

**THE EXPERIENCES  
OF FIVE WOMEN LIVING  
WITH HIV/AIDS IN THE  
WENTWORTH AREA**

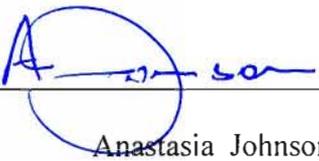
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A thesis submitted in partial fulfilment of the requirements for the degree of Master of Education in the Faculty of Education, University of Kwazulu-Natal.

**January 2007**

## DECLARATION

I, Anastasia Johnson, declare that this thesis is my own work, that all the sources used have been acknowledged and that this dissertation has not been previously submitted by me for a degree at any other university.

  
Anastasia Johnson

Date: 02.04.2007

## **Abstract**

HIV/AIDS remains overpoweringly an illness of the marginalized and stigmatized in society, particularly women. Initially, HIV prevention campaigns were aimed at changing individual behaviour, or changing the behaviour of individuals in specific high-risk groups. Educational campaigns emphasised abstinence from behaviours that would put individuals at risk of HIV. A key criticism of some early prevention initiatives was that they failed to give due recognition to women's economic and social subordination and their resultant susceptibility to HIV.

This thesis draws on interviews with five women living with HIV in the area of Wentworth and chronicles their experiences. Data generated from the study helps highlight women's economic and social subordination and the impact that this has on their ability to negotiate safe sex practices. This study therefore: (1) explores the experiences of five women in the Wentworth area, living with HIV; (2) explores reasons why their experiences were constructed in particular ways and (3) draws on the findings of this study to formulate guidelines and recommendations for schools, on how to support women living with HIV/AIDS and their affected children, more effectively. Schools, that are intentional about social justice, have little choice but to take up the colossal challenges of addressing the complex needs of learners in a world of HIV/AIDS.

## ACKNOWLEDGEMENTS

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## **Introduction**

### **Background**

Approximately 95 percent of HIV-positive people reside in Sub-Saharan Africa (Dejong 2003; Walker, Reid & Cornell 2004). It is ironic that it is in developing countries, where the fastest and most inexorable growth of the pandemic is being experienced since these, are the countries, characterized by wide spread poverty and inadequate social networks. Furthermore, “widespread mal-nutrition weakens resistance to infection generally, and poverty and social alienation are the prime factors motivating risky sexual behaviour.” (Dejong 2003: 5). HIV/AIDS is not just a medical issue but also a multifaceted social issue. HIV/AIDS remains overpoweringly, an illness of the marginalised and stigmatised in society, particularly women. The pandemic, in many ways, reflects and underlines the disparities of our world (Walker et al 2004: 8).

The fact that the virus bears the faces of mainly women is not surprising when one is cognizant of the socio-economic status of women and the power imbalances which characterize gender relationships in South African society (Freudenthal 2001; Walker et al. 2002). Women’s susceptibility to HIV/AIDS is closely related to women’s lack of autonomy in decisions relating to sexuality (Walker et al. 2002; Collins & Rau 2000). Women’s rights to safer sex is most inextricably linked to economic dependence and is most violated in contexts where sex is used as a resource for survival, not as in the case of sex workers or prostitutes, but rather, as basic social and economic arrangements

between men and women, agreements, characterized by male command over women's lives in the context of poverty. Freudenthal (2001: 10) argues:

Poverty and gender are intertwined in relation to HIV/AIDS. It is poor women and men that are most susceptible to HIV infections. 70 percent of the world's poor are women. Women are more vulnerable to HIV/AIDS because they have less secure employment, lower income (if any), less access to healthcare and social security, less entitlement to assets and savings and little power to negotiate sex. They are more likely to be poorly educated and have less access to land and credit than men.

Poverty and gender inequity are critical factors driving the HIV pandemic. The women in my study are all products of families characterised by severe indigence and members of a community where gender inequity is rampant as is evidenced by their various declarations. Upon exploring their experiences, it becomes clear that this combination of poverty and gender inequity were the two most potent factors which rendered them susceptible to HIV.

Whilst much has been written about HIV/AIDS, there is a dearth of literature available depicting women living with HIV/AIDS in KwaZulu-Natal, particularly in the Wentworth area. This study represents an attempt to fill this gap. Redressing the inequity that characterises gender relations in terms of women's economic subordination, lack of power in sexual relationships, and their resultant susceptibility to sexual abuse, represents a pivotal step in effectively addressing the proliferation of HIV/AIDS. Knowledge of women's experiences in this regard and research that makes this knowledge accessible is invaluable in promoting an understanding of these issues.

As an educator, I believe that a study which promotes an understanding of the life worlds of HIV-positive women will make a significant contribution to the body of knowledge of education. HIV/AIDS poses one of the greatest threats to socio-economic stability in many communities and in our country as a whole. The fact that the virus bears the faces of mainly women, many of whom are mothers or mothers to be, is of extreme significance. This scenario has serious implications for the children of these women as well as for the schools (educators) responsible for the holistic development of these children. Solomon (2002: 40) argues that in the context of education, HIV/AIDS alters the traditional equilibrium between schools and learners who, are orphans, infected or affected, often decreasing the school's ability to respond appropriately and adequately. School-based educators are being called upon to take up new roles in the context of HIV/AIDS. Francis & Francis (2006) contend that the contexts of children affected by HIV/AIDS are characterised by many difficulties which alter their roles and compel them to assume new roles of responsibility as their parents become ill or die as a result of the pandemic. Educators are being increasingly called upon to create secure, inclusive environments for learners who are infected or affected by HIV/AIDS (Francis & Francis 2006). Inevitably, information gained about the nature of seropositive women's experiences, will be useful in equipping educators to effectively heed this call. Understanding the contexts of seropositive women will: improve the educator's understanding of affected learner's socio-economic contexts; promote empathy for the affected learner's social context; sensitise educators to their unique needs and enable educators to effectively meet the challenges of addressing such needs by the drawing up

of education policies, procedures, programmes, regulations and structures formulated to address HIV/AIDS and mitigate its impact.

### **The study area**

All of the research was conducted in Wentworth. Wentworth is a former Coloured Group Area situated south of Durban. It is a fairly small area in Durban, demarcated for the occupation of Coloured people, during the apartheid era. Prior to the apartheid restructuring during the 1950's and early 1960's, Wentworth housed a cross/section of people (Jones 1998; Scott and Ridsdale 1997). Coloured people were formerly moved into this area as a result of the apartheid restructuring programmes between 1961 and the mid 1970's (Jones 1998; Scott and Ridsdale 1997). The total population of Wentworth ranges between 18000 and 35000 people (Jones 1998; Scott and Ridsdale 1997). Wentworth has a youthful population, with 38 percent of its population being younger than 18 years of age (Jones 1998; Scott and Ridsdale 1997). Approximately 58 percent of the adult population is unemployed. While some of its residents are middle class, Wentworth is largely an impoverished, working class community (Jones 1998; Scott and Ridsdale 1997). "Wentworth's low income and high unemployment levels have over the years also contributed to it developing a notorious reputation for high incidents of social problems" (Jones 1998: 76).

Dwelling units in the Wentworth area were originally old military quarters. The Department of Community Development later erected flats in this area (Rankin 1992;

Jones 1998). The area comprises two and three bedroom houses and flats (Pictures 1 and 2), which house the 'middle-class' of the area.



**Picture 1**



**Picture 2**

However, it also consists of a number of sub-economic, flat-roofed, two-roomed houses (known as The Rainbow Chickens– Pictures 3 to 5 below) which house the most underprivileged (Rankin 1992; Jones 1998).



**Picture 3**



**Picture 4**

A lack of recreational activities and open space has contributed to social struggles (Jones 1998: 86). Political and economic factors have shaped the identity of the people of Wentworth, many of whom have lived there for a very long time (Jones 1998: 86). Inevitably, “the people of Wentworth have developed a strong sense of place centred on attachments to family, friends and personal experiences which make them feel rooted to the soil (soul) of Wentworth.” (Jones 1998: 86)



**Picture 5**

With regard to HIV/AIDS, a recent study conducted in Wentworth (Naran 2005) indicated that HIV/AIDS had become well established in this community and that failure by authorities to implement vital and instantaneous preventative measures, could result in an HIV epidemic explosion in this community. This highlights the reality that HIV/AIDS

is predominantly an illness of the economically and socially marginalised in our society and as highlighted earlier, HIV/AIDS is more than just a health concern, it is a much larger social issue (Walker et al 2004; Corea 1992).

## **Description and Structure of Thesis**

This thesis draws on interviews with five women living with HIV in the area of Wentworth and chronicles their experiences. Data generated from the study helps highlight women's economic and social subordination and the impact that this has on their ability to negotiate safe sex practices. Each experience chronicled in this thesis reveals a moment of truth, a reality about the impact of the pandemic on the lives of the participants. Their experiences of abject poverty, gender disparity and sexual abuse, predisposed them to acquisition of the virus. It is worth citing Walker et al. (2002: 87) in this regard:

Economic disparities and social transitions shape the nature and pattern of the disease. A key lesson to be learned from other epidemics is that they cannot be separated from the social environment in which they occur. They thrive in a context of social inequality. AIDS is no exception.

The experiences and contexts of people living with HIV can only be understood and appreciated against the backdrop of the social and economic environments which shaped those experiences.

This study therefore: (1) explores the experiences of five women in the Wentworth area, living with HIV; (2) explores reasons why their experiences were constructed in particular ways and (3) draws on the findings of this study to formulate guidelines and

recommendations for schools, on how to support women living with HIV/AIDS and their affected children, more effectively.

By asking participants to share their experiences with me, I was able to consider multiple perspectives and to explore and understand the influences of varying social systems on participant's perspectives and behaviours (Babbie & Mouton 2001: 281). Furthermore, by exploring the experiences of participants, I was able to "understand social action in terms of specific contexts, rather than attempting to generalise to some theoretical population." (Babbie & Mouton 2001: 281). A major criticism of some early HIV/AIDS prevention initiatives was their lack of focus on specific socio-economic and socio-cultural contexts of infected and affected individuals. Collins & Rau (2000: 100) assert:

HIV/AIDS is now too pervasive and too deeply embedded in society to be managed through top-down public health approaches alone. Placing the epidemic within the context of a set of development issues and drawing upon the resources and experiences of local initiatives might at first appear to be a step back from the urgency demanded by an epidemic; in fact, it is the only effective response.

By using life-course research and in-depth interviewing as a mode of inquiry, I was able to afford participants the opportunity to recount their experiences (Seidman 1991: 2-3). This enabled me to comprehend not only participant's experiences within specific socio-economic and gender contexts, but gave me insight into their actions, decisions, behaviour, practices and the meanings they attach to all of these (Babbie & Mouton 2001: 271).

The first part of this chapter comprises discussion about factors that underpin women's increased susceptibility to HIV/AIDS. Next I identified my reason for engaging in this research and discussed the objectives of my study. This was followed by a discussion on the socio-economic characteristics of the Wentworth community. A discussion on the advantages of life course research (life experiences) and in depth interviewing as the mode of inquiry and exploration used in this study, ensued. Next, I give an overview of the chapters that follow.

Chapter two, structured in 10 parts, provides a review of social science research focusing on HIV/AIDS issues related to women. In part one; I explore HIV/AIDS from a medical viewpoint. This is intended as a means of empowering myself as well as the reader since an understanding of the medical facts about HIV/AIDS is extremely essential in promoting a deeper understanding of the virus, its formation and growth. Such knowledge will not only be effective in helping to eradicate myths about the transmission of the virus, but will also promote a sense of empathy for people living with the virus. The discussion on the differences between HIV and AIDS is an attempt to clarify an issue which in certain contexts of our society is still surrounded by large amounts of confusion and a lack of specific knowledge sometimes even ignorance, not unlike my own, prior to my engagement in this research.

Part two, presented in tabular form, explores the ways in which the HI virus is transmitted. Parts three to six deal with the epidemiology of HIV/AIDS. The section on

epidemiology attests to the fact that the number of people, particularly women, living with HIV continues to increase, as does the number of those affected by the pandemic.

Part seven explores the dynamics of HIV/AIDS against a backdrop of social, economic and gender inequality. Both local and international research is explored. Parts eight and nine explore the leverage of stigma and poverty on behaviour and attempts to expose the relationship between stigma, poverty and high HIV prevalence. Finally part ten explores the social impact of the pandemic

Chapter three provides a description of the research design and gives an account of and rationale for the research methodology used in this thesis. The purpose of chapter four is to present the data generated by my study. Chapter five presents the discussion of the data. In chapter six, I present the conclusions, recommendations and guidelines, for the education sector, formulated by using the findings gleaned from my study. I also discuss implications for further research. Chapter seven is a reflection on how this study has impacted me.

### **Literature Review and Theoretical Framework**

In this chapter, I review literature that is related to the focus of my study: The experiences of women living with HIV/AIDS and reasons why their experiences are conducted in particular ways. The chapter is structured in 10 parts each addressing a discussion on an issue or topic related to women and HIV/AIDS or aspects of HIV/AIDS that are essential in promoting an understanding of the various medical (physical), social and emotional dynamics of the pandemic and without which, we cannot fully appreciate the context of the participants of this study.

I begin with a discussion which explores HIV/AIDS from a medical viewpoint. This information has been included as a means of empowering myself as well as the reader. Personal experience has taught me that there are still people in our society, who (like myself, before my engagement in this research), have a very limited understanding of the medical facts about the HI virus and who still talk about HIV and AIDS as if there is no distinction. My inclusion of this information represents an attempt to promote a deeper knowledge and understanding of the virus, its formation and growth, its phases and its impact on the physical well-being of people who live with the virus.

Part 2 presented in tabular form, explores the ways in which the virus is transmitted. Parts 3 to 7 discuss data pertinent to the epidemiology of HIV/AIDS. The inclusion of this information represents an attempt to foreground the evolution of the HIV/AIDS pandemic.

By including parts 1 to 7, my intention is to educate those readers, who (like me, prior to this research), have a lack of specific knowledge about the medical and epidemiological aspects of HIV/AIDS. It is worth acknowledging the argument of Walker et al. (2004: 7) that from the very onset HIV/AIDS has been as much a conflict about bodies, organisms and cells, as it has been about socio-economic marginalization and other social issues. My thinking then, is that a meaningful account of people living with HIV/AIDS must of necessity take cognizance of the medical, historical, social and cultural trajectories of the pandemic.

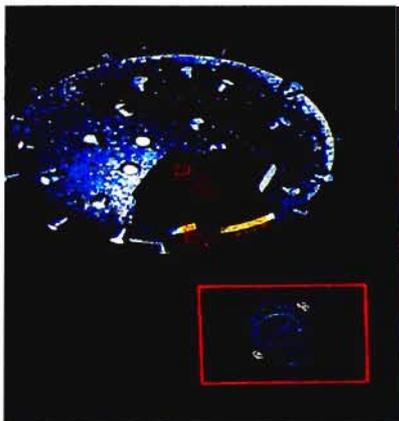
Part 8 explores the dynamics of women and HIV/AIDS against the milieu of the social, economic and gender inequality that characterises the patriarchal disposition of society. Both local and international research is explored. Part 9 explores the concept of stigma and moves on to discussions about HIV/AIDS –related stigma, its forms and contexts in society and its impact on the proliferation of HIV/AIDS. Part 10 focuses on the leverage of poverty on behaviour, its relationship to high risk behaviour in the context of HIV and its role in the escalation of HIV/AIDS. Parts 9 and 10 are included in an attempt to promote in the reader an understanding of the social milieu of the participants of the study and an appreciation for the ways in which their social settings shaped their thinking, decisions and experiences.

I end this chapter with an exploration of the social impact of HIV/AIDS. This information is intended to improve our understanding of HIV/AIDS in a social context, to inform us of what is actually going on in households affected by HIV/AIDS and to

create in us an earnest desire to be part of the social networks that provide practical support for these households, so that our responses become a social context, seen as fundamental to our roles as citizens of not just South Africa but citizens of the world.

### 1. What is HIV/AIDS?

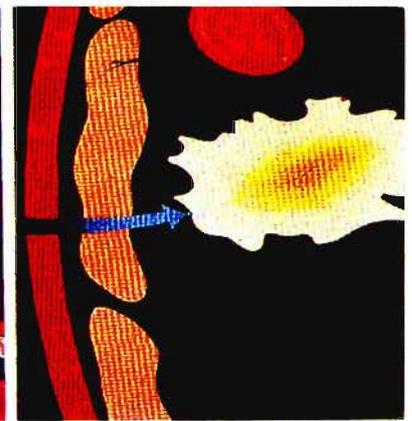
HIV is the Human Immunodeficiency Virus. A virus is one of the smallest germs which cause infection by occupying particular cells in plants, animals or humans. Some viruses are only able to live inside human cells. The Human Immunodeficiency Virus is a blood and tissue-borne virus which can only cause infection by locating and inhabiting specific cells in which they can grow. Infection occurs only once it accesses the white blood cells of humans called CD4 cells, T4 cells or T- helper cells (Armstrong 1990: 8; Houle 2003: 19; Mbuya 2000:14).



AIDS virus with RNA inside



AIDS virus enters bloodstream and seeks out a helper T cell.

