

**An insight into the experiences of
educators living with HIV/AIDS in the
context of schooling and beyond**

By

Indrashnee Devi Appalsamy

**Dissertation submitted in fulfillment of the requirements for the
degree**

Doctor of Education

In the School of Education Studies

University of KwaZulu Natal

Promoters: Professor R Sookrajh and Dr S Reddy

2010

ABSTRACT

South Africa has a severe HIV/AIDS epidemic and the majority of the people infected are in the economically active age group. The education sector is particularly affected by HIV/AIDS because both the demand for and supply of educators are affected. Women make up a great majority of the teaching fraternity and their vulnerability to HIV and AIDS will be discussed

The focus of this study is on educators living with HIV and AIDS in the province of Kwa-Zulu Natal in South Africa. Educators are perceived as 'icons of morality' hence their difficulty in disclosing their HIV status. This study offers an insight into the lives of the educators in this study, and explores how educators managed their lives and the disease on a daily basis at home and in particular at school. The participants for this study were obtained through convenience sampling given the sensitive nature of the study.

Through the use of a life-story approach, all five participants, (current and previous) are educators and were interviewed over a period of time. Focus group discussions were also done in selected areas with school management teams (SMTs), to ascertain attitudes towards and support for educators living with HIV.

During these many interviews with my research participants, I listened to their life experiences, felt their grief and trauma, and really understood their feelings of hopelessness. During these interactions, I was able to gather first hand information on the plight of educators living with HIV and AIDS, their voices spoke of their psychological emotions, and this confirmed that the general public and more especially the school fraternity needed to be educated about the disease, in order to dispel the myths and stigma surrounding HIV and AIDS. The grounded theory approach was used to analyse the data collected. Apart from the analysis of data, the life story interview of each participant is included in this thesis. The lack of support and the secrecy that has become imperative on issues around HIV and AIDS has brought about un-savory labels

like 'us' and 'them.' The data also emphasized the importance of schools and the school community to work together in order to manage HIV and AIDS. The adherence and effectiveness of school policies concerning HIV and AIDS in terms of the constitution are also discussed.

In conclusion the voices in this thesis have highlighted the importance of HIV/AIDS empowerment and support, individual empowerment equals the antithesis of vulnerability. HIV/AIDS can be looked upon as a serious chronic ailment which can be handled with medication and a safe healthy lifestyle, with the express hope of keeping our educators in the classroom in a good state of health for longer.

LIST OF TABLES

Table 2.1. HIV/AIDS Statistics, a comparison between years 2005-2007	24
Table 2.3. HIV/AIDS Prevalence among educators by province in South Africa-2004	33
Table 4.1 Sample of Participants in this Study	112
Table 5.1 Representation of Participants Profiles	118

LIST OF FIGURES

Figure 2.1 Adults and children estimated to be living with HIV in 2005	22
Figure 2.2 Estimated number of people living with HIV globally between 1990-2007	23
Figure 2.3 HIV prevalence among 15-49 year olds by province, South Africa	26
Figure 5.1 Map of KwaZulu Natal showing residences of Participants	120
Figure 5.2 Physical Phases of HIV Infection	126
Figure 6.1 Relationship between HIV/AIDS and pre-existing sources of stigma Discrimination	211
Figure 6.2 Stigma's vicious cycle	213
Figure 6.3 Dilemma of the HIV-positive person illustrating non-disclosure	223
Figure 6.4 Dilemma of the HIV-positive person illustrating disclosure	224

TABLE OF CONTENTS

CHAPTER ONE

A Scan through this Thesis

1.1 Introduction	1
1.2 Rationale	2
1.3 Objective and Need for this Study	4
1.4 HIV Surveillance	7
1.5 Surveying the intervention Terrain	9
1.6 The Epidemic at Work in the School Environment	10
1.7 Implications for Education	12
1.8 Research Approach	15
1.9 Chapter Outline	16
1.10 Conclusion	18

CHAPTER TWO

A Global glance on HIV/AIDS

2.1 Introduction	19
2.2 The Global Situation-HIV/AIDS	20
2.3 Sub-Saharan Africa's High Infection Rate	23
2.4 The Pandemic in South Africa	25
2.5 Women in this Pandemic	27

2.6 Government's Response	30
2.7 KwaZulu-Natal's Infection Rate	32
2.8 Impact on Education System	34
2.9 Conclusion	39

CHAPTER THREE

LITERATURE REVIEW- scanning the HIV/AIDS scenario

3.1 Introduction	40
3.2 HIV/AIDS impact on SOCIETY	41
3.2.1 Discussing HIV/AIDS through a Human Rights-Based Approach	43
3.3 Anthropological Issues	45
3.3.1 Gender and HIV	46
3.3.2 Gender Inequalities and Poverty	48
3.3.3 Gender Agenda	50
3.3.4 Traditional Cultural Practices in an HIV Climate	52
3.3.5 Gender, Education and HIV	56
3.3.6 Gender and Vulnerability	59
3.3.7 Undressing Stigma	61
3.3.7.1 A Social perspective on Stigma	62
3.3.7.2 Stigma promotes HIV and AIDS	63
3.3.7.3 Stigmatism and its relationship to Gender	63
3.3.7.4 Stigma makes the epidemic (HIV) Invisible	65
3.3.7.5 Identity Crisis and the HIV positive Women	66

3.3.7.6 Progression or Regression on the Stigma Senario	67
3.4 HIV/AIDS and Education	67
3.4.1 HIV and AIDS Infects and affects Education Systems in Africa	68
3.4.2 The Impact of HIV and AIDS on Education in South Africa	69
3.4.3 KwaZulu-Natal: the Epicentre	72
3.4.4 The Impact of HIV Positive Educators on Teaching and Learning	73
3.5. Looking at HIV/AIDS and Education through Political Lenses	75
3.5.1. Issues around Human Rights and HIV and AIDS	76
3.5.2. Implementation of HIV and AIDS Education Policies	77
3.6. Conclusion	78

Chapter Four

Methodology

Mapping out an Introspective Journey of Educators living with HIV and AIDS

4.1 Introduction	80
4.2 The use of Qualitative Research in Researching Sensitive Issues	81
4.3 Feminist Research within a Life Story Approach	83
4.4 Grounded Theory within a Life Story Research	85
4.5 The Life Story/Life History Story	91
4.6 Sampling Technique: Choosing Participants for Life Story/Life History	96
4.7 Strategies used for Data Collection	98

4.8 Conducting a Life Story Interview-The Interviewee	101
4.9 Data Analysis	104
4.10 Ethical Considerations	106
4.11 A Challenging Journey in search of Positive Participants	110
4.12 Validity in Life Story Research	113
4.13 Conclusion	113

Chapter Five

On Analysing Participant's Voices and Emotions

5.0 Preamble	115
5.1 Introduction	115
5.2 Representation of Findings	116
5.2.1 Participant's Profile, Biographical Data and Personal Information	116
5.2.2 Engaging with the Participants' Profiles	121
5.3 Emerging Analytical Framework of Phases and Themes	121
5.4 PART ONE: Phases of HIV and AIDS	124
5.4.1 Phase One-The Primary HIV Infection Phase	127
5.4.2 Phase Two-The Asymptomatic Latent/Silent Phase	128
5.4.3 Phase Three-The Minor Symptomatic Phase	128
5.4.4 Phase Four-Major Symptomatic Phase	129
5.4.5 Phase Five The Severe Symptomatic Phase	130
5.4.6 Conclusion to Part One	133

5.5 PART TWO: Participants' Emotional Experiences	134
5.5.1 Initial Psychological Anxieties after Diagnosis	135
5.5.1.1 Disclosure of Status	135
5.5.1.2 Anxiety, Fear and Anger	140
5.5.1.3 Shame	143
5.5.1.4 Depression and Stress	145
5.5.1.5 Secrecy	146
5.5.1.6 Denial	147
5.5.1.7 Vulnerability and Commitment	151
5.5.1.8 Issues of Morality	153
5.5.2 Further Psychological Anxieties	157
5.5.2.1 Conclusion	181
5.5.3 Recurring Psychological Anxieties and Concerns	181
5.5.4 Living with HIV in the Workplace: Impacts	182
5.5.5 Conclusion to Part Two	184
5.6 PART THREE	187
5.6.1 Departmental Support/Non-Support	187
5.6.2 Findings from Focus Group Discussions	188
5.6.3 Empower Management	195
5.6.4 Teacher Union Response on Educator Support	199
2.6.5 Summarising Focus Group Responses	200
5.6.6 Conclusion to Part Three	200
5.7 Conclusion	201

CHAPTER SIX

Emerging Insights and Conclusion

6.1 Introduction	202
6.2 Part One	203
6.2.1 Significance of Data	203
6.2.2 Testing Times in an attempt to Harness Stigma and Discrimination	205
6.2.3 HIV/AIDS in the context of Individualism and Universalism	217
6.2.4 Teacher Identity	219
6.2.5 Disclosure/Acceptance/Morality	220
6.2.6 Impacts of Denial, Depression, Labeling and Blame on the HIV positive Person	226
6.2.7 Coping Strategies	228
6.2.8 ‘Metaphorising’ the Illness	229
6.2.9 The Feminisation of HIV and the Vulnerability of Women	233
6.2.10 Policy Issues and the impact of HIV on Education	235
6.2.11 Male/Female Relationships	236
6.3 Part Two	
6.3.1 Emerging Insights	237
6.3.1.1 Behavioural Change/Personal Empowerment	237
6.3.1.2 Knowing Knowledge	238
6.3.1.3 Privileged Access	238
6.3.2 Conclusion	239

REFERENCES

APPENDICES

Appendix 1 Annaline's Story

Appendix 2 Ashwin's Story

Appendix 3 Delene's Story

Appendix 4 Siwina's Story

Appendix 5 Thandiwe's Story

Appendix 6 My journey in search of Participants

Appendix 7 Ethical Consent

Appendix 8 Impacting on our lives-words from the hearts of study participants

CHAPTER ONE

A Scan through this Thesis

1.1 Introduction

Access to education improves employment opportunities and income security. According to UNESCO (2006), the education system plays an important role in the economic development of the country, and educators are an integral part of this system. The ill health and deaths of educators due to HIV and AIDS poses a huge threat to economic development, because the education of learners will become compromised.

In rural areas, where schools depend heavily on a principal and two educators, the loss of an educator can deprive an entire class of learners of their schooling. Educators take on the responsibility of educating the youth with knowledge, skills and capacity to protect themselves against HIV and AIDS which is a prerequisite for turning the epidemic around. But as educators succumb to the virus and schooling deteriorates, the ideal venue for prevention programmes can be depleted.

Thus, HIV and AIDS have major implications for education systems, illness or death of an educator compromises curriculum delivery because learners are without an educator. The learners are not the only ones that suffer, but the whole education system becomes compromised. Illness of an educator results in absenteeism, prolonged absenteeism can be very disturbing to the proper functioning of the school. The emergence of HIV and AIDS has brought with it the waning of socio-economic progress by robbing communities and nations of their greatest wealth, their people, which in turn destroys their capacity for delivery and eventually their national wealth. Productive capacities are weakened when workers and managers fall prey to the virus, because of the dynamic and vicious nature of HIV and AIDS. Heywood (2004) contends that successful human development is diminishing as the epidemic is gaining foothold, especially in a climate of inequality and exclusion, because HIV and AIDS and negative development form a dynamic relationship, where one feeds the other. According to UNAIDS (2002), the

average life expectancy in sub-Saharan Africa is now 47 years, when it would have been 62 years without AIDS.

I believe educators are an integral and essential part of the education system and other related systems, HIV is affecting these systems. According to Heywood (2004), HIV has and is still having a huge impact on the health services which has a negative effect on society. He further adds that the rising rates of HIV infection among health workers leads to more absenteeism, reduced productivity and higher training and recruitment costs. He contends that access to treatment is not a human rights imperative only, but also prolongs a healthy life and enables HIV-positive people to remain in their jobs for a longer period, hence reducing the stigma and discrimination.

1.2 Rationale

The rationale for this study draws from different imperatives. The first is a personal interest as a educational trainer where I am required to give workshops to educators on HIV/AIDS. The HSRC (2005) contends that in the past 15 years, HIV and AIDS have moved from obscurity to one of the leading cause of mortality in the world. In my experience the subject of HIV and AIDS is a very sensitive one and is surrounded by a veil of secrecy. HIV and AIDS carries a stigma and infected educators are reluctant to talk about their HIV status. My interest in HIV arose after I had attended workshops on HIV and AIDS. There was much discussion (amongst and with educators) on the plight of HIV-positive individuals and on all aspects of the virus, but especially on the issues of disclosure and empowerment around HIV, because the topic of HIV is taboo in most communities. Educators at workshops also spoke about their uneasiness in discussing their HIV positive status because they either lacked the knowledge or the topic was too sensitive. As my interest intensified, I wanted to interact with educators who were living with HIV, to understand how they managed their HIV positive status, and their jobs as educators. This of course was in the context of the demanding nature of delivering an educational curriculum and managing their HIV positive status, which carries both huge stigma and discrimination.

Secondly, in view of my personal involvement with educators, I was interested in gaining insight into the experiences of educators who were HIV positive. Educators are seen as belonging to one of the most powerful institutions in any country, the education system, and as such they are entrusted with the responsibility of educating the children of the country (who are the future decision-makers and leaders). Educators are expected to display a moral high standing at all times. Thus, because of their profession, they tend to keep their status a secret for fear of stigma, discrimination and ostracisation. Educators are afraid to fall off the pedestal that the school communities put them on, and hence keep their HIV-positive status a secret.

Ignorance and fear underlie HIV-related stigma even in the case of teachers. An inadequate understanding of the modes of HIV transmission leads to fear of transmission from casual contact. This fear, combined with a better understanding of the deadliness of HIV, can lead to physical and social ostracisation of people living with HIV and AIDS and other forms of discrimination. Society often blames infected people for being ill and justifies discriminatory acts against them, while asserting the innocence and health of those who stigmatize.

Thirdly, the policy context within the ambit of education has been used as another rationale for conducting this study. Given the complexities of the HIV and AIDS attack on education systems, Kelly (2002) contends that education can no longer be “business as usual”, learning institutions in an HIV-infected world cannot be the same as those in an HIV-free world. He believes that HIV is a huge challenge and because of it the paradigm of education is shifting, in that schools have a bigger part to play in this pandemic. Schools are the ideal venues to disseminate knowledge about HIV and AIDS, the education sector has a special responsibility to all its stakeholders with regard to HIV and AIDS.

It is a general belief that if a person is HIV-positive, it is a death warrant. Thus people need to be empowered with the knowledge on how to manage the epidemic. In the absence of a medical cure for HIV and AIDS, educators are the next best people to

educate and empower learners and communities about the disease. These considerations spurred my interest in ascertaining to what extent the Department of Education in KwaZulu-Natal provides support and informational needs of educators who are HIV-positive. It is hoped that society at large (through the educators), the Department of Education and the infected/affected educators in particular will benefit from this study. Meaningful and sustainable educational needs cannot be fulfilled if the HIV and AIDS epidemic is allowed to drain education's human resources.

1.3 Objectives and Need for this Study

The objective of this study is to ascertain how educators living with HIV manage their positive status, deliver a curriculum in the classroom, and manage their lives beyond the school environment. Educators are looked upon as a means to develop the human resources of the nation, and their role does not include only the teaching of the curriculum but also that of shaping young minds to be worthy citizens. They are transmitters of values and are often looked upon as role models for learners to emulate. Second to parents, educators are powerful agents of change and growth in a learner's life. Strike (1988) believes that teachers are special and they serve as role models for impressionable young people. It is therefore incumbent on the school community and the Department of Education to support educators who are HIV-positive. This research will endeavour to investigate support for HIV-positive educators by trying to answer the primary critical question and the secondary questions that have shaped this study, namely:

1. What are the experiences of HIV-positive educators and how do they constitute themselves as educators within and beyond the school environment?

The following subquestions have been designed to assist in responding to the key question asked in the study:

1.1 To what extent and in what ways are they supported in the education system (by

colleagues, school community, and different levels of the Department of Education (DoE)?

1.2. What kinds of support do they see as suitable for the needs of HIV-positive educators?

Kelly's paper, *Preventing HIV transmission through education*, is based on a presentation to an International Policymakers Conference in New Delhi (11-12 May 2002). In this section Kelly is cited frequently as it is one of the most significant studies that emphasises the link between education and prevention programmes: "education is the only 'social vaccine' available against HIV infection". 'Social vaccine' could be synonymous to departmental support in the form of psychosocial support, medical support, counseling, didactic support, governance section support, and provision of temporary educator (substitute educator) support. Kelly writes extensively on teacher mortality and HIV/AIDS.

Kelly (2002) further adds that general statistics related to life expectancy, which are failing in many countries has widened the gap in comparison with developed countries. He contends that life expectancy had fallen to less than 40 years in Malawi, Botswana, Mozambique and Swaziland, while for the region as a whole it is 47 years compared with an estimated 66 years in the absence of HIV and AIDS. An average life span of 47 years for an HIV-positive educator is a huge cause for concern. Educators at this age are in the prime of their lives with many years of experience and expertise and an invaluable human resource both to education and to their families.

According to Kelly (2002), key social sectors such as health and education are affected by the epidemic both directly and indirectly. He believes that the HIV epidemic is eroding the capacity of the education sector, and the likelihood exists that the problem will worsen over the coming decade. Kelly (2002) argues that at the systemic level there are notable gaps in both knowledge and responsiveness:

- Data on the loss of human resources throughout the education sector are lacking.
- There is a lack of information concerning the level of absenteeism across the sector caused directly or indirectly by the epidemic at all levels of education and across skill and experience categories (teachers, assistants and administrative support).
- Valuable social investments are being lost due to HIV and AIDS. Capacity cannot be replaced through formal training alone, and the loss of experience and organizational capacity cannot be easily replaced in the face of premature deaths of senior teachers, teacher trainers and administrators.
- Many ministries of education in Sub-Sahara Africa seem to be primarily concerned with issues related to HIV prevention through curriculum reform, but do not seem to realise that whatever the merits of such activities, they have to be seen as secondary to sustaining sector capacity. If the capacity to teach is not maintained then over time the curriculum cannot be delivered.

Kelly (2000) observes that high teacher mortality rates have a serious impact on the future and quality of primary education, and that without professionally trained teachers it will be difficult to maintain high quality instruction and keep schools open. He adds that schools are often forced to combine learners from different grades into one classroom, and that while estimates of teacher mortality vary from country to country, a striking trend towards increased teacher HIV infection levels and mortality is emerging.

This study intends to find out what facilities (social, medical, financial, counseling) are in place to assist HIV-positive educators, because educators are an invaluable human resource and they need to be in the classroom to deliver the curriculum. Herek and Glunt (1988), and Mann (1987) are of the opinion that the HIV epidemic has been accompanied by fear, ignorance and denial, leading to stigmatization and discrimination against people with HIV and AIDS and their families, hence the reluctance by HIV-positive people, especially educators, to disclose their status and seek assistance.

Nyblade and Field (2000) contend that the fear of being identified with HIV has prevented people from learning their serostatus, changing unsafe behaviour and caring for people living with HIV. A study in Botswana and Zambia found that stigma and discrimination against HIV-positive people and fear of mistreatment prevented people from participating in voluntary counseling and testing (VCT) programmes to prevent mother-to-child transmission (MTCT).

Disclosure of an HIV-positive status is advocated, but acknowledged as difficult and unusual. It is therefore incumbent on all stakeholders to support HIV-positive educators in order for them to be in a comfortable frame of mind to deliver the curriculum, and this may be possible through support and empowerment in managing HIV.

Having explained the rationale for the study of HIV-positive educators and the intended outcomes of this study in the previous section, the following section will discuss other issues relevant to this study.

1.4 HIV Surveillance

The HIV epidemic is a slow, silent virus: it slowly destroys families and school systems, and changes the way schools work. Initially, only a few learners in a school were orphans and only a few educators were often ill, but over time more learners and educators succumbed to the disease, and these have added up to a considerable drain on the education system.

Everatt and Milner (1994) believe that the prevalence of HIV and AIDS is spreading, and if it is to be contained, education and action among South Africa's young workforce is necessary. They add that any national campaign dealing with South Africa's AIDS epidemic must have the young workforce as a major target group. They argue that the people with the greatest risk of becoming HIV positive are those in the sexually most active phases of the lives, i.e. the youth, and the working age population of South Africa. Everatt and Milner (1994) contend that to slow down the HIV incidence, 'safer sex'

practices have to be inculcated into the South African youth while their values and behaviour patterns are being formed. They are of the opinion that many adverse socio-economic realities facing black youth in South Africa make this difficult. Life for many people in South Africa is marked by poverty, unemployment, homelessness and grossly inadequate health or welfare facilities; all of which contribute to spreading HIV.

According to Sir Donald Acheson, Chief Medical Officer, Department of Health and Social Security, United Kingdom, in his address at the AIDS Prevention Conference (WHO, 1991), “if we are to succeed in slowing down or stopping the spread of this virus there has to be wide spread changes in human behaviour; dissemination of correct information as the key to changes in attitudes and behaviour, and the learning of new skills”.

In South Africa and even globally, increasing attention has been paid to the important role of education in preventing HIV infections. HIV is challenging the all important provision of education, as well as the quality of education. Attawell and Elder (2006) contend that whilst the impact of HIV and AIDS on education is recognised, there is the urgent need to expand efforts to address issues related to care and support of educators and learners infected and affected by HIV and AIDS. The prevalence of HIV infection amongst educators is alarmingly high, the Education Labour Relations Council (ELRC) report of 2005 has stated educator HIV prevalence to be 12.7 nationally. The participants in this study are from the province of KwaZulu Natal, the educator HIV prevalence in this province according to Hall et al (2005) is 21.8%. The increase in educator HIV prevalence is significant, the Mobile Task Team (MTT) (2005), report findings show an increase in teacher mortality from 7.9% in 1997/98 to 17.7% in 2003/04. according to this report, gross teacher mortality calculated on in-service deaths and on the number of post-service educators who died within the first year of resignation, is calculated to be 14,192 in this period. There is this growing fear of teacher shortage, and the National Policy Framework for Teacher Education and Development in South Africa (2007) acknowledges the contribution of HIV and AIDS to the ‘impending shortage of teachers in the country’.

1.5 Surveying the Intervention Terrain

According to Badcock-Walters (2001), anything that threatens or diminishes the role of education, directly impacts and reduces personal, community and national development and also reverses previous gains. HIV and AIDS represents the largest single threat to the education process by increasing the scale of every existing problem of supply, quality and output. Badcock-Walters (2001) contends that to place this in perspective, it should be noted that one third of all HIV-infected persons were infected during their school years, while a further third were infected within two years of leaving school. This confirms schools as a high risk environment but also suggests that school is the key strategic ground on which the battle to mitigate the impact will be won or lost. He further argues that the threat of HIV and AIDS requires both a systemic and sustainable management response and the parallel address and improvement of appropriate curricula, sexual and reproductive health education and relevant materials development in order to effect behaviour change. Irrespective of the quality of the curricula and education driven interventions, the success of these will be limited by the structural stability and comparative functionality of the system.

Educators are generally perceived as role models, therefore educators whose personal behaviour and standards of discipline are questionable, may not be appropriate role models or credible communicators on subjects such as low risk behaviour and informed personal choice, nor are such educators likely to reform or improve their own behaviour if the school in which they teach is inadequately or ineffectively managed and disciplined.

Badcock-Walters (2001) goes on to state that education administrators need to take a long-term view of the impact of HIV and AIDS if the public education system is to survive as an effective delivery mechanism for teaching and learning. He further suggests that the existing high attrition rates for educators and managers will be exacerbated directly as a result of the morbidity and mortality in the system, and indirectly by the recruitment from other affected sectors. This whole situation can be

mitigated to a greater or lesser extent through recognition and understanding, enlightened planning, management reform and improved discipline.

The primary impact of HIV will be to increase the incidence and length of temporary educator absence due to illness, occasional and compassionate leave (for funerals and associated family trauma). All these factors together with the psychological impact will reduce contact time, performance and quality, and will lead to increased health and replacement-educator costs in the system. This temporary educator loss may in fact be harder to measure and understand than permanent educator loss from the system, since it involves subtle degrees of absence, from attendance for some part of the teaching day, to physical disassociation and detachment from the teaching task, in spite of being physically present. Most provincial systems neglect to keep educator attendance records. The consequent impact may be consistently underestimated and more damaging than more measurable absence, since it creates the assumption that teaching and learning is taking place.

The loss of educators and managers through death, relocation employment change, retirement or chronic illness is already very high, confirming that HIV and AIDS will exacerbate existing attrition rates. HIV prevalence rate for educators in KwaZulu-Natal (the province in which this study is being done) stands at 21.8% (ELRC Report 2004/5).

1.6 The Epidemic at Work in the School Environment

Many educators have been lost from the education fraternity due to illness. According to Cullinan (2003) over 680 educators in KwaZulu-Natal-more than 55 a month died in-service in 2000, the average age at the time of death was 36. Cullinan further adds that AIDS-related deaths of 1% in 2000 are expected to reach 5% by 2010. Badcock-Walters (2003) argues that the educator mortality pattern in terms of age and gender is consistent with what is known of the impact of AIDS on the general population, he warns that unless the Department of Education trains and recruits large numbers of teachers by the end of the decade, it may not be able to meet KwaZulu-Natal's educational needs.

All planning of delivery and services will have to integrate the impact of both HIV and AIDS in every aspect of activity and budgeting. The planning and building of classrooms and schools will have to take into consideration the local demographics, as will the rationalisation and merger of under-utilised facilities, such as small and farm schools. The provision of piped water/portable sanitation and health and counselling services will take on a new significance and may record planners' traditional priorities and goals

Johnson (2000) is of the opinion that the education sector needs to firstly acknowledge that HIV and AIDS education is not only about ensuring good life skills and other prevention programmes. It has to recognise that a significant percentage of the teaching population will become ill and die. He further adds that learner numbers will decline due to either illness or home circumstances, schools will also have to deal with teacher absenteeism and infected, affected and orphaned children. Cohen (2002) is in support of Johnson's views, adding that the impact of HIV and AIDS in education is primarily related to the decimation of manpower. A host of influences on government, from drought economic structural programmes to political upheaval and prejudice, along with some strong suggestions of enlightened self-interest, have combined to de-prioritise the HIV and AIDS epidemic in both the minds and the pockets of key decision-makers. Flemming (1992: 428), who was based at Baragwanath Hospital in Soweto in South Africa, notes: " Professor Ruben Shar in reviewing the present situation says that South Africa has lost the battle to prevent AIDS. I disagree: the battle was never joined." In understanding the epidemic, the role of key organisations in influencing people's behaviour is vital, and lessons learnt can be implemented at a local level in order that hospitals, local governments, non-governmental organisation (NGO) and community based organisation (CBO) activity can have maximum impact in preventing the spread of HIV.

AIDS will continue to cause population loss, resource depletion and psychological and social reactions. Economic disruptions and resource depletion will continue in many countries and painful choices in resource allocation lie ahead. Resource depletion may make a society vulnerable to other types of attack. In the psychological and social realm,

the AIDS epidemic has the potential for creating political visibility in developing nations whose public order is already precarious.

1.7 Implications for education

HIV and AIDS have major implications for education systems, since the incapacitation or death of an educator leaves many learners without education. Combining classes and/or grades may seem to be the only option, but this measure comes with its fair share of problems, such as increased class units, difficulty in handling a large group of learners, and difficulty in delivering the curriculum to a combined class. The problem is compounded when there is a shortage of furniture. Another challenge for the Department of Education is the huge number of AIDS orphans left by very young parents. According to UNAIDS (2004), 15 million children in sub-Saharan Africa who were orphaned as at December 2003.

According to the ELRC Report (2005), some factors seem to render educators more vulnerable to HIV infection: placement of educators away from home and the lack of housing make it impossible for the educator's family to go with him/her. The Report suggests that since an educators' salary is higher than that of the general public, he/she is placed in a position of power. A combination of these two factors may result in educators engaging in risky behaviour. The perception of an individual's personal vulnerability to health issues and the ability to reduce one's risk, are key determinants of healthy behaviour. Perceived low vulnerability reduces an individual's motivation to take precautions.

Coombe (2000) believes that the impact of HIV and AIDS on morale can extend to both the infected and affected in schools. HIV-positive educators are likely to lose interest in furthering professional development. Badcock-Walters et al (2003) agree that issues of declining health, and increased rate of absenteeism may impact on the ability to teach. In relation to what Coombe and Badcock-Walters have shared above, Baggaley et al (1999) add that training in counselling and stress management for educators who work in

environments where there are learners and educators affected and infected by HIV and AIDS, is important.

The Mobile Task Team (MTT) Conference paper (2003) highlighted that educators were dying at three-times the rate of the equivalently aged general population without AIDS. The education sector is extremely hard hit by HIV: not only are learners dropping out of school, so are educators, who are becoming infected and dying. Sustainable development is crucial to every country and education is most effective in the creation and advancement of human capital. According to HEARD (2003), a 1999 educator demand and supply projection model in South Africa suggests that AIDS would increase the high levels of educator attrition and that a replacement of as many as 60 000 educators will be required by 2010.

According to Cohen (2002), there are notable gaps in both knowledge and responsiveness at a systemic level, such as:

- A lack of firm data on the loss of human resources throughout the education sector across skill and experience categories.
- The loss of human resource capacity cannot be replaced through formal training alone, and the loss of experience and organisational capacity cannot be replaced in the face of the premature deaths of senior teachers, teacher trainers and administrators.
- Many ministries of education seem to be primarily concerned with issues related to HIV prevention through curriculum reform, which is secondary to sustaining sector capacity, because if the capacity to teach is not maintained then over time the curriculum cannot be delivered.

Cohen (2002) sums up his views in three points: firstly, the epidemic is systematically eroding the capacity of education sectors, making it difficult for education to meet its core responsibility. Secondly, the effects of the epidemic on the education sector are complex, but the education ministries do not appear to understand the impact of this on the educational capacity, nor do they understand the need to re-structure organisations to

respond better to intensifying demands. Thirdly, government and ministries of education need to be energized so that they will understand the issues and develop effective and relevant policies and programmes, perhaps with external assistance.

The loss of educators who are in-service due to HIV and AIDS, is preceded by a long period of illness, depression, denial, and trauma, for both the infected and affected. While the HIV-positive educator suffers the consequences of the virus, the school community is also negatively impacted on, through educator absenteeism, resulting in loss of teaching time, educator illness and a declining capacity to teach. Hence the learners become disadvantaged, and in general, education suffers.

Cohen (2002) explains that the whole education system is affected by educators' morbidity, which leads to extensive disruption of activities. The epidemic also impacts on the morale of educators and causes internal and external disharmony. Bennell (2003) supports this, saying that it is assumed that each infected educator loses a total of 18 months of working time, which is a great loss to the school system.

HIV and AIDS have brought about a major crisis for communities around the world, but more so in sub-Saharan Africa, where classes are combined to cope with educator absenteeism or death, thus increasing the already unmanageable class units, and compromising the learner/educator ratio. According to the ILO (2004), in Botswana death rates of educators increased from 0.7 per 1000 in 1994 to 7.1 per 1000 in 1999. Thus the workload of the remaining educators increased and this in turn compromised the quality of education.

In the light of this context, this study aims to document the experiences of HIV/AIDS educators and understand the nature of support provided to them by the Department of Education. In the next section, the research approach is discussed.

1.8 Research Approach

The research approach in this study has to acknowledge the sensitivity of the study, and the fact that its participants are vulnerable, given the stigma associated with the disease. Silva (1995: 15) suggests that a vulnerable person is an individual who experiences “diminished autonomy due to physiological/psychological factors or status inequalities”. Liamputtong (2007) considers the vulnerable person to be “difficult-to-access”, referring to the “hidden population”, people with “disabilities, chronically and terminally ill”. In the absence of a cure for HIV and AIDS, HIV-positive people also fall into the category of vulnerable people. I realised at the outset that the task of finding willing HIV-positive educators was going to be a formidable one, because of the nature of the data I would require for this study. De Laine (2000: 67), refers to sensitive areas as ‘back regions’ which are ‘private space’, and therefore difficult to find.

Owing to the sensitive nature of the topic, identifying and getting participants to agree to share their experiences with me was a long journey. I met my first participant, Annaline, (all participant’s names are fictitious) at a workshop, she worked in the same group as me, we shared telephone numbers, after a few calls we met. I told her about my study and asked her if she would be willing to be interviewed, at first she was hesitant, I had to really convince her that the interview was for the sole purpose of this research and that confidentiality would be maintained at all times (this was also done with the other participants), she then agreed. I met Delene, my second participant through an article (on HIV) in a newspaper, being an HIV and AIDS facilitator allowed me to discuss this topic with her, she was also comfortable with this, after a few meetings and much convincing she agreed to be interviewed. At a workshop I facilitated (facilitation skills in HIV education) in a rural area I met Siwina my third participant, she approached me after the workshop to discuss some aspects of the workshop that I had presented. Siwina had attended all the workshops I facilitated in her area, she showed keen interest in the information that I shared, on my third workshop meeting she disclosed to me. I told her about this research, and asked her if she would agree to be a participant, she promised to give the matter some thought before she committed herself, after a period of two weeks

she agreed. At a similar workshop in another rural area I met my fourth participant, Thandiwe, whilst she was very reserved, I believe she wanted to talk to me about her 'secret', she had not disclosed to her family, she may have found comfort in disclosing to me because of the content that I presented at my workshops. I met Ashwin my fifth participant almost 18 months later, (through a colleague) he is the only male participant and also the most difficult to convince to participate in this research. I was keen to pursue Ashwin as a participant, he agreed to participate almost six weeks after our meeting because he believed that talking was therapeutic.

Qualitative research methods were used because they allow researchers to be able to hear the voices of those who are "silenced, othered, and marginalized" (HIV-positive) by those who consider themselves as the dominant class (HIV negative). Feminist research also features because of its worldview approach, where women and their concerns are the focus of investigation. O'Neill (1996: 131 cited in Liamputtong 2007), says that the concern of feminism and feminist research is to construct knowledge that "writes women into history and exploring, challenging, resisting and changing sexual and social inequalities". She contends that feminist research aims to give voice to the marginalized through its reflexive nature, and is concerned about the 'othered', and is a more caring research environment that is non-hierarchical.

1.9 Chapter Outline

In Chapter One of this study, I briefly discuss the impact of HIV and AIDS on human resources in the Department of Education and the delivery of the school curriculum. The whole thesis is based on the one critical question *What are the experiences of HIV-positive educators and how do they constitute themselves as educators within and beyond the school environment?*

Chapter Two provides the context and background to the study. In this chapter the impact of HIV on learners and educators is discussed. I endeavour to place HIV and AIDS in perspective, focusing the discussion on the global situation on HIV and AIDS,

HIV and AIDS in Africa, the HIV crisis in South Africa, and HIV and AIDS in KwaZulu- Natal, the province where this study was carried out.

Chapter Three offers a literature review, and presents a global picture of HIV and AIDS, with discussions on the situation in sub-Saharan Africa. Emphasis is also placed on HIV and AIDS in South Africa, more especially on the province of KwaZulu-Natal, where the participants for this study reside. The impact of HIV and AIDS on society is discussed in general. Another important aspect that features in this chapter is the issue of the vulnerability of women with the emphasis on stigma and discrimination. Education in an HIV climate is also shown to be a serious concern. The chapter concludes with a discussion on political issues around HIV and AIDS.

Chapter Four discusses the methodology used to collect data. While the primary data source was the life story interviews, other supporting means of data collection was used. These were focus group meetings with SMTs in selected areas, and where possible, interviews with spouses, close family and friends. The grounded theory approach was used in this study because the data collection methodology was compatible with this approach.

In Chapter Five, the findings are presented through an in-depth analysis of the data collected through interviews with participants. Findings are discussed within the selected frameworks borrowed from the theorizing of van Dyk (2008). An analysis of focus group meetings that took place with school management teams in certain areas is included in this chapter.

Chapter Six discusses the significance of the data and conclusions. In terms of the insights that emerged, the issues around stigma and discrimination featured strongly. Fear of contagion, teacher identity, and public versus private concerns are discussed, as well as the politics surrounding HIV and AIDS.

1.10 Conclusion

Despite the growing need for HIV and AIDS-related services, the health systems in South Africa are extremely limited in their capacity to prevent transmission, to manage and provide support to people living with HIV and AIDS. The poor handling of the pandemic is a result of medication not being freely available to those who need it; service providers have not been adequately trained, and HIV and AIDS stigma is rife. There is also the ever-present threat of the danger of infection for care-givers and patients alike, because systems and protocols for infection control are often not in place.

This chapter discussed the rationale, objective and need for the study, noting that the nature of this study is highly sensitive. The research approach adopted has been explained, and the destructive nature of HIV exposed. A brief discussion on HIV intervention is presented. The chapter shows the focus of the research to be on HIV-positive educators and the impact the pandemic has on education. In the next chapter the context of this study will be discussed.

CHAPTER TWO

Context Development

A Global Glance at HIV and AIDS

2.1. Introduction

In this chapter I will briefly outline the global situation in respect of HIV¹ and AIDS², then move on to the situation in Africa, and finally to sub-Saharan Africa. I concentrate on the effect of the pandemic on South Africa with particular emphasis on KwaZulu-Natal, the province with the highest prevalence (HSRC Survey 2008) in South Africa. In this chapter, I also discuss the impact of HIV and AIDS in the context of schooling, infected and affected educators, learners and the functioning and morale of the whole school. As mentioned in Chapter One, schooling in an HIV-free society cannot be the same as schooling in an HIV-infected society. The focus of this study is on HIV positive educators and how they managed their HIV positive status in the context of schooling, and the ripple effect their HIV positive status management may have on those around them. On the issue of whole school functioning, no one aspect within the school stands alone as every aspect of schooling is a small cog in a huge wheel, and each has to do their bit for the smooth turning of the huge wheel (school). Educators play at least seven roles³ in a day. Since this task is demanding, this study seeks to explore how educators handle this demanding task in the context of their HIV positive status. Thereafter, the subject of vulnerability of women will be given specific attention. My reasons for including this section are that statistics show that women (HSRC Report 2005) are more vulnerable than their male counterparts to HIV infection, and the fact that the majority of the respondents in this study are women (four out of five).

¹ HIV-Human Immunodeficiency Virus, an organism that causes an infection that depletes white blood cells and leads to lessened immunity (Singhal & Rogers 2003)

² AIDS-Acquired Immune Deficiency Syndrome. It occurs when an HIV-positive individual has such lowered immune levels that s/he falls prey to a variety of opportunistic infections.

³ See National Education Policy Act 27 of 1996 that outlines these roles

2.2. The Global Situation on HIV/AIDS

HIV and AIDS first surfaced more than thirty years ago. In 2004, 40 million individuals were estimated to be living with HIV and AIDS (UNAIDS 2004a). This figure escalated to 40, 3 million in 2005 (UNAIDS/WHO 2005) a sharp increase from just a handful of cases in the early 1980s. Of great concern is the high infection rate in sub-Saharan Africa, which has reached double digit figures. While the figures in other parts of the world are high, they are considered low in comparison to sub-Saharan Africa.

AIDS has killed more than 25 million people since it was first recognized in 1981, making it one of the most destructive epidemics in recorded history (UNAIDS/WHO 2008). Figure 2.1.shows the rapid increase in the prevalence of HIV and AIDS; despite the claims of interventions by governments. Sub-Saharan Africa is most affected by HIV and AIDS, which is the leading cause of adult morbidity and mortality. According to UNAIDS, most if not all of the 25.4 million people in sub-Saharan Africa who are living with HIV and AIDS will have died by the year 2020 (UNAIDS 2004a). Sub-Saharan Africa is home to 67% of all people living with HIV (UNAIDS/WHO 2008).

HIV and AIDS is also spreading dramatically in Asia, an estimated 4.9 million people are living with HIV and 300,000 have died from AIDS-related illnesses in 2007. India leads the region in numbers of HIV infection estimated at 5.1 million, and China has approximately 840,000 HIV positive people (National AIDS Control Organisation 2008). Sub-Saharan Africa has just over 10% the world's population, but more than 60% of all people living with HIV, live in sub-Saharan Africa. Women are disproportionately affected by HIV. Women and girls make up almost 57% of adults living with HIV in sub-Saharan Africa (UNAIDS 2004). While Southern Africa remains the most affected region, South Africa has the highest number of people living with HIV in the world A Department of Health (2005) survey has shown the HIV prevalence among pregnant women has reached its highest level of 29.5% (South Africa HIV & AIDS Statistics 2008).

Life expectancy has dropped below 40 years in nine African countries, namely, Botswana, Central African Republic, Lesotho, Malawi, Mozambique, Rwanda, Swaziland, Zambia and Zimbabwe (UNAIDS 2004b). HIV/AIDS has been sighted as the single most important reason for this fall in life expectancy. In Zimbabwe, life expectancy was 34 years in 2003, compared with 52 years in 1990 (UNAIDS 2004b).

With reference to figure 2.1, in Latin America and the Caribbean, the total number of people living with HIV is still rising with current estimates for Latin America at 1.7 million in 2007, and the Caribbean is estimated to have 230,000 living with HIV in 2007. Three countries in the Caribbean have national HIV prevalence levels of 3%, namely, the Bahamas, Haiti and Trinidad and Tobago. Barbados is at 15% and Cuba's prevalence is well below 1% (UNAIDS/WHO 2008).

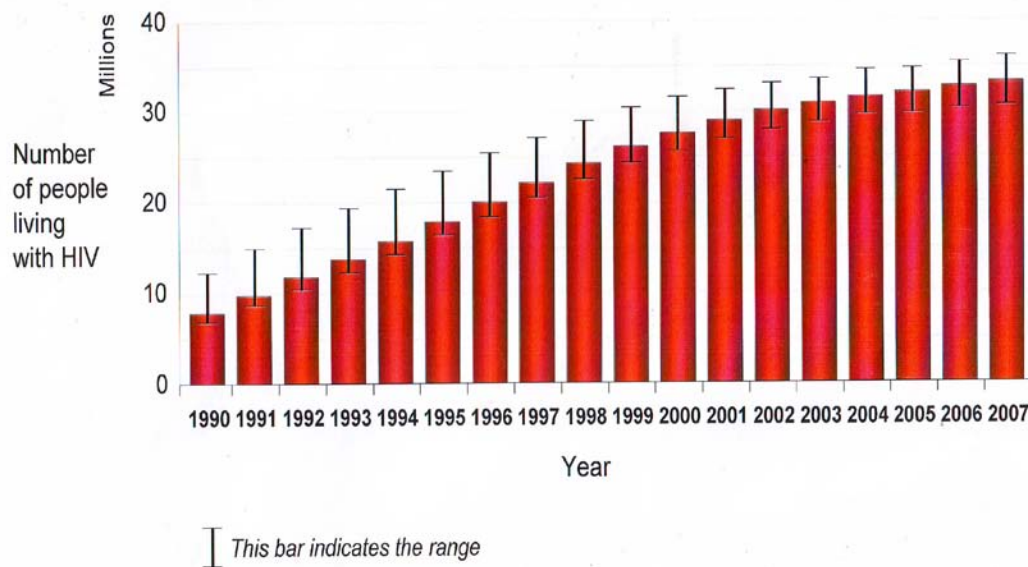
In 2007, 81,000 new infections occurred in North America, Western and Central Europe, raising the number of people living with HIV to 2 million. The number of women living with HIV rose to 450,000, while life-prolonging ARV treatment kept the number of AIDS deaths at 25,000 in 2006 (AIDS Epidemic Update 2007).

In Eastern Europe and Central Asia, the number of people living with HIV has risen dramatically, reaching an estimated 1.4 million at the end of 2004. This is a nine-fold increase in less than 10 years. Around 490,000 women are living with HIV in this region. Approximately 210,000 people were newly infected in 2004, while an estimated 60,000 died of AIDS. In the Ukraine, the epidemic continues to rise, it is estimated that 1.63 percent of Ukrainians were living with HIV in 2007 which is a 1.46 percent increase from 2005. More than 40% of people living with HIV are women (UNAIDS 2008). Figure 2.2 shows a bar graph that depicts the rise in HIV infection globally from 1990 to 2007.

Figure: 2.1 Adults and children estimated to be living with HIV in 2005 adapted from (UNAIDS WHO 2005).



Figure: 2.2 Estimated number of people living with HIV globally, 1990-2007. (Adapted from AIDS Epidemic Update 2007)



The rapid spread of HIV and AIDS is facilitated by those conditions that make it difficult for societies to respond and take action, such as inequality and poverty. Stillwaggon's (2000) work shows a clear link between poverty, inequality and HIV infection. With this in mind, I now turn my attention to Sub-Saharan Africa.

2.3. Sub-Saharan Africa's High Infection Rate

Sub-Saharan Africa has just over 10% of the world's population, but is home to more than 60% of all people living with HIV and AIDS, and where more than 76% of all AIDS deaths in 2007 occurred (AIDS Epidemic Update 2007). During the course of 2007, an estimated 1.7 million people in the region became newly infected, while 2.4 million adults and children died of AIDS; the majority of people living with HIV are women (AIDS Epidemic Update 2007). Table 2.1 shows a comparison of HIV and AIDS statistics for the years 2005 and 2007. While there are claims made that the issue of HIV

and AIDS is being addressed, the infection rate is on the increase as seen on the table below. Table 2.1 reveals that there is an increase in all aspects of the virus.

Table 2.1 HIV and AIDS statistics, a comparison between years 2005 and 2007
(AIDS Epidemic Update December 2007:7)

YEAR	HIV+ Prevalence	HIV+ Women	Newly Infected with HIV	HIV/AIDS Related Deaths
2005	25.8 million	13.5 million	3.2 million	2.4 million
2007	22.5 million	15.4 million	1.7 million	1.6 million

It is important to note that in some parts of Southern Africa, such as Uganda and Zimbabwe, the virus is abating (UNAIDS/WHO 2005). In Uganda, HIV prevalence declined sharply among women from 20% in 1994-1995, to 13% in 2003, and among men from 15% to 9% over the same period. These declines have been attributed to behavioural change (AIDS Epidemic Update December 2005). Uganda has also made strides in expanding access to treatment. More than one third of people in need of antiretroviral treatment were receiving it in mid-2005 (UNAIDS/WHO 2005).

In Zimbabwe, there was a decline in HIV prevalence among pregnant women from 26% in 2002 to 18% in 2006 (AIDS Epidemic Update 2007). In rural eastern Zimbabwe, a decline in HIV prevalence was reflected among both men and women (Mundandi et al 2005). However, the Human Rights Watch (2005) argues that factors such as population mobility, spousal separations and livelihood insecurity following the forced displacement of several hundred thousand Zimbabweans in 2005, could reverse these recent trends. Another cause for concern is that one in five pregnant women are still testing HIV-positive, which underscores the need to bolster prevention activities (Human Rights Watch 2005).

According to Heywood (2004) the response of the Zimbabwean government has been both tardy and ineffectual, during the 1980s when HIV was first diagnosed in Zimbabwe.

The government failed to move quickly to contain the pandemic. He further adds that while the battle against the HIV and AIDS pandemic was raging, another war was being waged on the political front, hence HIV and AIDS fell into the background.

The above discussion shows the seriousness of HIV in sub-Saharan Africa. It would appear that some moves have been made to address this epidemic in Uganda and to a small degree in Zimbabwe. In the next section I discuss the situation in South Africa.

2.4. The Pandemic in South Africa

The HIV and AIDS epidemic began to spread through South and Southern Africa during the late 1980s. By the 1990s, HIV prevalence was rather high and continuing to rise (Development Update 2004). South Africa has the largest number of HIV infections in the world, HIV prevalence among pregnant women was 29% in 2006, this according to the Department of Health South Africa in 2007 (UNAIDS/WHO AIDS Epidemic Update 2007). The adult HIV prevalence rate increased so rapidly because South Africa's history has been exploitative and bloody (Barnett & Whiteside 2006). The HIV and AIDS epidemic reflects how migration and mobility have created patterns of sexual behaviour which set the scene for the spread of sexually transmitted infections and HIV. Whiteside and Sunter (2000) explain that during the apartheid era, land inequalities meant that 71% of the rural population – mainly black – lived on 14% of the land, while the balance of the land was occupied by the elite whites. They argue further that the congested living environment led to mass urbanization, which gave rise to squatter settlements. They contend that families were left to fend for themselves in the rural areas, and this arrangement often meant that the breadwinner (father/son) visited his home a few times a year, and during his time away from his family he socialized with people in his urban environment, often engaging in 'risky' behaviour, then taking the consequences of his 'risky' behaviour to his wife back home.

Figure: 2.3 HIV prevalence among 15-49 year olds by province, South Africa 2008 (adapted from HSRC Survey 2008)

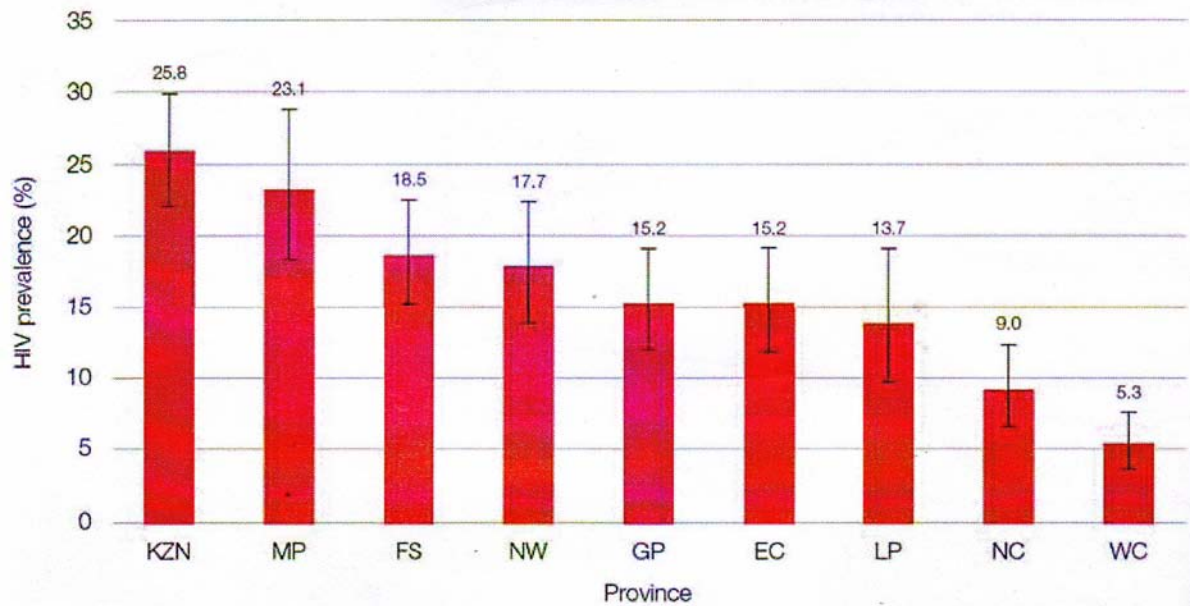


Figure 2.3 shows the HIV prevalence among the 15-49 age group, I have focused on this group because all the participants in this study are in this age group. The graph above shows that the highest HIV prevalence is in the Kwazulu-Natal province (the participants in this study are from this province). According to the HSRC survey (2008) the highest HIV prevalence is amongst females in this age group

About 50% of the total number of HIV positive Southern Africans live in South Africa, where death rates have increased dramatically in the 15-49 age group (Statistics South Africa 2005). The increased mortality has been borne by women, who are more easily infected than men because of their anatomy and also the social and economic disadvantages they experience (Walker & Gilbert 2002; IFAD 2001:9-11). This pattern of increased vulnerability of women to HIV infection is replicated across Africa (Baylies & Bujra 2001:1-24).

2.5 Women in this Pandemic

The proportion of women infected by HIV is still increasing: according to an HSRC survey (2008), HIV prevalence in the age group of 15-49 (most productive years) increased from 15.6% in 2002 to 16.2% in 2005 and 16.9% in 2008. The AIDS Epidemic Update (2005) has reported that the increasing impact on women is apparent also in South and South East Asia (almost 2.5 million women are HIV positive here) and in Eastern Europe and Central Asia. In sub-Saharan Africa, almost 61% of adults living with HIV in 2007 were women; in the Caribbean that percentage was 43% (compared to 37% in 2001). The proportions of women living with HIV in Latin America, Asia and Eastern Europe is also growing. In Eastern Europe and Central Asia, it is estimated that women accounted for 26% of adults with HIV in 2007 (compared to 23% 2001), while in Asia that proportion climbed to 29% in 2007 compared with 26% in 2001 (AIDS Epidemic Update 2007). The status of women is relevant to this discussion:

...throughout history, women and children have been classed together and viewed as subordinate. One of the common tasks of both groups is to gain recognition as independent human beings (UNICEF et al, undated).

Although they are exceptionally vulnerable to the epidemic, millions of young African women are dangerously ignorant about HIV/AIDS.
(UNAIDS/WHO, 2001)

In the previous paragraph, the issue concerning women in this pandemic was discussed, and it was clearly stated that more women than men are HIV positive, both Reproductive Health Outlook (2004 as cited in ELRC Survey 2005) and Pettifor et al (2004) are of the opinion that gender equality, lower social status of women and economic dependence on men are contributory factors to more women than men being HIV positive. Pettifor et al (2004) argue that young women and girls are often the target and older men will look for 'safe' sexual partners. The vulnerability to men's demands also means that women are more likely to become infected with HIV at an earlier age.

Leclerc-Madlala (2003) says that Africa has the highest HIV infection rate and women comprise 55% of the infected group, culture contributes to the difficulties women face. She contends that some African countries such as Ethiopia and Somalia continue the practice of genital mutilation, a form of torture and human rights abuse that increases the chances of tearing of the vaginal tissue during intercourse and makes women more susceptible to infection. Whilst Leclerc-Madlala (2003) contends that African women are expected to play a subservient role, to be obedient and to produce children, so condom use is not negotiable, Pettifor et al (2004) are in agreement about the subservience of women and hence their vulnerability to HIV infection. Leclerc-Madlala (2003) explains further that while having multiple sexual partners is an accepted practice for men, a woman requesting the use of a condom may incite violence. She further states that the African culture also encourages women to marry older men who are sexually more experienced but have a greater chance of being infected.

In South Africa there has been a steady increase in rape statistics. In 2001, South African police reports indicated that there were nearly 25,000 reported rape cases (Human Rights 2001). Jewkes (2001) of the South African Medical Research Council argues that there is a culture in South Africa where men believe that they are sexually entitled to women, and rape occurs in situations where massive gender inequalities exist.

As discussed earlier, the general powerlessness of women in African society is responsible for the lack of control over HIV and AIDS. Poulsen–Dobbys (Medecins Sans Frontiers 2003:10) says that,

In Africa, AIDS is a feminist issue. The position of women in society prevents them from being able to speak out on many issues, but particularly issues of a sexual nature.

She further states that sexual activity is very important for men in Africa: because they believe that it is unhealthy to have semen in their bodies, they have many sexual partners and it becomes exceedingly difficult for women to prevent this from happening.

Tlou (2003 cited in Australian Nursing Journal), an African HIV expert from the University of Botswana, agrees with Dobbyns:

Women's economic subordination to men in many African communities limits their negotiating power and makes it difficult for them to refuse unsafe sex.

Tlou (2003) further explains that in Africa, men control much of the productive resources such as land, and inheritance customs dictate that they are the beneficiaries of family property. These issues perpetuate the low status of women. Tlou (2003) adds that it is imperative that social, economic and political inequalities be eliminated, as the HIV and AIDS epidemic is Africa's greatest threat to sustainable development.

Frasca (2003:14) is in agreement Tlou (2003) about women's vulnerability:

The African epidemic is further understood as one in which women, especially poor women are significantly more vulnerable to HIV infection than men. Such vulnerability is based both on biology and the lower status of women.

They are of the opinion that women find themselves in coercive relationships where they are unable to insist on condom use, frequently remaining faithful to abusive partners who are not themselves faithful.

From anecdotal evidence⁴ the opinion that emerges is that men are attracted to 'good women' and good women are ignorant about sex and passive about sexual interactions, Leclerc-Madlala (2003) states that whilst African men have multiple sexual partners, women's role is one of obedience and child-producing. Abdool Karim (2005) is of similar opinion that women in most societies are seen in a subordinate, dependent and passive role, where their ideal virtues include virginity, motherhood, obedience and ignorance, particularly about their bodies, and in contrast, masculinity is seen in terms of

⁴ Opinion expressed by educators at an HIV workshop in the Inchanga Ward in September 2004

aggression, dominance, independence and invincibility, where the key values are strength, courage and virility.

A patriarchal society privilege men on the issue of HIV in that they are expected to be more knowledgeable and more experienced about sexual issues whilst ‘good women’ are expected to be ignorant. Abdool Karim (2005) refers to this imbalance of knowledge as a direct contradiction of the moves to empower the youth and especially females about their bodies and about protecting themselves. She believes that this knowledge imbalance is a major obstacle to women’s ability to assess their risk which seriously challenges HIV prevention efforts targeted at promoting monogamy and fidelity.

2.6 Government Response

In order to address the HIV and AIDS pandemic, much emphasis has been placed on the importance of partnerships between governments and civil society and on the involvement of people living with HIV and AIDS in planning and implementing responses to it (Development update 2004). Partnerships against HIV and AIDS in the Southern African Development Community (SADC) exists more on paper than in practice, with governments responding to this crisis in ways they determine best, as compared with collective agreement (SADC HIV and AIDS Framework and programme of action 2003-2007, as cited in Development Update 2004).

The HIV infection rate has raced ahead of attempts to contain it. In *Towards a Ten Year Review*, published in early 2004 by the Presidency of the South African Government, it is recorded that the prevalence of HIV and AIDS showed an increase from 0.7 percent in 1990 to 26.5 percent in 2002 (Department of Health 2002, 2003). In April 2004, the S.A. Medical Journal reported that between 1997 and 2003, adult mortality had undergone ‘a real increase’ of more than 40% (Bradshaw et al 2004: 278-279). By 2004, the HIV and AIDS epidemic in South Africa has emerged as one of the greatest threats to post-apartheid reconstruction and development.

A great deal of controversy has surrounded the South African government's response to HIV and AIDS. The HIV and AIDS debacle in this country (in my view) has been treated as a difference in perceptions, hence the slow pace in addressing the ravages of HIV. The fear that HIV is now in its third decade, and no cure has been found to address the virus is reason enough to treat it with the utmost urgency. The impact of the virus is having an impact on all sectors of society due to ill health and absenteeism. At the South African AIDS Conference in Durban in June 2005, the Chief Director of HIV and AIDS, South African Department of Social Development⁵ had this to say: 'the development gains of this country have been taken back because of the impact of the pandemic'

The urgency of addressing issues around HIV and AIDS cannot be over emphasised, especially when it is affecting people who are mainly in their most productive years of their lives (15-45 year group). At a media briefing in Lusaka on 18 March 2009⁶, Dr Mutukwa (SADC Parliamentary Forum secretary general) said that SADC (Southern African Development Community) has failed to address issues around HIV adequately. He added that SADC was the epicentre of the HIV pandemic, and not enough was being done to address it. Whilst there are good intentions by parliamentarians in the SADC the impression that prevails is that the pace of delivery is too slow. Dr Mutukwa further called for the establishment of HIV and AIDS desks within each parliament in the region to fast-track HIV-specific legislation and programmes. Another issue of urgency is that the SADC countries (South Africa is a member of SADC) have committed themselves to a number of international goals concerning HIV, one of these according to Safaids (2009) is Millennium Development Goal 6 (MDG), which aims to halt and reverse HIV and AIDS by 2015 and achieve universal access to treatment for all who need it by 2010. In addition to the previous commitment, Safaids further states that SADC governments have also pledged to meet indicators set by United Nations General Assembly Special Session (UNGASS) on the reduction of new HIV infections of 15-24 year-olds by 25 percent and mother-to-child transmission by 50 percent. Kelly (Safaids 2009) notes that whilst the

⁵ See Intersearch-strategic management intelligence available on www.intersearch.co.za.

⁶ See SAFAIDS-Southern Africa HIV and AIDS information Dissemination Service: Southern Africa: Politicians Fail to Address HIV(2009). available on www.safaids.net

intentions are there, little has happened to implement these intentions, he believes that these promises must be fulfilled in order to address issues around HIV and AIDS. SADC HIV and AIDS policy advisor Boemo Sekgoma (Safaidis 2009) concurs with Kelly, saying that a UNAIDS study in 2008 shows that more than half of all Southern and Eastern African countries have planned HIV prevention strategies but only 20 percent of those are being implemented. He believes that the lack of implementation is caused by inadequate and divided leadership, weak strategies and a lack of results-based accountability. HIV and AIDS impacts on all sectors of society, whilst the focus of this study is on educators living with HIV and AIDS, educators are part of the community and a valuable resource needed to empower the youth and their families, any progress in handling this virus will also be beneficial to these educators.

2.7. KwaZulu-Natal's Infection Rate

The Kwa-Zulu Natal Department of Education is South Africa's largest provincial education system. This department is responsible for over 2,6 million learners and approximately 76,000 educators in over 6,000 schools⁷. A 1999 educator demand and supply model⁸ suggested that AIDS would add to existing high levels of educator attrition, and that this crisis may require the replacement of as many as 60,000 educators by 2010.

Badcock-Walters et al (2003) say that while AIDS mortality among educators was estimated to be about 0.64% in 1999 in KwaZulu-Natal, it is expected to rise to around 5% by 2010. Statistics have revealed that the prevalence rate of HIV infection in this province is the highest in the country, and according to Badcock-Walters, is still increasing.

⁷ See paper on Educator Mortality in-service in KwaZulu Natal. Demographic and Socio- Economic Conference, 28 March 2003.

⁸ Developed by HEARD & the MTT, based on a national model developed by Dr Luis Crouch, SA DoE & RTI

A survey carried out by the HSRC & MRC for the Education Labour Research Council (ELRC), showed that KwaZulu-Natal educators had the highest HIV prevalence of 21.8% when compared to the other eight provinces. Table 2.3 draws a comparison of HIV prevalence with other provinces in South Africa

Table 2.2 HIV prevalence among educators by province in South Africa 2004 (Adapted from ELRC Survey 2005)

PROVINCE	HIV+ PERCENTAGE
Western Cape	1.1%
Eastern Cape	13.8%
Northern Cape	4.3%
Free State	12.4%
KwaZulu-Natal	21.8%
Northern Cape	10.4%
Gauteng	6.4%
Mpumalanga	19.1%
Limpopo	8.65

This table shows that the HIV prevalence rate is the highest in KwaZulu-Natal, with Mpumalanga province following closely. It is clear that there is a huge discrepancy in the prevalence rates throughout the provinces in South Africa, such as the difference between Western Cape and KwaZulu- Natal. The figures above demand urgency in the way society in general and the government in particular should be handling this deadly pandemic. An HSRC survey⁹ (2008) has found that HIV remains disproportionately high for females in comparison to males, in the next section I discuss the dilemma faced by women.

⁹ See South African National HIV Prevalence, Incidence, Behaviour and Communication Survey,2008

‘throughout history, women and children have been classed together and viewed as subordinate. One of the common tasks of both groups is to gain recognition as independent human beings’ (UNICEF et al, undated).

2.8. Impact on education systems

South Africa and more especially the province of Kwa-Zulu Natal, has the highest prevalence rate of HIV infection in the country, knowledge and skills training on HIV is imperative. Most programmes designed to mitigate the impact of HIV depend on education, such as knowledge on coping strategies, information on keeping the immune system healthy and general information on wellness.

It is a belief that a well-educated community and work force is an asset to national health and welfare, and this combined with sound macroeconomic policies will be beneficial, as education is generally a key factor in promoting social well-being and poverty reduction. For a country to achieve economic growth, it must first assure the education of its population. It is said that education and training is the cornerstone for achieving lasting and sustainable development; it is the sector that provides skills, shapes young minds and builds the necessary human resources. According to AIDS Epidemic Update (2007) HIV and AIDS affects people of all ages, it is most prevalent among young people between the ages of 15-29 years, the group that is school/college-going, trainable and child-bearing. HIV hits education the hardest because of the ‘person-intensive’ nature of the education sector.

The physical presence of the educator in the classroom is invaluable, The escalation of HIV prevalence amongst educators is evident. Kelly (2000)¹⁰ likens the effect that HIV and AIDS has on the whole education system to what happens to a person when he/she becomes infected with HIV. The invasion on the immune system is gradual until the system is overcome and too weak to protect the individual against opportunistic

¹⁰ Kelly M.J. (2000), ‘Planning for Education in the Context of HIV/AIDS.’ UNESCO International Institute of Educational Planning, Paris.

infections and eventually succumbs to death. He further explains that in the same way, HIV and AIDS erodes the 'vital' cells of the education system, the individuals, organisations, structures, programmes and projects that propel the functioning of the education system. When the pandemic takes its toll, the system becomes vulnerable to opportunistic infections, hence uncertainty, disarray, paralysis, bewilderment and a crisis of untold proportions results.

Discussions with School Management Teams (SMTs)¹¹ have revealed that many schools, especially in the rural areas, do not have their full complement of educators under normal circumstances, and when educators are absent due to illness, the problem is compounded.

Kelly (2002) explains the impact of HIV and AIDS on the education system in three broad categories, namely demand, supply and quality of education, each of these categories has a bearing on the other. In respect of demand it can be said that the high incidence of HIV and AIDS affects the demand for education. HIV-infected children, do not generally live beyond their fifth birthdays. Older children drop out of schools because of AIDS-stresses, such as taking care of ill parents, insufficient time for homework and financial problems. Supply would mean that the education sector is experiencing significant losses in educator numbers and other personnel such as supervisors, senior teachers and higher level managers. Kelly cites examples from studies carried out in the early 1990s, such as the World Bank Projections: by 2010, some 14,460 teachers would have died from HIV and AIDS in Tanzania; in Zambia, teacher mortality stood at 39 per 1000 in the late 1990s; in Botswana, it is estimated that 2-5% of teachers are lost annually, and in South Africa, infection rates are estimated at 20-30%.

In respect of quality the net results of the impact of HIV and AIDS infection on supply and demand is the negative effect on the quality, efficiency and effectiveness of the education and training system. As Sheffer (1994: 23) aptly puts it, "relatively fewer pupils, students and adult learners may seek an education, those that do, may be faced

¹¹ School management teams formed the focus group in the areas of Inchanga, Hammarsdale and Ndwedwe. These discussions took place at the end of 2005.

with fewer available places, a more 'random' sequence of teaching and learning, and fewer teachers." The possibility exists that many of those educators that remain in the system may be less well-trained and supervised by fewer senior officials.

The school/learning institution may also be affected by the psychological effects of having infection, illness and death in its midst. Illness of managers and education officials also results in the erosion of considerable competence, and the system's capacity to plan, manage and implement educational policies, programmes and plans. Hence, the quality and efficiency of the education system are seriously undermined.

Coombe (2002) says that HIV and AIDS has placed focus on the management fragilities of education systems worldwide. She explains that the main lesson learned from the past twenty years, for education, is that education ministries and departments at all levels are not adequately equipped to fight HIV. She further adds that since saving lives is of paramount importance, this creates an opportunity to improve education provision at all levels, and that only in this way, HIV and AIDS may have a positive impact on education.

Badcock-Walters and Gorgens (2001) and Coombe (2000) argue that HIV and AIDS affects the supply of education through the attrition of skilled educators and that educator mortality and morbidity from the epidemic deprives the education sector and learners of experienced senior educators and managers. Increased absenteeism on the part of the HIV-positive educator has costly implications for the quality of teaching and learning, and on the workload and working conditions for educators in most affected schools (Sadu 2003). Kelly as well as Coombe argue that the value of the educator in the era of HIV and AIDS cannot be treated lightly. Kelly (2002) explains that HIV positive educators will not always work to their full potential. It is estimated that repeated illness could lead to an educator losing approximately six months of teaching time during the period. Kelly is of the opinion that ARV treatment should reduce the rate of illness as well as educator attrition. The morale of affected educators is also likely to fall as they deal with the illness and mortality of colleagues, relatives and friends. Whilst educators are affected by the plight of their infected colleagues these educators are also troubled by

the increased work load. Coombe (2000) suggests that affected educators will also have to assist with the additional responsibilities of infected educators, offering counseling and caring for infected/affected learners. These stresses may need to be addressed and incorporated in initial and continuous educator training and development initiatives.

Baggaley et al (1999) stress in a Zambian study, the importance of training in counseling and stress management skills for educators who work in environments where there are learners and educators infected and affected by HIV and AIDS. Continuous professional teacher development (CPTD)¹² is another important factor to note in the management of HIV at school, CPTD will assist the educator with information on HIV management.

Earlier in this chapter, I alluded to issue of the high HIV prevalence amongst females, this high prevalence rate has a chain reaction in that it impacts on almost every sector of society. Badcock-Walters and Gorgens (2001) say that learner enrolments and group out rate will be heavily impacted on because of the AIDS mortality and morbidity. A reduced primary school learner enrolment is anticipated in South African over the coming decade because of mother-to-child transmission of HIV (Sadu 2003). From anecdotal evidence¹³ it is believed that HIV is a condition of the poor. Coombe (2000) argues that another reason for low enrolments in both primary and secondary schools is the effect of the epidemic on disposable income. Affected households will have less money for fees, books and uniforms as money will also be needed for health care costs and funerals. The pattern in enrolments will also be affected between boys and girls. Desmond, Michael and Gow (2000) and Marcus (1999) state that female children will drop out earlier than male children to help with household chores and take care of the sick, and here to the vulnerability of the female child is foregrounded.

Hesitancy and uncertainty (I believe) on the part of the education sector has led to the high HIV prevalence among educators. Kelly's (2002) paper, "preventing HIV

¹² Continuous Professional Teacher Development (CPTD), courses are offered by the DOE in order to assist educators in their professional development in various aspects/ subjects, attendance at these workshops generate Professional Development points.

¹³ This evidence from educators in the rural areas of Inchange, where they have experience and discussed the impact of poverty on the community in the context of AIDS.

transmission through education,” based on a presentation to an international Policymakers Conference in New Delhi (11-12 May 2002), emphasizes the link between education and prevention programmes. Education, he says is the only ‘social vaccine’ available against HIV infection. ‘Social vaccine’ could be synonymous with departmental support in the form of psychosocial support, medical support, counseling, didactic support, governance section support, and provision of temporary support. In addition to this, empowerment on HIV would help reduce stigma and discrimination and encourage HIV positive people seek assistance.

South Africa as part of SADC has a commitment to the Millennium Development Goals (MDG), to halt and reverse the impact of HIV by 2015. Kelly (2002) argues that education can make a significant contribution towards the prevention of HIV transmission, in order to meet the International Millennium Development Goals. He is of the opinion that if preventive education messages are to have the desired impact, they must be affirmed with a single, unanimous voice, whereas conflicting messages may lead to confusion and lack of action.

Coombe and Kelly (2001) explain that school education has been shown to be related to the reduction of HIV prevalence rates among the youth in both Uganda and Zambia. School, where formal education takes place, is the ideal place to teach the youth about HIV. The information is given to the learners in their most formative years and will become a way of life for the youth, hence its importance to both learners and educators.

The networking with and the capacity-building of educators will give educators the confidence to empower learners with knowledge and the management of HIV and AIDS. Kelly (2002) stresses the need to mainstream HIV and AIDS into every aspect of education, which he refers to as the most devastating disease known to man, which could weaken the education system through the loss of educators, impairment of quality, numerous negative effects on learners, educators and managers, and constraints on resources. He also mentions the need to ensure that education policies, procedures and regulations are reformulated to accommodate HIV and AIDS.

2.9. Conclusion

More than three decades since its discovery, HIV and AIDS has become the worst health crisis in the history of the world. More than 25 million people worldwide have died and at least 33.2 million more are currently living with HIV and AIDS and approximately 2.5 million were newly infected in 2007 (AIDS Epidemic Update 2007). The Centres for Disease Control indicate that the global pandemic is still in its infancy (New York Amsterdam News). Sub-Saharan Africa is home to approximately 10 percent of the world's population, but has more than 75 percent of the world's HIV and AIDS cases (New York Amsterdam News).

In this chapter I have endeavoured to place this study in context in an HIV climate by briefly discussing the global situation, and then focusing on the HIV situation in sub-Saharan Africa, where the HIV prevalence is extremely high. The discussion subsequently moves to South Africa, a country with one of the highest HIV prevalence rates, and finally to the province of KwaZulu-Natal, which has the highest HIV prevalence in the country, and is home to the participants in this study. The vulnerability of women in this HIV climate was also discussed, noting that 80% of the participants in this study are women.

