

**A PSYCHOLOGICALLY ECOSYSTEMIC PROGRAMME FOR  
SUPPORTING LEARNERS INFECTED WITH HIV/AIDS**

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**in**

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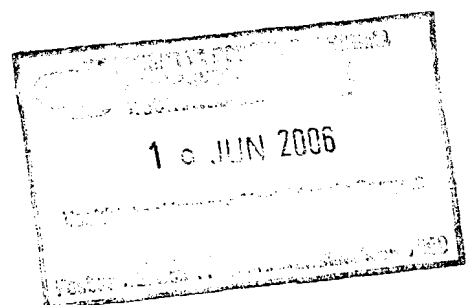
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## SUMMARY

The aims of this research were to investigate the effects of HIV/AIDS on the psychological and physical well being of learners; determine whether learners suffering from HIV/AIDS are ecosystemically supported; and make suggestions for an ecosystemic approach to supporting learners who are suffering from HIV/AIDS.

The literature review revealed that the HIV/AIDS epidemic is seriously affecting the psychological and physical well being of learners. This is due to the effects of the epidemic's associated opportunistic diseases such as, among others, weight loss, dry cough, recurring fever or profuse night sweats, profound and unexplained fatigue, swollen lymph glands in the armpits, groin, or neck, diarrhoea that lasts for more than a week, white spots or unusual blemishes on the tongue, in the mouth, or in the throat, red, brown, pink, or purplish blotches on or under the skin or inside the mouth, nose, or eyelids; memory loss, concentration, creativity, depression, and other neurological disorders; tuberculosis, pneumonia, gastro-enteritis, meningitis and cancer which affect both the physical and psychological well being of learners suffering from both HIV and AIDS.

The empirical investigation revealed that learners infected with HIV/AIDS have emotional responses to their condition of being infected with this disease. For example, both learner participants who formed the case study of this research experienced shock, blaming the parent who infected them, having nightmares, suicidality, confusion, fear of death and denial; participants were withdrawn after their status was revealed to them, it took them time to recover from the shock of being diagnosed HIV positive. The empirical research also revealed that it becomes difficult for learners suffering from HIV/AIDS to concentrate on their school work as their minds are always preoccupied with the idea that their death can come at any time.

Recommendations for further research and for practical implementation of findings from both the literature review and empirical research were made.

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## **CHAPTER ONE**

### **ORIENTATION**

#### **1.1 INTRODUCTION AND STATEMENT OF THE PROBLEM**

It is generally accepted that the HIV/AIDS epidemic is seriously affecting the psychological and physical well being of learners. This is due to the effects of the epidemic's associated opportunistic diseases. Among others, weight loss, dry cough, recurring fever or profuse night sweats, profound and unexplained fatigue, swollen lymph glands in the armpits, groin, or neck, diarrhoea that lasts for more than a week, white spots or unusual blemishes on the tongue, in the mouth, or in the throat, red, brown, pink, or purplish blotches on or under the skin or inside the mouth, nose, or eyelids; memory loss, concentration, creativity, depression, and other neurological disorders; tuberculosis, pneumonia, gastro-enteritis, meningitis and cancer affect both the physical and psychological wellness of learners infected with HIV and AIDS (Baylies & Bujra, 2000:20). Behavioural efficiency, interpersonal relationships and personal productivity are also limited (Cohen, 2001:46). Because of the physical and psychological demands involved in coping with this dreaded disease, it is not surprising that physicians and psychologists have suggested that the experiencing of HIV and AIDS, whether by an infected or affected learner or educator, will have a negative effect on his or her general functioning in school (Arndt & Lewis, 2000:856-86).

However, even at this relatively late stage of the epidemic and the havoc that the epidemic causes on the physical and psychological well being of learners, very limited, if any study has been conducted on the ecosystemic approach of supporting learners infected with HIV/AIDS. It is, therefore, necessary to conduct such a study in South Africa because of the rapid pace in its becoming a major site of HIV/AIDS in the world. For instance, research estimates that there are 1 700 new infections every day in South Africa (Gernholtz & Schleifer, 2003: 46-90) and about 4,2 million South Africans

were living with HIV and AIDS at the end 2004 (Sloth-Nielsen, 2004:67). Learners are included in these statistics.

The South African Department of Health report (2000:13) states that HIV/AIDS attacks and slowly destroys the immune system by entering and destroying important cells that control and support the immune response and system. These important cells are called CD4 or T4 cells, which do the following, they:

- directly or indirectly protect the body from invasion by certain bacteria, viruses, fungi and parasites;
- clear away a number of cancer cells;
- are involved in the production of substances involved in the body's defence; and
- influence the development and function of scavenger cells in the immune system.

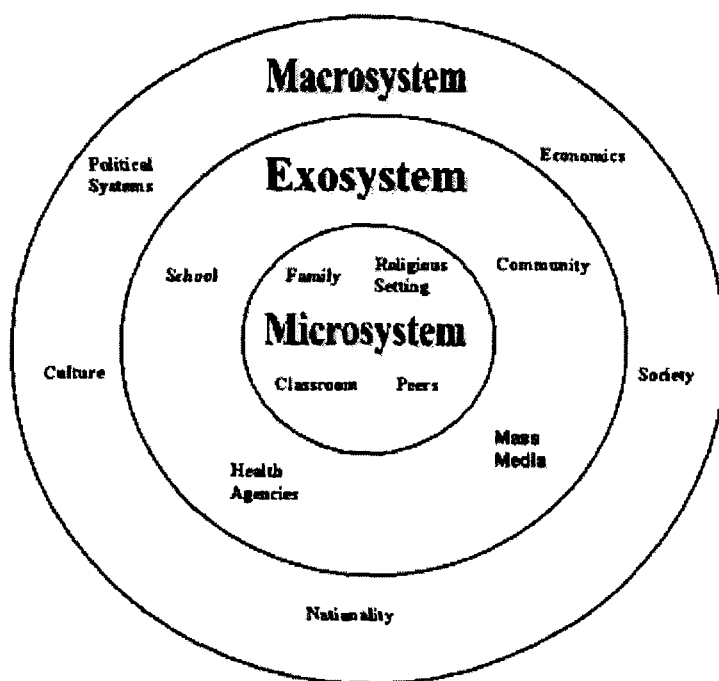
Subsequently, some T-cells of the body's immune or defence system are destroyed by HIV and AIDS. After a long period of infection, usually three to seven years, enough of the immune cells have been destroyed to lead to immune deficiency. The immune deficiency in a learner will lead to a situation in which he/she is:

- unable to execute tasks in the form of homework and school projects that have to be completed at school;
- incapable of being involved in extra-curricular activities such as sporting activities, cultural activities, and debates; and
- falling behind with school work (Sidley, 2000:1016).

Friedman and Mottier (2004:56) contend that a situation like this will also be accompanied by long periods of absence from school due to sickness and ill-health.

Given the effects of HIV/AIDS on the psychological and physical well being of learners, a major challenge in conceptualising effective responses to both HIV/AIDS epidemic lies in generating interventions which go beyond the concept of individual risk. Increasingly, researchers are turning to an ecosystemic framework to understand and describe the interplay of personal, situational, and socio-cultural factors that combine to create patterns of supporting learners suffering from HIV/AIDS (Department of Health, 2000:1). Often represented as a series of concentric circles (see Figure 1.1 below), such a framework locates the individual within a larger social system comprised of interrelated and dynamic parts.

Figure 1.1: The social context of human development



(Bronfenbrenner, 1979:24)

In figure 1.1, the innermost circle represents the biological and personal history that each individual brings to his or her behaviour in relationships. The second circle represents the immediate context in which behaviour occurs –

frequently the intimate relationships within the household. The third circle represents the community – which includes the institutions and social structures in which relationships are embedded (peer groups, social networks) as well as the broader economic and social environment. The interface between these dimensions is fluid, and factors at one level may influence - and in turn be influenced by - those at other levels. In relation to HIV, an ecological framework recognizes that behaviour change is complex and dynamic - and that a learner's ability to make decisions about their reproductive and sexual life is inextricably linked to their ability to make meaningful decisions in other areas of social life. For example, personal individual agency may in turn be influenced by factors such as power relations within the household, or broader social networks within the community (Grumbine, 1997:24).

In light of the latter paragraph, broadening the scope of HIV/AIDS interventions requires new collaborations across multiple social sectors and disciplines such as bringing together a range of expertise extending beyond the health field can raise significant challenges for creating effective synergy for dealing with HIV/AIDS. Moving away from individual-focused interventions to ecosystemic interventions shifts the emphasis towards concepts of community participation, community mobilisation and empowerment in dealing with HIV/AIDS. The importance of community-led peer education and the participation of local stakeholders is emerging as a guiding principle for interventions which seek to engage the broader contextual factors relevant to learners suffering from HIV/AIDS (Hecht, Adeyi & Semini, 2002: 36-39). Yet, involving communities in the conceptualisation, implementation and/or evaluation of programmes dealing with the psychological and physical well being of learners infected with HIV/AIDS can raise significant challenges, and there is minimal understanding about the process of community mobilisation or the techniques that best promote sustainable community participation in supporting learners who are suffering from HIV/AIDS.

The foregoing paragraphs highlight the significance of an ecosystemic approach to psychologically supporting learners who are suffering from HIV/AIDS. The questions that now come to mind are:

- What are the effects of HIV/AIDS on the psychological and physical well being of learners?
- Are learners suffering from HIV/AIDS ecosystemically supported?
- How can these learners be ecosystemically supported?

In order to solve the problems, the research has to concentrate on certain aims.

## **1.2 AIMS OF THE STUDY**

The aims of this research were to:

- investigate the effects of HIV/AIDS on the psychological and physical well being of learners;
- determine whether learners suffering from HIV/AIDS are ecosystemically supported; and
- make suggestions for an ecosystemic approach to supporting learners who are suffering from HIV/AIDS.

## **1.3 METHODOLOGY**

The methodology of this study entailed the following components:

### **1.3.1 Literature study**

A literature study was done to acquire understanding of the theoretical framework of ecosystems and HIV/AIDS, especially as it impacts on the psychological well being of learners. To achieve this, all the available data bases (both national and international) were consulted during the study, for example, NEXUS, SABINET – On-line, the EBSCOHost web and various other web-based sources as well as a DIALOG search were conducted to

gather recent (from 1990-2004) studies on the subject. The following key concepts/words were used in the search: ecological theory, systems theory, HIV, AIDS, psychological well being of students infected with HIV/AIDS, learning support.

It ought to be mentioned that an on-line internet search was conducted in 2004 and 2005 on the mentioned key words.

### **1.3.2 Empirical research**

In order to realize the aims of this study a qualitative empirical research method was employed in the form of a case study. Creswell (2003:18) is of the opinion that the case study is a research method in the qualitative paradigm which involves the in-depth study of a single event or entity bounded in space or time. This method follows an inductive model of thinking and reasoning about the elements of the case being studied which will allow the findings to emerge from the data. The four key parameters of case studies, as defined by Miles and Huberman (1994:56), are:

- the setting, where the event or entity exists;
- the actors, the informants who are observed or interviewed;
- the events, what the actors are observed doing or reporting about during the interviews; and
- the process, which is the dynamic process surrounding the actors and the events being studied.

The qualitative research method which entails interviews and observations in the formulation and development of it is effective in revealing the social contextual and the psychological and physical well being of learners infected with HIV/AIDS, including the nature and extent of the support they receive from school, family, community and society contexts. Through interviews and observations, this study investigated the effects of HIV/AIDS on the psychological and physical well being of learners; determined whether learners suffering from HIV/AIDS are ecosystemically supported; and made

suggestions for an ecosystemic approach to supporting learners who are suffering from HIV/AIDS.

Creswell (2003:34) states that in qualitative studies the interview format is either open-ended or semi-structured. As such, semi-structured qualitative interviews based on the designed interview schedule (see Appendix A for the interview schedule) were conducted in the form of an open-ended format in investigating and determining the effects of HIV/AIDS on the psychological and physical well being of learners; and if learners suffering from HIV/AIDS are ecosystemically supported. The findings from these interviews helped the researcher to make suggestions for an ecosystemic approach to supporting learners who are suffering from HIV/AIDS.

### **1.3.2.1 Purposive sample**

According to Maxwell (2004:83), purposive sampling is a central component of naturalistic research. A sample is selected by the researcher based on decisions about the sources that will most help to answer the basic research questions and fit the basic purpose of the study. Since the issue of HIV/AIDS is currently delicate and it is always very difficult for a researcher to easily get cases of learnerren suffering from HIV/AIDS, it was necessary for the researcher to work collaborately with the social workers of the Sebokeng Department of Social Development in identifying a case for this research. Social workers counsel learnerren who are suffering from HIV/AIDS and have a list of all learnerren who are HIV/AIDS positive. The researcher requested them to assist him in getting an information-rich case of school going learnerren who are suffering from HIV/AIDS for purposes of research. Patton (1990:169) defines an information-rich case as that from which a researcher can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling.” They gave the researcher a case of two brothers who congenitally got infected with HIV/AIDS, whose mother died of HIV/AIDS and the whereabouts of the father are not known. They drove the researcher to their home to introduce him to their caretaker who is their aunt. The researcher then got permission from their aunt to

conduct interviews with them. They also told them that they had the right to refuse to participate in the research. The participants agreed to participate.

### **1.3.2.2 Data generation**

The two brothers who agreed to participate were visited at their homes for interviews and observation. The researcher conducted two interviews with both brothers together in the same sessions. Rapport was easily developed during the interviews due to the unstructured nature of the interviews, which allowed spontaneous development of the conversations. The researcher verified his understanding of the content of the conversation by summarizing periodically throughout the interviews, asking the informant to clarify any misunderstanding on the researcher's part. This is the first step in a process that is known as member-checking and is the most crucial technique for establishing credibility (Patton, 2001:24) in naturalistic studies.

Each interview was also summarized and member-checked with the two brothers. Written summaries of the interviews were shared with the two brothers who were asked to check the summaries for accuracy.

The two brothers were invited at the beginning of the second interview to make changes in the summaries if inaccuracies or misinterpretations of what they reported were evident. A final summary of interview data was provided to each of the two brothers for member-checking.

All interviews were transcribed, summarized and member-checked for accuracy, following the process described above.

Copies of all verbal communication between the researcher and the two brothers were used to document critical issues in the psychosocial development of the two brothers. Critical incidents are defined by Patton (2001:21) as specific events in the context of the study that reflect "critically" on what is happening.

By collecting information using multiple sources and methods such as interviews and observations, the data was triangulated (Shank, 2002:34).

### **1.3.2.3 Data analysis**

Data analysis began with the first interviews. In naturalistic studies, data analysis is conducted during data generation rather than after it and informs the researcher prior to subsequent data generation. Interviews were transcribed, unitized and coded with a word or phrase that represented the content of the unit, as suggested by Patton (2001:13) and Marshall and Rossman (1999:34). Units with the same word or phrase were placed together in stacks. Each stack or category was analyzed and assigned a title or category to represent the stack. This method was repeated for all interviews and all units of data. Each category was listed, along with representative phrases that had been assigned to the category, which allowed for further refinement of the category titles. After the first set of interviews were coded, the themes that emerged were tested against the data. The same process was used for second interviews.

### **1.3.2.4 Case study reporting**

The case study format for reporting is appropriate for naturalistic inquiry because case studies “may be epistemologically in harmony with the reader’s experience and thus to that person a natural basis for generalization” (Denzin & Lincoln, 2005:12). By providing a thick description, case studies allow the reader to decide what elements and situations in the context might transfer to other settings and contexts encountered by the reader.

Case studies can be either single, such as it is the case in this research or multiple-case designs. Single cases are used to confirm or challenge a theory, or to represent a unique or extreme case (Gillham, 2000:21). Single-case studies are also ideal for revelatory cases where an observer may have access to a phenomenon that was previously inaccessible such as HIV/AIDS because of the difficulty of disclosure that people who suffer from it have. Single-case designs require careful investigation to avoid misrepresentation and to maximize the investigator's access to the evidence.

## 1.4 ETHICAL ISSUES

The highest ethical standards need to be upheld when collecting behavioural or biological data on sexually transmitted infections such as HIV or AIDS. Conducting HIV-related studies poses particular ethical challenges given the urgency to find effective ways for preventing and mitigating the epidemic, and the stigma associated with being HIV-positive that can result in discrimination or harm. The need to document effectiveness, that is, to collect data, must be balanced with every effort to ensure the safety and protection of all participants in data collection activities.

In light of the above paragraph, the researcher considered the following factors in conducting interviews with learner participants who took part in this research:

- **Minimal risk:** Health, psychological or social risks to participants was minimized by using procedures that are consistent with sound research design and do not unnecessarily expose participants to risk. Risk to the participants in the case study as a whole was considered.
- **Informed consent:** The participants received an explanation of the purpose for which the data were being collected, the expected duration of the participants' involvement, and a description of the procedures to be followed; description of the measures to be taken to ensure the confidentiality of the participants' records; information about who can be contacted for questions about their rights as a participant or in the result of injury to a participant; explanation that participation is entirely voluntary, refusal to participate will not result in a penalty and that participants may refuse to answer any questions, and that it is permissible to withdraw from the study at any time.
- **Confidentiality:** Strict measures were taken to ensure confidentiality to the greatest extent possible because of the stigma associated with being HIV positive and with people who are HIV positive or identified as a member of a population participating in socially discouraged behaviour that puts them at high risk of being HIV-infected (gays and lesbians and

prostitutes). In qualitative research it is often possible to record no names or personal information about participants at all. Consideration was also given to the storage of collected data so that only the researcher had access to it, and disposition of the data at the end of the study (Barton, 2000:13; Lincoln & Guba, 1999:397).

## **1.5 CHAPTER DIVISIONS OF THIS RESEARCH**

Chapter 1 is primarily an orientation chapter preparing the reader for the subsequent chapters.

Chapter 2 presents the literature review on HIV/AIDS and ecological and systems theories.

Chapter 3 presents the empirical design.

Chapter 4 presents the analysis and interpretation of the empirical research results.

Chapter 5 presents the summary, conclusions and recommendations of research.

## **1.6 CONCLUSION**

This chapter presented an orientation chapter with the aim of preparing the reader for the subsequent chapters.

The next chapter presents the literature review on HIV/AIDS epidemic.

## **CHAPTER TWO**

### **LITERATURE REVIEW ON HIV/AIDS AND ECOSYSTEM**

#### **2.1 INTRODUCTION**

This chapter presents literature review on HIV/AIDS and ecological and systems theories.

This section, defines concepts such as HIV/AIDS, the immune system, immune deficiency, syndrome and attitudes and, also, the history of the pandemic receives attention.

#### **2.2 DEFINITION OF CONCEPTS**

The following concepts that are mainly used in this research are defined below.

##### **2.2.1 HIV/AIDS**

HIV is an acronym for the Human Immunodeficiency Virus. It is a retro-virus which in the past was called Lymphadenopathy Associated virus (LAV) or simply AIDS virus (Phiri & Webb, 2002:24). When HIV gets into a human being's body, it slowly breaks down the body's immune system (Pick, 2003:67).

The virus connected to HIV is about one sixteen thousandth the size of the head of a pin. Its make-up consists of a double-layered shell or envelope full of proteins, surrounding a 'ribonucleic acid' (RNA) which is a single-stranded genetic molecule (Mkandawire, 2001:13). This explains that HIV is a very small germ or organism which cannot be seen by naked eyes, but only through an electron microscope. It only survives and multiplies in body fluids such as sperm, vaginal fluids, blood, and breast milk (UN, 2003: 60), which means that human beings can only become infected with HIV through contact with infected body fluids. Once it infects the body, it attacks the body's immune system, that is, the body's natural ability to fight illness and its

defense against infection, and reduces the body's resistance to all kinds of illness including flu, diarrhoea, pneumonia, tuberculosis and certain cancers.