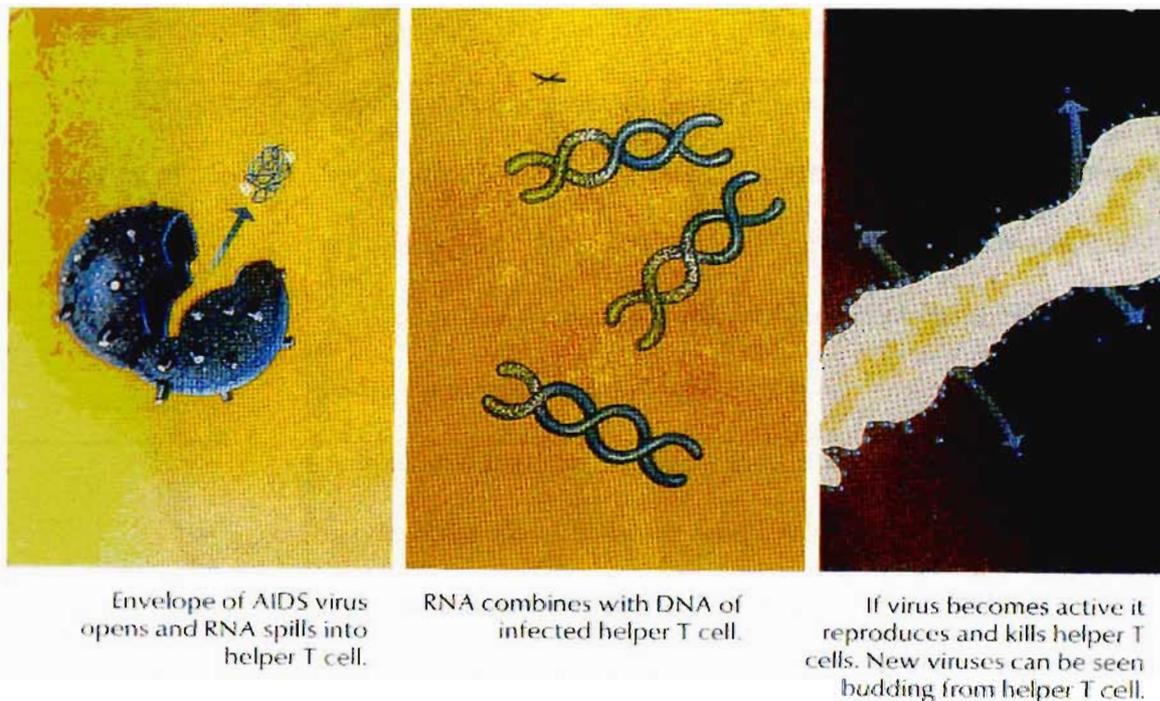


AIDS virus docks on the surface of a helper T cell.

Source: Colman 1998

Picture 6

These cells are among the most essential components of our immune systems. In order to understand why the virus is so harmful, it is crucial to comprehend how the body's immune system works. The immune system is a composite association of parts that maintain good health by defending the body against germs that try to invade it (Colman (1998; Jussim 1997). The term "Immunodeficiency" means that there is a deficiency, a crisis with the body's immune system. HIV is different to other viruses in that it is a retrovirus. This enables the HI-virus to utilize an enzyme called a 'reverse transcriptase' to transform its genetic material from RNA to DNA and this allows the virus to integrate into the host cell's own genetic material. Cells constantly die off and new cells are manufactured, using old cells. This process is termed cell production. In essence, HIV reproduces in human cells by "tricking" the reproductive machinery of invaded cells (intended to manufacture new cells) into manufacturing more viruses instead (Colman 1998: 33; Jussim 1997: 19).



Source: Colman 1998

**Picture 7**

There is a difference between HIV and AIDS. AIDS or Acquired Immunodeficiency Syndrome refers to the final stage of HIV infection, accounting for the collective use of the terms HIV and AIDS as HIV/AIDS. Acquired refers to the fact that the illness is transmitted or spread, one acquires it. HIV lives and reproduces in body fluids such as blood, semen, virginal fluid, and in very small amounts in saliva and breast milk.

## 2. Transmission of HIV

Transmission occurs via contact with infected body fluids (Jussim 1997: 21). Next, I summarize in tabular form the specific ways in which HIV may be acquired and transmitted.

**Table 1** **Ways in which the virus is transmitted**

CAUSES	CAUSAL CONTACT
Sexual activity	Unprotected anal and/or vaginal sex are the major vehicles of HIV transmission. HIV can also be transmitted via oral sex
The sharing of needles	When people inject drugs like cocaine and heroine, they use hypodermic needles to inject or ‘pop’ the skin. It is not uncommon for drug users to share needles and syringes. In such instances and individual could unwittingly inject blood containing HIV into his/her body, via the needle or syringe.
Mother to child	A fetus in the womb shares its mother’s blood. If has HIV, her baby may acquire the virus in her womb or while it is passing through the birth canal where it is exposed to its mother’s vaginal fluid.  In rare cases a baby acquires the virus via HIV- positive mother’s breast milk.

Exposure to contaminated blood.	People who receive blood transfusion may acquire HIV if the blood they receive is infected. Haemophiliacs (people whose bloods do not clot normally), use products made from donated blood to assist their blood to clot. These individuals may contract the virus if they are exposed to infected blood.
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Adapted from Armstrong 1990: 10 & Jussim 1997: 21.

A person who has acquired the HI- virus is described as HIV-positive or seropositive. The blood of a seropositive person contains HIV antibodies (chemicals created by the immune system in response to the virus). The presence of these antibodies is indicative of a person's acquisition of the virus (Armstrong 1990; Forbes 1996; Houle 2003).

As the illness progresses, the individual acquires several opportunistic illnesses. Hence, the word 'Syndrome', which describes a collection of signs and symptoms which constitutes a variety of illnesses, occurring simultaneously and known as opportunistic illnesses. Opportunistic illnesses are indicative of severe immunosuppression. Immunosuppression refers to the fact that the immune system has been unhinged with, unbalanced or suppressed. Eventually, people with AIDS (PWA) die of one or more opportunistic illnesses (Armstrong 1990: 9; Forbes 1996: 13; Houle 2003: 8-20).

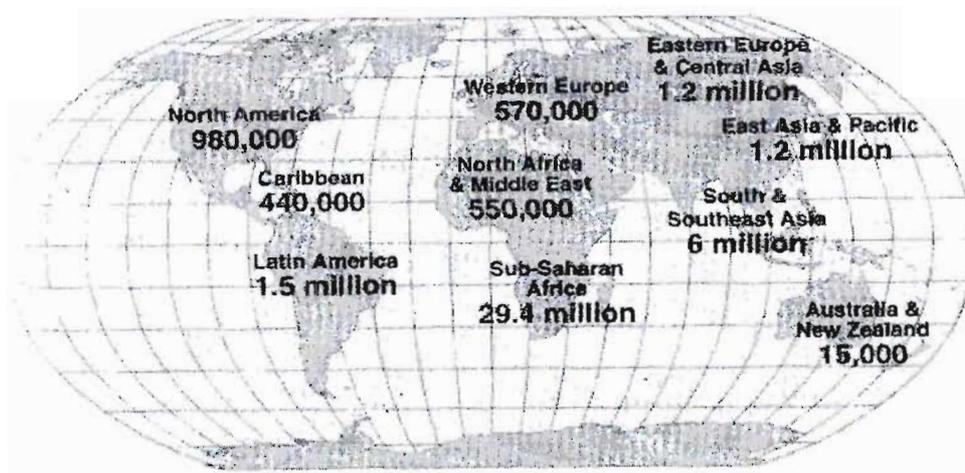
Next, I present a discussion on the global prevalence of the pandemic, followed by discussions on its prevalence in Africa, South Africa and KwaZulu-Natal.

### 3. Prevalence

During the past two decades more than 65million people across the globe have acquired HIV (Behrman 2004: 11). In 2002 alone, 3.1 million people died from HIV/AIDS-related causes and an estimated 5 million were newly diagnosed. To date, approximately 25 million around the world have died, while an estimated 42 million are currently living with HIV/AIDS (EngenderHealth 2004; Houle 2003).

#### MAP 1

### Adults and children estimated to be living with HIV/AIDS as of the end of 2002



**Total: 42 million**

Source: Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization, "Aids Epidemic Update 2002," 2002.

On a daily basis, approximately 15 000 people acquire the virus while a further 8000

people lose their lives to it (EngenderHealth 2004; Houle 2003). Anderson (2000: 22) has advised that AIDS is now the fourth leading cause of mortality worldwide. However, despite these daunting figures, AIDS is still an emerging and evolving pandemic (World Bank 2000: 5).

#### **4. HIV/AIDS in Africa**

Africa has been the most vulnerable to the pandemic (Colman 1988; Grant & Palmiere 2003). Research indicates that the illness appears to be focused on Southern and South eastern Africa, where at least one in five adults is currently living with the virus (Routh 2004: 35). Next, I explore the pandemic in the context of South Africa.

#### **5. HIV/AIDS in South Africa**

Walker et al (2004: 14) affirm that: South Africa has the largest number of people living with the virus; infection is concentrated in the socially and economically productive groups (15-45) and that many South Africans will die before they attain the age of 48 years. WHO (in Walker et al 2004: 14), has estimated that the life expectancy in South Africa will drop to 43 years by 2010, which is 17 years less than it would have been in the absence of the pandemic. Next, I focus on prevalence in our province.

#### **6. HIV/AIDS in KwaZulu - Natal**

Recent statistics on the prevalence of HIV / AIDS in South Africa depict that KwaZulu – Natal has the highest level of prevalence with one in four people being seropositive (Young 1999: 5). KwaZulu – Natal has been described as an environment of abject

poverty, unemployment and a host of other socio-economic hardships. The inflated levels of poverty coupled with high levels of mobility means that HIV/AIDS is an illness “waiting to happen” in this province (Walker et al. 2004). For example, in the city of Durban, there are approximately seven male hostels with more than 43 000 beds, a female hostel with a little more than 1000 beds and one mixed hostel with 11 000 beds (Walker et al. 2004: 69).

A study exploring the determinants of HIV/AIDS in KwaZulu-Natal (Walker et al. 2004: 75), found that seropositive rates are much higher in women than men. Findings reflect that 2.3 percent of rural women between the ages of 15 to 44 in KwaZulu-Natal, are HIV-positive compared to 0.5 percent of their male counterparts (Walker et al. 2004: 75).

## **7. Women and HIV/AIDS.**

The dynamics and demographics of HIV/AIDS have been explored extensively. Findings indicate that women constitute the majority of people living with HIV/AIDS (UNAIDS/WHO in Tharao & Massaquoi 2001: 72). In view of the fact that my study is a study about women living with HIV/AIDS, the social and economic issues that render women vulnerable to the virus and secondly, that hamper effective prevention and access to care for HIV-positive women, are of particular interest to this research. In the sections that follow, I explore literature highlighting issues related to women living with HIV. I also explore factors that inflate women’s vulnerability to the virus.

By the end of 2002, women constituted 58 percent of HIV- positive adults in Sub-Saharan Africa, 55 percent in North Africa and the Middle East and 50 percent in the Caribbean (EngenderHealth 2004: 1). Aids is the leading cause of death for African American women aged 15 to 44 in New York and New Jersey, is the third highest cause of death for all women in that age category in these states and has been predicted to become one of the five leading causes of death in all women, aged 15 to 44, worldwide (Hunter and Rubenstein 1992: 5). According to the United Nations (in Agenda 44, 2000: 60), 30 percent of adult infections in South East Asia are women. Tharao & Massaquoi (2001: 72) maintain that women comprise the fastest growing proportion of new HIV/AIDS infections in Canada. In South Africa, approximately one in four sexually active women is already infected with HIV. The pandemic has already reached extremely high levels among pregnant women in KwaZulu- Natal and Mpumalanga (Young 1999: 5; Abdool-Karim 1998: 15). Evidently, women are over represented in the prevalence of the pandemic. Following, is a discussion which explores reasons for this trend.

The gender disparities which characterize traditional, social and economic values coupled with woman's physiological make-up have pre-disposed woman to the virus. Gender discrimination results in woman's economic dependence on men. Women enjoy less protected employment, have smaller incomes, reduced access to social security and have fewer claims to possessions, property and investments (Anderson 2000; Dejong 2003; Walker et al 2004; Routh 2004; Freudenthal 2001).

Another deep-seated form of gender inequality, which has rendered woman more vulnerable to the virus, is that of violence against woman (Walker et al 2004). The rape and domestic violence which characterizes large sections of South African society makes the negotiation of safer-sex almost impossible. A study conducted in a rural area of the Eastern Cape, revealed that a large number of woman had been coerced into sexual activity against their will. (Walker et al 2004: 39). Reportedly, an estimated one in six women, are part of an abusive relationship, with 80 percent of woman in rural areas having been subjected to domestic violence. Corea (1992: 296) declares:

“We need to name sexual exploitation of women as a public health issue- it is key to the worldwide spread of the AIDS pandemic- and as a human rights violation. We can politically challenge it in all its manifestations: incest, rape, prostitution, sexual harassment, pornography.”

The insights above foreground the reality that HIV/AIDS is not merely a health issue but very much a larger, multifaceted, social issue (Corea 1992; Anderson 2000; Dejong 2003; Walker et al. 2004)

## **8. Stigma**

This section explores the leverage of stigma on behaviour, and attempts to expose the relationship between stigma and the prevalence of HIV. Data generated in this study signified that all the participants in this study contacted the virus sexually. Economic subordination, gender-based violence and stigma were identified as primary determinants of high risk sexual behaviour. High risk behaviours underlined in this study included unprotected sexual intercourse and having sex with multiple partners.

Sexual transmission represents the most predominant mode of HIV transmission in the world (Anderson 2000: 3). The next section examines the role of stigma in the sexual transmission of HIV and explores the dynamics of HIV/AIDS-related stigma.

### **8.1 HIV/AIDS-related Stigma**

A common theme in literature of people with AIDS (PWA) is stigma. Around the world, reactions to HIV/AIDS have ranged from silence and denial to hostility and outright violence (Webb 1997; UNICEF 2000; Coombe 2001; Aggleton 2002; Morrell 2003; Behrman 2004). De Bruyn (1999:1) affirms that coupled with the AIDS pandemic is an “epidemic of stigma and discrimination”, which has had an even wider and greater effect than the virus.

Stigma and discrimination are mutually reinforcing and remain the most harmful aspects of the pandemic (Aggleton 2002; Collymore 2002). Professor Peter Aggleton (2002: 5) contends that stigma and discrimination associated with HIV/AIDS is a “highly combustible fuel” for the pandemic, since these are the most serious impediments to prevention, treatment and support initiatives. Diseases associated with the highest degree of stigma are usually progressive, incurable, poorly understood, have conspicuous symptoms and the ill are blamed for their illness. HIV/AIDS fits this profile. Since the earliest days of this pandemic, seropositive people have been subjected to social ostracism, discrimination and even violence (Goffman 1963; Freire 1970; Herek & Glunt 1988; Gostin & Webber 1998).

Aggleton (2002) has created a useful framework for examining stigma association with HIV/AIDS. He asserts that HIV-related stigma is perceived as a “mark of shame”, where the seropositive person is blamed, and marginalized (Aggleton 2002: 8).

The genesis of HIV/AIDS-related stigma lies deep within society, reinforcing and reproducing existing social inequalities (Aggleton 2002: 3). HIV / AIDS related stigma is unmistakably linked to gender, racial and class divisions in society. These divisions espouse the notion of “otherness” (Aggleton 2002, Corea 1992). Consequently, AIDS is widely perceived as an illness of “others”, “outsiders”, “An African Disease”, or “Women’s Disease” (Aggleton 2002; Corea 1992, Houle 2003).

HIV/AIDS-related stigma represents a major barrier to prevention, treatment and care initiatives (Aggleton 2002: 3). As a result of HIV-related stigma, seropositive individuals have been prevented from seeking or obtaining the health care and social support that they need, adults have lost their jobs, been denied employment, insurance, housing and other services, while seropositive children have been barred from school (Tavanyar 1992 Cameron 1993; Takahashi 1998; De Bruyn 1999). Research has indicated that seropositive people are viewed and treated as undesirable and deviant and labelled as “promiscuous”, “immoral”, “a curse from God”, “ sinners” or “ disciples of Satan” (Mthembu 1998; UNAIDS 2001; Aggleton 2002; Francis 2003; Francis 2004). Aggleton (2002: 3) argues: “HIV/AIDS-stigma and discrimination are universal, occurring in every country and region of the world.”

In a study of People With AIDS in Africa Webb (1997: 167-171) found that stigmatization is most manifest in the desire to see PWA isolated. In his study of PWA in KwaZulu–Natal, Francis (2003: 23) discovered that participants had endured negative labeling, unprovoked attacks on their person and property, institutional discrimination and exclusion.

Mthembu (1998: 27), a South African woman who has experienced the trauma of disclosure explains that stigma results in many seropositive people being evicted from their homes, losing their jobs and being denied medical care. The story of Gugu Dlamini (Young 1999), a KwaZulu–Natal woman living with HIV/AIDS (murdered by members of her community) illustrates the fatal consequences for individuals who disclose their serostatus in contexts where stigma is rampant.

A meaningful account of women and HIV must of necessity incorporate the ways in which gender norms and inequalities influence HIV/AIDS- related stigma. In view of the fact that my study is essentially a study of women living with HIV, gender–based stigma and discrimination requires special mention.

In the next section I discuss the interconnection between gender-based stigma and high risk behaviour. It is my thinking that an understanding of the forms and contexts of HIV/AIDS-related stigma will be facilitated by a preliminary understanding of how stigma and discrimination interacts with pre–existing stigma and discrimination associated with sexuality and gender and the unequal power in sexual relationships.

HIV/AIDS-related stigma and discrimination is inextricably linked to sexual stigma. This is due to the fact that, HIV is mainly sexually transmitted and because the pandemic initially affected people, whose sexual practices or identities, were considered as being different from the “norm” (Anderson 2000; Walker et al. 2004; Eckmani et al. 2004).

Traditional attitudes toward women’s social status, around the world, not only help feed HIV-related stigma but also promote high risk behaviour. Norms of femininity inhibit knowledge and assertiveness and decrease ability to negotiate safer sex. In certain cultures, gender norms for women dictate sexual innocence, passivity, virginity and motherhood (Walker et al. 2004; Eckmani et al. 2004). Consequently, women have limited access to this information, inhibiting their ability to negotiate or execute safer-sex practices.

While gender norms for women inhibits sexual knowledge, the norms of masculinity, on the other hand dictate that men be the authority on the subject of sex and sexuality, with much more sexual experience than women (Gertholtz & Richter 2002; Abdool-Karim 1998). As a result, the concept of multiple partners for men (in certain societies) is condoned. This results in risk taking and poses major barriers to effective STI and HIV prevention (Eckmani et al. 2004: 3).

