

**LIFE KILLS:  
Surviving the Battles of Everyday Life in  
an age of HIV/AIDS**

by  
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*Thesis presented in partial fulfilment of the requirements for the degree  
Master of Philosophy at the University of Stellenbosch*



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December 2010

## **Declaration**

I, the undersigned, hereby declare that the work contained in this assignment/thesis/dissertation is my own original work and has not previously in its entirety or in part been submitted at any university for a degree.

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## **ABSTRACT**

This study gives us insight into the daily lives and battles for survival of poor women in an age of HIV/AIDS in rural areas of the Western Cape, South Africa. I set out to get an understanding of the shortcomings of the current interventions aimed at combating HIV and AIDS. Soon after I commenced my fieldwork I realised that it is the socio-economic circumstances of the people I encountered that was mostly responsible for their HIV positive status or the reason why they are living with HIV/AIDS rather than the choices they make. However, most of the interventions aimed at combating the global HIV/AIDS epidemic focuses on behavioural interventions or the provision of medical care. By entering the spheres in which women living with HIV/AIDS live their daily lives I aimed to get a better comprehension of the challenges they encounter and why the interventions that focus on behaviour and medical treatment fail to address the needs of these women. In doing so I learned about their struggles to merely stay alive and that protecting yourself against a disease like HIV/AIDS can appear as a luxury. A luxury you cannot afford when your only means of an income is your body which you need to barter in exchange for money or food and shelter. I learned about their powerlessness in protecting themselves against the disease and the loneliness they have to endure once they learn they are infected with the virus. In addition to this, it also came to my attention that their conditions of poverty are of such an extent that even 'free' medical treatment can sometimes be too expensive for them to afford because of hidden costs such as transport. At the end of my study it was my conclusion that we need to pay more attention to the root causes of the spread of the HIV/AIDS epidemic in order to combat it successfully, also at the entry levels of the healthcare system.

## OPSOMMING

Die studie bied insig in die daaglikese lewens en stryd om oorlewing van arm vroue in 'n tyd van MIV/VIGS in die landelike gebiede van die Wes-Kaap, Suid-Afrika. Ek het die studie begin met 'n poging om die tekortkominge van die huidige intervensies om MIV/VIGS te bekamp beter te verstaan. Kort nadat ek met my veldwerk begin het het ek reeds tot die besef gekom dat die sosio-ekonomiese omstandighede die oorsaak is dat die vroue met die virus leef, eerder as die keuses wat hulle vrywilliglik maak. Ten spyte van my bevinding fokus meeste intervensies tans op gedragsveranderinge en mediese behandeling. Ek het die lewensruimtes van hierdie vroue binnegegaan in 'n poging om die daaglikse uitdagings te verstaan, asook die redes hoekom die huidige intervensies nie hierdie vroue se behoeftes aanspreek nie. Deur dit te doen het ek geleer hoe dit as 'n luuksheid beskou kan word om jouself teen infeksie met die virus te beskerm. 'n Luuksheid wat jy nie kan bekostig indien jou lyf jou enigste bron van inkomste is wat jy moet gebruik om geld mee in te win of kos en woonplek te verseker nie. Vroue is dikwels magteloos om hulself teen infeksie met MIV/VIGS te beskerm en die eensaamheid waarmee hul moet saamleef wanneer hul wel met die virus ge-infekteer is. Dit het ook onder my aandag gekom dat die armoede van so 'n aard is dat selfs 'gratis' mediese behandeling soms onbekostigbaar is as gevolg van versteekte kostes, soos vervoer. Aan die einde van my studie was dit my gevolgtrekking dat daar meer aandag geskenk moet word aan die oorsake wat aanleiding gee tot die verspreiding van die MIV/VIGS epidemie indien ons dit suksesvol wil bekamp, ook op die intreevlakke van die gesondheidstelsel.

## **ACKNOWLEDGEMENTS**

I would like to thank my family and friend for their continuous support. I am also especially thankful for Steven Robins' motivational talks, support and ideas throughout the years, and the NRF funded programme which enabled me to conduct this study. This was a unforgettable journey where I did not only gain academic knowledge and skills. It was also a learning school about life which enriched me as a person on a personal level as well as academically.

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## **LIST OF ABBREVIATIONS**

AIDS	acquired immune deficiency syndrome
ART	antiretroviral treatment
ARV	antiretroviral
AZT	zidovudine
CSW	commercial sex workers
FAS	fetal alcohol syndrome
FBO	faith based organization
HAART	highly active antiretroviral treatment
HIV	human immune virus
ID	infectious disease
NGO	non-governmental organization
NPO	non-profit organization
PLWHA	people living with HIV/AIDS
PMTCT	prevention of mother-to-child transmission
STD	sexually transmitted disease
STI	sexually transmitted infection

TAC	Treatment Action Campaign
TB	tuberculosis
VCT	voluntary counselling and testing
WHO	World Health Organization
UN	United Nation
UNAIDS	Joint United Nations Programme on HIV/AIDS

# CHAPTER ONE

## INTRODUCTION

### 1. Introduction

Life in townships is associated with many social issues. People face high levels of unemployment, they are poor and struggle to make basic ends meet. In this thesis I am going to argue that it is the desperation to stay alive that drives people to participate in behaviours that put them at risk of HIV/AIDS and other life threatening illnesses. Though HIV/AIDS undeniably contributes to the poor socio-economic circumstances of the majority of those living with the disease, many were already living in similar situations before they were infected. Therefore, I would like to argue that it is their socio-economic circumstances that is their real challenge and that HIV/AIDS is not the reason for the constant suffering and hardship, but the broader socio-economic circumstances are, and being infected with HIV/AIDS is but one of the consequences thereof. With the little resources available to them they can fight HIV/AIDS once they have acquired access to the necessary healthcare services, such as being provided with ARVs. They can take the medication and live a normal life. However, they do not have the resources to protect themselves from getting infected. Nor do they have the resources to take care of themselves holistically, because they can barely afford food and shelter. Self-help methods to improve your life when living with HIV/AIDS are simply too expensive for most to afford. To the women I encountered during the course of my fieldwork, HIV/AIDS is a 'scapegoat' and the real challenge they face is surviving the battles of life.

Trying to understand people's local perceptions about global issues can be regarded as one of Anthropology's goals. In this thesis it is my goal to understand why it appears as if we are losing the war against HIV/AIDS. Though progress has been made in reducing the number of new infections in a few countries, there are still countries where no progress has been made, or where the number of new infections is still increasing annually (United Nations, 2009:32). According to the Millennium Development Goals Report 2008 (United Nations,2008: 28) "the number of people living with HIV rose from an estimated 29.5 million in 2001 to 33 million in 2007". Women continue to represent a growing percentage of people living with HIV/AIDS. In sub-Saharan Africa 59 percent of people living with HIV/AIDS are women (United Nations, 2008: 29). In countries with a high HIV/AIDS prevalence rate, "AIDS has become a leading cause of illness and death among women of reproductive age" (World Health Organization, 2007 (a): 5). This is alarming and reflects how other developmental issues, such as gender equality continues to put women at a higher risk of infection and consequently hampers the fight against HIV/AIDS. Despite South Africa's development accomplishments in the past decade, and being one of Africa's economic leaders, its population is severely affected by the epidemic. In 2005, an estimated 5.4 million South Africans were living with the disease. As is the case in many other parts of the world, South African women are disproportionately affected, accounting for 55% of those living with HIV/AIDS (National Department of Health, South Africa, 2007: 7).

Since the lack of access to treatment was declared a global health emergency in 2003, tremendous progress has been made in making life saving drugs available to those in need of treatment, reducing the burden of HIV/AIDS related morbidity and mortality. However, millions of people continue to suffer from HIV/AIDS related morbidity and eventually die because of opportunistic infections since the demand continues to outweigh the availability of ART. In sub-Saharan Africa alone, “some 5 million people ... were denied antiretroviral therapy” in 2008 (United Nations, 2008: 30). I visited clinics providing HIV/AIDS related services as well as community centres concerned with these health related issues in an attempt to understand why so little has been achieved in the war HIV/AIDS despite global efforts to combat this epidemic.

Throughout my nine months of research, the harsh realities of being poor dawned onto me. The poor are at the mercy of their environment, social and political, and unable to escape from it. Attempts to do so often put them at risk of getting infected with HIV/AIDS, especially in the case of women and the youth. Prevention programmes are essential in the war on HIV/AIDS. Reducing risky sexual behaviour, especially having a lower number of sexual partners and practicing safe sex, has yielded significant results in reducing the number of new HIV infections (United Nations, 2008: 29). However, women, especially young girls, remain at the mercy of men and have little say in regards to condom use or their infidelity. The physical body is often the only valuable commodity poor women possess. Trading their bodies, in the form of commercial sex work or transactional sex, is often a last resort to escape the situation they find themselves in. Insisting on the use of condoms put them at risk of losing the basic necessities, without which they cannot survive.

Women fear abandonment, or physical and sexual abuse if they insist on condoms during sexual intercourse. As a result they often resort to having unprotected sex in order to feed themselves, putting them at risk of being infected with HIV. Thus, “gender inequalities continue to affect women’s decision-making and risk-taking behaviour, and vulnerability to HIV infection is often beyond a woman’s individual control” (United Nations, 2009: 33).

Life in townships is hard. Though HIV/AIDS is often blamed by people living with the virus for the daily hardships they have to endure, uninfected people face the same circumstances. Poverty, unemployment, poor housing, lack of sanitation, and malnutrition makes people vulnerable for infections and ‘forces’ them to engage in high risk behaviour. Poverty ‘breeds’ misery and is responsible for many of the social problems present in our modern world.

*Poverty is pain; it feels like a disease. It attacks a person not only materially but also morally. It eats away one’s dignity and drives one into despair*  
(International Monetary Fund, 2000: 6).

People living with HIV/AIDS had to endure these poor social and economic circumstances before they were infected with HIV. It was estimated in 2005 that 51 percent of sub-Saharan Africa’s population earn less than US\$1.25 per day, approximately ZAR10. Just enough for a loaf of bread and with some small change to spare (United Nations, 2009: 6). This picture is worsened by the current global economic crises and rising food prices. It is estimated that 64 percent of the people living in sub-Saharan Africa lived below the poverty line in 2008. The number of people working but unable to lift themselves, and their families, above the poverty

line are also likely to worsen (United Nations, 2009: 8-9). People engaged with vulnerable employment<sup>1</sup> is also likely to increase dramatically because of the economic crises, making them economically more vulnerable. It is estimated that “well over 80 percent of the female labour force in Oceania, sub-Saharan Africa and Southern Asia ... have been engaged in vulnerable employment in 2008” (United Nations, 2009: 9). In order to combat poverty “full and productive employment and decent work for all” (United Nations, 2008: 8) is essential. Poverty and unemployment also has a direct influence on hunger and malnourishment (International Monetary Fund, 2000: 9), especially for the urban and landless rural poor (United Nations, 2009: 6). Due to people’s dire financial status they have to resort to living in informal settlements which commonly lack “at least one in four basic elements: water, improved sanitation, durable housing and adequate living space” (United Nations, 2009: 47). These circumstances are common in most South African townships, including the communities which I visited during my fieldwork. In fact, it is because of these circumstances that many of them got infected with the virus. Before HIV progresses to AIDS, and once AIDS patients started to take ARVs, their lives are the same as before they were infected, as long as no one knows they are living with the virus. The stigma associated with HIV/AIDS results in social actions that can put people’s lives in danger. The virus itself is not a threat if people seek treatment in time. However, being refused food or being thrown out on the streets can jeopardise treatment outcomes and result in a patient falling ill with opportunistic infections and possibly result in an HIV/AIDS related death.

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<sup>1</sup>Vulnerable employment refers to unpaid work, such as family members making a contribution to a family business or own-account holders (United Nations, 2009: 9).

HIV/AIDS is no longer regarded as a death sentence, but rather as a chronic condition. This point is stressed in the public health sector, using it as one of the reasons why people should get tested, regardless of having reason to believe they are infected because of poor health or not. Knowing your status enables you to seek HIV-specific treatment, care and support at an early stage of the disease which helps the HIV positive individual to better cope with the disease, and adapt safer behaviours which can prevent the transmission of the virus to others (World Health Organization 2003(a): 1). However, healthcare providers often fail to provide people with the services as it is prescribed to them because they too often underestimate patients' risk of infection. Some healthcare providers are also influenced by social meanings and stigma of HIV/AIDS and treat patients accordingly, compromising the service patients receive. Healthcare providers who do not treat patients and their health confidentially do not only act in an unethical manner but put patients at risk because there are several risks involved when your status becomes known to the public. The public health sector is the corner stone in the war on HIV/AIDS, and it is crucial that it does not fail in its duties towards to public.

For the poor, living in townships, with little or no hope that their lives will change, it is life, rather than HIV/AIDS, that kills them. Whether they are infected with the virus or not, they are likely to die prematurely as a result of their environment, be it through violence, or other preventable diseases for which they could not afford the required treatment. More should be done to change the harsh living conditions of the poor, for them to be able to associate life with living rather than dying. HIV/AIDS is often blamed for the poor living conditions of those infected and affected by the disease. Consequently authorities refuse to intervene and such conditions of poverty

and hopelessness will only result in more people being infected and affected by the virus, worsening the situation. People get infected with HIV because of the vulnerability of their actual lives, and people often die from HIV/AIDS related diseases because of the social meaning of the disease, not because of a virus.

### **1.1 Problem Statement**

Despite global efforts to combat the rapid spread of the virus, each year millions of people are newly infected. The success stories of countries which have been able to prevent the rapid spread of HIV to epidemic proportions or to lower the rate of transmission have been attributed to behavioural and medical interventions.

Behavioural interventions mainly focus on encouraging safer sexual and recreational drug use practices. Safer sexual behaviour encourage abstinence, being faithful to a single monogamous partner and correct and consistent condom use. This is also known as the ABC programme. Needle exchange programmes have been encouraged in countries where intravenous drug use is common and believed to be responsible for high levels of transmission. Medical interventions include access to antiretroviral (ARV) drugs, voluntary counselling and testing (VCT), treatment and prevention of opportunistic infections, prevention of mother-to-child transmission (World Health Organization, 2008: vi). With the help of modern medical technologies, vertical transmission from mother-to-child has substantially been lowered, with almost no babies being infected by their mothers during pregnancy, birth or breastfeeding in developed countries. Success in this regard have mainly been limited to developed countries (World Health Organization, 2007 (a): 5). However, it is strongly believed

that these programmes' success is not limited to the North and the success can be expanded to other world regions. Though not equally effective,

... the use of simple and less expensive combination antiretroviral prophylactic regimens, such as short-course zidovudine (AZT) combined with single-dose nevirapine, can reduce significantly in utero and intrapartum transmission. However, this efficacy is diminished over time in breastfeeding populations due to postnatal HIV-transmission through breast-milk. (World Health Organization, 2007 (a): 7).

This, again, relates to conditions of poverty, where women are too poor to afford formula feed and the accompanying costs, such as bottles, for their babies, or where risk of water borne disease, due to the lack of access to safe drinking water, makes breastfeeding the best, or only option for HIV positive mothers (Evian, 2009). Thus, the success of both behavioural and medical interventions to combat HIV/AIDS is being undermined by conditions of poverty.

Uganda is an exceptional example of a poor country which successfully stopped HIV/AIDS in its tracks and lowered the number of new infections (Cohen, 2003; HELLERINGER & KOHLER, 2005: 266). Being a sub-Saharan country makes this accomplishment even more impressive. Sub-Saharan Africa is the world region with the highest HIV prevalence rate and interventions to slow down the rate of new infections have had little success. Limited access to medical services and ARVs, cultural sexual practices such as polygamy, the belief that "males are biologically programmed to require sex with more than one woman" (HELLERINGER & KOHLER, 2005: 165), traditional 'African' beliefs on health and illness and even Africans' perceptions

of time have been blamed for this. However, these claims contradict with the content of conversations I have had with HIV/AIDS patients and local health care providers over the years. Many scholars have also disagreed with these claims. It was with an interest in the disparities on why HIV/AIDS interventions enjoy such limited success that I entered local rural clinics in the Western Cape, South Africa, to investigate these matters more closely. Each individual, community, nation and region face their own unique challenges. We can only challenge these challenges if we truly comprehend what they are.

In order to understand these challenges I started fieldwork in a rural clinic in the Cape Winelands districts of the Western Cape, South Africa. I later on expanded my fieldwork to another clinic and a community centre in another town in the Cape Winelands in order to get a more comprehensive view of people's daily challenges and the services available to help them cope with these challenges. Once I started my research contradictory feelings and opinions about women living with HIV/AIDS who choose to fall pregnant soon caught my attention. Some medical staff being opposed to the idea, others embracing it, and sometimes the same person expressing different opinions in this regard when talking about different patients. Reasons for these contradictory opinions were always based on concern for the patient, her health, as well as the health and life of the child that is to be born. In all this talk patients' voices about their personal feelings and views on HIV positive motherhood were mostly absent.

In conversations with HIV positive mothers whose children are also living with HIV/AIDS, feelings of guilt and fear for the future of their children, having to live with this virus, which does not only have the ability to end their lives at a very young age, but also opens them up to social stigma, were frequently expressed. I wanted to know more about HIV positive pregnancy and motherhood. My study was refined to understand the complexities involved in the relationship between medical science, the reproductive human body and the everyday living experiences and needs of these reproductive bodies. However, after numerous conversations with mothers, little was said about their personal desire to have a child, nor the beauty of pregnancy and the prospect of bringing a new life into this world. Feelings of helplessness dominated conversations. For these women you can't decide whether you want to be pregnant or not, it simply happens to you or it does not. This is also the case for many other events in their lives. I then expanded my research to the communities in which these women lived to understand why they feel like helpless victims of life. Finally my research question was refined to *why does life kill?*

## **1.2 Methodology**

To collect data for this thesis I used participant observation, informal interviews and semi-structured interviews. In total I conducted nine months of research. Most of the research took place at three sites of which two were ARV- roll out sites and one a community centre of a non-profit organization. In addition to this, I did in-depth interviews with managers and staff of other non-profit organizations, faith-based organizations, non-governmental organizations and community-based organizations located in the township where I attended the community centre to get a more

comprehensive picture of the services available to people, as well as the social dynamics in the township. These organizations, as well as the people connected to them are all interconnected with one another. People will often have part-time jobs at more than one organization or be a staff member at the one and a client at the other.

At each of the three sites my role was different. At clinic A I started as an observer in the nursing room, making informal conversation with patients and conducting formal interviews with them privately. I soon became a much more active participant in the clinic. Due to the high patient load and never having enough hands to do the clinical observations and completing the paper work I soon got involved and helped out with minor tasks in the nursing room. This involved counting pills, weighing people and searching for lost files. Being involved in this way provided me with valuable insight into the operation of the clinic, as well as their logistical difficulties. In addition, it also provided me with more opportunities to have informal conversations throughout the day with staff and patients. After establishing a better equilibrium between participation and observation patients were less resistant when I asked their permission to interview them. At clinic B my role never expanded beyond passive observer and interviewer. However, being able to observe the daily activities of the clinic provided me with more in depth knowledge of what people are talking about when we had conversations about clinic visits. In addition, I could compare the different operational styles of the clinic as well as the interactions staff had with the patients.

The community centre had different programmes and each of these programmes provided me with a different role. On Monday mornings I sat in on the weekly meeting of the health care workers and their coordinator. After the meeting I joined them on their home visits. Depending on everyone's schedule for the week I would join them for home visits during the week as well. At the support group for HIV positive women on Tuesdays, I joined in as a visitor. Visitors from outside were common. Sometimes I would explain the operations of the support group to other visitors. After the support group I assisted with serving lunch to the members of the group. On Thursday afternoons I also attended the life skills programme presented to children as part of the after school caring programme. Here my role was more that of a class assistant than that of a researcher doing participant observation. Engaging with the children during this time provided me with valuable insight into the lives of the youth in a township and the challenges they face.

