Making sense of HIV/AIDS in Cape Town, South Africa

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Abstract
The purpose of this thesis is to investigate how women in Cape Town reflect over and deal with HIV/AIDS in their everyday lives and also how they explain the cause and spread of the virus. The thesis is based on two months of fieldwork in Cape Town, South Africa, where I got the opportunity to interview three women about HIV/AIDS and how they related to the disease as well as how people in general relate to it. The women I interviewed were all working with HIV/AIDS as counsellors and educational staff. The women work in Nyanga, Observatory and Wynberg, three very different areas in Cape Town.

Keywords: Social Anthropology, HIV/AIDS, women, Cape Town, South Africa


Nyckelord: Socialantropologi, HIV/AIDS, kvinnor, Kapstaden, Sydafrika
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**Introduction**

When I wrote my application to SIDA I could not imagine even in my wildest dreams that I would travel to South Africa, the other side of the world, to write my final thesis. I didn’t think I was competent enough but when I arrived at the airport in Cape Town I realised I had to prove I was. Going alone to another country for two months may seem like a nightmare for an inexperienced person like me and from time to time it actually was. Pretty soon I understood that I had to change my preferences or go home in less than two weeks.

I spent my first week in a hostel called The Backpack. It was situated in a clean and nice area not far from the city centre. After the first week I moved to an area in Cape Town called Observatory. I took a taxi to the address where I was supposed to live for the next seven weeks and as the driver turned from the highway I was stunned, absolutely shocked. I thought he was kidding me since the view that met us was nothing like the pictures I had seen on the Internet. Through small narrow streets he drove me to the old factory building that was supposed to be my home. My landlord met me outside and showed me the room. The stench in the apartment was a mixture of mould and cigarette smoke. I suppose I got used to it because after a while the only thing that bothered me was the dripping ceiling and the big mould stains in my room. This sounds far worse than it actually was. I lived together with ten other people from five different countries. We all had our own reasons to be in Cape Town and in spite of all our different experiences, goals and cultures we got along well and I made friends for life. I had a wonderful time and the bad things mentioned above are just a note in the margin.

Before I went to Cape Town there were many things I worried for but strangely not travelling on my own as woman. I did not expect to be treated any differently in South Africa than I was used to be treated in Sweden, but of course the social life is different in South Africa and consequently the behaviour in social areas is. In Cape Town walking on your own as a woman it won’t take long time until someone is speaking to you, flirting with you, asking you questions and so on. In the beginning I thought the attention was pretty nice but after a while I got tired of not being able to go outside my apartment and just be on my own.

Just as the apartment I lived in, Cape Town is a diverse city with many cultures living side by side, but it has not always been like that. The remains of apartheid are still visible today. In Cape Town there are eight million people living and the differences in economy, gender, class and skin-colour are clearly visible. There are some “white areas” and a lot of “black areas” and the difference between them is depressing to see. The city spreads
from homeless people via townships to fancy nightclubs and shopping malls for the tourists. The situation that some of the people I met lived in just made me so sad I wanted to cry.

Even though living in Cape Town was hard from time to time I have to admit it also was the most amazing experience I have had in my life so far. This journey has made me grow not only as an anthropologist but also as a person. Initially I thought that the education ratio was lower than it is, that people in townships had much less information than people living in the city and that HIV was not very noted in society at all. My expectations were all wrong and I soon realised that the root to the HIV problem was something else than poor education and silence.

**Purpose**

In South Africa the government and NGOs have recently made an enormous effort to inform the public about HIV/AIDS. There are numerous campaigns and workshops throughout South Africa, working to enlighten people to prevent further spread of the disease. Still, the number of people catching the disease is steadily growing in South Africa, and hundreds of thousands of people in South Africa have to live with HIV/AIDS on a daily basis. One crucial question is what knowledge people in South Africa have about the disease and how it is spread. My purpose with this essay is to see how women in Cape Town reflect over and deal with HIV/AIDS in their everyday lives. I also want to investigate how they explain the cause and spread of the virus. To get an understanding of this I used semi-structured interview questions, designed to address those issues. (The questions are attached in appendix 1)

**Disposition**

This thesis is divided into five parts. The first part is *Introduction* where I give the reader a picture of my experiences in Cape Town and a historical description of HIV/AIDS in general and of HIV/AIDS in South Africa in particular. I explain what challenges I see with the subject and also what my purpose with the thesis is and what issues I will try to answer. *Methods and methodological criticism* is the second part where I critically discuss my methods with all strengths and weaknesses I find in them. I will also mention what it is like to use an interpreter, introduce my informants and discuss the ethical dilemmas this kind of research bring. In *Previous research and theoretical framework*, the third part of the thesis, I will present the theories and articles that I find relevant for this subject. Besides the
anthropological theories I will use theories from other disciplines because I think they will contribute to the thesis and complement the anthropological perspective in a good way. In the fifth part Empirical results the interviews will be presented as they happened and the informants will tell their stories. The sixth part in the thesis is the Summary where I will go through my results to answer my purpose. The seventh part, Analysis, is where I am going to bring the theory and empirical results together, talk about the outcome of the thesis and analyse the results.
Methods and methodological criticism

Before I could carry out my fieldwork I had to decide how I wanted to work during the time in field. I had to choose my informants as well as my methods. I can not say I consciously chose my informants; luckily they were there when I needed them most. When choosing my methods I had to find a way to make it easy to collect the data in two months without losing significant information doing so. With that in mind I selected not one but three methods; semi structured interviews, literature studies and observation. Using these methods I think my result is relevant in spite of the short time spent in field and the few informants. In the three following paragraphs I will explain the methods I used and what advantages and disadvantages I think they have.