In settings where the virus is associated with heterosexual sex, seropositive women carry the greater burden of stigma, attracting more rejection than men (Collymore 2002;

Mthembu 1998; UNAIDS 2001 UNICEF 2001). In an Indian study it was discovered that negative responses to serostatus are more particularly metered out to women. Seropositive women were reportedly refused shelter, denied a share of household property, denied access to medical treatment and care and also blamed for their husband's serostatus (UNAIDS 2001: 9).

In South Africa, the story of Promise Mthembu (1998) highlights some of the challenges that seropositive women face in this country. Mthembu (1998: 27) describes how she was subjected to daily beatings from her husband, from whom she had contacted the virus.

Gender inequity pervades all aspects of women's lives (Abdool- Karim 1998; Francis 2003; Mthembu 1998). It is therefore, no secret why many women engage in precarious sexual behaviour. For example, some women may not want to submit to HIV tests (despite secret suspicions of having the virus) because they are afraid of the consequences of a positive test result. In these circumstances, they continue to engage in unsafe sex. Often, they do not possess the skills to negotiate safe sex, or are afraid to insist on safe sex for fear of raising suspicion from a sexual partner. This may be due to the fact that condom use (in certain contexts) is seen as suitable for casual sex, inappropriate for long term relationships and is often associated with prostitutes and mistrust. In these circumstances, women are caught up in a cycle of hazardous sexual behaviour, where even women who may be aware of their serostatus, remain silent, rather than be exposed to the possible wrath of, or rejection by a sexual partner (Walker et al. 2004; Tallis 2000; Abdool- Karim 1998).

The impact of gender roles on sexuality is one of the most significant variables in predicting sexual risk behaviour. An understanding of the interplay between gender, inequity and HIV/AIDS-related high risk behaviour is essentially an understanding of the society in which we live.

Like gender inequality, poverty represents yet another indivisible link to HIV/AIDS-related high risk behaviour. In the following paragraphs, I explore this link.

## **9. Poverty and HIV/AIDS**

The relationship between poverty and HIV/AIDS is “bi-directional” (Collins & Rau 2000: 100) Firstly, I discuss poverty as a factor in HIV transmission. Next, I explore ways in which poverty exacerbates the impact of HIV/AIDS.

As with other health problems, AIDS has disproportionately affected the underprivileged. O’ Sullivan (2000: 26) expounds: “The poorer you are, the harder HIV/AIDS will impact on every area of your life.” The relationship between poverty and high risk behaviour (in the context of HIV transmission) becomes evident in a number of settings. These include: education, behaviour and healthcare, each of which will be discussed hereafter.

Inadequate knowledge about HIV and its transmission increases an individual’s vulnerability to the virus. Cohen (1993: 5) affirms: “Poverty is associated with weak endowment of human and financial resources, such as low levels of education, with

associated low levels of literacy.” Many developing countries (where the pandemic is rampant) do not have the financial resources to finance effective public education initiatives. This lack of access to appropriate information often results in high risk behaviours.

Abdool-Karim (1998: 21) argues that the issue of access to HIV/AIDS information must receive top priority. She argues that: “There is a need to increase women’s access to appropriate information on how to reduce risk behaviours as one form of conscientisation.” Cohen (1993: 5) has a slightly different perspective, contending that even in the unlikely event of information reaching the poor; messages are often “irrelevant” and “inoperable”. Policies and programmes which advocate deferral of gratification will not be heeded as economically marginalized individuals are constrained in their decision making, often resorting to high risk behaviour as a survival strategy.

Like Cohen, Collins & Rau (2000: 100) maintain that for economically marginalised women, short-term urgent gratification of starvation, shelter and general well-being are priority and supplant the long-term consequences of hazardous sexual behaviour. Poverty propels many women into the arena of commercial sex. Often, sex is used as a resource by indigent women, who engage in sex as a trade-off for economic stability. The use of sex as a resource means that these women are exposed to multiple sexual partners and multiple health risks.

The lack of access to suitable health services is another correlate of poverty which has influenced the spread of HIV. Health care was and continues to be characterised by huge disparities between the private and public sectors, resulting in decrepit, unfavourable health care for the economically marginalised (Walker et al. 2004: 73).

Health care remains a problem for indigent people, who, because of inferior housing, lack of clean water and poor nutrition, are predisposed to ill health. This script results in greater risk since it means that STIs (which increase the risk of HIV transmission per contact) are widespread, go undetected and untreated (Walker et al. 2004: 68). STIs affect men and women differently.

The impact of HIV/AIDS is proving to be most devastating on the economy of the household. The approximate length of the illness between acquisition and death (for adults) is approximately eight years. This period is characterized by phases of opportunistic illness and alternating good health. Meagre resources are swallowed up by the cost of medical bills and funerals, as levels of HIV/AIDS infirmity and mortality, pose an astronomical threat to proper nutrition, schooling and house keeping.

Research initiatives in Africa have indicated that in the absence of income from a seropositive breadwinner, an older member of the family (usually the grandmother) is obliged to assume full-time care for the seropositive person and their children. This places great strain on the extended household, who may have to sell off productive assets (if they have any) in an attempt to meet the demands of caring for the sick person and

their children. Households that are already economically unstable slip further and further into a dark hole of indigence and destitution (Walker et al. 2004: 117-119).

The preceding three parts: Women and HIV/AIDS; Stigma; Poverty and HIV/AIDS serves to substantiate the growing evidence (Abdool-Karim 1998; Cohen 1993; Walker et al. 2004), that the irregular proliferation of HIV/AIDS may be attributed to both contextual and behavioural determinants.

## **10. Socio-Economic Impact of HIV/AIDS**

The World Bank (2000: 19), reports that twenty three countries have an adult HIV-prevalence of less than seven percent while twenty one countries have an adult HIV-prevalence of seven percent or more. Essentially, what these countries have in common is that the pandemic remains overwhelmingly, an illness of the marginalised and stigmatised in society, particularly women. “Aids therefore mirrors, but it also accentuates the disparities of our world.” (Walker et al 2004: 8).

The pandemic is having a devastating effect on social safety networks. The emotional and economic impact on households and communities defies adequate description, as large numbers of men, women and children acquire the virus on a daily basis. Grandparents, parents and children die prematurely, increasing household expenditures in a setting which is already permeated by financial chaos, eventuated by HIV-related illness (World Bank 2000; Walker et al. 2004). Often, children and grandparents battle to sustain families after the death of parents (World Bank; Cohen 2002) This script is usually

characterized by children exiting the school system (early) to save educational costs; to support siblings; increase household labour (domestic work) and even head households (World Bank 2000; Walker et al. 2004).

People living with HIV/AIDS subscribe to a range of health care needs. The maintenance of a healthy population is or should be a key objective in any country as this is critical to the development and sustenance of a health, productive workforce. However, research has proven that the countries most affected by HIV / AIDS are not the same that have the most advanced medical technology or the highest GDPs. The World Bank (2004: 11) explains that health care systems are stretched beyond their limits as they battle to meet the needs of seropositive people in addition to other basic medical needs. According to the World Bank (2004: 11), AIDS care is consuming resources earmarked for other life-saving, cost-effective programs.

In reviewing the literature on HIV/AIDS, I began from a medical viewpoint. The physical changes that accompany acquisition of the virus are elucidated for the reader. This helps by creating in our minds a starting point for understanding the journey we are about to take into the life worlds of the participants. It is through the physical changes or cues from their bodies that many HIV-positive people, first begin to truly believe that they have acquired the virus.

The section on epidemiology attested to the fact that the number of people, particularly women, living with HIV continues to increase, as does the number of those affected by the pandemic.

The literature on women and HIV/AIDS of necessity explored the social, economic and gender settings which render women disproportionately susceptible to HIV and in fact, predispose poor women to acquisition of the virus. This literature underlined crucial considerations in the dynamics of women and HIV/AIDS.

Vital conceptions and examples of HIV/AIDS –related stigma were rendered in the section on stigma, emphasizing the role of stigma and discrimination in the proliferation of HIV and foregrounding the double impact in the case of HIV-positive women, who, were already a marginalised group before their contraction of the virus.

It was argued that poverty represents a crucial correlate of risky behaviour in the context of women and HIV since many women engage in unsafe sex as a trade-off for the satisfaction of basic needs. The relationship between poverty and high HIV prevalence was underlined.

The sections comprising: Women and HIV/AIDS; HIV-related Stigma and Poverty and HIV/AIDS serve to substantiate the growing evidence (Abdool-Karim 1998; Cohen 1993; Walker et al. 2004), that the irregular proliferation of HIV/AIDS may be attributed to both contextual and behavioural determinants. I found this script analogous with the

experiences of the participants of my study. Furthermore, these sections have underlined the reality that HIV/AIDS is not only a health issue but also a hugely complex social issue.

The next chapter discusses the methodology employed in this study.

## **RESEARCH DESIGN AND METHODOLOGY**

The purpose of this chapter is to provide a description of the research design and an account of and rationale for the methodology and methods employed in this study. I begin by presenting the problem statement and the research objectives. Next, I discuss the characteristics of the qualitative research paradigm and discuss its compatibility with my study. Subsequently, the research methodology, research process and data analysis is explained. I will conclude by discussing the ethical considerations of this study.

### **Problem Statement**

In recent years, knowledge of women's increased vulnerability to HIV has become fairly widespread. However, a preliminary search for studies focusing on the experiences of women living with HIV/AIDS in the Wentworth area, revealed a lack of appropriate research. Research that generates information which can be employed in prevention, support and care initiatives, as well as in the mitigation of the impact of HIV are essential in our battle against the illness. HIV/AIDS is too insidious and too profoundly entrenched in society to be managed via top-down public health schemes alone. Placing the pandemic within the milieu of a set of social and economic issues and drawing upon the experiences of local HIV-positive and affected people is the only effectual response (Collins & Rau 2000: 100). This study represents an attempt to place the pandemic in the context of the Wentworth community by drawing on the experiences of local, HIV-positive women.

### **Research Objectives**

The primary objective of this study is to explore, understand, interpret and describe the experiences of women living with HIV/AIDS in the Wentworth area. Through the use of qualitative research methods, this study seeks to explore reasons why participant's experiences are constructed in particular ways and subsequently, to utilize this information to explore ways to offer forms of support. The advantages of qualitative research as a vehicle for understanding people in terms of their own definitions of their world and the meanings they attach to their experiences, will be discussed in subsequent paragraphs.

### **Research Design**

People have always been interested in finding new ways (research) to enhance their understanding of their environments and their experiences. This is done with a view to adding to their perspectives, informing their practice and enlargening their concepts of life. Research trends are linked to particular philosophical and ideological positions and reflect the times and the broader societies within which they emerged (Harley, Bertram & Mattson 1999: 68). A researcher's understanding of the world influences his/her style of research. For example, a human science researcher will employ the methodology and methods that are compatible with this type of research (Harley, Bertram & Mattson 1999; Durrheim 2002). Presently, social science research is conducted by employing either a quantitative, qualitative or combination of the two methodological paradigms. The quantitative and qualitative research paradigms differ vastly from each other. Next follows a discussion on, the characteristics of the quantitative approach, followed by a

similar discussion on the qualitative approach, incorporating the reasons why this approach is compatible with this study.

A quantitative research approach maintains that scientific research should be conducted in an objective, detached, unbiased manner (Babbie & Mouton 2001; Terre Blanche & Durrheim 2002). This approach, based on positivism, aims to measure the social world by using the natural science approach. The positivist view holds that the logic of inquiry applied in the natural sciences can be applied in the social sciences and that social phenomena adheres to underlying social laws in the same way that physical phenomena adhere to physical laws (Singleton & Straits 1988; Babbie & Mouton 2001). Furthermore, this approach seeks to establish casual relationships, to predict and control what goes on in the phenomena being studied, and maintains that for such causal relationships to occur, certain conditions have to be in existence (Singleton & Straits 1988: 76; Babbie & Mouton 2001: 49-53).

Whereas quantitative research emphasizes the similarities between natural and human phenomena, qualitative research emphasizes the differences. Qualitative researchers aim to explore, understand and describe the subjective reasons and meanings that lie behind social situations (Terre Blanche & Durrheim 1996; Mouton 1996; Bless & Higson-Smith 2000). Babbie & Mouton argue that in qualitative research, the goal of the researcher is to “study the human action from the insider’s perspective.” In contrast to quantitative research, qualitative research is derived from an antipositivist interpretative approach. Interpretivists underline the fact that not only are human beings constantly embarking on processes of interpreting, creating and making sense of our life worlds and actions,

but that these interpretations, rationalizations and perceptions are also constantly evolving (Babbie & Mouton 2001: 28). Furthermore, Terre Blanche & Durrheim (1996: 35), foreground qualitative research as an ideal approach to emphasize rich experiential data. In keeping with this view, De Vos (2002: 79) advocates that this approach is “idiographic and thus holistic in nature, and aims mainly to understand social life and the meaning people attach to everyday life.”

The research design is informed by the research objective (Eisner 1998: 35). In keeping with the objective of my study, to explore, understand and describe rather than to measure participants experiences, feelings and perceptions, I identified the qualitative research paradigm as the most compatible with my study and subsequently employed this approach in the study. The use of qualitative research enabled my participants to divulge their experiences, accounts of meaning and perceptions in their natural language, using their own words. Furthermore, the qualitative approach allowed me to identify participant’s beliefs and values related to their experiences. It is worth reiterating the sentiments of Eisner (1998) in reference to qualitative research. This type of research is field-focused and enables the researcher and participants to conduct an in-depth exploration of participant’s experiences, knowledge, feelings and perceptions regarding the phenomenon under focus (Rubin and Babbie 1993; Eisner 1998). By employing this approach in my study, I was exposed to verbal and non-verbal cues projected from the participants. This apprised me of the opportunity to be instrumental in creating meaning, making my research interpretive. The study made use of life course research as an appropriate tool for gaining access to the accounts of participant’s experiences.

## **Life Course Research**

The key building blocks of life course research comprise people's own testimonies of their lives in their own words (Giele & Elder 1998; Plummer 2001; De Vos 2002). Life course research is primarily attuned to unearthing the perplexities, uncertainties and inconsistencies that embody our life experiences (Babbie & Mouton 2001: 284).

As people review episodes in their lives, they discover things about themselves they had not known or up until then, had not realised. Seidman (1991: 2-3) advocates: "The best stories are those which stir people's minds, hearts and souls and by so doing, give them new insights into themselves, their problems and their human condition." Relating narratives of experience has been the primary way throughout recorded history that people have made sense of their experiences.

One of the fundamental insights of life course outlook is that people's lives are inimitably moulded by the timing and sequencing of life events in conjunction with the wider sociohistorical influences represented by the interconnection of the various strands of individual trajectories such as those concerning schooling, family and socio-economic status, among others (Elder & O'Rand 1995; Giele & Elder 1998; Denzin 1989; Denzin 1999).

To comprehend how previous events impinge on the present (and future), or to appreciate the process by which diverse life changes arise, it is vital to have truthful information about the past and present. What is it then about life experiences that the life course

researcher wants to know? Life histories or life experiences comprise a series of events and actions that characteristically and interchangeably merge data accounts on education, employment, family and environment. Furthermore, the scope of life experiences should include subjective states such as attitudes, ethics, expectations and self-esteem as these have tangible consequences and as such should be regarded as relevant life experiences (Thomas 1966; Bogdan 1974; Giele & Elder 1998).

Giele & Elder (1998: 100) advocate three categories of life experience data, which I have espoused in this study. These include: event history; the culmination of experiences and the assessment and interpretation of experiences. The first category refers to life experiences encompassing past events or histories (for example family or employment history). The second category refers to experiences that evolved directly from people's past histories (category 1) in conjunction with the influences of environmental factors. Variables in this category comprise an individual's past (example family background), present, or future status with regard and related to how he or she arrived there. The third category of life experience data refers to the assessment of life's experiences as well as the meanings and interpretations an individual assigns to their experiences. The life course perspective patently foregrounds the need to explore individual lives from the individual's point of view. Evaluations of experiences are in these circumstances subjective and in a broad sense, represent the meanings individuals place on the variables in the last two categories.

Life course research is constructed via in-depth interviews (employed in this study) and

may be divided into long and short life histories ( Parson and Lyons 1979; Marshall and Rossman 1989; Giele & Elder 1998; Plummer 2001). For the purposes of this study, I have chosen to adopt the short life story approach as this approach is less time consuming, more resolute and is more conducive to the capturing of autobiographical data. Seidman (1991:71) argues that the most significant attributes an interviewer must possess, is a authentic interest in other people, a deep consciousness of the significance of their (other people's) stories and the value these stories can offer to the interviewer's experience. With these sentiments in mind I attempted to remain loyal to the natural language of participants (whose identities I have disguised), whilst attempting to bring order, structure and meaning to the huge mass of data which my study generated, by editing, sequencing and finally sorting the data into a manageable set of themes and categories which address the research objectives of the study (Creswell 1998; DeVos 2002). Next I discuss the research methods employed in this study.

### **Research Methodology**

Van Manen (1990: 27) refers to methodology as: "the philosophic framework, the fundamental assumptions and characteristics of a human science perspective, the theory behind the method." Elsewhere, Cohen, Manion & Morrison (2000: 44) describe methodology as "the process of enquiry." Based on these definitions, it becomes apparent that methodology specifies how the researcher may proceed (practically) in studying the phenomenon he wishes to focus on.

This study draws on the experiences (as communicated in their interviews) of five women living with HIV in Wentworth. They volunteered to be interviewed following my presentation made to a local church support group. Participants chose whether they wanted to be interviewed in their homes, in my home, the site of their support group or at the school (after hours) where I teach. Interviews were conducted over two successive weeks. Following is a more detailed discussion of the procedures and techniques engaged in this study.

### **Participant Selection**

Participant selection is also referred to as sampling. Sampling involves making decisions about whom or what will be studied (Babbie & Mouton 2001: 100). The population of the study comprises a subset of the population or a representation (according to research) of the population being studied (Babbie & Mouton 2001: 100; De Vos 2002: 198). We study the sample (participants) in an attempt to explore and understand the population from which they were drawn. Sampling may be divided into either probability or non-probability sampling (Babbie & Mouton 2001: 100; De Vos 2002: 198). Whereas probability sampling is based on randomization, non-probability sampling excludes randomization (De Vos 2002: 203).