While much emphasis is placed on this pandemic during World AIDS Day, and the promise to beat HIV and AIDS, the world is losing the battle because of stigma and discrimination. By stigmatizing those living with HIV and AIDS, societies distance themselves from the virus, rejecting the notion that HIV is everyone's problem. This chapter has offered a context for this study; in the next chapter I will present a comprehensive review of relevant literature.

CHAPTER THREE

LITERATURE REVIEW: Scanning the HIV and AIDS Scenario

3.1 Introduction

In the previous chapter a global picture on HIV and AIDS was presented, in which emphasis was placed on sub-Saharan Africa and more especially the province of KwaZulu-Natal, which has the highest prevalence rate. The vulnerability of women and educators was discussed selectively, while the impact of HIV on education was briefly addressed. In this chapter, the HIV and AIDS pandemic will be discussed as an “imprecise catastrophe” because of the tardiness of policy and education and attitudes to the pandemic (Economist 2004).

This literature review will have a broad framework, consisting of social issues, anthropological aspects, educational issues and political issues. Firstly, the impact of HIV and AIDS on society will be discussed in general. Secondly, a discussion follows on political issues around HIV and AIDS, and what HIV and AIDS education policies are saying and not saying about the virus in the workplace and the impact these policies have on the day-to-day running of schools. The findings of the recent HSRC national research report (2005) on HIV and AIDS in our schools are discussed and how policy reviewers view the HIV and AIDS education policies. Thirdly, my discussion will centre on gender issues and power relationships, and the impact of gender equality on HIV and AIDS. The part played by the school on the gender issue will also be highlighted. Stigma and discrimination and its impact on HIV and AIDS and disclosure will also be discussed. Lastly, I will briefly examine literature on education and HIV and AIDS in Africa, then in South Africa, the main focus being the province of KwaZulu-Natal, and the challenges facing HIV-infected and affected educators on teaching and learning. The issues of absenteeism and attendance will be explored.

3.2 HIV and AIDS impacts on Society

As discussed in Chapter Two (Sections 2.2 and 2.3), the number of people infected with HIV worldwide has increased from just a handful of cases in the early 1980s to about 40 million by the end of 2005; more than 25 million people have already died of AIDS. Despite the improved access to antiretroviral treatment and care in many regions of the world, the AIDS epidemic claimed 3.1 million lives in 2005 (UNAIDS 2005). Sub-Saharan Africa remains the hardest-hit and is home to 25.8 million people living with HIV, almost one million more than in 2003 (UNAIDS 2005). The HI-Virus is a clever virus as explained below.

Abdool Karim (2005) explains that the HI virus is a retrovirus; it insinuates itself into the DNA of its host, becoming a Trojan horse in the immune system and systematically weakening the host until the body can no longer efficiently fight infection. The impact on those infected, the stigma attached to infection and the social and economic effects of that infection, cause HIV to have a broad effect on the economy, on issues of ethics, and on politics. HIV infection has not yet peaked, but poses a huge challenge for all South Africans in the twenty-first century. In support of this view, Lewis (UN General Secretary on AIDS in Africa 2004) states that:

The defining characteristic of the HIV and AIDS pandemic has been the needless loss of life, millions upon millions of lives. And even as we inch towards hope, the lives continue to be lost, daily, relentlessly, catastrophically.

HIV has been described as a new force of impoverishment in sub-Saharan Africa, which could reverse the progress made thus far, and set off a cascade of economic and social disintegration. Malloch Brown (2004), administrator for the United Nations Development Programme (UNDP), comments as follows in its Human Development Report:

The HIV and AIDS epidemic is Africa's most serious development crisis, with Southern Africa bearing the brunt with one in seven of the adult population living

with HIV and AIDS. The scale, severity and impact of HIV and AIDS on these societies is destroying the capacity of governments and communities to function effectively.

Whilst the powers that be have dragged their feet on mitigating the damaging effects of HIV, Brown (in the same report) warns that:

It is no exaggeration to say that unless the world meets the HIV and AIDS Millennium Development Goal, we have little prospect of reaching the other seven goals - which include the overarching target of eradicating extreme poverty and hunger by 2015, as well as achieving universal primary education, promoting gender equality, reducing child and maternal mortality and ensuring environmental stability - because the impact of HIV and AIDS is felt across all these areas¹.

From the above it can be said that HIV affects many more people than it infects. The epidemic impoverishes families as they try to meet the costs of patient care and funerals. Despite this growing crisis, the world is making poor use of behaviour change communication strategies for HIV and AIDS prevention.

In identifying three phases Foster (1996) suggests that in the cycle of illness and death from HIV and AIDS:

- The illness-during this phase and the concentration of HIV infection has significant implications for the productive capacity and income of affected households. In the informal sector, the HIV-positive individual generally moves from a production job to a servicing job, because there will be days when the individual will be too ill to work. The women folk are the care-givers and in many cases, young school-going girls drop out of school to

¹ Millennium Development Goal on HIV is to combat HIV and AIDS, malaria and other diseases. The target by 2015 is “to have halted and begun to reverse the spread of HIV and AIDS”.

assist. Household budgets have to be modified to include the additional medical expenses.

- The death of a prime-age adult is a tragedy for any household, as survivors have to contend with the loss of their loved one and cope with medical and funeral expenses, and the loss of an income. In most African countries, a large funeral is an important statement. The transportation and feeding of guests and the cost of a coffin can drive families into debt and financial devastation.
- The longer-term aftermath of a prime-age adult death has a devastating impact on families and households; survivors suffer economically, and the extent of this economic stress can be measured by social indicators such as orphan-hood, schooling, child nutrition, health, and poverty.

The above phases are common phases that a family may experience when a member of the family is HIV positive and reinforces the views expressed by Brown. Added expenses will surface when a person becomes ill, the household income will have to accommodate medical expenses and other necessities for the ill family member. When the family member who is the bread winner becomes ill and succumbs to HIV and AIDS. The blow is very hard and takes the family a very long time to adjust, at the same time one has to be mindful that both the HIV infected and affected are entitled to their human rights and dignity.

3.2.1 Discussing HIV and AIDS through a Human Rights-Based Approach

According to the South African Constitution, human rights are a universally recognised set of norms and standards for ensuring the human development, well-being and dignity of every person. HIV positive individuals may suffer from violations of their human rights when they are treated differently, marginalized or discriminated against, they may be victims to human rights violations when attempting to access health services, education and social services. Freedom from discrimination is a human rights principle which ought to be upheld at all times. Stigma, discrimination and human rights

violations form a vicious cycle where one feeds the other to form the cycle. The impact of discrimination against HIV positive individuals can be devastating, not only for the infected individual but also for the affected family members, they too suffer stigma and discrimination. Stigma and discrimination also affects the HIV positive person's chances of employment and also of holding down a job, even the fight against HIV and AIDS can be compromised. Hachonda and Adudah (2004) explain that a rights-based approach is important because it is the most effective means of addressing the social, political and economic factors that contribute to the spread of HIV and mitigating the social and economic impact of AIDS. They further added that it carries a moral obligation on governments to protect and respect the human rights of their citizens,² which includes respecting rights, protecting rights and fulfilling rights.

The Constitution promotes human rights, which in this study is discussed in the context of HIV and AIDS. It is in this context that most human rights violations occur. Hachonda and Adudah (2004) argue that the violation of human rights in the context of HIV and AIDS is serious because in most cases it infringes on the freedom of choice. Women and girls often cannot choose who they have sex with, and whether or not they use some form of protection.

According to Hachonda and Adudah (2004) health as a human right is defined as a "state of complete physical, mental, and social wellbeing, and not merely the absence of HIV or infirmity." Such rights (health rights), Hachonda and Adudah (2004) emphasise, include access to medicines. In recognition of this in 1998, the International Guidelines³ on HIV and AIDS and human rights were adopted by the UN Office of the High Commissioner on Human Rights and the Joint UN Programme on HIV and AIDS (UNAIDS). Another issue of great concern on the human rights agenda is one of confidentiality. Friends, relatives and colleagues are trusted when a disclosure is made about an HIV positive status, and it is expected that this trust and confidentiality is upheld. The flip side of this

² The integral link between HIV and AIDS and human rights was recognised at the UN General Assembly Special Session on HIV and AIDS (UNGASS) in 2001 (UN General Assembly. Declaration of commitment on HIV and AIDS, Paragraph 80).

³ Guidelines on HIV and AIDS and Human Rights, as adopted by the 2nd International Consultation on HIV and AIDS and Human Rights. See Secretary General's Report, 20 July 1997.

confidentiality issue is one that is faced by a medical practitioner, should the medic keep confidentiality when there is the danger of the HIV positive persons' spouse becoming infected. This poses a huge dilemma for the medical practitioner. All people have human rights, even the marginalized and stigmatized, in order to address the HIV pandemic human rights must be upheld. One wonders if this health human right is really in practice in Africa, when citizens have to pay for health services, thereby turning health into a commodity for profit and promoting fertile ground for HIV infection. HIV and AIDS is not just a health, moral or humanitarian issue, it is also a security issue. It has the ability to destroy societies, robbing the youth of people they need to shape their futures, their parents, families and educators.

3.3 Anthropological Issues

This section on anthropological issues will include discussions on gender and HIV, gender inequalities and poverty, traditional cultural practices and HIV and gender and education HIV and AIDS shows up global inequalities, and its presence and impacts are felt most profoundly in poor countries and communities. HIV and AIDS programmes must take into consideration the contexts and environments that people live in, so that programmes are effective. Kincaid et al (2008) says that while levels of knowledge are generally high in South Africa, there are still gaps on the issue of HIV risk and multiple partners. UNAIDS (2008) concurs that this is not a problem unique to South Africa, but is fairly common throughout the world. According to AIDS epidemic update (2005), development is about hope for the future and changing social and economic situations for the better, HIV and AIDS will alter the history of many of the world's poorest societies, in the absence of effective and available vaccines or economically feasible and effective treatments, AIDS may wipe out much of the development gains. United Nations (1996) believe that in least developed countries, such as sub-Saharan Africa, global life expectancy of 36 years in the early 1950s rose to 52 in the early 1990s, but that this progress should not mask the fact that health conditions remain grim in these parts of the world, adding that a child born in the worst affected countries between 2005 and 2010

can expect to die before his or her birthday. The prevalence rate amongst women in most southern African countries is a huge cause for concern, WHO Regional Office for Africa (2003); Reproductive Health Research Unit & Medical Research Unit (2004), suggests that more than three quarters of all young people living with HIV are women, the next sub-section will expand on the discussion concerning women.

3.3.1 Gender and HIV

Gender roles vary and is dependent mainly on the socio-economic and cultural context of the environment, gender relations are usually characterized by an unequal balance of power between men and women. When women have fewer legal rights, especially where patriarchal laws prevail, and less access to education, then preventing and managing HIV is difficult. Anecdotal evidence⁴ shows that most HIV prevention programmes attempt to persuade people to change their lifestyle and sexual behaviour, and for women to change that of their partners as well, these programmes assume that men and women can be given knowledge which will lead them to make rational decisions to practise safer sex and to implement those decisions, but, the difficulties facing women who attempt to do this are often not taken into consideration. Shisana & Simbayi (2002) say that more women than men are HIV positive, Maman et al (2000) volunteer a reason for this increased risk for women as biological and social risk factors. They argue that violence against women is too often regarded as an individual and private matter, and this has become a major concern for women's groups. Men and boys are not excluded from this discussions

The 2000 World AIDS Campaign (UNAIDS 2001) focused on men and boys for four main reasons:

- Men's health is important but receives inadequate attention
- Unprotected sex between men endangers both men and women

⁴ From discussions at a HIV trainer workshop in Loskop (Estcourt) in October 2007, with educators from the Loskop ward.

- Men need to give greater consideration to STIs as it has an impact on the whole family
- Men's behaviour puts them at risk of HIV

Baylies and Bujra (2000) argue that in studies done on women, the main focus was that “gender” was synonymous with “women”, and that gender relations are now recognised as a key factor in vulnerability to HIV and the impact of HIV and AIDS on women and their families. Another issue of concern is the attention paid to men concerning their role in the transmission of HIV and their own vulnerability. A contributory factor to this concern, according to Mhloyi (1995), is “cultural entrapments” which make men as well as their partners vulnerable to HIV. Akeroyd (2004, as cited in HIV and AIDS in Africa) argues about “cultural entrapments”. She believes that to reorder the social system, the men who control it need empowerment, which would in the long run help meet the strategic interests of both women and men.

Prevention strategies also recommend faithfulness within a sexual relationship as a means of ensuring that sex is safe. But Reid (1992) argues that this will mean little to the millions of women who already confine their sexual activity to their husband or long-term partner. He further adds that between 50-80 percent of all HIV-positive women in Africa have had no sexual partners other than their husbands. Allen et al (1993: 55) support Reid's view, citing a study⁵ in Rwanda, which found that although two-thirds of women claimed to have had only one life time partner, 21 percent were HIV-positive. Hence, the risk for many women comes not from their own sexual behaviour but from that of their spouses/partners over whom they have little control.

Holding a similar view is Kisekka (1990), who notes that in Uganda, government educational campaigns have not only exhorted themselves to adhere to strictly monogamous behaviour called “zero grazing” but women are expected to be “moral guardians”, thus giving them the responsibility for controlling not only their own behaviour but that of their partners too.

⁵ See Allen et al (1993) ‘HIV Infection in Childbearing Women in Kigali, Rwanda’

In my opinion, if women become infected, gender inequalities also affect their chances of survival and the quality of care they receive. Women's lower social status and greater poverty means that they have less access than men to health care.

HIV prevalence rates among women in South Africa is among one of the highest in sub-Saharan Africa, according to a health survey.⁶ HIV prevalence among pregnant women has reached its highest levels to date, as 29.5% of women attending antenatal clinics were HIV-positive in 2004. Prevalence was highest among women aged 25-34 years, with more than one in three living with HIV. The latest data, according to UNAIDS (2005: 21), reveals the frightening speed at which the epidemic has evolved: national adult HIV prevalence of less than 1% in 1990 rocketed to almost 25% within 10 years.

Patton (1994) and Wilton (1997) say that the AIDS epidemic is a "gendered epidemic". Richardson (1994) supports their view, asserting that the intricacies of women's experiences would differ from context to context and that commonalities of women's experiences in relation to the AIDS epidemic need to address the issue of relative power in sexual relations.

3.3.2. Gender Inequalities and Poverty

The focus in this section will be on unequal power relations and poverty and how these issues play a part on HIV infection. Gender relations are characterised by an unequal balance of power between men and women, with women having fewer legal rights and less access to education, training, health services, property and income generating activities. Baylies and Bujra (2000) argue that HIV and AIDS are often referred to as a women's issue and women are assumed to be carriers of the virus. They further state that one needs to ask how HIV and AIDS affects women specifically, and how women's subordination influences their risk status and experience of HIV and AIDS, and in what ways does the unequal position of women play a significant role in HIV infection in

⁶ See Department of Health, South Africa (2005). National HIV and syphilis antenatal sero-prevalence survey in South Africa 2004.

women? The question of the extent to which women's ability to reduce their risk of infection, and the impact that HIV and AIDS has on their lives, is not only a reflection of their unequal position in society, but also reinforces male power and control over women. Do HIV and AIDS or, more specifically, social and political responses to HIV and AIDS, actually increase women's oppression?

Worldwide, according to UNAIDS (2005), there are as many women as there are men with HIV infection. In South Africa, according to the Department of Health (2005) prevalence was highest among women aged 25-34 years, more than one in three was estimated to be living with HIV. More women have HIV infection in South Africa compared to men, and women are infected at a much younger age. Abdool Karim (2005) believes that it is crucial for men to take greater responsibility and be actively involved, individually and at a community level, in efforts to reduce women's risk of acquiring infection with HIV.

From a study⁷ done by Eaton et al (2003) on unsafe sexual behaviour of youth in South Africa, a conceptual framework for the factors that promote sexual risk behaviour, or that cause barriers to safer sex practices, was developed. This model distinguishes among three levels of factors or domains of analysis which overlap to a certain extent and reciprocally influence each other. The three levels of factors identified are **personal factors**, which reside within the individual, such as feelings related to sexual behaviour; **proximal factors**, which encompasses features of relationships and the environment that intimately impinge on an individual, and the **distal factor**, which refers to the less immediate elements of a person's environment such as cultural and traditional aspects.

While there has been much awareness created through workshops, talks at schools (especially during World AIDS Day) and the mass media, Aggleton and Homans (1988), and Campbell and Hayes (1998) argue that HIV-prevention programmes have tried to alter sexual behaviour by providing information about health risks and sexually transmitted infections management, and by distributing condoms. However, they say

⁷ See Eaton et al (2003) 'Unsafe sexual behaviour in South African youth'.

these interventions typically have had limited success and it has been acknowledged that HIV-related information in isolation plays a limited role in HIV management.

The issues of gender and poverty are closely linked to HIV and AIDS. Ankrah and Long (1996) argue that poverty places women at greater risk of AIDS, since they engage in transactional sex in order to meet their basic needs and those of their family members. Wingwood and DiClemente (1998) support their argument, saying that often the male partner provides assets such as money, status and security to relationships on which the female partner relies. While the male partner is seen as the breadwinner, the female partner is seen as the provider, regardless of how this is done. Strebel and Lindegger (1998) believe that poor women are more likely to depend on a regular partner or multiple partners for financial survival, and they may be less able to insist on safe sex for fear of jeopardizing these relationships. MacPhail (1998) argues that the imbalance of power relations between men and women makes attempts by men to coerce women into sexual relationships appear acceptable. This imbalance of power, according to Doyal (1994); Heise and Elias (1995); MacPhail (1998) and Wingood and DiClemente (1998), make any negotiation of safer sex very difficult, and may lead to violence directed towards women who suggest condom use.

3.3.3 Gender Agenda

Women in developing countries are expected to prove their worth by marrying, having children, and caring for their families (Jewkes & Abrahams 2000). As discussed, women are especially vulnerable to HIV, and are the least empowered to avoid being at risk. Women are more stigmatised than men if they become HIV positive.

In the AIDS crisis, women are most of time completely invisible, face severe and sometimes insurmountable obstacles to coming out with a positive HIV status, are rarely provided with adequate care, and have to take care of the most people' (The ACT UP/New York Women and AIDS book group, 1990: 243).

The above quotation clearly shows that women's subordination influences their risk status and experience of HIV and AIDS. The unequal position of women in society plays a significant role in HIV infection in women. Among reasons for the muted response of feminism to HIV and AIDS, according to Richardson (1994), is the view of men as "the norm" in the AIDS crisis. This has not only helped to render women invisible to researchers and those involved in the diagnosis and treatment of HIV and AIDS, it has also shaped the development of, for example, educational, housing, health and social services policies, which do not successfully meet women's specific needs.

Such situations demand a need for a feminist response in challenging assumptions of framework for understanding women's position in the AIDS crisis, which could inform the policy-making process and help determine service provision. Policy-makers and managers need to recognise how health-care reform, privatisation and the shift from institutional to home and community-based care affect the lives of women.

Scott (1987: 18) is of the opinion that, "AIDS has promoted the open discussion of sexual practice on an unprecedented scale". She added that, "we should seize the opportunity to get into debate, proposing alternatives to a penetrative heterosexual morality and place a radical, feminist, analysis of sexuality firmly on the agenda". Scott further added that sexuality is identified as a site of struggle in feminist theory, in which men exercise power over women, and it is these power relations embedded in sexual relations that help to explain both how and why women find the process of negotiating safer sex difficult.

In support of the above, Holland et al (1990: 5) argue that "from a feminist perspective, using or not using a condom is not a simple, practical question about dealing rationally with risk, it is the outcome of negotiation between potentially unequal partners". In many sexual encounters, women have little choice about whether or how to engage in sexual activity with men, the options being physical injury or more subtle forms of sanction.

At education campaigns much is said about "safe sex", but what exactly is safe sex? From a feminist perspective, the concept of "safe sex" incorporates much broader concerns. "Safe sex," Richardson (1990: 34-35) says, is about not getting other sexually

transmitted diseases, making sure you do not get pregnant unless you want to, reducing the health risks associated with certain forms of contraception and preventing cervical cancer. There are all sorts of reasons why sex for women is often unsafe for emotional as well as physical reasons. Women get raped and sexually abused. Women often feel pressurised into having sex just to please their partners. Richardson (1990) argues that when women are forced into having sex, it can shatter their self-esteem, and leave them feeling exploited and used. Safer sex is about sex that individuals enjoy and feel good about. It is about sex on consensual terms; “sex that reduces the risks to minds as well as bodies”.

3.3.4 Traditional Cultural Practices in an HIV Climate

Another aspect of great concern in the HIV scenario is the issue of traditional cultural practices. A study in Kenya⁸ aimed to highlight the challenges of some of the traditional cultural practices of women in the fight against HIV infection. The National AIDS Control Council (NACC 2000) believe that within the age range of 15-24 years, females were found to have twice as many HIV infections as their male counterparts. Otieno (2007) concurs that the early exposure to HIV among women leads to early deaths usually by mid-twenties to early thirties, and believes that the pandemic is being fueled by ignorance and traditional cultural practices that are deeply embedded in society for centuries, despite the danger they now pose with the spread of HIV and AIDS. Otieno adds that Kenya like most African countries, is rich in its various cultural practices, and that Kenyans believe that if cultural practices are violated, they will perish.

Omwega (2001) argues that the Kenyan government, churches and families were in denial about HIV infection (because of the stigma attached to HIV) until two years ago. It is estimated that at least seventy people die each day as a result of HIV Wagiri (2001) contends that female genital mutilation (also known as female circumcision) contributes to the subservience of women and the spread of HIV because it is carried out in less than

⁸ Otieno T N (2007) The Dilemma of Kenyan Women: Questioning Tradition in the Battle against HIV/AIDS.

hygienic conditions by women who are not trained. The danger in this practice is the possibility of HIV transmission, but for a community in denial of HIV, the practice is all the more dangerous.

Marrying girls off at a young age, according to Kimani (2002), may appear awkward and inhumane, but this practice is widely followed among ethnic groups in Africa. Kimani further explains that the danger here is that men who marry these young girls are much older and a teenage bride is probably a second or third wife, thus promoting polygamy and the spread of HIV. Leclerc-Madlala (2003) agrees with Kimani's view in that African culture encourages young women to marry older men. The NACC (2000) concurs that the African tradition of polygamy often poses difficulties in prevention strategies against the spread of HIV and AIDS. Okongo (2001) concurs with the above views saying that it is difficult to manage the spread of the virus in a monogamous relationship, but the situation becomes more complicated where multiple wives are involved, and this polygamous, submissive role played by women for many centuries is posing a huge threat to their health and the spread of HIV.

South Africa's neighbour Botswana has one of the highest prevalence's of HIV in the world (*Botswana 2003*), estimated at 37% of adults aged 15-49. A survey⁹ was done with people who were recruited from three private clinics in Botswana by their caregivers. The people in this survey were interviewed on issues of HIV-testing, stigma and discrimination. The respondents in this study explained their fear of an HIV-positive diagnosis, hence the reluctance in getting tested; this fear was also related to the stigma and discrimination associated with HIV. The survey revealed that stigma and discrimination were huge obstacles to getting tested and seeking treatment; from this survey it was noted that 94% of the participants kept their HIV positive status a secret from their communities; 69% withheld this information from their own families and 47% stated that HIV affected their ability to work, resulting in frequent sick leave, and fear of job-loss.

⁹ See Effects of HIV-related stigma among an early sample of patients receiving antiretroviral therapy in Botswana. *AIDS Care*, November 2006.

According to Botswana's Strategy (2004), stigma is a key barrier to HIV testing and treatment in African settings, and this should be recognised as a major target for intervention. Botswana's "opt-out" policy as stated by *The Ideal* (2004, cited in *The Economist* 2004) was introduced in 2004 and intended to reduce AIDS exceptionalism by making HIV testing a routine part of all medical interactions and allowing patients to obtain results without others knowing. This initiative, according to reports (LaFraniere, 2004: *Rolling out*, 2004), suggests that the numbers of patients undergoing testing and enrolling in ARV therapy has increased significantly. The high HIV prevalence amongst females is attributed to the female anatomy, and they are often referred to as carriers of the virus.

The unequal status of women have put them in a predicament concerning HIV, according to a study done on African-American women¹⁰. Murray (2007) says that statistics reveal that African-American women are 23 times more likely to be infected by HIV compared to European-American women. She believes that factors like socio-economic status, self-esteem issues, the myth that HIV and AIDS only affects gay men and a false sense of security with their partners, are responsible. The study also revealed that African-American women represent 64% of female HIV and AIDS cases, and that blacks in the United States maintain one of the highest rates of HIV and AIDS infections in the nation although they are just 13.4 % of the population. In my view HIV is considered to be a colour-blind, classless virus, the spread of HIV is strongly related to life-style choices, ignorance about the transmission of the virus and the stigma and discrimination related to this ignorance.

Here in South Africa, women live in a patriarchal society, and are generally labeled as carriers of the disease. This claim is highlighted in a study done in a black township in CapeTown¹¹ to explore how women experience and deal with AIDS stigma under conditions where they have little formal support. The study found that after the women in the study received their HIV positive diagnosis, they viewed themselves as dangerous,

¹⁰ See Murray's article (2007), New HIV/AIDS study seeks to include African-American women.

¹¹ See Rohleder & Gibson (2006), 'We are not fresh': HIV positive women talk of their experience of living with their 'spoilt identity'.

dirty and contagious. The women took on an image of a “spoilt identity”, which was difficult to manage in the social context in which they lived. While they attempted to do so, its effects were at times overpowering, leaving them with an overwhelming feeling of loneliness and sadness. The study also reported that HIV remains a highly stigmatised condition that affects the deviant “others”.

The KwaZulu-Natal province in South Africa is considered to be the worst hit by the HIV and AIDS epidemic (ELRC Report 2005; Motsemme 2007). This is evident from a study¹² by Motsemme (2007) in the township of Chesterville¹³ in Durban. In this study Motsemme explains the plight of the women she interviewed in a township, which is one of the poorer ones. The township has acquired the status of one that “harbours HIV and AIDS”, and people from there are considered to be dangerous, polluted, and potential carriers of HIV. Motsemme further adds that such sentiments reinforce notions which tend to fuse poverty with women, thus linking them to symbolic and physical pollution. Her study alludes to linking such people as hyper-vigilant and self-conscious about anything that may link them to this “death-promising virus”, including speaking about HIV and AIDS in “veiled and masked” forms.

HIV and AIDS has become feminised and racialised, with women always being blamed as carriers of the virus. McFadden (2004: 12) agrees:, ”...the dominant discourses of disease and sexuality have traditionally portrayed the Black female body as the essentialised vector of “evil” and “promiscuity”.

For any programme to be effective, there must be monitoring and evaluation, anecdotal evidence often criticises programmes that are not monitored and evaluated as ineffective. A study¹⁴ by Hoosen & Collins (2004) suggests that education programmes have not reached enough people, and are not sufficiently effective. They emphasise that future AIDS programmes need to challenge discursive practices that disempower women.

¹² See Motsemme N. (2007), ‘Loving in a time of hopelessness’: On township women’s subjectivities in a time of HIV/AIDS.

¹³ Chesterville is a township in the city of Durban in the province of KwaZulu-Natal in South Africa.

¹⁴ See Sex, sexuality and sickness: Discourses of gender and HIV/AIDS among KwaZulu-Natal women. South African Journal of Psychology; Sept 2004, Vol.34 Issue 3, 487-505.

3.3.5 Gender, Education and HIV

The HIV and AIDS pandemic in South Africa has conspicuous gender features. Females are particularly vulnerable to this virus primarily because of their anatomy. Whiteside and Sunter (2000) explain that women are estimated to comprise approximately 56% of those infected with HIV, with the single largest group of women comprising those aged 15–34. Young school girls are also vulnerable to the HIV and AIDS pandemic. Morrell et al. (2001), state that in KwaZulu-Natal, it is estimated that among 15–19 year olds, 64% of African girls are likely to be HIV-positive compared to 55% of African boys. This high rate of infection among girls and women in the 15–34 age group can be attributed to power inequalities in heterosexual relationships. According to Jewkes and Abrahams (2000) and Jewkes et al (1999), a study done in three South African provinces¹⁵ showed that coerced or violent sexual relationships meant that women were not able to insist on condom use, making them vulnerable to HIV infection. They added that education and information about safe sex are unlikely to make any impact on individuals, unless men and women understood the importance of gender equality in relationships. Schools could play a big role in changing mindsets of the youth in understanding the importance of gender equality.

While the school was considered to be the best place to raise HIV and AIDS awareness through education, this reliance on the school as a means for changing attitudes and sexual behaviour has been somewhat misplaced. It has been noted from anecdotal¹⁶ evidence that many schools are reported as sites of high levels of gender violence directed at girls. Gordon (1993) and Hallam (1994) say that the existence of serious sexual harassment and abuse in schools in sub-Saharan Africa, has been documented as early as 1993-4. Recently, in-depth studies have been carried out, which include studies in South Africa by the Human Rights Watch, (2001); Morrell, (2000); in Zimbabwe by Leech & Machakanja (2001); in Kenya by Omale (2000), in Botswana, Uganda and Malawi as part of the study of HIV and AIDS and education by Bennell et al (2002); in

¹⁵ See Jewkes et al (1999) 'He must give me money, he mustn't beat me. Violence against women in three South African provinces. Report prepared for CERSA, MRC, Pretoria.

¹⁶ View expressed by educators at an HIV workshop in Mtwalume (UGU) in 2007.

Namibia by Daniel (1998) and in Ghana by Leach, Fiscian, Kadzamira & Lemani, (forthcoming).

Schools are expected to be “safe places” and a “haven” against abusers, where parents know that their children are safe from harm, yet there is a contradiction between schools as effective forums of teaching and learning and places of high risk sexual practices. In a study undertaken by Grant and Hallam (2006) on pregnancy related school dropout, it was found that young girls bear the brunt of school sexual practices and have to drop out of school when they become pregnant. Leach & Machakanja (2000) and Mirembe & Davies (2001) suggest that the school, far from discouraging high risk sexual behaviour, actually encourages it through a culture which allows the development of stereotypical masculine and feminine behaviours and promotes “compulsory” heterosexuality. This makes girls vulnerable to aggressive sexual advances from male learners and educators within the school, as well as adult men (sugar daddies) outside it.

In my view inequality and gender violence in school is a reflection of inequality and gender violence in society. When inequality and violence exist in the home and the community, it regrettably prepares young people to expect and to accept inequality and violence as a part of their daily life both at home and outside the home.

3.3.6 Gender and Vulnerability

This issue of violence against women is a violation of human rights, and a major contributory factor to women’s vulnerability to HIV infection. The importance of gender equality must be upheld, especially in the light of the Millennium Development Goals to turn the tide of HIV by 2015. Morrell (2009) argues that gender equality is a global goal enshrined in the Millennium Development Goals, he further stated that the importance of gender equality would raise the living standards of vulnerable groups, contribute to development, better relations and a healthy planet.

Whilst the debate around the relationship between gender and vulnerability is ongoing, Campbell (2003: 1) argues that the gender and vulnerability analysis does not take us very far in explaining why “people knowingly engage in sexual behaviour that could lead to a slow and painful premature death”. Women’s bodies, say Holland et al (1994), are the basis of their material existence - their few pleasures and many pains and if women are to confront the global HIV epidemic with effective strategies for safer sex, then they need to understand, recognise, control and take care of their bodies. They further add that sex as a social activity means negotiating sexual practices with partners. They argue that if heterosexual women are able to control their bodies, they must come to terms with the ways in which the social construction of masculinity and femininity estranges women from their bodies. Holland et al (1994) stress that safer sex is possible when women are able to assert and express their desires, and are able to understand and respond to the risks that women run in heterosexual encounters. Safer sex requires that women embody their own desires that they are informed about their bodies and the risks they can run into. They believe this embodiment provides a social space within which women and men can negotiate sexual encounters so as to ensure that sexual safety is a shared concern.

Holland et al (1994)¹⁷ emphasised that sexual safety cannot, however, develop in isolation in the privacy of sexual encounters, since these encounters are constrained by gendered power relations. Gatens (1988) points out that feminists have made women’s bodies a focal point around which struggles for autonomy have been fought. She contends that conflict around women’s rights to contraception, abortion, control of childbirth and pleasure have clearly been central to feminism. She argues that men have been seen as having power over women in battles for control of the body, and that this view of gendered power, which is so central to feminism, is disputed by Foucault and his poststructuralist followers. Gatens (1988) is of the opinion that feminist theory has developed with little reference to his theory of the body, sexuality and the nature of power, while Foucault has largely ignored feminism. She contends that an analysis of the

¹⁷ See Holland et al (1994) *Desire, Risk and Control: The Body as a Site of Contestation* (as cited in Doyal et al.

tensions between Foucault and feminism can be a productive way of understanding the disembodiment of femininity, and therefore the problems of achieving safer sex.

Holland et al (1994) have reported that, according to radical feminists, the most important factor of women's oppression is located in men's control of women's bodies, with male power exercised through men's control over female sexuality and reproductive capacity. They further argue that at an abstract level, the concept of patriarchy has helped to understand the nature of male-power. Feminist studies have explained the exercise and threat of male violence as entwined with sexuality.

Holland et al (1994) argue that Foucault's work raises problems for feminist conceptions of patriarchy and women's liberation, arguing that in his view, women cannot understand power as a possession which can be held by a group or groups in society. As there is no such possession, there cannot be patriarchal power held by men and opposed by women. According to Foucault (1988), power is diffuse rather than located in some central group, institution or source. He therefore believes gender then cannot be a source of power, but this does not mean that power is shared. He further adds that some categories of people will be subjected to power exercised by others and that their bodies will be disciplined and controlled. The body for Foucault is changeable, since it is a social site in which ideas and discourses about sexuality are played out. Sawicki (1991) asserts that the body is both material and, at the same time, a social space where the larger-scale organisation of power is connected to minute and local practices.

Foucault (1988) emphasises that the body is both a target of power, since it is constituted by discourses, as well as a site of resistance. The meaning of resistance is one point where feminist politics diverge from Foucault's relativism and pluralism (Hekman, 1990).

Braidotti (1991: 18) summarises the problems of Foucault's position by arguing that he is trapped in a gender-blind theoretical discourse, which is not just politically unacceptable but, in leaving women out, is inaccurate as a theory: "the notion of power which Foucault

develops rests on a masculine view of the body.” Although he identifies the body as a site of power, he rejects the idea of women confronting a patriarchal system. Issues of sexual identity, the body, its desires and acts are foregrounded by HIV and AIDS, and must be confronted within discourses of health promotion and social policy as never before (Frutchey, 1990; Patton, 1990b; Watney, 1990a).

Jefferys (1990) believes that while sexual identity is used as a “hook” to grab people’s attention, the social ascription of masculinity demands that biological males achieve masculinity through a variety of actions, central to which is penetrating women sexually. Wilton (1994) in her paper¹⁸ argues that a Feminist/Foucauldian analysis of femininity suggests ways in which dominant discourses of femininity construct the female body as a paradigmatic site for establishing and perpetuating gendered relations of power. All these discourses show that the female body is a “hot-bed” for “power-contestation”. In addition, Bartky (1988: 89) argues that woman is a “self-policing” subject, a self committed to a relentless self-surveillance. This self surveillance is a form of obedience to patriarchy and it is also a reflection in the woman’s consciousness that “*she*” is under surveillance in a way that “*he*” is not, and no matter what her status is, she is importantly a body designed to please or “*excite*”. Or as Berger (1972: 89) says, “women are there to feed an appetite, and not to have any of their own”. This positioning of women as the object of desire, “*innocent*” of sexual agency, has far-reaching implications for the sexuality of both men and women. Stimpson (1988: 89-90) points out that this image of women as “*innocent*”, makes logically necessary the image of women as “*victims*”. If desire is unavailable to women, then sex can only be something done by men to women. If mutual sexual pleasure is not available to women, then sexual practices which foreground male pleasure are inevitable. This vicious cycle of the discursive structuration of femininity has profound implications for how views about women are related to HIV and AIDS issues.

¹⁸ See Wilton (1994) *Feminism and the Erotics of Health Promotion* (cited in Doyal, *AIDS: Setting a feminist agenda*).

Kitzinger (1994) says that HIV and AIDS is carelessly referred to as a women's issue, and the claim that women spread the disease, leads communities to ask not only how HIV affects women specifically, but also how women's subordination influences their risk status and experience of HIV and AIDS. Hence, Kitzinger (1994) unpacks the term "women" as untainted by any prefix, representing the "ordinary person", a symbol for "the family", the "general population" and all the "innocent victims" of AIDS. Generally the mention of HIV is followed by stigma and discrimination, hence the fear and silence around HIV disclosure. In the next sub-section a discussion on HIV-related stigma will be provided.

3.3.7 Undressing Stigma

In the section on stigma, a sound perspective is offered and a discussion of the relationship between gender and HIV is presented. This section will include discussions on social perspectives on stigma, how stigma promotes HIV and its relationship to gender, stigma and identity. In the context of this study I use the definition of stigma according to the World Book Dictionary (1990: 2056), *stigma* refers to a mark of disgrace or shame, a stain or reproach on one's reputation. Goffman (1963) defines *stigma* as a deeply discrediting attribute that reduces a person to someone who is in some way tainted and can therefore be denigrated.

Cabe and Sorkin, (2002) explain *stigma* as a pervasive problem that affects health globally, threatening an individual's psychological and physical well-being. Enacted stigma refers to the real experience of discrimination, according to Brown, Macintyre and Trujillo (2003). Discrimination arises out of any point of difference that can be consistently labeled, such as physical deformity or disfigurement or any factor that sets the person as different to the perceived norm. Goffman (1963) describes discrimination as the sum total of acts or omissions in which the content of stigma is applied, either at an individual or social/community level. Stigma has four components: distinguishing and labeling differences; associating human differences with negative attributes; separating "us" from "them" and status loss and discrimination.

Link and Phelan (2002) explain stigma as entirely dependent on social, economic and political power, as power is required to be able to introduce stigmatisation. Stigma removes power from the stigmatised group or person's social status and self-worth.

3.3.7.1 A Social Perspective on Stigma

Society officially opposes racism, sexism, ageism and other types of prejudice, and the unequal treatment of certain individuals. Singhal and Rogers (2003) find that outlawing discrimination is seldom very successful in changing human behaviour. Stigma, which is very deep-rooted, can be modified over a period of several generations, although laws and policies demand such change. According to Goldstein (1989: 84),

Many illnesses transform their victims into a Stigmatised class, but AIDS is the first epidemic to take Stigmatised classes and make them victims.

The above quotation has bearing on how stigmatized HIV positive people are viewed, whilst HIV has no cure to date and it is referred to as a serious condition. Schiff et al (2003) are of the opinion that stigma has interfered with effective societal response to HIV and AIDS, whilst Parker and Aggleton (2003) argue that assessments of attitudes and knowledge about HIV transmission associated with stigmatizing attitudes are important to guide efforts to remove barriers. On the same issue London and Robles (2000) and Herek et al (2002) believe that members of the public understand how HIV is transmitted, but they are less knowledgeable about how HIV is not transmitted. The impact of stigma and discrimination not only affects the HIV-positive person, but also disrupts society and the functioning of communities in their attempt towards prevention and treatment.

Stigma sweeps HIV under the carpet, out of public sight, thereby reducing the pressure for behaviour change. The fear of stigma disallows an individual from knowing his/her status, which leads to the delaying of testing and accessing treatment. Stigma undermines an individual's identity and capacity to handle the disease.

3.3.7.2 Stigma Promotes HIV and AIDS

The HIV and AIDS epidemic is accompanied by fear and denial and this brings about stigmatisation and discrimination against people with HIV and their family members (Herek & Glunt 1988; Mann, 1987). Gupta (2001) believes that individuals who do not know their serostatus live in fear of facing stigma and discrimination should they become HIV positive.

Stigma and discrimination has caused much anger, pain and shame internationally; in South Africa it took on a particularly horrendous form in the apartheid system. Stigma plays a major role in society in creating difference and social hierarchy and in legitimizing and perpetuating social inequality (Parker, Aggleton, Attawell et al 2001). Petros et al (2006) argue that the issue of 'othering', illustrates the stigma, discrimination and blame for HIV infection. The attachment of discrimination to illness has a long history, impacting on people with mental illness and physical disorders such as cancer, TB, STDs and leprosy (Sontag, 1988). Some of the illnesses mentioned by Sontag are incurable or air-borne, hence the discrimination and isolation. Stigma and discrimination as cruel social processes offer some sense of protection to the powerful, while increasing the load on the individual who is the victim. Stigma is also seen as a tool used by more powerful groups to protect themselves as people against tainted individuals. The next section discusses the apportioning of stigma and discrimination according to gender.

3.3.7.3 Stigmatism and its Relationship to Gender

According to CADRE¹⁹ (2005), stigma makes the consequences of the AIDS epidemic much worse than it would otherwise be. They say that communication interventions can decrease the stigma with which the virus is perceived, adding that the growing numbers of women with HIV and AIDS are concentrated in the poorest countries, where medical assistance and support is scarce or in some cases non-existent. Bassett and Mhloyi

¹⁹ Centre for AIDS Development, Research and Evaluation (CADRE)

(1991: 146) in a study²⁰ in Zimbabwe, say that, “For many women faced with divorce or dire poverty on the one hand and the risk of HIV infection on the other, the choice becomes one of “social death” or “biological death”.

Women have been blamed and discriminated against for spreading the epidemic. They are contradictorily expected to provide sexual services to men, to be chaste and pure, and to take on the responsibility of preventing pregnancy and disease (Crewe, 1992; Madlala, 2002). According to UNAIDS (2001a), a women’s vulnerability to HIV infection is four times greater than that of men, and due to many social and economic power imbalances, women may not have the power to insist that their sexual partners wear a condom; ignorance and fear underlie the HIV-related stigma. UNAIDS and Herek et al (2002) argue that poor understanding of the modes of transmission leads to fear of transmission from casual contact. Herek and Glunt (1988) believe that for many of the people living with the virus, the impact of HIV-related stigma is compounded, as people who experience it are often members of already disempowered or stigmatised groups such as women, sex workers, the poor or homosexuals. They further add that through stigma, society often blames infected people for being ill and justifies discriminating acts against them while asserting the innocence and health of those who stigmatise, making it a case of “us” and “them”.

Stigma around HIV is connected to the historical racism and gender discrimination, and has developed a particular form of discrimination. Blame, Madlala (1997; 2002) and Shefer (2003) explain, is often assigned to black people or to women. Men blame women for infecting them and spreading the virus. According to Sontag (1988) and van der Vleit (1996), stigma around HIV often attaches itself to existing stigmatizing frameworks.

Warwick et al (1998); Aggleton and Warwick (1999), are of the opinion that the family is the main source of care and support for people living with HIV. However, negative family responses are common. This is a possible reason for the reluctance of disclosure

²⁰ See Bassett M. and Mhloyi M (1991) Women and AIDS in Zimbabwe: the making of an Epidemic.

of HIV status. Bharat and Aggleton (1999) add that infected individuals often experience stigma and discrimination in the home, and women are often more likely to be badly treated compared to men or children, given negative community and family responses to women with HIV and AIDS. The latter include blame, rejection and loss of children and home. Herek (1999) and Schiff et al (2003) argue that in many cases, secondary HIV and AIDS stigmatisation was extended to families, friends and neighbours. This secondary stigmatisation and discrimination has played an important role in creating and reinforcing social isolation of those affected by the epidemic.

3.3.7.4 Stigma makes the Epidemic (HIV) Invisible

The main impact of discrimination and stigma is that it pushes the epidemic underground, forcing people with HIV into hiding. This makes disclosure very difficult if not impossible. Apart from the fact that people living with HIV (PLWH) are discriminated against, they are also isolated and stigmatised. Relatives and friends who are associated with the HIV positive people are also discriminated against. Skuiner (2001) argues that this stigmatisation forces the disease to remain hidden, and so its perceived threat is reduced. It also makes HIV someone else's problem. He further adds that stigmatizing beliefs then facilitate the use of denial by individuals and communities as defensive processes against the epidemic, thereby reducing the need to adapt, and creating barriers between those infected and the rest of the population. This belief then robs the intervention of some of the best advocates for behaviour change, especially those who are directly affected. The epidemic is left with a few public faces, which gives it a false sense of prevalence. This in turn is dangerous, leading people to assume mistakenly that they are safe. The big problem arises when those with the power to construct interventions use discrimination as a basis for not promoting such programmes.

Stigma and discrimination have a significant impact on diagnosis and treatment in that people are not always willing to get tested. For the HIV positive person it can delay diagnosis and also entry into treatment and practice of a safe and healthy lifestyle. According to Karim et al (1992), there is no motivation to be tested, as the person sees no

benefit when the diagnosis of HIV is considered to be equivalent to death, and they are likely to experience discrimination. Lie & Biswale (1994) say that in certain contexts, research respondents have shown themselves to be more fearful of the stigma than of the virus itself, so even with treatment, stigma may be a block to access.

3.3.7.5 Identity Crisis and the HIV Positive Women

Kalichman (2004) finds that the impact of stigma on women living with HIV and AIDS is difficult to measure. He contends that stigma and discrimination become internalised into their self-perception and sense of identity (women's identity in this context is one of subordination, and borders on anger for their predicament; hence, their self-imposed isolation). This in turn impacts on women's perceptions and how they interact in the workplace. Research has found that people with HIV feel isolated, guilty, dirty and full of shame, which is often incorporated into identity (Kalichman 2004). In the workplace, women feel that their movements and general participation in activities become restricted by their self-perceptions and assumed perceptions of their colleagues, and the stigma that is prevalent around HIV positive people. Link and Phelan (2002) explain that HIV-positive women also feel rejection, causing them to feel compromised. They blame themselves for their situation. Certain behaviours such as the use of condoms have become signifiers of the epidemic, leading to the possible rejection of those who initiate their use (Link and Phelan 2002).

Sexual culture and power places women in a vulnerable situation regarding HIV infection, which is exacerbated by poverty, as poverty encourages women to engage in sex as an economic strategy for survival (Akeroyd 1997). Poorer women know less about how HIV is transmitted, and are less able to access and use condoms, than their better-off counterparts (Booyesen 2002a: 403-4). Women do not always participate in the sexual economy only out of desperation: as Leclerc-Madlala (2002: 30) explains, sexuality is conceptualised as a resource that can be drawn upon for material or economic advantage, such as securing a job or to acquire material benefits from men. The sexual economy operates on a continuum or scale of benefits, ranging from trading for sexual favours to

secure basic needs such as food and rent, to obtaining expensive fashion accessories such as clothes and jewelry. The price of participating in this “sexual economy” results in greater vulnerability to HIV infection, especially for young women. Research done in South Africa by Kelly and Ntlabati (2002: 52) has found that relationships premised on money and the need for status, make for circumstances in which young women have little power to insist on condom use.

3.3.7.6 Progression or Regression on the Stigma Scenario

While the stigma surrounding HIV and AIDS (according to Daily News reporter Irene Kuppan 22 February 2008), appears to be declining, there is still a long way to go before it is eradicated. According to this report, academics from six countries were involved in this multi-national African study of the perceived AIDS stigma. Uys, a member of the team, found that their data showed a reduction in stigma attached to HIV and AIDS; she emphasised that this disease was not just going to go away and has to be addressed by the community, adding that stigma is still a major problem and can be a barrier preventing people from getting tested for HIV and AIDS or getting treatment. Chirwa, another member of this team from the university of Malawi, said that in her country divorce was very common when either spouse disclosed they were HIV-positive. Greeff, a member of this team, described how during the research in South Africa, she found that a room in an informal settlement would be divided and the person with AIDS would be passed food through a slit in the partition. The study also found that nurses who worked with HIV-positive patients were also victims of discrimination. The literature review now focuses on HIV/AIDS and education in the next section, given that this is the context of the research.

3.4 HIV and AIDS and Education

This section begins with a discussion of how HIV and AIDS affects the education system in Africa. The focus then moves to South Africa and KwaZulu-Natal, a discussion on the

impact of HIV positive educators on teaching and learning will follow. The role of teachers in disseminating HIV and AIDS information is critical for the success of school-based programmes. Peltzer (2000) is of the opinion that teachers often lack adequate knowledge of HIV. Dawson et al (2001) add that many teachers with sufficient knowledge feel uncomfortable discussing these issues with learners, especially topics relating to safe sex and homosexuality.

3.4.1 HIV and AIDS Infects and Affects Education Systems in Africa

The injury of HIV and AIDS goes deeper than it otherwise might because HIV and AIDS is destroying families. Families are the mainstay of schooling in any country, but in African nations, it is often the only social safety net that can keep children in school (Classen 2006). That net has now become frayed by HIV and AIDS-related illnesses and deaths of men and women in their most productive working years. O'Grady (2004) says that in Southern and Eastern Africa, the HIV infection rates are high, and the effects on social stability and education are so great that young people are being robbed of hope and national development is being stunted. Added to this is the decline in education that reduces the chances of arresting the pandemic, because school may be the most effective way to reach uninfected young people with the information, skills and attitudes that would protect them. The loss of parents affects school enrolments and learning; in cases where learner's needs are met, the grief and insecurity all too easily interfere with learning. HIV positive educators need all the support they can get in order to live with this epidemic. Zambia, in its hope to preserve its teaching force, has recently begun offering anti-retroviral therapy to infected teachers; South Africa is hoping to follow suit (Education Week 2005).

The prevalence of HIV and the impact of AIDS on the education sector are real and manifested through indicators such as morbidity and mortality of teachers and huge population of orphans. Kelly (1999)²¹ and Badcock-Walters (2001)²² explain that the

²¹ See Kelly M.J.(1999) Conference paper on education, What HIV/AIDS can do to education and what education to HIV/AIDS.

effect of this massive epidemic on the education sector is increasingly evident in respect of the demand for education, equality of access to education, supply of education, and quality of education services. They further added that ministries of education are designing policies and strategic plans to deal with the problems wrought by AIDS in the education system. Lawrence (2002: 56)²³ states that the impact of HIV and AIDS is felt most in the education sector, because, “education is a main line for defence against HIV and AIDS”, and, “education systems are themselves acutely vulnerable. Morbidity and mortality among personnel is a huge and growing problem, making the role of education in combating HIV and AIDS deeply compromised”. These types of impact are prevalent throughout sub-Saharan Africa.

3.4.2 The Impact of HIV and AIDS on Education in South Africa

Education is considered one of the pillars of development, and providing universal access to primary education by 2015 is a target of both the Millenium Development Goals and the Education for All (EFA) Initiative (UNESCO, 2000). To date, current rates of progress in school enrolments need to quadruple in sub-Saharan Africa and double in South Asia, to reach the 2015 goal. Currently, only 64% of children in Africa and 83% of children in Asia are enrolled in primary school (UNESCO, 2006). UNESCO states that along with armed conflict and high fertility rates, ‘HIV and AIDS is a major global constraint on the provision of good-quality education’ (UNESCO, 2005).

In South Africa a survey²⁴ showed that thousands of teachers died of HIV and AIDS during 2003 and tens of thousands are infected with the AIDS virus. Shisana, Executive Director of the Council’s National Research Programme on HIV and AIDS and Health, reveals that 4000 educators died in 2004, 80% of whom were under 45 years of age; also, the prevalence rate amongst educators was 12.7%, which roughly translates to 45,000

²² See Badcock-Walters (2001) Paper presented 11-15 November, HIV/AIDS as a management challenge in the education sector.

²³ See Lawrence (2002) The Internet and social development: African voices on HIV/AIDS and education. Paper as cited in Perspectives in Education Vol 20 (2), July 2002.

²⁴ See ELRC Report (2004/5) A focus on HIV/AIDS in South African public schools.

educators out of a population 356,000. Peltzer et al (2005) observe that South Africa's education system is struggling with a variety of problems, in that the total number of state school teachers has declined between 1998 and 2003, the net reduction being over 5%. Along with retirement, emigration and resignation of teachers, death while in service was one of the main factors in this decline. They further added that HIV prevalence among South African teachers is 21% among those aged 25-34 and 13% among those aged 34-44, and the number of young teachers graduating from teacher training colleges is also declining.

South Africa is a developing country and education is an essential tool for developing countries. However, it is being jeopardised in South Africa by the high rate of deaths amongst educators and students, through HIV and AIDS. In Africa, HIV and AIDS is more than just a health crisis: it is an education crisis, causing shortages of skilled educators in several countries in Africa. Statistics on the deaths of African educators due to HIV and AIDS is very disturbing. In South Africa, an average of 1000 educators die from the disease every year (Dialectical Anthropology July 2004, 329:337).

According to a study coordinated by UNAIDS, UNICEF, UNESCO and the World Bank, three educators lost their lives to AIDS every week in Cote d' Ivoire. The World Bank study also indicated that more than 30% of educators are HIV-positive in parts of Malawi and Uganda, 20% in Zambia and 12% in South Africa (Dialectical Anthropology July 2004, 329: 337).

Anecdotal evidence²⁵ has shown that the death of an educator has great psychological impact on uninfected educators. Added to educator deaths, staff absenteeism is rising mainly because of illness with HIV and AIDS, the need to look after family members with the HIV, and attending funerals. HIV- positive educators often have increased periods of absenteeism that continue until they are too ill to return to their schools.

²⁵ Discussions with principals in the Inchanga area in 2007

Malaney (2000) explains that many schools cope with the shortage of educators due to HIV and AIDS by hiring substitute educators, combining classes, or closing schools altogether. This has had a severe impact on the quality of education. He goes on to add that educators are often placed in schools far away from their hometowns and this forces them to indulge in extra-marital sex. They then become carriers of the virus to their spouses when they return home.

A 1999 educator demand and supply projection model²⁶ in South Africa suggested that HIV and AIDS would add to existing high levels of educator attrition and that this attrition rate may require replacement of as many as 60,000 educators by 2010 (HEARD 2003). Educator mortality was estimated at about 0.64% in 1999 in KwaZulu-Natal, and is expected to rise to 5% by 2010 (Badcock-Walters et al 2003). Staff mortality has a ripple effect on the whole education system. It can lead to extensive disruption of activities and affect morale and internal and external harmony (Cohen 2002).

A study conducted by Bennell (2003)²⁷ found that low educator morale and motivation coupled with low pay, poor conditions of service and inept school management, also played a major role in the handling of this epidemic. Hall et al (2005) argue that the prevalence of HIV infection among educators is higher than the 11% national average figure (ELRC Report findings of HIV prevalence among educators is 12.7% nationally), yet Coombe (2000) makes reference in her report, 'Managing the impact of HIV and AIDS on the Education Sector in South Africa' to DOE commissioned research into the prevalence of HIV and AIDS among South African Educators, at least 12% of educators were reported to be HIV positive. This study was undertaken five years prior to the ELRC study but the findings are not very different. The overall capacity of the education sector can be adversely affected by high levels of morbidity of educators, managers, inspectors and education officers. It is thus crucial to sustain human resources in education. The focus of the study now moves to KwaZulu-Natal, the specific geographical context from which my participants are selected.

²⁶ Developed by HEARD & the MTT, based on a national model developed by Dr Luis Crouch, SA DoE 7 RTI.

²⁷ See Bennell (2003) The impact of the AIDS epidemic on teacher mortality in sub-Saharan Africa.

3.4.3 KwaZulu-Natal: the Epicentre

The discussion in this section focuses on some of the reasons why this province has the highest HIV prevalence rate amongst its' teaching fraternity. The KwaZulu-Natal Department of Education (KZNDEC) is the largest provincial education department in South Africa, with 2.6 million learners and 74,000 educators in over 6,000 schools (The Mobile task team, 2003)²⁸. The education fraternity has been hard hit by the HIV and AIDS pandemic. More than 21% of teachers in KwaZulu-Natal (KZN) are HIV-positive (one of the findings of a study commissioned by the Education Labour Relations Council (ELRC). The study also revealed that 4000 teachers died in 2004, and that the most affected groups were those aged between 25 and 34 years, of whom 21.4% nationally were HIV- positive. The health of our educators does not auger well for education, as the study also revealed that in the past 12 months, 10.6% of educators had been admitted to hospital, and 75% reported a visit to a health practitioner in the six months before the study (ELRC Report 2005).

While the Department of Education is spending millions of rand on HIV education, it is debatable whether this is making a difference in behaviour patterns. Proper monitoring and evaluation will be able to evaluate if this information is properly cascaded. Shisana (2005) says that "the level of awareness was high, but awareness does not always translate into behaviour change, one needs an environment that is conducive to doing that". A major problem is one of migratory teachers, or urban teachers taking up jobs in rural areas and *vice versa*. Regardless of the knowledge that the person has a family and if the environment itself is socially supportive, the chances of engaging risky behaviour are much greater. Shisana (2005) adds that the HIV prevalence rate of educators who worked away from home was 27 percent compared to 8 percent if they worked near their home. The HSRC (2005) argues that if this issue is not addressed, there could be a "massive problem" because teachers are dying young and many older teachers are

²⁸ The Mobile Task Team 9MTT) is a network of Southern African professionals in complementary disciplines, currently working in 12 African countries, to assist MoEs to manage and mitigate the impact of HIV/AIDS through the strategic planning and implementation of sustainable and systemic interventions. It operates from the Health Economics and HIV/AIDS Research Division (HEARD) of the University of Natal and is funded by USAID.

retiring. The HSRC recommends that a comprehensive HIV and AIDS prevention programme be implemented in areas of high prevalence, the placing of educators in areas where they live, and the distribution of ARVs immediately to teachers who need it.

3.4.4 The Impact of HIV-Positive Educators on Teaching and Learning

Teachers are considered to be central pillars in any education system, and their survival and well-being is crucial for the sustainability of the education system. Whilst the World Bank (2002: 2) alludes to the view that “education offers a window of hope unlike any others for escaping the grip of HIV and AIDS”, and Fylkesnes et al (2001) believe that education has been shown to be related to the reduction of HIV prevalence rates amongst young people. They note that Uganda and Zambia have both experienced dramatic declines in the infection rates of young girls, and add that in Zambia, it has been found that a girl who has dropped out of school is three times more likely to be HIV-infected than one who remained at school.

Educators are a high risk group in several countries in sub-Saharan Africa. Testing of educators in Zambia found high levels of infection in the group compared to other groups in the population (Badcock-Walters & Whiteside 2000; Kelly 2000; Unicef 1999), including Malawi and Uganda (World Bank 2002). The Sadtu preliminary study into the mortality of its members showed that out of 701 deaths from August 1999 to May 2000, a significant number were considered to be AIDS-related (Mannah 2001).

Increased absenteeism of the HIV-positive educator has costly implications for the quality of teaching and learning, as well as workload and working conditions for educators in most affected schools. Kelly (2002) explains that HIV-positive educators will not always work to their full potential; it is estimated that repeated sickness could lead to an educator losing approximately six months of teaching time during that period. ARV treatment should reduce the rate of illness as well as educator attrition. Coombe (2000) argues that the morale of affected educators is also likely to fall as they deal with the illness and the mortality of colleagues, relatives and friends. She says that affected

educators will have to assist with the additional responsibilities of infected educators, such as counseling and caring for infected/affected learners. She also advised that these stresses may need to be addressed and incorporated in initial and continuous educator training and development.

The following information from the HSRC Report (2005)²⁹ is included to provide some statistics on the prevalence of HIV infection among educators. This report was used extensively in this chapter, given its reliability as a national research unit. Conspicuous racial differences in HIV prevalence were observed. Blacks had a prevalence of 16.3% compared to whites, coloureds and Asians, who had a prevalence of less than 1%. Young women educators had a much higher HIV prevalence of 17.4%, compared with 12% among their male counterparts. At age 25-29 years, female educators had a much higher prevalence rate of 30.4% in contrast with 14.5% among men in the same age group. HIV prevalence amongst women peaked at 25-29 years and thereafter declined to 17.5% at age 35-39 years and continued to decline to 5.2% for educators aged 50-54 years. A 12% prevalence was recorded among men aged 18-24 years, to 14.5% among those aged 25-29 years. This rose sharply and peaked at 22.1% among men aged 30-34 years and remained high at 20% among men aged 35-39 years, then declined rapidly to a low 2.2% among men aged 55 years and older.

The report found that the highest prevalence of HIV infection was among single educators, whilst married educators had the lowest HIV prevalence rate. Another important factor of note from the report is that the educators with a degree or higher have the lowest HIV prevalence rate and educators with a diploma have a higher HIV prevalence rate. The study investigated the HIV prevalence of educators by province and found significant differences. KwaZulu-Natal (the province in which this study was carried out) had the highest HIV prevalence of 21.8% when compared with other provinces. The HSRC Study (2005) showed that educators with fewer years of teaching experience had a significantly higher HIV prevalence when compared to other senior

²⁹ Report prepared for the Education Labour Relations Council (ELRC) on the factors determining educator supply and demand in South African public schools.

educators. The issue of residence is worthy of note, because it has an impact on an educator's HIV status. Educators residing and teaching in rural schools were found to have significantly higher HIV prevalence than educators residing in urban areas and teaching in urban schools. Educators who traveled more than 10km away from home also had a slightly higher HIV prevalence rate than educators who traveled less than 10km to their school. According to the Mobile Task Team (MTT) (2005) educator mortality had increased significantly from 7.9% in 1997/8 to 17.7% in 2003/4, educator attrition due to medical reasons has also grown from 4.6% to 8.7% during the same period. HIV and AIDS has also been cited as a contributing factor to what the National Policy Framework for Teacher Education and Development in South Africa (2007) acknowledges as an 'impending shortage' of teachers in the country.

The HSRC Study (2005) argues that educator absenteeism and attendance is a crucial issue at all schools. Educators who perceived that they had support from the DOE, SGB, learners, parents, unions and religious groups in the community in their role as educators, reported significantly less absenteeism and fewer "unhealthy days".

Coombe & Kelly (2001) support the above view: the package of habits and dispositions that learners accumulate throughout their schooldays; the way school education opens one up to future prospects and the increased opportunities it provides for economic independence which helps to keep learners focused, highlight the importance of focusing on the educators' health and wellbeing. The World Bank (2002) observes that school education is among the most powerful tools for transforming the poverty and gender inequality environment in which HIV and AIDS flourishes, adding that it is universally acknowledged that growth out of poverty and growth in education are almost synonymous.

3.5 Looking at HIV and AIDS and Education through Political Lenses

For the education system to function, all categories of the education staff must know about HIV and how to protect themselves against it. There is also a growing need for

attention to the management and mitigation of impacts. On the political implications, Kramer (1990: 110) states that, '*There is nothing in this whole AIDS mess that is NOT political*'.

According to the above quotation, there appears to be much political interference regarding this serious pandemic, in handling this pandemic, cognisance must be taken in upholding human rights.

3.5.1 Issues around Human Rights and HIV and AIDS

HIV and AIDS presents many challenges with respect to socio-economic and Human Rights throughout the world. People living with HIV or AIDS have the same basic rights and responsibilities as all other citizens. The Charter of rights on HIV and AIDS which was launched in 1992 is the Bill of Rights of people living with HIV or AIDS (Van Dyk 2008). The human rights principles enshrined in the charter are necessary to ensure non-discrimination and public health in South Africa. The following aspects are some of the crucial issues in maintaining the rights of people living with HIV and AIDS:

- Liberty and freedom of movement-all HIV positive people must be able to go wherever they want to without any restrictions placed on them
- Confidentiality and privacy-they have a right to confidentiality about their health and HIV status, health care professionals are legally and ethically bound to maintain patient's health information confidential
- HIV testing- no person may be forced to take an HIV test without his or her informed consent
- Education on HIV and AIDS-all people have the right to proper education about HIV and AIDS
- Employment-HIV testing should not be compulsory in any employment policy and it ought not to be used as grounds for refusing employment
- Health and support services- all HIV positive people have a right to housing, food, social security, medical assistance and welfare

A rights-based approach is essential because it is the most effective means of addressing the social, political and economic factors that contribute to the spread of HIV and AIDS. According to the South African Constitution, all its people have a right to state health care, and should not be discriminated against because of their HIV status. It also carries a moral obligation on governments to protect and respect the human rights of their citizens. HIV impacts negatively on people's lives and this is compounded by marginalisation and stigmatisation on the basis of race, behaviour and status. The violation of rights can also be as basic as the right to freedom of choice. Closely linked to the idea of rights is the issue of policy position.

3.5.2 Implementation of HIV and AIDS Education Policies

In an era of HIV and AIDS, there is a range of national and provincial education specific policies that deal with issues regarding the educator's right to employment without discrimination and learners' rights to education without fear of discrimination. The issue of human rights in relation to HIV and AIDS permeates almost all the education policies, the core elements of The National Policy on HIV and AIDS for Learners and Educators in Public Schools and Students and Educators in Further Education and Training Institutions focuses on human rights and is heavily entrenched in the South African Constitution. This policy recommends that each school have a strategic plan to cope with the epidemic and support its learners and educators with the dissemination of correct information, eliminate discrimination and make the school the centre of hope and care.

The DoE's Workplace Policy for HIV and AIDS provides guidelines for all its employees on the management of HIV and AIDS. This policy emphasises the creation of a supportive environment for employees living with and affected by HIV and AIDS, the policy also advocates the elimination of discrimination. The South African Schools Act (DoE:1996) provide for 'quality education for all learners of school going age', whilst this is commendable, one needs to question whether this is always possible in an era of HIV and AIDS when learners drop out of school to work and supplement the family income or to care for ill family members.

The above policies have a common thread running through them, that of upholding human rights, elimination of discrimination and support for the infected and affected. Policies are designed to govern practice but Lewin et al (2004b) argue that policy is useless if it is not practiced. HIV and AIDS pose a huge challenge in the school environment, that of educator absenteeism due to ill-health, death of an educator and learner drop out rate. At times policies are formulated and the context and environment are not taken into consideration, then the policy cannot be implemented, therefore it is important for all stakeholders to come on board for the successful implementation of a policy. As mentioned earlier that educator absenteeism because of ill-health is a huge problem, the Employment of Educators Act 76 of 1998 provides a framework for employment, which address pertinent issues of conditions of service, procedures for termination of services, misconduct and a host of related issues. This policy was developed to provide schools with mechanisms that protect educators from unfair treatment, but at the same time hold them accountable for delivery of quality education

3.6 Conclusion

Although much research has been done around HIV and AIDS, there is still a need for expansion in our understanding and knowledge of new challenges of the HIV and AIDS epidemic, more especially the management of the disease, especially in countries where the prevalence rate does not seem to be abating. The main obstacle to successful HIV and AIDS prevention and mitigation programmes is implementation and sustainability at grassroots level.

In this chapter I have discussed the impact of HIV and AIDS on society, the fragmentation of homes and families, and the plight of girls and women in trying to protect themselves. The section on anthropological issues focused on gender inequality and problems generated. An in-depth discussion of stigma was also provided in this section as a feature of anthropology. Education issues in an HIV climate were discussed and the many challenges experienced in the school environment highlighted. Following

the education issues, HIV/AIDS school policies were discussed in the section on political implications.

In this era of the HIV pandemic, an additional responsibility is placed on the school community, that of providing care and support to both learners and educators on the HIV management journey. This chapter focused on literature relating to social, anthropological, educational and political issues of HIV and AIDS.

Chapter Four will concentrate on the methods used to collect data for the study and argues for the use of qualitative methodology in working with the vulnerable who constitute my sample in the study.

CHAPTER FOUR

Methodology

Mapping out an Introspective journey of educators living with HIV and AIDS

4.1 Introduction

'Sharing one's story is a way of purging, or releasing, certain burdens and validating personal experience; it is in fact central to the recovery process... Life stories can help other people see their lives more clearly or differently, and perhaps be an inspiration to help them change something in their lives.'

(Atkinson 1998: 26)

Atkinson's words could be aligned to the saying, "a problem shared is a problem halved". Sharing an experience or a problem generally lightens the load and also creates an awareness in the listener about his/her own life. On reflection, the listener may be inspired to re-look/re-organise his/her own life. This chapter begins with a discussion of life story as a methodology, which is used to study the lives of HIV-positive educators. By choosing life story within a feminist approach, I hope to capture my participants' stories in their own voices as far as possible, because women's voices and feelings are generally ignored. The nature of this study is sensitive; I have therefore chosen qualitative research as an approach because of the reflective nature of the process.

I acknowledge at the outset the use of Liamputtong's works (2007). Since the data collection process was ongoing for many months, grounded theory was used, which allowed for the data to be analysed as it was being collected. Life story and life history aspects are also discussed, mainly to show the suitability of using life story to collect data for this study, because life stories generally refer to real events and experiences. The

main data collecting method used was the interview, hence a discussion on relevant aspects of the interview has also been included in this chapter. In order to have successful interviews, the research participants have to be carefully chosen. In this chapter, I also share my sampling technique. The sensitive nature of this research required me to pay careful attention to ethical considerations, which are discussed.

While the interview was the primary data collecting method, I have also included relevant input from focus group meetings I had with members of school management teams (SMTs)¹ from three different areas in KwaZulu-Natal, namely, Maphumulo, Inchanga and Ndwedwe. The families, and in some cases close friends, were also part of these groups. The focus group discussions were guided by the five questions I asked at the meetings. Permission was granted to me to meet with one participant's spouse, the mother of another participant and close friend of yet another. Their responses to my questions are recorded in Chapter Five. Three teacher union representatives also granted me brief interviews, and their responses are likewise recorded in the next chapter.

The participants in this study were opportunistically chosen given the sensitive nature of the research. Opportunistic sampling involves following new leads (participants) during fieldwork. Finding willing participants for this study was very difficult, and I discuss the challenges I encountered in the search for participants. The chapter concludes with brief comment on the issue of validity in this type of research.

4.2 The Use of Qualitative Research in Researching Sensitive Issues

Qualitative methods are especially appropriate for this study because of the sensitive nature of the study. Flexibility is a feature of qualitative research, as is the reflective nature of the research process (Liamputtong 2007). Qualitative research lends itself to the life story approach in different ways. According to Tewksbury and Gagne (2001: 72, cited in Liamputtong 2007), "Qualitative investigations are not explorations of concrete,

¹ School Management Teams (SMTs), in South Africa this team is made up of the school principal, the deputy-principal and Heads of Departments (HOD).

intact frontiers; they are movements through social spaces that are designed and redesigned as we move through them. The research process is fuelled by the raw materials of the physical and social settings and the unique set of personalities, perspectives, and aspirations of those investigating and inhabiting the fluid landscapes being explored". The views of Tewksbury and Gagne are appropriate for this type of study, allowing for "open-endedness". Warren (2002: 7) contends that qualitative research is more "open-ended" as "it is more concerned with being attuned to who is being researched, than with setting out a precise route for all to follow, as in survey research". Liamputtong and Ezzy (2005) have a similar view to that of Warren: they say that qualitative research methods are flexible and fluid, and therefore suited to understanding the meanings, interpretations and subjective experiences of vulnerable groups, in that qualitative research methods allow researchers to hear the voices of their participants. Qualitative research allows the researcher to become immersed in the social setting of the research environment, to an extent that enables the building a sound relationship of trust between the researcher and the participant.

Trust and rapport are also important aspects in research, and especially so in sensitive research, because the data that is being sought sometimes concern intimate and confidential aspects of a participant's life.

Becoming trusted and seen as someone with whom research participants are comfortable spending time, talking, and sharing their lives is called 'establishing rapport'. In order for a researcher to truly understand the world from the perspectives of those being studied and to see how persons being studied think about their world it is critically important for rapport to be established.

(Miller & Tewksbury 2001:55)

Building trust and rapport (as suggested above by Miller & Tewksbury) are extremely necessary for conducting research especially with vulnerable and hard-to-reach people. Building this trust and rapport at an early stage of the interview process will reap the rewards of rich data. Fontana and Frey (2005) are in agreement with Miller and

Tewksbury, they believe that a critical aspect of research success is a researcher's ability to establish rapport and a trusting relationship with participants. Simple actions like having a cup of tea with a prospective participant can be the beginning of building trust and rapport. Dickson-Swift (2005) contends that a participant will share their lived experiences, (which they consider confidential) with the researcher if they have a good relationship and can trust the researcher. I developed trust and rapport with my participants very early in our association, I took time to chat and get to know them and also for them to be comfortable with me.

In this study, the main data source was through interviews with the study participants. Data collected through voices were rich with emotions and un-doctored. Qualitative research methods, according to Hesse-Biber and Leavy (2005: 7, cited in Liamputtong 2007), allow researchers to be able to hear the voices of those who are "silenced, othered, and marginalized by the dominant social order". Talking about an unpleasant experience (as was the case in this study) allows the individual to 'share the burden' and 'lighten the load', in Warren's words (2004 cited in Liamputtong 2007). This suggests that qualitative research provides researchers with an opportunity to listen to people tell their life stories, and these stories offer researchers a clear window into the lived experiences of the participants.

