agree].

L: "You think that it is something not clean in your blood?"

All: "Yes".

L: "How does your blood becomes unclesaned?"



All: *"The blood got dirty because you have lost your husband and than again, maybe you miscarriage and you did not take any medication to clean the blood. That is what caused the blood becomes dirty".*

Except for these two examples, more patients were telling about the cleansing story. In contrast, these patients did not belief HIV come from the death of a loved one.

The HIV positive patients who visit the investigated clinics around Rustenburg mention the scientific approved possibilities of becoming HIV infected. However, the belief HIV is caused by the death of a loved one is still a quite common belief.

Representatives about cleansing

The patients who belief the cleansing story are mainly influenced by their family members or other people; *"Some people say you get HIV from that, sometimes it is that when your are HIV positive because you did not take the medicine after your husband died. They believe HIV is that, HIV is because of you did not take the right medicines and your blood becomes dirty"* (woman, 42 (19)).

"Like parents will tell you that they have been using this herbals and traditional medicine for long and that it really helped. HIV is a virus in blood and than blood can be cleansed by using traditional medicine. They [the parents] find it difficult to believe that yes treatment from the clinic can help" (woman, 35 (20)).

All: *"People think it [HIV] is the result of not being cleansed. From the rituals when a husband or wife dies. Or if they did not cleaned after miscarriage".*

L: *"After a husband dies or a miscarriage? Do you agree with that, that people think that?"*

All: *"Agree"* (Female FGD, 5th of May, 2009).

This is a myth that some parents or grandparents' belief and this belief influence the health experience of HIV positive patients.

Traditional healers keep this misconception alive due to the fact this is part of the African culture and the income they make by selling these medicines; *"And than the other one will go and be, you know in our culture you have lost a husband or a wife you have got to go to a certain period of mourning and take certain medicines from the traditional healer and then they will tell you no, it is because you did not have been taking medications after you have, your partner died so that is why you are like this [HIV infected]"* (professional head nurse, 11th of May, 2009).

The professional head nurse (11th of May, 2009) explains the cleansing ritual from her point of view; *"If you are not taking that medication you are going to die because your blood is not clean. Even if you are not HIV, but your blood is not clean".*

L: *"Do people belief when they are diagnosed with HIV that they got the HIV because they did not do the cleansing ritual?"*

H: *"No, I don not thinks so. They don not even think HIV than. The partner dies and probably the partner died from AIDS. And because they would belief I did not have proper cleansing of the blood,*



then it is not HIV, I am just sick because, it has got its own name a Tswana name. It is not HIV, it is something else, it is called Boswagagadi and you are suffering from that. So it means your partner had died and you did not have proper cleansing of blood. So your blood is not clean. But is not HIV".

When it comes to the cleansing ritual patients are influenced by several perceptions in their social environment. Family members and traditional healers encourage them to perform the cleansing ritual. The professional nurse explains patients there is no such thing.

5.1.1.2 Ancestors

When it comes to ancestors, some people do belief in them, but not related with HIV. Ancestors can cause misfortune as discussed in the meso cosmos of the African worldview, but not a disease like HIV; (Female FGD, 5th of May, 2009);

L: *"Do you believe in ancestors?"*

(participant 4, 26): *"Yes, it is cultural".*

L: *"Are ancestors related to HIV?"*

All: *"No they are not. Like saying they are angry but they can never infect you with HIV. They can maybe react in many ways but definitely not HIV".*

L: *"Can the ancestors protect you against HIV?"*

(participant 1, 27): *"No they cannot".*

L: *"Can the ancestors protect you to any kind of disease?"*

(participant 4, 26): *"Not necessarily diseases but if you are suffering, if you have problems you can go to them and ask for help. They make your life better".*

L: *"Other problems, not with any disease?"*

All: *"No".*

It is a common belief that ancestors can cause mental problems or spiritual diseases that must be cured with traditional medicines. A physical disease that can be cured or treated with Western medicines cannot be caused by ancestors. These mental problems can start when somebody refuses an offer of the ancestors, like for instance to become a traditional healer. Male FGD (participant 4, 50); *"Yes, say for an example they [the ancestors] come to you in a dream and they offer you a gift of you being a traditional healer and you refuse to do that. Yes you will get sick".*

L: *"And you [participant 2, 35], what do you think? Can the ancestors make you sick?"*

P: *"It is only spiritual diseases that they can bring to you. Not necessarily a disease that needs medication or something. Should you refuse their offer".* Thus a disease like HIV cannot be caused by the ancestors according to the questioned patients.

Representatives about ancestors

Family members and mainly elderly family members belief in the ancestors; *"The elders believed in them and we still belief in them that we can slaughter a cow and giving thanks for them and giving something for them"* (participant 4 male FGD, 5th of May, 2009). The belief in ancestors is decreasing



among the younger generation. Due to education and media like television patients start to believe there is no such thing as ancestors that can make you sick.

People who believe in ancestors and who need to be a traditional healer because of their ancestors, must go to a person who is already a traditional healer. A certain fee must be paid to become a traditional healer; *"Some of them, one of the things that they mainly tell them is that you need to go and it is because your ancestors want to be you a sangoma yourself. So you need to go for the training as a sangoma and this training will be done by whatever sangoma. It takes so many months and you pay a certain fee and it is quite a fee"* (professional head nurse, 11th of May, 2009).

The professional nurses state the belief in ancestors is cultural. Fortunately they do not believe HIV is caused by ancestors; *"I have not met a case that a person talked about a relationship with HIV and the ancestors"* (professional nurse Kanana clinic, 7th of May, 2009).

5.1.1.3 **Nota bene; remarkable stories about HIV infection**

The stories of two individual interviewed patients about becoming infected with HIV were remarkable. One woman believes HIV is already present in the human body and another woman believes she is HIV positive because God gave her this status to be able to help other people.¹⁴

P: "I believe, I think that HIV is an infection that you have been having all along, it never had been treated to a point that it turns into HIV virus, HIV infection".

L: "So you think you can have it already and then it can become HIV?"

P: "Yes, it can start like pneumonia or something else and in the end it will develop into the HIV virus. You find that you have been having, like that pneumonia, has been pneumonia all along to a point that you realize now it is pneumonia and it is too late for it to be treated. That is turned out to a point that it is now HIV".

L: "Who gave you this information?"

P: "It is my own belief".

L: "Do you talk with other people about that?"

P: "I do not stand in front of a crowd and present whatever. What I usually do when we are waiting for a doctor or a nurse and somebody starts to talk about this and then I would say do not blame your boyfriend or your girlfriend. Look back where you come from, look back from the life that you have been living. Do not blame another person".

L: "Do I understand it correctly if you blame yourself if you have it?"

P: "Yes I do blame myself. The reason being if I attended the problem before it was too late. I would have never been where I am now".

L: "You have to blame yourself and not somebody else?"

P: "Yes I do blame myself".

(...)

L: "Do people disagree with you where HIV comes from?"

P: "Yes some disagree. They say HIV comes from a boyfriend or a girlfriend. I always say no that is not from either of the partners" (woman, 43 (1)).

¹⁴ These two patients were referred to the professional nurse



A 35 year old woman (20) believes she is positive through God to help other people;

P: (...) *"I think the reason why I got [HIV] positive was the idea of me helping other people. It happened so I can help other people because I usually talk to other patients who are already thinking of giving up. But now I can see they are now hopeful and continue their treatment and feel much better"*.

L: *"You just said you think you got positive so you could help other people?"*

P: *"I believe God had proposed for me cause the thing is after I tested and I turned positive and I told my partner and he left me. He did not told me you are positive but you did not see the results that he is negative I have not seen the results"*.

L: *"Your partner was negative?"*

P: *"My partner said he was negative but I did not see the results. And than he also accused me of having affairs and what really bothered me was that I was faithful to one partner and yet I was positive. So it really bothered me, I did not asked him why, I just though God had proposed"*.

L: *"So it was God who made you positive so you can help other people?"*

P: *"Yes"*.

These two individual misconceptions and the quite common belief in the cleansing ritual the lack of knowledge towards HIV infection do still occur.

5.1.2 'I do not belief in these muthi's'

In the South African culture, the belief in traditional medicine is not only present, but also widespread. Almost on every street corner muthi's can be bought. With regards to HIV there is scientifically approved Western medicine and, on the other hand, traditional medicine which is deeply embedded in the South African culture. For a HIV positive patient this might be a difficult choice.

Patients that visit the clinics have been educated about using only the medicines provided by the clinic; *"After I found that I am positive that is when I stopped using the traditional medicine"* (woman, 34 (13)). Other patients do not belief in traditional medicine at all due to their religion; *"In Christianity we do not use these medicines"* (woman, 41 (5)).

Within the research group two patients who used to be traditional healers have used traditional medicine after finding out they are HIV positive. Since the traditional medicine was not working they came to the clinic and started using ARV's. Another reason for the abandonment of traditional medicine in relation to HIV is the curiosity of the plants that are used as traditional medicine in the area around Freedom Park; *"I think that is a very difficult life because as for traditional medicine you have to go in the fields and look for those medicines. Sometimes you find that at this place [clinic in a dry and destroyed area through the mine shafts] you cannot find anything"* (woman, 49 (12)). This woman who used to be a traditional healer and thinks traditional medicines are better, but since they are scarce, ARV's are preferred.