Babbie & Mouton (2001: 166) argue that social research is often conducted in situations that do not favour probability sampling. In keeping with this view, Terre Blanche & Durrheim (1999: 35) foreground the fact that where research is less concerned with statistical accuracy (qualitative), non-probability sampling is the most viable. Purposive

sampling provides rich experiential data. Based on these insights and in keeping with the objectives of this study, as articulated earlier, I identified and engaged purposive sampling as the most compatible sampling technique for my study.

In the selection of participants, I prescribed that participants had to be female, HIV-positive, residents of Wentworth who were willing to participate in the study. In an attempt to gain access to the sample, I contacted a local AIDS initiative group (NGO). I was then invited to attend a support group meeting, to be held the following week. I was advised that I would be able to access possible participants at the proposed meeting. Unfortunately, I arrived to find that no HIV-positive individuals were in attendance at that meeting. Two student social workers who were in fact, responsible for conducting the support group meetings were present. In an ensuing discussion with the students, I was advised that people living with HIV seemed unwilling to attend meetings at that particular venue because they felt that the community was taking note of their attendance. (I wish to emphasize that this was the perception of the two students and thus not necessarily a fact). Apparently, according to the two students, members of the community recognized that centre as an HIV/AIDS clinic and presumed that all who entered there were HIV-positive. Inevitably the attendance at the support group meetings had dwindled. (Once again, I feel the need to emphasize that this lack of attendance could have been the result of other factors, for example the attitudes and behaviour of those running the centre. Reasons for the lack of attendance had not been explored or investigated at that point in time. This scenario was and remains unrelated to this study). Subsequently, I was advised about an alternative HIV/AIDS support group in another

area of the community, organised by a local church. I had heard about this group prior to this from one of my colleagues, whose sister was an HIV/AIDS home-based care worker.

I contacted my nephew, a member of the church responsible for hosting the support group meetings. He gave me the contact details of the man responsible for conducting the HIV/AIDS support group meetings. Next, I made telephonic contact with the man identified as the group leader. During our ensuing discussion I was surprised to learn that this man was a parent of one of my ex-pupils. I distinctly remembered him because his wife had died approximately ten years ago, whilst his daughter was still a learner in my class. He expressed his excitement at the fact that I (an educator) was interested in conducting a study about HIV/AIDS and told me about his work with HIV-positive people in the area and about the support group he had initiated on behalf of the church. He also advised me that he had been living with the virus for more than ten years. I was invited to make a presentation at a support group meeting to be held the following day.

The support group meeting was conducted in a room behind the church building. In attendance were three males (including the group leader) and six females. All the males and five of the six females were HIV-positive. The sixth female was actually a volunteer worker. During the course of the meeting, I was introduced to the group and given an opportunity to discuss my proposed study. During my presentation, I explained as accurately and as clearly as possible, the reason for my visit. The study, the need for participants, the criteria for participation and the implications for participants was clearly

explained. Female members of the group were requested to give the matter of participation a fair amount of thought and to advise me, some time in the near future, if they wished to participate. I advised them that once I had the required number of participants, I would arrange a meeting, via their group leader (they all did not have telephones), to explain the study and procedures in great detail. I also advised them to come prepared with any questions or concerns as these would be addressed during the proposed meeting. The group leader then concluded the meeting by articulating his thoughts about how people who have the virus need to talk about living with HIV/AIDS. He said that he felt this would be a way for members of the support group to do something positive towards preventing the spread of the virus and combating the ignorance that characterized community members' stance towards the virus. During his speech, there were murmurings of: "Yes"; "That's right" and "True". After the meeting, four of the females verbally indicated to me their desire to participate in the study. I needed one more participant. The group leader then informed me that he was going to contact one of his absent group members and gain her permission to supply me with her contact details. A few days later, I telephoned him and he supplied me with her address. She had given him permission to do so. Since I had no telephonic contact number, I drove to the address I had been given. After introducing myself, I once more explained the reason for my visit, reiterating all that I had said in my presentation at the support group meeting. To my surprise, this lady answered my question before I could even ask it. She informed me that she was very willing to be interviewed. She explained further: "People in Wentworth are full, riddled with HIV/AIDS and when you ask them what is wrong with them, they say they have TB or pneumonia. They hide it away. That is why

this thing is spreading so much! People don't want to talk about this sickness!" After our discussion, I advised the lady that I would inform her (via her support group leader) of the date of our next meeting where the study, procedures and questions/concerns about the study would be addressed, which I subsequently did.

### **Data Collection**

In this section, I outline and discuss the data collection techniques employed in this study. These included: one focus group interview; two in-depth phenomenological interviews and regular recordings of observations in a journal, kept for the duration of the study.

#### **Focus Group Interview**

Once I had the required number of participants, I contacted the support group leader to set up a date for a focus group interview. I requested that he discuss the matter with participants at their next group meeting and that after their input we would arrange a final date for the meeting. A day after he had met with his group, I telephoned him and was happy to hear that participants had agreed on a date and time that was convenient to all stakeholders.

I made use of the focus group interview to establish trust and respect with participants by comprehensively explaining the role and rights of participants as well as the procedures of the study. According to Babbie & Mouton (2001: 292), focus group interviews provide the researcher with an opportunity to observe a vast amount of interaction on a topic in a limited period of time. I used the focus group interview as a vehicle to explore participant's feelings and thoughts about the proposed study. The discussions that

prevailed not only provided direct evidence of participant's opinions, but as I discovered during the course of the interview, also negated some of my presumptions about the behaviour and opinions of the participants.

My presumption that these individuals would be in a fragile psychological state, which could easily be shattered, was soon disproved. I found them eager to share their thoughts, feelings and opinions about the study. One of the first to voice her input was a lady who was actually a founder member of the group and who had lived with the virus much longer than the others. She told of her desire to encourage all HIV-positive people to speak openly about the virus. She argued that: "Because people remain silent in Wentworth, the virus continues to destroy lives." Other participants indicated their agreement by utterances of "absolutely" and "That is true." Four of the participants articulated their input freely and without the need for a second invitation to do so. However, the fifth participant was rather quiet and only gave input when I asked directly for her opinion. She was much more subdued than the rest of the participants. I learned later on that she had just lost her sister to the pandemic.

During this interview, one participant advised me that her husband did not like the idea of her discussing her seropositive status since this reflected negatively on him. Another told me that her family had originally forbidden her to tell others that she had the virus because they found this embarrassing to the entire family. However, both participants told of their concerted efforts to still the concerns raised by family members. They also made it clear that they chose to talk about their status rather than hide it. At the

conclusion of the focus group interview, I was able to gain informed consent from all participants. Tentative interview dates, times and venues were also negotiated during this time.

### **In-depth Phenomenological Interviews**

In addition to a focus group interview, I used in-depth phenomenological interviews. In-depth interviews are particularly compatible with life course research. As discussed earlier, life course research seeks to understand social events and the significance participants affix to their lived experiences. Seidman (1991: 3) strongly advocates in-depth interviewing as a means to understanding the experiences of other people and the meanings they append to their experiences. Interviewing provides access to the context of people's thoughts, feelings and behaviour (De Vos 2002: 304; Seidman 1991: 4; Terre Blanche & Durrheim 1999: 382). In keeping with this idea, De Vos (2002: 292) maintains that interviewing is the predominant method of data collection in explorative research and is an effective means of uncovering people's life worlds in their own words. In keeping with this theme, Seidman (1991: 5-7) argues that the advocacy of a research method depends on the purpose of the research and that as a method of inquiry, interviewing is most consistent with people's ability to make meaning through the use of language.

With regard to the making of meaning, Seidman (1991: 3) advocates that people's behaviour becomes meaningful and coherent when located in the context of their life histories and the lives of those around them. With a view to accessing and

contextualizing participant's experiences, feelings and perceptions, I identified the need for an interactive data collection tool which would assist me in assembling the data for my study. Babbie & Mouton (2001: 249) argue that due to the relatively low level of literacy of the South African population, face to face interviews are popular. These interviews allow researchers to ask the questions orally and record participant's responses. By using face to face in-depth interviewing, I was able to explore and understand the experiences, thoughts, feelings and behaviour (using language) of participants.

In an attempt to preserve the original data, all the interviews in this study were tape recorded. With regard to the tape recording of interviews, Seidman (1991: 87) argues that "the primary method of creating text from interviews is to tape-record the interviews and to transcribe them." Tape recorded interviews are beneficial since they provide an accurate record of participant's responses, represent evidence to guard researchers against accusations of mishandling of data and afford researchers the opportunity to revise and if necessary to improve their interviewing technique (Seidman 1991; Terreblanche and Kelly 2002).

I conducted two semi-structured in depth interviews aided by a tape recorder and an interview guide. These allowed me not only to gain a detailed account of participant's beliefs, perceptions and accounts of meaning, but also catered for a vast amount of flexibility in my interactions with participants as advocated by De Vos (2002: 302). I used a set of pre-determined questions (an interview schedule). These questions served

as a guide rather than a prescription. Babbie & Mouton (2001: 289) expound on qualitative interviewing:

A qualitative interview is an interaction between an interviewer and a respondent in which the interviewer has a general plan of enquiry but not a specific set of questions that must be asked in particular words and in a particular order. A qualitative interview is essentially a conversation in which the interviewer establishes a general direction for the conversation and pursues specific topics raised by the respondent. Ideally, the respondent does most of the talking.

In this study, data was collected using an interview schedule, designed to elicit the three categories of life experience data, as advocated by Giele & Elder (1998: 100), discussed earlier in the section on life course research. During interview one, I attempted to elicit information on participants past lives, socialization history and the process which culminated in the participant's HIV- positive status.

The second interview was designed to elicit information on participant's experiences, perceptions and feelings in the context of HIV/AIDS. I attempted to explore details of experience rather than opinions, or experiences that have informed participant's opinions. Experiences related to family, community, healthcare and employment were explored. The meaning and understanding which participants attach to their experiences and to their future was also explored. Vygotsky (1987 cited in Seidman 1991: 12), maintains that the very practice of articulating experience via language is in itself a meaning making process.

Interviews were spaced at intervals of one week apart. Seidman (1991: 14) maintains that such spacing allows participants enough time to review the previous interview, but not sufficient time to lose the link between the two.

Three of the five participants were uncomfortable about having the interviews in their homes and expressed their desire that this would not be the case. One participant preferred to have the interviews at her home, whilst the last participant did not mind where the interviews were conducted. Of the three who did not wish to use their homes as an interview venue, one explained that her husband did not like her discussing her HIV status and that even though she did not mind openly discussing her status, she did not want to deliberately offend him by having the interview at home; the second merely articulated the fact that she would prefer to come to the school to be interviewed. She did not give a reason for her preference. The third lady felt that she needed to “get out of the house” and would prefer being interviewed at the school. Eventually, the participant who had wanted to be interviewed in her home decided against this after all. She had reconsidered and felt that there would be far too many disturbances from friends and neighbours.

After gaining permission from the school principal to use the school premises (after the school day), I telephonically enlisted the help of the support group leader. It was agreed that since none of the participants have access to telephones, the group leader would liaise between myself and participants. Once the interview dates drew closer, the group leader was given a list of possible dates and times allowed participants to make their

preferred choices. This information was gathered during a group meeting at a date approximately two weeks before the beginning of interview sessions. At the end of each first interview, I negotiated a date with the participant, for the second interview.

### **Journal**

During the course of the study, I kept a journal recording miscellaneous details about the study as well as observations made during various encounters with participants. I found this an effective method of recording emotions, preconceptions, expectations and prejudices (Lincoln and Guba 1985; De Vos 2002). De Vos (2002: 304) advocates the practice of engaging in observations and the compilation of observational notes as a valuable contribution to the final report.

### **Data Analysis**

This study uses a grounded theory approach (Strauss 1987; Strauss & Corbin 1990). Grounded theory is used to develop an inductively-derived theory about a phenomenon by breaking down, examining, comparing, conceptualizing and categorizing data. Coding signifies the technique by which data are broken down, conceptualized and put back together in new ways (De Vos 2002). This is the fundamental process by which new theories are developed from new data. In essence, grounded theory refers to the construction of a theory based more on observation than on deduction (De Vos 2002: 276).

A detailed analysis of data was conducted in an attempt to examine links and connections in the data. According to De Vos (2001: 339): Data analysis is the process of bringing organization, structure and significance to the accumulation of collected data. Qualitative data analysis involves the breaking up of the complex whole into themes, patterns, trends and categories (De Vos 2002: 339; Babbie & Mouton 2001: 490). In this thesis (chapter 4), major themes and related categories which emerged from the data are presented using direct quotes of participants. Findings are then recontextualised by using literature to critique the themes and categories.

### **Trustworthiness**

Lincoln & Guba (cited in Babbie & Mouton 2001: 276) foreground the notion of trustworthiness as a pivotal principle of good qualitative research. De Vos (2002: 351) underlines that all qualitative research must respond to precepts that represent gauges or yard sticks against which the trustworthiness of the research can be evaluated. These precepts can be phrased as requisites to which all research must respond. These include questions about validity, credibility and transferability (De Vos 2002: 351). Next, I discuss these concepts and the ways in which this study addressed these requisites.

Credibility according to Babbie & Mouton (2001: 276) describes: “the compatibility between the constructed realities that exist in the minds of respondents and those that are attributed to them.” With reference to credibility and validity in qualitative research, De Vos (2002: 351) explains:

“The strength of the qualitative study that aims to explore a problem or describe a setting, a process, a social group, or a pattern of interaction will be its validity. An in-depth description showing the

complexities of variables and interactions will be so embedded with data derived from the setting that it cannot help but be valid. Within the parameters of that setting, population and theoretical framework, the research will be valid.

In an attempt to contribute to the credibility of the study (Kirsh 1999; Durrheim and Wassenaar 2002), I have clearly articulated the parameters of the study thereby placing limitations around this study. Furthermore, I have adhered to a number of precepts. These include the tape-recording of interviews; the verbatim quotations of participants (De Vos 2002: 352); taking my findings back to participants in an attempt to verify findings and enhance validity (Babbie & Mouton 2001: 277). In addition, the interview structure used in this study incorporated features that promote the achievement of validity. The process as well as the time management (spacing) encouraged internal consistency in participants, promoted participant's understanding and meaning of their own experiences, and allowed them to make sense to me as well as to themselves. These characteristics promote validity (Seidman 1991: 14).

Transferability of a study refers to the applicability of the findings to other settings, contexts and participants. (Babbie & Mouton 2001: 277; De Vos 2002: 352). With reference to transferability, Babbie & Mouton (2001: 277) advise that generalizations are not priority in qualitative research, neither do qualitative researchers lay claim to this in the contexts of their research. The participants in this study are unique individuals with unique views and perceptions. Given this profile, I do not claim that this set of participants constitutes a sample fully representative of the total seropositive population. Generalization is not intended. Hence, the title of the study: *The Experiences of Five Women Living with HIV/AIDS in the Wentworth Area*. However, to contribute to the

transferability of this study I have made use of purposive sampling to maximize the range of specific information, obtainable from and about this study, by selecting participants that differ from one another. In conjunction with purposive sampling, I have made use of a literature review (concepts) to guide my data collection and analysis (De Vos 2002: 352); I have also engaged in a thick description (comprehensive and accurate) of data in order to allow judgments about transferability to be made by the reader (Babbie & Mouton 2001: 277).

### **Ethical Considerations**

Mouton (2001: 238) describes research ethics as extensively conventional moral principles about proper conduct and behavioural expectations towards participants and other researchers. These principles represent guidelines which allow the researcher to assess his conduct as a researcher.

Key on the itinerary of ethical considerations was my application for ethical clearance. My application to the university's ethical clearance committee included details about: location; objectives, work plan and approaches and methodology that I intended to use in the study. Only once I was granted this clearance (HSS/O5106A), was I able to begin collecting data for my study.

In order to ensure an ethically sound study, I thoroughly explained the research objectives and process to potential participants before requesting for volunteers in the study (Babbie & Mouton 2001; De Vos 2002).

The participants were assured of the strictest confidentiality and anonymity and advised of their right to withdraw from the study at any point, should they so desire (Babbie & Mouton 2001; Creswell 2003). Furthermore, in the interest of proper ethical conduct, I obtained written informed consent from each participant (Mouton 2001: 244; De Vos 2002: 65) prior to the commencement of the first round of interviews. Furthermore, life course studies are unlikely to be conducted without the knowledge and consent of participants, who are in fact the sources of detailed, narrated life experiences (Plummer 2001: 221).

### **Limitations of the study**

There are a number of limitations to the study. It must be noted that life course research poses some limitations by virtue of the fact that such studies are autobiographical. Data can be very misleading especially when the individual's (participant's) efforts to present a lucid, socially acceptable self get in the way. Secondly, the vastness of the interpretive process precludes the likelihood of a comprehensive analysis of texts, as there will always be new interpretations that can be developed (Berg & Kearns 1996; Maines 1992). This is an issue relevant to all social scientists who engage in life course analysis. In this regard, Maines (1992: 1137) proclaims: "All social science data are made up of human interpretations." It is therefore acknowledged that this study will present a particular interpretation of research data.

The small sample size and the fact that all participants belong to the same church organisation may limit the generalisability of the findings. However, it must be emphasized that the intention of this research was to explore and describe rather than to make generalisations. Only the perspectives of the HIV-positive women in this study were assessed with regard to the various themes highlighted in this study. The participants in this study are unique individuals with unique views and perceptions. Given this profile, I do not claim that this set of participants constitutes a sample fully representative of the total seropositive population.

This chapter presented the research design and methodology as well as the rationale for each. In the next chapter, I present the data.

## **Data Presentation**

### **Introduction**

In keeping with the fundamental principle of life course research, which is to provide an account of people's own testimonies of their lives in their own words (Giele & Elder 1998; Plummer 2001; De Vos 2002), I have attempted as much as possible, to remain loyal to the natural language of the participants despite having to break up the data into manageable themes, patterns and categories, used to address the research objectives of my study; and despite having to disguise identities to ensure anonymity.

