

**AN EXPLORATION OF THE EXPERIENCES OF FOUR INDIAN WOMEN  
LIVING WITH HIV/AIDS IN THE CHATSWORTH AREA**

By

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A thesis submitted in partial fulfillment  
of the requirements for the

Degree of M.Ed. (Social Justice)

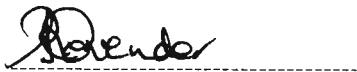
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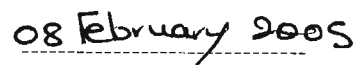
## DECLARATION

This Masters dissertation represents original work by the author and has not been submitted in any form to another university. Where use has been made of the work of others it has duly been acknowledged and referenced in the text.

The research for this dissertation was performed in the School of Education at the University of KwaZulu-Natal. Research was undertaken under the supervision of Dennis Francis during the period March 2004 to January 2005.



Rangavelli Govender



Date

DEDICATION

**This thesis is dedicated to all women living with HIV/AIDS**

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## LIST OF ACRONYMS USED

- AIDS** - Acquired Immunodeficiency Syndrome
- HIV** - Human Immunodeficiency Virus
- ICW** - International Community Of Women Living With HIV/AIDS
- KZN** - KwaZulu-Natal
- NGO** - Non-governmental organization
- UNAIDS** - Joint United Nations Program on HIV/AIDS
- UNICEF** - United Nations International Children's Emergency Fund
- WHO** - World Health Organization

## INTRODUCTION

All over the world HIV/AIDS has created a new stigma and discrimination, bigotry and ignorance that have resulted in a new class of outcasts.

**AIDS 2000 will break the silence on this affront to human dignity.** This was the theme of the XIII Annual AIDS Conference held in Durban in 2000. Four years later, there is little evidence of this reality. There are communities of people living with HIV/AIDS that still live lives cloaked in secrecy. HIV/AIDS is not losing momentum. HIV/AIDS has infected 50 million, and killed 16 million since the epidemic began (The Mercury, 19 May 2000).

In Africa, HIV positive women now outnumber infected men by two million. Recognition of the potentially devastating effects the disease could have, took place very slowly, in Africa. It is only since the middle to late nineteen eighties that a general understanding has established itself in society of how important the fight against HIV/AIDS will be.

In South Africa the dramatic transition to democracy in the early nineteen nineties meant that political considerations had to be given priority. In 1997, the KwaZulu Natal (KZN) cabinet launched an initiative to bring public attention to the effects the epidemic would have on our society. In 1999 this was followed up with the Cabinet's AIDS Challenge 2000 strategy which was to have been funded to the extent of R20 million per year (The Mercury, 19 May 2000).

HIV/AIDS has established itself at pandemic levels in the province of KZN (The Mercury, 19 May 2000). Unofficial figures of people living with HIV/AIDS stand at 40%. This has huge implications for education as it is stated that there will be at least 750 000 orphans- children with no parents in KZN by 2010 (The Mercury, 19 May 2000). This means that educators who are already burdened with responsibility will have to respond in direct and indirect ways to the pandemic.

The researcher in this study has lived in Umhlatuzana, a suburb on the outskirts of Chatsworth for the past twenty years. I teach History and Life skills at a secondary school in Chatsworth. Since the introduction of Outcomes Based Education in 2000, HIV/AIDS has become a part



of the Life Orientation programme. My interest in HIV/AIDS grew with the launch of the Government initiated Tirisano project – an HIV/AIDS awareness initiative.

As HIV-AIDS coordinator, my duties included teaching learners about HIV/AIDS awareness and about the causes and prevention of HIV/AIDS through responsible behaviour. Accordingly, I have set up a school HIV/AIDS committee made up of both learners and staff, drafted and implemented a School AIDS Policy and held workshops at school. As the HIV/AIDS coordinator I have attended many training workshops and seminars in and around Chatsworth. This exposure to issues concerning HIV/AIDS, together with available literature has led me to conclude that HIV/AIDS is still very much a taboo subject, even among so called 'enlightened educators'.

Due to the scarcity of available literature regarding Indians<sup>1</sup> living with HIV/AIDS and according to The Mail and Guardian, because media representations and billboards depict Black, White or Coloured but no Indian representations of people living with HIV/AIDS, many Indians still think that it is someone else's disease, or 'that sickness' (02 December 2003).

While studying the module 'Diversity and Education' at Masters level, I began to understand that being an HIV/AIDS coordinator was much more than teaching learners about HIV/AIDS awareness of prevention and modes of transmission. The module 'Diversity and Education' was designed to develop a deeper understanding of the critical issues and skills required to create safe and inclusive schools for learners and educators who are living with and are affected by HIV/AIDS.

Through the Diversity and Education module I developed a raised understanding of the negative impact of HIVism on the lives of people living with HIV/AIDS. According to Francis, HIVism refers to the negative treatment meted out to people living with HIV/AIDS (2004). Although the Department of Education has to be applauded in creating an awareness of the epidemic, there is concern that an important area of HIV/AIDS has been neglected: The issues regarding human rights and HIV/AIDS. It was especially during the Diversity and

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<sup>1</sup> The categories Indian, Coloured, White and African are part of the nomenclature of the apartheid system, and to some extent continue to shape post-apartheid understandings. Like McMillan (2003: 114) I argue for their use in sociological description of the South African reality and reject the racism and racial essentialism in the use of racial labels.

Education sessions together with related literature that I discovered that globally, many women have negative experiences of living with HIV/AIDS.

An article that appeared in the Sunday Tribune, Herald (07 December 2003) prompted my research. It was a story of an Indian woman, Theresa Naidoo, who was HIV positive. In her story she communicates her experiences of betrayal, prejudice and discrimination. Her story has inspired the researcher to explore the experiences of other Indian women living with HIV/AIDS.

The researcher contacted the Chatsworth HIV/AIDS coordinator, Kogie David, who is based at the Chatsworth Child and Family Welfare Centre. She coordinates the HIV/AIDS counselors in the Chatsworth district. The researcher explained the nature of her research study and was informed that there were many women like Theresa, living with HIV/AIDS.

## 1.1 RATIONALE

When first identified in the early 1980s, HIV/AIDS was primarily associated with stigmatization, and marginalized groups in society. In South Africa there has been a shift in the demographics of the disease. The syndrome has moved from one that was believed to affect only gay men to one in which women and children comprise an increasing proportion of those affected (Whiteside 1990). Studies have concluded that heterosexual transmission is the primary mode of transmission in South Africa (Whiteside 1990; Spier and Edwards 1990). Almost two decades later, it is clear that HIV/AIDS is increasingly being viewed as more than just a medical syndrome but one with significant social implications for society. There is an abundance of literature that suggests that as a group, the experiences of women have largely been negative. However, there is a scarcity of available literature on Indian women living with HIV/AIDS in KZN, and South Africa as a whole. The researcher is interested in finding out what are the experiences of Indian women living with HIV/AIDS

## 1.2 PURPOSE

This research study is exploratory in nature and seeks to establish what the experiences of four Indian women living with HIV/AIDS are. The study is borne out of concerns raised in the newspaper article (Sunday Tribune, Herald: 07 December 2003).

The article reveals clear evidence of the existence of stigma, prejudice and oppression.

The critical questions are:

What are the experiences of four Indian women living with HIV/AIDS?

Why have their experiences been constructed in such ways?

While this study may focus on the lived experiences of 4 Indian women living with HIV/AIDS, one might question, what the relevance of the study is to knowledge in educational studies or how this study might contribute to knowledge in education?

I believe that the study is relevant for the following reasons:

- The women living with HIV/AIDS are mothers and also parents of learners who could be HIV positive.
- The women living with HIV/AIDS have real life experiences that can serve as lessons and can contribute to awareness about HIV/AIDS.
- The women's experiences can contribute towards a clearer understanding of the issues surrounding HIV/AIDS.

### 1.3 CHATSWORTH: THE CONTEXT OF THE STUDY

Chatsworth is a predominantly Indian township almost 45 years old, with a population reaching 300 000 (Desai 2000). Chatsworth was created out of the Apartheid government's Group Areas Act. During the 1950s thousands of Indians from all over Durban were corralled into Chatsworth's ten square kilometer precincts south of Durban. According to the then mayor of Durban, Mayor Percy Osborne, the Group Areas Act was 'the lifeline whereby the European city of Durban will be preserved' (Desai 2003:13).

Thus thousands of Indians were forced to give up their homes and marshalled off to the outer reaches of Durban. The apartheid government's 'promise of a better life in Chatsworth' was nothing more than "glorified stables" (Desai 2000). The promised homes were tiny semi-detached buildings situated alongside the Higginson Highway.

The poorest of the poor were housed in badly built, ugly tenement blocks, which were overcrowded and unsafe. Chatsworth is an area of extreme contrasts. Chatsworth has units that comprise of both economic and sub-economic council housing. Unit 2 (Bayview), Unit 3 (Westcliff) and Unit 10 (Woodhurst) are the poorest areas with blocks of flats sometimes housing six families each. Adjacent to these low cost tenements were certain areas of Chatsworth, which became the preserve of the middle class. Mobeni Heights was placed at the entrance to Chatsworth, Silverglen between Units 2 and 3, Kharwastan and Umhlatuzana adjacent to Unit 10. In addition, to the flats, there are informal settlements or shanty towns (Welbedacht, Seven Tanks) (Desai 2000).

From the mid 70's, gangsterism and drugs flourished. The people of Chatsworth found that their lives were an endless struggle. This depressing scenario turned inwards. Alcoholism, suicide, child abuse, rape and gangsterism were on the increase (Desai 2000). To add to the burden of the poor, the downward spiral of the clothing industry saw tens of thousands of jobs lost. To the many families whose lives already lay in ruins, was the threat of evictions, water and electricity cuts. Many families whose lives were already an endless struggle, never fully recovered from this loss (Desai 2000). Relevant literature also supports the theory that HIV/AIDS flourish most in areas that have high rates of unemployment, homelessness, welfare dependency, crime, prostitution and high school drop out rate (Webb 1997).

HIV/AIDS is still considered as 'someone else's disease'. According to a newspaper report, Indians, especially those in Chatsworth, feel it is a Black man's disease. After two decades since the first known case of HIV/AIDS, in Chatsworth, Indians still believe that it would never happen to them. This attitude is very dangerous as it could create a context for further spread of the syndrome (Mail and Guardian, 02 December 2003). In fact, throughout the research study, the participants never used the words HIV or AIDS, unless prompted by the researcher. The words, "that sickness" and 'that thing' were used constantly. This is supported by a report in the Mail and Guardian headlines, AIDS still 'that thing' to many Indians (02 December 2003). Contrary to the belief that the incidence of HIV/AIDS is relatively low or that it is fairly isolated in the Indian community, AIDS is having a devastating effect on the Indian community (Sunday Times, 06 December 2003). This is further supported by statistics from the Chatsworth Hospice, which stated under the heading, 'Chats hospice alarm over AIDS

admissions', that forty seven percentage of the patients admitted to the hospice were Indians (Sunday Tribune, Herald: 23 August 2004).