In Zion Christian Church (ZCC)¹⁵ some herbal teas are prepared in order to 'heal' a patient. The church does play a significant part for a HIV positive patient; *"The support that I get from the*

¹⁵ The ZCC is the largest African initiated church in Southern Africa (Anderson, 1999)



church is from the quire at church I sing with. The other support I get from the church are the church prayers what they do at my church, but through their prayers I get support. And the tea which I may not take together with the ARV's" (woman, 29 (4)). Fortunately, due to education given by the clinics patients do not believe these teas and stick to their ARV's.

Representatives about traditional medicines

Besides an individual belief in ARV's or in traditional medicine, the representatives are a major influencing party when it comes to the attitude towards traditional medicine. This belief exists especially among elderly family members. Patients have great respect for their parents and grandparents and do not want to let them down; *"These are parents and when they tell you [to use traditional medicines], you have to listen. They are parents, that is somehow being taken with respect. But some know that if you are using the right thing, what my parents say this or that. This is the right thing and this is what I know. So some of them do not get influenced and some of them do, yes get influenced because of no choice"* (woman, 35 (20)). But also fellow patients, the traditional healers themselves and the professional nurses influence the patient about the use of traditional medicines. These influencing factors can advise against or stimulate the patient in using traditional medicine.

Nevertheless, patients have their own persuasion what is best for their individual situation. *"The family, the aunts and the grannies and the maybe the mothers in law they yes, they push and make me to push that I should drink¹⁶ the traditional medicines"* (woman, 53 (2)). Also other family members try to convince the patient; *"My mother believes in them and we quarrelled a lot [the patient does not want to use traditional medicine]"* (male, 34 (23)).

The opposite might also happen; *"My children were educated they are actually the ones who explained it to me that...mama, stop using these things [traditional medicines], rather keep these ones [ARV's] are best for me and these ones [traditional medicines] are not"* (woman, 53 (2)).

Fellow patients influence patients about using traditional medicine; *"Someone once said just go to this traditional doctor and then she will help you. Just leave the tablets and go for her herbs. Than the person who was saying that, realized it was wrong"* (woman, 53 (2)). Furthermore, patients at the clinics might also experience the drawbacks of traditional medicine when a fellow patient will use it; *"Because I have seen were it ends with people who consult traditional healers. They end up death"* (woman, 32 (18)). Bad examples of patients who do use traditional medicines is a reason for patients to stick to the ARV's; *"They took him to the traditional healer and than he finally died"* (woman, 36 clinic (22)).

Traditional healers still influence patients about the use of traditional medicine. The main reason for this is the money traditional healers make with selling their *muti*. A traditional healer will tell a patient their physical complaints are caused by 'segeso'; *"Somebody gave them poison in their food. They have got 'segeso'. Like if I have got a poisonous herb and put it in your food and you eat it and than that herb inside there [in stomach] it makes some erosion. Because some would cough and would say it is because of this 'segeso'. Cough, and than chest pains and like diarrhoea to and they [traditional healers] say it is that herb"* (professional nurse at Chaneng clinic, 4th of May, 2009). The

¹⁶ South African people say; "I have to drink my ARV's at 8 o'clock" instead of; "I have to take my ARV's at 8 o'clock".



nurses state patients do not longer belief this 'segeso', however patients do mention this; *"Sometimes when people get infected with HIV they start claiming being poisoned. They claim they are poisoned"* (translator during interviewing a woman, 51 (17)).

Another professional states; *"Patients who use traditional medicine get in 90% worse"*. *"I do not know why they do not listen, if it is lack of education or stubborn, they are just like that"* (Tapologo employee, 8th of May, 2009). The professionals educate the patients about not to use traditional medicines. A professional nurse at Freedom Park clinic (11th of May, 2009) replenishes; *"That is why we do ongoing counselling. And there is a support group were we sort of support and educate a re-educate them about traditional healers, about traditional medicine (...). We teach and teach. Without education really, we feel that even if they are educated the problem can start. Every minute they must hear this. Every time we see them we counsel them"*. This focus on education by the clinic staff and the knowledge level education of HIV infection within the research group of patients implies that the use of traditional medicine might not be the result of lacking education and knowledge. Using traditional medicine is deeply embedded in the South African culture and might be therefore the reason to use it. Though, according to the interviewed patients they do not use traditional medicine, but they know other people who do. *"They believe as South Africans, we still have that strong belief our medicines are better than Western ones. It is strong in black people"* (Tapologo employee, 8th of May, 2009).

The South African belief in traditional medicine together with influencing people around a patient explains the common use of traditional medicine as treatment for HIV positive people.

5.1.3 'You do not wake up being HIV negative'

Knowledge about the incurable character of HIV is central issue in understanding the disease and using the medication on a lifelong basis. In the investigated situation this is not clear for all patients, though most patients are aware HIV is incurable and therefore they must use their medication for the rest of their life; *"I have never seen anyone been cured"* (woman, 43 (1)). *"HIV, you do not just wake up one day and you find that you are HIV negative. If you are positive, you are positive"* (woman, 42 (19)). *"The rest of my life I take the medicine [ARV's]"* (male, 51 (17)).

For some of the patients the difference between 'feeling better' and being 'cured' is not completely clear and they think ARV's can cure them;

P: *"They [the nurses] always advice us to take the treatment and tell us if we will take the treatment we will get better"*.

L: *"You get better...you get better or do you get cured?"*

P: *"They just say you are getting better. They do not say anything about getting cured"*.

L: *"You believe the treatment can cure HIV?"*

P: *"Yes". (...)*

L: *"So you believe ARV's can cure HIV because you saw people who were very sick and now doing better?"*

P: *"Yes"*.

L: *"Are those people positive or negative?"*



P: *"They are still positive but I believe they will be negative"*.

L: *"Because they are doing so much better than before?"*

P: *"Yes"* (woman, 28 (15)).¹⁷

During the female FGD the women were talking about curing HIV. They are aware ARV's must be used for the rest of their lives, but they can be cured. Later on in the interview they said curing is not possible. This shows they interchanged feeling better with being cured.

According to the majority of interviewed patients HIV is an incurable disease. However, a very few still believe they can be cured. It is not clear whether this is false hope or lack of knowledge.

When it comes to caring, some women experience resistance from their partner or husband; *"I am willing to help my boyfriend, but he is not helping me"* (woman, 53 (7)).

Naturally there are some men who will help their partner; *"He helps me with my house tasks"* (woman, 49 (12)).

Representatives about caring and curing

Among the representatives there are different dispositions about caring and curing. The family members care for the patients¹⁸. A traditional healer will talk mainly about curing. Thus there are different perceptions towards the health experience of a patient. Many patients experience care from family members; *"She [aunt] always telling me not to lose hope. As long as I stay alive she just accept this disease. She is really helping me to stay all right"* (woman, 38 (10)). Fortunately there are parents who will encourage the use of ARV's; *"My mother forced me to take the medication [ARV's] with some porridge, something to eat, so she was helping me"* (woman, 35 (23)). When a patient talks with family members about curing HIV, traditional medicines come up for discussion; *"You [said by the mother] will tell me that I do not want to be cured [because I do not want to use traditional medicines] I do not get cured and I will tell him¹⁹[mother]"* (male, 34 (21)).

Fellow patients care for one other by listening to each other; *"We usually talk about how I feel, physically, emotionally like those. And they also tell me how they feel and than sometimes we comfort each other so it really helps"* (female focus group, participant 4, 26). Except for listening, patients help each other with, for instance, preparing food; *"But they help each other like, sometimes when I am a little bit sick, sick. When I am in bed, this other person comes and make soft porridge for me. That is when we help each other"* (woman, 41 (5)). Curing is not a common topic patients share with each other because they are aware there is no cure; *"We all have the hope that one day the cure will come and we will be cured"* (woman, 34 (13)).

Traditional healers are still influencing and confusing parties when it comes to curing; *"They went to traditional healers who announced themselves to be healing. They are curing the disease"* (professional nurse Chaneng clinic, 4th of May, 2009). Collaboration between the HIV management programmes and the traditional healers tries to end this; *"They are aware for now but they are used to be confused by traditional healers who are saying that they are able to cure HIV and AIDS. But,*

¹⁷ This woman was referred to the professional nurses

¹⁸ For more information about social support see the master thesis of Maaïke Hootsen; *'Blood is definitely thicker than water! but sshht....what will the neighbours say!??'*

¹⁹ Black South African people use him, her, she and he disordered



because now with our program we do work hand in hand with the traditional healers. They educate our patients and also traditional healers when they get, when some of our patients go to them than they refer them to the clinic to be tested. And what I like with the traditional healers, they tell our patients they do not cure HIV and AIDS” (Tapologo home based care manager, 11th of May, 2009).

Professionals working at the HIV management programs educate a patient about the fact HIV is incurable. According to the professional nurse of Chaneng clinic (4th of May, 2009); *“They do understand that (HIV is incurable) because we give examples. We examples, for instance about myself, I am a sugar diabetic. I say diabetes is never cured, that is a lifelong disease. You have got to treat yourself, take care of yourself. Take care of your medication, good habits, that is all. And take treatment, that is all. As long as you care. So they know already. They take ARV’s not for a cure”.*

Despite the education given by the professionals, a few patients still believe ARV’s can cure HIV, but not as much as there used to be; *“There are people, very few, very few. When we started many of them used to think that. We are convinced it is no more curable. It is not curable because those who told us they cannot cure it. When they come to us we are not going to tell them and lie and say we are going to cure it. We are going to make you better. You would be better and you go back to work and do all what a normal person does. But one thing definitely, you have got the HIV germ in yourself and you got to control it by taking medication”* (professional nurse Chaneng clinic, 4th of May, 2009). This nurse tells her patients they will be ‘better’. This is true, a patient on ARV’s is feeling ‘better’, nevertheless, this word might also elicit obscurity for a patient. The nurse is aware ‘better’ is not cured. However, for a poor and uneducated patient this might be misinterpreted. Moreover, it is generally known bad news can be denied or might be hushed up by the receiving party. This obscurity is replenished by the professional nurse at Tlaseng clinic (8th of May, 2009); *“We do get cases that are negative, that you can be negative, like when it is (the viral load) undetectable”.* This nurse does tell that HIV will be detectable again when the treatment is interrupted. Nevertheless, this information might cause vagueness for a HIV positive patient.