Interviews

Collecting data via an interview does take a lot of the researcher’s time in consideration but I still think that interviews are the best method to use in this sort of study. There are many forms of interviews a researcher can use to gather the information; structured, semi structured and open interviews. More than that, the interview can be held in many different ways. The researcher can sit down with the informant to do a single interview, do a group interview with many informants at a time or do the interview via telephone, Internet or text messages. These are not to be seen as separate forms which mean that they of course can be used together as a complement to each other.

There are many things the interviewer has to keep in mind before during and after the interview. The examples I will discuss here are based on a semi structured interview (see appendix 1). Before the interview there are questions to be written. These questions have to be formulated in a way so that the informant is not lead to answer in a specific way. Of course one can not be completely certain that the informant do not interpret the questions in a way I did not think of when I wrote them. I also have to consider the fact that the subject I was studying is difficult to talk about and write my questions so that they did not offend my interviewee. During the interview the interviewer has to have an open mind and be prepared to follow the informant to discover things that the researcher had not been thinking of before the interview. As a researcher you also have to be able to see the loose ends that the informant leaves in an answer. These loose ends do not always lead to an interesting discussion but often they do. When the interview is over you as a researcher have the hardest work left. You have to be able to analyse your material as objectively as possible, and try to see the informants’
answers in their own light, from their point of view and on their conditions. The interview as a method is a very complex tool to use.

The reason to why I chose to use the semi structured interview instead of any other method is because I wanted to listen to the informants’ stories and only using my questions as guidelines for a discussion. Another reason to why I chose the semi structured interview is the risks of using the structured or open interview. In a structured interview both I and the informant are locked to my questions and if the informant brings something up that is interesting I would miss it because the question to her answer is not written down in my protocol. Another risk in using the structured interview is to only get the answers I came for and miss the things that are important to my informant. The reason why I will not use open interviews is because they often tend to be very complex and not seldom becomes impossible or very heavy to analyse and compare with other material and interviews (Jacobsen 2002, p. 163).

**Literature studies**

As a researcher I can get much information from literature studies in a little amount of time. I chose to use literature studies because I wanted to have knowledge about South Africa before I went there. Not just about HIV/AIDS but about the people, language, culture, customs and traditions to understand the country I was going to live in for two months. I see two distinct problems with literature studies; credibility and the constant flow of new information we have today. What I mean with the problem of credibility is that just because something is written in a book or on a website it does not necessarily mean it is true. As a researcher I have to be critical to every text I read. Everyone that writes something does it with a purpose so you have to keep in mind that not every text is objective. Not even all academic texts are objective even thought they are supposed to be. The other problem that I mentioned was the constant flow of new information. These two problems connect to each other. Since we live in the age of Internet the updates of information happens faster now then in the sixties. What was fact yesterday might not be a fact today. I have been aware of that when I have studied my literature and used theories.
Observation

Observation is yet another way of gathering data that takes a lot of the researcher’s time in consideration. This is the method I have spent most time on, which is natural when you live in your field for two months, but I did not reflect actively over this. All the things I saw and all the things I did in Cape Town was my unconscious observation. I realised that I had observed all that time just some weeks before I went home to Sweden again, but my observations had formed a background, against which my perception of HIV/AIDS in South Africa must be understood.

There are different ways in how you can observe your field. The researcher can do an observation by just looking at the people or phenomenon he or she has come to collect the data about. That sort of observation can happen with or without the people’s knowledge. Another form of observation the researcher can apply is the participant observation. When using that type of observation, the researcher takes part in the thing he or she came to research. A problem in taking part in the observed group is that you can not avoid affecting the group in one way or another. Even if you behave the way the members of the group do, the dynamic of the group has been changed as soon as you enter it. The problem of studying a group from a distance is that you want them to behave as they would if you were not there. The only way of achieving that is to not tell them that you observe them. However if you decide not to tell them there is an ethical problem. Many people within the academic world would say that you should always tell the people concerned in the research that they are part in a study. I would say that I have used a mixture of the two types of observation. I personally do not think that there are any clear pros or cons for observation as a method; the only problem is that it takes a lot of time and the researcher can not stop and ask questions along the way. (C.f. Agar 1996)

During my two months in Cape Town I carried out loads of observation without knowing it. I realised that I had done so when I started to write my thesis. When I walked around, took the train or a minibus in Cape Town I observed a lot of things that I interpreted as a big change in the society. At all train stations there were huge billboards with commercial for help lines that anyone could call if they wanted to ask or talk about issues concerning sex. I could also see a lot of posters for different abortion clinics and in every street corner it was a health centre with the red ribbon. All the free condoms laying at the train stations, how one can talk about sex, how women dress and how men dress, the differences between youths and older people when it comes to clothing, customs, what they talk about and so on. It was not only in Cape Town I made observations but also in the very apartment I lived in. When I put
on the television it was not uncommon to see all these half hour commercials for life insurances for people living with HIV and also commercials for HIV positive people that wanted to take a loan but could not because of their health status. All of this I somehow registered when I was in South Africa and I would say that my observations of life in Cape Town helped me understand my informants and process my material.

**Using an interpreter**

Many anthropologists stress the importance of speaking the language of the place of your fieldwork fluently. In South Africa that is a difficult task to do since there are approximately thirty languages spoken in the country. I made a pathetic effort to learn Afrikaans as it is the language spoken by five million South Africans and is wide spread in the Western Cape Province (URL 1), but pretty soon I realised that it was not going to help me. The people in the township were not speaking Afrikaans – they were speaking Xhosa, and instead of learning a new language once again I had to use an interpreter. I only used an interpreter once during my interviews, even though when looking back I could have needed an interpreter twice. Using an interpreter is not easy especially since English was not mine or her first language, but luckily this time it did not end up as the whispering game I played as a kid.