4.3 Feminist Research within a Life Story Approach

Feminist research has had a great impact on life story research. In this section I focus mainly on the views of Hesse-Biber & Leckenby (2004 cited in Liamputtong 2007), who believe that feminist research differs from other types of research by its "worldview rather than method". Olesen (2000) argues that the emphasis on giving a voice, consciousness-raising, empowerment, collaboration and attention to meaning and experience, have had widespread influence while also being subject to much debate within qualitative approaches and further afield. Stone (2003) argues that vulnerable women want to be listened to. In this study women will be listened to through the interview process. Eighty percent of the participants in this study are women, this

research methodology will provide a platform for them to talk about lives. Gluck and Patai (1991a) explain that the insights of the women's movement began to have a transformative effect on fields such as oral history when women's experiences were accorded value, and writers began to regard oral accounts as a means for recording women's social and historical experiences. Hesse-Biber and Leckenby (2004), and Hesse-Biber and Leavy (2005 cited in Liamputtong 2007), state that within feminist methodology, women and their concerns are the focus of investigation. Campbell and Wasco (2000) contend that feminist methodology, is about giving voice to personal, everyday experiences of individuals, especially those who are marginalized in a society. A clear intention of feminist research is to undertake research which is beneficial for women, and not just be about women. Women's feelings and voices are generally unnoticed, hence Campbell and Wasco (2000) argue that the ultimate aim of feminist research is to "capture women's lived experiences in a respectful manner that legitimates women's voices as sources of knowledge". They add that the process of feminist research is as important as its outcome. A similar view was also discussed by Fonow and Cook (1991), namely, that a commitment to social change has been translated into a need for research methods that consider and witness everyday processes of women's lives, and that would limit the isolation between participants.

With feminist research comes a fair amount of resistance, as Renzetti (1997) notes: feminist research calls for qualitative inquiry which is less structural and more flexible than that of positivist science. Allen and Walker (1992: 201) agree with Renzetti (1997) when they say that "feminist research contends that due to the standardized nature of positivist science, much of what occurs to individuals and groups involved in the research including the researcher and the researched remains 'unsaid and unanalysed'". Allen and Walker (1992: 11) suggest that feminist research is "consciously reflexive", while Stanko (1997) contends that reflexivity is the process of standing outside and gazing back to see what can be seen. She believes that it is a tool for researchers to become more sensitive to 'silence' in the research. Hesse-Biber et al (2004) argue that research carried out from a feminist perspective pays attention to issues of difference, questions social power, resists scientific oppression, and commits to political action and social reform. De-Vault

(1999) concurs with Hesse-Biber, and is of the opinion that a feminist methodology aims to construct knowledge which may benefit women and other minority groups. Hesse-Biber and Leckenby (2004: 210, as cited in Liamputtong 2007) “allows for ‘new’ types of questions about women’s lives and those of ‘other/ed’ marginalized groups to be addressed within their respective fields of research”. Campbell and Wasco (2000) and Campbell (2002) contend that feminist methodology embraces qualitative methods, but more often feminist methodology utilizes familiar methods of data collection in qualitative approach including focus groups, in-depth interviews and oral history.

Hammersley (1990) explains that the life history method came under much scrutiny during the late 1930s when qualitative methods were rapidly developing. The survey method developed criteria and procedures. He went on to explain that life history appeared inadequate according to scientific standards and relatively expensive, long-winded and cumbersome. Surveys could provide more accurate representative information in a much shorter time. He argues that the method appeared deficient according to standards of reliability and validity. Feminist methodology, says Liamputtong (2007), embraces qualitative methods, although contemporary feminist researchers promote both qualitative and quantitative approaches.

4.4 Grounded Theory in Life Story Research

Grounded theory, according to Glaser and Strauss (1967), is another procedure used for relating research and theory generation. In this study, data and theory was generated through life story interviews. Charmaz (1995: 30) explains that the intention is to provide a systematic approach to qualitative research which clearly outlines the connection between data and theory and how conceptual development can be achieved and checked. Whilst Strauss and Corbin (1990) say that theory is generated during research through an ongoing inter-relation between systematic data collection and analysis, Olesen (2000) argues that the process should be open to ideas and conceptualization arising from the data, rather than dependent upon the individual and social action.

Grounded theory is the discovery of theory from data (in this study through life story interviews), which are systematically obtained and analysed, thereby forestalling the opportunistic use of theories that have dubious fit and working capacity (Glaser and Strauss 1967). Goulding (2002) believes that the roots of grounded theory can be traced back to a movement known as symbolic interactionism, the origins of which lie in the work of Cooley (1864-1929) and Mead (1863-1931). The latter were on a mission to avoid the polarities of psychologisms and sociologism. Blumer (1969) explains psychologism as a view predicated on the assumption that social behaviour is explicable in genetic terms and by logical or neurological processes, while sociologism is the opposing theory which looks at personal conduct as if it was in some way programmed by societal norms. Schwandt (1994) is of the opinion that according to this paradigm, individuals engage in a world which requires reflexive interaction as opposed to environmental response. They are purposive in their actions and will act and react to environmental cues and objects, according to the meanings held. These meanings evolve from social interaction which is itself symbolic because of the interpretations attached to the various forms of communication. Schwandt (1994) further adds that the researcher engages in symbolic interaction and is expected to interpret actions, transcend description and develop a theory which incorporates concepts of “self, language, social setting and social object”.

Annells (1996), analyses human behaviour, and states that symbolic interactionism is both a theory of human behaviour and an approach to enquiry about human conduct and group behaviour. He explains that humans come to understand collective social definitions through the socialization process. The notion of symbols is intrinsic to this perspective and social life is expressed through such symbols which include the most powerful of all, language. From these beginnings of symbolic interactionism, Glaser and Strauss (1967) set out to develop a more defined and systematic procedure for collecting and analyzing qualitative data. The method they developed was labeled “grounded theory,” to reflect the source of the developed theory which is ultimately grounded in the behaviour, words and actions of those under study. Glaser (1992: 16) sees grounded theory as being “the active role of persons in shaping the worlds they live in through the

process of symbolic interaction, and the interrelationship between meaning in the perception of subjects and their action". Strauss concentrates on sociological aspects, such as a recurring emphasis on histories, social situations and identities developed through interaction. Hesse-Biber and Leavy (2005: 151) suggest that life story permits researchers to access the invaluable knowledge and rich life experiences of marginalized individuals and groups which would otherwise remain hidden. They further added that the symbolic interactionism aspect affords a means of reaching unprivileged voices and life stories, offering "the collaborative generation of knowledge" between the participant and the researcher. They contend that this can be an empowering experience for the researched as they are able to gain an insight into their own "pivotal moments" in their lives. Goulding (2002) explains that grounded theory, in contrast to theory obtained by logico-deductive methods, is theory grounded in data which have been systematically obtained through 'social' research. The development of grounded theory was an attempt to avoid highly abstract sociology, as part of an important growth in qualitative analysis in the 1960s and 1970s. An important aspect of this movement was to bridge the gap between theoretically 'uninformed' empirical research and empirically 'informed' theory, by grounding theory in data. Goulding (2002) emphasises the role of grounded theory as the careful and systemic study of the relationship of the individual's experience to society and to history.

According to Goulding (2002), part of the rationale proposed by Glaser and Strauss was that within the field of sociology there was too great an emphasis on the verification of theory, resulting in a:

...de-emphasis on the priori step of discovering what concepts and hypotheses are relevant for the area one wished to research...in social research generating theory goes hand in hand with verifying it; but many sociologists have diverted from truism in their zeal to test either existing theories or a theory that they have barely started to generate,

(Glaser & Strauss, 1967: 1-2).

Grounded theory was thus intended to be a methodology for developing theory that is grounded in data which are systematically gathered and analysed.

In this study a constructivist grounded approach was used to analyse the data collected. This approach was chosen because it best lent itself to the method I used to collect data (life story interviews), which was the interview approach. According to Charmaz (1995), grounded theory has the goal of generating concepts that explain people's actions regardless of time and place. The constructivist approach to grounded theory reaffirms studying people in their natural settings and redirects qualitative research away from positivism. Charmaz (2000) stresses the following arguments for grounded theory:

- Grounded theory strategies need not be rigid or prescriptive.
- A focus on meaning while using grounded theory furthers, rather than limits, interpretive understanding.
- Grounded theory strategies can be adopted without embracing the positivist leanings of earlier proponents of grounded theory.

According to Charmaz (2000), the rigor of a grounded theory approach also offers qualitative researchers a set of clear guidelines from which to build explanatory frameworks that specify relationships among concepts from the data collected. In this study, both the emotional as well as the physical stages of the virus were used as a starting point in the analysis of the data collected. The strategies of grounded theory lend themselves to the simultaneous collection and analysis of data, which allows the researcher to 'fine-tune' any collected data during the process of collection, and the data source was easily accessible.

Grounded theory, Charmaz (2000) believes, has an advantage in that analysis begins early, and data can be coded whilst it is being collected. This allows the researcher to pose questions on the collected data with the possibility of gaining a new perspective on such data, and to focus on further data collection that may lead the researcher in an unforeseen direction. Unlike qualitative research that requires data to fit into preconceived standardized codes, the researcher's interpretations of data here shape his or her emergent codes in grounded theory.

The coding of collected data also allows the researcher to make comparisons, which is a technique in grounded theory. According to Charmaz, (1995c), the constant comparative method of grounded theory allows for the following:

- Comparing different people (as was evident in this study with the five participants).
- Comparing data from the same individuals with themselves at different points in time (data from the participants in this study highlighted their psychological emotions through the various stages of the virus).
- Comparing incident with incident (in this study the participants experienced many incidents that comparisons could be made between such as diagnosis, disclosure etc.).
- Comparing data with category (many categories of psychological anxieties were experienced and highlighted throughout the analysis in Chapter Five).
- Comparing a category with other categories (such as blame and shame in this study).

Glaser (1996) stresses that ‘grounded theory’ is the systematic generation of a theory from data, an inductive process in which everything is integrated and in which data pattern themselves. He (1996) finds that constant comparative methods are in keeping with the issue of rigor in research. Strauss, (1987), is also in favour of comparison and called for comparison in his research and teaching at every level of analysis. Strauss and Corbin (1990) introduce new procedures: dimensionalising, axial coding, and the conditional matrix, which they believe, are intended to make researchers’ emerging theories denser, more complex, and more precise. The issues of complexity and precision emerge as the researcher progresses through the various levels of analysis. Schatzman (1991) had earlier developed the concept of dimensionality to reorganize and account for complexity beyond one meaning of a property or phenomenon Strauss and Corbin (1990) build on his notion by urging researchers to divide properties into dimensions that lie along a continuum, and this in turn can be developed into a ‘dimensional profile’ of the properties of a category. They further propose techniques for reassembling data in new ways through what they call ‘axial coding’. This type of coding is aimed at making

connections between a category and its subcategories, which was evident with the issue of disclosure and non-disclosure.

Disclosure allows the individual to share his/her problem. This may lead to support or stigmatism which in turn may give rise to possible empowerment or isolation. Non-disclosure leads to secrecy and suspicion, which brings about fear and risk, and eventually isolation.

Critics have made assumptions about the nature and limitations of the use of grounded theory. Riessman (1990a) states that grounded theory methods were insufficient to respect interviewees and to portray their stories. Richardson (1994) is of a similar opinion and found the prospect of completing a grounded theory analysis to be alienating. He then turned to literary forms, observing that qualitative research reports were not as straightforward as their authors represented them to be. He believed that authors chose evidence selectively, cleaned up subjects' statements, unconsciously adopt value-laden metaphors, assumed omniscience, and bored readers. The above criticisms are a challenge to researchers' representations of their subjects and their stories, and also their authority to interpret subjects' lives and voices, implying that grounded theory methods gloss over meanings with respondents' stories.

Conrad (1990) and Riessman (1990b) suggest that 'fracturing the data' in grounded theory research might limit understanding because grounded theorists aim for analysis rather than portrayal of subjects' experience in its fullness. According to the grounded theory perspective, fracturing the data means creating codes and categories as a researcher defines themes within the data. Codes and categories in this study were established by fracturing the data.

Glaser and Strauss (1967) propose this strategy for several reasons, namely, to help the researcher avoid remaining immersed in anecdotes and stories and unconsciously adopting subjects perspectives; to prevent the researcher becoming immobilized and overwhelmed by voluminous data, and to create a way for the researcher to organize and

interpret data. They argue that criticisms of fracturing the data imply that grounded theory methods lead us to separating the experience from the experiencing subject, the meaning from the story, and the viewer from the viewed. In their view, a constructivist grounded theory assumes that researchers create and maintain meaningful worlds through dialectical processes of conferring meaning on their realities and acting within them.

Blumer (1969) is supportive of this view, adding that a constructivist grounded theory fosters the development of qualitative traditions through the study of experience from the standpoint of those who live in it. In the next section I discuss issues around life story and life history.

4.5 The Life Story/Life History Story

Life history research is an exciting and stimulating field, which seeks to understand the changing experiences and outlooks of individuals in their daily lives, what they consider important and the interpretations they provide of their past present and future (Denzin 1989).

Life story as a narrative form has evolved from the oral history, life history and other ethnographic and field approaches. It is a qualitative research method for gathering information on the essence of a person's life. It begins with a recorded interview, and is transcribed and reported as a flowing narrative, in the words of the person telling the story. In a life story interview, the interviewee is the narrator of the story being told and the interviewer is a guide or a director in the process. Together they collaborate, compose and construct a story with which the narrator will be pleased. The researcher is never really in control of the story told, the process may not go as smoothly as hoped, or the narrator may be too brief and unemotional in relating the story of his/her life. This could result in short listing of factual events that have occurred. We must also be mindful of the fact that the point of the life story is to give people the opportunity to tell their story the way they choose to tell it.

While biographical research shares a common outlook with qualitative research, it also has its own challenges. An initial problem in the field of biographical research is the use of terminology such as oral history, life history biography and autobiography. A common distinction is made between life story and life history. According to Atkinson (1998: 8), “a life story (the term that I am using in this research) is the story a person chooses to tell about the life he or she has lived, told as completely and honestly as possible, what is remembered of it, and what the teller wants others to know of it, usually as a result of a guided interview by anotherA life story is a fairly complete narrating of one's entire experience of life as a whole, highlighting the most important aspects”. This definition has relevance to my study, in that my participants will be talking about their experiences, that of living with HIV and managing their jobs as educators.

The life history is usually taken to refer to the collection, interpretation and report writing of the 'life' in terms of the story told or as the construction of the past experiences of the individual (from various sources) to relate to the story (Denzin 1970: 219-59; Fischer-Rosenthal and Rosenthal 1997: 9). The term **life story** is commonly applied to the narrated story by the author, while **life history** discusses the presentational work of the researcher. According to Becker (1970), there was a concern for the traditional lack of use of life stories within sociology, possibly because the dominant '**scientific**' hypothetical-deductive method produced the notion that hypotheses were to be constructed for testing, and life stories did not provide the 'findings' that sociological researchers were required to obtain. Life story research was alleged to be found wanting when measured against criteria of reliability and validity. It may be worth noting here that writers have observed that qualitative methods differ on the balance between reliability and validity (Kirk and Miller 1986; Perakyla 1997). This study is based on data that is authentic, and generated from a first-hand account of educators living with HIV and AIDS.

According to Denzin (1989), life story research rests on a view of individuals as creators of meanings which form the basis of their everyday lives. A strong debate within much life story research is '**realism**' versus '**constructionism**' in the study of lives. Realism,

according to Denzin (1989), holds that there is some objective knowledge of reality, an empirical, material produce meaning together. They place 'narratives' at the centre of their interview method and also show how 'free association' should be given priority over narrative coherence. Participants say the question of voice allows for the experiences of groups which are not usually heard, to be heard. They mention women, communal and other groups with a feminist or radical view of research practice, and connect the notion of voice to the raising of consciousness or the reclaiming of history (Hollway & Jefferson 2000). Oral history also has a place in research; it gives voice to those who want to share their past experiences, and claim historical experiences and views relating to historical events affecting the working class. In this study, ideas of realism and constructionism are operationalised through life story interviews, through interacting with participants, in some cases their families, close friends and spouses.

Thompson (1988:157) claims that telling a life story can have a 'therapeutic' effect on the giver - a consequence that may become apparent to the researcher. During my interview sessions with my interviewees, I had seen and felt the willingness of my interviewees to talk and 'off-load' what had happened to them. At times some of them had become emotional, and I got the sense that this was a release of 'pent- up' emotions, which thereafter gave them the strength to carry on. I heard the strength in their voices: they wanted to be strong for their families, and two of my interviewees had children they wanted to see grow up. The therapeutic effect of life story is also helpful to interviewees in coping with stressful times. According to Manning and Cullum-Swan (1994: 465), medical writing using life stories is very diverse in approach, usage and theorisation, but often there is a common assumption that story-telling by a patient to a listening audience is part of the healing process in 'self renewal'.

Plummer (1983: 86-116) in his assessment and advocacy of the method, offered a procedure for life history research and the choice of subjects with reference to methodological and theoretical intent, rather than the usual procedures of sampling collection of lives by the informal interview, a procedure which lies between the conversation and the closely structured interview; and organization of materials, usually

by tape transcriptions but also including a variety of written and visual materials. He also emphasizes the need for careful attention to questions of reliability and validity and the writing and editing of the story for presentation (also see Plummer 1995a)².

Clandinin and Connelly (1994: 421) discuss the area of personal documents. They say a wide range of materials can be used, such as letters, diaries, photographs, jewelry, old birthday cards, notes and artifacts from earlier days which can signify personal attachment to relationships in time and place. Some of these artifacts may have a special place in the home or the office. Artifacts, photographs, ornaments and certain scents (perfumes) revive memories and stories which we can retell about ourselves and intimately connect with self-identity. Golby (1994: 105) says that in writing autobiographies, letters and diaries, 'factual information' is given but the detail of values and beliefs of individuals are also present.

Feminism has had a considerable influence on biographical research, because biological research discusses people's lives. Reinharz (1992: 250) explains that in order to avoid the separation of the 'personal' from the 'socio-political' and uncover the hidden lives of women, a guiding principle from feminist research is the use of an historical perspective in which to place the research activity and the previous influences on the researched. Evans (1993: 5) points out that the interest in biography has increased due to the focus on the personal or intimate in the social sciences, including the uncovering of the lives of women but also the attempt to rectify the neglect of various minority groups.

Reinharz (1992: 250) argues that feminist researchers are attracted to writing across disciplinary boundaries and broadening methodological conventions. As mentioned previously, talking about one's life is therapeutic, Olesen (2000) say that feminist analysis places emphasis on the reflective aspects of practice; the self-monitoring but interrogative nature of research is a basis for individual experience and stories reflect a lived reality. Denzin (1989: 14) contends, when talking about realism, the tendency towards a

² See Plummer K. (1995a) *Life Story Research*, in J. A. Smith, R. Harre and L. Van Langenhove (eds) *Rethinking Methods in Psychology*. London: Sage.

'constructionist' or 'narrative' position, the reliance on the 'text,' the analysis of 'intertextuality' and multiple 'voices' offer ultimately a retreat from any idea of reality; interpretation feeds upon interpretation in a swirl of language and symbols.

Both the respondent's 'story' and its interpretation by the researcher are shaped by narrative conventions. The emphasis in analysis is also on how the story is formed, including the 'performance' and collaboration with the researcher (Evans 1993). The focus turns to the process of "writing up" of research from the taped stories and field notes, rather than representing an 'objective reality'. Narrative structures and rhetorical devices become resources for constructing a text (Richardson 1995: 199).

Life stories commonly refer to 'real' events and experiences and the narrators may be the only witness to these events. However, their accounts can be checked against other written, visual or oral accounts. When analysing events and lived experiences, a constructionist view can be used to help shape the telling of life stories to bring out the reality in them. In life story research, a pragmatic orientation is often taken, relying on the similarities in approaches and procedures. The emphasis is on purpose, to gain insight into individual lives (Miller 2000: 18).

Reinharz (1992: 37-8) adds that voice and power in the interview relationship are major areas in feminist writing, in that women should be empowered to give their voice and to speak for themselves. He also cautions that the difficulty here is how much the researcher should mediate and whether some mediation is unavoidable. Reinharz points out that even when the researcher is not speaking, it does not mean that interpretation is not taking place. He goes on to explain that involvement brings interpretation and feminist researchers should give the audience an analysis, which indicates the approach being applied.

Life history/story research provides a way of gaining a first-hand account of social experiences from the participant's point of view. This study will be an exploratory one where in-depth interviews will give the researcher insight into the lives of HIV-positive

educators. In the process of telling a life story, important personal truths are shared and in so doing vital links are created with those who participate in the exchange. Telling and listening to life stories is a powerful experience, which is evident in my interviews with HIV-positive participants.

One of the most important uses of the life story interview is the therapeutic effect it can have. However, relating a life story is not just about this value: it can often help the narrator clarify or understand something that might not have been understood as clearly before the narration. Cohler (1988) says that psychotherapy is known as the *talking cure* and by interviewing HIV-positive educators it is hoped that both the participant and the researcher will benefit from and help each other as a way of making meaning, identifying life influences, and interpreting experience. There may be no better method than the subjective narrative of the life story to help the researcher understand a life from the insider's point of view.

What an HIV-positive (narrator) educator includes in a life story, tells who he/she is at the core, since telling a life story is like telling a sacred story. The researcher examining a life story can see clearly what matters most in the educator's life; it is an indication of the struggles, conflicts and fears that are being faced.

As an approach to understanding a person's life and connecting with his/her experience, there may be no equal to the life story interview. When a person tells his/her own story, he/she reveals more about his/her inner life than any other approach could. Sharing one's story (especially in the case of HIV), is a way of purging or releasing certain burdens and validating personal experiences, and central to the recovery process. At the same time, cognisance must be taken that this could be a painful process to the interviewee. In the next section I discuss the sampling technique.

4.6 Sampling Technique - Choosing Participants for Life Story/History

Many aspects have to be considered when embarking on life story research. Cohen et al

(2007) argue that it involves the researcher both in selecting an appropriate problem and devising relevant research techniques. An important issue for the life/story researcher is the decision about who to research. Life story research is exploratory and intensive and participants are not taken as typical or representative. According to Walford (2001), the gaining of access and becoming accepted is a slow process. The sampling is strategic rather than random. Purposive sampling was used in identifying my participants.

Giele and Elder (1998a) say that in life story work, participants are selected not because they represent some statistical norm but because they typify some historical process. As the name suggests, the sample has been chosen for a specific purpose, in this case to study how HIV-positive educators manage the virus in their daily lives and in the context of schooling and beyond. Good participants for research are those who are articulate, able to tell a story and have a grasp of a particular cultural world.

A purposive sampling technique would produce rich insight into the lives of HIV-positive educators. Participants would be able to generate a valuable experimental account of their daily lives, both on the inside and outside of school. In purposive samplings, researchers handpick the participants. In this study, I did not have a pool of respondents to choose from, but included voluntary participants in my sample, provided that the selection criteria were satisfied. The criteria were that participants were educators and HIV- positive.

In purposive sampling, the participants were chosen for a specific purpose. In this study, participants were chosen as respondents to research how HIV-positive educators manage their lives both at school and out of school. This type of sampling may satisfy the researcher's needs, but it does not represent the wider population, as it is deliberately selective.

Obtaining a sample for this research was riddled with problems because of the social stigma associated with HIV. It resulted in educators being reluctant to take part in this research. The image of the educator as the 'ideal role model' and the 'perfect citizen' is

very important both to the educator and the community, and HIV-positive educators view themselves as falling short of this image, which forces them into secrecy and hiding.

I used the grounded theory approach to analyse the data collected. According to Cohen et al (2007), sample size in grounded theory is relatively immaterial, as one works with the data one has, provided that the researcher has sufficient data to be able to generate and 'ground' the theory in the research context. Grounded theory methods, according to Denzin and Lincoln (2000), specify analytic strategies, not data collection methods. They add that the data collection process includes multiple sources such as observations, conversations, formal interviews and diaries; however, grounded theory analyses of these materials begin with coding, take form with memos and are fashioned into conference papers and articles.

4.7 Strategies used for Data Collection

“The emotions of researching emotionally difficult topics are often over-looked in academic discourse. Yet, the emotionally engaged researcher bears witness to the pain, suffering, humiliation, and indignity of others over and over again”.

(Campbell 2002: 150)

This quotation encapsulates the two sides a researcher may possess, a professional side to stay focused, and an empathetic side to almost involuntarily empathise with the participants.

Life histories/stories, Goodson (1983) argues, have the potential to make a far-reaching contribution to the problem of understanding the links between the “personal troubles” and “public issues”. Their importance, he asserts, “is best confirmed by the fact that teachers continually import life history data into their accounts of classroom events”. Miller (1999) demonstrates that life story research is a distinctive way of conceptualizing social activity, and mentions three main approaches to analysis, namely, the realist, focusing on grounded theory techniques; the neo-positivist, employing more structured

interviews, and the naturalist, using the interplay between interviewer and interviewee to actively construct life stories.

In order to understand the lives of HIV-positive educators, I needed to have intensive interaction with them. To understand how the HIV-positive educators handled their status, coped with HIV and managed in the work environment, I chose to use the life story method. As mentioned earlier, a life story approach provides a way of gaining a first-hand account of the HIV-positive educator's experiences in his/her own voice. Asking questions and getting answers is a much harder task than may seem at first, because of the chances of ambiguity. One of my main strategies of data collection was the interview, as interviewing is one of the most common and powerful ways in which we try to understand our fellow human beings.

According to Atkinson and Silverman (1997), using interviews to acquire information is so extensive today that it has been said that we live in an "interview society". Qualitative researchers are realising increasingly that interviews are not neutral tools of data gathering but active interactions between two (or more) people leading to negotiated, contextually-based results. Gubrium and Holstein (1997) explain that the focus of interviews is to encompass the *how* of people's lives (the constructive work involved in producing order in everyday life) as well as the traditional *what* (the activities of everyday life).

For my interview with participants, I prepared a semi-structured interview schedule. In formulating my guiding questions I had to be mindful of the objectives of my research and stayed focused. The objectives of my research were discussed with my participants prior to the actual interview: my participants were thus able to discuss issues that were relevant to my research. This procedure did not guarantee that the participant would not deviate from the focus, but my guiding questions allowed me to bring them back on track. Kerlinger (1990) comments that "open ended" questions supply a frame of reference for respondent's answers, but puts a minimum of restraint on the answers and their expression. Open-ended questions are feasible and they allow the interviewer to probe so

that he/she may go into more depth.

Focus group meetings with school management teams in selected areas were also held and provided data for this research. In some cases, where possible, spouses and/or close friends (identified by the research participants) were also interviewed, in order to gain insight into their observations about how the participant managed HIV.

Focus groups are a profound experience for both the researcher and the research participants that generate a unique form of data. They tell the qualitative researcher things about social life that would otherwise remain unknown.

(Hesse-Biber and Leavy 2005: 197)

This observation promotes and explains the value of focus group interviews. Focus group interviews allow for group dynamics and a sharing of lived experiences, especially in the workplace. Hesse and Leavy (2005) are of the opinion that focus groups create data from multiple voices. Wilkinson (2004) argues that focus groups decrease power and control of the researchers due to the number of participants simultaneously involved in the group interaction, and the fact that the balance of power shifts from the researcher. From my experience working with focus groups in the Inchanga, Maphumulo and Ndwedwe areas, I noticed that once the group began talking, inhibitions waned and valuable information surfaced.

The ethical choices we make as researchers are motivated by an underlying morality (for example, a desire to: respect and care for others; promote justice and equality; protect others' freedom and avoid harming others), which guide our behaviour, not just during the course of our research, but in all of our social interactions.

(Hallowell et al 2005: 149)

Hallowell alludes to the qualities researchers ought to be mindful when working with participants and collecting data, that humane qualities must always be uppermost so that respect is always maintained and nobody is hurt.

4.8 Conducting a Life Story Interview - The Interviewee

The doing of interviews is personal, transactional, and emotional. It is embodied work that can have implications for the researcher as well as the researched.

How does the researcher present him or herself? How is the interaction embodied? How are feelings presented and managed?

(Kong et al 2002: 250)

This comment succinctly captures the very essence of life story interviews. Life story research, according to Hesse-Biber and Leavy (2005), is an inquiry involving collecting personal stories from an individual over his or her life course. They add that life story is a specific method of interviewing which requires the researcher and respondents to invest lengthy periods together in a process of telling and listening to life stories.

The choice of an interviewee/participant (the term *participant* will be used in place of *interviewee*) will depend on the research use I as the researcher will have for the life story. For this study, the life story will serve the purpose of gaining insight into the life of an HIV-positive educator. It was extremely important for me to be honest with the participant. I had an obligation to explain the purpose of the interview, assure the participant that confidentiality will be respected at all times, and request permission to use a tape recorder during the interview. I had to comply with the wishes of the participant so that the participant would be at ease, and would feel that support is at hand, which is crucial for success in this process. The secret to establishing rapport is to be able to find a balance between guiding and following, and knowing when it is more important to let the pace and direction of the process be set by the participant. A very important quality in a life story interview is the ability to be humane, empathetic, sensitive and understanding, rather than formal and scientific.

The researcher prepared for an interview by getting to know the interview questions and the tape recorder respectively. The interview will be successful if the participant is

allowed time to prepare, as he/she might want to freshen his/her memory and get his/her thoughts organised.

During my interviews with my HIV-positive educators, I did a sample interview for approximately ten minutes, to let the participant get the feel of the interview and relax. Photographs are good memory joggers, they help a participant recall the stories and events of their lives; favourite photographs help the participant look back and relive the memories and experiences that the photographs rekindle. While this data is being collected, it could also be analysed, Denzin and Lincoln (2000) argue that grounded theory consists of systematic inductive guidelines for collecting and analyzing data to build frameworks that explain the collected data.

The venue where the interview took place is also very important, as a familiar setting such as the participant's own home was often most suitable: it offered security and comfort and gave the participant a sense of hosting and control. An individual's choice of venue may also hold many emotions and memories which help steer the interview in the right direction. I requested my participants to choose the venue for our interviews. My first participant chose her home; the second chose her office and the third and fourth chose the Botanical Gardens because they felt that their homes in the townships were not conducive for interviews. The Botanical Garden was chosen for the serene, beautiful and natural setting and away from the noise and prying neighbours. The fifth participant chose to be interviewed in my office.

During the actual recording of the interviews, I allowed my participants to hold the floor for as long as possible without interruption on a given topic. This allowed for free association of thoughts and therefore deeper responses. As the flow wound down, I asked questions that I had prepared to draw on other aspects. As the interviewer, I had to be a very good listener and guide so that I got all the details and also made sure that the interview did not lose focus. Listening well also meant having openness to the participant's personal wisdom. Thus a bridge of trust is built between the interviewer and the participant.

Interviewing an HIV-positive educator is very a sensitive issue and is heavily loaded with ethical constraints. I had to be very careful how I asked difficult, emotionally-laden questions. I was fortunate in that my participants appeared to trust me and felt that they could discuss sensitive issues with me. During some of my interview sessions, some of my participants would break down and weep. I had to play counselor, and be patient until we could resume the interview. Although time was a crucial factor, I had to be very careful not to push the participant further than she was ready to go with the topic, as respecting the boundaries the participant presented is very important.

The interviewer's primary task is to help the participant create and convey his/her story, hence an informal approach, eliciting open-ended responses and in-depth comments is what is recommended. An informal approach helps draw out the participant's personal feelings as well as deep reflective thoughts on life. Both the interviewer and the participant were involved in meaning-making work, and thus turned the interview into an active process. The type of questions in an interview are very important for the success of the interview, as a closed question with a yes/no response could lead to a dead end, while *open ended*, descriptive, structural and contrast questions encourage more thoughtful, developed answers. The majority of the questions I asked were open-ended, which gave the participant a chance to really 'speak her heart'.

An interview which involves sensitive issues, explains Hesse-Biber and Leavy (2005: 119), is generally referred to as an intensive or in-depth interview, and is most commonly used by qualitative researchers. They further explain that, within this method, it is assumed that people have particular and essential knowledge about the social world that is obtainable through verbal messages, and which is accessed through "active asking and listening", such as the "lived experiences" of the participants in this study. Schoenburg et al (2005: 93 cited in Liamputtong 2007: 96) share a similar view. They believe that intensive interviews allow researchers to access complex knowledge from an insider "without the preconceived biases inherent in using existing structured instruments that may contain items irrelevant to local populations".

Intensive interviews, according to Johnson (2002: 103), usually connote a face-to-face and one-on-one interaction between a researcher and her participant. He adds that intensive interviews “seek to build the kind of intimacy that is common for mutual self disclosure”. An intimacy and sense of trust needs to be established before a participant can openly speak about his/her HIV status. On this issue, Hesse-Biber and Leavy (2005: 123) argue that in-depth interviews are valuable for “assessing subjugated voices and getting at subjugated knowledge”, hence their suitability for collecting stories from vulnerable and marginalized people. Johnson (2002) echoes these views, suggesting that the researchers who use in-depth interviewing techniques are searching for great depth of information and knowledge from the participants. He (2002) contends that the information often concerns “personal matters, such as an individual’s self, lived experience, values and decision, occupational ideology, cultural knowledge or perspective”. Life stories and personal narratives are increasingly being used in a wide range of disciplines and settings, and serve as an excellent means for understanding how people see their own experiences, their own lives and their interactions with others.

4.9 Data Analysis

Data analysis is the process of summarizing and reporting on the main contents of data and their messages. Codes are generally used to code the data, and can vary from general to specific. According to Cohen et al (2007), codes are astringent, pulling together a wealth of material into some order and structure. Charmaz (1995c) and Glaser (1978) are of the opinion that making explicit decisions about selecting codes gives the researcher a check on the ‘fit’ between the emerging theoretical framework and the empirical reality it explains. They further explain that categories for synthesising and explaining data arise from the focused codes, and in turn, categories shape the developing analytical frameworks and often subsume several codes. Charmaz (1991) says that categories turn description into conceptual analysis by specifying properties analytically. She offers the following example:

A significant event stands out in memory because it has boundaries, intensity, and emotional force.... The emotional reverberations of a single event echo through the present and future and therefore, however subtly, shade thoughts.

(Charmaz as cited in Denzin & Lincoln 2000: 516)

The experiences of the participants in this study bear testimony to this view, in that many of their psychological emotions arose from the effects of stigma and discrimination. This issue of relevance is another important aspect in grounded theory, because relevance, according to Glaser (1978), deals with the real concern of participants, evokes “grab” (captures the attention) and is not only of academic interest. The preconscious processing that occurs when coding and comparing gives rise to new ideas as the researcher moves from participant to participant and the awareness of serendipity of the method is noted. All the participants in this study were and some still are, educators in the school environment. The “attention grabber” here is the irony of the school environment, for while school is a place of learning and shaping minds and attitudes, the participants suffered most in this environment. There are HIV and AIDS school policies in place, but these seem to go unheeded, and acts of stigma and discrimination have provided new ideas in the analysis.

Charmaz (2000) suggests that memo writing is the immediate step between coding and the first draft of the completed analysis. She expands on this by saying that this step helps to spark the researchers’ thinking and encourages him/her to look at data and codes in new ways. She believes that memo writing aids the researcher in linking analytic interpretation with empirical reality. The nature of this study lent itself to this method, and because the data was analysed at various levels, it allowed me, the researcher, to probe and reach more depth when analyzing the various psychological emotions that were generated during my many interview sessions.

The in-depth analysis of the many psychological anxieties allowed me to probe some of the psychological anxieties that the participants experienced, and gave me a glimpse of the complexities of emotions that were taking place within them. As mentioned earlier in the participant’s stories, the HI-Virus played itself out through the various physical

phases. My participants, by the very nature of their profession, were not comfortable to openly disclose their status, and in view of this dilemma were at times playing a dual role. Externally, all was well: if they felt ill, they used an excuse, such as flu coming on or maybe a stomach bug, but internally they stressed out over their HIV infection.

4.10 Ethical Considerations

Research should, as far as possible, be based on freely given informed consent of research subjects who have been provided with adequate information on what is being done to them, the limits to their participation, as well as any potential risks they may incur by taking part in research.

(Sin 2005:279 as cited in Liamputtong 2007)

In the above quotation Sin (2005) emphasizes the rights of the research participants within the research process, information about the pros and cons, and their right not to be coerced. Ethical concerns encountered in social research can be very complex and subtle, and can often give rise to moral predicaments for researchers, such as a dilemma which requires them to maintain a balance between the demands placed on them as professionals in pursuit of truth and their respondent's rights, values and even health, which may be threatened by the research. Ethical considerations are crucial issues. Beyer and Kass (2002) contend that the first international code of ethics which was established to protect the rights of people from research abuse was the Nuremberg Code in 1949. Other codes of agreement include the World Medical Association Declaration of Helsinki Agreement in 1964 and the Belmont Report in 1979.

The nature of my research on HIV-positive educators is extremely sensitive, and I had to tread very carefully in every data collection process. My starting point was an informal discussion with my participants, basically informing them about the nature of the research. After a lapse of approximately two weeks (time for participants to think about the implications of a research of this nature), I discussed the informed consent form (which I presented to each participant at individual meetings) with my participants. I had

to give my participants approximately one week to sign the consent form. Because of the sensitive and personal nature of this research, I was forced to be patient at this delicate stage of negotiating with my participants. I had to refrain from being too demanding in terms of time. Parnis et al (2005) and Hess (2006 cited in Liamputtong 2007), believe that the confidential nature of research may permit a person to open up and reveal his/her concerns, and this may also provide him/her with a therapeutic experience which may be empowering. In relation to this, Kong et al (2002: 252) contend that “forming an ethical strategy is as much art as science and figures as much in personally sensitive research of any kind”. On the issue of protection when engaging with sensitive issues, Lee-Treweek and Linkogle (2000b) argue that researchers need to protect their research participants; discussions around the ethics of bringing people through painful experiences are essential. They add that sensitive researchers must carefully manage the emotions of the participants and ensure that by participating in their studies, the vulnerable research participants are not left with painful experiences.

Informed consent is absolutely essential whenever participants are exposed to substantial risks or asked to forfeit personal rights. Frankfort-Nachmias and Nachmias (1992) say that when research participants are to be exposed to pain, physical or emotional injury, invasions of privacy, or physical or psychological stress, or when they are asked to surrender their autonomy temporarily (as for example, disclosing their HIV status), informed consent must be fully guaranteed. They believe that participants should know that their involvement is voluntary at all times, and they should receive a thorough explanation beforehand of the benefits, rights, risks and dangers involved as a consequence of their participation in the research project.

Informed consent works on the principle that arises from the subject's rights to freedom and self-determination. Freedom is a condition of living in a democracy and when restrictions and limitations are placed on that freedom they must be justified and consented to. The issue of consent protects and respects the right to self-determination and places some of the responsibility on the participant should anything go wrong in the research. Informed consent, according to Emanuel et al (2000), is defined as the

provision of information to participants, about the purpose of the research, its procedures, potential risks, benefits, and alternatives, so that the individual understands this information and can make a voluntary decision whether to enroll and continue to participate. Participants suffering from life threatening diseases may not always be in a position to make rational decision. Dickson-Swift (2005) contends that researchers seeking informed consent from participants need to ensure that the participants fully understand what it means for them to participate in the study and that they have really consented to do so. When seeking informed consent, timing is important; Booth (1999) suggests that obtaining informed consent from individuals who are under the influence of medication or drugs, who are mentally ill, intoxicated or under-aged, necessitates clear and simple language for easy comprehension. Warren (2002) suggests that researchers read the consent to the participants, as some may not be able to read properly, or fear some negative consequences on signing the consent form.

In research of a sensitive nature, and especially where stigma is rife, confidentiality is of paramount importance. Dickson-Swift (2005) stresses that researchers must ensure that these participants are not easily identified, and ways to protect them must be used. These include the use of fictitious names for research sites and participants. In this study, the true identity of the participants was confidential, and the names used are fictitious.

The right to self-determination also gives the participant the right to refuse to take part, or to withdraw once the research has begun. It can safely be said that informed consent could also imply informed refusal. Informed consent, according to Emanuel et al (2000: 2703), is defined as the provision of information to participants, about purpose of the research, its procedures, potential risks, benefits, and alternatives so that the individual understands this information and can make a voluntary decision whether to enroll and continue to participate.

This definition according to Diener and Crandell (1978), involves the following four elements:

- Competence - responsible mature individual who will make correct decisions and

- give relevant information.
- Voluntarism - informed consent, or to be able to choose freely to take part in the research.
 - Full information - the consent is fully informed.
 - Comprehension - participants fully understand the nature of the research project.

Life story research has its fair share of ethical dilemmas and this is explained by Frankfort -Nachmias and Nachmias (1992) as a conflict between two rights, the right to research and acquire knowledge and the right of individual research participants to self-determination, privacy and dignity. A decision not to conduct a planned research project because it interferes with the participant's welfare is a limitation on the first of these rights. A decision to conduct research despite an ethically questionable practice is a limit on the second right. For the researcher this dilemma has no right or wrong answers, but the proposition favoured will depend on the experience and personal values of the individual researcher.

Privacy in life story research is of paramount importance and must be upheld at all times. This is a very sensitive dilemma especially in my research on HIV and AIDS. Privacy, according to the Social Sciences and Humanities Research Council of Canada (1981), is defined as that which extends to all information relating to a person's physical and mental condition, personal circumstances and social relationships which are not already in the public domain. It gives to the individual or collectively the freedom to decide for themselves when and where, in what circumstances and to what extent, their personal attitudes, opinions, habits, eccentricities, doubts and fears are to be communicated or withheld.

In the light of the above definition, the right to privacy in the context of research may easily be violated during the course of an investigation or denied after the research has been completed, and the participant is vulnerable at both points. However, participants can be protected through anonymity and confidentiality. Frankfort-Nachmias and Nachmias (1992) explain that the obligation to protect the anonymity of research

participants and to keep research data confidential is all-inclusive. It should be fulfilled at all costs unless arrangements to the contrary are made with participants in advance.

Information provided by participants should not reveal their identity. In the case where questionnaires are handed out to be filled, the absence of identifying marks, names or occupational details ensure total anonymity. A face-to-face interview can in no way allow anonymity, of course, such as in this study. I had to rather promise participants confidentiality at all times, and hence my interviews took much longer to complete than interviews of a less sensitive nature. During my initial meetings I had to make sure that my participants were comfortable with me and trusted me. It was not a matter of getting them talking, record them, and go. Each interview lasted from anything between 20 minutes to 2 hours, depending on their frame of mind and their moods. Interviews of a sensitive nature cannot be rushed and have to be handled with care and compassion. In this case I had a responsibility to my profession in the search for knowledge and truth and also to the participants on whom I depend for my work. At every step I had to take into account the effects of the research on participants and act in such a way as to preserve their dignity as human beings.

For most, if not all of us, harm is the very last thing we want to happen, particularly where those we research are already socially excluded.

(Barnard 2005: 13)

In the next section I discuss my quest in search of suitable participants for this study.

4.11 A Challenging Journey in Search of Participants

This study is mainly located within the qualitative research methodology. It utilises a life story approach within a qualitative research methodology, because qualitative research is located within an understanding of human behaviour: in other words, the researcher observes and interacts with people in order to conceptualise the world as the participants see it.

This study explores how HIV-positive educators manage their lives and illnesses both at home and in the workplace. The journey during my search for HIV-positive educators as participants was an extremely difficult one with numerous hurdles. Some of the challenges I faced during the search for my special participants are described below:

- While teacher unions claim to be aware of HIV-positive educators, they were not prepared or willing to negotiate/mediate a meeting between the HIV-positive educator and myself. The 'buck kept getting passed around' and this drew a blank.
- At one of the teacher union offices, the person in charge of the HIV portfolio tried to persuade some HIV-positive educators to agree to an interview with me. The reply she got was "...how will this interview help me, what is there in it for me?" Another no entry.
- Introductions and referrals to school principals who were in a position to organise a meeting with HIV-positive educators on their staff drew the following response: "...if any of my teachers are HIV- positive, I am not aware of it."
- Educators at HIV workshops were informed of my research on HIV-positive educators, and although they had colleagues and friends who were HIV-positive, their response was, "...HIV-positive educators will not disclose their status for fear of victimization."
- I discussed my research with some medical doctors who did say that they had HIV-positive educators as patients. These doctors with the exception of one, were not agreeable to organising a meeting with their HIV-positive patients and myself because of the extreme sensitivity and confidentiality of HIV.
- The one doctor who was keen to help me meet one of his HIV-positive educators, called me a month later with a negative response.

The various difficulties that I encountered on this journey caused many delays in the research process. Though I was very disappointed, eighteen months later I met my first participant (see Appendix for the rest of the journey).

The participants in this study were purposely chosen given the sensitive nature of the

research. As noted, finding willing participants for this study was very difficult. I had approached teacher unions, lifeline counselors, doctors and clinics but was unsuccessful in finding HIV-positive educators who were willing to participate in this study. I met Annaline, my first participant at a seminar, 18 months after I embarked on this research, Five months later, at a Saturday afternoon talk on HIV and AIDS, I met Delene, who had a bubbly personality and agreed to be interviewed for this study. 8 months later I met Siwina and Thandiwe at one of my HIV and AIDS workshops in Inchanga; they agreed to be interviewed for this study. All the participants are females: this was not what I had set out to do. I had hoped to interview both male and female participants, but unfortunately no HIV-positive male educators were willing to be interviewed for this study. Fourteen months later, a male HIV-positive educator agreed to be interviewed for this study this educator was referred to me through a counselor. At this late stage of data collection, I ought to have stopped interviewing participants, but I was eager to get a male perspective on living with HIV. I could not refuse. I subsequently had approximately 6 hours (over a period 3 months) of interviewing time with my new participant. Table 4.1 shows a summary of relevant details of my sample of participants in this study.

Table: 4.1 Sample of Participants used in the Study

Critical Question	Participants	M/F	Age	Present Occupation	Residence
What are the experiences of HIV-positive educators and how do they constitute themselves as educators in the school environment and beyond?	Annaline	F	32	Lay-counselor	Glenwood
	Ashwin	M	40	Educator	Stanger
	Delene	F	32	HIV-facilitator	Bluff
	Siwina	F	39	Educator	Adams Mission
	Thandiwe	F	31	Deceased	Imbali

The table above shows that the participants are in the 30-40 age group; three of them are still educators; two are in HIV/Counseling/Facilitating jobs. They come from different

areas of KwaZulu-Natal; a map of South Africa and another of KwaZulu-Natal have been included to show the positioning of the province of KwaZulu-Natal within South Africa (see figures 4.1 and 4.2 respectively). In the next section I discuss issues of validity in life story research.

4.12 Validity in Life Story Research

Validity is an important aspect to effective research, and a requirement for both qualitative and quantitative research. While there are various types of instruments to measure what the research has to measure, recently validity has taken many forms. According to Winter (2000), in qualitative data validity may be addressed through honesty, depth, richness and scope of the data achieved, the participants approached, the extent of triangulation and the disinterestedness or objectivity of the researcher. Plummer (1983) says that the question of reliability and validity have featured extensively in discussions of the life history method. He explains that validity has to do with the measurement instruments used (e.g. questions or scales), in the production of data and the development of explanations, and that reliability concerns whether the same instrument provides the same measurement each time. He elaborates further on the issue of personal documents: the charge is made that stories can be made up or that the participant may respond according to a passing recall, or even propound untruths and deceive themselves and the researcher. Plummer (1983: 101) states that validity becomes more attainable when the study of a topic remains close to the actual context. Cohen et al (2007) argue that reliability in life story/history research hinges upon the identification of sources of bias and the application of techniques to reduce them.

4.13 Conclusion

In this chapter I have discussed a comprehensive methodology plan for data collection, in order to answer the study's critical question, namely, what are the experiences of HIV-positive educators within the context of schooling and beyond? A study of this nature has

an inevitable leaning towards a qualitative research design. The sensitive nature of this study lent itself to the life story methodology, and for this methodology, individual interviews were used as the main data collection source. The grounded theory approach was discussed as a means for analyzing the data, because it allows the very essence of the participant's experiences to be captured and reported.

The sampling issues were also discussed, along with the difficulties experienced in finding suitable participants. Ethical considerations in a study of this nature are imperative, as discussed in this chapter. Chapter Five will present an analysis of the data collected from interviews with educators living with HIV and AIDS, focus group meetings, meetings with spouses, close friends and relatives.

CHAPTER FIVE

ANALYSIS

On Analysing Participants' Voices and Emotions

5.0 Preamble

In this chapter I present an analysis of the life story interviews of the participants in this study, and a discussion of the data collected. This chapter will be presented in three parts: Part One will discuss all the phases of HIV, presenting the physical aspects of the virus. Part Two will discuss emotional aspects of HIV and AIDS. Part Three will discuss the professional support/non-support that HIV-positive educators receive during this period. These phases do not necessarily occur in a particular sequence but I have captured these as experienced by the participants in the study. The reason for doing this is that I would like to present the participants' voices as they experience living with HIV and AIDS in a progressive way. The phases provide an interesting framework to capture these experiences. The voices of the participants are made audible to elaborate and create themes for discussion. I have included relevant input from focus group meetings I had with members of school management teams (SMTs)¹ from the three different areas, namely, Maphumulo, Inchanga and Ndwedwe. KwaZulu-Natal has the largest teacher population and the highest HIV prevalence rate amongst its teacher fraternity (HSRC/ELRC document 2004/5). Professional support in the workplace is a crucial issue and requires discussion in the light of this claim.

The chapter begins with an analysis of the profile of the respondents in the study. Thereafter the various parts as described above are presented.

5.1 Introduction

As mentioned in the methodology chapter (Chapter Four), the participants in this study were purposely chosen given the highly sensitive nature of this study. This research on educators

¹ School Management Teams (SMTs): in South Africa this team is made up of the school principal, the deputy-principal and Heads of Departments (HOD).
D.Ed Thesis: An insight into the experiences of educators living with HIV and AIDS in the context of schooling and beyond

living with HIV is seeped in notions of vulnerability and sensitivity and establishing a definition of vulnerability in this context was difficult. Moore and Miller (1999) state that a precise definition of “vulnerable” is problematic because it is a socially constructed concept. However, Silva (1995: 15) suggests that a vulnerable person is an individual who experiences “diminished autonomy due to physiological/psychological factors or status inequalities”. In response to Silva’s definition, Moore and Miller (1999: 1034) argue that vulnerable individuals are people who “lack the ability to make personal life choices, to make personal decisions, to maintain independence and to self-determine”. Melrose (2002) and Benoit et al (2005) say that the term “vulnerable” is often used interchangeably with such terms as “sensitive”, the “hard-to-reach”, and “hidden populations”. The use of such descriptions compounds the problems that researchers encounter when trying to find suitable participants for research of a sensitive nature. Throughout this chapter I have tried to use the words of the participants in order to capture the emotions and concerns they experience because of their HIV status, and to do justice to their life stories, which they shared with me with so unselfishly.

5.2 Representation of Findings

Table 5.1 provides the profiles of the five participants, which gives the reader a brief history of each. This profile highlights relevant issues for this study, namely, age, health status, history of infection and period of infection. It is believed that this profile is necessary as it illustrates how HIV-positive educators manage their lives in a stigmatizing society and more especially in the school environment, which has its own set of roles and expectations (see 7 roles of the educator in Section 2.1).

5.2.1 Participant’s Profile, Biographical Data and Personal Information

Participants’ profiles (see Table 5.1) reveal that all the participants in this study fall in the 30 to 40 year age group. People in this age group are assets to any workforce, in the prime of their lives and have the responsibilities of their families; in some cases, they are breadwinners. All the participants in this study were from the province of KwaZulu-Natal. While the sample of participants was purposely chosen, it included Black, White, Coloured and Indian participants. Participants came from varying marital statuses and family backgrounds. All the participants were in possession of a basic teacher’s diploma, two had a second diploma, four of the five had a

Bachelor of Arts degree, and two had a Bachelor of Education degree. One educator in this cohort is an H.O.D. and the others are level one educators. The history of infection (Table 5.1) shows how each of the participants contracted HIV, and the profile also indicates each participant's period of infection.

As mentioned earlier, the focus group meetings took place in three areas in KwaZulu- Natal. The discussions were guided by the five questions I asked at the meetings. Permission was granted for me to meet with one participant's spouse, the mother of another of participant and close friend of another. Their responses to my questions are also recorded in this chapter. Three teacher union representatives granted me brief interviews, and their responses are also presented

The plan I had in mind at the beginning of this study was one that would represent participants from all the race groups and both genders, however given the sensitive nature of this study this was not possible, hence the gender imbalance. The race group of participants was incidental because the sample was purposive. The marital status of each participant also indicates the impact of HIV on the private lives of these educators. The family background of each participant helps the reader to understand the possibility of support bases.

PARTICIPANTS PROFILE HERE

In figure 5.1, the demographic profile of the participants is presented. A map of KwaZulu-Natal shows the approximate area of residence of each participant, whether coastal, north, south or inland.

Figure 5.1. Map of KwaZulu-Natal

- 1 & 2 Glenwood and Bluff residence of Annaline & Delene respectively
- 3 Stanger residence of Ashwin
- 4 Adams Mission residence of Siwina
- 5 Imbali Township residence of Thandiwe

Figure: 5.1 Map of KwaZulu-Natal (inset map of South Africa)



5.2.2 Engaging with the Participants' Profiles

With reference to the participants' profiles, the health status of the HIV-positive person and the dependents that an HIV-positive person has, also describes the stress and coping challenges the individual faces. From the history of infection of these participants, it is evident that besides sexual promiscuity, there are other ways of becoming infected, hence the urgent need to eradicate stigma.

The place of residence of each participant proves that HIV is widespread and not confined to certain areas only. The race classification also shows that vulnerability to HIV is widespread despite the relatively stable families the participants came from. The period of infection of each participant is an indication that the virus can be managed by a healthy lifestyle and medication. Annaline has been living with HIV for more than 12 years, Delene for more than 9 years, Siwina for more than 8 years and Ashwin for more than 5 years. I had spent approximately six hours of interview time with Thandiwe (not at one stretch, but over a period of a few months), unfortunately Thandiwe lost her battle to AIDS, 18 months after her diagnosis.

5.3 Emerging Analytical Framework of Phases and Themes

The participants in this study described their emotional experiences on hearing their HIV-positive diagnosis, and insight was gained into both the physical and emotional aspects of the virus and the trauma that ensued. Many themes emerged from the life story interviews with the participants (see appendix). When I interviewed the participants, my attention was focused on their stories and capturing their words and emotions, but when I listened to their voices and transcribed their stories, I realized that my participants were in different phases of the HIV infection. The objective of this study is create an understanding and to gain insight into the experiences of educators living with HIV. As far as possible, prominence was given to the voices of the participants, in order to avoid 'sanitising' participants' voices.

HIV-positive individuals and their families undergo several phases of management of HIV. While the handling of the virus varies from person to person, they all experience the phases of HIV. The phases of the virus do not have a time frame, but are dependent on the individual's

state of health, their emotional well-being, coping ability and their support base. Mention was made earlier that HIV-positive people experience both physical phases and varying emotions caused by HIV. As indicated in the introduction, these phases have been represented in a way that articulates with the development of each participant and may not necessarily reflect the general trend for others who are infected. My discussion on the physical phases is an adaptation from van Dyk (2008). Figure 5.2 represents the framework that has been used to represent these phases. The physical phase is generally visual and tangible whilst emotions are experienced. These phases map the journey traveled by an HIV-positive person, from the struggles and initial shock of the virus to managing and adjusting their lives to live with HIV. HIV and AIDS were almost unheard of about 30 years ago, but has now become a major part of life for many people around the world.

In discussing the physical phases of HIV (Figure 5.2), it is noted that during the Primary Infection Phase, only Ashwin knew of his HIV-positive status, and none of the other participants suspected that they were HIV-positive. Their fever, tiredness and flu-like symptoms (according to the data) were dismissed as common colds. Similarly, during (phase 2) the Asymptomatic Phase, generally referred to as the 'silent phase,' all the participants with the exception of Ashwin was not even aware that they were carrying the virus. In the context of this study, this phase is referred to as the 'silent phase' because the virus is in incubation and there are no visible symptoms. During Phase 3, the Minor Symptomatic Phase, Annaline, Delene, Siwina and Thandiwe became anxious when coughs lasted more than three weeks, the rash on the body became irritating and tiredness and lethargy prevailed; weight loss was a cause for concern. Although Ashwin was a relatively strong person, the issue of being HIV-positive was a remainder to him that his body was invaded by the HI Virus and this clouded his demeanor and made him miserable.

With reference to Figure 5.2, four of the participants in this study were in Phase 3 of the physical side of the disease. In the next stage, phase 4, which is the Major Symptomatic Phase, the immune system becomes compromised and opportunistic diseases begin to appear. Phase 5, the Severe Symptomatic Phase, is the AIDS stage, from which the patient's health deteriorates fast to Phase 6, death. Data evidence shows that all the participants in this study were anxious to learn about the virus in order to practise a safer lifestyle, and also to know how the virus will progress and what

precautions need to be taken. Annaline spoke about her health status changing from Phase 3 to Phase 4, and then back to Phase 3 (see appendix for life stories, this reference will not appear elsewhere in the chapter). Annaline² has been living with the virus for the past 12 years, Ashwin³ for 5 years, Delene⁴ for 9 years, Siwina⁵ for 8 years and Thandiwe⁶ lost her fight to AIDS within 18 months. The participants in this study were determined to manage the virus like a chronic ailment and to be around for their families for as long as possible.

While the physical phases of HIV were experienced and visible, the emotional aspects of the virus posed another challenge. The participants in this study spoke of the pre-disclosure aspect of HIV disclosure as very difficult, in which they had many debates and emotions raging within their minds, such as coming to terms with the diagnosis, understanding the virus and the negativity surrounding it, the decision to disclose or not to disclose, and most of all not knowing what this virus is going to do to their bodies.. Emotions do not have clear cut boundaries; but vary from person to person. Disclosure varies from person to person, as the HIV-positive person will disclose when he/she is confident of support from family and friends, or may never disclose. In the context of this study, the participants had to learn to adjust to the situation when he/she would have more or less come to terms with the situation and is in the process of adjusting his/her lifestyle. Delene voiced her anxiety about the symptoms that would appear during the symptomatic phase and the virus cannot remain 'hidden' anymore, she and her family members believed that the end may be near, she may even be hospitalised. Thandiwe moved through all these phases of HIV and AIDS rapidly and as mentioned, within 18 months succumbed to the virus.

HIV infection is divided into different phases theoretically, as suggested by van Dyk (2008), but in practice, these phases are not separate: they merge and are not easily identifiable. An HIV-positive person may not necessarily move in order from one phase to another, as the progression or development of HIV-related symptoms of the virus will depend on the health of the person's immune system. As this analysis progresses, I will attempt to discuss the lives of my participants

² See appendix 1 for Annaline's story

³ See appendix 2 for Ashwin's story

⁴ See appendix 3 for Delene's story

⁵ See appendix 4 for Siwina's story

⁶ See appendix 5 for Thandiwe's story

as they share what is inside them with what we see on the outside. Their testimonies describe their feelings, much of which is beyond our comprehension

Many themes emerged from the life story interviews with the participants. I categorized the data collected from the interviews into common themes that emerged from the life stories, I will discuss the various themes within the HIV phases to show the impact of the various emotions (themes) on the HIV-positive person. These themes were loosely linked into similar categories to provide insight into the trials and tribulations of educators living with HIV. The following themes emerged from the data collected from interviews:

- Shock, fear, anxiety, disbelief, confusion and devastation, anger, shame, guilt, blame, depression, stress and spouse's anger.
- Secrecy, suicide, isolation, rejection, loneliness, frustration.
- Loss of self image, lifestyle change and self-motivation.
- Stigma, discrimination and exposing family to stigma.
- Denial, vulnerability, trauma and pain, accepting the situation.
- Poverty.
- Need for empowerment and support, empower management, departmental support, support groups.
- Workplace insensitivity, name calling/labeling, ignorance and deteriorating health.
- Absenteeism, angry colleagues and work backlog, disclosure at school.
- Coping problems and financial burden.

In the next section, part one, I will discuss the phases of HIV infection .and the impact it had and has on the participant's life.

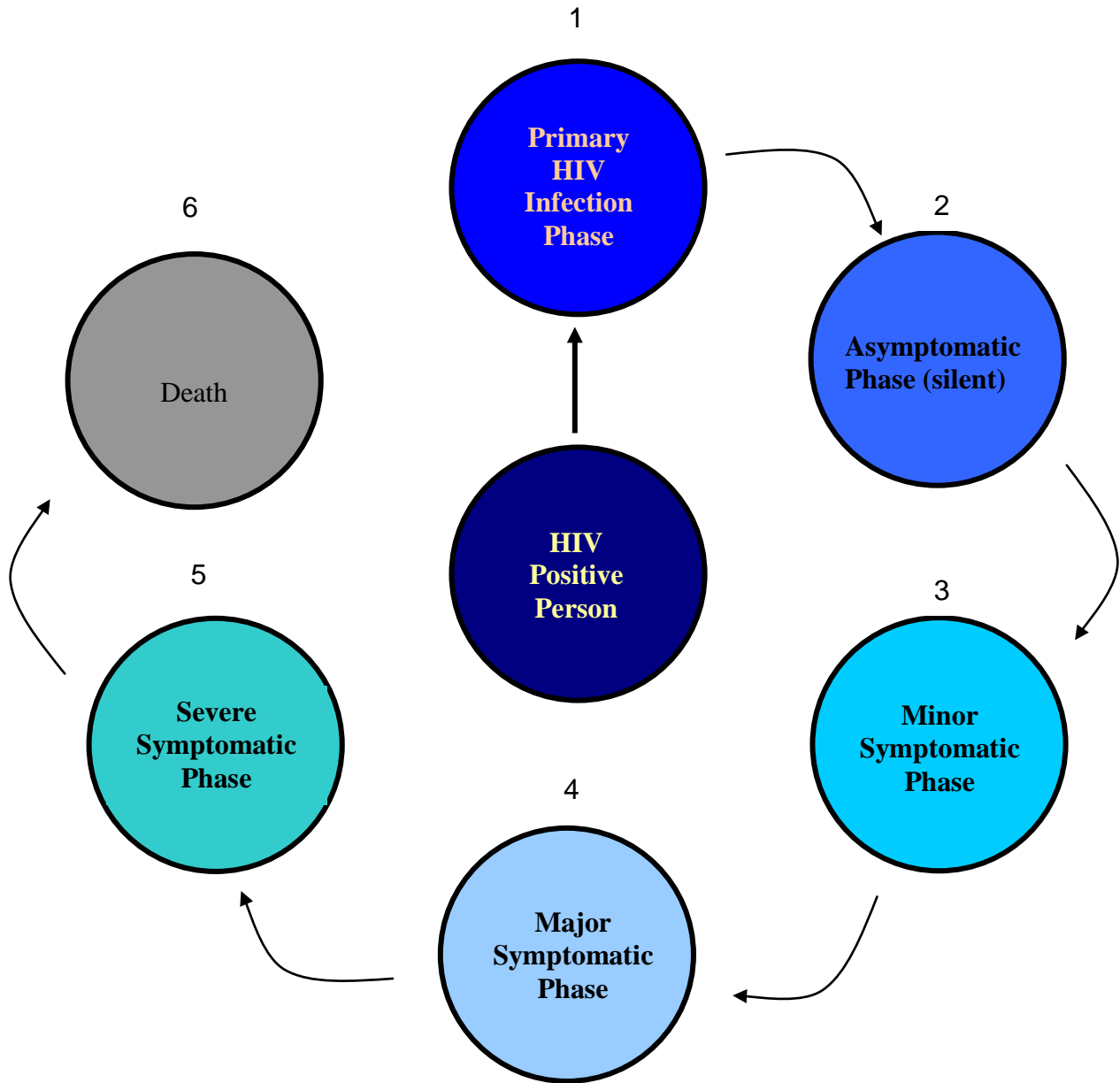
5.4 PART ONE - Phases of HIV and AIDS

HIV is theoretically divided into different stages, but in practice these stages are not separate and distinct with easily identifiable boundaries. It must be noted that the stages that have been

identified cohere with those suggested by Dyk (2008) in different ways. According to van Dyk (2008) HIV infection is divided into the following clinical stages:

- Pre-clinical Stage-Primary HIV infection (or acute seroconversion illness)
- The asymptomatic stage
- The minor symptomatic stage
- The major symptomatic stage
- The severe symptomatic stage

Figure: 5.2 Physical Phases of HIV Infection (adapted from Van Dyk 2008: 51)



5.4.1 Phase One– The Primary HIV Infection Phase

HIV infection occurs immediately when a person contracts the virus. Seroconversion⁷ begins, generally when an HIV test reveals that a person's status changes from HIV negative to HIV-positive. This phase usually occurs about six weeks after infection with the HI virus. The participants in this study with the exception of Ashwin were unaware of their HIV positive status.

Van Dyk (2008) explains that the HIV viral load is very high during seroconversion. This happens because of the rapid multiplication of the virus after infection. The HIV-positive person is highly infectious during this phase because there are many HI viruses in the blood. The HI viruses replicate very fast before the immune system has had time to develop an immune response to it.

All the participants in this study discussed their procrastination and anxiety when deciding to have a blood test. In Annaline's case, her insurance contract required her to have a blood test to check her HIV status, and an HIV-positive diagnosis was the furthest thought from her mind. Delene's sore throat and loss of appetite was a cause for concern which made her have a blood test; in her case too, an HIV-positive diagnosis was not a possibility. Ashwin, being a victim of hijack and rape, had to have a full medical check and he was very worried about the results, his worst fear was confirmed. Siwina, being a mother of two young children, was taking the necessary precautions about the recurring rash on her skin and went to have a blood test as suggested by her doctor, but did not expect to be told that she was HIV- positive. Thandiwe's concern stemmed from her low energy levels, tiredness and itchy skin; she did not expect her blood test to reveal an HIV-positive diagnosis.

Delene, in her story discussed these symptoms before her HIV test.

I had lost my appetite and no matter what I ate I could not taste, my mouth also felt sore, I looked into my mouth and I was shocked to see some white scaly substances in my mouth. I was terrified

⁷ Seroconversion means the point at which a person's HIV status changes from being HIV negative to HIV positive. After seroconversion an HIV test will be positive. Seroconversion usually occurs 4 to 6 weeks after infection with the HI virus van Dyke (2008: 52).

Siwina spoke of an irritating rash that prompted her to visit the doctor and have a blood test.

I noticed that my skin was feeling strange and itchy, I had tried applying lotions to soothe it but nothing helped

The above information from the participants in this study show what prompted them to have blood tests.

5.4.2 Phase Two- The Asymptomatic⁸ Latent/Silent Phase

In this stage, an infected person does not display any symptoms. The Asymptomatic Phase, is also referred to as the “silent phase,” because individuals are often not even aware that they are carrying the HI virus and may unknowingly infect a partner. Some HIV-positive people can remain healthy for many years, without showing any symptoms, while others may deteriorate rapidly and develop AIDS and die in a few months. Thandiwe in this study found it very difficult to come to terms with her HIV positive status and could not bring herself to disclose her status to anyone, and Annaline’s asymptomatic phase lasted more than two years.

In some cases the HIV positive person may be ignorant of the presence of the virus in his/her body, the virus nevertheless remains active in the body during this stage and continues to compromise the immune system. HIV positive people can enjoy good health for a long time without showing any symptoms (like Siwina and Annaline in this study), whilst there are some who deteriorate fast, develop AIDS and die (Thandiwe in this study).

5.4.3 Phase Three-The Minor Symptomatic⁹ Phase

During this phase of the infection, early or minor symptoms may begin to appear as was noticed by participants in this study. The stage begins when people with HIV antibodies start showing one or more of the following symptoms:

- Fatigue, lethargy and/or sleepiness
- Weight loss up to 10% of body weight

⁸ The Asymptomatic Phase is usually associated with a CD4 cell count of between 500 and 800 cell/mm. The normal CD4 count in healthy (non-infected) individuals is approximately 800-1200 cell/mm (van Dyk 2008)

⁹ The minor symptomatic phase is usually associated with a CD4 cell count of between 350 and 500 cells/mm
D.Ed Thesis: An insight into the experiences of educators living with HIV and AIDS in the context of schooling and beyond

- Mild to moderate swelling of lymph nodes in the neck, armpits and groin
- Occasional fevers
- Recurrent oral ulcers
- Skin rashes, itchy skin, dermatitis and shingles
- Recurrent upper tract infections

All the participants in this study did complain of many of the above symptoms. During this phase, the HIV-positive person is able to continue to carry on with everyday activities depending on the individual's health status. The important goal is maintaining a healthy immune system. The time that it takes a person to reach this stage will vary from individual to individual. The HIV-positive person now concentrates on managing the virus by changing or adjusting his/her lifestyle. In some cases, families may still be in denial in order to cope and hope for the best. This being the minor symptomatic phase, not many symptoms are visible. HIV-positive people and their families have to adjust to living with stigma and discrimination. While little or no HIV symptoms may be visible, the person living with HIV is very sensitive to the way colleagues look at him/her or walk away when he/she approached (this behaviour was experienced by some of the participants in this study). This type of behaviour sometimes gave a false sense of suspicion. This phase is easier to manage when there is support both in the home and the work environment.

5.4.4 Phase Four-Major Symptomatic¹⁰ Phase

In this phase, according to van Dyk (2008) major symptoms and opportunistic diseases begin to appear because the immune system becomes compromised, the CD4 count decreases and the viral load¹¹ increases. Van Dyk (2008) explains that opportunistic diseases are evident and in some cases become very severe; oral and vaginal thrush and recurrent herpes infection such as cold sores and shingles are commonly the first clinical signs of extreme immune deficiency. When a person has reached this stage, they would usually be spending 50% of the day in bed. In the case of educators, much absenteeism was noticed, at times for periods of a month or more. Annaline spoke about her experiences when her CD4 count was below 200, and she coughed most of the time; she also spoke of the times when she was absent for lengthy periods; she stayed

¹⁰ The major symptomatic phase is usually associated with a CD4 cell count of between 200 and 350 cell/mm. (van Dyk 2008).

¹¹ Viral load refers to the amount/percentage of HI viruses in the body. Van Dyk (2008).

in bed and did not want to get up, and on her return to school she had to face an angry principal, who was very insensitive and queried her absence.

Thandiwe reached this fourth phase of the virus within a year of her diagnosis, and spoke of her deteriorating health and the clearly visible symptoms of HIV:

Some HIV symptoms began showing such as loss of hair, loss of weight and glands in my armpits. After two weeks into the first school term, I became very ill and had to be hospitalised

By this stage Thandiwe reported that her absenteeism from school was becoming rather pronounced, which made her feel sad because her class was missing work and her colleagues were not happy serving relief for her.

5.4.5 Phase Five-The Severe Symptomatic¹² Phase

When the HIV-positive person enters phase five, the last stage of HIV infection, the person is said to have AIDS. One of the participants in this study (Thandiwe) reached this phase and I will be using much of the data generated from the last few interviews I had with her for this discussion. During this phase of the infection, the symptoms become even more pronounced, and the immune system deteriorates rapidly making the body vulnerable to opportunistic infection. A person with AIDS would have a very high viral load and a very low CD4 count (below 200); at this stage Thandiwe's CD4 count was 165, making her immune system very weak. Her body became vulnerable to opportunistic infections. Some common conditions¹³ that affect the person include diarrhoea, nausea and vomiting leaving the person thin and emaciated. Oral infections such as thrush in the mouth and throat may be very painful to the extent that the person is unable to eat or swallow. Skin infection and cancer is also a common condition. Thandiwe had become very thin because she had oral thrush and could not eat; she also experienced diarrhoea and vomiting, and this inability to cope caused her to spend much of her time in hospital. Her learners and school work suffered and this made her very unhappy.

¹² In the severe symptomatic stage the patient usually has a very high viral load and severe immune deficiency with a CD4 cell count of below 200 cell/mm (van Dyk 2008)

¹³ See HIV/AIDS Care & Counselling p. 43-45 van Dyk (2008).