### **1.3 Context of the Study**

Research for this study took place in two clinics in separate rural towns in the Western Cape, South Africa. Due to logistical difficulties only one of the two towns' township were visited on numerous occasions. Superficially these two towns share many characteristics. The wine industry is at the heart of economic activities. Though rural, both towns offer access to all essentials, and more, for a comfortable life. The population sizes are slightly above and below 100 000 people respectively. The location of the respective clinics within the local area as well as the proximity of the two towns to its neighbouring towns and their population sizes contributed to many

differences between the two clinics. These differences will be discussed in more detail in the following sections.

### **1.3.1 Clinic A**

Clinic A is located on the premises of the region's secondary hospital. At the time of my research the clinic was in the main building along with other specialized clinics.

On a permanent basis there were three staff nurses and one permanent doctor. On Tuesdays, Wednesdays and Thursdays doctors from other clinics rotate to help out at this clinic. These doctors only treated the adolescents and adult patients. A private paediatrician was responsible for the treatment of infants and children. The hospital also acts as a training site where medical students do their community service.

Courses in nursing are offered at the hospital and these students, as well as medical students from the university, often assisted in the clinic. Though there were many hands to help the patients, every morning was chaotic with twenty to forty patients' observations that needed to be done in a small room of approximately 20<sup>2</sup>m to 25<sup>2</sup>m.

Apart from the patients and nurses occupying this small space, it also acted as the kitchen for the staff of the clinic which added to the number of people in this already overcrowded space. Frustrations with overcrowding were met with excitement about the new premises to which they will move, hopefully before the end of the year.

Initially, the idea of enjoying beverages in the same space where urine and blood samples are being taken was difficult to digest. Especially when I had to wash my glass or mug in the same basin as the urine collectors. However, within a matter of a day or two it no longer bothered me. The limited choice between dehydration and not being that squeamish had a great influence in this regard.

Space was not only limited in the nursing room. The hallway outside was the official waiting area for the patients attending the clinics located in that area. A collection of old wooden benches and chairs provided patients with a place to sit. Children entertained themselves in the passage and sometimes got hold of the toys in the consultation room used for the children. The toys were brought out into the corridor and provided them with entertainment and few complaints about the day they had to spend at the clinic. It was not clear which patients were there because of their HIV status or for other reasons. Patients often walked into the room thinking it was a different clinic. Thus, entering this room was not associated with HIV/AIDS by people other than the patients specifically attending this clinic and medical staff. Apart from the high number of patients waiting to be seen at the various clinics, there was the file room in the area next to the nurses' private consultation room as well as bathrooms. This added to the traffic in the hallway.

Available consultation rooms for the use of the ID clinic staff were also limited. The three counsellors had to share one room. This set up was not an ideal space for patients to discuss sensitive and confidential issues privately with counsellors. As a result, counsellors were constantly running up and down the corridor looking for an empty room. They could choose between their official consultation room, consultation room B and C and the nurses' private consultation room. For my interviews with patients, I also joined this search. Despite the logistical difficulties, and the added strain of an extra person in need of a room to speak privately with patients, space was always shared and offered without hesitation.

Despite the general organised chaos in the nursing room, the spirit was always high. It was mentioned to me more than once that staff from other clinics are jealous of them because they had such a nice team that worked well together, enjoyed their work and were always laughing and joking with one another. Staff members from other clinics did come by the clinic for a quick chat regularly. The staff supported one another morally, whether it was work related or personal problems they experienced at home. Working in the clinic was about more than just a pay check at the end of the month and patients were more than a file number. There was, what I experienced, as a generous concern for the health and well being of the patients. This was also expressed by many of the patients.

The ARV clinic is a specialized clinic. This means that the clinic works purely on a reference basis from other clinics. Most of the patients who are referred to this site are from primary clinics or other specialized clinics within the hospital. Most of the references they receive from within the hospital are from the internal medicine department.

The main responsibilities of the clinic and their staff are to prepare patients to start ARVs and to take care of their health while they are on ARVs. It is not the responsibility of the doctor or nurses at the ARV clinic to take care of patients' other "primary-level" health problems such as colds. They only need to take care of ARV-related health care problems. Primary health care problems are the responsibility of

the nurses at their local primary health care clinic. However, when patients have a primary health care problem when they see the doctor or nurse for their monthly ARV appointment, these ailments are usually treated. In the past, the ARV clinic's staff used to see all patients who turned up at the clinic, whether it was in relation to HIV/AIDS or ARVs or not. However, they had put an end to this because it took away unnecessary time from the patients who have to be seen for their monthly check ups and ARV-related emergencies. The ARV clinic also had the right to do this, since it is not part of its official responsibilities to take care of primary health care problems.

On Mondays local prisoners on ARVs are seen. From Tuesdays to Thursdays, the rest of the patients are seen. On Fridays, they try to have no patients in order to get up to date with paperwork. The clinic is open between 07h00 and 16h00. Most of the observations are done by the nurses before 13h00 or 14h00. The paediatric patients have their observations taken and consultation done entirely by a private doctor. The paediatric clinic starts between noon and 14h00. During the winter however, patients tend to show up later and consequently observations tend to take up the rest of the afternoon. On rainy and windy days fewer patients attend the clinic and they are likely to turn up later than usual. Despite the inconvenience that this can cause the staff they try to understand the patients' situations. Most of them are poor and many live in shacks. The first morning when I noticed it is almost 09h00 and there have only been one or two patients I asked the nurse what is going on, where are the patients? She said: "They don't come when the wind blows [it was a sunny winter's day]. You will see, when it is winter they come later and when the wind blows or it rains, they don't come at all. I don't know why, but I guess we can't blame them.

Maybe it is hard for them to get up and out of their houses when it is cold”. The town is known for vicious winds and when the surrounding mountains are covered with snow the freezing winds are unbearable. Most people prefer staying indoors.

In the afternoons, after the last patients have been seen, the nurses prepare for the next day. The files of the patients who are to be seen the next day are requested from the file room and prepared. On days when there is a shortage of staff, the head nurse will also see some of the patients who are considered “easy cases”. These patients’ files are separated from the rest beforehand. They also prepare the orders for the satellite clinics. There are no regular staff meetings set on specific weekly or monthly dates, but Fridays are kept open by all staff members for such purposes.

How long you have to wait once you have reported to the nurses depend on your time of arrival and the number of patients who were there before you. Once your name has been called from the door of the nursing room, one of the nurses will hand you a urine collector. You then need to go to the bathroom, urinate and take the sample back to the nursing room where the nurses test it. Any abnormalities in the urine can alert the nurses of possible side effects the patient might be experiencing. These abnormalities, along with the other observations, are then reported in the file so that the doctor can address the issue when consulting the patient. When women menstruate, blood in the urine sample is ignored. Next, you move to the scale, where you need to take off your shoes (a significant number of patients need to be reminded to take their shoes off every time, at both the clinics), and are weighed. Nurses usually comment on patients’ weight. Weight gain is complemented and the patient is

encouraged to keep doing what he/she is doing because it is showing good results. Weight loss on the other hand raises concern and patients are encouraged to tell the nurses why they think they might be losing weight. There was one patient who was asked to lose a little of the weight he gained on his annual hunting trip because he was overweight and was also being treated for high blood pressure. After putting your shoes back on you have a seat, take off any thick jerseys or jackets to get your blood pressure taken. Patients' temperature was also taken at this time. After the observations have been done, the patients need to go and wait at the doctors' consultation rooms or see a counsellor if they feel the need to. HIV positive patients not yet taking ARVs typically see the counsellors once a month to prepare them for the day they have to start ART. Patients already on treatment did not have to see the counsellors but was advised to see them at least once every three or six months. Here they had to wait again until their names are called by the doctor or counsellor. If the doctor thought it necessary to have a patient's blood tested he/she had to go back to the nursing room, tell the nurse and wait until the nurse can draw the blood. Once all of this is finished at the clinic, they take their files to the pharmacy, where they need to 'drop' their files and once again, wait till their names to be called by one of the pharmacists and receive their medication. Space around the pharmacy is cramped and many have to stand in line for a few hours before they get their medication. By now it is late in the afternoon and little time is left before the ambulance or last taxi leaves. After another, usually long drive, you finally arrive back home, bombarded by questions about why you had to go to the clinic once again.

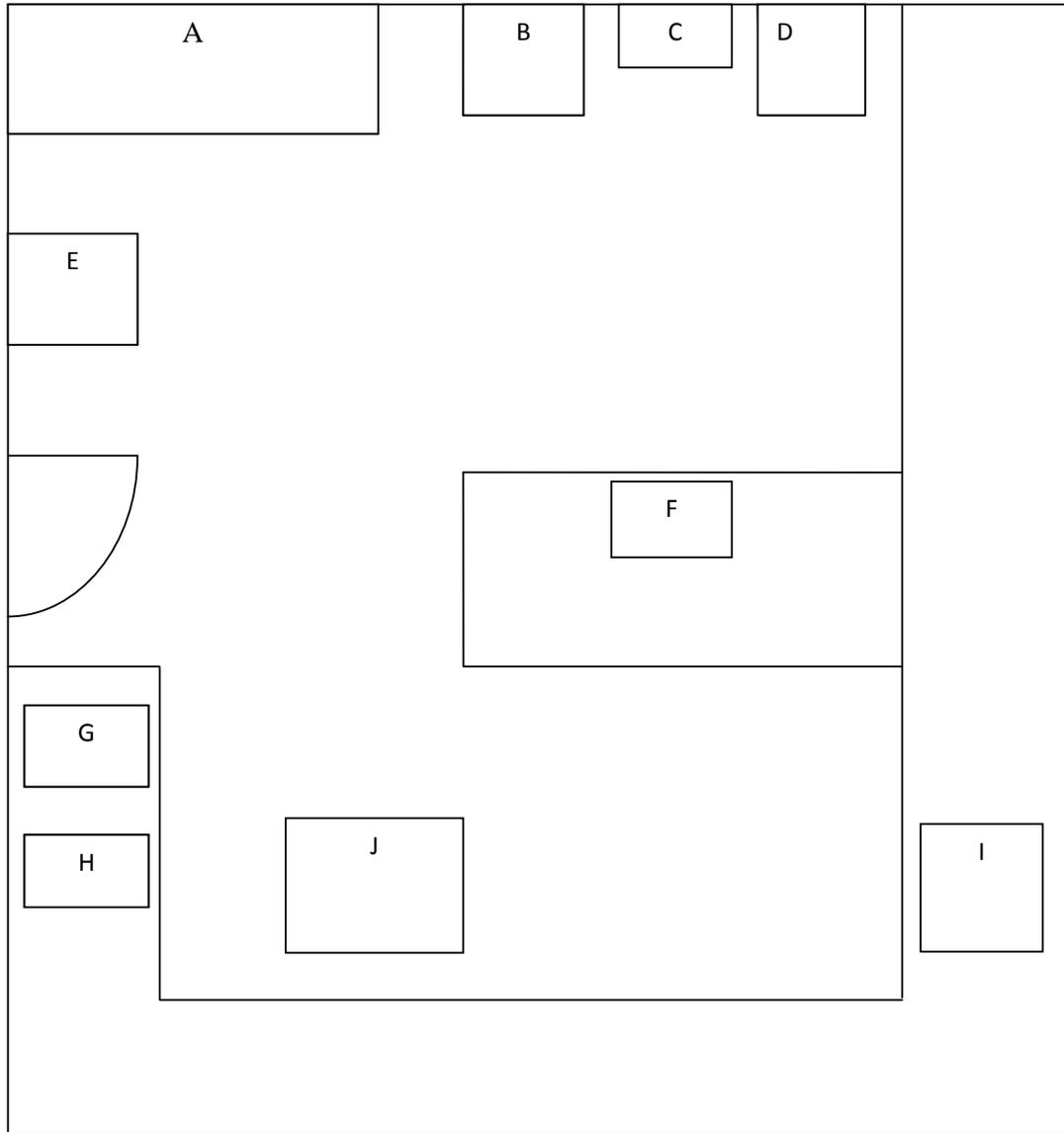


Figure 1: Nursing Room

A: File Cabinet

B: Chair for Blood Pressure

C: Blood Pressure Machine

D: Chair for Blood Samples

E: Scale

F: Files of Patients for Observations

G: Files of Patients to be seen by  
counsellors

H: Files of patients ready to see the doctor

I: Wash Basin

J: Kettle, Coffee, Tea area

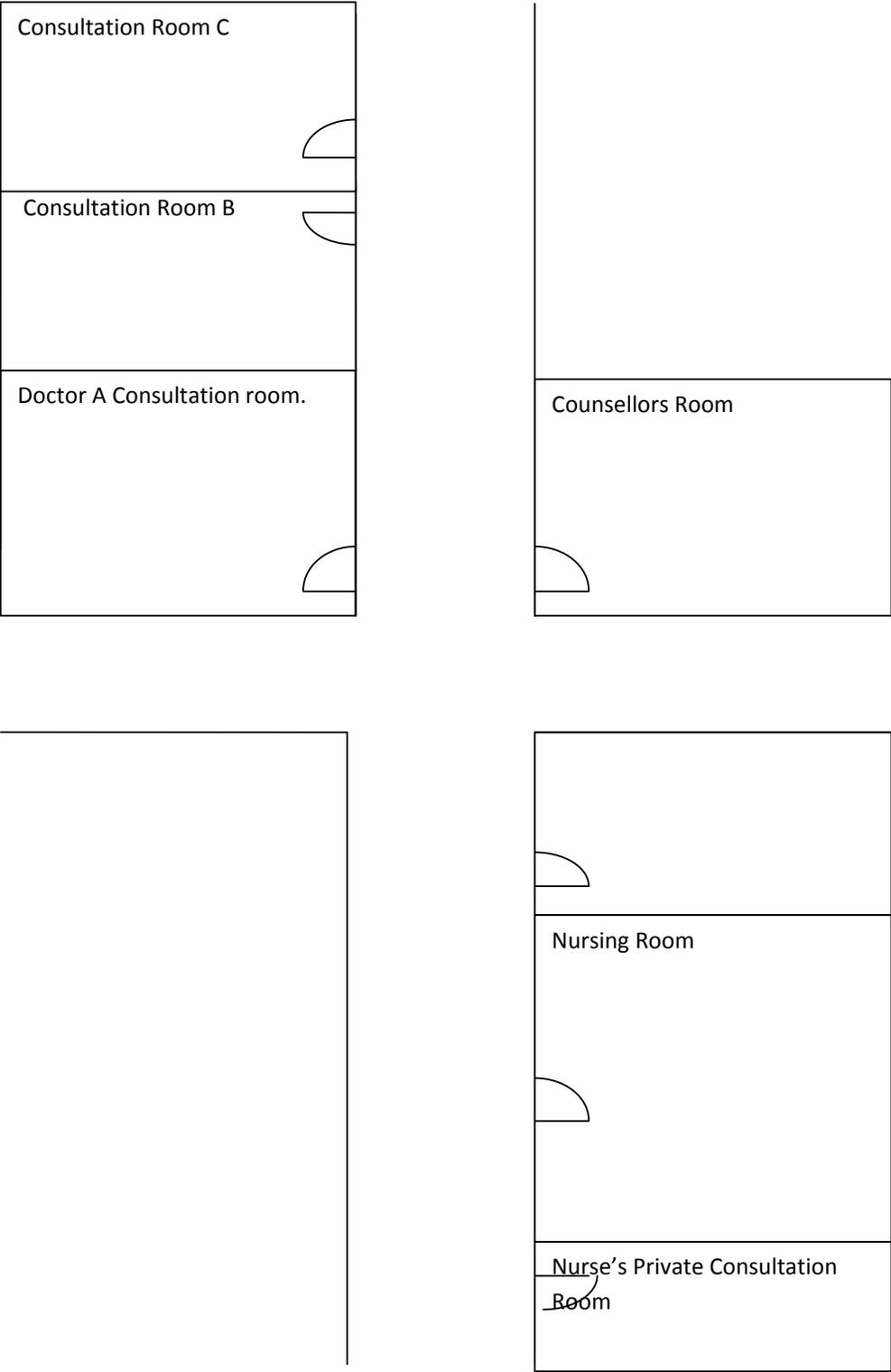


Figure 2: Diagram of ID Clinic Set-up

### **1.3.2 Clinic B**

Clinic B I visited, not so much to investigate the operations of the clinic and its staff, but rather to be able to get a better understanding of what the people were talking about when they refer to the clinic they attend. I started to visit this clinic in the later stages of my research. Most of the staff and clients at the community centre attended this clinic. However, they had a choice in terms of which clinic they wished to attend. This clinic was not the township where they lived, it was in another part of town which made for quite a walk. The ARV roll out site was located at a primary clinic. Compared to clinic A, this clinic was rather spacious for the number of people it had to serve. The waiting area was seldom full. Each of the two nurses had their own, private consultation room. Monitoring of patients' adherence was done separately by the adherence counsellors. Doctors and counsellors' consultation rooms were in the corridor just outside the waiting area. There were no other clinics in the area of the ARV roll out site. Patients who were here, were here because of their HIV positive status.

Two nurses, three doctors, two adherence counsellors, and three general counsellors staffed the clinic. Apart from me conducting research, there were two other students doing research for their theses and two international students who volunteered at the clinic. The two international students were 'pre-med' students and helped nurse A with observations. Though the clinic had a large surface, and a generally low number of patients attending, space was limited for the three of us doing research. We shared a room next to the pharmacy, which was relatively far from the clinic.

Limited conversation took place between the patients, as well as between the nurse (where I was allowed to observe the clinic) and the patients. Despite the lower patient load, compared to clinic A, as well as other clinics in the area, staff had an aura of tiredness and low morale around them. A patient was just another person whose observations needed to be done. Staff at this clinic complained about patients not adhering to their medication, or following their advice on behavioural and lifestyle adjustments, and thus, from the staff's perspective, not giving their cooperation. Each day was just another day where the same motions had to be repeated. In the waiting area there were several informative and educational posters on the walls as well as flip charts on small coffee tables. Above the 'adherence table' there were posters with examples of all the different types of ARVs, the actual pills as well as its containers. The 'adherence table' is a table where patients had to complete a form, if they were literate, indicating which medication they used and how many doses they missed of each medicine. This lessened the work load of the adherence counsellors having to count all the pills of each patient. The flip charts included general information used to educate people about HIV/AIDS. This included the signs and symptoms of HIV/AIDS, how to protect yourself and others, opportunistic diseases and safer sex. I never saw anyone looking at these charts. There was also a small corner with a few toys to occupy children while they and their parents were waiting.

Upon arrival at the clinic, patients have to report to the general reception desk where they are given a number. If you are number one you are first in line to be seen by the nurses, counsellors, and doctor. Once you have received this number, patients have to proceed to the waiting area of the ARV clinic. While they are waiting here the adherence counsellors count their pills, or the patients can do it themselves. Patients

adherence for the month is then recorded into their files. If a patient had poor adherence, these counsellors would attempt to find out from the patients why this is the case. When the adherence counsellors are finished with a patient's file, it is taken to nurse A who is responsible for the general observations of the patients. Nurse A will then call a patient's name. They then have to go to the bathroom which is just outside the waiting area and bring her a urine sample. Then they are weighed and their blood pressure and temperature is monitored by the nurse. Once this is finished, patients can proceed directly to the pharmacy to collect their medication for the month. Stable patients only have to see a doctor once every three months, or when they experience complications. Patients who need to have blood taken for tests have to go back to the waiting area until the senior nurse can see them, since she was responsible for taking blood samples. If patients needed to see the doctor they also had to wait in the waiting area for the doctor to call their name. After a patient has seen the required nurses and doctors for the day he/she can proceed to the pharmacy and collect his or her medication.