Patients feel they are being cared for by the nurses; *“We feel comfortable, we do not have a problem”* (Female FGD; participant 4, 26). Nurses mention they comfort the patients; *“I had a lot of them who cry and I had to stand up and come on, come on [comforting a sad patient]”* (professional nurse at Kanana clinic, 7th of May, 2009) and pray for them; *“I pray for a patient. If I counsel a patient and he tells me you know what, my spirit is down today because I think I am going to die before the time and my children.....I pray with that person and than I do not end up there”* (professional nurse Freedom Park clinic, 11th of May, 2009).

5.1.4 ‘It is like wearing your socks’

All the patients are aware they must use a condom and they have to insist on using one during sexual intercourse. This is quite remarkable in a surrounding with a lot of Catholic influences brought by the faith based organization that heads for the HIV management programmes. The is a good reason for using a condom as is explained by a 35 year old woman (20); *“It is to protect ourselves from each others maybe whatever diseases we contaminated. He would not know were I am suffering from. He*



might get infected from what I am infected with. So we just protecting each other from different infections or diseases. We are just using a condom to protect ourselves”.

Using a condom is also a form of taking responsibilities, towards your husband and to other women; *“It is very dangerous not to tell your husband because then if you have to sleep with him without a condom you are killing him and maybe he will go out and sleep with another women so you are killing more than one”* (woman, 36 (22)). A 36 year old woman (22) describes the positive aspects of using a condom; *“Since ever we have started to use a condom he has gained his weight again because they does not get weak²⁰”.*

Within this research, all the patients indicated they always use a condom which is by any standard an outstanding result. A marginal comment must be made when it comes to condom use. There are condoms offered for free at the clinics, unfortunately they are not always available. Sometimes Tapologo receives condoms and distributes them among the clinics or a professional nurse collects the condoms for her clinic at a governmental hospital. This is not on a structural basis, sometimes the condoms are out of stock or a nurse is convinced that giving the advice about using a condom is the same as providing condoms. Patients prefer condoms bought at the chemist over the condoms provided by the clinic. Conversely, some patients mention they are hungry, so how can they buy condoms instead of a bag of mealie meal²¹?

Gender inequality might also influence the use of condoms, a woman is in general submissive towards her husband²². Not among the interviewed patients, but there are still quite a number of pregnancies observed under the HIV positive patients who visit the investigated clinics. In sum, there are several premises to question the given answers in regards to condom use.

Surprisingly, a large group the interviewed women claim they always use a condom and their boyfriend does not have a problem with using condoms. This seems to be a doubtful claim because a large group of interviewed males do have a problem with condoms. The males state for instance; *“Males do not accept, I do not know why. I say, you have to use the condom. Someone they say not feeling alright. They want flesh to flesh. Why do you want to eat the banana with the skin”* (male, 51 (17)). Or; *“They say they want meat to meat and they do not want to eat meat wrapped in plastic”* (Female FGD; participant 4, 26). For some females condom use is also a difficult topic. They develop a rash due to an allergic reaction or they are afraid the condom will remain inside the body; *“The ones you get at the clinic sometimes break and they are left inside”* (Female FGD; participant 1, 27).

The males who participated in the male focus group (5th of May) had different opinions about condom use. Participant 2 (35 years) *“Yes you must use a condom to protect your CD 4 count level, because it might just go down. Prevent from falling down (...). After taking treatment for a month or maybe two weeks you have to use a condom. But after a month I think you can stop using a condom”.* Participant 1 (36 years) disagrees; *“I differ with that, I think always use a condom. Whether you are*

²⁰ When a condom is not being used between two HIV positive partners re-infection might occur when one of the partners has a higher viral load, this can be transferred to the other partner.

²¹ Corn flour to make 'pap' (porridge), the most important food source in Southern Africa

²² The dependence of a woman on a male is elaborated in the master thesis of Mariëlle Lunenburg; *'You cannot eat a sweet with a paper on it'*



positive, whether you are not positive. Whether your partner is positive, whether your partner is not positive. Always use a condom, it is safe to use a condom to avoid everything. Any kind of a STD”.

This implies the condom issue is still there. Most people know, or at least talk about the importance of using a condom. Others have their own reasons not to use it. There are some women who really insist on the use of condoms; *“Sometimes he does not like to use a condom. But he has no choice, he has to use them”* (woman, 38 (10)). A 53 year old woman (2)) wipes difficulties with condom use away; *“But the guy does not know how to use a condom. But I said it is more like wearing your socks”.*

In several literary sources a myth is mentioned stating: HIV is caused by condom use. Within the research group only one patient made a reference to this myth; *“They [others] do believe that AIDS was never there before the condoms were there. So it is caused by the condoms. The condoms were there, so there is HIV”* (woman, 36 (22)).

Representatives about condom use

Patients only talk with the professional nurses and their boyfriends or husbands about condoms. In most cases males are the ones who do have a problem with condom use which influences the health experience of female patients. Some women are afraid to tell their husband or boyfriend they want to use a condom, because they provide their source of income²³; *“Women are afraid of the man because the man will dump them and how do they get food?”* (Tapologo employee drugs, 8th of May, 2009). If a man leaves, there is no maintenance allowance paid for the children; *“They struggle, women really struggle with their children”* (professional head nurse, 11th of May, 2009). For a woman this can be a reason not to bring up the condom issue to avoid unpleasant discussions or more serious repercussions like abandonment. The most radical approach on avoiding the condom discussion is complete nondisclosure of her HIV status; *“It is because those patients who would not convince their partners do not disclose. I cannot say lets use a condom if I do not tell you that I am HIV positive”* (professional nurse Chaneng clinic, 4th May, 2009).

The professional nurses play an important part in educating and convincing the patients to use a condom; *“You must live an active life, you must have a sex partner but use a condom. And if you are not taking a condom with ARV’s than you would not get better. Perhaps that person has got a higher viral load than yourself, your sex partner, and than now, you have an intercourse, a sexual intercourse with him he transfers the germs on to you and yours now are double, multiply them”²⁴* (professional nurse Chaneng clinic, 4th of May, 2009).

The Catholic background of the clinic could have lead to a negative attitude towards condoms based on religious reasons. Astonishingly enough this is not the case, the nurses at the clinics advocate condom use and they indicate this is in accordance with the approach of the religious leader of Tapologo; *“Bishop Kevin²⁵ broke the ice, giving the people their rights of using condoms. But I think the Catholic Church is still amending that you are not supposed to use a condom”* (professional head

²³ The dependence of a woman on a male is elaborated in the master thesis of Mariëlle Lunenburg; *‘ You cannot eat a sweet with a paper on it’*

²⁴ Without using a condom there is a risk of re-infection, see annotation number twenty

²⁵ Bishop Kevin Dowling of the Catholic Diocese in Rustenburg is closely involved with the programmes of Tapologo Centre



nurse, 11th of May, 2009). *"It is really not an issue here because Bishop Kevin does not have a problem with that [condom use]"* (professional head nurse, 11th of May, 2009). As the Tapologo home based care manager (11th May, 2009) replenishes; *"The Catholics do have problems with condoms and I am not talking Tapologo, I am just talking Catholics"* One of the nurses (Chaneng clinic, 4th of May, 2009) is even aware abstaining is not a solution which is preached by the Catholics and the Zion Christian Church (ZCC); *"They say, they believe, they think one must just abstain. No one on earth can just abstain!"* These statements made by a Catholic organization are quite outstanding and are sophisticated. They place and evaluate the HIV problem in a broader context, were most Catholics are persuaded otherwise.

5.2 Encountering own health

Being diagnosed with a lethal disease, such as HIV, is a dreadful process to go through. HIV positive people encounter several physical complaints and try to find a way to deal with these symptoms. The acceptance process starts after the dreaded word: 'You are HIV positive. Each and everyone deals with this process in their own way. There are quite some differences between the interviewed patients and some answers are questionable. Disclosing is the final step in the acceptance process. Likewise, disclosing is encountered in dissimilar ways between the patients. There are people who make their status a secret and others use their status to inform and warn others.

5.2.1 'I feel weak, weak, weak'

HIV positive patients meet physical complaints although this will varies from patient to patient and from day to day. Some patients find out their status because their child is HIV positive. A recent mother experienced no physical complaints but is faced with her HIV positive status through her child; *"It was after the birth of Balisa, the child here [sitting with the mother during the interview]. She was something like 2 weeks old. So she started being restless and vomiting. (...). She started vomiting and I took her to the doctor, to the hospital. When I get there she kept vomiting and that is when they asked me can we at least check her status, her HIV status because I did not checked my status while I was pregnant. (...). Then they counselled me and that is when they told me the child was positive. And then I also got tested myself and I was positive too"* (woman, 43 (11)).