The first problem I came across was that I felt out of control and left outside of the conversation from time to time. Not speaking the language is hard, not just because you can not explain what you mean in a correct way – something that I experienced for my self and for the interviewee. The second problem I encountered was that the interpreter who worked at a health centre “interrupted” my interview with the woman. At the beginning I was irritated because I thought the interpreter disrupted my interview and did not let the woman speak for herself. I did not know how to handle the “problem” – so I didn’t. In the end I was happy about it for the reason that they started a discussion that I would not have been able to create just by doing my interview. Instead of getting one informant I got two – or more correctly one and a half. The time when I felt I should have used an interpreter ended up as a “wasted” interview. The communication problems became so great that we could not cope with them. When I asked questions about common ideas of wherefrom HIV origin and how it spreads but she did not understand what I meant by this so I tried to explain but I did not come through. I feel sad that I can not use that interview since I do not know what or how much she understood of what I said. Some of the things I will use, but only the things that I am certain of, when I felt the communication between us was clear.
Interviewees
When I arrived in Cape Town I had no informant and I discovered it would take a while before I found my first one. The plan I had when I applied for the Minor Field Study scholarship was to interview eight people with a spread in gender, age, skin colour, class and social status. I also wanted to have equal many informants working with HIV/AIDS as informants infected by it. My plan did not work out as I thought and I can not say I chose who to interview. A problem I encountered when looking for interviewees was that all the health centres I contacted to see if they were willing to let me interview someone from their staff wanted economic compensation for their help. I did not have the sufficient funds to pay for my interviews therefore I had to settle with those who could help me without compensation. Since it took a while for me to find people to interview I took the informants I got without being able to consider the above mentioned criterions. It turned out to be a very homogenous group with similar experiences from life, which also will alter the thesis and analysis. My four informants were all black middle-aged women. Two of them were working with HIV/AIDS at two different health centres and the other two were infected by HIV and one of them were also working as much as she could at a health centre. The reader will get more acquainted with my informants where I present my empirical results.

Ethics
For me it has been important to explain to all my informants what the study is about and what my goals with the interviews were. I gave my informants all the details concerning the interview, how I will handle the material, that they could be anonymous if they wished to and of course I asked them if they thought it was a problem that I recorded and took notes during the interview. It is vital for me that my research has not affected my informants in a negative way. I have done everything in my power to ensure that my “[...] research does not harm the safety, dignity, or privacy of the people” (URL 2) I have interviewed. I have not only a responsibility towards my informants; I also have a responsibility towards the scholarship, the discipline and the science at large.
Previous research and theoretical framework

Background
HIV has been known to the world for almost thirty years and was first discovered among homosexual men in Los Angeles and New York. At that time the doctors and scientists did not know what the disease was but they did notice that the men had a lack of the CD4 cell that is a very important cell to get the immune system to work properly. In 1983 – two years after the discovery – researchers in the United States and in France described the virus that caused AIDS. (URL 3) Many years have gone by since we first discovered HIV and unfortunately it continues to be a major problem in most states, including Sweden. Although HIV/AIDS is a problem for everyone infected by the virus, the possibilities of controlling through medication and a healthy living differ greatly between rich and poor people.

South Africa has had a turbulent past, not only during the last 80 years (URL 4) of apartheid, but a continuous oppression of the native South African people has been maintained for centuries. Today South Africa is a free country with a democracy governed by the African National Congress (ANC) and so it has been since the apartheid system was abolished in 1994. Even. One of the major issues ANC has to deal with is the health problem in South Africa where 20 percent of the entire population, or 43 million people, are living with HIV/AIDS (Hague & Harrop 2004:213). That means that 1/10 of all the people in the world infected by HIV/AIDS are now living in South Africa. (URL 5)

There are of course not only health problems in South Africa. Though the economy is on its way up, South Africa has big problems with poverty and a lack of education in many groups of the society. There is also a high level of unemployment in the country. 31 percent of the black population is unemployed - only 5 percent of the white population. The youth unemployment is extremely high, with 70 percent of the black and colored youths between 16 and 24 are unemployed. The total amount of unemployed were in 2006 39 percent. (URL 6)

The bad possibilities for education, the persistent poverty and a high level of unemployment are contributory factors to the HIV/AIDS problem in South Africa and the numbers of people infected keep rising day by day.

In contrast to Sweden, South Africa has not been able to deal openly and publicly with the HIV/AIDS problem until just a few years ago. This is a problem related to government policies. The president Thabo Mbeki had for a long time denied the relation between HIV and AIDS and he also supported the statement saying that antiretroviral drugs are life-threatening. This has delayed the constructive discussion concerning HIV/AIDS
necessary to raise the awareness among the South African people, and has probably contributed to the large number of infected people in South Africa today.

**Diagnosis and treatment**

There are two types of HIV (HIV-1 and HIV-2) which both can lead to AIDS. HIV has its origin in Africa and scientists have shown that both of these types of the virus have been transmitted from monkeys to humans. The monkeys’ immune deficiency virus (SIV) has mutated and that mutation has made it possible for the virus to spread from monkeys to humans. Among humans the virus spreads via bodily fluids such as seamen, secretion, breast milk, saliva and blood.

When it is established that a person is HIV positive the doctor can keep track of how serious the infection is by counting the CD4 cells on a regular basis. The CD4 cells are not cells themselves, they are T cells (helper cells) with a molecule called CD4 attached to them. This molecule helps the T cells respond to micro organisms such as viruses in the body. To measure the CD4 cells the physician takes blood and counts the cells per cubic millimetre. The CD4 cells in a healthy HIV negative adult should be between 600 and 1200 per cubic millimetre of blood. It is only 2 percent of the body’s CD4 cells that actually is in the blood (the rest is in lymph nodes and tissues). When a person is HIV positive the number of CD4 cells decrease. When you test for HIV the nurse does not look for the virus itself but for the antibodies that the immune system produces when you get infected by HIV. The HIV is active in your body from the moment you get infected but the antibodies are not visible until three months after the infection. In some rare cases it can take up till six months before you can detect the antibodies. It is recommended that you get tested three months after the suspected infection. During this period of time the person is also most infectious. (URL 7)

When a person is handling syringes (that is known to be used in an environment where HIV/AIDS exists) for a medical or another reason and they accidentally get pricked by a needle that has been used will start with post exposure prophylaxis (PEP) to decrease the risk of getting HIV.