When HIV has weakened the person's immune system, such a person gets ill more often (Fox, Fawcett, Kelly & Ntlabati, 2002:17). In the human blood stream, HIV is attracted to white blood cells, known as T4 helper lymphocytes. These are among the most important cells in the working of the body's immune system because of their effect in causing various different cells to become active in fighting infections, including the cells that produce antibodies (Hall, 2003: 76).

From the foregoing paragraphs it is apparent that HIV causes damage in the following ways:

- it enters T4 helper cells and uses the cells own reproductive material to reproduce itself. Eventually numerous copies of the virus break out of the cells, killing them;
- they then find other T4 cells to invade and the process starts again;
- next, they cause uninfected T4 helper cells to clamp around infected T4 cells, thus immobilising them; and
- finally, tiger types of cells dependent on T4 helper cells cease to function properly as the T4 cells become depleted. Some cells, other than T4 helper cells, may be directly attacked by the virus or by the damaged immune system itself (Richter, 2004:45).

This destruction of the immune system, according to Binswanger (2000:90), means that infectious organisms can invade the body largely unchallenged, and multiply to cause serious opportunistic diseases and illnesses called the Acquired Immunodeficiency Syndrome (AIDS), which manifest in the form of, among many other diseases:

- weight loss;
- dry cough;

- recurring fever or profuse night sweats;
- profound and unexplained fatigue;
- swollen lymph glands in the armpits, groin, or neck;
- diarrhea that lasts for more than a week;
- white spots or unusual blemishes on the tongue, in the mouth, or in the throat;
- red, brown, pink or purplish blotches on or under the skin or inside the mouth, nose, or eyelids;
- memory loss, depression, and other neurological disorders; and
- tuberculosis, pneumonia, gastro-enteritis, meningitis and cancer (Abdool-Karim, 2001:193; Case, 2003:34).

According to De Waal (2003:12) these opportunistic diseases affect both the physical and psychological health and wellness of learners infected with HIV and AIDS. It is during this period of opportunistic diseases that full-blown AIDS begins.

AIDS is defined as the presence of an opportunistic infection or disease in a previously healthy person with no other causes for immune deficiencies (Hecht, Adeyi & Semini, 2002:39; Luzanda, Senabulya & Musiitwa, 2000:20).

The five stages of the development of the HIV disease in the human body are:

#### **2.2.1.1 The primary HIV infection**

This happens within a few weeks of HIV infection and it is during this time that individuals' physical health changes from being HIV negative to being HIV positive (Hellinger & Fleishman, 2000: 182). About half of the infected individuals develop a flu-like illness with fever, sore throat, swollen glands, headache, muscle aches and sometimes a rash. This stage of the HIV

disease lasts only a week or two, and after this, the individual returns to feeling and looking completely well (Bollinger, Opuni & Bertozzli, 2002:58).

#### **2.2.1.2 The asymptomatic or silent stage**

Brugha (2003:1382) states that, after recovery from the primary HIV infection, individuals infected with HIV continue to be completely well for long periods, often for many years. During this time, the only indication that the individual is infected with HIV is that he/she tests positive on standard HIV tests and may have swollen lymph glands. This means that the person looks and feels healthy and can easily infect other people through unprotected sex, especially if he/she does not know that he/she is infected.

However, at this stage, HIV is still very active and is continuing to destroy the body's immune system.

#### **2.2.1.3 The early HIV symptomatic disease**

Several years after infection, some individuals begin to show mild symptoms of the HIV disease. These can include, among other diseases, shingles, swollen lymph glands, occasional fevers, mild skin irritations and rashes, fungal skin and nail infections, mouth ulcers, chest infections and weight loss (Gaillard, Bollinger, Stover, Moteete, Jaase & Khobotle, 2002:60).

#### **2.2.1.4 The medium-stage HIV symptomatic disease**

This stage of the HIV disease was once known as 'AIDS-related complex'. This is when individuals with HIV become quite ill without developing the 'AIDS-defining illnesses'. Typical problems include tuberculosis, recurrent oral or vaginal thrush, recurrent herpes, diarrhoea, and blisters on the mouth or genitals and on-going fever. More than ten percent of the HIV infected human beings develop significant weight loss (Makgoba, 2000:1171).

#### **2.2.1.5 The late-stage HIV disease AIDS**

National AIDS Control Council (2000:12) and Giese, Meintjies, Croke and Chamberlain, (2003:55) posit that without effective anti-retroviral therapy and

treatment, the long-term damage caused to the immune system by HIV results in severe opportunistic infections and illnesses (see 2.2.1) and HIV-related damage to other organs such as the brain and lungs. This stage is usually called AIDS.

### **2.2.2 Immune deficiency**

This is a condition where the human body's natural defence mechanisms cannot defend themselves against illnesses (Butler, 2005:3).

### **2.2.3 Syndrome**

This is a term given to a particular pattern of illnesses, which human beings develop as a result of contracting AIDS. The definition of AIDS is based on the secondary complication that develops in a human being infected with HIV. The virus itself, therefore, is not a killer, but it is the complications it produces in a victim's body which are often lethal. The virus that causes what is termed 'full-blown AIDS', breaks down a human being's natural immunity against disease. This leaves a person vulnerable to serious illnesses that would not normally threaten someone whose immune system is functioning normally (Nattrass, 2004:21).

The onslaught of these illnesses (secondary complications) is referred to as 'opportunistic'.

### **2.2.4 Immune system**

The immune system is a flexible and highly specific defence mechanism that kills micro-organisms and the cells they infect, destroys malignant cells and removes the debris. It distinguishes such threats from normal tissue by recognizing antigens, that is, substances that induce the production of antibodies called immunoglobulin when introduced into the body (Pick, 2003:50; Tesa, 2001:80).

### 2.2.5 Stigma and discrimination

Stigma can be defined as the identification and recognition of a bad or negative characteristic in a person or group of persons, and treating them with less respect or worth than they deserve due to this characteristic. Stigma also generally refers to a negatively perceived defining characteristic, either tangible or intangible. It is an attribute used to set the infected persons or groups apart from the normalized social order, and this separation implies devaluation (Wray, Rabeneck & Menke, 1999:748). In regard to HIV/AIDS, the stigma may be the actual infection or it may be based on behaviours believed to lead to infection. The association with an incurable disease is then used as medical justification for established patterns of exclusion of groups already deemed morally questionable (Meintjies, Budlender, Giese & Johnson, 2003:23). Conversely, people living with HIV/AIDS may become implicitly associated with stigmatized behaviours, regardless of how they actually became infected (Phiri & Webb, 2002:59). These pathways of stigma are difficult to disentangle, but mutually reinforce each other.

Furthermore, stigma may be applied with varying degrees of force, depending on local moral judgments about means of acquisition (United Nations, 2002:70). In South Africa, a clear gradient of “guilt” and “innocence” has formed the discourse surrounding HIV/AIDS. Sex workers or injection drug users who contract HIV are classified as most guilty, with learnerren of sex workers following (Phiri & Webb, 2002:59). At the other end of the spectrum, monogamous wives infected by their husbands who use drugs or visit sex workers are considered to be “innocent” and “vulnerable,” while their HIV positive learnerren, infected during pregnancy, birth, or breastfeeding become the ultimate “defenceless victims” (Wray *et al.*, 1999:748). Varying degrees of stigma are applied to these groups of people living with HIV/AIDS, and often to their family members or immediate communities.

Discrimination is composed of the actions or treatment based on the stigma and directed towards the stigmatized (Geeta, 2000:45). The stigmatized find themselves ostracized, rejected, and shunned and may experience sanctions, harassment, scapegoating, and even violence based on their infection or

association with HIV/AIDS (Hellinger & Fleishman, 2000:185). Discrimination may result from social disapproval of the infection and its implied behaviours or from fears due to lack of knowledge about how HIV/AIDS can or cannot be transmitted. Because the HIV pandemic emerged so suddenly and progressed so quickly, in many countries discrimination could result from people's belief that not enough time remains to carefully weigh the strengths and weaknesses of various alternative solutions to an AIDS-related problem (Lawyers for Human rights, 2004:16) and the reaction is thus to err on the side of caution, even at the expense of individual rights.

Ultimately, however, the concepts of stigma and discrimination are closely linked, and they are frequently referred to together, as throughout this research. Some authors choose to refer to discrimination as "enacted stigma" (Loudon, 2002:29). Because discrimination often includes public restrictions and punishing actions, however, it can frequently be more easily identified, and thus will remain separately defined in this review.

### **2.3 MODES OF HIV TRANSMISSION AMONG LEARNERS**

The HIV virus is transmitted through the exchange of bodily fluids (blood, semen, vaginal fluids). In the context of this research, learners who are infected with HIV or are suffering from HIV/AIDS are:

#### **2.3.1 Learners born with HIV/AIDS or infected during breast feeding (Mother-to-learner-transmission)**

Mauskopf, Tolson, Simpson, Pham and Albright (2000:310) note that there is about a twenty-five percent chance that a learner born to an HIV infected mother will be infected. Commonly, maternal and foetal blood are separated by the placenta, however during the final trimester of pregnancy, small ruptures may occur in the placenta and in turn this can lead to the entry of blood cells from the mother's bloodstream to the foetus's bloodstream. During the birth process, the learner may come into contact with the mother's blood as a result of bleeding that occurs during the delivery (Kober & Van Damme, 2004:7).

### 2.3.2 Learners infected through early sexual activity

Infection transpires through sexual intercourse (Khanna, Sunita & Kasturi, 2002:1990). The presence of venereal infection, specifically those, which cause ulceration or lesions, namely syphilis and genital ulcer disease, increase the probability of transmission by four (Bhatt, Guinness & Arthur, 2002:906).

There also are those learners who become infected through sex in cases of being abused and raped by HIV positive men. The link between learner sexual abuse and risk for HIV infection has been cited by several authors in the past (Binswanger, 2000:90; Casa, 2000:150; Fassin & Schneider, 2003:497), and recent research strongly confirms that association. Sexually abusive situations are characterized by a lack of consent and ambivalence on the part of the victim, exploitation, secrecy, force, and intent on the part of the abuser (Berkely & Ross, 2003:80). In addition, the abuser has more power by virtue of his age, size, or gender, thus creating a power imbalance between the abuser and victim. Some of the most common symptoms that learners who have experienced abuse exhibit include - emotional effects, such as guilt, shame, anxiety, fear, depression, and anger. Physical effects include psychosomatic complaints, injury and pregnancy. Cognitive and school related problems include behavioural effects, such as learned helplessness, aggressive and antisocial behaviours, withdrawal, self-destructive behaviours and psychopathology, as well as interpersonal problems, including sexual problems and poor self-esteem (Reinecke, Dattillio & Freeman, 2002:50).

Bertozzi, Opuni and Bollinger (2002:69), who refers to sexual abuse as “soul murder” believes that sexual abuse “has a lasting and profound effect...mobilizing certain defences and structural changes, most of which tend to interfere with full, free emotional and intellectual development, and modifying the primal fantasies that motivate human behaviour”. Barnette and Whiteside (2002a:25) assert that sexual abuse is “an experience that alters a learner’s cognitive orientation to the world and causes trauma by distorting the learner’s self concept, worldview, or affective capacities.

Subsequently, learners who contract HIV/AIDS through being sexually abused, suffer all maladies and are also burdened with living with the virus as well (Giese, *et al*, 2003:50).

### **2.3.3 Learners contracting HIV/ AIDS through unsafe health practices**

Johnson and Dorrington (2001:66) note that the second most frequent transmission route for HIV is through blood transfusions. When infected blood is transfused, the risk of acquiring HIV is remarkably high, ranging from ninety to hundred percent (Parkhurst & Lush, 2004:1920). Infection *via* blood transfusion occurs through the transfusion of contaminated blood and through the use of contaminated needles and syringes (Beck, Miners & Trolley, 2001:20).

## **2.4 THE HISTORY OF HIV/AIDS**

The signs of HIV/AIDS were first seen by doctors in 1981 among ill gay men in the United States of America. These men had developed unusual conditions such as a rare chest infection and skin disorders, and special tests showed that their immune systems were damaged (Achmat, 2004:19; Smart, 2000:11). In 1983 French researchers identified a new virus, now known as HIV, as the cause of AIDS. This type of HIV also became known as 'HIV-1' (Broomberg, Soderlund & Mills, 1996:50). In 1985, a second type of HIV was identified in sex workers from Senegal. This virus, called 'HIV-2,' is found mostly in West Africa, and seems to be less easily transmitted and slightly less harmful than HIV-1 (Richter, Manegold & Pather, 2004:50).

Scientists have since discovered that there are also many different strains or sub-types of HIV. In South Africa, sub-type C is the most common (Achmat, 2005:3). Sloth-Nielsen (2004:78) describes the isolation of a novel retrovirus characterised by an enzyme known as 'reverse transcriptase' which has become known as a second HIV Type II which may cause AIDS.

The following are a few interesting features regarding infection caused by this newly identified retrovirus (Sheon & Crosby, 2004:2108; Barnett & Whiteside, 2000b:60):

- firstly, HIV infection demonstrates an exceptionally lengthy incubation period (time between initial exposure and appearance of first symptoms, followed by a slow relentless progress leading to death);
- secondly, although often very high counts of specific anti-bodies are found, they seem totally incapable of combating the infection (Blain, Tawfik & Kinoti, 2002:34);
- thirdly, the degree of immune suppression seen in HIV infection is considerably more intense than that found in any other generalised virus infection; and
- lastly, these viruses are much harder to combat than other viruses, because they become part and parcel of the genetic structure of the cells they infect and there is therefore no way of getting rid of them (Campbell, 2003:22).

After Aids was discovered among gay men, it was also discovered in drug users in Western Europe, South East Asia, China and India (Gertholtz & Schleifer, 2003:55). Although homosexual activity accounted for most sexually transmitted cases in the early years of the epidemic in the United States, heterosexual transmission is rapidly increasing (Hall, 2003:5). Blood-borne transmission has resulted in infection in three major groups:

- intravenous drug users, who interchange a small amount of infected blood when sharing needles;
- people who receive a transfusion of infected blood or blood products such as the clotting factor for the treatment of haemophilia in the early years of the epidemic, before stringent testing for HIV became the rule; and
- health-care workers who become infected as a result of accidents involving needles contaminated with infected blood (Hooper-Box, 2005:29; Alessandra, Bott, Ghezmes & Helzner, 2002:180).

In South Africa, people initially linked AIDS to gay men, but when a study in 1987 showed a relatively high level of infection among Malawian gold miners,

the blame shifted to people who come from other African countries. Later many people thought AIDS was a White man's disease. Many White people are under the impression that AIDS is a Black person's disease (National AIDS control council, 2000:12). This shows that South Africans have always displayed certain stereotypes and perceptions about the AIDS pandemic. Shalev (2000:59) contends that because of these stereotypes and perceptions, many years were wasted and HIV began to spread rapidly among all South Africans (UNICEF, 2003:65). Between the years 1990 and 2003, the level of HIV infected pregnant women rose from less than one per cent to over twenty-one per cent.

In the past, politicians in the South African apartheid government sometimes blamed AIDS on terrorists coming from other African countries. As a result, they did very little to educate South Africans about HIV/AIDS (Bollinger *et al*, 2002:60).

#### **2.4.1 The attitude of black people toward HIV/AIDS**

The attitude towards HIV/AIDS among Black South Africans is different. Definitions of health, sickness and sexuality have different meanings in the traditional African context than in the Western world. It has been very difficult to change Black people's attitude in this context, because all HIV/AIDS education and prevention programmes have mostly been based on Western principles, without understanding the diverse cultural and belief systems of Africa and incorporating them into such programmes (CANADIAN AIDS SOCIETY, 2002:8; Case, Paxson & Ableidinger, 2003:483).

Bayles and Bujra (2000:26) opine that illness among Black people is not a random event. Rather, every illness is a product of destiny and has a specific cause. For Blacks, in order to eliminate the illness, it is necessary to identify, punish, eliminate and neutralise the cause, the intention behind the cause and the agent of the cause of intention. Illness, according to Black cultural beliefs, can be a result of disharmony between a person and the ancestors, caused by God, spirits, witches and sorcerers, natural causes, or a breakdown in relationships between people.

Ancestors are seen to have an integral influence on the lives of Africans. They are believed to protect people against evil. However, ancestors could purportedly punish people by sending illness and bad luck if people are ignorant of observing traditions that keep the ancestors happy. People can also cause disharmony between themselves and the ancestors if certain social norms and taboos are violated (Brugha, 2003:1384).

Kober and Van Damme (2004:7) postulate that ancestors do not always send illness, but through the withdrawal of their protection, people become susceptible to illness, tragedy and spells cast by witches and sorcerers. Illness caused by ancestors is seldom serious or fatal, and through offerings and sacrifices, a positive relationship is restored between people and their ancestors. There is no available evidence that traditional Africans link AIDS to the anger of the ancestors or to punishment from God. Some Christians do, however, believe that AIDS is God's punishment for immorality and sin (Sidley, 2000:1016).

Whiteside and Sunter (2000:11) state that witches and sorcerers are frequently blamed for illness and misfortune in traditional Black African societies. Because traditional Africans often use the services of witches and sorcerers to send illness and misfortune to their enemies, they in turn, believe that whatever bad luck or illness is incurred, is a product of witches or sorcerers.

Among many rural, poor and uneducated Africans, HIV/AIDS is seen as being caused by witchcraft. Many people ascribe sexually transmitted diseases (STD) to witchcraft. They base this belief on the argument of: Why does one man become infected and the other remain uninfected, when both men have had sexual contact with the same woman (Cullinan, 2002:423)?

When relationships are in conflict, or threatened, accusations of witchcraft are raised against members of a group or a community. In African societies, death is only accepted as natural when the elderly die. When younger people die, it is viewed as untimely and attributed to punishment or the work of evil spirits or witches. This psychological rationale of blaming witchcraft implies that

Africans are not taking responsibility for their actions and are displaying an external locus of control. This viewpoint prevents people from exercising their personal initiative in preventing a fatal illness such as HIV/AIDS (Smart, 2000:16; Wolitski, Valdiserri, Denning & Levine, 2001:885).

Abdool-Karim (2001:104) posits that due to this misconception, many Africans cannot fully appreciate the need for engaging in HIV preventative methods. By blaming witches as the cause of illness, the victim's status suites those who are infected. However, this faulty belief has resulted in many witch-hunts and deaths. By ignoring or undermining traditional witchcraft beliefs, prevention efforts are hindered. Fox *et al* (2002:55), Natrass (2004:30) and Sheon and Crosby (2004:2110) believe that these beliefs should be incorporated into HIV/AIDS prevention programmes at schools. Interventions should recognise the personal or ultimate cause of an illness, which may be witchcraft, but the fact that the immediate cause is a "germ or virus" which is sexually transmitted, should be emphasised.

Many traditional Africans believe that witches or sorcerers use sexual intercourse as the entry point for their medicines or spells to infect people with sexually transmitted diseases and HIV. For many years, traditional Africans have worn charms which they believe have preventative and proactive powers (Schneider, 2000:61). If the use of these "protective" charms prevent misfortune and illness, (Wray *et al*, 1999:750) ask why the introduction of condoms "blessed" by traditional healers cannot be used to increase their use among traditional people.

Traditional Africans believe that some causes of illness can be ascribed to a failure to "purify" themselves adequately through rituals (Achmat, 2004:27). Ritual impurities are usually associated with sexual intercourse (especially sex with a taboo person), with activities of the reproductive system or with coming into contact with corpses and death. In order to cleanse oneself of these "impurities", a person has to perform extensive cleansing rituals that involve washing, vomiting and purging (Schwartz, Coatsworth, Pantin & Szapocznik, 2003:88).