Other patients experience physical complaints like weight loss; *"I weight 69 before, but by then I weighted 61"* (woman, 42 (19)). Physical complaints like coughing, vomiting, night sweats, tiredness, loss of appetite or loose of strength; *"Right now I do not have any strength to do whatever job. I am weak"* (woman, 53 (7)) are the most common physical problems.

The Tapologo head nurse (11th of May, 2009) replenishes the physical complaints of the patients; *"One of the things that we see a lot are sores, vaginal sores. And TB²⁶, very big TB"*. The physical complaints can lead to all sorts of problems, like not being able to take care of the household; *"I cannot wash the clothes, and cannot clean up the yard, but I wish I could do that"* (woman, 35 (23)). *"I would wake up to day, hoping I would clean up my yard, than I would wake up and would not be able to do anything"* (woman, 43 (1)).

²⁶ Tuberculosis (TB) is an infectious disease, mostly pulmonary. TB is a common opportunistic infection that goes often together with HIV. Physical complaints are coughing and night sweats and this disease can be very contagious (Coelho, 2000).



Representatives about physical complaints

When a patient encounters a physical complaint most of them will go to the clinic. One patient mentions her mother; *"The thing is, my mum is staying in Northern Cape. If I call her when I got a headache and stuff she will think it is something very serious. I do not want to cause pain to her and do not want to stress her. I do not usually say small things like those"* (woman, 28 (16)). Due to the distance and the lack of extended family this patient prefers to go to the clinic.

Traditional healers would try to convince a patient to use their muthi's for any physical complaint, whether it is HIV related or not. Fortunately this is a declining practice as a result of the educating that has been given on traditional healers by the Impala mine²⁷. Traditional healers are as a result more inclined to refer a patient to a clinic when HIV is involved.

The professional nurses educate the patients about the physical complaints that might occur when tested positive; *"The most complaint is they loose weight, they loose weight and loose strength, no energy, you come and say I feel always feel tired. I always feel like a small parcel and then when it goes well in life and then they would be having sores on their mouth, on their tongue, I cannot, I am weak, I am have been having diarrhoea since three days. You know, they complaint, the most thing is lost of weight, coughing, oral thrush and especially peripheral neuritis, which is the painful limbs, painful bones, I can say the bones are, peripheral neuritis. They will always complaint about painful feet"* (professional nurse Chaneng clinic, 4th of May, 2009). To deal with living with HIV, patient must be able to talk about their physical problems and to receive support and possible help. Nurses at the clinic give the patient the opportunity to share and deal with these problems.

The professional nurses will listen to the patients and give them advice or prescribed medication for, for example, a headache or painful joints. In some cases a nurse has to interrogate with a patient to find out his or her complaints. These patients are most often too ashamed to talk about certain, mostly genital, complaints. Moreover, patients do not feel completely free to talk about their problems because they are afraid of the nurses reaction; *"I think again, I tend to say they are linking it that goes back to the condoms. They are thinking now, probably if I say I have got burning urine and vaginal discharge sister will think I do not use condom, you see? So rather they keep it quiet"*. (professional head nurse, 11th of May, 2009). This implies patients can have the feeling they will be judged when they talk about these kinds of problems. It is possible nurses do pass judgement on the patient.

5.2.2 'I have just accepted it'

After finding out their status and patients start to understand where the physical complaints come from, the acceptance process will start. Some remarkable stories were told by the patients during the interviews. Accepting a lethal disease like HIV takes time, however, some patients say they accept their status immediately after testing; *"I accepted everything immediately [after testing] my status by then everything. The thing that made me accept was the counselling that they gave me before and after the results"* (woman, 42 (19)). This woman contradicts herself by saying she cannot talk about

²⁷ Impala mine is one of the largest mining companies around Rustenburg. Besides employing many residents of the areas around Rustenburg, Impala mine also provides medical assistance for HIV positive mineworkers and an education program for traditional healers in Freedom Park clinic (<http://www.implats.co.za/business/impala.asp>, 20th of July, 2009).



her status and finds it hard to disclose her status within the community. This woman has not reached a state of acceptance, yet, although she says she has. The phrase "It is not the end of the world" after finding out their status is used by several patients. This puts the condition in perspective but can also be a denial strategy to avoid accepting the devastating effect HIV will have on their life. It might be plausible the patients copy each other or copy a professional who would tell them being HIV positive is not the end of the world. A patient can think he or she has accepted their status or pretends he or she has because they know they must accept their status. However, complete acceptance can not be obtained until a patient is able to talk about his or her status within the social environment.

Nevertheless, there are some patients have reached a state of acceptance and use their own status to warn and inform other people for HIV. A 38 year old woman (10) admits there are peaks and valleys through out the acceptance process; *"Sometimes I do feel down, but at this point I have accepted my condition, especially seeing other people who are infected before I was and they are still doing fine and still looking okay. I think I just accepted it and I know I will get somewhere"*. This woman gives an argument why she has accepted her status instead of stating "I have just accepted it", like a 32 year old woman (18); *"I just accepted, immediately when I was told about it that I was HIV positive"*. Patients who use their status to inform others; *"I am the one who experienced this disease so I am able to talk to other people and tell them that you have to be safe"* (woman, 41 (8)).

"I tell somebody that HIV is a very dangerous especially the young people, they must take care for themselves. Especially the young people you see?" (male, 51 (17)).

"I would really love to be a living example, like to be able to help others, to be able to encourage others. (...). I advice them not give up and I usually tell them to come here and I even tell them about the other patients that I met here at Tapologo who looked really sick and now they look really different and much better. So I always explain them and that if you are sick you have to go to Tapologo and test" (woman, 35 (20)). Patients, who do talk about their status, can use their status to warn and inform other people, have more likely accepted their status.

Representatives about acceptance

Family members can help patients accept their situation by accepting the patients; *"There are some [family members], they sit down and say this is not the end of the world. Give you examples, so many you know people with greater status have HIV, but they still live, they still care for their children. They do al the normal activities, you are the same, you are still my child and you be my child for ever and ever. I like you like I used to like you. And once you are accepted at home and it becomes freshened up"* (professional nurse Chaneng clinic, 4th of May, 2009). However, also the opposite occurs; *"I come from the clinic, I am positive. They [family members] say you been sleeping around, they will make it worse"* (professional nurse Chaneng clinic, 4th of May, 2009).

Talking with fellow patients who have accepted their HIV positive status to a greater extend can help a patient advance in her own acceptance process; L: *"What do you think if you see people who are already further in the process, like these women?"*



(female FGD, participant 4, 26): *"It really comforts me and it teaches me something like, okay, there will be a point when I will accept it and acceptance is also possible. I will accept it one day"* (female focus group, 5th of May, 2009).

Traditional healers might disturb the acceptance process by stating the patient does not have HIV but is being bewitched; *"Whereas it is a pure disease, like oedema²⁸ or whatever. They [patients] are being bewitched, or I have seen [in a dream] my grandmother [who passed away] and she told me to do this and I did not do that so that is why I got a punishment"* (Tapologo employee, 8th of May, 2009). If a patient acts on the interaction with the traditional healer this can result in the patient using muthi's instead of using ARV's from the clinic.

The professional nurses understand that every patient has to undergo the acceptance process in their own way. The acceptance process can depend on the (former) lifestyle of the patient; *"And those who are knowing well what their lifestyle was. For instance let me make an example. If I am a prostitute and I test, I know that I might be positive. And there are those who are married and they are sitting in their homes every day and their husbands are running around. Those are the people who do sometimes show the depression because I was always fit, but here am I, HIV positive, someone else brought me this. People are not the same. It all depends on the human being"*. (professional nurse Freedom Park clinic, 11th of May, 2009).

Assistance in the acceptance process is given by the professional nurses through counselling and in the support groups during the ARV roll-out days. The professional nurse at Chaneng clinic (4th of May, 2009) has her own way of helping the patients with accepting their status; *"When we counsel them we tell them that once one is pointing a finger at you like that you are HIV positive the other finger is pointing at her. If you would come across on somebody who is going to be negative against you or against your status you tell him or her. I am better of because I know my status, I now that I am positive and I am dealing with it, I am addressing it but you...you have never tested, perhaps you got double the germs I have. I am happy, you rather concentrate go and test before you point fingers at me. And than sometime they become heat up when they tell them, I am better, I am going there and getting my treatment while you are sitting at home with your multiple HIV or viral load"*.

The acceptance process is important for the patient and the professional nurses are influencing this; *"But once you manage to make the patient accept, then you are number one"*. (professional nurse Kanana clinic, 7th of May, 2009).

Doubts were rising about the acceptance process (see paragraph 5.2.2). Patients would state they have accepted their status although the moment of testing is only a few weeks or months ago. Moreover, these patients did not disclose their status with their social circle and find it hard to talk about their status. But still they state; 'I have accepted my status, immediately after testing'. This contradiction was displayed during the interviews with the professional nurses.

The professional nurses supply several examples which give an insight in the acceptance process of the patient and the discrepancy between the message in the spoken word and the message derived from the displayed behaviour. These insights show that acceptance can be a lengthy process and not all the signs can be interpreted in the same manner. A patient can be aware of their

²⁸ Oedema is an excessive accumulation of fluids in for instance the ankles (swollen ankles) (Coelho, 2000).



status for already a year and undergo several HIV tests at a Tapologo clinic to confirm their status for the second or third time. During this period they decide whether or not to start the ARV treatment. These people have to make several steps in the acceptance process before they can be 'HIV-patients'; *"They are not coming for the first time, if it has not been the first time that they test. In other words, they knew about their HIV status for some time. They have sort of gone through all the stages and coming to acceptance. Maybe it is now a year"*. (Tapologo head nurse, 11th of May, 2009). But this nurse was aware of the fact accepting takes time; *"I do not think you can think you can you status hear today and accepted this today, no....."*. (Tapologo head nurse, 11th of May, 2009).