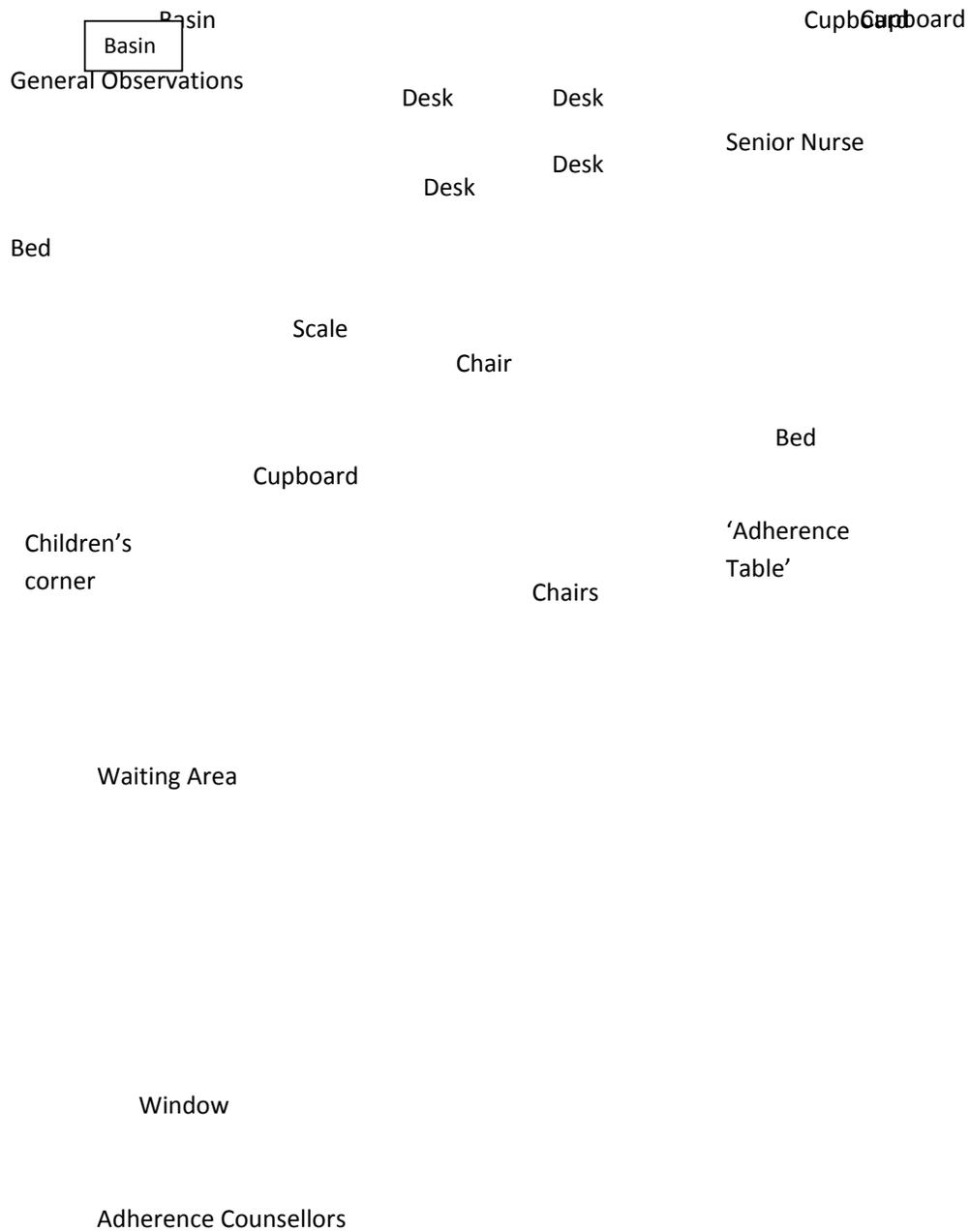


Figure 3: Clinic B Waiting area, nurses' consultation rooms and adherence counsellors

### **1.3.3 The Centre**

The centre is affiliated with a local church in town (not in the township). Despite the centre's relationship with a religious organization, it is registered as a non-profit organization (NPO) and not as a faith based organization (FBO). They do not preach the gospel to the people they serve, nor do they impose Christian values on them. The organization believes that they should rather live by example than preach to people. The centre had a number of programmes, provided to both children and adults. Apart from the centre's own activities, part of the centre is used for a kindergarten during the week and a church meeting on Sundays. In order to raise additional funds the centre can be rented for functions. The centre's kitchen makes it ideal for this purpose.

In relation to HIV and AIDS, the centre has a support group, as well as community health care workers who visit support group members during the week for moral support and to monitor their general health and well-being. Occupational health students, who were at the time of my research doing their community service at the centre, offered a domestic work course to those who were interested. They recognised the women's, who come to the centre, need to be empowered. The women enrolled in this programme did not qualify for training at other institutions because they did not have the required level of schooling. The staff of the centre also assisted those who finished the course to secure a job. Again these women did not meet the requirement of other recruitment companies focusing on the poor because they did not have the required level of literacy, which is grade 12. Most of these women could not read or write, and they could not speak English or Afrikaans which limited their employment

opportunities. A house was being build to serve as a place where people, who have been released from hospital but whose living conditions at home are not suitable for the recovery of a patient, can stay until they are ready to go home. This house will not only be used for HIV/AIDS patients, but for all patients who are ill and in need of care.

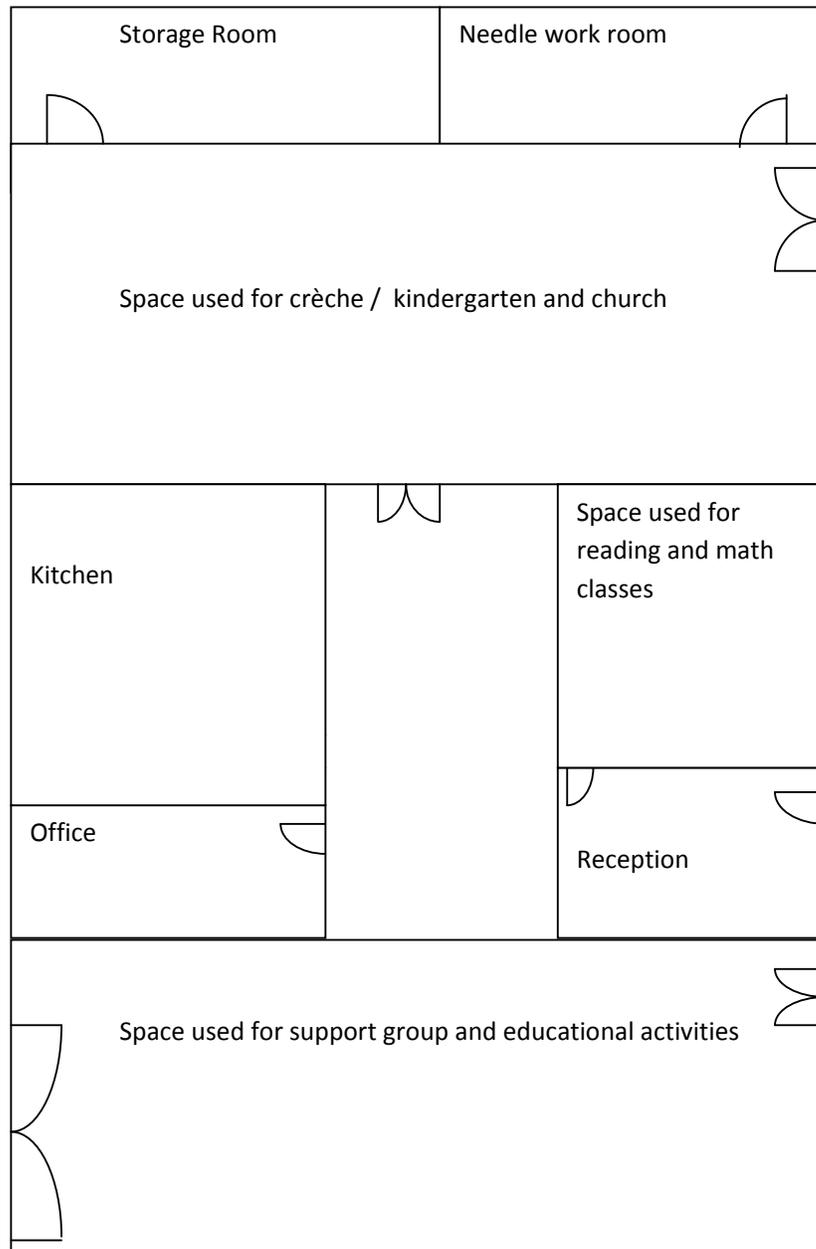


Figure 4: Diagram of Centre

Youth is regarded as an important target population by the organization and they have a large caring project. At the centre they believe that interventions are needed early in life, before the youth make poor choices and land themselves in difficult situations, such as teen pregnancies or being HIV positive. They focus on proactive interventions, rather than reactive ones. Educating the youth is a high priority and joined with the local school they offer extra reading and math courses. In the afternoons they offer an after school programme for primary school children. Participants can be up to fourteen or fifteen years of age. The afterschool programme includes art, drama, English, Afrikaans, and life skills courses. Volunteers present these classes. Many of these volunteers are members of the affiliated church of the organization. An isiXhosa-speaking youth worker is also present during these classes to ease language barriers. The vast majority of the children attending the after school programme are isiXhosa- speaking. Annually, approximately 60 children enrol in the programme.

Next to the centre there is a vegetable garden. This garden started as an income generating and skills development programme. People were taught gardening skills and sell the vegetables for an income. Other income generating initiatives at the centre are dress making and beading. The women involved in these programmes are also part of the support group.

#### **1.4.4 Beyond these Walls**

Interaction with people living with HIV/AIDS was mostly confined to the inside of the walls I described above. Despite South Africa having one of the world's highest HIV/AIDS prevalence rates people are still afraid to disclose their status and openly talk about life with the virus. Though the impact of the epidemic is clearly visible in South Africa, the faces of those living with the virus are hidden to the public behind the fear of stigma and discrimination. Protected from the outside world by the walls of these rooms and buildings are some of the few places where people living with HIV/AIDS feel comfortable enough to openly talk about the virus. However, for many entering and being associated with these spaces which is synonymous to HIV/AIDS is too much of a risk to take. It is because of people's fears of living openly with the virus and strangers being aware of their HIV positive status that my research context was mostly confined to these walls, because outside of these walls HIV/AIDS cannot be spoken about openly. Though I did visit people's homes in the townships, these visits were also with individuals who had links with these places and were assured of protection from the outside world by these organizations.

#### **1.5 Thesis Outline**

Once I completed my fieldwork, I came to the conclusion that the roots of the problems associated with HIV/AIDS are not so much the lack of access to medical services, or treatment for the disease. Rather, it is the circumstances of people's daily lives that fosters the spread, and progress of the disease.

In this thesis I will argue that it is because of the social-economic situations of people living with HIV/AIDS that we are struggling to win the war on HIV/AIDS. I will start my argument by giving a short literature overview on the relationship between HIV/AIDS and poor socio-economic circumstances. The relationship between poverty, gender and HIV/AIDS.

Chapter three discusses the social meaning of HIV/AIDS. Many South Africans live in conditions of poverty. Millions are unemployed and live in overcrowded slums. Hope for a better future is limited because employment opportunities are limited and many are illiterate which further limits their prospects to lift themselves and their families out of poverty. These poor socio-economic circumstances of many South Africans forces them to engage in behaviours which put them at risk of getting infected with HIV/AIDS, which in turn impoverishes many even more. People who are infected with HIV or living with AIDS often have to endure harsh stigma and discrimination because they are living with the disease. These acts of stigma and discrimination can put people at risk of losing everything they have. In some cases they can even lose their lives.

In the fourth chapter I will discuss the difficulties people encounter in accessing treatment. For long infection with the HI virus used to be regarded as a death sentence due to the absence of effective medical treatment. However, since the introduction of ART people have been able to live long and productive lives despite

being infected with the virus. In poor and developing countries, such as South Africa, this treatment has been out of reach of those most in need of it because they could not afford to pay for the treatment. Though treatment is available free of charge for all in need of treatment, there are still many people who cannot access the treatment because of financial and social costs associated with accessing treatment. Because of these costs, many in need of treatment do not access it, and many only access it when it is almost too late.

In chapter five I will address some of the issues I encountered in regards to the medical services provided to people in order to combat the war on HIV/AIDS. Knowing your status is regarded as key in order to combat the global war on HIV/AIDS because it raises awareness about the disease, it provides people with valuable information and enables people to protect themselves and others against infection with the disease. However, due to stigma and prejudices about people living with the disease, in addition to the shortage of medical staff, many opportunities to turn the tide on the local epidemic are missed. I conclude this thesis by highlighting what I believe to be the major contributing factors to why it appears as if we are losing the war on HIV/AIDS.

## CHAPTER TWO

### LITERATURE REVIEW

#### **2.1 Social Inequality and HIV/AIDS: A Literature Review**

*“HIV/AIDS...follows the path of least resistance, tracking the economic and social inequalities that exist globally and within particular national contexts”*  
*(Albertyn, 2003: 597).*

People’s circumstances greatly contribute to their vulnerability for HIV infection because the behaviour they choose is often a last resort in order to survive (Adimora & Schoenbach, 2000: 710). These ‘survival’ behaviour is often regarded as high risk behaviour because it involves unprotected sex, often with multiple partners. Some argue that the conditions of poverty are related to global forces the poor cannot control. Paul Farmer (2004: 307) calls this structural violence. Structural violence is a form of institutionalized violence and can broadly be defined as “‘sinful’ social structures characterized by poverty and steep grades of social inequality, including racism and gender inequality” (Farmer, 2004: 307). Economic structures, often stimulated by neo-liberal trade agreements, which fuels economic inequality and makes the rich richer and the poor poorer, is at the root of this institutionalized violence. As life expectancy increases for the rich and new cures are discovered for previously untreatable diseases, millions of people suffer and die from preventable conditions because they cannot afford treatment. They “are simply too poor to stay alive” (Sachs & Sachs, 2004: 5). Hope for people in such conditions of poverty is

virtually non- existing, since these people are also “too poor to achieve economic development, falling into what economists, in their formal models, call a poverty trap” (Sachs & Sachs, 2004: 6).

Conditions of poverty are responsible for many HIV transmissions (Whiteside, 2002: 316). President Mbeki regarded the role of poverty so important that he argued “AIDS (is) the result of the ravaging effects of poverty on the body’s immune system” (Posel, 2008: 16) and questioned the relationship between HIV and AIDS altogether. Though this thesis accepts the mainstream scientific theory on HIV/AIDS and the relationship between HIV and AIDS, I do regard poverty as a driving force behind the epidemic proportions present in Africa and other poor and developing regions of the world.

Poverty and the associated disempowerment of poor people is one of the key factors influencing the spread of new HIV infections (Craddock, 2000: 156). Zulu, Dodoo and Chika-Ezeh (2002: 311) noted that rapid urbanization in sub-Saharan Africa is central to poverty and the high HIV/AIDS prevalence in this region’s urban areas. Poor economic circumstances enhance the probability that women, especially adolescent girls, will engage in high risk sexual activities, such as unprotected sex and have multiple, concurrent partners, which is closely linked with HIV infection and transmission. Financial needs of women often acts as motivation to get involved in commercial sex work, or for young girls to have a relationship with older men, the sugar daddy phenomenon (Hunter, 2005: 218; Zulu et.al., 2002: 311). In addition, poverty is associated with violence against women, which increases women’s vulnerability even more. On the other hand, violence against women can impoverish

women, and in turn, make them more dependent on men, which increases their vulnerability to further violent acts, and decrease their resources to escape from it (Terry, 2004: 470, 471). Masculine identities arising from poverty can also result in domestic violence as an attempt of the husband to maintain his traditional power and role in the household (Terry, 2004: 471).

## **2.2 Poverty and HIV/AIDS**

### **2.2.1 Poverty, Gender and HIV/AIDS**

Generally women are more affected by HIV/AIDS than men. Seventy percent of the world's poor are female. In addition to women's vulnerability to HIV infection because of conditions of poverty, they are also biologically more at risk of contracting the disease. It is estimated that women are three to four times more likely to contract HIV in comparison to their male counterparts due to physiological differences such as the lining of the vagina that provides a large area for contact with infected body fluids despite exhibiting lower risk behaviour (Albertyn, 2003: 597; Bonner, 2001: 149; Teti, et.al., 2006: 42). In South Africa, as well as most other developing countries, the HIV prevalence rate is higher for women than for men. In some African cities it is estimated that the infection rate is two to eight times higher in adolescent girls than in their male counterparts (Brady, 2003: 134). However, not all women are equally vulnerable to HIV infection. Younger women are more vulnerable than older women. This relates to young girls' social status, involvement with older men and more pressing economic needs. Poor women are more likely to get infected with HIV than financially secure women because they often turn to transactional sex or commercial sex work to secure money for essentials. The marital status of women can also increase or decrease their vulnerability. Married women, as well as unmarried women

in stable, long term relationships, often find it difficult to negotiate safe sex with their partners because condoms are associated with promiscuity and would imply that they are unfaithful to their partners and thus would risk the possibility of losing their financial support. In addition, places of residency has been indicated to have an influence on women's vulnerability. Research has indicated that women living in rural areas have a higher risk of being infected with HIV than women residing in urban areas; and slum dwellers have a higher risk than women living in formal housing. Choice of occupation has been associated to vulnerability. Commercial sex workers and women who are required to travel frequently have a higher risk of infection than those staying in one location. Women of different races have different degrees of vulnerability in relation to being infected with HIV. Black South African women are more vulnerable than women of other racial groups due to the legacy of Apartheid laws and policies that disempowered blacks, especially black women. Currently, most poor people in South Africa are black women (Albertyn, 2003: 597, 598; Feldman & Maposhere, 2003: 165, 171; Hunter, 2005:217; Zulu et. al., 2002: 311,313).

### **2.2.2 Poverty, Commercial Sex Work and HIV/AIDS**

Commercial sex workers (CSW) form a group at high risk to get infected with HIV. Often, CSW are transient, which increases their risk for HIV infection. One of the main reasons women become CSW is poverty (International Organization for Migration & Sida, 2003: 13). Unemployment, unstable sources of income and low paying jobs often push women into such desperate economic circumstances that they resort to commercial sex work to cover basic costs or to supplement their income (Albertyn, 2003: 598; Castle, 2004; 14; Zulu et.al., 2002: 322).

Failure to use a condom during sexual intercourse with a client greatly increases CSW's risk of being infected with HIV as well as transmitting the virus to their clients. The most common reasons CSW give for not using condoms are because they need the money and fear that the client will go somewhere else, or will become physically or verbally abusive if they insist on the use of a condom during the session. Sex workers can also ask higher prices for sex without a condom (International Organization for Migration & Sida 2003: 13).

In many societies, CSW are stigmatized and have a low social status. The illegal status of their occupation enhances their vulnerability to exploitation and violence by their clients, as well as law enforcement officers. Often, they find it hard to access health care services which increases the likelihood of untreated STIs, which in turn increase the likelihood of infection with, as well as transmission of the HI virus (Albertyn, 2003: 598).