Major themes and related categories are presented using direct quotes of participants. The context of each theme or category is indicated by preceding headings. Participants' contributions, are preceded by their names in bold, and within brackets []. As advocated by Seidman (1991: 93), I have omitted certain features of speech that the participant would not utilize in writing e.g. "uhms", "ahs" and "you knows" and I have used ellipses to indicate omissions of material from a paragraph or when skipping paragraphs or pages in the transcripts. Whenever necessary, I have inserted my own words amidst those of the participants in an attempt to elucidate a word or phrase and also to avoid ambiguous reading. My insertions appear within [] so that they are easily distinguished.

Next, I present a profile of participants, followed by a summary of themes. Both are presented in tabular form. In chapter 5, findings are then recontextualised by using literature to incorporate the themes.

**Table 2****PROFILE OF PARTICIPANTS**

<b>Name</b>	<b>Age</b>	<b>Time since discovery of seropositive status</b>	<b>Marital Status</b>	<b>Home Language</b>	<b>Employment Status</b>
Lillian Caven	30	10 years	Married	English	Unemployed
Whitney Abbot	34	4 months	Single	English	Unemployed
Gwen Fisher	21	3 years	Single	English	Unemployed
Marianne Milton	37	8 years	Single	English	Unemployed
Violet Blake	48	3 years	Single	English	Unemployed

**TABLE 3****THEMES AND CATEGORIES**

<b>THEMES</b>	<b>CATEGORIES</b>
Social History	Family background Educational Background
Information about HIV/AIDS	Knowledge about sexuality and reproductive health Knowledge of HIV/AIDS

Gender Identity	
Disclosing seropositivity	Participant's Attitudes Related to Disclosure Responses to Disclosure
Social support systems	Clinics and hospitals The Church: Spirituality

### Socio-Economic Backgrounds

#### Family Backgrounds

The following data emerged with regard to family background and relationships:

#### **Lillian**

*I was born here [Wentworth]. There are four of us, three from my late father and one from my step-father. I got one sister and two brothers. Sometimes I just think about you know when we were young. When we would come home, my mother was laying there drunk, no food cooked. Sometime she'd tell us to go and ask so and so for a cup of rice, for potatoes, for a cup of oil. We had to go. Because, if*

*you don't go my stepfather will hit us. Sometimes, even if it is pouring with rain and all that there we must go in the rain. While we're gone, my mother will stand by the stove and she'll cook a big pot of porridge. All the nice things in the cupboard, she and my stepfather would eat. Me and my sister and my brother must eat porridge. And if we don't eat it, my stepfather used to hit us. He would turn us around and hit our backsides until we can't sit. When we go to school, we can't even sit nice. That's why my sister also left school too, she left in standard three. Because she had to stand by the primus stove and pump the primus and cook for us, me and my brother. My mother was in the shabeens, drunk. That's why sometimes now when we fight, she'll [her sister] swear and say she got no education because of us, because she had to leave school to feed us and do our washing and to cook for us. But we also got no education because of how we grew up.... If I had children, I wouldn't want my children to go through what I went through. We had a hard time growing up. My father had a good job. He could have bought us a house. We could have been educated. But God took him, God knew the reason why he took him. He was in a bus accident and he died there at Addington... No communication we had with her [her mother], nothing. We come home she's drunk, when she's drunk she's swearing. There my stepfather is fighting with her. She'll stand by the pots and maybe she'll cook but if she cooks, he'll take the food and throw it in the toilet. We mustn't eat his money and all that there. Sometimes, we go and eat by other people's houses. Maybe next door, they'd give us food.... I never had a chance to talk to her. Not one day she'll be sober to talk to.... She used to leave us with this child, my small baby brother. Me*

*and my sister we were still very small and we had to wash napkins and see to him. She used to get up early and go to the shabeens. Here, by ten o' clock, she was drunk already. We'd have to go and pick her up from the streets and take her home. I don't think she even knew what the days were, what's today or what's tomorrow. That's the life she lived. My stepfather would go to work and come back and everyday he'd hit her, but she wouldn't stop. She used to stay with blue eyes [from being punched]. She was fair, her body used to stay blue and black. The way he used to hit her until we started growing up and my sister got tired of him hitting my mother like that. And she poked him, she nearly killed him. And that's how he stopped abusing my mother. He used to hit my mother everyday before that.*

### **Whitney**

*We were eight children in the family. I didn't know my mother until I was almost eight years old. I used to see her coming and going but I didn't know she was my mother. It was a hell of a thing! I knew my father because he took care of us. She didn't respect my father. My father used to cook for us. He used to work and chop grass for the government....my mother used to go and spend all her time at the compound in Jacobs, drinking. Maybe she didn't like us because she was fair skinned and we were dark like my father. Because I can't understand why then she didn't want to be with us. She used to go to the compound and sleep with all the men! My father used to find her drinking spirits, the mentholated spirits,*

*imagine! Besides cutting grass, my father used to clean and shine. After school I used go and help him there at his work. I used to help him to shine the floors with my shoes off and only my socks on. Then on our way home my father will buy himself a nip of wine .... My parents were married but my mother was nothing but rubbish, a whore! My father was hustling. We had to cook on a primus stove and now we still got a primus stove! I hated my mother. I still hate my mother even though she's dead and I still call her rubbish. Sometimes I blame her that I have this sickness today. She was never there to teach me the facts of life.... After my father died they took my younger brother and me to the homes. He went to Cape Town and I went to Sydneham. So we all got separated.... Nobody ever came to visit us in the homes. My bigger brothers and sisters were not placed in homes because they were too big. By that time they were drinking and taking drugs. I lost out in life because my mother was such a ticky line! I tell you if she didn't do what she did I wouldn't be where I am today.*

## **Gwen**

*I lived in Wentworth from the time I was born. My father used to work. We used to live with my mother's sister and then when my mother lost her job, we went to live with my granny. Me and my mother had a good relationship, we would sit on the veranda and we would talk and talk. I would play with her hair and things like that. If she wanted to go and buy a nip [alcohol] I would go with her. I just loved being with my mother. After my mother lost her job, she became an alcoholic. My mother started stealing things from my grannies house, to sell them for drink. My*

*granny kicked her out of the house and she had to live on the veranda for about a year and a half. She was coughing and all that but nobody actually knew that she was that sick. They thought it was the liquor. She actually had TB and pneumonia. Only when she was on her last, last then they put her back in the house. When I was thirteen, my mother died and that's when my life just went wrong. I just wanted to do my own thing. I felt like had nothing more to live for. I used to run away from home. I felt hurt and angry. I felt rejected. I blame God a lot. I said: "Why? Why did you take her away?" I couldn't forgive people. I blamed my granny because my mother was her daughter and yet she used to fight with her and kick her out of the house. My granny couldn't handle it anymore so she sent me to live with my aunty in Johannesburg. I lived there till I was fourteen, but then my uncle raped me and I came back to Wentworth to live with my granny. All the fighting started again. My granny would tell me that I was useless and that I would amount to nothing. She would say all these words to me. It was like a pattern.*

### **Marian**

*I grew up in a bad way, [I had a] hard life and all that. My mother was a alcoholic and even my father, so my aunty had to look after us. My father's sister she grew us up. We were all living in one flat, my cousins, my sisters and me. There were ten of us living in a two bedroom flat. Some of us used to sleep in the lounge on the floor. When we were growing up and we asked fro something, all you used to hear was: "I haven't got money!" that's why I say we had a tough*

*life. I never ever stayed with my two parents. My mother was this side, my father was this side.*

### **Violet**

*My mother died when I was ten years old. We were four sisters. I don't know whether she got knocked or what happened to her, they just found her dead in the middle of the road. No one knew how that happened. All our lives, I won't say that we actually had a mother. She was always working and we always stayed with my aunty and grandfather. When my mother was not working, she was out drinking. I never ever had a father. And that's the way we grew up. In the house I became like the second mother. I had to do all the washing. On a Saturday morning, I had to go to the market with my aunty. Then I had to go home and cook. I was always busy, busy. I couldn't have time for myself. And you know how when you are thirteen or fourteen how it is. The other young girls used to go out, but we couldn't even go. One Friday I decided it was enough. I went home to another girl's house. I stayed at her house and I hid there for ten years. In those ten years, I had four children.*

### **Educational Background**

The following data emerged with regard to participant's educational background:

#### **Lillian**

*I had to leave school at an early age because we use to go to school with no food. We come back from school there is no food, the house is dirty, we go to school with no shoes, torn uniform, there is no lights in the house and so we really had a hard time growing up. So I thought to myself, how can you go to school with no food, you can't think properly, you are not eating, you stealing the children's lunches, you getting a hiding now because you stealing the lunches and stuff like that. So I got tired of school, and I left school in standard five. I stayed at home, my mother was collecting a grant for us at that time, and a friend of mine got me a job. I was doing washing people's hair.*

### **Whitney**

*I used to go to school without combing my hair, and I couldn't afford school shoes so I went barefoot. My teacher used to say: "This child is raw!" But that time, I had absolutely nothing. I just put that uniform on and I went to school, walking. When I get to school, my teacher would say: "Just go to my house and have a bath and comb your hair!" She would give me her house keys. When I come back to school after bathing at her house, the children in the classroom would plait my hair. I was rotten because I used to go to school even though I was dirty, but I was an intelligent student. My teacher didn't know that at my home there was drinking, there was dagga, buttons and everything at my house. For five years I was in the orphanage and I went to school there. I took an overdose because I wanted to go back home for the weekend and the nuns wouldn't let me. I got thrown out of the orphanage and had to go and live with my uncle who is a policeman. The nuns forced him to keep me there. By now I was doing standard*

*ten. I had to travel from Marianridge to Sydenham to go to school. I had no coupons so my uncle made me wash his overalls every week so I could get a weekly coupon to go to school. I had to jump in the bus at ten past six in the morning and come home at ten past six at night. I had to wash my shirt and socks everyday because I only had one pair of each. After washing my shirt and socks, I would have to help my aunty prepare the meal and do ironing for her. Then I must see if I could study and she used to say: "Please put the light off because you are irritating the people that must go to work!" that's how I failed my standard ten. I lost that whole year because I couldn't study.*

### **Gwen**

*I enjoyed my school time. I was free. I was a child. I didn't have problems. I was always happy and laughing. I had lots of friends. I left school in standard seven because of home circumstances and [we had] money. There were my other brothers and sisters too and my granny was supporting us on a grant.*

### **Marian**

*You know when you're a child, sometimes you naughty. You don't even go to school. When you go to school then you ducking and diving. You come late and then you can't get in the school gates. But, we had fun. I'm really missing my school too. And there was nice teachers. They used to give us things if we don't have, like green pencils and things like that. I had to leave school in standard three because things were hard at home. I couldn't make it because we were*

*under welfare. My father was late and there was no one helping my aunty to look after us. At least when he was alive, he used to give us a little bit of money to buy pads [sanitary towels] and all those things [toiletries]. Now there was no one to help to see to my family. My aunty couldn't make it by herself, I had to go and work to support my family, so I got a job at the tearoom near our flat. I worked about eighteen years by the shop.*

### **Violet**

*I was very clever at school. But then, there were eight of us now. My mother's four and my aunt's four. My grandfather couldn't support us all. My grandfather said only the boys can go to a high standard. He said because if he sends me to school until a high standard, somebody will come and take me to be their wife, and then he has lost out on me. All the girls had to leave by standard six and go and work. Only the boys went to standard eight or nine. If I had the opportunity, I would have went further. I passed standard six and then I left to go and work. I worked for about one or two years and then I went away from home.*

## **Information about HIV/AIDS**

This theme focuses on participants' knowledge about sex, sexuality and HIV/AIDS.

### **Knowledge about sex and sexuality**

Many people do not welcome the idea of sex education in schools and argue that this is the parents' responsibility to educate their children about sex (Houle 2003: 73). On the other hand, many parents do not discuss sex or sexuality with their children. All the

women in this study indicated that their parents and teachers did not discuss sex or sexuality with them.

**Lillian**

*They never really used to talk too much about sex. But sexually when I grew up, even my own parents, my own mother never sat me down and told me: "Right this is about sex, when you sleep with a guy you get pregnant."*

**Whitney**

*My parents never used to worry to talk about sex. I never had boyfriends, till I was eighteen. I was just finished school. It was my first sexual experience and I got pregnant.*

**Marianne**

*Your parents don't have time to discuss things like that. My aunty used to look after us but she didn't talk about sex to us also. She was very busy working and making sure that we went to school. At school there was no time for talking about such things*

**Gwen**

*With my friends, we used to talk about it. But not with my family. My one friend I had, she taught me how to kiss a boy. She used to teach me things like that. She was always faster than me. She used to explain things to me. My family didn't*

*think it was something to talk about, we never ever spoke about sexual relationships.*

**Violet**

*Nobody spoke about it at home. They say you learn by your instincts. You learn sex from the boys, they teach you because they always know about sexual things. My aunty who brought us up had no time to talk to us about anything like our bodies or menstruation and all that.*

As highlighted in the previous chapter, gender norms for femininity often mean that women and girls are not supposed to be conversant about sex and sexuality. As a result, the women in this study had limited access to relevant information. As is evident from the data, women and girls who are ignorant about sex and sexuality are predisposed to the risk of acquiring HIV.

**Knowledge about HIV/AIDS**

The following data surfaced with regard to knowledge about HIV/AIDS:

**Lillian**

*The people always used to say to me: "Hey this man is sick, he is dying. I thought maybe the lady was saying that because she also smarked [liked] him and so he wanted me he never used to like her and so she always used to tell me he was sick. But I always say to myself you must not judge them from outside and say they are*

*beautiful because we don't know what they are carrying on them. And for myself I was blind because I didn't know this guy was infected. He was a well-looking somebody, all the time he was infected. We went out for about a year or so. I started getting sick. First it started when I had sores in my womb and outside my womb I couldn't pass urine, nothing and I went to the clinic in town and they gave me something. They said that I have got an infection, they didn't worry about having an HIV test and all that. Glands started growing on the side of my face. So when I went to Addington to sort these glands out, I also didn't know that I was infected and Addington saw to me, they lanced this gland and they took blood from me. I wasn't aware of HIV at that time so all the signs my body was giving me didn't make me realise my body was giving me some messages that I have HIV. So the doctor asked me do I know what HIV is and I said no. They didn't ask for my permission can they take my blood and have the test done, like they are doing now. So anyway they explained me about HIV what it does and all the effects it does in the body, you can't have kids and all that there. They said to me, you know you are HIV –positive. I sat there in shock now. You say HIV. I'm trying to think now how did I get this thing now? Because they were saying sexually you can get it. So I sat there shocked and I started asking them all kinds of questions. Now when I sit back and I think about how I was infected, it was because of a lack of knowledge. I didn't know about this thing. I didn't know about this virus. I didn't know how to prevent [protect] myself.*

**Whitney**

*I never knew anything about that because we never spoke about it, nothing. My parents never used to worry about me to talk about sex. I didn't know anything about HIV and AIDS at this time. We never ever spoke about it. My family didn't think it was something to talk about. I don't think they knew the story about this thing either. I can't really tell you anything about it because I only had it for four months now. I don't know much about it. But I'm learning to speak about it.*

### **Gwen**

*One day my cousin said to me. "Can we take you to the doctor, and then we'll find out what's wrong with you, okay?" On the way to the doctor, she said to me: "Gwen do you want to do an HIV test?" So I looked at her and I said: "Now what are you saying?" But knowing my world, I said: "Yes" She said: "Are you sure?" Although I had answered yes, it was like it was nothing, if I do it, I didn't expect anything. So, I did the test. After this, as the days went, I was waiting for my results and I started getting better. One day they came and they called me, I was down the road. Everyone was sitting in the lounge, my granny, my aunty, my sisters! You know like when somebody dies in the family, they are all there. They all looked so sad. They said: "Gwen your results came. You know me, I'm just like: "Okay, fine!" I was ever ready to just get everything over with. My cousin told me: "It's positive" No one knew the results before this. When my cousin told me, everyone heard with me. My sister, the eldest one, she started screaming and pulling her hair, saying: "Why? Why?" She was crying and screaming and I looked at her like she is mad because I didn't understand it. My family started*

*hugging me. I thought: "Please! Wait!" We don't even have that relationship, you know. I went right back down the road. My friends go: "What did they call you for?" I said: "Ha, nothing!" My life just carried on. It never hit me that I was sick. I wasn't scared. There wasn't doubt in my mind, nothing. It was just like, you know, a normal thing. I didn't really understand properly then about what HIV was.*

### **Violet**

*I used to go to Wentworth hospital 'cause I was always getting sick and they kept on saying: "Did you go for blood?" I said: "Blood? Blood for what?" I kept getting sick. When I had my shingles, I went to the doctor at Natraj. He didn't even want to touch me. And I said to my cousin: "How, what's wrong with this doctor here?" But he's taking my R150, 00 but he don't want to touch me. He said: "My girl! Have you had yourself tested?" And I asked my cousin: "What's tested? Tested for what?" Then he said to my cousin: "No, can't you see she is sick?"*

Only one of the participants claimed to have a prior knowledge of HIV. However, lack of specific knowledge about HIV is displayed by the fact that she appeared to believe that staying faithful to one person would protect her from the virus.

### **Marianne**

*I wasn't really like a sex person, you know. I only had one sexual boyfriend. I understood about it. When we used to go to the clinic, they used to talk about it. I couldn't understand how I got it because I only had one sexual partner. I used to tell him to when we are having sex that he must use condoms but he would always say: "I trust you!"*

In view of the fact that all participants in the study were older than 20 years of age, serious questions arise as to reasons why none of them in fact, possessed the specific knowledge about a pandemic that is more than twenty years old. Next, I explore possible reasons for this scenario.

Participant's definitions of HIV and AIDS are indicative of a lack of explicit understanding of the medical definitions of HIV and AIDS. However, responses are indicative of a basic but limited knowledge of the terms HIV and AIDS.

