SOUTH AFRICAN INDIANS AND HIV/AIDS: Contextual Factors in the Experiences of HIV/AIDS in Chatsworth, KwaZulu-Natal

Y. Naidoo (Dhee)
200272842

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School of Anthropology, Gender and Historical Studies

Department of Anthropology

Faculty of Humanities, Development & Social Sciences

University of KwaZulu-Natal

Durban (Howard College)

DECLARATION

In accordance with the regulations of the University of KwaZulu-Natal, I hereby declare that this dissertation- entitled: “**South African Indian and HIV/AIDS: Contextual Factors in the Experiences of HIV/AIDS in Chatsworth, KwaZulu-Natal ”** is my original and independent research. It as not previously submitted for any degree or presented in candidature in any other university. All sources and literature have been duly acknowledged.

CANDIDATE’S SIGNATURE:__________________ DATE:______________

SUPERVISOR:

Prof. Suzanne Leclerc-Madlala:_________________ DATE:______________

DATE:

School of Anthropology, Gender and Historical Studies

Department of Anthropology

Faculty of Humanities, Development & Social Sciences

University of KwaZulu-Natal

Durban (Howard College)

DEDICATION

THIS THESIS IS DEDICATED TO MY FAMILY, IN PARTICULAR MY PARENTS JAY AND SARAH NAIDOO, WHO ENCOURAGED ME THROUGHOUT MY PERIOD OF STUDY. I AM FOREVER GRATEFUL.

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Abstract

This study set out to examine contextual level drivers of HIV among the South African Indian community of Chatsworth. Very little is currently known about HIV/AIDS among South African Indians. It was from this starting point that I set out to research this largely unexplored study topic, to gain insight into and understanding of the non-biological factors that underlie the spread of HIV/AIDS among people in Chatsworth. In-depth interviews, informal discussions and participant observation were carried out among community members, including members who were HIV positive.

Findings revealed that poverty, gender power relations and stigma were major social factors contributing to the growth of HIV/AIDS within the South African Indian community of Chatsworth. Poverty places many in vulnerable positions, having to choose between treatment and disability grants to buy food for example, and gender inequalities make women more susceptible to contracting HIV than men. Culture plays a role in placing women in high risk situations. Furthermore stigma, denial and discrimination against people living with HIV/AIDS makes it very difficult for HIV positive people to disclose their status and to live their lives in the community. The importance of understanding the context in which the HIV/AIDS pandemic is occurring and the various cultural

factors that play a role in the experience of HIV/AIDS in people's lives, is argued to be vital to the development of successful strategies to prevent and manage the disease.

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Chapter One

Introduction

1.1 Contextualising the HIV/AIDS Pandemic in South Africa

Three decades into the AIDS pandemic the number of new HIV infections has not yet declined, rather it is growing at an alarming rate. Almost 40 million people around the world are living with HIV/AIDS and half of them women. The pandemic has cost more than 25 million lives, and in 2005 nearly three million people died of AIDS-related illnesses. The AIDS pandemic has rapidly rocketed from a public health challenge into an unparalleled development crisis (UNAIDS, 2005).

At present sub-Saharan Africa is home to 25.8 million people living with HIV, almost one million more than in 2003. Two thirds of all people living with HIV are located in this region, as are 77% of all women with HIV (UNAIDS, 2006). As of 2005, an estimated 2.4 million people in the region died of HIV-related illnesses, while a further 3.2 million became infected with HIV (UNAIDS, 2006).

South Africa is currently experiencing one of the most severe HIV pandemics in the world. By the end of 2005, there were five and a half million people living with HIV in the country and almost 1,000 AIDS deaths occurring every day, according to UNAIDS estimates. A survey published in 2004 found that South Africans spent more time at funerals than they did having their hair cut, shopping or having barbecues. It also found that more than twice as many people had been to a funeral in the past month than had been to a wedding (UNAIDS, 2006).

A number of factors have been blamed for the rapid rise in HIV prevalence in South Africa, and debate has raged about whether the Government's response to the pandemic has been sufficient (UNAIDS, 2006). South Africa has had a turbulent past, and this history is relevant to the explosive spread of HIV in the country.

In 1985, a State of Emergency was declared in South Africa that would last for five years. This was a result of riots and unrest that had arisen in response to Apartheid, the system of racial segregation that had been in place since the 1950s (Pope, 1995). Apartheid prohibited mixed-race marriages and sex between different ethnic groups, and categorised separate areas in which different races lived. In the same year (1985), the Government set up the country's first AIDS Advisory Group in response to the increasingly apparent presence of HIV amongst South Africans.

The first recorded case of AIDS in South Africa was diagnosed in 1982, and although initially HIV infections seemed mainly to be occurring amongst gay men, by 1985 it was clear that other sectors of society were also affected. Towards the end of the decade, as the abolition of Apartheid began, increasing attention was paid to the AIDS crisis (Pope, 1995).

The first national antenatal survey to test for HIV in 1990 found that 0.8% of pregnant women were HIV positive. It was estimated that there were between 74,000 and 120,000 people in South Africa living with HIV. Antenatal surveys have subsequently been carried out annually (Pope, 1995).

According to Pope (1995), by 1991 the number of diagnosed heterosexually transmitted HIV infections equalled the number transmitted through sex between men. Since this point, heterosexually acquired infections have dominated the epidemic. Several AIDS information, training and counseling centers were established during the year. The Government’s first significant response to AIDS came in 1992 when Nelson Mandela addressed the newly-formed National AIDS Convention of South Africa (NACOSA), although there was little action from the Government in the following few years. The purpose of NACOSA was to begin developing a national strategy to cope with AIDS. In 1993 the National Health Department reported that the number of recorded HIV infections had increased by 60% in the previous two years and the number was expected to double in 1993. The HIV prevalence rate among pregnant women was by then 4.3% (Pope, 1995).

The pressure group Treatment Action Campaign (TAC) was founded in 1998, to advocate for the rights of people living with HIV/AIDS and to demand a national treatment plan for those who were infected. Then Deputy President Thabo Mbeki launched the Partnership Against AIDS, admitting that 1,500 HIV infections were occurring every day (TAC, 2005).

The Department of Health outlined a five-year plan in 2000 to combat AIDS, HIV and STIs. A National AIDS Council was set up to oversee these developments. At the 2000 International AIDS Conference in Durban, the new South African President Thabo Mbeki made a speech that avoided reference to HIV and instead focused on the problem of poverty, fuelling suspicions that he saw poverty, rather than HIV, as the main cause of AIDS. President Mbeki consulted a number of 'dissident' scientists who rejected the link between HIV and AIDS (Iclinic, 2000).

The most rapid increase in South Africa's HIV prevalence took place between 1993 and 2000, during which time the country was distracted by major political changes (Lawn et al, 2005). While the attention of the South African people and the world's media was focused on the political and social changes occurring in the country, HIV was silently gaining a foothold. Although the results of these political changes were positive, Lawn et al (2005) argued that the spread of the virus was not given the attention that it deserved, and people did not realise the impact of the epidemic in South Africa until prevalence rates had begun to accelerate rapidly.

Many people have argued that the response to HIV/AIDS in South Africa has been hampered by 'AIDS denialism', a minority scientific movement that refutes the orthodox idea that HIV causes AIDS. Some leading figures in South Africa have flirted with this school of thought, much to the dismay of AIDS activists (Tarisai, 2002). According to Science (2000), President Mbeki has consistently refused to acknowledge that HIV is the cause of AIDS; he argued that HIV is just one factor among many that might contribute to deaths resulting from immunodeficiency, alongside others such as poverty and poor nutrition.

In October 2000, Mbeki stated that he would withdraw from the public debate about whether HIV causes AIDS, after admitting that his stance had created confusion amongst the public (Iclinic, 2002). Since making this statement he has largely avoided the issue of what causes AIDS, but has repeatedly suggested that the impact of AIDS in South Africa may have been overstated (Iclinic, 2002).

In 2002 the Cabinet issued a statement on their latest AIDS campaign, declaring:

"*In conducting this campaign, Government's starting point is based on the premise that HIV causes AIDS" (Piot, 2004: 30).*

While this remains the official stance of the Government, there is evidence that certain politicians continue to question scientific consensus on AIDS. President Mbeki has repeatedly stressed the importance of a good diet in halting the progression of AIDS, as has the previous Health Minister Manto Tshabalala-Msimang, who famously urged people to eat lots of beetroot and garlic to fight off the illness (France-Presse, 2004).

The Health Minister has also voiced support for the Dr Rath Health Foundation, an organisation that promotes vitamin supplements as a substitute for ARV drugs. The foundation has previously published adverts in South Africa claiming that antiretroviral drugs are toxic and cause AIDS (Mail & Guardian Online, 2006). In August 2005, the Advertising Standards Authority ruled that such statements were a threat to public health, and that the organisation would not be allowed to make such claims in future adverts. Manto Tshabalala-Msimang later stated in newspapers that:

“No reason exists to criticise Rath, his treatments and his foundation” (Mail & Guardian Online, 2006).

The Dr Rath Health Foundation continues to promote its vitamin treatment in South Africa despite widespread international condemnation. The organisation has been banned from almost all other countries in which it has tried to operate (Mail & Guardian Online, 2006). The TAC, which won a court case to prevent the Rath Foundation from wrongly labelling them ‘a front for the pharmaceutical industry’, has strongly criticised the Government for failing to condemn the organization (Mail & Guardian Online, 2006).

The Health Minister continues to make statements that play down the importance of ARVs, and it is likely that the attitude towards the drugs taken by her and other politicians has been central to the slow rate of progress in providing access to treatment. Amongst the scientific community there is little doubt about the benefits of ARVs; a recent study in South Africa reported that 93% of HIV positive people surveyed were alive after one year of treatment (WHO, 2006).

Alongside AIDS denialism and misinformation about AIDS treatment, false beliefs about how HIV can be transmitted are also a concern. In April 2006, on trial for the alleged rape of a HIV positive woman, South Africa's former Deputy-President Jacob Zuma was found not-guilty but confessed that he had had consensual sex with the woman despite being aware that she was HIV positive (IOL, 2006). He stated his belief that HIV was not easily transmitted from women to men, and that he had showered after sex in the belief that this would minimise his chances of contracting HIV. There was widespread dismay amongst the AIDS prevention community that a politician (particularly one who had once been head of the National AIDS Council) could display such ignorance, and a fear that his statement would cause confusion amongst the public, undermining years of AIDS prevention campaigns (IOL, 2006). The National AIDS Helpline was subsequently inundated by callers querying the validity of his statement.

Many people believe that the widely publicised views of politicians such as Mbeki, Tshabalala-Msimang and Zuma have added to the climate of misinformation that surrounds the problem of AIDS in South Africa. Zackie Achmat, leader of the TAC, has argued that the real hindrance to antriretroviral drug provision in the country is not lack of funding, but the attitude of the Government:

"The biggest problem we have in South Africa is that we have a President who doesn't believe that HIV causes AIDS" (TAC, 2005:5).

AIDS in South Africa has inverted valuable development gains, and resulted in illness and death among the most productive age group of societies. The long-term human development impact is being felt in all sectors of public and private life. National and local budgets have been strained by AIDS-related costs, sectors such as education and health are being deprived of skilled workers, and the capacity of various sectors to sustain previous levels of productivity and services is weakened (Nattrass, 2004).

The pandemic has impovished families, including families within the South African Indian community of Chatsworth. In this community as in many others HIV/AIDS has resulted in social exclusion and countless human rights violations, where women and girls are particularly vulnerable to infection and are bearing the burden of providing care for affected families.

1.2 Chatsworth in Context

A recent study commissioned by former president Nelson Mandela through the Human Science Research Council provides us with what is widely thought to be the most systematic and comprehensive view available on how HIV/AIDS is affecting South Africans according to race, gender, age and geographic location (Shisana et al, 2005). According to this study, South African Indians currently make up 2.6 percent of the 46 million South African population and represent approximately 1.6 percent (+-80000) of the 5 million HIV positive South Africans.

Chatsworth is a predominantly South African Indian township that was established 45 years ago with an estimated present-day population of 400000 (Desai, 2005). The township of Chatsworth was created out of the Apartheid government's Group Areas Act. During the 1950's thousands of South African Indians throughout Durban were relocated into Chatsworth's ten square kilometer precincts south of Durban, the major city of KwaZulu-Natal province (see Appendices 1 & 2). According to the then mayor of Durban, Mayor Percy Osborne, the Group Areas Act was the 'lifeline' whereby the European city of Durban would be preserved for members of the White racial group only (Desai, 2005).

As a result thousands of South African Indians were forced to leave their homes and were marshaled off to the outskirts of Durban. According to Desai (2005), the apartheid government's promise of a better life in Chatsworth was not to be realised. The promised homes were nothing more than glorified stables, small semi-detached buildings situated alongside a major highway (Govender, 2005). The majority of people were housed in one room flats, which were overcrowded and unsafe. Chatsworth today is an area of extreme contrasts. It has sections called units that comprise of both economic and sub-economic council housing. Unit 2 (Bayview), Unit 3 (Westcliff) and Unit 10 (Woodhurst) are regarded as the poorest areas with blocks of council flats sometimes housing six families each (Govender, 2005). Adjacent to these low cost flats one finds the middle/upper class sections of Mobeni Heights, placed at the entrance to Chatsworth, Silverglen located between Unit 2 and 3, Kharwastan and Umhlatuzana located adjacent to Unit 10 (Govender, 2005).

According to Desai (2005), from the mid 1970's gangs and drugs flourished. The people of Chatsworth found that their lives were an endless struggle. This depressing scenario turned inwards, resulting in a rise of alcoholism, suicide, child abuse, rape and gangsterism in the area. To add to the burden, the closing down of textile companies in the 1970's and 1980's saw tens of thousands of jobs lost. With the high rates of unemployment, homelessness, welfare dependency, crime, prostitution and high rates of school drop outs, rates of HIV/AIDS soon started to increase within the community of Chatsworth (Govender, 2005).

For the most part HIV/AIDS within the Indian population of South Africa is still considered to be someone else's disease. Many in Chatsworth believe that it would never happen to them (Govender, 2005). This attitude, coupled with the existing realities of poverty, unemployment and existing gender inequalities, set the context for the un-checked spread of HIV/AIDS within the community.

1.3 Rationale for Choosing the Topic

There is currently a paucity of both quantitative and qualitative research and thus HIV/AIDS knowledge among South African Indians. This very fact precipitated the selection of the present topic. The research investigated the experience and impact of HIV/AIDS among the South African Indian community of Chatsworth in order to make a contribution towards this under-studied topic.

My aim was to explore the ways in which members of the Chatsworth community made sense of HIV/AIDS and what impact it was having on their daily lives. I also hoped to gain insight into some of the underlying HIV transmission factors within that community.

1.4 Aims of the Study

This study sought to unveil the meanings that South African Indians in Chatsworth attach to HIV/AIDS and to explore some key driving forces that social scientists' have identified as important factors in the local spread of HIV/AIDS such as social and economic inequalities, gender imbalances, stigma and denial, low levels of sexual communication and education within homes.

1.5 Problem Statement

This research endeavoured to contextualize the national HIV/AIDS crisis and its growth in the South African Indian community as it was being experienced, thought about, talked about and responded to by the people of Chatsworth. The study took the form of an exploratory research into issues of poverty, gender power-relations, stigma and aspects of sexuality socialization along with reported knowledge and practices related to HIV and sexual behaviour among community members.

1.6 Structure of the Thesis

This current Chapter One has comprised the introductory chapter. Thus far I have discussed the background to the study, the content and background of HIV/AIDS in South Africa, as well as providing a brief overview of Chatsworth. I have also presented the study rationale, the aims of the study and the problem statement. The rest of this thesis is structured as follows:

Chapter Two: Literature Review

The aim of this chapter is to review previous studies in the chosen area of research. These include studies related primarily to co-factors that contribute to the spread of HIV/AIDS. For purposes of this study the co-factors selected for review included poverty, gender inequalities and stigma.

Chapter Three: Theoretical Framework

This chapter discusses culture theory which in this study is examined in relation to HIV/AIDS.

Chapter Four: Methodology

This chapter discusses the research methods adopted in the study. The study is qualitative in design with multiple methods of data collection were employed in the data-gathering process. These methods are presented and discussed.

Chapter Five: HIV/AIDS in the context of Policy and Poverty in Chatsworth

This chapter examines the role of government policies in relation to HIV/AIDS, specifically focusing on government grants and AIDS treatment, as well as, poverty, unemployment and the spread of HIV/AIDS within the South African Indian community of Chatsworth.

Chapter Six: Gender, Power and Inequalities in the Era of HIV/AIDS

This chapter describes the unequal power relationships that currently exist between men and women in Chatsworth that play a role in facilitating the transmission of HIV within the community.

Chapter Seven: Stigma, Denial and Revenge

This chapter looks at discrimination against HIV positive people in Chatsworth. It also briefly examines issues of anger and revenge in relation to HIV infection.

Chapter Eight: Discussion and Conclusion

This chapter presents an overview of the findings, highlighting what I argue to be key contextual factors underlying the spread of HIV/AIDS among the people of Chatsworth. This chapter closes with recommendations for more culturally sensitive HIV/AIDS prevention that are more closely tailored to the social and cultural specificities of people’s lives.

