BEING HIV AND AIDS AFFECTED: HOW IT AFFECTS THE SCHOOL LIFE OF AN AFRICAN FEMALE ADOLESCENT LEARNER IN KWAZULU-NATAL

by

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Declaration

Unless specifically indicated to the contrary, this research report is the result of my own work.

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SUMMARY

The HIV and AIDS pandemic has affected millions of people worldwide. In 2004, statistics released by UNAIDS revealed that the number of people infected with HIV and AIDS had reached 42 million worldwide. Much has been written about the plight of those infected with the disease but not as much attention is focused on those who, although uninfected, suffer the effects of living with a family member or close friend who is HIV positive. There are those children of school-going age who live with, care for and are affected by the HIV and AIDS infected. These children are affected in all spheres – in their home life, their relationships, and their academic life at school.

Studies show that these HIV and AIDS affected adolescents constitute an at-risk population. This study attempts to understand the impact of being HIV and AIDS affected on adolescent learners. A qualitative approach was employed in conducting this research. Purposive sampling was used to select an information rich individual, one African, female, articulate adolescent learner. The case study method was employed. The data was obtained by means of open-ended questions in numerous interviews.

The findings indicated that the HIV and AIDS affected learner experienced significant difficulties, such as depression, isolation, fear of stigma and developmentally

inappropriate responsibilities. These difficulties had an impact on all areas of her life – her school life, peer relationships, relationships with teachers, her family life, and her development.

Key words

- HIV and AIDS affected

- Adolescents

- Learner

- Educational psychology

- Ecosystemic framework

List of Acronyms

HIV : Human Immunodefiency Virus

AIDS : Acquired Immunodeficiency Syndrome

DoE : Department of Education

ARVs : Antiretroviral medication

CD4 cells : Immune cells

UNAIDS : United Nations Aids Program

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CHAPTER ONE
GENERAL ORIENTATION, PROBLEM STATEMENT, AIM, RESEARCH METHODOLOGY AND COURSE OF STUDY

1.1 INTRODUCTION

*"I feel the stigma thing, that they'll just feel touched, and then...
they'll think I'm different."*

HIV and AIDS affected adolescent

Much research has focused on the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) infected members of South African society (Moletsane, 2003), but not enough studies in this country have documented the plight of the 'affected not infected', those who are healthy, yet live with family members who are infected by the disease.

In South African schools, one of the most relevant and prevalent topics for discussion should be HIV and AIDS. The Global Overview and Statistics from UNAIDS (2004a) report that the number of people living with HIV and AIDS is 42 million. The number of people newly infected with HIV in 2003 was 4.8 million. The AIDS related deaths in 2003 were 2.9 million. In South Africa alone, there are between 4.5 million people and 6.2 million people living with HIV and AIDS. Women account for 57% of all people living with HIV, and 15-24 year olds account for nearly half of all new infections worldwide (UNAIDS, 2004b).

Unfortunately, not much local literature is available relating to the experiences of South African HIV-affected high school learners. The statistics suggest that the number of children affected, but not infected by HIV and AIDS might be significant. In an emergency document from the Department of Education (2002:27), President Thabo Mbeki stated that HIV and AIDS was the fastest spreading infection in South Africa. He also stated that 1500 people in South

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Africa were being infected daily and that 3 million people had already been infected. The latest data from UNAIDS (2004a) reveals that there are up to 14 000 new infections a day worldwide and 95% of these infections occur in developing countries. Yet little is said on the subject of HIV and AIDS in schools. Apart from the occasional official document left in the staff room, which may be briefly perused by staff-members, yet never discussed, it is like the 'elephant in the corner', obvious to all but never talked about.

In a study done by Shisana and Simbayi (2002) at Ekuthuleni in KwaZulu-Natal, levels of disclosure are minimal due to the vicious stigmatization of people living with AIDS. People with AIDS and their families generally collude in attributing their ill-health to a more socially respectable disease such as tuberculosis. So successful was this that most people said that they were not aware of any HIV-positive people in the community (Campbell, Fouls, Mailman & Sabina, 2005: 472). Generally, an adult coming into a school classroom and attempting to teach adolescents on abstinence as the only prevention to HIV faces scorn and marginalization.

School is often the place where the behavioral and emotional problems of adolescents are exhibited. This is in line with the findings of a pilot study done in the United States of 40 HIV-affected families, including 59 children between the ages of 10 and 19. Thirty-four percent of the children were reported as having problems at home, seventy-three percent had problems at school, and fifty-eight percent had experienced lower school grades (Draimin, Hudis, Segura & Shire, 1999: 43). The researchers noted that when HIV-affected children are acting out their most disturbing emotions, their behaviour confuses and distracts parents and teachers, who are "so preoccupied with the surface behaviours that they are unable to address the underlying emotional issues involved" (Draimin et al., 1999: 44). The above has led to an awareness of the need to explore the experiences of similar children in South Africa, so that we can come to an understanding of what life is like for learners from HIV and AIDS-affected families, and the impact of being HIV-affected on their school lives.

Educators working with and interacting with troubled learners have become aware that many of these learners are HIV-affected. The experience of living with HIV and AIDS infected family members has many and various effects on the school life of the learner. These can be examined through an ecosystemic framework. According to Donald, Lazarus and Lolwana (1997: 36), ecosystemic theory sees different levels and groupings of the social context as 'systems' where the functioning of the whole is dependent on the interaction between all parts. To understand the whole, the relationship and interaction between the different parts of the system must be examined. In the case of the HIV and AIDS affected learner, the effect of home life on school life may be explored. A child who lives with a sick relative may suffer various effects as a result of the situation at home. These effects may be carried over into the school environment where it may affect the child's academic work, her relationships with her peers, teachers, and aspects of her development.

In addition, the question of how HIV and AIDS affected learners have barriers to learning must be addressed. Thus one must link the topic to Inclusive Education, which protects the right of every individual to attend school and to have his specific educational needs met (Naicker, 1999: 45).

The stigma and secrecy surrounding HIV and AIDS has an enormous impact on how one helps HIV and AIDS affected learners. This qualitative, interpretive and explorative study (Denzin & Lincoln, 1994: 142) could help the helpee as much as the helper by enabling the affected participant to make sense of her feelings and behaviour. By entering the helpee's frame of reference and accurately communicating an understanding of the helpee's experiences, the study could facilitate the helpee's exploration of her experiences and develop her insight (Carkhuff & Anthony, 2000: 19).

Much has been reported about HIV in general: Baggaley, Sulwe, Kelly, Macmillan and Ndovi in Zambia (1996) explored the experiences of HIV counsellors; Draimin et al (1999) studied HIV affected adolescents, as did Lewis (1995), Gewert and Gossart-Walker (2000) and others in the United States; Stein, Riedel and Rotheram-Borus (1999) in Australia focused on 'parentification', a

role reversal in which HIV-affected children, in effect serve as parents to their parents or siblings; De Lange, Mitchell, Moletsane, Stuart and Buthelezi (2004) researched many aspects of the HIV and AIDS experience through visual representation in South Africa; but extensive searches of academic databases, both local and nationally brought forth no research dealing with the plight of HIV affected African girls in South Africa, and the effect on their schooling. It is therefore necessary to explore learners' perceptions on being HIV affected and the effect it has on their school life.

1.2 PROBLEM STATEMENT

The problem facing many educators in South African schools today is that many of their learners may be HIV and AIDS affected, yet, due to the tremendous stigma associated with the disease, the learners will not come forward and admit to the problems associated with living with people who have HIV and AIDS. Instead, learners mask their pain by acting out their most disturbing emotions, thus distracting teachers who become "so preoccupied with the surface behaviours that they are unable to address the underlying emotional issues involved" (Draimin *et al.*, 1999: 44). Therefore these learners would require specialized support in the educational context and attention would have to be given to the needs of the individual learner. Educators would need to know how learners might manifest their problems in every aspect of school life.

Considering the above information, two research questions can be generated:

1.2.1 Research Questions

How does being HIV and AIDS affected affect the school life of an African female adolescent learner?

How can the information gained be used to formulate guidelines and recommendations so that the school can address the issues associated with HIV and AIDS affected learners?

1.3 RESEARCH OBJECTIVES

In line with the research question the objectives of this study are twofold:

The primary research objective is to explore and describe how being HIV and AIDS affected affects the school life of the African female adolescent learner.

The secondary research objective is to use the information gained to formulate guidelines and recommendations so that schools can address the issues associated with HIV and AIDS affected learners.

1.4 CONCEPT CLARIFICATION

1.4.1 HIV and AIDS affected

The Human Immunodeficiency Virus (HIV) is a virus that attacks the immune system and reduces the human body's resistance to other illnesses and disease. HIV is often a sexually transmitted infection, and can also be transmitted through blood and other bodily fluids (DoE, 2002: 4-5). The final stage of HIV infection is full-blown AIDS (Acquired Immune Deficiency Syndrome). A syndrome is when several symptoms occur at the same time (DoE, 2002: 4-5). To be HIV and AIDS affected is to be not infected with HIV, but to be affected by it, as in living with close family members who are infected with HIV and AIDS. HIV and AIDS, therefore, could have a profound impact on all aspects of the affected person's life.

1.4.5 African

An African is a person from Africa (Collins Dictionary, 2001: 13). In the South African context, to be described as African would imply certain physical and cultural characteristics. The physical characteristics of an African generally include black skin colour, and in South Africa, most African people are of the Nguni tribal groups, incorporating tribes such as Xhosa, Zulu, Sotho, etc. An

African may have internalised specific traditional beliefs associated with African culture (Blackwood, 2003: 576).

In the context of this study, it would be relevant to describe traditional African beliefs regarding illness and disease. It is common in many traditional African cultures to attribute illness to spirits and supernatural forces. In South African traditional belief systems of health and disease, specifically, ancestors and God are the ultimate causes of illness (Blackwood, 2003: 578). People become ill because they have done something to anger the spirits of ancestors or God. Ancestors may either send illnesses themselves to the afflicted person or may have withdrawn their protection (Van Dyk, 2001: 43). With AIDS, beliefs that the condition comes from spirits are reinforced by the fact that some people have AIDS and others do not without any recognizable differences in their lives. Attributing the cause of AIDS to ancestral spirits or an angry God leads directly to stigmatising beliefs about people with HIV and AIDS as they have surely brought their condition upon themselves and their community (Goffman, 1963: 27).

Attributing the cause of HIV and AIDS to the afflicted brings about a sense of repulsion as well as the justice of social sanctions, two major dimensions of stigmatising beliefs (Kalichman & Simbayi, 2002: 578). In other words, the two main stigmas against HIV and AIDS involve disgust or repulsion for the afflicted person, and ostracising, shunning and avoiding them. Stigmatization is the process of judging individuals and groups to be unworthy of social investment (Reidpath & Chan, 2005: 425).

Thus, to be an African adolescent and to be HIV and AIDS affected can be to be caught in a double bind – one has to deal with the trauma of living with relatives who are infected with HIV and AIDS and the possibility of being ostracised in one's own community due to traditional African beliefs.

1.4.3 Adolescent

Adolescence is defined as the developmental period of transition between childhood and adulthood; it involves biological, cognitive and socio-emotional

changes (Santrock, 1998: 24). The biological, cognitive and socio-emotional changes of adolescence range from the development of sexual functions to abstract thinking processes to independence. According to Erikson (1968: 127), at this time individuals are faced with finding out who they are, what they are all about, and where they are going in life (identity formation *vs* identity confusion - the fifth developmental stage). Individuals move beyond the world of actual, concrete experiences and think in abstract and more logical terms, the formal operational stage (Piaget, 1954: 47).

The physical development of the African adolescent follows the universal stages set out by Western developmental theorists, except that in African culture some of these developments are followed by certain customary rituals (cf chapter two) (Mwamwenda, 1995: 75). These differences in culture and a possible lack of internalised understanding of African issues may limit access by non-African researchers wishing to explore the effects of being HIV and AIDS affected on African learners' lives.

1.4.4 Female

Women are becoming the face of HIV, accounting for about half of all HIV infections globally and 57% of infections in sub-Saharan Africa. Women and girls also bear the brunt of the HIV burden, as they are often the most likely to care for sick relatives, drop out of school and lose income. Women also continue to face discrimination and cultural inequalities that significantly affect their ability to stay HIV-free (UNAIDS, 2004b: 12). Curtailing HIV's spread cannot be accomplished without addressing women's rights, including reproductive rights, and gender-based violence. Women also take issue with the "ABC" – or Abstain, Be faithful, use Condoms – approach to HIV prevention that is promulgated by many U.S. officials. Those three approaches ring hollow to women who have little control over their reproductive life and little legal status in comparison to men. Abstinence is seen as meaningless to women who are coerced into sex. Faithfulness is seldom a reality to wives whose husbands have several partners or were infected before marriage. Condoms require the cooperation of men (UNAIDS, 2004b: 12-13). For the purpose of this research 'female' refers to an

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eighteen year old female African adolescent learner. It is important to look at the effects of being HIV and AIDS affected on this eighteen year old female learner, since her experience is likely to be parallel to millions of school-going females across South Africa.

1.1.1 Learner

A learner is described by Van den Aardweg and Van den Aardweg (1993: 196) as one who is taught and accepts the teaching of the educator, while Van der Horst and McDonald (1997: 13) state that in an outcomes-based education approach, the learner's achievement of outcomes is facilitated by the educator, whilst the learner, as an interested participant, is actively involved in the process.

For the purpose of this research, learner refers to an African female Grade 12 learner.

1.4.6 School Life

A school is the main environment in which the formal education of society's children takes place (Donald *et al.*, 1997: 81). School life refers to all those aspects of a learner's life that occur at school – academics, emotional life, social life, identity development and relationships with peers and educators. The research was done at a secondary school in KwaZulu-Natal.