### **Lillian**

*Now at least I got more understanding about what HIV really is. I was so illiterate about it but now I'm more educated about it, what it does. I know that its caused through sexually sleeping together, with somebody or else by the blood, if you're having blood transfusion or else mother to child, if you're giving birth like that there. That's the least I know.*

### **Whitney**

*HIV is called a virus. If you look after yourself, I have got HIV, if I live*

*positively, I just need people to speak out about it. If everyone can come out about it. When you go there to the clinic, they take a bottle of whatever and they put what water, but if you tell them you have HIV. You'll get the real medicine without water. There's always a medication that they can give you that will help you with the virus*

### **Marianne**

*It's a sickness. It's a sickness that is in your body which you must fight to get yourself right. It's a killing disease. You get so sick that you can't help yourself. You have to get people to come and see to you.*

### **Gwen**

*To me, it's not a death sentence. It's not something that I must be afraid of. It's just an eye opener to me, it's just like: "GF you are not really different, you just gotta be more careful, you gotta be more, and you've always gotta think twice than another person. But I still live like a normal person. I must be careful in everything I do. I must think. "Is that good for me?" If I still wanna be with my friends and they drink, you know you, you always think twice! You can't just be how you wanna be. You have to take more care of yourself. You get different stages where you are when you are sick. And when you are HIV-positive, you are not really bad. When you've got AIDS, there's nothing they can do for you. You really in that bad stage. So when you HIV-positive, you prevent yourself to getting to that, to AIDS.*

**Violet**

*It's like a germ in your body. It's not active yet, its just there in your body. It eats your immune system, so if you don't eat healthy and if you carry on drinking and smoking, then your immune system gets weak. The germs start moving around, they get active, then you start getting sick. I won't actually say I know about AIDS.*

Participants discuss their understanding of how HIV/AIDS is transmitted.

**Lillian**

*I know it's caused by sexually sleeping together with somebody or else by the blood. If you are having blood transfusion or else mother to child, if you giving birth like that there, that's the least [most] I know.*

**Whitney**

*We are getting the virus because some people are very selfish, but besides that, if some people can say to you, like me now, let's say, today I don't have paraffin in my stove. If someone comes next to me, near me and says: "Whitney come let's go. I'll give you a R20." I don't know if that person is infected. So what I want to do is, I want to go and get that money, so I can put paraffin in my stove and cook for my children and family. So I'm gonna go and sleep with that person to get that money. Even if I'm hungry, I'll go there and I'll say: "Buy me a Kentucky and we'll have a nice time!" I won't tell the person that I'm HIV-positive or maybe, they won't tell me. So that is how this thing is getting spread, you understand?*

**Marianne**

*Boys run a mock and all that. He'll have you as a girlfriend, but he'll leave you and go somewhere else. And these people, they don't want to believe in condoms and stuff like that. They feel it's fine if they sleep around because they are men and you are just a woman.*

**Gwen**

*HIV happens through sex, and also through blood. I just know those two ways. I don't know much.*

**Violet**

*Every time people say they've got pneumonia, pneumonia or TB. But you see the people have sores on their mouth, everywhere sores. People tell lies to hide their HIV. They don't want to be treated like they are tainted. They don't want people to act as if they are dirty. They hide the truth instead of saying: "I'm HIV-positive." Nobody knows that's why it spreads like that. They are passing it on and on not saying anything and they feel ashamed instead of just saying the truth.*

**Gender Identity**

All the participants in this study contacted the virus via sexual intercourse, as result of risky sexual behaviour. The investigation of reasons for participant's risky sexual

behaviour i.e. participant's participation in unprotected or unsafe sex thus became a point of exploration of the study. Findings indicated a strong link between gender identity, and risky sexual behaviour, particularly in the context of the economically marginalised participants of my study. The following data emerged:

### **Lillian**

*I was sexually active from a very young age and I loved making love all the time. My first boyfriend, I was 15 years old. He took my virginity and I was staying with him in Johannesburg.... I wouldn't just say I would fall in love with them [sexual partners] straight away and sleep with them the very same time. I would first build a relationship with them. Go out with them, maybe go to discos, maybe go to a party. Get to try and know how he is. What sort of person, is he a raw person? Is he a giving person? Is he a stingy person? If I would ask him for something, would he say no, or would he give me. And if I felt he's okay, he's a understanding person, maybe I can talk to him or tell him about my problems at home, like: "I got no food at home." Maybe I'd say: "My mother's drunk" or "She drinks too much, I'm not working, I need toiletries" I'd tell him: "You can't expect if you want to sleep with me, I tell you to take my panty off and there's a big whole in it and there's a big whole here in my panty. You want to take off nice underwear. If you wanna hold me, I must be smelling nice. I mustn't be smelling funny, putting soap here under my arms." I was conscious of things like that, so I would tell them: "I need cash". If the man didn't want to give me, I won't force, I'd leave him just like that. Then I'd say: "Okay, we'll carry on seeing one*

*another." But if I see continuously I'm asking you [a man] and you're not giving to me, I would leave you then and look for somebody else. But once, if I'm in a relationship with you and I see, okay, you're a giving person. I talk to you and you are a understanding person, we'd decide okay, from here on we'll go. Because it's not just meet and eat like that there. Because you find out, you meet the person today, you sleep with them and tomorrow they gone, they don't come back. Some men are like that, they'll sleep with you and they'll still come back, some won't. That's how I was. I would try and build maybe that small relationship with him and then I'll say: "Okay, this is the guy I will give it to." And then I would sleep with him. And I used to enjoy the sexual part knowing that I'm giving him freely. He's not forcing it from me, no. I've offered myself to him. And as long as he's giving me support, giving me money, he's seeing that I got whatever my needs were. Then it's fine with me. My mother was not supporting us, she wasn't seeing to us, so we had to go and look for support from men out there. And she never saw things like that there that we were bringing money in to buy food for ourselves. How were we going to live if we didn't feed ourselves? So we had to go out and go and look for men to give us money to feed ourselves.*

### **Whitney**

*When I was eighteen, I had sex for the first time and I got pregnant just from that one time. I didn't stay with my child's father because I moved back to Wentworth and we grew apart. When we used to see each other some times we still remained friends. After the first one [her first boyfriend] I met this guy that I am living*

*with now and I had a child from him too. When my second boyfriend started staying with me, he kept hitting me and so one day, I decided to run away that's how all this nonsense of sleeping with other men started. I ran away and I went to town. He came to look for me and took me back home. Every time he used to hit me and I used to run away again. I had this habit of running away. Whenever I ran away from my boyfriend, I went to my first child's father in town, my ex-boyfriend. My new boyfriend was a drug addict and he used to stab me. My child saw him put this big knife into my head and the blood was just streaming down my face. I took the first kombi I could find and I ran away. Now this time I ran away, my ex was not there when I ran to him in town where he was living. He was in Ladysmith. I was looking for him and I could not find him. I didn't know where to go, so I went to that place at Addington, near the security, where all the boys that smoke glue sleep. I went and I slept there for three days. One day I met up with a nice guy. He gave me a R10 to buy some food and said that he would meet me later that day after he had finished work. That night, he came back to meet me and he booked us both into the shelter. We stayed together in the shelter for three weeks like husband and wife. At least I did not have to worry about shelter fees as long as we were sleeping together. One day he lost his job and he went to look for some money for us but he never came back. I was back on the streets again. Then I met another guy. He bought me lunch and booked us into a hotel for a few hours. He said to me: "Whitney let's see how many times you can make me happy." He gave me a R10 for every time I made him have a climax. I was very tired but at the end I ended up with more than R80. This was more money than I*

*ever had in my hands before. I was happy because I had enough money now to buy a pair of shorts and two pairs of underwear and pay for shelter [for homeless people] fees and still keep some money. It became like a pattern. I used to meet this same guy every Monday at the same time, at that hotel. After a while I started a relationship with another guy and we lived in the shelter together as husband and wife.... I had a few other sexual relationships after that. You know what its like, its either you sell yourself or you gonna die in the cold.*

### **Marianne**

*I wasn't a fast moving girl. I was about eighteen when I had sex for the first time in my life. My aunty never gave us a chance to have boyfriends. She used to send the smaller ones to watch us. There were ten of us, living in a two-bedroomed flat. We had a tough life. When you ask for something, all you hear is: "I haven't got money!" So, what you're gonna do besides to get a boyfriend who can give you money? You have to find a way. But they don't tell you that they got the virus and you are trying to support your brothers and sisters and your whole family. That time, my aunty was looking after us but there was not enough money because I had a lot of cousins too. I was working in the shop too but the money was quite little, you didn't even have enough to buy pads [sanitary towels] because you thinking what's more important, food and board or that. I used to ask my boyfriend for money sometimes and he wanted sex too. We used to go to his home to have sex. At least there it was better, not so many people and all squashed up, sharing little bit of food. I used to be happy going to his house.*

## Gwen

*My first time I had sex was because I was raped. I was only fourteen. I was living in Johannesburg with my auntie. I wasn't working. My mother was dead. I had nowhere to live. My auntie was working and I was staying at home helping her with the cooking and cleaning. My uncle was also at home because he had no job. He used to always come into my room and bring me cigarettes. He knew I smoked and I thought he was just being a 'cool' uncle by giving me cigarettes. Then he started touching me. I had to keep quiet because I was living in his house. Things started getting worse until one day he raped me. I was too scared to tell anybody. The day I told my cousin, I had to leave my auntie's house and go and live with my granny. They all blamed me and said that I had encouraged him and wanted him. It was terrible. My family, I mean my mother's family, they didn't believe me that my uncle had raped me and yet he was an outsider, not me.... After I was raped I felt so rejected by my family's attitude. I got close to a taxi driver and we started having sex because I felt he cared about me. That was my first real sexual relationship. The other one was rape. I didn't want that sex. It was forced on me. I was sleeping with this taxi guy and we were together almost all the time. I couldn't believe it when I heard he had so many other women... after that I got sick. Some years after that, this one guy I got involved with, well not really got involved with. I was in a tavern and he drugged my drink. And while I was in that state, drugged, he took me to a place and slept with me.... Some months later, I met another guy and I started living with him because my granny had kicked me*

*out of home. He used to give me his money so at least I had a place to stay and some money for myself.*

## **Violet**

*I was thirteen when I had sexual intercourse for the first time. I ran away from home that's how I got involved again sexually for the second time.... I had to go and work because my grandfather said that only the boys can go to a high standard, not the girls. The girls must go and earn a living after six. So I went to work at a firm in Jacobs. I was only fourteen. I got tired of working and working and I also had to do all the washing and buying at the market and cooking. I was always busy. I ran away from home and I went to stay with my friend on the farm. I met this boy from the farm and I started sexual relationships with him. We had a daughter. I came back to Wentworth to ask my aunty if I could come back home but she chased me away. I went back to this man on the farm. We had three more children after that.... So after ten years with this man, I had it hard, hard and this man used to give me a hiding. You see this man was half Black and half Coloured. And every time I used to give birth, he used to give me a hiding because I was always giving birth to girl children, not boys. I couldn't take it anymore and I ran away from him.... I was still young then, only thirty years and I still had feelings. I got a fifth child from a man in Wentworth and then I got my first son from a different man. If that first man treated me better I shouldn't have ran away and had so many different fathers for my children.*

## Disclosing Seropositivity

### Participant's Attitudes related to Disclosure

The following findings emerged with regard to participant's attitudes and feelings about disclosing their HIV status to family members and friends and members of the community:

#### **Whitney**

*After I found out I was the HIV-positive I came back home. I was thinking to myself: "Must I wait until I'm drunk or must I tell them now?" I waited for a few days until one day when we were all sitting and drinking and I had some drink in me. I just blurted it out.*

#### **Gwen**

*I was very scared to tell them that I was HIV-positive. You know with your friends and family you sometimes share things like maybe an apple, you share things. I felt I would be rejected. I felt things wouldn't be the same. They'd talk bad about me. I didn't think they would accept me because it's not just any sickness, you know. It's a sickness that people really talk bad about. You know you hear when they talk about HIV. They say "Ooh that one's got HIV, she's sick." They don't even put it in a nice way or show concern like: "Oh shame she's sick." They always make it sound bad.*

#### **Marianne**

*I took time to tell my family because I was scared, I didn't know how they were gonna feel. They were gonna feel bad. Maybe they wouldn't love me any more. I thought they gonna tell someone else. And some time you got enemies. Maybe they would go and tell your enemies. That's what I was scared of too. I remember when the doctor gave me the letter to say I was HIV-positive, I was saying: "Don't give me that letter!" On my way home after that I felt like throwing myself in front of a car. I didn't want anyone to know that I had HIV.*

### **Violet**

*I didn't tell my family for five months. I was so scared to tell them that I was HIV-positive because my family is a Christian family. My aunty looked after me from small. She grew me up. Her children were never disobedient and all that. They never ran away from home like I did. I thought that they would say that I deserved the HIV because I ran away from home. I was scared they would chase me out of the house if I told them and I would have nowhere to go.*

### **Lillian**

*We were sexually active and we weren't using condoms too as well. And, so I just kept on sleeping without condoms too, as well. That was the wrong part, I used to do. And it used to worry me because I did not have the guts to tell him. I didn't want him to leave me alone.*

## **Responses to Disclosure**

The following data emerged in regard to negative responses from family and friends:

**Lillian**

*After I was first diagnosed. When my sister used to get drunk, she would stand outside there by us [where they lived] and swear me and say that I got AIDS, that I'm dying of AIDS. It used to hurt me because I knew by trusting her, she was my eldest sister, trusting her, I opened up to her first before everybody else. And that's what she could do. Disgrace me outside and tell people that I've got HIV, but they never used to say HIV, they would say AIDS, so everybody thinks: "Oh, she's got AIDS, she's dying, you know." But I used to take all that, humble it, just, cry, sit by myself, mind my own business. So even if you didn't want to think about it, automatically now, everything starts playing in your mind, thinking: "Now I'm dying now, what are people going to be thinking? [They must be thinking] She was moving around, going to discos, that's why she's got AIDS, she's dying now. You know when I used to walk on the street when I was first diagnosed. After my sister used to swear me, the people used to point fingers at me: "Oh there's she! She's got AIDS." I used to get T.B and you lose weight. People start pointing fingers at you, looking at you bad. Even one time, I went to my friend's house, she invited me for a weekend. I never told her that I was HIV. After some time, she came to my house and asked: "When you were at my place, did you use my toothbrush?" I asked her: "Why are you asking?" she said: "I'm just asking". I think she heard from somebody that I was sick and I never told her, you know. And from that time, she just stopped coming to my house. If she sees me on the*

*street, she just greets me: "Hello." And that's it. She doesn't act like we were ever close before.*

### **Whitney**

*One day we went to a funeral and we were having a beer. My brother said to his wife: "Don't give WA my beer to drink!" So his wife said: "Why?" he said: "Ooh, she's got that thing!" When we went home I told him: "This is it! Do you want me to get you books and all? It doesn't mean because I am HIV – positive, you are going to get it!"*

### **Gwen**

*You know my granny, when we argue, she always throws these things in my face. She says: "Good! You're in that position! You know why you're in that position? God, I wouldn't wish it on my enemy but you! You deserve it! You were looking for it!" You know when she's angry, she throws all these words at me, and that's the most things that bring me down. I don't care if she shouts at me to correct me, but not in her way, she shouts at me, using my sickness to hurt me so badly.*

### **Violet**

*But it was hard because my brother-in-law, he thought I was gonna give his children the virus. And one day I cried and I told him: "You know, I'm staying here. You don't want me to cook food anymore. You always call someone else to make you tea or dish up food for you even if I can, what's so wrong with me? I*

*have no sores or anything like that!" Instead of getting better you are getting worse because every night you are crying a silent cry on your own. Because of the way you are being treated. And so I went and spoke about it to my aunty. I asked her to tell him that this thing was not contagious.*

The next section records data indicative of positive responses which replaced the initial negative responses to disclosure.

### **Lillian**

*After I was diagnosed one of my friends introduced me to a counsellor and she became like my friend, she became like my sister because everything I wanted to say and I wanted to speak I would go to her. She was such a pleasant person. And she used to take me out when I'm feeling down, take me for lunch. We'd go to bioscope and that time I used drink. If I felt I wanted to have a beer she would buy me a beer, sit down and let me talk my stories, if I got stories. And that's how I really started accepting that the virus is in me and saying okay this is how I'm going to live, this is what I'm going to do. I really thank God for my friend that introduced me to that lady and for that lady, for helping me to start accepting this virus. I always think about her still.... They [her family] all accepted it. We sat down, we cried about it. They were all upset, because they knew my heart, how I want children, what a kind person I am, stuff like that. So it was like a shock for them, because they knew like, I was a homely person, I wasn't one that slept around with a lot of guys and we just had lost my mother and it was sad for them*

*to get news. They are not funny towards me, saying: 'Don't drink out of the cup, don't do this, don't do that.' Even if I get sick, they're there for me, they come and help me. They are very concerned. And that's where I think I really get my strength from, it's from my family because they are really supportive.*

### **Whitney**

*My friends are very sympathetic towards me. They're also very supportive. They're always telling me that I must look after myself, I mustn't worry. One thing I've friends that won't go from one to the other to talk. If I didn't tell you, the other one won't come and tell you. They like that because they all love me the same. At home everybody is okay with me, even my neighbours. My neighbours and my cousins all know and we discuss my HIV openly. They treat me with respect not like I am unhealthy and they are going to get sick from me.*

### **Marianne**

*I told my brothers and sisters and they hugged me. They said I mustn't worry, they were there for me. My sister told me that whatever happens, she'll take care of me, and she will take care of my child when I am gone one day. At least this made me feel much more happier with all their support and care.*

### **Gwen**

*All my friends accepted me. I was pleasantly surprised. They continued to treat me the same way. Nothing changed. I didn't feel like I was different from them.*

*It's still the same. I don't feel out of place. I don't feel lost. We talk about everything, even my sickness. When I go for my appointments they ask me how it was and things like that. We talk about it like its just normal life. It helps you a lot when they understand. Before I had to go through it on my own. Sometimes I can say to my friend: "I couldn't eat the food because it is hot food and I have thrush in my mouth." She will say: "I cooked this or I cooked that, can you eat it?" sometimes when I visit her, she just says: "Gwen I'm cooking curry today do you still have thrush. Can you eat it or must I cook macaroni for you?" And I'll say: "No I can eat curry now."*

### **Violet**

*Most of my family was very considerate about my feelings. They didn't say nothing bad. They just said: "Look after yourself Violet. You must think of your children." Now my family treat me like a normal person. They don't make me feel like I'm tainted. My cousin who used to tease me doesn't tease me any more. He talks to me nicely. He even gives me money now. Even my sisters said: "No don't worry. If we can help you we'll help with whatever we can afford to help you with. You not gonna die now. It's not yet active. You are looking well too!" They've all accepted me.*

## **Social Support Systems**

The link between social support and psychological well – being is inextricable. Not only do seropositive people require informal support from family and friends, they also require

and benefit greatly from institutional support given by clinics and hospitals and other institutions in the community.