## 2.4.2 HIV prevention programmes

Barnett and Whiteside (2000:68) state that although HIV infection is not commonly thought to be a consequence of “ritual impurity,” some of the sexual prohibitions may be useful in HIV prevention programmes. For example, the prohibition against sexual intercourse with a woman during menstruation, with a widow before she is cleansed (her husband might have died of AIDS) or with women who have had an abortion or miscarriage should be encouraged because they can prevent HIV infection (Fassin & Schneider, 2003:498; Geeta, 2000:55).

Traditional Africans believe that some diseases such as colds, influenza and diarrhoea in learnerren, sexually transmitted diseases and malaria are caused by natural causes such as germs and viruses (Hellinger & Fleishman, 2000:185). Although it is believed that witches may sometimes use germs and sexual intercourse to cause illness, traditional Africans acknowledge that the immediate cause of sexually transmitted diseases is virus-related, that is, it is transmitted through sexual intercourse and can be prevented by behavioural change (Richter *et al*, 2004:55).

However, the link between STDs, AIDS and sexual behaviour change is often not made in traditional Africa. Many Africans do not understand that they have to alter their sexual behaviour to prevent HIV infection, since the disease affects all organs in the body besides the sexual organs (Sloth-Nielsen, 2004:8). The AIDS message should therefore be strongly linked to STD prevention in Africa. The knowledge and assistance of traditional healers should be actively employed in the control and prevention of HIV (UNAIDS, 2001:80).

Most African patients consult traditional healers for STD treatment since they are believed to be competent in preventing the spread of STDs such as HIV/AIDS. Traditional healers advise their patients to:

- abstain from sex while undergoing STD treatment;
- not have sex with prostitutes; and

- locate and advise all recent sex partners to be treated (Wolitski *et al*, 2001:885).

## 2.5 AFRICAN CULTURAL NORMS AND PRACTICES

Polygamy is also a way of life for most Africans (Arndt & Lewis, 2000:860). Polygamy is valuable to migrant labour, where men leave their wives in the rural areas to seek work in the cities. If a man has several wives, he could take one at a time to live with him in the city, while the other wife/wives remain behind to take care of the household (Beck *et al*, 2001:28).

Casa (2000:154) states that in some societies sexual intercourse between husband and wife is banned while she is pregnant and this abstinence is practiced until after learner-birth or even until the learner is weaned. In such situations, polygamy prevents husbands from turning to casual sex. Therefore, in areas where polygamy is practiced, AIDS educators cannot effectively preach monogamy. They need to emphasise loyalty and fidelity between a husband and all his wives and discourage sex outside that group (Gaillard *et al*, 2002:55).

Hooper-Box (2005:29) finds that the resistance to condom use in Rwanda has nothing to do with ignorance, but relates to social and cultural dimensions of Rwandan sexuality. They believe that the flow of fluids involved in sexual intercourse and reproduction are indicative of "gifts of self" which Rwandans regard as vital in a relationship. The use of condoms, according to them, blocks this vital flow between partners, and causes infertility and other illnesses. There is also fear that the condom may stay blocked in the vagina and cause "blocked beings." In many parts of Africa, there is a widespread belief that repeated inseminations of semen are needed to form or "ripen" the growing foetus in the womb (Khanna *et al*, 2002:40). It is also believed that semen contains important vitamins that are necessary for the continued physical and mental health, beauty and future fertility of women (Loudon, 2002:33).

The literature has revealed that there are learners who believe that HIV/AIDS can be transmitted through forms of casual contact, such as kissing, sharing a

drinking glass and contact with a toilet seat (Loudon, 2002:30). These lingering misconceptions are contributing factors that create prejudice against HIV-positive individuals, since learners who believe that HIV can be transmitted in these ways are much more likely to express discomfort about attending schools with those learners who are infected with HIV/AIDS.

The foregoing paragraphs highlight the socio-culturalness of aspects of HIV/AIDS in Africa. Research findings indicate that Africa has the largest number of people living with HIV/AIDS in the world, and the fastest growing epidemic. The reasons for this are complex; nevertheless, certain socio-cultural factors have been identified as responsible for the rapid spread of the disease. These include gender inequality and male dominance, violence and sexual violence, political transition and the legacy of apartheid in the case of South Africa, poverty, commercialisation of sex, lack of knowledge and misconceptions about HIV/AIDS and cultural beliefs and practices (Benell, Hyde & Swainson, 2002:8).

### **2.5.1 Gender inequality and male dominance**

South African culture is generally male-dominated, with women accorded a lower status than men are. Men are socialised to believe that women are inferior and should be under their control. Women are socialised to over-respect men and act submissively towards them. The resulting unequal power relation between the sexes, particularly when negotiating sexual encounters, increases women's vulnerability to HIV infection and accelerates the epidemic. Women's inferior status affords them little or no power to protect themselves by insisting on condom use or refusing sex (Gupta, 2001:5). Many women also lack economic power and feel they cannot risk losing their partners, and thus their source of financial support, by denying them sex or deciding to leave an abusive relationship. Entrenched ideas about suitably "masculine" or "feminine" behaviour enforce gender inequality and sexual double standards, and lead to unsafe sexual practices. Abstinence and monogamy are often seen as unnatural for men, who try to prove themselves "manly" by frequent sexual encounters, and often the aggressive initiation of these (Halperine, 2001:12).

Examples of other prevalent ideas which result in sexually unsafe behaviour include the following:

- sex on demand is part of the marriage “deal”;
- sexual violence is a sign of passion and affection;
- men have natural sexual urges that cannot be controlled in the face of women’s powerful attractions; and
- sex is necessary to maintain health and gender identity.

These views serve to justify men’s sexual behaviour to some extent. Men are given a “license” to be sexually adventurous and aggressive, without taking responsibility for their actions (Page, 2001:44).

Women’s respectability is derived from traditional roles of wife, home-maker and mother. Learnerbearing and satisfying her husband, sexually and otherwise, are key expectations for a wife - even if she is aware that her husband is unfaithful. Refusing a husband sex can result in rejection and violence. The low status accorded to a woman without a male partner may be an additional reason making women less likely to leave an abusive relationship. Too much knowledge about sex in women is seen as a sign of immorality, thus insisting on condom use may make women appear distastefully well-informed. Married women who request safer sex may be suspected of having extra-marital affairs or of accusing their husbands of being unfaithful (Tallis, 2002:15).

### **2.5.2 Cultural norms and practices related to sexuality**

Certain prevalent cultural norms and practices related to sexuality contribute to the risk of HIV infection, for example:

- negative attitudes towards condoms, as well as difficulties negotiating and following through with their use. Men in southern Africa regularly do not want to use condoms, because of beliefs such that “flesh to flesh” sex is equated with masculinity and is necessary for male health. Condoms also

have strong associations of unfaithfulness, lack of trust and love, and disease (Barnett & Whiteside, 2002a:13);

- certain sexual practices, such as dry sex (where the vagina is expected to be small and dry), and unprotected anal sex, carry a high risk of HIV because they cause abrasions to the lining of the vagina or anus (Benell, Hyde & Swainson, 2002:8);
- in cultures where virginity is a condition for marriage, girls may protect their virginity by engaging in unprotected anal sex;
- the importance of fertility in African communities may hinder the practice of safer sex. Young women under pressure to prove their fertility prior to marriage may try to fall pregnant, and therefore do not use condoms or abstain from sex. Fathering many children is also seen as a sign of virile masculinity (Gupta, 2001:5);
- polygamy is practised in some parts of southern Africa. Even where traditional polygamy is no longer the norm, men tend to have more sexual partners than women and to use the services of sex workers. This is condoned by the widespread belief that males are biologically programmed to need sex with more than one woman (); and
- urbanisation and migrant labour expose people to a variety of new cultural influences, with the result that traditional and modern values often co-exist. Certain traditional values that could serve to protect people from HIV infection, such as abstinence from sex before marriage, are being eroded by cultural modernisation (Halperin, 2001:13);

### **2.5.3 Physical and sexual violence**

Violence against women is a major problem in South Africa, and is linked to its male-dominated culture. Men often use violence in an attempt to maintain their status in society and prove that they are “real men” by keeping women under their control. Physically abusive relationships limit women’s ability to negotiate safer sex. Many men still do not want to use condoms, and some

become violent if women insist on protected sex. Women may not even raise the issue of safer sex for fear of a violent response (Pathe, 2002:30).

One result of apartheid-era violence by the state and the armed resistance movement is that violence came to be accepted as a familiar, acceptable way of solving conflicts and wielding power. In addition to heterosexual relationships, violence pervades a wide range of social relations, including same-gender sexual relationships such as those between male prisoners (Nicoletti, Spencer-Thomas, Bollinger & Prial, 2001:24).

In South Africa, where a woman has about a one in three chance of being raped in her lifetime, the highest sexual violence statistics in the world prevails with obvious implications for the spread of HIV/AIDS. The genital injuries that result from forced sex, increase the likelihood of HIV infection - when virgins and learnerren are raped, the trauma is more severe, and risk of infection even higher (Page, 2001:40).

Increasing numbers of rapes of female learnerren may represent males' attempts to seek sexual relations with young girls to avoid HIV infection or because of the belief that sex with a virgin will cure AIDS (Dutton & Sonkin, 2003:15).

Women with a history of being sexually abused are more likely to risk unsafe sex, have multiple partners, and trade sex for money. Men who are violent to their partners are also more likely to have sexually transmitted infections (STIs). These factors as well as poverty combine to put women who suffer sexual violence at very high risk of contracting HIV/AIDS (Copeland & Harris, 2000:58).

#### **2.5.4 Poverty**

High levels of unemployment and an inadequate welfare system have lead to widespread poverty, which renders people more vulnerable to contracting HIV because of the following factors:

- the daily struggle for survival overrides any concerns people living in poverty might have about contracting HIV;
- strategies adopted by people made desperate by poverty, such as migration in search of work and “survival” sex-work, are particularly conducive to the spread of HIV/AIDS (Bass & Davis, 2003:10);
- people living in deprived communities where death through violence or disease is commonplace tend to become fatalistic. The incentive to protect oneself against infection is low when HIV is only one of many threats to health and life. Poverty may also breed low levels of respect for self and others, and thus a lack of incentive to value and protect lives (Makgoba, 2000:12); and
- poverty is generally associated with low levels of formal education and literacy. Knowledge about HIV and how to prevent it, as well as access to information sources such as schools or clinics, is subsequently insignificant in poor communities (Tallis, 2002:5).

Ironically, socio-economic development and poverty relief can, in fact, sometimes accelerate the epidemic. This is particularly the case when development is linked to labour migration, rapid urbanisation, and cultural modernisation – all of which occur to a significant extent in South Africa. Thus, although poverty contributes to the spread of HIV/AIDS, alleviating poverty can do likewise. For example, improved infrastructure such as new transport routes and improved access are seen as positive developmental goals. However, this often results in a larger migrant population, and facilitates the spread of AIDS to previously inaccessible parts of the country (Gupta, 2001:25).

### **2.5.5 Commercialisation of sex**

A prominent aspect of South African culture that undoubtedly contributes to the HIV/AIDS epidemic is that sexuality is frequently seen as a resource that can be used to gain economic benefits (Badcock-Walters, 2001:8).

The country has seen the rapid development of a relatively affluent Black middle class with a desire for material goods, and a sexual culture that associates sex with gifts. Men gain social prestige by showing off material possessions and being associated with several women (Whiteside, 2003:66).

Young women are often persuaded to have sex with “sugar daddies” - older, wealthier men in exchange for money or gifts. Some girls enter the sex industry for similar reasons. Young women infected with HIV by sugar daddies then infect younger men, who in turn infect other young women and in time become HIV-positive older people themselves and so the cycle continues. Older men also infect older women, usually their wives. Both younger and older women give birth to learnerren, some of whom will then be HIV-positive (Epstein, 1995:701; Sidley, 2000:16).

### **2.5.6 Lack of knowledge and misconceptions about HIV/AIDS**

It appears that the majority of South Africans have heard about AIDS, and have a fairly good level of knowledge of the basic facts which is that the disease is spread sexually, and that condoms reduce the risk. Nevertheless, there are still many people, especially those with low levels of formal education and who lack access to accurate, relevant information on HIV/AIDS and sexuality, who are unaware of the risks (Page, 2001:24).

Women in particular have high rates of illiteracy, and many girls do not complete basic education. Also, women may be unaware of risks because their time is taken up with tending the home, and they have limited links with the outside world ().

Added to this is the problem that dangerous myths and misconceptions about HIV/AIDS abound. These include believing that the virus can be contracted by sharing food, that infected people can be recognised by their symptoms, and, perhaps the most notorious of all, the belief that sex with a virgin can cure the disease. Beliefs such as this, give people a false sense of their level of risk, and contribute to confusion about how HIV is transmitted (James, 2001:66).

People who do possess some knowledge about HIV, often, do not protect themselves because they lack the skills, support or incentives to adopt safe behaviours. High levels of awareness among the youth, a population group particularly vulnerable and significant as regards the spread of HIV/AIDS, have not led, in many cases, to sufficient behavioural change. Young people may lack the skills to negotiate abstinence or condom use, or be fearful or embarrassed to talk to their partner about sex (Department of Social Development, 2004:14). Lack of open discussion and guidance about sexuality is often lacking in the home, and many young people obtain misinformation from their peers instead.

## **2.6 SOCIAL ISSUES FOR LEARNERS INFECTED WITH HIV/AIDS**

This section provides some social issues, which are, in most cases, associated with HIV/AIDS.

### **2.6.1 Stigma and discrimination**

Sexually transmitted infections have always been imbued with stigma due to their association with behaviours considered deviant or immoral (Ebersohn & Eloff, 2002:15). Similarly, societies have historically reacted with fear to disfiguring, debilitating, and fatal diseases and have translated this aversion into discriminatory actions against the infected (Mauskopf *et al*, 2000:42; Geeta, 2000:20). The HIV/AIDS pandemic has presented the world with a condition that combines these characteristics and it has frequently been met with stigma and discrimination, a reaction dubbed “the second epidemic” (Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002:16).

Despite the widespread attachment of stigma to people infected or affected by HIV/AIDS, the experience of discrimination has not been constant or consistent across time or place. As with many natural phenomena, societies have “ their own meanings and explanations for sickness, ideas about disease transmission and sexual behaviour. Fears associated with illness, disease, and sex therefore need to be viewed in this broader social and cultural context” (Kelly, 2002:4). Regional, national, and cultural differences can and

do shape the level and manifestations of HIV-related stigma. Subsequently, the impact of these social responses shapes the wider HIV epidemic itself.

The driving forces of HIV are almost always difficult to extricate, but clear evidence, even if anecdotal, exists to indicate that both actual discrimination and fear of stigmatization affect transmission patterns and contribute to determining the success or failure of prevention and care as well as support efforts. Despite insufficient research on this topic, it is increasingly becoming acknowledged that effective prevention and treatment strategies require an understanding of cultural frameworks, including of stigmatization (Mkandawire, 2001:21).

Since the onset of the HIV epidemic, discrimination and stigmatization have tended to fall into two basic categories, which are:

- legislative forms of discrimination, which reflect stigma that has been officially sanctioned and legitimized through laws or policies; and
- community-level forms, in which marginalized groups experience discrimination in a variety of less formal contexts, often those related to family and other structures of civil society (Brown, 2003:49).

Widespread negative attitudes perpetuated through shared social discourse, such as by the media, could be said to constitute a third, societal-level form of discrimination. For the purposes of this research, however, the influence of pervasive and stigmatizing media images will be considered within the perplexity of discrimination at the community-level (Dorkenoo, 2001:23).

In reality, these forms of discrimination may not be easily delineated. Laws and policies can mirror community beliefs, and civil society operates within institutional norms. As a result, interventions that attempt to reduce discrimination may also blur the distinctions. Advocating for policy change may eventually lead to redressing injustices committed in the community, while working at the grassroots from the start, may stimulate popular support for changes at the policy level. In general, however, strategies targeting stigma and discrimination usually focus on either the legislative or the

community level. Although this research only concentrates on the latter in reference to South Africa, only one category of discrimination is briefly described below (Kelly, 2002a:30).

Most people participate in many “communities”, either simultaneously or at different times throughout their lives. As a result, to consider social responses to HIV/AIDS at the community level, requires scrutiny of numerous contexts. Specific instances of discrimination in South Africa are plentiful. According to () despite almost a decade of the epidemic and continued public health advocacy:

- infected learnerren form a large percentage of street learnerren (Busza, 2001:441)
- HIV-positive learnerren are denied entry to schools (Dorrington, Bourne, Bradshaw, Laubscher & Timaeus, 2001:84); and
- some hospitals continue to refuse to treat identified HIV-positive people (Carr-Hill & Peart, 2003:58).

The persistence of such discrimination in a country known for its successful and rapid response to HIV/AIDS may be a result of the style of the early campaigns, which inadvertently contributed to the widespread social stigmatization, and fear of people living with HIV/AIDS (James, 2001:24).

As in other countries, however, rejection of HIV-positive people by family, forced isolation from the community (Parker & Mundwarara, 2002:18). Families keep the household items, clothing, and personal belongings of people living with HIV/AIDS separate from others. In some instances, the entire family experiences rejection by the wider community (Badcock-Walters, 2001:8).

These instances of discrimination, and the fears they induce, affect the progress of the HIV epidemic in numerous detrimental ways. The discussion below demonstrates impacts on the pandemic and explores how interventions

working within the contexts listed can successfully counteract community-level discrimination.

### **2.6.2 Changed notions of what constitutes family**

On the socio-cultural level, the impact of HIV/AIDS has also challenged and broadened traditional notions of what constitutes a family. Many of those infected by the disease live in non-traditional arrangements, prompting reconsideration of who is and who functions as a family. For the purpose of this research, family members are defined as individuals who by birth, adoption, marriage or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need (Dorkenoo, 2001:4). Operationally the family includes the spouses, partners, learnerren, parents, siblings, friends and caregivers of the person suffering from AIDS.

In terms of the systems theory, families are social systems. Consequently, the effect of a family member's infection will reverberate throughout that system and over time. According to MacIntyre (2001:168), the psychosocial impact of HIV/AIDS on families usually begins with the disclosure of HIV infection. The disclosure of HIV-positive status may be the manner in which parents first learn of their infected learner's sex activities. Consequently, together with the prospect of being infected themselves, the learner's family life and/or pattern of denial may be shattered,

Reactions to and feelings of families of persons living with HIV/AIDS include social stigma and isolation as secrecy cuts off potential sources of support, fear of contagion, which may limit intimacy and involvement of parents, fear of infecting others or straining their impaired immune system (Barnett, 2002;25). Fear of abandonment, also results as caregivers are unable to keep up with the physical and emotional demands of care-giving and of watching a loved one suffer and deteriorate. Guilt by family members resulted after having estranged themselves from the ill individual because of his/ her lifestyle and psychological and physical exhaustion.

## 2.7 COPING MECHANISMS

How people cope with HIV/AIDS depends on many conditions, the following deserve to be noted:

- the severity of the illness - the very ill have to apportion all their energy into healing and may not have possess energy for emotional growth;
- the social support available - if a person is willing to ask for help and has a wide support network, such person will have an easier time than if being isolated; and
- the pre-illness personality of the person - if a person has always been adoptable such person is likely to have flexibility in coping with the illness (Glauser & Bozarth, 2001:142).