1.2 RESEARCH DESIGN AND METHODOLOGY

1.4.5 Research Design

The research design will be qualitative, interpretive, hermeneutic, explorative and descriptive, according to Denzin and Lincoln (1994:84). Qualitative research covers a spectrum of techniques, the centrepiece of which is observation, interviewing and documentary analysis. Furthermore, qualitative research depends on the presentation of solid, descriptive data to ensure that the researcher leads the reader to an understanding of the meaning of the phenomenon being studied. The

phenomenon being studied in this research is the effect on a learner's school life of being HIV and AIDS affected.

The data will be assembled through the use of a case study. Cresswell (1998:61) describes a case study as an exploration or in-depth analysis of a 'bounded system' (bounded by time and/or place) or a single or multiple cases over a period of time. A case-study is a strategy used to report on and document an individual's life and her experiences as told to the researcher.

1.4.6   The Sample

Sampling will be purposive (De Vos, Strydom, Fouche, & Delport, 1998: 334) in that this particular grade 12 black adolescent female learner was chosen because she is sufficiently mature and extremely articulate in the English language so as to express herself comprehensively about life as an HIV and AIDS affected learner. The study will therefore explore the experiences of one primary participant, a Grade 12 Zulu-speaking female who is HIV and AIDS affected. Two of her siblings are infected with the HI virus. One has AIDS; the other is HIV positive.

Permission for the research has been obtained from the principal of the school. Participation will be voluntary. Confidentiality and anonymity of the school and participant are ensured.

1.4.5.   Data Collection

The exploration and description of the case take place through detailed in-depth data collection methods, involving multiple sources of information that are rich in context. These can include interviews, documents, observations or archival records (De Vos *et al.*, 1998: 287). This study will rely on open-ended, unstructured, in-depth interviews with the primary participant. This form of interview was selected because such a method merely extends and formalises conversation (De Vos *et al.*, 1998: 287). At the root of unstructured interviewing is an interest in understanding the experience of other people and the meaning they make of that experience. It is used to determine the individual's perceptions,

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opinions, facts and forecasts, and their reactions to initial findings and potential solutions. The events recounted and experiences described are made more substantial and more real in being recorded and written down (Lincoln & Guba, 1985: 78).

It is stressed that the researcher selected the primary participant because she is adequately mature and articulate in the English language so as to express herself comprehensively about life as an HIV-affected learner. The interview question posed will be: "How does being HIV-affected affect your school life?"

School life can be divided into several categories, of which some are: academic life, emotional life, the relationship with peers, and the relationship with teachers. Probing and clarifying questions will focus on these aspects.

1.4.5   Data Collection and Analysis

Data analysis will take place through development of theories, induction of themes and coding of data (Terreblanche & Durrheim, 1999: 141-3). Tesch's descriptive analysis technique (Cresswell, 1994: 153) is to be used. Units of meaning will be identified and categorized, and emerging themes would be sought. Guba's measures to ensure trustworthiness will be applied (Lincoln & Guba, 1985: 290). Independent coding of the data will be done, ensuring investigator triangulation (Duffy, 1993: 143) as well as a literature control that will be undertaken to recontextualise the findings (Poggenpoel, 1998: 342). Consideration will be given to the ethics involved in the research. The welfare and rights of the participant will be protected throughout (Terreblanche & Durrheim, 1999: 65).

1.6   DELIMITATION OF THE STUDY

The effects of HIV and AIDS on the affected learner's school life, incorporating the social, emotional, identity and other aspects of development, will be looked at in the context of Educational Psychology and Inclusive Education.

1.7 COURSE OF STUDY

Chapter two will consist of a literature survey regarding HIV and AIDS, the effects of being HIV and AIDS affected on learners' school lives, and the different aspects of the development of the adolescent learner. A theoretical framework (ecosystemic) will be provided to place HIV and AIDS and its impact on the affected learner's school life in context.

In **Chapter three,** the research design and research method will be put forward. The sample, data collection, data analysis, and the ethical measures will be further explained.

In **Chapter four**, the findings will be presented. The analysis and interpretation of data will also be discussed and the findings will be recontextualised.

In **Chapter five**, conclusions and recommendations of the research will be discussed. Recommendations for further research in this regard will be made. Limitations of the study will be revealed.

1.4 SUMMARY

The purpose of this study is to explore, and describe the potential effects of being HIV and AIDS affected on a learner's school life. It will also hopefully contribute to the eradication of HIV and AIDS discrimination and stigma in schools. It is important that all educators, parents, learners understand how being HIV and AIDS affected affects all aspects of the learner's school life from her relationship with her peers and with teachers to the effect on her academic performance and the academic environment. This will be fully explored in chapter two.

CHAPTER TWO

A THEORETICAL FRAMEWORK FOR THE EXPLORATION OF BEING HIV AND AIDS AFFECTED AS AN ADOLESCENT AT SCHOOL

1.4   INTRODUCTION

The impact of HIV and AIDS on South Africa as a whole, and learners in particular, was recognized by the Department of Education when it published its National Policy on HIV and AIDS in 2002. In this policy document, it was predicted that by 2012, three quarters of a million South African children would have been made orphans due to HIV and AIDS (DoE, 2002: 2). These children are HIV and AIDS affected. Not all these children will become infected with HIV themselves, but the experience of living with an immediate family member or friend who has been ill with, or dying of HIV and AIDS will have a profound effect on every aspect of their lives, including their school life. Schools are affected because their educators, learners and family members are infected and affected by HIV and AIDS. This epidemic disrupts learning and teaching. In the National Education Policy on HIV and AIDS (DoE, 1999: 24), the commitment of the government with regard to HIV and AIDS is clearly stated and gives a clear indication of the importance it attaches to understanding and communicating the impact of HIV and AIDS on South African learners.

It is well documented that HIV and AIDS causes devastating human suffering, death and unquantifiable physical, psychological and emotional suffering (Kelly, 2000: 8). HIV and AIDS are destroying the most productive members of society, those between the ages of 15 – 49 years of age (thus including adolescents). The mothers and fathers, brothers and sisters, sons and daughters of those infected are profoundly affected by the suffering they bear witness to and by the legacy of poverty created by existing resources being directed towards the ill (Draimin *et al.*, 1999). Disruption in social systems, worsening of poverty, a decrease in productivity and a decline in human self-worth are all results of this disease.

Of particular importance for this research, is how being HIV-affected affects the school life of the adolescent female, on an academic, social, emotional, moral and relational level.

2.5 AN EDUCATIONAL PSYCHOLOGY PERSPECTIVE

Considering the paragraph above, the focus of this research is the learner and the school. An educational psychological perspective will therefore enable the researcher to look at how being HIV and AIDS affected affects the adolescent female learner.

Educational Psychology has its origins in both science and education. Psychology is the science of human behaviour, and as such is focused on the description and uncovering of the nature of human beings, and probing the inner being and human motivation (Sprinthall & Sprinthall, 1990: 43). Educational Psychology is concerned with the practice of education, more specifically focused on the teaching-learning process, the learner, the educator, the learning situation, the understanding of educational objectives and learner development (Good & Brophy, 1990: 27).

It is thus important to examine the impact of being HIV affected on the adolescent learner, and become aware of how living with one or more family members who are sick with HIV or AIDS affects all aspects of the learner's life, i.e. the learner in totality – their academic life, their emotional life, their relationships, and their identity.

2.3 AN ECOSYSTEMIC PERSPECTIVE

The ecosystemic perspective provides a framework for understanding how all areas of the learner's life overlap and have an impact on all other areas. According to Donald *et al.,* (1997: 36), every learner is born within a specific social environment and her learning and development occur within these surroundings. These surroundings are referred to as her social context which includes the

physical places where learning and development takes place, namely the family, the school, community and broader society. As Donald *et al.* (1997: 36) states, "A school, for instance, is a system which has different parts, consisting of its staff, its students, its curriculum, its administration. To understand the whole, we must examine the relationship between the different parts of the system... whatever happens in one part will affect all other parts."

Engelbrecht (1999:4) concurs that an individual's actions, values and understanding are difficult to comprehend if they are divorced from the social context in which they occur. Learning and school life (a wider system of the learner) cannot help but be affected by illness (in this study, HIV and AIDS) within the learner's primary subsystem (the family). The learner's experience of being HIV and AIDS affected is influenced by the wider community's attitudes and beliefs about HIV and AIDS. In each case the learner reinforces the effects of the disease on her life by maintaining silence and upholding traditional beliefs about the virus, thus perpetuating these beliefs, and enhancing or worsening the effects on her family life, school life and aspects of her development.

The following diagram illustrates the interaction between different systems:

Table 1: Levels of system related to the education process
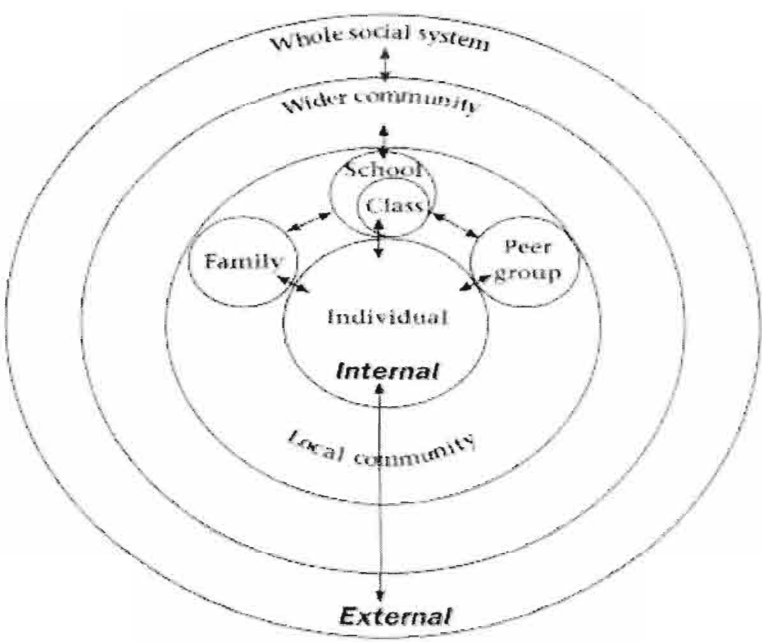
(Donald *et al.*, 1997: 177)

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To this model could be added aspects of the development of the individual, such as social, emotional, identity, cognitive and moral development, because these are aspects of the individual subsystem which may be affected by HIV and AIDS.

1.4 HUMAN IMMUNODEFICIENCY VIRUS / ACQUIRED IMMUNE DEFICIENCY SYNDROME

1.4.5 What are HIV and AIDS?

Human Immunodeficiency Virus (HIV) is an ultramicroscopic infectious agent which infects living things. This virus only survives and multiplies in bodily fluids such as semen, vaginal fluids, breast milk, blood, and saliva. Infection occurs through contact with infected body fluid, primarily during sexual intercourse. The virus attacks the immune system and reduces the body's resistance to illnesses such as influenza, diarrhoea, pneumonia, tuberculosis and cancer. The immune system is the body's natural defence against illnesses. HIV eventually makes the body weak so that it cannot fight sicknesses (Jackson, 2002: 40).

AIDS (Acquired Immune Deficiency Syndrome) is the final stage of the HIV infection. People with AIDS usually have several different illnesses at the same time, as in the word 'syndrome' (several symptoms occurring at once) (Education Labour Relations Council, 1999: 22-23). It may take 3 to 7 years after being infected with HIV for the signs and symptoms to develop. People infected with HIV can remain well for a long period of time. More rapid progression of the disease can take place if the individual suffers from poor nutrition or is exposed to opportunistic infections such as tuberculosis (TB), meningitis, and pneumonia. HIV infection weakens the immune system which normally helps the individual's body to fight infections (Evian, 2000: 9). With a weakened immune system, the individual is at risk of getting all sorts of infections. These are called opportunistic infections because they take the 'opportunity' of the weakened immune system to establish themselves. HIV-negative people are also prone to some of these infections – like TB or diarrhea, but in people who are HIV positive, these infections are usually worse and last longer. Other opportunistic infections, like pneumonia and some skin infections, are unusual in people with healthy immune

systems. When an individual's CD4 count (the blood cells of the body's immune system) is low, opportunistic infections will be more serious. It is opportunistic infections that cause death in AIDS, not the HI virus itself (Jackson, 2002: 41).

1.4.6 Prevalence

In 2004, about 40 million people around the world were living with HIV, with almost 5 million people acquiring the virus in 2003 – the greatest number in any one year since the epidemic's beginning, according to the report on the global AIDS epidemic (UNAIDS, 2004a) which was released in July 2004 by the Joint United Nations Program on HIV and AIDS. Sub-Saharan Africa is home to about two thirds of all people living with HIV as well as about 12 million children who have lost one or both parents to the virus (UNAIDS, 2004a: 2-4).

Statistics from the Department of Health (Gouws, Kruger & Burger, 2000: 168) indicated that in 1994 the rate of infection amongst pregnant adolescents younger than 20 years was 6.47%; that by 1997 it had risen to 12.7% and that by 1998 it had increased to 21.0%. An increase of 65% was apparent (Gouws *et al.*, 2000: 168).

Between 1999 and 2000, HIV prevalence increased significantly amongst pregnant women in their twenties only. Women in their late twenties showed the highest infection rate at 30.6% whereas survey participants aged 20-24 yielded a point prevalence of 29.1% (Department of Health, 2000: 24). The survey noted that over the years, pregnant women in their twenties had consistently shown the highest levels of HIV infection, making up on average, not less than half of the HIV positive population.