Her emotions reached crisis point, when she became very ill and had to be admitted into hospital. Denial dissolves, and secrecy is difficult to maintain. With the onset of this and subsequent illnesses, there may be impairment, job loss, applications for social services and disability, concern for surviving children, frustration with medical and insurance systems. At times, it is necessary to sit down and cry and scream with an understanding family member or friend because it helps to cope with this illness. Thandiwe reached this phase within 18 months of her diagnosis. She lived with her secret for almost a year, and because of her secrecy she did not know how to cope with HIV and AIDS. Her condition deteriorated rapidly when she reached the stage of full-blown AIDS. She had thrush in her mouth and could not eat, and had become very weak. She drank liquids through a straw and this gave her diarrhoea; her skin also looked dry and painful, and she was in a lot of pain and described her condition as follows:

I am so miserable, now I just want to die, to be relieved of this pain

After staying in hospital for eight days, Thandiwe was discharged, but the anguish caused by the pain made her very weak and she decided to take sick leave for the rest of the term, so that a substitute teacher could teach her class. Thandiwe's family was very upset about her deteriorating health; her mother cried bitterly during this time, suspecting that Thandiwe was dying. Her little daughter also cried because she missed her mother while she was in hospital. Thandiwe also cried bitterly, because she suspected the end was near. Six months before her death, Thandiwe confided in her sister and disclosed her status, making her promise to keep it a secret always. She also asked her sister to take her daughter to have an HIV test:

I needed to know her status, I did not want her to suffer like me, fortunately my daughter was HIV-negative

Thandiwe went back to school in term two but collapsed by mid-morning and had to be rushed to hospital by the paramedics. She was in hospital for ten days and then sent home to recuperate. My last interview with Thandiwe was postponed on three occasions. I had telephonic contact with her. My requests to visit her at her home were turned down because it would have raised too much suspicion. My association with Thandiwe began about ten months after she was diagnosed HIV-positive, and I empathized with her after listening to her sensitive plight and hoped that she would be granted the strength to see her daughter grow up. The downward turn in her condition also affected me, because Thandiwe was a victim of circumstances. Renzetti and Lee (1993: ix) suggest that sensitive research includes studies which are "intimate, discreditable or

D.Ed Thesis: An insight into the experiences of educators living with HIV and AIDS in the context of schooling and beyond

incriminating” Lee (1993: 4) argues that sensitive research is “research which potentially poses a substantial threat to those who are or have been involved in it”. Jones and Tannock (2000) concur with Lee, adding that “not only the research participants but also the researchers are affected”. Thandiwe finally lost her battle to AIDS on 20 August 2005.

Some HIV-positive people also go into remission generally between phases three to four. These are long stretches of healthy time between illnesses, with the re-establishment of routine and homeostasis. All the participants in this study had “bad” as well as “good” days; there were times when Delene spoke about not being able to face the day because she was in so much pain, and when this happened she stayed away from school for lengthy periods. Annaline, in her story spoke about her decreasing CD4 count and her bordering on AIDS. Ashwin also discussed his physical pain which was aggravated by his emotional pain which was caused by the break up with his family. As illnesses occur more frequently, the family is stressed by the health ups and downs. The unpredictability of health makes it difficult to plan and anticipate the future. Family members are also at risk for depression and burn-out and must have a break from AIDS; unfortunately the infected and the affected person may experience depression, and eventually as he/she accepts impending death, he/she talks about funeral plans, making a will and arrangements for children. It is obvious that as death approaches, the strain on the family is overwhelming: they struggle to keep the patient comfortable and face difficult decisions about hospice care. Thandiwe’s family experienced this phase five, when Thandiwe was very ill. They did not know how to make her comfortable because she was so ill and in so much pain. The family was also grieving over Thandiwe’s pain. After Thandiwe’s death, the family had to take care of her daughter, to console her; at the same time the family needed time to come to terms with the loss of a family member.

Before an HIV diagnosis, an individual plans ahead, sometimes planning five years in advance, but after an HIV diagnosis, the individual is eager to go on medication and plan for the short-term, because everyday brings with it a new coping challenge and a good day is considered a bonus. Annaline had great plans for the future: she and her then future husband planned their wedding with their family, but after her HIV-positive diagnosis, they had to reorganize their plans. Ashwin was well-settled in his job, marriage and family, and had set his goals for the future. After his HIV-positive diagnosis, his plans had to change. Siwina had to divorce her

husband and become a single parent after her diagnosis. Life for the immediate family of the HIV infected person is also a great painful challenge, hence HIV is often referred to as a family predicament. Family and friends stress and are anxious about their loved one's state of health.

5.4.6 Conclusion to Part One

In this section the phases as experienced by the participants in the study were discussed. Each phase was elaborated on in terms of CD4 count and symptoms. The participants expressed shock, fear, denial, shame, guilt and even anticipatory grief. At this stage they believed that an HIV diagnosis equaled death, and anxiety and stress about their families came to the fore. Evidence from the data showed that an HIV diagnosis placed a heavy burden on the mental health of the participants and in some cases on their families as well. The fear of dying was expressed at this early stage. Much of the fear and anxiety stemmed from a lack of knowledge of HIV and how it will manifest itself as time progresses. Much of the anger and anxiety resulted from future danger: AIDS, death and dying.

During phase three, the minor symptomatic phase, some of the HIV-positive participants no longer saw themselves in control of their lives. Their illness now dominated their lives, and images of death were ever-present, as they spoke of their fear of the coming days and their health taking a downward spiral. Concern for their families also caused much anxiety. Thandiwe's case was extreme in that she had not yet confided in any immediate family member for fear of the consequences. At this stage both infected and affected people see HIV as an end-of-the-road infection; some of the participants in this study spoke of suicide as a way out of this misery. Even at this stage of the virus, the participants were not comfortable with openly disclosing their status because of the stigma and discrimination. While education about HIV is of paramount importance, mindset must also change. Data evidence also showed that by the time the participants reached this phase, some of them were reasonably empowered about the virus and were able to adjust to living with HIV, to the extent where they changed their lifestyles to try and maintained a healthy immune system.

From the data evidence, the participants were also angry that there was no cure for HIV and AIDS, and expressed their helplessness and hopelessness. Secrecy is another issue that the

participants had to deal with; evidence showed that the participants were not counseled. Disbelief and denial and the “it won’t happen to me” syndrome also accompanied the initial stages of an HIV diagnosis. Much discussion occurred around denial as a coping mechanism. From the verbal and emotional outbursts of the participants in this study, it appeared that their fear stemmed from the stigma first and then the virus.

Whilst educators who are HIV-positive experience the virus just like any ordinary person, their profession as educators comes into question. Educators are looked upon to be icons of morality and can do no wrong, hence the reluctance to disclose their status. The participants also spoke about their self-imposed loneliness because of their fear and suspicion that people will know their status. Many debates raged within the HIV-positive educators to disclose or not to disclose. Personal ethical issues around self and self-esteem also came into focus as the educators had to lie to colleagues about the nature of their illness, when they returned from being absent.

On analyzing the data generated from the life story interviews with the five participants in this study, many emotional experiences/themes emerged. In the following section I discuss their emotional experiences, and as far as possible using their voices to do so.

5.5 PART TWO: Participants’ Emotional Experiences

All the participants in this study expressed their shock and sense of helplessness on receiving their HIV positive diagnosis. This was a very trying time for all the participants, and he/she may either be open about the results or keep it a secret. Participants in this study explained that a person who discloses his/her status immediately is either very brave and sure of his/her family or panic stricken. Immediate disclosure may mean anger and rejection (as Ashwin had experienced), or it may bring an outpouring of love and support. None of the participants in this study disclosed their status as soon as they had been diagnosed HIV-positive. There is also the need for the HIV-positive person to talk with another, thereby extending the circle of people who know. Siwina and Delene spoke about their efforts to maintain normal behaviour and relationships, but at times they withdrew from the family; Thandiwe explained that living in fear and secrecy is highly stressful, but that some people found it safer than disclosure.

This section begins with a discussion of Initial Psychological Anxieties after Diagnosis, thereafter it moves into a discussion of 5.5.2/5.5.3.

5.5.1 Initial Psychological Anxieties after Diagnosis

It must be noted that these stages have been presented as they have been experienced by the participants and may differ considerably from one individual to another. During the period immediately after diagnosis, the participants experienced a range of emotions such as shock, fear, anxiety, disbelief, denial, confusion, devastation, anger, shame, blame, depression, stigma, discrimination, guilt, stress, secrecy, vulnerability and anticipatory grief.

5.5.1.1 Disclosure of status

- **HIV positive results**

Disclosure of an HIV positive status requires much serious thought, van Dyk (2008) argues that the decision to disclose one's HIV positive status is difficult because disclosure or non-disclosure may have major life-changing consequences.

In this section I will discuss the attempts made by the participants to disclose their HIV status, as by this time the participants have more or less accepted their status and are debating within themselves to disclose or not to disclose. The decision to disclose is difficult because the decision may have major consequences. The HIV-positive person has to carefully weigh the positive and negative aspects of disclosure, because disclosure is a very personal and individual decision. While disclosure may be accompanied by easy access to medical services, care and support, it may also result in negative consequences such as isolation, rejection and stigma. When an HIV-positive status is disclosed to members of the family, it is a rather emotional time, marked by anxiety, fear, guilt and sorrow. The HIV positive person needs support from friends, support groups, counselors and religious leaders to guide him/her through this process and provide emotional and/or physical refuge. From the data it can be shown that disclosure to the family is at best a transition, and at worst, a crisis. Family members differ in their knowledge about the HI Virus, some fear contagion, such as was reported by Annaline about her sister not visiting her or

allowing her children to visit Annaline. Family members vary tremendously in the type and intensity of their emotional reactions; some are accepting, loving and positive. More often, there is shock, such as was expressed by Siwina's father: "not you," "not in our family." Delene's mother was angry: "How could you let this happen?" Ashwin was so ashamed: "what will other people think?" Thandiwe's fear of family stigmatization led her to secrecy and isolation. Disclosure creates some kind of change within the family, and life will never be the same again.

HIV-positive participants had to decide whether they were comfortable with disclosure, and if they decided to disclose, they had to decide whether disclosure was to be full (public disclosure) or partial disclosure (telling a few people such as parents, spouse, siblings and close friends).

Some of the participants in this study said that personal ethical issues also weighed heavily on them when they lied about their illnesses and their absenteeism. Annaline explained her persistent coughing and listlessness as recurring flu, and Delene said that her illness was due to leukemia. This dishonesty, according to some of the participants, about their illness and absenteeism raised ethical dilemmas, which in turn brought on personal ethical consequences about self-worth and self-esteem, that questioned their standing in the school community and especially in front of young learners. On numerous occasions the participants in this study were caught in the midst of a tug-o-war between truth and lies. The decision not to disclose an HIV-positive status may also be viewed as an act of compassion and protection. Annaline, Delene and Siwina delayed disclosure to their parents because they feared the inability of their parents to handle the news, Thandiwe did not disclose her HIV status to anybody until just before her death (to her sister) because she wanted to protect her family from stigma and harm.

Disclosure of one's HIV status is a very personal issue and it is also not a very easy decision, and may take the individual many days, weeks or months to take the bold step to disclose. Hays et al (1993) explain that the phenomenon of disclosure of one's HIV seropositivity to immediate family members, colleagues and close friends is often perceived as a double-edged sword, because it could provide an opportunity for social support, but may lead to added stress because of stigma, discrimination and a break-up in relationships. They also said that the concealing of one's HIV status may be stressful and can interfere with obtaining and adhering to potentially critical medical treatments. Hays et al (1993) also say that there is a direct relationship between

the mental health status of an individual and the degree and comfort of disclosure of one's seropositive status. Disclosure can be of various types and the decision to disclose can be influenced by a range of factors. Mason et al (1995) mention ethnicity as a demographic characteristic of an individual which has a great influence on disclosure. Ethnicity can be a sensitive issue. In Thandiwe's case, she spoke of keeping her HIV status a secret because she feared for her and her family's lives; although she was infected through a blood transfusion she suffered the same degree of stigma like other HIV-positive people.

Mansergh et al (1995) discuss symptomatology as a factor that has an influence on disclosure. When the symptoms begin showing, then suspicion about a persons health also begin showing. All the participants in this study agonized about disclosure fearing the worst. In Ashwin's case he only disclosed to a counselor, because he was afraid that if he died in his flat nobody would know.

It can be suggested that the absence of a medicinal vaccine for HIV, has brought about a paradigm shift from symptom management to improving the overall quality of life. A person's quality of life is a product of physical, social, emotional and environmental harmony. A good quality of life is important for effective coping with HIV, and disclosure is important for a person's well-being, provided that those disclosed to respond in a positive manner. Hays et al (1993) believe that voluntary self-disclosure of one's HIV status may contribute to improved psychological well-being. The support from those disclosed to has been associated with less depression and anxiety resulting in benefits of disclosure in the form of emotional support, financial assistance and care in illness. Data from this study show that Delene and Siwina were supported by their immediate families, whereas in cases of a necessity to disclosure to a spouse, the individual is not sure of the benefits of disclosure, and the chances of disclosure becoming a failure by increased discrimination and stigma are very high (as was the case with Ashwin, when his family disowned him). This in turn will result in increased anxiety and depression. Delene disclosed her status to her family four months after her diagnosis, after she became really ill:

I made the painful decision to tell my family. I should never have kept my HIV status a secret for so long because I re-lived all the agony that I initially experienced. My family was devastated

Delene received support from her family after their initial shock. Ashwin also disclosed to his family, because he could not keep his status a secret from them.

I had to tell my wife about this as soon as possible, I gathered up as much courage as possible and prayed that she will understand. When I told her that I was diagnosed HIV-positive, she hit the ceiling and asked me to get out of her life and the house

Ashwin's decision to disclose his status did not work in his favour; he lost his family after his disclosure, moved out of his house and relocated to another area, then resigned from his post and sought a new teaching post in another city.

The very nature of an HIV diagnosis is rather traumatic, and the infected individual needed to come to terms with it, before the decision to disclose or not to disclose can be taken. Disclosure is a very personal and individual decision and its consequences need to be carefully thought through. The participants in this study expressed a great fear to disclose their status because they did not know how their families and friends would react to the news. According to van Dyk (2008), men and women experience fear of HIV for different reasons; women's fears were based on powerlessness, loss of security and violence, men feared the loss of their sexuality and sex appeal to women and the lack of care when they became really sick. All five participants in this study decided not to disclose at school, because the corridor talk and staffroom experiences (according to the participants) made the school environment a cold, clinical and unfriendly place to disclose an HIV positive status (see Appendix 8). There are various reasons for non-disclosure and the participants shared their reasons.

Annaline:

I was so confused I just didn't know what path to take; something told me that if I disclosed to anybody the bad news would get around so fast that I would be left hurt and abandoned

Ashwin forwarded his reason for not disclosing his status:

My colleagues, most of them are very insensitive and make hurtful comments, therefore, at school I keep very much to myself, because I feel that everybody knows my status. They still ridicule HIV-positive people, I feel very hurt about this

Delene explained that in her school the atmosphere was so unfriendly and she did not want to tell anyone about her HIV status:

I have not disclosed to anybody on the staff yet, some of them enquire about my health, whilst

some of them have made comments like, 'oh shame you are too young to be so sickly'; this makes me feel very embarrassed

On speaking with Delene's mother, I realized that she was very distraught and emotional about the HIV diagnosis initially. After some consoling, she spoke about the trauma and grief her family suffered for almost six months. She said that she was happy that Delene confided in the family, in this way the family was in a position to provide a safe comfortable environment for her. With Delene being in their midst they could monitor her health and also provide the moral support for her especially on "bad days".

Siwina is of the opinion that while she enjoys a good relationship with her colleagues, an HIV disclosure may drive them away:

I have a good relationship with my colleagues and I do not want to spoil it by disclosing my status, I don't know what I am going to do when the symptoms start showing.

Thandiwe was very afraid of disclosing her status and forwarded a reason:

I have not told any of my colleagues about my status, I cannot see myself disclosing to them; if word gets out that I am HIV-positive then my whole family will be destroyed, their house will be burnt to the ground

This fear for her family's safety arose out of an HIV-positive person's home being burnt to the ground in her neighbourhood. Having to go for an HIV blood test is daunting, and this experience was very traumatizing for all five of the participants in this study. All expressed great shock when given their HIV-positive results. Annaline described her shock:

He told me that I had tested positive and that Tim was HIV-negative. I just froze.

Ashwin followed routine after his hijacking ordeal, and went for a medical check and blood test. He described his first moments of diagnosis:

I was told that I was HIV-positive. My HIV diagnosis came as a huge shock to me because the doctor did not ask my permission to do an HIV test.

HIV testing (according to Ashwin) is a sensitive issue, and permission has to be given by the individual concerned before this test is done. The results of this test are absolutely confidential, and the individual concerned has to be pre-test and post-test counseled. In Ashwin's case, it was procedure that an HIV test be done, as he was physically and psychologically wounded.

However, he did not receive any pre- or post-test counseling. For Ashwin it seemed that his rights were violated again after the rape and he felt devastated, saying that:

“big men do cry”.

Both Siwina and Delene described their diagnosis as leaving them speechless. Thandiwe too, felt that going to get her test results was a very bad experience and she explained her feelings as follows:

I felt a rope tighten around my neck, like a death sentence was placed over my head

During this first phase of HIV (the primary HIV infection phase) none of the participants expected to be given an HIV-positive result. Once given their results, the participants voiced their extreme shock and disbelief; some in their despair went for a second test just to be sure.

5.5.1.2 Anxiety, Fear and Anger

- **Anxiety and Fear**

Discussions around HIV and AIDS is almost always accompanied by negative connotations, some of these being fear and anxiety. These feelings were expressed by Annaline:

I was also worried about tell-tale symptoms, I didn't know how I was going to explain my illness when it came

Ashwin also experienced extreme fear and anxiety when he said:

I am now afraid to face my colleagues, just in case they see symptoms of HIV on me

Delene's fear and anxiety stemmed from other factors in addition to her positive status; anticipatory grief was evident in her emotions, as she lived alone and was really afraid. This came to light when she said:

I wanted a shoulder to cry on, I wanted to feel the comfort of the family home, I did not want to die alone

She was also very anxious as to what would happen to her in the later stages when she became really ill, and this fear and anxiety was revealed when she pondered about the future:

I will end up a cripple in a wheelchair; who will be pushing me around?

Delene's fear and anxiety was further highlighted when Brenda (her good friend) told her that she suspected her (Delene) to be HIV-positive all along. Delene explained that her concerns were not without reason:

That evening I cried, really cried, I was also frustrated because my secret may be out

Siwina and Thandiwe, like Delene, were of the opinion that an HIV diagnosis equals a death sentence. Here too, anticipatory grief was evident. Siwina explained her fear when she said:

I was completely shattered. I knew that I was going to die

Thandiwe shared this fear and anxiety:

The terror of dying and grief that my life was over now and that I will soon die and the horror of what will become of my child and my parents hit me very hard

According to van Dyk (2008), chronic illnesses have often been associated with increased psychological anxiety, fear and distress, but an HIV-positive diagnosis places a huge depressing burden on the mental health of people affected with HIV and AIDS. Anxiety is a unique problem for HIV-positive people because of the distress that HIV creates in the lives of the infected. Anxiety is a common problem for these individuals, and is one of the most prominent symptoms recognized by physicians among people with HIV. Kerrihard et al (1999) say that anxiety relates to several factors including HIV testing, number of symptoms, gender, overall adjustment to the HI Virus, higher pre-infection rates of psychiatric disorders, greater sources of severe stress, and socioeconomic issues. Kaplan et al (1997), Kerrihard et al (1999) and Perretta et al (1996) explain that, although anxiety and fear are predominant symptoms experienced by persons living with HIV, there is still very little information on management of HIV, the level of anxiety varies with the stage of HIV and the time since notification.

The participants in this study were particularly afraid and anxious because of their ignorance of HIV, how the virus was going to manifest itself, and whether they will be able to manage the infection as it progresses. All the participants viewed their HIV-positive diagnosis as a death sentence and expressed their fear of dying. Their HIV diagnosis changed their lives overnight.

Anxiety and fear, in many cases, arise out of ignorance about the consequences. In the case of HIV, the participants voiced their ignorance about HIV, and not knowing what to expect next or how to handle the virus. Participants also highlighted the fact that they did not have knowledge of self-care and feared the management of their well-being as the virus progressed. Thorne et al (2000) described self-care in health as all activities that individuals undertake with the intention of improving health, preventing infections, limiting the effects of illness, and restoring health after illness or injury.

Management of HIV and AIDS includes a change in lifestyle in order to lessen the impact of the virus and also to keep the immune system strong and healthy. In addition to medication it is this change in lifestyle that many HIV-positive individuals are anxious about. Stearns et al (2000) suggest that self-care practices used to manage symptoms or other effects of chronic illness are determined by a person's decision-making ability, knowledge of available resources, and a capacity to use those resources, with the hope that these self-care practices and treatment will greatly enhance their quality of life.

- **Anger**

Another common emotion that comes into play is anger, and all five participants expressed anger at their HIV results. Ashwin expressed this as follows:

My moods changed from numbness to deep anger and then sorrow, and anger because the A in Aids is for acquired, I did not go out there and acquire this disease, it was thrust onto to me. I was a victim. Now I have to surrender and accept it

Siwina said:

My first reaction was one of anger... 'are the doctors in a conspiracy to give mean HIV-positive result?' At this stage I did not know whether he had time to counsel me, all he said was 'Sorry, you are HIV-positive

Some HIV-positive people become very angry with themselves (as was noticed in this study), and this anger is often directed to those closest to them. Much of the anger stems from the fact that there is no cure for HIV and hence the uncertainty of the future. Anger is also directed at the people who infect innocent people and those who discriminate and stigmatise.

A persistent pattern of denying and suppressing could lead to “pent up” anger that could cause chronically elevated blood pressure. Annaline explained that her consistent pent up anger led to her experiencing recurrent anger-generating relationships with her sister, especially when her sister discouraged her children from going near Annaline or to be hugged by her.

Leserman (2001) explains that anger, anxiety and a lack of social support could negatively affect HIV infected individuals. Bartlet and Finkbeiner (2006) are in agreement with Leserman, as they contend that nearly everyone with HIV infection has, to varying extents and at different times reacted to HIV with anger, depression, uncertainty, fear and guilt. They further add that all the feelings are part of human nature and are reasonable reactions to HIV infection. This is in the experiences of the participants in this study, where “future danger” was AIDS, death and dying.

All the participants in this study expressed anger at themselves and with those responsible for infecting them, also because there is no cure for HIV. They were angry with society’s stigmatization of HIV-positive people. Ashwin was extremely angry because he was a victim of circumstances and ended up being infected.

5.5.1.3 Shame

Shame is another emotion that was clearly experienced by the respondents. In this study shame is also related to secrecy. Given all the negativity surrounding HIV, the general view that HIV infection is transmitted through sex and promiscuity, hence the shame. This is not true about the participants in this study (see Table 5.1) yet they all suffer stigmatization. Because of shame, the self-esteem of the individual is severely threatened. Van Dyk (2005: 217) says, “rejection by colleagues, friends and loved ones can cause loss of confidence and loss of one’s sense of social identity, leading to feelings of reduced self-worth”. Shame causes the individual to isolate him/herself from socializing and continue with teaching. This issue was highlighted by all the participants in this study when they spoke about staying away from the staffroom and from staff meetings. Their “bad days” were also cause for concern, as the learners missed out on learning when educators were absent and colleagues were resentful because they had to serve relief for absent educators. Siwina spoke of her shame:

I also cried very much, I felt very ashamed and guilty to have brought this unhappiness upon my family

In Siwina's case, she felt ashamed because she caused her family grief. Ashwin expressed his shame when he said:

Yet an HIV diagnosis is considered a shameful and sinful thing because of the prejudices around the manner in which it is transmitted

His shame was a result of the manner in which he was infected. Bartlett and Finkbeiner (2006) argue that one of the peculiarities of HIV is the amount of guilt it inspires, they believe that many people feel guilty about the behaviour that put them at risk. They further add that even those whose exposure to the virus came through conditions society does not disapprove of such as blood transfusion and victims of rape, such as the case of Thandiwe and Ashwin. Guilt arises from thoughts of how friends and relatives will view them, given the nature of the transmission of HIV; feelings of blame surround the destruction of the individual's life and future, and the trauma of the affected relatives and friends.

Allen et al (2000) says that no matter how the virus is contracted, the patient feels the guilt and the shame attached to the virus. This was evident in Ashwin and Thandiwe's cases, as these two participants were infected through a hijacking and blood transfusion respectively (see Table 5.1). Family members may express their feelings in a variety of ways: the HIV-positive person may be ignored, left out of family affairs, avoided, snubbed but not openly criticized. While the HIV-positive person has to contend with living with the virus, he/she also has to live with the projected guilt and shame attached by others. All five participants spoke of this guilt and blame feelings that they suffered from time to time.

Annaline spoke of comments that were made in the staffroom:

One staff member asked if I was hiding something, another said that maybe I had a 'skeleton' in my cupboard. All these comments made me feel guilty and upset

Ashwin added that he was blamed for the unhappiness he caused his family, but he could not accept the blame given the circumstances under which he became infected (see Table 5.1). Siwina and Thandiwe too, expressed their guilt and blame in strong terms. Siwina appeared to be an innocent party in the whole HIV issue but she felt guilty:

But when I think about it I ask myself where did I go wrong, I was a faithful wife and a good mother, I am just being punished

Thandiwe also spoke about her guilt feelings and blamed herself for bringing unhappiness in the home:

I was very frustrated with myself for causing so much pain for my family, I was also very anxious as to how I was going to cope with my huge dark secret

5.5.1.4 Depression and Stress

Bin et al (2003) argue that depression amongst people who are ill is generally considered normal, but depression amongst people who are HIV-positive is something that lingers on. They further add that depression is accompanied by stress and is generally viewed as a consequence of helplessness, is a relatively long-term state of dissatisfaction and low morale. HIV is accompanied by much pain as Breitbart (1990) notes. He adds that among the various distressing physical symptoms reported in AIDS, pain and depression are the most closely associated.

Depression and stress was discussed by all five of the participants and each one talked about their experiences. For Annaline the fear of coping was causing her much stress and was uppermost in her mind,

I needed time to think about this but time was not on my side, this stress of my diagnosis was making me sick and the thought of not being able to cope was almost destroying me

Stress was a common thread that ran through the experiences of all five participants in this study. Each participant experienced stress differently and from this stress other conditions emanated. Handling and coping with this stress varied from individual to individual. Cohen et al (2007) argue that stress plays a role in exacerbating HIV progression, cardiovascular disease and depression. They further suggest that stress can trigger biological changes such as hormonal imbalances and nervous system changes that interfere with immune function. Stress is an inevitable aspect of the human condition, but it is coping that makes a big difference in adaptational outcome. Stress emphasizes the relationship between the person and the environment that is approved by the person as taxing or exceeding his/her resources and endangering his/ her well-being.

5.5.1.5 Secrecy

Secrecy about their HIV-positive status prevailed throughout the interviews with some of the participants, Ashwin found it difficult to talk about his HIV status because he was ashamed of the circumstances surrounding his infection; his disclosure came about only when he felt threatened by his deteriorating health. Annaline maintained her secrecy until her wedding; she waited until she could handle the news and then told her close family and friends, but kept the news from her mother for almost a whole year, because she felt that her mother could not handle this disclosure. Thandiwe took her secret to her grave because she did not trust anyone with it and also wanted to protect her family from the stigma.

People differ in their sensitivity and vulnerability to different events in their lives, they differ in their interpretation and reactions. From the data collected in this study, the participants all chose to keep their HIV positive status secret, until they came to terms with the reality of an HIV positive diagnosis. The most common manner through which HIV is transmitted is considered to be through sexual contact, hence the negativity attached to HIV. An initial reaction of the participants in this study was secrecy.

Annaline's response to this issue:

We decided to keep this news confidential because we did not know how to handle it, we were not counseled

Ashwin adds:

I decided to remain silent about my HIV- positive status, I still had to deal with this depressing news myself. How do I tell my family, will they believe me?

Delene said:

All this time I kept the news to myself because I needed to be sure, HIV is a taboo topic that people do not discuss openly or if it is done, it's done in hushed tones

Siwina's visits to the doctor and the library were secret:

My visits to the doctor on these two occasions were secret, I did not want anybody to become too concerned for me. I tried to build my confidence by chanting to myself that I am HIV negative

She also shared her anxiousness to be empowered with HIV information:

I went to the library in Amanzimtoti and found some books on HIV, I had to sit in the library and read because I did not want my family or neighbours to see me with these books, it would have caused suspicion. This was a very trying time, I felt very guilty about being so secretive

Thandiwe explains her secrecy too:

I was not close enough to any of my colleagues to talk about my positive status, I always had the feeling that my colleagues were suspicious about my health. I also decided not to tell my family about my HIV-positive status.'

The above utterances highlight the extent of fear and the need for secrecy experienced by the participants in this study. A major dilemma for the participants was who to tell about their status, whether the person they choose to disclose to will keep their secret and still be their friend, and how to disclose an HIV-positive status? Whilst disclosure is an individual's right, secrecy may have negative consequences, such as alienation and isolation from the much needed social and medical support, as was the case with Thandiwe. Annaline, too, did not know how to handle HIV. Delene felt that she could not talk about HIV as the topic was taboo, and Ashwin shared her views. The negativity around HIV made Thandiwe keep her status a secret.

When Siwina received her results, she was overcome with disbelief and the "it won't happen to me" syndrome generally accompanies the initial stages of an HIV diagnosis.

5.5.1.6 Denial

Denial takes away the pain and allows the HIV-positive person to cope by being in denial. All five participants in this study were in denial at some time and they spoke of how being in denial helped them come to terms with the disease temporarily.

Annaline said:

Besides feeling drained of energy, having itchy skin and bad headaches, I did not have all the other symptoms, so maybe I will just put this whole thing behind me and carry on like I usually did and pretend that it was a bad dream

Ashwin explained:

I then went on a mission blaming myself, at the same time determined to keep my secret. I was in denial, maybe the blood tests got mixed up, I may have got someone else's results

Ashwin added that he went through a period of introspection and realised that his denial had caused him to shut his mind out to most things and sleep. At times he had forgotten who he was and why he was there. He said that it was like having a nightmare, just that nightmares went away when you got up and his stayed with him even when he was awake. He further shared that,

Being in denial and putting on a brave front caused an emotional drain on my life and I became extremely sick. I suffered high fevers and constricted breathing; at times I wanted to overdose myself so that I will not have to face another day

Delene also found her HIV-positive diagnosis very difficult to accept:

I did not handle this news, for almost six months I told myself that I was having a bad dream and that I will soon get up and realize that it was all a bad dream

Siwina was vocal about her feelings and firmly believed that the doctor must be wrong. She was also upset by the other people in the surgery, as they just looked at her unsympathetically. She further added:

Me HIV-positive, no, never, I need a retest, this time with another doctor

She refused to believe her HIV-positive results, because she was and still is a one-man woman, and could not believe that she was HIV-positive. Siwina felt the need to be absolutely certain about her diagnosis and her denial was uppermost in her mind. She explained that she went to another doctor to have a second blood test. She questioned herself as to why she was having a second blood test, and again she could not believe that she was HIV-positive: she was a faithful wife and could not be HIV-positive. She did some positive thinking and told herself that her blood test would come back negative, but she was wrong.

Thandiwe too, was very upset about her diagnosis,

I felt that my life completely stopped, I couldn't breathe or speak. When I gained my composure, all I could say to the doctor was, 'I don't believe you, it is a mistake

Van Dyk (2008) argues that most HIV positive people go through a phase of denial. She describes denial as a defence mechanism which temporarily reduces emotional stress. She further explains that people who are in denial over a serious matter, be it a personal problem or illness, will experience greater emotional ease on the initial occasions, but will pay for that ease by continued vulnerability on subsequent occasions. When the participants in this study got their HIV-positive diagnosis, their first reaction was one of denial via utterances like, “no, not me,” or “there must be some mistake”. This denial behaviour was noticed in initial responses made by Annaline, Ashwin, Siwina, Delene and Thandiwe.

Denial in a life threatening infection, such as HIV, is considered ineffective because the person fails to engage in appropriate coping strategies such as counseling and/or medical attention. Denial could be looked upon as a stay of execution because it closes the mind to whatever could be threatening. Lazarus (1983) and Carver et al (1989) include denial as a possible emotion-focused mechanism used by humans to deal with stressful encounters. Lazarus differentiates between denial as beneficial, when used in uncontrolled or acute situation, and denial used in controlled situations which may be harmful, since it prevents the person from exercising the appropriate precautions against danger. Ben-Zur and Breznitz (1997)¹⁴ explained that denial has been included in the framework of at least three different theoretical approaches to coping and adaptation namely: (1) the defence mechanisms derived from psychoanalytic theory; (2) self-deception tactics from the evolution theory of deception, and (3), coping strategies developed in stress theory and research. With reference to Ben-Zur and Breznitz’s theoretical approaches to denial and coping, all five participants in this study used denial as a defence mechanism for coping with the shocking news of their HIV-positive status. Siwina went to the extent of having a second blood test. Self-deception tactics were also used by participants, as when Annaline deceived herself when she said that besides feeling drained of energy and having itchy skin and bad headaches, she did not have any other symptoms. Ashwin also indulged in self-deception when he said that maybe the blood tests got mixed up and that he may have got someone else’s results. Coping strategies were also used much later into living with the virus when participants discussed their change of lifestyles in order to promote their health status.

¹⁴ See Ben-Zur & Breznitz (1997) Denial, anxiety, and information processing, for more information on theoretical approaches to coping.

Bowler et al (1992: 357) say that “many young people tend to feel vulnerable to HIV and AIDS...others practice denial as a means of coping with experiences perceived to be beyond their control”.

For an HIV-positive person to accept his/her HIV-positive diagnosis, is not something easy and normal. It is not like any other illness, because of the manner in which HIV is perceived to be transmitted. Denial, here was used as a coping mechanism. As discussed earlier, many emotions come into play. There are other life threatening illnesses and diseases that people contract and suffer from, but the fear and acceptance of an HIV diagnosis is somewhat different, and frightening not only because of the negativity surrounding the virus, but also the ignorance about HIV and its infectious nature. Another important issue for an HIV-positive person is where the individual is coming from, a background of love or a background of fear, and handling HIV is influenced by the baggage an individual is carrying. A caring background/environment will make disclosure easier.

All five participants shared their experiences about accepting their HIV diagnosis. Annaline’s problem was coping with the virus:

I needed time to think about this but time was not on my side, this stress of my diagnosis was making me sick and the thought of not being able to cope was almost destroying me.

For Ashwin, an HIV diagnosis was the furthest thing from his mind:

My HIV diagnosis came as a huge shock to me, it could either break the individual or make the individual. In my case, it broke me

Delene explained that the news was a life-changing experience; she disguised her disclosure by using an avoidance tactic:

I could not disclose my status to anyone just yet, I had to think about it first, I had to hold back tears, and tell everyone that I had leukemia, no ways could I tell my colleagues that I was HIV - positive, I would lose my job and be thrown out of school

For both Siwina and Thandiwe, their families were uppermost in their minds, but after the initial shock, they went about doing whatever they could to help themselves. Siwina was anxious to equip herself with knowledge of HIV and AIDS:

The first thing I looked for in the HIV books was the HIV symptoms and as I read I recalled

my husband complaining about tiredness and loss of appetite and these were symptoms of HIV

For Thandiwe, her family's reputation and safety was very important, so she kept her HIV-positive status a secret:

I loved my family and did not want to stress them anymore. I decided to carry this burden alone to my grave. But I was going to keep myself well, up and about for as long as I possibly could. I want to be with my daughter for as long as God will allow me to

From what I gleaned during the interviews with the participants, it is evident that their greatest fear arose from the stigma surrounding HIV. Delene spoke of her fear of being thrown out of school if her colleagues knew of her HIV positive status. From this verbal outburst, it is clear that the virus took second place to stigma. Religious and faith issues (according to the participants) are generally present when serious illnesses befall an individual or community and it was not uncommon for the participants to suggest that ancestors can punish their people by sending illness and misfortune if people violate social norms and taboos. However, while there is no literature that attributes AIDS to the anger of God, some African Christians believe that AIDS is a punishment from God for immorality and sin (van Dyk, 2008).

5.5.1.7 Vulnerability and Commitment

In respect of vulnerability, HIV prevalence rates amongst women are higher than that of their male counterparts. The issue here is whether women are more vulnerable than men. Ashwin presented a view that women were vulnerable to HIV infection for two main reasons:

Firstly, society generally sees females to be there to serve the needs of males, and secondly, females are physically weaker than males, and can be forced to give in to the sexual demands of males. Males are also vulnerable to HIV infection, look at what happened to me

Delene presented a similar view to that of Ashwin:

When you think of polygamy, women almost become slaves to their husbands... the high rape statistics also show that women are vulnerable

Delene also spoke about harassment in the workplace and the vulnerability faced by women in terms of their relationships with their bosses. Men feel that they are in authority and can demand sex when, where and with whom they desire. She also discussed how women resorted to

prostitution to make ends meet, once again making them vulnerable to social demands. Delene believed that in troubled times people seek solace in their places of worship, but she spoke of women leaving their places of worship because of stigma and discrimination.

Siwina was also of the opinion that women are vulnerable to HIV infection and spoke of her own infection:

I was and still am a one-man woman, but I was infected by my husband

She also discussed the plight of black women and their cultural demands:

In our black culture, women can endanger their lives if they refuse sex to a black male; in our culture the men decide when, how and with whom they have sex, and females are often powerless to refuse, so women are vulnerable

Siwina elaborated on another aspect of black culture:

Also the issue of female genital mutilation poses a great risk for HIV infection. We do have a constitution in our country but I am sad to say that female genital mutilation is still practised especially in the rural areas

In this study, four of the five participants are women. But all five felt vulnerable when they were diagnosed as HIV-positive. Women are generally perceived as vulnerable through cultural norms, economy and in terms of physical strength. The one male in this study felt extremely vulnerable because he was a victim of rape and hijack by other males.

In order to understand vulnerability, I attempted to provide some explanations of the terminology. Melrose (2002) and Benoit et al (2005) contend that the term 'vulnerable' is often used interchangeably with terms such as 'sensitive', the 'hard-to-reach', and 'hidden populations'. Falk (2001) is of similar opinion to Melrose and Benoit et al (above) and contends that women who sell sex services are discriminated at and rejected by other societal members, this increases their vulnerability to stress, depression and other ill health.

All of the participants had problems coping with their HIV diagnosis and lacked coping resources, adding to stress. The participants mentioned that they did not know much about HIV at the time of their diagnosis and this may have contributed to their capacity to cope. Adultery,

poverty and female genital mutilation belittle women, who have little or no social support. This gives them a sense of low self-esteem resulting in an inability to cope.

Other commitments also play a huge role in shaping vulnerability. All the participants in the study had responsibilities and commitments, such as work, family and children, and the threat of HIV made them feel more vulnerable. Stone (2003) explains that the greater the strength of the commitment, the more vulnerable the person is to psychological stress in the area of that commitment. All the participants in this study spoke passionately about their commitments. Annaline had a commitment to her husband and her marriage, and also had her ailing mother who relied on her. Although Delene was single, her parents depended on her and they were devastated when they learned of her HIV status. Ashwin has a young family and holds a senior position in his school; he has family and work commitments. Siwina also has two young children who need to be looked after for many years before they can take care of themselves. Thandiwe has one little daughter who still needs her mother. These are very challenging commitments that the participants in this study face and they have now become highly vulnerable because of HIV. Educators who are HIV-positive experience the virus no differently from other HIV-positive people.

- **Commitment**

Siwina spoke of her strong commitment to her ageing parents and her little children, this sense of commitment, she explains, kept up her fighting spirit. The depth with which commitment is held determines the amount of effort a person is able to put forth to ward off threats to that commitment. Both Siwina and Thandiwe spoke about the “will to live” for their children, as this was a huge concern to them. Vulnerability goes hand in hand with commitment; the stronger the commitment, the more a person cares.

5.5.1.8 Issues of Morality

Educators are an important part of the functioning of the school, according to the National Education Policy Act 27 of 1996, educators are expected to uphold and display the seven roles of the educator, one of these being the nurturing and shaping of young minds through education

which includes sound moral values, hence educators are considered to be icons of morality, “in loco parentis” (parents in the classroom/school). They are entrusted with promoting sound, moral values that are acceptable in society. Hence an educator’s words and actions are expected to display moral overtones. Apart from parents, teachers are possibly the most powerful agents of change and growth in a child’s life, teachers possess the power, through their personhood, to transform the lives of learners. Zappulla (1997) says that moral and ethical obligations are placed on teachers to act as quintessential role models through their words, gestures, and actions. They are expected, through personal example, to embody model qualities of character such as respect, dignity, integrity, compassion, and tolerance. Bellah et al (1991) explain that the collective moral character of the classroom is not created and defined once and then permanently fixed for all time, but with each new word, gesture and action, the teacher creates, recreates, and then recreates again the nature and quality of that experience. Bellah et al (1991) contend that educators are one category of people that make up an educational institution and they exist in a dynamic relationship with the larger community which touches many lives. While much has been said about the important role of the educator in the school environment, and the advocacy for empowerment and support via the various education policies on HIV and AIDS, the stigma and discrimination against HIV-positive teachers is still rife, as Delene, Siwina and Thandiwe shared some of their experiences at their schools.

Living with HIV is very difficult, especially for an educator, as Ashwin described. In terms of his experiences in his school on a daily basis, he isolated himself because he was afraid to face his colleagues in case they saw HIV symptoms on him and asked questions. He further added that the stress of living in secrecy made him very ill and he had to be put off work. He even did his shopping during the very early hours of the day so that he did not meet anyone he knew.

Delene, Siwina and Thandiwe also had similar experiences at their schools, as Delene explained:

I was still battling to come to terms with my HIV status, I needed all the love and support I could get and here were my colleagues discriminating against me; school was not the place for me, I had to think seriously about another job

For Siwina, an HIV-positive diagnosis was very difficult to accept, because she was true to her husband and did not stray out of the marriage. She believed that her husband was also true to her,

hence her anger, as a victim of circumstances. She was angry that people would judge her as a promiscuous women who deserved what she has got. Siwina shared her experiences:

I cannot explain to you how I felt, I think I just went numb, I was hollow and empty inside. I began thinking about all the people and the stories I heard about HIV- positive people, their isolation, the stigma and discrimination. I now feared that I was going to be put in that group where others referred to me with three fingers (HIV)

Siwina went on to describe what happened at her school:

At school we have a staff member whose sister is HIV-positive and people at school are very unfriendly towards her; this teacher is affected by her sister's HIV status and the staff are isolating her. I am in a worse position, I am infected with HIV... the staff will throw me out of the school if they know my status

While anxiety is highlighted in this first phase of the infection, this psychological emotion along with fear, shame, stigma and discrimination, is present in all the stages of the virus. In Siwina's description of the incident at her school, it is evident that the stigmatization of HIV is rife, hence the anxiety suffered by her and the other participants in this study. Siwina's fear of the staff's reaction should they find out about her secret made her very anxious, so she had to maintain her secrecy at all cost.

Thandiwe described her unhappiness at her school:

I have stopped going to the staffroom because I often sit by myself and nobody talks to me, I don't know how much more of this I can take. I ask you, 'what could I do, I can only pray for strength to see me through the rest of my days

The unfriendly behaviour of her colleagues, her poor state of health and keeping this huge secret from her family caused much anxiety and stress for Thandiwe.

▪ **Isolation**

When a person is diagnosed HIV-positive, the fear, anxiety and stress caused them to go through various stages in order to handle the virus. Some of these stages are isolation, rejection, loneliness and frustration. At times the infected individual brings about their own isolation by retreating into themselves; they may go about their normal routine, but psychologically retreat

into themselves. Annaline described her feelings of isolation and rejection after people learnt that she was HIV positive:

After giving that talk at the bank and how cruel people were towards an HIV- positive person, people still behave in that hurtful fashion - I felt like a leper, isolated by society

Some HIV-positive people can remain healthy for many years, without showing any symptoms, while others may deteriorate rapidly, develop AIDS and die in a few months. Thandiwe in this study found it very difficult to come to terms with this virus, and her problem was compounded by her secrecy and isolation. All the participants in this study suffered isolation, which came about as a result of fear, stigma and discrimination: HIV positive people suffer in silence. Silence, because of their decision not to disclose for fear of being caught up in the vicious cycle of stigma and discrimination

▪ **Loneliness and Frustration**

From the data, it is evident that loneliness and frustration is experienced by HIV-positive people when they isolate themselves, because of the secrecy around disclosure, and the perception by the HIV infected person that people are suspicious about their loneliness and frustration. Loneliness during this first phase of the virus is mainly self-inflicted. Ashwin is of the opinion that isolation causes loneliness and this is related to secrecy. He said:

Now that I am living alone, this loneliness just about kills me, I try to immerse myself in my school work, my preparation and marking are all up-to-date because I try to keep myself occupied. I do not go out much, I don't have many friends and my relatives shun me because of my HIV status

Siwina spoke of her loneliness which also caused her frustration. In her case, she was infected by her husband, but she was too afraid to talk about her status to him and since the questions she asked went unanswered, this caused her much frustration:

At this stage I did not know whether I was more angry or more afraid of what was happening to me. I heard about pre-and post-HIV test counseling but I did not have any and I was too upset to ask. How did I become infected?

Siwina was a single parent, and spoke of her loneliness and the anxiety about looking after her children. At times she was very angry because she was infected. Both Ashwin and Siwina spoke about loneliness and frustration. In Ashwin's case he became a victim of secrecy, as he was

shocked into silence after his immediate family disowned him. His perceived solace came out of immersing himself in his school work, which kept him busy. Although Siwina had her family, she too was lonely. Her little children needed her, and she had to see to their every need. Her parents were old and she did not want to stress them, so she carried the burden of her infection alone. She did not have anyone to converse with at her level. Weiner, Perry & Magnusson (1998) argue that people allocate more blame to those who contract stigmatised diseases that are perceived as controllable and stable than those who have supposedly less controllable and less stable stigmatised diseases.

A sense of loss and loneliness was a common thread that ran through the emotions of the participants in this study, and especially for people living alone. It was clearly seen when Delene expressed her feelings:

I wanted a shoulder to cry on, I wanted to feel the comfort of the family home, I do not want to die.

For Delene, loss and loneliness was exacerbated because she lived alone; she wanted her family around her, she was afraid of death. In Thandiwe's case, loneliness meant not having anyone to share her secret with. Her daughter is her only child, and her concern was that her daughter will not have a sibling for comfort when she is alone.

Whilst loneliness and frustration has been experienced by all the participants, the issue of self-imposed loneliness must also be taken into consideration. Thandiwe said that she stopped going to the staffroom and Ashwin chose to keep to himself by immersing himself in school work. Data evidence showed that in addition to the above discussed emotional issues, other psychological anxieties prevailed.

5.5.2 Further Psychological Anxieties

In this section the following aspects will be discussed: fear of death/suicide; helplessness/hopelessness; secrecy, stigma, discrimination and spouse's reaction.

The participants in this study experienced many psychological anxieties, they learnt to cope and live with these. The participants also handled these anxieties differently and in their own ways,

some anxieties are more conspicuous than others during certain phases of HIV. When minor symptoms began to show some of the participants stayed away from people lest symptoms are questioned, and the participant experienced a period of self-stigmatization and isolated him/herself.

- **Fear of Death and Dying/Suicide**

The diagnosis of a fatal, incurable and transmissible illness causes a great deal of fear for future health, for the well-being of children and other dependents and the fear of death. From the time of the initial diagnosis, the HIV-positive person agonises about a sense of borrowed time, and lives with a temporary certainty of each day. Bowlby (1977) explains that separation or loss initiates a process of grief, which is a very basic biological reaction that may cause aggressive behaviour and stimulates attempts to regain the lost object. Annaline and Ashwin expressed their anger when they were diagnosed HIV-positive, anger because they felt they were victims of circumstances. Annaline was infected by her unfaithful boyfriend and Ashwin was a hijack and rape victim. According to Kubler-Ross (1969 as cited in van Dyk 2008), people who are diagnosed with a life threatening virus (such as HIV) often go through five stages of bereavement: shock and denial, anger, bargaining, depression and acceptance. Kubler-Ross (1969) explains that in the first stage the reaction is disbelief, the person is in denial. All the participants in this study experienced this. The next stage according to Kubler-Ross (1969) is anger, anger with God and others who were responsible for letting this happen to them. The third stage is bargaining: people often bargain with God, and also with the virus in the case of HIV, for good health in order to handle the virus, the fourth stage is depression. During this stage, according to Kubler-Ross (1969) the person experiences severe sadness and shows symptoms of depression such as withdrawal, a depressed mood, apathy, tearfulness, irritability and changes in eating and sleeping patterns. The fifth stage is the acceptance stage, where the person has resigned to accept his/her fate. Kubler-Ross explains that these stages may not follow each other, as some stages may be experienced concurrently depending on the individual.

An HIV-positive person experiences varying degrees of anxiety throughout all the phases of the infection. This anxiety is uppermost in their minds because of the prognosis of the illness, the

risks of opportunistic infections,¹⁵ hostility, abandonment, isolation, fear of dying and rejection. The uncertainty of future health and coping also caused anxiety. Thandiwe spoke about her anxiety and her guilt feelings during the time when her health was rapidly deteriorating:

I was very frustrated with myself for causing so much pain for my family, I was also very anxious as to how I was going to cope with my huge dark secret I cannot tell anybody that I am HIV-positive

After their HIV-positive diagnosis, the participants in this study spoke of their illness taking centre stage and thoughts of the future are punctuated with images of death. For Annaline, her HIV diagnosis came as a big blow; she felt that she had lost control of her life. Being a family-orientated person she looked forward to marriage and children, but now HIV was in control, and when the doctor told her the results of her blood test, her immediate response was that her whole world fell apart. She spoke about her sense of loss becoming so conspicuous after her diagnosis:

I long to have a friend whom I can talk to, I don't have friends anymore, because my friend fled when they heard that I was HIV-positive

Ashwin's life also did an about turn when he was diagnosed HIV-positive; he too displayed anticipatory grief when he said:

The only thing that I was absolutely sure about was that I had very little time left and that I was going to die soon

Like Annaline, Ashwin also sensed a deep sense of loss:

This pain and stress is killing me, "so near yet so far". I value my family, "I love them" but they don't want me

Ashwin, unlike Annaline does not have a partner anymore to talk to and he seemed to be living one day at a time:

I do not look forward to a new day because it is bringing me closer to my grave

The fear of death for the HIV-positive participants in this study is an extension of the fear and anxiety of infection and severe impairment because death is perceived to be close. Van Dyk (2008) explains that the anticipation of dying carries with it the same emotional stress as the reality itself. All the participants in this study experienced grave loneliness especially in their

¹⁵When an immune system is unable to defend the body because it is being destroyed by HIV, opportunistic infections will 'take any opportunity' to attack the body. Van Dyk (2008).

work environments and also during their private moments, but an added burden was their anxiety for their close families. Their deep anxiety was expressed during my interviews with them. For Siwina, dying at an early age was uppermost in her mind and her great concern was for her two little children. Anticipatory grief was also experienced by her:

I had fears about wasting away and dying. When I become very ill my children will be neglected.

Siwina's premature concerns were about her future deteriorating health, and her ability to take care of her children. Thandiwe, too, like Siwina had great concerns for her little daughter who would soon be orphaned:

I look at my little daughter and my heart just breaks, I ask God "why me?" In my prayers I ask God to spare me so that I can be there for her until she is independent, I stress for her safety, I may not always be there to protect her, I can only pray that she will be safe

Some of the participants in this study saw HIV and AIDS as the end of the road situation, they spoke about suicide as a way out. Annaline endorsed this view when she and her then boyfriend discussed their moments after receiving their results:

Tim became suicidal and said there was nothing more for him to live for

Ashwin and Thandiwe shared the same view after they were given their results. Ashwin's expression of devastation was:

I had to come to terms with my plight. Suicide crossed my mind a few times during the days that followed, why should I go through life with this huge cloud hanging over my head

Thandiwe added:

The stress and anxiety caused my health to deteriorate further, at times I felt that I did not belong in this world, I wanted to run away from home or even commit suicide

Suicide as defined by Valente & Saunders (1998) is the voluntary and intentional taking of one's own life. One of the participants in this study, Ashwin showed a strong tendency to suicide, when he said:

Suicide crossed my mind a few times during the days that followed, why wait for HIV to decide when my life should end

While HIV and AIDS is a world-wide pandemic, suicide is of grave concern too. According to the World Health Organisation (WHO 2002), almost a million people die annually by suicide

across the world, but it is not clear what percentage of these suicides is by HIV and AIDS victims or otherwise. Lonnqvist (2001) adds that there is a significant association between HIV and AIDS and depression and such symptoms as hopelessness. Dorrington et al (2001) refer to South Africa's HIV and AIDS epidemic as "shattering".

Harber (2002) argues that up to the year 2002, about 200,000 persons died of AIDS-related illnesses and about 5 million people in South Africa are infected. Schlebusch¹⁶(2004) found the fatal suicide prevalence rate for South Africa to be 17.2 per 100,000 of the population and the non-fatal suicide rate up to 20 times more. Hunter (2003) says that not much information is available on suicide among HIV-positive people in South Africa, because the study was difficult due to the high taboo and stigma attached to HIV and AIDS. When a person is diagnosed HIV-positive, grief is another emotion they have to come to terms with because they feel that they have lost everything that really mattered. All the participants in this study feared the loss of their independence and their ability to look after their families. They mourned the loss of life itself. A life-threatening virus like HIV is an experience of psychological complexity and intensity and portends the possibility of death as a final outcome. As human beings we tend to take time for granted. Delene explained that a positive outcome of her HIV diagnosis was her sincere appreciation of life, and after an HIV diagnosis she said that life was very precious. Time is considered a universal part of experience which includes an individual's orientation to past, present and the future; while people live in the present they oscillate among the three perspectives. Therefore a diagnosis of life-threatening illness heightens the sense of time for the patient and family. Delene moved back into the family home because she wanted to be with her family always; HIV made her see life differently and she believed that each day was a bonus and must be enjoyed with loved ones. She also believed that death would come soon. When a young adult is confronted with a life-threatening illness, he/she experiences the sense that life's candle has been blown out, especially when the individual has planned and is fulfilling his/her goals. The underlying anxiety here is the fear that life will end before the individual has the chance to live it as planned. All the participants in this study felt that the HIV infection had robbed them of a chance of fulfilling their goals and living a longer life. The participants were between the ages of 30-40 years. Siwina, Thandiwe and Ashwin are parents with minor children and the children's future was of great concern to them.

¹⁶ See Schlebusch 2004. *Current perspectives on suicidal behaviour in South Africa.*

Loss of control was evident in the life stories of all the participants in this study when they described their state of confusion and hopelessness, Ashwin said:

The only thing that I was absolutely sure about was that I had very little time left and that I was going to die soon

Thandiwe said:

I could not see myself even living for the next five years, the future was gone

Delene said:

As I walked out of the hospital, I began crying uncontrollably, I felt so alone I longed to share my troubles with somebody, I was going to die alone

HIV virtually controlled how their day went, hence the hopelessness they experienced.

Thandiwe kept her secret to herself, she did not have a shoulder to cry on:

At night I could not sleep, I used to sit on my bed and weep for my family, for the fact that I was going to die and leave my baby and my family

Ashwin grieved from the time of his diagnosis, but did not have any support from his wife and children. His parents are late:

I do not look forward to a new day because I feel that it is bringing me closer to my grave

Siwina, in her story spoke of her parent's grief when they were told of her HIV-positive status. The anticipatory grief experienced by the participants in this study reflects the emotional response to the trauma of separation prior to the actual loss. The HIV-positive person grieves multiple losses, of self, of close family and loved ones. The stress, fear, anxiety and awareness of being alone in facing the unknown are heightened. Delene and Annaline discussed the positive side of being HIV-positive as the value they placed on time and relationships, they no longer took time and people for granted. The HIV-positive person lives with a sense of borrowed time and is grateful for the temporary certainty of each day. However, there is the problem as to whether the individual concentrates on living or dying, Ashwin at one stage spoke of suicide, because he could not live with the uncertainty of when death will come, and wanted to put an end to his life and get over with it. Another great cause for concern is when an HIV-positive person gets AIDS

and suffers opportunistic diseases and becomes very ill. The HIV-positive person anticipates this deterioration in health and stresses about it.

Anxiety accompanied an HIV diagnosis throughout all phases of HIV. Physical pain and the fear of dying in pain and without dignity was uppermost in the minds of many respondents who have AIDS. Thandiwe experienced intense anxiety during this phase because she feared the ability of her loved ones and family to cope after she died.

The low self-esteem that an HIV-positive person suffers is caused by rejection by colleagues especially in the school environment. Rejection brought about a loss of confidence and a loss of social identity, and the inability to continue teaching reduced a person's self-esteem.

From the data it can be suggested that the participants grieved in anticipation of their future; they also grieved for the friends and family they will be leaving behind. The issue of guilt intensified because the individual saw things in clearer perspective and felt guilty for having contracted HIV. In Thandiwe's case she was a victim of circumstances. There was also guilt about the pain, trauma and sadness the family had to endure because of HIV and AIDS.

All participants expressed a sense of helplessness/hopelessness, a feeling that their lives were slipping away, and that they did not know how to handle the days to come. Thandiwe felt a sense of loss from the time of diagnosis, but this loss intensified as the virus progressed. This feeling of loss stemmed from the loss of independence, loss of control, loss of friends, and loss of self-worth caused by rejection. In addition to this, Thandiwe feared that she may lose her job because of her absenteeism during the latter stages of the virus, and with the loss of job the issue of financial stability became a concern.

- **Stigma and Discrimination,**

Crawford (1996) explains that the term "stigma" goes back to the days of Greek civilization, when it referred to a tattoo mark branded on the individual's skin for a wrong doing. The physical mark publicly identified the blemished individual as one too be avoided. Stigma and discrimination go hand in hand. Discrimination against HIV- positive people is dependent on a

variety of perceptions and misconceptions, such as gender, race and socio-economic status. Singhal and Rogers (2003) argue that tangible consequences such as denial of rights and segregation in the workplace/school take place and stigma brings about discrimination which causes a violation of rights and this legitimises stigma. The fear of stigma causes anxiety about disclosing one's HIV status. People who disclose their status may leave themselves open to stigmatization, isolation and loss of self-esteem. None of the participants in this study openly disclosed their status for fear of stigma and discrimination. People who openly disclose their HIV status, are often treated as outcasts, as was mentioned earlier.

When people are afraid to openly disclose their HIV status, denial of the infection prevails, and so does stigma and discrimination; then the means to seeking health advice is discouraged. Although the stigma of HIV and AIDS is due to ignorance, education alone cannot eradicate the virus, as mindset must also change.

All five participants discussed the hurt and uneasiness they experienced in the school environment; this even made some of them give up their jobs. Annaline gave up her teaching job when life became difficult for her at her school:

I am a living example of an educator who opted out of school because of stigma and discrimination

Annaline believed that a big plus factor in this HIV climate was to talk about the epidemic and ask questions, hence her decision to do school talks, and on one such occasion she was sitting in the staffroom when she overheard educators in the school staffroom. This is what they said:

It's just another AIDS talk by an infected black person, one educator remarked, with so many partners what's new. This shows that people still believe that HIV is a black person's disease

Annaline continued:

By the time I came to terms with my HIV status, the management and staff were already indifferent and unfriendly towards me and I knew that it will get worse if I disclosed my status

On speaking with Annaline's husband Tim, I learnt that Annaline underwent a very difficult phase in her life (her parents divorced, and she nursed her sick father for many years) and he was thankful that he was with her to provide the support she required. He believed that divine intervention had brought them together. Annaline did say that she was absolutely grateful for her relationship with Tim, adding that had it not been for Tim's love and support, she would most

probably have committed suicide. Tim was also full of praise for Annaline, explaining that she was confronted by so much adversity in her school and within her extended family, and having to cope with the trauma of HIV; he proudly said that she had “weathered the storm” thus far.

Although Ashwin maintained his secret, he was also hurt by the insensitive comments made in the staffroom:

They still ridicule HIV-positive people, I feel very hurt about this, so I make excuses and pretended to be busy in my classroom to avoid going to the staffroom

Delene also gave up her teaching job, because she could not tolerate the stigma and discrimination. She shared a painful experience that took place after a talk she was invited to give at a school in Sherwood. Someone who attended the talk wanted to contact her and asked the educators at the school for her contact details; the response he/she got was “...we do not associate with Delene, she is HIV-positive”.

Ashwin also experienced much stigma, although he did not disclose his status until much later:

An HIV diagnosis is also shrouded in secrecy, and is considered a shameful and sinful thing because of the prejudices around the manner in which it is transmitted. HIV-positive people are generally labelled as promiscuous and “bed hoppers.”

He further added:

This disease carries a very high stigma, because society believes that only sinners are infected because of their promiscuity and that this guilty feeling is a punishment from God

Ashwin suffered self imposed stigma/self-stigmatisation. Because he did not experience a window period, his diagnosis and method of infection traumatized him, hence the self- imposed stigma. Millar & Kaiser (2001) argue that internalization of stigma is generally considered a maladaptive response to stigma, whilst Freund and McGuire (1991) cited in Alonzo & Reynolds (1995: 304), suggest that self-stigmatisation is a consequence of repressed anger as a result of being stigmatized. Therefore when the situation at school became unbearable, that is when the educators denounced HIV-positive people constantly, Ashwin’s energy levels began dropping. He gave up his job for a job at another school, away from his home town, and had this to say about the management of HIV in his school environment:

Although there is a HIV and AIDS policy for schools and our school also has a HIV and AIDS policy, nobody takes this policy seriously, stigma and discrimination is an important aspect in the

policy but stigma and discrimination is openly practised

During phase three of the infection when symptoms became visible, the HIV-positive individual becomes really desperate. For educators in this study the fear and anxiety was becoming intense, especially when educators are expected to be icons of morality. Apart from stigma in the school environment, the educators in this study also suffered much stigma in society. This became an added burden to them, because they feared that their families would also be stigmatized. Annaline had this to say about her experiences with people outside of school:

I tell people that I am HIV-positive and how people stay away from me and the response I generally get when I am face to face with people are “oh I’m so sorry to hear about your positive status, how can people discriminate, don’t worry we will exchange telephone numbers and meet sometimes,” that is the last I hear from them, people are false

An added anxiety for Siwina was the stigma she could be exposing her family to:

The other matter that troubled me was the risk I might be exposing my parents to, the neighbours and the community do become aggressive towards families where a member has HIV, sometimes stoning and burning their homes. They believe that the burning will get rid of the disease

Thandiwe too, had this grave fear for her family’s safety:

I have not told any of my colleagues about my status, I cannot see myself disclosing to them if word gets out that I am HIV-positive then my whole family will be destroyed. I did not want to go back to school...

Gugu Dlamini¹⁷ epitomized HIV stigma at its strongest, and international attention to HIV-related stigma has grown. Jewkes (2006) explains that stigma and fear of stigma are recognized barriers to HIV testing, disclosure, and treatment seeking, but unless there is a more nuanced approach to understanding stigma, differentiation between external stigma and self-stigmatization will be difficult. Despite these forms of stigma being related, the strategies needed to overcome them are different. Jewkes (2006) further explains that unless both types are independently and appropriately addressed, people with HIV will not fully benefit from the developments in medical interventions for people with HIV and AIDS, including antiretroviral therapy. Ashwin’s silence about his trauma and HIV status would have been handled in a friendly manner, if stigma had not gagged him.

¹⁷ Gugu Dlamini was stoned and beaten to death after she had spoken about her HIV status. (Sunday Independent, August 14, 1999).

Stigma sweeps HIV under the carpet, out of public sight, thereby reducing the pressure for behaviour change. The fear of stigma, disallowed the participants from knowing their status and this led to the delaying of testing and accessing treatment. Stigma undermined the study participant's identity and capacity to handle the virus as in the case with Annaline. She explained that personal problems in the life of an HIV-positive person caused much stress and depression:

I've had lots of issues to deal with, financial problems, family problems, my mom's health was not too good and these types of stresses are bad for the immune system and also for the CD4 count. I am now going to concentrate on increasing my CD4

Ashwin concurred with Annaline on the issue of stress and depression. He was living alone for two years, and explained that after living with his wife and children, this lonely life was very difficult, but he resigned himself to this lonely journey to his grave. He continued to talk about his depression at school:

There are days when I just don't want to get out of bed, sometimes my body aches so much that each step is agony, at other times the uncaring, unfriendly atmosphere at school really depresses me even more

Delene too, spoke about stress and depression at her school, so much so that she resigned from her job:

I was very uncomfortable at school and felt very angry and stressed. The next day I handed in my resignation, one of the reasons for my decision to quit school was that I needed to focus on my health, and the stressful situation at school was not helping me

Siwina explained that one of her greatest fears about being HIV-positive was stigma and discrimination:

I began thinking about all the people and the stories I heard about HIV-positive people, their isolation, the stigma and discrimination. I now feared that I was going to be put in that group where others referred to me with three fingers (HIV)

She further added that society's perception of HIV-positive people,

Most people believe that HIV can only be sexually transmitted, and that people who are HIV-positive are sinners and people with low morals and do not deserve any sympathy and support

Thandiwe, too, suffered greatly because of the fear of stigma and discrimination:

People keep away from you if they are suspicious about your HIV status, how much worse it will become if they know for sure that you are HIV-positive

These reports on experiences of stigma suffered by the participants in this study show the extent of harm and retrogression HIV-positive people face. There is also a relationship between social support and stigma. The negative relationship between stigma and support was reinforced by quantitative studies of Lee and colleagues (2002)¹⁸, Heckman and colleagues (2002)¹⁹, and Emlet (2006)²⁰, who suggest a parallel relationship between stigma and social support. Lichtenstein and associates (2002)²¹ provide qualitative evidence that social support is related to managing stigma.

Thandiwe shared her experiences of pain at the hands of her colleagues when,

...one of the educators who served relief in my class asked one of the learners to fetch a chair from the staffroom for her, this learner took my chair from behind my table and gave it to this educator, but this educator refused to take the chair saying, "boy take that chair away from me quickly, I don't want to sit on that dirty chair and get sick like your teacher"

In response to Thandiwe's experience above, I have included a section of The National Policy on HIV/AIDS for Learners and Educators in Public Schools in Further Education and Training Institutions. This policy discusses the HIV epidemic, and emphasizes issues of human rights that are heavily entrenched in the South African Constitution, including the right to education, protection from discrimination, privacy, basic freedom and a safe environment. The policy empowers institutions to be proactive in their response to the epidemic. The policy also recommends that each school has its own plan to cope with the epidemic and works closely with local communities to provide information and support. Some of the roles of educators that the policy sets out are: to create a work environment which does not discriminate against those who are infected or affected; to support those who are ill, and also to make the school a centre of hope and care in the community. The above excerpt clearly talks about human rights and the

¹⁸ See Lee and colleagues (2002), Internalised stigma among people living with HIV/AIDS. *AIDS and Behaviour*, 6, 309-319.

¹⁹ See Heckman and colleagues (2002), Depressive symptoms in older adults living with HIV Disease: Application of the chronic illness quality of life model. *Journal of Mental Health and Aging*. 8, 267-279.

²⁰ See Emlet (2006), A comparison of HIV stigma and disclosure patterns between older and Younger adults living with HIV/AIDS. *AIDS Patient Care and STDs*, 20, 350-358.

²¹ See Lichtenstein and associates (2002), Chronic sorrow in the HIV-positive patient: Issues of Race, gender and social support. *AIDS Patient Care and STDs*, 16, 27-38.

constitution, education and empowerment in relation to HIV and AIDS, protection from discrimination, and support for those who are ill.

With regard to educators who are HIV-positive, The Department of Education Workplace Policy for HIV and AIDS provides guidelines for all employees on how to manage HIV and AIDS in the work environment for both infected and affected individuals, by providing a supportive work environment. This policy declares a zero tolerance for discrimination. Educators do not only face the HIV pandemic in the workplace, they also handle it in the classroom. In view of the advocacy of this policy, empowerment on HIV and AIDS issues is crucial to eliminate discrimination against persons with the virus, and to inform employees about their constitutional rights. The above policy also advocates support and emphasizes constitutional rights.

The Norms and Standards Policy emphasises competencies in HIV for educators and a supportive environment for fellow educators. All workplace HIV and AIDS policies emphasise empowerment, support and human rights, yet all the participants in this study have experienced stigma and discrimination in the workplace. The need to bring in a discussion on HIV policies in this analysis is important because these policies govern the handling of HIV and AIDS related issues in the school environment. For policies to be successfully implemented, there must be an awareness and total commitment on the part of all stakeholders.

Delene explained that she was battling to come to terms with her status. She needed love and support, but her work colleagues were discriminating against her. Siwina shared her experiences, by explaining her feelings of hollowness and emptiness when she heard that she was HIV-positive. She said that she was haunted by the many nasty comments that had been made by her colleagues about HIV-positive people, and feared being stigmatized and referred to by three fingers. Siwina is an educator in a rural area and according to her, in the rural areas the words HIV and AIDS is taboo, so these words are replaced by other references to three. Siwina cried when she demonstrated how this was done, explaining that as the HIV-positive person passed by a group of people, no greetings were exchanged but the last three fingers were raised and pointed to the infected person. This translated into the “us” and “them” theory.

Francis's (2004) paper on HIVism²² discusses the negative treatment suffered by HIV- positive people at the hands of colleagues, friends, family and community. He also discusses aspects similar to those that emerged in this study, where the five respondents suffered name-calling, discrimination, isolation and internal HIVism.

Francis (2004) argues that the treatment of people living with HIV by those who are HIV-negative or unaware of their serostatus, constitutes oppression. His study focused on HIV-related stigma and its growing repercussions on people, and how this issue was being handled. He added that the experience of HIV-related stigma and its associated prejudice and discrimination in South Africa, revealed a lack of appropriate research. He aptly quotes O'Sullivan (2000: 25) on the matter of the silence of people living with HIV/AIDS:

We are the women (and men) others write about, talk about, imagine. Our realities are diverse. Now we want to put our own voices, experiences, hopes and fears on the agenda. Our numbers are growing and it's increasingly clear that we have to organize together to change the conditions of our lives

The issue of name-calling was very common during my interactions with the participants, and was also mentioned by both Siwina and Thandiwe. They further added that among the black people, the words HIV and AIDS was taboo, hence the labeling and name-calling, such as Hlengiwe Ignatius Vilakazi (HIV), Z3, OMO, or the 3 fingers (HIV). The utterance of the letters HIV is taboo in most black communities, hence the replacement of HIV with words, letters and the figure 3. Other names used in Francis's study include 'House In Verulam' (HIV), Umlazi 3 (named after a bus), Isifo (disease commonly found in hostels), African sickness, Punishment from God, prostitutes, and Amagama Amathathu'.²³

Brown et al (2001) and Irwan et al (2003) explain that HIV-related stigma and its associated prejudice and discrimination is a major stumbling block in addressing all aspects of HIV prevention, diagnosis, treatment and care.

²² See Francis D. *HIVism: A pervasive system of oppression*. Social work 2004:40(1)

²³ *Amagama Amathathu* – zulu word meaning three names; the last 3 fingers are raised when reference is made to HIV.

Francis (2004) suggests that every society has “up groups” and “down groups” and that the “down group” members are often subjected to negative treatment and denial of basic human rights. This type of treatment was also experienced by all the participants in the study: the “up group” (HIV-negative) stigmatized and oppressed the “down group” (HIV- positive) within the school environment where HIV-positive educators are isolated and discriminated against. Stigma as defined by Aggleton et al (2002: 8) is perceived as “a mark of shame” where the carrier of the virus is blamed, “devalued and significantly discredited”. In this study, Thandiwe was infected through blood transfusion and Ashwin was a rape and hijack victim. They too, were prejudiced, stigmatized and discriminated against like all other HIV-positive people by their families and society.

Thandiwe felt that signs of HIV was beginning to show on her skin, so she stopped going to the staffroom because nobody wanted to sit at her table and during this stage she became really ill:

Now HIV symptoms really began showing such as loss of weight, loss of hair, patchy skin and sores and glands in my armpits. I was hospitalized

Ashwin refused to attend staff meetings because he was isolated and very self-conscious about his bad skin, as his symptoms were beginning to show:

One of the most agonizing aspects of HIV is when the symptoms begin showing and the extreme pains I experienced in my groin, armpits and legs, peeling skin is also very embarrassing, especially when people stare at you

Siwina also suffered some “bad days” especially at school:

I have this cough that just won't go away, on a 'bad day' my body becomes too heavy and I feel very tired, I have to put my head on the table and lie down

This display of stigma against people living with HIV in the school environment causes much depression and anxiety amongst HIV-positive people. Individuals are thus reluctant to get tested, and if they did get tested and were HIV-positive, they were reluctant to disclose their status mainly for the reasons given by the participants in this study. Prevention strategies will become far more successful if HIV is treated like any other virus, and when people feel safe to be open about their HIV status. Most of the participants in this study were in the third, bordering on the

fourth phase of HIV, with the exception of Thandiwe. Annaline yo-yoed between stages three and four.

- **Social/Spiritual Support**

Social support networks have always been acknowledged as an important aspect of Annaline's ultimate dream of marrying and having a family, but the latter part of this dream could not be realised because of her HIV status. She spoke of being hurt and disappointed when her sister and the children stayed away from her, and of her pain when her friends abandoned her after they heard of her status. She needed their support. Similarly, Ashwin found it very difficult to handle the virus. The only people he disclosed to were his wife and children and he did so expecting their support, but through his disclosure he lost his family. For Ashwin this was a double blow: he had to handle the infection and the abandonment of his family, which almost pushed him to suicide. Delene became very independent when she started teaching. She got her own flat and moved out of the family home, but when she learned that she was HIV-positive, she was afraid of being alone. She needed her family support and moved back to the family home. Siwina also moved back to her family home because she needed support. Thandiwe longed for support but was afraid to disclose her status, because she wanted to protect her family. All the participants in this study spoke of their need for support in order to handle HIV.