### **2.2.3 Poverty, Sexual Violence and HIV/AIDS**

It is estimated that rape statistics greatly underestimate the number of rapes that do occur. Not only are not all rapes reported to the police, it excludes the majority of rapes that takes place in 'conventional relationships' where women are coerced or forced into sex (Draper, 2007: 57). Victims of sexual violence have an increased risk for HIV infection, apart from it often being unprotected, because of the likelihood that blood will be present during the assault (Pendry, 1998: 31). Perpetrators of these crimes include family members, community members, work colleagues and

individuals in the uniformed services (Oyediran & Isiugo-Abanihe, 2005: 39). Data obtained in South African studies, as well as other sub-Saharan African countries, indicate that both men and women accept coercive and even violent sex and regard it as 'normal' (Albertyn, 2003: 600; Feldman & Maposhere, 2003: 165). A cross-sectional study found that 40% of South African women reported that their first sexual intercourse was forced (Oyediran & Isiugo-Abanihe, 2005: 39). Both men (31%) and women (27%), in a study done in Gauteng Province, South Africa, "agreed that forcing someone you know to have sex with you is never seen as sexual violence" (Albertyn, 2003: 601). The large number of women coerced to having sex or have non-consensual sex reflects the high rate of domestic violence in South Africa. Although the majority of rape victims are women, and a considerable number of them under the age of 16, men as well as boys also report being forced to have sex and being victims of rape, including gang rape (Draper, 2007: 57; Kalichman et.al., 2001: 1; Kuate-Defo, 2004: 27). Domestic, and intimate partner violence is interrelated to certain behaviours and societal/environmental factors, such as "cultural practices, unemployment, low socio-economic status, lack of education, alcohol abuse, and traditional myths and beliefs (Draper, 2007: 59). Forced sex often follows an episode of physical violence or is part thereof (Watts, 1998: 60). In some communities it is regarded as a sign of love when men beat their wives (Oyediran & Isiugo-Abanihe, 2005: 39).

Since 1994, several policies have been put into place to increase women's social status. However, these policies do not necessarily become a reality. There is an increasing concern about the sexual violence against women and young girls (Snell, 2003: 508). Cultural beliefs, such as that sex with a virgin can cure AIDS, further

expose women and young girls to sexual violence and rape (Albertyn, 2003: 602; Kuate-Defo, 2004: 28; Smith, 2002: 64; Terry, 2004: 474).

#### **2.2.4 Poverty, Youth and HIV/AIDS**

It is estimated that approximately one third of South African children “live apart from both their parents and that about the same proportion live with only their mother” (Snell, 2003: 507). Children orphaned by HIV/AIDS, are more exposed to poverty, exploitation, child labour and high risk sexual activities (Kuate-Defo, 2004: 23; Smith, 2002: 67). Female headed households are generally poorer than male headed households, threatening children of these households’ educational opportunities because of a lack of money to pay for school fees and the need for children, especially female children, to assist in domestic chores at home, or to become financially active outside of the home. Children’s perception that they are better off working than going to school, especially because of the high number of unemployed schooled people they know, increase the likelihood that they will not complete school and thus compromise their future financial security (Kuate-Defo, 2004: 23; Smith, 2002: 66, 67; Snell, 2003: 507). Street children are among the most vulnerable to HIV infection. Apart from high risk sexual involvement, they also report substance abuse and have limited knowledge about HIV/AIDS – what it is as well as how to protect themselves and others from getting infected (Snell, 2003: 512).

In Africa’s major cities, the phenomenon of survival sex appears to be on the rise. Survival sex refers to commercial sexual exploitation of children who voluntarily engage in sexual activities, or are coerced into doing so, for material reasons, such as money, food, clothes or school fees (Snell, 2003: 508). Both girls and boys are

sexually exploited by men and women, who are international tourists, as well as of their own nationality, from all levels of society (Snell, 2003: 509). Adding to the problem is communities' awareness of the sexual exploitation of children, but ignoring it, because it is seen as a 'necessary evil' because children have to help supplement household income (Bamford, 2000, cited in Snell, 2003: 509).

Cross-generational relationships between young girls and older men (sugar daddies) or young boys and older women (sugar mommies) where sex is exchanged for money and/or material goods and/or other benefits, such as payment of tuition fees, is increasingly common. If one sugar daddy or sugar mommy can't provide the desired amount of material benefits, young girls and boys will have more than one in order to increase their financial resources (Kuate-Defo, 2004: 15, 27). Reasons for engaging in these relationships vary, as well as the acceptance thereof in their local communities. In some instances these relationships are encouraged by the youngsters' family members, especially in the case of a possible prospective marriage with the sugar daddy, because it involves financial gain for the families as well (Kuate-Defo, 2004: 23, 24). Several girls have reported their motivation for having a sexual relationship with an older man was based on the prospect of marriage proposed to them by the sugar daddy. Generally, prevention methods for pregnancy and STIs, such as condom use, have been reportedly very low which increases the risk of getting infected with STIs, including HIV, or falling pregnant and subsequently being abandoned by the sugar daddies or mommies (Kuate-Defo, 2004: 24, 25). The unequal power relationship between youngsters and their sugar daddies or mommies and a lack of confidence on the side of young boys and girls makes negotiation for safe sexual intercourse even more difficult (Kuate-Defo, 2004: 28). Not all

relationships with sugar daddies are for financial gain. Some are involved in such relationships to increase their social status among their friends and look more fashionable and privileged than their peers (Kuate-Defo, 2004: 26). Because of the material nature of the relationships between young girls and boys and their sugar daddies and sugar mommies, the adolescents often also have a partner of their own age groups for emotional and physical intimacy and satisfaction (Kuate-Defo, 2004: 27). It has been argued that the higher prevalence rate among young girls in relation to their male peers, is associated with girls who are more likely to engage in cross-generational sexual relationships than boys. Adolescent boys, on the other hand, are more likely to have sexual relationships with girls of their own age. The young girls boys have sexual intercourse with are more likely to be HIV negative than the older men young girls have sex with (Smith, 2002: 64).

### **2.2.5 Poverty as a result of HIV/AIDS**

Not only does poverty put people at risk of HIV infection. People infected and living with HIV/AIDS are also more likely to become poor because of the disease. Household income is affected because of the financial costs of the care, medicines and treatment for the patient, as well as the possible loss of income if the infected individual used to be economically active before falling ill. High funeral costs could also have financially devastating effects on the family's economic resources, especially when there are multiple HIV/AIDS related deaths in one family or household (Ansell & Van Blerk, 2004: 674; Smith, 2002: 66; Whiteside, 2002: 320,322). Terminally ill HIV/AIDS patients usually need someone to take care of them, resulting in additional family members having to retire their economic activities (Whiteside, 2002: 321). Reports of children, especially girls, being taken out of

school in order to take care of ill family members are common. Lack of education is positively correlated with poverty increasing their risk for possible infection later in life (AF-AIDS eForum, 2005: 11). The financial affluence of the household and communities in which PLWHA are residing contributes to the economic impact the disease will have on infected individuals (Whiteside, 2002: 320). Because of the clustering effect of HIV/AIDS, households and communities often have to deal with multiple persons' illnesses which has a magnified impact on them and reduce the support they can provide collectively to sick individuals and those left behind, especially children orphaned by HIV/AIDS (Whiteside, 2002: 324).

HIV/AIDS does not only affect individuals, but also families, communities and whole nations. Apart from being vulnerable to HIV infection, HIV negative and positive women are also vulnerable in their families and in the broader society because of the impact HIV/AIDS has on their lives. In their familial lives, women face the risk of losing the resources provided to them by their male partners if they disclose their HIV positive status or fall sick due to AIDS. When women disclose their status to their partners and/or in-laws, they are often blamed for bringing the virus into the relationship and risk being abused or ostracized (Albertyn, 2003: 601; Castle, 2004: 13; Hunter, 2005: 217; Smith, 2002: 65, 66; World Health Organization, 2004:5).

It is usually expected of women to care for family members who fall ill due to AIDS or other diseases (Gilbert & Walker, 2002:1094). In order to do so they often have to give up their own income generating activities, and in the case of school aged girls, end their academic careers. Women, widowed due to HIV/AIDS, living in customary

communities, often have no legal right to inheritance. Thus, again women's resources are being threatened. Widows, known or suspected to be HIV positive, face the risk of being abandoned by their deceased husband's family. They will also find it hard to access resources through another man because of her (suspected) HIV positive status. Many people blame women for the spread of HIV and have to endure stigmatization and discrimination because of this association (Albertyn, 2003: 601; Castle, 2004: 13; Hunter, 2005: 217; Smith, 2002: 65, 66). Thus, the effects of HIV/AIDS on women goes beyond women's increased vulnerability for infection with the virus, but also affects other aspects of their lives, including the lives of HIV negative women, who can also become even more vulnerable to infection because of the impact of HIV on women's lives in general (Albertyn, 2003: 601; Castle, 2004: 13).

### **2.3 The Social Meaning and Impact of Living with HIV/AIDS**

Being infected with HIV/AIDS does not only have implications for your physical health, but also your social identity. Throughout the world, meanings are being given to diseases and the people who are infected with these diseases. This can have far reaching consequences for the person(s) infected with the disease. In the case of HIV/AIDS, people infected with the virus are often ostracized from their families and communities due to the social meaning of the disease and the stigmatization and discrimination that is the consequence of living with the disease. In the following section I will elaborate on how a physical disease acquires a social meaning and the consequences thereof. I will also give an overview of the social meanings of gender in different contexts and how these social meanings contribute to many women's vulnerability to get infected with HIV.

### **2.3.1 The Social Meaning of a Diseased Body**

Diseased bodies and the causes and cures of diseases are given symbolic meanings and differ from culture to culture. Lorber (1997: 1), writes:

In every society, the symptoms, pains and weaknesses called illness are shaped by cultural and moral values, experienced through interaction with members of one's immediate social circle and visits to health care professionals, and influenced by beliefs about health and illness, The result is transformation of physiological symptoms into diagnoses or illness names, socially appropriate illness behaviour, and heroic and stigmatized social statuses.

Thus, the interpretation of a physical condition depends on the social and cultural environment of the body that is inflicted with the condition.

Common symbolic meanings of HIV/AIDS include impurity, sexually promiscuous behaviour, engagement in commercial sex work, and unfaithfulness to your partner. Individuals thought to be guilty of these behaviours are in themselves stigmatized, regardless of their HIV status. However, because HIV/AIDS is associated with these behaviours, individuals thought to be infected with the virus or suffering from AIDS are accused of committing these immoral acts. Thus, bringing the burden of disease onto themselves.

These perceptions that people are infected with HIV/AIDS because of their own immoral behaviour is strengthened by beliefs common in many African cultures. In many African traditions HIV/AIDS is classified into the broad category of sexually

transmitted diseases (STDs). STDs are commonly believed to be caused by witchcraft. This seems to be the case because of the high value placed on fertility and reproduction. In African thought fertility is perceived to be the ultimate force of protection against harm, hence it being a preferred target for witchcraft. By targeting fertility, witchcraft can also inflict other ailments related to fertility and reproduction, e.g. “sterility, miscarriages, stillbirths, and the death of infants” (Liddell, 2005: 593). The transmission of STDs take place when an individual breaches moral conduct. Since they disobeyed the moral rules of the ancestors they are no longer protected and are vulnerable to the punishment of ancestors or the evil of a witch (Liddell, 2005: 693; Simmons, 2007). Contrary to the belief of biomedicine that only sexual intercourse or contact with other body fluids like blood is necessary to transmit an STD from one person to another, it is believed in African medicine that contact with any pollutant or even misbehaviour, such as stealing or failing to honour family obligations, can cause the onset of an STD (Liddell, 2005: 693).

These behaviours believed to cause HIV/AIDS are regarded by many as socially unacceptable and immoral. Consequently these behaviours are often stigmatised and the people believed to be guilty of these behaviours can experience discrimination. Because these behaviours are believed to be responsible for HIV/AIDS, people infected with the virus or living with AIDS are automatically also accused of being guilty of these behaviours and undeserving of any sympathy or endearment.

### **2.3.2 Stigmatization as a Result of the Social Meanings of a Diseased Body**

According to the definition provided by Goffman ( 1963:3; cited in Link &Phelan, 2001: 364), stigmatizing refers to negative ideas about others that results in the sick person being seen as unworthy of complete social status. In relations to stigmatized diseases and illness the sick person is seen as a shameful, contaminated individual instead of being a victim. Jones et.al. (1984, cited in Link & Phelan, 2001: 365), based on Goffman’s definition, argues that stigma is a ‘label’ ascribed to certain individuals, that associates them with a certain undesirable characteristic. It is important to note that stigma always refers to a tag *given by others* to the person, not something which is inherent in the stigmatized person (Link & Phelan, 2001: 366). According to Link and Phelan (2001:377) stigma occurs “when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them”. Diseases that evoke stigma commonly share four characteristics. Firstly, sufferers of the disease are seen as responsible for being infected with the disease and that infection takes place voluntarily and can be avoided. Degenerative diseases and diseases which are contagious and could place others in harm’s way, such as HIV/AIDS, is associated with greater levels of stigmatization. Finally, in cases where diseases are apparent, especially when it is perceived as repellent, stigmatization is more likely to occur (Herek, 1999: 1108). In the case of HIV/AIDS, and other STIs, infected people are seen as promiscuous. This characteristic is often associated with immorality and that the ill brought it upon themselves, thus they do not deserve empathy or compassion (Castle, 2004: 10, 13; Smith, 2004: 426).

Discrimination is related to, but different from stigmatization. It involves derogatory behaviour that can harm the person to whom it is addressed. The behaviour can be

verbal or physical. Patients suffering from stigmatized diseases are blamed for being sick and is not regarded as victims by society. In contrast with the usual care and support patients usually receive, patients of stigmatized diseases are usually met with blame, social isolation and rejection by their communities and even their families (Castle, 2004: 1; Draper, 2007: 60; Schulte, 2002: 82). Studies evaluating stigmatizing attitudes towards PLWHA found that avoidance, decreased willingness for interaction, support for coercive policies, and the ascription of negative personality traits, were common among non-infected individuals (Schulte, 2002: 85). Stigmatization is also positively related to limited knowledge and misperceptions of HIV/AIDS transmission (Castle, 2004: 6, 12; Herek, 1999: 1107). Acts of discrimination include physical and social rejection, the loss or limitation of opportunities, and “gossiping, blaming and labeling” (Draper, 2007: 60). Thus, because of the social and cultural meanings of HIV/AIDS, people living with HIV/AIDS are stigmatized and often have to endure discriminatory acts against them.

### **2.3.3 Symbolic Meaning of the Female Body and Its Relationship to HIV/AIDS**

Our bodies acquire symbolic meaning according to the physical characteristics thereof. The body has several different social meanings depending on the specific context in which the body finds itself. As HIV/AIDS is given symbolic meaning, male and female bodies also acquire symbolic meanings.

Biologically most people are born with either male or female genitalia and are thus classified as either male or female. However, the gender roles which are ascribed to these male and female bodies depends on the cultural and social context in which it

lives. Sex differences are determined by a DNA in the same way as other biological characteristics such as a person's height. Gender is defined as "the socially constructed rather than biologically determined notions of 'femininity' and 'masculinity'" (Moffet, 2008:105).

Gender socialization is a never ending process which starts the moment a child's sex is known. Moffet (2008:106), argues that gender socialization is the result of "complex social, cultural and legal processes that translate biological sex into gender differentiation". Despite gender being a social construction which is only related to biological characteristics by means of symbolic meaning which is ascribed to it, gender is often treated as a biological given. Gender often determine which opportunities a person would or would not have in life. The regulation of occupations suitable for men and women is an example of this. It was believed in the late eighteenth century that men are more suitable for the public arena and occupation in it because of their physical characteristics. Because men are generally physically bigger than women, they were regarded as leaders and capable of doing demanding physical work which was considered not suitable for women because of the 'softness' of their bodies. Women had to refrain from engaging in harsh physical or intellectual work because it was believed that it could cause the masculinisation of women (Jordonanva, 1999: 37). Perceptions like these are still common today. Though it is no longer believed that intellectual activities can lead to the masculinisation of women, men are still often socialized to believe that they can and must have sex whenever they want to and women that they have no control over their own bodies and that they are at the mercy of men. Thus, gender socialization plays a crucial role in the spread of HIV. Moffett (2008:114), writes

Gender is at the heart of the tension that arises when one partner wants to, and the other doesn't. Gender determines whether that condom is used. If the person who loses the condom argument changes their mind and says, 'No! Then we're not having sex!', gender determines whether a rape will then take place. Finally, it is gender that will determine whether someone gets infected with HIV that night. So it is no exaggeration to say that gender is a matter of life and death.

#### **2.4 Conclusion**

Thus, the high risk behaviour associated with exposure and infection with HIV/AIDS is not always by choice. Many women, youth and sometimes men often engage in such high risk sexual activities because their circumstances leave them no choice. It is the conditions of poverty, and their inability to escape from these conditions that force them to do so. Gender and the social meanings of gender can also influence a person's vulnerability for infection. Women are not only biologically more vulnerable for infection, they are also more likely to be forced to engage in high risk sexual activities due to their social status. The lower social status women enjoy in society related to the cultural and symbolic meanings of gender in a specific context. In South Africa women are still occupying a lower social status than men, despite advances being made in regards to legislation on women's rights and equality.

In addition to HIV/AIDS being a highly stigmatized disease, behaviours associated with HIV transmission, sexual promiscuity and intravenous drug use, are also

stigmatized behaviours. Because of this stigmatization people living with HIV/AIDS are often blamed for bringing the pain and suffering of the disease onto themselves and therefore undeserving of sympathy. However, though people living with HIV/AIDS often participated in high risk sexual activities, the circumstances, which I believe are the main roots of the rapid spread of the disease, in which these behaviours took place is seldom taken into consideration.

## **CHAPTER THREE**

### **LIFE IN A TOWNSHIP**

#### **3.1 The Battle for Survival**

During the time I spent with women, living with HIV/AIDS, in townships I was faced with a different war than the one usually associated with HIV/AIDS. It was the war between life and death. Every day was a battle for survival. This time it was not a battle between science and nature but a primordial fight for survival from day to day. Here the scientific battle confined to the human body between the HI virus and ARVs is almost forgotten in the daily struggle to secure basic resources. For the people I encountered during my visits to the community food and shelter is a daily worry. They are poor and households struggle to fill all the empty plates at dinner with the most basic of foods despite pulling all their financial resources together in an attempt to take care of themselves and their extended family members. Food, water, shelter, sanitation, and safety are regarded as basic human needs. Needs which are not fulfilled in the lives of millions of people globally and locally. In addition to this they are also faced with an array of social problems.

Townships are almost synonymous with an array of multiple social problems. These problems are being exemplified by the interconnectedness of different problems, creating a cycle that reinvents itself repeatedly. Generally, residents of the townships believe that poverty and people's inability to secure jobs are the core of the social issues flooding their communities. Frustrated and unable to free themselves from the

harsh circumstances of poverty they spend the little resources they have on recreational activities that can 'free' them from their daily realities.

Over weekends people just want to enjoy themselves. They go to the shebeens and get drunk (Conversation with a community health worker).

Alcohol and other substance misuse and abuse have widely been reported to contribute to risky sexual behaviour, domestic and sexual violence because it reduces inhibitions and impairs judgement (Phinney & Hovre, 2003: 70). Fetal alcohol syndrome (FAS) is an increasing concern to health authorities, especially in the Western Cape. FAS is an irreversible, but preventable, mental retardation (Capaldi, 2008: 11). Children who are affected by FAS often suffer from learning disabilities (National Organization for Fetal Alcohol Syndrome, 2009), and are likely to have limited opportunities in life to free themselves from conditions of poverty as a result of this disadvantage. Other substances, such as Tik, are also dangerous to children and the social environment in which children grow up. Apart from dangerous birth defects associated with substance abuse during pregnancy, parents misusing and abusing alcohol and other illicit substances are negligent towards their children (Capaldi, 2008: 9; Edwards, 1999: 4). Children whose parents are reported to abuse substances are more likely to be underweight and malnourished, unsupervised and run the risk of being physically and/or sexually victimised. The age of alcohol and drug users is decreasing and people are experimenting with more serious drugs, such as Tik (conversations with community members).