The South African Department of Health's survey on the prevalence of HIV, based on 16548 blood samples tested in October 2000, estimated that nationally, 24.5% of pregnant women who presented at the public health facilities were infected with HIV (DoH, 2000: 24). Further statistics (Norval, 2002: 2) have indicated that HIV infection is still on the increase; while the Department of

Health (2000) concluded that the trend observed between 1990 and 1998 – an exponential rise - has begun to slow down between 1998 and 2000.

2.4.3 HIV and AIDS and stigma

Stigmatization is the process of judging individuals and groups to be unworthy of social investment (Reidpath & Chan, 2005: 425). Unlike some other diseases such as cancer or diabetes, HIV and AIDS are highly stigmatized conditions and are associated with immorality, preventability, disenfranchisement, and lack of social support (Moletsane, 2003: 56).

When looking at HIV and AIDS from an African perspective, it is common in many traditional African cultures to attribute illness to spirits and the supernatural. Kalichman and Simbayi (2002) and Blackwood (2003) observed that because African people may believe that those who are infected with HIV and AIDS must have done something to anger their ancestors, stigmatising beliefs arise. Communities may believe they the infected deserve to be ostracised from their communities.

Similar to HIV and AIDS, the barriers that prevent people from seeking treatment for alcohol abuse include stigma. Alcohol abuse, in the same way as HIV and AIDS, is viewed as a moral issue. Substance abusing women, for example are often viewed as sexually promiscuous, weak-willed, negligent of their children, and irresponsible in their decisions to bear more children (Finkelstein, 1993: 3). Stigma, shame and guilt lead to high denial of drinking problems by both the woman herself and by family members and friends, who conceal the abuse from outsiders to protect the abuser (Finkelstein, 1994: 45).

Stigma is considered to be one of the greatest barriers to preventing further HIV infections, and to the provision of care and support for people living with HIV and AIDS. It is argued that reducing HIV stigma is an integral component of a comprehensive approach to the control of the HIV and AIDS epidemic (Reidpath & Chan, 2005: 425).

1.4.5 Being HIV affected

HIV-affected means "affected not infected" with the Human Immunodeficiency Virus (HIV). The person therefore, while not ill with the disease, does however, live with, encounter and interact with those who are HIV positive. Therefore they are 'affected' by HIV. The effects of living with someone who has HIV and AIDS can be profound.

Gilbert (2001: 53) writes that children from HIV-affected families are exposed to major psychological risk factors, including "stigma, secrecy, exposure to acute and chronic illness, death of parents and/or siblings, separations, losses, orphanhood, and foster home placement." Although some of these children are remarkably resilient (Draimin *et al.*, 1999: 574) some children's ability to cope with a parent's or sibling's infection may manifest in severe behavioural and psychological problems, such as destructive acts, suicidal ideation, uncontrolled defiance, running away, and withdrawn, non-compliant behaviour.

Linsk and Mason (2004) found that in cases where the mothers were infected, the children had more internalizing problems (for example, depression) and more externalizing behaviours (for example, aggression). They were also less socially and cognitively competent (for example, in reading achievement) than non-affected children. HIV affected children were found to be more withdrawn, had more attention problems, and were more depressed than children who did not have infected family members. The affected members faced feelings similar to those of the infected person – fear, anger, shame, sadness, isolation, uncertainty of the illness process, and the avoidance of personal stigma. The needs of an infected family member may compete with demands from other family members, leading to feelings of inadequacy and strained family relations. Because of the stigma of HIV and AIDS, the family also lives with a "conspiracy of silence" which prevents the healing process and isolates the family from traditional forms of support (Linsk & Mason, 2004: 72).

The effect of living with people who are HIV and AIDS infected is profound and all-encompassing. The effects on the learner cross over to affect all aspects of the learner's life.

2.5 THE EFFECT OF BEING HIV AND AIDS AFFECTED ON THE LEARNER'S SCHOOL LIFE

2.5.1 Introduction

School is often the venue where adolescents spend up to three-quarters of their waking hours. It is here that adolescents interact with peers, educators and others. School is also often the place where the behavioural and emotional problems of HIV-affected children and adolescents are exhibited. In Draimin *et al's* (1999) pilot study of 40 HIV affected families, including 59 children between the ages of 10 and 19, 73 percent had problems in school, and 58 percent had experienced lower school grades. The researchers noted that the emotional problems of HIV and AIDS affected learners were often misinterpreted at school. When HIV affected children were acting out their most disturbing emotions, their behaviour confused and distracted parents, educators, and social workers, who were "so preoccupied with the surface behaviours that they are unable to address the underlying emotional issues involved (Draimin *et al.*, 1999: 44)". Of the children in Draimin *et al's* study, 43 percent had received counselling and the vast majority of those had obtained counselling through the school system. In South Africa, school counsellors are not available at government schools, and therefore the problems of the many, perhaps millions, of HIV and AIDS affected learners go unrecognised or misinterpreted, and unaddressed.

As a result of the AIDS stigma forces many families are forced into secrecy and isolated mourning and therefore subtle behavioural changes (withdrawn behaviour, disorganized play or aggressive behaviour) related to children's grieving processes may be misinterpreted in school settings (Gilbert, 2001: 78).

Other aspects of school life are also affected by the learner being HIV and AIDS affected. Kelly (2000: 12) observed that HIV and AIDS can also affect school

attendance and enrolments of learners. This happens when learners are taking on the responsibility of being care-givers to dying parents and relatives. Van Dyk (1999: 331) concurs that girls between 11 and 16 years are helping to care for parents and relatives with HIV and AIDS. These children exhibit emotions of fear and helplessness as they anticipate the worst outcomes. They report taking care of their relatives through the night and suffer from tiredness and lack of sleep. As a result they neglect their homework and extra-mural activities. Consequently the girls drop out of school and therefore have no opportunity for tertiary education. Many such learners are taking on the role of heading families or having to work and take care of younger siblings. They are also not able to attend school because of a lack of finance because the finances they have are used for the care of the sick parents or alternatively there is no source of income in the home (Van Dyk, 2001: 332).

Large numbers of learners therefore drop out of school due to them being HIV and AIDS affected. The motivation for learners wanting to attend school is minimal because of the trauma they suffer through the experience of HIV and AIDS in their families. There seems to be no hope for these learners, who, overwhelmed by the effects and the destruction that this disease has caused in their families, cannot see the value of education (Kelly, 2000:12).

1.4.5 National Education Policy on HIV and AIDS

In 1996, the Department of Education attempted to address the needs of HIV and AIDS infected and affected learners by implementing a policy on HIV and AIDS in South African schools.

The National Educational Policy Act 27 of 1996 on HIV/AIDS of the Department of Education (DoE, 1999: 23-27) committed the Ministry to minimize the social, economic and developmental consequences of HIV and AIDS in the education system, to the learners and educators, and to provide the infrastructure to implement an HIV and AIDS policy. It was hoped that with such a policy in place effective prevention and care within the context of the education system would be promoted. This would be in the best interest of all stakeholders. The Department

of Education set up workshops across the country in an attempt to educate educators and learners in the prevention of HIV and AIDS.

However, by 2003, one in ten South Africans aged 15 to 24 was HIV positive, despite numerous HIV prevention interventions through the media, schools and local community groups. There has been much research on HIV prevention programmes. The effectiveness of these HIV prevention programmes has been disappointing. Existing research has tried to explain the failures of these interventions by citing the inappropriateness of the educational messages, or the attitudes or behaviour of the target audience (Campbell, Foulis, Maimane & Sibiya, 2005: 472)

Studies by Campbell *et al.* (2005: 472) showed that in spite of numerous prevention programmes aimed at adolescents, various factors prevented them from acting on this information, resulting in many youth becoming HIV infected, thus increasing the number of adolescents who were HIV and AIDS affected.

Curiosity was one factor leading youth to disregard HIV prevention messages. Adolescents wanted to experiment with sex, especially "flesh on flesh" (Campbell *et al.*, 2005: 473). Fatalism and bravado was another. Youth wanted to prove they were not afraid to die. Adolescents also complained about information overload. They were tired of being told about HIV and AIDS all the time. In addition, in conditions of poverty, girls often depended on sexual partners for gifts such as money or clothing, and had limited power to insist on condoms in such contexts. Some were willing to risk HIV in order to have a baby to access child support grants, or to establish a stronger connection with a desirable boyfriend (Campbell *et al.* 2005:473).

The National Policy on HIV and AIDS is not as yet broad enough to alert educators and other stakeholders to the psychosocial inconsistencies inherent in the education system as evidenced by the failure of many of the HIV prevention programmes. HIV and AIDS infected and affected individuals should have their special needs met within the school system, be assisted to reach their full potential, and have the same rights and opportunities as others (DoE, 1999: 24-

25). The constitutional rights of all the stakeholders within the educational system must be equally protected. A learner may be able to flourish within the school system as long as her basic rights to education (to be taken care of by adults, to be treated equally and with dignity as a human being, amongst others) are adhered to.

1.4.6 Basic rights of the learner

According to Section 28 of the South African Constitution, the child has various rights that are "in a child's best interests and of paramount importance in every matter concerning the child" (DoE, 2001: 8). Educators and parents need to understand that the learner has basic rights such as the right to be educated, and the learner needs to be aware that she has basic responsibilities towards others such that she does not violate others' rights to an education.

The basic rights of the learner, with regard to Education, (DoE, 2001:2), embodied in the South African Constitution, are as follows:

❖ The learner should receive education so that he/she can develop mentally and physically.

❖ The learner must listen, learn and be prepared to be educated.

❖ The learner must be guided and be taken care of by adults.

❖ The learner should respect and support adults.

❖ The learner should receive equal treatment and be treated with dignity as a human being.

❖ The learner should treat others with dignity, respect and always protect the rights of others. Learners should have access to information and be allowed to make a meaningful input in society.

❖ The learner must allow and assist others to communicate and also to learn with and teach others.

❖ The learner has a right to a safe environment that is conducive to learning and allows individual development.

❖ The learner should help others to sustain a safe environment for all and to respect the different levels of ability and understanding of others.

- ❖ The learner should be allowed to aim for the highest possible standards and has the right to be treated as an individual.
- ❖ The learner has the responsibility to work diligently and to treat others as individuals and with respect.
- ❖ Learners have the right to be taught by qualified educators in the language of their choice.
- ❖ The learner has the responsibility to accept the language choice of others.
- ❖ Learners have the right to choose the religious practice of their choice, but at the same time be willing to accept, promote, and protect the religious and cultural choices of others.

According to the Education Labour Relations Council (1999: 20-21), the Bill of Rights in the Constitution of South Africa, Act 108 of 1996, states that the rights of all people and the human dignity, equality, and freedom of all people should be cherished, and people should not be discriminated against. Every learner has the right to privacy, to respect and to dignity. They have the freedom for non-violence and the freedom of expression.

The Bill of Rights paved the way for inclusive education, which will be addressed next.

1.4.7   The right to inclusive education

UNESCO (2000) defines inclusive education as addressing and responding to the diversity of needs of all learners, reducing exclusion within and from education in order to provide all with their basic rights to education, equal opportunities and social participation. Inclusive Education has a special concern with learners who are experiencing barriers to learning and development. This could include girls, children in poverty, street children, child labour, learners with learning disabilities, learners who learn in a language other than their mother-tongue, children affected by HIV, pregnant learners, abused learners, refugees, ethnic minorities, and children with inadequate schools and teaching (UNESCO, 2000: 60).

Adolescents affected by HIV should be considered to be Learners with Special Needs (LSEN) as they also need support to discover their potential and achieve their dreams. Being HIV-affected is therefore a barrier to learning and development. According to the NCSNET/NCESS Report (Dept. of National Education, 1997: 12) barriers to learning and development are factors that prevent the system from accommodating diversity, causing learning breakdown or preventing learners from accessing educational provision.

The Salamanca Statement (UNESCO, 1994: viii) states that because adolescents have unique characteristics, abilities, interests, and learning needs, an education system should be designed to take into account this diversity. Every child has the right to education and every school should accommodate all children irrespective of their physical, intellectual, social, emotional, linguistic or other conditions. Schools and educational institutions have to find ways of successfully educating all children, no matter how serious their disadvantage or disability. The educational arrangement made for the majority of children must include learners with special educational needs (UNESCO, 1994: 6).

Children with special educational needs should receive all the extra support they require in order that they can be provided with quality education within inclusive schools. Inclusive education could help to build solidarity amongst learners and their peers (DoE, 2000: 2).

According to Goss and Adams-Smith (1995: 9), discrimination against HIV positive persons is in strict violation of their human rights and leads to exclusions and ostracism. The same discrimination has been seen to apply to HIV affected persons. An environment in which non-discrimination occurs can exist. According to the Salamanca Statement (UNESCO, 1994: 17), there are inclusive schools that effectively combat discriminatory attitudes, welcoming communities have been created, and the achievement of an inclusive society for all has been achieved.

2.5.5 The effect on the educator-learner relationship

Teachers are increasingly acknowledged as adults whose relationships with children contribute to the social, emotional and cognitive development of those children (Stulman & Pianta, 2001: 148). The relationship that a child has with her teacher is associated with a range of outcomes, including children's competent behaviour in relationships with peers. Aspects of the teacher-learner relationship are also linked to school adjustment and academic achievement. In addition, positive teacher-learner relationships can serve as a buffer against risk (Stulman & Pianta, 2001: 149).

In cases where no relationship between educator and HIV and AIDS affected learners exists, when learners act out their most disturbing emotions (Draimin *et al.*, 1999: 44), their educators may be confused and resort to punitive measures to discipline the HIV and AIDS affected learner because they misinterpret the behaviour instead of addressing the underlying issues of shame, stigma, fear and humiliation.