Collins (1994) and Gielen et al (2001), find that inadequate social support has been associated with lower physical functioning. Cox (2002) is of the opinion that adequate social support has been found to improve compliance with HIV medications. Catz et al (2002), and Cowdery & Pesa (2002) support the idea of social support as being good for psychological functioning, such as psychological well-being and mental health. Turner-Cobb et al (2002) believe that social support helps the individual to cope with the stress of the virus. While social support has been acknowledged as good for a person living with HIV, as Delene in this study experienced, the lack of social support has been a cause for great concern amongst people living with HIV as was experienced by Ashwin. Lubben and Girona (2003: 326) characterized social isolation as having "extremely limited social support networks". There is a strong association between social isolation, morbidity, and mortality. It therefore stands to reason that social isolation negatively affects the lives of people living with HIV, and that family and friends play a significant role in

the composition of social networks. When family support networks are unavailable, people may turn to formal services for support. This too, can be problematic if it is not well-advertised and therefore under-utilized. Emler, (2004)²⁴ found that older HIV-infected adults of colour were less likely than their white counterparts to have heard of various HIV services available in the community.

All the participants said that their schools were not supportive, and that the unfriendly and hostile environment at the participants' schools made life very unbearable and extremely stressful. At this stage, the HIV-positive participants indicated a strong need for support and encouragement, and not a violation of their rights. The progression of the virus through the various phases is accompanied by more concentrated forms of fear, anxiety and stigma. In the first two phases of the infection, the HIV-positive participants were struggling to accept the diagnosis and to understand the virus; in phase three, minor symptoms began to surface. Trying to hide the symptoms brought about renewed stress and anxiety. Educators spoke about a great part of their daily lives being spent in the school and that social support to HIV-positive educators would be helpful.

The participants in this study agonized about the future and the progression of the virus. Thandiwe was in a desperate state, her health was deteriorating fast and she cried most of the time that I spoke to her. She was scared of death and worried about her parents and her daughter. Thandiwe also spoke of her anguish and sorrow when she had to go into hospital because her little daughter cried uncontrollably and her mother prayed for her recovery, not knowing that she was sick with AIDS.

Towards the end some individuals do have spiritual concerns and look for religious support; they may want to discuss issues of guilt, sin and forgiveness. Sunderland & Shelp (1987), and Van Arkel (1991) explain that counseling HIV-positive people is very difficult especially from a religious perspective²⁵ because of the nature of its transmission and the taboos surrounding it. When Thandiwe became very ill and was hospitalized for lengthy periods, she wanted to visit the pastor in a church in her township and talk about her HIV-positive status. She felt that she needed

²⁴See Emler (2004) *Knowledge and use of AIDS and aging services by older, HIV-Infected adults*. Journal of HIV/AIDS and Social Services. 3 (1), 9-24.

²⁵ See HIV/AIDS Care and Counselling, p. 249-253. van Dyk (2008).

to “clear her path” and ask for forgiveness for the pain and anxiety she caused her family and neglecting her class children at school, but (according to her) she did not end up going because of the stigma attached to the virus existed even in a house of prayer.

Ashwin complained about a cough that persisted for along time. Annaline was absent from school for lengthy periods because her energy levels were deteriorating. The affected members of the family also went through a very trying time: the pain of seeing their loved ones wasting away was not easy for them to handle. Annaline, Siwina and Delene spoke of family members who displayed so much grief that they had to pretend to be strong for family members and console them. The participants spoke fearfully of their impending death and the stigma that accompanies this type of death which will always be uppermost in their minds.

▪ Spouse’s Reaction

Another issue of great stress to a person testing HIV-positive, especially if he/she has a spouse, is how will that spouse react. Two of my participants, Siwina and Ashwin, were both married when they tested HIV-positive. Siwina explained her spouse’s anger:

I decided to talk to my husband, he went mad, screaming, shouting and swearing me, he accused me of being unfaithful to him, I tried to convince him that he was my only partner

Ashwin shared his pain after he disclosed to his wife. His relationship with his wife became so strained, that he felt he needed some time away from her to think. He knew that his family was also going through a tough time. Their relationship became so strained that they no longer had their meals together or went out together. He found it difficult to talk to his wife:

We could not even discuss the way forward together so I wrote a letter to my wife and children and explained to them that it was best that I moved out of the house

According to the life story interviews, both Siwina and Ashwin were victims of consequences but were faced with the wrath of their spouses at a time when they needed the most support during the disclosure phase. Apart from parents, teachers are possibly the most powerful agents of change and growth in a child’s life, teachers possess the power, through their personhood, to transform the lives of learners.

▪ Coping

An HIV-positive person's rejection by colleagues, friends and loved ones can cause loss of confidence and of one's sense of social identity, which leads to feelings of reduced self-worth. Ashwin displayed his low self-esteem when he spoke of his HOD²⁶ status in his school; he felt that he could not do the supervisory tasks expected of him, because of the HIV-infection.

When an individual is confronted with an illness, the initial response is to seek a cure for it. In the case of HIV, the initial response experienced was fear, anger and despair, because of society's labeling of the virus as certain death. After the individual comes to terms with the news, the slow coping process begins, and the speed and success of this process varies from individual to individual. In this study, Annaline has been living with HIV for approximately 12 years while Thandiwe lost her battle to HIV within 18 months (see Table 5.1).

Awaiting and then knowing the outcome of an HIV test is an event which really taxes the coping ability of individuals and those they live with. Stress is part of everyday life and individuals handle stress in different ways. Stressors may be external (a disagreement with a loved one or a family member) or internal (pain, fear of death, anxiety about the future). Annaline, Delene and Siwina handled their HIV diagnosis with suspicion and disbelief; after coming to terms with the diagnosis they needed to cope with their diagnosis. Their initial coping strategy was self-empowerment with information about the virus, and this HIV knowledge empowerment led to other coping strategies such as change of lifestyle, exercise, dos and don'ts concerning the diet (see life stories in Annexure). The impact of stress and experiences depended on how an individual coped with them. Each of the participants in this study used different coping strategies, Ashwin struggled to cope for a number of years because he closed up and did not trust anybody after his break up with his family. After he moved to Pietermaritzburg he felt more isolated, he then decided to contact a counselor. With some difficulty he shared his secret with her.

²⁶ HOD in the South African Education system means Head of Department. ?? Is the first use of HOD?
D.Ed Thesis: An insight into the experiences of educators living with HIV and AIDS in the context of schooling and beyond

The increase in medical bills will also cause financial strain which will impact on the individual's quality of life. Bandura (1995) explains that the extent to which individuals believe they can organize and execute the courses of action required to deal with events is called "self-efficacy beliefs". Self-efficacy beliefs are the outcome of the primary and secondary appraisal process which is the balance between situational demands posed by a stressor and a number of intra-personal and contextual variables. Bandura (1995) further explains that relevant intra-personal variables influencing perceived self-efficacy are personal coping skills and biological resilience or vulnerability; important contextual variables are the availability of social support and material resources for coping. All the participants in this study resorted to denial as a means of coping. On receiving their HIV-positive diagnosis, the participants said that there was some mistake; three of them said that they may have received someone else's result, others said that they would go for a second opinion.

While coping is considered an important aspect in handling a serious virus such as HIV, the individual's capacity to cope is also crucial. This capacity to cope was clearly evident amongst the participants in this study. Socio-psychological support is very important at this time because the participants needed all the love and support to handle this condition. For Annaline, knowledge about HIV helped her cope with the virus and change her lifestyle:

I felt a strong need to learn more about HIV and AIDS, I collected information from the library and wherever else I could find information. By that time I had gained a good amount of knowledge about the disease I felt somewhat empowered

Ashwin suffered in silence for many years, until the fear of dying alone made him decide to talk to a counselor:

It was with this extreme fear that I decided to contact the counselling service, I also needed to 'off load' and share my dark secret

Delene, being single, lived alone and had great fears for her health. Like Ashwin, Delene too, did not want to be alone and she moved back into the family home. Delene helped herself by educating herself about HIV:

I went to the CNA to look for a book to help me. I went to the section on HIV/AIDS; after looking through some eleven odd books, I came across this book that caught my eye, its title read "Living positively with HIV". I browsed through this book, and I read how an HIV-positive person's immune system can be boosted with the correct types of food, exercise, medication and change of mindset

Siwina was also ignorant about HIV and her diagnosis was a huge “wake up” call for her:

I have been living with this disease for almost 8 years, I was ignorant about HIV, but after the shock of my diagnosis, I made the attempt to educate myself, I have changed my lifestyle to stay healthy

From the experiences of the participants in this study, it is evident that coping is a dynamic process, which involves a series of reciprocal responses between the individual and the situation at hand. Taylor (1986) explains that coping responses are not a momentary occurrence, but rather form a chain of interactions which take place over time. Emotional responses are part of this interaction; anger and depression are sometimes outcomes of HIV. As this analysis proceeds, it will become evident that the coping strategies of the participants are built upon and become stronger.

Stress is experienced by all HIV-positive people throughout all the stages of the infection. In this study participants discussed their stressful times as they passed through the various stages, some coping better than others. Annaline, Delene and Siwina went out to empower themselves with information about the HIV, and worked on changing their mindset and their lifestyles. Annaline and Delene picked themselves from the depths of their despair and began helping other people who are HIV-positive to manage the virus by giving talks at schools about the virus. They also worked on self-motivation in order to keep their immune systems healthy and also to manage the virus. This gave them a new outlook on life and they coped despite fluctuations in their CD4 counts. Delene at one stage appreciated being HIV-positive because she appreciated each day more than the previous one and she did not take life nor her health for granted. Annaline, Siwina and Delene have done much introspection and believed that a healthy outlook on life could help one heal from the inside. Most of the participants eventually underwent a change in mindset after their diagnosis; they understood that their handling of HIV depended on their knowledge of the virus and living a healthy lifestyle. At the time of their interviews, four of them had been living with HIV for more than 5 years (see Table 5.1).

In the late 1970s, an approach to the mind-body dynamic emerged and was called Psychoneuroimmunology (PNI). Patient & Orr (2004) are of the opinion that PNI examines how a person's coping styles, emotions, attitudes and the events of life affect an individual's nervous

system, hormones, immune system and ultimately, health. Initially medical and psychiatric researchers investigated the biological mechanisms and how, if at all, psychological states impact on the body. The immune system is extremely important to the body and its ability to function at an optimum level (especially in the body of an HIV positive person), cannot be emphasized enough. Patient and Orr (2004) explain that the term ‘suppressed immune system’ is used when the body does not send the necessary fighter cells to fight enemies that enter the body. They say that PNI looks at the connection between a person’s psychology (mind, emotions and attitudes) and the immune system. A common question that is asked is, why some people who are HIV-positive handle the virus better than others and live longer despite the fact that they are taking similar medication, and following similar diets and exercise routines. An HIV- positive person experiences many emotions during the various stages of the virus and has to learn to handle these emotions and stresses. Thus a relationship between psychological factors and bodily health ought to be a long-standing one. Psychoneuroimmunology is the study of how the mind influences the development or progression of the virus. Patient & Orr (2004) believe that one of the main objectives of psychoneuroimmunology is to establish whether there is an association between psychological factors and immunological function, such as depression and anxiety. They ask whether psychological distress can alter a person’s ability to resist infection, autoimmune diseases or HIV. If so, can the person alter immunological function and therefore susceptibility to the diseases through psychological interventions?

Cohen and Herbert (1996) explain that immunological function may be influenced by psychological factors through the direct innervation of the Central Nervous System, or via the endocrine system (hormone levels may be affected by psychological factors such as chronic stress). Thandiwe related how stress had affected her in school when she was overcome by tiredness:

When I sit and teach I am fearful just in case the principal sees me, sometimes I feel I just cannot go on living with my secret

Thandiwe’s classroom stress and fear of her principal had an impact on her psychologically and this in turn affected her immune system.

Cohen and Herbert (1996) also suggest that behaviour may also have important influences on the development and progression of HIV (such as lifestyle, diet, exercise, and substance abuse). Annaline spoke of her CD4 count decreasing (below 200) whenever she was careless about her diet and exercise:

When I was stressed I started “comfort eating” and I put on a lot of weight, this additional weight made me very tired and sluggish

Annaline, like Siwina, empowered herself about healthy living; when she felt sluggish and ill she knew that she had violated the rules of healthy living and tried to put this right.

Ader et al (1991) associate clinical depression with an increased risk to physical morbidity and mortality; changes in effect produce immune system responses. Herbert and Cohen (1993) argue that clinically depressed individuals have lowered numbers of B, T and helper T cells²⁷, and lowered lymphocyte activity. Both Annaline and Thandiwe suffered clinical depression; when Annaline was stressed or depressed she indulged in “comfort eating” and no exercise, her immune system was compromised and her CD4 cell count decreased.

- **Identity Issues**

All the participants experienced loss of identity when they were stigmatized and discriminated against by friends, colleagues and relatives. In the school, educators who were ill and absented themselves from school were criticised and suffered loss of dignity. They were not respected as colleagues ought to be respected. Some of the participants felt that they were lesser beings and some contemplated suicide. Physical changes and conspicuous symptoms of the illness often had a major impact on the individual’s sense of identity. Ashwin felt that his identity as an HOD²⁸ was challenged when he was expected to supervise the work of educators in his department. He felt that he was incompetent and should not be overseeing another educator’s work: because of his HIV status he felt inferior and tainted, and was also uncomfortable in the classroom:

How do I stand I in front of my class and preach a moral lifestyle to them, when HIV-positive people are labeled as immoral?

²⁷ B, T and helper T cells are cells in the immune system van Dyk (2008).

²⁸ HOD. Head of Department in Education Departments in South African schools

Loss of relationships was experienced by all the participants in this study both in the home and in the workplace. Siwina divorced after she learnt her status, and she did not tell anybody at school about her HIV status:

Nobody at school knows that I am HIV positive. I have a good relationship with my colleagues and I do not want to spoil it by disclosing my status, I don't know what I am going to do when the symptoms start showing

The loss of relationship is shared by both the HIV-positive individual and the family. All tried to handle and come to terms with the transformation of presence (being physically present) into absence (death).

After diagnosis, nothing is the same again. The events surrounding the diagnosis are indelibly imprinted in the memory of the patient and family. This was evident in the diagnosis of all the participants in this study. Shock and disbelief accompanied the diagnosis of all the participants; in some cases participants sought a second HIV test (see life stories in appendix). The emotional shock of an HIV diagnosis is rather unnerving and an individual can absorb only a limited amount of information at the outset, therefore the facts must be presented slowly. Siwina displayed this shock when she was given her test results: she said that she did not hear anything else the doctor said after her diagnosis, but walked out of his rooms blindly and wept. A difficult challenge that faces the HIV-positive person and the family is the maintaining of a “normal” life in an “abnormal” situation which is the presence of life threatening infection.

- **Shock**

Annaline explained that she had to wait a long time before she disclosed to her mother:

I waited this long because I felt that my mother was not strong enough emotionally. As I had predicted, she just fell apart when I disclosed my status to her. She felt the end was in sight for me

Siwina disclosed her status to her parents three months after her diagnosis, for fear of their reaction:

My parents were in shock, my father cried uncontrollably saying that this should never have happened to me because I was such a good girl. I had to console my parents instead of them consoling me, my mother became very ill and my father was never the same again.

Ashwin described his shock when he got the results of his blood test:

I froze, I got up and left his rooms in shock, I just could not register, I could not see anything in front of me, I felt like a damaged boat tossed about in the ocean

All the participants and their families experienced varying degrees of shock when they learnt of the HIV diagnosis. All the participants needed to come to terms with the diagnosis first and then disclose to their families.

Annaline kept her HIV-positive status a secret from her mother for almost a whole year. She was worried that her mother would not be able to handle the news, and she was right, because her mother wept bitterly when Annaline disclosed her status. She was afraid that Annaline was going to die and leave her alone:

She felt that the end was in sight for me, she cried and refused to come out of her room for three days, she kept on saying, 'you are going to die and leave me alone.'

Delene also had to console her mother after she disclosed her status, as her mother cried and said that she was not going to bury her child:

I had to do all the consoling, my mother kept saying, 'you must bury me, I am not going to bury you, you got to get better and look after me.'

5.5.2..1 Conclusion

It is obvious from the data that an HIV diagnosis is very depressing for the person concerned; this depression is further increased because the life span is now shortened and the individual is powerless to do anything. All the participants in this study experienced this powerlessness. The knowledge that others have succumbed to the virus was also very depressing. In the next section I discuss recurring anxieties and concerns.

5.5.3 Recurring Psychological Anxieties and Concerns

In this section recurring psychological anxieties that have caused unhappiness and stress in the workplace are mentioned. These include:

- Stigma and discrimination
- Spiritual concerns
- Socio-economic concerns
- Absenteeism
- Angry colleagues
- Work backlog
- Departmental support
- Empower management
- Support groups/ life after HIV

The above anxieties and concerns have a great impact on the lives of HIV-positive people both in the workplace and in society.

5.5.4 Living with HIV in the workplace: Impacts

It is evident from the data that HIV-positive educators do have “bad days” and in some cases “extremely bad days”. With reference to the life stories, some educators have shared their really bad days, so much so that they could not go to school, and their absence lasted more than a day. This absence from school due to ill health has a snowball effect: the infected educator is stressed due to his/her illness, and colleagues are stressed and angry because they have to serve relief and have to deal with an additional task. HIV-positive educators also suffer the stress of coping with a growing backlog of work because of their absenteeism.

All five participants in this study have had to face insensitivity from management and/or colleagues about absenteeism and work backlog. Siwina, spoke of her concerns about her low energy levels and the impact this was having on her school work:

Another worrying matter was not being able to cope with my school workload, I was always tired, my marking was piling up, my record book needed to be filled in, my prep book had many blanks, I just didn't look forward to going to school

She added that her ill health made her stay away from school and her principal and colleagues were not too happy about this:

I began staying away from school more often and my colleagues were not very happy about this

because they were required to serve relief for me, and when I returned to school some of them looked at me suspiciously and quizzed me about the nature of my illness

Thandiwe too, had many coping problems because HIV made her very ill and the stress of secrecy added to this:

I feel drained, no energy and too many vitamin tablets gives me stomach problems. My backlog of work is of great concern to me, and the learners also lose out, all these are stressful to me

Thandiwe also discussed her principal's insensitivity; after she returned from sick leave of 18 days, he told her that he was not happy with her absenteeism and that he needed a person with better health to teach the learners. Thandiwe's principal did not understand her plight:

My principal does not allow educators to sit and teach, but there are times when I have to sit and teach, and when I do this I am very scared just in case the principal see me sitting, sometimes I feel I just cannot go on living with my secret

Delene, on the other hand, always wanted to portray an image of being able to keep her "head above water" but she had to admit that it was tough:

I was not coping, at work I could feel the subtle stigma, many of the staff members were ignoring me and that made me suspect that their suspicions were strong. On one occasion I returned after a three day absence, one of the teachers commented, "oh, you back, and for how long this time"

She also discussed her principal's insensitivity to her absence:

he suggested that I book off sick for the rest of the term, so that I could recover properly and at the same time he could get a teacher to stand in for me

Delene shared her concern for HIV infected educators:

There is a perception that HIV-positive educators pose absenteeism problems in the workplace and other educators are burdened to serve relief and this becomes a contentious issues, the sooner you leave, the sooner you can be replaced

Ashwin spoke of a deep concern for his wellbeing and that of other HIV-positive educators:

This stress of living in such secrecy took its toll on me and I became very ill, my doctor put me off work for a whole month, the days just passed by I even lost sense of what day in the week it was, on some days I hardly got out of bed, I just lay in bed and waited to die

Ashwin was very sad about the insensitive attitude of his colleagues towards him; they made hurtful comments about HIV-positive people, and he felt that they suspected he was HIV-positive. He also agonised about his family during his lengthy illness, and felt that to them he was already dead. Annaline also tried to be brave and carry on normally but the headaches and tiredness took their toll:

I tried to be brave but two weeks later I began feeling very ill, I just couldn't cope with the tiredness, by mid-morning I was very exhausted and had to put my head down and rest

She explained that because of her headaches and low energy levels, she spent much of her time catching up on her marking and other administrative matters. Her colleagues commented that she had become “anti social” and another asked if she had a “skeleton” in her cupboard. This anxiety and stress took its toll on her and she took two weeks sick leave, and on her return, she comments:

My principal called me to his office and questioned me about my staying away, my indifferent attitude and my work backlog, he was not very sympathetic and told me that I should consider taking sick leave and come back when I am 100%, so that he could employ somebody who will be there to teach the children everyday

The principal is accountable for the smooth running of the school in terms of curriculum delivery and good learner results. Educator absenteeism posed a huge problem for the management in respect of serving relief for the absent educator, keeping the learners gainfully occupied and meeting deadlines as required by the department. At the same time, school is regarded a home away from home and the people in the school are one large family, and ought to be supportive of each other. It is evident from the above incidents that the HIV-positive educator has little or no moral or social support from the school community, hence the secrecy, stigma and resignations that ensue.

5.5.5 Conclusion to Part Two

When a person is diagnosed HIV-positive, fear and stress caused them to experience much emotional anxiety. Some of these being isolation, rejection, loneliness and frustration. At times the infected individuals brought about their own isolation when they retreated into themselves.

They may have gone about their normal routine, but psychologically they retreated into themselves.

Anxiety was always uppermost in the minds of HIV-positive people because of the risk of opportunistic infections. Thandiwe experienced this stage of AIDS and suffered the trauma of the virus first hand. The other participants in this study worked on self-motivation in order to keep their immune systems healthy in order to manage the HIV; their mindset also underwent a change after their diagnosis. Most of the participants had been living with HIV for more than 5 years at the time of their interviews. The value of psychoneuroimmunology (PNI) was also discussed to show how coping styles, attitudes and emotions affect the nervous system, immune system, hormones and ultimately, health. The explanations of Patient (Patient has been living with HIV for more than 20 years) and Orr (2004) on the issue of PNI was also incorporated; they are of the opinion that PNI has a bearing on how the HIV-positive person handles the virus. The mind, nervous system and the immune system have to work together to handle the virus. An account of the participants' experiences around their immune systems and CD4 counts is also included.

Stress also affects the immune system and participants also spoke of their fear of death and how the HIV infection had robbed them of a chance of fulfilling their goals and living a longer life. The participants shared their experiences of loss of identity especially when they were discriminated against by friends, colleagues and even relatives. When the participants were ill and absent from school, they suffered a loss of dignity and criticised by colleagues. All the participants spoke about the emotional shock they suffered. The anticipatory grief experienced by the participants and their immediate families was also discussed.

When an HIV-positive person enters stage five of the virus, the person is said to have AIDS. One of the participants in this study, Thandiwe, reached this phase, where the symptoms of the virus are clearly visible and the immune system is very weak, making the body vulnerable to opportunistic infections. When a person reaches this phase he/she is very ill, has a very low CD4 count and has to be hospitalized, as was the case with Thandiwe. During this phase Thandiwe was overcome by fear and anger, and she reported that close family members were at a loss not knowing what to do. Being the researcher in this study, Thandiwe's plight also affected me. This

feeling is normal, according to Jones and Tannock (2000): “not only the research participants but also the researchers are affected”. The unpredictable nature of an HIV-positive person’s health makes it difficult to plan and anticipate the future. Thandiwe was the only participant who reached phase five of the virus. When a person reaches this stage she spends much time in bed or in hospital, and suffers pain and fear. Thandiwe explained her fear and pain, fear because of the unknown and pain because of death and leaving loved ones behind. The knowledge that others have succumbed to the disease is also very depressing.

The issue of vulnerability was also discussed, women are generally viewed as vulnerable, but Ashwin drew attention to men also being vulnerable with his account of his hijack ordeal. Women and especially women who undergo the cultural process of genital mutilation are also highly vulnerable. The participants spoke about seeking solace in places of worship, but stigma and discrimination drove HIV-positive people away from places of worship. The issue of commitment had a strong bearing on vulnerability: the stronger the commitment, the more vulnerable the person becomes, especially where children are concerned.

Participants in this study also spoke about the verbal abuse they experienced at the hands of their colleagues after they returned from being absent. At this stage of my analysis I have included relevant aspects of the National Policy on HIV/AIDS for learners and educators in Public Schools in Further Education and Training Institutions, which addressed human rights issues entrenched in the South African Constitution. The Department of Education Policy for HIV/AIDS provides guidelines for all employees on how to manage HIV and AIDS in the work environment. Other relevant HIV and AIDS policies are also included in this section.

While the Norms and Standards Policy emphasizes a supportive environment for fellow educators, other workplace HIV and AIDS policies emphasise empowerment, support and human rights. The participants in this study still suffered stigma and discrimination. Francis’s (2004) paper on HIVism (to which I have referred), also discusses aspects of stigma and discrimination, “up groups” and “down groups,” which can be equated to the people who stigmatise as “up groups” and the people with HIV as “down groups”(like the people in this study).

Name-calling and labeling was also an issue with which that the participants had to contend. The effects of social support for people living with HIV was also highlighted. An HIV diagnosis also tests an individuals coping ability and the ability to cope with the disease varied from participant to participant. .

Also in this section, I discussed the impact of living with the virus in the workplace. It was evident from the data that HIV-positive educators have to live through many “bad days”.

5.6 Part Three

5.6.1 Departmental Support/Non Support

In this section I discuss the support/non-support available to HIV-positive educators, including information from the participants in this study and focus group discussions. Educators are a vital national human resource and make up one of the country’s largest workforce. How important is this human resource to the Department of Education, for the purposes of delivering the curriculum and educating the future generation—the youth? On examining the views of the participants in this study, all five participants said that they were not aware of any support or initiative by the Department of Education to support HIV-positive educators. This section responds to the second research question asked in the study **Question Two:** Do you think schools ought to have support systems in place to assist HIV-positive educators?

Annaline did not hear of any programme to assist HIV-positive educators. Ashwin was not sure if educators would take advantage of any programme offered for fear of stigmatization:

If there were programmes in place to support the HIV-positive educator, it will be debatable if educators will take advantage of these programmes because of the fear of being identified as “one of those” infected educators and also the stigma associated with HIV

Delene and Siwina are of the opinion that all educators and managers ought to be educated about HIV in order to assist learners and educators who are living with the virus and also to reduce the stigma and discrimination. According to Delene:

Educators are still very much in the dark about HIV, they need to be educated so that they can educate the learners and maybe then the stigma and discrimination will decrease and people will

openly declare their status

According to Siwina:

As an HIV-positive educator I would welcome every educator being educated on the basics of HIV/AIDS so that we educators could get rid of or reduce stigma and discrimination

Thandiwe on the other hand, would have attended any programme on HIV offered by the Department, provided that the programme was for HIV infected/affected people so that she could maintain her secrecy. She was devastated by her HIV status, and her priority was keeping her status secret in order to protect her family. Her isolation, secrecy and lack of knowledge about the virus was the cause of her death barely 18 months after her diagnosis. The question on the lips of many HIV-infected and -affected people, including the participants in this study is, “why can we not get rid of the stigma and discrimination around HIV and AIDS, and is enough being done by all the relevant stakeholders to address this epidemic?”

5.6.2 Findings from Focus Group Discussions

The focus group discussions were done with school management teams from the areas of Maphumulo, Inchanga and Ndwedwe. These areas were especially chosen because two of the participants were educators in these areas (Siwina and Thandiwe).

These focus group discussions were engaged in to estimate the type of support available in their (Siwina and Thandiwe) schools from the perspective of SMTs. These discussions were facilitated through a set of four questions concerning support in the workplace for HIV positive educators. Their responses are recorded as intertexts, with a commentary below it.

5.6.2.1 Maphumulo Area-Analysis of SMT's responses (10 participants)

Question One: Do schools have a support system in place to support HIV-positive educators?

Response: Nine out of ten participants (90%) said that there was no support system in place at schools for HIV-positive educators. One out of ten participants (10%) said that a group of educators at his School had a support group up and running to provide moral support for HIV-positive educators.

The crucial question about the support system in school for HIV-positive educators drew a negative response. Support did exist in some areas through the initiative of concerned educators.

Question Two: Do you think schools ought to have support systems in place to assist HIV-positive educators?

Response: Ten out of ten participants (100%) agreed that schools ought to have support systems in place to assist HIV-positive educators. Added responses in support of the yes vote were:

- *HIV- positive educators' lives will improve*
- *Assistance will be readily available when educator discloses*
- *To help infected/affected educators morally, emotionally and to wipe out stigma*

There was unanimous support for schools to have a support system in place for HIV positive educators for the reasons cited in the intertext

Question Three: What type of support does the KZN Department of Education have in place to help the HIV-positive educator?

Response: Ten out of ten participants (100%) said that the department did not have any support system in place to assist educators who are HIV-positive. Emotions ran high at this point, and responses included:

- *Department must help, educators are dying, who will teach the learners?*
- *Department must help financially, medical aid must not get exhausted.*
- *Department must provide substitute teachers when educators are ill, learners must not be left without an educator.*

There was an unanimous “no support” response to this question. Focus group participants angrily voiced reasons for the need for Departmental support.

Question Four: What type of support would you like to see the department provide for HIV-positive educators?

Response: The following suggestions were made:

- *Presently workshops are held in some areas but these are grade or phase specific - we need workshops to help educators*
- *Bring back school counselors*
- *Reduce the paperwork and the long wait for a substitute educators*

The (SMTs) in this area are of the opinion that educators need to be empowered and supported with knowledge and counseling respectively. Concern was also expressed on the delay in providing substitute educators, hence the loss of teaching and learning time.

5.6.2.2 Inchange Area-Analysis of SMT's responses (10 participants)

Question One: Do schools have a support system in place to support HIV-positive educators?

Response: The whole group (100%) agreed that schools did not have a support system in place for HIV-positive educators; however, three participants from this group spoke of a community support group for HIV-positive people, but the sad point here is that this group did not welcome HIV-positive educators. Educators are viewed as individuals who teach learners to be good citizens and abstain from sex, hence educators cannot be HIV-positive because they must practise what they preach. In the rural areas educators are held in high esteem and can do no wrong.

In the Inchange area the whole group of ten participants were of the opinion that there was no support system in place to support HIV-positive educators. It was shocking and sad that HIV-positive educators were not allowed to join this support group. This response can be seen as a double disadvantage for HIV-positive educators. Educators are placed on a pedestal and are not allowed to deviate from the norm of acceptable behaviour.

Question Two: Do you think schools ought to have support systems in place to assist HIV-positive educators?

Response: The whole group (100%) agreed that all schools ought to have a support system in place to help HIV-positive educators. Added responses in support to a yes vote included:

- *At school we are a family and we must support each other, HIV-positive educators must feel comfortable to discuss their problems with SMTs*
- *Stigma and discrimination is caused by ignorance - the school community must be educated about HIV and AIDS on an ongoing basis*
- *The department must also support the school when the HIV-positive educator falls ill by sending a substitute teacher to assist*

The whole group agreed that schools must have support systems in place to assist HIV-positive educators. This group referred to the school staff as a family which must be supported. The group also cited stigma and discrimination as a problem caused by ignorance that needs to be addressed.

Emphasis was also placed on the department to assist schools where substitute educators were required when the HIV-positive educator falls ill.

Question Three: What type of support does the KZNDEC have in place help the HIV-positive educator?

Response: Ten out of ten participants (100%) said that the department did not have any support system in place to assist educators who are HIV-positive. Individual responses included:

- *Other large corporations provide support for their employees, educators are the backbone of a community and must be supported by the employer*
- *The young people-matriculants - do not appear to be interested in becoming educators so the department must look after educators in the system*
- *Financial support for medication*

The whole group was in agreement that the KZN Department of Education did not offer any support for its HIV-positive educators. This group felt that educators are a valuable human resource and must be supported both financially and psychologically; they also hastened to add that matriculants were not interested in becoming educators, therefore the department needs to support its educators so that they can be well enough to be in the classroom.

Question Four: What type of support would you like to see the department provide for HIV-positive educators?

Response: The following suggestions were made:

- *Empower the community so that they do not discriminate and stigmatise*
- *You only do better when you know better i.e. become knowledgeable about the disease*
- *Special medical aid for HIV-positive educators to assist with the expensive medicines*
- *Beef up the pool of substitute educators and cut out the red tape*

The group reiterated the need for empowerment about HIV and AIDS in order to address the issue of stigma and discrimination. A call was also made for financial assistance to cover the

D.Ed Thesis: An insight into the experiences of educators living with HIV and AIDS in the context of schooling and beyond

costs of expensive medication, and also the need to speed up the process of sending substitute teachers to the schools that needed them so that learners did not lose out on learning time.

5.6.2.3 Ndwedwe Area – Focus Group (12 participants)

Question One: Do schools have a support system in place to support HIV-positive educators?

Response: Twelve out of twelve participants (100%) said that schools were not in a position to support HIV-positive educators. Individual comments included:

- *Apart from giving educators moral support, we do not have the means to give any other type of support.*
- *Moral support can only be given in a case where the educator discloses his/her status*
- *I suspect that one of my educators is HIV-positive, but I cannot offer assistance because she has not disclosed her status to me*

The SMTs in this area agreed that there was no support at school for HIV-positive educators. While the SMTs are prepared to give moral support to the HIV-positive educators, disclosure is a huge problem for fear of being stigmatized and discriminated against. One member of the group spoke about his suspicion that a member of his staff was HIV-positive but there was nothing he could do until the person disclosed her status to him.

Question Two: Do you think schools ought to have a support system in place to assist HIV-positive educators?

Response: There was a 100% yes response. Additional comments included:

- *The school environment must be a supportive one, so that educators who are HIV-positive, will not be afraid to disclose*
- *School management teams must now take it upon themselves to create an environment in the school where support can be provided for HIV-positive educators.*

This whole group was of the opinion that there must be a supportive environment in the school so that HIV-positive educators feel comfortable should they decide to disclose. One of the focus group members stated that the SMTs ought to create a safe environment in the school to assist the HIV infected/affected educators.

Question Three: What type of support does the KZNDEC have in place to help the HIV-positive educators?

Response: “None” was the unanimous response (100%). Additional comments included:

- *Our educators are valuable to education and the department must provide support for HIV- positive educators.*
- *The young ones do not want to become educators, the old ones are retiring, the young educators are ill or dying because of HIV – soon there will be no educators.*
- *The department is too large – each district must now take the initiative to support their educators-resources to be provided by the department*

This focus group responded unanimously that no support was evident from the department. Members of the group voiced their concern that the educator population will soon dwindle if the department does not step in to provide support, because younger people did not seem keen to become educators. A suggestion was also made that the districts get involved in providing support for their educators.

Question Four: What type of support would you like to see the department provide for HIV-positive educators?

Response: Seven out of twelve participants (55%) felt that the department ought to provide financial support for the purchase of medication. Five out of twelve participants (45%) said that the department must provide support in terms of relief educators so that learners do not lose out. Additional responses included:

- *The provincial education department ought to mandate the districts to start support groups in their areas, in order to provide a support base for educators.*
- *HIV/AIDS awareness programmes must not be focused around world AIDS day only but must be done on an ongoing basis to conscientise people*

Two suggestions were forwarded by this focus group on the issue of type of support the department ought to provide: the majority were in favour of financial support for medication for HIV-positive educators in their districts, whilst others felt that there was an urgent need to send relief/substitute educators to assist when the HIV-positive educator became ill. There was a need for districts to become involved in supporting educators, and ongoing HIV/AIDS awareness in school, not only on World AIDS day.

5.6.3 Empower Management

According to Zappulla (1997: 11), “the first, and perhaps the most profound consideration is that the teacher’s role in the socialization of children is a singularly moral role, the word “moral” refers to the social and ethical principals of right and wrong in human conduct”. Zappulla further believes that educators want to and try to portray an image of a “model citizen” to the public; society generally makes the assumption that educators must hold a higher standard of personal behaviour because they are entrusted with the task of shaping young minds in partnership with parents.

Whilst educators strive to uphold this prestigious image, they grapple between their desire for openness and secrecy, the secrecy that is driven by the fear of stigma and isolation (just to mention a few of their concerns). The school management team members are the custodians of the school and its environment, they set the tone in the school and are responsible for setting acceptable norms for the benefit of the school community. How do they fare in the HIV scenario? In examining the views of the participants in this study it was found that all five participants ventured strong views about management and all said that it was very important for all members of the management team to be empowered with HIV education.

Annaline:

I would like to see the management team at every school attend HIV/AIDS courses, so that they will be knowledgeable about the disease, because ignorance equals stigma and discrimination. If the management team treated ill staff and learners with compassion and concern the rest of the staff will follow

The education sector is facing major challenges in the fight against HIV and AIDS, and the virus is threatening quality education. If the management team is empowered, and uses this empowerment to build the capacity of the staff, the information will cascade to learners and mindset will change. This small effort will help in the HIV scenario.

Ashwin:

No the management team was not supportive, although there is an HIV and AIDS policy for schools and our school also has an HIV and AIDS policy, nobody takes this policy seriously, stigma and discrimination is an important aspect in the policy but stigma and discrimination is openly practised

Every school has the relevant policies on HIV and AIDS. In addition to this, schools draw up their own policies using the departmental guidelines, and an important aspect in all the HIV policies is that the support and human rights of an HIV-positive person must always be upheld, and that stigma and discrimination is taboo. It is evident from the above testimonies that policies are ignored.

Siwina:

No, I sometimes think that they just want to be policemen, to make sure that you are at school and that you are teaching, they are not concerned about your problems. I would like to see HIV and AIDS education taught properly by every educator in the school, so that everyone will know that they cannot become infected if they treat their HIV-positive colleagues and learners normally, this education will also get rid of stigma.'

Siwina has also stressed the need for HIV and AIDS empowerment in the schools. According to the data, stigma and discrimination is rife in the school environment. From the information on the participants' profiles (Table: 5.1) most of the participants in this study have been living with the virus for more than five years, and need support in the home and workplace.

Delene:

No, the management team at my school did not support me or even care to inquire about my health, their main concern was to get a substitute for me, I am still not sure if they knew that I was HIV-positive. If the principal showed me some compassion then maybe the staff would have followed suite

As mentioned earlier, the principal sets the tone in the school and the rest of the school will follow his example. The principal will thus, to a certain degree help the HIV-positive educator cope with the virus.

Thandiwe:

The school principals must attend an HIV course so that they will know about the disease, and not stigmatise, people need to understand that HIV cannot be passed on by touching or speaking politely to an infected person

Thandiwe shared the views of the other participants on HIV and AIDS empowerment. She was a victim of self-stigma and was also stigmatized by her colleagues. As a result, her condition deteriorated rapidly. Thandiwe spent much of her days dwelling on her misery and would have been able to disclose her HIV status and get assistance, had it not been for the stigma that HIV carries.

More and more educators and learners are either infected or affected and they need to be supported. At this stage empowerment is the only tool at people's disposal to address this epidemic.

The focus groups also responded to a question concerning school management.

How would you as a manager assist an educator who discloses his/her HIV-positive status to you?

Maphumulo Area

Response: Ten out of ten participants (100%) said that they would help in a personal capacity and provide moral support. Other views included:

- *Discuss the advantages and disadvantages of disclosure*
- *Too much support to one educator may cause problems in the school-favouritism.*
- *Danger of infected educator taking advantage*

The focus group in this area was willing to pledge its moral support to educators in the schools, though problems concerning disclosure and favouritism were raised.

Inchanga area

Response: All the participants (100%) said that they would support the educators in their personal capacity and provide moral support. Individual responses included:

- *As from today I am going to empower my staff about HIV and AIDS so that they will not discriminate. I am not going to wait for the Department to empower them*
- *I will hold workshops for the school governing bodies on HIV and AIDS so that they can build capacity in the community*
- *With more education about the disease we will probably see less discrimination*

Participants in this focus group also pledged their support to HIV-positive educators in their schools, and are of the opinion that ongoing education and awareness (involving all stakeholders) about HIV will help address issues around stigma and discrimination.

Ndwedwe Area

Ndwedwe is a deep rural area in KwaZulu-Natal, hence the response that approximately 50% of the focus group did not consider HIV amongst educators a reality in their schools. From some of their responses they appear to believe that schools do not have the skills to assist HIV-positive educators.

Response: Approximately 50% of the participants were taken aback by this question and said that they did not consider this as a reality in their schools – and had not given this scenario any thought.

Other responses included:

- *I can only provide moral support in, my personal capacity.*
- *A very sensitive issue – I will maintain my educator’s confidentiality.*
- *Our schools lack the skills to provide any support. I don’t know what to say*

5.6.4 Teacher Union Response on Educator Support

The teacher unions (Sadtu, Apek, and Saou) that I was in discussion with were unanimous in their views that the Department of Education was not really addressing the issue of HIV and AIDS amongst educators. They are of the opinion that the Department must put the relevant structures in place to support HIV-positive or infected/affected educators, such as moral support at district level, more in the way of financial support for medication. The teacher unions also said that the department needs to increase their pool of relief/substitute teachers to assist when HIV-positive educators take ill, because educator absenteeism is a huge problem in schools and there is a chain reaction to the detriment of the school community. The unions also spoke appreciatively of the many HIV school policies, but questioned if these policies were really considered in the school environment (see policy discussion in Chapter Three).

5.6.5 Summarising Focus Group Responses

The focus group discussions centered around issues of school support and departmental support available to HIV-positive educators. While the focus group discussions took place in three different areas which are not in close proximity to each other, the views expressed by the SMTs at these discussions were similar: there was very little or no support available to HIV-positive educators, and where support did exist it was mainly on humanitarian grounds. Stigma, discrimination and disclosure were cited as major barriers to addressing HIV. The SMTs are of the opinion that the employer, in this case KZN Department of Education, ought to provide financial and psychological support to HIV-positive educators. Another strong issue raised by the SMTs was the bureaucracy around the provision of relief/substitute educators when HIV-positive educators became ill: not only is there backlog of work but the learners also lose out.

SMTs also voiced their concerns in that they did not have the skills to assist HIV-positive educators.

5.6.6 Conclusion to Part Three

Participants in this study said that there was no support from the Department of Education for HIV-positive educators. Some of the participants were of the opinion that apathy exists amongst their colleagues therefore stigma and discrimination are rife, and more ought to be done to educate society so that stigma and discrimination will decrease.

The discussion with focus groups in the areas of Maphumulo, Inchanga and Ndwedwe also drew negative responses. The participants in the three focus groups believed that the HIV-positive participants needed moral and financial support. Another suggestion by one of the groups was that districts must take the initiative to support their HIV- positive educators on an ongoing basis and not only on World AIDS Day.

Educators, according to the data, want to uphold their status as icons of morality, but the nature of the transmission of HIV makes them keep their HIV status a secret. A discussion on empowering management stresses the responsibility of the SMT in setting the tone in the school and this includes issues around how HIV ought to be handled. School policies on HIV/AIDS are also mentioned here. A question put to SMTs on educator support in their schools raised responses that not much was being done by SMTs. The teacher union response on HIV-positive educator support was also included, and again, the unions were of the opinion that not much was being done to support HIV- positive educators.

5.7 Conclusion to Chapter

This chapter was presented in three parts. The objective of this separation was to focus on the effects of HIV at the various stages of its progression and to explain both the physical (part one) and the emotional impacts (part two) of the disease on the HIV-positive person. Workplace support was also discussed (part three). This analysis focused on the responses generated from

the interviews with the five participants in this study. The responses of the three focus groups (SMTs) from the areas of Maphumulo, Inchanga and Ndwedwe, were also discussed in this chapter. Teacher union comments were noted. The views and comments of some family members have also been included. My data analysis relied on the participant's accounts of how they managed their lives living with HIV and AIDS in general and school in particular. The data revealed the participant's everyday experiences, their trials and tribulations, and their physical and emotional anxieties as they moved from one phase of the disease to the next. The data also provided insights on how these participants were perceived by their colleagues and members of their families. Both the physical and emotional aspects experienced by the participants were emphasized and theorized, showing the intensity of the pain suffered by both the infected and affected individuals. In the next chapter I present a synthesis of the findings from this study.

CHAPTER SIX

Emerging Insights and Conclusion

6.1 Introduction

This chapter is discussed in two parts, in the first part the significance of the data is discussed in an extended way, in the second part I discuss emerging insights. My primary source of data (as discussed in the methodology chapter) was from the participants' life stories in their own words. The other data sources were teacher unions and SMT focus group discussions. Where possible, discussions took place with close family members or close friends. Through the many interview sessions and interactions with the five participants in this study, the insights that emerged were the fear of stigma and discrimination (given the 'icon of morality' image that educators are expected to portray) and the ability to cope with deteriorating health. Many other psychological and emotional issues emerged as well. In this chapter I attempt to present an understanding of how educators living with HIV and AIDS managed their lives on a daily basis, in the home and community in general, and more specifically in the school. I also attempt to discuss some of the insights that emerged from the analysis of the participants' life stories. This chapter draws from three main aspects, namely, methodological insights, contextual insights and literature insights. The main methodological tool used was in-depth interviews with each of the five participants in this study over a three year period. While the methodology used was comprehensive, it was also rather complicated in terms of identifying willing educators to participate in the study, meeting deadlines and progressing to the next stage of the research.

The emotional insights that emerged from this study resulted from both self- stigmatization and a violation of human rights by colleagues in the workplace, friends and family in the home and community.

Some salient literature insights noted were: the politics of AIDS, privileged access, the feminization of HIV and AIDS and the vulnerability of women, male/female partnerships,

gender issues, playing a dual role with HIV and AIDS, psychomatics, psychoneuroimmunology and policy issues.

6.2 PART ONE

6.2.1 Significance of Data

The significance of data in this study (apart from the physical aspects) highlights the emotions and challenges experienced by the participants. Issues around stigma and discrimination, disclosure, denial, labeling, depression, shame, blame and stress (to mention a few) are presented as part of the significance that emerged in the data. All the participants in this study were able to discuss their lives and the many emotions they experienced through the various stages of the HI Virus, because of their self-knowledge. The first moment of insight was drawn from the fact that I, the interviewer was granted *privileged access* into the lives and emotions of these participants. While the participants in this study shared their lived experiences, at times I suspected that almost all of them had moments when they put up a brave front. Putnam (1978:125), is of the opinion that building the link between evidence and truth into the very concept of truth, as epistemic theories do, is usually proposed as an alternative to the ‘realist’ view that truth is ‘radically non-epistemic’. He describes this as entailing the claim that even ‘the theory that is ‘ideal’ from the point of view of operational utility, inner beauty, and elegance, plausibility, simplicity, conservatism, and so forth, might be false’. ‘Verified does not imply ‘true’ even in the ideal limit’, as mentioned earlier, a ‘brave front’ was suspected at times, perhaps to avoid embarrassment or sympathy.

The accessing of suitable willing participants was a huge challenge, given the nature of the virus and the stigma associated with it. The confidentiality aspect of HIV also slowed the process of finding suitable participants. Melrose (2002) and Dickson-Swift (2005) contend that accessing potential participants becomes more difficult when the research issues are more sensitive or threatening since these people have greater need to hide their identities and involvement. The vulnerable participants in sensitive research need to trust the researcher, and this quality in a researcher is extremely important. Dickson-Swift (2005) says that the vulnerable people we need

in our research are 'marginal, hidden or unwilling' to speak about their experiences, as they do not 'trust the researchers'. Another important aspect was that rapport between researcher and participant was very important in order for the research participants to 'open up' to the researcher. While participants provide the data required for the study, I the researcher had to be mindful of the sacrifice made by participants, and therefore the need to tread carefully. It could not be a case of just grabbing the data and leaving. Wadsworth (1984 cited in Liamputtong 2007) refers to this as "data raid", where the researchers do a "smash and grab", meaning getting in, getting the data and getting out. This raises the question of whether the researcher has any real interest in the participants.

Ethical considerations in a study is also of primary importance, and more especially when researching the vulnerable. Although the University of KwaZulu-Natal's ethical clearance committee granted me the ethical clearance for this research, the ultimate responsibility for ethical behaviour lay with me. Amongst the guidelines for research with humans, the identities of individual participants must be kept confidential and their right to privacy must be upheld at all times. As part of the ethical research conduct I had to be mindful of the fact that participants must not be coerced into participating in the research. The research becomes richer and more valuable when participants agree to take part on their own free will: they then find it easier to discuss their experiences with the researcher and it becomes a "win-win" situation, where the participant talks to a willing listener. This is therapeutic, and the researcher gets the story required for the research. According to Hall and Kulig (2004), and Hess (2006, cited in Liamputtong 2007), the research participants may find that by taking part in a research project, they are able to talk about matters which they might not have otherwise had a chance to talk about in daily life. Evidence from the data shows that stigma and discrimination gags HIV positive individuals from talking about the virus.

While many contextual insights emerged from this study, I have chosen eight of the more impactful aspects (in my opinion), which I believe posed the greatest challenges for HIV-infected and affected people. The first and most damaging challenge is stigma and discrimination. From stigma other offshoots arose, these being disclosure, denial, labeling, depression, shame and blame, anxiety and stress, and anger. With all of these issues the coping

strategy that is used is crucial and will allow the individual to either sink or swim. I have also discussed the impact of metaphors on the general understanding of HIV and AIDS.

The stigma attached to HIV and AIDS meant that disclosure could sometimes lead to negative consequences. Possible consequences included relationship problems with spouses/partners (as was the case with Ashwin and Siwina), friends (as in Annaline and Delene's case). Thandiwe was too traumatized to confide in anyone until just before her death, but all the participants in this study suffered at the hands of employers and colleagues. When HIV-positive people experienced rejection after disclosure they felt that they were being constantly judged. In this study the educators reported that they were no longer seen as educators but as HIV-infected people, a case of "us" and "them".

6.2.2 Testing Times in an attempt to Harness Stigma and Discrimination

In this section I discuss the many facets of stigma and discrimination, namely, the larger portion of stigma apportioned to women, HIV-related stigma, sources of stigma and discrimination, fear of contagion, the manifestation of stigma and discrimination, and stigma's impact in the institutional context. The data from this study revealed that HIV and AIDS related stigma is a double-edged sword especially for women. HIV-positive women suffer stigma, discrimination and isolation, and in some cases if her husband dies, she is disinherited. Because of existing stigma and discrimination against women in various societies, attitudes towards those who become infected are often less accommodating compared to the attitudes towards men in the same situation. In an attempt to harness stigma and discrimination, a Buddhist monk said:

*HIV/AIDS is like a huge rock in society. Only if everyone in society
keeps breaking the rock into smaller pieces will it eventually become dust*

(Sommai Punnyakamo 2001: 25)

Infected women are often blamed for infecting their husbands and unborn children and are described in stigmatizing terms such as "vectors", "diseased" and "prostitutes", terms that are rarely used when describing infected men. The participants (educators) in this study were and

still are victims of stigma and discrimination; their plight (according to data collected through interviews, see Appendix 8) in this HIV scenario was underpinned by stigma and discrimination.

Self-stigmatization is common amongst HIV-infected individuals in most cultures; this was clearly evident amongst the participants in this study when they spoke of their low self-esteem and sense of worthlessness. Parker and Birdsall (2005: 5) note that stigma is part of that identity that has to do with prejudice and values. They explain that while the phenomenon may occur at the individual level, it is also influenced by social processes related to existing assumptions and stereotypes of people belonging to particular social categories, adding that ‘stigma involves the social expression of negative attitudes and beliefs that contribute to processes of rejection, isolation, marginalization and harm to others’.

From a *classic sociological text*, Goffman (1963) points out that, the ‘stigmatised’ and the ‘normal’¹ are social roles, which are not simply complementary or symmetrical, but characterized by a clear power differential. Based on these views, stigma can be defined as an enduring condition, status, or attribute that is negatively valued by society, hence allowing for the distinguishing of stigma from prejudice and discrimination. While prejudice is a negative attitude that involves emotions such as fear, disgust, anger and contempt and resides in the minds of individuals, stigma resides in the structure and relations of society. Evidence from this study has shown that stigma brings about feelings of fear and hostility directed at people with HIV, who suffer pain, isolation and hardship (see Appendix 8).

- **Prejudice**

HIV and AIDS-related stigma accompanied by prejudice and discrimination are significantly shaped by misunderstanding and fear of HIV and AIDS. This ignorance, coupled with social attitudes towards the people who contract it, and the general manner of transmission, play a central role in the maintenance, enactment, and experience of stigma. Prejudice is a negative attitude that evaluates or judges members of a social group. While stigma resides in the structure

¹ ‘Normal’ is the term used by Goffman for the ‘non-stigmatised’, see Goffman, (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall.

and relations of society, prejudice resides in the minds of individuals, and discrimination which is the act, is distinct from prejudice. Participants in this study were openly discriminated against by their colleagues and in some cases by senior management. As mentioned earlier, stigma results from ignorance. Empowered school management teams will be in a position to address the issues around stigma and discrimination, because the head (principal) sets the tone in his/her school.

Scrambler (as cited in Journal of Law, Medicine and Ethics 2002) distinguishes between *enacted stigma* and *felt stigma*. He explains enacted stigma as overt acts of discrimination and felt stigma as a person's internal sense of shame and fear of persecution. Both these types of stigma were experienced by the participants in this study (see Appendix 8), when they were isolated in their staffrooms and at staff meetings and also when they struggled with their own internal conflicts and were at pains trying to keep their secret. Felt stigma was also experienced in the absence of enacted stigma.

Ogden and Nyblade (2005) argue that apart from self-stigma, secondary stigma, which occurs by association, often affects those related to the infected, such as the immediate family members, children, friends and caregivers. Family members may suffer the same expressions of blame as the HIV-infected individual through gossip, being socially ostracized, loss of income, employment or housing. Ogden and Nyblade (2005) in their study² found that stigma and discrimination are fanned by sensationalist public messages in which immorality is linked to promiscuity, moral transgression and bad behaviour and punishment from God, whereas normative social values are related to what is considered appropriate or good behaviour. They also found that gender in AIDS is a cross-cutting issue where women are generally expected to be faithful, chaste and morally upright.

Parker and Birdsall (2005) in their study in Soweto³ argue that women who had experienced partner abuse were more likely to be HIV-positive than those who had not, and that infected women received a greater portion of blame than men. The stigmatizing labels on HIV and AIDS

² See Ogden & Nyblade (2005). Common at its core; HIV- related stigma across contexts. International centre for research on women.

³ See Parker & Birdsall (2005). *HIV/AIDS and faith-based organisations: A review*. Centre for AIDS development.

are a product of the many social expectations, influences and beliefs that HIV-positive individuals are contaminated.

Goffman (1963) in his theory of social stigma, identifies three aspects of stigma that are characteristic of HIV and AIDS: blemishes of personal character, stained social identity, and physical deformity or defects. Parker and Aggleton (2003) argue that AIDS stigma also produce inequalities of class, race and gender. Herek (1999) is of the opinion that people who are HIV-positive are often ascribed the responsibility for their condition because HIV is contracted from behaviours that are considered avoidable, namely unsafe sex and drug use. Novick (1997) believes that stigmas linked to HIV and AIDS are also inextricably linked with other stigmas associated with risk behaviours, such as sexual promiscuity, homosexuality, sexual exchange, and drug use.

The debate about HIV and AIDS stigma as a social versus an individual issue is on-going. Although Herek (2002) has been criticised for individualizing stigma, he does see stigma as a social construct, and defines it as ‘an individual’s negative attitude towards a social group which matches the negative evaluations of society towards the attributes held by that group’. Parker and Aggleton (2003) argue that stigma is about power relationships which are seen as crucial in developing a more holistic theory of stigma. Joffe (1999) also sees stigma as a social process, drawing on existing forms of social representation that are rooted in social power relations.

- **Stigmatising Discourses**

Stigmatizing discourses perpetuates and allows people to distance themselves and their in-groups from the risk of infection by blaming contraction of the virus on characteristics generally associated with out-groups, who are classified as deviant and “other”. In the next section I discuss the larger portion of HIV and AIDS stigma shared by women.

.In discussing a larger part of blame and stigma apportioned to women, I allude to *The Scarlet Letter*, a novel written by Hawthorne in 1850, where Hester Prynne was found guilty of adultery and forced to wear a scarlet ‘A’ on her front bodice, and given a place in society deemed

appropriate for someone who sinned against God and society. Hawthorne's novel was written in the 1600s, but the treatment that women with HIV and AIDS receive today is similar to that meted out on Hester. The participants in this research experienced similar negative treatment. The participants in this study contend that HIV-positive women are also blamed and labeled as those who have sinned against God, hence they are perceived as being punished. Whilst the awareness of HIV and AIDS is widespread, it is in human nature to think that these diseases only happen to "others", and when women become one of the "others" they are more concerned with the stigma-related rejection. The fear of this rejection is so overwhelming that on diagnosis women focused more on psychosocial issues, than on physiological changes. The fear also became a barrier to women receiving support in order to maintain and enhance their health. According to the Centres for Disease Control and Prevention (2002), the number of women living with HIV and AIDS continues to increase, and women with HIV are not rare but hidden. Women are afraid to disclose their HIV status because of the stigma, they do not want to become the Hester Prynnes of today. Goffman (1963) says that stigmatized individuals possess a characteristic that labels them as different in a negative way.

Piot (2000), executive director of UNAIDS, identified stigma as a 'continuing challenge' that prevented concerted action at community, national and global levels. USAID (2000) argues that the poor understanding is due to the complexity and diversity of stigma and discrimination; the limitations in the current thinking within the field and the inadequacy of available theoretical and methodological tools.

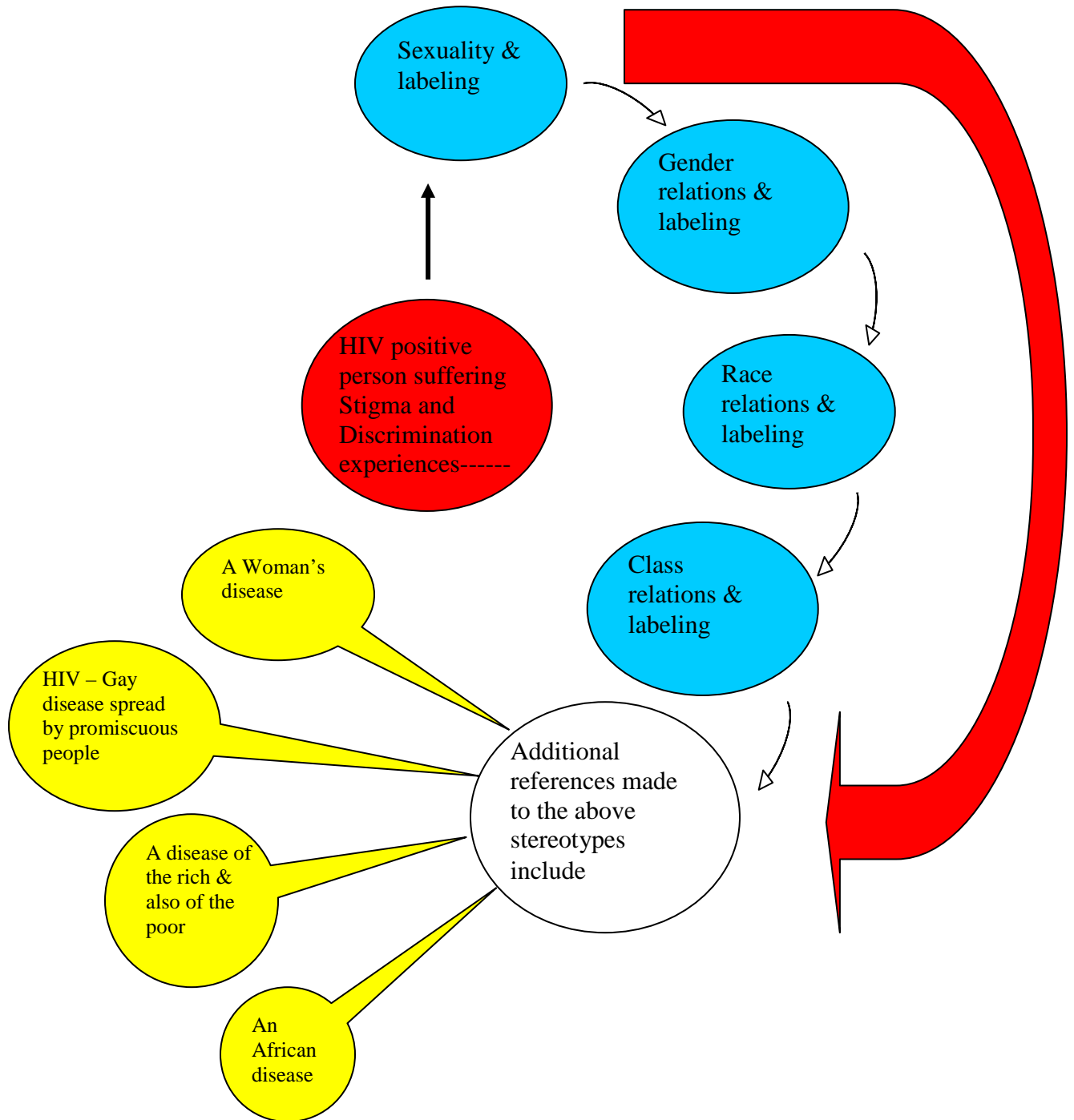
In the next section I discuss sources of stigma and discrimination. The discussion below is presented in conjunction with figure 6.1 (adapted from Parker & Aggleton 2002) which was a useful way to synthesize the data. HIV and AIDS-related stigma and discrimination interact with pre-existing stigma and discrimination associated with sexuality, gender, race and poverty,⁴ It also has pre-existing fears and metaphors about contagion and disease such as death, as horror, as punishment, as guilt, as shame, as otherness. These have increased fears, legitimising stigma and discrimination.

⁴ See Horizons Programme (2000), HIV/AIDS related stigma and discrimination: A conceptual framework and an agenda for action.

- Sexuality - because HIV is mainly sexually transmitted and mainly affected people whose sexual practices or identities were different from the “norm”. Weeks (1981) is of the opinion that HIV-related stigma and discrimination reinforce pre-existing sexual stigma associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution, and sexual deviance. It is a general belief that all HIV-infected people became infected through sexual deviance, but it is evident from the data in this study that sex is not the only means of becoming infected. Thandiwe was not infected through sex.

- Gender-HIV and AIDS related stigma and discrimination (4 out of 5 participants in this study are females) is linked to gender-related stigma. Aggleton and Warwick (1999) argue that the impact of HIV and AIDS-related stigma and discrimination on women reinforces pre-existing economic, educational, cultural, and social disadvantages and unequal access to information and services. Female sexual behaviour that is not consistent with acceptable social norms is also blamed; female sex workers are blamed as “vectors” of the infection who put their clients at risk. Three of the four women in this study were infected through sex, but not through deviant behaviour (see stories in annexure). For example, Siwina married her first and only boyfriend and was infected by him.

Figure: 6.1 The Relationship between HIV and AIDS and pre-existing sources of Stigma and Discrimination. (adapted from Horizons-HIV and AIDS-related Stigma and Discrimination by Parker & Aggleton 2002)



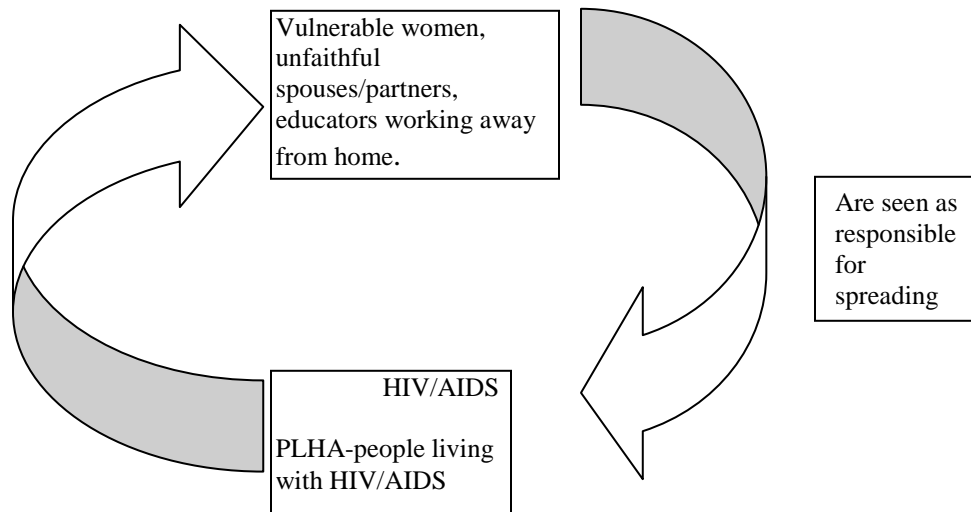
- Race and ethnicity – also interact with HIV and AIDS related stigma and discrimination. The epidemic has been characterized both by racist assumptions about “African sexuality” and by perceptions in the developing world of the West’s “immoral behaviour”. According to African culture, male sexual advances ought not to be shunned, and the issue of condom use is taboo in most relationships. This is evident from data collected for this study (Siwina’s husband refused to wear a condom, and she finally divorced him) and also from anecdotal evidence⁵. The West’s modern outlook on sex is not an issue, hence pre-marital sex is not an issue
- Class – does have an impact on HIV and AIDS. The participants in this study were and still are educators and financially stable. According to Castells (1996, 1997, 1998), the HIV and AIDS epidemic developed during a period of rapid globalization and growing polarization between the rich and poor. Parker et al (2000) argue that new forms of social exclusion associated with global changes have reinforced pre-existing social inequalities and stigmatization of the poor, homeless, landless and jobless. As a result, poverty increased vulnerability to HIV and AIDS, and HIV and AIDS exacerbates poverty. The participants in this study agree that poverty is a huge contributory factor in this pandemic, and that especially women and young children from the lower economic group engage in prostitution to put food on the table.

HIV-related stigma is unique in that it equals to fear of contagion and ‘otherness’. People are afraid of becoming infected with HIV because it is a life threatening virus. The participants in this study were very fearful when they were diagnosed HIV-positive and experienced many painful psychological experiences. UNAIDS (2000), Malcolm et al (1998), and Daniel and Parker (1993) argue that various metaphors associated with AIDS have also contributed to the perception of ‘fear’ and ‘otherness’ (already stigmatized sex workers, gender, race, or socioeconomic status) and this has enabled some people to deny that they personally could be at risk or affected.

⁵ Participants in HIV and AIDS workshops in 2005,2006 in Inchanga and Vryheid respectively.

Figure 6.2 Stigma's vicious cycle

(Adapted from Horizons May 2002 HIV and AIDS-related Stigma and Discrimination)



The above diagram (Figure 6.2) shows that HIV and AIDS is associated with vulnerable women, unfaithful spouses/partners and migrant workers which also includes educators working away from home. They are seen as the people responsible for spreading HIV and AIDS. The figure also shows that people living with HIV and AIDS (PLHA) are stigmatized because they are assumed to be from marginalized groups.

This cycle (Figure 6.2) works in two ways. Firstly, because HIV is associated with marginalized groups, it is assumed that all HIV-positive people belong to the marginalized group. Men are reluctant to disclose their HIV status because they may be labeled homosexual (Siwina's husband was also reluctant to get tested, Annaline's boyfriend infected many women so that he would not die alone). Similarly, women are afraid of being labeled promiscuous, hence the participants in this study were so determined to keep their HIV status a secret. Secondly, HIV compounds the stigmatization of individuals who are already oppressed and this increases their vulnerability to HIV and AIDS, which causes further stigmatisation (all the participants in this study reported suffering stigma and discrimination at school).

When an individual is put in a risk category of 'otherness', they are separated from other sources of identity, stigmatized and degraded. The category of 'otherness', allows those in power to dehumanize, to scapegoat, to blame and feel justified. Link and Phelan (2001: 370) say, 'in the extreme, the stigmatized person is thought to be so different from 'us' as to be not really human, and again, in the extreme, all manner of horrific treatment of 'them' becomes possible'. HIV and AIDS has been 'othered' as the preserve of the deviant individuals, and associated with sexual promiscuity and moral deviant behaviour. In South Africa, this process of 'othering' has been directed towards poor black women who carried the burdens of negativity around HIV and AIDS. In the next section I discuss the manifestation of stigma and discrimination.

Whilst much advocacy is being done to educate society about HIV and AIDS, UNAIDS (2000) and Malcolm et al (1998) suggest that HIV and AIDS-related stigma and discrimination take different forms and are manifested at different levels, in societal, community and individual contexts. Parker and Aggleton (2003: 19) suggest that stigma and discrimination should be understood as 'part of the political economy of social exclusion present in the contemporary world'. This was evident in the schools in which the participants taught. They also believe that HIV and AIDS stigma exacerbates social divisions by stereotyping marginalized or disempowered groups as responsible for the illness and its spread. Parker and Aggleton (2003) argue that because stigma which leads to discrimination has the power of reproducing relations of social inequality that are advantageous to the dominant class, these forms of stigmatization are functional in the sense that they help to maintain the socio-political status quo.

In discussing the impact of stigma in institutional contexts, Gilborn et al (2001) report that children with HIV and AIDS or associated with HIV through infected family members have been stigmatized and discriminated against in schools in many countries. Stigma has led to teasing by classmates of HIV-positive children. Discrimination in the workplace is also rife; Gostin and Larrarini (1997) reported that discriminatory practices such as pre-employment screening, denial of employment to individuals who tested positive and the termination of employment of PLHA still takes place in developed and developing countries.

Panos (1990) and Bharat et al (2001) report that failure to respect confidentiality by clearly identifying patients with HIV and AIDS, revealing serostatus to relatives without consent and releasing information to the media or police, are further problems that pose challenges to curbing stigma. The participants in this study were at pains trying to manage the virus in the school environment, and they needed support in the work situation but were afraid to disclose their status. HIV and AIDS-related stigma and discrimination are highly prevalent in some religious organizations. Singh (2000) reports that in some cases religious leaders have used their power to reinforce the stigma and discrimination status quo, rather than challenge the negative attitudes. He also observes that at the international symposium, *Religious Health Organisations Break the Silence on HIV and AIDS*, organized by the African Regional Forum of Religious Health Organisations during the International AIDS Conference in July 2000, it was noted that religious doctrines, moral and ethical positions regarding sexual behaviour, sexism, homophobia, and denial of the realities of HIV and AIDS have helped create the perception that those infected have sinned and deserve their “punishment” thereby increasing the stigma associated with HIV and AIDS. Delene, one of the participants in this study, experienced the denouncement of HIV-positive people by the pastor of her church.

Support varies in the community context. Kegeles et al (1989) argue that in societies with cultural systems that placed greater emphasis on individualism, HIV and AIDS may be seen as a result of personal irresponsibility, and therefore blamed for becoming infected. Panos (1990) and Warwick et al (1998) argue that in societies where cultural systems place greater emphasis on collectivism, HIV and AIDS may be seen as bringing shame on the family and the community. Therefore the way stigma and discrimination is manifested depends on the influence of the cultural system and where it fits on the continuum between individualism and collectivism. Annaline (a participant in this study) expected to receive support and sympathy from her church pastor after being diagnosed HIV-positive, but was very disappointed when the pastor asked her to see a counselor and also to keep her status a secret. According to Warwick, illnesses that are believed to be the result of “immoral” or “improper” behaviour, such as HIV and AIDS, may reinforce stigma of those considered to be “deviant”.

While the family is the main source of care and support for people living with HIV, such as in Delene, Annaline and Siwina's cases, negative family responses are common, as was experienced by Ashwin from his immediate family, and Annaline by her siblings. Bharat and Aggleton (1999) report that infected individuals experienced stigma in the home, and women were more likely to be badly treated than men. Horizons (2002)⁶ observes that HIV and AIDS-related secondary stigma and discrimination extended to families and friends, played an important role in creating and reinforcing social isolation of those affected by the epidemic. Thandiwe, a participant in this study, did not disclose her status for fear of her family becoming victims of stigma and discrimination. Amongst individuals, the manifestation of stigma and discrimination depended on family and social support. In a context where HIV is highly stigmatized, fear of stigma and discrimination may cause individuals to isolate themselves to an extent where they no longer feel part of society. Gilmore and Somerville (1994) report that "internalised" stigma has led to premature death through suicide. Although laws exist to protect the rights and confidentiality of PLHA (People Living with HIV and AIDS), few individuals are willing to litigate for fear that this will result in disclosure of their identity and HIV status. Suicidal thoughts crossed the minds of all the participants in this study.

