

**A SUPPORT PROGRAMME FOR HIV INFECTED  
LEARNERS**

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## **DEDICATION**

**THIS DISSERTATION IS DEDICATED TO MY SISTERS AUMA AND DISEBO,  
MY DAUGHTER LERATO AND MY BROTHERS IN LAW AUPA AND  
TSIETSI.**

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# CHAPTER ONE

## ORIENTATION

### 1.1 INTRODUCTION

Both national and international research reveals that the human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) have become the most common diagnosis among learners (Barnett & Whiteside, 2000:49). Many schools in South Africa are likely to see a huge increase in the prevalence of infection and manifestation of this epidemic among learners over the next few years. This increase in prevalence is caused by a number of factors, *inter alia*:

- the learner's temptation to explore their sexual identities and often not only experiment with sex but also with drugs;
- learner's sexual behaviour which tend to be impulsive and greatly influenced by peer pressure;
- being sexually active at a very tender age; and
- ignorance and illiteracy concerning the way HIV is contracted (Wenger, 2001:54).

As most researchers have pointed out, HIV/AIDS wreaks havoc on the psychological health and mental functions of learners such as memory, concentration, and creativity (Badcock-Walters, 2001:8). Behavioural efficiency and effectiveness, interpersonal relationships and personal productivity are also limited (Gronewald, 2005:152). Because of the physical and psychological demands involved in coping with this dreadful disease, it is not surprising that physicians and psychologists have suggested that the experiencing of HIV and AIDS by an infected learner, will have a negative effect on his or her general functioning at schools (Gwatkin & Deveshwar-Bahl

2002:91). Learners infected and affected by HIV/AIDS cannot function effectively and this impacts on effective learning.

In the light of the foregoing paragraphs, it is clear that children who are suffering from HIV/AIDS need comprehensive support from schools, families, communities and society in general. That is why schools need to develop support systems which can help learners suffering from HIV/AIDS, cope with the disease.

Findings from an assessment of the need for care and prevention for children and adolescents living with HIV in New Hampshire indicated that there were challenges, but also opportunities, for health care and social service providers to collaborate with schools in integrating prevention messages into health care settings (Velas, 2001:29; O'Connor, 2001:88). According to the study, there were gaps in the way social support and prevention were integrated into school HIV risk reduction programmes, including how social networks of children living with HIV/AIDS and their families were integrated into short-term and long-term counseling programmes (Brown, 2003:49).

A cross-sectional study, which was based on the buffering and diathesis-stress (predisposed to stress) models, sought to predict hopelessness among a sample of 50 HIV+ school going children and adolescents who were interviewed in outpatient medical clinics in Chicago (Dickinson, 2003:48). Paeinski and Laloo (2001:91) found that social support was pivotal in combating hopelessness among these respondents.

Past research on primary and secondary HIV prevention in the developing world, has shown that social support may buffer stress (Kelly, 2002:80). However, further research is needed to specify the types and amounts of social support needed by children and adolescents living with HIV/AIDS to buffer HIV status stress in such a way that it would be possible for them to protect themselves and prevent primary and secondary HIV infection. The direct effect hypothesis involves assuming that the presence of social support directly impacts the dependent, or outcome, variable (Kiragu, 2001:10).

Carr-Hill, Kataboro and Katahoire (2002:20) conducted a study of 30 HIV-infected children and adolescents who reported being members of an AIDS activist group. The investigation compared them to 144 other HIV-infected children and adolescents who were not involved in such a group. The study results revealed that participation in AIDS activist groups, made a difference in creating social and personal behavioural change. Those involved in an AIDS activist group felt more supported, so they were more likely to make action plans and/or adhere to schedules instead of engaging in wishful thinking in the hope that their problems would go away (Mitchell & Smith, 2001:56). In addition, those who had social support from groups compared to those who did not, showed greater awareness and use of HIV/AIDS information resources (Parker & Mundawarara, 2000:26).

In a qualitative study that explored the care and prevention needs of children and adolescents living with HIV in New Hampshire, the participants reported turning to health care providers for informational support on reducing HIV re-infection and transmission (Rie, Dore, McDonald & Kaldor, 2000:31). In Zimbabwe, results from a study by Bertozi, Opuni and Bolinger (2002:58) showed that supportive counseling for the social and emotional needs and problems of newly diagnosed seropositive patients attending public health services, go beyond the pre-and-post test phase. Supportive, ongoing counseling is able to assist newly diagnosed children and adolescents living with HIV/AIDS in meeting needs and addressing problems which appear over time.

Children and adolescents living with HIV/AIDS are able to replace fear-inducing HIV campaigns with interactive, constructive information about HIV prevention and care (Smith, 2002:53). These studies suggest, therefore, that supportive counseling establishes supportive interactions with supportees so that, over time, they begin to perceive care providers as part of their support network (Clinton, 2003:348; Van Aard, 2002:10; Cross, 2001:131; Siebert, 2000:15). A study by Kiragu and Kangurai (2001:28) reported positive results from a brief intervention that combined HIV testing, sero status feedback, risk-

reduction counseling, and condom provision for individuals and sexual-partner dyads in Kenya, Tanzania, and Trinidad.

Above study enrolled more than 4,000 participants who were randomly assigned either to the counseling and testing intervention or to a health-education control group. After seven months, the proportion of HIV counseling and testing participants who reported unprotected intercourse with non-primary partners declined by 35%, relative to a reduction of 13% among controls (Lyubormisky & Lepper, 2001:240). The results demonstrated how combining HIV testing with counselling can be an effective strategy to increase adherence to HIV/AIDS treatment and prevention. This effect could partly be attributed to the ability of counselling to enhance the children and adolescents living with HIV/AIDS's social support, which, in turn, may lead to enhanced internal health locus of control, thus enhancing the children and adolescents living with HIV/AIDS' adherence to HIV/AIDS treatment and prevention (Crepaz & Marks, 2002:135; Cohen, 2001: 45).

After consideration of the above, the questions that now come to mind are:

- What effects does HIV/AIDS have on the infected learner's psychological well being?
- What effects does HIV/AIDS have on the infected learner's scholastic performance?
- What support systems can schools, families and communities develop to help these learners deal with their health conditions?

## **1.2 AIMS OF THE STUDY**

The aims of this research were to:

- investigate the effects of HIV/AIDS on the psychological being of learners;
- determine the effects of HIV/AIDS on the infected learner's scholastic performance; and

- determine support systems schools, families and communities can develop to help these learners deal with their health conditions

### **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 psychological effects of HIV/AIDS on infected learners. To achieve this, all the available data bases (both national and international) were consulted during the study, for example, the NEXUS, SABINET – On-line, the EBSCO Host 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: psychosocial problems, support, 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 Leedy and Ormrod (2005:56), 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 well being of learners suffering from HIV/AIDS; determined the effects of HIV/AIDS on the scholastic performance of these learners; and determined support systems schools, families and communities can develop to help these learners deal with their health conditions.

Leedy and Olmrod (2005:22) state 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. The findings from these interviews helped the researcher to make recommendations on the psychological support of these learners.