1.5 THE EFFECT OF BEING HIV AND AIDS AFFECTED ON THE LEARNER'S FAMILY LIFE

When one takes into account the reciprocal nature of different areas of the learner's life, one may observe that what occurs in one area of her experience will affect all other areas, and vice versa. The learner is influenced by her family life while she simultaneously influences relationships at home.. Being HIV and AIDS affected, and its effects on all aspects of the adolescent's life, often has its roots in the family home, as in this study where the participant shares her house with her HIV infected sister and her AIDS afflicted brother. According to Moletsane (2003: 57), AIDS stigma generates secrecy and isolation in the lives of HIV and AIDS affected families. The family experiences a great deal of difficulty in disclosing their illness within and outside the family unit (Gilbert, 2001: 78). Talking about AIDS and HIV within the affected family is restricted or taboo. This secrecy impacts on the adolescent's life. She may have difficulty making friends due to fear of them becoming close enough to find out about her secret.

This leads to isolation at a time when peers are most important to an adolescent's development (Gilbert, 2001: 79). If an adolescent is mourning the expected demise of a family member, yet having to keep it a secret, her feelings may be manifested in behavioural changes such as withdrawn behaviour, disorganized play, or aggression. They are also confronted with the knowledge that life as they know it is limited. They are faced with a crisis, which is unsolvable with any means or resources they possess. Anxiety about the future, fears of the death of the family member and others, concern that there will be no-one to take care of them, and fear that they may also die of AIDS are common in HIV and AIDS affected children (Reyland, McMahon, Higgins-Delassandro & Luthar, 2002).

HIV affected adolescents often find themselves becoming 'parentified' as a result of taking responsibility for their parents or siblings at an early age (Stein *et al.*, 1999: 169). Children who must take on the role of caretaker for an ill parent or sibling may feel unfairly burdened or punished, particularly when the added responsibilities are not developmentally appropriate. Developmentally, adolescents are attempting to gain autonomy and may perceive any additional responsibilities at home as a threat to new independence. Alternatively, the adolescent may assume the role of 'super child', in which they take on household and adult responsibilities to keep busy and avoid painful feelings, gain approval of parents, or convey a sense of readiness to handle life without the parent (Gilbert, 2001). Such changes in familial roles can affect the relationship between the parent and the child, as well as social relationships and school performance.

The quality of the relationship between siblings can greatly affect the dynamics of family life. In all types of families, sisters are typically more warm and supportive, and less antagonistic than brothers. It is apparent that it is usually girls who take on the responsibility of taking care of the family if a member is sick. Siblings can be sources of support in times of conflict, such as during illness and parent incapacitation. Sibling relationships often determine whether the family is highly adaptive to stress in family life, but some sibling relationships are typically ambivalent, and there can be considerable amounts of negativity and conflict, especially during the teenage years (Deater-Deckhard, Dunn & Lussier, 2002: 571). Therefore, one can see how the quality of sibling relationships is a factor in

the family's coping with the crisis of HIV and AIDS. If it is a negative relationship, it can affect all areas of the adolescent's life.

The relationship between parent and child also impacts on all spheres of an adolescent's life. Parents' fears of others learning about their or other family members' HIV infection could have the negative outcome of a poor parent-child relationship. This fear could lead to isolation and imposition of limits on the adolescent's activities and interaction with peers which may, in turn, cause the adolescent to withdraw socially at school and from her immediate community. This fear of disclosure, which is transmitted from parent to child, leads to dysfunctional relationships affecting all areas of the adolescent's life. Fear of losing important relationships, discrimination, ostracism, and reduced opportunities prolong the family's silence. This secrecy may initially serve a protective function by sustaining denial, but this burden of secrecy often takes an emotional toll by increasing anxiety, isolation, and withdrawal from potentially supportive relationships (Reyland *et al.*, 2002).

1.6 THE EFFECT OF BEING HIV AND AIDS AFFECTED ON THE LEARNER'S PEER RELATIONSHIPS

Adolescents strongly need peer group affirmation. They may fear rejection from peers if others become aware of their siblings' or other relatives' HIV infection. This fear is not unique to adolescents. Few people contemplate voluntarily disclosing that they are HIV affected because of the fear of AIDS-related stigma.

However, it is widely accepted that holding back one's feelings results in stress that can negatively impact on physical health. For an adolescent struggling with schoolwork, peer relationships, and the stresses at home, this added stress of not disclosing may exacerbate an already depleted immune system. Pennebaker, Kiecolt-Glaser and Glaser (1988) conducted controlled clinical studies which indicated that inhibition affects the immune system. It was demonstrated in these studies that immune functions are significantly heightened after expressing long-held secrets or traumatic experiences, even if doing so is painful. Although

participants of the study group initially experienced some negative feelings, they were significantly happier than the control subjects three months after the experience. Pennebaker *et al* (1988) states that: "Whereas inhibition is potentially harmful, confronting our deepest thoughts and feelings can have remarkable short- and long-term health benefits" (Pennebaker *et al.*, 1988: 561). Other qualitative studies support these findings. For example, Schatzow and Herman (1989) concur that disclosure of a traumatic secret related to sexual abuse can be an important step to recovery. By unburdening the weight, the shame is lifted. Similarly, by revealing the shame to a peer of having an HIV and AIDS affected family member, the adolescent can hold her head high again. The authors argue that disclosure can be empowering regardless of the response because the power of the act lies in the "truth-telling itself. A successful disclosure is almost always followed by exhilaration... The patient feels surprised at her own courage and daring. She has broken the secret and survived; no great catastrophe has befallen her or her family" (Schatzow & Herman, 1989: 347-348).

Timewell (1992: 33) states that the AIDS-related stigma creates secrecy, which in turn creates psychological isolation and depression. Disclosure, on the other hand, produces an immediate and lasting end to the depression. Disclosure to individuals who respond in a helpful manner contributes to improved psychological wellbeing.

For adolescents, group psychotherapy is considered the treatment modality of choice. Paxton (2002: 246) attributes this to "adolescents' well-known hunger for peer-group involvement." Adolescence is a time of rising psychosocial vulnerability where either psychopathology or self-actualizing can occur. Group therapy can provide the therapeutic environment wherein adolescents can work through interpersonal problems and examine the four basic identity problems: Who am I? With whom do I identify? What do I believe in? Where am I going? (Paxton, 2002: 252). However, as group therapy implies it means disclosure to one's peers, which is the very thing many HIV and AIDS affected South African adolescents want to avoid.

1.7 THE EFFECT OF BEING HIV AND AIDS AFFECTED ON THE COMMUNITY IN THE AFRICAN CONTEXT

Disclosing one's relationship with regards to AIDS is not as easy in Africa as in Western countries. Meursing (1997: 56) examined the impact of living with HIV on 96 Zimbabweans. Most participants found decisions to disclose their status extremely difficult. Despite Zimbabwe's high HIV prevalence, participants' need for family support, and counsellors' encouragement and assistance, only half the sample disclosed their status to anybody.

In Zambia, where HIV affects everyone, there are additional stresses on counsellors. They face the death of friends, family, partners, and are forced to confront their own mortality; they face the fear of infection themselves without the medical and psychological support that is available in the West; they have the continuing battle against stigma and discrimination of those with HIV, and women in particular are often not able to protect themselves from infection because of the behaviour of their partners and difficulties in discussing sex (Baggaley *et al.*, 1996: 342).

The situation regarding HIV disclosure in South Africa is dire. The death of Gugu Dlamini (Mcneil, Jnr, 1998: 4) who went public in the South African media on World AIDS day, 1998, and was killed three weeks later at the hands of her neighbours, provides a solemn warning to those who dare to break down the wall of silence surrounding AIDS in South Africa. The message is that no person should disclose except to someone who is outside the community, who can be trusted, and can ensure their personal security where they live. That is why disclosure in South Africa is such a paradox - disclosure is essential to ensure peace of mind and success for those who are affected, but disclosure itself has fearful consequences that go beyond the emotional and extend to the threat of physical violence.

1.8 DEVELOPMENT OF THE ADOLESCENT

The school has a significant role to play in the learner's development. Learners spend most of their day at school, and it is here that friendships form and knowledge and skills concerning all spheres of life are absorbed. In this study, only the aspects of development pertaining to the adolescent's school life will be examined. In order to understand how important development is to the adolescent, one needs to look at adolescents themselves.

'Adolescence' means to grow into adulthood, as it starts with puberty and ends with adulthood and the responsibilities thereof (Mussen, Conger, Kagan & Huston, 1990: 568). Santrock (1998: 22) and Mwamwenda (1995: 63) agree that the adolescent period can range from 12 to 21 years of age.

Santrock (1998:22), Mussen *et al.* (1990: 569) and Mwamwenda (1995: 63) concur that adolescent development is determined by biological, cognitive and socio-emotional processes. Biological processes involve changes in an individual's physical nature, and are largely determined by genetic factors. Cognitive processes involve changes in an individual's thought, intelligence and language. Socio-emotional changes involve changes in an individual's relationships with other people, in emotions, in personality, and in the role of social contexts in development. Santrock (1998: 22) reiterates the point that biological, cognitive and socio-emotional processes are intricately interwoven. What occurs in the socio-emotional context (eg. relationships in the home) shape the adolescent's cognitive processes (eg. the learner's attitude to school), and cognitive processes can advance or restrict socioemotional processes.

A crisis in the life of the adolescent could lead to delays in all areas of the adolescent's development and functioning. As mentioned before, affected learners could become 'parentified', as in 'child-headed households', too early. This may lead adolescents to miss out on stages of their adolescence all together. Most importantly, the burden of the secret will prevent the adolescent from forming peer relationships, and the concomitant social and emotional isolation. In this

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study, the social, emotional, identity, cognitive, and moral development of the HIV and AIDS affected adolescent will be unpacked.

2.9.1 Social development

One of the most critical developmental tasks which have to be performed by the adolescent is that of socialization: finding out where he/she fits in society, developing interpersonal skills, developing self-confidence and learning tolerance for the personal and cultural differences of others (Gouws & Kruger, 1994: 110). Friendships with the same sex deepen at this time and their relationships with the opposite sex, or even occasionally with the same sex, become romantic or sexual. The adolescent strives for independence, self-reliance and autonomy in their relationships with their parents. Peers play a very important role in the social development of the adolescent. Peer relationships are more important to adolescents than any other relationships and they are dependent on these relationships. Adolescents spend most of their social and personal life with their peers, away from their family (Mussen *et al.*, 1990: 609-610). If this closeness with the peer group is interrupted by the secrecy and stigma associated with being HIV affected, it can critically damage the social development of the adolescent.

2.9.2 Emotional development

An adolescent's emotional life can be described as feelings, passions, moods, sentiments and whims which are influenced by the environment as well as hereditary factors (Gouws & Kruger, 1994: 94). Peer groups, educators, social expectations and her own personality also influence aspects of the adolescent's emotional development. The adolescent also encounters intense emotional experiences such as extreme emotions, emotional outbursts and mild or severe emotional tension. Feelings of inadequacy and heightened emotions stem from the unrealistic expectations parents and society place on the adolescent. Interaction with the environment, the adjustment to the environment and the longing for independence by the adolescent often result in conflict and emotional tension (Gouws & Kruger, 1994).

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According to Mwamwenda (1995: 75), the adolescent's relations with peers, parents, educators and society cause her to experience many emotions. These emotions are expressed in an aggressive, inhibitory or joyous way. In early adolescence, outbursts of anger and physical violence often come to the fore and this behaviour declines somewhat as they grow older. As adolescents develop emotionally, they will form relationships with the opposite sex and fall in love whether their parents approve or not. These relationships need to be encouraged if acceptable behaviour is practiced. However, opposite-sex relationships must not be formed at too early an age, according to Mussen *et al.* (1990: 610); otherwise they will deprive themselves of meaningful same-sex friendships and run the risk of stifling their development in becoming mature, self-reliant and independent.

As stated in the paragraph on social development, if the time spent with peers is interrupted by the secrecy and stigma associated with HIV and AIDS, it can critically damage the emotional development of the adolescent.

1.4.5 Identity development

Another core task for adolescents is identity development. This includes integrating sexual and gender identity, and consolidating these identities with race and ethnicity (Ryan, 2003: 138). Adolescence is characterized by experimentation, exploration, and risk-taking, and many adolescents become sexually active as well as explore the use of drugs and alcohol. Friendships are very important to the adolescent and these provide emotional support (Mussen, *et al.*, 1994: 608). Within these friendships they are allowed to change their behaviour, ideas and tastes without fear of rejection.

Adolescents' well-organized self-descriptions and more differentiated sense of self-esteem provide the cognitive foundation for forming an identity. This was first recognized by psychoanalyst Erik Erikson (1968: 45) as a major personality achievement and as a crucial step toward becoming a productive, happy adult. Teenagers sometimes experience an identity crisis, defined as "a temporary period of distress as they experiment with alternatives before settling on a set of values and goals" (Berk, 2000: 456-7). Erikson described the negative outcome of

adolescence as identity confusion, a condition that comes about because of unresolved conflicts or society's restrictions.

For youth who are learning to explore intimacy and sexuality, it is thus a time of increased vulnerability, including risk for HIV infection. If an adolescent has come to associate sexual intimacy with a member of the opposite sex with HIV, the adolescent may explore other sexual avenues, such as homosexuality, as a self-preservation measure, i.e. to protect herself from infection. These alternative sexual experiences become more complex as youths negotiate sexuality without guidance or help from adults who routinely provide support for children and adolescents (Ryan, 2003: 139). These youths then have to learn to manage stigma of another kind, a complex task regardless of age, and to cope with social, educational, and community environments where victimization and harassment are normative.

Many adolescents avoid sexual intimacy altogether. Studies on why students avoided having sex (Van Minnen & Kampman, 2000: 48-9)) rated the fear of contracting AIDS as a primary reason for not engaging in sex. Thus, the fear of AIDS has become a great barrier to sexual intimacy. Being HIV-affected may increase the likelihood of adolescents associating normal heterosexual relations with the contracting of HIV, and therefore may affect their identity development at a particularly vulnerable stage.