A second insight the professional nurses supply, implies that patients copy the words of a professional nurse concerning a positive attitude and acceptance; *"It could be that probably somebody said you know they heard about positive attitude, maybe that is why they are say they have not reached the stage of acceptance, but somebody, somewhere they heard you need to have a positive attitude towards the diagnoses to be able to live longer. Probably that is why they say that"*. (Tapologo head nurse, 11th of May, 2009).

A third insight the professional nurses give in the variations within the acceptance process is related to the stigma surrounding HIV. A patient can have reached the acceptance stage, although he or she is not yet ready to disclose their status. This could be interpreted as a sign of denial or incomplete acceptance. In fact this reluctance is due to the stigma's surrounding HIV; *"Some of them, even if they not disclose to other people, it is only that is that slight stigma, people should not know that I am HIV positive they think that I am a bad person, that I have been sleeping around. But within himself he accepts and you see that the viral load will go down and the CD 4 count will go up. But disclosing is difficult, is very, very difficult. Unless if you undergo the treatment for 2 to 3 years, than there you start to say things out. But the first year is difficult"*. (professional nurse Chaneng clinic, 4th of May, 2009).

A fourth insight the professional nurses share is their own belief that it happens that a patient is denying his or her status and still say they have accepted their status; *"I can say that [I have just accepted it] is a pure lie. Most of our patients are on that denial stage, they are denying it. It is a shock, even if, you know that, in the counselling room they are trained not to have a serious shock when they reveal their status. I am surprised to hear that, knowing this is a bad disease, there is no cure for it. And seeing how the people are suffering, I do not understand"* (Tapologo employee, 8th of May, 2009).

The fifth explanation is given by the Tapologo home based care manager; *"I think once, when a person is saying that [I have just accepted it], I would think it would be a person who really got the right one who prepared her for everything. Those are the ones, it can that they have been properly counselled"*. This professional nurse states a person with the right counselling is more likely to accept their status.

These are five different insights in the variations within the acceptance process of a patient. Insight one is quite plausible, patients do test a lot, occasionally up to five times. During this testing period a patient might have already started with his or her acceptance process. The second reason when patients copy the words of a professional can be acceptable, due to the fact professionals and



several individual patients react in the same way when testing positive; "it is not the end of the world" (see paragraph 5.2.2). Another explanation of insight two is the fact a patient depends on the clinic and wants therefore a good relationship with the professionals. A patient can therefore repeat the words of the professional nurse.

Shame is still a reason for patients not to, or have difficulties with, accepting their status. This is also part of the fourth insight which is denying their status because of guilt feelings. The fifth insight might be implausible. Proper counselling is a part of the acceptance process and counselling can probably ease and accelerate the process, but accepting is a task a patient must complete on his own and this does not depend as much as stated on the counselling given by a professional nurse.

According to the Tapologo home based care manager (11th of May, 2009) acceptance is the first step in disclosing your status; *"And who also told her the importance of acceptance because it is really important for one to accept. We always say to them you first have to accept yourself before anybody else can accept you"*.

5.2.3 'Everybody knows my status'

The acceptance process and disclosure to others are closely interconnected. When patients are able to accept their status, they can open up to family members, friends and eventually the community. However, due to the still attached stigma on HIV, this is a difficult process for patients to go through; *"Because people like talking about other people's problems if you try to talk to someone confidentially, the next day she is running around talking about your problems, your family problems"* (woman, 49 (9)). *"They start pointing fingers at you, some even laugh, including your family"* (woman, 53 (2)). *"People do not take those who are positive alright"* (woman, 43 (14)). These fragments show patients still encounter derogatory and blaming reactions towards their status. For a patient these reactions are the main reason not to be open about their status.

In contrast, some patients are very open about their status and try to educate other patients; *"I do not have a problem disclosing my status. I always tell the patients here at the clinic because some of them have not accepted themselves yet. I always tell them they should for their CD 4 count to get up they should stop drinking, stop smoking and they should start using protection for the sake of their CD 4 count to get up. I do not have a problem, I have accepted myself the way I am. (...). I am proud that I am open"* (woman, 35 (3)). For patients it feels good to talk about their status; *"I do that (talking about their status) and it feels good. (...). I just talked and feel relieved"* (woman, 36 (22)).

When starting a new relationship disclosing is a difficult task; *"I had a problem with telling my status, I could not tell my status. So I must use a condom so maybe he would be safe. I could not tell him"* (woman, 49 (9)). A reason for a woman not to disclose their status is the fear of poverty. In most cases when a male partner finds out the female's status, he will leave her she is left alone with nothing²⁹. Patients within the research group expressed that this only happened to other people and they did not experience this themselves; *"Most of them they do not, they are not disclose. The reason for some of them not telling their partners, is that they think that after disclosing to their partners, partners will leave them. So that is why they do not disclose"* (woman, 29 (4)). *"There are a many of*

²⁹ See 'You cannot eat a sweet with a paper on it'. Master thesis of Mariëlle Lunenburg



them who have problems with their partner when disclosing their status. Some do not disclose their status to their partner and keep it quiet” (woman, 35 (3)).

One patient told that her husband was HIV positive and he did not disclose his own HIV positive status to his own wife; *“So I do not even know I got it from there because my husband was denying that he is positive, even though I tried to go with him to a doctor for some check ups. He refuses and he claimed he had diabetes and that my son was always telling me....no mama, this is HIV. I think my dad is suffering from HIV, but the father is still denying it so I only found out after the death of my husband. That he actually had HIV and I am also positive” (woman, 53 (2)).*

Acceptance takes time, there are people who die as a result of HIV but are still in complete denial as shown in the quote above. For those people who do take a first step in the acceptance process, the period of time a patient is aware of his/her HIV positive status seems to be related to the stage and level of acceptance and the ability to disclose. The longer a patient is aware of his status, the more common it is that a patient has accepted his status.

Representatives about disclosing

The representatives deal with the disclosure process in different ways. Family members can be supportive or give the patients a hard time. A traditional healer can also have a negative influence on a patient when it comes to disclosure. The professional nurses form an opposing positive force and encourage the patients to disclose. According to the answers of the patients, they are aware of the importance of disclosing and accepting. This awareness can act as a stepping stone which the professional nurse can use to deliver their assistance to the acceptance process when necessary.

A family member is usually the first and in some cases the only person a patient discloses his status to; *“I have decided to make this my family secret. Only my family knows as in my closer family. Not even my sisters not even my relatives because people have the tendency of laughing at others. So I preferred to keeping it in the family” (woman, 53 (2)).* For some patients disclosing is necessary because it is impossible to keep their status secret; *“It was very difficult to disclose to him, because I was staying with him there was no use to keep it a secret. It was hard for me because when I had to take my medication I could not take it alone by myself. I had to tell him. I am the one he disclosed to him” (woman, 34 (13)).* As discussed in the previous paragraph, family members can give HIV positive patients a hard time in accepting their status.

Talking with fellow patients is very easy and a patient does not have to disclose his or her status. Some patients do feel free when visiting the clinic; *“Even those who are in the same position as me here at Tapologo. It is very easy here at the clinic cause we have the same condition” (woman, 53 (2)).* Another patient tries to help fellow patients to accept themselves; *“I do not have a problem disclosing my status. I always tell the patients here at the clinic because some of them have not accepted themselves yet” (woman, 35 (3)).*

A traditional healer has, according to the interviewed patients, nothing to do with disclosing their HIV status. Nevertheless, as discussed before, there are still quite some traditional healers who claim a patient is bewitched instead of HIV positive. This claim might influence the patient and he or she would deny their HIV status based on the information given by a traditional healer.



The professional nurses underline the importance of, and encourage disclosing by stating; *“Most special to start with their family, to make sure that in their family there is someone who knows that you are positive. Because there will be a time will by a person who will be unable to help himself. And the members of the family will have to help. Like we have got old people who are HIV positive how.... They come back being sick. They do not tell [their HIV positive status] them. They continue to nurse them...”* (professional nurse Tlaseng clinic, 8th of May, 2009).

The professionals admit disclosing can be very difficult for patients, they do underline the importance of disclosing; *“They know, they must if one is infected he must disclose to his relatives and to their partner so that he must prevent the spread of the disease”*. (professional nurse Chaneng clinic, 4th of May, 2009).

Some patients need help to open up and they are referred to other professionals like a priest; *“Sometimes they get spiritual inspiration from the priest or from the counsellor if also they open up about it. If a person is talking, it is something else, but if you are too much secretive, I cannot know what is going on in your mind and heart. That is what killing most of our patients”* (Tapologo employee, 8th of May, 2009).

5.3 Costs and benefits of the treatment

Using ARV treatment on a daily basis is a constant interaction between the advantages and the disadvantages of this medication. The advantages are prolonged life expectancy and the quality of life if the medicine is used correct and the treatment is combined with a healthy lifestyle. This healthy lifestyle contains eating healthy food, sexual intercourse with protection and abstinence from alcohol, cigarettes and muthi's. There are quite some disadvantages to use ARV's, like the risk of being seen when visiting the clinic, since these clinics only treat HIV positive people and stigmatizing might start.