### **1.3.2.1 Purposive sample**

According to Flick (1998:83), 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 children suffering from HIV/AIDS, it was necessary for the researcher to work collaborately with the social workers of the Bophelong Department of Social Development in identifying a case for this research. Social workers counsel children who are suffering from HIV/AIDS and have a list of all children who are HIV/AIDS positive. The researcher requested them to assist

her in getting an information-rich case of school going children who are suffering from HIV/AIDS for purposes of research. Zinck and Littrell (2000:55) 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 a learner who congenitally got infected with HIV/AIDS, whose parents died of HIV/AIDS. They drove the researcher to her home for introduction and assuring them that they had given the researcher permission to conduct interviews with the learner suffering from HIV/AIDS. They also told the family that they had the right to refuse to participate in the research. They agreed to participate. The researcher interviewed four participants (N=4).

### **1.3.2.2 Data generation**

The learner suffering from HIV/AIDS who agreed to participate was visited at her home for interviews and observation. The researcher conducted two interviews with the learner and her cousin as she indicated that she feels comfortable in her presence, they were interviewed together in the same sessions. It was necessary to interview the infected learner's aunt and her school teacher. The latter were interviewed separately. 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 her 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 (Bogdan & Bicklen, 1998:14) in naturalistic studies.

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

The participants 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 participant 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 participants were used to document critical issues in the psychosocial development of the infected learner. Critical incidents are defined by DeMarrais (1998:176) 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 (Kvale, 1998:69).

#### **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 the fact 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 Marshall and Rossman (1999:45). 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 was 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,

2001:98). 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 (Maxwell, 2004:14). 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 the light of the above paragraph, the researcher made the following considerations:

##### **1.4.1 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.

### **1.4.2 Informed consent**

The participants received an explanation of the purpose for which the data was being collected, the expected duration of the participant's involvement, and a description of the procedures to be followed; description of the measures to be taken to ensure the confidentiality of the participant's 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.

### **1.4.3 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. 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.

## **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 psychological well being.

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**

#### **2.1 INTRODUCTION**

In the two decades since HIV/AIDS was first identified in 1981, the body of research into the disease has been steadily growing. Today this research covers a wide range of topics ranging from strictly medical studies to the social and demographic implications of the study as well as to research the interventions and the best practices that may help to halt the spread of the disease (Anderson & Scharlander, 2002:75; Mann, 2001:26).

This chapter provides an overview on HIV/AIDS and its psychosocial impact on human beings in Africa, and further discusses various strategies that have been used both nationally and internationally to address the effects of HIV/AIDS on individuals.

#### **2.2 DEFINITION OF TERMS**

The following concepts, which are used throughout this research are defined below:

##### **2.2.1 HIV**

It stands for human immunodeficiency virus. It is a retrovirus also referred to in the past as LAV (Lymphadenopathy Associated Virus), ARV, HTLV – iii or simply the AIDS Virus (Barraclough, Chapman & Richems, 2001: 36).

It 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 module (Wild, 2001:22).

##### **2.2.2 AIDS**

Acquired immune deficiency syndrome can be explained as follows:

### **2.2.2.1 Acquired**

This means that it is caught and transmitted from someone or something as opposed to being inherited genetically (Beck, Miners & Tolley, 2001:39).

### **2.2.2.2 Immune Deficiency**

This is a condition where the body's natural defence mechanisms cannot defend itself against illnesses (Sherman & Bassett, 1999:109).

### **2.2.2.3 Syndrome**

This is a term given to a particular pattern of illnesses one can get as a result of contracting AIDS (Coombe, 2003:11) such as 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; depression and other associated neurological disorders such as anxiety, psychosis and so on; tuberculosis; pneumonia; gastro-enteritis; meningitis; and cancer. This means that the definition of AIDS is based on the secondary complications that develop in someone infected by HIV. The virus itself, therefore, is not a killer; but it is the complications it produces in a victim which are often lethal.

The virus that causes what is termed 'full – blown AIDS' breaks down a person's natural immunity against disease (Groenewald, 2005:45). This leaves a person vulnerable to serious illnesses that would not normally threaten someone whose immune system is functioning normally.

The onslaught of these illnesses (secondary complications) is referred to as 'opportunistic,' and as a result the context of AIDS is defined as the presence of an opportunistic infection or disease in a previously healthy person with no other cause for immune deficiencies (Kumar, Larkin & Mitchell, 2001:40; Hargreaves & Glynn, 2002:90).

### **2.2.3 Immune system**

This is the body's defence against infection (Kumar, Larkin & Mitchell, 2001:35). It is a flexible and highly specific defense mechanism that kills micro-organisms and the cells they infect; and destroys malignant cells and removes the debris. It distinguishes such threats from normal tissue by recognizing antigens (substances that induce the production of anti-bodies called immuno-globulin when introduced into the body) (Whiteside & Sunter, 2000:136).

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 tissues by recognizing antigens, that is, substances that induce the production of antibodies called immunoglobulin when introduced into the body (Anchard, 2000:55).

### **2.2.4 Universal precautions**

This concept refers to the concept used world wide in the context of HIV/AIDS to indicate standard infection control procedures or precautionary measures aimed at the prevention of HIV transmission from one person to another and includes procedures concerning basic hygiene and the wearing of protective clothing such as latex or rubber gloves or plastic bags when there is a risk of exposure to blood borne pathogens or bloodstained body fluids (Carr, Lamptey & Wigley, 2002:57).

## **2.3 REVIEW OF THE HIV/AIDS STATISTICS**

### **2.3.1 The HIV/AIDS pandemic globally**

Gupta (2001:4) states that the statistical proportions of the reality of HIV/AIDS worldwide are intense. More than 40.3 million adults and children worldwide

have been infected with HIV and AIDS since this pandemic has begun. 17.5 million of those infected people are children younger than 15 years. Theron (2004:56) states that more than 22 million people have passed away worldwide due to this pandemic.

Shisana, Rehle, Simbayi, Parker, Zuma, Bhana, Connolly, Jooste and Pillay (2005:17) estimated at the end of 2005, their high and low estimates are 16.8% and 20.7% respectively. According to their own estimate at total population, this implies that around were living with HIV at the end of 2005, including 240 000 children under 15 years old.

An estimated 38.6 million [33.4 million–46.0 million] people worldwide were living with HIV at the end of 2005. An estimated 4.1 million [3.4 million–6.2 million] became newly infected with HIV and an estimated 2.8 million [2.4 million–3.3 million] lost their lives to AIDS. Overall, the HIV incidence rate (the proportion of people who have become infected with HIV) is believed to have peaked in the late 1990s and to have stabilized subsequently, notwithstanding increasing incidence in several countries (Shisan *et al.*, 2005:9).

Favourable trends in incidence in several countries are related to changes in behaviour and prevention programmes. Changes in incidence along with rising AIDS mortality have caused global HIV prevalence (the proportion of people living with HIV) to level off. However, the numbers of people living with HIV have continued to rise, due to population growth and, more recently, the life-prolonging effects of antiretroviral therapy (Hall, Altman, Nkomo, Peltzer & Zuma, 2005:17).