- **Theorising Stigma**

An emerging insight from the data has shown that HIV stigma both in the school environment and in the community was a huge obstacle. In understanding the theory of HIV and AIDS stigma, Herek (2002) contends that cognisance must be taken of the three important characteristics, **first**, that stigma attached to an undesirable condition tends to be more intense when the condition is understood to be the bearer's responsibility. The condition is stigmatized if it is perceived to have been contracted through voluntary and avoidable behaviours; if the behaviour evokes social disapproval, this type of illness will evoke anger and moralism rather than pity or empathy. **Secondly**, intense stigma is associated with conditions that are lethal and incurable. HIV and AIDS are perceived to be a fatal condition despite new drug regimens on offer (all the participants in this study viewed HIV as a fatal condition), as these drugs are not user friendly or affordable to all who need it. **Thirdly**, greater stigma is apportioned to a

⁶ See Horizons (2002) HIV/AIDS-related stigma and discrimination

condition when it is a risk to others, and intense negative attitudes are directed at an infected person because of the perception that others can be physically, socially or morally tainted by interacting with him or her.

6.2.3 HIV/AIDS in the Context of Individualism and Universalism

In this section I discuss individualism and universalism, which I consider to be another important insight drawn from this study. The consequences of HIV that unfolded in the lives of the educators in this study over a period of time saw them experience many psychological anxieties, anxieties caused by the decisions they had to make in terms of disclosure, acceptance of the diagnosis, rejection by society, health issues, family responsibilities and demands of the workplace. While these psychological anxieties are aspects of the HIV, they do not and cannot stand alone, but are intertwined as consequences of HIV. The participants had to cope with these issues, which are virtually impossible to handle in isolation. Three issues in this study are conspicuous and play a pivotal role: acceptance, disclosure and coping. I consider them pivotal because the individual has to accept the HIV diagnosis: this is a difficult aspect and is not easily accepted. All the participants in this study found difficulty accepting this diagnosis, and some sought second opinions. After acceptance of the diagnosis, the dilemma of disclosure has to be overcome, and the individual then has to cope with either decision, disclosure or non-disclosure.

How an individual copes and adapts to the various challenges in life is somewhat determined by the society and environment in which the individual lives. With this in mind, I have adopted Lazarus and Folkman's perspectives on individualism to gain better insight into the individual as viewed in the context of society. In an HIV and AIDS climate of psychological anxiety, society is viewed as making stressful demands on individuals and imposing constraints on the ways such an individual might deal with these demands. Cultural beliefs and practices may also be an influencing factor on stress levels of individuals, especially infected individuals.

In the present climate of the HIV and AIDS pandemic, the notion of absolute narcissism will not work. According to Kavanaugh (2007), the very nature of humanity is interdependency and there are hidden dangers in the gift of autonomy. He believes that there is no rule higher than one's self, and there is no other source than one's self to consult. He refers to this notion of

narcissism as the myth of the self-made man, and that this myth ignores the inescapable reality that no human is ever self-made. He says that individuals are at times unaware of their interdependence. Ignorant of the countless ways that cultural dogmas influence their self-construction, individuals presume that they are atomically alone in the choices they make, and imagine themselves individual monads, their window on the world, a mirror. In this study two participants bordered on narcissic tendencies. Thandiwe kept her HIV-positive status to herself, and hoped that she would have been able to cope with her condition. Ashwin, too, isolated himself after his family shunned him, and he too, hoped to be able to cope alone (see Appendix 8).

Lazarus and Folkman (1984) are of the opinion that society plays a huge role in how an individual adapts or is shaped when they are faced with challenges. They cite three important perspectives which have an important bearing on the individual:

- *society as a means of adaptation*
- *society as a shaper of persons and groups*
- *society as affected by persons and groups*

The first perspective, *society as a means of adaptation*, is explained as follows. Mechanic (1974: 33) suggests that “man’s abilities to cope with the environment depend on the efficacy of the solutions that his culture provides, and the skills he develops are dependent on the adequacy of the preparatory institutions to which he has been exposed”. Individuals vary in their personality and psychodynamics resulting in different behaviour types. The participants in this study experienced fear, shame and pain, when they were diagnosed HIV-positive; disclosure of their status was not a viable option because society stigmatized people with HIV, and because of society’s view on HIV, the HIV-positive individual had to adapt to society’s norms and values and keep his/her diagnosis a secret. The participants in this study suffered a double disadvantage, as individual members of a society, and more especially as members of the educator fraternity, as their teacher identity was under scrutiny and this has a great bearing on disclosure and stigma.

6.2.4 Teacher Identity

In this section I discuss the identity the teacher/educator is expected to portray in order to remain on the pedestal that society has placed him/her. Strike and Ternasky (1993: 207) argue that one of the most powerful societal presumptions about teacher conduct is that they must be held to a “higher standard of personal behaviour” than people in other occupations. This presumption is based on the conception of teachers as role models. Because teachers are perceived as “icons of morality” and are entrusted with the task of moulding young minds to become worthy, upright citizens, and the socialization of young children, they are pressurized to live by this perception. The word ‘morality’ in the context of school has a loaded meaning. Strike (1988), says the word “moral” (apart from the religious and spiritual context) refers to the social and ethical principles of right and wrong in human conduct, and concerns our duties and obligations to one another. Society expects teachers to live by what they preach, because the teacher’s character plays an important role in creating and moulding the learner’s educational experience.

Another perspective is of *society as a shaper of persons and groups*. According to Goffman (1971), we live in the midst of a complex web of human relationships, ranging from intimate family groups to large social entities. By belonging to the human race and a society, the individual is duty-bound to follow a complex set of rules for daily living, such as acceptable behaviour when crossing a busy street, or behaviour at a wedding as compared to a funeral. Human beings reveal delicate nuances of meaning through culturally shared patterns of conversation and body gestures. Lazarus and Folkman (1984) say that to utilize the perspective of society as a shaper of persons, we must move from the ‘macro’ level of the large and complex social system to the ‘micro’ level of the individual’s actual life context and ask how the former influences the latter. Every individual is a part of a larger social system, as an educator is part of the staff of a school, which is part of the education system. House (1981), emphasizes the importance of cultural forces which are passed from generation to generation as a key issue in shaping the individual. The cultural component of a social system has a major impact on the individual’s emotional life. Gordon (1981) believes that the shaping of an emotional reaction, as well as how it is expressed or managed, hinges on the meaning and significance that culture gives to human transactions with the environment. Kemper (1978) refers to this shaping as a

social reality; he says that each of us has a private identity, a subjective world that is never completely opened to others. Individuals have their own private thoughts, feelings, wishes and goals, and their own consciousness and unconsciousness. He believes that what each individual knows is not exactly what anyone else knows, and therefore the way social reality is constructed differs from individual to individual. Because society has the power to sanction unacceptable behaviour, HIV-positive individuals are reluctant to disclose their status, for fear of not being accepted in society. In this study the participants had varying views concerning disclosure, which depended on the socio-cultural climate in their environment. For example, Siwina did disclose to her parents and was supported by them, whereas Thandiwe did not disclose to any member of her family until just before her death. Both these educators were respected in their communities, hence disclosure was not easy.

6.2.5 Disclosure/Acceptance/Morality

An HIV-positive diagnosis requires much strength and support to be accepted, and disclosure may come much later after the individual has accepted his/her HIV-positive status. An individual who has been diagnosed HIV-positive faces difficult decisions. Firstly, he/she has to accept the diagnosis and come to terms about the management of the virus; he/she also has to think about disclosure of his/her status, and who to disclose to if disclosure is to take place. Disclosure of an HIV status is synonymous to gambling: the individual does not know what response he/she will receive until it is done. For educators, it is all the more difficult because of the “morality status”. Disclosing to a few chosen people about an HIV-positive status may help the individual to come to terms with his/her diagnosis, but keeping the diagnosis a secret makes the individual’s status a burden all the heavier to carry, as was the case with Ashwin. He took a very long time to seek assistance, but by disclosing his status to a social worker his load became lighter to bear. By disclosing to people, the individual’s trust will set him/her free, as Delene explained her experience of disclosure to her family, who were very supportive. Confining disclosure to a few close friends and family who can give an individual comfort and confidence to share feelings, often lessens the individual’s sense of isolation. Joining a support group can be very therapeutic, as sharing information and experiences with other HIV-positive people eases the burden and gives one a sense of belonging, thus the individual’s quality of life may also

improve. Disclosure cannot be forced, and acceptance of an HIV-positive status comes to different individuals within different time frames. Annaline was with her future husband when she received her results, and had a shoulder to cry/lean on, whereas Ashwin, Delene and Siwina found difficulty in accepting their HIV-positive diagnosis. Siwina sought a second opinion, Ashwin and Delene took time to come to terms with the diagnosis and Thandiwe agonized over her diagnosis and kept her secret until just before her death.

The participants in this study were of the opinion that disclosure could not take place immediately after diagnosis, the participants had to think through the surrounding issues very carefully. Issues for and against disclosure had to be carefully considered; in reality, the choice the individual made could have major implications. The decision to disclose or not to disclose becomes a dilemma for the HIV-positive person. Dilemmas arise when the individual is scared about what others will think; it is a conflict within the individual, not to disclose (see Figure 6.3) or to disclose (see Figure 6.4).

Disclosure was a major problem for all the participants in this research and they struggled to maintain their secrecy especially in the school environment. Delene and Siwina voiced their concerns about the possibility of losing their jobs if their secrets were revealed. The participants in this study were also very concerned about their identity in the community, which was one of morality, as educators were seen as role models that were responsible for shaping and moulding young minds to become respectable citizens of the future. Therefore disclosure for these educators was not an option, given the nature of the transmission of the disease, and the stigma attached to people living with HIV. An almost “impeccable high standard” of behaviour was expected of educators by society. Strike and Ternasky, (1993: 207) state that teachers are seen as “ideal role models”. Being diagnosed HIV-positive posed a moral dilemma on the participants in this study, and this “ideal role model” image had a negative impact on the participants and how they viewed themselves. They believed that others would judge them and see them as having fallen off the pedestal of “ideal teacher”. Parents and the general community place a moral and ethical obligation on teachers to act as good role models through their behaviour, and a teacher’s personal character is generally expressed through his/her behaviour. Another cause for concern around disclosure that the participants in this study feared was rejection. Once their

secret was known, the stereotypes around the transmission of HIV was also a painful issue, especially for Ashwin (he was a victim of hijack and rape), Thandiwe (infected through a blood transfusion) and Siwina (infected by her husband who had several partners).

Personal ethical issues also weighed heavily on the participants when they made excuses about their illnesses and their absenteeism. Annaline explained her persistent coughing and listlessness as recurring flu, and Delene said that her illness was due to leukemia. This excuse-making about their illness and absenteeism raised ethical dilemmas, which in turn brought on personal ethical consequences about self-worth and self-esteem, which questioned their standing in the school community especially in front of young learners. On numerous occasions, the participants in this study were caught in the midst of tug-o-wars between truth and excuses. The decision not to disclose an HIV-positive status may also be viewed as an act of compassion and protection. Annaline, Delene and Siwina delayed disclosure to their parents because they feared the inability of their parents to handle the news, and Thandiwe did not disclose her HIV status until just before her death (to her sister) because she wanted to protect her family from stigma and harm.

Some people living with HIV chose not to disclose because they felt that there was too much to lose (as was the case with Thandiwe). Non-disclosure could also have severe consequences such as a lack of support, and not having anyone with whom to discuss your status. The issue of risk was ever-present, as was the danger of being re-infected and the possibility of infecting a spouse or partner. Lack of care, of access to the required medical care, counseling, may make an HIV-positive person avoid a support group because of the fear of being identified as HIV infected. An HIV-positive person is so wrapped up in his/her own dilemma, self-stigmatisation and isolation, that he/she does not notice the suspicion around him/her.

Figure 6.3: Dilemma of the HIV Positive Person-**Illustrating Non-Disclosure**

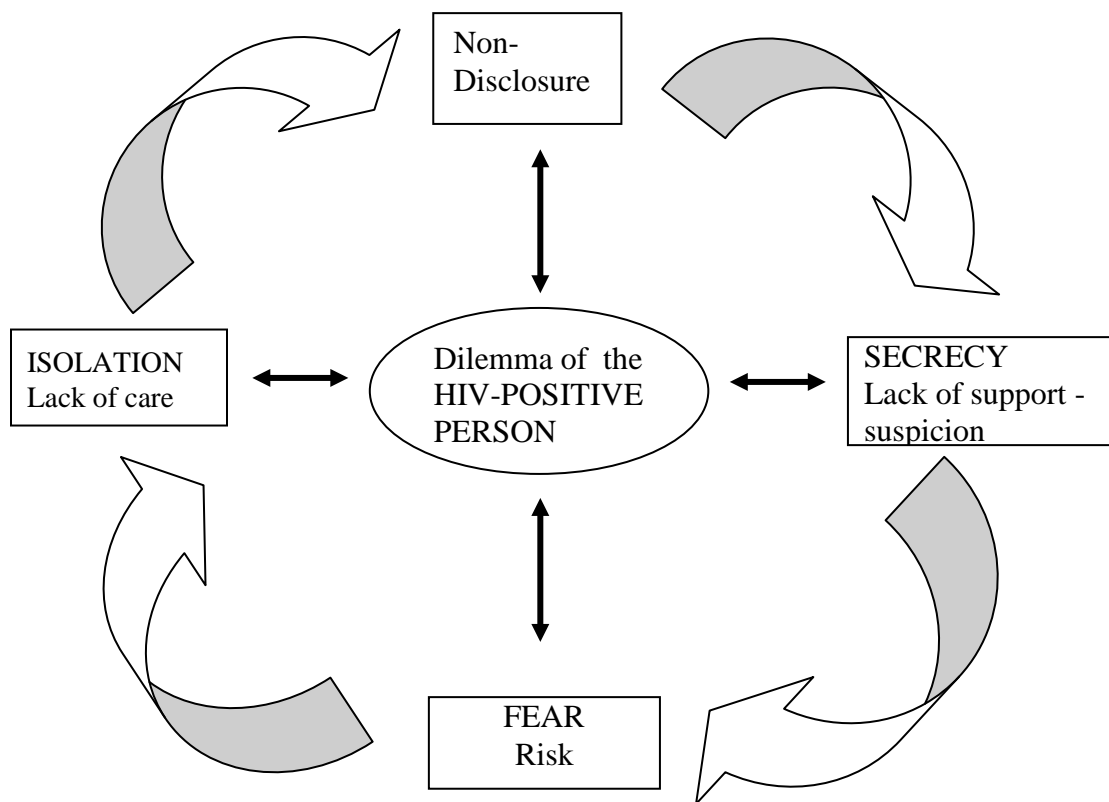
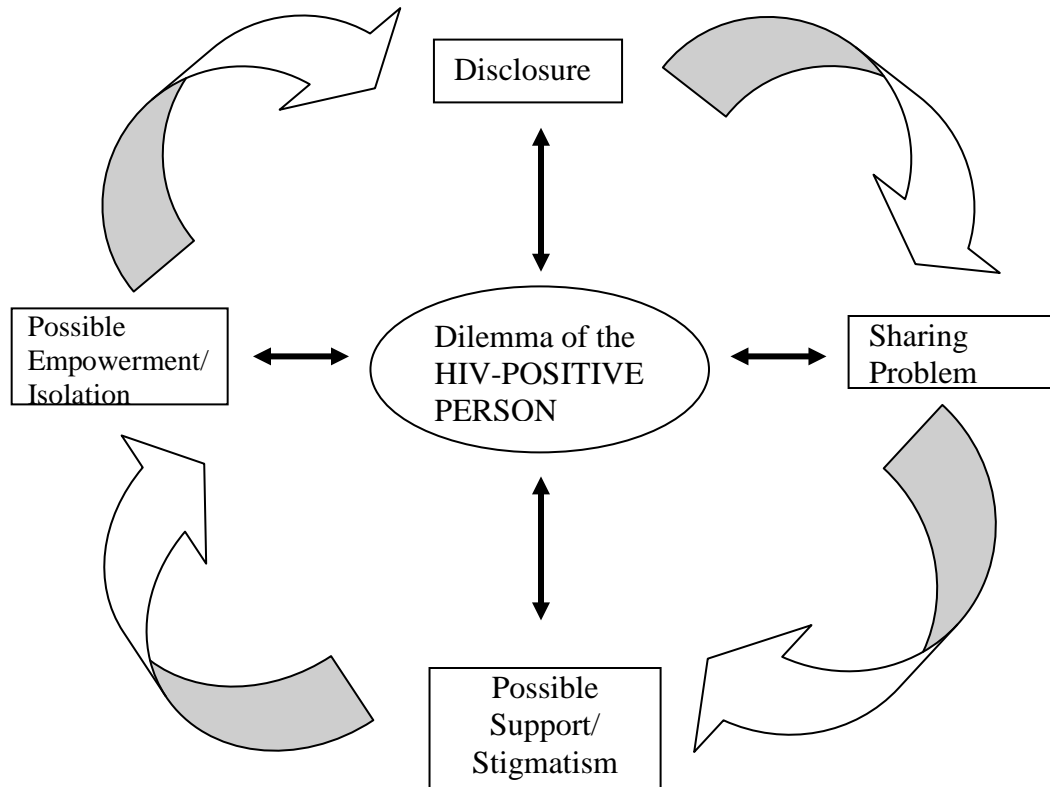


Figure 6.3 explains that when an individual chooses not to disclose his/her status, the secrecy weighs heavily on the individual, and he/she loses out on possible support. The individual becomes so wrapped up with this dilemma, that it raises suspicion around this behaviour both at home and in the workplace. By maintaining non-disclosure, the individual becomes engulfed in fear which poses a risk both mentally and physically. This fear causes the individual to isolate him/herself, and in the process lack of care and neglect sets in.

Figure 6.4 explains the dilemma of a person who chooses to disclose his/her status. Admittedly this is a very difficult decision, because there is no reversal once it is done, or once the HIV-positive individual has shared his/ her problem. Following this disclosure the individual may receive sympathy and support or may be stigmatized. If the individual receives support, care and

empowerment will follow, but if the individual is stigmatized, isolation will follow, and thereafter the individual must learn to cope in either scenario.

Figure 6.4: Dilemma of the HIV Positive Person-**Illustrating Disclosure**



In terms of the the third perspective, *society as affected by persons and group*, individuals are a part of society and therefore have a bearing on society. McFall (1982) points out that not only are individuals born into a social system that affects their thoughts, feelings and actions throughout their lives, but they in turn influence this system thereby producing social change. This perspective on the individual and society appears to be given little emphasis, yet it is very important in stress and coping theory, which is also concerned with how the individual affects the environment through coping.

Lazarus and Folkman (1984) are of the opinion that the two perspectives, people as shapers and people as shaped, have political implications. They argue that disease, deviance, and

maladaptive outcomes can be viewed as the failure of the individual to cope adequately. Because of genetic defects or the lack of effective adaptation skills, the individual could be blamed for failing to adapt. Alternatively, the inadequacies of societies could be blamed for failing to adapt, and for not providing suitable niches for those who need them.

An HIV-positive person's health status and well-being depend largely on the support they received and their coping skills. Coping is a dynamic process, where a series of reciprocal responses between the individual and the environment are involved. Lazarus and Folkman (1984: 141) define coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. The participants in this study struggled to manage external/internal demands. On the issue of external demands, almost all the participants made excuses about their illnesses, at times recurring illnesses were explained as having "a low resistance". Internal demands, according to the participants, bordered on "nightmares" because participants were alone with their thoughts, and during these times, issues of self-stigmatisation, blame, fear, guilt, and anxiety crowded their minds and in some cases suicide, were also considered. The participants reached this stage through their self-empowerment.

In this study, coping as a process could be seen in the long duration of the anxieties, fears, and denial among other stressors that took place over time for all the participants, except for Thandiwe. Initially, the reality of an HIV diagnosis is accompanied by shock, disbelief and tearfulness, or brave struggles to carry on socially or at work. Later stages often involve disengagement and deep depression, followed ultimately by the acceptance of loss, re-engagement, and even confiding in another person. The coping process is more manageable if the individual has support from loved ones, as was the case with Annaline, Delene and Siwina.

Evidence from the data collected in this study has revealed that each of the five participants reacted and coped with the virus differently, mainly because of their situations, their capacity to handle HIV and the social support available to them. There was great individual variation both in terms of how the significance of the virus is appraised and how it is coped with. Schrimshaw (2002) contends that each patient faces a particular set of circumstances within the context of a

unique personal history. When Annaline received her HIV diagnosis, she had a fiancé who stood by her; in Delene's case, her boyfriend fought with her, she had to escape and finally she went to stay with her mother. Siwina abandoned her husband and went to live with her parents who were very supportive. Ashwin being a hijack victim, isolated himself. Thandiwe just did not cope. Society plays an adaptive and shaping role in the life of an HIV positive person, at the same time society is affected by persons and groups. In the next section I discuss how denial, depression and labeling impacted on the live of the HIV-positive person.

6.2.6 Impacts of Denial, Depression, Labeling, and Blame on the HIV positive person

HIV-positive people generally indulge in *denial*, or even avoidance, as a means of coping with stressful news or stressful encounters like HIV, because through denial they experienced greater emotional ease during the initial period after their HIV-positive diagnosis. This denial may ease the emotions initially, but the individual may experience continued vulnerability on subsequent occasions. Generally, people who face a threat will be extremely stressed at the beginning, but will be able to accept the situation and experience less distress with time, because they will be prepared to handle the infection.

All the participants in this study used and experienced denial during the initial period of their HIV diagnosis, though some were in denial for longer than others. Thandiwe had many symptoms of HIV but she refused to believe that she was HIV-positive. Ashwin refused to believe that he was HIV-positive, he believed that the blood tests got mixed up, and he got someone else's results. Ashwin also spent much of his spare time sleeping, to shut his mind out to the disease. Siwina was also in denial, so she went for a second blood test, but felt that the 'doctor was mistaken'. HIV and AIDS-related denial may function in several ways: it can prevent the individual from acquiring HIV related information, but it can also strengthen negative attitudes. Ben-Zur and Breznitz (1997), believe that denial is considered to be an emotion-focused, avoidant type of coping, and that its specific essence is expressed in the negation of reality in word or act, its main characteristic being self-deception

Denial or avoidance in relation to illness is dangerous because the person fails to seek or engage in appropriate problem-focused coping such as seeking medical attention or adhering to a medical routine, as was the case with Thandiwe. Denial closes the mind to whatever could be threatening, and gives a person a brief, false sense of relief.

People are generally depressed when they are ill, but people who are HIV-positive experience extreme **depression** because they feel that they have lost everything, their families, their jobs and peoples' trust (this was experienced by the participants in this study). Guilt, blame and shame haunts them for the upheaval that has been brought upon themselves and their families. The depression suffered by both the affected and the infected is further exacerbated because there is no cure for HIV and AIDS. Annaline spoke of the indifference of her colleagues towards her, which caused her much depression, so much so that, she had to take two weeks sick leave during the term just to get away from all the nastiness at school. She was also very depressed when her friends deserted her after hearing that she was HIV-positive. Siwina was very depressed at her school, she feared what would happen to her if her colleagues suspected her status. Thandiwe's depression stemmed from her secrecy, her condition was rapidly deteriorating. She stressed about not being around for her little daughter. HIV and AIDS-related depression does not go away after the individual has accepted his/her status, it lingers on. Ashwin is a living example of HIV-related depression, as he constantly focused on his ill-fated experience that caused his world to crumble; when the depression got the better of him, he spoke of death.

Labeling HIV-positive people is very painful, as is evident from this study. The words HIV and AIDS (according to Siwina) are taboo in some communities, especially the black community, hence individuals resorted to name-calling. Siwina was very afraid when she received her blood test results, and to her the name-calling or labeling was more serious than the HIV virus. She was anxious about being put into the group where others referred to her with **three fingers which denoted HIV**. Delene was also labeled as having the **slimmers disease** after she returned from sick leave, meaning that she was "wasting away". Participants also spoke of their feelings of worthlessness when insensitive colleagues and community used words such as **OMO, Z3, House in Verulam (HIV), Hlengiwe Ignatius Vilakazi (HIV), Amagama Amathathu (HIV 3 letters)**

*and Umlazi 3*⁷, to describe people living with HIV. Comments and name-calling/labeling by people who did not know their status demeaned people living with HIV. Aggleton et al (2002: 8) confirmed this view in his perception of HIV as ‘a mark of shame, where the carrier of the virus is blamed, devalued and significantly discredited’.

Evidence from the data in this study clearly shows that *shame and blame* was experienced by the participants both in their schools and in the community. Social norms and attitudes also played an important role in the negative feelings, stigma and discrimination towards people living with HIV and AIDS. Apart from the infected individuals, the affected family members also suffered shame. All the participant’s family members experienced varying degrees of shame. Ashwin’s family life was destroyed when he disclosed his status, and his family was so ashamed of him that they blamed and disowned him. The intensity of the shame attached to HIV prevented Thandiwe from disclosing her status even to her immediate family.

6.2.7 Coping Strategies

HIV is an emotional illness. All the participants in this study reported that it was a devastating experience to be diagnosed with a life-threatening virus like HIV. It is at this crucial time that support is of paramount importance from friends and family, but the negativity that surrounds HIV and AIDS prevents the individual from seeking this support. The nature of the virus is such that the person concerned has to come to terms with and accept the diagnosis. This coming to terms, acceptance and coping varies from person to person.

Taylor (1986) explains that coping is a dynamic process, which involves a series of reciprocal responses between the individual and the environment. He argues that coping responses are not momentary occurrences, but rather form a chain of interactions which take place over time. Coping, he says, is an interactive process between the coping person, the problem, and the environment. In this study it would be the participants, the virus and the school environment, which refer. Taylor (1986) argues that the coping strategy depends on the nature of the stressor,

⁷ Labeling-HIV is 3 alphabets, because mentioning HIV is taboo in certain communities and cultures, words and phrases consisting of 3 alphabets and/or 3 words is used.

intrapersonal factors and the availability of social resources. In this study, the stressor is stigma and discrimination, while the intrapersonal factors would be culture, beliefs, values and relationships, and the social resources would be family, friends and support systems.

Individuals are more likely to deal with stressful situations in an active manner, if they are confident of having control over them; when they are not confident, denial, a coping mechanism, is then used to decrease the emotional strain. In this study all the participants were in denial about their HIV status during the initial stage. Some were in denial for longer than others. In the next section I discuss metaphors that are used to describe HIV and AIDS.

6.2.8 ‘Metaphorising’ the Illness

Illness is considered to be the dark side of life, and everyone will at some time in their lives experience this dark side. Some illnesses are very much darker than others, and it is these that carry a stigma. A few decades ago, learning that one had tuberculosis (TB) was as severe as hearing a death sentence, and not so long ago cancer also equaled death. Concealing the identity of these illnesses was common, so much so that family members were reluctant to discuss these illnesses freely.

Sontag (1991) argues that etymologically, the word “patient” means sufferer. It is not suffering as such that is most deeply feared, but suffering that degrades the patient while the issue of HIV and AIDS refers to society as being either infected or affected on the one hand, on the other hand, HIV-positive people are still referred to as ‘them’ and those who stigmatise as ‘us’. A range of metaphors are used in HIV and AIDS discussion and research, which tend to influence thinking and views concerning issues around HIV and AIDS. Riconer (1978) explains that metaphors lead us to think about problems in certain ways and this feature makes them very influential in determining how society will respond to those problems. They also play an important role in the realms of imagination and feeling, serving as powerful rhetorical devices for declaring and affecting attitudes. Some metaphors that are used to understand HIV and AIDS threaten to entrench existing forms of oppressions against women as well as against people of colour, hence the need to investigate and endorse alternative metaphors that will assist to reduce

some forms of oppression. When metaphors are firmly entrenched, they become invisible and difficult to remove, as Sherwin (2001) explains in her article on feminist ethics, she uses the example of doctors referring to HIV and AIDS as a *war*; they are thus likely to think of only certain kinds of strategies for responding to the virus, such as aggressiveness, but ignore other, valuable strategies such as the development of coping strategies. The *war* metaphor conjures up feelings and attitudes of fear and dependence in patients and feelings of power and responsibility on the part of the medical practitioners.

AIDS is not a disease, but it is a syndrome associated with a variety of illness. Sherwin (2001) adds that metaphorical references to AIDS include a *modern-day plague*, the retribution of God, an illness of poverty and neglect, a form of genocide, a death sentence and an assault on a besieged community. She goes on to explain that these conceptions demand emergency public health measures, atonement and behavioural changes, resistance or denial, community building strategies, political activity directed against perpetrators, resignation and spiritual accommodation or a sympathetic and responsive set of health care workers.

Sherwin (2001)⁸ also discusses how reference is made to those who are identified as being seropositive to HIV. She explains that the expressions *patient* client, victims, survivor and person living with HIV and AIDS all carry distinct metaphorical roles and prescribe very different relationships between individuals and the health care system. While many bio-ethicists have opted for the traditional patient-physician relationship to that of autonomous contracting consumer or client, most activists within the community of HIV-infected persons prefer to describe themselves as ‘persons living with HIV and AIDS’. This is to make an explicit statement that they are whole persons (not just illness sites); they are very much alive (even if they are ill). By choosing labels like ‘person living with HIV and AIDS’ over that of ‘AIDS victim’ or ‘AIDS patient’, they are showing that this virus is something that happens to people, but does not constitute them.

In an effort not to incorrectly label people living with HIV, Sherwin (2001) explains that there has been a concerted move to abandon the name ‘AIDS’ and the term ‘HIV disease’. This

⁸ See Feminist Ethics and the Metaphor of AIDS in the Journal of Medicine & Philosophy (2001: 343-364)

revision shifts the focus from that of the symptoms of advanced illness to the *power of infection*. Sontag (1989) cautions that there are problems with this move, saying that it is rooted in an implicit appeal to a biological model of maturing entity according to which the virus progresses through defined stages; infection, followed by a potentially long period of latency, early and manageable symptoms and ultimately, ‘full blown’ AIDS and death. Sontag further explains this view of the virus to people who are still healthy and free of symptoms. This approach makes a contradiction of being ‘healthy but infected’, and those who test seropositive for HIV are readily deemed both *contaminated and ill* and face a significant likelihood of being cut off from jobs, family, housing, and insurance. Also, if infection is thought of as inevitably fatal, their confidence in pursuing treatment may be seriously undermined. HIV and AIDS is identified by the media and by communities as a disease of *them* or the *other*, which threatens *us*: these issues make it easy to adapt the images and fears that HIV and AIDS promotes to serve the interest of repressive ideologies.

Trebilot (1986) explains that HIV and AIDS discussions continue to appeal to a binary division separating *us* from *them*. Feminists believe that there is good reason to seek to undermine the power of the politically dangerous images that many medical experts propose for understanding and controlling HIV and AIDS, and for trying to find and encourage the adoption of mere liberating metaphors to take the place of the politically oppressive ones that promote the stigma.

HIV and AIDS is so heavily stigmatized because the general society thinks of HIV and AIDS as *pollution*. Society is inclined to want to isolate those who are infected to prevent contamination of *others*. When HIV is referred to as *a deadly virus*, society wants to destroy it and keep far away from it, hence *we* (society) want to stay away from *them* (the HIV-infected).

In contrast, when HIV and AIDS is thought of as a chronic disease that can be controlled and kept in check for many years, it becomes necessary to consider ways to care for those who are directly affected as continuing members of our communities. Sherwin (2001: 361) says that feminists should become sensitive to the power that metaphors hold in the area of HIV and AIDS policies because these metaphors affect women’s interests both directly and indirectly. It is

therefore crucial to identify metaphors that make space for an enriched and meaningful life for people with HIV diagnosis rather than focusing on HIV diagnosis as a *death sentence*.

Some salient literature insights were: the politics of AIDS; the feminization of HIV and AIDS and the vulnerability of women; government's denial on the HIV and AIDS issue; male/female partnerships; gender issues; playing a dual role with HIV and AIDS; psychomatics and psychoneuroimmunology, and policy issues.

In this section, the politics of HIV and AIDS suggests that *poverty and powerlessness* are central to understanding how this virus gets managed. Klouda (1992: 797) says:

The critical factors in controlling the epidemic do not lie among people who can make choices, but rather among those who cannot – especially the poorest least powerful, most vulnerable and most isolated.

The HIV and AIDS pandemic can be equated to a 'run away fire' in South Africa, more especially in the province of KwaZulu-Natal,⁹ where the prevalence rate among educators stands at 21.8%, compared to an average of approximately 12% amongst educators in other parts of South Africa (ELRC Study 2004). The data suggests that HIV and AIDS had become both a product of and a metaphor for the times. HIV and AIDS is often referred to as an illness of the poor. Larson (1990: 5) confirms this by agreeing that the virus surfaced first among those already marginalized and stigmatized. When the virus appeared in Africa, the media called it 'the African disaster', portraying a continent facing 'insurmountable calamities', rather than 'problems with social and political causes'. The data respond to the idea of 'insurmountable calamities' through the testimonies of the five participants in this study. The stigma, discrimination and prejudice that accompanies an HIV-positive status, made three participants leave the profession, with one passing-on and losing the battle to AIDS.

Power exists as a counterpoint to powerlessness. This issue has an impact on how the HIV-positive person copes. Stigma and discrimination jeopardizes the coping process because

⁹ HSRC (Human Sciences Research Council) and MRC (Medical Research Council) Study: The Health of our Educators (2004), commissioned by ELRC (Education Labour Relations Council).

marginalizing and blaming those HIV-positive disempowers them, and their self-stigmatization makes them believe that they are lesser beings. The participants in this study spoke of the way the diagnosis had shunned and shut them into a category of the 'un-dead' or 'waiting for death category'; and in most cases, they endeavoured and fought to cling on to life, and tried to be seen as 'living with HIV and AIDS' as opposed to 'dying of HIV and AIDS'.

HIV differs from other serious diseases such as cancer, tuberculosis and heart diseases because it is sexually transmitted, rather than environmentally transmitted. Poor health and living conditions compromise people's immune systems which makes them more vulnerable to HIV infection, and accelerates the progression to full-blown AIDS. A compromised environment (this does not only mean poor living conditions but also an unsupportive, unfriendly environment) is ideal for potential opportunistic infections with poor immune systems, especially when there is still no cure for HIV and AIDS. In countries where the prevalence rates are high, such as South Africa, the poor, the powerless and the vulnerable need special attention, with carefully prepared education programmes which are sustained.

The issue of blame (a great concern amongst all the participants in this study) in relation to HIV and AIDS is also controversial: who is to be blamed for the epidemic? Will it be the infected person (given the nature of the transmission of the disease) because of his/her lifestyle, thereby absolving the state and social institutions from blame and responsibility for creating an environment that promotes HIV and AIDS, or are the state and social institutions to blame, thereby making the infected individual appear to be a victim?

6.2.9 The Feminisation of HIV and the Vulnerability of Women

Women are at a particularly higher risk than their male counterparts to HIV infection, because of their vulnerability due to biological and socio-cultural forces. Crewe (1993: 28) states that women are exposed to greater concentrations of semen during intercourse than men are to vaginal fluids. This fact alone multiplies women's risks as much as tenfold. In most African countries, and Southern Africa in particular where the greatest percentage of infected women live, women tend to become infected younger than men, because men choose partners younger

than themselves. Fleming (1993: 297) notes that ‘transmission of HIV to females in Africa is largely a phenomenon of adolescence, but HIV is a virus of young adulthood, with a peak of frequency coinciding with the age when women are most often pregnant’.

Van Dyk (2008) argues that certain sexual practices, such as ‘dry sex’, or female circumcision may also increase risks, to achieve dry sex (more for male pleasure and satisfaction), women use a variety of agents which are designed to tighten the vagina and dry up its natural secretions. She further adds that both mechanical and chemical methods could cause inflammation, lesions and the danger of haemorrhages, with an increased susceptibility to HIV and other infections. Condoms which require lubrication would be unpopular if dry sex is a cultural preference. Both Siwina and Thandiwe mentioned the above cultural practices as barriers to addressing the HIV pandemic. Pregnancy and childbirth also expose women to additional HIV risks, particularly in developing countries where ante-natal health care is poor, and women become mothers at a young age.

The youth in general and women in particular, face a formidable array of hurdles in their quest for control over their lives which will help them avoid AIDS. One of the participants in this study married her first and only boyfriend, and became infected. This is evidence of women’s vulnerability, and not having control of their lives.

According to the AIDS epidemic update released by WHO/USAID (2005), there were 25.8 million people living with HIV in Sub-Saharan Africa. Of these 13.5 million were women, which is more than 50%. Walker and Gilbert (2002) believe that women are biologically more vulnerable than men to HIV infection because of their anatomy, and also the social and economic disadvantages they experience. Four of the five participants in this study are women. Though they are educators, cultural practices and norms also have an impact on them. In most societies, cultural norms and values have placed restrictions on women’s freedom of sexual choice, and many have little control over their partners. This is reflected in the growing visibility of the HIV and AIDS pandemic statistics.

The gendered power view which is central to feminism can be attributed to men being seen as having power over women in battles for control of the body. Gatens, (1998) points out that women's bodies have been made the focal point around which struggles have been fought. The concept of patriarchy has contributed to the nature of male power. Foucault (1988) is of the opinion that women should not understand power as a possession. For him, the body is changeable because it is a social site in which ideas and discourses about sexuality are played out.

In this HIV and AIDS crisis, women are almost always completely invisible, face severe and sometimes insurmountable obstacles to coming out with a positive HIV status, are rarely provided with adequate care, and have to take care of most people. In the next section I discuss issues around government's denial and some policy issues concerning HIV and AIDS.

6.2.10 Policy Issues and the impact of HIV and AIDS on Education

Many policies are in place concerning HIV and AIDS. Almost all the education-related policies advocate basic human rights and empowerment on the issue of HIV and AIDS and direct the school to provide a supportive environment for the HIV-infected and -affected learners and educators. Whilst policy formulation is done by experts, the policy success depends on its implementation, and successful implementation needs all stakeholders to come on board. Differences also exist between policy ideas, classroom realities and practices which do not take context into consideration. The idea of having policies is excellent only if the desired results are achieved, and assumptions are minimized.

According to the Millenium Development Goals and the Education for All Initiative (EFA, UNESCO 2000), education is considered to be one of the pillars of development, providing universal access to primary education and with 2015 as a target date for this achievement. UNESCO (2006) states that current of progress has to quadruple in Sub-Saharan Africa to reach this goal.

The classroom is one of the most powerful tools for HIV and AIDS prevention, but this silent killer is shrouded in secrecy, and educators are not very comfortable discussing the topic, which is taboo in many homes. Peltzer et al (2005) say that South Africa's education system is struggling with a variety of problems: there has been a decline in the number of state school teachers between 1998 and 2003, which is a 5% reduction. Teacher retirement, resignation, emigration and death while in service are some of the crucial factors for this decline. They also state that the number of young teachers graduating from teacher training colleges is declining. The HIV and AIDS pandemic is not only a health crisis, it is also an education crisis.

6.2.11 Male/Female Partnerships

It is evident from this study that a partnership is urgent in order to address the deadly HIV and AIDS pandemic. Men need to take responsibility, and become partners in prevention and education, and must practise healthier sexual behaviour. Violence against women is a human rights abuse, and is increasingly becoming a factor in the spread of HIV. Women suffer direct violence from their husbands and their husband's families when their HIV status is known.

According to Kisekka (1990), economic and social security causes many women to face the threat of physical violence, and men beat women who attempt to protect themselves from HIV infection. Hence many women prefer to risk unsafe sex in the face of more immediate threats to their physical well-being.

The HIV and AIDS prevalence rate is alarmingly high in South Africa, and especially in KwaZulu Natal. One of the main contributing factors, according to Whiteside and Sunter (2000), is the conspicuous gender features and their vulnerability to the disease. Morrell et al (2001) shared alarming statistics about young African girls in the 15-19 age group, in KwaZulu-Natal. 15.6% of African girls as compared to 2.5% of African boys are likely to be HIV-positive. They believe that this high rate of infection can be attributed to power inequalities. Jewkes and Abrahams (2000) and Jewkes et al (1999) say that coerced or violent sexual relationships mean that women are not able to insist on condom use, making them vulnerable to HIV infection.

Education and information about HIV and safe sexual practices will be useless, unless men and women understand the importance of gender equality in relationships. In the next part I discuss emerging insights.

6.3 PART TWO

6.3.1 Emerging Insights

The emerging insights identified are behavioural change, personal empowerment, knowing and knowledge, stigma and privileged access

6.3.1.1 Behavioural Change/Personal Empowerment

While the search continues for ‘the grand solution’ to HIV, behavioural change seems to be the only promise of success. Behavioural changes such as premarital chastity, safer sex strategies (condom use) and marital fidelity, are simple norms which, if everybody could be persuaded to heed, would stop the epidemic. However, cognisance needs to be taken of the fact that individual behaviour change is itself dependent on social factors such as gender inequalities, cultural norms and health services, which facilitate or retard behaviour change. This view is summed up thus: ‘personal empowerment is the antithesis of vulnerability’ (AIDS in the world 1992: 579). The thesis of this study from data evidence has demonstrated the varying degrees of ignorance initially experienced by the participants, and also revealed how the participants struggled to empower themselves (sometimes in secrecy), because they realized that ‘personal empowerment’ was their only hope. The participants in this study felt the need to empower themselves because they suffered through denial, labeling, stigma and discrimination, they needed knowledge about the virus in order to help themselves. All the participants in this study knew and had heard about HIV and AIDS, but knowing about HIV and AIDS does not equal knowledge about the virus. The participants in this study went out to seek this knowledge, for them at this stage knowledge was power (see appendix for their stories).

6.3.1.2 Knowing Knowledge

In practice knowing and knowledge are used synonymously, but dictionaries separate their meanings, the New Elizabethan Reference Dictionary (n.d.) (as cited in Amin 2008) describes knowing in the following terms: ‘to be acquainted with, to have personal experience of, to be on intimate terms with, to be aware of, to understand from learning or study’, in the light of these definitions, knowledge can be interpreted as precise, and knowing as tentative, also knowing as pre-knowledge and knowledge as post-knowing. In order to understand the difference between knowing and knowledge, Cunliffe (2005) defines knowledge in terms of knowing, he believes that knowledge constitutes two types, namely, ‘procedural knowledge or knowing how and declarative knowledge or knowing that’, he believes that these two forms of knowledge are often conflated and confused. Whilst Cunliffe’s interpretation connects knowledge and knowing, it blurs their differences and this challenges the separation of these concepts. Dooyeweerd (1997) on the other hand makes a distinction between these two terms; knowing, he argues is an activity of the mind, and knowledge, a commodity that is produced, exchanged, and circulated as academic currency.

According to Siemans (2006) knowing knowledge is a timely revisit of emerging perceptions and a collection of deep thoughts around a subject of importance to business, education, learning and personal development. It is a useful meta commentary on the nature of knowledge itself. Siemans argues that a learning environment is open, self managed, fostered and conducive to knowledge flow. He implies that ‘just in time’ learning is usually better than ‘just in case’ learning, and that collaboration, receptiveness, engagement, pattern recognition, direct experience and sense-making are essential or conducive to the learning process.

6.3.1.3 Privileged Access

Methodological insights arose from working with the vulnerable participants in this study. The issue of privileged access is crucial in sensitive research. Gertler (2003) explains privileged

access as a striking intuitive contrast between self knowledge on the one hand, and knowledge of other minds and of the external world, on the other. Gertler further explains that our epistemic access to the external world, for instance, is perceptual and inferential. The participants in this study discussed their discomfort when colleagues at their schools appeared to be discussing them, or isolated them at staff meetings without knowing their HIV status; their colleagues' discriminatory behaviour was based on perceptual inference. On the issue of HIV and AIDS, society's minds are prejudiced by the many negative perceptions about the virus, hence the perceptions formed when a colleague loses weight, inference is made to the "slimming disease" (HIV). Perceptions are also made about a colleague's absenteeism and isolation, with inferences made about their behaviour, and the secrecy surrounding their actions. These were experienced by all the participants in this study.

Gentler (2003) is of the opinion that we enjoy at least some kind of "privileged" access to some of our own mental states. He further adds that the problem of privileged access is twofold: there is the descriptive problem, which is the common sense view of self- knowledge which has privileged access to one's own mental states, and there is also the explanatory problem. If the intuitive differences between self- knowledge and other types of knowledge are not illusory, they cry out for explanation. Gertler adds that an explanation was needed to explain why self- knowledge is so unlike ordinary empirical knowledge, while empirical knowledge tells us about the stages of the HI virus.

Privileged access arises out of all kinds of mental states. In the example above, Annaline, the person living with HIV, had privileged access to her own "conscious" experience through self- knowledge. While common sense takes self- knowledge to be a "cognitive achievement" regarding knowledge of one's own experiences, some believe that it is not a cognitive achievement and is unlike ordinary empirical knowledge.

6.3.2 Conclusion

This chapter highlighted the significance of data and various insights that emerged from this study. Behavioural change, personal empowerment, knowing knowledge, stigma and privileged

access were conspicuous insights that emerged from the data collected and this aspect was discussed at length. Issues around individualism and universalism in the context of HIV were alluded to, including the fear and reluctance surrounding disclosure and how the participants coped. An exploration of metaphorising the illness was also presented.

While there is no medical cure available for HIV, education and support are presently the only vaccine available. Overcoming HIV and AIDS successfully is a people-centered quest, which requires human resource development and empowerment as a key element. HIV is seen as an enemy with the ability to place so many obstacles in our paths. The participants in this study spoke of their feelings of guilt, fear, hopelessness, helplessness and shame as they came to terms with their HIV diagnosis. They also spoke of their fear of rejection and isolation if they disclosed their status. They were of the opinion that there should be no difference in how cancer and HIV are viewed, because there is no cure for either, but this is not the case because HIV is commonly transmitted through sex. The HI Virus causes AIDS, and that makes it a medical condition no different from any other. HIV has been elevated to the greatest and most powerful monster, causing communities families and individuals to forsake all logic, love and compassion and replace it with stigma and discrimination.

This study captured the innermost anguish, anxieties and fears of educators living with HIV and AIDS. The educators had to make an *intrinsic* choice, to exist or to live; they chose to live, tracing their way through their darkest moments, best understood by themselves.

References

Abdool Karim Q. (2005) *HIV in South Africa*. Cape Town, Cambridge University Press.

African National Congress (ANC) (1994) *A National Health plan for South Africa*. Pretoria, available at www.anc.org.za/anxdocs/policy/health.htm

Aggleton P. & Parker R. (2002) *A conceptual framework and basis for action: HIV/AIDS stigma and discrimination*. UNAIDS: Geneva.

Aggleton P. and Homans H. (1988) *Social aspects of AIDS*. London: Falmer Press.

Aggleton P. and Warwick I. (1999) *Household and Community Responses to HIV and AIDS in Developing Countries: Findings from Multi-site Studies*: Geneva, UNAIDS.

AIDS Care (2006) Effects of HIV-related stigma among an early sample of patients receiving antiretroviral therapy in Botswana. 18(8): 931-933.

AIDS Epidemic Update (2005) Special Report on HIV Prevention. UNAIDS/WHO.

AIDS Epidemic Update (2007) UNAIDS/WHO.

AIDS Epidemic Update (2007) Uniting the world against AIDS. Accessed on 01 September 2009

AIDS in the World: A global report(1992) The Global AIDS policy coalition, edited by Mann J., Tarantola D.J.M. and Netter T.W. (eds) Cambridge, Mass: Harvard University Press.

Akeroyd A. (1997) 'Socio-cultural aspects of AIDS in Africa: occupational and gender issues'. In G. Bond, J. Kreniske, I. Susser and J. Vincent (eds.) *AIDS in Africa and the Carribbean*. Boulder, Colorado: Westview Press.

Akeroyd A V (2004) *Coercion, Constraints, and 'Cultural Entrapments'* (as cited in HIV/AIDS in Africa beyond epidemiology) Kalipen E; Craddock S; Opong J R and Ghosh J. Blackwell Publishing. USA.

Allen K. R. and Walker A. J. (1992) 'A Feminist Analysis of Interviews with Elderly Mothers and their Daughters'. 198-214. In *Qualitative Methods in Family Research*, edited by J.F.Gilgun, K. Daly and G. Handel. Newbury Park, CA: Sage Publications.

Allen S.; Lindan C.; Serufilira A.; Van de Perre P.; Chen Rundle A.; Nsengumuremyi F.; Carael M.; Schwalbe J. and Hulley S.(1993) 'HIV Infection in Childbearing Women in Kigali, Rwanda', In: Berer, M. with Ray, S. (Eds) *Women and HIV/AIDS: An International Resource Book*, London: Pandora Press.

Ankrah E. M. and Long L. D. (1996) Epilogue: What next? A policy agenda. In L. D. Long and E. M. Ankrah (Eds) *Women's experiences with HIV/AIDS: An interntional perspective* (388-397). New York; Columbia University Press.

Atkinson J. H.; Giant I.; Kennedy C.J.; Richman D.D.; Spector S. A. & McCutchan (1988). Prevalence of psychiatric disorders among men infected with HIV. *Arch Gen Psychiatry*, 45, 859-863.

Atkinson P. and Silverman D. (1997) Kundera's Immortality: The interview society and the inventions of self. *Qualitative Enquiry*, 3, 304-325.

Atkinson, R. (1998) *The Life Story Interview*. London: Sage.

Attawell K. and Elder K (2006) *Good Policy and Practice in HIV and AIDS Education Booklet One: An Overview*. UNESCO: Paris.

Australian Nursing Journal; May 2003, 10(10) 10:22.

Badcock-Walters P. & Gorgens M. (2001) *HIV/AIDS impact on education in Africa. An analysis of conferences, workshops, seminars, meetings and summits focusing on HIV/AIDS impacts on education in Africa-December 1999 to June 2001*. Durban: HEARD.

Badcock-Walters P. & Whiteside A. (2000) *HIV/AIDS and Development in the Education Sector*. Durban: HEARD.

Badcock-Walters P.; Desmond C.; Wilson D.; Heard W & Mobile Task Team (2003) *Educator mortality in-service in KwaZulu-Natal: A consolidated study of HIV/AIDS impact and trends*. Paper presented at the HEARD Demographic and Socio-Economic Conference, Durban.

Badcock-Walters P. (2001) *Where have all the flowers gone?* Provincial Education Development Unit (PEDU). Durban.

Badcock-Walters P.(2001) *HIV/AIDS as a management challenge in the education sector*. Paper presented at the training workshop of the Senior Staff of the Department of social Development, Government of South Africa at the Aloe Ridge Hotel, Johannesburg, 11-15 November.

Baggaley R. C.; Sulwe J.; Chilala M. and Mashambe C. (1999) HIV Stress in Primary School Teachers in Zambia. *Bulletin of the World Health Organisation* 77(3): 284-287.

Barnard M. (2005) 'Discomforting Research: Colliding Moralities and Looking for 'Truth' in a Study of Parental Drug Problems'. *Sociology of Health & Illness*, 27(1): 1-19.

Barnett T. and Whiteside A. (2006) *AIDS in the twenty-first century*. Palgrave Macmillan

Bartkey S.L. (1988) "Foucault, Femininity and the modernization of Patriarchal Power", in Diamond I. and Quinby L. (Eds) *Feminism and Foucault: Reflections on Resistance*.

Boston: Northeastern University Press, 61-86. Bassett M. and Mhloyi M. (1991) 'Women and AIDS in Zimbabwe: The making of an Epidemic'. *International Journal of Health Services*, 21(1): 143-156

Bartlet J.G & Finkbeiner A.K. (2006) *A Guide to living with HIV Infection*. John Hopkins University Press Baltimore London.

Baylies C. and Bujra J. (2000) *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia*. London: Taylor & Francis.

Baylies C. and Bujra J. (2001) with the Gender and AIDS Study Group, *AIDS, Sexuality and Gender in Africa: The Struggle Continues*. London: UCL Press

Becker H.S. (1970) The life history, in P. Worsley (ed.) *Modern Sociology: Introductory Readings*. Harmondsworth: Penguin.

Bennell P.; Hyde K.; and Swainson N. (2002) *The impact of the HIV/AIDS epidemic on the education sector in sub-Saharan Africa*. Brighton: Centre for International Education, University of Sussex.

Bennell P. (2003) *The impact of the AIDS epidemic on teacher mortality in sub-Saharan Africa*. Brighton: Knowledge and Skills for Development.

Benoit C.; Jansson M.; Millar A. and Phillips R. (2005) 'Community-Academic Research on Hard-to- reach Populations: Benefit and Challenges'. *Qualitative Health Research* 15(2): 263-82

Ben-Zur H. & Breznitz S. (1997) Denial, anxiety, and information processing. In M. Myslobodzky (Ed) *The Mythomaniacs*, Mahwah, NJ; LEA.

Berger J. (1972) *Ways of Seeing*. Harmondsworth, Penguin.

Berger P.L. & Luckmann T. (1966) *The social construction of reality*. New York: Doubleday.

Beyrer C. and Kass N.E. (2002) 'Human Rights, Politics and Reviews of Research Ethics'. *Lancet* 359(9328) 246-51.

Bharat S. and Aggleton P. J. (1999) 'Facing the challenge: Household responses to AIDS in India'. *AIDS Care*, 11: 33-46.

Bharat S. with Aggleton P. J. and P. Tyrer (2001) India: HIV and AIDS-related Discrimination, Stigmatisation and Denial. UNAIDS Best Practice Collection.

Bin H., Xiao-yong L. and Bo W. (2003) Epidemiological survey of depression prevalence in Jiang Xi Province, *Chin. J. Psychiatry* 36,242-245.

Blumer H. (1969) *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.

Booth C. (1999) 'Researching Health and Homelessness: Methodological Challenges for Researchers Working with a Vulnerable, Hard-to-Reach, Transient Population.' *Australian Journal of Primary Health*, 5(3):76-81.

Booyesen E. (2002a) 'Poverty and health in Southern Africa: evidence from the demographic and health survey'. *South African Journal of Economics*, 70(2).

Botswana 2003 Second generation HIV/AIDS surveillance. (2003). Gaborone, Botswana: The National AIDS Coordinating Agency.

Botswana's Strategy to Combat HIV/AIDS: Lessons for Africa and President Bush's Emergency Plan for AIDS Relief. (2004) Washington DC: The centre for Strategic and International Studies.

Bradshaw D.; Pettifor A.; MacPhail C. & Dorrington R. (2004) Trends in Youth Risk for HIV. In *South African Health Review*, 2003/2004. Durban: Health Systems Trust

Braidotti R. (1991) *Patterns of Dissonance.* Cambridge, Polity Press.

Breitbart W. (1990) Psychiatric aspects of pain in HIV disease. *Focus: A guide to AIDS research and counseling*, 5, 1-3.

Breznitz S. (1983) The seven kinds of denial. In S. Breznitz (Ed) *The denial of stress.* New York: International University Press.

Brown M. (2004) Development Update: From disaster to development? *HIV and AIDS in Southern Africa.* 5(3): 60-61.

Brown G.R.; Rundell J.R.; McMamis S.E.; Kendall S.N.; Zackay R. and Temoshok P. Prevalence of psychiatric disorders in early stages of HIV infection. *Psychosom Med*, 54, 588-601.

Brown L.; Trujillo L.; & Macintyre K. 2003. *Interventions to reduce HIV/AIDS stigma: What have we learned?* Tulane University: Horizons Programme.

- Cabe J.& SorkinB.(2002) Stigma, global health research explored. Available at [://www.nih.gov/news/nih-record/](http://www.nih.gov/news/nih-record/)
- CADRE (2005) HIV/AIDS, Stigma and Faith-Based Organisations: A Review.
- Cameron E. (2001) AIDS in Context Conference, 4-7 April, University of the Witwatersrand, Johannesburg.
- Campbell C. (2003) *Letting them Die: Why HIV/AIDS Intervention Programmes Fail*. South Africa: Double Storey Books.
- Campbell C. and Haynes G. (1998) Editorial-Special Issue: Social approaches to HIV/AIDS. *Psychology in Society*, 24: 1-3.
- Campbell R. (2002) *Emotionally Involved: The Impact of Researching Rape*. New York: Routledge.
- Campbell R. and Wasco S.M. (2000) 'Feminist Approaches to Social Sciences: Epistemological and Methodological Tenets'. *American Journal of Community Psychology*, 28(6): 773-91.
- Carswel W. (1993) HIV in South Africa. *The Lancet*, 342,17 .
- Carver C. S.; Scheier M. & Weintraub J.K. (1989) Assessing coping strategies: A theoretically based approach, *Journal of personality & Social Psychology*, 56, 267-283.
- Centers for Disease Control and Prevention (2002) Update: The AIDS epidemic in the United States, 2001, *Morbidity & Mortality Weekly Report*, 51 :592-595.
- Charmaz K. (1995) Grounded theory, in J. A. Smith, R. Harre, & L. Van Langenhove (eds) *Rethinking Methods in Psychology* London: Sage.

Charmaz K. (1995c) Grounded theory. In J.A. Smith, R. Harre, & L. Van Langenhove (Eds.), *Rethinking methods in psychology*, (27-49). London: Sage.

Charmaz K. (2000) Grounded Theory, *Objectivist and Constructivist Methods*. In Denzin, N. K. and Lincoln, Y.S. (2000). *Handbook of Qualitative Research* second edition. London: Sage Publications.

Christie G. (1991) *AIDS in South Africa*, South Africa international, July 1991, 23-27.

Clandinin D.J. and Connelly F.M. (1994) Personal Experience Methods, in N. K. Denzin and Y. S. Lincoln (eds) *Handbook of Qualitative Research*. London: Sage.

Classen M (2006) Budget Allocations for the Provincial HIV/AIDS Interventions in Education. Paper presented at the IIEP HIV/AIDS Impact on Education Workshop Paris.

Cohen D. (2002) *Human capital and the epidemic in sub-Saharan Africa*. Working Paper 2. Geneva: International Labour Organisation.

Cohen D. (2002) HIV and education in sub-Saharan Africa: responding to the impact. *Perspectives in Education*, 20(2):13-22.

Cohen L.; Manion L. and Morrison K. (2007) *Research Methods in Education*, 4th edition. London: Routledge.

Cohen S. & Herbert T.B. (1996) 'Psychological factors and physical disease from the perspective of human psychoneuroimmunology.' *Annual Review of Psychology*, 47, 113-142.

Cohler B. (1988) The human studies and life history. *Social Service Review*, 62(4), 552-575.

Conrad P. (1990) Qualitative research on chronic illness: A commentary on method and conceptual development. *Social Science and Medicine*, 30, 1257-1263.

Coombe C. (2000) Managing the impact of HIV/AIDS on the Education Sector. [://hivaidsclearinghouse.unesco.org](http://hivaidsclearinghouse.unesco.org).

Coombe C. (2002) Editorial, in *Perspectives in Education*, 20 (2) July 2002.

Coombe C. and Kelly M.J. (2001) Education as a vehicle for combating HIV/AIDS. *Prospects*, XXX1(3), September.

Cullinan K (2003) Centre for the study of AIDS. [.csa.za.org/article/articleview/185/1/](http://csa.za.org/article/articleview/185/1/)
Accessed 01/06/2006

Crewe M.(1992) *AIDS in South Africa: The myth and the reality*. London: Penguin.

Crewe M. (1993) 'Learning AIDS', *Work in Progress* (December):25-28

Daniel L. (1998) *Life beyond teenage motherhood*. MA dissertation, Institute of Development Studies. University of Sussex

Dawson L.J.; Chunis M.L.; Smith D.M.and Carboni A.A. (2001) The role of academic discipline and gender in high school teachers' AIDS-related knowledge and attitudes. *Journal of School Health*, 71(1): 3-8.

De Laine M. (2000) *Fieldwork, Participation and Practice: Ethics and Dilemmas in Qualitative Research*. London: Sage Publications.

Denzin N.K.and Lincoln Y.S. (2000) *Handbook of Qualitative Research*, 2nd edition. London: Sage.

Denzin N .K. (1989) *Interpretive biography*. Newbury Park, LA Sage.

Denzin N.K. (1970) *The Research Act in Sociology*. London: Butterworth.

Department of Health and Health Systems Trust. (2002) Report from the National Scientific Consultative forum on HIV/AIDS, Getting Scientific Knowledge into Policy, Turning Knowledge Gaps into Research, August13-14.

Department of Health (2003) National HIV and Syphilis Antenatal Seroprevalence Survey in South Africa 2003. Pretoria.

Department of Health (2004) National antiretroviral treatment guidelines. South Africa: DoH.

Desmond C K, Michael and Gow J (2000) 'The hidden battle: HIV/AIDS in the household and community.' *South African Journal of International Affairs*, 7(2).

DeVault M.L. (1999) *Liberating Methods: Feminism and Social Research*. Philadelphia, PA: Temple University Press.

Development Update (2004) From disaster to development? 5 (3).

Dialectical Anthropology, July 2004, 28 (3/4): 329:337.

Dickson-Swift V. (2005) *Undertaking Sensitive Health Research: The Experiences of Researchers*. Unpublished doctoral thesis, Department of Public Health, School of Health and Environment, La Trobe University, Bendigo, Australia.

Diener E. and Crandall R. (1978) *Ethics in Social and Behavioural Research*. Chicago: University of Chicago Press.

Dorrington R.; Bourne D.; Bradshaw D. et al (2001) *Technical report on the impact of HIV/AIDS on adult mortality in South Africa*, 2, 1-4.

Douglas J.D. (1985) *Creative interviewing*, Beverly Hills CA: Sage.

Doyal L. (1994) *Putting women on the global agenda*. In L. Doyal; J. Naidoo; and T. Wilton. (Eds) *AIDS: Setting a feminist agenda* (11-28). London: Taylor and Francis.

Eaton L.; Flisher A.J.; Aaro L.E. (2003) 'Unsafe sexual behaviour in South African youth' *Social Science and Medicine*, 56: 149-165.

Economist (2004) 371, (8376) 68-71.

Education Labour Relations Council (ELRC). Report (2005). *The Health of our Educators*. Cape Town: HSRC Press..

Emanuel E.J.; Wendler D. and Grady C. (2000) 'What Makes Clinical Research Ethical?' *Journal of the American Medical Association*, 283(20): 2701-11.

Emlet C.A. (2004) Knowledge and use of AIDS and aging services by older, HIV Infected adults. *Journal of HIV/AIDS and social service*,3 (1), 9-24.

Emlet C.A. (2006)..A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS. *AIDS Patient Care and STDs*, 20, 350-358.

Evans G. E. (1993) *The Crooked Scythe*. London: Faber and Faber.

Evans M. (1993) Reading lives: How the personal might be social. *Sociology*, 27 (1):5-13.

Everatt D. & Milner S. (eds) (1994) *Creating a future: Young policy for South Africa*. Johannesburg: Raven Press.

Evian C. (2003) Paper presented to the "Demography and Socioeconomic" conference, Durban. und.ac.za/und/heard/papers/

Fischer-Rosenthal W. and Rosenthal G.(1997) Daniel Bertaux's complaints or against false dichotomies in biographical research, in *Biography and Society Newsletter*, 5-11, ISA Research Committee, 38: 5-11.

Flemming A.F. (1992) South Africa and AIDS - seven years wasted, *Current AIDS Literature*, 5(11), 425-428.

Flemming A. (1993) Lessons from tropical Africa for addressing the HIV/AIDS epidemic in South Africa, in Cross S. and Whiteside A. (eds) 295-317.

Fonow M.M. and Cook J.A. (1991) 'Back to the Future: A Look at the Second Wave of Feminist epistemology.

Foster S. (1996) 'The Socioeconomic Impact of HIV/AIDS in Monze District, Zambia'. Unpublished PhD thesis, Department of Public Health and Policy. London School of Hygiene and Tropical Medicine, October.

Foucault M. (1988) Politics, Philosophy, Culture: *Interviews and Other Writings* (Ed. L.D. Kritzman), London, Routledge.

Francis D. (2004) HIVism: A pervasive system of oppression. *Journal of Social Work*, 40(1), 61-71.

Frankfort - Nachmias C. and Nachmias D (1992). *Research Methods in the Social Sciences* London: Edward Arnold.

Frasca T. (2003) Men and Women-Still Far Apart on HIV/AIDS. *In Reproductive Health Matters*, 11(22): 12-20

Frutchey C. (1990) "The role of Community-Based Organisations in AIDS and STD Prevention". In Paalman, Maria (Ed) *Promoting Safer Sex*. Amsterdam, Swets and Zeitlinger.

Gatens M. (1988) 'Towards a Feminist Philosophy of the Body', in Caine B; Grosz E.A. and Lepervanche M. DE, (Eds) *Crossing Boundaries: Feminisms and the Critique of Knowledge*, Sydney, Allen and Unwin.

Gentler B.(2003) *Privileged Access: Philosophical Accounts of Self Knowledge*. Aldershot: Ashgate Publishing.

Gerth H.H. & Mills C.W. (1953) *Character and the social structure*. New York: Harcourt, Brace.

Giele J.Z. and Elder G. H. (1998a) Life Course Research: development of a field, in J. Z. Giele and G. H. Elder Jr. (eds) *Methods of Life Course Research: Qualitative and Quantitative Approaches*. London: Sage.

Gielen A.C.; McDonnell K.A.; Wu A.W.; O'Campo P. & Faden R. (2001) Quality of life among women living with HIV: The importance violence social support, and self-care behaviours. *Social Science and Medicine*, 52, 315-322.

Gilborn L. et al (2001) *Making a Difference for Children Affected by AIDS: Baseline Findings from Operations research in Uganda*. Washington, DC: Population Council.

Gilmore N. & Somerville M.A. (1994) Stigmatisation, scapegoating and discrimination in sexually transmitted diseases: Overcoming "them" and "us". *Social Science and Medicine*, 39(9),1339-1358.

Glaser B.G.; & Strauss A.L. (1967) *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

- Glaser B.G. (1978) *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser B.G. (1992) *Basics of grounded theory analysis: Emergence vs forcing*. Mill Valley, CA: Sociology Press.
- Glaser B.G. (1996) Grounded Theory: an interview with A. Lowe, *Programme 8 of Doing a PhD in Business and Management*. Glasgow: University of Sterling and Heriot-Watt University.
- Gluck S.B. and Patai D. (1991a) Introduction in S. B. Gluck and Patai (eds) *Women's Words: The Feminist Practise of Oral History*. London: Routledge.
- Goffman E.G. (1963) *Stigma: Notes on the management of spoilt identity*. New York: Simon & Schuster.
- Goffman E. (1971) *Relations in public*. New York: Basic Books.
- Golby J. (1994) Autobiographies, letters and diaries, in M. Drake and R. Finnegan (eds) *Sources and Methods for Family and Community Historians: A Handbook*. Cambridge: Cambridge University Press.
- Goldstein R. (1989) AIDS and the Social Contract, in Carter and Watney, 81-94.
- Goodson I. (1983) The use of Life Histories in the Study of Teaching. In M. Hammersley (ed) *The Ethnography of Schooling*, Driffield, UK: Nafferton, 129-54.
- Gordon R. (1993) *Causes of girls' underachievement: The influence of teachers' attitudes and expectations on the academic performance of secondary school girls*. Harare; HRRC, University of Zimbabwe.

Gordon, S. L. (1981). The sociology of sentiments and emotions. In M. Rosenberg & R.H. Turner (Eds.), *Social psychology: Sociological perspectives*. New York: Basic Books.

Gostin L.O. and Lazzarini Z. (1997) *Human Rights and Public Health in the AIDS Pandemic*. New York: Oxford University Press.

Goulding C. (2002) *Grounded theory: A Practical Guide for Management, Business and Market Researchers*. London: Sage Publications.

Government Communication and Information Service (GCIS). (2003) *Towards a Ten Year Review*. Pretoria.

Gramsci A. (1970) *Prison Notebooks*. London: Lawrence and Wishart.

Grant M; Hallam K (2006) Study Pregnancy-related school dropout and prior school performance in South Africa. Available on [.popcouncil](#). Accessed on 20/06/2009

Gregory M.D. and Smeltzer M.A.(1983) *Psychiatry: essentials of clinical practice*, Boston MA: Little Brown.

Guba E. G.; and Lincoln Y.S. (1994) Competing paradigms in qualitative research. In N. K. Denzin & Y.S. Lincoln (Eds.). *Handbook of qualitative research*, (105-117). Thousand Oaks, CA: Sage.

Gubrium J. F.; and Holstein J.A. (1997) *The new language of qualitative method*. New York: Oxford University Press.

Hachonda H. and Adudah R. (2004) *Development Update: From disaster to development? HIV and AIDS in Southern Africa*. 5(3): 110-112.

Hallam S. (1994) *Crimes without punishment: Sexual harassment and violence against female students in schools and universities in Africa*. Discussion Paper 4, London: Africa Rights.

Hallowell N.; Lawton J. and Gregory S. (2005) *Reflections on Research: The Realities of Doing Research in the Social Sciences*. Berkshire: Open University Press.

Hammersley M. (1990) *The Dilemma of Qualitative Method*. London: Routledge.

Harber R. (2002) We need to structure our environment to combat AIDS. *The Mail and Guardian*, May 17, 2002.

Hatch J.A. and Wisniewski R. (1995) *Life history narrative: Questions, issues, and exemplary works*. In J.A. Hatch and R. Wisniewski (Eds) *Life history and the narrative* (pp.1 13-136). Philadelphia: Taylor and Francis.

Hays B.R.; McKusick L.; Pollack L.; Hilliard R.; Hoff C. & Coates T.J. (1993) Disclosing HIV seropositivity to significant others. *AIDS* 7, 425-431.

HEARD (2003) Educator mortality in-service in Kwa Zulu Natal: A consolidated study of HIV/AIDS impact and trends. *Paper presented at the Demographic and socio-economic conference, Durban*.

Heise L.L. and Elias C. (1995) Transforming AIDS prevention to meet women's needs: A focus on developing countries. *Social Science and Medicine*, 40(7): 931-943.

Herbert T.B. and Cohen S. (1993) 'Depression and immunity: a meta-analytic review', *Psychological Bulletin*, 113, 472-486.

Herek G. & Glunt E.K. (1988) 'An epidemic of stigma: Public reactions to AIDS'. *American Psychologist*, 43(11), 886-891.

Herek G. (1999) AIDS and Stigma, *American Behavioral Scientist*, 42 , 1106-1116.

Herek G. M; Capitanio J. P. and Widaman K. F. (2002) HIV-related stigma and knowledge in the United States: Prevalence and Trends, 1991-1999. *American Journal of Public Health*.92, 371-7.

Herek G. M. (2002) Thinking about AIDS and Stigma: A Psychologist's Perspective. *The Journal of Law, Medicine and Ethics* 30: 594-607.

HIV & AIDS Statistics for South Africa (2008). Available on [://www.avert.org/saficastats](http://www.avert.org/saficastats). Accessed on 2008/05/06

Hess R.F. (2006) 'Post-abortion Research: Methodological and Ethical Issues'. *Qualitative Health Research*, 16(4): 580-87.

Hesse-Biber S.N. and Leavy L.P. (2005). *The Practice of Qualitative Research*. Thousand Oaks, CA: Sage Publications.

Hesse-Biber S.N., Leavy P.; and Yaiser M.L. (2004) 'Feminist Approaches to Research as a Process Reconceptualising Epistemology, Methodology, and Method'. 3-26. In *Feminist Perspectives on Social Research*, edited CCby S.N. Hesse-Biber and M.L. Yaiser. New York: Oxford University Press.

Hesse-Biber S.N. and Leckenby D. (2004) 'How Feminists Practise Social Research'. 209-26. In *Feminist Perspectives on Social Research*, edited by S.N. Hesse-Biber and M.L. Yaiser. New York: Oxford University Press.

Heywood M. (2004) Development Update: *From disaster to development?* 5(3), 104-109.

Hislop G.T.; Waxler N. E.; Coldman A. S.; Elwood J. M. and Kan L. (1987) 'The prognostic significance of psychological factors in women with breast cancer', *Journal of Chronic Diseases*, 40,729-35.

Holland J.; Ramazanoglu C.; Scott S.; Sharpe S.; and Thompson R. (1990) 'Don't Die of Ignorance-I Nearly Died of Embarrassment', 'Condoms in Context', WRAP Paper 2, London, Routledge.

Holland J.; Ramazanoglu C.; Scott S. and Thompson R. (1994) cited in, *AIDS: Setting a Feminists Agenda*, edited by Doyal L; Naidoo J and Wilton T. Taylor & Francis. London.

Hollway W. and Jefferson T. (2000) *Doing Qualitative Research Differently*. London: Sage.

Holmshaw A. (1992). When will they ever learn? *Current AIDS Literature*, 5(5), 145-150.

Hoosen S. and Collins A. (2004) Sex, sexuality and sickness: Discourses of gender and HIV/AIDS among KwaZulu-Natal women. *South African Journal of Psychology*, 34(3): 487-505.

Horizons (2002) *HIV/AIDS-related Stigma and Discrimination: a conceptual framework and an Agenda for Action*. The Population Council Inc.