The next chapter deals with the review of related literature from previous studies.

Chapter Two

Literature Review

2.1 Introduction

This chapter reviews previous academic research and articles about HIV/AIDS that have informed my research. Glesne (2006: 18) states that, “knowledge of the literature will help you to judge whether your research plans go beyond existing findings and may thereby contribute to your field of study.”

Since there is a limited availability of literature on HIV/AIDS among the South African Indian community, my review will draw upon related studies such as that conducted by Govender (2005, unpublished) entitled “An Exploration of the Experiences of Four Indian Women Living with HIV/AIDS in the Chatsworth Area”; as well as Ramjee’s (2004) biomedical study on the prevalence on HIV/AIDS in Chatsworth.

In addition I have looked at other studies relevant to my area of research, namely: Leclerc-Madlala (2006), Ganyaza-Twalo & Seager (2005), Whiteside (2004), Cohen (1998), van Donk (2002), Tsafack Temah (2007), Karim (1998) and Karim & Karim (2005). This chapter will also examine studies that have explored issues relating to poverty, gender inequalities and sexual violence, stigma, as well as cultural dimensions that have been found to be contributing co-factors in the local spread of HIV/AIDS in sub-Saharan African.

2.2 Poverty and HIV/AIDS

According to Govender (2005) the majority of people in Chatsworth who are living with HIV/AIDS are not empowered to deal with the situation. Many still live in substandard, overcrowded conditions with poor accessibility to health facilities due to financial constrains. It is these conditions in which disease and ill health flourish and renders those who are poor and economically desperate, vulnerable to infectious diseases, particularly to sexually transmitted diseases.

One way to comprehend the association between HIV/AIDS and poverty is to understand how these two forces impact on the functioning of the households. The connection between HIV/AIDS and poverty is synergistic and symmetrical (Ganyaza-Twalo & Seager, 2005). As much as HIV/AIDS intensifies poverty through morbidity and mortality of income earning adults, poverty also contributes to the transmission of HIV (Ganyaza-Twalo & Seager, 2005). According to these authors HIV/AIDS in South Africa is reaching a stage at which AIDS morbidity and mortality are increasing rapidly. Adults are becoming sick and some are bedridden, forcing the young and elderly to care for them. The situation can lead to unsustainable pressure on households in their struggle for survival. Poverty stricken households are often the worst hit and more vulnerable to the long-term effects of HIV/AIDS and poverty.

According to previous research by Govender (2005), many Indian women in Chatsworth who have died of HIV/AIDS were poor and dependent on their families. Many of these women, when their husbands had become seriously ill, had to care for them with no means of support. They had to rely on others, in most cases their elderly parents (Govender, 2005).

HIV/AIDS impacts households on two main levels, the social and the economic levels (Ganyaza-Twalo & Seager, 2005). On a social level, households have to deal with problems surrounding stigmatisation, social exclusion and disintegration of family structure and social support networks. Women, particularly, are burdened with care and support roles. When a member of the household is terminally ill and eventually dies as a result of AIDS-related illnesses, the rest of the family members are severely affected (Ganyaza-Twalo & Seager, 2005). On the economic level, households and the surviving family members have to pay for medical costs and funeral expenses and, if the deceased was a breadwinner, there will be added financial impacts in a form of a loss of income, in these ways then HIV/AIDS can be seen as directly contributing to poverty.

According to Ganyaza-Twalo & Seager (2005: 3), “poverty is a “capability deprivation”, where a person lacks the “subsistence freedoms” he/she needs to lead the kind of life he or she has reason to value.” This freedom has two aspects: one being opportunity and the other security. Opportunity needs education and a selection of political and economic freedoms (Ganyaza-Twalo & Seager, 2005). Security is seen as a result of the successful use of the opportunities presented to a person and their household (Ganyaza-Twalo & Seager, 2005). Hence poverty is not only a situation of reality but also a process with multiple dimensions and complexities. It is usually characterized by deprivation, vulnerability, and powerlessness. These characteristics joined together can impair people’s sense of well-being (Ganyaza-Twalo & Seager, 2005).

Poverty then is not a lack of income only, but goes beyond that to take into account the social context in which the person lives that influences the intensity of poverty a person or family may experience. Poverty does not only increase susceptibility to HIV infection, it also decreases the ability of people living with and affected by HIV/AIDS to cope with the consequences of infection. According to van Donk (2002) who studied HIV affected households in South Africa HIV/AIDS is connected with frequent short periods of illness, which tend to last longer as the immune system becomes progressively more weakened. The lack of adequate nutrition considerably decreases resistance and speeds up ill health and death.

van Donk (2002) tells us that poor households are less capable of accessing proper health care services because the available services lack the resources (including medicines and human resources) to provide effective health care, or because a household contribution is required, or because public transport to these services are unaffordable for poor households.

Poverty and HIV/AIDS do not transpire in a vacuum, but to a large extent in a social context. Economic suffering intensifies poverty, destabilizes families, and increases people's dependences (Ganyaza-Twalo & Seager, 2005). As a risk factor, poverty is connected with weak financial resources such as low levels of education and few marketable skills, generally poor health status and low labour productivity (Cohen, 1998).

The inability to generate income by adults, as a result of HIV infection and high unemployment, morbidity and mortality drops poverty stricken households into deeper poverty. Poor households may find it even more difficult to clear themselves from extreme poverty for many more years and generations to come (Ganyaza-Twalo & Seager, 2005). According to these authors poverty, as a consequence of HIV infection may possibly see the poor adopting a range of mitigation strategies to cope with the disease.

Focusing specially on the Chatsworth community, Govender (2005) explains that many residents face hardship on a daily basis, while HIV/AIDS is not viewed as a priority since its effects and consequences were not immediately felt. This particular reality was said to create a context for the further spread of the disease. HIV/AIDS according to Govender (2005) flourishes most in areas, such as Chatsworth, were there are high rates of unemployment; the main concern is simply to survive.

Jackson (2002) argued that HIV/AIDS impacts on the most vulnerable in society and has devastating effects on communities, contributing to a rise in poverty which ultimately reduces the ability to cope with the disease, while Luthuli (2008) in a study of KwaZulu-Natal learners with HIV found that HIV/AIDS generates new poverty as people lose their jobs due to ill health. This ill health often leads to further impoverishment of already poor households which is difficult to reverse.

Govender (2005) suggests that poverty is the single heaviest burden of Chatsworth's people and is a direct result of the lack of resources available. Poor HIV positive people in Chatsworth barely survive, yet they are told to eat healthy foods and maintain a healthy lifestyle by doctors in the clinics and hospitals. Govender (2005) goes on to say that this is not possible given the poverty context the people are living in. Their living conditions are mostly unsatisfactory and unhealthy to sustain a healthy lifestyle.

Nutrition and poverty are very closely related many aspects of being poor such as hunger, inadequate health care and strained living conditions deprives many of adequate nutritional status (Luthuli, 2008). For the people living in Chatsworth it is not merely being poor but rather that they are impoverished. Govender (2005) has argued that people are made poor and kept poor by the dominant social, economic and ideological forces that define their lives. This in turn impacts on HIV/AIDS, for many especially those who have only known poverty, have unequal access to resources and have always lived with some sort of risk that hinders an adequate health and nutritional status. Hence HIV/AIDS is seen as a relatively low concern for people who feel mostly powerless to change the realities of their lives (see Chapter Five for further discussion).

According to the Chatsworth residents who participated in Govender's (2005) study, most were unable to get proper care or treatment. The people had no choice but to attend state hospitals and clinics where they only received multi-vitamins and rash medication, as there was a long waiting list for ARV treatment. Govender (2005) stated that some of the participants had been told by the hospital staff that they were not sick enough to go on ARV treatment. They were told that only when they start losing weight and getting really ill will they be considered for treatment, as the waiting list was extremely long. Most of the people who were HIV positive and awaiting treatment relied on government grants (discussed further in Chapter Five), as most had no jobs. These grants help many of the poverty stricken people in Chatsworth to cope with day-to-day survival.

Whiteside (2004) has argued that HIV/AIDS related illnesses and poverty affect household resources and income, making households go deeper into poverty. Rising costs of medical care/treatment went along with increased need for nutritious foods. With the progression of the illnesses, the demand for care and proper nutrition also rises, leaving many desperate and reliant on government assistant. The deprivation of education could place the household at further long-term risk for poverty, lack of skills and disempowerment. The latter was said by Whiteside (2002) to result in a cycle of household impoverishment that may take decades to reverse.

According to Govender (2005) most people and in particular women living with HIV/AIDS in Chatsworth are poor. Many women, especially those who have only known poverty, have unequal access to resources and have always lived with risk of some sort. Therefore, HIV/AIDS was said to deepen poverty and inequalities, particularly gender inequalities. It is frequently recognised that HIV/AIDS follows social divisions and patterns of inequality, with factors like gender and socio-economic status, as van Donk (2002) has argued, having particular relevance in the Chatsworth context.

2.3 Gender Inequalities and HIV/AIDS

Globally women comprise an increasing proportion of people living with HIV/AIDS, accounting for almost half. This trend is occurring in most regions of the world, and is particularly pronounced in sub-Saharan Africa, where women represent more than half (59%) of all adults living with HIV/AIDS (Leclerc-Madlala, 2006). Gender inequalities in social and economic status and in access to prevention and care services increase women's vulnerability to HIV (see

Chapter Six). Sexual violence may also increase women's risk and women, especially young women, are biologically more susceptible to HIV infection than men (Leclerc-Madlala, 2006). In South Africa the pandemic has multiple effects on women including added responsibilities of caring for sick family members; loss of property if they become widowed and/or infected; and even, violence when their HIV status is discovered (Leclerc-Madlala, 2006).

The increase in mortality has been especially horrific for women, who are more vulnerable than men to HIV infection. A study undertaken by the Medical Research Council between 2004-2005, revealed a high prevalence of HIV/AIDS in the Chatsworth community. The study posited that Chatsworth was sitting on a time bomb. Of the 319 women who volunteered to take part in the study, it was found that 143 were HIV positive. This would suggest a current prevalence rate of between 40% and 50% of women infected. Researcher Professor Gita Ramjee said that the study found that 37.1% of the total number of people screened, were infected and another 5% became infected a year later, mainly women (Medical Research Council Report, 2006).

According to Tsafack Temah (2007), there are important differences between women and men in the underlying mechanisms of HIV/AIDS infection and in the social and economic consequences of HIV/AIDS. These stem from biology, sexual behaviour and socially constructed 'gender' differences between women and men in roles and responsibilities, access to resources and decision-making power.

In sub-Saharan Africa most traditional strategies to prevent the spread of HIV have focused on behavioural changes such as abstinence, faithfulness and the promotion of condom use. While the ‘ABC’ approach has possibly prevented large numbers of people from becoming infected, many of the world’s women are simply not in a position to abstain from sex, rely on fidelity, or negotiate condom use. There is clearly a need to address the role of gender inequalities on women’s susceptibility and vulnerability to HIV/AIDS (Tsafack Temah, 2007). According to that author the question must be asked: what makes women prone to HIV infection? Gender itself is a determinant of health and is interlinked with biological and social determinants. The transmission of HIV in women must be considered within the context of gender roles, access to social and economic capital and cultural values. Moss (2002) states that it is now clear that most dimensions of economic and social life are characterised by a pattern of inequalities between women and men that routinely value what is 'male' over what is 'female'.

Tsafack Temah (2007) suggests that the distinct roles and behaviours of men and women in a given culture, dictated by that culture's gender norms and values, give rise to gender differences. This suggests that most of the differences are in fact gender discrimination, that is, differences between men and women which systematically empower one group to the detriment of the other. In many societies, women have fewer educational opportunities than men and receive unequal access to resources such as food and income, all of which are strong predictors of health status. Even in settings where women have access to the resources they need to improve their health, Karim (1998) argued that power relations in the household as well as social norms often prevent them from making good use of what is available to them.

Like poverty, gender relations not only influence people’s ability to select dependable sexual behaviour and decide on the suitable risk prevention method, gender imbalances also influence their capacity to cope with the consequences of HIV infection (van Donk, 2002). Women often prioritise the well-being of family members at the cost of their own health and well-being. Thus, male members of a poor household tend to be the first to receive food and care, with what is leftover shared between women and children. This compromises the nutritional intake of women, thereby leaving them more susceptible to ill health and death as a result of HIV/AIDS.

Gender inequality and discrimination harm women's health directly and indirectly, throughout the life cycle; and neglect of their health needs prevents many women from taking a full part in society (Tsafack Temah, 2007). Moreover, better access of women to resources would allow for improvement not only of women’s health, but also children’s and the entire family’s health. Gender characteristics, which are socially constructed, determine the capacity of both women and men to realise their potential for health or lack there of (Karim & Karim, 2005). The economic vulnerability of women makes it more likely that they will exchange sex for money or favours, less likely that they will succeed in negotiating protection, and less likely that they will leave a relationship that they perceive to be risky (Whiteside, 2004).

In the context of HIV/AIDS, gender inequality implies that women have a lack of negotiating power in sexual relations and with regard to sexual behaviour (van Donk, 2002). For many women, it is not possible to insist on safe sex with their husbands or boyfriends.

Govender (2005) asserts that male dominance among South African Indians encompasses every aspect of women’s lives including family, social, religion, legal and institutional and influences their ability to be assertive and to protect themselves, hence women’s inequality intensifies their vulnerability to HIV/AIDS. Govender (2005) argues that women have minimal power in relationships and therefore, are not in a situation to negotiate safe sex practices. According to Ramjee (2004) the pattern of women's and men's roles and relationships in Chatsworth was also found to put women at greater risk. She found that polygamy, sexual coercion and violence against women all contributed to the distressing gender gap in HIV/AIDS in Chatsworth.

Karim (1998) identified the reasons for South African women’s greater susceptibility to transmission and argued for holistic intervention, which recognised the role of gender inequality in the spread of HIV/AIDS. Karim (1998) found that it was widely acknowledged that marginalization, alienation and impediments to the development of one’s full potential, were factors that contributed to the increased exposure to HIV infection. Karim & Karim, (2005) argued that cultural factors contributed to the increase of HIV risk among women in South Africa, with men hiding behind culture and using culture to suppress women.

From an anthropological perspective gender is a culture specific construct, that is, it stipulates the specific roles of men and women, and in doing so created inequalities and imbalances of gender roles. Gender inequality within the Indian community is a process that begins in the family and is perpetuated through cultural values and beliefs and is reinforced throughout society (Govender, 2005). Gender roles tend to subordinate women in the households, in authority and in public positions of decision making.

Even marriage is not a protection for a woman in many countries. Women's infidelity is not only frowned upon but actually criminalized in certain places, whilst men's extramarital sexual relationships and use of female sex workers are seen as being almost acceptable, or to be expected (Karim & Karim, 2005). Women remaining faithful to their husbands won't help them to stay safe from HIV if their husbands are the ones who infect them. This appears to be one of the most common ways in which women are infected in Chatsworth (see Chapter Six for further discussion).

Govender (2005) states that in Chatsworth it was observed that it was mostly monogamous women who were infected and who were victims of their partner’s risky behaviours. Male dominance prevented these women from asserting themselves; they were powerless to question their partners because it was still a custom among the more conservative South African Indians for a woman to not question a man’s judgment.

Within the Indian community generally it is generally expected that ‘good’ women are ignorant about sex and passive in sexual interactions. This makes it difficult for women to be informed about risk reduction or, even when informed, makes it difficult for them to be proactive in negotiating safe sex (Govender, 2005). It is the gendered context of society, defining females largely as inferior and the weaker sex, as the ones who are socialized to become ‘good’ women and who should respect the male head of the household. This creates an environment in which women are not in a position to make decisions. Hence, as Karim (1998) suggests, women will remain more vulnerable to HIV/AIDS for some time to come.

2.4 Stigma, Silence and other related Prejudice

Stigma is a complicated process with various inter-related and complex factors and is affected by dynamics such as race, gender, and socio-economic status.

The process of stigmatization involves labeling differences, and separating “us” from “them.” The process creates blaming and shaming, and often results in isolation (O’Sullivan, 2000).

Goffman (1963) defined stigma as a ‘significant discrediting’ attribute possessed by a person with an ‘undesired difference’. Stigma is a powerful means of social control applied by marginalizing, excluding and excising power over individuals who display certain traits. Goffman (1963) further stated that a stigmatized individual is a person with a ‘spoilted identity’ who is ‘rendered unworthy’ by others. In the case of HIV/AIDS, stigma may be applied to actual infection or to behaviours believed to lead to infection (UNICEF, 2001). Govender (2005) found that HIV related stigma in Chatsworth is perceived as a mark of shame where the carrier of the virus is blamed, devalued and significantly discredited.

HIV/AIDS is associated with attributes and behaviour that is seen by many people to be contrary to prevailing norms or accepted ways of behaving in society. O’Sullivan (2000) suggests that HIV/AIDS gave renewed life to the concept of disease as punishment and other moral judgments. The association of HIV/AIDS with death and sex further stigmatized those infected; death and sex are taboo subjects in many societies. It is fueled by ignorance or lack of understanding about the disease, and modes of transmission (O’Sullivan, 2000).