There are no clear signs of declining HIV prevalence elsewhere in southern Africa including in Botswana, Namibia and Swaziland, where continue. In Swaziland, national adult HIV prevalence is estimated at 33.4% [21.2%–45.3%]. HIV prevalence among pregnant women attending antenatal clinics rose from 4% in 1992 exceptionally high infection levels to 43% in 2004 (Sonneberg, 2004:662). Botswana's epidemic is equally serious, with national adult HIV prevalence estimated at 24.1% [23.0%–32.0%] in 2005. Lesotho's epidemic seems to be relatively stable at very high levels, with an estimated

national adult HIV prevalence of 23.2% [21.9%–24.7%]. On the eastern coastline, a dynamic epidemic is underway in Mozambique, where the estimated national adult HIV prevalence is 16.1% [12.5%–20.0%]. HIV is spreading fastest in provinces linked by major transport routes to Malawi, South Africa and Zimbabwe (Avert Organisation, 2005:3).

Latest estimates show some 8.3 million [5.7 million–12.5 million] people (2.4 million among adult women [1.5 million–3.8 million]) were living with HIV in Asia at the end of 2005—more than two-thirds of them in one country, India. In Asia, about one in six people (16%) in need of antiretroviral treatment are now receiving it (Avert Organisation, 2005:6).

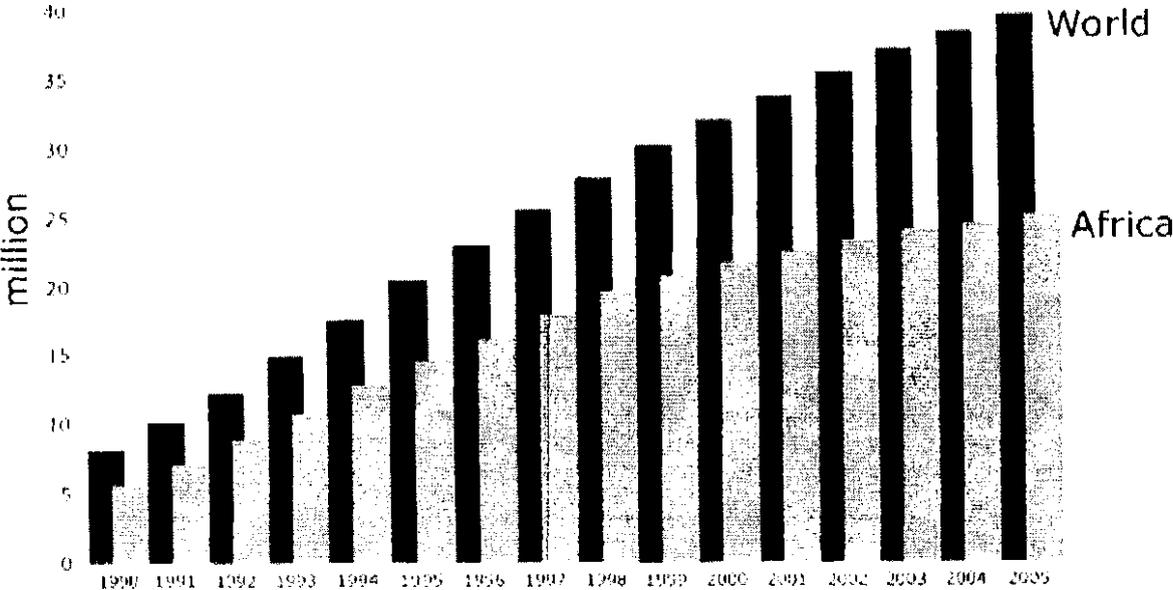
**Table 2.1: Global estimates at the end of 2005**

	Estimate	Range
People living with HIV/AIDS in 2005	38.6 million	33.4 – 46.0 million
Adults living with HIV/AIDS in 2005	36.3 million	31.4-43.4 million
Women living with HIV/AIDS in 2005	17.3 million	14.8-20.6 million
Children living with HIV/AIDS in 2005	2.3 million	1.7-3.5 million
People living with HIV/AIDS in 2005	4.1 million	3.4-6.2 million
HIV/AIDS deaths in 2005	2.8 million	2.4-3.3 million

Source: Shisana *et al.* (2005:8)

The number of people living with HIV rose from around 8 million in 1990 to 38.6 million in 2005, and is still growing. Around 63% of people living with HIV are in sub-Saharan Africa (Hall *et al.*, 2005:7).

**Figure 2.1: Number of people living with HIV**



Source: Avert Organisation (2005:6)

**2.2.3 The HIV/AIDS pandemic in South Africa**

The high prevalence of HIV/AIDS in South Africa poses major challenges for both government and civil society groups, who are doing their utmost to curb the spread of the disease and help those affected by it. An estimated six million South Africans are expected to die from Aids-related diseases over the next 10 years. Based on the Department of Health’s national ante-natal survey, involving anonymous testing of pregnant women at state health facilities, an estimated 4.5-million South Africans were living with HIV in the year 2000 (Department of Health, 2001:12).

Much of the reporting on AIDS in South Africa has centred around the fact that President Thabo Mbeki has in the past questioned the link between HIV and AIDS (Shisana *et al.*, 2005:18). Far less has been said about the tremendous efforts being mounted year after year around the country by local, provincial and national government agencies, as well as myriad non-governmental organisations, to combat AIDS by creating awareness around the disease, promoting behaviour change and providing medical, social and economic

assistance to those affected and/or infected by the epidemic (Avramidis, Bayliss & Burden, 2000:197).

South Africa is currently experiencing one of the most severe HIV epidemics in the world. By the end of 2005, there were five and a half million people living with HIV in South Africa, and almost 1,000 AIDS deaths occurring every day, according to UNAIDS estimates (Sink & Strorh, 2003:364). A survey published in 2004 found that South Africans spent more time at funerals than they did having their hair cut, shopping or having barbecues. It also found that more than twice as many people had been to a funeral in the past month than had been to a wedding (Vahtera, Kivima, Pentti, Linna, Virtanen, Virtanen & Ferrie, 2004:557).

A number of factors have been blamed for the rapid rise in HIV prevalence in South Africa, including ignorance and lack of information on HIV and AIDS epidemic, and debate has raged about whether the Government's response to the epidemic has been sufficient (Boyden, 2003:36).

**Table 2.2: Estimated HIV prevalence among South Africans, by age**

Age (years)	Male prevalence (%)	Female prevalence (%)
2-4	4.9	5.3
5-9	4.2	4.8
10-14	1.6	1.8
15-19	3.2	9.4
20-24	6.0	23.9
25-29	12.1	33.3
30-34	23.3	26.0
35-39	23.3	19.3

40-44	17.5	12.4
45-49	10.3	8.7
50-54	14.2	7.5
55-59	6.4	3.0
60+	4.0	3.7
Total	8.2	13.3

(Source: World Bank, 2002:18)

Among females, HIV prevalence is highest in those between 25 and 29 years old; among males, the peak is in the group aged 30-39 years. According to these results, males aged 15-49 years old are 58% as likely to be infected as are females in the same age group (11.7% in men versus 20.2% in women) (Avert Organisation, 2005:19).