Schultz and Schultz (2001:10) contend that personal meaning systems act to influence the manner in which individuals respond and cope with stress throughout the life span. They argue that individual 'patterns of commitment' determine the manner in which certain events are appraised in terms of their possible impact on both psychological and physical well being, and should influence the manner in which these events are managed. Events, which challenge important commitments, are generally perceived as threatening, and should increase the individual's vulnerability to stress. However, it is noted that this vulnerability also propels the individual into action, which relieves the threat and maintains coping. Thus, patterns of commitment create a state of meaningfulness (Yalom, 2000:27).

The coping mechanisms that are used in response to stress, perform a vital role in determining the character and extent of the stress impact. Coping influences health both indirectly, through health and illness behaviour or in directly through physiological responses. Thus, an individual's coping strategies have meaningful effects on their physiological responses to stressful situations and the way individuals cope with stresses in turn, effects overall health and mortality (Glauser & Bozarth, 2001). Coping can be defined as "a person's cognitive and behavioural efforts to manage with internal and

external stress” (Hatch, 1998:17). According to this framework, problem-focused coping is understood as behavioural attempts at management of the external environment, and emotion-focused coping as the regulation of internal stress. Typically, people use both types of coping, although one type may be dominant depending on the context, appraisal of the situation and personal factors (Lemons, 1996:433). Problem-focused coping tends to predominate when people feel that something constructive can be done, whereas emotion focused coping tends to prevail when people feel that the stressor is something that must be endured (Ludwig, Walker & Holling, 1997:66). Masterpasqua and Perna (1997:19) contend that meanings in situations influence human resilience and initiative. Thus, in the case of HIV/AIDS, what determines the crisis of the disease is not the illness, but the meaning attributed to it and in turn affecting a person’s coping style. Those who remain angry, disconnect from the world with an attitude of ‘nobody cares’, prompting a chronic stress response. Those that imagine possibility, perceive change as a challenge, commit to engaging with the self and others and refuse to feel powerless and develop proactive coping styles (Mcphee, 1995:73). It is expected that at varying points of the HIV/AIDS progression, different coping requirements will be made. Furthermore, the effectiveness of the types of coping strategies and the psychosocial resources used in meeting those demands may be dependent on the disease stage (Overman, 1999:118). A number of studies exploring the role of coping styles and coping strategies in persons with HIV/AIDS disease have been conducted. One of these studies conducted by Wheatley (1999:35) attempted to document ways of coping with HIV/AIDS.

There are three methods of coping, namely active cognition (re-assessing the situation to cast it in a more positive light), active behaviour (attempting to master the situation), and avoidance coping (avoiding thinking about it). Increased emotional adjustment to HIV/AIDS has been found to be associated with an active behavioural coping style. Also coping strategies comprising of control, optimism and interpersonal coping have been found to be correlated with enhanced adjustment to HIV/AIDS. Similar to these findings Allen, Tainter and Hoekstra (1999:404) found avoidance coping to be associated with

regressed worse emotional adjustment to HIV/AIDS as opposed to more active coping strategies. Berk (2000:24) argues that there are three coping strategies that may be dysfunctional, namely venting emotions, behavioural disengagement and mental disengagement.

Use of emotional and behavioural disengagement by the individual may indicate an avoidance of satisfactory cognitive appraisal, which has been identified as being critical for coping with stress. It was discovered that the venting of emotions suggests a reluctance to partake in cognitive appraisal or other coping responses that may alleviate stress. Venting of emotions is in fact related to increased distress over a period of time. Butler (2005:16) exploring the use of more avoidance and less support seeking was confirmed to be significantly related to lifetime suicidality, as determined by means of the Diagnostic Interview Schedule, in a sample of HIV-infected homosexual men.

Contrary to above findings and despite much criticism, Capra (1996:7) observes that avoidant coping expressed through an ability to fantasize, correlates with fewer psychological symptoms, suggesting that this style may nevertheless, be useful. It is however, noted that when avoidant coping is expressed through withdrawn behaviour, it correlates with higher symptom levels. The results of these studies suggest that at times a more active style of coping may be beneficial, while at others, a more avoidant style may be protective in buffering the stress of illness (Cohen, 2001:40).

Subsequently, it becomes evident that the experience of diagnosis incorporates and facilitates a complex process involving the typical responses of denial, anger, bargaining, depression and acceptance which inevitably forces an individual to choose a mode of being and responding to the illness which facilitates a way of coping. These responses involve the reworking and restoring of personal experience in such a way that a biographical reworking of one's self and the world is undertaken. However, this reworking of the understanding of self often involves an initial disruption of typical psychosocial responses associated with the stages of human development.

## **2.8 THE ECOSYSTEMS THEORY**

This section provides a literature review on the ecological and systems theories. These theories were chosen for this research because of their philosophy which propounds that families, communities and societies provide effective environmental contexts and systems in the development of learnerren and learners. The foregoing paragraphs of this section highlighted that acute and chronic medical conditions such as HIV/AIDS in people, have the potential to bring about a range of psycho-social challenges such as stigma and discrimination in communities. The overlapping of social, individual, family, financial, cultural, and illness factors, poses a challenge to the learner suffering from HIV/AIDS.

Because of the experiences that these learners go through, it is imperative to discuss the two types of theories that are significant in psychologically supporting these learners both at school, home and in the community. These are seen as ecological and systems theories.

### **2.8.1 The framework of ecological and systems theories**

The word 'ecology' comes from the Greek word *oikos* which means household. In this sense, ecology is the study of the way in which the household operates (Gurney & Nisnet, 1998:7). More precisely, it is the study of the relationships that interlink all members of the households in the world. Therefore, being ecologically literate, or ecoliterate, means, understanding the basic principles of ecology and being able to embody them in the daily life of human communities. In particular, it is believed that the principles of ecology should be the guiding principles for creating sustainable learning communities and school organizations. In other words, ecoliteracy offers an ecological framework for the transformation of educational psychology practice in South Africa (Gunderson, Holling & Light, 1995:13).

The ecological paradigm represents an integration of research and theory in developmental psychology and sociology, with experiential knowledge of social work, family support, early intervention and early learnerhood education. It represents a consolidation of what researchers are learning

about the way different social environments and relationships influence human development. Because it is a developing model with many as yet unexplained elements, the ecological model is still in a state of proliferation (Ulanowicz, 1997:30). However, the basic tenets of the ecological model have been established for some time and can be stated as:

- human development is viewed from a person-in-environment perspective;
- the different environments individuals and families experience shape the course of development;
- every environment contains risk and protective factors that help and hinder development;
- influence flows between individuals and their different environments in a two-way exchange. These interactions form complex circular feedback loops; and
- individuals and families are constantly changing and developing. Stress, coping and adaptation are normal developmental processes (Axlerod, 1997:18; Coetzee & Streak, 2004:85).

#### **2.8.1.1 An ecological model**

An ecological perspective focuses on dynamic developmental processes including the way stress, coping and adaptation contribute to development. A useful concept for understanding this view of development is the "goodness of the fit" model. This model suggests that healthy development and effective functioning depend on the match between the needs and resources of a learner or family and the demands, supports and resources offered by the surrounding environment. The developing individual responds to the "environmental fit" through developmental processes associated with stress management, coping and adaptation (Hatch, 1998:17).

The "goodness of fit" model is useful for understanding how to support and strengthen families as well. Families develop and move through predictable developmental stages just as learners do. Families should also respond to

the demands and expectations from work, social groups, community institutions and the society as a whole. Stress builds up when the resources and coping skills of a family are inadequate to meet the demands and expectations of the social environment. Family stress levels are a predictor of "rotten outcomes" for learnerren. If stress increases beyond a certain point, for whatever reason, a family's ability to nurture its learnerren decreases (Ulanowicz, 1997:30).

A lack of fit or a mismatch can happen between learnerren and their family or school environments or between a family and community environment. Problematic behaviour in school may often be attributed to a mismatch between a learner and the expectations of the school setting (Shrader-Frechette, 1997:20). Mismatches also happen when the home culture and values are at odds with the dominant values of the school environment. This poses a threat to the linkages between family and school. The threat is lessened when both sides respect and recognize the importance and value of each to the learner. When a mismatch occurs and a learner is disruptive or a family needs help from outside, it may not be due to a deficiency in the learner or family. The mismatch may be the result of a lack of resources or support from the social environment (Sterelny, 2001:440).

#### **2.8.1.2 The impact of ecology on development**

It can be inferred that environments help or hinder development. For example, a given environment may be beneficial and supportive to development or impoverishing and threatening to development. Negative elements or the absence of opportunities in family, school or community environments may compromise the healthy development of learnerren or inhibit effective family functioning (Kirkman, 1997:380). Examples of different environments in a learner and family's ecology and their impacts follow:

- as learnerren move out into the world, their growth is directly influenced by the expectations and challenges from peer groups, care-givers, schools, and all the other social settings they encounter;

- the depth and quality of a family's social network is a predictor of healthy family functioning. During normal family transgressions, all families experience stress. Just having someone to talk to about the learner over a cup of coffee, exchange learner care issues, or offer help with projects, buffers family from the stresses of normal family life (Castle, 2000:160);
- strong linkages between families and community organizations such as schools, should open channels that allow vital information and resources to flow in both directions, support families, schools, and communities; and
- the work environment, community attitudes and values, and society at large shape learner development indirectly, but powerfully, by affecting the way a family functions (Meyer, 1997:40).

When considering the ecology of a particular learner, a person might assess the challenges and opportunities of different settings by asking the following questions in different settings such as:

- in settings where the learner has face-to-face contact with significant others in the family, school, peer groups, or the church, the following questions come to the fore, which are;
  - is the learner regarded positively?
  - is the learner accepted?
  - is the learner reinforced for competent behavior?
  - is the learner exposed to enough diversity in roles and relationships?
  - is the learner given an active role in reciprocal relationships?(Cooper, 2001:490; McDonnell, Pickett, Groffman, Bohlen, Pouyat, Zipperer, Carreiro & Medley, 1997:25)

- when the different settings of a learner's ecology such as home-school, home-church, school-neighbourhood interacts, the following questions are raised:
  - do settings respect each other?
  - do settings present basic consistency in values?
  - are there avenues for communication?
  - is there openness to collaboration and partnership? (Taylor, 1999:198)
  
- in the parent's place of work, the school governing body, local government - settings in which the learner does not directly participate, but which have powerful impact on family functioning, question that follow can be asked:
  - Are decisions made with the impact on families and learnerren in mind?
  - Do these settings contain support to help families balance the stresses that are often created by these settings? (Cuddington, 2001:470)
  
- in the larger social setting where ideology, social policy, and the "social contract" are defined, the following come to the fore:
  - Are some groups valued at the expense of others (Is there sexism or racism)?
  - does an individual or a collectivist orientation exist?
  - Is violence a norm? (Castle, 2001:50)
  
- if a learner with a genetic disability has supportive nurturing care-givers, the developmental impact of the disability is reduced (Grove & Burch, 1997:260);

- a teen mother's strong social support network reduces risks to the mother-learner relationship; and
- if a learner has a healthy one strong parent-learner relationship, the risk associated with marital discord is reduced (Shrader-Frechette & McCoy, 2000:55).

It is common practice to think about the environments learnerren experience, but the environments families encounter also contribute to learner development through their impact on family functioning. In a community there may, or may not, be the resources and relationships a family needs. Within its community setting, each family fabricates its own web of support from the formal and informal resources available. A family may forge many connections, a few strong connections, or no connections at all with assistance of the community resources (Keller & Golley, 2000:15). These connections link families to the tangible and intangible resources of the community.

### **2.8.1.3 The impact of the community on development**

Similar to the way the learner's environment offers challenges and opportunities, community settings also offer challenges and opportunities for healthy family functioning. Generalizations about family-community interactions found in the literature include:

- rural families have few employment opportunities, less economic well being, fewer educational opportunities and less access to health care and social services. Urban families, on the other hand, have higher crime rates, more impersonal ties, higher density, and noisier living conditions (Costanza, 1998:2).
- many parents are expected to cope with the threat of violent crime in their neighbourhood. A family's response to demands and challenges from a community environment may promote or hinder family functioning and learner development. Withdrawing emotionally, keeping learnerren inside, and restricting learner activity are coping strategies parents use when

faced with violence in their neighbourhood, but they may also impede normal development (Cooper, 2004:59).

- families are affected by the manner in which community organizations are responsive to family needs. Shrader-Frechette (2000:59) identifies five strategies that make early learnerhood programmes more amenable to families. These include: increasing parent-programme communication, giving parents choices between different programmes, assessing family and learner needs, re-defining staff roles and using community residents, and involving parents in decision-making.
- the relationship between families and their community changes and evolves over time. The needs and interests of family members change over the life- span. Issues of responsiveness also change with ageing and the stage of development (Colyvan & Ginzburg, 2003:46).
- "Community" may refer to relationships and social networks as well as a physical location. A family's informal social support network often provides services that are more accessible, culturally appropriate and acceptable than the services offered by formal support systems (Sterelny, 2001:445).

A focus on the individual, isolated and independent, is deeply embedded in Western communities and schools' culture and values. In contrast, an ecological model emphasizes the interconnections of events and the bi-directionality of effects between organism and environment. An ecological perspective views human development from a person-in-environment context, emphasizing the principle that all growth and development takes place within the context of relationships (Castle, 2000:153). Thus, a learner must be studied in the context of the family environment and the family must be understood within the context of its community and the larger society. The language of the ecological model provides a sharp contrast to the image of the lone frontiersman pulling himself up by his bootstraps, the "paddle my own canoe" mentality upon which communities' legal, educational, and social service delivery system are often based (Kirkman, 1997:380). Perhaps,

Western cultures can learn more from the African philosophy of Ubuntu/Botho whose ideals entail communalism and co-existence among Africans.

#### **2.8.1.4 The impact of relationships on development**

The most appropriate theoretical framework for ecology is the theory of living systems, hence the use of the concept ecosystems in the following paragraphs. This theory is only now fully emerging but has its roots in several scientific fields that were developed during the first half of the century such as organismic biology, gestalt psychology, general systems theory, and cybernetics. In all these scientific fields scientists explored living systems and this led to a new way of seeing the world and a new way of thinking, known as systems thinking, or systemic thinking, which means thinking in terms of relationships, connectedness, and context (Costanza, 1998:2). This is a key aspect of systems thinking. It implies a shift of focus from objects to relationships. A vibrant community is aware of the multiple relationships among its members. Nourishing the community means nourishing these relationships (Shrader-Frechette, 1997:67).

Understanding relationships is not natural for educators who were educated and trained in a Western way only, because it is something that functions counter to the traditional scientific enterprise in Western culture. In science, a person has been taught to measure and weigh things. Relationships cannot be measured and weighed, and consequently, need to be mapped. It is possible to draw a map of relationships, interconnecting different elements or different members of a community (Cooper, 2001:500). When this is completed, it will be discovered and certain configurations of relationships appear again and again, called patterns. The study of relationships leads to the study of patterns. Understanding ecosystems, then, leads to understanding relationships and patterns of the way of life, philosophy of life, convictions, religion, language, values and norms which form the core cultural virtues of communities and schools (Meyer, 1997:49).

Considering the above issues, the question can be raised:

How do ecosystems organize themselves? The first thing that is recognized when an ecosystem is observed, is that it is not just a collection of species but a community, which means that its members all depend on one another. They are all interconnected in a vast network of relationships, the web of life, that is, “All living systems share a set of common properties and principles of organization” (Castle, 2001:52)

The application of ecological-systems framework to school, family and community interventions assists post-modern and social constructivist educators to view learners in the light of various social systems and to integrate techniques across diverse educational psychology practice perspectives. Such an application of theory to practice has been found to be a useful framework for developing integrative and empirically supported clinical interventions such as the Multisystemic Therapy (MST), for example. The MST is a family and community-based treatment approach that is theoretically grounded in a social-ecological framework (Bronfenbrenner, 1979:32) and family systems (Grove & Burch, 1997:266). Ecological-systems models such as MST emphasize an empirically supported approach for using research knowledge to examine and explain the etiological and risk factors within learner systems that promote particular problems. Empirically supported practices are used to purposefully design effective interventions and systems of care within a community-based setting. The ecological-systems perspectives further emphasize the need for community development and maintenance strategies within the community systems network to assure that learners continue to progress and change (Taylor, 1999:209).

The ecological systems theory (Bronfenbrenner, 1979:45) considers, in the context of this research, a learner and adolescents’ development within the context of the system of relationships that form his or her immediate environment. Bronfenbrenner’s theory defines complex “layers” of environment, each having an effect on a learner’s development. This theory has recently been re-named *bio-ecological* systems theory to emphasize that a learner’s own biology is a primary environment fueling her/his development. The interaction between factors in the learner’s maturing biology, his

immediate family/community environment, and the societal landscape fuels and steers his development. Changes or conflict in any one layer will ripple throughout the other layers. To study a learner's development then, educators must look not only at the learner and their immediate environment, but also at the interaction of the larger environment as well.

**Bronfenbrenner's** structure of 'environment' is as follows:

- the *microsystem* – this is the layer closest to the learner and contains the structures with which the learner has direct contact. The microsystem encompasses the relationships and interactions learner have with their immediate surroundings (Cuddington, 2001:470). Structures in the microsystem include family, school, neighbourhood, or learner-care environments. At this level, relationships have impact in two directions - both away from the learner and toward the learner. For example, a learner's parents may affect his beliefs and behaviour - however, the learner also affects the behaviour and beliefs of the parent. Bronfenbrenner (1979:23) calls these *bi-directional influences*, and he shows how they occur among all levels of environment. The interaction of structures within a layer and interactions of structures between layers is key to this theory. At the microsystem level, bi-directional influences are strongest and have the greatest impact on the learner. However, interactions at outer levels can still impact the inner structures;
- the *mesosystem* – this layer provides the connection between the structures of the learner's microsystem (McDonnell *et al*, 1997:30). The connection between the learner's educator and his parents, between his church and his neighbourhood, serve as example of this system;
- the *exosystem* – this layer defines the larger social system in which the learner does not function directly. The structures in this layer impact learner's development by interacting with some structure in their microsystem (Keller & Golley, 2000:27). Parent workplace schedules or community-based family resources are examples. The learner may not be

directly involved at this level, but they do feel the positive or negative force involved with the interaction with their own system;

- the *macrosystem* – this layer may be considered the outermost layer in the learner’s environment. While not being a specific framework, this layer is comprised of cultural values, customs, and laws (Cooper, 1998:555). The effects of larger principles defined by the macrosystem have a cascading influence throughout the interactions of all other layers. For example, if it is the belief of the culture that parents should be solely responsible for raising their learnerren, that culture is less likely to provide resources to help parents. This, in turn, affects the structures in which the parents function. The parents’ ability or inability to carry out that responsibility toward their learner within the context of the learner’s microsystem is likewise affected; and
- the *chronosystem* – this system encompasses the dimension of time as it relates to a learner’s environment. Elements within this system can be either external, such as the timing of a parent’s death, or internal, such as the physiological changes that occur with the ageing of a learner. As learnerren get older, they may react differently to environmental changes and may be more able to determine the way that change will influence them (Colyvan & Ginzburg, 2003:57).

Having explained the ecological and systems theories in this section, it is now imperative to, in the next section, look into the ecological and systems theory’s view of nature and nurture. Nature and nurture are important in the optimal development of learnerren and adolescents’ learning and psycho-physical and emotional well being.

### **2.8.2 The ecological systems theory’s view of nature and nurture**

More modern learner development theories accept that both a learner’s biology and his/her environment play a role in change and growth. Bronfenbrenner’s ecological systems theory focuses on the quality and context of the learner’s environment. He states that as a learner develops, the interaction within his/her environment becomes more complex. This

complexity can arise as the learner's physical and cognitive structures grow and mature. This theory concurs well with Piaget and Erikson's theories on psycho-social development of human beings.