Govender (2005) found that stigma created barriers to HIV/AIDS prevention and care in Chatsworth by creating an environment in which it is difficult to talk openly about the ways in which HIV is transmitted and how to stop it from being transmitted. It also created the false impression that only certain people can become infected. When thoughts of stigma, prejudice and stereotypical thinking move into the sphere of behaviour, the result is one of discrimination. This is similar to the argument by Goffman (1963) where people living with HIV/AIDS are blamed and stigmatized. The negative treatment given out to people living with HIV/AIDS by the community who are unaware of the disease constitutes as oppression (Govender, 2005). According to Ramjee (2006), the prevalence of misinformation about AIDS in Chatsworth has not only hampered efforts to increase access to treatment, but has also created a climate of confusion in which prejudice towards people living with HIV thrives.

It is evident from the study conducted by Govender (2005) that for many of the people in Chatsworth living with HIV/AIDS, stigma, prejudice and discrimination from family and friends are a daily reality due to misinformation that surrounds the disease. Govender (2005) argued that most Indian families maintained high moral standards because of their upbringing and closely knit family structure, and therefore HIV/AIDS cannot affect them. Govender (2005) goes on to say that they are living in total denial. HIV/AIDS, according to Ramjee (2004) is spreading at an alarming rate in the Indian community of Chatsworth, with poverty only worsening the spread of the disease.

In South Africa there is some correlation between extreme poverty and high HIV prevalence, although the virus is prevalent across all sectors of society (Pope, 1995). By 1998, although people from more affluent, largely white society were starting to come out as being HIV positive, stigmatisation of the condition remained still deeply rooted in township areas. In October of that year, the then Deputy President Thabo Mbeki made the Declaration of Partnership Against AIDS, in which he called for an end to discrimination against people living with HIV (Iclinic, 2000). However, it was clear that there was a long way to go before this goal could be achieved. Less than two months later, Gugu Dlamini, an AIDS activist in Durban, was beaten to death by her neighbours after declaring that she was HIV positive on World AIDS Day (UNAIDS, 2006).

In 2000, Justice Edwin Cameron of the South African court announced in a speech that he was HIV positive. The public response to this declaration was, on the face of it, largely supportive (Iclinic, 2000). However, coming out as HIV positive can in many cases have a negative effect on employment and housing opportunities, as well as social relationships (Tarisai, 2002). A study conducted on stigmatization and HIV in 2002 revealed that only one third of respondents who had revealed their HIV positive status were met with a positive response in their communities. One in ten said that they had been met with outright hostility and rejection (Tarisai, 2002). Govender (2005) reaffirmed this by saying that most of the people she had interviewed in Chatsworth were afraid of disclosing their status in fear of being ostracized, as most of the respondents feared disclosing because according to them a woman did once disclose her status and she was rejected by the community and faced hostility.

From the moment scientists identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the disease. Discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV or AIDS (O’Sullivan, 2000).

It goes without saying that HIV and AIDS are as much about social phenomena as they are about biological and medical concerns. Across the world the global HIV/AIDS pandemic has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities (Piot, 2004). But the disease is also associated with stigma, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities. This rejection holds as true in the rich countries of the north as it does in the poorer countries of the south (Piot, 2004).

Stigma is also said to be a powerful tool of social control. Stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics. While the societal rejection of certain social groups (e.g. 'homosexuals, injecting drug users, sex workers') may predate HIV/AIDS, the disease has, in many cases, reinforced this stigma (Karim, 1998). By blaming certain individuals or groups, society can excuse itself from the responsibility of caring for and looking after such populations.

This is seen not only in the manner in which 'outsider' groups are often blamed for bringing HIV into a country, but also in how such groups are denied access to the services and treatment they need (UNAIDS, 2006). In many societies people living with HIV and AIDS are often seen as shameful. In some societies the infection is associated with minority groups or behaviours, for example, homosexuality. In some cases HIV/AIDS may be linked to 'perversion' and those infected will be punished. Also, in some societies HIV/AIDS is seen as the result of personal irresponsibility (UNAIDS, 2006).

This indeed appears to be the case in Chatsworth where HIV and AIDS is believed to bring shame upon the family. Negative responses to HIV/AIDS were often found to feed upon and reinforce dominant ideas of good and bad with respect to sex and illness, and proper and improper behaviours (Govender, 2005).

2.5 Conclusion

The relationship between HIV, poverty, gender and stigma is complex. Pressing concerns for short-term survival may lead women to engage in survival sex which paradoxically can expose them to the long-term risk of illness and death through

HIV infection. The denial, blame and stigma surrounding HIV often silences open discussions, delaying effective responses, and adding to the burden of those living with HIV and AIDS. Women's sexuality is particularly subject to stigma and control. Indeed, the social construction of sexuality - who should or should not express it and how- including men who have sex with men, young people, people with disabilities, and those beyond reproductive age, means they are often denied appropriate sexual health information and services.

Poverty also limits people's access to sexual health information, prevention technologies and treatment. Whilst this is true for women and men, gender inequality and stigma shapes different experiences of poverty and impacts on women and men's ability to move out of poverty. Social spending cuts often lead to increased pressure on women and girls to take on the role of social safety net, caring for sick relatives and securing a livelihood as earning family members become sick and die. This is one of the invisible impacts of HIV/AIDS. Poverty, gender inequality and stigma have all been found to be helping to drive and shape the HIV/AIDS pandemic within South Africa, including within the Indian community of Chatsworth.

In the chapter to follow I will be looking at the social/cultural context of HIV/AIDS and focusing on culture theory in relation to the HIV/AIDS pandemic.

Chapter Three

Theoretical Framework

3.1 Introduction

HIV/AIDS has been called a disease of modernity (Schoef, 2001), a disease of globalization (Barnett & Whiteside, 2002) and has also been referred to as a disease of development (Schoepf, 1995; Treichler, 1999). According to Treichler, (1999:117), "it is precisely the difficult social landscape of recent history that raised awareness of the challenging nature of undernourishment, conflict, social turmoil, poverty, widespread disease and movement toward democracy that has been unavoidably illuminated and scrutinized in the international light of the AIDS crisis". Treichler (1999) draws attention to a shift in the last decade in terms of how HIV/AIDS has been perceived by international researchers, namely a shift from a mainly biomedical discourse about HIV/AIDS to a greater acknowledgement of the central role of both macro- and micro-economic, political and socio-cultural factors in shaping the construction of disease.

The work of medical anthropology has been central to this transition. As Barnett and Whiteside (2002) pointed out, western interpretations have often viewed HIV/AIDS and other diseases as a problem of the body alone. But bodies, they argue, must be understood as products of history, culture, society, and economy of AIDS are more than merely biological phenomena. It can thus be argued that the slowness to achieve such an understanding is closely linked to the failure thus far to stop the pandemic, despite the successful biomedical advances that have been made (Schoepf, 1995; Webb, 1997). This oversight in early research and intervention strategies in turn had a range of negative implications for HIV/AIDS intervention programmes, their success rate and how they are carried out (Leclerc-Madlala, 2008).

In light of this, this chapter aims to explore the role of the cultural context in shaping the way HIV/AIDS is understood and experienced within the South African Indian community of Chatsworth. I will firstly consider the ways in which the notion of culture has been generated and in the predominantly biomedical response to HIV/AIDS.

3.2 Culture Theory and HIV/AIDS

The notion of culture has a complex history and is regarded as a fundamental concept in twentieth-century anthropology (Barnard and Spencer, 1996). The current mainstream anthropological concept of culture is that the world is made up of a diversity of cultures, which in turn explains differences among humans. The central premise is that culture infuses and influences all aspects of life, including the social, political, and economic.

In relation to HIV/AIDS, many social scientists have disputed the limitations of biomedical models in terms of intervention and prevention in that biomedicine only looks at the disease itself and not at other contributing factors that impact on the person. In the last decade social researchers have produced a growing literature on non-biomedical interpretations and explanations of the AIDS epidemic, much of which gives culture a central role. This is not to say, however, that early social science approaches were not at least partly determined by the demands and funding of epidemiologists, which in turn had implications for how culture was presented and understood in the literature. It is within the framework of the shift towards non-biomedical understandings of HIV/AIDS, and in the series of ‘encounters’ between epidemiology and anthropology, that we gain some insight into how the notion of culture has been variously understood and employed by both sides, specially with reference to Sub-Saharan Africa (Schoepf, 1995).

It is clear that the meaning of culture in this varied literature cannot be assumed. Indeed, several authors argue that epidemiological and socio-cultural accounts of HIV/AIDS causation contain conflicting versions of culture (Glick Schiller, 1992; Preston-Whyte, 1995). According to Schoepf (2004) the concept of culture has been ‘bandied about’ and yet hardly any authors have attempted a more systematic account of the ‘bandying about’ itself. Culture proves to be a dynamic and shifting concept with a range of meanings, engaged with both shallowly and deeply. As Schoepf (2004) argues we need to ask in what different ways the concept of culture has been useful, and to whom.

Culture is dynamic, and an understanding of culture would seem to be a precondition for designing interventions to prevent HIV infection. In some contexts the concept has been employed as a means to exercise power, whereby culturally defined ‘risk’ groups are identified, berated, surveilled and regulated, that is, as “a fundamental method of enforcing inequality” (Abu-Lughod, 1991: 139). Govender (2005) states that the poor of Chatsworth are more marginalized and hardest hit by HIV/AIDS. Women especially face economic, social, sexual and cultural subordination and inequality, making them most vulnerable to HIV/AIDS. Hence culture can play a role in the spread of diseases by enforcing inequalities (particularly gender inequalities) within communities.

In other contexts the use of the culture concept remains a more subtle tool for maintaining difference. Frankenberg (1995:128) has suggested that “the effect of work on AIDS seems to have had a schism genetic effect on anthropologists’ use of their core concept of culture”, implying that the concept is victim to internal divisions and lack of transparency. More importantly, Frankenberg (1995:128) states that, “On the one hand, to please epidemiologists who have appealed to anthropologists for help, hence anthropologists have intensified, without even noticing it, their tendency to reify culture, to see it as a thing to be possessed. People, who want to act on others, however noble their intentions, behave in this way. People who want to act with others, on the other hand, have to emphasise the importance of recognizing individually and categorically determined differences in the continuous process of culture creation, use and change”. One of the challenging products of anthropological work on HIV/AIDS has thus been to re-look at culture in facilitating the exercise of power by more powerful actors over certain groups. According to Govender (2005), power in terms of male dominance pervades every aspect of South African Indian women's lives (see Chapter Six) and influences their ability to be assertive to protect themselves. The majority of HIV positive women in Chatsworth, according to Govender (2005) lack proper information and support. They live in fear because of continued stigma (from the community and their families) associated with HIV and the fear of their husbands blaming them for the disease even though it was the husbands themselves who may have infected them.

Frankenberg's (1995) claim needs to be paid more attention to, as it may help to explain why many are left with a sense of confusion about the exact role of culture in HIV/AIDS interventions, despite the multiple insights of socio-cultural analyses of the pandemic itself. Furthermore, following Sobo (1999), social scientists researching HIV/AIDS in relation to culture would do well to pay attention to broader non-AIDS focused anthropological debates about the concept (Abu-Lughod, 1991; Ferguson & Gupta, 1992).

Packard and Epstein (1991) argue that the Western medical research community predetermined the early contributions of social scientists to HIV/AIDS research in Africa through the narrow range of questions that epidemiologists asked. Social scientists were brought under the biomedical wing to provide information not on broader social contexts, but on the practices, customs and patterns of social intercourse (i.e., 'risky' behavioural practices) that provided opportunities for HIV transmission. These authors state: "While asking about contexts would have allowed for open ended discussion of a wide range of social, political and economic conditions which may be affecting health levels in Africa, the medical scientists' formulation quickly narrowed discussion to an inquiry into the 'customs of the natives'. At the same time, it placed responsibility for transmission on the actors themselves in a not too subtle form of victim blaming" (Packard & Epstein, 1991:774). The authors imply that as a result of the biomedical co-option of social scientists, information presented often dug out of the ethnographic record, was inappropriately 'excised' from its social context. In this instance culture, or rather certain aspects of certain culture, have been decontextualized and reified.

The decontextualisation and generalisation of culture allowed biomedical discourses to hypothesise culture as both the reason behind the spread of HIV (Schoepf, 2004) and as a limitation to change. In turn, culture could also serve to justify policy failure (see Chapter Five), because it did not account for the social context that impacted on peoples' daily lives. As Schoepf (1995:44) remarks, "the failure of AIDS education to effect widespread change has been ascribed by many biomedical researchers to the idiosyncrasies of peoples' behaviour rather than to the possible inappropriateness of educational programmes and the research on which they are based".

Glick Schiller's (1992) paper on the cultural construction of HIV in the United States describes how the culture concept became one of the examining tools of public health researchers for pursing and preventing HIV/AIDS. Glick Schiller (1992) maintains that anthropologists do not collaborate with, but rather critique public health researchers' notion of culture, which became linked to disease through the epidemiological concept of 'high risk' groups. These groups, namely drug users in this case, were seen to be distinct in both behaviour and identity, and what distinguished them was culture (Glick Schiller, 1992). This public health notion of risky cultures also included racial and ethnic classifications. It was suggested that drug users are a product of Hispanic or African American culture. Biomedical practitioners in this case study chose to sideline Glick Schiller's research findings about gender and power differentials and economic disadvantages within and between communities (Frankenberg, 1995:123). Glick Schiller (1992) affirms that public health officials used culture in this context to generate differences, subordinate the 'other', and maintain a hegemonic social order. The use of the culture concept here is clearly attached to the use of power, and resonates with Foucault's influential work on observation, control, and governmentality (Burchell, Gordon, & Miller, 1991; Foucault, 1977 & Foucault, 1980).

Whilst Glick Schiller's paper does not directly seem relevant to the Chatsworth context, it presents another example of the biomedical construction of culture and how biomedical practitioners view the contribution of anthropologists to the study of HIV/AIDS.

The biomedical understanding of culture outlined above employs a naive yet power-wielding concept of culture, frequently linked to racial otherness, as a descriptive tool for what Treichler (1999: 234) describes as "information campaigns developed in pristine ignorance of structural forces and the myriad material environments in which behaviour acquires shape, meaning and consequence”. Treichler's (1999) view may be an overstatement for some places but it resonates in sub-Saharan Africa where externally driven campaigns largely function with inadequate ‘local knowledge’ that surrounds the spread of HIV/AIDS, such as entrenched poverty, gender inequalities and stigma. This is not to say that social scientists have not also used culture as a descriptive tool. When they do however, they follow different types of explanations from epidemiologists. The major contributions that social scientists have made to HIV/AIDS research has taken place in the last decade (Whiteside, 2004). Much of this research has been at least partly catalysed by dissatisfaction with biomedical models, and highlights their limitations. The culture concept is central to much of this literature, and therefore I will examine the ways in which the notion is used.

3.3 The Culture Concept in Anthropology

Much like those social scientists who have looked into the flaws and unintended consequences of development projects (e.g., Ferguson, 1990), so too have HIV/AIDS researchers raised the question as to why intervention programmes have in most Sub-Saharan African countries often failed (Bujra, 2000; Campbell, 2003; Maharaj, 2001; Schoepf, 1992), and why people continue to place themselves at risk in spite of having improved biomedical knowledge about HIV transmission. Dilger (2003:24) proposes that “it is this gap between biomedically defined knowledge and actual behaviour that increasingly raises doubts about how AIDS campaigns are planned and implemented.” The gap that Dilger (2003) makes mention of has given rise to questions into what might help or hinder intervention, including the issue of culture. Overall, Dilger and others argue for an understanding of cultural (in addition to political and economic) contexts in order to construct suitable and successful HIV/AIDS intervention programmes. The models of culture used by HIV/AIDS researchers may be restraining, as in some of the biomedical models, but cultural norms are also acknowledged as flexible, with the possibility of being reinvented and restructured. Whether restraining or flexible, culture in this aspect of interpretation supports rather than compromises HIV/AIDS interventions. Nonetheless, the use of the concept remains a form for creating and asserting difference; the concept is itself reliant on a self/other dichotomy (Abu-Lughod, 1991; Ferguson & Gupta, 1992).

The major feature of this body of literature that explores the myriad uses of the culture concept is that increasing attention is paid to the links between local and macro processes that promote the social production of disease, including the role of national and global political economy. Farmer's (1992) influential ethnography on AIDS in Haiti paved the way for the development in this research area. These works holds more complex understandings of structural, institutional (poverty) and cultural (gender, stigma and inequalities) contexts that give rise to the power of the AIDS pandemic, in addition to a new emphasis on vulnerability rather than ‘risk’ (Akeroyd, 2004; Campbell, 2003; Setel, 1999). Vulnerability is understood to be the result of power and inequality, poverty and economic inequity (see

Chapter Five), which act as virulent co-factors in the spread of HIV (Farmer, 1992). Schoepf (2001:53) explains the impact of economic crisis and structural alteration programmes on the AIDS pandemic in Africa, stating that “AIDS is truly a disease of the global system, emblematic of permanent crisis in the South and encapsulating global inequalities of class, gender, and ethnicity”. Schoepf's (1995) Zaire research links macrolevel political economy to microlevel socio-cultural analysis, presenting how continued crisis, gaps in wealth, and institutionalized male dominance contributed to the growing pandemic.