## Clinics and hospitals

The following surfaced in regard to clinics and hospitals:

### **Lillian**

*I don't have a problem when I go to the clinic. Even when I go there and I'm sick, they see to me without complaints. Now and again you do get one or two of those nurses that's in their own mood. But I really haven't been having any problems, even at the hospital too. It's good because at the hospital there are counsellors there. Every time you go, you don't go straight to the doctors, you go to the counsellor first. Then they talk to us and ask us how we are. That is nice because we like to build a relationship and when we go there, they know us well. They even get so happy to see us. They see if we are looking nice or if we picked up weight and all that. They take your pressure, your weight. The last time I was so happy because I was staying 45 kgs for so long. Sometimes it used to drop below 45 but now it was staying 45 for so long. And then I saw hmm I'm hitting 50! I was so happy and then they were just wondering why I'm smiling like that and then I the doctor that I was so happy that I picked up weight. It's because of the vitamin tablets they give us. They give us this Centrum.*

### **Whitney**

*All the people at the clinic are very pleasant and helpful. They do not treat you bad, you know. Their advise us about our diet and we must not stress and they give us vitamins and all that. It helps us a lot when they treat us so well.*

**Marianne**

*So far the nurses and doctors haven't been funny with me. Whenever I go there, I greet them nicely. They greet me back too. They never talk funny to me. If you treat them with respect they also treat you with respect. You can't just shout at them and tell them to hurry up when you waiting for long. You must have patience too. They give me tablets or injections and they always ask how you are and they show care for a person.*

**Gwen**

*At the hospital where I go to, we are not seen to with other people who are not HIV – positive. So when you go there, it's like: "Hi, how are you doing?" we are able to just talk about everything. Like someone will say: "Are you coming to do another CD4 count?" or something like that. we can just talk about it. You don't mind going to the hospital because all the people you meet there have the virus. The doctors and nurses treat us well too. They care. They want to know: "How are the tablets treating you?" How are you eating?" They ask you all these questions. They show us a lot of concern and support.*

**Violet**

*At the clinic I go to they have never been horrible to me. They don't say bad things to me because I'm positive. They treat you okay always. They even ask me how am I feeling and how the tablets are helping me. They are so nice, they even give us bread and tea or coffee. They say: "We know that some of you have no food at home. Take even two slices of bread and eat with your tea." They know that we leave home early in the morning and we have no time to eat before taking our tablets. I'm very happy with the way we are treated there. When I go to the hospital, it's the same thing. They are not prejudice and all that. We all got the virus, that's why we all attend that hospital, it's the same thing. That's why it is so good because we are all the same. When you go there and you talk you can see that it's not just you the tablets are affecting, its others too. The doctors and nurses are very nice and caring too. They always ask about us and how we are doing.*

## The Church: Spirituality

The following data emerged in this regard:

### **Lillian**

*We have a support group at our church and they are very supportive there... We do visitations to bring new members into the group... When we visit people we don't act like we are coming to tell them that we know they are HIV-positive or act like we have an AIDS centre and we want them to come and visit and all that. No. We go and we give them our testimonies. And we tell them about our lives,*

*what God did through us. How we could have also been dead too as well. But by the grace of God we are still living...Because we believe we've got to have God in our lives too so we can live positively... I do volunteer work for the church. I go around counselling people and praying for them and their problems. I think my testimony, that's what makes me strong everyday...Sometimes when we go through things we want to sit back and feel sorry for ourselves. We want to sit back and wait for things to happen. We can't wait for things to happen, we got to make things happen...But I feel that's my purpose, that's my calling. That's the work that I'm supposed to do. That was my desire when I was growing up, to reach out to people and to teach children...That's what really keeps me strong. And my husband doesn't like me to walk around too much and do home visitations because he feels that I'm tiring myself. But I feel that's my purpose, that's my calling. That's the work that I'm supposed to do. That was my desire when I was growing up, to reach out to people and to teach children. I have got such a soft heart. I cry very quickly, but I love working with people. Even though it's tough because you get some difficult people. I think that if I'm gonna sit back, I'm giving the devil an opportunity. That's what really keeps me strong.*

### **Whitney**

*I am actually closer to God now. I don't just go out and do my own thing any more, like I used to before. People tell me, that I look nice now, especially when I'm carrying my Bible. My Bible helps me a lot. I don't associate with the people I used to, the wrong company I mean. I rather sit and read the Bible. I'm not sad*

*anymore. I know it was my mistakes, my season. We all have a season to go through what we have to go through. God knows why I have to go through this. I have so much hope now since going to the support group at our church. I feel like I can be healed. I don't feel sick all the time like before. Before I was very, very weak, my bones were like breaking. When I came here to the church support group, the prayer just put me right because I'm well now. By the time I saw the doctor again, there was nothing wrong with my bones anymore, so the prayer really worked. The prayer that they do really worked. The prayer that they do here is really powerful. I've been feeling much stronger. This group has made me feel much stronger and hopeful too.*

### **Marianne**

*The man in charge of the church support group started coming to visit me. That time I was very sick. I had a rash all over. I couldn't even walk that time. I had terrible sores full on my body. So they came in and prayed for me. They asked me if I would like to come to the church support group. I said: "Ya, I want to." I started and carried on going and God has healed me. I became strong and all that after they prayed for me. God was there for me at all times. I feel I have more hope now since I belong to the support group. I'm not too scared like before.*

### **Gwen**

*Our support group is a church run group. It's not like other support groups. It's more about God and putting your faith in God...That makes me more*

*stronger...Even your thinking is better. You don't see just around here, you see beyond. You see everything. You see the day you gonna be married. Belonging to this group and to God makes you want to live now. Before you just thought about how you were going to die. You just thought: "I won't be somebody's wife or grandmother." You used to think of things that make you feel down. Now I really have seen beyond just here. I've seen possibilities. I have a lot of hope now.*

### **Violet**

*Ever since coming to church and the support group. I have more hope, really. It's like a second chance. I never knew that God can give you a second chance. Because the way I was sick. I was worse off than my cousin that died of AIDS. I don't know what I can say to tell you how bad I looked and how sick I was. Everything was just on top of me. I had sores in my mouth and I had strangles and boils and my hair was thinning out. But today, I'm living like all the ordinary people. There's nothing that say I'm living like all the ordinary people. There's nothing that says I'm HIV-positive. I'm not sick in the bed. I do the same job they do. I even told my aunty that I want to go and look for a job. Even if I die today, I'll die a happy woman because God provides for the birds then why can't he provide for my children. I see things very differently now.*

In the next chapter, I present the discussion on the findings of my study.

## **Discussion**

In this chapter, I present the discussion on the data generated from my study. The discussion is presented in themes, namely, (1) social backgrounds, (2) information about HIV/AIDS, (3) gender identity, (4) disclosing seropositivity, (5) social support systems.

### **1. Socio-Economic Backgrounds**

In describing their family backgrounds, all participants made reference to extreme poverty, parental substance abuse and a general lack of familial cohesion.

Marianne

*I grew up in a bad way, [I had a] hard life and all that. My mother was an alcoholic and even my father, so my aunty had to look after us. My father's sister she grew us up. We were all living in one flat, my cousins, my sisters and me. There were ten of us living in a two bedrooms flat. Some of us used to sleep in the lounge on the floor. When we were growing up and we asked for something, all you used to hear was: "I haven't got money!" that's why I say we had a tough life. I never ever stayed with my two parents. My mother was this side, my father was this [that] side.*

Economic deprivation, coupled with emotional impoverishment seems to be a common thread. The findings in this regard are in agreement with previous research (Herbert

1974:126) which has indicated that distorted intra-familial relationships involving a lack of affection and dissension negatively impact children's dispositions and future behaviours.

The participant's accounts of schooling further emphasized the economic deprivation experienced by these families. Consider the comments below:

Lillian

*I had to leave school at an early age because we used to go to school with no food. We come back from school there is no food, the house is dirty, we go to school with no shoes, [and] torn uniforms, there is no lights in the house and so we really had a hard time growing up. So I thought to myself, how can you go to school with no food, you can't think properly, you are not eating, [so] you [are] stealing the children's lunches, [and] you getting a hiding now because you stealing the lunches and stuff like that. So I got tired of school, and I left school in standard five.*

Whitney

*I used to go to school without combing my hair because we had no comb and I couldn't afford school shoes so I went barefoot. My clothes were not ironed because we had no iron. My teacher used to say: "This child is raw!" But that time I had absolutely nothing. How can you keep going to school when you got nothing?*

The link between HIV/AIDS, poor socio-economic backgrounds (resembling those indicated by the narratives of my participants), and low levels of education has long been recognised. Children who drop out of school are more likely to: engage in sex at a young age; consume alcohol earlier and become infected with HIV (Department of Education 2003). Research has established that girls, who exit the school system very early, are three times more likely to contract HIV than their peers who remained in school. (Kelly 2002; Department of Education 2003).

Walker et al. (2004: 87) contend that economic and social marginalisation predisposes individuals to HIV and that in the context of these individuals; HIV/AIDS is in fact an illness “waiting to happen.” Findings of this study underline the relationship between poverty and HIV/AIDS, highlighted by Walker et al (2004) and other HIV/AIDS literature (O’ Sullivan 2000; Collins & Rau 2000; Tharao & Massaquoi 2001) which conforms to this argument.

## **2. Information about HIV/AIDS**

All five participants mentioned that they had acquired the HI virus sexually. This theme focuses on participants’ knowledge and perceptions about sexuality, reproductive health and the sexual transmission of HIV/AIDS. I have chosen to explore participants’ knowledge base about sex and sexuality since these issues are directly linked to the sexual transmission of HIV. I also wanted to explore whether these findings conform to previous literature/research, which contends that open dialogue about sexuality and

sexual issues remain complex in many cultures, where, gender stereotypes continue to sanction the view that women should know very little, if anything, about sex (Abdool-Karim 1998; Houle 2003).

### Knowledge about sexuality and reproductive health

The women in this study indicated that neither their parents nor teachers had discussed sex or sexuality with them. For example, look at what Violet and Marianne stated:

Violet

*Nobody spoke about it at home. They say you learn by your instincts. You learn sex from the boys, they teach you because they always know about sexual things. My aunty who brought us up had no time to talk to us about anything like our bodies or menstruation and all that.*

Marianne

*Your parents don't have time to discuss things like that. My aunty used to look after us but she didn't talk about sex to us also. She was very busy working and making sure that we went to school. At school there was no time for talking about such things because those are not wonderful topics especially for girls.*

The findings above are synonymous with the literature (Abdool-Karim 1998; Gertholtz & Richter 2002) which depicts the ways in which the gender norms for women inhibit women and girls' access to relevant information about sex and sexuality, and consequentially, their predisposition to the risk of HIV.

Many people do not welcome the idea of sex education in schools and argue that it is the parents' responsibility to educate their children about sex (Houle 2003: 73). On the other hand, many parents do not discuss sex or sexuality with their children.

Violet's comment above brings sharply into focus the reality (emphasized in Chapter one) that HIV/AIDS, is about social ideas and social patterns of behaviour and not only a battle about bodies, organisms and cells. The gender norms for women's socialisation around issues of sexuality and sex greatly inhibit their access to sexual knowledge while the norms of masculinity on the other hand, dictate that men be the authority on the subject of sex and sexuality, with much more sexual experience than women (Gertholtz & Richter 2002; Abdool-Karim 1998). Women and girls' sustained limited access to information about sex and sexuality is absurd in view of the fact, that women constitute the majority of people living with HIV/AIDS (Tharao & Massaquoi 2001; EngenderHealth 2004) and, that it is this lack of access to essential information that has predisposed many women and girls to the risk of acquiring HIV.

Cohen (1993: 5) insists that poverty is not only linked to a feeble endowment of human and fiscal resources but also to low levels of education, with associated low levels of literacy." It is hardly surprising that all participants displayed a lack of specific knowledge about HIV. For example, look at what Whitney and Lillian had to say:

Whitney

*I didn't know anything about HIV and AIDS at this time. We never ever spoke about it. My family didn't think it was something to talk about. I don't think they knew the story about this thing either. I can't really tell you anything about it because I only had it for four months now.*

Lillian

*They said to me, you know you are HIV – positive? I sat there in shock now. You say HIV. I'm trying to think now: "What is this thing and how did I get this thing now?" Because they were saying sexually you can get it. So I sat there shocked and I started asking them all kinds of questions. Now when I sit back and I think about how I was infected, it was because of a lack of knowledge. I didn't know about this thing. I didn't know about this virus. I didn't know how to prevent [protect] myself.*

A good understanding of the medical facts about HIV/AIDS is extremely essential and empowering since a deeper understanding of the virus and how it is formed and multiplied in the cells of the body, is pivotal in prevention initiatives.

Marianne's declaration below mirrors another aspect of HIV/AIDS ignorance:

Marianne

*I understood about it. When we used to go to the clinic, they used to talk about it. I wasn't really like a sex person, you know. I only had one sexual boyfriend. I couldn't understand how I got it because I only had one sexual partner. I used to*

*tell him when we are having sex that he must use condoms but he would always say: "I trust you!"*

Despite the fact that Marianne was the only participant who claimed to have a prior (to her diagnosis) understanding of HIV/AIDS, her comments indicate a lack of specific knowledge. It seems that she believed that having one sexual partner would ensure her immunity to the virus. Similarly, confirming her own earlier lack of specific knowledge about HIV/AIDS, Mthembu (1998: 26) maintains that she did not expect to acquire the virus because she "was not sleeping around".

Four out of the five participants maintained that they had a lack of knowledge about HIV/AIDS prior to their acquisition. This lack of knowledge about a global pandemic that is more than twenty years old raises serious questions about awareness and prevention initiatives in this area and could be attributed to one or a combination of the following factors:

Participants may have had no access to media (newspapers, television), which is not unusual in instances of extreme poverty; they may have attended schools which did not engage in life orientation education (reproductive health and sexuality education) or they may have had some vague notion about HIV/AIDS and its fatalities but lacked specific information or motivation to regulate sexual behaviours to conform to non-risk behaviours. Whatever the reality in this regard, findings indicate both a limited knowledge of sexuality and reproductive health and a lack of specific knowledge about

HIV. Findings in this study parallel Houle's (2003: 67-74) argument that a lack of specific knowledge regarding HIV is a major contributor to the growth of the pandemic.

The association between HIV/AIDS knowledge deficiency, gender identity and transmission of HIV will be explored next.

### **3. Gender Identity**

The amalgamation of poverty and gender inequity has been identified as a powerful associate of high risk behaviour in the context of HIV transmission (Cohen 1993; Abdool-Karim 1998; Collins & Rau 2000; O' Sullivan 2000; Tharao & Massaquoi 2001). This is comparable to the circumstances indicated by the narratives below:

Whitney

*When my second boyfriend started staying with me, he kept hitting me and so one day, I decided to run away that's how all this nonsense of sleeping with other men started... I didn't know where to go, so I went to that place at Addington, near the security, where all the boys that smoke glue sleep... You know what it's like, it's either you sell yourself or you gonna die in the cold.*

Marianne

*At home when you ask for something, all you hear is: "I haven't got money!" So, what you're gonna do besides to get a boyfriend who can give you money?*

Data generated from this study parallels research (Cohen 1993; Abdool-Karim 1998; Walker et al. 2004), which has underlined the correlation between economic marginalisation, gender disparity and women's vulnerability to HIV.

All five participants acknowledged having sex as a result of coercive factors. This is comparable to studies conducted in KwaZulu-Natal (Walker et al 2004: 42). The study explored women's various motivations for engaging in sex. Data indicated that women in poor economic contexts used sex to obtain basic necessities and also to acquire a range of commodities. Findings indicated that many women were economically vulnerable, needed to use sex as a resource and that women who are economically dependent on their boyfriends, tend to choose boyfriends who will be able to meet this need, considerations of other qualities like fidelity, respect and freedom of choice. Providing the men can give them some economic stability, the women will maintain sexual relationships with them.

Whitney's statement above, about her experience of gender-based violence, further underlines the interconnection between unequal power distribution (between men and women) and women's greater pre-disposition to HIV. It was as a result of constant beatings from her boyfriend that she ran away from home, lived on the street, used sex as a resource and contracted the virus. It is worth quoting O'Sullivan (2000: 25) once again, who argues: "Until women have more control over their lives, they will remain vulnerable to HIV infection."

#### **4. Disclosing seropositivity**

My decision to explore issues of disclosure had a two-fold purpose: To establish whether the findings in my study would conform to previous literature/research ( Mthembu 1998; UNAIDS 2001; Collymore 2002), which identify HIV/AIDS stigma as a common theme in the lives of HIV-positive individuals particularly women. Secondly findings could help to educate the general society as well as HIV/AIDS care givers and support providers about the kind of attitudes and behaviour (related to disclosure) that HIV-positive people find constructive.