Bronfenbrenner sees the instability and unpredictability of family life societies all over the world have allowed their economies create as the most destructive force to a learner's development (Pathe, 2002:25). Learnerren do not have the constant mutual interaction with important adults, which are necessary for development. According to the ecological theory, if the relationships in the immediate microsystem break down, learnerren will not have the equipment to explore other parts of their environment. Learnerren looking for the affirmations that should be present in the learner/parent (or learner/other important adult) relationship seeking attention in inappropriate places such as gangs and peer groups which leads to parents losing control of their learnerren. These deficiencies show themselves especially in adolescents as anti-social behaviour, lack of self-discipline, and inability to provide self-direction (Sterelny, 2001:15).

This theory has important implications for the practice of educational psychology. It seems now that it is necessary for schools and educators to provide stable and long-term relationships to learnerren and adolescents. Yet, Bronfenbrenner believes that the primary relationship needs to be with someone who can provide a sense of caring that is meant to last a life-time. This relationship must be fostered by a person or people within the immediate sphere of the learner's influence (Bronfenbrenner, 1979:46). Schools and educators fulfil an important secondary role, but cannot provide the complexity of interaction that can be provided by primary adults, that is, parents. For the educational community to attempt a primary role is to help societies continue their denial of the imminent real issues. The problems learners and families face are caused by the conflict between the workplace and family life – not between families and schools. Schools, educators and educators should work to support the primary relationship and to create an environment that welcomes and nurtures families. Educators can do this while they work to realize Bronfenbrenner's ideal of the creation of public policy that eases the

work/family conflict (Taylor, 1999:18). It is in the best interest of all societies for educators to advocate and support political and economic policies that enhance the importance of parent's roles in their learnerren's development. Bronfenbrenner's theory fosters societal attitudes that value work done on behalf of learnerren at all levels - parents, educators, extended families, mentors, work supervisors, legislators.

The next section considers the family as a system for learner development. This is significant because families form the core of communities.

### 2.8.3 The family as a system

From an ecological perspective, the most logical model of a family is a system. While there are critics of this conceptualization (Waller, 2001:17), researchers now approach the family from what could be called a "systems perspective" (Wheatley, 1999:29). A systems approach to human development considers the way relationships within the family and between the family and social environment influence individual development and family functioning.

The systems theory has guiding principles that apply to all kinds of systems including business and industry, community organizations schools and families. These principles are helpful in understanding how families function and how families and communities interact. Some principles of systems relevant to a Family-Centred Approach are:

- **Interdependence.** One part of the system cannot be understood in isolation from the other parts. Learnerren cannot be understood outside the context of their families. Any description of a learner has to consider the two-way patterns of interaction within that learner's family and between the family and its social environment. Describing individual family members does not describe the family system. A family is more than the sum of its parts.
- **Sub-systems.** All systems are made up of sub-systems. Families' sub-systems include spousal sub-system, parent-learner sub-systems and

sibling sub-systems. A family's roles and functions are defined by its sub-systems (Bazzani & Feola, 2001:15).

- **Circularity.** Every member of a system influences every other member in a circular chain reaction. A family system is constantly changing as learners develop; thus it is almost impossible to know for certain the causes of behaviour.
- **Equifinality.** The same event leads to different outcomes and a given outcome may result from different events. What this suggests is that there are many paths to healthy development and there is no one-best-way to raise learners (Boyden 2003:18).
- **Communication.** All behaviour is viewed as interpersonal messages that contain both factual and relationship information.
- **Family Rules.** Rules operate as norms within a family and serve to organize family interactions.
- **Homeostasis.** A steady, stable state is maintained in the ongoing interaction system through the use of family norms and a mutually reinforcing feedback loop.
- **Morphogenesis.** Families also require flexibility to adapt to internal and external change (Bronfenbrenner, 1986:76).

A Family-Centred Approach stimulates the family systems theory. The family systems theory gives us useful principles for studying learners within the context of their family relationships. This framework requires people to avoid operating as if learners exist in isolation. Effective interventions understand and respect each family's system (Capra, 1996:64).

A basic ecological premise stresses that development is affected by the setting or environment in which it occurs. The interactions within and between the different environments of a family make up the "ecology" of the family and are key elements of an ecological perspective. The environments of a family's ecology include:

- **Family.** The family performs many functions for its members essential to healthy development and mediates between the learner and the other environment.
- **Informal Social Network.** A family's social network grows out of interactions with people in different settings - extended family, social groups, recreation, and work. Ideally, this network of caring for others arouse feelings of self-worth, mobilizes coping and adapting strategies and provides feedback and validation (Castle, 2001:35).
- **Community Professionals and Organizations.** A community's formal support organizations provide families with resources related to professional expertise and/or technology (Colyvan & Ginzburg, 2003:45).
- **Society.** Social policy, culture and the economy define elements of the larger ecology that impact the way a family functions.

From the foregoing paragraphs, it is apparent that the family is the closest, most intense, most durable, and influential part of the mesosystem (see section 2 above). The influences of the family extend to all aspects of the learner's development, for example, language, nutrition, security, health, and beliefs, which are all developed through the input and behaviour related feedback within the family (Cooper, 2001:17).

The learners and adolescents that attend schools and educational psychology practices are largely a product of the family they form part of. Educators need to be able to deal with a great variety of family systems in understanding their learner and adolescent learners. In today's society, the family is less frequently the archetypical combination of stay-at-home mother, working father, and sibling learnerren. Single parent families, generation skipping families, and other non-traditional groupings are more common today than the traditional family. Another common force that has changed the family landscape in societies is divorce. Learnerren of divorced parents often have a split family life such as living with fathers for the weekend, and with mothers during the week, or any number of other situations. Divorce is an excellent

example of the type of interaction between systems that Bronfenbrenner (1977:39) describes. The divorce arrangement can have a profound effect on the family and the development of the learner, but it is often a product of society, decided by a judge and enforced by social services. In turn, the divorced family affects the community and society, because of divorce changes social attitudes and the social perception of a family is modified (Costanza, 1998:17). The school is also affected by the changes in a divorced family. "Where does the report card go and who comes to parent-educator conferences?", this question can be raised.

A number of other systems, such as the community, religion, school, society, and cultural forces from within the mesosystem and the exosystem directly affect the family. Society and the culture of both the family and the neighbourhood influences the learner's perception of the family's stance in the community. The family can affect the community through its needs for services and its contribution as taxpayers and voters (Cuddington, 2001:35).

Subsequently, the post-modern educator has to adopt a Family Centred Approach in working with families. A Family-Centred Approach is a process for delivering services to families that will fit many different "content areas," be it support for teen parents, family literacy or education for low-income learnerren. It is not a set of particular practices but rather a "philosophy" in which families are recognized as having unique concerns, strengths and values (Della & Diani, 2004:59). A Family-Centred Approach represents a paradigm shift away from deficit-based, medical models that discover, diagnose and treat "problems" in families to an ecological model. The ecological model views families from the perspective of "a half-full cup" rather than half empty (Epstein, 1992:96). This approach builds and promotes the strengths that families already have. The key components of the Family-Centred Approach are the following:

- **Creating partnerships and helping relationships.** Families are supported and learner development is enhanced through helping and partnership relationships.

- **Building the community environment.** Families gain information, resources and support through their connections to the community environment.
- **Linking families and community support.** Participation, two-way communication, and advocacy strengthen both the community support network and family functioning (Fine, 1992:67; Kay, 2000:23).

The following set of assumptions and beliefs about families and service delivery principles has evolved from the application of ecological perspectives by family support programmes, which are that:

- all families need support at some time in their lives, but not all families need the same kind or intensity of support;
- a learner's development is dependent upon the strength of the parent/learner relationship, as well as the stability of the relationship among the adults who care for and are responsible for the learner (Kirkman, 1997:18);
- most parents want to and are able to help their learner grow into healthy, capable adults;
- parents do not have fixed capacities and needs - like their learnerren, they are developing and changing and need support through difficult, transitional phases of life (Lewin, 2000:29);
- parents are likely to become better parents if they feel competent in other important areas of their own lives, such as jobs, in school, and in their other family and social relationships; and
- families are influenced by the cultural values, and societal pressures in their communities (McCormick, 1999:37).

These beliefs and assumptions about families guide the delivery of services by family support programmes. The service delivery principles of family support programmes are grounded in the practical experiences of serving

families and are an important part of a Family-Centred Approach (McPhee, 1995:57).

When the family is examined from an ecological point of view, no one person or thing can be realistically identified as the “cause” of a problem (Meyer, 1997:39). Behaviour from an ecological perspective, is more complex than the fact that stimulus A causes a predictable response B. The environmental demands and the reciprocal relationships between people interact with individual characteristics in complex chains of influence that define behaviour. Although parents have a profound influence on the ability of the learner to develop in a healthy, competent manner, learnerren also influence their parents’ behaviour. When dealing with a learner's “acting out” behaviour, or addressing a family's financial need, educators need to consider not only the individual but also contributing factors from the environment and interpersonal relationships (Shrader-Frechette, 1997:39).

The next section will now enquire the school as an important system in the community. Schools considered as significant nurturing systems in communities.

#### **2.8.4 Schools as systems**

Traditionally, public schools have not had a strong emphasis on family involvement and support. Universities’ Faculties of Education have also typically offered insignificant direct and practical training to aspirant educators in forming parent/educator relationships. A University of Minnesota report on improving educator education listed what researchers identified as the thirty-seven most important teaching skills, and learning how to work with parents was not among them (Carpenter, Brock & Hanson, 1999:36). However, a number of factors have contributed to the current focus on parental involvement as a way to improve educational outcomes for all learnerren, particularly learnerren from low-income families.

During the last twenty years, vast economic and demographic changes have resulted in increased economic hardship and stress for many families and an accompanying pressure on schools to increase nations’ competitiveness in a

global economy (Coetzee & Streak, 2004:18). There is growing recognition that fostering "readiness" for the kindergarten section and for succeeding, educational environments will require addressing the strengths and needs of the whole learner. The National Education Goals Panel endorsed a complex, multifaceted definition of readiness, which includes physical well-being and motor development, social competence, approaches toward learning, language and literacy, cognitive development, and general knowledge (Cooper, 2004:56). This comprehensive definition requires a new approach to schooling, one, which includes a shared responsibility for learnerren's development and will likely permanently alter the schools' relationships with families and communities (Duraiappah, 2004:65).

Recognizing the vital role that parents play in their learnerren's education, Title IV of the National Education Goals 2000: Education America Act encourages and promotes parents' involvement in their learnerren's education, both at home and at school. Three decades of research have demonstrated strong linkages between parental involvement in education and school achievement (Fine, 1992:64). Family involvement is the strongest among middle and upper-class families. However, regardless of parents' education, parental involvement with learnerren's schooling is associated with better attendance, higher achievement test scores, and stronger cognitive skills. In addition, when parents support elementary school learnerren with their schoolwork, social class and education become far less important factors in predicting the learnerren's academic success (Gopalan, 2004:27).

Menial-income, minority, and limited-English-proficient parents, however, may face numerous barriers when they attempt to collaborate with schools. These - include: lack of time and energy, language barriers, feelings of insecurity and low self-esteem, lack of understanding about the structure of the school and accepted communication channels, cultural incongruity, race and class biases on the part of school personnel, and perceived lack of welcome by educators and administrators (Hatch, 1998:45; Kirkman, 1997:375).

Given these potential barriers, it is not surprising that research has demonstrated that successful parent involvement programmes must have a

strong component of outreach to families. Studies show that school practices to encourage parents to participate in their learnerren's education are more important than family characteristics, such as parent education, socio-economic and marital status (Lemons, 1996:433). A 1988 study of parental involvement in schools concluded that it wasn't parents who were difficult for schools to reach, but schools that were problematic for parents to reach out to (McCormick, 1999:41). If schools are to become places where families feel welcome and recognized for their strengths and potential (Nattrass, 2004:35), school personnel must not only embrace the concepts of partnership and parent involvement, they must be given training and support to translate their beliefs into practice (Richter, 2004:56).

While traditional forms of family involvement have focused on the supposed deficits of low-income and/or minority families, new models, congruent with the Family-Centred Approach, emphasize building on family strengths and developing partnerships with families, based on mutual responsibility. In these approaches, parents are involved as peers and collaborators, rather than learners. Shrader-Frechette (2000:45) has identified four tenets of programmes which have been shown to improve the educational outcomes for all learnerren, particularly those of menial-income and minority learnerren:

- parents are learnerren's initial educators and have a life-long influence on learnerren's values, attitudes, and aspirations;
- learnerren's educational success requires congruence between what is taught at school and the values expressed in the home (Sterelny, 2001:473);
- most parents, regardless of economic status, educational level, or cultural background, care deeply about their learnerren's education and can provide substantial support if given specific opportunities and knowledge; and
- schools must take the lead in eliminating, or at least reducing, traditional barriers to parent involvement (Waller, 2001:8).

The relationships learners develop in schools become critical to their positive development. Because of the amount of time learners spend at school, the relationships fostered there are of utmost importance. Also, learners may for the first time be developing relationships with adults outside their immediate family and these connections help a learner develop cognitively and emotionally (Bazzani, Noronha & Sánchez, 2004:45). The importance of these bi-directional interactions with caring adults in the learner's life are highlighted. The following five propositions, which describe how relationships develop at home and at school for positive development are outlined by Bronfenbrenner (1986:38):

- **Proposition 1:** The learner must have on-going, long-term mutual interaction with an adult (or adults) who have a stake in the development of the learner. These interactions should be accompanied by a strong affiliation to the learner that ideally is meant to last a life time. It is important for this attachment to be one of unconditional love and support. This person must believe the learner is “the best,” and the learner must know that the adult has this belief (Castle, 2000:87).
- **Proposition 2:** This strong affiliation and the pattern of interpersonal interaction it provides, should assist the learner relate to features of his or her mesosystem. The skills and confidence encouraged by the initial relationships could increase the learner's ability to effectively explore and grow in relation to external activities.
- **Proposition 3:** Attachments and interactions with other adults will help the learner progress to more complex relationships with his or her primary adults. The learner will gain affirmation from a third party relationship, and will bring those new skills to the primary relationship. Also, these secondary adults will give support to the primary adults, and help the learner see the importance of the primary role (Crowfoot & Wondolleck, 1990:52).
- **Proposition 4:** The relationships between the learner and his primary adults will progress only with repeated two-way interchanges and mutual

compromise. Learnerren need these interchanges at home and at school or learner-care parents need these interchanges in their neighbourhoods and workplaces (Luzanda, Senabulya & Musiitwa, 2000:24).

- **Proposition 5:** The relationships between the learner and adults in his or her life require also a public attitude of support and affirmation of the importance of these roles. Public policies must enable time and resources for these relationships to be nurtured, and a culture-wide value must be placed on the people doing this work. This includes the work of parents and educators, but also the efforts of extended family, friends, co-workers, and neighbours.

These five propositions have implications for practice in schools today. Bronfenbrenner sees the instability and unpredictability of modern family life as the most destructive force to a learner's development (Carpenter, Brock & Hanson, 1999:25). This destructive force may spill over into the school setting. Some learnerren do not have the constant mutual interaction with important adults that is necessary for personal development. According to the ecological theory, if the relationships in the immediate family break down, the learner will not be equipped to explore other parts of his/her mesosystem. Learnerren looking for the affirmations that should be present in the learner/parent (or learner/other important adult) relationship seek attention in inappropriate places such as gangs and peers. These deficiencies show themselves especially in schools as anti-social behaviour, lack of self-discipline, and inability to provide self-direction (Coetzee & Streak, 2004:80).

### **2.8.5 The impact of communities on development**

It seems imperative that schools and educators should provide support for stable, long-term relationships between learners and parents, and also between learners and mentors, and learners and educators. Schools and educators should work together to support the primary relationship and to create an environment that welcomes and nurtures families. Educators can do this in the course of their work to realize Bronfenbrenner's ideal of the creation of public policy that eases the work/family conflict (Cooper, 2004:56).

The next section enquires into spirituality or religion as an important system in the development of learnerren and adolescents.

### **2.8.6 Religion or Spirituality**

The relationship of religion to the developing learner is usually seen as a source of moral and ethical values. In most communities, religion is an integral part of culture. Whether Irish-Catholic or Syrian-Baha'i, Shembe-African Umvelinqangi, Basotho-Badimo, or Nguni-Amadlozi, a learner's religion is usually based on the family's preference or heritage. There is a great variation in intensity of religious belief from family to family. Some have a very casual relation with a church, perhaps only observing major feasts or holidays, and some are very involved and their religion dictates everything from mode of dress to food preparation (Eigen & Oswatitsch, 1996:43).

Educational policies sometimes conflict with religion, as in the evolution versus creation argument. In these cases, the effects of scientific theory that conflicts with religious dogma rather than any moral or ethical issues are clear. The minority of people would dispute that the basic concepts of most established religions are similar in the areas of morals and ethics (Forget & Lebel, 2001). Once the sectarian details are eliminated, the basic virtues of most religions are nearly identical, for example, love, respect, tolerance, and honour. These are certainly the same ideals communities wish to instill in learnerren and adolescents, and a curriculum based on these would re-inforce the positive values received from church or family (Grumbine,1997:12).

Educators of the twenty-first century need to empower learnerren, adolescents and families to live by their highest values. Education is the key to transformation, but it must involve education which touches the human spirit. Educators should therefore adopt an approach which reminds people of the virtues, the qualities of character and the simple elements which are spirituality honoured by all cultures and sacred traditions (Hilborn & Mangel, 1997:65). This approach has to be applied in a wide variety of ways which include community development, healing projects after a traumatic experience such as terrorism, and faction fighting. Programmes with street learnerren and

learner-headed families, an enhancement of the religious life of "virtues congregations" of diverse faiths, in drug and alcohol rehabilitation programmes and prisons as well as restructuring of the curriculum and culture of schools. Enhancing unity in school organizations to counteract racism, racialism, sexism and monoculturalism as a tool in day-care centres, palliative care programmes, and personal development, in parent education programmes should also receive attention (Keller & Golley, 2000:76).

By being involved in community matters in this manner, educators could be serving humanity by having an empowering impact on the moral and spiritual development of people of all cultures, by helping them to remember who they really are and to remind them to live according to their highest values. They will also be providing multi-cultural products and programmes of excellence and simplicity, which can serve as equipment for the cultivation of virtues in individuals, families, organizations and communities (Kirkman, 1997:23). In this way they will not be focused on the beliefs or practices of any particular religion but rather on the common thread that runs through all religions, which are the virtues. The virtues are the simple elements of spirituality, the universal values found in all cultures and sacred traditions.

All the systems mentioned in sections 4, 5 and 6 above are part of communities. It is therefore necessary to look into the community as a system in the development of learnerren and adolescents.

#### **2.8.7 The community as a system**

The involvement of the structures in a learner's mesosystem is meant to provide the adult relationships required for positive development. The bio-ecological systems theory of Bronfenbrenner holds that these bi-directional relationships are the foundation for a learner's cognitive and emotional growth (Loreau, Naeem, Inchausti, Bengtsson, Grime, Hector, Hooper, Huston, Raffaelli, Schmid, Tilman & Wardle, 2001:43). Structures of the exosystem, such as community, society, and culture provide the support for these relationships. They provide the values, material resources, and context within which these relationships operate.

Increasingly, however, societies have seen a rupture in the structures of a learner's mesosystem. For example, most learnerren live with single parents. Furthermore, the majority of learnerren and adolescents live in households whose annual income falls below the poverty level. Increasing number of hours worked outside the home by both mothers and fathers means that they have less time involved in their learner and adolescent's development (Meyer, 1997:32). With this breakdown occurring on the mesosystemic level, the structures of Bronfenbrenner's exosystem must be brought into feneration to provide primary relationships.