Than there are the side effects of the medication, the strict regime (condom use, alcohol, cigarettes muthi's abstinence), the weekly or monthly visits at the clinics are expensive for patients that live far away and need to pay for the taxi. The use of the drug is submitted to a strict time schedule, for instance if the ARV's are taking at eight o'clock in the morning, they have to be taken at eight o'clock in the evening as well.

Before taking ARV's a patient must eat to protect their stomach against the tablets. When there is no food available the medication cannot be used; *“Usually there is nothing that really disturbs me from taking my ARV's but usually I had a problem when I do not have anything to eat I skip them, because if you eat the medication without food they can really make you feel sick if you do it, even today I did not take them because I did not had anything to eat”* (woman, 49 (9)).

A patient must navigate between the costs and the benefits of the treatment for their individual situation. Fortunate most patients see more benefits compared to the costs; *“I was weak before but since I have taken the treatment that I get here. I'm strong as you can see and my CD 4 count has gone up. I am strong because I can even work”* (woman, 29 (4)).

“Sometimes when I like forgot to take them with me (...). My body reacts and feels I have not take the treatment at that time. I just know, even after taking treatment I feel that it just changes something, I



do feel when I have not taking them and I also can feel when I did. I feel a difference, a change” (woman, 53 (2)).

“I started regaining my strength immediately after I started taking the ARV’s. that is when I realized my CD 4 was rising” (woman, 42 (19)). Some patients stop eventually their medication when they feel better and they misinterpreted this as being cured. However, only other patients stop their medication according to the interviewed patients.

The costs of following the treatment are a strict lifestyle of using the medication at the same time every day. For some patients this is not a problem; *“The ARV’s are really taking me all right. I usually drink them at 8 o’clock in the morning and 8 o’clock in the evening. I usually wear my watch and always keep my cell phone with me so I do not miss the time”* (woman, 43 (11)). Others have problems integrating the use of ARV’s in their daily life; *“The only thing is that when you attending a funeral and you are at the graveyard you do not have water with you, the pills you have got. Even if you have got water with you, but it is very difficult to draw yourself from the crowd”* (woman, 43 (1)).

The strict times of ARV treatment are another disadvantage. Using the ARV’s day in and day out at a set moment during the day is a difficult task for a patient to fit in their daily rhythm. Some patients do not have a watch or a cell phone and therefore they do not take their medicines at the right time; *“If someone does not have a watch, they do everything by the sun. they can tell the time by the sun, so they do not drink the tablets at the right time”* (Tapologo employee, 8th of May, 2009).

The side effects of the ARV’s are also a disadvantage and these can make it difficult for a patient to continue; *“When it comes to treatment, I did not react well to the treatment at first. Yes, so they made me sick in a way”* (woman, 53 (2)). A reason not to stop their treatment are examples of other at the clinic; *“The ones I know that have stopped taking their medication they have passed away”* (woman, 36 (22)). For most patients there are more benefits compared to costs and therefore they are willing to use the medication for the rest of their life; *“Because of the ARV’s I would not give up in life”* (woman, 41 (8)).

Representatives about the costs and benefits

Out of the representatives there are some parties that encourage the patient to continue their ARV’s. Others try to convince the patient to quit and start using *muthi’s*. This can bring the patient in difficult situation.

One patient was considering ending the treatment but her boyfriend urged her to continue the treatment with ARV’s (woman, 49 (12)). Children support their parents to take the treatment; *“My children talked to me and told me that every tablet you put in your mouth can have a certain reaction, but your body will apparently adjust to the changes”* (woman, 53 (2)). Family members, like for instance a husband can also suggest to leave the treatment and start to use traditional medicines; *“My husband did try to suggest them [traditional medicines]”* (woman, 38 (10)). According to the patients this never happened due to the education given by the professional nurses, only with other people; *“My uncle was always using traditional medicines and going around traditional doctors for treatment and he was only getting worse. So I tried to convince him to come to the clinic but still he refuses to*



come to the clinic because he is taking traditional medicines and now he is death" (Female FGD, participant 4, 26).

Fellow patients can underline the costs of using the treatment; *"Before I started the treatment other patient would scare me by saying, this treatment when you started taking it you go crazy, things like that* (woman, 43 (1)). Nevertheless, the same patient will experiences herself the benefits of the treatment; *"But immediately I started I realized there is no such things. I found out they are very good. Like if I have a headache, but after drinking³⁰ them I will be okay"*

Traditional healers do try to win 'their' patients back; *"The traditional healers were busy attracting them. They used to tell them ARV's are not right"* (professional nurse Chaneng clinic, 4th of May, 2009). Nevertheless, this happened on a more regularly basis a few years ago since patients nowadays know some traditional healers are not completely honest. They just want to earn money to make a living which is also understandable. Since educating the traditional healers by Impala mine, they even refer patients to the clinic when suspecting HIV. Contrary, a patient who is a former traditional healer states the benefits of ARV's because they are always available; *"What will you do if sometimes you come around and I am very sick and I cannot go to find some traditional plants for you. So it is better for you to go to the clinic"* (woman, 49 (12)).

The professionals explain the patients about the medication that is necessary to keep the viral load down and the CD 4 cells to increase. To improve medication adherence, the time of intake will be deliberated together with a patient; *"They are the ones who choose the time that suits them. We do not say to them listen, you have to take your treatment at 10 am and 10 pm. We normally ask them, what time is the best for you so that you can be able to take your treatment and not forget it. We also advice them if you are going somewhere and you think you might be coming late, take you evening treatment with you"* (Tapologo home based care manager, 11th of May, 2009). Patients are also informed and educated about using ARV's in a practical and an involving approach. The professionals inform the patients about the benefits of the ARV treatment, give them examples of other patients and eventually see the positive progression; *"It is going tremendously, they are well, cannot you see, most of them could not walk, who came in on a stretcher"* (professional nurse Chaneng clinic, 4th of May, 2009).

To prevent medication non-adherence due to side effects of the treatment, professional nurses inform the patients about the side effects and explain the side effects will disappear eventually; *"My experiences has told me that a few patients do have side effects, only when it is that medication. But after 2-3 weeks to a month, that is when the side effects ripe off. Most of them do know they have side effects going to get"* (professional nurse Kanana clinic, 7th of May, 2009).

Others must convert a lifestyle of visiting taverns³¹ and alcohol consumption into a lifestyle of using medication at specific times. The professionals are aware of this turning-point and support the patient; *"It is difficult for patients to change their old activities"* (professional nurse Chaneng clinic, 4th of May, 2009). They really try to convince the patient to stick to the ARV regime and in the beginning it might go very well; *"The majority of them are using it well and a few of them are not adhering. One*

³⁰ South African people say; "I have to drink my ARV's at 8 o'clock" instead of; "I have to take my ARV's at 8 o'clock".

³¹ A South African bar or café



thing that we have seen, is that when they first start, the first 2,3,4 moths they are exceptional. They are very good and that is because they are very ill and they want to get better. Once they start feeling better, are able to walk around, gained some extra kilo's, some of them start not using it well, not sticking to the regiment" (Tapologo head nurse, 11th of May, 2009). The nurses are struggling to prevent this from happening, because eventually the patient might come back in a very weak and fragile state; *"I feel very bad, sometimes I do cry. I tell her that we made you to be so well and than you left medication and there you come now back, and you will die"* (professional nurse Chaneng clinic, 4th of May, 2009).

This can happen when patients stop their ARV's because it is a burden to them when using the medication; *"Yes, not really a lot, yes only a few. It is only a few and probably to many reasons. Lack of understanding, ignorance, negligence. Because the come here they are very sick. Although it helped them, do counselling, it helped them. You must take this for the rest of your life. If you stop your medication, the virus is going to build resistance and the medication is not going to work and the virus is going to multiply. You take it in respect whether you feel healthy, but people are not perfect. As soon if they feel healthy they are sick and tired of doing this thing. But is not that often, it is decreasing"* (professional nurse Kanana clinic, 7th of May, 2009).

Using ARV's on a strict daily basis causes difficulties because of the social background of the patients. Almost all the nurses mention this problem; *"Problem number one: social background of the patient. You cannot take ARV's on an empty stomach. You must eat and you must eat enough. There are those that do not have enough food, so how can you take ARV's without food* (professional nurse Freedom Park clinic, 11th of May, 2009). *"Sometimes the food also counts, they do not have food to drink the medicine. So it does not work"* (Tapologo employee, 8th of May, 2009).

The nurses try to help their patients with food parcels, unfortunately there is an insufficient supply and as a result these patients will be unable to follow the strict regime of medicine intake. This is a situation the professional nurses face daily at the clinic which is a difficult task for them. The nurses provide the information and knowledge, but do not have the resources to help the patients on a structural basis when it comes to healthy food.

5.4 Answer to the main research questions

The answers on the sub questions feed the main research questions. Research question one; *What is the prevailing health perception of Tapologo professionals and the health experience of HIV positive patients at the HIV management programmes at four Tapologo clinics around Rustenburg, South Africa?* This question is answered within the summary of the sub questions one and two.