## **2.4 THE EFFECTS OF HIV/AIDS ON PSYCHO-PHYSICAL WELL BEING OF LEARNERS**

HIV/AIDS seriously affects the psychological and the physical well being of human beings. This is due to the effects of its associated opportunistic diseases such as, *inter alia*, 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, depression, and other neurological disorders, tuberculosis, pneumonia, gastro-enteritis, meningitis and cancer (Heyzer, 2003:80).

Herpburn (2002:26) posits that when a person is infected with the human immuno-deficiency virus, the body's immune system weakens and eventually breaks down. The weakening of the immune system leaves the individual a

prey to the hazards of a multitude of opportunistic diseases such as those mentioned above. In the absence of the anti-retroviral counselling that can slow the progression of HIV infection, the infected individual eventually succumbs to the assemblage of opportunistic illnesses (Hausler, Naidoo, Campbell, Karpakis, Pronyk & Matji, 2001:39). This means that the course of HIV and AIDS in a human body:

- starts when HIV enters the system through unprotected sex or contact with infected blood;
- followed by weakening of the body as the virus multiplies, the breaking down of the immune system; and
- finally followed by opportunistic illnesses which make the immune system less able to fight off infections and illnesses with the person eventually dying.

The course of HIV/AIDS in a human body manifests itself in different stages that will be discussed below.

#### **2.4.1 First signs of illness**

The first thing that happens after infection is that many people develop a flu-like illness. This may be severe enough to mimic glandular fever with swollen glands in the neck and armpits, tiredness, fever and night sweats (Gwatkin & Deveshwar-Bahl, 2002:10). Virus is being released, when some of these white cells are dying, and for the first time the body is working hard to produce adequate anti-bodies (Musinguzi, Okware & Opio, 2001:13). At this stage 'sero-conversion' (a process of converting the blood from negative to positive) takes place and the HIV blood test will usually be positive as it picks up the tell-tale anti-bodies. Most people do not realise what is happening at this stage, although when they later develop AIDS they think back and remember it clearly. Most people have produced antibodies in about twelve weeks (Kidanu, Nyblade & Rohini, 2003:52).

## 2.4.2 Latent infection

After this acute stage, everything settles down. The person now has a positive HIV test, and feels completely well. The virus often seems to disappear completely from the blood again (Mendel, 2002:29). However, during this latent phase, HIV can be found in large quantities in lymph nodes, spleen, adenoid glands and tonsils (Pick, 2003:59). San Franciscan studies show that in developed countries, without use of the latest therapies, 50% of people with HIV develop AIDS in ten years and 70% in only fourteen years. Of those with AIDS, 94% die in five years time (Amrhein, 2004:18). The rate of progression can be much faster in those with weakened immunity systems from other causes such as drug users or those in developing countries who have no access to anti-retroviral therapies. It can be far slower in people who undergo various other types of treatment (Kidane, Banteyena & Nyblade, 2003:16).

The next stage of HIV begins when the immune system starts to break down (Holmes, 2003:62). This is often preceded by subtle mutations in the virus, during which it becomes more aggressive in damaging white cells (Garcia-Moreno & Watts, 2000:7). It is during this stage persistent generalised lymphadenopathy (PGL) takes place, that is, several glands in the neck and armpits may swell and remain swollen for more than three months without any explanation (Friedman, 2004:8).

Sonnenberg (2004:662) says that, as the disease progresses, the person develops other conditions related to AIDS. A simple boil or wart may spread all over the body. The mouth may become infected by thrush (thick white coating), or may develop some other problem (Desmond, Barnett & Whiteside, 2000:30). Dentists are often the first to be in a position to make the diagnosis. People may develop severe shingles (painful blisters in a band of red skin), or herpes (Dixon, McDonald & Roberts, 2002:21). They may feel overwhelmingly tired all the time, have high temperatures, drenching night sweats, lose more than 10% of their body weight, and have diarrhoea lasting more than a month. No other cause is found at this stage and a blood test will usually be HIV positive. This stage is called AIDS related complex (ARC) (WHO, 2002:4).

### **2.4.3 Late HIV illness (AIDS)**

The final stage of HIV is AIDS. Usually the entire immune system of a person is intact and the body can deal with most infections, but one or two more unusual infections become almost impossible for the body to get rid of without medical help and usually intensive anti-biotics have to be prescribed (Barnett & Whiteside, 2000:24).

These infections can be a nightmare for physicians and HIV/AIDS infected people. It results in a desperate struggle to find the new germ, identify it, and administer the fitting drug in huge doses to kill it (Barnett, Whiteside & Desmond, 2000:56). Barraclough, Chapman and Richens (2001:37) and Beck, Miners and Tolley (2001:39), say that the germ may be hiding deep in a lung requiring a tube (bronchoscope) to be inserted into the windpipe into the lung to get a sample which requires the person to be sedated. The germs may also be hiding into the fluid covering the brain and spinal cord, requiring a needle to be inserted the spine (lumbar puncture), or it may be concealing itself in the brain, or it may lurk in the liver or gall-bladder or bowel of the person.

### **2.4.4 Chest infections**

The most common infection incurred by HIV/AIDS is a chest infection which causes high temperatures, short breath and flushes because of a rare germ found in the lungs of HIV/AIDS infected people called pneumocystis carinii which does not respond to anti-biotics (Carr, Lamptey & Wigley, 2002:3). Eighty-five out of a hundred people infected with HIV/AIDS having these chest infections, are infected with pneumocystis carinii, but others are infected by several maladies simultaneously (Coombe & Kelly, 2001:435). Globally, the commonest HIV-related chest infection is tuberculosis (TB) (Gregson, Waddell & Chandiwana, 2001:467). HIV damage to CD4 white cells allows re-activation, rapid deterioration and death (Hagreaves & Glynn, 2002:489). As HIV spreads globally, the incidence of TB increases, with possibly a million extra cases a year as a result of HIV (Henry, 2002:10). Latent TB infection is common in the general population.

#### **2.4.5 Damage to nervous system**

According to World bank (2002:21), half of the people who have AIDS develop signs of brain impairment or nerve damage during their illness. In one person out of ten it is the first symptom. HIV itself seems to attack, damage and destroy brain cells of the majority of people with AIDS who survive long enough. The virus is probably carried into the brain by macrophages, that is, special white cells of the body, which then produce more viruses there. Brain cells have a texture on their surfaces similar to CD4 white cells, which enables the virus to attach themselves and enter the cells (Aspinwall & Staudinger, 2003:246).

The damage happens gradually and often is not noticed until a significant part of the brain has been destroyed (Carr-Hill *et al.*, 2000:12). A brain scan will always show a shrunken appearance with enlarged cavities. The signs can be threefold, namely:

- difficulties in thought processes;
- difficulties in co-ordinating balance and moving; and
- changes in behaviour.

Sometimes the problems are caused by other infections spreading throughout the body, or by tumours, all brought on by AIDS (UNAIDS, 2004:11).

Brain damage affects children as well. In one study, sixteen out of twenty-one children who suffered from AIDS developed *encephalopathy*, that is, progressive brain destruction (Peterson, 2000:13). Any part of the nervous system can be damaged in adults or children, not only the brain, and AIDS can mimic just about any other disease of nerves (UNAIDS, 2005:9).