The macro–micro accounts are realistic in that HIV/AIDS prevention must be understood as part of a larger process of social transformation aimed not just at the decline of risk, but at the recognition and redressing of socio-economic inequality and injustice (Parker, 2001). Culture in these instances has quite a different appearance from that in the biomedical models. It is contextualized within, rather than removed from, broader frameworks, and it is understood to be historically shaped rather than bounded and frozen in time. Culture is not reified as being the main constraint to HIV prevention, but given more equal status together with other factors, such as the political and economic.

Regardless of their overall influence, the prominence of macro-level factors in these works may be problematic from the position of those who need effective HIV prevention. Webb (1997) stresses that irresolvable macro-processes can lead to an ‘ethos of hopelessness’ because these are often beyond the capacity of health-related interventions. To this extent, does culture at the micro-level, rather than ‘economy’ or international relations at the macro-level, remain the most viable locus for intervention? In turn, does this take us back to the idea of bounded ‘cultures’ ‘out there’, available to be scrutinized or acted upon by intervenors? Reflecting on these questions, Webb (1997) suggests that there may be more similarities here with biomedical models than at first imagined.

Another important tendency particular in the current social science literature on HIV/AIDS supports the latter observations, directing culture as a central player in local interventions. These works present evidence to show that health interventions fail to meet their goals when they fail to consider culture's impact on health-related behaviour (Dilger, 2001; Offe, 2001; Sobo, 1999; Webb, 1997). The objectives of intervention projects take biomedically supported literature within the context of pre-existing systems of meaning, and through a filter of indigenous health knowledge and experience (Campbell, 2003; Heald, 2002; Ingstad, 1990; Parker, 2001; Probst, 1999). Understandings of HIV/AIDS are modified in local cultural idioms, creating more substantive explanations for AIDS than the biomedical discourse, which offers neither cure nor explanation for the disease. An example of this is work by Leclerc-Madlala (2002) on widespread belief in KwaZulu-Natal that HIV/AIDS can be cured by having sex with a virgin. This belief has been identified as a possible factor in the rape of babies and children in South Africa and elsewhere in the region. It may be in many instances that men believe that they have nothing to lose by attempting to cleanse themselves of AIDS by having sex with a virgin to be cured, despite of whether they believe in the myth or not. Wolf (2001) explains how indigenous concepts of sexually transmitted diseases are also applied to AIDS in a number of southern African countries, including Zambia, Botswana, Malawi, and South Africa. HIV infection is said to be related to sexual misconduct and social transgressions, the sick body becomes a 'model for social disharmony'. Whilst people are aware of the differences between AIDS and other more familiar diseases, "the link they make empowers them to interpret, understand and react to a threatening phenomenon" (Wolf, 2001:97).

In these approaches, culture is acknowledged as a constraint to HIV/AIDS prevention, but not as a fixed constraint as in the biomedical models. Rather, culture is seen to hold the potential to combat the epidemic due to the possibility of changing moral and material constructions of social relations (e.g., gender relations) and practices which have thus far impeded recognition of risk (Akeroyd, 2004; Craddock, 2004; Gausset, 2001; Schoepf, 2004). Communities, rather than individuals, can be targeted through interventions. 'Upstream interventions' rather than behavioural interventions, in particular enhancing the position of women, are advocated as having particular value for curbing the epidemic (Barnett & Whiteside, 2002). In addition, certain cultural practices or institutions, as will be further discussed in Chapter Six and Seven, can in their existing form be made useful for the purposes of HIV/AIDS prevention.

Overall, work such as Ingstad's and Schoepf's suggests that an integrated approach to HIV/AIDS intervention, one which aims to combine certain biomedical knowledge with 'local' perspectives, will have much greater success than applying transcendent biomedical models which disregard local contexts. Culture here becomes part of the solution to the AIDS crisis, a variable to assist success. Culture entails a host of practices and institutions which can be made useful; it is simply a question of finding what aspects of it are most pertinent, whether in the form of religious beliefs, ideas about sexuality, ideas about gender, indigenous ideas about illness, and so on.

3.4 Conclusions

The notion of culture and various ideas about its shaping influence in the context of HIV/AIDS has been employed in a host of different ways by both biomedical and social scientists researching HIV/AIDS in the last decade. Undoubtedly, the concept is not exclusively the field of anthropologists, despite their long-standing use of it. The concept is also used in a variety of ways within anthropology itself, helping anthropologists to understand the rapid spread of HIV/AIDS within communities.

For biomedical researchers and epidemiologists culture commonly appears to undermine interventions, whilst for anthropologists culture is often seen to have the potential to assist interventions. Culture is a complex and overcrowded concept with varying assumptions, from culture being bounded and unchanging to culture being linked to macro-processes, historically shaped, and challenged. In turn, culture has variously been understood as both the cause of, and solution to, the pandemic. It is also understood as having structured local interpretations of and responses to HIV/AIDS. The use of the culture concept has been shown to more often than not involve assertions of difference and the subtle enforcement of inequality between self and other through that difference (Frankenberg, 1995).

Researchers seem to agree that HIV/AIDS research, especially that by anthropologists, may be improved through an awareness of analysis from anthropological literature that specifically addresses the underlying problems of the concept of culture. The work of Abu-Lughod (1991) and Ferguson & Gupta (1992) as outlined earlier, provide two such examples. It is not a question of abandoning the culture concept, but rather being aware of its subordinating potential. Abu-Lughod (1991:149) proposes that one tool for “unsettling the culture concept and subverting the process of othering is to write ethnographies of the particular”. That is, to resist generalization and to foster forms of writing about societies and culture that best conveys the complexities of macro- and micro-processes and the relationships between them. This in turn may go some way towards undoing the ‘schism genetic’ effect that work on HIV/AIDS has had on anthropologists’ use of the culture concept (Ferguson & Gupta, 1992). In this current study, I draw upon and take cognizance of these pertinent debates for attempting to understand how cultural factors linked to socio-economic and gender inequalities as well as stigma, ‘asserts’ itself into daily experiences of HIV/AIDS among people in the community of Chatsworth.

In the chapter to follow, I discuss how I went about conducting my research using an anthropological approach. Employing a perspective that acknowledges the nature and nurture dimensions to understanding the spread of HIV/AIDS within the community of Chatsworth, I explain the qualitative methodologies used.

Chapter Four

Methodology

4.1 Introduction

This chapter investigates the research methods and the procedures employed in analyzing the data. This study was qualitative in design and multiple methods were used in the data-gathering process. The research problem investigated in this study, conducted in the Chatsworth area, required an approach that would allow my participants to talk about their perceptions and experiences, and provide explanations in their own terms as to how they understood HIV/AIDS in their community. It was hoped that the in-depth qualitative methodology used in this study would provide explanations of how, why and to what extent culture influenced the attitudes and perceptions held in relation to HIV/AIDS in Chatsworth.

This study's main focus was on the understanding of the growing incidence of HIV infection in the South African Indian community of Chatsworth. The research problem required a methodological approach to elicit the subjective experiences of the people and how it impacted on their lives. I found the choice of a qualitative research approach through in-depth interviews, participant observation, and focus group discussions to be appropriate to achieve this objective, given that the study sought to understand the range of meanings that people associated with the HIV/AIDS virus and the way in which its significance was framed or shaped within the context of an individual’s life. I felt that this research project involving peoples’ experiences of HIV/AIDS required a qualitative approach.

4.2 Reflexivity

Reflexivity is the act of recording the participant’s life and the act of self-interpretation by the researcher. These are parallel because both are the product of people’s reflecting on one another and thereby influencing and changing one another (Shields & Dervin, 1993). Taking reflexivity into account, the key questions outlining the topic and using an open-ended interview style, would allow the participants to reveal and recollect their narratives. It was anticipated that the narratives would provide rich material for developing and understanding how their (participants) lives are shaped within the context of social/cultural factors in relation to attitudes, perceptions, knowledge and reported behaviours related to sexuality and HIV. Ramazanoglu and Holland (2002) argue that any researcher who sets about to understand social realities and grasp their impact on people’s lives, has to consider how social realities can be understood, how people, especially women, make sense of their experiences and how power inhibits knowledge production.

Therefore decisions about methodology are particularly important in the politics and practices of knowledge production. Lentin (2002) asserts that in-depth interview methodologies are ways of seeking “truths” and at the same time empowering people to talk about the issues that impact on their lives.

4.3 Research Design

This study is qualitative in design. According to Rudestam and Newton (1992), qualitative methods are especially useful for understanding human phenomena and the investigation of the interpretation and the meanings that people attach to experiences. Qualitative research designs usually depend on written, spoken and observed data or behaviour and allows for telling the story from the respondents view point, thus providing rich descriptive data (Neuman, 1997). Oral method is generally used for identification, description and explanation, an approach that I judged to be ideal for this type of research.

4.4 Sample

Thirty participants, both women and men, ranging from ages fifteen to fifty-five years were interviewed, all residents of the Chatsworth area. People interviewed came from both middle and lower income groups, sixty percent of the people interviewed were HIV positive. The choice of this age group was maintained to reveal their reflections, self-perceptions, personal opinions and emotions to unveil meanings associated with selected themes (inequalities, gender, socio-economic/political) and how these are informative of a culture that they have ultimately internalised and became part of in relation to HIV/AIDS within their community.

4.5 Data Collection

Field work took place in the Chatsworth community, fifteen kilometers South of Durban. Individual interviews were conducted with all participants. Data collection took place between December 2006 and March 2008. The in-depth interviews provided the bulk of the data used in the study. In addition data was collected through in-depth (face-to-face) interviews, participant observations and focus group interviews. Interviews took place primarily at the participants' homes, with the assistance of Rani Pather from 'A Ray of Hope' community based organization in Chatsworth. This organization, established in the late 1990's, offers counseling to HIV positive people and their families, provides poverty elevation (for example food and clothing) within the community, rape/trauma counseling and skills training for income generation.

4.5.1 Interviews with respondents

Qualitaive in-depth interviews were conducted with a wide range of people through the Chatsworth area. Participants ranged from HIV+ people, the youth, people who had lost loved ones as a result of HIV/AIDS and community members from the area. They came from various occupations and different generations, social and economic classes. The participants were recruited by the director of A Ray Of Hope and were affiliated with this organisation. Rani Pather, current director of A Ray of Hope, explained the purpose of my study to the participants and all were more than willing to be interviewed, giving their informed consent (see Appendix 3).

An open-ended interview guide was used. This chosen interview format made it possible for the participants to narrate to a large extent what they felt comfortable to discuss, while simultaneously providing opportunities for the probing and rephrasing of questions when necessary. This combination of specificity and flexibility in the interview process encouraged the participants to determine the shape and direction of their narratives, while also allowing for the gathering of particular information.

The substance of the interviews centred around the following areas: the growing rates of HIV in the community, an exploration of people's ideas on why this was happening; socio-cultural and socio-economic factors in relation to HIV, and attitudes, perceptions and knowledge that participants currently held in relation to HIV/AIDS.

My subjectivity as a researcher could not be avoided. Mies (1983) argues that the concept of "partial identification" is important, that we proceed from our own contradictory state of being and consciousness. This means that one is aware of the structures within which one lives and works. According to Mies (1983) "conscious partiality" is more than subjectivity and empathy. It creates "a critical and dialectical distance between the researcher and the researched" (Mies, 1983: 68). To handle subjectivity I attempted to widen my consciousness to correct distortions of perceptions on my side and those being researched. Constant reflection helped me keep in touch with the reality of things and not just my “insider” view of what that “reality” constituted. Here I had to decide how much to participate and how intensely to become involved in the participants lives. The implications as an “insider” was clear to me as the nearness and involvement afforded by my shared experiences to gain access and establish trust, but at the same time I maintained, whenever possible, the necessary distance in order to encourage a full account of the participants’ experience. Each interview was recorded using a tape recorder. Recording of in-depth interviews made it possible to listen to the discussion a number of times in order to ensure the participants’ responses were accurately quoted and to assist with analysis of the data later on.

4.5.2 Participant Observation

Participant observation of the routine activities of members of A Ray of Hope was also employed. In doing this, I stressed the “observer” role and placed less emphasis on the “participant” role. In discussing observation, Neuman (1997) says that there is only one kind of phenomenon in the whole realm of social life, which is observable: specific actions of individuals, which are physical moments, people do not behave in isolation but in interaction with and towards others, which makes interaction meaningful.

Data was collected by the use of observations. Most especially during individual interviews, I was informally observing the body language and emotional state of the participants while they related their stories. The individual interviews allowed for ‘in- depth’ discussions without interruption, getting a particular person’s feelings or opinions that may not correlate to what the group discussions or the observations and informal conversations had produced, thus giving me the opportunity to get more data.

The success of my data collection depended on the competence with which I interacted socially with the participants. I felt my moral as well as my academic research responsibility was to approach them with humility and integrity. Participant observation afforded me the privilege of an insider and I believe enhanced the study findings.

4.5.3 Focus Group Discussion

Focus groups, sometimes referred to as “group interviews” or “group discussions”, may take many forms but their defining feature is that of a small group of people engaging in the collective discussion of a topic, pre-selected by the researcher (Frith, 2000). Focus group discussions allow the researcher to interact directly with research participants, thus providing opportunities for clarification of responses for follow up questioning and for probing of responses (Stewart & Shamsadani, 1990). Focus groups are applied to collect opinions, beliefs, attitudes and experiences about issues of interest to the research, checking assumptions, encouraging discussion of a topic, and to provide opportunity for facilitator and participants to learn more about a topic of issue (Simon, 1999).

Two focus group discussions were held. Both focus groups took place at the homes of two participants. The aim of the focus group discussions was to gain insight into the personal experiences, beliefs, attitudes and feelings of the participants in the study towards their understanding of the rise of HIV/AIDS within the context of the South African Indian community. The group size was five and seven (both men and women, age ranging from sixteen to fifty-five) and included participants from various socio-economic backgrounds.

Each focus group was started with an introduction of myself and the purpose of the focus group. I reminded the participants that at any time during or after the focus group, they could anonymously resign their input. A series of questions were asked regarding basic knowledge of HIV/AIDS. These questions were established to validate my assumption that basic knowledge of HIV/AIDS is understood in terms of shared opinions, beliefs, and attitudes that surround HIV/AIDS in Chatsworth. There after, questions were asked to guide the focus group and it was carried out in a more conversational group format.

The focus group discussions enhanced the disclosure of material in three ways: it brought an awareness of shared experience and encouraged discussion of some sensitive issues; agreement between group members helped to build en elaborate and further picture of their views; disagreement led some of them to defend their views and provide further explanations (Haralambos & Holborn, 1995)

Each focus group discussion lasted approximately one hour and a half and was recorded using a tape recorder, transcribed and checked for accuracy. Recording the focus groups made it possible to listen to the discussion multiple times to ensure that the participants responses were accurately captured.

4.6 Ethical Considerations

A number of concerns relating to sensitive areas of research have been raised authors such as Babbie, 2001; O'Kane, 1998; Bhopal, 1999; Kirsch, 1999; Ramazanoglu & Holland, 2002. These authors emphasize the importance of maintaining ethical guidelines in qualitative research when researching sensitive areas of focus, i.e. HIV/AIDS.

One important ethical issue involves "informed consent" (Kirsch, 1999). I informed my participants about the purpose, methods and risks associated with the research. The following issues were discussed verbally as well as written (informed consent form that I had drawn up for them to sign) with the participants before the interview (see Appendix II):

- A brief description of the nature and purpose of the study.
- A guarantee of anonymity and confidentially.
- The identification of the researcher and information about where to reach him/her.
- Participation was totally voluntary.
- Potential value of the study.
- Participants were informed of their rights to withdraw from the study at any stage during the research process.

Confidentiality was an important ethical issue in studies dealing with HIV/AIDS. An ethical concern of qualitative interviews of this nature is the "researcher-participant relations". This issue addresses the dynamics of the researcher and the participant (Kirsch, 1999). Open-ended interviews make it easy to establish an understanding with the participants and to validate their concerns, values and experiences when the researcher shares a similar background with the participants interviewed, who readily trust with personal or confidential information (Kirsch, 1999). For this study, the participants' names and addresses are concealed to guarantee anonymity.

The relationship of power in the research process can be an ethical dilemma. The researcher-researched dichotomy is one of power relations because of the familiarity of the researcher with the subject matter and the casual style with which information is shared (Bhopal, 1997). Throughout the research process I remained mindful of these inherent power dynamics between the researcher and the researched, and tried to be as sensitive, respectful and accommodating as possible.

4.7 Conclusion

In this chapter I have documented my methodology of qualitative research. In addition to the research design, I have provided my rationale for the use of in-depth interviews, participation observation and focus group discussions. The ethical considerations presented by the study were also addressed in this chapter.