The prevailing health perception of the Tapologo professionals is based on their knowledge of HIV. Their knowledge basis is similar to the information given by for instance, the World Health Organization (WHO) about HIV. They will teach the patients about HIV as a disease, the ways of becoming infected, how to use the ARV's and patients are educated about how to life healthy. With this information the misconceptions concerning HIV, such as witchcraft or the use of traditional medicines are declining. A remarkable apperception is the progressive attitude towards condom use. The health perception of the professional nurses is partial based on the Catholic background of the



HIV management programmes. Nevertheless, the professional nurses *encourage* the patients to have sexual intercourse with a condom. Unfortunately the information of the professional nurse supplies can in itself be complicated for an uneducated patient that can result in obscurity when it comes to feel better or being cured. The health perception of the professional nurses is aimed to inform the patient about HIV and to assist the patient with the acceptance process and disclosing his or her status.

The health experience of a patient is in general quite good. Feeling healthy is important for HIV positive patients, although their interpretation of health differs from the WHO definition. The WHO states; health is a condition when a person is in a complete social, physical and mental wellbeing. For the interviewed HIV patients health is when a person is strong, happy, being able to do things for themselves, people who smile. All the patients said they are healthy, although they are HIV positive and encounter several complaints because of that ailment. Adjacent to this patients encounter stigma and poverty. Following the WHO definition these patient would not be healthy. Nevertheless, they do feel healthy according to their own standards.

Most patients have the appropriate knowledge about the disease, the right lifestyle and how to use the ARV's. Some of the patients use their information to warn and educate other people. Only a few patients belief HIV is caused by unproved causes such as witchcraft or the death of a loved one which needs the cleansing ritual. Using a condom is still an issue according to female and male patients. The people are aware of the importance of condom use and have the right information, some of them do not use condoms due to poverty. They are unable to buy the condoms. Shame for their HIV status is another reason for not using condoms.

The health experience of a patient is in general quite good and influenced by the health perception of a professional nurse. This perception is based on approved knowledge that is similar to the information given by the WHO about HIV.

Research question two is; *How is the health experience of the patients of the four Tapologo influenced by the health perception of representatives of the three sectors of health care?* This question can be answered by summarizing sub questions one and two. The representatives are family members, fellow patients, traditional healers and professional nurses. Each of these representatives influences the patients' health experience in a different manner. Family members care for their sick brother, sister, son or daughter and encouraging to take their medication. On the other hand, especially elderly family members, they try to convince the patient to use traditional medicine or tell myths about HIV like the cleansing ritual.

Fellow patients comfort each other and share their experiences with one another. Harmful influences also occur when patients tell stories about the side effects of ARV's or talk about and encourage visiting a traditional healer. Nowadays, traditional healers are being educated about HIV and they start being able to recognize the signs and symptoms of HIV and refer the patient to the clinic. However, there are still traditional healers claiming they are able to cure HIV.

According to the patients who veer to the professional nurses, they are the most important source of information. For instance, when talking about traditional medicine, almost al the patients would say they are not supposed to use them as they are thought by the professional nurses.



Obscurity appears when it comes to feeling better and cured. This is probably due to an educational gap, professional nurses might, accidentally, misinform the patient about becoming HIV negative. In sum, the representatives influence the patients in a positive and negative manner. This will be schematically represented in figure 2.

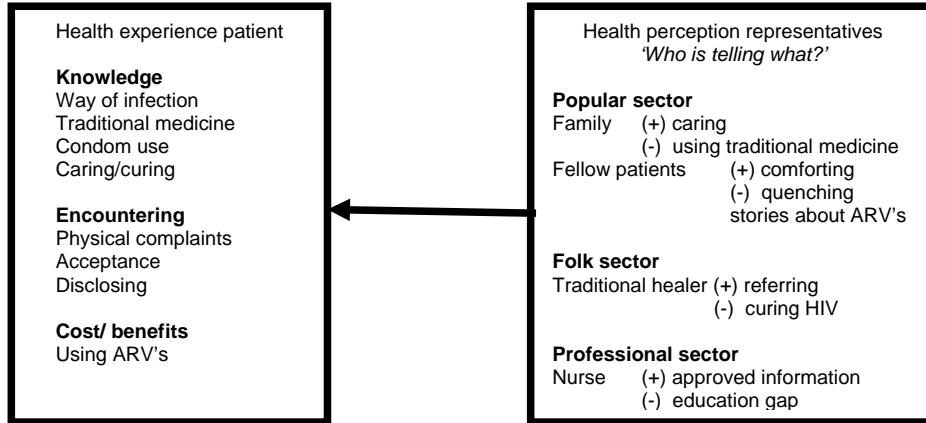


Figure 2: schematically influences on the health experience of a patient

Chapter 6 Conclusion

In the conclusive part of this thesis, the conclusions of my research in South Africa are represented. The results will be linked to the existing literature as described in chapter three and will be put in a broader South African context. In the final part of this chapter the limitations and several recommendations will be represented.

6.1 Results and theoretical framework

The most important question within this study is how the health perception, of the representatives of the three different sectors, influences the health experience of a patient. In the previous chapter the health experience of the patient was placed in the centre of interest. To answer the main research question, linked to the theoretical framework, the health perception of the representatives is classified in accordance with the three sectors of healthcare.

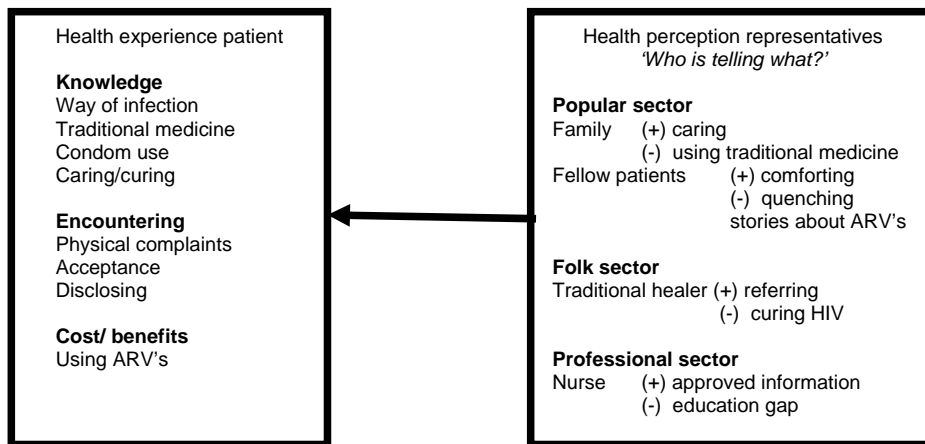


Figure 3: schematically influences on the health experience of a patient

6.1.1 Popular sector

The popular sector is a non-professional realm of society (Helman, 2000). The representatives of this sector are family members and fellow patients. Within the popular sector there are several forms of self-treatment and lay beliefs in the health perception of family members and fellow patients (Helman, 2000). The cleansing ritual that can be perceived as a lay belief (Liddell et al, 2005) is a disposition for both family members and fellow patients. Cleansing contains using traditional medicines after the death of a loved one. This is in compliance with the investigated situation in South Africa. This persuasion is part of the health perception of this sector and is mainly found amongst elderly family members. This health perception of family members shows similarities with the folk sector and is believably based on the folk sector (next paragraph).

According to the interviewed patients and professional nurses the cleansing ritual plays a part when it comes to HIV infection. For the participants of the female FGD (fellow patients) it is their conviction that when this ritual is relinquished this can result in a HIV infection. The influence of the health perception family members and the fellow patients according to the cleansing ritual is



influencing the health experience of the patients. Patients mention mainly (elderly) family members and fellow patients to explain the belief in the cleansing ritual. Because of the urge to use traditional medicines within this ritual this influencing health perception of family members and fellow patients can have negative influences on the patient's health experience. Fortunately this belief is decreasing and the knowledge about HIV infection via sexual intercourse and blood to blood contact is growing.

Another feature of this sector is the strong family bond in South Africa (Dilger, 2006). The main part of the provision of care takes place in this segment (Helman, 2000). The opinion of elderly family members is quite important and can therefore lay the foundation for a strong influencing health perception. According to Helman (2000) misconceptions between the patients and family members are relatively rare. In the investigated situation the opposite happens. Patients mention the importance of the health perception of an elderly family member. But when a patient is persuaded that this health perception will not prolong their life-expectancy, they will follow their own health experience. The use of traditional medicines which is part of the health perception of certain family members is an example of this when a patient rejects the use of this due to their own health experience.

Fellow patients share the same illness and can therefore create a powerful and positive support structure (Thoit, 1995). Interviewed patients share these common grounds and this supplies them with the ability to relate and sympathize with each other. The recognition of fellow patients and the ability to reciprocate feels comforting and positive for a patient. When a fellow patient will base his or her health perception on the use of traditional medicines or quenching stories about the ARV's this can result in negative influences on the patient's health experience.

6.1.2 Folk sector

The folk sector contains healers who are not part of the official healthcare structure (Helman, 2000). The representatives of this sector are traditional healers such as herbalists that use muthi's to treat illnesses. The statement of Helman (2000) that traditional healers are not part of the official healthcare structure is not completely the case in the South African context. According to Richter (2003) traditional healers can join an official organization, the Traditional Healer Organization (THO). Moreover, in the investigated situation, some traditional healers refer patients to the HIV management programmes due to the corporation between Impala mine and traditional healers. This implies their health perception is changing. Instead of convincing patients to use only their prescribed muthi's, the traditional healers comprehend HIV as an incurable disease that needs to be treated with ARV's.