A serious problem for social workers in Chatsworth is the stigma that surrounds HIV/AIDS. This has prevented many women from seeking treatment and care (The Mail and Guardian, 02 December 2003).

There are many reasons for this secrecy in Chatsworth. Pre-existing local practices and beliefs are the major determinants 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, e.g. sexually 'promiscuous' individuals, sex workers, drug users (Aggleton 2001; Francis 2003).

This dissertation contains five chapters. This chapter has provided an overview of the study, discussing the rationale, the purpose of the study, and the context of the study.

Chapter two discusses the literature review arranged into sections that include: history and definition of HIV/AIDS, international perspectives on the spread of HIV/AIDS, AIDS in South Africa, literature on the experiences of women living with HIV/AIDS globally, and the theoretical framework.

Chapter three presents the methodology. It discusses the choice of the research design, the sampling procedures and data collection techniques, reliability and validity and concludes by discussing the limitations and ethical considerations.

Chapter four presents the analysis of data.

The final chapter presents the conclusions.

## CHAPTER 2

### LITERATURE REVIEW

This chapter explores literature on the experiences of people living with HIV/AIDS. The purpose of this research is to study the experiences of four Indian women living with HIV/AIDS. It is born out of concerns raised in an article which appeared in the Sunday Times; Herald (07 December 2003) 'Betrayed- Now Shunned' which communicates the experiences of an Indian woman living with HIV/AIDS in Chatsworth, a former Indian township, which mushroomed out of the Group Areas Act. In the article a woman living with HIV/AIDS describes her experiences of rejection, betrayal and stigma. My study is exploratory in nature and seeks to establish what the experiences of a select group of women living with HIV are. Despite a scarcity of available literature on the experiences of Indian women living with HIV/AIDS, related literature has proved invaluable in informing the related issues present in this study. To this end, this chapter is structured as follows:

- History and Definition of HIV/AIDS
- AIDS in South Africa
- The HIV Epidemic in KwaZulu-Natal
- Theoretical framework

Related literature: I have limited my literature review to experiences of women living with HIV/AIDS. Since there is a limited availability of literature on the experiences of Indian women living with HIV/AIDS (websites –The Mail and Guardian and the Sunday Times), I have looked at literature that describes the experiences of women living with HIV/AIDS globally. These include Aggleton (2001), O'Sullivan (2000), Mthembu (1998), Karim (1998) and Tallis (1997). I have also included the work of Francis (2003; 2004) and Webb (1999), as their works deal with the experiences of both men and women in Kwazulu-Natal and South Africa.

All literature I have cited deals with the negative experiences of people living with HIV/AIDS. However, I have come across other literature that describes the positive experiences of people living with HIV/AIDS. These are 'Wise Before Their Time' by Bolle and Richardson (1992) and an article by Florence Ngobeni (2003).

## 2.1 HISTORY AND DEFINITION OF HIV/AIDS

One of the greatest and unresolved challenges that face the world today is HIV/AIDS and the effects that it has on people and society as a whole. Since its advent in the early 1980s, the syndrome has been viewed as primarily medical in nature.

In recent years, HIV/AIDS has increasingly been viewed as more than just a medical syndrome but one with significant social implications. It is seen as a pandemic that is having a destructive effect on all spheres of life and until a cure is found, it will continue to pose a threat to the world (Whiteside 1993).

The first intimation of the impending AIDS crisis was noted at the beginning of 1980 when five male homosexual patients in North America were identified as having a rare form of pneumonia. Initially known as the Gay-Related Immune Deficiency Syndrome, the term Acquired Immunodeficiency Syndrome (AIDS) was formulated in 1982. In the same year, the virus causing AIDS – human immunodeficiency virus (HIV) was isolated (Spier and Edwards 1990).✓

What is HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immunodeficiency Syndrome)? HIV is a virus. Antibiotics cannot cure illnesses caused by a virus (although medicines can help reduce the symptoms). When a person contracts HIV the immune system tries to fight off the virus and does produce some antibodies, but these antibodies are not able to defeat HIV (Spier and Edwards 1990).

According to Spier and Edwards (1990), when a person has HIV he or she is said to be HIV positive or someone who has a positive serostatus. The HIV virus is invisible to the human eye and individuals could be HIV positive and not be aware of any difference. They may display no symptoms for several years. HIV acts by destroying the immune system of the person living with HIV.

With the onset of symptoms the second, and more highly visible, epidemic emerges. The person with HIV may lose weight and become ill with diseases like persistent diarrhoea, fever or pneumonia and skin cancer. He or she has now developed fully blown AIDS. HIV and

AIDS thus cannot be separated, as HIV is clearly the beginning of the process that progresses towards AIDS (Educators Resource Guide 2000). At the moment, in spite of much research, there is no cure for HIV or for AIDS. AIDS is not just a public health problem. It is a major developmental, economic, social and political crisis.

According to UNAIDS (1998), AIDS is reversing decades of progress in improving the quality of life in developing countries. Every day 8500 people contract the virus. 23 million are living with the virus worldwide. Nine out of ten are in developing countries and nearly half of them are women. Almost three decades after the appearance of the HIV, an estimated 44 million have contracted the virus, and six million have died of HIV/AIDS (UNAIDS 1998).

HIV/AIDS is a condition that brings about tremendous fear for social reasons. Firstly, there is no cure for HIV/AIDS. Secondly HIV infection is spreading at an alarming rate. Thirdly, apart from the HIV- antibody test, it is not always possible to tell who is a carrier of the virus. Fourthly, because HIV can be transmitted through some sexual activity, it is associated with 'promiscuity' and 'deviance' and with negative moral judgments (UNAIDS 1998).

According to Professor Jerry Coovadia, who serves on President Thabo Mbeki's HIV/AIDS advisory panel and who also served as conference chair of the 13<sup>th</sup> Annual AIDS conference held in Durban in 2000, four to five million people will die in the next ten years. That will have a huge impact on South Africa (The Sunday Times, 06 December 2000).

HIV/AIDS is currently viewed as a pandemic, that is, 'an epidemic with global spread' (Spier and Edwards 1990: 58). It transcends national, cultural, racial and ethnic boundaries. Statistics on the global incidence of HIV/AIDS are inherently problematic because in many countries, gross under-reporting occurs. According to Spier and Edwards (1990: 58), various reasons have been offered for this. These include:

- Governments of certain countries conceal the true extent of the epidemic in an attempt to ensure investment
- Governments may experience a sense of denial or unwillingness to admit to the extent of the problem
- A person may display the clinical symptoms of HIV/AIDS but not fulfill the clinical criteria for a diagnosis of HIV/AIDS to be made



- Due to the long incubation period of HIV, there may be an under recognition of the true extent of the incidence of HIV/AIDS as not all cases are clinically apparent

Globally the HIV/AIDS pandemic continues to spread despite efforts by governments and other concerned parties to stop the spread of HIV/AIDS. The demographic patterns of HIV/AIDS are also changing significantly, with a reported increase in the numbers of young people infected with the virus. The HIV/AIDS epidemic has been described as increasingly becoming an epidemic of young people, with 50% of the new infections occurring to people under the age of 25. In reaction to this development, South Africa's ex-president Nelson Mandela appealed for a renewed fight against HIV/AIDS at the World Economic Forum in 1997 (Mail and Guardian, 1997). He is quoted as saying that 'AIDS creates new pockets of poverty when children leave schools earlier to support remaining children who are made orphans by AIDS'.

The World Health Organization (cited in Spier and Edwards 1990) has identified three distinct global epidemiological patterns. In countries with Pattern 1, HIV began to spread in the 1970s and early 1980s. Those affected were mainly gay men and drug users. Areas affected included North America, Western Europe, South America, Australia and New Zealand. The male to female ratio was 10:1 and paediatric (children living with HIV/AIDS) was not common.

Pattern 2 was characterized by predominantly heterosexual transmission, with the male to female ratio being 1:1. The first two patterns indicate that initially the incidence of infection among women and children was low and the incidence of HIV infection between men and women was equal in heterosexual transmission.

However, recent evidence suggests that a new pattern has emerged where more women are affected than men and the incidence of paediatric HIV/AIDS is high. Pattern 3 has emerged recently in countries where HIV/AIDS prevails in homosexuals and heterosexuals in equal numbers. This is the pattern seen in Africa and noted in South Africa (World Health Organization cited in Spier and Edwards 1990).

## 2.2 AIDS IN SOUTH AFRICA

South Africa has already experienced changes in its demographic structure, with the number of young people living with HIV/AIDS who are between the ages of 20-25 having increased. The prevalence of HIV among girls aged 15-19 has also increased significantly (Whiteside 1999).

The first case was reported in 1982 and to date it is estimated that 3 million people are already living with the virus. A number of social interpretations of HIV/AIDS in South Africa relate to the consequences of Apartheid and the context of poverty, especially amongst the black population (Crewe 1992 cited in Mohanlall 1998).

According to Crewe (1992 cited in Mohanlall 1998) the spread of HIV/AIDS was 'laying bare' and exacerbating the social prejudices, economic inequalities, discriminatory and political injustices that have been the cornerstone of apartheid.

The initial response of the then apartheid government was that of negligence and reluctance to take decisive action (Webb 1997). Although the first deaths from HIV/AIDS occurred in 1985, Webb (1997) pointed out that the government continued to systematically neglect and refuse to take responsible action with regard to designing programmes for those at risk of infection. By the time the Government of National Unity came into power in 1994, 1.4 million people had already contracted the virus and the fatality rate was estimated at 16.09%.

The majority of people who are living with the virus are not empowered to deal with the situation. Presently many still live in substandard, overcrowded conditions with poor sanitation and poor accessibility to health facilities. It is these conditions in which disease and ill health flourish and renders those who are poor and economically depressed, vulnerable to infectious diseases, particularly to sexually transmitted diseases (Webb 1997).

In South Africa apartheid laws were designed to keep the races separate and to ensure white supremacy. These laws had the consequence of maintaining the black population in a condition of poverty. For many South Africans who faced these hardships on a daily basis, HIV/AIDS was not viewed as a priority since its effects and consequences were not immediately felt. This particular socio-political reality in South Africa created a context for the further spread of the syndrome. HIV/AIDS flourishes most in areas that have high rates of unemployment,

homelessness, welfare dependency, crime, prostitution, high-school dropout rate and social unrest (Mohanlall 1998).

### 2.3 THE HIV EPIDEMIC IN KWA-ZULU-NATAL

The province of KwaZulu Natal is a province on the eastern coast of South Africa. The latest statistics on the prevalence of HIV/AIDS in South Africa reflect a disproportionate distribution of the epidemic among the nine provinces of this country. KwaZulu-Natal has the highest incidence of HIV infection (Whiteside 1999). According to Whiteside, it is projected that total annual deaths, including deaths from HIV/AIDS related illnesses and from all other causes will peak at about 130 000 in 2004, and during the next 20 years 2 million people will die from HIV/AIDS in KwaZulu-Natal alone. These statistics should, therefore, sensitize policy makers in the province to make comprehensive policies to provide care to those reaching terminal stages as well as working towards curbing the spread of the virus.