In the next three chapters I provide discussion and analysis of findings from the information I collected. I start with a discussion on some aspects of the policy environment in which HIV/AIDS in Chatsworth is occurring. All names used in the text have been changed to protect the confidentiality of the participants with exception of the director of ‘A Ray of Hope’, Rani Pather, who specifically requested that I use her name in the thesis.

Chapter Five

HIV/AIDS in the Context of Policy and Poverty in Chatsworth

5.1 Introduction

Policy is a fundamental technical, rational, action-orientated tool that decision makers use to solve problems and affect change (Shore & Wright, 1997). Titmuss (1974: 23) suggests that "policy denotes the principles that govern action directed towards given ends". Policy has a more dispersed impact when, through descriptions of the individual and society, it influences the way people construct themselves, their conduct and their social relations as free individuals (Shore & Wright, 1997). In other words policy is used as instruments of power for shaping individuals, by influencing people's norms of conduct so that they themselves contribute, not necessarily consciously, to a government's model of social order (Shore & Wright, 1997).

According to Shore & Wright (1997) policies are inherently and unequivocally anthropological phenomena. They can be read by anthropologists in a number of ways: as cultural texts, as classificatory devices with various meanings, as narratives that serve to justify or condemn the present, or as rhetorical devices and discursive formations that function to empower some people and silence others.

An anthropological approach to policy can be extremely useful. It is standard anthropological practice to focus on a concept that appears, to the people concerned, to be clear and unproblematic, and to explore its different meanings and how it works as an organizing principle of society (Shore & Wright, 1997).

By focusing on policy, the field of study changes, it is no longer a question of studying local community but rather seeking a method for analyzing connections between levels and forms of social process and action, and exploring how processes work in different levels (Shore & Wright, 1997); trying to understand a top-down effect, from a macro level filtering to the micro level.

Shore & Wright (1997) explains that, treating policy as a new anthropological field means not only working in various levels, but also with new kinds of materials, among the most important are policy documents. There is a long anthropological tradition of treating historical material as a valuable source of ethnographic data. Shore & Wright (1997) further explains, the same approach can be taken in analyzing policy documents as cultural text (Refer to chapter three), by using qualitative methodologies to analyse the social dimensions of how policy impacts on the spread HIV/AIDS.

In this chapter I examine how policies work as instruments of governance, as ideological vehicles and as agents for constructing subjectivities and organizing people within systems of power and authority in Chatsworth. I look at how government disability grants in particular are impacting on the lives of people who are burdened by poverty in this era of HIV/AIDS.

5.2 Coping with HIV/AIDS, Grants and Treatment in Chatsworth

Welfare expenditure in South Africa has developed radically since in last decade. Currently South Africa has one of the largest welfare systems in the developing world, with an estimated 25% of the population receiving direct cash transfers from the state (Leclerc-Madlala, 2005). According to Rani Pather from 'A Ray of Hope' community based organization in Chatsworth, *"Many of the people living in the Chatsworth area rely on government grants to survive, they have no other means of income, many of the people living here were retrenched when the textile and leather industries started to close. Many of the families survive on the old age pension, others on the child grant and disability grants. They rely on this money to pay their rents and buy food for the household."*

Expanding the social grant system to support helpless children and their families has thus far been the major government strategy to alleviate this problem. The 2005 budget allocation increased the child support grant for children under the age of fourteen to R180 (R200 in 2007, www.capegateway.gov.za) per month, the foster care grant to R560 (R600 in 2007, www.capegateway.gov.za) per month and the pension payout to R780 (R870 in 2007, www.capegateway.gov.za) per month (Leclerc-Madlala, 2005). Anthea explains, *"I am too young to collect the old age pension, my husband pasted away a few years ago,* *I have three children to feed I did not know what to do, no one wanted to help me, I did not even know about the child grant luckily I did manage to find out, a friend told me about the child grant, I was so happy, at least now I can feed my children and put a roof over their heads."*

According to many of the participants interviewed, experiences to date have revealed that there are common minor problems hindering the process of obtaining these forms of government assistance. They include a lack of knowledge about the grants (as we have seen in the case of Anthea), lack of transportation to obtain applications and advice, lack of essential documentation such as birth certificates and identity documents and the lack of efficient administration (Leclerc-Madlala, 2005). Mangla explains

"How must I go to the place to apply for the grant when I don't even have enough money to buy food, it is really hard, I do not have money to go and I have lost my I.D book I do not have the money to go and reapply for another I.D book and also to get the child grant and disability grant. I got AIDS and I saw somewhere that people with AIDS can get grant."

The number of disability grant beneficiaries in South Africa is growing rapidly, mainly because of the HIV/AIDS pandemic. Addressing the nation in September 2005, South African Minister of Finance, Trevor Manuel raised interest in the growing demand for social grants and the drastic rate of growth of the welfare system (Leclerc-Madlala, 2005). Recognising that much of the increasing demand for government support is certainly a result of the HIV/AIDS pandemic, the Minister had made several media briefings that suggest an approaching decrease of the rising demand for disability grants by HIV/AIDS affected people. In one such media announcement, the Minister stated that HIV was not a disability and many people with the disease live long and productive lives, they don't need disability grants (Leclerc-Madlala, 2005). Sashin, HIV positive said,

"These big shots government people don't know how the poor people live. They have a big house, drive fancy cars and eat well, they don't know what is going on in the communities. How people suffer to survive just to put food on the table. It is even worse if you got this AIDS, I'm sick all the time and I need this grant and I can not find a job I have tried so hard, what I must do then?"

Sashin went on to say,

"We are poor and dying here and the government does not see that, being poor is like a curse. Government does not care about us, I am sick and I get this disability grant that helps me to get by. Most of the people here depend on these grants just to get by."

Evidence obtained during the research would seem to suggest that growing numbers of South African Indians from Chatsworth are suffering from AIDS related disabilities and many are dying from the disease. Sandra, a nurse at a local clinic in Chatsworth says,

"I see so many patients a day who are HIV positive, it is really sad to see so many Indians coming into the clinic for AIDS related treatment. Most of them are really poor,

so we at the clinic advise them to go and apply for the disability grant for HIV positive people. For many patients that are on the grant it is their only means of income."

Currently the government is providing antiretroviral (ARV) treatment, individuals should either be in clinical stage four of AIDS or have a CD4 count of 200 to be entitled to the disability grant, this is based on a purely biomedical model, not taking the social context into consideration (see chapter three) (Nattrass, 2004); many people in Chatsworth living with HIV/AIDS stand to lose their grants as a result of resorted health, Isha elaborates,

"The HIV grant helps me to put food on the table as I am not working and always sick, if they stop my HIV grant how am I going to feed my children? How will we survive? All I care about is my children, what will happen to them?"

Nattrass (2005) argues that people who become AIDS sick and qualify for disability grants can expect to lose their grants when they start their ARV treatment and their CD4 count is boosted above 200, measured according to biomedical medical model (see chapter three) standards. Treatment therefore would result in a restored health for the person, and once health is restored the person would be able to work. Hence, the welfare grant will fall away. For many of the participants the disability grant is the only source of income to the household, Pat says,

"I rely on this disability grant, I am sick and I have three children to worry about, this grant is a life saver for us, I know can buy food and pay the rent."

Disability grants have clearly become an essential source of income for many HIV/AIDS-affected households in Chatsworth. The importance of the disability grant was illustrated by Adeline who said *"thank god for this grant"*. She further goes on to say

"I really thank god for this grant because I have the grant to support my family…I live with my parents who are pensioners, before the grant they used to take care of me and my children, at least now I have this grant to make life much easier for my parents. I am able to contribute to the house now and buy food and clothes for my children. We are surviving on this grant money now at least I don't have to stress about not having enough food in the house."

According to most of the participants, counselors and doctors at the clinics and hospitals claimed that they did their best to explain to the people that they could only qualify for a grant when their CD4 count is low and if they are seriously ill. Many of the participants felt that the money could be better used for buying food to eat so that they can be healthy and able to fight the disease. Veronika explains,

"The grant helps put food on the table for my family, when I found out about the grant I was overjoyed, at least I could buy the essential food so we can survive."

James further states,

"With this money we now can buy food so we can feed ourselves, what is the use going to the hospital for treatment when we don't have food to eat so that we can get better. With this grant the government gives we now can feed our families."

This, Nattrass (2004) argues is understandable when one thinks about the desperate situations that people can find themselves in when they do not have access to an income-earner. The arrival of the disability grant can be a major life-line for entire families, as was clear in Adeline's quote. The chance of it being taken away as a result of ARV treatment is thus certainly serious. Shirley (caregiver) goes on to explain,

"This disability grant helps the poor Aids affected people survive, by helping them get the staple food so that they do not starve. This grant puts food on the table. Many of the people I work with are too sick and weak to work, they rely on this grant for survival."

For many of the participants in this study the disability grant is a source of vital income for families that do not have a breadwinner. The disability grant provides a means for them to survive, enabling them to purchase food and provide shelter for their families. However, once the person's CD4 count is over 200 their grants can potentially be stopped, cutting an important life-line for poor HIV/AIDS affected families. This means lower food expenditure that would affect the nutritional status of the person on ARVs, therefore reducing the effectiveness of the treatment (Nattrass, 2004). Hence one can say to an extent HIV/AIDS is driven by poverty, this could also worsen the AIDS pandemic in the Chatsworth area. Rani states,

"The disability grants are life lines for many of the families here in Chatsworth; they have no other source of income. Most depend on these grants to put food on the table; it's the only means of support for them, as they are deeply impoverished. If the grants are taken away, most the families here in Chatsworth will not survive, as they depend on these grants for survival."

5.3 Poverty, unemployment and HIV/AIDS

Poverty plays a role in the spread of HIV/AIDS in the Chatsworth area; according to many of the participants interviewed. Van Donk (2002) suggests that there is a defined link between poverty and HIV/AIDS, with the poor comprising the unquestionable predominance of those living with HIV/AIDS. However, the link between poverty and HIV/AIDS is not simplistic. Even though the bulk of people living with HIV/AIDS in sub-Saharan Africa are poverty stricken, not all poor people are HIV-positive and a considerable number of middle class people are infected with HIV (van Donk, 2002). Rani from 'A Ray of Hope' says, "*HIV/AIDS is not only a poor person's illness, it can affect everyone, a small number of the people I do counsel come from rich backgrounds. Everyone thinks it is a poor person's disease but it is not. It is also important to note that poverty does play a role in HIV/AIDS."*

Therefore, poverty ought to be understood as a co-factor among other factors. It is helpful to recognize underlying poverty as a core factor in the spread of the HIV/AIDS within the Indian community of Chatsworth.

According to van Donk (2002), poverty does not only enhance exposure to HIV infection, it also decreases the capacity of people living with and affected by HIV/AIDS to manage with the consequences of infection. HIV/AIDS is connected to the repeated short periods of illness, which tend to last longer as the immune system gets further damaged. The lack of sufficient nutrition considerably reduces resistance and expedites ill health. According to one thirty four year old HIV positive participant,

"I can not work because I get sick so often, I had to leave work, I was a truck driver because I get sick and can not manage driving anymore, now there is no income in the house, we struggle to buy food and rely on the help of other people, all these worries are making me more sick."

Furthermore, poor households are less able to access suitable health care services, either because the available services lack the resources (including medicines and staff) to supply effective health care, or because a household income is required, or because public transport to the clinics and hospitals are unaffordable for poor households (van Donk, 2002). Sarika, an HIV positive mother mentions, *"My husband died and he was the breadwinner in the family, I do not work and can not find a job, I collect government grant but that is not enough, I buy food and the money is finished, I have no extra money to go to the clinic, taxi fees are expensive and I can not afford it."*

HIVAIDS intensifies poverty and increases inequalities at every level, household, community, regional and sectoral. This pandemic undercuts attempts at poverty reduction, income earning, productivity and economic growth (Barnett & Whiteside, 2002). Barnett & Whiteside (2002) further explain that HIV/AIDS can lead to financial, resource and income impoverishment. Households become poorer as a consequence of the illness and death of individuals, and in numerous cases it is the income-earning adults who have died. Rani from 'A Ray of Hope' community based organization, expands on this point by saying,

"Many of the households in the Chatsworth community have lost the breadwinner as a result of HIV. For most they have lost their husbands and sons who were the only source of income for the family, now that they have died, this has put lots of stain on the family unit, putting them more into poverty. They do not know where their next meal will come from as the remaining people in the households are unemployed and can not find a job. These people are really suffering here."

Collin from 'A Ray of Hope' further states,

"Given prevalent poverty, lack and several social ills in Chatsworth, HIV/AIDS may be the "last straw" for the poor of Chatsworth. As the community are with a wide range of economic and social problems besides HIV/AIDS: extreme disempowering and

unbearable poverty; economic decline due to massive unemployment; and now HIV/AIDS. The HIV/AIDS outbreak makes up not only the worst curse and attack with which people must face but also face unemployment which leads to extreme poverty."

Unemployment is a key driving force of poverty in the community of Chatsworth; the situation is further worsened for many by the HIV/AIDS pandemic.

Leclerc-Madlala (2005) pointed out that South Africa has a high unemployment rate (40%, 2007: www.assa.org.za) that effectively hinders many people from finding work, even when in good health, pushing them further into poverty, leading to a dependence on government grants, as Mary points out,

"Even before I found out I was HIV positive it was so hard to find a job, I tried and tried but nothing came through for me and then I started to get sick all the time, my husband just lost his job in the factory, he was also very sick. Then I found out I was positive I couldn't believe it, I was so angry at my husband. I was told by the nurse in the clinic that I can get disability grant, me and my husband went and applied. When they stop my grant when I get better I have no idea how we are going to survive. It so hard finding a job, how will we feed our family…?"

The boost in disability grants was assisted by institutional adjustments to the disability grant system that allowed local policy-makers to respond to the mounting pressure from communities to use the disability grant in part as a form of poverty relief (Nattrass, 2006). According to Nattrass (2006) this pressure is a direct result of South Africa’s high unemployment rate and the lack of any social security for the unemployed. Rani further elaborates,

“Most of the people in this area rely on these disability grants as a source of income, government does not provide for the unemployed and poverty is growing. It is so hard for normal people to find jobs imagine for HIV positive people, it is ten times harder, so most HIV positive people are dependent on these grants to survive.”

Poor households have a more reduced ability to deal with the consequences of morbidity and mortality than do richer households for very obvious reasons (Cohen, 1998). These consist of the lack of savings and other assets which can reduce the impact of illness and death. Poor households, like the one’s in Chatsworth, are already on the boundaries of surviving and are also incapable to deal with the subsequent health and other costs. These include the costs of medication when available to treat opportunistic infections or awaiting ARV treatment for which there is a waiting list, transport costs to hospitals and clinics, reduced household productivity through illness and change of labour to caring roles, losses of employment through illness, high levels of unemployment, funeral and related costs, and so on (Cohen, 1998). Sheila explains,

“How must I have saved when what little my husband and I earned went to pay for the rent and food and to care for my children. My husband died a year ago, he had AIDS, when he got sick that he couldn’t work anymore and transport to the clinic is expensive I just couldn’t afford it, it was also so hard to do the funeral, I had to borrow money from family. Now that he gave me this death sentence and died, I have become too sick to

work. I have moved in with my parents who collect pension. So they are taking care of my children and me. I am on the waiting list for ARV treatment and I have applied for the disability grant to keep my children and me going in the mean while."

It is exceptionally dreadful that Chatsworth's HIV/AIDS pandemic is rising at a time when the unemployment rate is high and rising as well. Participants stated that unemployment is a major driving force of poverty in the Chatsworth area. According to Nattrass (2004) the loss of employment has a major impact on households in terms of living standards; households without a breadwinner are forced to rely on friends and relatives, as well as government grants. James says *"I was the only one working in the house, when I lost my job I did not know what to do, at that stage I did not know I was HIV positive and I did not know about the grants. My wife, children and I had no choice but to move in with my parents in their two bed room flat, both my parents are pensioners. My parents were supporting us."*

For some of the participants (one being James above), they had to move in with close family in particular pensioners so that they can be taken care of, thus rising the burden already placed on them. HIV/AIDS affected households experience a great deal of employment losses because of HIV/AIDS, and people living in households with limited access to wage employment are more susceptible to HIV infection because of poverty (Nattrass, 2004). Shirley further states,
"Many of the families I help rely on the old age pension, as most of the breadwinners of the families had taken ill and could no longer work, so they move in with their parents for

help. This is really stressful for the old people, they have to now take care of their children's family."