Besides the antiretroviral therapy (ART) there are many ways that a person tested HIV positive can control his or her CD4 levels and thereby live a healthier life. According to the information at the UNAIDS home page first of all it is important for a person infected by HIV to follow the doctor’s instructions and keep the appointments, secondly it is wise to prevent other infections by getting immunisations, thirdly a HIV positive person should eat
healthily and stay away from water that may be polluted, fourth it is important to stay in a
good shape and exercise and last but not least getting enough sleep and rest. All of these
things may seem poor in comparison to taking antiretroviral drugs (ARV) but in fact a healthy
living strengthens your immune system and that makes the patient more able to fight off the
diseases he or she catches. (URL 8)

**HIV/AIDS and the government**
The government in South Africa has been infamous for its denial of the connection between
HIV and AIDS during a long period of time. The government has now changed its view and
accepted the world known fact, but the way to that understanding has been far too long. Along
the way many South Africans have died a premature death, and according to researchers at
Harvard it is as many as 365,000 people in just five years (2000 – 2005) that have died
because of the lack of antiretroviral drugs. What also contributed to this was the former health
minister of South Africa, Manto Tshabalala-Msimang that suggested that persons infected by
HIV could use garlic, beetroots and lemon juice as prevention to develop AIDS. (URL 9)

It is pretty clear that the South African government has had some unorthodox
solutions to the HIV problem that unfortunately is reflected in how people think and react
towards HIV/AIDS. Luckily in the last years the people of South Africa have seen
improvement and even though the progress is slow the attitude and work with HIV/AIDS
issues is moving forward. Examples of what the government has done for the people of South
Africa is donating money to organisations working with education and counselling and they
have also provided to free condoms in various public places so that people do not have to go
to the store to buy them.

**The political framework of IGOs and NGOs**
There has been a lot of clinical research on the virus itself during these thirty years. I think
that type of research is very important when it comes to tell how the virus is mutating, how it
spreads and most importantly that research is the foundation to how we hopefully in the future
can find a cure to this disease. In the meantime we have to find other ways to decrease the
spread. This is where the vital work of NGOs and IGOs comes in. Most of what we know of
HIV/AIDS that is not related to clinical studies comes from these organisations. They are very
important when it comes to observe the social and demographic aspect of the virus such as
gender issues, how many people it is that are infected, how fast the spread of the virus occurs over the world and so forth. When one thinks of NGOs it is often that the big organisations like Medécins Sans Frontières (MSF) or the Red Cross is mentioned and not the more local and regional organisations that also provide help in the work against HIV/AIDS.

**HIV/AIDS in a gender perspective**

HIV is a disease with many aspects and I think gender is one of the most important. The discourse when one is talking about HIV/AIDS is almost always about heterosexual intercourse because heterosexual women are at greater risk to get infected than heterosexual men and homosexual women. The reason for this is thought to be that a woman during sexual intercourse has much more mucous membrane uncovered than a man and thus is exposed to a greater quantity of contaminated fluids. A woman is clearly more exposed than a man when you look at heterosexual relations but when it comes to homosexual relations the picture is quite different. First of all the intercourse does not look the same in heterosexual as in homosexual relations. Anal penetration is more common in male-male sex (MSM) than in male-female sex. When practicing anal sex the lining of the rectum can easily tear and thus the infection will spread more easily. There is one group at particular risk when one look at the spread of HIV via intercourse. This group is sex workers and here gender is not the big issue but rather the frequency, multiple partners, unwillingness to use condom and poor health care in many situations. (URL 10)

It is important not to forget that sexual transmission is not the only way for the virus to spread and that it is not just the sexual relationship that should be put under the magnifying glass when it comes to gender issues. A common outcome of unprotected sex is childbirth, and with childbirth comes breastfeeding. Because of the stigma of not breastfeeding your child many women do breastfeed, in spite of the increased risk of transmitting HIV to your child. This phenomenon is more commonly known as MCT (mother to child transmission). Another aspect of transmission is the needle sharing among drug users. Outside sub-Saharan Africa nearly 30 percent of the HIV-infections are caused by infected needles (URL 11). Since HIV spreads through needles as well as sexual intercourse, drug abusing sex workers are therefore at double risk.

There are many myths that surround this disease, including claims from traditional doctors to be able to cure the disease through magic and/or traditional medicines (Wickström, 2007) such as herbs to cure someone sick from HIV. Yet another persistent belief is the one
where an HIV infected man can get cured by having sex with a virgin (baby) girl. This belief also connects to the important gender dimensions of the disease.

**Balance of power and risk behaviour**

Power and power relations as vital factors for our understanding of different societies is something that is noted and debated in many, if not all, disciplines. Michel Foucault has written about power in his book *History of sexuality* and he explains power as relations of strength that exists within, and organises, the area where they occur. They change or get reinforced through continuous confrontations and battles between groups and interests in the society. These power relations are visible in the institutions that society is made up of. (Foucault, 2002) Foucault writes that the power is everywhere and nowhere at the same time – all the time. This is not in line with the traditional power theories that say that power goes from the top down.