This disturbing trend occurs in an environment of abject poverty, unemployment and a host of other socio-economic hardships. Poverty, which has been described as the greatest co-factor in the global incidence of AIDS, together with unemployment and homelessness render some HIV strategies meaningless, thus posing a major challenge to stemming the tide. Educational efforts are hampered by low levels of literacy (one of the lowest in the country) and poor access to rural areas (World Bank of South Africa 2000).

### 2.4 THEORETICAL FRAMEWORK

Sociologist Irving Goffman (1963), defined stigma as a 'significantly 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 (UNICEF, 2000). Goffman (1963) goes on to state further that the stigmatized individual is a person with a 'spoiled 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). Hence, HIV related stigma is perceived as a 'mark of shame' where the carrier of the virus is blamed, 'devalued and significantly discredited' (Aggleton 2002).

Francis (2004), in his article 'HIVism: A Pervasive System of Oppression' argues that, when feelings of stigma, prejudice and stereotypical beliefs move into the realm of behaviour, the result is discrimination. This is similar to the argument put forward by Goffman (1963) where people living with HIV/AIDS are blamed and stigmatized.

Francis (2003) goes a step further when he argues that the negative treatment meted out to people living with HIV/AIDS by people who are HIV negative and those who are unaware of their HIV status constitutes oppression. He uses the term HIVism to name the oppression of people living with HIV/AIDS:

HIVism is a pervasive system of discrimination and exclusion that oppresses people living with HIV/AIDS. The manifestation of HIVism creates a climate of harassment and discrimination that forces them to live their lives as second-class citizens (Francis 2003: 70).

Sue O'Sullivan (2000), in her article 'Uniting across Boundaries – HIV Positive Women in Global Perspective' describes the experiences of members of an international organization called The International Community of Women Living with HIV/AIDS (ICW). ICW was created in 1992 in response to shared concerns about the lack of support and dearth of information available to HIV positive women worldwide. ICW is a community of individual HIV positive women and is represented by 15 key contacts and 1200 members from over ninety countries. Unlike the vast majority of women living with HIV, most ICW key contacts are 'out' about their status and are able to use their full names publicly. 'Isolation', 'secrecy', and 'stigma'- these are all words which individual positive women use time and time again (O'Sullivan, 2000: 25).

O'Sullivan (2000) argues that worldwide 46% of the 33.6 million people living with HIV/AIDS are women and that in Africa HIV positive women now outnumber HIV positive men by two million. O'Sullivan (2000), also states that women are more easily infected with HIV when they 'have sex with a positive man than when a man has sex with a positive woman'.

According to O'Sullivan's (2000) study, the poorer you are, the more marginalized you are, and the harder HIV/AIDS will impact on every area of your life. Women's economic, social, sexual and cultural subordination and inequality make frighteningly material impacts on each positive

woman's life. The respondents in O'Sullivan's (2000) study describe some of the instances of discrimination:

My husband died in September 1996. My in-laws would not permit me to use the toilet and went so far as to lock it up. (D'Costa cited in O'Sullivan 2000:26)

The majority of HIV positive women get the virus at home, not in the street. They get it in their own marriage bed. (Torres cited in O'Sullivan 2000: 26)

O'Sullivan (2000) concludes her article by arguing that the majority of the world's HIV positive women are still denied their basic rights. They are isolated, without proper information or support and they live in a fear of discovery because of continuing stigma still associated with HIV in most parts of the world (O'Sullivan, 2000: 27).

Quarraisha Abdool Karim (1998), in her article, 'Women and AIDS', the imperative for a gendered prognosis and prevention policy', goes further to identify the reasons for women's greater susceptibility to transmission and argues for holistic intervention, which acknowledges the role of gender inequality in the spread of HIV/AIDS. As with O'Sullivan's study, Karim found that it is now widely recognized that marginalization, alienation, impediments to the development of one's full potential, are factors that contribute to increased vulnerability to HIV infection. Both Karim (1998) and O'Sullivan (2000) argue that biological and sexual practices are key contributing factors to efficient HIV transmission. Karim (1998) goes further to state that because of gender inequality, women have little power in relationships and therefore, are not in a position to negotiate safer sex practices. She adds that it is increasingly being observed that it is monogamous women who are infected and who are victims of their partner's risky behaviours. Male dominance pervades every aspect of women's lives including family; social; religious; legal and institutional lives, and influences their ability to be assertive and to protect themselves.

According to findings from Karim's (1998) study on 'Women and AIDS' in a township in KwaZulu-Natal, Karim (1998) found that the women have little power in relations and are therefore not in a position to negotiate safer sex practices with their partners. Evidence of this

is abundant in the literature of other authors such as Mthembu (1998), Tallis (1997) and O'Sullivan (2000).

Dr Krish Nair, director of the Chatsworth Regional Hospice, presented the most recent statistics at a launch of the ARV roll-over programme at the Chatsworth hospice. The statistics reveal that the province of KwaZulu Natal in South Africa is the province hardest hit. Surveys conducted in KZN by the Department of Health reveal that HIV is about four times more common among young women compared to men. Evidence also suggests that HIV/AIDS is the same ratio for both Indians and Africans. The evidence supports the literature that women living with HIV/AIDS outnumber men living with HIV/AIDS (Sunday Tribune, Herald: 27 August 2004).

Vicci Tallis (2000) in her article 'Gendering the response to HIV/AIDS', reinforces the arguments made by O'Sullivan and Karim. She argues that women's inequality heightens their vulnerability to HIV/AIDS. According to her article, nowhere is this more starkly demonstrated than in South Africa – Black people, particularly African women, are being the hardest hit by this epidemic. The power imbalances between men and women and gender roles are recognized as crucial contributing factors to women's excess vulnerability. This is supported by the evidence found in the writings of both O'Sullivan (2000) and Mthembu (1998).

According to Tallis (1997), most women living with HIV/AIDS are poor. HIV, in turn impacts on poverty. Many women, especially those who have only known poverty, have unequal access to resources and have always lived with risk of some sort. HIV may be of relatively low concern for women who feel powerless to change the realities of their lives. This is also evident in O'Sullivan's (2000) article. It is clear that there is a strong gender bias in HIV/AIDS – related discrimination, stigmatization and denial. Women and men are not dealt with in the same way when they are living with or believed to be living with HIV/AIDS. There is evidence that men are more likely to be accepted by family and community. Women, on the other hand, are more likely to be blamed; even when they have contracted the virus through their husbands in what for the women have been monogamous relationships (Aggleton 2001; Mthembu 1998; Tallis 1997, O'Sullivan 2000). The literature is full of stories of the differential treatment to men and women living with HIV/AIDS (Aggleton 2001; Francis 2003; Francis 2004; O'Sullivan 2000; Karim 1998; Mthembu 1998).

Promise Mthembu (1998:27), in her article 'A positive view', writes about her own experiences as a positive woman living with stigma, discrimination and hardship. Some of her experiences are:

I knew about AIDS but I just did not think that it could 'happen to me-I had one partner, was from a religious family and was not sleeping around.

I was his wife and he paid lobola for me. My life became an endless cycle of beatings and unprotected sex especially if he was drunk.

(Mthembu 1998: 26-27)

However, according to Mthembu (1998), disclosure is a double-edged sword. On the one hand it may be constructive and on the other hand, it can be quite destructive. Some women with HIV/AIDS are chased out of their homes when they disclose their status (Mthembu 1998).

It is evident from the experiences of Mthembu and other themes in the literature, that for many women living with HIV/AIDS, stigma, prejudice and discrimination from family and friends are a daily reality. It is also evident in the literature globally, where powerful imagery, metaphors and euphemisms are used to define people who are HIV positive or living with AIDS (Francis 2004; 2003).

A UNICEF (2001) study on the extent of perceived and enacted HIV/AIDS related stigma conducted in four countries reported that people living with HIV/AIDS were viewed as deviant or different from the agent (those who were HIV negative and those who were unaware of their status) group. According to the UNICEF (2001) study, people living with HIV/AIDS in Zambia were labelled with terms such as zayero (prostitute) and mombwe (men having sex with many women). Similarly, in India, people living with HIV/AIDS were frequently associated with immoral behaviour and were referred to as khoon kharaab ho gaya (those with dirty blood) and gandi naali ke keede (worms from the gutter). This is no different to the experiences of the individuals in the studies conducted by O'Sullivan (2000), Tallis (1997), Karim (1998) and Francis (2003).

Physical violence and systematic harassment has been a common experience for many people living with HIV/AIDS. They experienced violence and harassment from people other than

family members and friends. A study conducted by Douglas Webb (1997) in his book 'HIV and AIDS in Africa', revealed a desire to kill and isolate people living with AIDS. Some responses include:

They must get what they deserve... they should be killed because they will infect other people; they must be imprisoned for life in jail; they shouldn't live with normal people

(Webb 1997: 168-172)

The most tragic example of this was the death of Gugu Dlamini from Inanda, KwaZulu-Natal. Newspaper reports state that Gugu Dlamini was stoned and beaten to death after she had spoken out about her HIV status. Neighbors accused Gugu Dlamini of shaming the community by revealing her HIV status (Sunday Independent, August 14, 1999).

A search for literature on Indian women living with AIDS revealed a lack of available research. However, the websites (The Mail and Guardian and the Sunday Times Online) were able to produce some valuable information, directly linked to HIV/AIDS among the Indian community in Chatsworth.

The Sunday Times (December 06, 1998) reported under this headline, 'AIDS Shock for Indians':

The scourge of AIDS, which is sweeping through KZN is beginning to have a devastating effect on the Indian community, leaving over 40 people dead this year alone.

In Chatsworth alone, at least 30 people, including eleven children, have died of AIDS in the last 10 months. These are only the reported cases. Although these figures may seem quite small, AIDS has become a serious problem in the Indian community (Sunday Times, 06 December, 1998). The director for community health services in the Durban North Region said that traditionally most Indian families believed in high moral values because of their upbringing and closely knit family structure. Western influence has changed that, with many becoming promiscuous. There also appears to be ignorance among many of them towards practicing safe sex (Sunday Times, 06 December 1998).



The HIV/AIDS programme coordinator at the Chatsworth Child and Welfare Society, Honey Allee, said that the disease was spreading at an alarming rate in the local Indian Community (Sunday Times, 02 December 1998). She states:

Most of them (Indians) do not believe AIDS will affect their families. During some of our campaigns, Indians have told us that AIDS is a Black man's disease.

The majority of the Indian women who had died of HIV/AIDS had been factory workers and housewives. This is supported by O'Sullivan (2000); Tallis (1997); Karim (1997) and Aggleton (2001) whose studies show that HIV/AIDS impacts more heavily on the ordinary women who are poor and dependent.

Research in other regions in South Africa reveals the following:

In Johannesburg, the incidence of HIV/AIDS among Indians may be deceptively low as many people in the community were either too afraid or embarrassed to report their HIV positive status.

At least about 2% of Indians in Fordsburg and Lenasia are HIV positive. The bottom line is that Indians who have HIV/AIDS don't want to come forward

(Sunday Times, 06 December 1998)

In Laudium (Indian township in Pretoria) the social worker reported that HIV/AIDS was relatively unknown. She states that:

The subject is still very much taboo and people are sensitive about reporting it openly

(Sunday Times, 06 December 1998)

The Mail and Guardian (02 December 2003), in their headline, AIDS still 'that thing' to Many Indians, reported that stigma and gender inequality are helping to drive HIV/AIDS in South Africa's traditionally conservative Indian communities.