2.9.4 Cognitive development

Cognitive development is about knowing, thinking and perceiving, intuition, imagination, insight, experiencing and conceptualizing. Cognitive development occurs differently for each adolescent. Adolescent thinking is dominated by concepts such as love and hate, justice and injustice. Adolescents are often very critical of themselves and others, especially their parents (Gouws & Kruger, 1994: 46-53). They are extremely self-conscious which leads to self-criticism and self-evaluation.

Adolescents think more abstractly and often ponder on what might be or what actually exists (Mussen *et al.*, 1990: 608-9). Therefore they often criticize social values. The adolescents' thought and behaviour often appears egocentric. Cognitive development plays an important role in the personality development and identity formation of the adolescent.

Piaget referred to this stage of cognitive development as the formal operational stage (Berk, 2000: 254-5). Adolescents think more about themselves. They also begin to imagine what others must be thinking. As a result, they become extremely self-conscious, often going to great lengths to avoid embarrassment. Adolescents are sure that others are observing and thinking about them.

An HIV and AIDS affected adolescent could therefore be convinced that others are observing and judging her in every way. She might be acutely afraid that to reveal her family's shame would be to invite humiliation and rejection from her peers.

2.9.5 Moral development

Adolescents should develop autonomous morality as they are able to think about what others are thinking, according to Piaget. Peer disagreements facilitate this transition and reciprocity should result, in which they express the same concern for the welfare of others as they do for themselves (Berk, 2000: 489).

Kohlberg (Berk, 2000: 490) suggested that adolescent morality fell into the conventional stage of moral development, which means that adolescents usually believe that actively maintaining the social order is important for ensuring positive human relationships and societal order. Individuals want to maintain the affection and approval of friends and relatives by being a good person – trustworthy, loyal, respectful, helpful and nice. Most adolescents usually believe that rules must be enforced in the same even-handed fashion for everyone, and each member of society has a personal duty to uphold them.

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Moral development is the ability of children to determine right from wrong. It is therefore an important task for adolescents to develop a personal value system. In order to do this they have to question their existing values, decide which values are acceptable to them and then incorporate them into their personal value system. An ability to approach moral issues in a more mature way is thus developed by the adolescent (Van Dyk, 2001: 183).

If an HIV and AIDS affected adolescent finds herself thinking in an immoral fashion about an infected loved one, she may feel tremendous guilt, and internalize bad feelings about herself as a result.

2.10 DEVELOPMENT FROM AN AFRICAN PERSPECTIVE

Adolescents of African descent often experience a very difficult time, according to Mwamwenda (1995:75), because they have to cope with synthesizing 'normal' (as described by western mainstream psychologists) as well as the traditional or cultural rituals and beliefs. In cases where these traditional rituals and beliefs have to be adhered to in a strict manner, the cultural pressures often can overwhelm the adolescent of African descent who is forced to conform to Western cultural standards while being pressurized by parents to conform to their African culture.

There was a social stigma attached to unmarried girls getting pregnant in African culture and the chances of these girls ever getting married were reduced. They may have had to contend with being rejected by their parents because they had brought disgrace upon the family (Mwamwenda, 1995: 75). Traditionally, African communities attempted to negotiate the tricky terrain between acknowledged adolescent sexuality and the risk of premarital pregnancy through establishing limited forms of sexual release and effective forms of sexual monitoring and management. Adolescents received some guidance in the contexts of family group and neighbourhood but probably the most striking aspect of these strategies was the central role played by peer group organization and pressure. This was far from uniform and there were considerable variations in the form that this took, eg.

ukumetsha, hlobongo, ukusoma (forms of masturbation) (Delius & Glaser, 2001: 7).

In some African cultures, adolescence for males is a time for proving your bravery and participating in tests of courage. It could also be a time for circumcision in some tribal groups. Special status is bestowed on youths as they are prepared to participate in their traditional lifestyle and all the responsibilities that accompany this culture. African adolescents gain their identity by participating in these cultural activities. Dancing, singing (*ukuxhentsa*), drumming, traditional rituals and ceremonies are instrumental in expressing emotions and overcoming anxiety (Bodibe, 1991: 153). The adolescent is taught important cultural values through dance, story-telling and music. In some African cultures, adolescent boys grow beards and to them this signifies independence. The growth of pubic hair is considered a sign of manhood and maturity, and allows special status. The younger boys should respect boys with pubic hair and they should not look when they undress at the river when swimming as a group (Mwamwenda, 1995: 73-7).

The physical development of the African adolescent follows the universal stages set out by western developmental theorists, except that in African culture some of these developments are followed by certain customary rituals. In traditional Zulu culture, for example, when a boy had his first nocturnal emission he rose early in the morning while it was still dark and drove all the cattle out of the kraal to a far off spot. When the rest of the inhabitants of the homestead awoke and realized what had happened the boys who had already reached puberty were sent out to look for him. This was the beginning of a rite of transition that marked his new status as an adolescent. Girls followed a similar pattern at puberty with the girl hiding away when she experienced her first period until found by her friends. A period of seclusion was followed by incorporation into a new group of marriageable girls (Delius & Glaser, 2001: 6-7). Many of these rituals are still followed today even in urban areas, and may affect school attendance.

Although Mwamwenda (1995: 75) states that adolescents are pressurized by their parents to adhere to African traditional culture, many adolescents have moved away from traditional ways and have been greatly influenced by Western culture.

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Delius and Glaser (2001: 30) suggest that traditional African socialization crumbled under the combined onslaught of Christianity, conquest, migrant labour, urbanization and western education. This led to a significant, though difficult to quantify, increase in premarital pregnancy and contributed to heightened levels of sexual coercion and violence. The peer group pressures which had previously restrained adolescent sexuality now urged youth on to greater levels of sexual experimentation and helped entrench models of masculinity which celebrated the commodification, conquest and control of young women. This lack of cultural direction may have contributed to the increase in the spread of HIV across African communities.

2.11 SYNTHESIS

With the dawning of democracy in South Africa in 1994, the South African government attempted to introduce startling and radical changes to the systems of apartheid education. The new government was determined to create a democratic society, free from discrimination, inclusive for all learners. National policies were designed and implemented to protect learners and attempts were made to equip educators to be able to empower all learners with the relevant skills and knowledge.

In this chapter, efforts were made to explain the educational psychology perspective, inclusive education and the ecosystemic framework, This should enable government officials, educators, parents and all other stakeholders to understand how all areas of the learner's life overlap and affect every other area, with the focus being on the effects of being HIV and AIDS affected on the school life of the learner.

CHAPTER THREE
RESEARCH DESIGN AND RESEARCH METHODOLOGY

3.1 INTRODUCTION

Educators and policy makers need to become aware of the needs of children affected by HIV. 30 million of the more than 42 million people infected by HIV live in sub-Saharan Africa. Ninety percent of the 14 000 daily new infections occur in this region (UNAIDS, 2004a). There are those children of school-going age who live with, care for and are affected by the HIV and AIDS infected. These children are affected in all spheres – in their home life, their relationships, and their academic life at school. National policies have been designed by the government for the protection of children against unfair discrimination, to ensure their rights to basic education, to guarantee equal access to public education, and to prevent injustices to learners affected by, or infected with, HIV (South African Law Commission, 1997:x).

This chapter presents the research design and method including the problem statement, the primary and secondary objectives, the research procedure, data analysis, and the ethical considerations of the qualitative research followed by the researcher.

3.2 PROBLEM STATEMENT

The effect of HIV and AIDS on schools in South Africa permeates all aspects of school life. It is important for educators, policy makers and other stakeholders to understand the potential impact of being HIV-affected on adolescent learners.

3.2.1 Research questions

The research questions were formulated as follows:

How does being HIV and AIDS affected affect the school life of an African female adolescent learner?

How can the information gained be used to formulate guidelines and recommendations so that the school can address the issues associated with HIV and AIDS affected learners.

1.4 OBJECTIVES OF THE RESEARCH QUESTION

The following objectives were derived from the above research questions:

3.3.1 Research objectives

The primary research objective was to explore and describe how being HIV and AIDS affected influenced the school life of an African female adolescent learner. A secondary research objective was to use the information obtained to formulate guidelines and recommendations so that schools can address the issues associated with HIV and AIDS affected learners.

3.4 RESEARCH DESIGN

3.4.1 Qualitative research

A qualitative, phenomenological, explorative and descriptive research design (Mouton & Marais, 1990:4) was used to explore and describe the effects of being HIV and AIDS affected on the school life of a female African adolescent learner.

This qualitative research was a naturalistic inquiry in which the use of a non-interfering data-collection strategy was used to encourage the natural flow of events and processes and the participant's interpretation thereof (Cresswell, 1998: 12). This qualitative research was an interpretive and naturalistic approach that

explained a social and human problem. It was phenomenological because it aimed at establishing a renewed contact with original experience (Van Manen, 1990: 31). The phenomenon was interpreted in terms of meanings created by the participant (Cresswell, 1998: 15).

The research took place in a natural setting; data was reported and analysed in a detailed and descriptive manner. A holistic picture was built based on the participant's meanings. The school experiences of an HIV affected adolescent was the phenomenon being scrutinized. The impact of HIV and AIDS on a female African adolescent learner became apparent at school.

Qualitative research enabled the participant to divulge her accounts of meaning, experience or perceptions. It produced descriptive data in the participant's own words. The participant's beliefs and values about the phenomenon were thus identified (Taylor & Bogdan, 1984: 5). The HIV and AIDS affected female adolescent learner shared her own experiences about living with family members who are HIV positive, and divulged the impact it had on her school life, and also her family, peer relationships, in the community and society as a whole.

The researcher was instrumental in creating meaning out of what was being investigated, therefore making it interpretive in character. Empathy with the participant was expressed through interaction with the participant and followed by scientific interpretation of the data collected (Eisner, 1998: 32).

This qualitative research was conducted to enable this researcher to explore and describe the effect on the school and other aspects of the participant's life. Eisner (1998: 35) and Cresswell (1998: 16) agree that the research design is determined by the research problem, which in this case, is the exploration and description of the school life of an HIV and AIDS affected female African adolescent learner.

3.4.2 Case study

The data was collected by means of a case study. A case study is a strategy used to report on and document an individual's life and her experiences as told to the researcher. Cresswell (1998:61) describes a case study as an exploration or in-depth analysis of a 'bounded system' (bounded by time and/or place) or a single or multiple case(s) over a period of time. The exploration and description of the cases can take place through detailed in-depth data collection methods, involving multiple sources of information that are rich in context. These can include interviews, documents, observations or archival records.

3.4.3 Trustworthiness

Trustworthiness is when reliability is ensured in qualitative research, as stated in Guba's model (Lincoln & Guba, 1985: 331). Guba's model of ensuring trustworthiness of qualitative data (Poggenpoel, 1998: 348-351) suggests criteria such as truth value, applicability, consistency and neutrality.

Truth value means that the researcher can be confident that the findings and the context of the research are truthful. To ensure the truthfulness of the information gathered from the participant, the researcher tried to establish a correlation between the verbatim accounts of the participant and the analysis of the study (Poggenpoel, 1998: 348). The participant was quoted verbatim to contribute to the credibility of the study and to confirm the researcher's analysis (Adler & Adler, 1998: 88). An understanding of the responses of the participant in totality was acquired through her verbatim account (Bogdan & Bilken, 1992: 391-392).

Applicability refers to the transferability of findings to other settings and contexts (Poggenpoel, 1998: 349). Descriptive data presented by the researcher allowed for comparison and ensured applicability. Generalization in this study was not intended. The participant is a unique individual with her own views. The researcher explored and described the participant's experiences of being HIV and AIDS affected and its effect on her school life.

Consistency refers to the consistency of the findings if the research was replicated using the same participant in a similar context. The findings should not change if the participant was consistent in her views and responses (Poggenpoel, 1998: 350). In some instances, the researcher re-enquired about certain issues to ensure consistency and clarity of responses.

Neutrality refers to freedom from bias in the research procedure and results (Poggenpoel, 1998: 350). The questions were unstructured and open-ended to allow the participant the freedom to reflect her own point of view. The researcher remained aware of the need for objectivity while the data was analysed and in presenting the findings.

3.5   RESEARCH METHODOLOGY

1.4.5   Literature review

The research was planned in a meaningful and scientific manner through a thorough study of the relevant literature. A literature review defined and redefined the research question (De Vos *et al.*, 1998: 104). The literature review revealed no previous research into the effects of being HIV and AIDS affected on South African learners.

 The literature review recontextualised the findings (Poggenpoel, 1998: 342). It revealed a lack of awareness on the part of education policy makers about the effects of living with HIV-positive people on those who were 'affected not infected'.

3.5.2   Research procedure

3.5.2.1   Sample

The sampling was purposive (De Vos *et al.*, 1998: 334) in that the Grade 12 learner was chosen because she was perceived to be sufficiently mature and

articulate in the English language so as to express herself comprehensively about life as an HIV affected learner. The participant attended an African all-girls school in KwaZulu Natal. The school had a predominantly African staff, with other races represented at management level. The school appeared to be representative of many schools in South Africa in that many of the learners and educators alike may have been affected by HIV and AIDS.

The study therefore involved one participant, a Grade 12 Zulu and English speaking female who was selected because she was HIV and AIDS affected. At home, she had a brother who was bed-ridden because of the HI virus, and a sister who was HIV positive. The participant cooked, cleaned and had taken over the day-to-day care of her brother while she was at home. Her father had never been present in her life, and her mother was a single parent. Her mother was extremely well-educated, having been educated abroad, and held strong religious beliefs.