Children growing up in townships are often left to take care of themselves. Families are broken. Most children's greatest wish is to know or see their fathers. A mother is

often abandoned by the father of her children and struggles to take care of her children on her own. Other children live with their grandparents, either in rural or urban areas. Apart from being separated from one or both of their parents, children often live apart from their siblings. Children are not only separated from their fathers because of physical distance. Many women said that the father of her child lives in the same town as she. However, he abandoned her and her child and is now living with another woman and the children he had with her. Stories such as the following are common.

I was studying law at the University of the Western Cape when I fell pregnant... I was studying law but when I found out I was pregnant I had to end my studies because I had to take care of my child... Her father and I are no longer together. He has no relationship with our daughter and he does not pay any child support or anything. ... No, he is still living here, sometimes I see him, but we don't speak or anything. He is with another woman now. .. They are living together and have a family of their own (Single mother).

If parents separate, the child is also separated from his/her biological father.

In addition to fractured families, parents spend most of their waking hours working for low paying wages. These wages barely cover the basic living costs and parents find it almost impossible to pay school fees. Day-care centres and kindergartens struggle to obtain monthly fees (which are commonly R10 per month) from parents. As a result, children are left without supervision. In some cases the older children take on the responsibility of caring for the younger ones, setting the stage for tragedy to strike. Children, barely able to walk, wander alone in the streets. Many mothers have no choice but to leave their children home alone while they are at work. Jan, the

centre manager said to me that the reason why parents are not taking care of their own children is “because during the day they (mothers) have to go and take care of other people’s children (domestic workers for the wealthy) and don’t have time to take care of their own children”. In some severe cases parents lock their children out of their houses, leaving them to the mercy of the streets unsupervised. Substance abuse also plays an important role in some of these cases. I came across two children in such a situation on a visit to Priscilla.

Priscilla is operating a community based organization from her home. With the help of a British woman, she acquired a house which she uses as a shelter for abused women and children. Her house is one of the few houses with no shacks in the yard and she shares the house with only her husband and son. This is also uncommon since most people share their houses and yards with extended family members. The community work she does mainly focuses on the provision of a safe haven for women who are the victims of domestic and sexual violence. If women are beaten by their partners and feel unsafe at home, they can come to Priscilla and stay there for the night, or until the women feels safe enough to go back home, or alternative arrangements have been made. On my first visit to her house there were two twin daughters playing with her son. I asked her whether they are friends of his.

No, they live across the street. Their mother does not know they are here...

They are here all the time. ... Their mother locks them out of her house in the mornings, sometimes as early as six o’clock in the morning and she does not open the door for them before it is evening already. Sometimes they are still

out here at ten at night. ... So when they are here, I feed them and look after them.

When I asked Priscilla why the mother treats her children like that, she explained that the mother and the father of the twins ended their relationship and now the mother does not want them anymore. Attempts to intervene from Priscilla's side has been unsuccessful and the mother refuses to change her behaviour.

The circumstances children endure in their childhood influences the behaviour they will exhibit later on in their own lives. Older children, typically of adolescent age, are fighting an internal battle between alcohol, sex, drugs and education. Most parents are uneducated and unable to assist their children with schoolwork. Others actively discourage their children from getting a proper education and finishing school because most people they know did not benefit from an education. Many youngsters also drop out of school because they see that their friends and family who finished school are still poor and unemployed. Those who do attend school with the intention of completing grade 12 run the risk of getting involved with gangs and drugs and giving up their education due to peer pressure. It is because of these influences the children encounter after school that so many NGOs provide after school programmes, where children can be supervised and participate in healthy, constructive activities.

Interventions to improve these social circumstances struggle to make a significant impact in the lives of the people. Because of limited resources, the state has done little to improve the lives and conditions of the poor. Corruption and inadequate

spending of resources magnified this problem even more. As a result community members have taken action in order to improve their own lives. Community based services, which are often financially supported by the state, are now offering many essential services to the poor in order to improve their lives.

### **3.2 Community Based Services**

Community based services aim to address many of the above mentioned social problems. Due to constrained resources, public services are not able to address all the needs of the poor, community based services attempt to fulfil some of the much needed, basic needs of the poor. The community based services I witnessed during my fieldwork all focussed their attention to issues related to HIV/AIDS. Welfare organizations try to avoid duplicating services and prefer providing people with specialized services, rather than trying to address all the issues, but with little success.

The healthcare services provided at the centre are independent from the clinics but complementary to it. These services focussed on providing people living with HIV/AIDS with emotional and psychological support. They also offered income generating opportunities, though the money that could be generated thereby were not much. Health care workers at the centre were paid a small salary and were responsible for doing home visits and facilitating the weekly support group. These services act as an unofficial extension of the healthcare services provided in the public health sector. It offers ongoing psychosocial support to people living with HIV and

AIDS and early detection of people who default on their treatment or who are unresponsive can be detected and reported to the clinics via these alternative channels.

The main purpose of the home visits is to monitor the health and welfare of the members of the support group. Healthcare workers visit the homes of the members in the mornings between 09h00 and 12h00. Independent visits are done on Wednesdays and Thursdays. Mondays they have their weekly meeting with the programme coordinator who is a retired nurse. This meeting usually takes place between 10h30 and 12h00. The weekly support group meeting takes place on Tuesdays between 11h00 and 13h00. They do not work on Fridays.

On Monday mornings, during their weekly meeting at the centre, all the activities of the week are shared with one another as well as their personal endeavours of the weekend. Concerns about individual cases are raised and they decide how to intervene. In cases where it is a serious matter they will alert a social worker to do a closer investigation. The agenda for the week's support group is discussed and decisions are made on who has to do what at this week's meeting. Weekly schedules are compared to decide who should attend which meeting in the upcoming week. These are usually meetings with other organizations of the township and surrounding area. This is also a time during which healthcare workers can discuss personal issues and concerns with the programme coordinator. Throughout the week they can contact the coordinator if they feel the need to discuss a personal issue or that of a patient with her.

### **3.2.1 The Support Group**

Tuesday mornings at 11h00 it is time for the weekly support group meeting.

Nokosazana is the facilitator of the group and it is clear through the women's behaviour that they regard her as the leader and no one else. Nokosazana has been interested and involved in healthcare work, especially related to HIV/AIDS, for many years. Before she started working at the centre in 2007, she used to do the same kind of work. She worked independently and was not paid. She works because of the passion she has for the work. When she was younger she dreamed of becoming a nurse or a doctor one day and started training as an auxiliary nurse in 2000.

Unfortunately she gave up on this dream because she failed some classes and could not complete the course. She then started this kind of work and sees it as a 'calling'.

At the support group everyone sits around a big table in the middle of the room. The meeting is started with praise and worship. Nokosazana is the lead singer and everyone follows her. When Nokosazana is not in the room (for whatever reason) to start the next song everyone seems lost and they are indecisive on which song to sing next and who the lead singer should be. If one of the other healthcare workers is there she would usually take over, but they are usually in the kitchen preparing the food for lunch. Praise and worship is followed by a scripture reading and prayer. One of the support group members usually takes on this responsibility. This is followed by the reading of the support group's Constitution. The importance of confidentiality and that what is shared among the support group members must not be told to others is stressed. Next on the agenda are the introductions. The women get up, one at a time,

and introduce themselves to the group. This is done at every session. For a proper introduction to the group you have to state your name and surname, as well as where you live. They also have to give a short summary of their health. That you are HIV positive, when you found out about your positive status (the year and month), why you decided to have an HIV test, whether you are taking ARVs or not and what your viral load and CD4 count is. Some of the mothers also tell the support group whether their children are infected with the virus or not. Many of them are, even though they are only a few months old and had access to PMTCT programmes. Women also make use of this as an opportunity to raise personal concerns to the group.

Introductions are followed by the weekly 'lecture'. These lectures are on educational HIV/AIDS topics such as the importance of adherence, alcohol and substance abuse, prevention of mother-to-child transmission, opportunistic infections and safe sex to name only a few. Afterwards women are provided with an opportunity to ask questions. These questions can be related to the 'lecture' or about anything else they had a desire to talk about. The meeting come to a close and a warm, cooked lunch is served. I often got the impression that this was the highlight of the day for most of the women. Once everyone finished their meals they would depart one by one until the next week.

The women were generally quiet during the meetings. Issues they raised usually centred around the topic of hopelessness. Ironically, though HIV/AIDS was often blamed as their reason for hopelessness, it is one of the only things they can have hope for. Women encourage one another by reminding them that the support group became their new family and they are there for one another. They also have God. Once, all of them were hopeless, but they used the medicine and now they do not need

to lie down in bed anymore, they can walk around and do things. However, there was little anyone could do to give them hope to find a job and acquire some kind of financial security. If women complained that they did not have food to eat, they could not depend on the others to offer them any, not even the healthcare workers, because all of them are suffering.

### **3.2.2 Home Visits**

Home visits depart from the carers' individual homes. Each carer covers a different area and they decide which support group members to visit on which days. The journey through the township is taken on foot. No appointments are made beforehand since most women attending the support group are unemployed and the chances are good to find them at home. Discouraged by repeated unsuccessful attempts to secure a job, many sleep till the late morning hours.

On home visits healthcare workers see to it that patients are taking their medication as prescribed and have enough food to eat. They also ask patients about their general health. Any concerns can be raised with the healthcare workers, such as troubles at home, domestic violence, and financial concerns. Information about other support group members are also often exchanged. In cases where members of the support group had disagreements this is reported to the healthcare workers and they try to resolve it. Resolving personal quarrels are important because members tend to refrain coming to the support group meetings when there is conflict between some of them. Individuals who have not been to the support group are questioned about their reasons

for absence and encouraged to rejoin the group. While they are out doing their regular rounds they also keep an eye open for people who might be in need of assistance.

Most of the women live in shacks. Some stand alone and others are extensions to formal houses. Each house is different. Some only have the basics, a table, pots, cutlery and crockery and maybe a chair or two. Others are rather spacious with complete lounge areas and fitted with a television and entertainment centre. Most of the shacks have 'pay as you go' electricity. This is one way to get your name on the waiting list for a government subsidised house. Ventilation is poor in all the houses making it a perfect environment to spread air borne diseases such as TB. Houses are remarkably clean and tidy regardless of the content. Outside is a different story. The streets and walkways are covered in litter. Broken glass poses an ever present danger to those who choose to walk bare foot or wear sandals. Toilets are dirty and it is unthinkable that people have to use it. Laundry areas are covered by dirty water and chickens flock around the area. Domesticated dogs are a common sight but their condition suboptimal. Many have visible symptoms of skin diseases and are underweight, and probably infected with worms. The narrow alleys between the informal dwellings are often flooded by heavy winter rains. Houses are built in close proximity to one another. In many places the alleys are only broad enough for one person to go through. Many regard this as dangerous because you can easily be cornered with no way out.

### **3.3 Lacking in Basic Human Needs**

While I was conducting my research the absence of some of the most basic human needs, and the effects thereof in the lives of the people I encountered came to my attention. Food and shelter is a constant worry, and being infected with HIV/AIDS makes you vulnerable to lose these basic necessities. Due to the little resources women have to secure these resources they are even more likely not to be able to secure food and shelter. Abraham Maslow (cited in Hergenhahn & Olson, 2003: 507) theorised that all people have needs which are categorised into different groups according to the importance thereof to an individual's survival. Physiological needs are the most important, followed by safety, belongingness and love, and esteem needs. Once all of these needs are satisfied self-actualization can take place. That means that they can make use of their full potential in life, and live life to the fullest. However, self-actualization is very rare since very few people's needs are fully satisfied.

Maslow (1954/1987: 17; cited in Hergenhahn & Olson, 2003: 507) wrote:

For our chronically and extremely hungry person, Utopia can be defined simply as a place where there is plenty of food. He or she tends to think that, if only guaranteed food for the rest of life, he or she will be perfectly happy and will never want anything more. Life itself tends to be defined in terms of eating. Anything else will be defined as unimportant.

For the majority of people I encountered during my fieldwork in the township, this was a reality. Food and shelter are both physiological needs (White, 2009: 20).

When these needs are not satisfied, all other things appear unimportant. If only they could be guaranteed food and shelter for the rest of their lives, life will be perfect. In

this section I will describe the daily challenges people encounter in an attempt to secure these resources and stay alive.

### **3.3.1 Food: The Most Basic Human Need**

Food provides the human body of the nutrients and energy it needs to function and maintain life. Without an adequate intake of healthy nutritious foods the body becomes malnourished and the person will fall sick. Food is regarded as a basic human right. Kent (2004) argues that merely being provided with the necessary nutrients and calorie intake does not fulfil this right. According to him “if people have no chance to influence what and how they were being fed, if they are fed pre-packaged rations or capsules or are fed from a throw, their right to adequate food is not being met, even if they get all the nutrients their bodies need” (Kent, 2004: 2). To fulfil the human right to food, people should have the sustainable power to access and provide food for themselves (ibid). For the hungry poor this human right is only words written on pieces of paper at meetings of international leaders with five star catering. Despite all the promises, people are still hungry and if you are HIV positive or suffer from AIDS, securing food becomes even harder.

The first thing she (founder of the organization) said to me when I started to work here was ‘... remember, if you want to do something and you want people to come you must have food available’. People attend things because they will get food and once they are there for the food then you can involve them in other things. If you want a programme to succeed you must get people

involved. They will come for the food because they are hungry (Conversation with NGO staff member).

You do not need to spend a lot of time in a township to realise that food and the lack thereof is a concern to the people. Soup kitchens are common and the queues are long. Crèche's and kindergartens provide children with breakfast, snacks, and lunch. For many of the children privileged enough to attend one of these centres, it is the only guarantee that they will have food that day. At afterschool programmes snacks are provided and there are never any complaints about "I do not eat this" or "I do not like that" as you would get in most middle income households. There is only appreciation that they are given something to eat. When I asked about the support group, lunch was mentioned repeatedly.

At the support group I could not help but to get the impression that lunch is the highlight of the meeting. There was only one meeting at which I was convinced the women showed up for more than just the food. That was when a doctor from the United States paid the centre a visit and answered all their health related questions to which they never receive satisfying answers at the clinic. All the other times there was little interaction and enthusiasm from the women during the meetings. They just went through the motions and ate, and ate some more. After a few weeks at the support group I realised that these women are not only hungry because of the absence of food in their homes. Many were hungry because they had HIV/AIDS.

Though I was not hungry it was obvious to me from day one that I have to eat with them. At first I felt guilty doing so. I have more than enough food at home and, like most middle class people, I often have to rid my fridge of spoiled food. How can I eat the little food they have when I have too much? But for them my eating with them was not so much about filling my stomach or not, it was about my willingness to eat with people infected with the virus, sharing plates, cutlery and glasses with them as I would with any other person. As one of the support group woman told me,

I love to cook, but before I came here (to the support group) I could not cook...

The people in my house did not allow me to cook at home because I am HIV positive. But here I am allowed to cook, so now every Tuesday I come here early to help prepare the food for lunch.

Stories like these are still common. People complain that they have to have their own separate plate, mug and cutlery. Some even complain that the people they live with do not want to give them food at all because they are positive. This happened to Thandi.

It is a late Monday morning and we just finished with the weekly meeting of the healthcare workers when the centre manager, Jan, comes to tell us that Thandi is there and she is having some kind of problem. I have seen Thandi before at the centre. She appears to be fine and it takes a while before I am filled in on the details of the story. For a while now Thandi has been complaining about problems at home. She is originally from the Eastern Cape and is now living with members of her extended family in a shack. We have been to her house before. She gave birth to a boy and we visited her a few days after she was released from the hospital to see how she was

doing. The child was born early and they had to do a caesarean because her blood pressure was dangerously high. I do not think I will be able to find the house by myself again. I can remember in which area it is, but I'll get lost in the maze of similar looking houses and flooded footpaths in between. The shack is small and had only two rooms. A kitchen, which doubled as a living area with barely enough space for the six of us to stand in, and a bedroom which was shared by all the residents of the house. From what I could tell that day she was living with two other women. They are the problem. Thandi is unemployed and can't find a job, and is still recovering after the birth of her child, but they do not want to give her food or money to buy food and are threatening to throw her out of the house. After days of worry and having nothing to eat she decided to come to the centre and ask for help.

Elizabeth is highly upset about this matter and decides that action should be taken immediately. Thandi has been planning to visit her mother in the Eastern Cape but does not have the money to do so. Elizabeth decides to lend her the money for a bus ticket. They decide that it would be best if she leaves today because here the matter is only getting worse. But before Thandi leaves for the Eastern Cape she must first get something to eat.

Elizabeth: Can anyone of you take her home and give her something to eat?

All three the healthcare workers say no.

Lisa: I don't have food at home. There is nothing I can give her.

Elizabeth: I will give you food. All you need to do is prepare it.

Nokosazana: Sorry, I can't. I have to be somewhere.

Elizabeth: I will give you the food, some of the centre's emergency food and you can keep the food you don't use for yourself. We just need a place to prepare the food because she (Thandi) can't go home and prepare it there. They won't let her.

Still no one volunteers. Then one suggests that we ask the centre manager whether he can do it. His house is close by after all. They call him and ask.

Jan: Yes, but I can't leave now because there are people coming here and there is no one at home to help her... Can't we use this kitchen here?

Everyone seems to think it is a good idea but Elizabeth still has a facial expression of disbelief. The expression I was trying to hide on my face. Just before Thandi showed up they were all anxious to get home for lunch but they can't take a desperate 'friend/family member', as they call each other at the support group, home and prepare some food for her, at no cost whatsoever.

Elizabeth: Okay, then we'll use this kitchen. What will we give her? ... How about bread then she can take some with her on the bus.

The healthcare workers respond with an almost eagerly 'yes'.

Elizabeth: Where is the closest shop where we can find bread and something to put on it?

Patience: There is a spaza shop just around the corner.

Elizabeth: Who can go there and come make the sandwiches?

Nokosazana: I can't. I have to go.

Lisa: I also have to get home.

Patience: I will go. Just bread and jam?

Elizabeth gives her some money and she quickly runs to the shop.

After this event it dawned on me that everyone, support group members and the healthcare workers, face the same challenges at home. Unlike most of the support group members, the healthcare workers are in the privileged position to be employed and enjoy more financial security, but the money isn't theirs to do with as they please. It is needed to fill the stomachs of those at their home who are unemployed and struggling to find jobs. There are no leftovers to share with members of the support group who are in need because they themselves barely have enough. As Lisa tried to explain to me: "Each night when we dish up there are seventeen plates we have to fill". I tried to imagine what that little kitchen looks like when seventeen people are waiting for dinner. "Wow, seventeen? That is a lot of people! How much does that cost?" I said, clearly surprised. "Yes, it is expensive and many of them don't have jobs, but we have to feed everyone... and on top of that it is my neighbour's birthday in a few days and she gave me a present so I have to give her something as well ... the present she gave me was expensive so I can't give her something cheap. And I have two sons and their dad is not here so I have to take care of them all by myself". I interrupted her and asked her more about her sons. "The one has just been initiated and I had to buy him new clothes and bedding ... yes, when they have been initiated they have to get everything new because they are men now and they can't use their old stuff from when they were boys anymore ... and the other one is going to high school, so he has to get new things as well and it is almost Christmas, so I have to buy a lot of people gifts... I worry, I don't know how I am going to pay for all of that."

Yes, the cost of living is a constant worry and community based healthcare workers simply do not have the financial resources to help the support group members in times

of need, but it is the fear of the social price they have to pay that makes them hesitant to take people in need home and invite them into their private spaces, even when there are no financial costs involved in doing so. Being HIV positive or suffering from AIDS makes you vulnerable to lose the most basic human need without which you cannot live.