According to article in the *The Mail and Guardian* (02 December 2003), Poppy Naicker, an Indian female is HIV positive and has been laid low by opportunistic diseases. She is shunned by the Indian community of Chatsworth near the port city of Durban, where she lives with her older sister and three teenage children in a small, overcrowded council flat. She is 30 years old and illiterate. Since her disclosure, her family has turned their backs on her and blames her illness on 'conduct unbecoming to an Indian woman'.

According to a recent study commissioned by former president Nelson Mandela through the Human Sciences Research Council, Indians represent 2.6% of the 46 million South African populations, but represent 1.6% of all HIV positive people (*The Mail and Guardian*, 02 December 2003). Savy Subramany, chief coordinator for the Chatsworth Community Care Centre, one of the few AIDS NGOs operating there, says that stigma regarding HIV/AIDS-that infection stems mainly from promiscuous sexual behaviour-has stopped many people in the Indian community from acknowledging their status (*The Mail and Guardian*, 02 December 2003). Savy Subramany states:

I have come across people who suffer silently without disclosing their status, and without counselling or appropriate care. Those who are not willing to disclose often die slowly, alone and in agony.

Gender based inequality leaves all women – not just those from the Indian community more vulnerable to contracting HIV/AIDS because they are less able to control how, when and where sex takes place (O'Sullivan 2000; Tallis 1997; Aggleton 2001; Karim 1998 and Mthembu 1998).

Forty five year old Nimmi Ramsarran found herself in this situation when her husband, who often travelled for his work, suddenly became quite ill. Nimmi says she suspected her husband might have contracted HIV during his road trips, but was afraid to confront him about it because of her commitment to him as a traditional Indian wife (*The Mail and Guardian*, 02 December 2003). According to her:

Apart from the fear of discrimination; she also had to conceal the cause of her husband's death when he died.

According to the project manager for the University of Natal's Health Economics and AIDS Research Division (HEARD), the HIV/AIDS pandemic is still largely regarded as a white or a black man's disease and recent advertising campaigns don't do much to change that perception (Mail and Guardian, 02 December 2003). She says that:

It is difficult for Indians... to relate to the urgency of AIDS awareness and behavioural change when you look at a billboard and see black or white or mixed race, but no Indians.

Although the literature on the negative experiences of women living with HIV/AIDS is staggering, there is also well-documented literature on women whose experiences have been positive as a result of HIV/AIDS:

Dietmar Bolle and Ann Richardson, co-authors of 'Wise Before Their Time'(1992), have written a book based on the perspectives of people living with HIV/AIDS themselves. It is they who know most deeply what it means to live day by day with a disease for which they may be shunned and for which there is currently no cure. The central message in this book is the dignity with which they can face their situation. The individuals in these pages do not present themselves as 'AIDS victims' but talk instead of the joys of life and the fundamental values to which they have been drawn. It is this transcendence over this disease, not their vulnerability, which gives voices real power. The individuals reveal that 'they have looked their own mortality in the eye and are wise before their time' (Bolle and Richardson 1992).

'Wise before Their Time' is a testament to the belief that people with HIV/AIDS along with everyone else, can be the masters of their own destiny. They each speak tellingly about their lives – living with the virus- their fears, their joys and their coming to terms with themselves. They come from diverse background – some are rich, some poor, young, old, some are happily married, others live alone. But each have conquered their demons and found a way to live positively with their situations (Bolle and Richardson 1992).

A similar experience is shared by Florence Ngobeni's story (The Oprah Magazine: use your life; June 2003). Unlike Promise Mthembu, Florence Ngobeni refused to hide away in the face of ridicule, contempt and verbal assault. After the birth of her child the doctor informed her that

both she and her baby were HIV positive. Shocked, she went to look for the baby's father, only to find he had died. His parents blamed her for his death, saying she had infected him.

I was labeled a prostitute in the township. People from the community used to come to my house and say horrible things to me. They laughed at my sick baby and me.

But Florence's experience of tragedy turned into triumph. When her baby died of AIDS, aged five months, Florence began counseling classes at the Chris Hani Baragwanath Hospital. She is an inspiration to HIV positive women globally, to take control of their lives. She has traveled extensively, attending conferences and workshops. She also motivates and counsels HIV positive women.

In the study of the literature on the experiences of people living with HIV/AIDS, I have argued the following:

- Many women living with HIV/AIDS have negative experiences.
- HIV/AIDS is still cloaked with secrecy and denial.
- Women who are HIV positive are not treated equally as HIV positive men.
- Poverty is a major stumbling block to HIV/AIDS prevention and treatment.
- Abuse, both physical and verbal is present in almost all cases.
- Living with HIV can also be positive as is reflected by Bolle and Richardson (1992) and Florence Ngobeni(2003) who argue that living with HIV is not a 'death sentence' but a chance to live a full and meaningful life.

METHODOLOGY:

3.1 INTRODUCTION

According to Babbie and Mouton (1998), qualitative researchers attempt to study human action from the insider's perspective (also referred to as the 'emic perspective) mentioned later in this chapter. The key research instrument is the human interviewer.

I am a human being conducting the research, not a machine devoid of emotion. As such, the whole experience of this research study had a profound effect on me. Although I had spent countless debriefing sessions with my supervisor preparing for the actual interview process, nothing prepared me for the reality of the actual experience. I believed that as a Masters Student and school HIV/AIDS coordinator, I was sufficiently equipped to conduct the interviews. I was filled with zealous notions of treading on uncharted territory, conducting research on a topic that was still viewed as taboo (The Mail and Guardian, 02 December 2003). My experiences as researcher were at times messy and uncomfortable. Firstly, as will be discussed later in this chapter, gaining access to the participants was problematic. I had never realized the extent of the secrecy surrounding issues of HIV/AIDS. It was only after I had contacted the Chatsworth HIV/AIDS coordinator and realized that I had taken on a mammoth task that I began to feel the first twinges of disillusionment and frustration creeping in. There was a point where I considered changing my research focus and topic. Fortunately, the Chatsworth HIV/AIDS coordinator was supportive and her assistance was invaluable. A month after she had identified four participants willing to participate in the study, I thought that surely I had passed the biggest hurdle and the rest would be easy. However, I encountered more obstacles. The addresses of two of the participants were in areas of Chatsworth that according to Desai (2000) was the domain of drug lords, prostitutes and gangsters. The third was in an informal settlement that was not accessible by car. I was frustrated but decided that the research study was in too advanced a stage for me to quit. I could not ask anyone to accompany me, as this would contradict the confidentiality contract I had agreed to with the coordinator and the participants.

Even the HIV/AIDS coordinator was not privy to the addresses since all contact with the women was made through the Chatsworth Child and Family Welfare Centre.

My first day as a field researcher was challenging. My first interview was with a participant living in a section of the Bayview area called the Zanzibar section. I had previously spoken via telephone to the participant to obtain directions to her place. But I was unprepared for the different streets, which had no names, and some were even misdirecting. I was lost and pulled over onto a verge. I was afraid because of the unfamiliarity of the people and the township. I locked my car doors as I had heard that this was one of the 'no go' areas in Bayview. I was approached by a group of black men dressed in traditional Muslim clothes. I cautiously rolled down my window and explained who I was looking for.

By this time quite a few curious onlookers had gathered around my car and a few women were standing in the front of their homes looking on. It was the most frightening experience of my life because I had never driven on my own to any unfamiliar place before. I was expecting to be hijacked or worse. To my surprise, one of the men offered to show me the place. Filled with trepidation, I opened the passenger door and let him in. He directed me to the correct address. I thanked him. When I knocked on the door I was in for even more surprises. I was told that the person I was looking for lived at the back. The participant, Shantal (not her real name), showed me her place. I tried to hide my dismay and shock on seeing the place she called home. She lived in a little shack, with no running water or electricity. Inside were a few crates, which served as furniture. On the floor was a makeshift bed where her partner who was also HIV positive and her two-month-old baby were sleeping. I grew up in a working class home so I was familiar with being poor but Shantal's home was an example of extreme poverty. I felt uncomfortable that human beings could live in such a manner. Shantal kept apologizing about the place. It was obvious that we could not conduct the interviews here, especially with her partner present. I arranged to pick Shantal up the following day. I interviewed her at my school. Participant number two, Tanya, was interviewed at her one-bedroomed flat in Bayview. Although Tanya's flat was overcrowded and noisy, she would not leave the flat. Maya, participant number three, preferred to be interviewed at my home. Vani, participant number four, also felt more comfortable being interviewed at my school.

But at the end of the interview session I felt a sense of satisfaction that I was able to get all four women to talk freely on very intimate and personal issues of their lives.

### 3.2 METHODOLOGY

To meet the research methods requirement and answer the research question, a qualitative approach reflecting a phenomenological paradigm was utilized. The rationale for choosing a qualitative approach and not a quantitative one is provided by Henning (2004):

The decision to work with qualitative data is linked to the type of enquiry that a researcher conducts; in other words, the purpose of the research would influence the type of research design a researcher utilizes.

Qualitative research has the distinct feature of trying to understand the social world and the meanings given to it through interactions with the social phenomena. This characteristic of qualitative research was relevant to my study because it provided the opportunity to explore the experiences of Indian women living with HIV/AIDS. According to Terre Blanche and Durrheim (1999) qualitative research is relevant where the purpose of the research is to study phenomena as they unfold in real world situations without manipulation.

The qualitative approach allows the researcher to capture what really goes on in the participant's everyday lives by incorporating the context in which the participants operate as well as their frame of reference (Francis 2002).

Qualitative researchers attempt to study human action from the perspective of the social actors themselves. The primary goal of studies using this approach is defined as describing and understanding human behaviour rather than explaining human behaviour (Babbie and Mouton 1998).

The major principle behind the qualitative paradigm is to understand the contextual meanings and patterns of relationships in the phenomena being studied. The focus is, therefore, to collect in-depth information from the subjects being studied so as to understand the subjective experience of phenomena (Marlow 1998). The tendency therefore is to have a small sample in order to solicit in-depth information. Unlike the quantitative study, this approach does not always insist on the use of numerical examination of data. This approach is used when one is trying to understand or study a particular phenomenon that is taking place, which in this case, are the experiences of four Indian women living with HIV/AIDS in Chatsworth. Reality is

considered subjective and attempts were made to understand the reality of the phenomenon as perceived by the participants.

This chapter is organized in the following way: - Type of study; research site; research sample; gaining access; research instruments; informed consent and data analysis.

### 3.2.1 TYPE OF STUDY

A qualitative approach, reflecting a phenomenological paradigm was utilized. The method of data collection uses in-depth phenomenological based interviewing. A semi-structured interview guide was constructed for this study.