House, J. S. (1981), Social structure and personality. In M.Rosenberg & R.H. Turner (Eds.), *Social psychology: Sociological perspectives*. New York: Basic Books.

HSRC Survey (2008) South African National HIV Prevalence, Incidence, Behaviour and Communication Survey. Available on hsrcpress.ac. Accessed on 30 June 2009.

Human Rights (2001) *Journal of the Section of Individual Rights & Responsibilities*

Human Rights Watch (2001) *Scared at school: Sexual violence against girls in South African schools*. New York: Human Rights Watch.

Human Rights Watch (2005). *Clear the filth: Mass evictions and demolitions in Zimbabwe*. Briefing paper. September. Human Rights Watch. New York. Available at [://www.hrw.org/backgrounder/africa/zimbabwe0905/](http://www.hrw.org/backgrounder/africa/zimbabwe0905/)

Hunter S. (2003) *Black death: AIDS in Africa*. London: Palgrave Macmillan.
International Centre for Educational Planning.

International Labour Organisation (ILO) (2004) *HIV/AIDS and work: Global estimates, impact and response*. Geneva: ILO.

Intersearch- strategic management intelligence available on [.intersearch.co](http://intersearch.co). Accessed on 2009/06/05

Irwan A.; Millen J. & Fallows D. 2003 *Global AIDS: Myths and facts*. Cambridge: South End Press.

Jeffreys S. (1990) *Anticlimax: A Feminist Perspective on the Sexual Revolution*. London. The Women's Press.

Jewkes R.; Penn-Kekana L.; Levin J.; Ratsaka M. & Schreiber M. (1999). *He must give me money, he mustn't beat me*. Violence against women in three South African provinces. Report prepared for CERSA, Medical Research Council, Pretoria.

Jewkes R. & Abrahams N. (2000) *Violence against women in South Africa: Rape and sexual coercion*. Pretoria: MRC.

Jewkes R. (2006) Beyond stigma: social responses to HIV in South Africa. *Lancet*, 368 (9534), 430-431.

Johnson J.M. (2002) 'In-Depth Interviewing' 103-119. In *Handbook of Interview Research: Content & Method*, edited by J.F. Gubrium and J.A. Holstein. Thousand Oaks, CA: Sage Publications.

Johnson S. (2000) The impact of AIDS on the education sector in South Africa. Presentation at the IIEP Meeting on the impact of HIV/AIDS on education. Paris, September 2000.

Jones C. & Tannock J. (2000) "A Matter of Life and Death: A Reflective Account of Two Examples of Practitioner Research into Children's Understanding and Experience of Death and Bereavement". 86-97. In *Researching children's Perspectives*, Lewis A. and Lindsay G. Buckingham: Open University Press.

Kalichman S. (2004) AIDS: *stigma as a barrier to HIV prevention, diagnosis and care*. Paper presented at African Conference on Social Aspects of HIV/AIDS Research Alliance, 9-14 May, Cape Town.

Kaplan M.; Marks G. and Merten S. (1997) Distress and coping among women with HIV infection: Preliminary findings from a multi-ethnic sample. *American Journal of Orthopsychiatry*, 67, 90-91.

Kegeles S.M. et al (1989) 'Perceptions of AIDS, the continuing saga of AIDS-related stigma,' *AIDS* 3, (suppl.1): S253-S258.

Kelly M.J. (1999) *What HIV/AIDS can do to education and what education can do to HIV/AIDS*: Paper presented to the All-African Conference on Education for all by the year 2000, held at Johannesburg, South Africa.

- Kelly M.J. (2000) '*Planning for Education in the Context of HIV/AIDS,*' UNESCO International Institute of Educational Planning, Paris.
- Kelly M.J. (2002), in *Perspectives in Education*, 20 (2) July 2002.
- Kelly K. and Ntlabati P. (2002) 'Early adolescent sex in South Africa; HIV intervention challenges'. *Social Dynamics*, 28(1): 42-63.
- Kemper T.D. (1981) Social constructionist and positivist approaches to the sociology of emotions. *American Journal of Sociology*, 87, 337-362.
- Kerlinger F.N. (1990) *Foundations of Behavioural Research*. New York: Holt, Rinehart and Winston.
- Kerrihard T.; Breibart W.; Dent R. & Strout P. (1999) Anxiety in patients with cancer and human immunodeficiency virus. *Seminars in Clinical Neuropsychiatry*, 4, 114-132.
- Kimani L. (2002 June 12) *How traditions abet humiliation of young girls. East Africa Standard*, 4-5.
- Kincaid DL, Parker W, Schierhout G, Connolly C & Pham VHT (2008) AIDS communication programmes, HIV prevention and living with HIV and AIDS in South Africa, 2006. Pretoria: JHHESA.
- Kirk J. and Millar M. L. (1986) *Reliability and Validity in Qualitative Research*. London Sage.
- Kisekka M.N. (1990) 'AIDS in Uganda as a Gender Issue' In Rothblum, E. and Cole,
- Kitzinger J. (1994) cited in *AIDS: Setting a Feminist Agenda* edited by L. Doyal, J. Naidoo and T. Wilton. London: Burgess Science Press.

Kong T.K.; Mahoney D. and Plummer K. (2002) 'Queering the Interview'. 239-58. In *Handbook of Interview Research: Context and Method*, edited by J.F. Gubrium and J.A. Holstein. Thousand Oaks, CA: Sage Publications.

Kramer L. (1990) *Reports from the Holocaust:: The making of an AIDS activist*. London: Penguin.

Kubler-Ross E.C. (1969) *On death and dying*. (cited in van Dyk A. 2008 edition South Africa: Pearson Education).

Lachenicht L.G. (1993) A skeptical argument concerning the value of a behavioural solution for AIDS. *South African Journal of Psychology*, 23(1): 15-20.

LaFraniere S. (2004) Mandatory Tests Bolster Botswana's War on AIDS. *The New York Times*, 8.

Larson A. (1990) 'The Social Epidemiology of Africa's AIDS epidemic'. *African Affairs* 89(354), 5-26.

Lawrence J. (2002) cited in, *Perspectives in Education*. 20(2): 52-53.

Lazarus R. S. (1983) *The costs and benefits of denial*. In S. Breznitz (Ed) *The Denial of Stress*. New York: International Universities Press.

Lazarus R.S. & Folkman S. (1984). *Stress, Appraisal, and Coping*. Springer Publishing Company: New York.

Leclerc-Madlala S. (1997) Infect one, infect all. Zulu youth response to the AIDS epidemic in South Africa. *Medical Anthropology*, 17(4), 363-380.

Leclerc-Madlala S. (2002) Youth, HIV/AIDS, youth and the importance of sexual

culture and context. *Social Dynamics*, 28 (1), 20-41.

Leclerc-Madlala S. (2003) Protecting girlhood? Virginitv revivals in the era of AIDS. In *Agenda* 56.

Leach F. & Machakanja P. (2000) *A preliminary investigation in to the abuse of girls in Zimbabwean junior secondary schools*. DFID Education Research No. 39 London: DFID.

Lee R.M. (1993) *Doing Research on Sensitive Topics*. London: Sage Publications.

Lee, and colleagues (2002) Internalised stigma among people living with HIV/AIDS. *AIDS and Behaviour*, 6, 309-319.

Lee-Treweek G. and Linkogle S. (2000b) 'Putting Danger in the Frame'. 8-25. In *Danger in the Field: Risk and Ethics in Social Research*, edited by G. Lee-Treweek and S. Linkogle. London:Routledge.

Leserman J. (2001) Anger in HIV Infection. US Centres for Disease Control & Prevention. Available on [.thebody.com/content/art](http://thebody.com/content/art). Accessed on 01/07/2009

Liamputtong P. (2007). *Researching the Vulnerable: A Guide to Sensitive Research Methods*. London: Sage Publications.

Liamputtong P. and Ezzy D. (2005) *Qualitative Research Methods*, edition. Melbourne: Oxford University Press.

Lichtenstein P. & associates (2002) Chronic sorrow in the HIV-positive patient: Issues of race, gender and social support. *AIDS Patient Care and STDs*, 16, 27-38

Lie G. & Biswalo P.(1994) Perceptions of the appropriate HIV/AIDS counselor in Arusha and Kilimanjaro regions of Tanzania: Implications for hospital counseling. *AIDS Care*, 6(2), 139-151.

Link B.G. and Phelan J.C. (2001) Conceptualising Stigma *Annual Review of Sociology*, 27, 363-385.

Link B. & Phelan J. (2002) On stigma and its public health implications.[http://www.stigma.conference.nih.govt/Link paper htm](http://www.stigma.conference.nih.govt/Link%20paper.htm)

London A. S. and Robles A. (2000) The co-occurrence of correct and incorrect HIV transmission knowledge and perceived risk for HIV among women of childbearing age in EL Salvador. *Social Science and Medicine*, 51, 1267-78.

Lonnqvist J. (2001) Physical illness and suicide. In D Wasserman (Ed) *Suicide - an unnecessary death*, 93-98. London: Mortin Dunitz.

MacPhail C. (1998) Adolescents and HIV in developing countries; New research directions. *Psychology in Society*, 24, 69-87.

Mail and Guardian, April 8-15 2004.

Malaney P.(2000) The Impact of HIV/AIDS on the Education Sector in Southern Africa CAER11, Harvard Institute for International Development, Cambridge USA.

Malloch Brown M. (2004) *Building Capacity, Restoring Hope: The Southern African Capacity Initiative*. Gabarine, Botswana.

Malcolm A.et al (1998) 'HIV and AIDS-related stigmatization and discrimination: its form and contexts,' *Critical Public Health*, 8 (4): 347-370.

Maman S; Campbell J; Sweat M D and Gielden A C (2000) The Intersections of HIV and Violence: Directions for Future Research and interventions. *Social Science & Medicine* 50: 459-478.

Manning P.K. and Cullam-Swan B. (1994) Narrative, content, and semiotic analysis, in N.K. Denzin and Y,S Lincoln (eds) *Handbook of Qualitative Research*, edition. London: Sage.

Mandela N. (1994) First State of the Nation Address to Parliament, <http://.org.za/ancdocs/history/mandela/1994/>, html.

Mann J. (1987) Statement at an informal briefing on AIDS TO THE session of the United Nations General Assembly, 20 October, New York.

Mannah S. (2001) *South African Democratic Teachers Union (Sadtu)*. South Africa : Sadtu.

Mansergh G.; Marks G. & Simoni (1995) Self-disclosure of HIV infection among men who vary in time since seropositive diagnosis and symptomatic status. *AIDS*, 9. 639-644.

Manuel C. et al (1990) 'The ethical approach to AIDS, a bibliographical review,' *Journal of Medical Ethics*, 16: 14-27.

Marcus T. (1999) *Wo! Zaphela tzingane-it is destroying the children-living and dying with AIDS*. Pietermaritzburg: CINDI.

Marshall G. (1998) *Oxford Dictionary of Sociology*. Oxford and New: Oxford University Press.

Mason H.R.C.; Marks G.; Simoni J.M.; Ruiz M.S. & Richardson J.L. (1995) Culturally sanctioned secrets? Latino men's non-disclosure of HIV infection to family, friends and lovers. *Health Psychology*, 14, 6-12.

McFadden P. (2004) 'HIV and AIDS: behind the iconic re-presentations of gender, race and class in Southern Africa', paper presented at the conference '*learning from our lives: women, girls and HIV/AIDS in Africa and the African diaspora*', Spelman College and Sister Love inc. 10-12 June.

McFall RM (1982) A review and reformulation of the concept of social skills. *Behavioural Assessment*, 4, 1-33

Mechanic D. (1974) Social structure and personal adaptation: Some neglected dimensions. In G. V. Coelho, D.A. Hamburg, & J. E. Adams (Eds) *Coping and adaptation*, New York: Basic Books.

Melrose M. (2002) "Labour Pains: Some Considerations on the difficulties of researching Juvenile Prostitution". *International Journal of Social Research Methodology*, 5(4): 333-51.

Mendelsohn, G. A. (1979) The psychological consequences of cancer: A study of adaptation to somatic illness. *Cahiers d' Anthropologie*, 2, 53-92.

Mhloyi M M (1995) Racing against Time. In *HIV & AIDS: The Global Interconnection*. Elizabeth Reid, ed. Pp. 13-25. West Hartford, CT: Kumarian Press.

Miller R.L. (1999) *Researching Life Stories and Family Histories*, London: Sage.

Miller R. L. (2000) *Researching Life Stories and Family Histories*. London; Sage.

- Millar C.T. & Kaiser C.R. (2001) A theoretical perspective on coping with stigma, *Journal of Social Issues*, 57(1):73-92.
- Mirembe R. & Davies L. (2001) Is schooling a risk? Gender, power relations and school culture in Uganda? *Gender and Education*, 13(4): 401-416.
- Mobile Task Team Demographic and Socio-Economic Conference, (2003).
- Mobile Task Team (2005) Educator Attrition and Mortality in South Africa for the Education Labour Relations Council: HEARD University of KwaZulu Natal, Durban.
- Morrell R. (2000) Considering the case for single sex schools for girls in South Africa. *McGill Journal of Education*. 35(3): 221-244.
- Morrell R.; Unterhalter E.; Moletsane L. & Epstein D. (2001). HIV/AIDS: Politics, schools and gender identities. *Indicator South Africa*, 18(2): 51-57.
- Morrell R (2009) The Witness 08/06/2009 available on [.witness.co](http://www.witness.co) accessed on 2009/06/08
- Motsemme N. (2007) 'Loving in a time of hopelessness': on township women's subjectivities in a time of HIV/AIDS. *African Identities*; 5(1), 61-87.
- Murray L.A. (2007) New HIV/AIDS study seeks to include African-American women. *New York Amsterdam News*, 98(9) 37-37.
- National AIDS Control Council (NACC) (2000) Empowering women in prevention skills. *Daily Nation*, 33.
- National AIDS Control Organisation (NACO) (2008) Available on [http:// www avert.org/indiaaids.htm](http://www.avert.org/indiaaids.htm) Accessed on 30 August 2009.

Nelson Mandela/HSRC Study of HIV/AIDS (2002) *South African national HIV prevalence, behavioural risks and mass media household survey 2002*. Cape Town: HSRC Publishers.

Nyblade L. & Field M.C. (2000) *Women communities and the prevention of mother-to-child transmission of HIV*. Issues and findings from community research in Botswana and Zambia. Washington, D.C.

Ogeden J. & Nyblade L. (2005) *Common at its core: HIV-related stigma*. Washington DC: International Centre for Research on Women

O'Grady M. (2004) *Development Update: From disaster to development? HIV and AIDS in Southern Africa*. 5(3): 95-96.

O'Sullivan S. (2000) Uniting across boundaries-HIV positive women in global perspective in *Agenda*, No.44.

Okongo P. (2001) AIDS in an endangered continent. *The Financial Standard*, 12.

Olesen V.L. (2000) Feminism and Qualitative research at and into the millennium, in N. K. Denzin and Y. S. Lincoln (eds) *Handbook of Qualitative Research*, edition London: Sage.

Omale J. (2000) Tested to their limit: Sexual harassment in schools and educational institutions in Kenya. In *No paradise yet: The world's women face the New Century*, Mirsky J. & Radlett M. (eds). London: Zed Press.

Omwega A. (2001) *The reality of HIV/AIDS in Africa: The case of East Africa*. Paper presented at the National Headquarters of the Luthern World Relief Annual Meeting. Baltimore, Maryland.

O'Neill M. (1996) 'Researching Prostitution and Violence: Towards a Feminist Praxis'. 130-47. In *Women, Violence and Male Power: Feminist Activism, Research and Practice*, edited by M. Hester, L. Kelly and J. Radford, Buckingham: Open University Press.

Otieno T. (2007) *The Dilemma of Kenyan Women: Questioning Tradition in the Battle against HIV/AIDS*. Jackson State University Researcher; Summer 2007, 21(2): 8-16.

Panis D.; Du Mont J. and Gombay B. (2005) 'Cooperation-Assessing the Methodological Benefits and Barriers Involved in Conducting Qualitative Research through Medical Institutional Settings'. *Qualitative Health Research*, 15(5): 686-97.

PANOS (1990). *The Epidemic: Repercussions of the Fear of AIDS*. London: Panos Institute.

Parker R. G., Easton D. and Klein C. (2000) 'Structural barriers and facilitators in HIV prevention: a review of international research,' *AIDS* 14(Suppl. 1): S22-S32.

Parker R. & Aggleton P.(2003) HIV and AIDS related stigma and discrimination: a conceptual framework and implications for action, *Social Science & Medicine*, 57, 13-24.

Patient D. & Orr N. (2004). *The Healer inside you*. Cape Town: Double Story.

Patton C. (1994) *Last served? Gendering the HIV pandemic*. London: Taylor and Francis.

Patton C. (1990b) "Safer Sex as Resistance to Societal Control and Moralism" paper presented at the First Nordic Conference on Safer Sex, Stockholm, March.

Peltzer K. (2000) Knowledge and attitudes about HIV/AIDS of a sample of school teachers in South Africa. *Psychological Reports*, 87, 1065-1066.

Peltzer K. & Promtussananon S. (2003) HIV/AIDS education in South Africa: teacher knowledge about HIV/AIDS: Teacher attitude about and control of HIV/AIDS education, *Social behaviour & Personality: An International Journal*, 31(4): 349-356.

Peltzer K. et al (2005) Educator supply and demand in South African public education system-integrated report. Johannesburg, Human Sciences Research Council. Available on <http://www.hsresearch.ac.za>.

Perakyla A. (1997) Reliability and validity in research based on transcripts, in D Silverman (ed) *Qualitative Research: Theory Method and Practice*. London: Sage.

Perkins D.D.; Stein R.A.; Golden R.N.; Murphy C.; Naftolowitz D. & Evans D.L. (1994) Mood disorders in HIV infection. Prevalence and risk factors in a non epicenter of the AIDS epidemic. *American Journal Psychiatry*, 151, 233-236.

Pettifor A E.;Rees H. V.; Steffenson A.; Hlongwa-Madikizela L.; MacPhail C.; Vermaak K. & Kleinschmidt I. (2004) *HIV and sexual behaviour among young South Africans:a national survey of 15-24 year olds*. Johannesburg: Reproductive Health Research Unit, University of the Witwatersrand.

Petros G; Airhihenbuwa CO; Simbayi L; Ramlagan S & Brown B (2006) hiv/aids AND 'Othering' in S. Africa: The blame goes on. *Culture, Health & Sexuality* 2006 Jan-Feb; 8(1) 67-77.

Piot P (1999) HIV/AIDS and Violence against Women. Presentation to the United Nations Commission on the Status of Women, Forty-Third Session: Panel on Women and Health, March 3, 1999. Electronic Document.

[://www.unaids.org/unaid/speeches/](http://www.unaids.org/unaid/speeches/) .

Piot P. (2000) Report by the executive director. Programme Co-ordinating board. Joint United Nations Programme on AIDS. Rio de Janeiro. 14-15 December.

Plummer K. (1975) *Sexual stigma: An Interactionist Approach*. London: Routledge and Kegan Paul.

Plummer K.(1995a) Life Story Research, in J. A. Smith, R. Harre and L. Van Langenhove (eds) *Rethinking Methods in Psychology*, London: Sage.

Plummer K. (1983) *Documents of Life*. London: George Allen and Unwin.

Poulsen-Dobbys M. (2003) Medecins Sans Frontiers. *Australian Nursing Journal*: May 2003.

Putnam H. (1978) *Meaning and the Moral Sciences*. London; Routledge and Kegan Paul.

Rao Gupta G. (2001) “*International Perspectives On Stigma*” presented at the conference Health, Law and Human rights: Exploring the Connections, American society of law and Temple University Beasley School of Law, Philadelphia, September 30.

Reid E. (1992) ‘Gender, Knowledge and Responsibility’, In Mann J., Tarantola D. and Netter T. (1992) *AIDS in the World: A Global Report*, Harvard University Press.

Reinharz, S. (1992) *Feminist Methods in Social Research*. Oxford; Oxford University Press.

Renzetti C.M. & Lee R.M. (1993) *Researching Sensitive topics*. Newbury Park, CA: Sage Publications.

Reverend C.Y. Wiley (2003) *The Body , Religion and AIDS*: [.thebody.com/religion](http://thebody.com/religion).

Richardson D. (1990) *Safer Sex: The Guide for Women Today*. London Pandora Press.

Richardson D. (1994) Issues for feminism in the UK. In L. Doyal, J. Naidoo and T. Wilson. (Eds) *AIDS: Setting a feminist agenda* (42-57), London: Taylor and Francis.

Richardson L. (1994) Writing: A method of inquiry. In N.K. Denzin & Y.S. Lincoln (Eds.) *Handbook of qualitative research* (516-529). Thousand Oaks, CA: Sage.

Richardson L. (1995) Narrative and sociology, in J. Van Maanen (ed) *Representation in Ethnography*. London: Sage.

Ricoeur P. (1978) The metaphorical process as cognition, imagination, and feeling. *Critical Inquiry* (Special Issue on Metaphor) 5, 143-159.

Riessman C. K. (1990a) *Divorce talk: Women and men make sense of personal relationships*. New Brunswick, NJ; Rutgers University Press.

Riessman C. K. (1990b) Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science and Medicine*, 30, 1195-1189

Sabatier R. (1988) *Blaming Others*. London: The Panos Institute.

SADC HIV/AIDS Framework and Programme of Action, 2003-2007: Managing the HIV and AIDS Pandemic in Southern African Development Community.

Sadtu (2003) HIV/AIDS and Public Education in South Africa. Focal points for a research agenda. Discussion Paper. South Africa: Sadtu.

SAFAIDS-Southern Africa HIV and AIDS Information Dissemination Service: Southern Africa: Politicians Fail to Address HIV. Available on [.safaid9](http://safaid9.org).

Accessed on 2009/06/08

Sawicki J. (1991) *Disciplining Foucault: Feminism, Power and the Body*. London. Routledge.

Schatzman L. (1991) Dimensional analysis: Notes on an alternative approach to the grounding of theory in qualitative research. In D. R. Maines (Ed) *Social organisation and social processes: Essays in honor of Anselm Strauss* (303-314). New York: Aldine de Gruyter.

Schiff M; McKay M; Bell C; Madison S and Paikoff R (2003) The role of personal contact with HIV infected people in explaining urban ,African American pre-adolescent' attitudes towards peers with HIV and AIDS. *American Journal of Orthopsychiatry*, 73(1), 101-8.

Schlebusch L. (2004) Current perspectives on suicidal behaviour in South Africa. Cape Town: Medical research council- UNISA, Crime, Violence and Injury Lead Programme.

Schneider H. (2002) On the Fault-line: The Politics of AIDS Policy in Contemporary South Africa. *African Studies*, 61(1).

Schoenberg N.E.; Hopenhayn C.; Christian A.; Knight E.A. and Rubio A. (2005) 'An In-Depth and Updated Perspective on Determinants of Cervical Cancer Screening Among Central Appalachian Women'. *Women & Health*, 42(2): 89-105.

Schrimshaw EW (2002) Social support, conflict and integration among women living with AIDS. *Journal of Applied Social Psychology* 32: 2022-2042.

Schwandt T. A. (1994) Constructivist, interpretivist approaches to human inquiry. In N.K. Denzin & Y.S. Lincoln (Eds) *Handbook of qualitative research* (118-137). Thousand Oaks, CA: Sage.

- Sheffer S.(1994) '*The Impact of HIV/AIDS on Education, A Review of Literature and Experience,*' UNESCO, Section for Preventive Education.
- Sheffer T. (2003) Heterosexuality. In K. Ratele & Duncan N. (Eds) *Social Psychology: Identities and Relationships*. Lansdowne: UCT Press.
- Sherwin S. (2001) Feminist Ethics and the Metaphor of AIDS. *Journal of Medicine and Philosophy*, 26(4), 343-264.
- Shisana O. (2005) as cited in The Health of our Educators: A focus on HIV/AIDS in South African public schools 2004/2005 survey. Report prepared for the Education Labour Relations Council.
- Siemans G. (2006) *Knowing Knowledge*. Lulu. Com.
- Silva M.C. (1995) *Ethical Guidelines in the Conduct, Dissemination, and Implementation of Nursing Research*. Washington, DC; American Nurses Publishing.
- Silverman D. (1993) *Interpreting qualitative data: Strategies for analysing talk text and interactions*. London: Sage.
- Sin C.H. (2005) 'Seeking Informed Consent: Reflections on Research Practice', *Sociology*, 39(2): 277-94.
- Singh B. (2000) 'Breaking the silence on HIV/AIDS: religious health organisations and reproductive health,' *Conscience*, Catholics for a Free Choice.
- Singhal A. and Rogers E. M. (2003) *Combating AIDS: Communication Strategies in Action*. Sage Publications.
- Sontag S. (1991) *Illness as Metaphor and AIDS and Its Metaphors*. London: Penguin.

Sontag S.(1988) *AIDS and its Metaphors*. London: Allen Lane: The Penguin Press.

Stanko E.A. (1997) "I Second that Emotion": Reflections on Feminism, Emotionality, and research on Sexual Violence'. 74-85. In *Researching Sexual Violence Against Women: Methodological and Personal Perspectives*, edited by M. D. Schwartz. Thousand Oaks, CA: Sage Publications.

Stanley L. and Wise S. (1990) *Method, methodology and epistemology in feminist research processes*, in L. Stanley (ed) *Feminist Praxis: Research, Theory and Epistemology in Feminist Sociology*. London: Routledge.

Stanley L. and Wise S. (1993) *Breaking Out Again: Feminist Ontology and Epistemology*, revised edition London: Routledge.

Statistics SA (2005) *Mortality and causes of death in South Africa, 1997-2003*. Statistics SA. Pretoria.

Stillwaggon E. (2000) HIV/AIDS in Africa: Fertile terrain. *South African Journal of Economics*, December, 68(5)

Stimpson C.R. (1988) *Where the Meanings Are: Feminism and Cultural Spaces*. London: Routledge.

Stone T. H. (2003) 'The Invisible Vulnerable: The Economically and Educationally Disadvantaged Subjects of clinical Research'. *The Journal of Law, Medicine and Ethics* 31(1): 149-53.

Strachan K. (1992) AIDS ignored by health department, say doctors. *Business Day*, 1992 September 30, 13.

Strauss A. L. (1987) *Qualitative analysis for social scientists*. New York: Cambridge University Press.

Strauss A.L. and Corbin J. (1990) *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Strebel A. (1992) 'There's absolutely nothing I can do, just believe in God': South African women with AIDS, *Agenda*, 12, 50-62.

Strebel A. and Lindegger G. (1998) Power and responsibility: Shifting discourses of gender and HIV/AIDS. *Psychology in society*, 24, 4-20.

Strike K.A. (1988) *The ethics of school administration*. New York: Teachers College Press.

Strike K.A.; & Ternasky P.L. (eds) (1993) *Ethics for Professionals in Education*. New York: Teachers College Press.

Sunderland R.H. & Shelp E.E. (1987) *AIDS: a manual for pastoral care*. Philadelphia: Westminster Press.

Taylor S. (1986) *Health Psychology*. New York: Random House.

Tewksbury R. and Gagné P. (2001) 'Assumed and Presumed Identities: Problems of Self-Presentation in Field Research'. 72-93. In *Extreme Methods: Innovative Approaches to Social Science Research*, edited by J. M. Miller and Tewksbury. Boston, MA: Allyn and Bacon.

The ACT UP New York Women and AIDS Book Group (1990) *Women, AIDS and Activism*, Boston, South End Press.

The Daily News 22 February 2008.

Thompson P. (1988) *The Voices of the Past*, edition Oxford: Oxford University Press.

Tlou S. (2003) as cited in Australian Nursing Journal: May 2003, 10(10):22

Treatment Action Campaign (TAC) (2000) on HIV/AIDS spending in Eastern Cape for 2000/2001 financial year'. Public Service Accountability Monitor, Rhodes University . Grahamstown.

Trebilcot J. (1986) Conserving women: notes on the logic of feminism. In M. Pearsall (Ed.), *Women and Values: Readings in Recent Feminist Philosophy*. California: Wadsworth.

UNAIDS (1998) AIDS Epidemic Update. Geneva.

UNAIDS (2001): Men and AIDS- A Gendered Approach: 2000 Worlds AIDS Campaign. New York.: UNAIDS.

<http://www.unaids.org/wac/2000/campaign>. . accessed March 20, 2000.

UNAIDS (2002). Report on the Global HIV/AIDS Epidemic. [.unaids](http://www.unaids.org).

UNAIDS (2004) Report on global AIDS epidemic. UNAIDS. Geneva

UNAIDS (2004). Global report on the AIDS epidemic. Geneva: UNAIDS.

UNAIDS (2004a) '2004 Report on the Global HIV/AIDS Epidemic: Global Report', UNAIDS.

UNAIDS (2004b) 'Africa Fact Sheet', UNAIDS, also available on [://www.unaids.org/html/pub/publications/fact-sheets04/fs_ssafrica_en_pdf](http://www.unaids.org/html/pub/publications/fact-sheets04/fs_ssafrica_en_pdf).

UNAIDS (2004c) 'AIDS Epidemic in Latin America and the Caribbean Fact Sheet',

UNAIDS, [://www.unaids.org/html/pub/publications/fact-sheets04/fs_lamerica-carib_en](http://www.unaids.org/html/pub/publications/fact-sheets04/fs_lamerica-carib_en).

UNAIDS (2004d) 'Asia Fact Sheet', UNAIDS,

[://www.unaids.org/html/pub/publications/fact-sheets04/fs_asia_en_pdf](http://www.unaids.org/html/pub/publications/fact-sheets04/fs_asia_en_pdf).

UNAIDS (2004e) 'Eastern Europe and Central Asia Fact Sheet', UNAIDS,

UNAIDS/WHO. (2001). AIDS Epidemic Update, December 2001. Available at

[://www.unaids](http://www.unaids).

UNAIDS/WHO (2005) AIDS epidemic update: Special Report on HIV Prevention.

UNAIDS/WHO (2005) AIDS Epidemic Update, December 2005.

UNAIDS (2008) Report on Global AIDS Epidemic. Geneva: UNAIDS

UNESCO (2000) *The Dakar Framework for action, Education for All (EFA) meeting our collective commitments*. Dakar, World Education Forum, 26-28 April 2000.

UNESCO (2005) EFA global monitoring report 2005; the quality imperative. Paris.

Available at [http:// portal.unesco.org/education](http://portal.unesco.org/education).

UNESCO (2006) EFA global monitoring report 2006 literacy for life. Paris, UNESCO.

Available at [://portal.unesco.org/](http://portal.unesco.org/) .

UNESCO. (2006) *Expanding the field of enquiry: a Cross-Country Study of Higher Education Institutions, Responses to HIV and AIDS*

UNICEF, Save the Children, DESA & IWARAW (undated) *The Human Rights of Women and Children and Opportunities*.

UNICEF (1993a) *AIDS: The Second Decade- a focus on youth and women*. New York:

United Nations Children's Fund.

UNICEF (1999) *Children orphaned by AIDS: Front-line responses from Eastern and Southern Africa*. NEW York: Unicef.

United Nation (1996) as cited in Development Update: *From disaster to development? HIV and AIDS IN Southern Africa*. 5(3): 82-84.

Valente S. M. & Saunders J. M. (1998) Suicide and HIV disease. In van Gorp WG., Buckingham SL.(eds) *Practitioner's guide to the neuropsychiatry of HIV/AIDS*, New York: Guilford, 263-293.

Van Arkel J. de J. (Ed.) (1991) *Living in an AIDS culture*. Pretoria; University of South Africa.

Van der Vleit V. (1996) *The Politics of AIDS*. London: Bowerdean Publishing.

Van der Vleit V. (2000) ' New Light on the Origin of AIDS (published in the electronic newsletter *PulseTrack*).

Van Dyk, A. (2005) *HIV/AIDS Care and Counselling: A multidisciplinary approach*. edition. Pearson Education; South Africa.

Van Dyk, A. (2008). *HIV/AIDS Care and Counselling: A multidisciplinary approach*. edition. Pearson Education; South Africa.

Van Niftrik J. (1992) The bumlbers play on - a decade of debacle, *AIDS Analysis Africa*, (Southern Africa Edition), 3(4), 1-4.

Wagiri G (2001) Fighting the female genital mutilation- Kiss of death is a must. *Daily Nation*, 2001, December 21.

Walford G. (2001) *Doing Qualitative Educational Research: A Personal Guide to the*

Research Process. London: Continuum.

Walker L. and Gilbert L. (2002) 'HIV/AIDS: South African women at risk.' *African Journal of AIDS research*, 1(1): 75- 85.

Walker L.; Reid G. & Cornell M. (2004). *Waiting to Happen: HIV/AIDS in South Africa - the bigger picture*. Cape Town: Double Storey Books.

Warr D.J. (2004) 'Stories in the Flesh and Voices in the Head: Reflections on the Context and Impact of Research with Disadvantaged Populations'. *Qualitative Health Research*, 14(4): 578-87.

Warren C.A.B. (2002) 'Qualitative Interviewing'. 83-101. In *Handbook of Interview Research: Context and Method*. Edited by J.F. Gubrium and J.A. Holstein. Thousand Oaks, CA: Sage Publications.

Warwick I. et al (1998) 'Household and community responses to AIDS in developing countries,' *Critical Public Health*, 8 (4): 291-310.

Weeks J. (1981) *Sex, Politics and Society: The Regulation of Sexuality since 1800*. New York: Longman.

Watney S. (1990a) "Safer Sex as Community Practice", in Aggleton P., Davies P. and Hart G. (Eds) *AIDS; Individual, Cultural and Policy Dimensions*, London, Falmer Press.

Whiteside A. and Sunter C. (2000) *AIDS: The challenge for South Africa*. Cape Town: Human and Rousseau Tafelberg.

Wilkinson S. (2004) 'Focus Groups: A Feminist Method'. 271- 95. In *Feminist Perspectives on Social Research*, edited by S.N.Hesse- Biber and M.I. Yaiser. New York: Oxford University Press.

Wilton T. (1994) *AIDS: Setting a Feminist Agenda*. London: Burgess Science Press.

Wilton T. (1997) *Engendering AIDS: Deconstructing sex, text and the epidemic*. London; Sage Publications.

Wingood G. M. and DiClemente R. J. (1998) Partner influences and gender related factors associated with non-condom use among young adult African American women. *American Journal of Community Psychology*, 26(1): 29-51.

Winter G. (2000) A Comparative Discussion of the Notion of 'validity' in Qualitative and Quantitative Research. *The Qualitative Report*, 4(3-4), March. [.nova.edu/sss/QR/QR4-3/winter](http://nova.edu/sss/QR/QR4-3/winter).

World Bank (2002) World development indicators. Washington, DC: World Bank.

World Book Dictionary (1990) United States of America: World Book Inc.

World Health Organisation (WHO). (2000) The World Health Report 2000: Health Systems- Improving Performance (Geneva: WHO).

World Health Organisation (WHO). (2002) *World report on violence and death*. Geneva

World Health Organisation. (1991) "AIDS Prevention Through Health Promotion: facing sensitive issues." *World Health Organisation*, 63-73. England.

Zappulla C. (1997) *Suffering in silence: Teachers with AIDS and the moral school community*. New York: Peter Lang Publishing.

APPENDIX 1

Annaline's Story

Interviewer: Thank you for granting me this interview, please tell me about yourself, your family, your school life, boy/girlfriends.

Annaline: My name is Annaline. I am the youngest of three children. I have two elder siblings, a brother and a sister. I belong to a white middle-class family. I live in the Glenwood area. Being the baby of the family, I was pampered and spoilt by all my family members including my extended family, aunts, uncles, grandparents and cousins. I was an above average learner at school. My fondest memories of my childhood are those that I spent at my paternal grandparent's home. My grandparents lived in the Greyville area of Durban, the weekends here were very happy ones, there were many children in this neighbourhood and I loved playing with them. Our favourite game was playing house and dressing up as grown-ups, using make up and experimenting with hairstyles.

When I got into high school I was a small fish in a big pond, I had to make new friends, the friends I had in primary school did not come to the high school that I went to. I became quite popular at my high school, because I was good at sports, and took part in track events, was in the hockey and netball teams. I received the victor laudorum for swimming. I was also very outspoken in high school, other's would follow my lead. Much of my time and energy was spent in sport and I excelled in this aspect. But by the time I got home, I was very tired and with the result my academic work suffered, especially maths. My maths teacher always embarrassed me in class. I requested a change of maths teacher, the principal was very sympathetic to my problem and accommodated me in another maths class. The maths teacher was very accommodating and her patience helped me get over my problems and my maths marks improved.

Interviewer: Tell me about your life after you finished matric.

Annaline: After matric I pursued a teacher-training course and qualified after three years. I must admit that it was not easy finding a job. The first year after qualifying, I did many odd jobs, office work in a legal firm, making tea, being a messenger, etc. In my second year after qualifying, I got a job in a senior primary school doing clerical work. I worked at this school for two years, at times minding classes. On the staff, there was a teacher who had applied for boarding. This was my lucky break, I had handed in my CV to the principal, the principal was quite impressed with my versatility during the time that I had done admin work. I was given the teaching load and the duties of the teacher who had been boarded, I was on a three month probation. I really needed this teaching post, I worked very hard to prove my worth. I also wanted to make my parents to be proud of me. I wanted my parents, especially my dad, to feel confident that he had helped me to be self-sufficient. I taught at this school for five years. A year later I was put on the permanent staff and I was very happy. I was now almost 30 years old. I had moved out of the family home and shared an apartment with a friend.

Interviewer: Tell me about your relationships.

Annaline: During this time I had many dates, but no steady boyfriend. In the second year of my teaching career I began going steady with this young man who lived on the same street as me. Our relationship lasted approximately one year, my boyfriend then decided to move to another town because he was transferred to another department. I was heartbroken because I really hoped that we would end up as a couple. This disappointment had really put me off relationships. An added problem was that my parents had separated, and this caused much frustration and unhappiness in the home, and being the youngest child, I felt rather insecure. Being a sensitive person, I began looking for other reasons as to why my boyfriend broke up with me, why did he not suggest that I come with him and find a teaching post in the town that he was moving to. Eventually I resigned myself to accepting the

situation and immersed myself in my work. I stayed in school long after the learners had been dismissed, I think that I did this because I needed to be kept occupied, I could not face going to a lonely flat. My school work was up to date, I gave my classroom a new look with charts, etc. My principal was pleased with my dedication and progress and commended me at a staff meeting. Unfortunately this acknowledgement of good work did have a downside, I lost some of my so-called good friends and I had to put up with unsavory remarks like 'she's out to impress with her window dressing' and 'she must get a life'. These remarks made me feel unhappy and isolated. One of my so-called friends told me that by being so dedicated to my job, I was showing them up. As time passed, I felt uncomfortable and unhappy that I now had to tow the line as to what the staff at my school wanted. I stopped volunteering to do extra curricular duties unless I was asked to do the duty.

At age 32, I met my second boyfriend, whom I had known previously (he used to join my group of friends on our outings), we became emotionally and sexually involved for about two years. My parents' separation also took its toll on me, by this time my father became ill and had to give up his job, the anxiety and stress of my family problems made me feel very insecure. By this time I felt that I needed to settle down, marriage and children. When I brought up this subject with my boyfriend, he was rather surprised and said that he was not ready for that sort of commitment and if that was what I wanted, then it was time for me to look elsewhere; that was the last time I saw him. This second disappointment made me feel bitter about relationships and I told myself never again would I become so emotionally involved. I told myself that I was not made for marriage, I was almost past marriageable age and that two disappointments was enough. My father's health deteriorated, and I decided to move in with him to take care of him. It took me some time to get over my second break-up. By this time I really let myself go, my appearance, my dressing and my whole outlook on life became sloppy. I was 'comfort eating' and had

put on a lot of weight. I snapped at the slightest disagreement. Some of my friends rallied around me and kept me company during weekends and occasionally I went out with them, there were times when I had to stay at home during weekends to look after my father when he became very ill. My father was ill with cancer of the lungs. My mother was now living overseas, and was not concerned about my father's health.

A year after breaking up with my second boyfriend, my friends organised a blind date for me. I was adamant that I was not going to meet any blind date, this determined feeling came out of my two previous disappointments. My friends then agreed that there will be no blind date and that we will go out as a group of friends. We went out to a German nightclub, my so-called 'blind date' was also part of the group, the moment I was introduced to him something clicked, I liked him and felt comfortable with him, he also felt that way about me and we spent the evening chatting. After this meeting, we kept in touch, we went out together a few times. There were times when I could not leave home because my father was very ill and my boyfriend (Tim) would come home so that my father would not be alone. Tim was very understanding; his parents were also divorced, so we shared something common. As my father got to know him, he liked and trusted Tim. Tim was also good with my father; he helped me take care of him.

Almost a year later, Tim and I spoke of marriage and planned our future, our tastes and goals were similar, we began saving for our wedding. By this time my father had become very ill and had to be hospitalised, a week later my father passed away. I was very distraught and was grateful to Tim for being there for me and helping with funeral arrangement. A month after my father's death, my mom moved in with me, I was very fond of my father and my relationship with my mother was somewhat difficult, but now that she was old and her health was not good I had to put our differences aside and adjust to her living in the same house as myself.

Three months after my father's death, Tim and I set a date for our wedding. With the initial mourning period for my father over, we began planning for our wedding, we planned to invite 150 guests for our wedding. The planning of our wedding was in its advanced stage by now, the church and priest were notified, the venue and caterers were booked for the reception, dresses had been bought, menus had been finalised, we just waited for the day. I was very happy in that I had found true love and happiness at last. Two weeks before our wedding Tim suggested taking out life insurance. I never gave it a second thought, but it made me feel more secure in our relationship. This relationship had grown from real friendship into deep love and it was just what I had been looking for because I had grown up without a mother around, looking after a sick father and had other disappointing relationships, this relationship was a godsend and I grabbed it with both my hands.

The application for life insurance included taking an AIDS test- this I considered a formality and I was not concerned about the result, Tim and I had chosen not to be sexually involved especially after my two previous boyfriends, who were just interested in physical pleasure. On the following day after our AIDS test, we had a phone call from the doctor asking us to come to his rooms. We went to the doctor, the doctor said that he wanted to speak to Tim alone, but Tim insisted that whatever the news was, Annaline ought to hear it as well. We both went into the doctor's office and then the bombshell fell, the doctor told him that he was sorry to inform him that he was HIV positive. Tim went pale in the face, all he could say was that he was not a "sleep around" person. We went back home and Tim told me that he was very sorry and he would understand if I did not want to go through this marriage. I was also very shocked; I loved Tim and I had to support him in his time of need. Tim became suicidal and said there was nothing more for him to live for and that we ought to call off the wedding and that I should move on because if we went through the

wedding, we would not be able to have a family. I was steadfast in my support, on that day Tim drank himself into a stupor.

On the next day we had a phone call from the doctor to say that I had to go to go to the doctor's rooms urgently. I told the doctor that I was not in a position to leave Tim alone because of his state of mind, and that he could tell me whatever he needed to say over the telephone. I was certainly not prepared for the news I got. He told me that I had tested HIV positive and that Tim was HIV negative, I just froze. I just sat and cried as if my heart would break, my world was crumbling around me. At age 32 my life was about to end, God was just not fair to me, he had handed me more than my fair share of bad fortune. He brought Tim into my life and then snatched him away again. What do I do now, just curl up and die because that seemed to be the only option left. I had worked so hard to find a teaching post and now that I had one I will have to leave it soon. My learners have enjoyed a very good relationship with me in that I always took time to listen to them when they were unsure about something, I consoled and counseled them when they fought with each other, now I am going to need the counseling. All these nagging thoughts troubled and stressed me, I was also worried about 'tell-tale' symptoms, I didn't know how I was going to explain my illness when it came. I also stressed about my telling my mother and about how I was going to cope with this illness, especially in the classroom. I agonized over the disclosure of my HIV status, I did not want to lose the friends and colleagues I made at school and I did not want to lose my job. There was this danger that if I disclosed my HIV status I would be seen as different and may be isolated. I felt completely helpless and hopeless. Tim heard me crying and came to see what had happened, it was his turn to support and console me, I asked him to move on and forget me because we had no future, Tim being the kind gentle soul told me that his love was unconditional. A few hours later both Tim and I went to the doctor's rooms and demanded an explanation. The doctor who had initially given us our results was conveniently not available, so his partner

attended to us, he explained that when his partner took the file to give us our results, he saw Tim's name on the first page and when he turned to the next page he saw that the results were HIV positive, what he did not realise at the time was that the pages were somehow stuck together and he read out Annaline's results. We went back home and just sat on the couch finding it very difficult to accept the news. We decided to keep this news confidential because we did not know how to handle it, we were not counseled but Tim was my pillar of strength. For a few days we dwelled on this bad fortune, thinking of what to do, the wedding was furthest from my mind. I suggested that we cancel the wedding but Tim felt that we should have the wedding. We did not take the doctor to task because we did not want attention focused on us, especially with the nature of the problem. A week before the wedding, we decided to tell Tim's parents, his mother was very shocked and told us that we must reconsider getting married, Tim told his parents that we had decided that the wedding was still on. Tim told his parents that if they did not approve of the wedding, they would not only be losing a wonderful daughter-in-law but that they will also be losing a son. After the initial shock and Tim's determination to marry me, his parents accepted the idea of our marriage going on. I understood Tim's parent's anxiety, they were concerned for Tim, would he remain HIV negative, there would be no children from this marriage and most of all the stigma attached to people infected with the disease.

I obviously wanted to find out who had given me this virus. I had sex with my two previous boyfriends, and Tim and I had chosen abstinence until marriage. I contacted my first boyfriend and he told me that he had recently had an AIDS test and he had tested negative, so that left one person, David, my previous boyfriend. I was very upset and angry with David for giving me this virus, he said that he was not the marrying kind, but he was going around infecting people, and I was determined to give him a piece of my mind. I tried to make contact with him, his mother told me that he was not at home, but that he was in Westville hospital. I questioned his mother as to why he was in

hospital, she asked me to go and see for myself. When I went to Westville hospital, I was told that David had been removed to the Highway Hospice. I went to the hospice and the lady at enquiries told me that David was in room number nine. I proceeded to room nine and did not see David there. There was a patient in the bed and he was a very thin small person, whilst David was a big strappy man. I went back to enquiries to say that I could not find David. A helper was asked to assist me to find David, the helper took me back to room nine and when I looked at the patient's face, I just couldn't believe my eyes, all my pent up anger just disappeared and was replaced by pity. David told me that he was dying of AIDS. I asked him why he had infected me and probably many other innocent young women, and what he said next really made me think. He said that he knew that he was HIV positive and that he was very afraid and also very angry at being HIV positive. He went on to say that he knew he was going to die (this was before the availability of anti retrovirals) and that he did not want to die alone and he was going to take other people along with him to his grave, he felt that he could not disclose his status to anybody, because people will isolate him, given the stigma the disease carries, this was around the year 1995- 1996. I fully understood David's reason for keeping his status a secret, I also feel that way. People want to stay away from you because they do not want to become infected. David asked me to forgive him, which I did, because I realised that he was on his deathbed and venting my anger would have no purpose. The helper explained to me that David was really in a bad way and that they could not even put clothes on his body, as his flesh was beginning to fall off his bones, and the helpers had to virtually wrap him up in a sort of cling wrap to maintain his dignity. David passed away a few days later. According to Annaline, David had been the first South African man to be taken to court on a charge of manslaughter by one of his former girlfriends, who was one of the five women in total he had infected. The judge ruled for the women and ordered him to pay R300 000 in damages.

Two weeks later Tim and I were married, by this time many people knew my HIV status. Of the one hundred and fifty guests that I had invited to my wedding, only eighty attended. I was very disappointed with the low response to my wedding and I knew the reason for this, my HIV status. I had really looked forward to our wedding and starting a family. I really wanted to have a baby, so much so that before the wedding I had already started buying baby things, clothes, booties, little toys, etc. After my HIV diagnosis my whole world fell apart, although there was much talk about nevirapine for pregnant mothers, Tim and I took the decision not to have children. We looked at the situation in a very realistic way, why bring a child into the world to probably suffer with us, and I may not be around with my child for as long as he/ she may need me.

I donated all my baby things away and resigned myself to enjoying babies and children belonging to family members. I have two sisters and after they learnt of my HIV status, they refused to allow their children to come anywhere near me, this really hurt me. In the flat where I stay, the neighbours on the one side of me have children and I enjoy doing things for them, I help them with their homework, they come to the supermarket with me, at times I treat them to a movie. At every chance that I got I educated the children around me about HIV. I did not want them to be ignorant about this disease.

Although my mum was now staying with me, I did not tell her of my HIV status, I felt that she would not be able to handle the news, my mother is a very emotional person. I used to visit the hospital regularly to get medication and have treatment and my mother often questioned me about my visits to the hospital and I told her that I had cancer, she was terribly upset and cried for a good few days, and I had to console and pacify her instead of her consoling me.

Interviewer: How did you handle the fact that you are HIV positive?

Annaline: For many days I walked around in a daze, I was so confused I just didn't know what path to take, something told me that if I disclosed to anybody the bad news would get around so fast that I would be left hurt and abandoned. In times like these, I was sure that I will have the support of the church that I attended from a very young age, but I was terribly disappointed, the pastor at the church was very honest with me and said that he could not help me and that I needed to talk to a counselor, the pastor also advised me to keep my status a secret from the congregation.

I needed time to think about this but time was not on my side, this stress of my diagnosis was making sick and the thought of not being able to cope was almost destroying me. I felt a strong need to learn more about HIV and AIDS and I befriended an AIDS educator at the King Edward the eighth hospital and asked if I could sit at the back of the room and listen to her lectures, she agreed. In this way my knowledge of the disease expanded, I collected information from the library and wherever else I could find information. By that time I had gained a good amount of knowledge about the disease and I felt somewhat empowered.

Interviewer: Do you have 'bad' days at work, how do you handle these days?

Annaline: Besides feeling drained of energy, having itchy skin and bad headaches I did not have all the other symptoms, so maybe I will just put this whole thing behind me and carry on like I usually did and pretend that it was a bad dream.

I tried to be brave but two weeks later I began feeling very ill, I just couldn't cope with the tiredness, by mid-morning I was very exhausted and had to put my head down and rest. On one such occasion one of my colleagues came into my room and she saw me with my head down, she queried as to what was wrong, I said that maybe I was starting flu, she believed me and left. My headaches and tiredness increased and I used the breaks to put my head down on the table for a small rest. This continued for almost the whole term

Interviewer: Tell me about your colleagues – how do they respond to you?

Annaline: At times the staff commented that I had become very anti-social because I just kept to myself, one staff member asked if I was hiding something, another said that maybe I had a ‘skeleton’ in my cupboard. All these comments made me feel guilty and upset, I wondered if they were beginning to suspect that I was HIV positive, many of them either ignored or avoided me. You know, I just didn’t look forward to going to school anymore. Due to anxiety and depression I took sick leave for the last two weeks of the term. Because of the trauma I was going through my school work suffered, I could not imagine how I was going to catch up, I was still not feeling any better. In the new term my principal called me to his office and questioned me about my staying away, my indifferent attitude and my work backlog, he was not very sympathetic and told me that I should consider taking sick leave and come back when I am 100%, so that he could employ somebody who will be there to teach the children everyday. There is so much hype about human rights, what about my rights, there are education policies on HIV/AIDS, these policies clearly state that there must be no stigma and discrimination and that support must be provided, but this is just not happening.

I was devastated by my principal’s insensitivity, how could I now disclose my HIV status to him, I had visions of him throwing me out of the gate. I began taking extra doses of vitamin tablets to boost my energy levels so that I would not be caught napping during breaks, this overdosing on medication gave me diarrhoea and I kept going to the toilet, I could sense that my colleagues were talking about me and I felt exposed, I felt that my secret was out, that evening I discussed my fears with my husband, I knew that whether I disclosed or not I am going to have to give up my teaching job. It was a very painful decision both emotionally and financially, because Tim did not have such a well paying job. Both Tim and I felt that the stress of secrecy was bad for me, he consoled me by saying that he will take care of me and that I needed to concentrate on keeping myself well.

As an educator I believe that by working together we can achieve a lot, when educators or their families are ill with ailments such as, heart disease, diabetes, cancer or hypertension, much concern and support is offered to that person, but with HIV it is a completely different story. For me, my colleagues' attitudes made me feel like a weakling, because I was succumbing to the disease, and this weakness symbolized worthlessness. If you are a worthless person, nobody wants to bother with you, therefore HIV positive people do not disclose their status. The very next day I handed in my letter of resignation, my principal did not question my decision to resign, he gave me the impression that he was happy to get rid of me. The news soon got around about my resignation, one of my colleagues even went to the extent of asking me, 'do you by any chance have HIV, because you are certainly behaving like you do.' The shock of this statement made me speechless I did not expect anybody to be so cruel to me, especially now that I was leaving. I was so upset that I could not go to work for the next three days, when I did go back, I was summoned to the principal's office and was told that I needed to make an attempt to come to work daily as I needed to update all my records and complete my teaching up to the point that I resigned. I didn't even make it to my room before I burst into tears, I felt that my time on this earth was so limited and I was being treated so badly. Anyway I struggled to serve my notice period and left the school without even an official goodbye.

Interviewer: Are you aware of any educational programmes that the education department has in place to educate/ support the HIV positive educator?

Annaline: No, I haven't heard of any HIV programmes for educators.

Interviewer: What type of education/support would you like to see implemented to help infected educators cope with HIV.

Annaline: I would like to see the management team at every school attend HIV/AIDS courses, so that they will be knowledgeable about the disease, because ignorance equals stigma and discrimination. If the management team treated ill staff and learners with compassion and concern the rest of the staff will follow. Our constitution states that no

person should be discriminated against because of their HIV status, I would also like to see some sort of funding made available to assist with medical expenses, medication required by an HIV positive person is very expensive. Just to give an idea of some of the medical expenses, blood tests are between R700 to R1000, R120 consultation, at a private clinic you will pay approximately R1250, at a state hospital you will pay approximately R700 for a blood test. When an advert talks about voluntary testing and counseling, somebody has to pay, in places of work the company pays, in community places perhaps NGOs will pay. The government pays for this testing when they have a drive for VCT. When I go to have myself checked, I have my CD4 count and my viral load checked and this costs about R600.

Interviewer: In your opinion do you think that females are more vulnerable than males to HIV infection? Why?

Annaline: Yes, most definitely, females are more vulnerable, if we look at the rape statistics, these are so high, women are generally not as strong (physically) as their attackers, and cannot fight them off.

I stayed at home for three months and I became more depressed, Tim didn't know what to do, and without my knowing he contacted a counselor and got some advice about handling HIV. My husband forced me to visit this counselor, I was not keen but I went and to my surprise I felt so much better and lighter because I shared my problem with another person. The counselor advised me to go to my doctor regularly and monitor my CD4 count which I did. Six months into retirement and I was feeling so much better, I realized then that ignorance was the cause of the bad attitude, discrimination and stigma. I had decided then that I wanted to educate other people about the disease. I began offering my services as an AIDS educator at religious organisations, parents' meetings at schools and a year later I joined the Hillcrest AIDS Centre. By this time I felt that I needed to disclose my status to my mother, I waited this long because I felt that my mother

was not strong enough emotionally. As I had predicted she just fell apart when I disclosed my status to her. She felt that the end was in sight for me, she refused to come out of her room for three days, she kept on saying, “you are going to die and leave me alone.” Her agony stemmed from the threat of me dying and the loss of her security. This goes to show how people view HIV especially if they are ignorant about the disease. When we are watching television and an issue about HIV is discussed she’d get up quickly and go into her room and cry and she says she’s afraid that I’m going to die.

There are days when I really feel depressed and I long to have a friend whom I can talk to, I don’t have any friends, because most of my friends fled when they heard that I was HIV positive. On some days I get up and I feel so depressed that I just crawl back into bed and sleep. I had three very good girl friends, I confided in them and they knew my status, and a month after I revealed my status to them, the one friend kept away from me and slowly the other two also moved away from me, I have no bosom friends besides my husband.

I attend many HIV/AIDS talks and over a cup of tea I tell people that I am HIV positive and how people stay away from me and the response I generally get when I am face to face with people are “oh I’m so sorry to hear about your positive status, how can people discriminate, don’t worry we will exchange telephone numbers and meet sometimes,” that is the last I heard from them, people are false. I did a talk at a bank on HIV awareness and I told the audience about how people treat people who are HIV positive and I also disclosed my status to them and people would respond like, “They are so cruel, how can they treat people like that, etc.” There was this one particular lady at the bank who said she was so sorry to hear that I was HIV positive and that she would love to have me and my husband over for lunch or maybe a braai, she said that she was a Christian and in the eyes of God, we were all equal. She gave me her phone number and address. I phoned her a week later to ask if I could visit and she said that she had to go to a

wedding, so I understood. I was in her area a fortnight later and I called her again and she made another excuse, then I wondered if she had second thoughts about the invitation, maybe she discussed my status with her husband and he was not happy to have an HIV positive person in his home. Again a fortnight later I called just to have a chat and not to visit, this lady did not seem to happy with my social call and said that she was busy and that I should not call her, she will call me when her schedule was a little slack. I felt very hurt and upset, that after giving that talk at the bank and how cruel people were towards an HIV positive person, people still behave in that hurtful fashion, I felt like a leper, isolated by society. People are so ignorant about this disease, they refuse to believe that by just speaking nicely and being in the company of an HIV positive person cannot give you AIDS. We read and hear so much about HIV/AIDS awareness but this seems to be falling on deaf ears, there is much more that needs to be done about HIV/AIDS education and I am trying to do my bit by giving these talks in schools and banks.

The people in the apartment block where I live know my status and they are very friendly towards me, I feel comfortable in their company, we do not go into each other's houses but chat in the corridors. I am now concentrating on doing HIV/AIDS talks in schools, both primary and secondary schools, my talks range from 30 minutes to one hour depending on the ages of the learners, I do a lot of visual teaching using a slide projector and talking around what is projected, in this way my audience is attentive instead of just presenting a lecture. I also do presentations for educators because I feel they need to have additional background knowledge to handle questions that may come from their learners. Some educators do have attitude and make comments like, "not another AIDS talk, or I am not infected or affected so I don't need this, and this AIDS topic is exhausted." I was sitting in the staff room at one school and the educators did not know that I was the HIV/AIDS presenter, a group of educators were talking and the one educator said, "its just another AIDS talk by an infected black person," another

educator replied, “with so many partners what’s new,’ this goes to show people still believe that HIV is a black person’s disease, you could feel the shock in the air when they realised that the white presenter is HIV positive.

Some of the educators who come to my talks do ask important questions concerning nutrition for an HIV positive person, medication and possible side effects. I have become so involved in the education about HIV and AIDS, I keep updating myself through the internet, going to talks by the Medical Research council etc. At one of my presentations I was asked some questions about HIV and homosexuality, I was not in a position to handle these questions confidently, thereafter I decided to learn more about the gay lifestyle, this was quite a mission. I managed to make some contact with a gay club and was allowed to visit. I had to explain my presence, I told the people that I was HIV positive and was now giving talks about the disease and wanted to know more about the gay lifestyle so that I will be in a position to answer some of the questions concerning this issue.

I have gone to many schools to educate about HIV and AIDS, I generally start my presentation by asking a few questions to ascertain their level of knowledge on HIV and AIDS, I am really shocked at times when I am faced with silence because the learners do not know much. On one occasion I spoke to a senior educator concerning this ignorance about HIV and AIDS amongst the learners, the senior educator replied saying “that is why we have called you in, educators feel that an expert ought to talk on this aspect.” But my feeling is that educators in many cases do not know much about HIV and AIDS, my advice to educators is to move away from this embarrassment especially in this ‘life and death’ issue. In the private schools, the school management team are rather guarded about HIV/AIDS education, fearing a reprisal from parents because of a lack of understanding between sex and sexuality education.

All educators need to be supported, both the infected and affected, more internal training needs to be done so that educators are confident enough to handle the many questions asked around this issue, instead of referring to the question elsewhere to be answered. Education around HIV and AIDS will also minimise issues of stigma and discrimination. Educators who are HIV positive need much, much more support from the Department of Education, apart from the education for all educators, the Department of Education needs to make available support packages such as 'Aid for AIDS' and other disease managed programs which has tremendous value such as counselling and education and support for the HIV positive person, these programmes are ongoing and sustainable and will be of great value to the HIV positive educator. I am a living example of an educator who opted out of school because of discrimination. Society tends to ignore the issue of support in most cases, support is essential from day one of diagnosis, not when the person is on his or her deathbed.

Insurances must also be considered at the early stages of the diseases, so that the children can be catered for in the event of death. An Occupational Health insurance policy is one that not only helps the family in death but also whilst the person is alive for medication.

Women are definitely more vulnerable to HIV infection because of the anatomy of the female body. I have been married now for almost eight years, Tim is not HIV positive, we practice safe sex, he has a check up twice a year. We are absolutely honest with each other, if one of us fever sores or cut our mouths whilst eating, we do not kiss, we take all the necessary precautions, and in this way we sustain our good safe relationship. I also have myself checked regularly, an HIV positive person ought have him/herself checked every month for the first three months and every six months thereafter, I must admit that this is a very costly exercise, blood tests are between R700 to R1000, R120 consultation, at a private clinic you will pay approximately R1250, at a

state hospital you will pay approximately R700 for a blood test. When an advert talks about voluntary testing and counseling, somebody has to pay, in places of work the company pays, in community places perhaps NGOs will pay. The government pays for this testing when they have a drive for VCT. When I go to have myself checked, I have my CD4 count and my viral load checked and this costs about R600. The last time I had a check up my CD4 count had dropped to 192, clinically I am no longer HIV infected but AIDS infected, physically I still look and carry on as when I was HIV positive. My choices now are to look at the end of the year to see whether I need to take additional medication to prevent opportunistic infections. My choice of medication will be Baxtrim and this will cost R200 per month or look at going onto an anti-retroviral drug. By going onto anti-retroviral it may push me back to being HIV positive. I cannot afford anti-retroviral drugs at this stage; but with the new government policies the price of drugs may just come down. I am just going to sit tight and wait. My previous CD4 was done about two years ago and the count was about 500, since then I've had lots of issues to deal with, financial problems, family problems, my mom's health was not too good and these types of stresses are bad for the immune system and also for the CD4 count. I am now going to concentrate on increasing my CD4 count. At this stage I made up my mind that I was going to take control of my health and my life, and that I was going to keep the HI-Virus in its place, I was going to control it by keeping my immune system healthy to fight the virus. I am too young to give in I do have a lot to live for, I am confident that I can overcome this disease.

When I was first diagnosed with HIV, I had a very hard time trying to deal with the news. I knew that one of the symptoms of HIV was loss of weight, so I really started 'comfort eating' and I put on a lot of weight, this additional weight made me very tired and sluggish, I looked at myself in the mirror, I certainly did not like what I saw and decided to do something about it. I started going for walks and going

to the gym. I reduced my red meat intake and instead started eating more fish and chicken, I also included lots of fruit and vegetable in my diet and drink lots of water. Too much of sugar in the diet of an HIV positive person causes tiredness. Yoghurt is also very good for me because of the live cultures that help to keep the mouth area bacteria free, helps the stomach and aids digestion.

I also use a soap that has an antiseptic in it, because one little sore on an HIV positive person's body, if not kept clean can become a big sore, your personal hygiene is of paramount importance.

My advice to the youth out there is, 'knowing your status is the best gift you can give yourself, knowing your partners status is a bonus.' I always tell people who are in a relationship, love does not equal sex, love is care and compassion and security, your partner must always hold you in high esteem. I enjoy the care and security that my husband provides for me, I want to enjoy reasonably good health to take care of my mom until it is time for her to go. I hope to live to the age of seventy so that and I can reminisce about the path we've walked, sometimes rough, some very rocky, we have also had some good times, and the important thing is to be positive about being positive, in this way you appreciate everyday and do not take life for granted.

APPENDIX 2

Ashwin's Story

Interviewer: Thank you for granting me this interview, please tell me about yourself, your family, your school life, boy/girl friends.

Ashwin: My name is Ashwin (not the person's real name), I am a 40 year old Indian male. I am an only child, both my parents are late. I am a head of department (HOD) at a prominent school in the Stanger area. I lived in the Stanger area all my life, my father was a school principal, and my mum was a house executive. I had a wonderful childhood and an equally wonderful school life, being an only child I had all the attention that my parents could give me. In return for all this attention, I was a very good son to my parents and made them very proud of me. As for friends, I had many because I was a patient listener and a very helpful person, at the same time I was also a shy person so dates were very few. My wife was my first real serious girlfriend.

Interviewer: Tell me about your life after matric.

Ashwin: I had very good results in matric and went on to pursue a career in education. I had a good university education and followed in my father's footsteps and became a good educator. my specialisation was English, I handled a heavy workload, being a HOD I was required to supervise the work of educators in my department, and teach my learners and prepare for the various competitions that I encouraged them to enter. I truly enjoyed my job.

Interviewer: Tell me about your relationships.

Ashwin: I did not have really have serious relationships, during college days I had the odd crush here and there, it was fashionable to do this, my wife was the girl of my dreams, she was also at the college, 2 years after me, we

went steady for 5 years before we married, we were happily married and have three children, a son and two daughters. 11 years after our marriage I lost both my parents in a car accident, a part of me also died on that day. I was devastated, I went through a period of extreme depression after the loss of my parents, I had to go through a period of difficult adjustment to learn to live without them and accept their death. I was great full for the support of my family.

Interviewer: How did you handle the fact that you are HIV positive?

Ashwin: I did not handle my HIV status, I did not know what to do, who to turn to or what to do.

My nightmare began at 18h00 on the August 2001, I was a hijack victim. I was hijacked near the Marianhill toll plaza by four men, these men virtually pushed me off the road, I had to stop, I was pulled out of my car and beaten. I was then gang raped by these men and left for dead in the bushes on the side of the road. I managed to crawl to the main road and get assistance by the early hours of the morning. I was taken to a nearby hospital and treated for my injuries and for shock. My family were frantic because I had not gone home that night, and I always maintained contact with them, my cell phone was also taken away, and my family was contacted by the policemen who attended to me. I remained in hospital for two days and was then discharged. Life was never the same again; I was very disorientated by my nasty experience. For a grown man like myself, father of three children and holding a senior position in my school to be held up and raped is unthinkable.

Initially my colleagues and family were very supportive towards me, but I was too ashamed to tell them that I was raped by men, me the head of my family, for this to happen to me was unthinkable, this was going to be my secret.

More horror followed, a week later I was contacted by the doctor who had attended to me, he asked to come to his rooms as soon as possible. I was very anxious and could not concentrate on my work. I called in sick the next day. I needed to go to the doctor and attend to the urgency of his call. When I arrived at the doctors rooms, I was told that I was HIV positive. My HIV diagnosis came as a huge shock to me because the doctor did not ask my permission to do an HIV test, but he later explained to me that it was routine to do an HIV test if a person has been raped. I knew that counselling had to be done before and after diagnosis, to me this is a very important stage, it could either break the individual or make the individual. In my case, it broke me, I cried like a baby, I did not know who to turn to for advice, especially since my permission for the doctor to do an HIV test was not requested and I was not expecting a diagnosis of this nature.

When I received this urgent call from the doctor's room for me to make an appointment to see the doctor, I was concerned, I expected to be diagnosed with maybe tuberculosis or sugar diabetes, but definitely not HIV. When I met the doctor, he told me that my blood test results came back but the news was very depressing, he told me, 'Ashwin you are HIV positive'. I froze, I got up and left his rooms in shock, I just could not register, I could not see anything in front of me, I felt like a little damaged boat in a wide ocean without direction or support, just tossed around in the water. I tried to recall what HIV was about, and I realised how little I knew about the disease, I had never bothered to read about the disease because we all want to believe that we will never be infected. The only thing that I was absolutely sure about was that I had very little time left and that I was going to die soon. The saying 'big men do cry' became a reality on that day.

In our school staffroom, my colleagues denounced and spoke in derogatory terms about HIV infected people, saying that they deserved what they got for their loose living and that society was better off without them. How could I now expect any support and sympathy from them when they learn that I am HIV positive. I decided to remain silent about my HIV positive status; I still had to deal with this depressing news myself. How do I tell my family, will they believe me? One of my major concerns was where do I get the information I need to deal with this disease, I do know that there are many books on HIV and AIDS, but the majority of these books deal with prevention and symptoms of HIV not managing HIV. Posters and leaflets also promote abstinence and safe sex, at this stage in my life, I did not need to know about abstinence and safe sex. If I went to a clinic or a counsellor, they would know immediately that I was HIV positive, I could not take this chance, this was my secret, and I will keep it a secret. I had this perception of myself as a person without any power and self-worth.

On the day that I was given this terrible news I walked around in a daze, not seeing anything or anyone, all I could think about was how long was I going to live, I then went on a mission blaming myself, at the same time determined to keep my secret. I was in denial, maybe the blood tests got mixed up; I may have got someone else's results. During this time, I lived a day to day existence, focussing on staying alive and ignoring this deadly disease. I had my family to consider, I had to tell my wife about this as soon as possible, I gathered up as much courage as possible and prayed that she will understand. When I told her that I was diagnosed HIV positive, she hit the ceiling and asked me to get out of her life and the house, I let her cool down and then tried to explain that on the day I was hijacked I was raped by four men, she did not believe me. From that day onwards my marriage and my family life took a downward slide. I considered HIV an enemy that placed obstructions in my path, the feelings

of guilt, fear, and helplessness continually occupied my mind. How do I stand in front of my class and preach a moral lifestyle to them, when HIV positive people are labelled as immoral?

Whilst I had been completely denying my condition, the symptoms of this disease of our time had already been ravaging my body for the past year. My moods changed from numbness to deep anger and then sorrow, and anger because the A in Aids is for acquired, I did not go out there and acquired this disease, it was thrust onto to me. I was a victim. Now I have to surrender and accepted it as God's plan for me, death at an early age. Now my limited time on this earth is very precious to me, but I do not have a family to share it with. This pain and stress is killing me 'so near yet so far'. I value my family, 'I love them' but they don't want me.

I remember an aunt of mine who was diagnosed with breast cancer about 20 years ago, much secrecy surrounded this diagnosis, people did not discuss cancer openly. An HIV diagnosis is also shrouded in secrecy, but these days cancer is not associated with shame and is more acceptable, yet an HIV diagnosis is considered a shameful and sinful thing because of the prejudices around the manner in which it is transmitted. HIV positive people are generally labelled as promiscuous and "bed hoppers".

My life with my family had become so strained that I felt I needed time out. My family was suffering just as much as I was, we no longer sat and had meals together or went out together. We could not even discuss the way forward together so I wrote a letter to my wife and children and explained to them that it was best that I moved out of the house. They thought that it was a good idea, I found a bachelor flat to rent and moved in.

Now that I have been living with this disease for approximately five years, I believe that medication is not the only thing an HIV positive person needs, other important aspects of coping with HIV are emotional, psychological and spiritual support. In order to return to 'normality', a holistic approach to health is essential and this process can only be possible if the people around you accept and support you. Living with HIV for two years made me realise that my situation is irreversible and that the rest of my life will be a lonely journey to the grave. So far I had spent my time in denial, I did some introspection and realised that my denial had cause me to shut my mind out to most things and sleep. At times I had forgotten who I was and why I was here, it was like having a nightmare, just that nightmares go away when you get up but mine stayed with me even when I was awake. I was moving through life unconsciously, this disease had taken over my life and was controlling me; I became a servant to HIV, because it was controlling my state of health and my mind.

My biggest fear is loneliness and rejection. These days when people are diagnosed with life threatening illnesses such as cancer, leukaemia and pneumonia, family members and friends rally around to support the sick person. When I was diagnosed as HIV positive I did not have any support. I still have nightmares about the manner in which this disease was disclosed to me, the doctor callously told me, "sorry, it's bad news. You are HIV positive", no pre or post test counselling. I had to digest what the doctor told me, I had to come to terms with my plight, suicide crossed my mind a few times during the days that followed, why should I go through life with this huge cloud hanging over my head, I can put an end to my life now, "why wait for HIV/AIDS to decide when my life should end". I decided at that stage not to share my bad news with anybody, because of the guilt and shame and the fear of rejection. This silence needed to be broken if we wanted to fight the loneliness that HIV/AIDS brought with it.

Only when stigma and discrimination are eliminated then only we will have a chance of winning the war against HIV/AIDS.

Now that I am living alone, this loneliness just about kills me, I try to immerse myself in my school work, my preparation and marking are all up to date because I try to keep myself occupied. I do not go out much, I don't have many friends and my relatives shun me because of my HIV status. From educating myself about HIV, I do know that good nutrition is very important, I try to cook my own meals and I must admit that it is not easy to cook for myself, the thought of eating alone depresses me so I don't cook. I feel the need for family support or even the support of friends, I need to talk to my relatives from time to time. I have now come to believe that the loneliness is worse than the disease, I need to feel wanted and to know that my family cares for me. The fact that there is no cure for HIV and AIDS is an added blow, what about all the plans I had for the future, my ambitions I had for my family and myself, they have all vanished, like my life that is about to be extinguished. This disease carries a very high stigma, because society believes that only sinners are infected because of their promiscuity and that this guilty feeling is a punishment from God.