### **3.3.2 Shelter: A Safe Haven**

Like many other developing countries, South Africa is experiencing rapid urbanization. This trend together with the legacy of Apartheid which prevented non-whites to reside, or own property in white urban areas creates significant housing challenges for the government. Not only is housing a problem for the government, but also land on which to build the houses and the provision of basic services such as sanitation, running water which is safe for human consumption, and garbage disposal. Government's inability to provide houses to the increasing urban population results in even larger townships and more people living in informal, unsafe housing where conditions are suboptimal and pose several health risks to those residing in these settlements.

From the outside it appears as if anyone can enter a township and erect a shack on an empty piece of land. The materials used for these shelters are not expensive and relatively easily obtainable. However, it is a lot harder than that. People move to the cities in search for a better life. The rural areas they have left behind are impoverished with no or only limited opportunities to escape from their poor socio-

economic status. When they arrive in the urban areas of the 'promised land' the context differs but the conditions remain the same. There are few employment opportunities and they have to rely on the kindness of others to provide them with a place to stay and other basic necessities. Women unsuccessful in attempts to secure employment often resort to transactional sex or commercial sex work in order to 'pay' for boarding in an already overcrowded shack or 'rent' her own. As is the case with food, those infected with HIV/AIDS find it more difficult to secure shelter, and run a bigger risk of losing it.

Marie is a 34 year old HIV positive woman. She is living in a small village outside of the town. She is a single mother of four children. The three older children, age 16, 14 and 12, are HIV negative, but the youngest, Rebecca, is positive. When Marie was seven months pregnant with her youngest daughter, who is now seven years old, she got tested for HIV and the results were positive. At birth she was given a single dose of Nevirapine and avoided breastfeeding at all costs, but all her efforts proved to be ineffective and her daughter is now also living with HIV. Rebecca's father is also positive and using ARVs but not playing an active role in their lives. Financially, Marie is on her own, and though she has a permanent job and only has to take care of three of her four children (the oldest daughter and her grandchild is living with her daughter's boyfriend) money is a constant worry. Her main concern is that the day would come that she will be unable to pay her rent of R50 per week on time and be asked to evacuate. That will leave her and her three children on the street. They are living in a shack in someone's backyard. It is a small shelter and they have no access to electricity or any bathroom facilities. There is access to running water on the plot. However, the conditions she described is clearly not in accordance with policies of

sanitation and the human right to "... housing, and the continuous improvement of living conditions" (Kent, 2004: 2). However, it is all Marie can afford as a single mother of three.

Living with HIV/AIDS the possibility to fall critically ill at any given time is always lurking in the shadows. If Marie falls ill she will be unable to work and thus be unable to pay her rent and consequently she and her children will be faced with life on the streets. In case of illness she will not be able to tell her landlord that she is suffering from HIV/AIDS and beg for mercy, because in her community "people reject you and besmirch your name when they find out you have the virus". If her worst nightmare becomes a reality she will not be able to rely on the mercy of others, because there is no mercy for people who bring the disease into public awareness. In fact, she fears that she will be asked to move out if her status is disclosed to her landlord even though she has good general health and pays her weekly rent diligently. Marie has applied for a government subsidised house, but has been waiting for years now and she does not know when her day will finally come to receive one.

This is a concern for many people living with the virus. People still believe that HIV can be transmitted by merely occupying the same space as an infected individual. As a result, the centre has decided to build a home where they can take care of people who have been released from hospital but who are still too weak to be taken care of at home. There are several difficult hazards involved when taking care of a critically sick person in an informal housing environment. People have to walk far distances to reach public toilets. Distances most sick people who have just been released from

hospital cannot undertake. Apart from the distance it is dangerous, especially at night. There is no light and the construction of the shacks makes it almost impossible to escape if you are attacked. Then there is the issue of hygiene. The toilets are shared with many and no one takes the responsibility of cleaning it. If they had a choice, most would not make use of it. However, people living with HIV/AIDS often complain that they cannot use the toilets. They say that once their positive status has been disclosed to their neighbours, or their neighbours suspect they might be infected with the deadly virus, they lock the toilets and refuse to give a key to the infected person. This is illegal but people choose to take matters in their own hands because they fear they will be infected if they share toilets with infected people. Water needs to be fetched from central water points and many only have limited electricity, and houses and rooms are overcrowded, leaving little space to take care of a sick person. In some cases families refuse to allow a person back into their homes after they have been released from hospital because they do not want to share their homes with someone living with HIV/AIDS. Despite all the educational campaigns on HIV and AIDS, many still believe that the virus can be transmitted by sharing public toilets, sitting on the same chair as an infected person, or using the same eating utensils. These misconceptions make it extremely difficult for those infected to live a normal life once they have disclosed their status to the community. Thus, as is the case with food, shelter can be taken away from an individual because they are infected with HIV/AIDS, leaving them vulnerable to the elements and making it almost impossible to fight off opportunistic infections and live a long and productive life despite being infected with HIV/AIDS.

### **3.3.3 Living Arrangements: Inadequate Satisfaction of Needs**

The houses the people live in are small, and include one bedroom dwelling, which can usually do with a new layer of paint and a floor repair. However, people with the privilege to live in a brick house do not complain about these things, though they do dream of the houses they see on television in lifestyle programmes and in magazines. For most people not living in a shack is something to be thankful for and they do not complain about the conditions of their houses. Most yards are filled with shacks where extended family members usually reside. Having a private space of your own is out of the question. All rooms in formal and informal houses are shared with at least one adult, and if you are a mother with a small child you are likely to share your bed, a single bed not a double or three quarter bed, with your child. In communities where TB infections have reached epidemic proportions, and is believed to contribute to the HIV/AIDS burden as well as general morbidity and mortality, such living arrangements are especially worrying.

Corbett and colleagues (2003, cited in Escombe, *et.al.*, 2007: 0310) reports “Infections transmitted by the airborne route are the leading causes of morbidity and mortality worldwide, with tuberculosis alone causing 1.8 million deaths each year”. Tuberculosis is an airborne disease which means that the TB bacilli is transmitted from one person to the next through air. It is estimated that “each person with active TB infects on average ten to fifteen people every year” (World Health Organization, 2009). Tuberculosis is regarded as a disease of the poor and people co-infected with HIV/AIDS are “20 to 40 times more likely to develop active TB” (World Health Organization, 2009) than their negative counterparts, and are less likely to fight it off.

Among people living with HIV/AIDS, TB is one of the leading causes of death (Centers for Disease Control, 2009). Approximately one third of all HIV related deaths are caused by TB infections (Cape Gateway, 2009). Preventing HIV/TB co-infections are key in the strategy to combat both epidemics. Ensuring proper ventilation is one of the most effective and economic preventative measures that can be taken to prevent the spread of TB. Rooms, with natural ventilation, where all doors and windows are closed that prevent almost all ventilation, pose the highest risk of TB transmission from an infected individual to those uninfected with the bacilli (Escombe, *et.al.*, 2007: 0314). These undesired conditions are the exact conditions most poor people, infected with HIV/AIDS and TB, live in.

On one of our home visits we go to Nandi's house. It is a cold, rainy day in August and we are paying her a visit with the healthcare programme coordinator because it has been reported that she is not taking her medication. This is not the first time she is showing poor adherence. Apart from being HIV positive she is also co-infected with TB.

Nandi lives in a room (shack) in relatives' yard outside their house. A narrow passage between her room and the house leads to more extensions in the back yard. In front of her room there is another room which is occupied by male relatives. Her father also lives in one of the rooms. In front of her room, next to the room of her relatives was a huge pile of bottles. Most of them appeared to have been filled with alcohol at one time or another. I could not tell whether it was the evidence of a good party over the weekend or collected by someone for recycling purposes because glass and plastic

were separated. From the outside, the front view of the room did not have any windows. A ramshackle door opened to a room with just enough space for two single beds and a nightstand. Nandi and her son shared this room with one of her relatives. The room is dark and there is no evidence of a window and the room is stuffy. When we enter Nandi and her son are sitting on the bed on the right.

She is visibly ill. Nandi is underweight, almost anorexia like, and is very weak. She whispers so softly that you can barely hear her. She fell ill in March that year and went to the hospital where they started her on treatment for AIDS and TB. When she was released from the hospital she started to turn her life around and quit her old, bad habits. She stopped drinking (or maybe she only says so because she is afraid the healthcare workers and nurses at the clinic will be angry with her if she tells them she still uses alcohol), attended the support group and adhered to her medication.

The coordinator takes the lead and is anxious to find out why she is not taking her medication. Repeatedly her questions are met with silence. She does not give any explanation to why she is not adhering to the doctor's prescriptions. After many attempts Nandi says that she has stopped taking her medication because one of the healthcare workers told her that she cannot go back to the clinic because she will infect the people there. Thus, when her medication was finished she could not go back to the clinic to get more. The accused healthcare worker, Nokosazana, was with us at the time and this statement angered her a lot. She said it was all lies.

I (Nokosazana) never told her that she must not go back to the clinic. What I said was that she should not come to the support group anymore because she has TB and is still in the stage where it can be carried over to the other people there. Once she cannot infect the other people anymore she should come back. That is what I said, not that she should not go to the clinic and not take her medication.

Then the healthcare worker stormed out of the room. The coordinator continued the conversation in a much calmer tone, trying to get to understand why Nandi does not want to adhere. Elizabeth goes through all the common reasons, “does the medication make you feel sick, did someone tell you something about the medication, are you depressed and want to die?” When there is still no answer or explanation for her actions, Elizabeth reminds her of her sister and asks Nandi whether she wants the same to happen to her and her child. Like Nandi, her sister was a single mother, HIV positive and co-infected with TB. She also defaulted on her medication and passed away. Now her child is living with people in Khayalitsha. Nandi is a single mother, if something happens to her, her son will be an orphan. His father is nowhere to be found.

Just as we were about to leave Nandi finally gives us an idea of what is bothering her and why she is not taking her medication.

It is because I am HIV positive. I can't go anywhere because I am positive.

Again, after months of coming to the support group and getting home visits from the healthcare workers, it is explained to her that she can't give people HIV by going to

the clinic or coming to the support group *for HIV positive* women. Untreated TB can be transmitted to others in these conditions and that is why it is so important that she takes her TB medication and not develop a resistant TB strain. However, I could not help but find it strange that there is such a big concern that she will transmit the TB bacilli to other members of a support group if they can ventilate the room properly - though most people are more concerned about being in a warm room than a well ventilated one to prevent TB transmission – and no one expressed any concern about possible infection to those who are sharing a room with her with no ventilation. Nor did I ever hear any of the healthcare workers tell people infected with, or sharing a house with people suffering from TB, that they should try to have good ventilation in the rooms or house to prevent transmission. HIV/AIDS is often blamed for many social, health, and socio-economic issues, as a result other opportunities to improve the health and lives of millions are overlooked.

In our modern society, money is needed to secure these basic needs. However, in a country like South Africa where there is an unemployment rate of 24,5% (Lehohla, 2009: X) there are millions who are unable to do so. Social grants from the government provide people with little support, especially when they need to support a whole family. As a result, too many people's basic needs are not met, preventing them to participate 100% in our society.

### **3.4 Disclosure and the Social Cost of HIV/AIDS**

People living with HIV/AIDS are strongly encouraged to disclose their status to at least one other person. In some cases disclosure is compulsory in order to obtain treatment for the disease or to work as a healthcare worker. It is regarded as a measure of whether people have accepted their status, and are willing to make the necessary adjustments to their lives. However, disclosing your status, as I mentioned above, can have devastating effects on your life. The more time I spent among HIV positive people in their living environment, the more I realised that to them disclosure has a totally different meaning compared to the meanings used by health organizations. Though some people say that they are living openly with HIV/AIDS, they have only disclosed to a selected few and are not living openly with the disease in the sense that they do not care who is aware of their positive statuses. As one of the women at the support group told me during an interview.

Before I did not want to leave my house. I was too afraid to come out. I just sat there (at home) and cried, waiting for the days to pass by. But since I have been coming here (to the support group) I live openly with HIV. Everyone knows I am positive and I am not afraid to leave my house anymore. I do not care what people say about me in the streets. ... I live with my son, he is fifteen years old. ... No, he does not know that I am positive. I will tell him when I feel the time is right.

This is not only a problem with support group members. Healthcare workers who have to set an example of what it means to live openly with HIV/AIDS also do not disclose to as is expected from them by their employers. A programme coordinator told me during an interview

We are having so many problems with the counsellors. It is our policy that the women who work for us should have disclosed their status to their family and must not be ashamed of living openly with HIV/AIDS. But, then later we find out that no one at home knows about their status and they say that they can't tell them (their family members).

Though healthcare workers have to be living examples to their clients of what it means to live an active life despite being infected with HIV/AIDS, they too encounter stigmatization in their communities, and sometimes from their own family members. When I asked a counsellor, who works for an organization that requires them to live openly with HIV/AIDS and not hide their positive status from anyone, she told me

You know what it is like. We can't tell the people in our community that we are positive. We only tell people that we are positive in one-on-one counselling sessions. That is the first time that they find out about it.

Because the social price of living with HIV/AIDS is so high, people living with HIV/AIDS, healthcare workers as well as their patients find it hard to be truly open about their status. At each support group meeting women talk about how much they enjoy the freedom of living openly with HIV/AIDS. How much lighter the burden is now that they have shared their secret with others. That they feel they can live again. But once there is an unsuspected knock on the door, everyone stops all talk about HIV/AIDS "because they (strangers who are not part of the group) will tell if they hear us talk about being positive". Living openly with HIV/AIDS is confined to the four walls of the support group.

For the members of the support group as well as the healthcare workers it is of utmost importance that those who attend the support group meetings will not tell anyone who is not part of the group about each other's status. While walking through the township during one of our home visits three women drinking outside of their house approach us. They were clearly intoxicated. They wanted to know whether we were from the centre and started to tell their story to the healthcare workers.

We are positive and we do not know what to do. We have no one to talk to so now we just drink to forget about it.

Part of healthcare workers' responsibilities include recruiting new members for the support group. These women are perfect candidates. They are HIV positive and need guidance on how to improve their lives and support in doing so. But, instead of talking to the women and providing them with emotional support and giving them advice on living a healthy, productive life with HIV/AIDS, they tried to get away from them as soon as possible. One of the healthcare workers took me by the arm and started to lead me away from them while the other one told them,

If you want to talk you have to come to the support group. There is a meeting next Tuesday, you can come then.

Being confronted with people who are openly talking about HIV/AIDS in a public space where it could be overheard by any bystanders was clearly too much to bear for the healthcare workers. The risks involved when too many people know about your status are just too much, even for the healthcare workers. All talk about HIV/AIDS

must, at all times, be confined to private spaces where only fellow bearers of HIV/AIDS can come to know about your secret.

### **3.5 Female Bodies as Commodities**

As is the case in other poor shanty towns young girls often rely on their bodies for financial security. Participation in commercial sex work was never mentioned by any of the interviewees but transactional sex was. Commercial sex refers to acts where money is exchanged for sex. Transactional sex refers to situations where a person enjoy material benefit because of a sexual relationship, such as food, clothes, or shelter. Though both transactional sex and commercial sex work involve share certain characteristics, such as it being non-marital sexual relationships which often involve multiple sexual partners and involve material benefit for one of the sexual partners, there are important differences. People participating in transactional sex “are constructed as ‘girlfriends’ and ‘boyfriends’ and not ‘prostitutes’ and ‘clients’, and the exchange of gifts for sex is part of a broader set of obligations that might not involve a predetermined payment” (Hunter, 2002: 100). Bartering your own body is frowned upon and no one admits doing it but knowledge about these practices are common. Only a few denied having knowledge about such relationships. Young girls are involved in sexual relationships with older men for material gain. This phenomena is also known as sugar daddies. Though some women said they are highly opposed to the idea that girls use their bodies for food and clothes and other luxuries, some said that these girls’ mothers encourage them to date older men to gain from the gifts their daughters receive. Others said that bartering their daughters’ bodies was the only means for them to get hold of basic necessities.

Teenage pregnancies are common and a concern to most. Peer pressure is blamed for the increasingly young age at which children become sexually active. Many also believe that parents' unwillingness to speak openly to their children about sex and the dangers thereof contributes to the high number of unwanted pregnancies among adolescents, as well as infections with HIV and other STD's. Young girls often fall pregnant in the hope that their boyfriends will ask them to marry. Unfortunately, most girls are abandoned by their lovers when it is revealed that she is pregnant. Leaving girls to take care of the baby all by themselves.

Thus, women, and girls at an increasingly young age, barter their bodies in order to secure basic necessities, and some of the luxuries they desire. Because of the unequal power relationship between the women and the men they depend on, these women have little power to negotiate safe sex with their partners leaving them at the mercy of fate. As women and young girls are often abandoned when they fall pregnant, they are also abandoned when it becomes known that they are infected with HIV. Men refuse to get a HIV test when their partners disclose their status to them. They believe that it is the women they slept with who had the virus before she met him, regardless of her age or sexual history.

When they (men) hear their girlfriends are HIV positive, they just simply leave because they believe they are negative and do not want to get infected ... No, they don't want to get tested to find out the truth, they just leave them and go on to the next girl and when she gets ill as well, they just do the same thing again because they blame the girls ... Yes, even if she is a lot younger than him

and only had one or two boyfriends, or maybe even no boyfriend before him, they still don't believe that they could have infected their girlfriends.

In other cases where women were in a romantic relationship rather than a materialistic one, and they told their partners that they were infected with HIV, the men usually agreed to get tested, but still refused to use condoms. In some cases the HIV negative men refused to use condoms though they knew their girlfriends were HIV positive.

My boyfriend does not want to use a condom... Yes, he knows I am positive. When I got tested I told him I tested positive and that he should also get tested. He tested negative. He goes for testing every three months and the last test was also negative.... He does not give a reason why he does not want to use a condom, he just does not want to do it despite knowing my status (HIV positive women).

### **3.6 Conclusion**

Life in townships is associated with many social issues. People face high levels of unemployment, they are poor and struggle to make basic ends meet. It is the desperation to stay alive that drives them to participate in behaviours that put them at risk of HIV/AIDS and other life threatening illnesses. Though HIV/AIDS undeniably contributes to the poor socio-economic circumstances of the majority of those living with the disease, many were already living in similar situations before they were infected. Therefore, I would like to argue that it is their socio-economic circumstances that is their real challenge and that HIV/AIDS is not the reason for the constant suffering and hardship, but the broader socio-economic circumstances are,

and being infected with HIV/AIDS is but one of the consequences thereof. With the little resources available to them they can fight HIV/AIDS once they have acquired access to the necessary healthcare services, such as being provided with ARVs. They can take the medication and live a normal life. However, they do not have the resources to protect themselves from getting infected. Nor do they have the resources to take care of themselves holistically, because they can barely afford food and shelter. Self-help methods to improve your life when living with HIV/AIDS are simply too expensive for most to afford. To these women, HIV/AIDS is a 'scapegoat' and the real challenge they face is surviving the battles of life.