As I said in the chapter HIV/AIDS and the government, the leaders of South Africa has long denied the connection between HIV. The case of South Africa is very special just because of the things I mentioned above. The people in South Africa have strong faith in the government because of the unusual bond between people and ANC. This bond can be traced back to at least the liberation from the apartheid system and when a strong and charismatic leader, as Thabo Mbeki was, supports the health minister of course the people of South Africa believe in what they say. The power Thabo Mbeki had was not just a political power in the form of a formal political leader but also a social power as a man of the people. He represented a strong man in the black culture and was seen as an equal by the people. This power relationship was not questioned by anyone strong enough to change anything and as time went by this made his position stronger than it was in the beginning. The government’s power and its influence on the people is one aspect, but there is power struggles that are gender related as well. These struggles are worst on women since it is women that tend to be the most vulnerable and subordinate party no matter what constellation the power relationship has. As I explained in the chapter HIV/AIDS in a gender perspective, it is women in general that are more easily infected. Women are subordinated in the relationship between a husband and a wife because the wife depends on her husband economically and this means that he can do pretty much as he wants without risking to lose her. Women with HIV are also inferior to women that are healthy. They have to cover the fact that they are ill from HIV even if this means that they have to breast feed their child and put them at risk of catching the virus as
well. Many women are also afraid of telling their families about their health status because of the fear of being disowned and being seen as promiscuous. The male and female ideals that exist increase the risk of exposure and spread of the disease and since the culture is such a strong player in the game of power we do not question those very ideals even if it will mean that we put our and others health and wellbeing aside. This may seem as a traditional top-bottom power relationship, but power is generated, reinforced and recreated within these social/cultural power relationships. This means that the players in the power game constantly check themselves and the other players against the set of rules they have been dealt. Since it is so important not to break the (cultural) rules no one has time to question them.

What is described above is often recognised as risk behaviours and can not easily be understood by people not living within a culture with the described premises. There are however a difference between risk and danger. The former is something that can be calculated and consequently the risk can be avoided if precaution is taken. The latter is more of an uncontrollable nature and can therefore not be avoided. As a result of the different natures of risk and danger the reactions from society differ whether you are considered to have taken a risk and thereby get blamed for irresponsible behaviour or just suffered from bad luck. (Hellmark Lindgren 2006:27-29)

**Striving for cleanliness**

In any culture or society in this world people are very keen to organise and categorise everything around them from things large as our continents down to the smallest microorganism. We do this to keep temporary order in our system that is constantly changing. Things that can not be categorised or repeatedly fall out of the box we put them in are considered dangerous or as a taboo. The facts we regard as uncomfortable we rather ignore or garble than face them. (Douglas 2004:55-57) These written or unwritten rules can be found in every society, but what is considered “right” and “wrong” and what is “clean” and “unclean” differs between societies. Despite the fact that classification of things is a social construction, people tend to perceive it as natural, and we find it difficult to grasp that not every culture perceive similar things differently. As a consequence of this, what is easy to talk about and classify in one context may be hard and uncomfortable to talk about in another.

We can find rules and laws on what is clean and what is unclean in all the major religions. Despite many differences, most religions have one thing in common: believing that body fluids are unclean and potentially contaminating. This perception of body fluids, and
especially body fluids outside of the body, as dirty and possibly dangerous, taps into the discourse around HIV/AIDS, and contributes to the powerful and negative images of the disease itself, how it is spread, and in what way people infected with the disease are perceived by others.
Empirical result

Interview in Observatory
After approximately one month I was able to meet with my first interviewee. I had told a flatmate of mine about my problem with finding people to interview for my thesis so she spoke with a woman at her work (she was doing an internship at a health centre) and came home one day and gave me the business card of a woman named Nomveliso. After I contacted Nomveliso I met with her three times. The first time she wanted to meet with me to do a “test-interview” so we could get to know each other and so that I could present the thesis and my purpose. I was so stressed up before the interview I probably smoked a pack of cigarettes in the five minutes walk from the apartment to her work. In comparison with my earlier interviews I have had this was a dream. This woman knew what she wanted and she was not afraid of showing it. We spoke for one hour and a half and I felt like I had material to write a whole book. The next interview I had with her, which according to her was supposed to be the real one, I used to double check the first one and to dig deeper in all the rich points that I found when I went through the first interview I had with Nomveliso. This time I was equally stressed if not worse in comparison to the first time so I told her that I was nervous and she asked me if it was because we don’t have that many black people my your country. I got sad, not because that she had offended me in any way but because she assumes that white people do not speak to or are not friends with black people. She told me to calm down and when I did we started the interview.

Nomveliso is a woman with a strong opinion and a big heart. She cares for those less fortunate and she told me that her family gets upset with her since a lot of her salary goes to air time, so she can talk to her friends and clients, and they also get upset with her since she herself is ill and they think that she should rest and not work so much, but as she said – change must come from somebody. When I asked her why she thought the spread of HIV/AIDS is so fast and out of control Nomveliso said that society’s social problems is the core of the HIV problem. Things that she mentioned was ability to read among the people, the access to proper health care, poverty (which leads to many other problems such as alcoholism, violence, sexual abuse and so on), unemployment and poor education. And the most important factor is that people are not accepting reality for what it is. She said that when an individual can not admit for herself that she is ill and needs treatment, how is she able to tell her family and friends? Nomveliso also said that the church in rural areas does not have enough knowledge and the knowledge that exists (old and new side by side) is sometimes
contradicting itself. She mentioned one example that is strongly related to the spread of HIV.

In rural areas people have learnt that one should not have plastics in the bedroom since it can suffocate small children that are left unattended. Condoms are made out of plastic and should therefore not be kept in the bedroom, what is worse – given that plastics can suffocate children – what will happen to the penis if you wrap a condom made of plastics around it? It probably will suffocate and no longer be useful.