I yearn to be part of my children's life. Two years ago my wife divorced me, I miss her dearly, fate has dealt me a cruel blow. I wanted her to get on with her life, during this trying time of the divorce, I became very ill, the depression, stress and finality of the divorce took its toll on me, my health suffered. During the time of my divorce, my CD4 count was bordering on AIDS (CD4 count was 258) I was the only person who could help myself and I had a choice to either throw in the towel and give in to the disease or do something to make my immune system stronger, I chose the latter, although suicide has crossed my mind again.

Interviewer: Do you have ‘bad’ days at work? How do you handle these days?

Ashwin: Yes, I do have ‘bad’ days at work, really speaking I’ve had many ‘bad’ days at work. There are days when I just don’t want to get out of bed, sometimes my body aches so much that each step is agony, at other times the uncaring, unfriendly atmosphere at school really depresses me even more.

Interviewer: Tell me about your colleagues – how do they respond to you?

Ashwin: My colleagues, most of them are very insensitive and make hurtful comments, therefore, at school I keep very much to myself, because I feel that everybody knows my status, none of my colleagues even bother to ask me why I isolate myself. They still ridicule HIV positive people, saying that HIV people have no place in the classroom, they should be banished to a lonely island and keep their contamination to themselves. HIV/AIDS is a worldwide concern, there are workplace policies and education/school policies on HIV/AIDS, but sadly for us these policies only exist on paper, school management teams and educators barely know the content of these policies. I feel very hurt about this, so I make excuses and pretended to be busy in my classroom. I am living from day to day, without any enthusiasm, I do not look forward to a new day because I feel that it is bringing me closer to my grave. I isolate myself to such an extent that I am now afraid to face my colleagues, just in case they saw symptoms of HIV on me. This stress of living in such secrecy took its toll on me and I became very ill, my doctor put me off work for a whole month; I stayed in my flat and ventured out very early in the morning to do my shopping. The days just passed by I even lost sense of what day in the week it was, on some days I hardly got out of bed, I just layed in bed and waited to die. Nobody called me, I was already dead to my family and colleagues.

During these two years, I felt that my stress and anxiety had made me curl up into a cocoon during that time I must have even forgotten how to smile, it was a miracle that I managed to do my daily teaching, well just barely,

being an HOD I was expected to guide and monitor educators in my department, and here I felt that I was slackening, I just did not have the energy or the confidence to advice or check on what they were doing. Being in denial and putting on a brave front caused an emotional drain on my life and I became extremely sick. I suffered high fevers and constricted breathing, at times I wanted to overdose myself so that I will not have to face another day. One of the most agonising aspects of HIV is when the symptoms begin showing and the extreme pains I experienced in my groin, armpits and legs, peeling skin is also very embarrassing especially when people stare at you. Experiencing this pain was not as bad as the fact that I had no one to confide in. My illness was severe and I missed many school days. Standing on the brink of suicide, my eyes rested on an article in one of the pages lying on my table, the article was on HIV/AIDS counselling, promising confidentiality. I had never considered the route of counselling yet, but I had not expected to live with HIV for two years, who knows how many more years I will still be battling on with HIV. I needed to exhale what was inside of me, so I decided to phone the counselling service to make an appointment, as luck will have it, I was answered by an answering machine. I cut the call, fearing that if I left a message, someone will recognise my voice.

Mentally I felt that I needed a change of scene, I was beginning to feel stifled and claustrophobic in my school and home environment. At times I longed to speak to my children, when I phoned them, they hang up after hearing my voice. They blamed me or destroying our family. That weekend, I bought the Sunday Newspapers and I saw an advert for a job in an adult learning school in the Pietermaritzburg district, I applied for the post and I was fortunate in getting the job. I resigned from my present post and I got the feeling that my principal and the staff were just waiting to get rid of me, nobody asked why at age 42 I had resigned or where I

was going to, at the end of the term I cleared out my cupboard and table and left school like any ordinary day.

My decision to leave my school was prompted by some incidents that made me uncomfortable such as at one of our staff meetings. I heard some of the staff members saying that it was an unforgivable shame for a grown man to abandon his wife and children and also that HIV positive people do not have any place here on earth. I also noticed that I always sat alone, no one came to sit near me because they may become infected. Thereafter I decided not to attend staff meetings, I was called to the office and asked to explain my indifference, I felt that I was now being labelled as a difficult person and a troublemaker. My principal told me that if I had a work related problem I needed to talk about it and if my problem was personal, then I needed to leave it at home, as far as my work place was concerned I could see that the doors were shut to my very grave problem. Many a times I wanted to run away from this unfriendly environment, if only I could turn back the clock. At times I felt that I did the right thing by handing in my resignation and going to another job.

Interviewer: Are you aware of any educational programmes that the department of education has in place to educate/support the HIV positive educator.

Ashwin: No, I am not aware of any support programmes for HIV positive educators. If there were programmes in place to support the HIV positive educator, it will be debatable if educators will take advantage of these programmes because of the fear of being identified as one of those infected educators and also the stigma associated with HIV. Although schools do have a policy on HIV and AIDS, there was no mention made about this at our school, I knew we do have learners at our school who may be infected and affected, no means to empower and or capacitate them was ever done, so, clearly I saw myself walking a difficult road ahead at this school.

It was in the second term of the school year that I took up my new position as an educator at this adult learning school in P Pietermaritzburg, this was a type of a convent school and here much emphasis was placed on religious teaching, I did not mind, during this time of despair I could do with spiritual upliftment. I also sensed, initially that everybody went about their work very quietly; this suited me fine, so I too could keep to myself. I found a bachelor flat very near to the school where I was teaching and this was very convenient for me. I am now far away from my family, they will now forget me completely and get on with their lives. I still support my children by depositing my contribution (for their upkeep and studies) in a special bank account opened for this purpose.

Interviewer: In your opinion do you think that females are more vulnerable than males to HIV infection? If yes, why?

Ashwin: Yes, females are vulnerable to HIV infection, for two reasons, firstly, society generally sees females to be there to serve the needs of males, and secondly, females are physically weaker than males, and can be forced to give in to the sexual demands of males. Rape statistics are high and growing daily, and in many cases the rapist is HIV positive. Single parents who are unemployed struggle to feed their children and therefore turn to prostitution. Males are also vulnerable to HIV infection, look at what happened to me.

Interviewer: Do you think HIV and poverty go hand in hand?

Ashwin: Yes, generally the poor people are not in a position to educate themselves and remain ignorant, and when they realise that they are infected they do not know what to do. In most cases they suffer because they do not have money to buy medication or even go to the hospital or clinic. Young children are resorting to prostitution because of poverty.

Interviewer: Did you receive any support from the management team at your school?

Ashwin: No the management team was not supportive, although there is a HIV/AIDS policy for schools and our school also has a HIV/AIDS policy, nobody takes this policy seriously, stigma and discrimination is an important aspect in the policy but stigma and discrimination is openly practised.

Interviewer: What type of support would you like educators like yourself, to receive?

Ashwin: We HIV positive educators would like to be treated like ordinary people, and not like dirty infected people who should be isolated. HIV positive need to be supported both at home and also at school. The school principals need to be trained first, so that they can educate their staff to handle the pandemic so that compassion can be shown to HIV infected or affected learners and educators. Principals and the school governing bodies must ensure that the HIV/AIDS school policy is not being violated, then maybe together we can fight the pandemic.

Interviewer: What plans do you have for the future?

Ashwin: I often agonised about my situation, I had not disclosed my HIV status to anybody and what would happen to me when I became really ill, will I just lie in my flat and eventually die? It was with this extreme fear that I decided to contact the counselling service that I had tried some months before, this time I got through and spoke to this pleasant person, the earliest and most convenient time for us to meet was a fortnight away, I did not mind, I needed time to prepare myself. I was very nervous to disclose my HIV status to a complete stranger. My mind began playing games, there were times when I felt that I did not want to see this counsellor and at other times I felt that I needed to let somebody know that there was this HIV infected soul living all by himself, I also needed to 'off load' and share my dark secret'. My mind was finally made up after the

events of the next few days, I developed a nasty cough and severe headaches and my skin felt itchy, I told myself that it is the change of environment that has brought on these conditions. A few days later I felt really sick, I needed to talk to somebody, but who? I did not want to chase away my work colleagues by telling them that I had all these worrying symptoms. By the next day I did not want to even go to work, I had not done any preparation because I did not have the energy to do so. My eating pattern also suffered because I did not have the energy to prepare my meals, I survived on buttered bread and tea. When I went to school I had noticed by mid morning I felt drained and sleepy, I began taking cal-c-vita to boost my energy levels, this gave me diarrhoea, I felt that now my condition was deteriorating, I needed help. I was not confident about driving to Durban to keep my appointment with the counsellor, so I phoned to let her know, but she sensed that I was in a bad way and said that she will meet me in Pietermaritzburg, I was not comfortable to invite her to my flat, so we met in a park.

The time had come for me to share my secret with another person and I was nervous, was I about to chase away another individual by my disclosure? But I was surprised by this person; her name is Carol (not her real name). Carol appeared to be about my age, after our introductions and some discussions around the weather and our occupations, I eased a bit, and without really knowing it I began telling Carol about my wife and children and my divorce and whilst telling her about my agony during my divorce, I disclosed my status, she did not look shocked or say anything, she just held my hand and through this small gesture, I found the strength to unburden my load, we spoke for more than two and a half hours and by the time we concluded our meeting, I felt that I had found a friend. As an interim measure Carol advised me to have a medical check up, to know the status of my disease in terms of CD4 count and viral load. She also advised me about my diet, the dos and don'ts, and also about an exercise

routine. Psychologically I felt a lot better, Carol also told me that she was HIV positive for the past eleven years, she motivated me and told me that there was life after HIV, we just needed support and love. Carol explained that society stigmatised HIV and discriminated against HIV infected people, because they lacked education, and moreover when the opportunity arose we needed to educate people about the disease, she also said that the educators were in the ideal position to empower learners and through them society about HIV. I am an educator and the very institution that I am employed in does not provide any support for HIV infected and affected educators and learners, so much so I am virtually on the run, when suspicion about my HIV status becomes conspicuous.

Interviewer: Finally – any advice for the people out there.

Ashwin: Yes, remember that HIV/AIDS is not race, class or gender specific, we all need to be on our guard. Do not discriminate or stigmatise people who are HIV positive, they need you so please support them, you never know when you or a close member of your family may be infected and will need love and support. Although I had not taken any medication, I felt so much at peace with myself after chatting with Cindy, if only my colleagues and my family could offer me this kind of support I would most probably be in a better state of health and be confident about handling this disease.

APPENDIX 3

Delene's Story

Interviewer: Thank you for granting me this interview, please tell me about yourself, your family, your school life, boy/girl friends.

Delene: My name is Delene, I live on the Bluff. I am a coloured person from a middleclass family, I am the eldest of three children, and I have a brother and a sister. Both my parents are teachers, my father and I have a special bond, as a little girl I was always at his side, he called me his shadow. My brother, sister and I spent much of our school lives at boarding school, and we only came home during the holidays. I had many friends at boarding school, I guess it was a case of making boarding school a home away from home. This boarding school was an all girls school so there were no boyfriends. I had a set of friends in my neighbourhood who were my companions when I was home from boarding school. My parents were very strict with us and made it very clear to us that whilst we were at school, our studies were most important, and that there was enough time for boyfriends, so life in high school was pretty uneventful.

Interviewer: Tell me about your life after matric.

Delene: After matric I went to do a three year teacher diploma at Bechet college, my parents were my role model and I wanted to follow in their footsteps, my parents were very proud of me and encouraged and supported me all the way. I specialised in English, I always enjoyed my set works, and by choosing to specialize in English, I knew I was going to enjoy my profession.

Interviewer: Tell me about your relationships.

Delene: At college, in my second year of study, I was involved in a relationship with a third year student, I was very happy and content and felt that my life was complete. My boyfriend Shaun was the chairperson of the Students Representative Council (SRC), and he was a very popular

person. I was very proud to be seen in his company, he was extremely good looking and many girls were secretly in love with him. I worked very hard at my studies, aiming to be at the top of the class so that I will also be popular for being a high flier. I also wanted to excel so that when I qualified I would get a job quickly, get married and set up home, my parents approved of Shaun and they supported me and my idea.

When Shaun completed his studies he got a teaching post in Greytown, I was very upset at letting him go but my mother advised and consoled me, saying that 'absence makes the heart grow fonder' and that by being away from each other we will appreciate each other more. I agreed that there was much wisdom in what my mother said but I still missed him and pined for him.

Six months later Shaun felt that he wanted to change his job, he applied for a job in Johannesburg, he was successful and he moved to take up his new position, his new job paid him a far better salary, I was happy for him, when he was settled he invited me to visit him in Johannesburg which I did, I was very impressed with the new set up. When I returned to Durban I could'nt wait for the end of the year to join him.

Towards the end of the year, I noticed that I was doing all the phoning and Shaun's visits to Durban were getting fewer and further apart, he kept on making excuses for not coming to visit. My parents were also not happy at the way things were going. My biggest shock came when Shaun told me that he was offered a position in Australia and that he had accepted the position and would be leaving for Australia within the month. When he did'nt invite me to accompany him, I offered to join him, but he told me that he needed some space to settle in and that he will let me know when he is ready for me to come over. I could'nt believe that this was really happening to me. Friends and relatives rallied around to support me, the worst part of this whole episode was that he departed from Johannesburg and he did not contact me again. Despite all this disappointment I successfully completed my studies and decided to get on with my life, I found a teaching post near my

home and concentrated on becoming a good teacher, this new chapter in my life took up much of my time and I had little time to cry over Shaun, I gave teaching my all and my principal gave me a good report for my first year of teaching. Six months after I started teaching I moved out of my parents home into my own flat, it was an exciting time, doing up my own place and my parents helped me get settled. During the Christmas holidays I felt rather off colour and just wanted to sleep all the time, my skin had a type of strange rash on it, I visited the local doctor who diagnosed the condition as a sensitive skin that could not take the summer heat, he prescribed some antibiotics and advised that I use a good sun block when I went out in the sun. The sun block did not seem to help instead it aggravated the problem, by now I was really feeling bad by the next day I felt so weak that I needed to hold the walls to support myself. My mother got me some lucozade to give me energy, this helped but I needed to know what was wrong so I went back to the doctor to have a blood test done. The doctor suggested that I also do an HIV test as well, I thought that he was joking but he was serious and I agreed. I was still feeling very weak and off colour, I had lost my appetite and no matter what I ate I could not taste, my mouth also felt sore, I looked into my mouth and I was shocked to see some white scaly substances in my mouth. I was terrified, I went to the chemist and asked for something to relieve mouth ulcers, the chemist gave me glycerine which just lubricated my mouth without easing the pain.

A week after my blood test, I was called by the doctor's receptionist, she told me to come to the doctor's rooms as soon as possible. I was very confused and very afraid because of the tone of the message, I debated with myself as to whether I should tell my mother about this urgent call, but I decided against it, I did not want them to become worried unnecessarily. So I went to the doctor on my own, I tried to put on a brave front, but when I sat in front of the doctor I almost passed out, I felt as if the death sentence was about to be pronounced on me. The doctor got straight to the point, he told me to brace myself because I was not going to like what he was going to tell me.

I expected him to tell me that I had cancer or TB, but no he told me told that I was HIV positive

Interviewer: How did you handle the fact that you are HIV positive?

Delene: I did not handle this news, for almost six months I told myself that I was having a bad dream and that I will soon get up and realize that it was all a bad dream. The doctor was so unfriendly and unsympathetic, maybe he was mistaken, how could I be HIV positive I was not in a relationship with anybody since Shaun. Did Shaun give me HIV? No, Shaun and I were very much in love he could not have given me HIV, so how did I become infected, I did not have a blood transfusion and neither did I come in contact with blood, I was truly baffled. I could not focus on anything I kept waiting to get up from this nightmare so that I could get on with my life. My life was so taken up with this tragedy that I lost count of the days, I kept asking people, 'what day is it today?' I must have appeared mad when I asked these questions. After dwelling on this bad news for about two weeks I decided to go for another HIV test because I felt that there was an error somewhere, since the first diagnosis my life was on hold and I was stressing on something that could be incorrect. All this time I kept the news to myself because I needed to be sure, HIV is a taboo topic that people do not discuss openly or if it is discussed it is done in hushed tones. I decided to go to a state hospital for my second blood test so that no body will recognise me, I went in disguise, wearing a scarf and large sunglasses, no make up and a very old skirt and top and hoped that nobody would recognize me. I joined the queue at 5h00, I always heard that going to a government hospital was a nightmare, I never thought that one day I would end up there, and this really frightened me and made me disorientated. At the hospital I was treated like a leper and the employees at the hospital gave me the impression that they were doing me a favour. My blood tests were an adventure of their own; finally it was over and I left the hospital at 15h50, what a day! As I walked out of the hospital, I began crying uncontrollably, I felt so alone I longed to share my troubles with somebody, was I going

to die alone? I wanted a shoulder to cry on, I wanted to feel the comfort of the family home, I did not want to die, I wanted to feel safe and secure, I wanted my parents, I wanted to feel protected in their embrace. But I knew my disclosure will destroy them, also I needed to verify my status and come to terms with the results. I went home and just wept the whole night,

I went to work the next day although I was still feeling miserable, I felt that being in school and my learners will help me to forget for a while, at school almost everybody could see that something was wrong.

During the first break a group of my colleagues asked about my illness, I just fell apart and cried and explained that the doctor could not diagnose what was wrong and that blood tests were being done. One of my colleagues, Brenda, whose classroom is next to mine became particularly friendly and caring towards me, I just grabbed this friendship, but I did not dare to disclose to anybody in case they isolated me. My principal also inquired about my health, he said that he noticed I was looking troubled and suggested that I go for counseling because he could see that I was stressing over my ailment.

I did not tell anybody that I had to go for my test results in the next two days. That afternoon I went for my first counseling session. I spoke from my heart. My counselor wanted to know what my coping strategy would be until the day I got my results. I told her it would be one of denial, she advised me to record my feelings and my thoughts. I decided that I would adopt a denial approach until my results came.

Three days before my results were due, I felt very restless, I knew something terrible was wrong but choose to ignore it. D. Day arrived, I went to the hospital at 5h30. I kept telling myself that I did not have HIV. Everything went wrong for me on that day, the nurse arrived 30 minutes late. The waiting room doors were still locked; the cashier was late, there was only one doctor on duty. How I longed to have a relative or even a friend next to me just to hold my hand and comfort me. I still thought that I was dreaming. It was now my turn to go into doctor's room to get my results, I was absolutely nervous; all my confidence of the previous days disappeared. I could feel all my

energy draining away and thought that I was going to faint. My life had been on hold ever since I had gone for a blood test, I just couldn't wait another day. Medical science has come a long way, medicines were improving lives and prolonging life, no one wants to be told that they don't have long to live, we human beings are powerless over death, and this thought alone makes us feel very fearful of the future. Finally the time arrived for me to get my results, I was still in denial and feeling positive about not being HIV positive, when the doctor told me that he had bad news for me, I froze, I felt like I was losing my mind, he told me 'you are HIV positive' I just couldn't focus, I couldn't register where I was or why I was there, I was speechless, I stared ahead without seeing anything, the nurse helped me out of the doctor's room and left me in the passage. It was a day I will never forget, a day that changed my life forever. It was the beginning of the end for me.

I could not disclose my status to anyone just yet, I had to think about it first, I had to hold back tears, and tell everyone that I had leukemia, no way could I tell my colleagues that I was HIV positive, I would lose my job and be thrown out of school

My immediate fears were:

- I live on my own, how will I manage?
- My life will go from independence to dependence
- I will end up a cripple in a wheelchair, who will be pushing me around?
- I did not know how HIV physically affected a person
- The building that I lived in was not designed for physically challenged people
- How would I cope financially?
- Antiretrovirals (ARVs) were not freely available and were costly
- How will I handle rejection? This was worse than cancer
- I was HIV ignorant.

I did not go to work for a whole week. I needed to get out of this dreamlike state and think about what I was going to do. I did not leave my flat for that whole week, I did not want to talk to anybody, I was not sure whether I wanted to disclose to anybody. I wanted to make sure that I was not just having a bad dream. My eyes were red and swollen with crying. Brenda and another colleague from school phoned me to enquire about my health and they wanted to visit me, I made some excuse and did not allow them to visit. I even considered taking an overdose of tablets to end my miserable life; but something inside me told me that I should not give up this quickly. After my HIV positive diagnosis I felt that I did not have any control of my life anymore, and death was not too far away.

My parents were always asking me what was worrying me because I always appeared to be stressed and depressed, I always used the pressure of school work as an excuse. I felt miserable lying to them, my skin problems became worse with all the stress and I was losing weight fast, I was only 25 years old and I needed help, I thought that help will prolong my life. I took a long hard look at myself in the mirror, I could'nt believe what I saw, I saw a miserable gaunt looking HIV positive female, I did not see a daughter, sister, friend or teacher, whatever I had achieved thus far was now cancelled out by my HIV positive status, I felt hopeless. Four months after my results I made the painful decision to tell my family. I should never have kept my HIV status a secret for so long because I re-lived all the agony that I initially experienced. My family was devastated, my father could'nt utter a word, for a moment I wondered if he heard what I said, my mother sobbed uncontrollably and then became hysterical, screaming 'where did we go wrong?' My sibilings just sobbed so bitterly, they were so upset, I did not imagine that they would be so devastated, our home was like a funeral home. I had to do all the consoling, my mother kept saying, 'you must bury me, I'm not going to bury you, you have to get better and look after me.' I stayed at home for the rest of the week because my parents needed support, both my parents booked off sick for the week. At the end of that week we had a small indaba

concerning me and what was best for me. My family were adamant that I needed to move back home, saying that I must be with people for support and companionship, I was agreeable about moving back home because I was now afraid to live alone.

After I had accepted my HIV status and weighed the consequences, I decided I would disclose my status to Brenda because:

- I needed all the help I could get
- I could not manage this disease on my own
- Fear of the unknown, how my body was going to react
- I needed to educate myself about the HI VIRUS

I went to work after the indaba weekend and decided to move out of my flat at the end of the month to go to my parent's home. At school many of my colleagues commented on how run down I was looking, I felt that they suspected I was HIV positive and this made me very uneasy. At lunch time Brenda came to my room, she offered me an apple, I thanked her but told her that I could not eat the apple because of the sores in my mouth. Brenda was very sympathetic and went on to tell me that her sister was also having this pain on her tongue and that it was sore, then she told me that her sister was HIV positive for the past 3 years, I was really shocked at this disclosure, I was also appreciative that she took me into her confidence. I wanted to confide in her but I just did not have the courage to tell her. I asked her if any on the staff knew that her sister was HIV positive, she told me that she dared not mention it, because the staff viewed HIV in a very bad way, they ignore learners who come from homes where somebody has HIV, they believe that HIV is a curse that infects sinners. Society is very accepting of men being promiscuous, but a women is considered easy, contaminated and sinful if she has more than one partner and worse still if she is HIV positive. Brenda has been teaching at the school for 12 years so she knows the staff well.

The next day I went for my first session of counseling. My counselor was very surprised when I told her that I had already disclosed my status to my family and the effect the news had on them.

Interviewer: Do you have ‘bad’ days at work,? How do you handle these days?

Delene: Yes, I have been having ‘bad’ days before I was diagnosed HIV positive, but now it has become worse. On ‘bad’ days I agonized about going to work, I dragged myself to my classroom, and once there I had to think of ways to keep my learners occupied, I battled to put on a brave front, I kept praying for strength to face the day. This pretence of ‘I am fine’ took its toll on me, on some days I just did’nt get out of bed and phoned school to say I was ill. I was very worried because I did not know how long I was going to keep up this pretence, I was also concerned that my learners were losing out on work. I had to use my tea and lunch breaks to catch up with my marking and other admin work.

Interviewer: Tell me about your colleagues – how do they respond to you?

Delene: I have not disclosed to anybody on the staff yet, some of them enquire about my health, whilst some of them have made comments like, ‘oh shame you are too young to be so sickly’ this makes me feel very embarrassed, one person even said,’ you are gone so thin I hope you don’t have the slimmer’s disease. Comments like these make me feel very upset, hopeless and useless. I feel like I am a menace to society After my counseling session I did some introspection and tried to decide what I was going to do with my life. I took note of the following;

- I was not expecting much support at my school, I had some very dear colleagues- I was not sure how they were going to react to my HIV status
- I had to build a stronger immune system in order to cope with this disease
- I did not know much about HIV, I needed to read more
- The situation at school is definitely not going to change, so I needed to look elsewhere, maybe change my job

That afternoon I went to the local library so that I could empower myself about HIV. I found a simple to read and understand book on

HIV which I borrowed and completed reading it that night. The next day I borrowed a book on living positively with HIV which gave me some hope, it explained that by practising a safe and healthy lifestyle a person could enjoy a good quality of life despite being HIV positive. I was too afraid to go to any HIV/AIDS talks just in case someone saw me there and suspected. I felt that I needed to confide in Brenda so that I could share with her my knowledge and my fears, fortunately I got the chance to confide in her. Brenda surprised me by saying that she suspected all along because she knew the tell-tale signs. I felt very upset by what Brenda told me and I stressed about how many of my colleagues suspected that I was HIV positive.

That evening I cried, really cried, this worried me because I am not a softy, I felt better after crying. By the next day I felt very sick, I was also frustrated because my secret maybe out. One of the major problems that HIV positive people face is that we are told how HIV is spread, but little or no information is provided that tells you, “now you are HIV positive, this is what you must expect, and this is what you must do to handle the disease.” I stressed over not knowing what was going to happen to me next, I also stressed about my learners because they were neglected every time that I was ill. To be honest I did not have the energy to go to work because I was not coping, at work I could feel the subtle stigma, many of the staff members were ignoring me and that made me suspect that their suspicions were strong. On one occasion I returned after a three day absence, one of the teachers commented, ‘oh, you back, and for how long this time, another added, ‘why don’t you just go permanently so that the learners will get a permanent teacher.’ I was devastated by these comments and became very emotional, Brenda came to my rescue and took me to the sick bay and told me to get a hold of myself and to get used to comments like these. I was so emotional that I began sobbing, a cleaner came into the sick bay and saw me in this hysterical state, she called the principal, he saw me in this condition and sent for Brenda, she came to me and put her arms around me until I calmed down. When I felt a bit composed Brenda suggested that I take some sick leave and learn to come to

terms with the situation and at the same time build up my health. I considered her advice because I could not see myself coping in this hostile school environment. By that afternoon the principal sent for me, he did not ask me what had upset me so much. But he suggested that I book off sick for the rest of the term, so that I could recover properly and at the same time he could get a teacher to stand in for me, I agreed, also my big concern now was, how will I manage teaching the learners, when I am in so much pain and feeling so miserable, so maybe a replacement for me would be a good thing. I dreaded it when questions were asked about my health, because I did not know what to say to them, I just didn't want to be with people when they asked so many questions.

I went on leave the next day and told myself that I needed to help myself. I went to the CNA to look for a book to help me. I went to the section on HIV/AIDS after looking through some eleven odd books, I came across this book that caught my eye, its title read living positively with HIV, I browsed through this book, and I read how an HIV positive person's immune system can be boosted with the correct types of food, exercise, medication and change of mindset. After reading a few pages of the book I realized that it was valuable because it was written by an HIV positive person, I bought the book and then went to a pharmacy and bought Selenium, Zinc, Magnesium and Vitamin C tablets. That afternoon I discussed my new lifestyle with my mom, she insisted that I included raw garlic in my diet and she brought a lot of green vegetables, by the next two days, my throat felt much better, I haven't stopped eating raw garlic, I never realised the importance of it previously. The book that I purchased, "Positive Living" went on to explain the value of joining a support group and the importance of meeting and talking with people who are "HIV" positive. I decided that I needed to join a support group, I made some enquiries at a few hospitals and I was told that there was a support group on the Bluff, I joined this group, I was very nervous on my first meeting, but I was made comfortable and at the end of that meeting I

felt much lighter because people spoke so openly and shared their experiences.

After reading the book on 'positive living' and attending the support group meetings I realized that living with HIV/AIDS was not a death sentence. Disclosing to close family members and a few friends I could trust relieved me of carrying the burden alone, family and close friends deserved to know. I believe that when you disclose your status, it suppresses the virus and frees your soul. When you disclose, people can either accept or discriminate against you. This is a great challenge for a person living with HIV. But I felt relieved after I disclosed to the few close people I trusted, I felt free of my dark secret. For those people who discriminate against people living with HIV, they must understand that as long as they have not tested they should consider themselves positive until they know their status.

By the time my sick leave was over and I had to go back to teaching, I felt much stronger but I did not have the desire to go back to school, I felt the school environment to be a very hostile place, besides Brenda no other staff member called to ask how I was doing. I went back to teach because I needed the money and I had an obligation to my learners. Going to work every morning and having to put on a brave front was the hardest thing I had to do. My colleagues were cold towards me, could it be my status? Two of my colleagues at work knew my status and the others may have got wind from it. I was still battling to come to terms with my HIV status, I needed all the love and support I could get and here were my colleagues discriminating against me, school was not the place for me, I had to think seriously about another job.

Interviewer: Are you aware of any educational programmes that the education department has in place to educate/support the HIV positive educator?

Delene: No, I only know of the curriculum related workshops that are grade specific. Educators are still very much in the dark about HIV, they need to be educated so that they can educate the learners and maybe then the stigma and discrimination will decrease and people will openly declare their status. I took sick leave for the rest of term after attending school for three weeks, I was very uncomfortable at school and felt very angry and stressed. The next day I handed in my resignation, one of the reasons for my decision to quit school was that I needed to focus on my health, and the stressful situation at school was not helping me. I had to be a good role model for my learners, put on a brave face when I just wanted to lie down and keep quiet, but how could I when I had to teach, the thrush in my mouth used to become very painful. I needed peace and quiet and to get my life in order, and to do this I decided to resign. I continued going to the support group meetings, I felt I was with my family at my support group meetings. At these meetings we all had turns to talk on issues that concerned us most such as, love, support, fear, death, family, etc. I soon became popular at my support group and was a source of motivation to others. I was asked to address HIV positive patients in a hospital and at a church meeting, I enjoyed this very much and at the same time I think I was handling the disease well myself. A member of the church where I had spoken asked if I will address the children at her school in Sherwood on some aspect of HIV for about 20-30 minutes, I agreed. After I did my talk at this school, I felt so good the talk lasted 1 hour because there were so many questions. This talk made me realise what my mission in life should be, I had to educate people about this disease. There is so much talk about how HIV is affecting people, and especially the educators and learners, I needed to make a contribution. At this school an educator asked me very confidentially whether a person could get HIV from the toilet seat, this alone shows the degree of HIV ignorance in general.

Interviewer: In your opinion do you think that females are more vulnerable

than males to HIV infection? If yes, why?

Delene: Yes, when you think of polygamy, women almost become slaves to their husbands, the high rape statistics also show that women are vulnerable. Harassment in the workplace also points to the vulnerability. Some men feel that they are in authority always and can demand sex when, how, and with whom they desire. Many women resort to prostitution to make ends meet making them vulnerable to social demands as well as to the demands of men. Many women choose to leave their places of worship when they discover their status and to some extent their fellow congregation contributed to this discrimination.

Interviewer: Do you think that poverty and HIV go hand in hand?

Delene: Yes, most definitely, in homes where there is poverty, parents work long hours, they do not have the time to talk to their children about HIV and young children fall victims to HIV. Women who are left destitute with children resort to prostitution, and vulnerable to HIV.

Interviewer: Did you receive any support from the management team?

Delene: No, the management team at my school did not support me or even care to inquire about my health, their main concern was to get a substitute for me, I am still not sure if they knew that I was HIV positive. If the principal showed me some compassion then maybe the staff would have followed suite. After my talk at the school in Sherwood, a lady tried to make contact with me, she asked many of the educators at the school for my details and she kept getting referred to other people until she got hold of one of my school educators and this educator told her that we do not associate with Delene, she is HIV positive. I was angry and in tears. After thinking about it for a while I realised that this was just the beginning, I will still have days, months and years ahead to encounter stigma, negativity and ignorance and if I was going to allow this to depress me, then I will never survive the

journey ahead. There is a perception that HIV positive educators pose absenteeism problems in the workplace and other educators are burdened to serve relief and this becomes a contentious issues, the sooner you leave, the sooner you can be replaced.

Interviewer: What type of support would you like educators like yourself, to receive?

Delene: HIV positive educators like myself would like to be treated like any person with a chronic illness, and not to be treated like we have sinned. Arrogance, rudeness and judgements should really be eliminated and then people will find it easier to disclose their status and in this way assist in de-stigmatisation and reducing ignorance. If every school management team was educated around HIV and AIDS and in turn practiced and imparted knowledge to those around them, imagine the difference it will make. But it is sad that most tend to do nothing and look the other way and hope HIV will go away, and on World AIDS Days, they rally around to create awareness so that they are seen as promoting HIV awareness and have many photos taken for the school magazine. Managers get involved for about a few minutes in assembly, have a speaker to talk on HIV/AIDS, pose for a photo and have a caption, "We care too." So to a large extent World AIDS day can be termed hypocrisy, what happens to AIDS awareness for the rest of the 364 days? When I see people discriminating against HIV positive people, I think they need a taste of HIV to let them know that each day is a gift because tomorrow might just be the start of a nightmare.

Interviewer: What plans do you have for the future and your family

Delene: For three months after I resigned, I concentrated on my health, I did a lot of reading around HIV/AIDS, I am now practising a healthy lifestyle. I often talk to the HI-Virus in my quieter moments, because I want to believe that I am in control of my body and my life, and I am the only person who can take control of my life. I still attend my support group meetings because I am now in a position to help and support others. I am going to stay healthy for my family, they have

been very supportive. I need a job very badly, my medical bills are very high, it is not so easy to find a job when you are HIV positive. I am hoping that I will get a job with maybe an NGO to promote HIV awareness

Interviewer: Finally – any advice for the people out there.

Delene: Yes, to the youth out there, delay sex for as long as possible, because let me tell you it is not cool to be HIV positive. To every one, know your status so that you can handle the situation and get the necessary help. Please do not discriminate or stigmatise, it is very painful. Do not take life for granted, safe guard your life, HIV has taught me that everyday is a precious gift.

APPENDIX 4

Siwina's Story

Interviewer: Thank you for granting me this interview. Please tell me about yourself, your family, your school life, boy/girlfriends.

Siwina: My name is Siwina, I am 39 years old. I live in Adams Mission, with my parents. I am the only girl for my parents and I have two older brothers. We are a very together family and we love each other very much. When I was ten years old I went to a boarding school in Eshowe. I enjoyed school very much, especially music and isizulu. I was promoted from standard five to standard seven because of my very good results. After high school, I went to a teacher training college in Eshowe to become a teacher. Three years later I graduated from college with a HDE certificate. My family was very proud of me, especially my father, because I was the only one in the family to get a professional qualification.

Whilst I was in school I had many girl and boyfriends. I have one very close friend, her name is Gloria, she was my friend in primary school and she is still my best friend today. Many boys liked me but I did not go on dates with any one of them. During my college days, I used to live in the college hostel and visited my family in Adams Mission during the holidays, it was during this time that I met my first boyfriend who I later married. My boyfriend was a taxi operator and we met during my trips from college to home. Two years after I met my boyfriend, I became pregnant with my first child. My child was born during my first year of teaching. My mother helped me to look after the baby when I went back to teach.

My job as a teacher required me to accompany the learners on excursions and to play sport with other schools, sometimes on the weekends as well, this was not acceptable to my boyfriend and we began quarrelling. He told me to refuse to take the learners to play sport, I could not shirk my duties. I felt that I needed to end my relationship, because this man was

unreasonable, and the only way I could avoid my boyfriend was to move away from the district and move schools. I eventually found a teaching post in Mpumalanga province, I took this post and moved away, I did not let my boyfriend know where I was going to. After six months, my boyfriend tracked me to my new school, he apologized to me for quarrelling, he said that he loved me very much and wanted us to get married, whilst I was in Mpumalanga he maintained our child, and I felt that I needed to give him a chance to prove himself, so I agreed to come back to Durban and to marry him. We were married in 1995, at the end of that year I had my second child. I continued teaching and my mother took care of my children. My mind was very much at ease whilst I was at school, because I knew that my precious children were well cared for. My husband was a good father to the children and saw to all their needs.

Interviewer: When did you discover that you were HIV positive?

Siwina: When my second child was two years old, I noticed that my skin was feeling strange and itchy, I had tried applying lotions to soothe it but nothing helped. My good friend Gloria suggested that I see a dermatologist. I visited a dermatologist, he advised me to have a blood test, which I did, and when my results came back, I was devastated to hear that I was HIV positive, I could not speak, I could not move. I was completely shattered. I knew that I was going to die. My big concern was my small children, what will become of them? My parents, I love them so much, do I tell them, how do I tell them, should I just take my secret to my grave. I walked out of the doctor's consulting room, I did not hear anything else the doctor said, when I reached the waiting room, I felt faint, I grabbed the first chair and sat down. I kept going over my meeting with the doctor in my mind, I must be dreaming I said to myself. Without knowing it I began crying, my whole life was turned upside down in those few minutes. I did not come to the doctor for a HIV test, my reason for coming to the doctor was to find out what was causing my skin problems. The doctor must be

wrong. The other people in the surgery just looked at me, no one offered any sympathy or kind words, the receptionist went about her duties, I felt so alone in my crisis, at this stage I felt that I was my only friend. Me HIV positive, no, never, I need a retest, this time with another doctor. I refused to believe my HIV positive results, because I was and still am a one man woman, how could I be HIV positive. I was so naïve, I did not think of the possibility that my husband could have infected me. I told myself that this is just a bad dream, I am not HIV positive. I took a taxi to go home, I was so deep in my thought and did not hear or notice that by the end of the journey I was the last passenger in the taxi and I had missed my stop.

The next day, I went to another doctor to have another blood test for HIV, my skin disorder was no longer important, I needed to know my HIV status. I also asked myself why am I doing this? I answered myself by thinking that this disease won't happen to me, I was not sleeping around, I was a decent married woman and mother, I am innocent and today's blood test will come back negative, but I was wrong. Two days later, I received a call from the doctor's rooms for me to collect my blood test results. My mood played yo-yo on me, from one minute to the next, my mood swung from 'no I am not HIV positive to maybe the doctor is right, I may just be HIV positive.' My visits to the doctor on these two occasions were secret, I did not want anybody to become too concerned for me. I tried to build my confidence by chanting to myself that I am HIV negative. When I sat in front of the doctor, my positive attitude just disappeared, my knees turned into jelly, the doctor's expression made me lose all hope. He did not take any time to counsel me, all he said was 'sorry you are HIV positive'. My first reaction was one of anger, 'are the doctors in a conspiracy to give me a HIV positive result?' At this stage I did not know whether I was more angry or more afraid of what was happening to me. I heard about pre and post HIV test counseling but I did not have any and I was too upset to ask. How did I become infected? I could not remember handling blood that may have been contaminated, I hadn't been to the dentist for a long time or to the hospital where I could have

come in contact with contaminated instruments, my last suspicion was my husband, but I found it hard to believe that he would cheat on me, he loved me and the children too much to hurt us, but a small doubt remained in my mind, he was in the taxi business and the possibility of him having a good time on the side could not be ruled out completely, and this thought destroyed me further. I stressed over the possibility of my husband cheating on me, but I dismissed this possibility, I was hoping that it was not true, maybe I was in denial.

Interviewer: Now that you know your HIV status – how did you handle the news?

Siwina: I didn't handle the news at all, I didn't know how to handle the news. This HIV/AIDS thing has been around for some time and everybody believes that they will not be infected or affected, so when it happened to me I was devastated. I cannot explain to you how I felt, I think I just went numb, I was hollow and empty inside. I began thinking about all the people and the stories I heard about HIV positive people, their isolation, the stigma and discrimination. I now feared that I was going to be put in that group where others referred to me with three fingers (HIV), Z3, OMO, Hlengiwe Ignatius Vilakazi, because HIV is taboo in the rural areas. What about school? I honestly could not tell anyone there, I will be thrown out of school and stoned to death like the people did to Gugu. So I decided to keep the news to myself, but for how long I didn't know, because when anyone spoke about HIV it was doom and gloom and death. Keeping a secret will not be easy, I had to think about my husband, how will I tell him, what about my suspicion that he infected me, will he blame me like most husbands generally do, I really needed some time to work out what I was going to do, I needed to be away from my husband's home, so I went to my parents home a short distance away. My husband was OK with this arrangement because he sometimes worked very late nights.

I was still not convinced about my diagnosis, so I decided to educate myself about the disease, I went to the library in Amanzimtoti and found some books on HIV, I had to sit in the library and read because I did not want my

family or neighbours to see me with these books, it would have caused suspicion. This was a very trying time for me, I felt very guilty about being so secretive, I love my children and enjoy being with them during the holidays, fortunately I was on school holidays. The first thing I looked for in the HIV books was the HIV symptoms and as I read I recalled my husband complaining about tiredness and loss of appetite and these were symptoms of HIV. Could it be possible that my husband was also HIV positive, was he cheating on me? I recalled my auntie telling my mother that when a man is cheating on his wife, she is the last person to find out, I wondered if this was true in my case. This new suspicion made me decide to talk to my husband when he returned from his long trip, in the meantime I needed to come to terms with this dreaded disease. Another very worrying issue was my parents and two brothers, they were so proud of me and now I have let them down, do I tell them, will they support me or will they throw me away, or will the shock of this disclosure make them very ill or may even kill them? I felt so angry with myself because my HIV positive status will cause so much pain and anxiety to my family, I kept asking myself 'why me?' Most people believe that HIV can only be sexually transmitted, and that people who are HIV positive are sinners and people with low morals and do not deserve any sympathy and support. When my anger subsided, I experienced intense fear, I was afraid of what was going to happen to my body, if I became too thin, people will know that I am HIV positive, if my family disowned me I will not have any where to stay, I had fears about wasting away and dying. When I become very ill my children my children will be neglected, I don't want to even think about what will happen to them when I die. With all these thoughts going through my mind I realised that I could not keep my positive status a secret, I needed to share my burden, I wanted a shoulder to cry on, I wanted to know that somebody will take care of my beautiful small children when I am gone. The only people I could rely on were my parents, I debated this issue in my mind, how will my parents handle this issue, will they understand or will they throw me out?

results were HIV positive, my husband refused to believe the results, saying that it was an error and he was in a rage by the time we reached home. He did not go to work the next day, he kept very quiet, by the afternoon he began crying and saying that he was afraid to die, I think I am stronger than my husband and I tried to console him. My husband refused to see anyone else concerning HIV, the only thing I could do now was to keep us healthy and be there for each other. A week later my husband confessed to me that he was unfaithful to me, I just couldn't handle any more bad news, so I walked out on him and went to live with my parents. It took me a further three months before I disclosed to my parents, my parents were in shock, my father cried uncontrollably saying that this should never have happened to me because I was such a good girl. I had to console my parents instead of them consoling me, my mother became very ill and then became very depressed, my father was never the same again, my brothers did not say much, and they just put their arms around me and cried. I also cried very much I felt very ashamed and guilty to have brought this unhappiness upon my family. But when I think about it I ask myself where did I go wrong, I was a faithful wife and a good mother, I am just being punished. My home was a home in mourning, sadness on everyone's face, my parents hardly went out of the house for almost two months. Although I was the cause of their problems I had to be the brave one

Interviewer: Tell me about school, how do you manage, does anybody at school know your status?

Siwina: No nobody at school knows that I am HIV positive. I have a good relationship with my colleagues and I do not want to spoil it by disclosing my status, I don't know what I am going to do when the symptoms start showing. At school we have a staff member whose sister is HIV positive and people at school are very unfriendly towards her, this teacher is affected by her sister's HIV status and the staff are isolating her, I am in a worse position, I am infected with HIV, the staff will throw me out

of the school if they know my status, they always say that they do not want any HIV infected educators infecting them, that they must stay with their own kind. I have been doing much reading to educate myself about the disease so that I can keep myself well for as long as possible. On the first day that I went back to school after my diagnosis, I found it very difficult to concentrate, I just waited for school to end, but time just moved so slowly, I felt that everyone was looking at me with suspicion, I felt so self-conscious I wanted to run out of school and hide. At the end of the day I felt so frustrated and stressed about how I was ever going to manage working, but I needed my job, it is my only source of income and I have two little children to look after so I had to just keep going for as long as possible. I noticed that by midday I felt very tired and wanted to rest, this was not possible because I had to be in the classroom. Before my HIV diagnosis I was a very organized person, all my work was up-to-date, now my work is lagging behind. One month into the new school term I became ill and took a weeks sick leave, I couldn't say what was really wrong with me, I just felt so depressed I felt as if the whole world was against me, but the thought of my children made me carry on. I had not been in much contact with my friend Gloria, she called me and when my mother told her that I was ill she came to visit, when Gloria saw me she expressed shock and asked, 'what's happen to you, what's worrying you, why are you not at school, where is your husband?' So many questions, so much concern I felt that I could not lie to Gloria, I was touched by her concern and decided to confide in her. She cried when I told her that I was HIV positive, she held my hand whilst I told her my story, at times I wondered if I was also going to lose her because of my HIV status. Gloria also told me that I had changed very much, and that I had lost my sparkle and ever ready smile. Gloria is an only child and I am the only girl in my family, we are very close, she is like a sister to me. When I finished my story, I was surprised at how much lighter I felt, I felt even nicer when Gloria hugged me and told me 'don't worry I will always be there when you need me.'

Two days later Gloria called me and told me that I needed to see to see a counselor so that my nerves could be soothed, I was not too happy about this because it meant that I would have to disclose to another stranger. I discussed this suggestion with my family and they agreed that it was a good suggestion, I then agreed to go along with Gloria to the counselor that she had made an appointment with. After my first counseling session, I cried a lot but after I dried my tears I felt a bit stronger. Another worrying matter was not being able to cope with my school workload, I was always tired, my marking was piling up, my record book needed to be filled in, my prep book had many blanks, I just didn't look forward to going to school, I noticed that I was spending my tea and lunch breaks in my classroom catching up on my work and this was further frustrating me. I began staying away from school more often and my colleagues were not very happy about this because they were required to serve relief for me, and when I returned to school some of them looked at me suspiciously and quizzed me about my illness, I had to lie to them and told them that I had severe flu and needed bed rest. I was really upset when my principal called me into the office and questioned me about my absenteeism, and about my learners being neglected, he also told me that if I had a problem and needed to take time off I should let him know so that he could find a replacement for me because other staff members were not happy to serve relief for me so often. This meeting with the principal set me back a great deal, I needed a shoulder to cry on, I needed to be comforted so I called Gloria, she visited me that afternoon and I told her about my meeting with the principal, she comforted me and told me that I should consider taking some vitamin tablets to increase my energy levels. I took her advice and bought some energy boosters, this did help me and I tried to do my best in the classroom, but I felt that my colleagues suspected that I was HIV positive. I told myself that I had to pick myself up and stay well for my children, so whenever I came across a story or an article on HIV I cut out the article for my scrap book, I read these articles over and over again to

motivate myself and also to educate myself, I read a story about a man, his name is David Patients, he has been living with HIV for 19 years, I felt that if he could do it so could I. I have been living with HIV for the past 6 years, my lifestyle has changed a lot, I am also on immune boosters and antiretrovirals, my medication takes out a great part of my salary, but I rather be well for my children.

Interviewer: Are you aware of any educational programmes that the education department has in place to educate/support the HIV positive educator?

Siwina: No, I am not aware of any support programmes for HIV positive educators. As an HIV positive educator I would welcome every educator being educated on the basics of HIV/AIDS so that we could get rid of or reduce stigma and discrimination. Everybody needs to know that HIV not infectious like TB, you cannot get HIV by working with an HIV positive person, HIV positive people want to be treated like any other person. Principals and the management teams must know about HIV, that it is not infectious and that their HIV infected/affected educators and learners need to be supported. People with heart disease, TB and cancer are supported, people living with HIV also need to be supported.

Interviewer: In your opinion do you think that females are more vulnerable than males to HIV infection? Explain your response.

Siwina: Yes, take me as an example, I am innocent, I married my first boyfriend, I did not cheat on him but I became infected because he cheated on me. In our black culture, women can endanger their lives if they refuse sex to a black male, in our culture the men decide when, how and with whom they have sex, and female are often powerless to refuse so women are vulnerable. Females of all ages are being raped; rapists do not use condoms, so again women are vulnerable to HIV. Also in the black culture, males marry more than once and women cannot force their men to wear condoms, so the chances of infection are great. Also the issue of female genital mutilation poses a great risk for HIV infection. We do have a constitution in our country but I am sad to say that female genital

mutilation is still practiced especially in the rural areas. Women must be respected by our men because we are the backbone of the family and we need to be healthy to look after our families.

Interviewer: Do you think that poverty and HIV go hand in hand?

Siwina: Yes, people who are poor often do not have access to education and are ignorant about the disease. People who do become infected do not have the money to buy the correct foods and medication to keep their immune system healthy. Many poor people sell their bodies for sex in order to put food on the table and to look after their families. I am working and earning a salary so I am in a position to buy medication for myself but I find it difficult to make ends meet. Poor people who are HIV positive really find it difficult to keep their bodies healthy and often go on to full blown AIDS.

Interviewer: Tell me about your colleagues – how do they respond to you?

Siwina: I haven't openly disclosed my HIV status, but I feel that they suspect. They are not very friendly towards me ever since I started becoming ill and staying away, I sometimes feel that some of my colleagues avoid me. During the time when I was ill, my colleagues were more interested in the nature of my illness instead of how I was feeling. My principal was very uncaring when I was ill, he said that I should stay at home if I had a problem so that he could get a relief teacher, but he went on to add that it was important for me to recover fully, because being in front of a class is very demanding for a sick person. These days HIV infection is so common and people are scared to say that they are ill because of the suspicion of colleagues.

Interviewer: Do you have 'bad days' at work? How do you handle these days?

Siwina: Yes I do have days when I don't want to get out of bed, I feel so depressed and miserable, I want cover my head with the blanket and shut out the world, and on some of these days I bunked work and spent my time moping around the house. I have had many bad days at school, I have this cough that would just not go away and it really makes my chest

very sore, on a bad day my body becomes too heavy and I feel tired, by mid - morning I have to put my head on the table and lie down, by the afternoon I cannot stand up and teach so I set some work for my class to do, something that does not require too much supervision, on one such day my principal came into my classroom, he was not happy, he just shook his head and walked away, I felt hurt and insecure, I was worried that he might write a negative report about me or get me transferred to another school. If the principal took the trouble to speak to me he would have seen that I was really ill, this worried me a lot and I could not sleep that night. I decided to go back to my doctor to explain my listlessness and weakness and also to get some medication that may help me. An HIV positive person has to be very careful when taking medication because some medication can make a person very ill.

Interviewer: Do you receive any support from the management team?

Siwina: No, I sometimes think that they just want to be policemen, to make sure that you are at school and that you are teaching, they are not concerned about your problems. For example on the day my principal saw me with my head on the table he didn't ask what was wrong or was I feeling unwell, his behaviour caused me more fear, pain and stress.

Interviewer: What type of support would you like educators like yourself, want to receive?

Siwina: Firstly, I would like to see HIV/AIDS education taught properly by every educator in the school, so that everyone will know that they cannot become infected if they treat their HIV positive colleagues and learners normally, this education will also get rid of stigma. Medication for HIV is very expensive, educators find it very difficult to cope with this additional expense and assistance in this respect will be good. I would also like to see a support group established for HIV positive educators, so that we can meet and exchange information and talk, this may help us to cope with the fear, stress and loneliness.

Interviewer: Tell me about your plans for the future.

Siwina: I have been living with this disease for almost 8 years, I was ignorant about HIV, but after the shock of my diagnosis, I made the attempt to educate myself, I have changed my lifestyle to stay healthy. The most important thing in my life is to stay well for my family, I want to look after my parents in their old age, I want to be there for my children for as long as they need me, I want to still be here when my children finish school and start working. I am lucky to have such a supportive family, I know that I would have perished a long time ago if it was not for them. My ex – husband has now got aids and is very ill, a few years ago I tried to share with him what I knew about HIV and advised him to change his life style, but he did not believe me when I said that he must avoid being re-infected, therefore HIV/AIDS education is so important. Many HIV positive people do not believe that it is important to practice safe sex because they do not believe that you can become re-infected.

Interviewer: Finally – any advice for the people out there.

Siwina: HIV/AIDS is destroying our country, please be careful, please be faithful to your partner, once you are infected there is no turning back. I appeal to everyone to get tested and know your status. Please treat HIV positive people with compassion we need friends. I now appreciate everyday more, everyday that I get out of bed I thank the Lord because it is a bonus, so don't take life for granted.

APPENDIX 5

Thandiwe's Story

Interviewer: Thank you for granting me this interview, please tell me about yourself, your family, your school life, boy/girlfriends.

Thandiwe: My name is Thandiwe, I am a black female from a low-income group family. I am the youngest child in my family, I have an older sister. We are a very close knit family and I come from Imbali Township in the Midlands area of KwaZulu Natal.

I remember my childhood as a happy one amongst my extended family on the farm. My sister, cousins and I attended a school on the farm where my parents worked. I remember as I was growing up, my extended family were moving away to other places and later I realised that the farmer who employed my family had decided to sell his farm and go overseas. School was not as I had first remembered it to be because there were very few children there. My parents also decided to move to another place, it was nearer to a city and we went to a proper school with lots of children, my mother got a job in the nearby supermarket and my father found a driving job.

My sister was at high school and we wore uniforms to school. This was a big change for us, we were very excited, this was the first time we were wearing uniforms to school. Two years later I joined my sister in high school and I did very well at school. I told my parents that I would like to be a teacher when I grew up because I admired my class teacher. My parents encouraged me in my schoolwork to help me achieve my goal and their dreams. My sister dropped out of school in Grade 11 and did a short secretarial course, and she held a few temporary jobs before she found a permanent job in a building company as a receptionist.

Interviewer: Tell me about your life after you completed matric.

Thandiwe: After I completed Matric I was accepted at a teacher training college to become a teacher, my parents were overjoyed, we had a big celebration in the neighbourhood to wish me well before I left home for my new college. I now had a new set of friends at the college and I really enjoyed their company, they also had to leave home in order to be able to study at the college, we stayed at the college residences because of the distance from our homes and traveling costs. At the college hostels we had many parties and I met many people coming from varied backgrounds. I did well in my first year at college and when I went home at the end of that year, my parents had a big party to celebrate my success at college. I was very happy with myself for achieving such good results and making my parents so happy.

The first quarter of the second year also went well I chose to specialize in science because I enjoyed science at school.

Interviewer: Tell me about your relationships.

Thandiwe: During my high school days I had many male friends but no serious relationships. When I went to college I did not have a boyfriend and my friends teased me, but I remembered what my mother told me, she said that I had my whole life for boyfriends, now was the time to study. Towards the end of my first year at college, when lectures were over we had many parties, at one of these parties I met Simphiwe, a very respectable young man who worked in a bank. Simphiwe and I began seeing a lot of each other and secretly I thought my parents will like him for a son – in – law. When I went home for the Christmas holidays I spoke to Simphiwe often on the phone, I was happy with the way my relationship with Simphiwe was going and I was also looking forward to going back to college in the new year so that I could be with Simphiwe. My studies were going well until I fell ill. I was really scared and worried, I was afraid to go home and tell my parents, when I felt that I could not manage anymore I went home, my parents were very upset to see me so ill. The next day my mother took me to the nearby doctor who diagnosed my illness as pregnancy, my parents were very disappointed and were very unhappy because I had let them

down. I went back to college when I felt better so that I could complete second year as my baby was due towards the end of that year. Simphiwe was father of my child and he is the cousin of my best friend, when I contacted him to tell him what had happened, he refused to take responsibility and just disappeared, on that day I promised myself never to trust a man again, I was truly heartbroken. I wrote my exams at the end of that year, but this time there was no celebration. My baby was born at the end of the December. I had to abandon completing my studies for a whole year to look after my baby. After that year my mother decided to give up her job to look after the baby so I could go back to college to complete my studies. When I returned to college, most of my colleagues had moved on and I felt very out of place. I just couldn't wait for that year to be over to write my exams and start teaching, I now had the responsibility of a child. By the time I completed my studies and got my diploma I was 26 years old. My first teaching job was near home, it was a temporary job, I took the place of a teacher who was on sick leave. My parents were really proud of me, and the community really looked up to my family because I had qualified as a teacher and brought honour to my family and also to the area that I was now living in. My stay at this first school lasted a term and then I had to start looking around for another school that needed a teacher. My search for another school took me to a primary school in Greytown, I worked at this school for two terms, life at this school was difficult but interesting at the same time. My new school in Greytown was a six-teacher school, which meant that as a teacher you did many different jobs from teaching to admin to caretaking. For the two terms I was at this school, I was replacing an educator who was on accouchement leave. It was easy to "settle in" at this school because I had so many jobs to do and this left me very little time to feel bored. Here again I was given a chance to prove my versatility and worth. I was soon accepted as part of the family of this school and enjoyed a good relationship with the staff. I was also given a sports code (netball) to be in-charge of, I enjoyed this very much. The only thing that bothered me was that with all the running and

jumping that netball demanded, my energy levels could not cope and at times I felt faint, and at one such training I did faint and the other educators came to my assistance. The following weekend I decided to go to the doctor for a check up. Being a very thin small person, I thought that I may be anaemic. My blood sample was taken for a test and I was given some iron tablets to take in the mean time. I did not find much improvement in my energy levels, but I continued to take my iron tablets. My doctor diagnosed my condition as something lacking in my blood and said that I needed more medication and blood transfusion. I had my blood transfusion in a hospital near my home in Imbali in Pietermaritzburg in the year 2003. Fortunately for me I went into hospital for my blood transfusion at the end of the year and my two term contract at the school had come to an end. I used the Christmas holidays to recuperate.

By the time school had started for the new year, 2004, I felt slightly stronger, but at times I did feel faint and went on a course of vitamin tablets. I was also looking for a new teaching job. I got a job at a school in Inchanga, I was referred to this school by the principal of my previous school, I needed this job because I had the responsibility of a child and the medication that I was taking to keep myself going. My new school was rather far away and the travelling really tired me out. I did not want to refuse the job at this school because I was not just replacing an educator, I was an additional educator and there was a possibility that I will remain at this school for sometime. The atmosphere at this school was very different to my previous school. At my previous school we were like a family. At this school the homeliness was lacking, but anyway I went about my work as best as I could. There were times when I felt that I did not have the energy to walk to the staffroom. I sat in my classroom and carried on with my work or preparation. Some of the educators felt that I was 'stuck up', but I explained that I had a lot of preparation to do and therefore sat in the classroom to complete my work. I did not feel close enough to any of my colleagues to tell them that my health was not good. During the

first six months at this school I worked myself to the bone to get preparation done and to be considered a good educator. My head of department seemed to be pleased with me, more so after I heard that she was a difficult person to please. I was very relieved when the July holidays came along, I spent much of my holiday looking after my child and resting. I did not go to the school to help out because I knew my problem, I was anaemic and needed to build up my resistance and strength. I ate foods that provided a rich source of iron and I also took my vitamin tablets. All too soon the holidays came to an end and I had to go back to school.

The third school term of 2004 was not a very good time for me, my health was really a great concern for me, I was tiring more easily and I was also getting thin and I just felt very miserable. On some days I did not feel like getting out of bed, the skin on my body sometimes felt very strange, and I suspected that there was more to my illness than just being anaemic, but the possibility of HIV never crossed my mind, after my baby was born I was not sexually involved with anybody, my pregnancy was a big eye-opener for me and I did not trust anyone anymore. Because of this I ruled out HIV.

As the term progressed, my resistance became lower and on some days, I had to put my head down during breaks just to rest. On one such day, about mid third term I felt very sick in school and had to take leave, I went home and just slept, I did not go to teach for the rest of that week. My parents were very concerned and worried about my deteriorating health. I was no more that lively, active and talkative daughter they once knew, I did not have much energy to look after and enjoy my child and all these factors were very painful to me. My mother advised me to go to another doctor because I was still very ill despite doing what the first doctor advised me to do. The quality of my life was slowly deteriorating and this made me very sad, because I could see the negative effect it was having on my family.

I was too weak and ill to go to school on the last week of the term, I then decided to go to another doctor in Pietermaritzburg, he told me that he had to do a few tests to diagnose my ailment, he also suggested an HIV test, by this time I just wanted to know what was wrong with me, so I had whatever tests the doctor had suggested. I really looked forward to the Michaelmas holidays, just to be at home. I went back to teach at the beginning of the fourth term of 2004, and I tried to be energetic just to put on a brave face. My ailment and my private lifestyle gave me a reputation at school as being a 'stuck up person' and I did not really have a close friend to confide in except the educators who occupied the classrooms on either side of my classroom. On Tuesday of the first week of term four I went to the secretary's office to collect leave forms, a group of educators were in the corridor talking, as I approached them they dispersed and went into their classrooms, I felt hurt because after being ill, I expected colleagues to inquire about my health, but these colleagues did not, they just ignored me.

At the end of the first week of the fourth term I had an appointment with the new doctor I had visited during the Michaelmas holidays to get my test results. The doctor knew the history of my anaemia and weakness and he was sympathetic. Now I had gone to get the results, I longed to have someone with me, I was so afraid that I was ready to pass out, I wanted to shout out 'please give me my results and get over with it,' I think the doctor sensed my anxiety. I plucked up courage and said, 'please tell me my results', all the doctor could say was, 'No, its not good news, it came back positive.' When I heard the word 'positive', I felt a rope tighten around my neck, like a death sentence was placed over my head, I felt that my life completely stopped, I couldn't breathe or speak. When I gained my composure, all I could say to the doctor was, 'I don't believe you, it is a mistake.' All the doctor could say to me was 'I am sorry,' I then began crying, I just cried and cried, I don't know what I felt, it must have been the terror of dying or grief that my life was over now and that I will soon die and

the horror of what will become of my child and my parents, will my daughter remember me when I'm gone? The doctor tried to console me and advised that I should go for counseling, yet he did not counsel me, I was beyond counseling and just thought about the time I had left.

Interviewer: How did you handle the fact that you are HIV positive?

Thandiwe: You know what, my mouth felt so dry, as if I was already dying. I felt so scared, I was so frightened to die, I was too young to die, I will not see my beautiful daughter growing up, who will mother her? So many questions but no answers. It was still very early on a Saturday morning that I had gone to the doctor to get my results, I had to come to terms with the terrible news that I had received, and I needed time to come to terms with the situation and how I was going to handle it. I kept telling myself that this is a big mistake I am not HIV positive. For moments I felt that this was a bad dream and I will soon awaken and realise that it was all a dream. I took a taxi and went to the city gardens and found a bench in a quiet part of the garden and sat there with my thoughts. I sat there for almost three and a half hours, I only realized this when my sister called to find out where I was, I had to decide whether I was going to burden my family with this problem or not. What about school, I was not close enough to any of my colleagues to talk about my positive status, I always had the feeling that my colleagues were suspicious about my health. I also decided not to tell my family about my HIV positive status, I knew that they would be devastated, I saw how upset they were everytime I stayed away from school or went into hospital. I loved my family and did not want to stress them anymore. I decided to carry this burden alone to my grave. But I was going to keep myself well, up and about for as long as I possibly could. I want to be with my daughter for as long as God will allow me to. My understanding of HIV/AIDS was very elementary, that is why I have joined your empowerment workshops to educate myself, and change my lifestyle.

The next burning question I had to deal with was how did I become infected, "was my child also infected, I was sexually involved with the

father of my baby, there were no other men in my life when did I become infected, was it when I had the blood transfusion?" There were so many questions and I did not have answers for all these questions. I did not have the energy to investigate how I became infected. The stress and anxiety further caused my health to deteriorate, at times I felt that I did not belong in this world, I wanted to run away from home or even commit suicide.

I was very frustrated with myself for causing so much pain for my family, I was also very anxious as to how I was going to cope with my huge dark secret. At night I could not sleep, I used to sit on my bed and weep for my family, for the fact that I was going to die and leave my baby and my family. My mind was continuously occupied with nagging doubts, conflicts and thoughts of how long will I be able to hide my secret, what will I do when the symptoms start showing? People keep away from you if they are suspicious about your HIV status, how much worse it will become if they know for sure that you are HIV+, I will just have to carry this shameful burden alone. I had visions of dying and my daughter being left alone. Last year a person in our neighbourhood was diagnosed HIV positive. The community were up in arms, they did not want her in the area and tried to drive the family out the area, when that did not work, their home was set alight and burned to the ground. The belief in the community was that an HIV positive person will contaminate the area and spread the disease. It was after this incident that I decided to keep my HIV status secret, I will have to take my secret to my grave, I could not allow my family to undergo the same fate, some people are so heartless and cruel. All I could think of was that I had to keep my HIV status my secret in order to protect my family and most of all my child, I did not want the stigma to be put on her.

Some of my very big concerns were that I will not be around to see my daughter growing up, her first day at school and who will guide her through her adolescent stage. All these thoughts were too painful for

me. I could not see myself even living for the next five years, the future was gone, time took on a whole new meaning for me, I felt that death was not far away. I did not want people visiting me hospital. On some days I felt so sick, I wished that death will come quickly so that I will be out of pain.

Interviewer: Do you have 'bad' days at work, how do you handle these days?

Thandiwe: Yes, almost everyday is a 'bad' day, I feel drained, no energy and too many vitamin tablets gives me stomach problems. On some days I get up with this severe headache, and these are really bad days, just keeping my head up is a big effort, on these days I just stay away because I don't manage. My backlog of work is of great concern to me, and the learners also lose out, all these are stressful to me. I do not sit and teach, my principal is very much against this, but there are times when I have to sit and teach, when I sit and teach I am fearful just in case the principal sees me, sometimes I feel I just cannot go on living with my secret, I wish I had the means to stay at home and be with my little daughter.

There are nights when I sit up with a great fright, and aish, I think about this thing, is it really true, is it destroying me and my family, I can't believe it. I look at my little daughter and my heart just breaks, I ask God 'why me?' In my prayers I ask God to spare me so that I can be there for her until she is independent.

Interviewer: Tell me about your colleagues – how do they respond to you?

Thandiwe: I have not told any of my colleagues about my status, I cannot see myself disclosing to them if word gets out that I am HIV positive then my whole family will be destroyed their house will be burnt to the ground. I did not want to go back to school, I felt that my colleagues knew, the way some educators looked at me, and stood around in corridors discussing, it was me they are discussing. I just did not trust anyone. Some of them were very nasty to me about being absent, they said that they were forced to do relief for me and that it was not fair on them and that I must do something about it.

I had been absent for about a week, I was really ill and on my return one of the learners in my class asked me why I was so ill and what was wrong with me, I was very shocked to be asked this question by a learner, but I made an excuse and explained that I had a problem with my blood being weak and that this caused dizzy spells. They all ooh:d and aah'd and some said 'sorry miss', then one learner said that during my absence, one of the educators who served relief in my class asked one of the learners to fetch a chair from the staffroom for her, this learner took my chair from behind my table and gave it to this educator, but this educator refused to take the chair saying, 'boy take that chair away from me quickly, I don't want to sit on that dirty chair and get sick like your teacher.' I was really very hurt and upset by this, I did not know who to turn to, I felt a constriction in my chest, I felt like throwing myself on the floor and crying, 'oh why did this happen to me, I didn't do anything wrong, God please help me. I have stopped going to the staffroom because I often sit by myself and nobody talks to me, I don't know how much more of this I can take. I ask you, 'what could I do, I can only pray for strength to see me through the rest of my days.

The rest of the fourth term went by with many deadlines to be met and I really struggled, the stress and anxiety did not help my condition, I was thankful when the school exams began, I stayed away from school for a total of eighteen days, my principal was not very happy about my absenteeism and mentioned that he would need somebody who had better health and not stay away so often, but nobody knew what I was going through. I managed to drag myself to school for the last two weeks of the fourth term. The December holidays arrived, I was so ill and on some nights I felt so sick and thought that I will not be able to wake up the next day. During the holidays I spent many days in hospital, I hated this, I wanted to spend as much time as possible as with my daughter. My parents were really affected by my illness, I cannot imagine what it will do to them if I disclosed my status to them.

Interviewer: Are you aware of any educational programmes that the educational department has in place to educate/support the HIV positive educator?

Thandiwe: No, if there were any programmes I would have attended, but I do not know of any.

What type of education/support would you like to see implemented to help infected educators cope with HIV?

Firstly the school principals must attend an HIV course so that they will know about the disease, and not stigmatise, people need to understand that HIV cannot be passed on by touching or speaking politely to an infected person. There are many infected and affected people in schools and something must be done to help them, at the moment I do not see any support, there are times when I feel that we HIV positive people are in a huge ocean with no where to turn.

Interviewer: In your opinion do you think that females are more vulnerable than males to HIV infection? Why?

Thandiwe: Yes, men really take advantage of females, especially among the black people, men always believe they are higher than women, and their commands must be obeyed. Demands for sex must be obeyed or else....., in our culture men are allowed more than one wife, males having more than one sexual partner makes women extremely vulnerable. The other frightening issue is rape, we hear of people being raped on a daily basis, this also is of great concern to because I have a little daughter, I stress for her safety, I may not always be there to protect her, I can only pray that she will be safe. I love my daughter very much, she has brought me so much happiness, but sometimes I wish that I never had her, like now when I am dying.....(sobbing)
(15 minute break to console her, she requested that we complete the interview today because her health was deteriorating)

Interviewer: Do you think that poverty and HIV go hand in hand?

Thandiwe: Yes, people who do not have food to eat will look for food in the bins, so a mother or any female who is desperate for money will sell her body.

Interviewer: Did you receive any support from the management team?

Thandiwe: No, absolutely no support, I hoped I could confide in some of my colleagues, this secrecy is killing me, I feel so isolated when I go to school, like an alien. About a month ago I was really very sick I felt that very soon I was going to die, so I called my sister and told her my secret, I made her promise me that she will keep the secret to herself because our family must be protected always.

The new school term in 2005 did not see me looking or feeling any better. Some HIV symptoms began showing such as loss of hair, loss of weight, patchy skin and glands in my armpits. After two weeks into the first school term, I became very ill and had to be hospitalised. The doctor at the hospital checked my CD4 count, I was shocked when he told me that it was 165, I knew now that I had no hope. My mouth is full of sores, I cannot eat, I have liquids through a straw, I have no energy, I am so miserable, now I just want to die, to be relieved of this pain. I was in hospital for eight days with diarrhoea and severe stomach cramps then discharged, I took sick leave for the rest of the term, so that the school could get a substitute teacher to replace me. During this time I managed to take my daughter for an HIV test, I needed to know her status, I did not want her to suffer like me, fortunately for us my daughter was HIV negative, I was now convinced that the blood transfusion I had, had infected me. After the Easter holidays I still did not have the energy to go back to work because I just didn't have the energy to get dressed and make the journey to school.

I have suffered this long with the disease, I thought of turning to God, to make my peace and clear my path, on the day I decided to visit the pastor, I did not have the courage to do it, because of the stigma and discrimination and protecting my family.

I went back to the school on the first day of term 2 of 2005, by mid morning I was very ill and collapsed, paramedics were called in to attend to me, and I was admitted to a hospital in Pietermaritzburg where I stayed for ten days and then discharged to rest at home. (At this stage I decided to stop my interviews with Thandiwe, because I realized that she was experiencing much pain, my last meeting with her was cancelled on three occasions, I had to be patient, I understood her plight, I offered to visit her in hospital or at her home, she appreciated the gesture but refused explaining that it would raise too much suspicion)

That was my last contact with Thandiwe, she was re-admitted to hospital a month later, her condition deteriorated rapidly and she was in and out of hospital, I was sure that I was going to have another interview with Thandiwe but Thandiwe finally gave up her fight for survival on 20 August 2005. My contact person with Thandiwe's family during the last few months was Thandiwe's sister, Cindy. Cindy told me how devastated her family was and her family was finding it extremely difficult to deal with her untimely death. Cindy had promised her dying sister to keep her HIV status a secret, so that her family will be protected from the stigma. Cindy did all the liaising with the hospital and made all funeral arrangements, she explained Thandiwe's death as a blood disorder and anaemia. Apart from grieving Thandiwe's passing away her family have the responsibility of looking after Thandiwe's little daughter. Thandiwe went to her grave with her HIV secret, she confided in her sister only, about six months before her death.