## CHAPTER FOUR

### ACCESSING TREATMENT

#### 4.1 Financial and Social Costs of Accessing Treatment

Health authorities argue that the war on HIV and AIDS can be won if people get access to the necessary medical services and information on how to protect themselves and others against infection with the virus. The vast majority of the interventions currently aimed on combating the global HIV/AIDS epidemic are based on the medical science of the virus and the disease. By 2003 the disease has claimed 30 million lives since the 1980s (World Health Organization, 2003 (b): 3). Most of its victims are people in the prime of their lives. People whose lives could have been saved if they had access to the necessary medical services. Antiretroviral treatment has been associated with a significant decrease in HIV/AIDS related morbidity and mortality (Naimak, 2006: 6). In 2003 the World Health Organization (WHO) declared the lack of access to ART a global health emergency. Various international organizations partnered in order to address this issue and the body is now known as the Joint United Nations Programme on HIV/AIDS (UNAIDS). To date, great advances has been made in this regard. In 2003, the goal was to give 3 million people in low and middle income countries access to ARVs by the year 2005. This goal has finally been reached by the end of 2007. However, in that same year, 70% of the people in need of ART did not have access to it (Joint United Nations Programme on HIV/AIDS, 2009: 9). This backlog is worsened when we take into consideration that for every two people who get access to treatment, five people are newly infected with the virus (Joint United Nations Programme on HIV/AIDS, 2009: 4). Thus, preventing new infections are crucial in the war on HIV/AIDS. However, as I explained in the

previous chapter, people's circumstances often 'force' them to behave in ways that can put them at risk of infection. Because of the significant impact of HIV/AIDS on local economies in high prevalence countries it is necessary to treat infected people to enable them to be active members of the society and prevent them from becoming a burden on the government and healthcare system. To accomplish this, ART is necessary.

For long the lack of ART in poor and middle income countries was attributed to possible poor adherence. In order to have a successful treatment outcome it is necessary to have 90% adherence rate. If not, resistance to ART can develop limiting future treatment options for the patient as well as those who might become infected by this individual. However, studies have indicated that poor adherence often observed in poor and middle income countries is because people can't afford the treatment. People barely have enough resources to feed themselves and their families. They simply do not have enough money to pay for life saving treatment as well. Consequently, the necessity to make ART available to people free of charge was recognised. Making ART available to people is usually regarded as having enough medical facilities and staff available to distribute the medicine, free of charge, to those in need of it, as well as having enough medication available to patients who require the treatment. However, despite having treatment available, free of charge, to those in need of ART, there are still financial costs, and social circumstances involved that can prevent people from accessing treatment and showing good adherence. It is these circumstances that will be discussed in this chapter.

For the HIV positive and negative people I encountered during my fieldwork, unemployment and the lack of financial resources and security is one of the biggest challenges they face on a daily basis. It is estimated that almost a quarter of South Africa's population is unemployed, excluding the thousands of South Africans who are too discouraged to continue to seek employment (Lehohla, 2009: X). This means that millions of South Africans are dependent on others' kind heartedness for a place to stay, and to be able to eat and dress themselves. Those who are supporting the unemployed are usually living on minimum wages themselves, which is barely enough to cover the living expenses of a single individual. When someone in a household falls ill, or worse, when the breadwinner of a household falls ill, it puts tremendous stress on the little resources available to them. Before ARVs were available, free of charge, to those in need of treatment, it was the costs associated with treatment that were blamed for poor adherence among patients in poor and middle income countries (Mills, et.al, 2006: 2056). Other issues associated with poverty, such as poor and unstable housing, and living far away from the clinic have also been associated with poor adherence (Davies, et.al. 2006: 896). Nguyen (2005: 133) argues that this is part of the 'illness/poverty' trap that is associated with HIV/AIDS. This means that people become poor(er) because they are ill, and they are unable to escape poverty because the costs associated with their illness are too high, and because they cannot afford treatment they remain sick and eventually die because they could not afford treatment.

In 2002, the Treatment Action Campaign (TAC) sued the government for not providing ART to people living with HIV/AIDS and consequently allowing people to die from a treatable disease (Treatment Action Campaign, 2005). The case was won by TAC and in 2003, a national ARV roll out programme was initiated. Highly

Active Antiretroviral Treatment (HAART) has been associated with slower progression from HIV to AIDS (Balfour, *et.al.* 2006: 830), and significantly reduces morbidity and mortality among people living with HIV/AIDS (Coetzee, *et.al.* 2004: S27; Davies, 2006: 895). Making this treatment available to people, free of charge, can thus save many lives and enable people living with HIV/AIDS to live a normal productive life. However, there are still many costs involved in accessing treatment. Both financially and socially.

#### **4.2 The financial cost of physically accessing a Clinic**

A 'visit to the clinic' entails a lot more than merely going to the clinic and having your monthly check up. If you are one of the patients privileged enough to have a job you need to seek permission from your employer to take a day off of work in order to visit the clinic without running the risk of losing your job. Many of the patients attending clinic A are from neighbouring towns. Depending on the town they are from, they need to make the necessary travel arrangements. Most patients make use of the ambulance travelling to and from their town to clinic A. They need to book a seat in the ambulance beforehand and pay a fee between R20 and R40. However, many of the patients do not live in town and they need to arrange additional transport from the farms they live on to town. Some get lifts from family members, friends or their employers. However, there are those who have to walk from home to the place of departure. Others try their luck hitching a lift to the clinic or place of departure along the road somewhere. However, these attempts are not always successful and they sometimes miss the ambulance or arrive at the clinic very late. Others, usually people from towns nearby, travel to the clinic by taxi. This is usually more expensive.

Only a very small number of people have access to private transport. This means that for most patients the actual 'visit to the clinic' starts at the break of dawn and with a minimum cost of R20. A cost that is almost double the poverty line of \$1.25 per day. In a country with high levels of unemployment and poverty, it is a price many can't afford to pay.

Once patients have arrived at the clinic, some after travelling for more than an hour, a day of long queues and waiting for the sound of someone calling your name awaits them. Upon arrival you have to report at the ID clinic or front desk. The sooner you do this the better because they work on a 'first come first serve' basis. Though the clinics open at 07h00, patients are only seen after 08h00. Patients have to wait in line to be seen by the nurses, doctor, as well as at the pharmacy where they have to collect their medicine. Even if you do turn up at the clinic at 07h00, you will most probably have to wait until 10h00 before you can leave. That is if you have access to transport that can take you home immediately after you are finished. Those who are dependent on the transport services offered by the public health sector (ambulance) has to wait until 16h00 before they can go back home. Some only arrive back home after sunset, and usually they are bombarded by questions about why you had to go to the clinic once again. Thus, repeated, regular visits to the clinic make people suspicious that a person might be infected with HIV/AIDS, because people know you have to visit the clinic regularly if you are infected.

Suffering from HIV/AIDS is not only a medical condition, but also a social one. As the virus can kill your physical body, knowledge of the disease in your community

can result in a social death. The disease is highly stigmatised and people whose status is known to the world often endure gross acts of discrimination and violence. In some cases people have been killed because of their status (Zaccagnini, 2009). Due to the highly sensitive nature of the disease, special precautions are taken to protect HIV positive people's identity. However, despite all the official attempts to keep people living with HIV/AIDS' status secret, there are many other situations, over which patients have no control, which can potentially disclose their status.

The South African constitution states that no individual can be forced to have an HIV test. After pre-test counselling a patient needs to sign a consent form indicating that he/she is having the test out of his/her own free will. Patients' medical records indicating that they are HIV positive or suffering from AIDS are often kept separate from their other medical records to ensure that their HIV/AIDS identity remains a secret between themselves and their health care providers. Unfortunately many patients feel that their identity is only treated confidentially on paper, and in real life your status becomes known to others by the places you visit.

#### **4.3 Financial loss due to a visit to the clinic**

The HIV status of many of the people I interviewed was often common knowledge to their employers. Questions about their frequent absence from work to visit the clinic often led to eventual disclosure. To my surprise many of these people were glad their employers know about their status because of the empathy and support they received from them. They did not fear losing their jobs because of their status. This was

especially the case for people working as domestic workers and some farm workers. However, most were initially afraid to disclose their status. The number of years they have been employed by the specific employer and the size of the organization appear to contribute to the support they got from their employers. The longer they have worked for the employer and the smaller the organization is, the more support they received. Some of them did not have to give up their sick leave to visit the clinic. Domestic workers said that though their employers are aware of their status they do not mind that they prepare their food or care for their children. Their employers appeared to have a good comprehension of the disease. How each of these patients' disease and the treatment thereof was treated by their employers differed. One of the domestic workers was encouraged by her employer to have an HIV test after she fell ill repeatedly and seemed unable to make a full recovery from any of her ailments. Throughout the process she was supported by her employer and still is. Another woman was especially thankful for the support her employer offered her with her monthly clinic visits.

Each month when I have to come to the clinic she phones the ambulance to book me a seat and gives me the money to pay the ambulance. When there is a mix up with the ambulance [the ambulance does not travel to the clinic everyday] she phones the clinic and asks the nurses to reschedule my appointment. One time it happened that we could not reschedule my appointment and she brought me to the clinic herself [it is approximately 140km return trip]... My appointment was not the only reason she came here. She scheduled her things for the same day as my appointment so that she can take care of it while I am at the clinic.

Two women also told me that their employers have arranged with the clinic to send them extra medication if they were unable to get to the clinic on the day of their appointment. An arrangement between the ID clinic and their local clinic would be made to send the patient's medication to their local clinic with an ambulance. Due to the regulations in regard to the roll-out of ARVs, this only happens on very special occasions.

Patients who were employed by larger organizations were not privileged to enjoy this kind of special treatment. Costs to large corporations with high numbers of employees living with HIV/AIDS will be too high. In addition, workers can insist that exceptions should be made for all employees living with a chronic illness, not only people with HIV/AIDS. Thus, logistically, and to remain fair to all the employees, it is better to treat everyone equally. Some of their employers had knowledge of their HIV status, but generally people were less comfortable sharing this information. The more impersonal work environment of bigger companies can be the cause of this. To most of these patients a visit to the clinic in relation to their work only meant that another day's sick leave has been used. When they had no more sick leave, they had to use their regular leave or take unpaid leave. Most patients only had ten or twelve days sick leave per year. This left them unable to come down with the flu or any other ailment that might keep them out of work. They also had to take a letter from the clinic to proof to the employer that they were in fact attending a clinic. Wage workers on the other hand had less administration to take care of. They just lost their income for the day all together. Thus, apart from the travelling costs involved in visiting a clinic, patients also often lose some of their income because they have to take the day off work. For people who earn a minimum wage, the loss of one day's

pay can have major consequences since they have no money to spare as it is, and having even less can mean going to bed without food. Nutrition is crucial in the treatment and care of people living with HIV/AIDS. It is argued that “proper nutrition helps to strengthen the immune system, manage opportunistic infections, optimize response to treatment, and may contribute to slowing the progression of the disease” (Castleman, Seumo-Fosso & Cogill, 2004: 3). Thus, if a person suffering from HIV/AIDS cannot afford healthy, nutritious meals, it can compromise the treatment outcome of that patient.

Most employed patients did not fear losing their jobs because of their positive status. However, unemployed patients did see their status as an obstacle in the process to secure a job. They fear that they will have to disclose their status in order to attend their monthly clinic visits or that employers will rather give the job to someone who is HIV negative because they will not have to be absent from work as often. Others fear that they will not be able to attend their monthly visits if they were permanently employed. This fear often goes hand in hand with the fear of having to disclose their status to an employer to be granted absence from work without disciplinary consequences, such as a written warning. Starting a new job was the reason of one woman, who has an exceptional attendance and adherence record for both her and her daughter, to miss an appointment.

The only appointment I have ever missed was when I just started at my current job and had an appointment the next week. I felt that I can't ask my new boss to give me a day's sick leave because I have only worked there for a week and was afraid that I will lose my job if I ask things like that after only one week.

Some even fear that having a job can create situations in which suspicion can be raised about their status. One woman refrained from seeking a job because she feared situations such as the following:

The only work available for me is farm work in the orchards. You can easily get hurt in that type of work. You can cut your finger or something and then when people want to help you, you need to tell them that they can't touch you without gloves and they will want to know why. Then you have to tell them or they will just figure it out themselves and people will know I am positive. I can't take that risk.

Constitutionally, there is no reason for people to have these fears. Some people do manage to hide their positive status from their employers and colleagues. People are not obliged to tell their employers the reason for regular visits to the clinic. Many resort to telling of 'little white lies'.

No one knows that I am positive. When people at work ask me why I have to come to the clinic every month I tell them it is because I am a diabetic.

Nor do official letters from the clinics state their reason for attending, only that they did attend a clinic. But, as the quote in the previous paragraph shows, the Constitution can't always protect people from the realities of life. However, unfortunately there has been several reports of people living with HIV/AIDS who were dismissed or refused employment because they were infected with the virus.

#### **4.4 The Social Risk of Attending an ARV roll-out site**

Despite health care professionals' and constitutional efforts to protect the identity of those who are living with HIV/AIDS, people still have the ability to observe their environments and that which takes place in it. People know the reasons for entering or leaving certain consultation rooms in clinics. Possession and consumption of large numbers of pills are associated with AIDS. Mothers leaving clinics with formula milk are identified as being HIV positive. Massive weight loss and visible signs of poor health such as skin rashes are believed to be caused by HIV/AIDS. The list of signs that can disclose your HIV/AIDS status is endless. Various strategies are employed in an attempt to hide these obvious signs of living with HIV/AIDS. Some clinics repack formula milk into other containers so that people in the clinic and streets can't tell what they have in their possession. Patients hide medication in big bags hidden from the curious eyes of those watching and try their best to maintain a healthy image. Not only is poor health associated with HIV/AIDS but regaining a healthy body can make people believe that you were never infected and that the rumours were false. People even personally apologised to one patient for believing the stories that she had HIV/AIDS, because "now that she is healthy again, they know it could not have been true". Despite the millions of people who are successfully treated, many still believe HIV/AIDS is a death sentence and that people can only be infected if they 'look' sick.

Many people's HIV positive status becomes known to the world whilst in the clinic. It is common knowledge which health care services are being provided in the different areas of the clinics and by whom. A counsellor explained it to me as follows:

The patients are afraid to come and speak to me, because everyone knows I am the counsellor. They always ask me if they can come to me in the afternoon or on days when the clinic is not likely to be busy.

Others go through great trouble to attend clinics far away from their place of residence in an attempt to keep their status a secret.

I prefer coming to this clinic, even though I have to travel a long distance to get here, because at the [ARV] clinic at home [you enter] through this separate door on the outside of the clinic and when people see you enter through that door they know you are there because of AIDS ... and the people talk, they will tell everyone what they saw.

Thus, despite treating patients' files confidentially, the physical spaces their bodies occupy leave little room for patients' right to privacy and confidential treatment of their HIV positive status. In some cases (all these patients referred to the same clinic) patients said the reason they come to this clinic rather than the one in their home town is because they do not trust the nurses at their local clinic. Though they attend the clinic in their town of residence for minor health concerns they do not want the staff to know of their HIV positive status because the nurses have a reputation of discussing their patients with family and friends!

#### **4.5 Conclusion**

Though millions of lives have been saved because of increased access to ARVs, there are still 'hazards' that can prevent people from accessing these life saving drugs. These 'hazards' mostly relate to poor socio-economic circumstances. People often

find it difficult, or impossible to visit clinics and access treatment because they simply can't afford the financial costs associated with travelling there. In addition to this, many feel that their right to privacy and the confidentiality is being compromised when they visit HIV/AIDS related services at clinics. HIV/AIDS is a highly stigmatised disease and people infected with the virus are often blamed for bringing it onto themselves and deserving of punishment because they must be guilty of sexual promiscuity or using drugs. As a result, people are often ostracised from their families and/or communities when their status becomes public knowledge. This leaves people who are poor and infected very vulnerable and they would therefore do almost anything to prevent people from knowing he/she is infected. Thus, in order to get people to access HIV/AIDS related treatment and services these financial and social costs must also be addressed. Poverty must be alleviated and in order to do so unemployment must be addressed. In addition to this stigma must be addressed for people living with the virus to go out and live a normal and productive life. They must have the courage to seek employment and not fear stigma and discrimination at the workplace. People must feel free to enter VCT sites, ARV clinics and other HIV/AIDS related services without fear of being ostracised in their communities and rejected by their friends and families when someone sees them there. Clinics and hospitals can have enough ARVs to treat all people living with HIV/AIDS with these life saving drugs, but it will mean nothing if people do not firstly know they are positive and need treatment, nor would it be of any help if people cannot access the health facilities due to financial constrains or social fears.

## CHAPTER FIVE

### FIGHTING THE WAR INEFFECTIVELY

#### **5.1 When Healthcare Providers Fail Patients: The Case of VCT**

Medical services are the corner stone in the war on HIV/AIDS. Providing people living with HIV/AIDS with ARVs is regarded as crucial in combating this global epidemic. As noted in the previous chapter, ARVs are believed to lower morbidity and mortality among people living with HIV/AIDS. This enables them to live a normal and active life. However, as also noted in the previous chapter, not everyone in need of ARVs have access to these life saving drugs usually because they cannot afford the medication, or in cases where it is available to them free of charge they can't access it because of the financial costs associated with travelling there or their fear of the social implications if their status have to become public knowledge. However, many others still fail to access treatment merely because they do not know that they are HIV positive. Knowing your status is regarded as one of the crucial elements in the war on HIV/AIDS.

Knowing your status enables timely medical interventions which have been associated with improved clinical outcomes. This includes early initiation of ART which could reduce disease progression and reduced mortality and the prevention of opportunistic infections. Early diagnosis is also believed to reduce high risk behaviour and consequently lower the uncontrolled spread of the disease (Anonymous, 2005:32; Beckwith, 2005: 1038; Koo *et.al.*, 2006: 962; World Health Organization, 2007 (b): 14). Because there is no cure for HIV/AIDS prevention is still regarded as the best

way to turn the tide on HIV/AIDS. Therefore, all interventions which can help to prevent new infections are crucial. Preventing the disease is also much more cost effective than treating the disease.

Access to voluntary counselling and testing is possible through a variety of different service providers. All primary health care facilities offer VCT as well as several non-governmental organizations (NGOs). To accommodate people's busy lives this service has been expanded from traditional health care facilities and taken to people in the form of testing campaigns and non-medical testing sites in business sectors. However, people are still reluctant to visit these sites despite its accessibility because they fear people they know will notice they are getting tested and would like to know why they thought they needed to get tested and what the results are. Sometimes the answer to the results can be told by just watching the door of the counsellor's room. As Jonny Steinberg writes in his book *Three Letter Plague* (2008: 30): "And to know who was positive and who was negative, you just had to stand and watch". Finding out that you are HIV positive can be a traumatic experience. Therefore people need to be counselled before the test to prepare them for a possible positive outcome, and afterwards to help them deal with the initial shock if they are indeed positive. People deal differently with shock and trauma and it is therefore important that they disclose their status to people they completely trust when they are ready to do so. If a person's status becomes public knowledge before he/she has dealt with the initial shock and are emotionally and psychologically ready to disclose, it can cause further emotional and psychological distress for the individual. It can also cause social rejection if the wrong people come to know about an individual's status.

Compared to other medical services, little resources are required to operate a VCT site. All that is needed is a private room to counsel a patient before and after he/she is tested, a lay counsellor to counsel the patient, a rapid test kit to test the patient's blood for HIV antibodies. These rapid tests are used because it delivers a test result within ten to twenty minutes and no clinical training is needed to operate the test device. In countries, such as South Africa, where there is a shortage of human resources this test is also beneficial because the lay counsellor can do the test (World Health Organization, 2007(b): 43).

## **5.2 Making the Decision**

Patients get tested for various reasons and choose the site to get tested at along with the reason why they want to get tested. At private clinics, patients with private health insurance often get tested because they get bonus points and extra benefits if they can prove they have been tested for HIV. A person with health insurance, guilty of infidelity, will choose not to go to such a site, because his/her partner will have questions when the bill arrives. Many people choose a clinic far from home, where no one who knows them, will see them entering the counsellor's room, and where the probability of knowing one of the staff members is low. Others get tested without any hesitation because they know they are very low risk and the chances that they will be HIV positive is perceived to be very low. Many low risk people get tested, not because they are concerned with the outcome of the test results, but because it is the right thing to do. Those who are more concerned with the test result are from all age, racial and income groups. Many of them got a wake-up call when a friend or family

member fell ill or was diagnosed with HIV/AIDS, or were strongly encouraged by a friend or family member to get tested. Some people who have tested positive previously want to be re-tested at a later stage. Why they do this is not clear, but disbelief and shock is believed to be their motivation. One of the women I interviewed told me that when she got tested for HIV the first time, and the results came back positive, she could not believe it. After three months she went back to get tested again, just to make sure that the test results were correct and that she was in fact definitely infected with this deadly virus. However, the majority of the people I spoke to during the course of my research were tested after a healthcare practitioner advised them to do so when they were either diagnosed with TB or in the case of women, realised they were pregnant.