#### **2.4.6 Skin rashes and growths**

The majority of people suffering from AIDS develop skin problems which are usually an exaggeration of maladies common to most people, such as acne and rashes of various kinds (Tawfik & Kinoti, 2002:31). Cold sores and genital

herpes may develop, or warts. Athlete's foot in severe forms, ringworm and thrush are common (Blower & Farmer, 2003:26). Rashes due to food allergy are also common which research not has provided reasons for yet (Brugha, 2003:28). Hair frequently falls out. Drug rashes frequently occur, often due to the life-saving *co-trimoxazole* used for treatment or prevention of the *pneumocystis carinii* pneumonia (Beeharry, Schwab & Akhavan, 2002:45).

*Kaposi's sarcoma* develops in up to a quarter of the people who have AIDS (depending on the country and route of infection) (UNAIDS, 2005:21). This produces blue or red hard painless patches on the skin, often on the face. In the majority of these people it is the first sign of AIDS (Benatar, 2002:77). Tumours can spread to lymph nodes, the gut lining and lungs where they can be confused with pneumocystis pneumonia. The growths may be caused by a second virus that is allowed to grow more easily if a person has AIDS (Barnett & Whiteside, 2002:39).

Because it often affects the face or may be visible elsewhere on the body and is so distinctive, people who develop *Kaposi's sarcoma* often feel especially vulnerable. In fact, people usually live longer if they first develop this tumour than if they first develop pneumonia (Bertozzi, Opuni & Bollinger, 2002:66). The other common cancer is a lymphoma, that is, a tumour which develops in the brain or elsewhere in the body (Kelly, 2002: 10).

#### **2.4.7 Problems in the gut, eyes and other organs**

Almost all people suffering from AIDS have stomach problems from strange infections and cancers caused by AIDS and HIV attacking the gut directly. All three cause food to be poorly digested resulting in diarrhoea and weight loss (Johnston & Graham, 2004:13). Stool samples can be examined or samples can be taken from within the gut using endoscopy, that is, special tubing to ascertain whether a second treatable infection in addition to HIV could be found (Berkman, 2001:44). AIDS can also seriously affect sight in up to a quarter of all those living with HIV, by causing an infection of the back of the eye (retinitis). This is usually caused by *cytomegalovirus* and is sometimes

amenable to treatment. In addition, the virus can cause damage to other organs of the body such as the heart as well (Blower & Farmer, 2003:21).

## **2.5 AIDS-RELATED ILLNESSES IN AFRICA**

According to UNAIDS (2002:11), the spectrum of illness seen in AIDS in African nations can vary, particularly in places where HIV-2 is more prevalent. The pattern is very different from that of developed countries:

- *Candida* (thrush) in the mouth 80 -100%
- *Oesophageal candidiasis* 30 - 50%
- *Tuberculosis* 30 - 50%
- *Cerebral toxoplasmosis* 15 - 20%
- *Herpes zoster* (shingles) 10%
- *Cryptosporidiosis* (diarrhoea) 50%

As indicated in the foregoing paragraphs, HIV/AIDS adversely affect the psycho-physical well-being of learners suffering from it, which makes difficult for them adjust.

## **2.6 HIV/AIDS AND RELATED PSYCHOSOCIAL PROBLEMS**

The statistics about the impact of HIV/AIDS world-wide are overwhelming. Estimates of the United Nations Agency for AIDS (UNAIDS) indicates that nearly 25 million people have died of AIDS since the disease was first discovered in the early 1980's. In Africa, HIV/AIDS has – since it was first discovered – been a predominantly heterosexually transmitted disease, which affects men, women and children, although in varying proportions (Holmes, 2003:53). Because the pandemic poses such enormous challenges, governments and health planners have been hard pressed to find adequate ways of containing its spread and over the last two decades a multiplicity of different approaches have developed, some which have since been discarded (Busza, 2001:456). In Africa, as in other continents, HIV/AIDS was initially

seen mainly as health concern, and it was widely assumed that preventive and supportive interventions which directly targeted vulnerable segments of the population (truck drivers, sex workers, as well as drug users) would succeed in containing the pandemic. However, as the dimension of the problem started to become increasingly evident, the woeful inadequacy of this approach became apparent and the disease quickly spread over to other segments of the population (World Bank, 2002:49).

At a human level, the financial burden of HIV/AIDS is at least 30% greater than deaths from other causes, because it affects the most productive age group (children and adolescents), and because the costs of medication and caring for the sick are staggering and can be prolonged (Coombe, 2003:29). HIV/AIDS leads to financial, resource and income impoverishment (Barnett & Whiteside, 2002:71), and puts severe strain on individuals and households. The psychological stress that is a direct consequence of the impact of HIV/AIDS on individuals and families can compromise school and work performance, family relationships, and the capacity to take care of children, and may also culminate in risk behaviour such as alcohol and drug abuse and in unsafe sexual behaviour (Coombe, 2003:60).

HIV/AIDS represents not only a tragedy at a human level but also heavily affects the economic development of the countries, many of which are already severely strained for resources. The weight on the health system is tremendous and the loss of productive workforce has implications for the economy (Kaplan, 2000:85). Cross country analyses conducted by the World Bank suggest that the region of Southern Africa is losing an estimated 0.7 to 1.0 percent per capita growth per year as a direct result of HIV and AIDS and that by the year 2010 it may have reduced the aggregate output by between 15 to 20 percent (World Bank, 2002:189). By some estimates between 50 and 80 percent of hospital beds in Southern Africa are occupied by people with HIV related infections (UNAIDS, 2002:205).

UNAIDS (2004:366) warns that unless drastic action is taken, the damage that has already taken place is likely to be very minor compared to what is still to come. In fact, as Kelly (2002:73) notes, all predictions to date have proven to

be conservative at best with dire projections about the progression of the pandemic needing to be revised every year because they are inevitably short of the mark.

The foregoing paragraphs necessitate that focus should now shift from approaches targeted very specifically to segments of the population from a health perspective to multi-sectoral plans and strategies, which seek to involve a wide variety of government and non-governmental agencies (Coombe, 2003:63). The rationale for a multi-sectoral approach arises from the recognition that HIV/AIDS requires an integrated response to break the cycle of poverty and gender inequality that is at the centre of its spread (UNAIDS/WHO, 2004:17). The education sector figures prominently within this newly emerging multi-sectoral approach (Coombe, 2003:27).

It has become generally recognized that acute and chronic medical conditions in people have the potential to bring about a range of psychosocial challenges (Van Aard, 2002:34). Of these conditions, HIV/AIDS presents perhaps the most complex psychosocial issues of any medical condition. The overlapping of social, individual, family, financial, cultural, and illness factors poses a challenge to both the infected individual and his/her community (Butler, 2005:25).

The effects of chronic illness are not limited to the arena of physical health. Instead, chronic illness tends to impact on many different areas of a child's life, including school, family, social, and psychological adjustment (Cross, 2001:147).

The HIV/AIDS related psychological and social problems are discussed in the next section.

### **2.6.1 Stress**

Stress has such an influence on a person's health and functioning that it can be expressed through both emotional and physical ways (Eaton & Flisher, 2000:124; Schmutte & Ryff, 1997:559). Often the former occurs when a specific situation is perceived as being too difficult to manage, while the latter

occurs as a physiological reaction of your body to a difficult experience. According to Feldt (1997:12), stress is any stimulus that upsets the dynamic balance of a person's body, which stress theorists have defined in terms of stimulus-response-stimulus (Honwana, 2001:47; Kaufman, Cook, Arny, Jones & Pittinsky, 1994:215).