A reason to the spread that I mentioned earlier in the text is poverty and unemployment and here Nomveliso could see the difference in colour of the skin. Getting good treatment is not always easy and the difference here is that white people go to private clinics to get the best help possible while the black people (in the townships) can not afford anything else but the help that is given to them. Another thing that is due to the poverty are the horrible choices Nomveliso told me that people had to make every day. She told me about the grant that people infected by HIV get (that is based on a CD4 count). When a person is sick and very poor (and in many cases has a family or children to support as well) and is given money as long as the person remains sick – that individual will stay sick so he or she does not have to suffer from the famine. Nomveliso told me there are several ways to keep the CD4 levels down. She brought up having sex with another HIV positive person, drinking alcohol, smoking, using drugs, not getting enough rest and lack of (healthy) food. The problem that she recognises with this is that no matter how you try to solve this without solving the poverty first it is going to end up in a negative spiral. When people get infected by HIV, they get depressed and ways to handle the depression is for many to drink alcohol and an outcome from drinking much alcohol is to do irresponsible things such as having unprotected sex. When a woman has had unprotected sex or sex at all with someone that is not in a relationship with her she is considered to be promiscuous and therefore she would not be willing to talk about it or seek help to prevent the HIV from developing into AIDS. Another thing connected to sex is the body and Nomveliso told me that the body is something that is a great taboo within the black cultures in South Africa.

Nomveliso and I also talked a bit about the myths and misunderstandings that surrounds HIV and does it even harder to talk about. She told me that a lot of people in South Africa in particular and the African continent in general argue that HIV is invented by the white man as a means to destroy sex. She said that AIDS when it comes to this idea is short for American Influence of Destroying Sex. Besides blaming the white man for the virus itself, there are still many that believe that witchcraft plays a strong role in the spread. Nomveliso said to me that she thinks that education is the most important factor when we try to solve the
problem. When I interviewed her in the spring of 2008 she was working with at least two different workshops. One of them was for HIV positive people without jobs, a course for them to be self employed so they can live a healthy life and another one focusing on men with HIV since there are few men in workshops and also she said that they generally have a harder time to admit for themselves and others that they are HIV positive.

**Interview in Nyanga**

The interview took place in the township Nyanga. I met up with the health worker that I had been in contact with and we drove to a woman’s home/children’s day care centre. The day care centre was in a bungalow without any furniture – there were just a big box with toys inside and on the sand covered yard there were some partially covered tires. We went behind the day care centre to a shed (what I believe was her home) to do the interview. The shed had two rooms as far as I could see – it might have had more. In the room where we sat down there were a couch, two armchairs, one chair, a shelf with a TV, some books and what to me looked as a board game. The room was dark even though it was mid-day and the sun was shining. The woman from the health centre that I had been in contact with was sitting in on the meeting first as an interpreter (the woman I interviewed happened to be Xhosa) but after a while also as an informant. In the beginning I felt like she was interrupting my interview but soon I realized that she was an asset to my work and that she had a lot of knowledge and experience. The interview begun.

Zoleka, the woman I went to Nyanga to interview, is 42 years old, single and a mother of two. She discovered that she was infected by HIV in 1993 when she went to the doctor to treat her tuberculosis. The doctor found out that it was not just tuberculosis but also syphilis and HIV. When the doctor told her that she had HIV she thought she would die and not live till this day. Zoleka did not take any ARVs until the year 2000, which means she went without medicines and counselling for seven years. During this period of time she got rejected from her family, friends and neighbours and sadly enough this is not unusual. Zoleka told me that she does not know why they reacted in that way but she thinks it is because they did not know enough and were afraid to get infected.

Zoleka’s youngest child is also HIV positive and she said to me that her neighbours did not allow their children to play with her youngest because Zoleka was HIV positive something that they did say to her child. Zoleka felt like she had to deny it because the stigma concerning HIV is so big. She told me that when she begun to take the ARVs her family took
her back and also did her friends and neighbours. Now that she works as a counsellor for HIV positive people she told me that all the people that rejected her before nowadays go to see her for advice.

Zoleka thinks that the spread of HIV is caused by the poverty, myths and misunderstandings and stigma and she also told me about the funding of R880 (687 SEK) per month that HIV positive people get from the state to be able to buy healthy food and thereby get better. However because many people in South Africa with HIV are poor, the quickly become dependent on the funding that they get when they take ARVs. Therefore, many poor HIV positive people try to keep down their CD4 levels by not taking their ARVs from time to time, engaging in unprotected sex with another HIV positive person and drinking a lot of alcohol that is known to weaken the immune system. For the poorest people this funding is the only source of income they have and that means that they will choose to destroy their bodies instead of going hungry.

Another reason to the spread that is connected to the stigma is the breastfeeding. Zoleka told me that the mothers do not listen to what the doctors say to them and continue to give their children breast milk just because the stigma is too great not to do it. She told me that if a mother is not breastfeeding her child her family and friends will think she is sick – something that she absolutely does not want anyone to know because then they will reject her.

An idea of how one can heal oneself from HIV that Zoleka mentions is the one where a man who rapes virgins is to be cured from the disease. She told me that this still is common even though there is so much information about HIV. Summing up, Zoleka says that it is rapes and breastfeeding that cause the wide spreading of HIV/AIDS but she adds the unprotected intercourse without telling the partner about the own health status as the greatest cause for the spread. She also said that it is not unusual that women get drugged at a nightclub and then get raped.

According to Zoleka her picture of the disease has changed from not having any information about HIV and thinking she was as good as dead to working with HIV positive and being a counsellor. She said that all people nowadays have access to information about the disease – even those who are illiterate. Even though she said that everyone who wants information can get it, she and her organisation do not think that it is enough so they arrange campaigns two till three times per year. They do this because the teachers who are leading the sexual education have difficulties talking about sex and they think that makes the education inadequate. The organisation that Zoleka works for is organising workshops for youths but since not everybody is showing up there the woman from the health organisation wants to
organise information meetings at the schools in the township where she thinks it should be mandatory to attend. She thinks it is important to give enough information to the youths so that they can make wise decisions because it is among youths that the greatest spread of HIV occurs.