Whereas going for an HIV test indicates to some that they are responsible citizens who are doing their part in term of creating a HIV free generation, to others it acknowledges the mortality of their own human body. Getting tested and receiving a negative test result signifies life. It proves that you are free of the virus responsible for millions of deaths in the world, and that you are able to live a full and productive life for many years to come on the premise that you remain HIV negative. For this pool of people there is no fear of getting tested and knowing their status, only joy. As my one 25 year old, female friend said: "I do not mind to get tested, I will get tested again and again, because I know I am negative...but I don't know if I would have felt like this if I thought I might be positive". Unlike my friend who is not afraid to get tested because she is so certain of it that she is negative, I am more sceptical about this matter. Doing research in the field of HIV/AIDS did not only provide me with above average knowledge about the disease and its epidemiology, but also made me

what some might say is a little paranoid. Though I am a strong advocate for the use of condoms, I have had, like most people, unprotected sex and/or a broken condom. Thus, living in a country where there is a generalized HIV/AIDS epidemic, there is a fifty-fifty chance that I could have been exposed to HIV. Therefore, I can be HIV positive.

I have been tested before, but each time is as nerve wrecking as the previous one. It has been a while since my last test and I have since dared to get tested several times, but never did this become more than a threat. Except for this one time. It was a lovely summer morning. The town was quiet since most people have already left for their summer vacations. Since I ended a romantic relationship a few months earlier, I decided that my ex was, to put it politely, not a very nice person and that he can't be trusted and that it would be wise to get tested just to make sure he didn't leave me with more than just a broken heart. Finally, the much anticipated day arrived where I got up, decided (again) that today is the day that I am getting myself tested but this time I actually went. On my way to the clinic I tried to think of good reasons why I do not have to get tested, but there was none. By the time I reached the counter I was a nervous wreck. After uttering the brave words "I want a HIV test" in a shivering voice, the nurse simply replied: "Sorry, we can't help you because we do not have a counsellor here today and the nurses can't do the test if you haven't been counselled. Try one of the other clinics". I could not believe what I was told. There was almost no one in the clinic and it was not even noon yet. Of course they could have told me that I have to wait, unfortunately they do not have a counsellor, but once one of the nurses is available they can do the counselling and test me. They are after all qualified to do so and in many respects more qualified to do so than lay counsellors.

So I left, but I never went to another clinic. I did not have the courage to walk into another clinic and ask for an HIV test. Poorly staffed clinics and prejudices among healthcare providers can compromise attempts to turn the tide on HIV/AIDS if it keeps them from providing the necessary services to the public. My desire to get tested did not disappear, only my courage to ask for one. Each time I went to the doctor or clinic I wished someone will just ask me, so that all I need to do is say “yes”. I am not the only person who feels like this. Others have also mentioned to me that they will easily agree to get tested if someone asks them to, but no one ever asked until a few years later when I visited a VCT site for my research. When asked, I immediately said yes. Though I was a nervous wreck when I realised what I agreed to, getting tested by people who know me in some way, I was strangely excited about getting tested. Luckily I tested negative. But the whole experience made me realise how difficult it must be for poor, unemployed, powerless, marginalised women to practice correct and consistent condom use at all times, if I (and so many people I know) who are an educated (especially on HIV/AIDS), empowered women sometimes fail. As Miss Y so kindly reminded me, “Come on, you have to admit that there was at least one occasion when you were about to have sex and realised neither of you have a condom on you and decided ‘What the hell, this one time won’t matter’”. How much more difficult must it not be for women to say no to sex if it is the price they have to pay for food and shelter. With no resources or education it is hard to find a job and their bodies are too often the only resource available to them. If poor women do not agree to have unprotected sex with their romantic partners, they would most probably be forced to sell their bodies for money in order to eat. Unfortunately, having unprotected sex only once changed the lives of so many women, especially the poor and powerless, for the worse.

When I was, all of a sudden , confronted with HIV testing on a personal level and had to answer the questions of “why do you have unprotected sex?” or “why are you scared of getting tested?” the humanity of innocent victims acquired new meaning to me. I do not see myself as irresponsible or uneducated about HIV/AIDS. I had unprotected sex because I am only human and even if I was a super human and never have had unprotected sex there is the small possibility that a condom can break, even if you use it correctly. The idea of getting tested is frightening because I realise that my life will change significantly if the results were to be positive. Though I trust that there are people in my life who will support me, there are many more who I fear will judge me. They will not see a positive result as a mere medical condition. To them I will be the embodiment of an immoral, promiscuous person, who is a threat to their health and wellbeing, because every single little scratch on my body, or a bleeding nose can put them at risk of being infected with the virus. I will become a virus in their eyes. It is because of the highly stigmatised status of the HIV positive person that people fear to get tested. When you get tested for TB or swine flu, it is just a test to determine why you are ill and you are treated equally by lay people as well as healthcare professionals. However, when you ask to get tested for HIV, you are being judged. Also by those who are supposed to treat you.

The World Health Organization (WHO) recommends that in countries considered to have a generalized epidemic health care providers should offer all patients a HIV test regardless of their reason for attending the health care facility or the presence of symptoms related to HIV and AIDS (World Health Organization, 2007 (b): 22).

Family planning and sexual health clinics are regarded as a crucial entry point for individuals who can potentially be infected with HIV (Berer, 2003: 10; Brady, 2003:139). Correct and consistent condom use is a very effective family planning method. It is estimated to have a 90 -95% efficacy. Apart from being effective in preventing unwanted pregnancies it is also the most effective way to protect yourself against sexually transmitted diseases (STD's). Because condoms are protective against STD's it can also protect fertility, since many STD's could cause infertility (Brady, 2003: 135). In a conversation with a nurse who is mostly responsible for family planning, but also does HIV tests when people request it, I asked her whether she ever asks patients if they want to have a HIV test and her response was no. She feels that people will ask her for the test if they want to know what their statuses are. "If they do not ask, they do not want to know", she said. On dual protection and counselling women about the health risks they are still exposed to when they only make use of contraceptives to prevent unwanted pregnancies, she said that there are condoms available in the waiting area which they can take if they want to use it. Not actively educating people on the benefits of condom use, together with contraceptive use misses an opportunity to educate people on how to protect themselves and other against HIV/AIDS and other STD's, as well as encouraging people to get tested. Despite all the campaigns aiming to educate people on HIV and AIDS, there are still many misconceptions about the disease out there. In conversations with women on the services of family planning clinics no one who asked for contraceptives, such as the contraceptive injection or the pill, reported ever discussing HIV/AIDS and STIs and the risk of acquiring one of these diseases if they do not use condoms as well with their health care providers. However, women who requested emergency contraceptives, also known as the morning after pill, said nurses responded very

negatively towards them. They were often scolded and told how irresponsible they are to have unprotected sex and whether they are not aware of all the diseases they can be infected with if they have unprotected sex. Thus, according to the stories women and nurses told me, nurses only do reactive ‘counselling’ on the risks of unprotected sex, when it could be too late, rather than raising awareness among their patients prior to possible exposure to HIV/AIDS and other sexually transmitted diseases. In addition, these women were not encouraged by the health care professionals to have an HIV test after possible exposure to the virus.

### **5.3 Conclusion**

Treatment for HIV/AIDS is very expensive and in many parts of the world, including some parts of South Africa, difficult or impossible to access. With no cure available, prevention is still the best weapon available to us to turn the tide on HIV/AIDS.

Voluntary testing and counselling is key in the prevention of new infections. If people are aware of their status, they can better protect themselves and others from getting infected. Counselling provided before and after testing also provides people with accurate knowledge of the disease, which can further empower them to protect themselves and others. However, many opportunities to educate people on protection and encouraging people to get tested are missed because of prejudices among healthcare workers and reactive approach to HIV exposure. In order to successfully win the war on HIV/AIDS, the realities of people’s daily lives must be recognised and appreciated. We will have more success in lowering the number of new infections if we were to judge the circumstances the poor and powerless have to endure as harshly as we judge the victims of poverty and marginalization.

## **CHAPTER SIX**

### **CONCLUSION**

I have started this journey with the aim to shed light on the weaknesses of the current HIV/AIDS interventions offered. HIV/AIDS is the biggest epidemic in our modern world. Despite all the medical technologies available to us, we are still unable to successfully turn the tide on HIV/AIDS. Governments and health authorities seem to be unable to control the spread of the virus responsible for the disease. In some areas progress has been made to lower the number of new infections and to give people in need of treatment access to ART, free of charge in many countries. This has had a tremendous positive impact on the lives of millions of people living with HIV/AIDS, but who could not afford the treatment. Before ARVs were available, being diagnosed with HIV/AIDS was a death sentence. There was no cure and no treatment. Eventually dying from this disease was inevitable. Now, people can live a normal, active life if they have access to ART, despite being infected with HIV. Women can bear children with little risk of infecting her child. People can plan their futures because they are simply living with a chronic disease, like diabetics. However, the demand seems to continue to outweigh the supply and governments, especially of poor and developing countries continue to struggle to afford enough treatment and medical services for those infected with HIV/AIDS. Because there is currently no cure for HIV/AIDS, prevention is still the best ‘treatment’ available.

HIV/AIDS is a sexually transmitted disease and completely preventable. Most people get infected because of exposure to the virus during sexual intercourse, intravenous drug users sharing needles, and an increasingly small number by contaminated blood products. In South Africa most HIV transmissions take place during unprotected sexual intercourse. Only one unprotected sexual intercourse is sufficient for the successful transmission of the virus. However, unprotected sexual intercourse is not so much associated with being HIV positive as is sexual promiscuity. As a result, many people do not see the need to use condoms in long-term, stable relationships. Because sexual promiscuity is regarded as socially unacceptable and regarded by many as immoral, victims of HIV/AIDS are often judged, endure stigmatization and are regarded as deserving of their fate. In addition to this, condoms, which are currently the best protection against HIV infection during sexual intercourse are also associated with sexual promiscuity. As a result, people often refuse to use condoms because they do not want to be seen as sexually promiscuous. However, people living with HIV/AIDS are not always sexually promiscuous, nor do they freely choose to have unprotected sex. Many, especially poor women, youth and children engage in these activities as a means of survival.

Africa, the world region with the highest HIV/AIDS prevalence rate, is also the world region with the highest levels of poverty. Conditions of poverty often force people to engage in high risk behaviour they would not have chosen if they had adequate financial resources to cover their daily expenses. Many have no financial income and have to rely on transactional sex as a barter for food, shelter and other basic necessities, or are forced to engage in commercial sex work. More women are affected by poverty than men. Women also commonly have lower levels of

education, which limits their employment opportunities. Many women are also illiterate which further limits their employment opportunities and often makes their bodies their only resource available to them. When women have to use their bodies to secure basic necessities they have little power over their own bodies and little say in whether condoms will be used or not. Commercial sex workers often refrain from insisting on the use of condoms because they can ask a higher price for unprotected sex, and because they fear that their clients might get aggressive if they insist on using condoms. Women and young girls involved in transactional sex are also often faced with the choice between having unprotected sex or their partner threatening to leave them or accuse them of being unfaithful. Even women in stable long-term relationships often find it hard to negotiate safe sex because their partners accuse them of infidelity if they do so. Apart from 'choosing' to have unprotected sex many women, youth, children, and even men are victims of sexual violence where they basically have no say in whether a condom must be used or not. In addition to this, victims of sexual violence have an elevated risk of being infected because blood is more likely to be present during sexual intercourse. The lack of financial resources is not the only factor related to poverty that can increase people's risk of infection. Alcoholism and the misuse and abuse of other drugs among the poor is common. The use and misuse of substances increase the occurrence of domestic and sexual violence as well as voluntary high risk sexual behaviour which further increases poverty's influence on the risk of getting infected with HIV/AIDS.

It is not only the poor who are more vulnerable to HIV infection and falling ill from AIDS because of their poor socio-economic circumstances. People can also fall into poverty because of HIV/AIDS. If people living with HIV/AIDS fall sick, often

because they do not have access to treatment, as a result, many lose their jobs. This can put a lot of financial strain on the rest of the household, especially if this person was the sole breadwinner in the household. In other cases, people, often women and young girls, have to take care of those who are ill and give up their employment making them financially vulnerable, or in the case of girls, leave school and compromise their future in order to do so. Many children are also orphaned by HIV/AIDS. Because of the impact HIV/AIDS has on whole communities, it is difficult to take care of all the children who are orphaned by the disease. As a result, many households are now headed by a minor. Such children are extremely vulnerable for exploitation. Often they also have to resort to selling sex in order to survive. Because people are poor they lack in resources to meet their basic human needs. Rapid urbanization has given rise to large informal settlements where living conditions are poor. Access to running water which is safe for human consumption is often scarce or people have to walk long distances to get access to it. Sanitation is also not according to the health standards. Housing is often overcrowded and has poor ventilation which makes the transmission of airborne diseases, such as TB, easy which further compromises individuals' health.

HIV/AIDS can not only make people poor because they are unable to work due to long periods of illness. People living with HIV/AIDS often have to endure stigma and discrimination. This can result in people losing their jobs or are unable to find a job leaving them financially vulnerable and as a result they can become dependent on family members and friends for food and shelter. Despite all the educational campaigns that aim to provide people with correct information on HIV/AIDS, there are still many misconceptions about the disease and how it can be transmitted. Many

belief that sharing a house or utensils can transmit the virus from one individual to another. Because of these misperceptions, many people living with HIV/AIDS have been thrown out of their houses because people refuse to live in the same house as an individual infected with HIV/AIDS. People have also refused to allow infected people to prepare food, or eat with them because they were infected. In extreme cases people do not want any contact or association with people living with HIV/AIDS and will not allow them to rent a house from them even though they will be living there alone. Because of this harsh discrimination people living with HIV/AIDS have to endure they are even more vulnerable to fall into poverty and be unable to take care of themselves.

Misperceptions about the disease are common and sometimes even find their way into spaces which were created to combat and correct these misperceptions. Healthcare providers who work at grassroots level, such as community healthcare workers, have limited education and often find it hard to explain complex medical terms and processes to others. In addition to this, crucial information can also get lost in translation when medical terminology and processes need to be translated from one language to another. Many people who are living with HIV/AIDS have no knowledge of physiology. Thus, in order for an individual to understand the biomedical explanation of HIV/AIDS and its interaction with the human body, a comprehension of the human body as it is understood in the field of biomedicine first needs to be developed.

In order to address this massive pandemic, community members have taken action into their own hands and started community based interventions. These interventions usually consist of emotional and psychological support for people living with HIV/AIDS in the form of support groups, home based carers or community based carers who visit individuals during the week to support them and monitor their health and adherence to medication, as well as income generating activities because most people who attend the support group meetings are unemployed. Support groups provide women with the freedom to talk openly about life with HIV/AIDS. Though the women I encountered at the support group I attended all said they lived openly with HIV/AIDS, it did not mean that it was public knowledge to all their family members, friends and neighbours. To them it meant that they have disclosed their status to at least one other person. Usually, only the other members of the support group and some close family members knew. The stigmatization that is attached to HIV/AIDS is so severe that most women, including some of the healthcare workers who are living with HIV/AIDS do not want to openly disclose their status to the public. They too only tell those closest to them whom they can feel they truly trust. Despite the financial security healthcare workers have, they are still financially vulnerable, because many of them are single mothers or have to support household members. The image which is created of a close knit family where people can talk freely and are supported by each other is different when the support group members are outside in the community. There the struggle is much more lonely, where everyone has to fight their own battle for survival. They cannot depend on one another for support because extended household members do not want to have people infected with HIV/AIDS in their houses because they themselves fear of being associated with HIV/AIDS. In other cases they cannot offer each other support in the

form of accommodation or food because it would raise questions which could disclose their status.

The disease became so highly stigmatized because it was highly feared and associated with stigmatized behaviour such as intravenous drug use and sexual promiscuity, especially homosexual promiscuity. To make matters worse, there was no treatment for the disease and being diagnosed with HIV/AIDS was a death sentence. In the mid nineties ARVs, which could successfully stop HIV in its tracks and slow the progression of the disease to such an extent that it is now regarded as a chronic disease, were developed. These drugs are very expensive and the majority of the people who are infected with HIV and suffering from AIDS could not afford these life saving drugs. However, today these drugs are available to all in need of it in South Africa, free of charge. South Africa currently has the largest national ARV roll-out programme in the world. Despite the drugs being free, many still struggle to access ART. Many live far from clinics, especially in rural areas and can't afford the transport to and from the clinics. In addition to the travelling costs, some also lose their income for the day because they have to take the day off at work in order to attend the clinic. Because people cannot afford the financial costs associated with ART, many wait until they are very ill before they visit a clinic to seek medical treatment. In some cases, people are too sick from AIDS when they first visit a clinic to be able to benefit from ART and die.

HIV/AIDS is treated in specialized clinics. People who visit these clinics are there because they are HIV positive or suffering from AIDS. If it happens that someone

who knows you recognises you when you are at the clinic it can have far reaching social consequences. People fear that their family members, friends and community members will learn about them living with HIV/AIDS and that they will be ostracised from their communities. People fear they will lose their accommodation and/or employment if their status has to become public knowledge. In order to get more people to visit clinics which are related to HIV and AIDS, these facilities should be able to better ensure people of the protection and confidential treatment of their identities.

Because there is no cure available for HIV/AIDS, prevention is still the most effective way to combat the epidemic. Knowing your HIV status enables you to better protect yourself and others against HIV/AIDS. Familiarity and knowledge of the disease is also believed to lower stigma and discrimination against people living with HIV/AIDS. Early diagnosis enables early intervention which is associated with more positive treatment outcomes. VCT is offered at all primary healthcare facilities.

There are many occasions where healthcare providers can offer patients medical care, for whatever reason, at clinics, especially family planning and sexual health clinics. However, nurses at these clinics seldom educate patients on the risks of unprotected sex and the advantages of condoms. Neither do they actively encourage patients to have a HIV test unless a patient is diagnosed with TB or a woman is pregnant. In addition to this, opportunities to educate people about the disease and how to protect yourself and others against infection is missed.

In order for us to turn the tide on the global HIV/AIDS pandemic, all of us should have a mind shift on what really causes HIV infection and what causes the disease to progress from a HIV infection to full blown AIDS. The majority of people who are infected with HIV got infected because their circumstances forced them to behave in ways they might have chosen not to if it was not for the desperate conditions of poverty they had to endure. In order to make behaviour interventions successful, the conditions which determine people's behaviour must also enjoy interventions. Though poor people are disproportionately affected by the disease, they are not the only individuals who are suffering from the disease. More should be done to effectively educate people about HIV/AIDS and to convince people that they should get tested. In order to do this healthcare providers must realise the immensity of the epidemic and how important it is that each and every individual should get tested on a regular basis. Despite people knowing about HIV/AIDS and that many are suffering from the disease, it is still hidden from most people because the faces of those who are infected are hidden from the general public. Very few people fall ill or die because of HIV/AIDS, other diseases are given the blame and HIV/AIDS still seems to be far away from home, when in reality it could be in your own home. In order for the general public to recognise the disease, they must become familiar with it and recognize it as a reality and not as something they hear about in the media.

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