Interactions between people and their environment, or among people, may, at times, be perceived by the individual experiencing the interaction as being stressful or threatening (Layman, 1996:56). There is constant adaptation to accommodate the stress arising from interaction processes, and many stress theorists argue that stress is unavoidable in everyday life (Mitchel & Shoda, 1995:268). Rather, it is often the way people cope with, or handle stressors that provide evidence as to whether they have moderate or excessive stress (Reid, 1999:33). Ryff and Singer (2000:44) argued that it is by responding to the daily challenges of life that people's stress load is assessed. Stress can be determined through:

- primary appraisal, which is a cognitive evaluation of the threats associated with a difficult event, or
- secondary appraisal, which is the assessment of resources to cope with the perceived threat (Spreitzer, 1995:42).

Coping resources vary from one individual to another and from one situation to another. Coping resources can be either internal (e.g., emotional) or external (e.g., financial) (Achat, Kawachi, Spiro, Demolles & Sparrow, 2000:130). The results of a study by Benell, Hyde and Swainson (2000:37) indicated that HIV-positive persons with lower incomes perceived greater stress in their daily lives than those with higher income, illustrating the importance of external coping resources. Reflecting the centrality of internal coping resources, the study also found that perceived stress was greater among those who reported more anxious or less secure attachment styles as well as those who reported greater use of behavioural or emotional disengagement strategies for coping with HIV/AIDS.

At a macro level, the socio-political environment can influence social policies that could either enhance coping resources or exacerbate stress (Aspinwall & Staudinger, 2003:289). In support of the argument for the influence of macro factors on stress, Basic (2000:68) argued that what people can positively achieve is "influenced by economic opportunities, political liberties, social powers, and the enabling conditions of good health, basic education, and the encouragement and cultivation of initiatives". According to Beck and Weishaar (2000:272), the institutional arrangements giving rise to these opportunities are also influenced by the exercise of people's freedoms, by their liberty to participate "in social choice, and in the making of public decisions that impel the progress of these opportunities" (Baingana & Bannon, 2004:107).

Bunn, Bosompra, Ashikaga, Flynn and Worden (2002:577) list stressors such as daily hassles, stressful life events, chronic stressors, traumatic events, chronic community stressors, and non-events which, apply to persons with HIV/AIDS, but it is chronic stressors that are of particular interest to this study since they represent persistent events that cause substantial strain on the individual (McMillien & Fisher, 1998:187). While acute stress may involve an encounter with a situation that poses immediate threat to an individual's well being (e.g., waiting for HIV test results), chronic stress involves on-going stressful situations (e.g., the loneliness that is common among people living with HIV/AIDS (PLHAs). Coping with a chronic stressor requires major readjustments and replenishments of a person's psychosocial resources so as to facilitate adjustment to a sustained change in your behaviour and lifestyle (O'Connor & Shimizu, 2002:184). In fact, the experience of being diagnosed with HIV infection alone is stressful (Jang, Poon & Martin, 2004:125). While the HIV diagnosis can be both a stressful life event and a traumatic event, the life-long experience of living with an HIV diagnosis is a chronic stressor (Sheldon & King, 2001:16). This is the kind of stress that is ongoing, long term, and persistent over a long period (James, 2001:15). Moreover, the members of the households and the communities of PLHAs often experience chronic stressors as well (Maruta, Colligan, Malinchoc & Offord, 2000:140).

A study investigating stigma among PLHAs in Ethiopia, Tanzania, and Zambia was recently conducted by Buve and colleagues (2002:11). The study found that stigma-related and discrimination-related stress impeded prevention of HIV/AIDS (Buve, Bishikwabo-Anzarhaza & Mutangadura, 2002:112). In fact, it is the stress associated with acts of prejudice and discrimination that gives AIDS activists and human rights activists cause for concern (Kendler, Thornton & Prescott, 2001:587). Past stress studies have shown that it requires adaptation (Lightsey, 1997:699). Stress theory has, therefore, incorporated such moderating and buffering factors as coping resources, coping strategies, and social support (Mitchel & Shoda, 1998:229), all of which may apply to the situation of the PLHAs in Tanzania as they have shown to apply to the PLHAs elsewhere in the world (Park, Moore, Turner & Adler, 1997:84).

Whether coping with stress will, indeed, positively or negatively influence PLHAs' appraisal of stress will depend, as it does in most cases, on the factors at play in each specific situation for each person at any given time and place (Salovey, Rothman, Detweiler & Steward, 2000:11). Receiving results of a test for the antibodies for human immunodeficiency virus (HIV) can be regarded as a stressful life event for those at risk (Schneider, 2001:50). Individuals experience a lot of stress both before making the decision to test and after testing while waiting for their test results (Sheldon & Kasser, 2001:30). Research on coping behaviour as well as associations of coping with psychological distress in 172 bereaved HIV sero-positive and sero-negative gay or bisexual men concluded that a HIV sero-positive status was significantly associated with increases in distressed mood (Lyubomirsky & Lepper, 2001:239).

When above is considered, losing a loved one due to HIV/AIDS brings the stress that the bereaved has been experiencing all along to its peak. Research on distress has also shown that stress can increase physical symptoms (Masten & Coatsworth, 1998:205). Such symptoms include psychosomatic disorders which, in HIV/AIDS, can include severe pains in the joints and muscle-aches (Pretzer & Walsh, 2001:321). A study of pessimism and emotional repression in the progression of HIV-related gynecological

conditions in HIV-1 seropositive black women concluded that a greater number of negative life events was associated with higher levels of progression, persistence, or repeated outbreaks in some of the conditions that were measured (Ryan & Frederick, 1997:529).

According to these findings, interventions should focus heavily on exploring the mechanisms of coping with stressors, both those related and unrelated to HIV (Sinclair & Tertric, 2000:25). The negative impact of stress on people living with HIV has drawn the attention of many researchers (Boyden, 2003:32). Some studies have shown that it is not unusual for long-term debilitation to result in stress (Coatsworth & Duncan, 2003:28). Although some studies on the effects of stress, depressive symptoms, and social support on the progression of HIV infection have found faster progression from HIV to AIDS to be associated with more cumulative stressful life events, more cumulative depressive symptoms, and less cumulative social support (England & Artinian, 1996:174), these studies did not support the view that an increase in stress and a decrease in social support significantly predicted the PLHA progression from HIV to AIDS (Lewis & Arndt, 2000:56).

To indicate whether, stress is indeed not a co-factor in contributing to the early deaths of African PLHAs, similar studies are needed on African PLHA populations. As to whether stress affects any other areas of the socio-biomedical functioning of PLHAs in a significant way (Meyer, 2003:64), future studies on African PLHAs are needed to establish whether there are levels of vulnerability in the African population of PLHAs for whom limited access to modern biomedical interventions may be yet another source of stress. A study by the Canadian Vanguard Project showed that HIV-infected men who have sex with men (MSM) are at a high risk for secondary infection if they had experienced sexual abuse in their childhood (Anchard, 2000:18).