The two women told me that within the black tribes in Africa there is a common taboo to talk about sex, the body and menstruation for example and this makes it hard to tell people that you are HIV positive and even talk about the disease. They also told me about so called circumcision schools where they send their young sons to get circumcised. This is not a school in a regular meaning but more of a rite de passage where the older men teach the young boys things that only men know. When they come home from there they are not children anymore – they are grownups. The big issue that this circumcision brings along is the unhygienic procedures that help the spread of HIV. Many circumcisers use the same instrument to circumcise the boys and often they do not clean them in between. Zoleka said that she choose to send her son to Durban to get circumcised because she thought that school was more secure.

Furthermore Zoleka said that she thinks that HIV positive people that do not want to talk about the disease many times are very selfish. She said that they have unprotected sex without telling their partner about their health status, they use the same needles as their friends because they want them to share their health status, they are unfaithful and so on. Now that Zoleka is HIV positive herself she feels it is easier to reach to other infected people since she has gone through everything they have gone through.

When I ask Zoleka and the health worker about their feelings toward the government and their actions towards HIV they said that they are happy about the governments input in the struggle against HIV. They are happy about the financial support to the organisations, the free condoms, free ARVs and funding to those who are ill. The only thing they are waiting for is “The Cure”. They have a little different view on the future though – Zoleka can not really see that HIV will decrease while the woman from the organisation hopes and thinks it will.

**Interview in Wynberg**

The last interview I did was very emotional for me. I knew that I had to leave Cape Town and all the people I love in just a couple of hours. I had the luck to be able to arrange the interview the day I left. Before the interview (it was quite late) I sat down with the secretary, drank a cup of rooibos and felt my tears running down my cheeks. I then met with the loveliest
woman, Ana. She was 32 years old, born and raised in Cape Town and she absolutely loved her job. Her whole being was sparkling and full of joy. She comes from a family of 11 with an aggressive father and a dependent mother and Ana was not withholding that she disliked men. She mentioned the example of her mother and father and also one of her sisters with her husband and she said to me that she did not want to find herself in the same situation. She was not married and not educated although she came from a well educated family. She told me that some people said that she was bewitched and that was the reason why she wasn’t married.

In 2002 she discovered that she was HIV positive and also had tuberculosis. She was then dating and thought that her boyfriend should stand by her side but he did not. Ana said that she was a real party animal at that time and lost a lot of weight. When people asked she said it was power slim that had helped her. It is legitimate to loose weight for aesthetic reasons, but a weight loss caused by an illness such as HIV will therefore be “covered” as an intentional weight loss. Being young, slim and a party animal is seen by the society as positive traits and very few would suspect that a party animal is seriously ill. Eventually she could not hide here illness.

As if tuberculosis and HIV wasn’t enough she also got meningitis and for periods she was so ill that she couldn’t even remember her own name. Ana got really sick and went to see Médecins Sans Frontières where she were about to meet a true friend and soul mate. The doctor that became her friend supported her through her suffering and Ana could call him whenever she needed someone. Ana told me that when she first came to MSF she was really sick. Her CD4 levels were so low that the doctors refused to give her the antiretroviral drugs because they were too strong for her at that moment. She said that she had to find a way without the ARVs to heighten her levels so she could get the medicine she needed. With a lot of love from friends and family, the support from her doctor friend and her stubbornness she told me that she got her CD4 level from 69 till 118 without drugs and with the ARVs she now has 1150. She said it was a miracle and I agree. When Ana managed to get her CD4 levels high she started to work with people sick from HIV as a peer educator. She loves her work and thinks it is very fulfilling and if she could chose career again she told me that she would choose this every time.

As I wrote before Ana has had some bad experiences of men in her life and the main focus in this interview came rather natural – the gender aspect of HIV/AIDS. She told me that in Kayelitsha there are more people infected by HIV/AIDS than we know of. She said that she would estimate it to be one or two people in every household. In these households 80 percent of the women are not working and consequently totally dependent on their husbands. Ana can
see a big problem in this. If a the man in the family is the only one that contributes to food for the children and providing shelter that will indicate that the woman in this family somehow have to stay with him so that her children will remain safe and do not have to starve. She will stay with this man even if he commits adultery or have a drug problem, which in turn means that she is willing to risk her own life and her future children’s lives by letting him engage in things that are considered high risk when it comes to contract HIV. She blames this on the black culture and she said that according to it, it is considered manly and macho for a man to sleep with many women even when he is in a relationship and accordingly it is considered feminine to stay a virgin or at least not be promiscuous and be a monogamist. An extension of these stereotypes that she also brought up is the taboo for women to get a divorce.

Ana and I also discussed the change of culture. She has a 16 years old daughter and a grandchild. Ana told me that she did not know who the father of her grandchild was or if her daughter had been raped since her daughter refused to talk about it. Ana said that the culture had changed since she herself was a teenager. Then people were more conservative about their own culture and the body was still a great taboo. Nowadays, she told me, the teenagers are becoming coconuts – black on the outside but white on the inside. She said that this cultural confusion and new experiments among the young ones are contributing to the spread of HIV/AIDS.
Summary
The aim of this essay was to see how women in Cape Town reflect over and deal with HIV/AIDS in their everyday lives, but as all people are individuals they all handle situations in life differently and there is of course no standard of how women in Cape Town handle HIV in their everyday lives. I also wanted to investigate how the women explain the cause and spread of HIV. The informants’ explanations to the spread of HIV were similar, but not exact. Nomveliso, the first interviewee, said that it was because of the social problems that South Africa was facing such as poverty, poor education, inability to read and unemployment. According to Nomveliso these things are connected to each other and as she explained it, it was a vicious circle. She also said that when people infected by HIV could not face reality and accept for themselves that they are HIV positive, how can they tell other people? Zoleka, the second informant, saw the spread of HIV as a result of social structures and stigma. She talked about mothers that are prepared to put their children at risk by breastfeeding them, so that the other women will not be suspicious. She told me that a woman who does not breastfeed her child is breaking the norms, so if an infected mother wants to cover her health status she has to act as if she is healthy. The last interviewee, Ana, mentioned a different cause to the spread. Ana had paid attention to the shift in cultural and sexual patterns. She said that the youth are influenced by many other cultures but especially the western and now are turning into coconuts, black on the outside and white on the inside. Because of their curiosity to try new things and their changed view of the body and taboos the spread is increasing in this particular group. Ana also said that the social relationship between a man and a woman and the expectations on gender roles worsen the spread.