3.5.2.2 Data collection

This study used open-ended, unstructured, in-depth interviews with the primary participant. The participant agreed to the interviews after rapport had developed between the participant and the researcher. Rapport between the researcher and the participant was developed during the researcher's time as a school counsellor at an African school in KwaZulu-Natal, South Africa. This form of interview was chosen because such a method merely extends and formalises conversation (De Vos *et al*. 1998:287). At the root of unstructured interviewing is an interest in understanding the experience of other people and the meaning they make of that experience. It is used to determine individual's perceptions, opinions, facts and forecasts, and their reactions to initial findings and potential solutions. The events recounted and experiences described are made more substantial and more real in being recorded and written down (Lincoln & Guba, 1985). The interviews took place at the high school, after school hours, approximately once a week, extending over a period of six months. Rapport took time to establish, and trust had to be built before complete disclosure occurred. The interviews were threatened by constant interruptions from other learners, at which point they were terminated

until privacy could again be insured. As the interviews progressed, dependency by the participant on the researcher was noted.

1.4.5.1   Data analysis

Data analysis took place through development of theories, induction of themes and coding of data (Terreblanche & Durrheim, 1999: 141-3). Tesch's descriptive analysis technique (Cresswell, 1994: 153) was used. This technique is to carefully read through all the responses to form a sense of the whole, and then to write down ideas that come to mind about what the participant said. Thoughts are written in the margin. Units of meaning are identified and categorized, and emerging themes sought. Measures to ensure trustworthiness were applied (Lincoln & Guba, 1985: 290). Problems were encountered during the transcribing phase of the analysis – many of the interviews were partially inaudible, and some repeated information already gained.

Independent coding of the data was done. A consensus discussion was held to reach consensus on the themes and categories, ensuring investigator triangulation (Duffy, 1993: 143).

3.5.2.4   Recontextualising / Literature control

Recontextualising the emerging theory was done through the reading of the published work of other researchers and establishment of existing theory. This was deemed to be important in order to place the findings in the correct context (Poggenpoel, 1998:342). The results were supported by the literature. New themes were discovered relating specifically to the context of the findings being extrapolated from African culture, specifically the physical consequences and extreme stigma existing in such context.

3.6   ETHICAL CONSIDERATIONS

Ethics can be described as a set of widely accepted moral principles about correct conduct and behavioural expectations towards those being researched and towards

other researchers (Terreblanche & Durrheim, 1999:66). The primary three principles are autonomy, non maleficence and beneficence. These principles ensure that the participant has control over what is discussed, that no harm will be caused to the participant by the research and the findings should be of benefit to the participant. These principles are guidelines for the researcher to evaluate her own conduct.

The following ethical considerations were made to protect the participant in this study. The participant was ensured of the strictest confidentiality, i.e. the information was handled in a confidential manner (Terreblanche & Durrheim, 1999: 70).

Anonymity was ensured for the participant and the school involved. Anonymity, according to Babbie (1990: 342), means that it should not be possible for any participant to be identified afterwards by anyone.

Verbal informed consent was given by the participant, which implies that correct and adequate information about the research, the procedure to be followed, and all other relevant information was given to the participant (Terreblanche & Durrheim, 1999: 66). The participant was therefore fully and completely informed.

In short, verbal permission was sought and granted by the school principal. Participation was voluntary. Confidentiality and anonymity of the school and participant were ensured. In addition, ethical clearance was obtained from the University of KwaZulu-Natal's ethics committee.

1.5   SYNTHESIS

The research design and the research methodology were discussed in this chapter. The reason for choosing qualitative research was discussed and explained. The case study method of data collection was revealed. Detailed information about the participant was included. The research procedure, data collection and analysis, ethical considerations and ways to ensure trustworthiness were also discussed.

The interpretation and discussion of the findings will be dealt with in the next chapter.

CHAPTER FOUR
RESULTS AND INTERPRETATION OF FINDINGS

1.4 INTRODUCTION

In terms of the ecosystemic framework, all areas of the learner's life overlap and have an impact on all other areas (Donald *et al.,* 1997: 36). Every learner is born within a specific social environment and her learning and development occur within this environment. This environment is referred to as her social context which includes the physical place where learning and development take place, namely the family, the school, community and broader society. The different levels of this social context are continuously developing and interacting with one another, influencing and being influenced by each other within the total ecological system.

As Donald *et al.* (1997: 36) state, "A school, for instance, is a system which has different parts, consisting of its staff, its students, its curriculum, its administration. To understand the whole, we must examine the relationship between the different parts of the system...whatever happens in one part will affect all other parts." An individual's actions, values and understanding are difficult to understand if they are divorced from the social context in which they occur (Engelbrecht, 1999). Learning and school life (a wider system of the learner) cannot help but be affected by illness (in this study, HIV and AIDS) within the learner's primary subsystem (the family).

The adolescent as a unique individual, actively takes part in her own learning process and influences and is influenced by the social context into which she is born (Donald *et al.*, 2002: 47).

Being HIV-affected often can negatively affect the learner's school-life, and in turn the negative effects that emanate from the school environment may influence the learner, her family and her relationships. It was therefore necessary to explore

exactly how the problem manifested itself in the life of the learner, especially related to aspects of schooling. It is unpacked in terms of the ecosystemic perspective which has been reviewed in chapter two.

The major themes and related categories (see Table 4.1) that emerged from the data are presented in this chapter. Direct quotes of the participant are used and the findings are recontextualised by using literature to support or refute the themes and categories. The words of the participant are presented in italics.

This chapter therefore contains the results of this study followed by discussion thereof.

1.5 THEMES AND CATEGORIES

Table 2: Themes and Categories

THEME 1: THE EFFECT ON THE LEARNER'S SCHOOL LIFE
Category 1: Fear of rejection
Category 2: Alienation and depression
Category 3: Fear of stigma
Category 4: Longing for friendship
Category 5: Negative feelings towards teachers
Category 6: Disruption of academic environment/ineffective studying
THEME 2: THE EFFECT ON THE LEARNER'S FAMILY LIFE
Category 1:Feelings of neglect/ being short-changed
Category 2: Feelings of resentment
Category : 3 Burden of silence
Category 4: Feelings of entrapment
THEME 3: THE EFFECT ON THE LEARNER'S DEVELOPMENT
Category 1: Social development
Category 2: Emotional development

Category 3: Identity development
Category 4: Cognitive development
Category 5: Moral development

1.4 THEME ONE: THE EFFECT ON THE LEARNER'S SCHOOL LIFE

1.4.5 Introduction

The participant was influenced by and influenced her situation. The participant suffered in the school environment. This was partially as a result of the school environment which was perceived by the participant to be hostile towards HIV and AIDS affected people, and also as a result of her own reactions to these attitudes. She felt she had no close friends and this she attributed directly to a fear that if anyone came too close to her, they might discover her secret and might reject her. She thus kept her peers at arm's length, alienating them in some instances, to prevent disclosure of the fact that her brother and sister are HIV-infected. She longed to form close relationships but was afraid of the stigma to which she might be exposed. Her feelings spilled over into her academic life.

1.4.6 Fear of rejection

She was afraid of the stigma she might experience should she disclose her secret.

The participant expressed the feeling that *like with* her *friends,* she *can't talk about it, 'cause* she *fears rejection, and they'll probably think that* she's *also got it, or* she's *gonna get it too or something.*

1.4.7 Alienation and depression

She kept friends at arm's length to avoid exposure of her secret. This self-imposed isolation appeared to lead her to experience extreme depression which seemed to be manifested in inappropriate ways.

She admitted to alienating other girls at times by *just generally making fun of people* and shrugged it off by saying that others *didn't like her at the time*. She claimed that the other girls, her classmates, *are not friends really*. They were *just hang-out friends*. They *didn't tell each other deep-dark secrets*, they *chatted all the time, and that was where it ended*. Significantly she added that *nobody knew*.

Her constant departure from friendships made her feel depressed about life. She said she *feels useless anyway*, she *always takes it on* herself, *it will always be* her *fault...and generally when* she's *just alone*, she *just goes down, down again*. She says she's *never happy...*she'll *always prefer being with people*.

4.3.4 Fear of stigma

She admitted that she didn't talk about her siblings' HIV-status because she *feels the stigma thing, that* they'll *just feel touched and then they'll think* she's *different*. She feared that *they're going to gossip about* her, *like they gossip about other kids*. She *doesn't want that. It's a bit of a sensitive topic to* her *and* she *doesn't think* she *could take their criticism very well*.

4.3.5 Longing for friendship

She revealed that she longs to be friends with some of the girls, especially *the understanding girls*. She admitted that she used *to think there was something wrong with* her, *but* she *noticed that* she *did that* (ended friendships) *a few times with people, and they* (two friends) *confronted* her *about it. They (*her friends) *say that they will be close until someone comes* (a new friend)*, and then* she (the participant) *left, or starts ignoring them or something like that*. She claims she *wants real friends who can be there for her, and you know they're not just using you, and they'll be there for you when you need them around. Yeah, one you can talk to about anything and who won't judge you*. She tended to terminate friendships before any level of closeness was achieved. Her defence as to why she dumped friends was *'cause it's like you leave them before they leave you, like don't become too attached to them 'cause usually you'll always feel hurt afterwards in the end. So like it's better to leave*.

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4.3.6 Negative feelings about teachers

The participant described how a teacher became so angry at her behaviour that he *punched or slapped* her because she *shouted for* her *bag in class*. She said she *used to like him and* she *doesn't know what got into him*. She described some of the other teachers as *having pets in class*; *they'd give higher CASS* (Continuous Assessment) *marks and pass marks and stuff, even when they* (the teacher's pets) *didn't deserve them*.

4.3.7 Ineffective study/disruption of academic environment

She could not study effectively because being on her own and being quiet left an opening for thoughts of her family to intrude. She said that *sometimes when* she *has a test to write,* she *can't think of studying, then* she *thinks of her family*. She admitted she *doesn't like studying much, 'cause you have to be quiet, and then it all comes back to* her. She'd *rather sleep, be with people, watch TV, anything else, just not study*.

She admitted to disrupting the class as a whole, thus violating other students' rights to study peacefully. She admits to *noise-making in class*, when the teacher stepped out, she *made the most of it, just started shouting, playing games while they're gone*. She confesses that in class she'd *become a whole lot more playful*. She'd *do anything to avoid working* and *not, like, participating fully in class. .* She *said when* she's *in the classroom and there's like five of* them *and they* have to *study,* she'd *rather chat to them and disturb them than face* her *books*.

The participant admitted to getting *in trouble a few times for laughing at people's hairstyles or whatever they did or for just generally making fun of people*. She'd *rather make fun and fiddle about than do whatever else*, and *act really immature*. She also admitted to dealing with her bad feelings by putting down other learners in class. She had been in trouble for *laughing at people, making fun of them sometimes. One time when a girl wore other shoes, not like ours, really not shiny, I had a good laugh for a few weeks*.

4.3.8 Discussion

The adolescent is influenced by and influences the school environment as she interacts within it. Part of this interaction process takes place between the learner and her peer group to which she is exposed. School is the environment where adolescents typically develop friendships because of the close daily proximity to their peers. The general public and academic researchers alike have long recognised the importance of youth's peer relations. Because adolescents spend more than a third of each day in the company of other adolescents, it is not surprising that it is their opinion and influence that is valued the most amongst themselves (Lashbrook, 2001: 748). Studies by Hallinan and Williams (1990) indicated that peer relationships have been found to be an important factor in a variety of educational outcomes. If this closeness with the peer group is interrupted by the secrecy and stigma associated with being HIV and AIDS affected, it can critically damage the emotional and social development of the adolescent and can have a negative effect on the academic life of the adolescent leading to lower grades and loss of potential.

Negative relations with teachers can also have a negative impact on the academic results of the adolescent learner (Peltzer & Promtussananon, 2003). If the adolescent constantly acts up in class, disrupting progress and violating other learners' rights to an education, the teacher may resort to extreme punitive measures to control the learner's behaviour. These punitive measures would most probably destroy any future meaningful interaction between learner and teacher, a factor that has been proven to be essential for effective learning to take place. Teacher effectiveness in relating to the learner might be compromised if they lack insight into the aetiology of the learner's behaviour (Stinnet, Cruce, & Choate, 2004).

Being HIV and AIDS affected in the school environment can be a severe barrier to learning (DoE, 1997) in that it can distract the learner from studying effectively by affecting her relations with teachers and other authority figures, and alienating peers through antisocial acts and violation of others' basic rights to education (DoE, 2001). It also leads to isolation from peers at a time when peers are the

most important relational figures in an adolescent's life (Mussen *et al.*, 1990), thus placing additional pressure on an adolescent struggling with the numerous challenges faced by all youngsters at her developmental stage worldwide. All these factors may accumulate to have a significant effect on the adolescent's school life.

4.4 THEME TWO: THE EFFECT ON THE LEARNER'S FAMILY LIFE

4.4.1 Introduction

The adolescent's immediate social environment is her family circle. The individual and her family directly influence each other. This is a two-way interactive process between the family and the individual. If tension arises in one part of the family, the whole family is affected (Donald *et al.*, 2002: 47). The responses from the participant indicated that being HIV-affected, having an HIV-infected sister and a brother with AIDS, had a significant effect on her family life. The findings suggested that the participant felt that she was neglected by her parent because she was 'well' and her siblings, in particular her brother, received all the attention and available resources because they were 'sick'. She in turn felt resentful and harboured thoughts of her sibling's death and leaving home to escape the situation.