Communities should attempt to provide parents with access to people with similar concerns that can function as resources and emotional support. Communities could also provide learner care, parent employment, and programmes designed to encourage interaction among families (Spencer, Dupree & Hartmann, 1997:87). Partnerships between community agencies and business and industry will provide invaluable resources for families. The community has always been an important influence on learnerren and the youth, but even more assistance from the community is needed in order to ensure learnerren and adolescents' success in academics as well as in life. Research by Szapocznik, Kurtines, Santisteban, Pantin, Scopetta, Mancilla, Aisenberg, McIntosh, Perez-Vidal and Coatsworth (1997:34) has shown that young people need and deserve five basics, which are:

- personal one-to-one relationship with a caring adult;
- safe place to learn and grow;
- healthy start and a healthy future;
- marketable skill to use after graduation; and
- a chance to compensate peers and the community.

Partnerships within the community can help provide for these needs. State-aided social agencies such as social workers and subsidized non-governmental social organizations exist within communities in order to help

provide for family needs. They create a series of referral contact points for families in need of health, financial, or crisis assistance. Co-ordination among these agencies, parents, and schools will help provide a safety net for families in crisis – and will provide a solid resource for strengthening all relationships within a learner's mesosystem (Ulanowicz, 1997:71).

Educating a learner takes co-operation and involvement from educators, parents, families, and the community. Everyone has heard the saying "It takes a village to raise a learner." Research has shown the greater the family and community involvement in schools, the greater the learners' achievement (Bazzani & Feola, 2001:21).

Parent involvement has an important influence on a learner's school success (Broomberg, Soderlund & Mills, 1996:51), but presently an increasing number of learners are raised for a substantial period of their learnerhood in less than ideal conditions. For example, in South Africa at least one-fourth of the learnerren live with one parent and among Blacks this figure increases to more than fifty-five (Coatsworth, Maldonado-Molina, Pantin & Szapocznik, 2005:21). At least one in five South African learners live in a family with an income below poverty level and this rate doubles among Blacks (Fine, 1992:9). More and more mothers are working outside the home and that means that many parents cannot be as involved in their learnerren's life as they should be.

With the increased burden on families, communities are making a definite impact on learnerren in a number of positive ways and community leaders continue to look for ways to impact schools and improve the behaviour of learnerren as well as adolescent achievement. In this way, adults other than a learner's parents are taking on significant learner rearing roles (Fiscus, 2002:21). For example, a programme established in 1977 called Communities in Schools (Grove & Burch, 1997:24) aims to provide mentors and volunteers that can provide support to schools. The purpose of CIS'is to connect essential community resources with schools to help young people learn, stay in school, and prepare for life. Their website (see bibliography) provides information about the programme and provide ways in which communities and

schools can work closely come together. This programme has reached over 500,000 young people and their families. According to the founder of CIS (Fiscus, 2002:16), the programme exists in over 1,700 schools and "surrounds young people with "a community of tutors, mentors, health care providers, and career counsellors - caring adults who can render support..."

### **2.8.8 An application of an ecological and systems theory to school and community interventions**

Knowledge of risks and protective factors is used in post-modern interventions to promote the enhancement of nurturing environments for learnerren in families, schools and communities. Hilborn and Mangel (1997:18) identify the following four mediating mechanisms which act in ways which:

- reduce the impact of risks;
- reduce negative chain reactions;
- maintain self-esteem and self-efficacy through relationships and task achievement; and
- open opportunities for positive development (Kay & Regier, 2000:17)

Risk is a statistical concept used to predict the probability of negative outcomes. Resiliency and protective factors are the positive side of vulnerability and risk (Keller & Golley, 2000:28). Risk and protective factors are found both within the learner (temperament, physical constitution, intelligence, education) and/or within a learner's environment (caring adults, high expectations, good schools, high crime levels).

A learner or family's developmental trajectory results from the negotiation of risks on one hand, and the exploitation of opportunities on the other. A way to conceptualize these interactions is visualised as an ever changing equation containing plus and minus numbers. At any given time two or more numbers may combine to boost development in a positive direction or push development toward negative outcomes (Lemons, 1996:13). If the "solution" of the equation were graphed repeatedly over time, it would represent the life

trajectory of an individual. For example, perhaps the subject biology contributes to a learner's high intellectual potential. This should set the course of the learner's development in a positive direction. If a school setting fails to provide an appropriate educational experience, this potential could be unrealized or move the learner in a negative direction leading the learner to drop out of school (Lewis & Morris, 1998:45). Various authors have highlighted the following statements about risk and protective factors:

- the presence of a single risk factor typically does not threaten positive development. In situations where a learner is vulnerable, the interaction of risk and protective factors determines the course of development;
- if multiple risk factors accumulate and are not offset by compensating protective factors, healthy development is compromised (Loreau *et al*, 2001:25);
- poverty increases the likelihood that risk factors in the environment will not be off-set by protective factors (McCormick, 1999:11);
- when a learner faces negative factors at home, at school, and in the neighbourhood the negative effect of these factors is multiplied rather than simply added together (Shrader-Frechette, 2000:39);
- resiliency studies explain why two learnerren facing similar risks develop differently. A core of dispositions and sources of support, or protective factors, that can foster development under adverse conditions have been identified (Sterelny, 2001:32);
- dispositions that act as protective factors include an active, problem-solving approach and a sense of self-esteem and self-efficacy. Resilient learnerren are characterized by a belief in their power to shape and have an impact on their experience; and
- caring and support, high expectations, and opportunities for participation are protective factors for learnerren found in families, schools and communities (Taylor, 1999:41).

From the foregoing statements it is clear that protective factors reduce the effects of risk and promote healthy development. Protective factors influence the way a person responds to a risk situation. The protective factor is not a characteristic of the person or the situation, but a result of the interaction between the two in the presence of risk. The presence of protective factors helps to change a developmental trajectory from a negative direction to one with a greater chance of positive outcome.

### 2.8.9 Making use of treatment, prevention and promotion

Emphasizing "prevention" or "promotion" approaches needs mentoring, when much of educators' thinking about how to work with communities and schools has been dominated by a treatment, prevention and promotion continuum, which, ranges from:

- **Treatment:** eliminate or reduce existing dysfunction (a deficit-based approach) to –
- **Prevention:** protect against or avoid possible dysfunction (a weakness-based approach) to –
- **Promotion:** optimize mastery and efficacy (a strength-based approach) (Waller, 2001:7).

A post-modern approach rejects the treatment model in favour of a blending of prevention and promotion models. It uses strength-based, non-deficit strategies to strengthen and support family, school and community functioning. A strength-based approach helps educational psychology practitioners to develop programmes that operationalize the ecological and systems perspective in their practice. The key components of a strength-based approach are - creating helping and partnership relationships, building the community environment and linking community resources (Axlerod, 1997:45). The applications of the ecological perspective in school and community intervention programmes result in:

- recognition of the strengths and capabilities of schools and communities;
- a re-definition of the parent-professional relationship toward greater collaboration and partnership with parents; and
- service delivery practices blurring the traditional boundaries between social welfare, physical and mental health, and education (Bazzani & Feola, 2001:76).

The foregoing paragraph implies that the post-modern educators' school and community interventions incorporates, which involves a:

- a comprehensive approach to learner development that combines health, education and social services;
- a strong emphasis on parent participation in the programme services and programme administration; and
- a re-definition of professional roles toward greater collaboration and partnership with parents (Bogensneider, Small & Riley, 2000:28).

Effective services for schools and communities should reflect the following support principles, should incorporate the following:

- programmes that work with whole families rather than individual family members;
- programmes that provide services, training and support to increase a family's capacity to manage family functions (Broomberg *et al*, 1996:15);
- programmes that provide services, training and support to increase the ability of families to nurture their learnerren;
- the basic relationship between programme and family should be one of equality and respect - the programme's first priority is to establish and maintain this relationship as the vehicle through which growth and change can occur (Carpenter, Brock & Hanson, 1999:19);

- parents are a vital resource - programmes should facilitate parents' ability to serve as resources to each other, to participants in programme decisions and governance, and enable them to advocate for themselves in the broader community;
- programmes should be community-based, culturally and socially relevant to the families they serve - programmes should provide a bridge between families and other services outside the scope of the programme;
- parent education, information about human development, and skill building for parents are essential elements of every programme; and
- programmes should be voluntary; seeking support and information is viewed as a sign of family strength rather than as an indication of difficulty (Castle, 2001:47).

#### **2.8.10 Risks associated with developmental handicaps**

Early intervention prevention programmes for learners with special needs (LSN) should include the reduction of the impact of risks associated with genetic and developmental handicaps - avoid negative developmental chain reactions resulting from this risk and open opportunities for learners with special needs. Bronfenbrenner (1977:28) indicates that interventions involving the family were more effective than those working with learnerren on their early intervention programmes re-defined the relationship between families and professionals. Early intervention programmes developed ways to create effective parent-professional partnerships which recognized a family's right to participate in decisions about their learner as well as a family's need for information and support (Bronfenbrenner, 1977:17; Carpenter, Brock & Hanson,1999:18).

Key lessons learned from early intervention programmes concern the important role family values and family strengths play in efforts to nurture learnerren with special needs. Parents are no longer treated as learnerren to be schooled by experts who know what is best for their learner, but as partners with different kinds of expertise. Early intervention programmes have

distilled guidelines for the way to build strong parent-professional partnerships (Costanza, 1998:12). These guidelines include:

- recognizing the knowledge and expertise parents have about a learner and learner needs; and
- empowering parents, as a way to provide support and information as well as to increase a parent's ability to nurture learnerren (Cuddington, 2001:56).

An alliance between the family's values, needs and goals and the professional's approaches, priorities and services should be negotiated.

## **2.9 CONCLUSION**

This chapter presented a literature review on HIV/AIDS and ecosystems theory.

The next chapter presents the design of the empirical research.

## **CHAPTER THREE**

### **METHOD OF RESEARCH**

#### **3.1 INTRODUCTION**

This chapter presents the research methodology employed for this study, as well as the design of the study, nature of the database, the subject selection, data collection and the method of analysis.

#### **3.2 RESEARCH METHOD DESIGN**

This study adopted the qualitative approach. A phenomenological orientation was incorporated since the aim was to explore subjective meanings, experiences, and interpretations. This strategy was considered appropriate since it facilitates the understanding of the essence of experience (Creswell, 2003:14). Semi structured interviews and observations were employed as the method of data collection in order to facilitate informality and freedom of expression in the minds of the participants. Questions, taking the aims of the study into consideration, were developed from the conversation. The questions asked included the following:

- do you know what your mother suffered from when she died?
- how did you feel when you were told that your mother was dying of AIDS, Skhalo?
- do you know your HIV/AIDS status?
- how did you feel when you were informed that you are HIV positive?

Observations made during the course of the interview were recorded. Interviews were conducted in the home of participants, observations about the setting facilitated an understanding of the environmental and situational context. Apart from this, observations of participants' behaviour during the

course of interaction contributed in highlighting their mood at the particular time and in underscoring their affective reactions to their predicament.

### **3.3 SAMPLE**

Purposive sampling was relied on, and hence an attempt was made to, first, ensure that the HIV/AIDS positive participants who formed the sample had to have at least one opportunistic infection. At such a stage of the infection, there is a greater likelihood of them to be in need of, and in receipt of, support. Secondly, only those seropositive individuals who have shared their serostatus with a family member were to be included in the study. Given the complexities associated with inquiries on stigmatizing illnesses, difficulty in identifying and retaining respondents was anticipated. The researcher therefore, simultaneously contacted a number of organizations involved in HIV/AIDS related work in the Sebokeng township of the Gauteng province. In keeping with ethical guidelines in HIV/AIDS research, the researcher did not approach potential respondents directly. The social workers of the Department of Social Development introduced the idea of, and explained the purpose of, the research to families (either seropositive individuals or their caregivers/family members) accessing services from them, and only after they agreed and were comfortable enough, was the researcher introduced to them. Two learners infected with HIV/AIDS who happened to be brothers, their aunt and their class educator who are participants in this research agreed to participate (n=4). Their mother died of HIV/AIDS and they do not know the whereabouts of their father. They contracted HIV congenitally and have never been engaged in any sexual relationship before.

Following rapport building and soliciting their co-operation, participants signed a consent form, informing them of the details of the study and their rights as participants. The location of the interview was decided by them, as was the possibility of tape-recording the interviews. They felt that they would be comfortable being interviewed at their home. Both learner participants were interviewed simultaneously. This preference was conveyed to the respondents during the rapport building process, in order to ensure that they made an informed decision regarding their participation. The process of getting

participants for the study was an arduous one largely because of the stigmatizing nature of the HIV pandemic, which makes positive people scared of getting involved. Fears related to confidentiality, use of data and consequent discrimination. Time constraints due to roles and illness severity and fluctuations were two other important considerations.

While interviews were conducted in IsiZulu, the mother tongue of the participants, all notes were written in English. Thus, interviews recorded on audio-cassettes were translated into English during transcription and those which were kept as field notes were also written in English.

### **3.4 DATA COLLECTION**

During the period of data collection, the researcher read the transcripts and field notes carefully and repeatedly “immersing” himself in the data (Maddi, 1999:34). Immersion allowed the researcher to identify themes emerging from the data. For example, through a reading of the data the researcher observed the presence of many life stories for seropositive respondents. Themes were developed into patterns that linked overarching themes, a process facilitated by Miles and Huberman’s (1994:13) such as:

- event lists;
- causal networks; and
- memos.

The use of such research equipment was interspersed with memoing, which allowed for the data to be developed to conceptual levels that integrated events, processes, and outcomes (Miles & Huberman, 1994:19), leading to the use of a nomothetic rather than ideographic language and to emergence of interpretations (Patton, 2001:16). Proceeding in this manner allowed for various understandings of the phenomenon under study to be developed. These understandings were used to inform further data collection, through which they were tested and challenged. Based on more recent data, they were further developed, thereby feeding back into the analysis (Shank,

2002:17). Iteration thus formed an integral part of the research process. When all the data were collected, the researcher immersed himself further in the transcripts and the preliminary findings. He not only identified more themes, but also through the use of Miles and Huberman's (1994:29) tools and memoing, he developed more patterns, thereby working towards more interpretations. Further, he subsumed under major themes, those patterns and themes and their linkages within and across respondents that held together in a meaningful yet distinct way (Maxwell, 2004:18). That is, immersion into and contemplation (an incubation stage) about the emergent constructs and patterns resulted in creative insights (Patton, 2001:17) as to how particular groupings collectively yet singularly contributed to a holistic understanding of various aspects of the phenomenon under study.

To illustrate, themes and patterns relating to the experiences of suffering from HIV/AIDS, perceived mode of infection and psychological support the participants get from significant others were seen as highlighting the dynamic complexity involved in the way care was organized in the family, school and community at large and were hence constituted into the key theme of the ecosystemic context of care. Methodological rigor was maintained through prolonged engagement (Flick, 1998:19) and peer debriefing. As mentioned above, particular importance was given to rapport building with the respondents. It was stated that making the respondents feel comfortable and establishing their trust would play a critical role in helping them to share their stories. During the course of the interview, the researcher used probes and cross-checks to improve his understanding of the respondents' narratives. Immersion in the data during the process of analysis helped the researcher gain insight into respondent experiences and to ensure the rigour of the findings. For peer debriefing and consensual validation, the researcher shared his analysis procedures and outcomes with academics and practitioners. Academics working in the areas of HIV/AIDS, family care and qualitative research methods as well as practitioners working in the field of HIV/AIDS care and support reviewed the researcher's methods, interpretations, and findings, providing critical evaluations, suggestions, and feedback. The incorporation of their inputs strengthened the analysis. This process continued

till most, if not all, the academics and practitioners agreed on the analysis and its outcomes. He designed the inquiry, collected the data, and completed the analysis. Primarily, the researcher's interest in the 'lived' experiences of learners and adolescents suffering from HIV/AIDS and his social involvement in matters affecting the psychological and physical well being of learners distressed by HIV/AIDS, served as the underlying motivation that initiated this study.

### **3.5 CASE STUDY DEVELOPMENT**

Verbatim data from each of the transcripts was reviewed repeatedly through the case study formulation, compared to the audiotape, summarized and reported in a case study format. Careful and repeated review of the data was carried out in order to assure accuracy in the final case study report. A case study was generated from the responses of both interviewees who are Skhalo and Mbulelo. The case study included an explanation of the respondents' personal experiences as told by the respondent/interviewee. The case study was presented as a holistic and descriptive personal account of the individual participant. Unique experiences of each of the boys were provided through direct quotes and details of influential factors that played a part in their psychological and physical well being. Basic information on family background was contained in the case studies.

### **3.6 ETHICAL CONSIDERATIONS DUE THE SOCIAL STIGMA ASSOCIATED WITH HIV/AIDS**

The HIV/AIDS pandemic is characterised by unique biological, social and geographical factors that, among other things, affect the balance of risks and benefits for individuals and communities who participate in HIV vaccine development activities. These factors may require that additional efforts are taken to address the needs of participating individuals and communities, including their urgent need to have their rights protected and their need to be able to be full and equal participants in the research.

The social stigma associated with HIV/AIDS poses serious ethical and methodological challenges. The ethical consideration is that the research

must not compromise HIV/AIDS infected people's right to privacy, which must be understood to mean that no member of the community should be inferred by others as infected by HIV/AIDS merely by virtue of having been approached by the researcher. This would have the effect of making participants in this research more vulnerable as a result of this research.

Although at first the researcher did not intend telling anyone that HIV/AIDS was a specific concern of the research, but the researcher ruled against this idea after he realized that this raises another ethical concern, that of conducting the research under false pretences. The methodological challenge is that it is difficult to draw inferences about the relationship between HIV/AIDS and social support when many of those infected are either unaware themselves, or are unwilling to impart that information to the researcher.

The researcher did not find an ideal solution to these challenges but rather a partially satisfactory one. On the one hand, there was no concealment of the fact that HIV/AIDS was an important part of the researcher's brief, but this was presented as part of a more general (and genuine) interest in chronic illness. Secondly, by virtue of interviewing the two participants who formed the case study at their home, there was little chance of participants being labelled 'infected' by inference.

It is necessary to clarify here how the researcher has understood and used the term 'infected'. In this study the term 'infected' is used to indicate those learners whose physical and psychological health has been affected by having contracted HIV/AIDS.

### **3.7 CONCLUSION**

This chapter described the research methodology employed during this study, as well as the design of the study, data collection and method of analysis.

The next chapter provides the analysis and interpretation of data collected during the empirical research.

## CHAPTER FOUR

### ANALYSIS AND INTERPRETATION

#### 4.1 INTRODUCTION

This chapter provides analysis and interpretation of the interview questions and responses by two participants from the same family, i.e. learners suffering from HIV/AIDS by means of a case study. Their responses are interpreted in the form of themes which encapsulate their 'lived' psychosocial experiences in their environment.

Although the participants are brothers who were interviewed at the same time, it should be noted that each participant employed unique descriptions, responses and accounts of integrating his experiences into his lived world. Although both participants exist within the same social context and have same set of circumstances, each of them has his own personality, dynamics and coping mechanisms, which will all contribute to his experience of being infected with HIV/AIDS.

In the following section, the verbatim transcripts of the interviews are dealt with first, followed by the analysis and interpretation of the case.

#### 4.2 VERBATIM TRANSCRIPTION OF SKHALO AND HIS YOUNGER BROTHER MBULELO

##### 4.2.1 Case study: Skhalo, Mbulelo, their aunt and their class educator.

This case presents a situation of two brothers who were congenitally infected with HIV, which in this research is referred to as mother-to-learner transmission, their aunt who is also their foster parent and their class educator.