The purpose of an in-depth interview study is to understand the experience of those who are being interviewed, not to predict or to control that experience. Because hypotheses are not being tested, the issue is not whether the researcher can generalise the finding of an interview study to a broader population. Instead the interviewer's task is to present the experiences of the people he or she interviews in compelling enough detail and in sufficient depth that those who read the study can connect to that experience, learn how it is constituted, and deepen their understanding of the issues it reflects (Seidman 1991).

### 3.2.2. RESEARCH SITE.

The field site chosen for research study is Chatsworth. As already discussed in Chapter 1, Chatsworth is a predominantly Indian populated township within the Durban Metro. It is a sprawling township with sharp socio-economic contrasts, where rich and poor reside side by side. The researcher has been both a resident and a secondary school educator of Chatsworth for the past twenty years. All four participants were residents of Chatsworth.

### 3.2.3 RESEARCH SAMPLE

In in-depth qualitative studies, it is not possible to employ random sampling or even a stratified sampling approach. Randomness is a statistical concept that depends on a large number of participants. True randomness would be prohibitive in an in-depth interview study (Seidman 1991) as the sample used in this type of study is very small.

The question that needs to be answered then is what alternative is there if random sampling selection is not an option. According to Patton (1989) cited in Seidman 1991), the most



commonly agreed upon answer is purposeful sampling. This is a non-probability sampling technique, which utilizes the purposeful and snowballing approach in participant selection. When purposeful sampling procedures are used it is left to the researcher to decide when a number of participants are considered sufficient, since actual numbers are not of primary importance to the study. In purposeful sampling researchers handpick the cases to be included in the sample. As the name suggests, the sample has been chosen for a specific purpose (Cohen et al 2000). Furthermore, interview participants must consent to be interviewed, so there is always an element of self-selection. Since the sample is selective, researchers will need to ensure not only that access is permitted, but also, practical. Access to sensitive areas might not only be difficult but problematic as well as was the case in this research study.

The researcher in this study selected participants who self identified as HIV positive. Since this study is highly sensitive because the issues under discussion were considered taboo, for example sexuality and HIV/AIDS, it was not easy to get women who were willing to talk.

The researcher in this study was able to use her position as HIV/AIDS co-coordinator in the Chatsworth South zone to enlist the assistance of two women in gaining access to participants. One of them was the regional co-coordinator of the Chatsworth Hospice and the other, a social worker and HIV/AIDS co-coordinator of the entire Chatsworth area based at the Chatsworth Child and Family Welfare Centre. Although the researcher was promised all the help and support, she was made aware of the pitfalls, such as consent, ethical confidentiality and secrecy associated with a research study of this nature.

The co-coordinator at the Chatsworth Hospice informed the researcher that patients who were admitted were in an advanced stage of AIDS, many of whom subsequently die. The difficulty would be that even if participants were willing to be part of the study, they might not live through the duration of the research process.

The co-coordinator based at the Chatsworth Child and Family Welfare reported that although she counsels many patients living with HIV/AIDS she still does not know the identity of many of them. All of the conversation is conducted telephonically. The reason for this is that they are afraid of disclosure. She stated that many of the women living with HIV/AIDS preferred to keep their serostatus a secret, even from their immediate family. There were some known cases where women had died without disclosing their status to family members (Sunday Tribune, 06

December 2003). As a social worker and HIV/AIDS coordinator, she is bound by the rule of confidentiality. The identities of many of the women are kept confidential even from their immediate families. However, she did promise to get in touch with a few women and explain what was required of them and to ascertain their willingness to participate in my study. A week later the researcher was contacted by the social worker. Out of the twenty women that she had approached, only two were willing to be interviewed. One of the women was in the advanced stages of the HIV, and her family was not aware that she was living with HIV/AIDS.

The researcher enlisted the assistance of the co-coordinator for the initial contact visit since the nature of the study was very sensitive. Review of relevant literature (Tallis (1997); Mthembu (1998); Karim (1998); O'Sullivan (2000), reveals that HIV/AIDS is still very much a taboo subject and participants would be reluctant to discuss intimate details of their lives and the researcher wanted to alleviate any misgivings on the part of the participants. Unfortunately before the actual contact visit, the participant with full-blown AIDS contracted pneumonia and was admitted to the hospice in a critical condition. The researcher was informed that interviewing her would not be possible.

As there was now only one willing participant the researcher used the snowballing technique, a technique often used when members of a specific population are difficult to locate (Babbie and Mouton 1998). It also refers to a process of accumulation as each located subject suggests other subjects. The available participant mentioned that she had spoken to another Indian woman at the R.K.Khan's clinic whilst collecting *Pellagon* (a milk powder that mothers who are HIV positive give to babies).

The researcher once again elicited the help of the HIV/AIDS coordinator who promised to contact one of her counselors based at the hospital. Contact numbers and addresses were thus obtained. The third participant was obtained in a similar manner, through the second participant. This participant had heard the fourth participant deliver a motivational speech during a workshop and was able to elicit her participation. This technique eventually led to the inclusion of three other participants. Thus the sample size of this research study was four women of Indian origin who self identified as being HIV positive.

The major disadvantage of snowball sampling is that, like purposive sampling, the sample is small and is not representative of the population. Hence the findings of the study may not be

generalized to the larger population. However, it has already been observed that qualitative research is more inclined to findings being transferable to similar contexts than arriving at generalizations.

### 3.2.4 RESEARCH INSTRUMENTS

#### *Data Collection:*

This section discusses the data collection instrument or research tool that was used for collecting data in this study. As mentioned previously, interpretive research uses a small sample with the intentions of collecting rich data. Hence research tools should enable the researcher and the research participants to deeply explore the subject being studied. This meant that an interactive data collection tool had to be adopted in this study since an interpersonal close-ended research tool, like those commonly used in the traditional research methods, would not have been effective at collecting the kind of data desired.

The method of data collection in this study therefore, uses in-depth phenomenological interviews. The reason for this mode of enquiry is that the researcher in this study is interested in other people's stories.

According to Seidman (1991), telling stories is essentially a meaning making process. When people tell stories, they select details of their experiences from their stream of consciousness. In order to give the details of their experiences a beginning, middle and an end, people must reflect on their experience (1991). He goes further to state, if given a chance to talk freely; people appear to know a lot about what is going on (Seidman 1991).

Seidman also admits that although interviewing is hard work and sometimes emotionally draining, he considers it a privilege to gather the stories of people through interviewing and to come to understand their experiences through their stories (1991: xv). This is supported by the researcher's own experiences during this research study.

Interviewing then is the basic mode of enquiry. The purpose of in-depth interviewing is not to get answers, not to test hypotheses but an interest in understanding the experiences of other people and the meaning they make of their experience. Being interested in other people's individual stories is the key to some of the basic assumptions that underlie interviewing

techniques. A basic assumption in in-depth interviewing research is that the meaning people make of their experiences affects the way they carry out that experience (Seidman 1991).

As a method of inquiry, interviewing is most consistent with people's ability to make meaning without denigrating the possibility of community or collaboration. It must be noted, however, that according to Seidman (1991) interviewing is especially labour intensive. It is time consuming and involves more contact time with the participants unlike when conducting a survey using the questionnaire method. Finally, it is deeply satisfying to researchers who are interested in other people's stories (Seidman 1991).

The model of in-depth, phenomenological interviewing involves conducting a series of two separate interviews with each participant. This is exclusive of the initial contact visit.

Mishler (1986 cited in Seidman 1991) states that researchers who propose to explore their topic by arranging a one- shot meeting with an 'interviewee' whom they have never met tread on thin contextual ice. In phenomenological in depth interviewing, the interviewer uses primarily open-ended questions. A semi-structured format of questions was drawn up and adopted. The major purpose of this method is to explore the participant's responses to those questions. The goal is to have participants reconstruct their experiences within the topic under study.

For my data collection I used two interviews, of about ninety minutes each, with each participant. This time frame allowed me to explore sufficiently the participant's experiences.

As I have indicated, I made a contact visit before the actual interview. During the contact visit I attempted to establish a relationship with the participants, to provide an overview of my research study and to ask for their consent to participate. According to Seidman (1991), the more care and thoroughness interviewers put into making contact, the better foundation they establish for themselves. I also discussed the duration of each interview so that the participants knew how much time was being asked of them. This was also done so that I could schedule appointments in advance.

In the first interview, I attempted to put the participant's experience into context by asking the women to tell as much as possible about their early experiences up to the present. This method is also non-threatening and serves to put the interviewees at ease. In the second interview, the

participants were asked to concentrate on the details of their present experiences and to focus on their understanding of their experiences of living with HIV/AIDS.

As an Indian woman researcher, I found that the participants were relaxed and comfortable with me. I felt that they were able to talk without inhibition. The initial contact visit was partially awkward but the rest of the interview process progressed well.

Prior to proceeding with the actual research, ethical issues have been considered. Each participant was presented with an informed consent form detailing all aspects of the research study (See appendix A).

In-depth interviewing requires participants to reconstruct their experiences as it relates to the subject of inquiry. This leads to a measured intimacy that can lead participants to share aspects of their lives that, if misused could leave them extremely vulnerable.

Furthermore, interviewers can protect themselves against misunderstanding, through the process of seeking informed consent, which requires them to be explicit about the range and purpose of their study – all parties are clear about what is going on. Informed consent is obtained by the participant's signature on an informed consent form.

An informed consent form, according to Seidman (1991) should contain the following details:

- The right to know
- Confidentiality
- Legal status of data
- Extensive use of interview data
- Anonymity
- Right of withdrawal
- Remuneration
- Review of data

All four participants were reminded that participation was voluntary and they could withdraw at any stage of the process.

### 3.3 PROCESS OF DATA ANALYSIS

The interviews were audio taped with the exception of one. This participant, who was not audiotaped, refused to be audio or video taped. The researcher respected her request and agreed not to audiotape the interviews. However, detailed note taking was employed for this particular participant. The tape recordings were transcribed after which they were stored in a safe place by the researcher. Two interviews plus the initial contact visit were conducted with each participant.

Data was transcribed and numbered numerically. Field notes from the observations were also documented. Files were created for each participant. Participants' responses were documented using pseudonyms. Data was then checked against tape recordings for accuracy.

#### 3.3.1 ANALYSIS OF BIOGRAPHICAL DATA

All four participants were Indian females living with HIV/AIDS in Chatsworth. The ages of the participants ranged from 20 to 35 years of age. Three of the participants were living in poverty. Two of the participants receive state grants whilst one has no source of income. Only one had a fixed income.

Shantal, aged 24 was living in a shack in a Zanzibar (African- Muslim) township with her partner and two babies. She is still legally married to her first husband. She is Christian and is not certain whether her two-month-old baby is positive or negative.

Tanya, aged 32 is a widow with two children who were diagnosed as HIV positive. She receives a state grant. She has two children from a previous marriage.

Maya, aged 30, is the only one of the respondents who does not live in poverty. She is married and has a son from a previous marriage. Her present husband and son are HIV negative.

Vani, aged 30, is married with a ten year old son. Her partner and son are HIV negative. She also belongs to the Christian faith and receives a state grant. A table has been inserted on page 32 to give a detailed description of the four participants.