Unfortunately not every traditional healer is changing his or her health perception when it comes to traditional medicines. The health perception these traditional healers is based on a holistic view that shows similarity in the African worldview. Traditional healers are strongly present in abundance around the investigated clinics. The belief in traditional healers is deeply embedded South African culture. This forms a strong basis for the traditional healers to advocate their health perception. They explain HIV³² based on ancestors (Ashfort, 2005) and witchcraft (van Dijk, 2001). This health perception of traditional healers to explain HIV as witchcraft (meso cosmos) does occur in the

³² HIV is in this situation not called as such. A patient was told he or she is being bewitched when in fact the patient is HIV positive and this status is causing the physical complaints.



investigated situation. The health perception of traditional healers to be able to cure HIV that is caused by witchcraft with muthi's and together with the African worldview, this has a strong influence on the patient' health experience. According to the interviewed patients and professionals there are people who quit their ARV treatment and eventually perish as the muthi's will not cure them. In a situation like this, the health perception of a traditional healer influences the health experience of a HIV positive patient in a negative way.

The belief in ancestors which is part of the health perception of traditional healers, as stated by Ashfort (2005), is declining according to the interviewed patients. The investigated patients are convinced HIV is not caused by ancestors and the younger generation is losing the commitment with the macro cosmos³³. The health perception of traditional healers is therefore not of strong influence on the patient' health experience.

6.1.3 Professional sector

The professional sector is an organized and legally sanctioned healing profession (Helman, 2000). Professional nurses are part of this sector and the representatives within this research. The South African Nursing Council (SANAC) registers the professional nurses and prescribes performance criteria. These criteria are a confidential, non-judgemental, emphatic, caring and protecting way of nursing (HIV) patients (www.sanac.co.za, 14th of May, 2009). The health perception of professional nurses is based on these criteria. The patients in the investigated situation in South Africa think the professional nurses assist them in a professional and emphatic way. Nevertheless, due to judgements of a professional nurse towards a HIV positive patient, the patients are not completely free to talk about genital problems³⁴. In these situations, the health perception of the professional nurse of judging patients with these problems is influencing the patient' health experience. A patient is as it happens not free to talk.

Feitsma et al (2007) mention a professional nurse can give a HIV positive patient advice. This advice is mostly based on scientific approved information that a professional nurse gathers during his or her training. Their health perception is based on this information and this perception influences the health experience of a patient. An example of this influence is the encouragement towards a patient to use ARV's instead of traditional medicines. Via the knowledgeable health perception a nurse influences the health experience of a patient that used to 'drink' traditional medicines for his or her (HIV related) physical discomfort.

The knowledge of a professional nurse can be too complicated for an uneducated patient which causes misconceptions. In this situation the health perception of a professional nurse that is based on scientific approved knowledge, can influence the health experience of a patient in a negative way, for instance when it comes to the undetectable viral load³⁵.

³³ The belief in God is strongly represented and at this point the commitment with the macro cosmos is still presence.

³⁴ These problems are mainly caused during sexual intercourse without a condom

³⁵ See paragraph 5.1.3; 'You do not wake up being HIV negative'



6.1.4 The influence of the health perception on the health experience

Traditional medicines are the preference of family members and traditional healers to treat a disease like HIV. According to professional nurses and fellow patients this is discouraged. The use of ARV treatment is encouraged by the professional nurses and fellow patients. On contrary, family members and traditional healers can advice against ARV's.

These are two examples of completely different health perceptions of the representatives of the healthcare sectors. A HIV positive patient is situated in the middle in this mix of health perceptions and his or her own health experience. These patients needs to navigate the different health perceptions and will eventually follow the health perception that suits best for his or her situation to prolong their life expectancy.

6.2 Conclusions in a wider context

In this study HIV positive patients are investigated in their own contextual and cultural living conditions. The contextual and cultural influences as described in the theoretical part of this thesis are, to a more or lesser extend, present in the investigated situation. The African worldview as discussed by van Dijk (2001) is crumbling, most questioned patients do not belief HIV can be caused by ancestors, so the meso cosmos does not seem to be of significant importance in regards to the HIV problems. However, HIV is still related to witchcraft according to some patients and therefore the African worldview, at least the meso cosmos does needs to be taken into consideration.

The former apartheid era is an underlying factor in causing poverty and this situation fuels the HIV epidemic. Poverty can undermine the strict intake regime for ARV's³⁶. This can jeopardize the effectiveness of the treatment and can lead to medication resistance. Poverty is also a factor when it comes to condom use. For a woman depended of a man' financial support, the condom discussion is a difficult task. A male partner might end the relationship because he does not want to use a condom and the woman is left with nothing.

The problems about condom use in relation to the Catholic background of the investigated HIV management programmes turns out better than expected since the Catholic reluctance towards condom use. The Catholic background of the clinics is subordinated upon the value of condom use which provides information for the patients to protect themselves and others. The Bishop who is interconnected with the HIV management programme has a progressive and problem facing approach on the protective character of condoms. Therefore patients are well informed about the use of condoms. Briefly worded, the specific South African contextual and cultural factors have a huge impact on the health experience of the people that are HIV positive.

6.3 Limitations

An outstanding point is, according to the patients, only other people do not follow the prescribed regime by the professional nurse. It is unlikely only well-behaved patients participated in this research. Patients were probably not completely free to talk and/or not convinced about the confidentiality of the interviews. For further research it would be better to reach a more trustful relationship with the patients that make them feel more comfortable to talk about themselves. Another plausible explanation can be

³⁶ ARV's cannot be taken without a proper meal



found in projection; patients talk about other people, but in fact they talk about themselves. This kind of projection can manifest itself when all the interviewed patients state they always use a condom, whereas there are many legitimate reasons for them not to use condoms.

The gathering of respondents was in a complete voluntary process. We need to consider that only the most self-confident patients participated in this study and are therefore not a representative group. Therefore the external validity of this research cannot be established indisputably.

The semi-structured character of this study gave patients the possibility to tell their individual stories. The disadvantage of this strategy is that certain topics that are more elaborately discussed with some patients than others. Still, the topics that were derived from the theoretical framework were discussed with all the patients. Out of the representatives in the theoretical framework, only the professional nurses of all the representatives were interviewed. By change, the perspective of the traditional healers came into the research population as two patients told me they used to work as traditional healers. The influence of family members, fellow patients and traditional healers was investigated through the interviews with the patients. For a better understanding and their side of the story it is recommendable to interview these participants themselves.

The decreasing belief in elements of the traditional South African culture such as witchcraft and the traditional healer is probably due to the increasing knowledge and information based on Western science. To determine the relevance and impact of Westernization on the decline of the South African culture, further research must be completed in the future.

6.4 Recommendations

This study concludes with advice for the investigated situation and recommendations for future research.

6.4.1 Recommendations for Tapologo

Advices for the investigated situation are mostly addressed towards the professional nurses. Despite their persuasion and affectionate way of caring some remarkable statements were made. One of the nurses would state a HIV positive patient can become negative when the viral load is undetectable. In theory this is correct, but practically implausible. Still, such a statement can cause obscurity for patients who really want to be negative. When their viral load is undetectable a patient might end his medication, thinking he or she is cured. It would be better for a nurse to say the viral load can be undetectable, but the HIV virus will never go away.

Another nurse would tell her patients she and her college's will make the patient better. A patient on ARV's will *feel* better, but will not *become* better as in cured. This causes obscurity for a patient and therefore it is important a nurse is be completely clear about the incurable nature of HIV. Some patients do think they can be cured or asked questions about curing during the interviews.

A few patients would state the nurses do not treat them equally at all time. This example is given by a patient who is too late for his appointment to collect the ARV box. Some patients are send away by the nurse without the ARV box while others are given the opportunity to still collect their box. A 36 year old male recommended a suggestion box so patients are able to tell anonymously what they think and what can be approved according to them. Patients would also state a nurse would react



grumpy but not on a structural basis. A reason for this behaviour of the professional nurses are the stressful circumstances under which they have to work. There is a structural shortage of man power. Adjacent to it the professional nurses have to deal fragile patients and the decease of many patients they cared for.

The distribution of condoms must be accomplished on a structural basis. Reasons as poverty and gender inequality make it difficult for patients, mostly females, to use a condom every time they have sexual intercourse. When condoms are free of charge distributed at the clinics patients would at least have the condoms. The problems related to gender inequality will not be solved by this intervention, but the effects of poverty on condom use would be dissolved.

6.4.2 Recommendations for future research

The explorative and qualitative character of this research on the contextual and cultural factors that might influences the health experience of patients can be used as background information for future research. For investigating in a more elaborated way how, for instance family members or a traditional healer, influence the patients' health experience, not only patient has to be interviewed, but also the other parties directly. This approach will lead to a more comprehensive insight in the influences on the health experience of a HIV positive patient.

Furthermore it is interesting to investigate to what extend the prevailing health experience leads towards medication (non) adherence. During this research other³⁷ patients stop their medication when feeling better. The influencing health perception of the popular and folk sector might cause this behaviour. On the other hand, the health perception of the professional sector encourages patients to continue their treatment. Future research is necessary to determine which factors influence the patient in acting on the messages from each healthcare sector.

As stated before, according to the interviewed patients, only other people show medication non-adherence. By investigating this population, their motives could become clear and the policy of the HIV management programmes can be adjusted.

³⁷ Only other, not interviewed people, would do this according to the interviewed patients.



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Appendix 1 Statistics Tapologo 2004 – 2009

Tapologo started ARV roll out in March 2004 (De Waal, 2008).

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 - LTFU | 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 - LTFU | 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 - LTFU | 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 - LTFU | 0 | 0 | 6 | 6 | 15 | 4 | 31 |
| Transfer out | 0 | 0 | 0 | 2 | 0 | 0 | 2 |