The brief introduction and the two brothers' family background is given below. The complete verbatim transcription of the interview that the researcher conducted with the participants follows.

#### **4.2.1.1 Introduction**

The interviewer had two interview sessions with Skhalo and his younger brother Mbulelo (not their real names) the two brothers were interviewed simultaneously, one session with their aunt and one with their class educator. Each session lasted for about an hour.

The interviewer commenced the conversation by explaining why he had requested an interview with the boys. He further explained that the conversation forms part of the research and that everything that they tell him will be kept confidential. The interviewer requested the family's permission to write down some facts and electronically record the conversation so as not to forget what was discussed.

#### **4.2.1.2 Family background of the two participants**

Skhalo is a 15-year-old, grade 7 learner who was born at Senaoane location in Soweto on 17 October 1990. Mbulelo, Skhalo's younger brother, is a 10-year-old, grade 3 learner who was born on the 8 of February 1995. Mbulelo is the last born in the family of five. Skhalo and his younger brother came to live with their aunt (their mother's younger sister) and their step-uncle in April 2003. The aunt and the step-uncle do not have learners. Skhalo and Mbulelo's relocation followed immediately after the death of their mother. Both boys had never left their home before and this was their first experience. Neither of them knows who their father is nor how to trace him. They have three older brothers who are not of the same father. This they were told by their aunt when they started living with her and the step-uncle. The eldest of the brothers is in jail, the second born is mentally handicapped and the third born stopped attending school before finishing matric. These three brothers stay together in the house that was left by their mother (where they all lived before their mother died). The mother was ill for about two years and for about six months she was unable to walk, because her feet were always swollen and she was always in bed because of flu and chronic diarrhoea. Skhalo used to take care of his mother as the other brothers were always out of the house. The grandmother, who is his mother's mother and the aunt they are now living

with, would come and help out with the cleaning of the house and washing of their mother's clothes.

#### **4.2.1.3 Transcription of Skhalo, Mbulelo, their aunt and their class educator's interview**

This story is based on the transcribed interview between the researcher and the participants. What follows is a *verbatim* transcription of the actual conversation that took place between the interviewer and the participants in both sessions.

**Interviewer:** Do you know what your mother suffered from when she died?

**Skhalo:** Yes, my grandmother and my aunt informed me when she was still sick that she was dying of AIDS. They shared this information with me because they wanted me to take care of my dying mother and my younger brother. They found it difficult to divulge such information to my younger brother, Mbulelo, as they believed that he was still too young and would be psychologically devastated by the knowledge of his sick mother.

**Mbulelo:** No, I was not told about the cause of her illness until after her death.

**Interviewer:** How did you feel when you were told that your mother was dying of AIDS, Skhalo?

**Skhalo:** At first this was very confusing and it, really, obfuscated my mind and completely blurred my vision. I did not know what to do, I was thinking of death, whenever my mother's health deteriorated. I thought that she was dying. I still think of death whenever people talk about HIV/AIDS. I felt very angry with my two older brothers for not helping out with taking care of our mother. I would not go to school for days when my mother was very sick, but sometimes my grandmother would come very early and tell me to go to school, that she was going to look after my mother.

**Mbulelo:** I was also very sad that my mother was always sick, but there was nothing I could do about it.

**Interviewer:** Do you know your HIV/AIDS status?

**Skhalo:** Yes, I was tested at a nearby clinic in April when Mbulelo and I first came to live with our aunt and step-uncle. The aunt told us when we arrived at home that the results revealed that we are both HIV positive.

**Mbulelo:** I also tested and I am also HIV positive.

**Interviewer:** How did you feel when you were told that you are HIV positive?

**Skhalo:** I was shocked, I did not want to live any more, I just wanted to die like my mother, and in fact, I wanted to die before I became too ill to go school. I started to hate my aunt for taking us to the clinic in the first place - I started hating everything including the house we were living in and everybody around me.

**Mbulelo:** I was also very shocked. I could not believe what the doctor was telling my aunt. I thought HIV/AIDS only infect elderly people - I was still too young to have HIV. I started having nightmares. I was always thinking of my mother's last days (how ill she was). I started having flu and for two weeks I could not go to school.

**Interviewer:** Aunt how were these learners after their HIV positive status was revealed to them?

**Aunt:** They started being ill, Mbulelo was even worse. They were both withdrawn, they are usually very playful, but for a week it was even difficult for them to go out and play with other learners. I even decided to keep them at home so that they can be able to recover from the shock.

**Interviewer:** How long did it take these learners to recover from the shock?

**Aunt:** It took Mbulelo the younger brother less time than Skhalo his elder brother. I can say it took Mbulelo about a month but I really had it tough with Skhalo, he recovered after eight to nine months.

**Interviewer:** What do you think made Skhalo to take that long to recover?

**Aunt:** I think that is due to the fact that he was the one who was taking care of his sickly mother. He has observed all the stages her mother went through. He even told me that he was worried about how ill he would be in his late stages.

**Interviewer:** Did being diagnosed HIV positive affect your performance at school?

**Skhalo:** Yes, I did not want anything to do with school anymore; I told myself that I was going to die anyway. I had no time to do class work and homework I was always thinking about my status and at school I did not want to talk to anyone, it was as if they could see that I am HIV positive.

**Mbulelo:** I think so although I am not sure whether my work deteriorated because of my HIV positive status or the death of my mother. After the death of my mother I do not remember doing well in class or even concentrating for that matter. It became worse when my HIV positive status was revealed to me. Things are happening so fast, I still had to adjust to the new environment (where we now live with my aunt) at the same time I have to deal with being HIV positive.

**Interviewer:** How is Skhalo's performance at school?

**Class educator:** Skhalo's performance started deteriorating. He was no longer a happy and active learner that I have known. He started not doing his homework, not completing his tasks and not participating in groups as he used to. He would always be quite and seem to be day dreaming.

**Interviewer:** How have you helped Skhalo to improve his performance?

**Class educator:** I try to explain in class I even go to an extent of giving him individual attention, but I do not seem to be breaking through. When I explain he seems to be understanding, but when he has to do the work on his own he goes wrong.

**Interviewer:** Have you tried counselling Skhalo or referring him to other educators who can help?

**Class educator:** I have never counselled him, we do not have time to do other things rather than teaching. I once thought of having an afternoon class for him and the others that are in the same predicament, but I could not because of time. We have a psychologist I would refer him to but it is a very long procedure to get to him. He is the only one who works with about thirty schools.

**Interviewer:** What do you think made you to recover, Skhalo?

**Skhalo:** My grandmother and my aunt took me to my mother's grave. I could not understand most of the things they said at the grave, I was also not interested because I was thinking that it would have been better if I died before my mother died. I think the support and care I got from my aunt and step-uncle made me to forget about my status and focus on my life. My aunt told me not to go to school for two days. She bought me nice things like fruit, yoghurt and other stuff. She would ask me for permission to talk to me about my status, she would tell me to focus on my studies and my future and that she and my step-uncle are going to care for and support me in everything. On the third day I was missing school and one friend I had. I started attending school and I have not missed a day ever since, unless I am sick.

**Interviewer:** Can you say you are alright you can carry on with your life normally?

**Skhalo:** I try by all means to do my best but it is very difficult. There has been improvement over the past year on my performance although slight. What makes me to relapse is seeing people who have AIDS die or watching programmes about People Living With AIDS on TV. I think about my own problem and start being ill. I think I would live a normal life and just forget about everything if there were no other people who are HIV/AIDS positive.

**Interviewer:** What do you think made you to recover, Mbulelo?

**Mbulelo:** My aunt took me to the clinic after a week. They gave me medication for flu and sulpha for my rash as I had also developed a rash.

**Interviewer:** Can you say you are alright you can carry on with your life normally?

**Mbulelo:** To a certain extent, but there are days when I feel down and depressed, that is when I think about my life and the fact that it will never be normal as other learners.

**Interviewer:** Who did you tell about your status?

**Skhalo:** No one.

**Mbulelo:** I also have not told any one.

**Interviewer:** Why have you not told your friends or your educators or maybe anyone who is close to you about your status?

**Skhalo:** There is nothing that the educators can do after knowing about my status, except to lie. They are going to tell me that I am going to be better, there is a cure for HIV/AIDS, or maybe just keep quiet as they never talk about HIV/AIDS in our school. Concerning my friends, I fear rejection, I am afraid that the only friend I have, will no longer want to hang out with me. I do not have friends at home and I no longer have contact with kids I grew up with at Soweto.

**Mbulelo:** I don't want to tell people about my status, I have friends at school but I do not know what they will think when they know that I am HIV positive. I am afraid they would treat me differently. I am happy though that my aunt and my step-uncle know.

**Interviewer:** Who have you told about these learnerren's HIV positive status?

**Aunt:** At first I did not know who to tell, but I was compelled to consult a social worker as I had to apply for a social grant for both my sister's boys. I also felt compelled to reveal their positive status to their class educator. I do not want to tell other people in our community or other members of the family. In our communities we still believe that if one of the members of the family is HIV

positive the entire family is infected. People start isolating that family, we really cannot afford that at the moment that is why I have not told anyone.

**Interviewer:** Do you think the support these learnerren get from the social worker, the educator and their grandmother is enough?

**Aunt:** I am aware that we all need support from whoever is willing to give it to us. I know that the support we get is not enough, we would be supported by our pastor if I had revealed the boy's status to him. The boys would also be able to attend support groups within our area especially Skhalo. I would also attend a support group for caregivers, I also think I would benefit a lot from these gatherings as they discuss ways of supporting the infected.

**Interviewer:** Considering the benefits of disclosing the boy's status to significant others in your area, do you still think it is better not to disclose?

**Aunt:** Yes, I still prefer not disclose to other people rather those who already know. I am really not ready for rejection by other members of the community and our family.

**Interviewer:** Have you changed the way you live after you have heard that you are HIV positive?

**Skhalo:** I think so, I now prefer to be indoors rather than going out to play with my friends.

**Interviewer:** What emotions/feelings go through you when thinking that you are HIV positive?

**Skhalo:** In the beginning I blamed God for making this happen to us, I also blamed my mother for infecting us. But now I think of my future, I would like to be a soldier but my mother told me this kind of work is very dangerous, I have opted for police work. I am sometimes worried about being sick. I cared for my mother for two years. The last days of her life, I was there. I have seen how she suffered. I do not think I want to suffer the way she did. It is the future that scares me most.

**Mbulelo:** I do not think of myself as HIV infected. Whenever I see anything on TV about AIDS I feel like switching it off. I do not like to listen to people talking about others that are HIV-infected. I sometimes think about my own status I try by all means to forget about the virus. I wish I was not infected. I do not know what the future holds. I do not want to think about the time I will be very sick, but I know that will happen eventually. I wish they could have a cure before I become too sick to continue attending school. The thought of death is paralysing, it is better for me to think about the good things that have happened to me, the treatment we get from my aunt and my step-uncle. That way I am able to face each day, but thinking about HIV is too heavy for me.

**Interviewer:** Have you ever been counselled?

**Skhalo:** Yes, I think so, at the clinic when we went for HIV/AIDS test, the nurse said something about counselling us.

**Interviewer:** What exactly did you talk about when you were counselled?

**Skhalo:** The nurse just asked me a lot of questions, about what I think I will do if the results reveal that I am positive, and if I am negative how will I ensure that I stay that way, what I know about HIV/AIDS and so on.

**Interviewer:** Where else have you been counselled?

**Mbulelo:** I have never been counselled.

**Interviewer:** What do you know about counselling?

**Skhalo:** I think it is where people are helped to face and may be solve their problems.

**Interviewer:** Do you think counselling at schools would help learners who are infected?

**Skhalo:** Yes, I think so, learners would have an opportunity to talk about their feelings, about what they are going through, about their fears and mostly I would have an opportunity to know more about HIV/AIDS, its stages and what one can do to live longer.

**Interviewer:** Do you think counselling can help you in any way, Mbulelo?

**Mbulelo:** Yes, I think it would help not only me but also other learners who are in the same predicament. I think it would help solve the problem of discrimination. It is very difficult to tell people about one's status as people tend to discriminate because of lack of knowledge.

**Interviewer:** How often do health workers visit you at school to talk to you about HIV/AIDS?

**Skhalo:** There is a health worker that sometimes visits us at home, she talks with my aunt for a long time, and she just asks us how we are and if we are still doing well at school. At school nurses from the clinic came twice last year. The first time they came it was early in the morning and we were at the assembly. They talked to us about HIV/AIDS, how it is contracted, the importance of using condoms, that we must go to the clinic for sexually transmitted diseases, and that AIDS kills. They allowed us to ask questions; a few learners asked a question. One of the questions was, "how long does it take a person to have full blown AIDS?" The nurse said it depends on whether the person is eating healthy, living positively, and exercising. The second time other nurses came was when we were celebrating the World AIDS day; I did not hear what they were saying that day, as our class was performing an item. I was concentrating more on how we were going to perform, I was very excited, it was my first time to be part of something that was to be presented in front of all the educators and parents.

**Interviewer:** When teaching Life orientation do you include HIV/AIDS?

**Class educator:** Yes I do in a way, I have to teach learners how it is transmitted tell them about its stages and progression in a human body and make them aware of the precautionary measures they have to adhere to, and address the issue of stigma.

**Interviewer:** Are you able to cover all these aspects?

**Class educator:** No, Life Orientation is very broad, there are a lot of other aspects to cover besides HIV/ AIDS, and moreover learners who have parents who are suffering from HIV/AIDS do not feel free to participate in discussions. I also feel that they are too young to be taught about HIV/AIDS.

The researcher thanked the participants after every interview for agreeing to participate.

### **4.3 ANALYSES AND INTERPRETATION OF THE ABOVE CASE STUDY**

In this section, the themes, which emanate from the above case study are presented.

#### **4.3.1 Theme 1: Psychological disturbance**

The analysis of the above case revealed emotional disturbance in the participants' lives. For example, both respondents indicated that they were disturbed by the knowledge that:

- their mother was dying of AIDS; and
- they themselves were HIV positive after a medical diagnosis.

#### **Analysis**

This is what the respondents revealed when they were asked how they felt about being infected with HIV/AIDS:

“At first this was very confusing and it, really, obfuscated my mind and completely blurred my vision. I did not know what to do, I was always thinking of death”

“I was shocked, I did not want to live, I just wanted to die like my mother, and in fact I wanted to die before I become too ill to go school”

“I started having nightmares I was always thinking of my mother's last days (how ill she was). I started having flu and for two weeks I could not go to school”

“I also blamed my mother for infecting us. I am sometimes worried about being sick”

“I do not think of myself as HIV infected. Whenever I see anything on TV about AIDS I feel like switching it off. The thought of death is paralysing, it is better for me to think about good things that have happened to me, the treatment we get from my aunt and my step-uncle. That way I am able to face each day, but thinking about HIV is too difficult for me”

The two boys suffering from HIV/AIDS became ill immediately after the disclosure of their HIV positive status. This is what their aunt said:

“They started being ill, Mbulelo was even worse. They were both withdrawn, they are usually very playful, but for a week it was even difficult for them to go out and play with other learnerren. I even decided to keep them at home so that they can be able to recover from the shock”

Skhalo and Mbulelo took different times to recover from the shock of the disclosure of their status. This is what their aunt said:

“It took Mbulelo the younger brother less time than Skhalo his elder brother. I can say it took Mbulelo about a month but I really had it tough with Skhalo, he recovered after eight to nine months”

There are different reasons why it took one of the boys longer to recover, his aunt highlighted some of the reasons as:

“I think that is due to the fact that he was the one who was taking care of his sickly mother. He has observed all the stages his mother went through. He even told me that he was worried about how ill he would be in his late stages”

## **Interpretation**

The above responses indicate that learners infected with HIV/AIDS have emotional responses to their being infected. Both respondents experienced shock, blaming the parent who infected them, having nightmares, suicidality, confusion, fear of death and denial. These emotions and experiences are typical of most people who have been diagnosed HIV positive. Infected learners appear to be lonely and depressed and they usually not have anyone to talk to about their plight. It is believed that the flirtation with suicide is the infected person's worst hazard of the anger stage; this can be the expression of the extent of one's rage with oneself and with those who infected her/him. The responses also indicated that they were withdrawn after their status was revealed to them, it took them time to recover from the shock of being diagnosed HIV positive. Being a caregiver seemed not to have prepared the boys for the positive diagnoses.

### **4.3.2 Theme 2: Poor scholastic performance**

#### **Analysis**

Respondents indicated that being diagnosed with HIV/AIDS affected their performance in class. When asked if their HIV positive status affected their performance at school, they revealed the following:

“Yes, I did not want anything to do with school. I told myself that I was going to die anyway”

“I had no time to do class work and homework I was always thinking about my status and at school I did not want to talk to anyone, it was as if they see that I am HIV positive”

The class educator also revealed Skhalo's poor performance in class, this is what was said:

“Skhalo's performance started deteriorating. He was no longer a happy and active learner that I have known. He started not doing his homework, not completing his tasks and not participating in

groups as he used to. He would always be quite and seem to be day dreaming”

### **Interpretation**

It is evident in the above responses that being diagnosed with HIV/AIDS affect learners' performance at school. It can be deduced from the statements above that it becomes difficult to concentrate at school if one is diagnosed HIV positive especially where there is no assistance to ensure that these learners get support and guidance they desperately need. Other factors that seemed to lead to poor performance in school are having no time to concentrate on schoolwork as one is preoccupied with death, inability to complete tasks because of illness and inability to participate in groups. If there are no measures such as the provision of antiretroviral medication in place to support the psychological and physical resilience of these learners, this could result in high levels of learner drop out.

#### **4.3.3 Theme 3: Blaming, denial, poor self-concept, continuous hoping and a combination of optimism and pessimism in their lives.**

### **Analysis**

When asked how they deal with being HIV positive, they revealed that:

“In the beginning I blamed God for making this happen to us, I also blamed my mother for infecting us” which confirms the theme of blaming.

“I do not think of myself as HIV infected” which confirms the theme of denial.

“I wish I was not infected” which confirms the theme of a poor self-concept.

“I wish they could have a cure before I become too sick to continue attending school” which confirms the theme of continuous hoping.

“It is better for me to think about good things that have happened to me, the treatment we get from my aunt and my step-uncle. That way I am able to face each day, but thinking about HIV is too heavy for me” which confirms the combination of optimism and pessimism in their lives.

### **Interpretation**

The above responses indicate that infected learners use different methods to deal with being infected. Responses reveal that blaming other people or a higher power, denial, wishing the disease away, hoping for a cure and thinking positively are some of the methods of dealing with the stress of being HIV positive.

Reaction to the stress of being diagnosed HIV positive is different for everyone. It is believed that over time, one finds a way of dealing with it that suits him/her, but it might be quite different to the way other people cope with it. It has been proven that thousands of other people live full and rewarding lives despite being HIV positive. This is made possible by the nature of support one gets from other people, ability to get medication, healthy living and positive thinking and or resilience.

#### **4.3.4 Theme 4: Not sufficient psychosocial support**

### **Analysis**

When asked if they were counselled as a way of helping them deal with the ordeal of being HIV/AIDS positive, they revealed the following:

“Yes, I think so, at the clinic when we went for HIV/AIDS test, the nurse said something about counselling us”

“I have never been counselled”

The educator indicated not having time to counsel learners suffering from HIV/AIDS at school, this is what was said:

“I have never counselled him, we do not have time to do other things rather than teaching. I once thought of having an afternoon class for him and the others that are in the same predicament, but I could not because of time. We have a psychologist I would refer him to but it is a very long procedure to get to him. He is the only one who works with about thirty schools”

Asked if they think counselling can help them in any way, they said:

“Yes, I think so, learners would have an opportunity to talk about their feelings, about what they are going through, about their fears and mostly I would have an opportunity to know more about HIV/AIDS, its stages and what one can do to live longer”

### **Interpretation**

It is interesting to note that infected learners are counselled before they are tested regardless of age - however it is worrying that no post-test counselling is provided on a continual basis, and that educators do not have time to counsel these learners. Continual good counselling can help learners suffering from HIV/AIDS make informed decisions about how they wish to:

- continue living their lives;
- cope in a better way with their health condition;
- lead more positive lives; and
- prevent further transmission of HIV.