**TABLE 1: Biographical Data of Participants**

NAME	AGE	MARITAL STATUS	INCOME STATUS	RELIGION	CHILDREN
Shantal	24	Single	No income	Christian	2
Tanya	32	Widow	State grant	Christian	4
Maya	30	Married	Employed	Hindu	1
Vani	30	Married	State grant	Christian	1

### 3.4 LIMITATIONS OF THE STUDY

This section discusses the limitations embodied in the research methodology used in this study and how they were overcome.

**Sampling:** It has already been observed that the sampling technique used in this study has a limitation in that the sample size is small, hence it cannot be said to be representative. The snowball and purposive sampling techniques used in this study have limitations in that they allow the researcher to select research participants, thereby making the representation of the sample to the larger population rather questionable. These techniques cannot be assumed to select a representative sample because the research participants are not randomly selected; hence the sample is not necessarily representative of the larger population. It has, however, been argued that qualitative research is more concerned with generating information rich data, and that the smaller the sample the more likelihood that quality rather than quantity data will be generated. This research study will, therefore, benefit from the in-depth information generated from the small sample, which will enable that data to be analyzed (Marlow 1998; Silverman 1994).

**Researcher bias:** Qualitative research has been criticized for its inability to eliminate bias because of its interactive nature. It is therefore important that the researcher acknowledges the active involvement of self and describes how the use of self influenced the research process. In my study, data collection involved recording on tape and detailed note taking, which was verified, such that the transcripts represent the actual words of the research participants, thus minimizing researcher bias.

**Participant bias:** This refers to situations where a participant attempts to preempt the researcher's expectations and responds in a manner that she/he assumes meets the expectations of the researcher. In my study, this was offset by further probing and the fact that data was recorded on tape made it possible to capture and identify responses as they were articulated.

### 3.5 RELIABILITY AND VALIDITY

The concepts of reliability and validity are very important to research. According to Silverman (1994), research has to be intellectually challenging, vigorous and critical, and that the researcher's reliability and validity determine the vigor. Reliability is defined as the degree with which the same methods used by different researchers and/or at different times produce the same results. This definition indicates that the concept of reliability is more applicable to quantitative research where the object of study can be controlled. Reliability in this study was assured by making available transcribed data and field notes so that references can be made to them. In addition, the use of the tape recorder made available original data with the actual voices of the participants to eliminate researcher manipulation and bias.

Tests for validity seek to establish the accuracy of the research findings. In qualitative research, validity tends to look into the content, and construct of the research instruments. The researcher in this research study took the following precautions to ensure validity:

- The researcher kept a detailed research journal.
- The three-phase interview (two interviews plus initial contact) technique served to alleviate inconsistencies.
- There were ongoing debriefing/consultation sessions with the research supervisor.
- Interviews were tape-recorded and transcribed and are available for perusal.

This chapter has presented the researcher's personal experiences, as well as the research methodology used in this study, discussing the rationale for selecting the research paradigm as well as its strengths and weaknesses. The next chapter presents the analysis of data collected.



## CHAPTER FOUR

### DISCUSSION

#### 4.1 INTRODUCTION

This chapter focuses on the analysis, and discussion of the data findings pertaining to each of the four women's experiences of living with HIV/AIDS. In analyzing qualitative data, the methods of analysis tend to be less structured than quantitative data. As outlined in Chapter three, data was collected through the use of semi structured, in depth interviewing. Each participant has been interviewed twice and the data collected reflects the experiences of four Indian women living with HIV/AIDS in the Chatsworth region.

The data collected in this study reveals that all four participants have had negative experiences. The following themes emerge: (1) stigma, secrecy and HIV related prejudice (2) poverty (3) family and community support in the face of HIV/AIDS and (4) gender inequality and disempowerment.

#### 4.2.1. STIGMA, SECRECY AND OTHER RELATED PREJUDICES

The findings of this study support what the literature (O'Sullivan 2000; Mthembu 1998; Karim 1998; Tallis 1997; Francis 2003 and Webb 1997) has to say about people living with HIV/AIDS. The participants in my study all shared experiences of living in isolation and secrecy where stigma is pervasive. Evidence from the literature supports my research study in that all four participants still see HIV/AIDS as 'that thing called AIDS'. Throughout my research study all the participants did not refer directly to HIV/AIDS but to 'that sickness'. This is also supported in other literature by Aggleton (2001); Francis (2003; 2004); O' Sullivan (2000) and Mthembu (1998), where it was reported that stigma and associated misconceptions regarding HIV/AIDS such as: "that only promiscuous and immoral people get HIV/AIDS" has prevented many women who are HIV positive from seeking treatment and support (Mail and Guardian 02 December 2003). All four women in my study maintain that they will never disclose their status to anyone but their immediate family. What emerges from the interviews with the four participants is that even two decades after the first known case of HIV/AIDS, in the Chatsworth community HIV/AIDS is still thought of as someone else's disease. To put it

more bluntly, Indians, especially those in Chatsworth, feel it is a Black man's disease (Sunday Times, 06 December 2003). Throughout the interviews with the women in my study the word HIV/AIDS was never used, unless prompted by the researcher. The words "that sickness" and "that thing" was used emphasizing denial.

Contrary to the literature available where interviewees have spoken openly about their experiences living with HIV/AIDS and where some have even disclosed their serostatus (Mthembu 1998), to the four participants, it is still something that is cloaked in secrecy. The participants all mentioned that they would never disclose their HIV status. They would rather pass it off as Tuberculosis or cancer.

There are many reasons for this secrecy. Pre-existing local practices and beliefs are the major determinants 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 (e.g. sexually 'promiscuous' individuals, sex workers, drug users). This in turn has an important role in 'policing' the behaviour of people living with HIV/AIDS, causing some to deny their serostatus, others to conceal it, and all to experience anxiety about telling others and seeking care (UNICEF 2000). My participants reveal similar feelings.

This attitude of denial and secrecy is the stumbling block to the accessing of proper treatment and care for people living with HIV/AIDS. Look at how Shantal attempts to conceal our relationship: Shantal was the most concerned over other people finding out about her HIV status.. She was even concerned that her landlord would find out why I was visiting. At the initial meeting she was adamant that she did not want any tape recordings or names mentioned. Even her own father is not aware of her status:

I have not seen my father for six months. After we were told to move out of the other place, I did not tell my family where I am now living. If they visit they will find out.

(Shantal)

The secrecy surrounding Indian women living with HIV/AIDS in Chatsworth was reinforced when I tried to gain access to the participants, as mentioned in the methodology chapter. I was discouraged from approaching the Chatsworth Hospice or the Chatsworth Child and Family

Welfare Centre because using these official gatekeepers involved a lot of red tape. I approached the Chatsworth HIV/AIDS coordinator, Kogie David, whom I was acquainted with through the school-based HIV/AIDS programmes. The coordinator made me aware that it was not going to be an easy task finding women who were willing to talk to anyone other than the counselors. This ethical confidentiality would pose problems to gaining access. She was correct because of the few women she knew who were living with HIV/AIDS, only two were willing to talk to the researcher. Meeting with the four she identified was another problem. Only those women who went in person to the Chatsworth Child and family Welfare Centre were known to the coordinator.

Evidence from this study reveals that the four women participants are in denial and are prepared to hide their status at whatever cost. All four of them state that the reason for secrecy is that people will judge them because of the lack of knowledge on issues surrounding HIV/AIDS and the prevalence stigma. These are some of their responses:

My two sons from my first marriage stay with my mother. There they can go to school without anyone finding out that I have the sickness. At least they will not go through what my two little girls go through.

(Tanya)

But for obvious reasons I would not disclose to just anyone. The reason is that I know for a fact that others would view it negatively. It would be a very long time before Indians in Kwa-Zulu would accept it.

(Maya)

The findings in my study confirm that disclosure is a major problem in this community. The literature (Sullivan 2000; Francis 2003; Tallis 1997; Karim 1998), reviewed reflects that many people are unable to talk about their HIV status because of fear of stigma and rejection by both families and the community in which they live. Similarly whilst interviewing all four of the women, this aspect came out very clearly. The denial is so extreme that many women do not seek help for fear of stigmatization. The women in my study are no different. This is supported by an article in the Sunday Tribune, Herald, and "Chats hospice alarm over AIDS Admissions" (27 October 2004). According to statistics released, most of the patients admitted were in the

advanced stages of AIDS when they were admitted (Sunday Tribune; Herald, 27 October 2004). The concern is that most of the patients come to the hospice when it is too late for any treatment. This is another indication of the denial and secrecy surrounding issues of HIV/AIDS. It is evident that the experiences of my participants are no different to the experiences of Mthembu (1998) and the study undertaken by UNICEF (2001) on the extent of perceived and enacted HIV/AIDS related stigma that people living with HIV/AIDS were viewed as deviant or different from the dominant (those who are negative or unaware of their status) group.

The stereotypes and name calling cited in the literature review in Chapter 2 are no different from the responses given by the four women in my study. All of the women in my study reported that they were labelled and were referred to in abusive terms. Some of these are:

'AIDS bitch'... 'diseased bitch'... 'loose'... 'Man crazy'... 'Sleep around'... 'Slut'

According to Aggleton (2001) and Francis (2003) these labels devalue people living with HIV/AIDS. They also become so ingrained because many Indian people refer to women who are promiscuous as 'loose' or 'bitch'. Other similar responses from the four women are:

When my aunt heard about my sickness, she said you must have been sleeping around to have caught the disease.

(Vani)

I had a hysterectomy because of the cysts in my uterus but my ex-husband told my in-laws that I was a slut and didn't want children.

(Maya)

My mother always says, 'Not like you sleeping with all the men and getting diseased'.

(Vani)

Because I am a widow with the sickness, the other women accuse me of sleeping with their husbands.

(Tanya)

When the neighbours (the men) get drunk, they call me vulgar words in front of my children.

(Tanya)

I made a mistake so I have to live with it. At least he's still married to me.

(Vani)

The findings in this study confirm that disclosure appears to be a major problem in this community. The literature reviewed (Aggleton (2001); O'Sullivan (2000); Mthembu (1998), reflects that many people are unable to talk about their HIV status because of fear of stigma and rejection by both families and the community in which they live. The denial is so extreme that many women do not seek help for fear of stigmatization. This has serious repercussions for it impedes their gaining access to essential services.

#### 4.2.2. POVERTY

According to studies conducted by Tallis (1997), Karim (1998) and O'Sullivan (2000) poverty leaves many women disempowered. Poverty in turn impacts on HIV/AIDS. Women are unable to gain access to proper medical care and treatment. This was very evident in my findings. Three of the four participants live in poverty. Tanya and Vani receive state grants and Shantal has no income at all, even though she has applied for a grant almost two years ago.

Poverty is the single burden of South Africa's people and is a direct result of the apartheid system and the grossly skewed nature of business. Poverty affects millions of people, the majority of who are women. In South Africa, Black women have been identified as the most disadvantaged group, many of whom come from low socio- economic circumstances (Karim 1998).