4.4.2 Feelings of neglect/feeling shortchanged

The feeling that she was being neglected or shortchanged at home was expressed when she referred to her brother as being her mother's *pet. Everything he says goes…whatever he wants he gets*. Her mother *when she gets her pension money, she'll just budget how much she has to give him, how little is left over for groceries, and nothing else except food. It's like brother first,* her *last.* She found it *irritating, because he gets everything; we're just the little outsiders.* All her *mum ever talks about is him, him having to go for his tests, and getting the test (*CD4 count*) results.*

4.4.3 Feelings of resentment

She felt resentful because the burden of caring for the house and her sick sibling fell on her shoulders. She was *the only one around during the daytime…* She was *expected to clean, cook, ensure that everything's OK, see to it that her brother has a good breakfast, good lunch, good supper.* She *has to stay at home the whole day…not really go anywhere else* to ensure that her AIDS-infected brother was taken care of. Her mother expected her to fulfill these tasks correctly. If she did not, she was reprimanded. If she didn't *clean the way* she *cleaned yesterday,* she would *get bad remarks, like* she's *stupid and lazy, and* she's *slow, that kind of thing, or* she's *a waste of time or something.*

Feelings of resentment at her brother's demands and the expectation that she would have to take care of him were revealed. She claimed that he *has become the child of the family* (he is her older brother), *because sometimes* she *thinks of him as a spoilt brat, cause if he wants cooldrink then someone's got to go buy it…and if* she *wants it, they'll just give* her *the whole money story…how it's being used for this and that.* She revealed that she didn't *want to be at home, not even for one day.*

4.4.4 Burden of silence

Added to the burden of looking after her sick brother was the fact that she could not talk about the cause of her brother's illness. Her mother didn't talk about AIDS as such, but about her son *being sick and she's got such a burden to carry. She teaches people about AIDS* yet won't mention the fact that her son has AIDS. *She doesn't like saying it.*

4.4.5 Feelings of entrapment

The participant felt trapped because her mother didn't like her leaving the house, possibly because she was afraid that her daughter might talk about what was really going on at home, or that she might also fall victim to the disease. The participant felt *stuck at home.* She had *got nowhere else to go.* Her mother *doesn't want* her *to*

go to her *gran's*, said she would be a *burden at* her *gran's* but said she *should stay at home.*

1.4.5 Discussion

As the participant's family life had an impact on her, reciprocally, she had an impact on the relationships within the family. HIV and AIDS affected adolescents often find themselves becoming 'parentified' (becoming the parent in the family) as a result of taking over the role of the caregiver in the family. In this study, the participant was obliged to care for her sick brother, a task that would 'normally' be the responsibility of one or other parent (Stein *et al.*, 1999). Parentification in the family entails a functional or emotional role reversal, a reversal of familial boundaries, in which the child sacrifices her own needs for attention, comfort, and guidance. 'Parentified' children, in effect serve as parents to their parents or siblings and fulfill this role at the expense of their own developmentally appropriate needs and pursuits (Castro, Jones & Mirsamili, 2004: 206). Studies cited in Castro *et al.* (2004: 205) suggest that 'parentified' children may struggle to develop an independent sense of self.

Adolescents who may wish to pursue autonomy and independence may become resentful at the impositions imposed on them by their family responsibilities. They may feel trapped at a time when it would be developmentally appropriate for them to spread their wings and form their own identity (Castro *et al.*, 2004). In the case of the participant, this resentment is likely to be greater because their mother is still alive.

Added to this would be the burden of silence imposed by the fear of others finding out about their family members' infection. Parents may directly or indirectly instruct their children not to speak about the situation at home. Adolescents may become isolated from the community, have limited interactions with peers, and even withdraw socially altogether (Reyland *et al.*, 2002).

The effects of being HIV and AIDS affected may lead to dysfunctional relationships within the family system. The natural closeness between parents and

adolescent and siblings may become under pressure because of HIV and AIDS, the adolescent could develop emotional tension and emotional distance may develop in the family (Bor & Elford, 1994:132).

The South African Law Commission (1997: iv) concurs that learners affected by HIV and AIDS are faced with the illness in their families and have to carry out household chores and take care of their sick siblings. This disrupts the learning process, is emotionally draining and may affect all other areas of the learner's life.

1.5 THEME THREE: THE EFFECT ON THE LEARNER'S DEVELOPMENT

1.4.5 Introduction

The effects of being HIV and AIDS affected may adversely influence aspects of the learner's development. Just as the learner's development is affected by HIV and AIDS so her development affects aspects of her life – school, family and relationships.

4.5.2 Social development

She *can't talk about it* (her problems at home) because she *fears rejection, and they'll* (her schoolmates) *probably think* she's *also got it (*HIV), *or* she's *gonna get it too or something.* She admitted to fantasizing about having a normal relationship, doing *normal things that you see people, other people, doing, just going out to the movies, and doing whatever.* She felt like she was *missing out* by not forming close friendships with others, but stated she'd *rather miss out than be sorry (*about disclosing*).*

1.4.5 Emotional development

The participant admitted to being depressed a lot of the time, a mood state she countered by trying to be with other people as much as possible. She said that *some days* she would *feel very down.* She would *feel like* she's *at the end of the*

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earth, like she *wants to die now,* she *wants to kill herself. Sometimes* she *just wants to be with friends,* she *doesn't want to be alone, cause then* she would *think about all these bad things. Generally when* she's *just alone,* she *just goes down, down again.* She confessed that she's *never happy.* She would *always prefer being with other people.*

4.5.4 Identity development

The participant spoke about her confusion regarding her identity. She confessed to her school-mates that she didn't *like male company much,* and they all thought she was *weird.* She said she's *not gay or anything.* She sometimes *admires men but that's where it ends.* She *doesn't like them (*men*) coming over, trying to be friendly.* She just *likes looking at them from a distance* and thinking, *like, yah, he's well-dressed, whatever, that kind of thing, not wishing for them to come over, yah.*

She admitted to experimenting with alternative sexuality, possibly in order to explore sexuality without fear of contracting HIV. However, she confessed to being *bored of this whole lesbian thing.* She had *decided to give it a go.* She thought *it would be better 'cause* she *really doesn't like men much.* She thought she'd *maybe like females but...it didn't work.* She *guesses it's the whole AIDS thing...when* she *thinks* she *doesn't want to waste* her *life like that...then* she *just stays away from men.* She *thinks to be gay is probably more fulfilling in a way, like,* she'd *be with someone who probably understands* her, *cause* she *doesn't know,* she had *just got the whole idea, like* she *thinks of men as conceited people sometimes.* She *just gets these prejudiced ideas and stuff about them and then...so yeah,* she *decided females would probably be better. But* she *wasn't right.*

She admitted to *not trusting men.* She *doesn't want to put* herself *in that kind of situation.* She *gets scared of the fact that you can't see who has AIDS and who doesn't, so* she'd *rather be safe than sorry, so* she'd *rather keep a big distance between her and men.*

4.5.5 Cognitive development

The participant reflected that *the studying part of* her *school life got affected* by thoughts of her home situation intruding. She admitted to at times becoming disruptive rather than have to think about the situation at home. She could not study effectively because being on her own and being quiet left an opening for thoughts of her family to intrude. She said that *sometimes when* she *has a test to write,* she *can't think of studying, then* she *thinks of her family.*
She thought that if her peers found out she would feel *the stigma thing, that…they'll think she was different.* She worried about what others were thinking about her, if they were *gossiping about* her *like they gossip about other girls' problems…It's a bit of a sensitive topic and she doesn't think she could take their criticism very well.*

1.4.5   Moral development

The participant had a moral dilemma when thinking about her infected brother. She wanted him to die, but also knew it was wrong of her to think that. When she *thinks about his death,* she *thinks how* she'll *miss him, but now, in a way,* she *wishes he could just go so he'll be out of his misery and* she *could probably get* her *mom back or something.* She *knows that sounds selfish, and at the same time* she *wants him to stay. He is* her *brother.*

1.4.6   Discussion

The adolescent's interactions with the many subsystems in her social context have a reciprocal effect. As she is influenced by the effects of being HIV and AIDS affected so part of the effect is her reaction. This may manifest in aspects of her development which in turn influences all her social contexts.

The feelings of shame, sadness, isolation and stigma associated with being HIV and AIDS affected seemed to impair the adolescent's social development by preventing her from forming close peer relationships at a developmental stage when such relationships are of paramount importance.

This in turn seemed to affect her emotional development as she struggled with feelings of depression resulting from her isolation. Her feelings that she will be shunned socially by her peers if they discover that she is HIV-affected is corroborated by Siamwiza (1999:24) who stated that children who have lost a parent to AIDS report being taunted and mocked by peers and also being excluded from peer groups. This leads to isolation. Kelly (2000:16) feels that because of their isolation these children are excluded from experiencing the joys and gaiety of normal childhood development.

Society and its connectedness to all areas of the adolescent's life, as well as its process of socialization of the individual are especially important for the development of the adolescent. According to Van Dyk (2001: 183) the interaction with peer groups is very important for the psychosocial development of the adolescent learner because they have an intense desire to belong. Belonging to a peer group satisfies the emotional needs of the adolescent learner. In this regard the isolated HIV and AIDS affected adolescent's needs are not being met.

The isolation and fear of discrimination lead to unlimited emotional feelings, which if not dealt with, could have a destructive effect on the life of the adolescent learner, who even in normal development is extremely sensitive and moody (Mussel *et al.*, 1990). Emotion is a barometer of an adolescent's well being. If the adolescent exhibits inappropriate feelings, this could negatively affect all areas of the adolescent's life.

In adolescence, teenagers develop their identity. For the participant, as the youngest in the family, the development of her identity may be compromised because she is expected to assume a more grown up parenting role. Missing out on this crucial developmental stage could have far reaching effects on all parts of the her life, leading to confusion and despair about sexuality, peer relationships, and other aspects of identity development (Ryan, 2003).

Adolescents typically think more about themselves and become more critical of them. If they perceive themselves to be different, for whatever reason, this may

affect the cognitive development of the adolescent. They may become absorbed in what they think about themselves and what they think others think of them (Berk, 2000). The fear of stigma may cloud a learner's thoughts and cause her to obsess about what others think of her, whether they know, what they will do if they find out. This may perpetuate her despair and isolation. Her fearful thoughts around HIV and AIDS issues may prevent her from forming friendships or socializing functionally with people.

From a moral developmental perspective, the participant was at a stage where she desperately wanted to maintain the affection and approval of friends by being a good person – trustworthy, loyal, respectful and nice. Moral development is the ability of children to determine right from wrong. It is therefore an important task for adolescents to develop a personal value system. In order to do this they have to question their existing values, decide which values are acceptable to them and then incorporate them into their personal value system. An ability to approach moral issues in a more mature way is thus developed by the adolescent (Van Dyk, 2001: 183). Being around HIV and AIDS infected relatives may cause the adolescent to experience feelings of anger and resentment at the monopolization by the infected members of the family's resources. These destructive feelings towards their family members may cause the adolescent guilt and remorse and contribute to feelings of low self-esteem.

The above aspects of the participant's development appeared to be affected by her being HIV and AIDS affected. This interruption in the process of her development may have significant repercussions on her school life and family life, leading to barriers to learning, and inhibition in school relationships.

4.6 SYNTHESIS

The effects of being HIV- and AIDS- affected on the learner's school life was explored in the related themes and categories. The effects on the learner's school life were explained in the context of the learner's ecosystem. The findings revealed that the adolescent learner was considerably affected by the situation in

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her home-life and the consequences of being HIV and AIDS affected spilled over in to all aspects of her life – socially, emotionally, cognitively - leading to confusion over her identity.

CHAPTER FIVE
CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter focuses on the conclusions, recommendations and guidelines that could provide insight and assistance into all areas of the adolescent's life so that schools can address the issues associated with HIV and AIDS affected learners.

As the adolescent develops she is influenced by, and influences, her ecosystem, which consists of the family, the school, the community and broader society. For the purposes of this research, HIV and AIDS are phenomena of the broader South African social context and are barriers to the learning and development of the adolescent. This development is described in terms of social, emotional, identity, cognitive and moral development. Her family life consists of mother, brother, sister, grandmother and any other significant others. This area of her life is the primary source of her dilemma and may influence all other areas of her life. In this study it is specifically her school life that is under scrutiny. The learner who is affected by HIV and AIDS may have barriers to her learning, development and participation as may be demonstrated in this study.

1.4 CONCLUSION – THEME ONE: THE EFFECT OF BEING HIV AND AIDS AFFECTED ON THE LEARNER'S SCHOOL LIFE

The key issue in the participant's school life appeared to be stigma which did not allow her to disclose the situation at home to her peers. This appeared to lead to intense feelings of isolation and deprivation. She did not seem to develop any close friends. Like every adolescent, she too has the need to belong to a peer group, a clique, or a crowd. Being HIV and AIDS affected seemed to destroy the possibility for the learner to develop normal friendships because of the fear of stigmatization, discrimination and rejection. This lack of close peer relationships

affected her school life and prevented her from enjoying the rich opportunities for social and emotional development that the school environment offers.

As a result of the participant's feelings of isolation at school she developed feelings of depression that was, at times, followed by a desire to always be in the company of others. This lead to her disrupting other student's studies, and neglecting her own. She expressed a deep longing to have real friendships but was too afraid of the disclosure and resulting stigma it might bring to risk placing herself in a position of vulnerability. This may have been a yearning to have some kind of attention or affirmation and may have led to her disrupting entire lessons and therefore violating other learners' rights to an education. This appeared to contribute to the breakdown of relationships between herself and her teachers.