Above findings support the view that HIV-infected MSMs are prone not only to primary HIV infection (i.e. being infected for the first time or infecting other people), but also to secondary HIV infection (i.e. causing re-infection to self and others), if they were sexually abused or raped as children (Department of Education, 2001:29). These findings suggest that the effects of any type of

stress that has not been previously addressed will emerge as a later barrier to primary and/or secondary HIV prevention in all PLHAs, whether gay or not, and whether they live in Africa or anywhere else in the world (Piot & Seck, 2001:12).

Stress can also act as a barrier to treatment adherence. A French prospective, controlled randomized trial involving a group that received a counseling intervention found that the counseling intervention resulted in lowering stress and increasing the ability of PLHAs to develop self-care management skills that improved their adherence to treatment (Bell, Shantayanan & Hans, 2003:94). Research sponsored by the US Centers for Disease Control and Prevention, conducted in one of three inner-city New York City hospitals, found that HIV-infected pregnant mothers who were experiencing stress were unable to follow the prescribed dosing schedule and were embarrassed or otherwise reluctant to admit this during follow up interviews for their neonate infants (Booyesen, 2003:57). A study of healthy men infected with HIV for more than 10 years found that accepting the diagnosis, but refusing to see it as a death sentence, and being able to communicate openly on subjects, including HIV, were important factors in living for a long period with the virus (Corbett, 2002:359), and these increase with social support. PLHAs need support in balancing the goals of living productive lives for a long period with preventing further HIV transmission (Debswana, 2004:6).

### **2.6.2 Depression**

Depression results from abnormal functioning of the brain. The causes of depression are currently a matter of intense research. An interaction between genetic predisposition and life history appear to determine a person's level of risk (Fontana & Rosenheck, 1998:485). Episodes of depression may then be triggered by stress, difficult life events, side effects of medications, or the effects of HIV on the brain. Whatever its origins, depression can limit the energy needed to keep focused on staying healthy, and research shows that it may accelerate HIV's progression to AIDS (Kenyon, Skordis & Boulle, 2003:56).

Symptoms of depression are being persistently sad, anxious, or "empty" mood; feelings of hopelessness, pessimism; feelings of guilt, worthlessness, helplessness; loss of interest or pleasure in hobbies and activities that were once enjoyed, including sex; decreased energy, fatigue, being "slowed down"; difficulty concentrating/ remembering, making decisions; insomnia, early-morning awakening, or oversleeping; appetite and/or weight changes; thoughts of death or suicide or suicide attempts as well as restlessness and irritability (Pretorius, 1997:29).

Although as many as one in three persons with HIV may suffer from depression, the warning signs of depression are often misinterpreted. People with HIV, their families and friends, and even their physicians may assume that depressive symptoms are an inevitable reaction to being diagnosed with HIV (Saragovi, Koestner, Di Dio & Aube, 1997:93). Depression is another type of illness that can and should be treated, even when a person is undergoing treatment for HIV or AIDS. Some of the symptoms of depression could be related to HIV, specific HIV-related disorders, or medication side effects (Watson & Tharp, 2002:17).

### **2.6.3 Stigma**

HIV-related stigma refers to all unfavourable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as toward their significant others and loved ones, close associates, social groups, and communities. Patterns of prejudice, which include devaluing, discounting, discrediting, and discriminating against these groups of people, play into and strengthen existing social inequalities-especially those of gender, sexuality, and race-that are at the root of HIV-related stigma (Coombe & Kelly, 2001:45).

Hailom, Kidanu & Nyblade (2003:13) is widely credited for conceptualizing and creating a framework for the study of stigma. His work was seminal in creating an environment for ongoing academic research on the topic. In his landmark book *Stigma: Notes on the Management of Spoiled Identity*, Lovelof (2001:3) described stigma as "an attribute that is deeply discrediting within a particular social interaction". His explanation of stigma focuses on the public's

attitude toward a person who possesses an attribute that falls short of societal expectations. The person with the attribute is reduced in our minds from a whole and usual person, to a tainted, discounted one. Benell *et al.* (2002:14) further explained that stigma falls into three categories:

- Abominations of the body-various physical deformities.
- Blemishes of individual character-weak will, domineering or unnatural passions, treacherous and rigid beliefs, or dishonesty. Blemishes of character are inferred from, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, or radical political behaviour.
- Tribal stigma of race, nation, and religion-beliefs that are transmitted through lineages and could equally contaminate all members of a family.

The stigma concept has been applied to myriad circumstances (Hay, 2002:28). Hay's ideas form a common thread in much of the published research and provide the theoretical underpinnings for much of the literature on stigma and stereotyping.

According to Hay (2002:27 and other researchers, diseases associated with the highest degree of stigma share common attributes such as that:

- the person with the disease is seen as responsible for having the illness;
- the disease is progressive and incurable;
- the disease is not well understood among the public; and
- the symptoms cannot be concealed.

HIV infection fits the profile of a condition that carries a high level of stigmatization (Kadzamira, Swainson, Maluwa-Banda & Kamlongera, 2001:18) because:

- firstly, people infected with HIV are often blamed for their condition and many people believe HIV could be avoided if individuals made better moral decisions;
- secondly, although HIV is treatable, it is nevertheless a progressive, incurable disease (Mlamleli, Mabelane, Napo, Sibiyi & Free, 2000:261).
- thirdly, HIV transmission is poorly understood by some people in the general population, causing them to feel threatened by the mere presence of the disease; and
- finally, although asymptomatic HIV infection can often be concealed, the symptoms of HIV-related illness cannot. HIV-related symptoms may be considered repulsive, ugly, and disruptive to social interaction (Mohlala, 2002:29).

The discrimination and devaluation of identity associated with HIV-related stigma do not occur naturally. Rather, they are created by individuals and communities who, for the most part, generate the stigma as a response to their own fears. HIV-related stigma manifests itself in various ways. HIV-positive individuals, their loved ones, and even their caregivers are often subjected to rejection by their social circles and communities at times when they need support the most. They may be forced out of their homes, lose their jobs, or be subjected to violent assault. For these reasons, HIV-related stigma must be recognized and addressed as a life-altering phenomenon (Kelly, 2002:6).

## **2.7 GENDER INEQUALITY AND SEXUAL ABUSE**

Although HIV prevention campaigns usually encourage people to use condoms and reduce their number of sexual partners, women and girls in South Africa are often unable to negotiate safer sex and are frequently involved with men who have a number of sexual partners (Jewkes, Caeresar, Maforah & Jordan, 2001:733). They are also particularly vulnerable to sexual abuse and rape, and are economically and socially subordinate to men. Police reports suggest that in 2004-2005 there were 55,114 cases of rape in South

Africa although the actual figure is undoubtedly larger than this since the majority of cases go unreported (Kilbourne, Herrdon, Andersen, Wenzel & Gelberg, 2002:9). In a 2006 study of 1,370 South African men, nearly one fifth of revealed that they had raped a woman. Rape plays a significant role in the high prevalence of HIV among women in South Africa (Marmot, Feeney, Shipley, North & Syme, 1995:124).