Shantal and Vani both live in makeshift shacks that have no running water and no electricity. They can barely survive. Yet they are told to eat healthy foods and maintain a healthy lifestyle by the doctors in the state hospitals. This is not possible given the poverty contexts they are

living in. Shantal tells me that there are times where there is absolutely nothing to eat. She is forced to wait for her mother-in-law to bring them something to eat after work. Vani talks about the condition of her home after a rain. There are puddles and ditches filled with muddy and filthy water. These living conditions are unhealthy to people living with HIV/AIDS.

The majority of South African women are not merely poor, they are impoverished. They 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. Many women, especially those who have only known poverty, have unequal access to resources and have always lived with risk of some sort. HIV may be of relatively low concern for women who feel powerless to change the realities of their lives (Tallis 1997).

This was especially true for three of my participants who are unable to get proper care or treatment. These women have no choice but to attend state hospitals where they only receive multi- vitamins. Shantal told me repeatedly that whenever she asked to be put on a treatment programme, the hospital staff told her that she is not that sick. She was told that when she begins to lose weight and gets really ill will she be considered. Tanya goes to the Chatsworth hospice for treatment. But she also states that all she gets are multi-vitamins. Maya's CD4 count was about a thousand compared to the other three who were battling to keep the count above 200. Maya was the first to admit that she considers herself lucky because she has a good job, access to medical aid and most importantly a personal physician to treat her unlike the other three women living with HIV/AIDS. Sadly, they had no jobs and had to rely on social grants just to survive.

According to Webb (1997), HIV/AIDS flourishes most in areas that have high rates of unemployment, a prevalence of welfare dependency, crime and prostitution. Three of the participants live in conditions similar to those described by Webb (1997). These are just some of their responses:

I can't afford a special diet. I have to feed my family with whatever handouts I get.

(Tanya)

I eat whatever there is. Mostly I eat whatever is cheaper.

(Vani)

Sometimes there is nothing to eat and we wait for my partner's mother to visit and bring us something to eat.

(Shantal)

I was tested in 1994 and it is ten years that I have the sickness. Doctors tell me to have garlic and to liquidize fresh vegetables and fruit. I live in a tin shack. How can I liquidize when I don't even have lights? I just eat rice and curry and I am okay.

(Vani)

#### 4.2.3 FAMILY AND COMMUNITY SUPPORT IN THE FACE OF HIV/AIDS

All the participants spoke about the ill treatment they received from their families. According to Poppy Naicker who is living with HIV/AIDS, Indian families are generally very supportive and this sometimes includes the extended family structures. However, when she disclosed that she was living with HIV/AIDS her family and community shunned her (The Mail and Guardian, December 2003). The experiences of the four women bear testimony to this. All four mentioned that while their families had abandoned them their mothers persevered with unconditional love and caring. All the participants in my study spoke about the support they received from their mothers:

My mother is the only one of my family who visits me. My father never speaks to me or visits.

(Tanya)

My father never spoke to me after my diagnosis. All my siblings have disowned me. No one from my family besides my mother comes to see or my sick little girls.

(Tanya)

My father couldn't handle what had happened to me. At first he cried when I told him what had happened because he did not understand what HIV/AIDS meant. Then he

accused me of bringing shame to the family. I was diagnosed in April and he died in May of a heart attack.

(Vani)

All four participants spoke about the abusive treatment they received from family members, siblings and their husbands. This is supported by other literature such as Mthembu (1998); Sullivan (2000); Francis (2003); Webb (1997) and Tallis (1997).

My husband was a drug addict and when he got drunk he was violent and abusive. Even when I left him, he would stalk me and tell my parents that I was having wild parties with other men.

(Maya)

From the day I was diagnosed my husband began to drink and beat me. He would drag me by the hair and kick me, shouting loudly for the neighbours to hear: 'AIDS bitch.'

(Vani)

My brother won't allow his children to come anywhere near me. I cannot even touch them, let alone kiss them.

(Vani)

When my sisters and brothers found out about my sickness, they were shocked and disgusted. I tried to tell them that it was not my fault but they would not hear anything they told me that I must not visit them because their children would be infected.

(Tanya)

The participants' responses reveal that HIV/AIDS related stigma and its associated prejudice and discrimination is prevalent amongst family. This contradicts Webb's (1997) argument that when the participants knew someone living with HIV/AIDS they were less likely to be shunned. According to his studies he found that generally family members were supportive.



However, my studies have revealed that once family members found out that the women were living with HIV/AIDS, their lives became unbearable.

#### *COMMUNITY*

The participants also reported instances of abuse and social ostracism from people other than family members. The four women spoke about the attitudes of people once they find out that they are HIV positive. Both Shantal and Tanya talk about the differential treatment that they receive compared to their partners who were living HIV/AIDS. According to them they are saddened to think that even though it was their partners who had given them the virus; it is they who are treated as outcasts. This is supported by the studies conducted by Webb (1997) and Francis (2003) who describes the violence and abuse perpetrated by those who are HIV negative and those who are unaware of their serostatus.

The neighbour's son smashed a cricket bat on my ten year old son's face. Before I could even enter his yard, they came out screaming horrible things at me, like 'diseased bitch get off our land. Don't bring your disease here. AIDS bitch, take your diseased son and don't enter our yard again.

(Vani)

My two girls are so innocent. They are infected through my husband and me, yet the children from the neighbourhood are not allowed to play with them or to touch them.

The other children tease them and make fun of them.

(Tanya)

The women in my study also talked about their self-imposed isolation. This supports the study by O'Sullivan (2000) and Webb (1997) where participants were always made to feel the 'other'. Being shunned or ignored has led to the women choosing to live very lonely and isolated lives. These are their responses:

I don't go to family functions anymore. It's too uncomfortable. Nobody talks to me and I sit all alone. No one comes near me.

(Vani)

Because of the sickness I don't like to go anywhere. I just sit in my room and pray.

It is better because no one is staring at you or talking about you.

(Tanya)

I only leave my house to go to the clinic and to church. I don't like to be around other people because they might find out.

(Shantal)

I know that once Indian people find out I have the sickness, they will kick us out. I prefer to stay with the Zanzibar people because here many of them have the sickness too.

(Shantal)

Similarly, in hospitals HIV related stigma and its related prejudice and discrimination were reported. Both Vani and Shantal claim that in the state hospital they are always treated as though they are stupid. They display a reluctance to visit the hospital but are forced to go there because of fear and because they do not have the money. Both are afraid that if they don't attend they would have no one to talk to about what is happening to them. But at the hospital they are never given any serious answers when they ask the nurses about special treatment for HIV/AIDS.

I keep asking them for medication for my 'partner' but they say that he has to come to the hospital. Even when I told them that he was too sick they would not listen.

Although I go to the hospital clinic every month, all I get is multi-vitamins.

(Shantal)

The nurses and doctors tell me that as soon as I get really sick they would put us in the programme. What use is the programme when we get sick? We need it now.

(Shantal)

The doctors did an AIDS test on me while I was in labour. Instead of waiting to tell me the results in private, they told my husband and his sister-in-law while I was in the labour ward. There was no counselling. She went and told the entire family.

(Vani)

I don't waste my time and money anymore. It is difficult to get taxi fare and for what?

Multi-vitamins, which I don't take?

(Vani)

I had to have a ligation because the nurses said that I was lucky the first time because my son was negative, I may not be so lucky the next time. I had no choice in the matter.

(Vani)

The participants' experiences at home, in the community and in hospitals describe the high prevalence of HIV related stigma and prejudice, where it is believed that people living with HIV/AIDS deserved their condition. This is supported by the study conducted by Francis (2003). According to Francis by attributing blame to people living with HIV/AIDS, the agent group is able to discredit, devalue and characterize people living with HIV/AIDS as unworthy (Francis 2003).

#### 4.2.4. GENDER INEQUALITY AND DISEMPOWERMENT

Male dominance pervades every aspect of women's lives including family, social, religion, legal and institutional and influences their ability to be assertive and to protect themselves. Tallis (2000) argues that women's inequality heightens their vulnerability to HIV/AIDS. They have little power in relationships and therefore, are not in a position to negotiate safer sex practices. This then makes them vulnerable.

This research study further supports available literature; that it is monogamous women who are infected and who are victims of their husbands' risky behaviours. According to O'Sullivan (2000) most of the women are infected in their own marriage beds. Three of the four participants reported that they were in a monogamous relationship and that according to them,

their husbands infected them in their own beds. Tanya and Maya both claim that their parents arranged their marriages. They are powerless to question this because it is still a custom among the more conservative of the Indians,

My husband's family knew that he had AIDS before they arranged the marriage but did not tell me. I only found out after my second child was born sick. Even though he was dying, he still did not tell me but told a committee member.

(Tanya)

My partner didn't tell me that he had gone out with a prostitute. I was pregnant when I tested positive. I found out about the prostitute after my diagnosis. She died of HIV/AIDS soon after my diagnosis.

(Shantal)

HIV/AIDS was not even an issue at that time. I was also very young and newly married. You never want to think that your husband would do that, even if you suspect that he is sleeping around, especially if you are Indian women.

(Maya)

According to Vani, it is better to keep quiet than question anything her husband says. Her HIV status renders her powerless. She says:

I can't ask my husband (who is HIV negative) for money because then there will be trouble. He will use that as an excuse to start hitting and kicking me. If I don't ask for anything then there's no problem.

It is evident from the related literature and from my findings that women who are HIV positive are not treated the same as their male counterparts who are HIV positive. The experiences of the four women reveal the extent of gender inequality that are similar to the experiences mentioned in the studies undertaken by Karim (1998); O'Sullivan (2000); Mthembu (1998) and Tallis (1997).

Many positive women around the world are agitating, organizing and demanding their rights as positive women. One of the participants in O'Sullivan's (2000) study has this to say:

Today, being a positive woman means a lot to me because I am empowered and I have learnt to appreciate life

(O' Sullivan 2000).

Two of the women interviewed have decided to empower themselves. Both Maya (who has been HIV positive for 8 years) and Vani (who has been HIV positive for 10 years) have decided to empower themselves. They each have found strength in their faith and believe that God has prolonged their lives for a reason. Vani has been positive for ten years. She has had good health with none of the initial symptoms of HIV/AIDS. She follows no diet, eats curry and red meat and takes no medication. She says:

I am tired of keeping it a secret anymore. By keeping it bottled inside it can slowly kill you. I am not afraid anymore. After 1996 I began to talk about it. I belong to a support group. I give them strength. When the newly diagnosed come, I am their inspiration. I feel needed. There I can forget my problems and be with others like me.

Maya will be living with HIV/AIDS for eight years in May 2005. She was in denial for about four years before she turned her life around. She is an attractive woman full of health and vitality. During those dysfunctional years she blamed everyone else for her predicament. She believes that she had to go through that period in order for her to appreciate life. She feels that she has been given a second chance. She has remarried and her partner is very supportive and also HIV negative. She counsels people who are living with HIV/AIDS and gives motivational talks. But she is very realistic about her situation.

I do not hide my status but for obvious reasons I would not disclose to just anyone. For example, although both my in-laws know, I would not disclose to my mother-in-laws extended family and cause grief for my in-laws. The reason is that I know for a fact that the others would view it negatively. It would be a very long time before Indians in KZN would accept.