HIV/AIDS alters the construction of communities; it is different from other diseases because it attacks income earning adults, the most productive part of the economy (Casale & Whiteside, 2006). Hence the breadwinners in Chatsworth are falling ill and incapable of working and providing for the household. The social and economic impact of HIV/AIDS is that it is a time consuming virus: as a result it can affect three human generations; the person infected, the children and grandparents affected (Casale & Whiteside, 2006). This observation points to the protracted link between poverty and the burden of AIDS in Chatsworth. Rani from 'A Ray of Hope' affirmed this link:

"Many people in the area have lost their jobs, a majority of them breadwinners and they rely on family, friends and neighbours for help. For most of these people they live off their parents and grandparents' old age pension, life is very hard for these people. Poverty is so high here in the community. One of my patients is HIV positive and was forced to go live with her mother as she had lost her job as a result of her ill health and could not take care of her children. She was getting really sick because of the lack of food, she had to move in with her mother, as her mother collects old age grant and can in a small way take care of her and the children. We run workshops in the area to educate people on grants. Most people in the area don't know about the disability grants for HIV/AIDS, as well as the foster grants, some didn't even know about the child grants. At

least in this way they can now apply for government grants and have an income coming into the home so that they can survive and get the basic foods for their family."

Many of the poor unemployed people in Chatsworth are not fully aware of the child and disability grants or even how to access them, as most of them are uneducated and suffer the burden of poverty due to high levels of unemployment. According to Mary,

"I did not know about the grant for my children or even the disability grant for HIV positive people. Even before I was positive I struggled to find a job. I found out about the disability grant and the child grant through a friend. A friend of mine told me about all this, she attended a workshop run by Rani, who told them about the grants and how to go about getting them. I am not working and can not find a job, this grant helps me and my children."

Surayasha further states, *"Thank goodness for Rani, as I only found out that I can get an AIDS grant when Rani had told me, I was so excited, she explained to me how I must go about applying for the grant. I really need it as I am not working."*

South Africa's high unemployment rates and lack of adequate welfare provisions for the unemployed, means that those who do not find work will suffer (Nattrass, 2004). They thus face a bleak prospect of going on the ARV treatment and lose their disability grants. Suraysha elaborates, *"I am not working and I am HIV positive, I am on the waiting list for treatment, I am also collecting the AIDS grant but once I am on the treatment and get better I do not know what I am going to do, as this grant helps me to buy food and pay the rent…but I will see what I am going to do when the time comes."*

"As specified in the Social Assistance Act (Act 59 of 1992/Act 13 of 2004) individuals are eligible for the disability grant if they pass a means test and if, as a result of mental or physical disability, they are unable to provide for themselves through employment or professional activity" (Nattrass, 2006:3).

The grant is intended for adults of working age under the sheer probability that those who are in theory able to work should not qualify. According to policy released by the national Minister of Social Development Doctor Zola Skweyiya, a person can only qualify if the extent of their disability deems them incapable of acquiring employment. The persons must not reject employment which they are capable of managing, or to obtain treatment which may improve their health (Nattrass, 2006).

In other words, the grant is not intended to compensate people for their disabilities, but rather to compensate them for the impact of their disability on income earning potential. That people may be capable and want to work, but unable to find it, is irrelevant to the legislation. Collin further explains, *"We see so many people in the community both HIV positive and normal average people looking for jobs but are unable to find any employment. For many HIV positive people, they rely on this grant as a source of income into the home. Many of them say to me if someone will offer them a job they will take it, they do not care what job it is as long as it is a paying job, so that they can provide for their family."*

James reiterates this point made by Collin, "*I have been looking for a job for so long, but list nothing, if someone offers me any job I will take it just so I can at least take care of my children".*

Shirley (caregiver) goes onto say, "*The disability grant is a life-line to many of the people here, they can not find jobs, some of them are waiting to go on treatment but they say if that means the grant will be stopped once they go on treatment, then they will not go on the treatment but if they are able find a job they are more than willing to work."*

According to Nattrass (2004), it cannot be anticipated that patients on ARVs will experience good employment opportunities when their health is restored. It is safer to presume that most of these people will happen to become unemployed and their household incomes will reduce as a consequence of the loss of the disability grant. Donnovan clarifies this by saying,

"I am worried to hear that the grant will be taken away because I don't think I qualify anymore. I am on AVR treatment and my health has improved. I am worried because the grant is my only means of support. I think I am only alive today because of the grant, as I

could buy food to keep me healthy. Maybe I should stop the treatment so I can continue getting the grant because I can not find a job I have been looking but know one wants to hire me."

For most participants HIV/AIDS is yet an additional form of hardship they face in their daily lives but it is not considered to be their most serious or immediate worry. Rather worrying about where their next meal will come from and how to care for their families is the dominant prevailing concern in the Chatsworth community. People are frustrated and desperately trying to survive, how can they be expected to be in good health when most are in dire straits and struggle with poverty on a daily basis?

Given such a situation, it is not unlikely (based on information gathered for this research) that people will choose to discontinue the ARV treatment (as can be see by Donnovan who was thinking about discontinuing ARV treatment just to continue getting the grant) so as to become sick again in order to qualify once more for the disability grant (Nattrass, 2004). In terms of health this will have a negative impact; such behaviour will intensify the likelihood of drug resistant strains of the HI virus, thus rendering the ARV treatment less effective (Nattrass, 2004). As Priya states,

"I am poor and I have AIDS, if it was not for my children I would have ended my life a long time ago. If I am not here who will take care of my children? We are living on this grant, it is an income for us, my husband left us a few years ago, I do not want him back,

he gave me this disease, he does not give me or the children any money. With the help of Rani I managed to get the disability grant. I am on the waiting list to go on treatment, but I heard that if I get better the grant will be taken away, how will we survive? Where will we get food to eat? I was thinking maybe I will just go on treatment for a while then can stop it and then carry on again, but I have no idea, I am just worried about the grant been taken away."

According to Leclerc-Madlala (2006), the question of who should or should not access financial assistance from government in this time of high unemployment and poverty coupled with the increase of HIV/AIDS pandemic, elicits much heated discussions among the poor of society. As Peter explains,

"The bloody government wants us to wait until we are sick and dying before they can give us the grant. I need food now, if I do not eat I will get sick, I think that is what they want from us, is to get sick. What is the use, government giving the grant when you get very sick, while I am fine now they should give it so I can buy food and be in good health."

Such responses serves to highlight the dilemmas that poverty stricken people in Chatsworth find themselves in at a time when unemployment is high and HIV/AIDS related illnesses are increasing. They are becoming increasingly dependent on government welfare grants, and this, in turn is contributing to their negative views on treatment.

5.4 Conclusion

Due to HIV/AIDS many poor households in Chatsworth are not improving their living standards, as their ability is being reduced through the losses of productive family members through death and through ill health. These processes are increasingly visible in many parts of Chatsworth today as more individuals become HIV infected and more households become HIV affected.

The experiences of participants shed light on how poverty impacts on the burden of HIV/AIDS within the community. Nattrass (2006), suggests that people would consider trading off their health in order to acquire and retain the disability grant and this can be seen as an act of dreadful desperation. This appears to be the case among South African Indians in Chatsworth.

In this chapter I revealed the huge difficulty of juggling poverty and unemployment in a situation where the only form of income for poor HIV positive adults in Chatsworth is the disability grant. This is a direct result of a welfare system that does not provide encouragement for the unemployed and that places poverty stricken people in desperate situations. Policy surrounding treatment and disability grants needs to go beyond a medical framework to consider the social context of poverty, unemployment and the basic needs of the people, especially during this time of a deepening HIV/AIDS burben.

In the next chapter I examine gender and existing gender inequalities in the Chatsworth community and the role that these play in shaping peoples' experiences with HIV/AIDS

Chapter Six

Gender, Power and Inequalities in the Era of HIV/AIDS

6.1 Introduction

Anthropologists who study HIV/AIDS have long argued that the transmission of HIV in women must be considered within the context of gender roles, access to social and economic capital and cultural values (Bolton & Singer, 1992). Moss, (2002) argued that most dimensions of economic and social life are characterised by a pattern of inequalities between women and men (see Chapter Two) that routinely value what is male over what is female.

The distinct roles and behaviours of men and women in a given culture, dictated by that culture's gender norms and values (see Chapter Three), give rise to gender differences, most of which are in fact gender discrimination, that is differences between men and women which systematically empower one group to the detriment of the other. Gender gaps are widespread in access to and control of resources, in economic opportunities, in power, and political voice. Women and girls bear the largest and most direct costs of these inequalities, but the costs cut more broadly across society ultimately harming everyone (Casale & Whiteside, 2006).

This chapter explores gender-power differences that are linked to an array of factors that increase risks of HIV/AIDS among women in Chatsworth. It looks at culture in terms of inequalities that place women in subordinate roles as well as in violent and abusive relationships and economic dependence that puts women at high risk for acquiring HIV.

6.2 Culture, Gender and the spread of HIV/AIDS

The definition of culture (as discussed in Chapter Three) emphasizes knowledge and behaviour patterns that are unique in the society. It is in these unique practices within the community of Chatsworth that we still find imbalances and inequalities between men and women. Shamla elaborates,

"I grew up in a very traditional home, where I was thought to always obey my husband, I was thought never to disrespect him and always be a good wife that cares for my family. My parents always told me that a husband is god and a good wife never questions a husband's word"

According to Govender (2005), South African Indian culture is generally male-dominated, with women accorded a lower status than men. Men are socialised to believe that women are inferior and should be under their control; women are socialised to over-respect men and act submissively towards them. Kavish states,

"We grew up learning that women should always respect men especially their husbands. Even my mother told me that a wife should always obey and respect her husband no

matter what. A wife is there to care for the family and a man provides for his family and as a provider he must be respected. As a man I do believe I am superior and my wife should obey me."

The resulting unequal power relation between the sexes, as reflected in Kavish's statement, is problematic particularly when negotiating sexual encounters. These inequalities mostly increase women's vulnerability to HIV infection and contribute to the growth of the HIV/AIDS pandemic. Prisha goes on to say,

"My husband was a dog, he slept around with many women, I knew this but how do I tell him to use a condom when sleeping with me, it was so difficult to do so. As a woman, you are brought up not to talk about all these things and to just be passive when it comes to sexual relation."

These gendered behaviours entrenched in both men and women play a vital role in the spread of HIV/AIDS within the South African Indian community. To put these dynamics into perspective, one could cite a practical example in a household where women are supposed to take orders from men in a way that they can not refuse, such as engaging in unprotected sex even if they do not want to (de Kat-Reynen, 2000). Shamla reflects this dilemma,

"I know my husband is sleeping with other women, but I do not dare ask him to wear a condom when we have sex. I am afraid of what he would do to me and growing up in a traditional home I was brought up to never question a man, he is my husband so I just keep quiet."

Shamla, like many other of the female participants can not challenge a man on sexual issues and can not talk about a condom since they feel that the man would be curious to know as to where she learnt about it. Dawn explains further,

"How can I ask my husband to use a condom, he is my husband, even though I now he is sleeping around I can not insist on him using a condom. He would think I am sleeping around and would ask me how I know about condoms."

Women in Chatsworth often find themselves in these predicaments where their husbands are promiscuous, leaving them exposed to the virus. Women reported that they often know that their husbands have been unfaithful, but feel incapable of taking the appropriate measures to protect themselves by demanding their husbands use protection while with them. Their husbands will question why they want to use protection, offended, as Leclerc-Mdlala (2006) found, by their suspicions that they have been unfaithful. Vanitha explains,

"My husband gave me the disease, I knew he was sleeping around with other girls but I didn't say anything. I was too afraid of confronting him about him sleeping around and *even more afraid of asking him to use a condom when he slept with me, how can a wife ask her husband to use a condom?"*

Evidence from this current study suggests that most women are expected to be faithful, while accepting the unfaithfulness of men with an inability to protect themselves against sexually- transmitted infections by demanding safe sex. Shantha says, *"I am HIV positive, I was a faithful wife. I knew my husband had other women, but what could I do? As an Indian woman you are brought up to not question a man and always obey your husband and be faithful. Look at me now I am HIV positive because I was too scared to confront my husband about his other women and to insist on safe sex."*

According to women informants most men in Chatsworth hide behind culture and regard it as giving them a right to sleep around. This misuse of culture Gupta (2000) states is male dominance over women and is seen as a key characteristic in defining manhood. Clive makes mention,

"As a man it is expected that I can have many women and at the end of the day I come home to my faithful, obedient wife. Women in our culture are supposed to always obey their husbands and be faithful to him and not to question him."

Within the South African Indian community, much like has been documented for the Black African community (see Varga, 1997), there is a culture of silence that surrounds sex and dictates that good women are expected to be ignorant about sex and passive in sexual interactions. Like most of the female participants, Shamla explains,

"As a woman you can not talk about sex, it is a taboo; no good, self respecting women will dare talk about issues surrounding sex."

Shantha goes onto say,

"We grew up in a very traditional way, where sex was never discussed. It was seen as a taboo topic. My parents always told me that decent women do not speak about sex, it was just wrong."

This makes it difficult for Indian women to be informed about risk reduction or, even when informed, makes it difficult for them to be proactive in negotiating safe sex. Most of the female participants were afraid of asking their partners to use a condom. Sex was a taboo topic for many; it is believed that good women never speak about such things.

Unequal power relations between Indian men and women, particularly when negotiating sexual relations, would increase women's vulnerability to HIV. In Chatsworth, male-dominated culture socialises men to feel that they are superior to women and should control them, and women to relate to men in a submissive manner. Women's inferior status means that they often have little or no power to negotiate for safer sex. Prisha goes on to say,

"My husband is the man of the house, I can not question him. It was the way I was brought up. As a husband I am to respect his wishes, even if he has other women I could not have asked him to use a condom. It was through this that I am HIV positive today."

Women in Chatsworth appear to have little power in relationships and perceive themselves not to be in a position to negotiate safe sex practices with their partners.

6.3 Violent and Abusive Relationships

Violence against women and girls is defined in the United Nations Declaration on Elimination of violence against women (1993) as “any form of gender based violence, that results in, or is likely to result in, physical, sexual, or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life.”

Violence against women takes many forms, including physical violence, sexual violence and psychological abuse. It usually occurs within the family and community (Watts & Garcla-Moreno, 2000). Many forms of violence are reported to be widespread among the South African Indian community in general, this is according to Rani Pather from A Ray of Hope, and this was clearly reflected in interviews for this current study.

Many women in Chatsworth face the threat of physical violence (both domestic violence and sexual abuse) if they are not sufficiently responsive to a partner's desires. Under these circumstances, many of the women will prefer to risk unsafe sex in the face of more immediate threats to their well-being. Monica explains, *"My husband used to be very physicaly violent towards me, I stuck in the marriage as I was too afraid to leave him. If I refused to have sex with him he would get very angry and punch me around and force himself on me, so I use to just give him sex when he wanted."*

Dashnie goes on to say,

"I face abuse from my husband nearly every day, he comes home from work and takes all his stress out on me. What can I do this is my life I have learnt to accept it, even in the bedroom if I do not want to have sex, he forces himself on me. I am his wife, I have to go along with what he wants even if I don't want it."

Violence is sometimes used by men in Chatsworth to maintain their societal status, and prove that they are "real men" by keeping women under their control. Clives states,

"If my wife argues with me, it is my position as the husband and the man in the house to put her in her place. So I hit her around a few times to remind her that I am the man in the house. It is her duty to respect and not question me."

Sexuality is one of the most common areas in which men exert power over women through violence: women may be beaten for refusing a sexual advance, wanting to end a relationship, or having or being suspected of having other partners (Watts & Garcla-Moreno, 2000). Kimeshni explains, *"When I found out that my husband had been sleeping around I refused to have sex with him. He then stated to beat me up saying I have other men that is why I do not want to have sex with him. He would then force himself on me."*

Karjal HIV positive goes on to say,

"I did try to leave my boyfriend once. He got really angry and assaulted me so bad that I landed up in hospital. He said if I ever left him he would kill me. I had no choice but to stay with him. Now looking at it now, I should have walked out along time ago, he gave me AIDS. I should have walked out back then and had him kill me instead of now living with this disease."

According to most of female participants, many men still do not want to use condoms, and some become violent in order to force women to have unprotected sex. Women may not even raise the issue of safer sex for fear of a violent response. Karjal explains,

"My boyfriend was a very violent person. I would not dare ask him to use a condom in fear of him hitting me. I was too afraid to leave him and now I got this disease from him."

Shantha further states,

"Growing up in a traditional home, sex was a taboo. Even though I knew my husband had been seeing other women I could not confront him about this or even deny him sex. I

was scared of him. He sometimes hits me. If I had confronted him on seeing other women or refusing sex I was scared he would hit me."

Violence in the form of coerced sex also results in the acquisition of HIV (as noted by most of the female participants), especially as coerced sex in the form of sexual abuse may lead to the tearing of sensitive tissues and increase the risk of contracting the HIV virus (Tsafack Temah, 2007). Vani says,

"My husband used to force me to have sex with him when I did not want to, if I refused him he would hit me and push me on the bed and have his way with me."

Monica also explains,

"If I did not want to have sex with my husband he would hit me and tell me that I am his wife and if he wanted sex I had to give it to him."

Young South African Indian women in Chatsworth view sexual violence or sex that is obtained through force, fear or intimidation as normal, reflecting perverse gender norms in their community. Ashnie elaborates,

"For me this is normal, it is a way of life for most of the women here in Chatsworth. My boyfriend hits me and sometimes forces himself on me. I grew up with my father hitting my mother all the time, so this is normal to me in my relationship. I just have to deal with it."