1.5 CONCLUSION – THE EFFECT OF BEING HIV AND AIDS AFFECTED ON THE LEARNER'S FAMILY LIFE

The key issue in the participant's family life appeared to be 'parentification'. The participant described how she was expected to spend her day cooking, cleaning and taking care of her brother, a role best served by a parent, or parents. Her needs were not considered because she was the 'healthy' child in the family. The participant displayed anger and resentment towards her brother for being sick, and towards her mother for directing all the family's resources towards the sick sibling in the family. She felt neglected by her mother yet seemed trapped at home by her mother's reluctance to allow her the freedom to go out, perhaps out of fear of the reality of their situation becoming public. This burden of silence also contributed to isolation from her peers and community. Here too, stigma was a key issue, preventing the family and the adolescent from getting sufficient support.

1.6 CONCLUSION – THEME THREE: THE EFFECT OF BEING HIV AND AIDS AFFECTED ON THE LEARNER'S DEVELOPMENT

The key issue in terms of the participant's development appears to be confusion with regard to her identity. The adolescent's feelings of shame, sadness, isolation

and fear of stigma prevented her from socialising normally thus keeping her from the interactions which are necessary for the adolescent to discover who she is, with whom she identified, what she believed in, and where she was going – the four basic identity problems (Paxton, 2002: 252). She expressed confusion regarding her sexual identity. She had tried to explore sexuality with other girls rather than men. She wondered if this was due to her fear of contracting HIV. This led to her worrying about being different from 'normal' people.

Stigma was another important issue that appeared to inhibit aspects of the participant's development. She could not interact normally with her peers, believing that they would shun her if they discovered that she was affected by HIV and AIDS. She confessed to sometimes feeling like dying rather than face the social rejection and stigma that she believed was the inevitable consequence of being HIV and AIDS affected. The participant worried a lot about what other people would think about her. She especially thought constantly of the rejection she might experience if others found out about her home situation. These thoughts intruded on her daily life and appeared to prevent her from performing optimally at school and in social interaction.

1.7 SYNTHESIS

The key issue running through all these themes is that of stigma. Stigma appeared to affect the participant's school life on a number of different levels. She found herself in a paradoxical position. She yearned for friendship, because friendship was what she needed most - for support and companionship, for maturation and development – yet the closeness necessitated by friendship threatened disclosure, which might lead to stigmatisation, which was what the participant seemed to fear most. This lack of peer relationships led her to feel isolated and depressed, to neglect her studies, to disrupt the classroom and alienate her teachers and classmates.

The issue of parentification emerged, which combined with the fear of stigma may have caused a delay in the adolescent's development of autonomy and independence – an important outcome of adolescence. The anger and resentment

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at her position at home – being a helper and carer at a time when she should be learning to take care of herself – appeared to spill over to her school life and affect her development.

5.6 RECOMMENDATIONS AND GUIDELINES

It is useful to be reminded that, in inclusive education, the whole school should own the problem and that the whole ecosystem should be involved in the solution. One-on-one counselling, though useful, would be insufficient to address the issue. Therefore the following recommendations and guidelines, based on the findings, could be offered:

5.6.1 For the school

The following should be taken into consideration in the school context in order to facilitate the optimal functioning of the HIV and AIDS affected adolescent:

❖ Schools should take ownership of the problem of HIV and AIDS and be aware of the effect it may have on learners within the school context, rather than passively regard it as the responsibility of professionals or government officials. The school should have a proactive attitude regarding the combating of HIV stigma and discrimination in their schools and in doing so also in their communities.

❖ Measures to curb discrimination and victimization of learners affected by HIV and AIDS, and opportunities for confidential disclosure should be encouraged by all educators.

❖ Every school should set up an HIV and AIDS support committee. Those learners who are HIV and AIDS affected could join with educators to learn about ARV therapy, positive living, and ARV adherence. They could be responsible for educating other staff and learners about HIV and AIDS issues.

❖ Awareness programmes and life skills training for learners should be compulsory where the 'ABC' of AIDS prevention could be discussed. "A" is for Abstinence, 'B' is for Be Faithful, and 'C' is for Condoms. These programmes might help ease the fears of HIV and AIDS affected learners who are worried about the AIDS-sex link.

❖ Desensitisation and sensitisation towards HIV and AIDS affected learners could be achieved through contact with learners affected by the disease. When learners come into contact with someone who is actually affected by HIV and AIDS, hear their stories and see that they are ordinary people, sometimes 'popular kids', sometimes 'cool kids', it could change perceptions. In addition, educators could make arrangements for HIV infected and affected celebrities to visit the schools, give talks and interact with learners and staff members. This would go a long way to dispelling the stigma, shame and discrimination associated with HIV and AIDS.

❖ Adolescents have specific needs and are at a certain developmental level that contributes to peer group reinforcement and interaction. It has been recognised that HIV-education programmes should involve adolescent peer education (Campbell & McPhail, 2002). Peer education is the participation of young people in youth-led programmes that ideally facilitate contexts in which adolescents can engage in debate and dialogue about high-risk sexual behaviours and the possibilities of changing them. The underlying assumption here is that adolescents are most likely to change their behaviour if liked and trusted peers are seen to be changing theirs (Rogers: 1995).

❖ Educating adolescents about sexuality, assertiveness, peer-pressure, decision-making and problem-solving could help to equip them to make informed choices. Cultural belief systems should be respected in this regard. Sex education should not be simply a form of cultural imperialism – the imposition of western concepts and principles onto other cultures.

❖ The attitudes of educators and parents towards HIV and AIDS affected learners ought to reflect understanding, compassion, and empathy so that the

learners could adopt similar attitudes. Programmes encouraging these attitudes should be organized for educators, parents and members of the community at schools as part of staff development initiatives.

❖ Educators should have access to educational material about HIV and AIDS affected learners and it should be at their disposal to peruse at any time when needed. School media centres and libraries should contain books, videos, posters and other resource materials about HIV and AIDS and the effect it can have on family life to increase knowledge and awareness about the disease.

❖ Accurate knowledge about health risks should encourage health-enhancing behaviour change. However, research shows that young people do have accurate knowledge about HIV transmission and prevention (Campbell et al, 2005: 474). Information about the various factors that prevent them from acting on this information, such as fatalism and bravado, need to be included along with basic HIV prevention methods. Educators should be made aware that they have a responsibility to be examples to learners and the community and modify their behaviour to reinforce these HIV programmes. Resources to assist educators with the implementation of these programmes are also very necessary.

5.6.2 For the family

In some cases, adult family members hide sick relatives away, thus passing on a strong message of shame, secrecy and fear about HIV and AIDS (Campbell *et al.*, 2005: 476).

However, the family should be working in conjunction with the school to eradicate discrimination and stigma, and promote positive attitudes towards those affected by HIV and AIDS. Together with the school, they should reflect understanding, compassion and empathy towards those affected by HIV and AIDS, so that learners could internalise similar attitudes and function optimally at school.

5.6.3 For the individual

The following could assist the HIV and AIDS affected individual:

❖ HIV and AIDS peer support groups should be essential in schools to assist those affected individuals experiencing emotional problems around HIV issues. These peer support groups should be made available when needed. They should also focus on acceptance issues and destigmatisation of HIV and AIDS so that learners are able to belong to a group and form close friendships. These support groups could be overseen by an educator.

❖ Through counselling, the individual could come to see that the HIV and AIDS infected members of her family have not received a death sentence, but that HIV is like any other chronic disease which can be treated with the appropriate medication (Anti-Retrovirals or ARVs). Counselling can thus help the affected learner put the disease in perspective so that she can carry on with her own life. Many schools or educational institutions do not have professional counselling services, so information about venues which offer Voluntary Counselling and Testing (VCT) should be made available to whoever needs it.

❖ The affected learner needs to be reassured that the infected family member can remain healthy and productive if on the correct ARV therapy, and the affected learner can feel proactive by becoming a 'treatment buddy' to the infected member, i.e. helping them take their medication on time and adhering rigidly to the schedule so that resistance to ARVs does not occur.

5.6.4 For South Africa

It is essential that South Africans generally should become accepting of people affected by HIV and AIDS. South Africans could educate themselves more about HIV and AIDS. Now that anti-retrovirals (ARVs) are available at most Department of Health hospitals and clinics, steps could be taken to destigmatise the disease by a deliberate effort on a national level to change attitudes towards HIV and AIDS. Describing HIV as just another chronic disease, like diabetes,

could go some way towards placing the disease in a new perspective. Those affected by HIV and AIDS continue to feel rejected, isolated and discriminated against. This situation can be addressed through government initiatives.

5.7   LIMITATIONS OF THE STUDY

❖ A limitation of the study was that the number of participants was limited to only one single adolescent African female, but being a qualitative research design, which does not aim to generalize, this was deemed sufficient.

❖ The participant had anxieties about revealing her home situation, and as a result her testimony could not be independently verified.

❖ The participant developed dependency on the researcher in whom she had confided, which could affect the independence of the participant.

5.8 RECOMMENDATIONS FOR FURTHER RESEARCH

Further research is suggested in the following areas:

❖ An exploration of South African black women's adolescent same-sex experiences.

❖ The impact of black adolescent sexual socialisation on HIV-prevention measures.

5.9 CONCLUSION

This chapter focused on the conclusions, recommendations and guidelines, suggestions for further research, as well as the limitations of the study.

Being HIV and AIDS affected is a danger to the education of adolescent youth. The Department of Education and schools should put structures and programmes in place so that South Africa does not experience yet another 'lost' generation of black youth, due to them being part of child-headed households with too many responsibilities for them to study effectively. How effective such programmes will be depends on the attitudes of educators, administrators, parents, government officials and other stakeholders, how comfortable they are with and how accepting and supportive they are towards these adolescent learners affected by HIV and AIDS.

> *"I want, like, real friends who you can be there for, and they'll be there for you when you need them around. Yeah, ones you can talk to about anything and who won't judge you...I wanna do normal things that you see people, other people doing, just going out to the movies, and doing whatever."*

> *HIV and AIDS affected adolescent*

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TO WHOM IT MAY CONCERN

Re: Permission

Permission was granted verbally by the Principal of the Independent School at which the study was conducted to Ms Helen Lamming to do the research.

Due to concerns about privacy, confidentiality and anonymity, the Principal declined to supply written permission for the study, but indicated verbally her support for the research.

APPENDIX B

INFORMED CONSENT FORM

I, Helen Margaret Lamming, an M.Ed student at the University of KwaZulu-Natal, am interested in exploring the extent to which being HIV and AIDS affected influences your school life. I am working under the supervision of Professor N. De Lange of the Edgewood Campus of the University of KwaZulu-Natal. (Tel: 031-2601342).

The aim of the research is to explore the extent to which HIV and AIDS may affect the school lives of adolescents who are affected, not infected, by the disease. As a school counselor I have learned that HIV and AIDS does not just affect those who are ill, but also influences the lives of all other family members, including their school lives.

I have identified you as a participant because you are an adolescent, you have family members who are sick and infected with HIV and AIDS, and this is greatly affecting every area of your life, including your school life.

To participate, you must agree to a series of taped interviews, which are conversations consisting of open-ended questions. There are no right or wrong answers. Everything that you say will be kept strictly confidential. The interviews will be up to 45 minutes long each, although if you become tired they will be structured according to your comfort level. The number of interviews is not specific, but may continue until the topic is saturated, or you do not wish to continue

All information you wish to share with me is voluntary and if you wish to withdraw from the interviews at any stage, that is your right. Everything that passes between us will be entirely confidential, and your anonymity in this research will be assured at all times.

There will be no financial payment for your time but any research, literature, and other information pertaining to the research topic will be shared with you. Allowing research into this aspect of your life may be beneficial in that it will help you to make sense of any confusion with regard to the affect of HIV and AIDS on your life.

I wish to reinforce that your anonymity will be respected at all times should you agree to the research. You are free to withdraw from the research at anytime, whether due to time constraints, illness, or no reason at all, without prejudice.

DECLARATION OF INFORMED CONSENT

I, hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

SIGNATURE OF THE PARTICIPANT   DATE

....
...

RESEARCHER'S NOTE

Due to the issues of confidentiality and anonymity, the participant did not wish to sign the informed consent, but agreed verbally to all that was mentioned within.

SIGNATURE OF RESEARCHER   DATE

....
.....

EXAMPLE OF INTERVIEW WITH THE PARTICIPANT

Helen: OK, today's the 10th of April 2005. Um. I'm sitting with a learner, a grade 12 learner at a school in KwaZulu-Natal. Um. The time is 11.30am. OK. Can you please tell me, how does being HIV-affected affect your school life?

Learner: In the classroom or with my friends?

H: OK. Um. Both.

L: Well in the classroom, I can't say it affects me much, but sometimes when I have to write a test, I can't think of studying, then I think of my family. And in the dorms, like with my friends, I can't talk about it, cause I fear rejection, and they'll probably think that I've also got it, or I'm probably gonna get it too or something.

H: OK. Can you tell me more about your family? You mentioned your family. Can you tell me more about your family?

L: OK. OK. I've got three brothers and two sisters. I'm the last born. And, um, two members of my family have AIDS, um, HIV, I guess; it's my brother and my sister. My sister, she's like my best friend in the family and she just ran away, like three months ago. So we haven't heard from her ever since. Well, when she told me about it, she said it was because she was depressed and she wasn't getting much support from...so she decided to find a better life somewhere else. My brother, he's at home. He doesn't work, he doesn't wanna work. He doesn't need to work, I guess, because my Mum gives him everything he needs, so...yah. The others are working.

H: Tell me more about your brother. At home.

L: At home he's like my mother's pet. Everything he says goes...um, whatever he wants he gets. My mother when she gets her pension money, she'll just budget how much she has to give him, how little is left over for groceries, and nothing else except food. It's like brother first, me last.

H: OK. And what is his HIV status at the moment? Er. How...what is his medical condition?

L: I dunno...maybe it's got pretty far.

H: Why do you think it's gone pretty far?

L: Cause he's probably had it for a long time.

H: OK, So...what are his symptoms? I mean, is he sick?