To sum it all up, the three informants have all recognized the patterns in society as the main cause to the spread of HIV. They may see different aspects as the most important cause, but it all lay within the frame of social and cultural patterns.
Analysis

South Africa is a divided country where the rich and poor live side by side. There are white areas, black areas, areas for tourists, for students and there are of course the townships. HIV occurs in every class in society and is not dependant on the colour of your skin, the monthly income, which part of the city you live in or if you live on the street or not. HIV can get to everyone, but those who are at particular risk are black women. The reason to why it is like this has nothing to do with the lack of information from NGOs and other organisations or that people do not understand the seriousness of the disease – because they do. The people of South Africa live with HIV as a next door neighbour and have done so for too many years now. I don’t think that the enormous spread has anything to do with ignorance, stupidity or arrogance. I strongly with my informants that said it has to do with poverty, social patterns, hierarchy, taboos and cultural power relations that are difficult to break.

The reason to why it is the black women in South Africa that more frequently get infected is divided in two parts. As I explained in the chapter HIV/AIDS in a gender perspective women are at greater risk of getting infected than men because of the amount of uncovered mucus membrane that will get in contact with the contaminated fluids during intercourse. The other reason is more complex and is embedded in social structures, gender ideals and expectations and risk perceptions. Women play a subordinate part in the power game and are inferior in every constellation. Because of the social and cultural structures she is forced into behaviour where she has to take risks. During my interview in Nyanga my informants told me about the expectations society had on women and they gave me two examples. The first is that according to their culture their sons have to go though a circumcision in order to become men so they get sent away to a circumcision school. They told me that they as mothers choose to send their sons across the country because of the more hygienic procedures of that school. This is an example where the society has expectations on the mothers, but they can choose between different options to decrease the risk for their sons to catch HIV. It is a little bit different for women themselves if they happen to be ill from HIV. Many taboos are related to the body, as I already explained in Striving for cleanliness, and within the black cultures people do not talk about the body or sex and sexuality (something that all of my informants agreed on). People are in general scared of HIV and many are afraid of getting disowned from their families or husbands if it is discovered that they have HIV/AIDS. As I said, women are forced into a risk taking behaviour and this is because they are dependent on their husbands or other male members of their family. A
woman can not risk losing her husband since he is the provider of the family, so if she is ill from HIV she will pretend for her friends and loved ones that she is not, even if it will mean that she will breastfeed her children so they will get infected too.

Another reason for the spread is that the culture is changing, something I and Ana talked about. That is not something new, but with all the information and media that is spread across the world it happens faster than it did twenty years ago. She told me her daughter was a coconut, black on the outside but white on the inside. The young generation in South Africa has been more influenced by the other cultures and lifestyles than their parents ever were and this results in a, according to my informant, more liberated sexual approach where young people tend to start having sex earlier, have more partners and experiment more than before. My informant was upset over the social gender patterns of her culture and it seemed like she wanted them to change, but on the other hand she wanted her culture to stay the same as it was when she was young when the black culture was not so affected by other cultures. That opinion is something that I felt all of my informants shared. They were proud of their cultures but were ambiguous towards the changes within them. They did not really question the old cultural structures but the consequences of them.

**Further research**

When I applied for the SIDA scholarship I had already decided not to write a thesis about gender issues, but as time went by and the thesis took form I realised that the HIV problem cannot be solved from one aspect only. I think it would be interesting to more thoroughly investigate the gender aspect of HIV/AIDS.
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Appendix 1

Of course I did not use this as a manuscript since not all of the questions were suitable for every interview and some of the questions got altered during the interview.

1. Tell me a little bit about yourself.
2. When did you get infected?
3. Do you know how you got infected?
4. How and when did you understand you were infected?
5. Do you use any ARVs? Any other help? Counselling, diet etc.
6. Do you feel it is a typical group in society that get infected or does the disease spread throughout the society?
7. Do you know many people infected by the disease?
8. What reasons do you believe are the cause of the spread?
9. What kinds of myths or misunderstandings surround the disease? Are they worsening the spread?
10. What is the most common misunderstanding about HIV that you have encountered?
11. Have you in your profession encountered problems that made it hard to get thru to your clients because of their misunderstandings?
12. What did you know about HIV before you got infected?
13. Would you say that your picture of HIV has changed since you got infected?
14. Where can people get information about HIV?
15. Is the information about HIV available for all people?
16. Are there any taboos connected to the disease?
17. Is it still difficult to talk about HIV?
18. Is sexual education on the schedule at every high school?
19. Do you think that sexual education is enough to raise awareness amongst school children?
20. What educational improvement would you like to see and why?
21. What does the government do?
22. Do you think they do enough?
23. What do you think needs to be done to stop the spread?
24. Is there anything you feel I have forgotten?
Appendix 2

AIDS – Acquired Immune Deficiency Syndrome

ANC – African National Congress

ARV – Antiretroviral Drug

ART – Antiretroviral Therapy

CD4 – The molecule attached to T-cells.

HIV – Human Immunodeficiency Virus

IDU – Injecting Drug User

IGO – International Governmental Organization

MCT – Mother to Child Transmission

MSF – Médecins Sans Frontières aka Doctors Without Borders

MSM – Men who have Sex with Men

NGO – Non-Governmental Organization

PEP – Post-Exposure Prophylaxis

SIV – Simian Immunodeficiency Virus