Such counselling can be provided at schools, homes, community clinics and so on.

#### **4.3.5 Theme 5: Strong family support**

### **Analysis**

When asked about the nature of family support they get, they revealed that:

“I think the support and care I got from my aunt and step-uncle made me to forget about my status and focus on my life”

“My aunt would ask me for permission to talk to me about my status, she would tell me to focus on my studies and my future and that she and my step-uncle are going to care for and support me in everything”

“Sometimes my grandmother would come very early and tell me to go to school, that she was going to look after my mother”

“It is better for me to think about good things that have happened to me, the treatment we get from my aunt and my step-uncle. That way I am able to face each day, but thinking about HIV is too heavy for me”

Skhalo reported that he was angry with his elder brothers who were not willing to support them in taking care of their mother. This is what him said about this:

“I felt very angry with my two older brothers for not helping out with taking care of our mother. I would not go to school for days when my mother was very sick”

### **Interpretation**

It is interesting to note that the two boys are receiving support from the members of their extended family. Family members can provide effective caregiving to learners suffering from HIV/AIDS.

#### **4.3.6 Theme 6: Support from the community or community agencies**

### **Analysis**

When asked about the social support they get from the Department of Social services and sometimes nurses from the Department of Health, they revealed the following:

“There is a health worker that sometimes visits us at home, she talks with my aunt for a long time, and she just asks us how we are and if we are still doing well at school”

“At school nurses from the clinic came twice last year. The first time they came it was early in the morning and we were at the assembly. They talked to us about HIV/AIDS, how it is contracted, the importance of using condoms, and that we must go to the clinic for sexually transmitted diseases, and that AIDS kills”

“They allowed us to ask questions”

“I did not hear what they were saying that day, as our class was performing an item. I was concentrating more on how we were going to perform, I was very excited, and it was my first time to be part of something that was to be presented in front of all the educators and parents”

### **Interpretation**

It is interesting to note that these learners get support from social agencies such as the Departments of Social Services and Health. Collaboration among health service providers such as physicians, nurses, occupational therapists, physiotherapists and social service providers such as social workers, non-governmental organizations with HIV/AIDS focus, educators, is needed now more than ever to address the needs of the growing population of learners living with HIV/AIDS and those who are at risk for HIV infection in schools.

#### **4.3.7 Theme 7: Spirituality and religion**

### **Analysis**

When asked about what made them better, they revealed that:

“My grandmother and my aunt took me to my mother’s grave”

“My aunt took me to the clinic after a week. They gave me medication for flu and sulpha for my rash as I had also developed a rash”

“In the beginning I blamed God for making this happen to us”

### **Interpretation**

It is interesting to note that people try different things when they face adversity. Some people start bargaining with God or with ancestors for health. Whatever things they believe in sometimes things do happen the way they expected.

#### **4.3.8 Theme 8: Fear of disclosure**

### **Analysis**

When asked about who they told about their HIV/AIDS positive status, they revealed the following:

“No one”

“I have not told any one”

When further asked why they have not told their friends, educators or anyone who is close to them, they revealed the following:

“There is nothing that the educators are going to do after knowing about my status except to lie. They are going to tell me that I am going to be better, there is a cure for HIV/AIDS, or maybe just keep quiet as they never talk about HIV/AIDS in our school. Concerning my friends, I fear rejection, I am afraid that the only friend I have managed to have will no longer want to hangout with me. I do not have friends at home and I no longer have contact with kids I grew up with at Soweto”

“I don't want to tell people about my status, I have friends at school but I do not know what they will think when they know that

I am HIV positive. I am afraid they would treat me differently. I am happy though that my aunt and my step-uncle know”

The boys' aunt also indicated fear of disclosing to other people, this is what she said:

“At first I did not know who to tell, but I was compelled to consult a social worker as I had to apply for a social grant for both my sister's boys. I also felt compelled to reveal their positive status to their class educator. I do not want to tell other people in our community or other members of the family. In our communities we still believe that if one of the members of the family is HIV positive the entire family is infected. People start isolating that family, we really cannot afford that at the moment that is why I have not told anyone”

“I am aware that we all need support from whoever is willing to give it to us. I know that the support we get is not enough, we would be supported by our pastor if I had revealed the boy's status to him. The boys would also be able to attend support groups within our area especially Skhalo. I would also attend a support group for caregivers, I also think I would benefit a lot from these gatherings as they discuss ways of supporting the infected”

“Yes, I still prefer not disclose to other people rather those who already know. I am really not ready for rejection by other members of the community and our family”

### **Interpretation**

The foregoing assertions highlight the hesitancy and fear of disclosure of HIV/AIDS, the learners in question and their aunt have and by so doing cutting themselves off the valuable support from significant others. As a result, in conjunction with coping with the psychological and emotional ramifications of being infected with HIV and AIDS, the learners in question and their aunt are forced to deal with a fear of disclosure of their HIV/AIDS status as a stressor.

#### **4.4 CONCLUSION**

This chapter dealt with analysis and interpretation of responses of all the participants in the case study of this research. The learners participants' experiences, which are the highlight of this chapter were also analysed and interpreted. Both learner participants were prenately infected with HIV/AIDS. This type of transmission is refered to as Mother To Child Transmission (MTCT) in this research.

The next chapter deals with the summaries, conclusions and recommendations of the research.

## **CHAPTER FIVE**

### **FINDINGS, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

This final chapter presents an overview of this research's findings and conclusions from the literature study as well as from the empirical research.

#### **5.2 SUMMARY OF FINDINGS FROM THE LITERATURE REVIEW**

In the literature study it was found that:

- It is generally accepted that the HIV/AIDS epidemic is seriously affecting the psychological and physical well being of learners. This is due to the effects of the epidemic's associated opportunistic diseases. Among others, weight loss, dry cough, recurring fever or profuse night sweats, profound and unexplained fatigue, swollen lymph glands in the armpits, groin, or neck, diarrhoea that lasts for more than a week, white spots or unusual blemishes on the tongue, in the mouth, or in the throat, red, brown, pink, or purplish blotches on or under the skin or inside the mouth, nose, or eyelids; memory loss, concentration, creativity, depression, and other neurological disorders; tuberculosis, pneumonia, gastro-enteritis, meningitis and cancer affect both the physical and psychological wellness of learners infected with HIV and AIDS (see 1.1).
- Given the effects of HIV/AIDS on the psychological and physical well being of learners, a major challenge in conceptualising effective responses to both HIV/AIDS epidemic lies in generating interventions which go beyond the concept of individual risk (see 1.1).
- The application of ecological-systems framework to school, family and community interventions assists post-modern and social constructivist educators to view learners in the light of various social systems and to

integrate techniques across diverse educational psychology practice perspectives (see 2.8).

### **5.3 SUMMARY OF FINDINGS FROM THE EMPIRICAL RESEARCH**

The empirical investigation revealed that:

- learners infected with HIV/AIDS have emotional responses to their being infected. Both respondents experienced shock, blaming the parent who infected them, having nightmares, suicidality, confusion, fear of death and denial (see 4.3.1);
- learner participants were withdrawn after their status was revealed to them, it took them time to recover from the shock of being diagnosed HIV positive. Being a caregiver seemed not to have prepared the boys for the positive diagnoses (see 4.3.1);
- scholastic performance of learners suffering from HIV/AIDS is affected. The study revealed that it becomes difficult to concentrate in school work if one is diagnosed HIV positive especially where there is no assistance to ensure that these learners get support and guidance they desperately need. Other factors that seemed to lead to poor performance in school were indicated as not having time to concentrate on school work as one is preoccupied with death, inability to complete tasks because of illness and inability to participate in groups (see 4.3.2);
- learner participants used different methods to deal with being infected. Responses reveal that blaming other people or a higher power, denial, wishing the disease away, hoping for a cure and thinking positively are some of the methods of dealing with the stress of being HIV positive (see 4.3.3);
- the infected learners were counselled before they were tested regardless of age (see 4.3.4);
- no post-test counselling is provided on a continual basis (see 4.3.4);

- educators indicated not having time to counsel these learners (see 4.3.4);
- the two boys are receiving support from the members of their extended family, social agencies such as the Departments of Social Services and Health (see 4.3.6);
- people try different things when they face adversity. Some people start bargaining with God or with ancestors for health (see 4.3.7); and
- the participants were hesitant and fearful to disclose their HIV/AIDS status to members of the community, the learners in question and their aunt have by so doing cut themselves off the valuable support from significant others (see 4.3.8) .

## **5.4 RECOMMENDATIONS**

The following recommendations are made:

### **5.4.1 Recommendations for further research**

This study would be more reliable and valid had it made use of more than one focus group in its research sample. More focus groups would have engaged learnerren and adolescents affected or orphaned by HIV/AIDS in all provinces of South Africa. There is, therefore, a need for a study to be conducted for all the provinces in South Africa on the psychological well being of learners affected with HIV/AIDS as this research focused only on one case study in the Vaal Triangle of the Gauteng province.

### **5.4.2 Recommendations for practical implementation of findings**

In light of the literature review and empirical research findings of this study, the following recommendations are made for an ecosystemic programme for supporting school-going learnerren and adolescents infected with HIV/AIDS:

The findings from both the literature review and empirical research of this study have lead the researcher to believing that schools can no longer react to exigencies of society by focusing exclusively on learnerren and adolescent's academic competence. The diverse and changing needs of the community,

plus increased political and social pressure for health-care transformation, require schools to address the general psychological, social and physical well being of learners and their families. This includes provisions for learners with HIV/AIDS. This research strongly recommends an ecosystemic collaboration and partnerships between schools and communities in order to slow the spread of HIV infection and improve the lives of all those infected and affected by it.

In light of the latter paragraph, schools in collaboration with community agencies oriented towards HIV/AIDS must be in a position to support learners suffering from HIV/AIDS and families affected by it. This research recommends the following ecosystemic programme:

- School-based prevention efforts should include:
  - **Safety precautions in the school.** This research recommends that all members of the school community, including school governing body members, receive training in the universal precautions concerning exposure to blood and other bodily fluids. This training should occur regardless of the known presence of a learner with HIV. In fact, the researcher believes instruction in the universal precautions concerning exposure to blood and other bodily fluids should begin at the pre-service level of professional training of educators.
  - **HIV/AIDS education for learners.** Schools must address all social and health problems relevant to a learner's learning. This research recommends that age-appropriate HIV/AIDS education should be provided at all grade levels to increase the likelihood that high-risk behaviours will be prevented before they become firmly established and resistant to change. The researcher believes an AIDS prevention curriculum should be jointly developed by school psychologists, parents, educators, school administrators, health educators, and appropriate community representatives; be designed to fit with the specific prevention needs and cultural norms of the group to which it is delivered; be

infused into a more general health education programme; provide scientifically accurate information about the various modes of HIV transmission and effective methods for reducing the risk of transmission; be taught by general education educators in the foundation grades and qualified health educators in secondary grades; describe the benefits of sexual abstinence for young people and, for teenagers approaching the potential age of sexual debut, address ways to reduce the risk of HIV infection and other sexually transmitted disease which should include discussion of the correct and consistent use of condoms; be guided by empirical demonstrations of programme efficacy, monitored periodically to determine effectiveness, and modified as necessary; include guidelines to address the epidemic of HIV/AIDS stigma. School-based curricular efforts typically stress virus prevention, but often overlook social reactions to those already infected. NASP believes the stigma surrounding HIV can be a formidable obstacle in the design and implementation of prevention education at school. NASP recommends the infusion of psychological and social constructs throughout school-based AIDS programming.

- **HIV/AIDS education for school staff (both teaching and non-teaching staff) and parents.** The researcher believes all school staff should be educated about physical, psycho-social, and developmental aspects of HIV. School staff and parents must recognize and address their own feelings and personal concerns regarding AIDS. HIV/AIDS education can alleviate fears and, thus, promote acceptance of learnerren with HIV. Furthermore, school staff and parents who are knowledgeable about HIV/AIDS are better prepared to educate learnerren and model appropriate behaviour and attitudes. Given their training in psychological and educational principles, the researcher believes that the engagement of educational psychologists at schools to advocate the use of empirically supportable HIV/AIDS

training programmes that promote prevention education and address psychosocial issues surrounding AIDS could benefit schools. It is therefore high time that the Department of Education in South Africa employs the services of educational psychologists at every school under its jurisdiction.

- **Confidentiality/disclosure/legal issues.** At the government level, the Bill of human rights protects HIV-infected learners and school staff from discrimination. This research strongly recommends that learners, parents, educators and community members become familiar with the South African National Policy on HIV/AIDS (Act 27 of 1996). As a general rule, the researcher believes only those who have a legitimate need to know should be informed of a learner or adolescent's HIV/AIDS status. In some cases, this may mean classroom educators will not have access to this information unless it can be documented that such disclosure will benefit the learner/adolescent, and a parent has consented to its release. Regardless of individual decisions regarding disclosure, school staff must be formally prepared to handle the spread of HIV-related rumours among learners and staff.
- **Psycho-educational interventions.** The researcher believes multidisciplinary teams should be involved in the assessment, intervention planning, and outcome evaluation of learnerren with HIV. This research advocates a repeated, comprehensive, and developmental assessment to describe the learner or adolescent's changes over time. This assessment should focus on current cognitive functioning, psychosocial status, the nature of physical impairments, receptive and expressive language, attention, memory, perceptual-motor skills, academic skills, and adaptive behaviour. This research also affirms the rights of learnerren with HIV to a free and appropriate education in the least restrictive environment. If special education services are needed, learners with HIV can be considered learners with special educational needs if they experience HIV-related cognitive and

physical impairments, as well as discrimination and ostracism related to perceived contagiousness.

- **Psycho-social interventions.** This research recommends that issues of social contamination and stigma be considered in all decisions regarding learnerren with HIV and their families. Negative reactions from classmates and school staff must be addressed through proper education. Educational psychologists can reduce learnerren and adolescent's social isolation by gaining greater knowledge of HIV/AIDS and by training others through in-service presentations that reduce the fear of contagion. The researcher believes schools must work to protect learnerren and adolescents with HIV from the ostracism that frequently accompanies HIV/AIDS. Pediatric HIV may indicate the presence of AIDS in other family members, and these individuals will experience intense emotional strain, social stigma, and bereavement. The researcher strongly believes schools must address family issues from a culturally relevant perspective, and should lead the community in a reasoned response to HIV/AIDS.
- **Bereavement issues.** The health of school-age learnerren with HIV tends to decline over time, and can lead to departure from school, and hospital-based care. The researcher believes educational psychologists must assist learnerren and adolescents with bereavement issues at school. These issues may include learners' bereavement due to the death of a classmate, AIDS-related deaths of educators and other school staff, as well as deaths of family members of the infected learner. Educational psychologists should be knowledgeable about learnerren and adolescent's developmental differences in understanding death and specific helping behaviours to use in school. In addition, educational psychologists must recognize the learner with HIV may experience family disintegration. AIDS not only creates orphans, it causes other major stressors for learnerren, such as witnessing the medical deterioration of a loved one, moving to live with an extended family member or foster parent, and/or legal battles regarding custody.

- Research and training. The researcher believes educational psychology should contribute to the limited research base regarding psycho-educational and psycho-social consequences of HIV/AIDS among learnerren and adolescents. This research is essential to better serve learnerren and adolescents suffering from HIV, and to meet the needs of others indirectly affected by the illness and its stigma. Educational psychologists should also accept this mission by sensitizing educators, parents and learners and training them about the complex issues surrounding HIV disease. The researcher believes educational psychologists must become actively involved in systematic programme evaluation of school-based AIDS curricula to refine the knowledge base of empirically supportable interventions.
- The campaigns at society or government level should provide a learner-focused framework for country-level HIV/AIDS programmes around the following 'Four Ps':
  - Prevent mother-to-learner HIV transmission by offering appropriate health services to pregnant women.
  - Provide paediatric treatment by providing either antiretroviral treatment or cotrimoxazole, or both, to learnerren suffering from HIV/AIDS.
  - Prevent infection among learnerren and adolescents by reducing the percentage of learnerren and adolescents suffering from HIV by twenty-five per cent globally
  - Protect and support learnerren suffering from HIV/AIDS by reaching at least eighty per cent of learnerren and adolescents most in need
- The government should provide a platform for learner and adolescent-focused advocacy on social AIDS issues such as
  - Mobilizing societal resources to combat HIV/AIDS. This means not only a significant increase in official development assistance overall, but also a bigger proportion allocated to HIV/AIDS and,

specifically, to protect, care, support and provide treatment for learnerren and adolescents suffering from this disease.

- Supporting school governing bodies as they develop socially responsible HIV/AIDS policies and programmes for educators, learners and parents.
- Putting the protection, care, support and treatment of learnerren and adolescents at the centre of the HIV/AIDS agenda and, also, putting the missing face of learnerren and adolescents suffering from AIDS at the centre of the HIV/AIDS agenda and making sure that the voices of learnerren and adolescents are heard on the issues that relate to them.

## **5.5 Conclusion**

This research investigated, by means of literature review and empirical research the psychologically ecosystemic programme for supporting school-going learnerren and adolescents infected with HIV/AIDS. On the basis of both the findings of the literature review and empirical research, recommendations were made in Chapter 5.

It is hoped that this research will make a contribution in the understanding of learners infected with HIV/AIDS and the way in which schools, families, communities and societies can collaborate in socially supporting school-going learnerren and adolescents to both psychologically, socially and physically develop in a healthy way.

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## **APPENDIX A**

### **INTERVIEW QUESTIONS FOR SKHALO, MBULELO, THEIR AUNT AND THE CLASS EDUCATOR**

Do you know what your mother suffered from when she died?

How did you feel when you were told that your mother was dying of AIDS, Skhalo?

Do you know your HIV/AIDS status?

How did you feel when you were told that you are HIV positive?

Aunt how were these learnerren after their HIV positive status was revealed to them?

How long did it take these learnerren to recover from the shock?

What do you think made Skhalo to take that long to recover?

Did being diagnosed HIV positive affect your performance at school?

How is Skhalo's performance at school?

How have you helped Skhalo to improve his performance?

Have you tried counselling Skhalo or referring him to other educators who can help?

What made you better, Skhalo?

Can you say you are alright you can carry on with your life normally?

What made you better, Mbulelo?

Can you say you are alright you can carry on with your life normally?

Who did you tell about your status?

Why have you not told your friends or your educators or maybe anyone who is close to you about your status?

Who have you told about these learner's HIV positive status?

Do you think the support these learner get from the social worker, the educator and their grandmother is enough?

Considering the benefits of disclosing the boy's status to significant others in your area, do you still think it is better not to disclose?

Have you changed the way you live after you have heard that you are HIV positive?

What emotions/feelings go through you when thinking that you are HIV positive?

Have you ever been counselled?

What exactly did you talk about when you were counselled?

Where else have you been counselled?

What do you know about counselling?

Do you think counselling at schools would help learners who are infected?

Do you think counselling can help you in any way, Mbulelo?

How often do health workers at school or at home talk to you about HIV/AIDS or visit you?

When teaching Life orientation do you include HIV/AIDS?

Are you able to cover all these aspects?