Vani HIV positive further states,

"Because of the abusive environment, with my husband abusing me all the time, my daughter was exposed to all this. Now she is in the same situation. Her boyfriend hits her all the time. When I asked her why she is still with him, she told me its one of those things, men are like that, look at daddy, he hits you all the time, men are like that, we just have to put up with it."

Gender-based violence in Chatsworth both reflects and reinforces inequities between men and women and compromises the health, dignity, security and autonomy of its victims. For many South African Indian women in Chatsworth the threat of violence that permeates their everyday lives exacerbates their vulnerability to HIV, as explained my many of the female participants.

According to the women participants fear of violence prevented them from accessing HIV/AIDS information, being tested, disclosing their HIV status, accessing services for the prevention of HIV transmission to infants, and receiving treatment and counselling, even when they knew they had been infected.

6.4 Economic Dependence

Many women are caught in a cycle of economic dependency on the men who are often not equal partners in the relationship with women (Gupta, 2000). Many

South African Indian women are economically dependent on men; this dependence renders them unable to take decisions on divorcing their husbands. According to Vanitha,

"I wanted to leave my husband many times, but how would I support my children? I am not working. I have never worked before, my husband didn't allow me to work; he wanted me at home to take care of the family. He provided me with what I needed. If I had left him and gone to my parents, how would I have supported my children, as my parents are pensioners? I was forced to stay with him for that reason."

Premila HIV positive further states,

"I could not leave my husband, who would care for me and my children if I had left him?"

This dependence is a product of the patriarchal culture that exists in communities such as Chatsworth. With this dependence on men, the women have little say in decisions about practicing safe. Since their husbands are bringing home the money, women do not have leverage to deny sex to their husbands. Leclerc-Madlala (2006) points out that in situations of poverty men are often the breadwinners in the family and therefore their wives do not have a lot of say in the relationship. Premila says,

"My husband was the only one that worked in the family, I knew he had other women, but since he was bringing in the money in the house, how could I have asked him for safe sex, when he was my only means of support."

Many of the female participants feared that if they spoke out, their husbands, as financial supporter, might leave them with nothing, as in the case of Premila. Shivani reflected the general view of women when she said,

“I was too scared of leaving my husband, my parents are poor. If I leave him and go back to my parents, who would take care of me and my children? It is for that reason I stayed with him, knowing all too well he had other women. I had no choice.”

Shantha further says,

“Coming from a traditional home, if I had left my husband my parents would have not *taken me in, they would have sent me back to him. So I was forced to stay with my husband, if I had left him I would have had nothing, no money, no home for my children, what was I supposed to do? I depended on him financially and could not ask him for safe sex.”*

The lack of communication between couples in Chatsworth regarding sexual decisions is linked to the predominant attitude that the male’s decision should never be challenged, as noted by the participants, especially if the women are financially dependent. Unfortunately the male’s opinion and decision might be the more risky one as it puts women in danger, which, in turn, is devastating to the family, the children, and the community more generally.

In these circumstances of gender inequalities and poverty, most of the female participants reported that they could not refuse their husbands sex. If they leave the marriage they lose their financial resource (as seen in the case of Shantha and others). Therefore many of these women stay in the marriage for economic reason.

6.5 Sex Work as a Last Resort

The situation of economic dependency has led some women and girls in the community to resort to sex work as a survival option. While the advice of using condoms is most likely to be ineffective with married women due to their financial dependence on their husbands, the advice of having only one or no sexual partners is unlikely to have much impact on many unmarried women and girls unless they also gain financial independence (Vallaeys, 2002). For many divorced, widowed or abandoned women who live in Chatsworth with soaring unemployment rates and low levels of education for girls, the chances of finding a secure job and therefore gaining financial independence are slim. Kevashnie HIV positive elaborates,

"When my father died, we lost everything. My mother could not find a job. We had no food to eat. I had to leave school to try and find a job but I couldn't get anything, so I decided to sell my body so that I could support my family. I had no choice, what could I have done? I could not find a job and my family was starving. This was an easy way to make money to feed my family."

Natasha further states,

"I have a two year old child, my husband left us for another woman. I was not working. When he left us I went out looking for a job but was unable to find anything. I needed a way to feed my child. That is why I have sex with men for money. The only thing I had that could get me money was my body."

While the path to exchanging sex for money may differ, the overwhelming majority of women and girls in Chatsworth who resort to sex work do so in order to survive financially. Rani explains,

"These women and girls have no choice but to exchange sex for money. They are poor and need to feed their families. Many of these women and girls do this as a last resort and are desperate leading them to sex work as a means of survival."

For the women and girls like Kevashnie and Natasha who exchange sex for financial security they are, for the most part, poor with low education and have no other means of ensuring that money will be available to feed and house themselves and their children. Kim goes on to say,

"I sell myself not because I enjoy it, I do this so my family can have food and the rent is paid. My father abandoned us a few years ago. My mother could not find a job. I had to leave school but could not find any work. I was sitting in the park on day when a guy came up to me and offered me fifty rand if I gave him a blowjob; I was desperate so I did it. And from there I realized I can make money in this way to feed my family."

These desperate situations of poverty that many of the female participants that are sex workers find themselves in make them extremely vulnerable to HIV. Even if they do want to use a condom, they might again find themselves in an unfavorable economic situation. Kevashnie explains,

"I would love to use a condom with every client I have, but sometimes you get a few that are willing to pay more to do it without a condom. If I refuse I loose out on that money and he will go to someone else."

These women and girls are at the mercy of their clients (as in the case of Kevashnie) during the brief sexual encounter. As with married women in Chatsworth who are unable to make their partner use a condom, unmarried sex workers are also mostly unable to practice safe sex. Natasha states,

"If I force the guy to use a condom, I would lose most of my clients. There is lots of competition here with the girls. You can not afford to loose a client or you will go home with no money."

According to Kevashnie and Natasha, it would be financially dangerous for a woman to ask her client to use a condom, because the man could simply walk away and find another woman who does not insist on the use of a condom. Again, the fear of financial loss results in the lack of women's freedom to protect their own health.

According Kevashnie, Natasha and Kim, this is their one way to obtain an income in order to pay rent and put food on the table. These women have only their body as a means of generating income. Unless the social and economic status of women in Chatsworth and elsewhere is changed to allow them financial independence and financial security, these pleas for sexual abstinence and safe sex are unlikely to result in behaviour changes that prevent the spread of HIV/AIDS.

6.6 Conclusion

Men and women are differentiated by social or gender characteristics on the one hand and by biological (or sex) characteristics on the other. The distinct roles and behaviours of men and women in a given culture, dictated by that culture's gender norms and values, give rise to gender differences, most of which are in fact gender discrimination. Gender inequalities in Chatsworth are deeply entrenched and pervasive. They limit women’s access to and control of resources, their economic opportunities and their power and political voice. Women and girls bear the largest and most direct costs of these inequalities.

Among South African Indian women such as those who participated in this study, their vulnerability to HIV has social roots, not just biological ones. For many of the female participants, their subordinate positions made it difficult if not impossible for them to protect themselves from HIV. They often cannot insist on fidelity, demand condom use, or refuse sex to their partner, especially when they are married and even when they suspect or know that their partner is HIV infected. In addition they often lack the economic power to remove themselves from relationships that carry major risks of HIV infection, or to find gainful employment other than high-risk commercial sex work.

Chapter Seven

Stigma, Denial and Desire for Revenge

7.1 Introduction

Stigma is a complicated process with various inter-related and complex factors and is affected by dynamics such as race, gender, and socio-economic status. The process of stigmatization involves labeling differences, and separating ‘us’ from ‘them’ (Smith, 2002).

The process creates blaming and shaming, and often results in isolation. It becomes easy to discriminate against people living with HIV/AIDS because people think that they no longer have the qualities that make them worthy of respect and dignity (discussed in the literature review in Chapter Two). People act on their beliefs and this often creates active discrimination and human rights abuses. Discrimination can be systemic (institutionalized) or individual (person/group directed against another person/group); as discussed in the theoretical framework in Chapter Three.

This chapter examines HIV related stigma, denial and ideas about revenge that are found in Chatsworth. It explores the community’s attitudes towards HIV/AIDS, as well as the stigma that HIV people experience within the community, and how some have turned to revenge as a coping strategy.

7.2 HIV/AIDS and Stigmatisision

HIV/AIDS is associated with certain attributes and behaviour that are seen to be contrary to prevailing norms within the community or accepted ways of behaving. According to Mani,

"All these young people today are losing their values and culture, which is why they get AIDS and die. Girls are gone too loose now; they do what ever they want and sleep with all the men, very disrespectful. People that got AIDS deserve it; it is through their immoral behavour that they are dying now of this sickness. I don't feel sorry for these people."

Verushka further states,

"I wouldn't want to associate with anyone that has AIDS. In today's world most of the people are loosing their values, that is why so many people are getting AIDS. It is the break down of family values and don't care attitude by many that leads them to immoral behaviour. So these people must not complain now that they got AIDS."

The coming of HIV/AIDS in Chatsworth gave renewed life to the concept of disease as punishment and other moral judgments, as noted by Mani and Verushka. The association of HIV/AIDS with the break down of family values and sex further stigmatized those infected by HIV. Sex is still largely a taboo subject in Chatsworth. Dheena says, *"Sex is never discussed at home. HIV is not talked about. People just choose to forget it ever exists. If the community finds out someone has HIV they will say the person brought it on themselves and will never accept them in the community."*

Nivisha also says,

"Sex is a taboo topic with many Indians. It is never discussed at home. Parents do not talk to their children about sex and HIV/AIDS. They see it as someone else's disease that can not affect their family."

HIV/AIDS is fueled by ignorance or lack of understanding about the disease, and modes of transmission. Rani States,

"The Indian community is totally ignorant about HIV. They choose not to think about it and even not to talk about it. They see it as someone else's disease."

Stigma creates barriers to HIV/AIDS prevention and care by creating an environment in which it is difficult to talk openly about the ways in which HIV is transmitted and how to stop it from being transmitted. It also creates the false impression that only certain people can become infected. Rani further states,

"Most of the people that I have counseled that are HIV positive, believed that HIV did not affect Indians, they said they thought it was only among the Black community or the homosexuals. They didn't believe it could have happened to them."

In Chatsworth HIV/AIDS, according to most of the participants, is still seen as someone else's disease. South African Indians largely perceive it to be a Black or homosexual disease. Rene explains,

"I never knew HIV could affect Indians, I always thought it was among gay people and black people. Everyone in the community when you talk to them say the similar thing."

From Rene's statement, it is clear that people are often ignorant of the fact that they are in as much danger of contracting HIV/AIDS as any Black African person or other South African. These stigmas are formed from stereotypes and a certain degree of fear. If people believe that a certain group is the only one that is susceptible to the disease then it creates a false sense of security for the people who are not within the designated infected group. Sam goes on to say,

"I did not think that HIV could affect Indians, I was always led to believe it was a Black and gay disease. This is what many people in the area think. Even my friends say they are safe because it can not happen to Indian people."

It is because of stereotypes like these that most of the HIV positive participants in this current study feared to disclose their status. Their greatest fears are associated with stigma that surrounds the disease and not the actual pain and suffering of HIV/AIDS. Jackie states,

"My boyfriend gave me AIDS. The both us did not ever think that an Indian person could get AIDS. I did tell him use a condom most of the time, as I feared getting pregnant. I did

not tell anyone I got AIDS, not even my family. I know I will be called names, as most people do not think it can happen to Indians."

A few participants did not use the word HIV or AIDS, they referred to it as 'this sickness' or 'this thing' emphasizing denial and had mentioned that they will never disclose their status. Vijay makes mention,

"I got this sickness and I am too afraid to tell anyone in the community. Most of them do not understand what this sickness is about. Most especially I am afraid to tell my family as they will not understand and be very angry."

Karena also says,

"This thing is killing me. My husband gave this thing to me. I will never tell my family and friends that I have this thing, I'm too scared of how they will take it."

There are many reasons for this silence. Pre-existing local practices and beliefs are a major determinant for HIV/AIDS-related discrimination, stigmatization and denial. These beliefs frequently establish categories of person or types of behaviour that are likely to be stigmatized. This in turn has a negative effect on people in with HIV/AIDS, causing some to deny their status, others to conceal it and all to experience anxiety about telling others and seeking care (Govender, 2005). The participants in this current study revealed these feelings. Neela says, *“I am too afraid of telling anyone. People living here do not understand about this disease. They will not just make up stories about me, I know them. I will be labeled and my children’s life will be made hell here.”*

Jackie also explains,

“I am too afraid to go to the clinic for treatment. What if someone sees me there? I do not want anyone to find out I have this disease.”

These attitudes as mentioned by Neela and Jackie of denial and silence causes a hindrance in accessing proper treatment and care for those infected with HIV/AIDS. According to some of the participants they would rather die than have the community and their families know their status. Karena explains,

“People in this community do not understand this disease. I know of one lady that came out with her status. The people in the community labeled her. No one talks to her or goes near her, as they are afraid they will get it. People tease her and call her an Aids carrier. It is for this reason I will never tell my family or the community, I would rather die first.”

Neela goes on to say,

“I worry about my children; I do not want any harm to come to them. It is for this reason I will not tell anyone. The community here does not understand this disease; they will gossip about me, I know them.”

Most of the information gathered from the participants revealed that many Chatsworth residents are in denial and are prepared to hide their status at the cost of their health. The reason for this silence is that they are afraid of being judged and labeled because of the lack of knowledge surrounding HIV/AIDS and the existing stigmas and stereotypes that surround the disease.

7.3 Stigma, Denial and Discrimination

Stigma is facilitating the growth of the HIV/AIDS pandemic within the South African Indian population. While poverty and low levels of education are amongst peoples' worries, HIV/AIDS stigma is also a big worry. Freddy states,

"I am HIV-positive and always getting sick. I am rejected by the community, my family doesn't want anything to do with me. Only my sister is willing to look after me. She took me in when her husband died. When I moved in with her, I used to talk about HIV and AIDS to educate them but the people are ignorant, they don't talk to my sister anymore."

Freddy is one of just a handful of people in Chatsworth who are willing to disclose their HIV-positive status. Most are shunned by the community. Vassie explains,

"*Since I told my family about my status, they turned their backs on me and blamed me for the illness, saying I was a loose woman that is why I got AIDS, no decent Indian women will sleep around and that is why I got AIDS."*

The experiences of people infected and affected by HIV/AIDS in Chatsworth stand testimony to the stigma and discrimination that they face of a daily basis. Shanthi says,

"When I told my parents I was HIV positive, they told me never to set foot in their house again. My husband died few years ago. My family does not want anything to do with me. I am all alone. I should have never told them."

Mish further states,

"My husband and I told our parents we were HIV positive. My parents were in shock and did not want anything to with me. My husband's parents blamed me and told my husband he should have married a decent woman."

HIV-related stigma directly hurts people in Chatsworth, who lose community support due to their HIV status, as noted by Freddy. Individuals are highly likely to be isolated within their family, hidden away from visitors, or made to eat alone. Freddy mentioned,

"When my family found out they did not want me anywhere near them and even threw away the plates and spoons I had used. They told me not to tell anyone I had the disease. Thereafter they kicked me out."

These outcomes mentioned by Freddy may be simple acts of heartlessness. They may be a well-intentioned but ignorant attempt to preserve the family. In the community, the entire family may be stigmatized because one member is ill. Veronika states, *"When people in the community found out I had HIV, no one wanted to have anything to do with me and my family. People gossiped about me, saying how did my parents bring me up. It was hard for all of us in the family."*

Discrimination experiences were common and internalized AIDS stigmas were prevalent among participants who were HIV infected. Most of the participants in this study had never talked with a friend or family member about their HIV status and a few that did disclose their status said that they were treated differently by friends and family since they had tested HIV positive, as seen in the cases of Freddy, Vassie, Shanthi and Mish. They experienced discrimination resulting from having HIV. These adverse experiences accounted for why most of the participants said that they had not told people about their HIV status because of fear of their reactions. Mangla states,

"I am too afraid of disclosing my status. My family and friends will not understand. I do know of people who are HIV positive and did tell their family, they were disowned and kicked out of their homes."

According to participants, South African Indian families normally had a strong support system for family members that needed help. More needs to be done about educating families about HIV/AIDS and making them speak more freely about the realities of having the virus and how to avoid infection. Vassie goes on to say,

"Traditionally Indian families always helped each other out. But now with HIV, no one wants to help anyone. They do not understand this disease and I think they are afraid of it, which is why they discriminate. More needs to be done to help them understand it."

Due to fear of discrimination many of the participants felt that disclosing their status is a huge challenge, one which they are not yet ready for. They would rather keep their problems hidden. Yet, by doing this the disease continues to spread in the community, unabated and shrouded in silence.

7.4 Suffering and shame

When participants in the study were asked how people with AIDS are treated, there seemed to be an understanding that they should be seen as normal. Kershni makes mention,

"I am a normal person and like to be seen that way, yes I am HIV positive but still a normal person."

Nitha HIV positive goes on to say,

"This is just another disease. I would like to be seen as any other person and not seen as that AIDS carrier."