HIV/AIDS stigma has been a common theme in the lives of HIV-positive individuals. Research (Mthembu 1998; Aggleton 2002; Abdool-Karrim 2004) shows that many women experience great difficulty in disclosing their serostatus. All my participants admitted to an initial apprehension to disclosing their serostatus. Consider the comments below:

Gwen

*I was very scared to tell them that I was HIV-positive. You know with your friends and family you sometimes share things like maybe an apple, you share things. I felt I would be rejected.*

Marianne

*I took time to tell my family because I was scared, I didn't know how they were gonna feel. They were gonna feel bad. Maybe they wouldn't love me any more.*

Violet

*I didn't tell my family for five months. I was so scared to tell them that I was HIV-positive. I thought that they would say that I deserved the HIV. I was scared they would chase me out of the house if I told them and I would have nowhere to go.*

Research (Mthembu 1998; UNAIDS 2001; UNICEF 2001; Aggleton 2002; Francis 2003) indicates that negative responses to people, particularly women with HIV/AIDS (Tallis 2000: 59) have been a universal reaction to the pandemic. Many women, by virtue of their disclosure, risk violence, abandonment, neglect, destitution and ostracism from the family and community (Tallis 2000: 59). Four of the five participants verbalised their fear of being treated poorly as a result of their disclosure.

The stigma and discrimination that has been so much a part of the story of HIV, and the silence invoked by such stigma, have been and in certain contexts, remain major barriers to prevention, treatment, care and support initiatives. This is articulated by Violet and Whitney.

Violet

*My cousin too died of AIDS nobody knew. She could have had treatment and lived longer if it wasn't made a secret to herself only.*

Whitney

*My sister just got more and more thin. She was withering away and we did not know why. She kept it to herself. She never told anyone until only when she died. She just stayed indoors without going anywhere. If we knew about it we could maybe have taken her for help and for multivitamins to help her immune system.*

The stigma and discrimination which has become synonymous with HIV has greatly impeded efforts to provide care, support and treatment for people living with HIV. As indicated in the accounts above, some women would rather die, keeping their serostatus a secret than to disclose their status and risk being treated poorly because of it.

Four out of the five participants in this study experienced negative responses from loved ones at the outset of their disclosure. Look at the participant's narratives in this regard.

Violet

*It was hard because my brother-in-law, he thought I was gonna give his children the virus. And one day I cried and I told him: "You know, I'm staying here. You don't want me to cook food anymore. You always call someone else to make you tea or dish up food for you even if I can, what's so wrong with me?"*

Whitney

*One day we went to a funeral and we were having a beer. My brother said to his wife: "Don't give Whitney my beer to drink!" So his wife said: "Why?" he said: "Ooh, she's got that thing!"*

The negative behaviour that characterised the early responses of participant's family members, parallel some of those found in other research ( Mthembu 1998; Aggleton 2000; Francis 2003, 2004). However, data generated from my study also suggests that the negative responses displayed initially by family members, emanated from a lack of specific knowledge about HIV rather than an intention to be discriminative or unsupportive. The findings of my study indicate that negative responses were withdrawn after participants had highlighted and discussed these with family members and friends. Participants then reportedly, experienced a shift in responses of family, friends and other members of the community. These responses will be explored next.

#### Whitney

*My friends are very sympathetic towards me. They're also very supportive. They're always telling me that I must look after myself, I mustn't worry. One thing I've friends that won't go from one to the other to talk. If I didn't tell you, the other one won't come and tell you. They like that [They are like that] because they all love me the same. At home everybody is okay with me, even my neighbours. My neighbours and my cousins all know and we discuss my HIV openly. They treat me with respect not like I am unhealthy and they are going to get sick from me.*

Participant's comments about the impact of various responses encountered from loved ones, indicate, that expressions of affirmation and emotional support from loved ones, are highly valued as a resource in their (participant's) battle against HIV. The findings of my study depict a shift from unconstructive to constructive responses and differ from many other research reports (Mthembu 1998; UNAIDS 200; Aggleton 2002; Francis 2003 ) where responses to seropositive status has been predominantly characterised by stigma and discrimination. Whilst four out of the five participants initially experienced some kind of stigma and discrimination from loved ones, this negative, unsupportive behaviour did not become established but evolved and was transformed into constructive, helpful responses to participants.

In many ways, what my five participant's stories bring to the fore is that perhaps, there is a shift in HIV related stigma and its associated prejudice and discrimination. The constructive and helpful responses from family, friends and community, in the contexts of the five participants, are indicative of a new response to HIV/AIDS. Earlier literature (Mthembu 1998; UNAIDS 2001; Aggleton 2002; Francis 2003) has depicted an initial response to HIV which was founded on fear and ignorance.

However, television programmes, movies and dramatisations of the experiences of people living with HIV/AIDS have served to create an awareness of HIV/AIDS- related stigma by putting a human face to the pandemic. Community leaders, politicians and prominent figures such as Nelson Mandela, Archbishop, Desmond Tutu and Magic Johnson (famous

American ex-basketball player), have also helped decrease the prevalence of HIV- related stigma, encouraging acceptance, compassion and understanding of people living with HIV/AIDS. School interventions such as HIV/AIDS education has also contributed to a reduction of stigma by challenging attitudes that were mainly based on misinformation and stereotypes.

## **5. Social Support Systems**

The link between social support and psychological well-being is inextricable. Not only do seropositive people require informal support from family and friends, they also require and benefit greatly from support given by institutions in the community. The data and discussions that constitute this section, attest to this contention and will be discussed in two categories namely, (1) clinics and hospitals, (2) the church and spirituality.

### Clinics and hospitals

Gwen

*You don't mind going to the hospital because all the people you meet there have the virus. The doctors and nurses treat us well too. They care. They want to know: "How are the tablets treating you?" How are you eating?" They ask you all these questions. They show us a lot of concern and support.*

Violet

*At the clinic I go to they have never been horrible to me. They don't say bad things to me because I'm positive. They treat you okay always. They even ask me how am I feeling and how the tablets are helping me. They are so nice, they even give us bread and tea or coffee. The doctors and nurses are very nice and caring too. They always ask about us and how we are doing.*

Seropositive people need both active care and emotional support. In the cases of the five participants, family and friends are not capable of meeting all these needs. As attested to above, the social support proffered by the hospitals and clinics, represent an invaluable source of comfort, social and practical support. The medical staff's demonstrations of genuine concern and in Violet's case, provision of nourishment are qualities that appear to be highly appreciated by participants. It would appear that the challenges imposed by HIV/AIDS are being aptly addressed by many nurses and doctors in local clinics and hospitals, particularly with regard to emotional support of seropositive people. Apparently, these findings are not a replication of previous studies which indicated that seropositive people were treated poorly by medical staff (Tharoa Massaquoi 2001; Francis 2004; Mthembu 1998). There appears to be a transformation since previous studies, at least, in the contexts of these ladies. The medical community appear to be providing the support and care which was missing from earlier contexts of HIV- positive women, as reported by (Mthembu 1998; Tharoa and Massaquoi 2001; Aggleton 2002; Francis 2004). It must be highlighted that this deduction about the shift in stigma is made in response to data received in this study and with regard to the clinics and hospitals attended by participants of this study.

## The Church and Spirituality

The spiritual dimension of an individual's life encompasses their beliefs, values and what gives meaning to their lives. Spirituality is an important aspect of life both during health and illness and an individual's belief or value system can have a crucial impact on their understanding or view of illness and treatment (Anderson 2000: 38). The participants in this study all identified the church and spirituality as an important resource of strength, hope and positivity.

Lillian

*We have a support group at our church and they are very supportive there...We do visitations to bring new members into the group... When we visit people we don't act like we are coming to tell them that we know they are HIV-positive or act like we have an AIDS centre and we want them to come and visit and all that. No. We go and we give them our testimonies. And we tell them about our lives, what God did through us. How we could have also been dead too as well. But by the grace of God we are still living...Because we believe we've got to have God in our lives too so we can live positively... I do volunteer work for the church. I go around counselling people and praying for them and their problems. I think my testimony, that's what makes me strong everyday...Sometimes when we go through things we want to sit back and feel sorry for ourselves. We want to sit back and wait for things to happen. We can't wait for things to*

*happen, we got to make things happen...But I feel that's my purpose, that's my calling. That's the work that I'm supposed to do. That was my desire when I was growing up, to reach out to people and to teach children...That's what really keeps me strong.*

Gwen

*Our support group is a church run group. It's not like other support groups. It's more about God and putting your faith in God...That makes me more stronger...Even your thinking is better. You don't see just around here, you see beyond. You see everything. You see the day you gonna be married. Belonging to this group and to God makes you want to live now. Before you just thought about how you were going to die. You just thought: "I won't be somebody's wife or grandmother." You used to think of things that make you feel down. Now I really have seen beyond just here. I've seen possibilities. I have a lot of hope now.*

The sense of isolation which is often portrayed in HIV literature, as a part of the lives of seropositive people, seems to have been assuaged by the social support provided by the family, health institutions and church support group. These women seem to be replacing the common images of HIV-positive women as fearful, hopeless victims of HIV with new representations of brave, resilient, hopeful, strong women who have not only learned to accept their serostatus, but who are willing and able to share this strength and hope with other HIV-positive people.

Just like Promise Mthembu (1998), a South African woman who chose to become a victor of HIV/AIDS rather than a victim, the participants in this study all appear to be champions and not casualties as is so often assumed or anticipated of HIV- positive people. It has been said that adversity causes some people to break and others to break records. This certainly seems to be the case with the participants of my study.

Whilst the findings of this study allow us insight into some of the personal journeys of HIV-positive women and highlight the some of the problems that women and more particularly, HIV-positive women have to contend with, their stories also remind us of the resilience of the human spirit.

The next chapter presents the conclusions, recommendations and guidelines.

## **Conclusion, Guidelines and Recommendations**

The heart of my research was: to explore the experiences of women living with HIV/AIDS in Wentworth, an area characterised by high levels of socio-economic deprivation; to explore reasons why their experiences were conducted in particular ways and to use this information to formulate guidelines and recommendations for schools, on how to support women living with HIV/AIDS and their affected children, more effectively.

In exploring the experiences of the women in this study, I have emphasized my allegiance to the credence that an individual's life world experiences cannot be extricated from their socio-economic environments and in fact, are shaped by these environments. I have attempted to disclose this credibility by: employing the life course research approach, where one learns from hearing and studying what participants say and do; reviewing a range of relevant literature review; organizing data generated into themes; engaging in discussions intended to elucidate these themes. The following findings emanated from this study:

- ⚡ All participants indicated that their parents and/or other adult guardians and teachers had never discussed reproductive health or sexuality with them. They 'picked up' an education from friends or through 'practice'. It was argued that the gender norms for femininity which often, mean that women and girls are not

supposed to be conversant about sex and sexuality predispose them to the risk of HIV.

- ✘ Major distortions characterised the early family lives of the five participants of my study. Acute economic deprivation, coupled with emotional impoverishment represents a common thread.
- ✘ The poor socio-economic conditions, low levels of education, lack of deeper understanding of reproductive health and a lack of specific HIV/AIDS knowledge attested to by participants, predisposed them to high levels of vulnerability to HIV/AIDS.
- ✘ Participant's divulged lack of knowledge, of a global pandemic that is more than twenty years old, raises serious questions about the effectivity and efficiency of awareness and prevention initiatives in this community.
- ✘ All the participants had acquired the virus sexually. In describing modes of transmission, participants listed factors such as: silence about HIV status; fear of stigma and sex for economic survival, as reasons for transmission of the virus.
- ✘ All the women in this study had sexual relationships which had evolved from coercive factors. The vulnerability of women to HIV/AIDS as being centrally related to the context of their lives within a patriarchal society was underlined.

- ⓧ The negative and unconstructive behaviours initially encountered were reportedly withdrawn after participants had highlighted and discussed these with family members.
- ⓧ The findings of this study indicate that emotional support of seropositive people is a key feature in local clinics and hospitals attended by my participants.
- ⓧ This study illustrates a possible shift in HIV/AIDS related stigma and discrimination, reported in earlier studies (Mthembu 1998, Tharoa and Massaquoi 2001, Aggleton 2002; Francis 2004). This shift may be attributed to a heightened awareness of the negative impacts of HIV- related stigma
- ⓧ Wentworth has a reputation for elevated incidences of social problems (Jones 1998; Scott and Ridsdale 1997). The data generated in my study indicates a shift in the context of Wentworth, from a context characterised by major social struggles, to a context of caring, tolerance and compassion.
- ⓧ The participants in this study all identified spiritually as an important resource of strength, hope and positivity.

✶ The five women seem to be replacing the stereotypical image of HIV-positive women as fearful, hopeless victims of HIV with new representations of brave, resilient, hopeful, strong women who have not only learned to accept their serostatus, but who are willing and able to share this strength and hope with other HIV-positive people.

Based on the findings of this study, the following guidelines/ recommendations can be offered:

Findings in this study highlight the importance of being more accepting and non-judgemental of people living with HIV. Up scaling of programmes which introduce structures, procedures and processes and behaviours for including HIV-positive individuals in society and in every aspect of societal life, are critical in ensuring that all HIV-positive individuals do not stick out like “sore thumbs” in our society. The school, which is a microcosm of society and has the task of inculcating in children the norms and values of society and of providing a holistic education for society’s youth, is obligated to be a forerunner in this regard.

Understanding, compassion, care, empathy and love are crucial to the psychological wellbeing of HIV-positive people and their families. The social disruption that HIV introduces into the lives of PWA also characterises the lives of their children. The support of the school, specifically the role of educators, could become a crucial coping resource.

A preliminary point must be educators' acknowledgement of the fact that education in a world of HIV has drastically altered the role of educators and the education sector (Hepburn 2002:94), particularly in regard to vulnerable children.

Schools also need to partner with NGOs and CBOs to address the adversity and challenges that are experienced by learners who are either HIV-positive or affected. Programmes that run along a continuum from prevention to care should be established.

The high drop out rate of young adolescents is a critical factor that needs to be addressed. Children who drop out of school early are more likely to have sex at a young age, drink alcohol earlier and become infected with HIV (Department of Education 2003: 6). It is imperative that the education sector explore techniques to enable children, especially girls to access education to secondary level and beyond as this will help provide a more effective defence against poverty and consequentially against HIV contraction (Kelly 2002: 3). Every school should have an HIV/AIDS policy and programme, underpinned by consistent, coherent HIV/AIDS related activities to combat ignorance, stigma and discrimination and to alleviate the impact of HIV on affected learners.

The school also has a crucial role to play in educating young adolescents about assertiveness, peer- pressure, decision making and problem solving in order to equip them to negotiate safe choices and thus assist them in the prevention of the contraction of STDs and HIV. Furthermore, the school is an important source of information for

addressing and transforming the gender inequity and gender- based violence that fuels HIV transmission.

## **Conclusion**

This thesis has explored the experiences of five women living with HIV/AIDS in the community of Wentworth, a largely impoverished, working class community, characterised by low income and high unemployment levels, which have over the years also contributed to it developing a notorious reputation for high incidents of social problems, a major one of which is the proliferation of HIV/AIDS.

This thesis highlights the ways in which social settings mould the experiences of individuals. This story of women and HIV/AIDS underlines the ways in which the social and economic marginalisation of certain groups of individuals has predisposed them to the virus and brings sharply into focus, the fact that HIV/AIDS is not just a health issue but a larger social issue.

## **Suggestions for Further Studies**

-  The small sample size and the fact that all participants belong to the same church organisation may limit the generalisability of the findings. Perhaps a comparative study could be conducted which includes participants from a collection of communities and of varying religious persuasions.

- ✂ Secondly, only the perspectives of the five HIV-positive women in this study were assessed with regard to the various themes highlighted in this study. Research which explores the perception of family members, health care workers, educators and other network members, would provide a valuable supplement to the data gleaned from this study.
  
- ✂ Three of the five participants indicated that they had lost family members to the pandemic. Further studies could explore the impact of: having multiple HIV-positive members in one family or the impact of multiple losses to HIV, on affected members of the family, specifically school children.

## **Reflection**

My research has not only greatly evolved and altered my view of the HIV/AIDS pandemic but it has also broadened my concept of life. I am deeply grateful to the women in the community of Wentworth, who trusted me enough to share their personal journeys (about living with HIV/AIDS) with me. Through their participation in my research, they have given me greater insight into the lives of not only individuals, who are HIV-positive, but also the impact on society, friends and family, most especially on their children. As an educator, the impact on the children is a key issue of concern for me.

Many children are living in households with an HIV-positive family member who may be very ill. These children then have to take on the responsibility of caring for sick parents and generating an income for food and other necessities. This script has serious implications for the education sector.

I have seen and heard some educators act as if HIV/AIDS is not their problem. Sadly, this kind of attitude is indicative of ignorance and a lack of empathy. As educators we are morally and professionally obligated to address the challenges of HIV/AIDS at school and at community level, in tangible ways. It is worth quoting our ex-state president, Nelson Mandela: “There is no keener revelation of a society’s soul than the way in which it treats it’s children.”

## **INFORMED CONSENT FORM**

### **Living with HIV**

Dear Participant

My name is Anastasia Johnson. I am a student at the University of KwaZulu-Natal. I am currently engaged in completing my M. Ed degree. As part of my degree, I have designed a research study to explore the experiences of women living with HIV/AIDS in the Wentworth area. The study is being conducted under the supervision of Dr. Dennis Francis. Should you have any queries, you are welcome to contact him telephonically at (031) 2603490. Your participation in this study will help by creating a better understanding of the experiences of women living with HIV/AIDS in this area. Please consider the following:

- ✓ As part of the study, I am going to ask you some personal questions. Your answers will remain totally confidential. Whilst the information you provide during these interviews will be included/used in my thesis, your name and the names of the people you mention, will not be used in connection with any of this information. Your identity will remain anonymous.
- ✓ The questions will be divided into two interview sessions. Each session will last approximately 90 minutes and will be tape-recorded.
- ✓ You do not have to answer any questions you do not wish to answer and you may end the interview at any time you wish to. However, I will greatly appreciate your total contribution since this will give me insight and help me to understand your unique experiences as a woman living with HIV/AIDS.
- ✓ You may ask to listen to the audio-tapes or view the transcripts at any time. However, these will remain my property.

Would you be willing to participate? Yes/No \_\_\_\_\_

I, \_\_\_\_\_ have read the above statements and do hereby agree to participate in this study of my own free will and under the conditions set out above.

\_\_\_\_\_

Participant's Signature

\_\_\_\_\_

Date

\_\_\_\_\_

Researcher's Signature

\_\_\_\_\_

Date

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