When the participants were asked what it meant to be living with HIV/AIDS in Chatsworth, their replies had one common thread. They were resigned to living in poverty and secrecy. They felt that nothing was going to change in their lives yet all of the women expressed the same wish: To watch their children grow up; to be there for them. As mothers they realized that it was up to them to make sure their children's lives were better than their own. Although they do not foresee a future where they would be accepted after disclosure, they have ensured that their children do not live in ignorance regarding HIV/AIDS and its implications.

My ten year old son came home from school very upset. A social worker had visited the school and given them a talk about HIV/AIDS. She then went on to say that a person with HIV/AIDS would die. He wanted to know if I was going to die too. I explained that if I was careful nothing would happen to me.

(Vani)

My son is seven years old. I am open with him about my condition. But nobody at school is aware of my condition. I would never expose him to that, knowing how people would react. I will spare my son at all costs.

(Maya)

The available literature supports the findings that Indian people regard HIV/AIDS as someone else's disease. That it could never happen to them. It is worth quoting Ester Thoraq and Notisha Massaquoi's article, "Black Women and HIV/AIDS: Contextualizing their realities – on the lack of knowledge and educational resources available to most Black women.

I never thought I was at risk, I was married, did not do drugs and I was not gay. From all the things I saw on TV or in the newspaper it looked a very white thing. In my mind there was no risk of infection for me.

The above literature supports the findings in this study. All of the women interviewed said that prior to infection they had either never heard of the word or had no idea what having HIV/AIDS meant. Almost all of the women interviewed never used the word HIV/AIDS but referred to it as 'that sickness'.

When they asked us to take an HIV/AIDS test, I was the one who told the others that there was nothing to be scared of. I never thought that I would be at risk. I was married, didn't sleep around and I did not do drugs.

(Shantal)

The experiences of the women in the study are similar to those experienced by Mthembu (1998) where she talks of her shock and ignorance on issues concerning HIV/AIDS. The responses given by my participants are no different.

I was laughing when we went to be tested, but I was the one crying when we came out.

(Shantal)

When I found out that I was HIV positive, I was shocked and frightened I didn't want to go home. I just wanted to kill myself because I didn't want to suffer with the sickness.

(Shantal)

After the diagnosis I walked out of the marriage. The next three to four years I was on a rollercoaster ride with drugs and alcohol. I can't even remember my father's funeral because I was in a drug induced state of denial.

(Maya)

I was unaware that my husband had AIDS. He refused to tell me until it was too late. If I had known I would never gotten pregnant.

(Tanya)

When my father died eight months after my diagnosis, my siblings blamed me for his death. He was perfectly healthy and there was no reason for him to die at age sixty-five. My family felt that if I hadn't told him about my status he would still be alive. I felt so responsible.

(Maya)

My father died a month after I tested positive. He was so angry with me. He didn't even speak to me after that.

(Vani)

Responses such as the above indicate that all of my participants have internalized HIVism. Francis (2003; 2004) explains that by accepting many of the stigmas and stereotypes, people living with HIV/AIDS experience self-blame, lack of self worth and depression. Similar findings were reported in the UNICEF (2001) study.

#### 4.3 SUMMARY

This chapter focused on the presentation, analysis and interpretation of data. Data was analysed using the technique of content analysis. The primary aim of the research was to explore the lived experiences of Indian women living with HIV/AIDS in Chatsworth. The researcher conducted the research with a sample of four Indian women living with HIV/AIDS. Through a process of in-depth interviewing, data was collated, interpreted and presented in this chapter. The conclusions drawn are presented in Chapter five.



CONCLUSION

This chapter presents conclusions derived from the research study. I will begin with a brief review of the research questions and the rationale for this study. Thereafter an overview of the research findings will be presented. Finally the researcher will give an account of what the implications meant to her in this study.

The purpose of this study was to explore the lived experiences of Indian women living with HIV/AIDS in Chatsworth. The research questions asked were:

- What were the experiences of the four women living with HIV/AIDS?
- Why are the experiences constructed in such ways?

Efforts have and continue to be made to find a cure and a vaccine for this killer disease. But sadly, the attempts to date have met with little success. Therefore it is safe to say that an effective vaccine is still far away from being discovered as well as a cure. In light of the above, people need to change their attitudes and behaviours towards people living with HIV/AIDS. I believe that this will help curb the spread of the disease.

The major findings of my study are that stigma and its associated prejudices, secrecy and denial appears to be prevalent in Chatsworth. There is a prevalence of HIV related stigma and its associated prejudice and discrimination and this was recounted by all four participants. Evidence from the findings reveals that in the Indian community HIV/AIDS is still seen as 'that thing called AIDS' implying that it is still seen as someone else's disease. HIV/AIDS is cloaked in much secrecy, and supports the newspaper perspectives written by the Mail and Guardian (02 December 2003).

Other findings include women's inequality and their disempowerment, the negative impact of poverty on women living with HIV/AIDS and the negative response of family members.

Findings support the view that family members are not always supportive, even when they are aware that the participants are not responsible for contracting the virus. Lack of knowledge appears to be the main factor that results in stigmatization and discrimination.

Concerns that emerge from my study are that HIV related stigma and its associated prejudice and discrimination prevent people living with HIV/AIDS from seeking treatments. This implies that the HIV/AIDS pandemic will continue unabated.

Finally, the findings in my study reveal that all four participants had negative experiences living with HIV/ AIDS because of the prevalence of stigma and discrimination. Three of my participants live in low socio- economic areas where proper medical care is problematic. The participants have cited instances of prejudice, being shunned by family and friends and discrimination because of their HIV status.

Reflection:

On a personal level, this research study has been a real eye-opener to me. As a Masters student, I had believed that I was suitably prepared to conduct research of this nature. Coming from a middle class background, I did go in with an element of prejudice.

I also carried a whole lot of assumptions about people living with HIV/AIDS such as that they will be sick and dying. All four participants were fit and healthy with no physical signs of the virus. I had had no personal contact with people who were living with HIV/AIDS other than the two women that formed part of a panel in my sessions on Diversity and Education.

My experience of visiting the participants made me aware of the level of poverty we have in South Africa. At first the poverty was embarrassingly awkward, but as I listened to their stories I became angry. The three women who lived lives in such poverty with little or no income were not bitter nor were they angry at what had happened to them. They were so accepting of their fate that I couldn't understand at first, but as the interviews progressed it became clearer. The women, especially Shantal, Tanya and Vani have no great expectations out of life. They have had very little formal schooling and have always lived in poverty and totally dependent on men. They feel that because they are living with HIV/AIDS they do not deserve anything better.

But as an HIV/AIDS coordinator and a Life Skills educator, this research has taught me important life lessons. I have always considered myself an excellent educator who has real empathy for the subjects I teach.

But I soon realized that previously I had always taught the lessons on HIV/AIDS in a detached manner because I was never personally involved with anyone living with the virus. The close interaction between the participants and myself has left an indelible mark on me. This research had given me first hand knowledge on much more than the mode of transmission and methods of prevention. It has taught me that people living with HIV/AIDS are very real people, people that can think and feel, not mere statistics. I have to impart to my learners that HIV/AIDS is also a human rights awareness campaign.

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**APPENDIX A**  
**LETTER OF INFORMED CONSENT**

**INSTITUTION:** UNIVERSITY OF KWAZULU NATAL  
**NAME OF RESEARCHER:** MRS. R. GOVENDER  
**TYPE OF STUDY:** M.ED. PARTIAL DISSERTATION  
**AIM:** TO EXPLORE THE EXPERIENCES OF  
INDIAN WOMEN LIVING WITH  
HIV/AIDS IN CHATSWORTH..

In a study of this nature, the anonymity of participants is a priority. Although anonymity cannot be fully guaranteed, the following steps are taken at each stage of the research process to protect your anonymity:

1. Access to participants has been gained in two ways: a) My personal contact (HIV/AIDS coordinator / social worker in Chatsworth) and b) contacts given by those being interviewed. All initial contacts with a potential participant will be made by the social worker or participant suggesting the person to be interviewed. I will contact the potential participant directly only if she has agreed to discuss the possibility of being interviewed.
2. All interviews will take place in a safe / private place to be designated by the participants.
3. The researcher will not interview more than one participant at a time.
4. There will be two interviews of 90 minutes each, in addition to the initial contact meeting.
5. With the exception of the dissertation committee chairperson and my supervisor, I will not discuss with the dissertation committee or anyone else any names, or identifying particulars of the participants.
6. Interviewing transcripts would be completed by my-self. If someone other than myself transcribes the audio tapes I will erase from the audio tapes all names and identifying particulars before submitting them for transcription.
7. As stated, fictitious names will be substituted in the transcripts for all names unless participants wish to disclose their true identities. Every step will be

taken to adequately disguise the participant's identity in any published materials.

8. The transcripts will remain in the direct physical possession of the researcher. All audio tapes and consent forms are kept safely in a safety deposit box.
9. The researcher is not funded by any institution or organization. All expenses incurred will be borne by the researcher.
10. There will be no monetary reward for participation in this research study.

The researcher would like to personally thank each and every one of the participants for sacrificing their personal time to participate in this research study.

**Veni R. Govender**

**Signed at.....on the.....day of the ..... Month 2004.**

**NAME: .....**

## **APPENDIX B**

### **QUESTIONNAIRE**

#### **SEMI-STRUCTURED INTERVIEW QUESTIONS**

- 1. Introductions.**
- 2. Ethical implications of the interview.**
- 3. BIOGRAPHICAL DETAILS**

Age

Sex

Marital status

When did you test as HIV positive?

Are you receiving any medical treatment?

Do you go to a clinic or to a hospital?

- 4. SOCIO – ECONOMIC BACKGROUND**

Tell me more about yourself and your family?

Where do you live?

With whom do you live?

How many dependants are there? How are they related to you?

Are these dependants attending school?

What about you, what level of schooling do you have?

When did you find out about your HIV status?

How did you find out about your HIV status?

Are you studying at the moment?

If yes, does being HIV positive affect your learning in any way?

What about your children, are they affected?

How do you earn your living?

Do you earn less than R500.00 or more than R500.00, R1000, R2000 or more?

In what area is most of your money spent?

**5 KNOWLEDGE ABOUT HIV/AIDS** (transmission, prevention, treatment and support in the community)

Before testing

After testing

Present

Is there any difference in your knowledge and your life from before to the present?

Considering the knowledge you have about living positively with HIV, has it been easy for you to implement this techniques? (E.g. using condoms to prevent re-infection, eating fresh food, disclosing your status to get support, avoiding alcohol, cigarettes etc).

What has made it easier / harder?

When you are sick or have other problems, to whom do you seek support from?

Have you disclosed your status to anyone? Why?

How does the community view people living with HIV/AIDS?

Have you ever lost someone to HIV/AIDS or other diseases? How did this affect you?

**6. EXPERIENCES WITH HIV/AIDS**

If you were to describe your life living with HIV/AIDS, how would you describe it?

What are the challenges that you have experienced living with HIV/AIDS? and how have you dealt with them?

How is your family dealing with the fact that you are HIV positive?

**7. LIVING POSITIVELY WITH HIV/AIDS**

What are the life lessons you have learnt through living with HIV/AIDS that you can share with us?