However, reality suggests that fear, suspicion, and victim blaming are still very common. Shirley (caregiver) noted,

"Treatment of people living with HIV in Chatsworth very much depends on individual families. But mostly they are ill-treated. Nobody likes to associate or share anything with an HIV positive person. In most cases they are considered revolting."

Shirley sees many HIV positive patients and has observed negative interactions. She says, *"They are treated differently by family and friends, they are isolated. Their family doesn't take care of them. They don't even speak to with them or listen to their problems. All they say is, you deserve it, why did you get it?"*

A few of the participants mentioned that HIV is so strongly associated with promiscuity that the terms are nearly interchangeable. Mani explains

"People now are just sleeping around with no morals anymore. Why should I feel sorry for them if they get AIDS"

Therefore, once labeled an AIDS victim, one is forced to accept personal responsibility for the illness that then implies little care and support from others. Being HIV-positive carries a strong sense of shame, with the disgrace also felt by the family. Even if the family does provide good care, the true diagnosis is rarely, if ever, mentioned. Vishnu goes onto say,

"When my family found out I was HIV positive they disowned me. My father called me a disgrace to the family and that I have brought shame to the family. They did not want to have anything to do with me anymore."

Nasima goes on to say,

"I was so ashamed when I found out I was HIV positive. I have brought disgrace to my family. When I eventually told my family they called me a disgrace. For the first few months after I told them, they did not talk about it, as if everything was normal. However I could see it was killing my parents. They took good care of me for a while and nothing

about me being HIV positive was mentioned. Until a few months later when my parents asked me to leave the house."

According to Smith (2002), stigma is part of the attitudes and social structures that set people against each other. It hinders any countervailing forces for social equality both in the community and the family, as seen in the case of Nasima. This in turn brings about a feeling of shame for both the HIV positive person as well as the family.

7.5 Anger and Revenge

Several of the participants interviewed revealed how they had responded to an HIV diagnosis with anger and a desire for revenge. Once they had found out that they were HIV positive they became extremely upset and vengeful. As all of them were women, they blamed all men for their disease and wanted to take revenge on them by infecting them with HIV. Pamela explains,

"My boyfriend and I were going out for years. I trusted him. We did not use protection when having sex; I just used the pill so I do not fall pregnant. When I found out I was HIV positive I became very angry and blamed him. I wanted revenge. Men are pigs; I became angry at all men. Why should I die alone? In that state of mind I went out and slept with as many guys as I could to infect them."

Susan goes on to say,

"When I found out that I had HIV, I was very angry and blamed my boyfriend. I had not been with any other boy except for my boyfriend. I had no idea he was sleeping around. Then again I should have known. All men are the same. It was at this time when I didn't care anymore. I hated men more especially my boyfriend for giving this to me. I went out and used to get drunk and sleep with any guy, I didn't care. I wanted them all to pay for me dying now."

From Pamela's and Susan's statements, the reason for their rampage according to them was justified, as having contracted the disease from the member of the opposite sex, now the entire gender would be made to pay. Janitha states,

"When I found out I was HIV positive I was in total shock, how could this happen to me? I was in a faithful relationship, or so I though. I became very angry at my boyfriend. I trusted him and he gave me a death sentence. I hated him and all men. Men are cheaters. Girls trust them in the relationships and love them and they go out and cheat. I wanted revenge on all cheating men. I went out to the clubs on fridays and saturdays and slept with lots of guys."

Statements such as these, point to the vital importance of good quality post-testing counseling. People who are newly diagnosed to be HIV positive need help and guidance on appropriate ways to come to terms with and manage their infection. These statements also speak to the fear people have of falling prey to a random act of violence at the hands of a person seeking revenge for a disease that they feel was wrongfully acquired. Rain says, *"This act of revenge from certain individuals in the community can be seen as an act of violence to the opposite sex. Especially when the motive is intentional. Some of the females that I do counsel felt angry and hurt when they found out that they were HIV positive. They blamed men for been promiscuous and they needed to be thought a lesson."*

The key motivation for these acts is one of revenge. These participants did not give their subsequent partners a choice by informing them of the risks. Rather these were motivated by pure anger and revenge for the wrong done to them. One could say that it is an act of 'health violence' with malice pre-meditation that could lead to the causing of harm to another person. Yet, like many aspects of HIV/AIDS in the community, the willful spreading of HIV is never talked about. It is part of the deep silence and denial that surrounds the disease.

7.6 Conclusion

Discrimination against those with HIV and stigmas attached to HIV/AIDS has grown rapidly within the community of Chatsworth, fuelling anxiety and prejudice against those living with HIV or AIDS. People's experiences with HIV clearly revealed that HIV/AIDS is as much about social phenomena as it is about biological and medical concerns. The disease is largely associated with stigma, repression and discrimination, as individuals infected or affected by HIV have been rejected by their families, their loved ones and their community more generally.

What is also worrying is that some people confess to a desire to take revenge when they find out that they have HIV/AIDS. They want to infect other people as a way to revenge what they see as a ‘wrongful’ acquisition of HIV infection. This motivation is no doubt spurred on by the pervasive stigma associated with the disease and HIV positive people’s awareness of how their community will henceforth view them as pariah members.

Chapter Eight

Discussion and Conclusion

This study set out to explore the experiences of HIV/AIDS and its impact on the lives of people in Chatsworth, KwaZulu-Natal. The intention of this study was to gain insight into and understanding of some underlying factors that may be playing a role in the spread of HIV/AIDS within the South African Indian community more generally.

In the year 2000, HIV became the world's leading infectious cause of adult death in the world and within the next ten years HIV was said to be set to kill more people than all wars of the twentieth century combined (Farmer et al, 2001). Coming into the third decade we have gained enough understanding of HIV to end its transmission, yet, according to UNAIDS (2008) the global phenomena is increasing rapidly. HIV is currently increasing in communities across Southern Africa which were once considered to be "low risk", such as the community of Chatsworth which is largely made up of an ethnically Indian population.

While prevention must remain a priority, the reality is that the impact of the disease in this part of the world must also be mitigated. AIDS has already become the number one cause of death in South Africa and the impacts due to illness, death and orphan-hood are in fact just beginning (Wight, 2006).

As the global pandemic rages on, we continue to find that our greatest obstacle in combating HIV/AIDS is not knowledge or resources, but the conceptual frameworks with which we understand health in terms of human behaviour (Shoepf, 2004). Findings from this study revealed that poverty and unemployment, existing gender inequalities, and pervasive stigma were among the major factors that shaped people's experience of HIV/AIDS within the community of Chatsworth.

HIV/AIDS is a very long wave event as compared to an epidemic of influenza (Dilger, 2001 & Whiteside, 2004). According to those authors the true death toll cannot be estimated until the full wave of the pandemic has been seen. It may be as long as 30 more years before we can say that the world pandemic has peaked and/or begun to decline. For communities such as the one portrayed in this thesis, another 30 years of coping with HIV/AIDS will surely have negative consequences at multiple levels.

A major response of the South African government to the HIV pandemic has been to mediate the effects by expanding the welfare system (Leclerc-Madlala, 2006). This has meant, thus far, expanding the disability grants to help HIV infected people meet their needs and ease poverty. For people who participated in this study treatment came with potential financial consequences, choosing between physical health and socio-economic survival. Faced with a range of more direct threats to well being due to poverty and unemployment, the disability grant offered many a sense of hope to survive. For those who are HIV infected and struggling to provide their families with food, the disability grant has become a major source of income.

It is not surprising that the prospect of loosing the disability grant might be met with hostility and to resolve this many participants suggested that they will do whatever it took to keep the grant. This meant that most were willing to stop the ARV treatments or not go on the treatment in the first place to keep their CD4 count below 200 in order to keep the grant. These desperate measures stem from poverty and could potentially lead to even deeper poverty.

Findings from this study revealed that the consequences of HIV and experiences with HIV/AIDS treatment are different among the poor of Chatsworth than among well-off people in the community, and this as implications for prevention. Having adequate food and shelter is the highest priority for the poor HIV infected people of Chatsworth, where high levels of poverty currently converge with high HIV rates and a rising dependence on disability grants.

Unequal power relations between men and women in the community, particularly when negotiating sexual relations, increases women's vulnerability to HIV. Findings revealed that among participants male-dominated culture socialises men to feel that they are superior to women and should control them. It also socialises women to relate to men in a submissive manner, as mentioned by many of the participants interviewed. Women’s inferior status means that they often have little or no power to negotiate safer sex in their relationships with men.

Many of the women interviewed in the study feared violence from their partners, and they were also economically dependent on their partners and could not leave them. Most of the women reported that they were brought up in a way to always obey their husbands and never challenge his word, even if it meant making themselves vulnerable to HIV/AIDS and violence.

Findings also revealed that commercial sex work, a coping mechanism for some women and girls struggling against poverty and lack of economic opportunities, is also a vehicle for HIV transmission. Again, we see how women are more vulnerable to becoming trapped in a cycle of poverty and HIV/AIDS.

Stigma and denial appear to be prevalent in Chatsworth. Findings show that HIV related stigma is deeply entrenched and this is associated with prejudice and discrimination. Within the community of HIV/AIDS is still seen as someone else’s disease. HIV/AIDS is cloaked in much secrecy, where people are too afraid to disclose their status in fear of rejection, or fear of being labeled and ostracized. Some Chatsworth residents experience fear and are ignorant about HIV. These fears are acted upon and prejudice leads to active discrimination. According to participants in this study there are numerous stories circulating in the community about people being discriminated against due to their HIV status.

The findings also revealed shocking information regarding the act of revenge. For those participants who reported a desire for vengeance, they felt that they were wrongfully infected and that men were promiscuous and should suffer the consequences of their promiscuity. There remains a need to address these feelings and behaviours in the context of culturally appropriate education and HIV/AIDS counseling.

It has been argued that HIV/AIDS deepens poverty and increases gender inequalities and stigma at every level, household, community, regional and sectoral (Whiteside, 2004). The pandemic undermines efforts at poverty reduction, income and asset distribution, productivity and economic growth, all which ultimately undermine democracy itself (Mattes & Manning, 2005).

To better understand how attitudes and misconceptions about HIV/AIDS in the South African Indian community are directly associated with poverty, gender, culture, stigma and location, interventions need to prioritise the social, economic, political, structural and cultural contexts within which the people live. In this thesis I have attempted to draw out some of these environmental factors that inform and shape the way people in one community, Chatsworth, are currently experiencing the HIV/AIDS pandemic in their midst.

There is a need for government to re-look at the policies surrounding the disability grants and ARV treatment. Policy makers need to go down to grass roots level to see what actually happens in terms of the implementation of their policies. People's behaviour must be understood in terms of the social and economic structures that ultimately influence their choices through complex and sometimes contradictory ways.

There is a need for government departments to work together more closely to ensure that an HIV positive person who takes up treatment is able to access appropriate, healthy and adequate food. As UNAIDS (2006) officials state, no new policies are needed; rather it is the urgent and more comprehensive implementation of these policies that is severely lacking. Government departments should devise strategies that would target the households of HIV positive people and make them aware of social support that they are entitled to, and assist them in accessing the social grants. This could potentially reduce the dependence of households on the disability grant. Hospital and clinics could do more to assist the poor with transport to medical facilities, if for example patients cannot afford to come for monthly consultations.

South Africa has a high unemployment rate and therefore more needs to be done in terms of investment in skills development programmes for the youth and the unemployed so that opportunities can be created for employment. Given the complexity of the pandemic, future research on HIV/AIDS among South African Indians, as well as among other 'minority' communities in South Africa, should be multidisciplinary and innovative, both in approach and with regard to research instruments used. The HIV/AIDS pandemic touches all facets of society; it is therefore not possible to fully comprehend its impact nor develop effective responses through a narrow focus on specific areas and on traditional methodologies. In doing research for this thesis I have come to realize the importance of adopting a broader outlook that cuts across disciplines and levels of analysis. This encompasses the need to explore and experiment with ways of collecting data and information, and reinforcing analyses with data from different levels and integrating various methodologies.

Within the community of Chatsworth more needs to be done to encourage people to speak openly about HIV/AIDS and providing opportunities for people to speak about their experiences and to reflect upon the many things that contribute to the spread of HIV in their community. Such opportunities can play a valuable role in helping people to confront this pandemic. Amongst South African Indians there remains a need for campaigns that focus on the existence of HIV/AIDS in their own communities, as the HIV/AIDS pandemic is still largely regarded as a homosexual or black person's illness. Recent HIV/AIDS awareness campaigns do not currently do much to change that perception. It is difficult for someone of Indian decent to relate to the urgency of AIDS when they too often look at a billboard or television adverts and see black or white, but seldom Indian people. Adding more South African Indians to HIV/AIDS media campaigns would be one way to start breaking-down the strong stigma and discrimination that currently surrounds the HIV pandemic in South Africa’s Indian communities.

This study has been a tentative attempt to reveal some of the meanings that South African Indians in Chatsworth attach to HIV/AIDS and has explored some of the underlying social factors in the spread of HIV/AIDS in the Chatsworth community. Much remains to be explored for a deeper understanding of HIV transmission dynamics, between individuals and between the different communities of KwaZulu-Natal.

While many of the contributing factors in the spread of HIV are similar across communities in South Africa, such as pervasive poverty, on-going stigma and gender inequalities, much remains to be explored among the Indian community specifically. As the pandemic continues to grow across all communities in the country, it is important that minority groups of all kinds are not overlooked in our desperate and ugent attempts to address this crisis.

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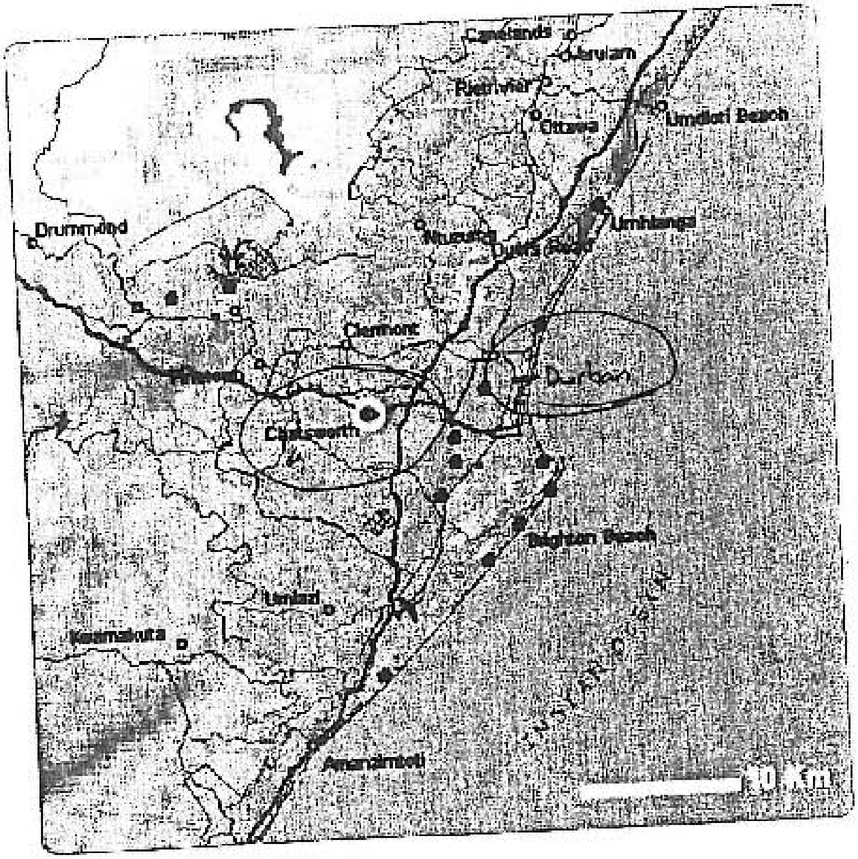
Appendix 1

Map of Coastal KwaZulu-Natal, showing location of Chatsworth in relation to Durban



Appendix 2

Map of Chatsworth, showing the various sub-areas that makeup Chatsworth

Appendix 3

UNIVERSITY OF KWAZULU-NATAL
Howard College
School of Anthropology, Gender & Historical Studies

Informed Consent Form

My name is Y. Naidoo (Dhee). I am a masters student at the University of KwaZulu-Natal. I am doing a research that I hope will contribute to a better understanding of why HIV/AIDS is on the increase among the Indian community.

Your participation in the study is entirely voluntary but I value your opinions. You may choose not to participate, in which case there will be no negative consequences. For the purpose of this study I am interested in looking at the various social factors that can make people vulnerable to HIV infection.

If you agree to answer my questions, your answers will be kept confidential. This form will not be linked to your answers and you names will not be used in any reports or publications arising from the study. You do not have to answer questions that you do not want to, and you may end the interview at any time. I cannot offer you any direct benefits but your honest answers to the questions will help better understand the possible reasons for the spread of HIV/AIDS among the Indian community.

With you permission, I would like to record the interview to ensure that I capture everything you say. The recording will be destroyed once the information has been written down.

Consent: I will sign to indicate that I have agreed to participate in this research project as explained above. If I wish, I may use only my initials or first name or just put an x in order to remain anonymous.

Participant: ______________________________ Date:________________