Post-exposure prophylaxis (PEP, a treatment that has been shown to significantly reduce the chances of HIV infection when taken within 72 hours of sexual contact) has been made available to victims of rape in South Africa since December 2002. However, a recent study suggests that access to PEP is not uniform throughout the country, and some rape victims report that the treatment was not made available to them (McMillen, Zuravin & Rideout, 1995:43).

Women are likely to face more severe discrimination than men if they are known to be HIV positive. This can lead to physical abuse and the loss of economic stability if their partners leave them. Since antenatal testing gives them a greater chance of being identified as HIV positive, women are sometimes branded as 'spreaders' of infection (Pawinski & Laloo, 2001:91).

The Government has acknowledged that many women face "triple oppression" in South African society - oppression on the grounds of race, class and gender – and has been making efforts to address this problem, through education and skills development schemes (Hepburn, 2002:17). The social restrictions faced by women mean that they are often powerless to enforce behaviour change when it comes to sexual relationships, even when they are aware of the risks involved in unprotected sex (Joseph, 2002:14).

## **2.8 IMPACT OF HIV/AIDS ON CHILDREN**

This section will provide the impact of HIV/AIDS on children. Physical, emotional, developmental impacts will be discussed. HIV/AIDS also impacts on learners' health and wellbeing, health services for children and on education.

### **2.8.1 Physical impact**

UNAID's State of the World's Children 2000 highlights the reversal in child and infant mortality rate in sub-Saharan Africa (UNAIDS, 2004:7). The statistics for South Africa show the child mortality rate (CMR) down from 130 per 1000 in 1960 to 81 per 1000 in 1990. According to WHO, by 2002, this figure had gone back up to 83 per 1000. This figure is disputed as not including the latest national health data, putting the CMR at 59 (WHO, 2002:18). If the latter is accurate, the most recent projects are even more shocking, they show the CMR will rise to 100 in the next couple of years, and remain around there until 2009. There is considerable provincial variation, with the Eastern Cape, KwaZulu Natal, Free State and Mpumalanga all having a CMR over the national average (USAID, 2002:19).

Currently there are an estimated 300 000 AIDS orphans in South Africa as a result of HIV/AIDS epidemic. By 2015 there will be almost 2 million AIDS orphans, an increase of over 60 per cent. This is clearly a catastrophe of considerable magnitude as these children could also be infected. These children, growing up without parental guidance, will for the most be unloved, uncared for, unsocialised and uneducated. Extended families absorbing these children are finding themselves with fewer resources, both psychological and financial, for existing family members (Avert Organisation, 2005:15).

HIV/AIDS causes damage to well being and smooth functioning of the societies affected, with the rise in prevalence rates at antenatal clinics exceeding 40 per cent, as in areas of KwaZulu Natal, and with a nation-wide adult prevalence rate in excess of the critical threshold of 20 per cent, South Africa is one of the countries most severely affected by this new challenge (Lovelif, 2001:6). The overall problem posed by AIDS has now been recognised, in most countries including South Africa, the specific impact of HIV/AIDS on children with the exception of the orphans and the infected poorly documented, analysed and understood, most of the recent debate on the impact of the HIV/AIDS has focused on adult prevalence and deaths rates, ways to control the spread of the disease over the short term and its economic impact (Pretorius, 2002:2). This approach have diverted people's attention

from the recent changes in infant mortality, enrolment rates and child malnutrition, from the new ways through which HIV/AIDS affects child well being, and from mitigating effects of old and new policy responses that need to be introduced under these circumstances (Somers & Piliawsky, 2004:17).

Core indicators such as infant and child mortality rates, immunisation and nutritional status of children have worsened. The latest data, and the projections based thereon, show a direct correlation between HIV/AIDS and both child and adult mortality indicators (Department of Health, 2001:13). The impact is highly visible and measurable at community and household level in both urban and rural areas, although it does not yet form part of the national picture of the epidemic (Stockdale, 2003:6). The national statistics on the cause of childhood deaths cite diarrhoea as the cause of 25 per cent of fewer than five deaths and acute respiratory infection as the cause of ten per cent of such deaths. While these are commonly AIDS-defining diseases, the deaths cannot be isolated as AIDS related. The official categorisation of deaths such that preventable but fatal childhood illnesses are recorded as natural causes also obstructs analysis (Beldini, 2000:84).

The rise in the CMR is directly due to HIV/AIDS that is through mother to child transmission (MTCT), and illustrates the vicious circle of the link between AIDS and poverty. A woman living in poverty is more vulnerable to HIV infection, less likely to be able to negotiate safe sex and does not have access to mother-to-child transmission prevention (MTCTP) treatment if she becomes pregnant (Diener, 2000:34). She will also not access to anti-retroviral drugs and other treatment and will therefore get sick and die sooner than a woman who can afford treatment. The HIV positive child and his/her siblings in the impoverished family will then be orphaned and plunge into deeper poverty. The HIV positive child is then likely to die without treatment (Farmer, Leandre & Mukherjee, 2001:4).

### **2.8.2 Emotional and psychological impact**

The HIV/AIDS epidemic is contributing to psychological problems, especially among young children. The emotional well being of the children is threatened.

This is evidenced by the increase in number of children coming onto the streets not only in the major cities but also in small towns (Hunter, 2002:99). In HIV/AIDS affected families relevant factors include bereavement and psychological depression in surviving parent or caregiver, which tends to incapacitate them in child rearing and impair their abilities to work, obtain food, and provide adequate meals for their children (Peterson, 2000:44). There are severe psychological health impacts for children of bereavement due to AIDS and indirect impacts from being cared for by someone who is exhausted, distressed and desperately poor. The effect of the bereavement on the children and on the way that AIDS related illness and death is being explained (or not) to children can be devastating (Wenstein & Sandman, 2002:34).

### **2.8.3 Developmental impact**

Prior to the emergence of HIV, large numbers of children and families already lived in poverty. The epidemic is worsening and deepening the poverty experienced by the poorest children and families (Layman, 1996:30). HIV/AIDS is contributing to increased vulnerability to poverty. The media has cited many examples of children taking physical care of their ill HIV/AIDS parents and relatives. Increasing numbers of children are leaving school due to AIDS related poverty, despite free education since 1994 (Whiteside & Sunter, 2000:11). Although caregivers can insist on the right to free education, pressure from principals of impoverished schools to pay school fees (48 per cent of schools still do not have electricity), on equally impoverished parents is considerable. Currently 1.6 million learners are cut off school. Without treatment intervention to improve and prolong life of HIV positive mothers, the number of maternal AIDS orphans is expected to rise from some 300 000 currently to around 3 million by 2011 (Barton, 2000:399). Taking into account the number of orphans, the increased care/dependency ratio due to these deaths, the level of impoverishment due to loss of breadwinners and the burden of care for those dying, the impact on education - recognised as providing the best chance of escape from poverty, is probably incalculable (Dean & Moalusi, 2002:3). All over sub-Saharan Africa, hard won gains in

school enrolment and the returns on investments countries have made to improve education are being crowded (WHO, 2002:11).

#### **2.8.4 Impact on learners' health and well being**

Children who are HIV/AIDS orphans are more likely than their peers to be malnourished, sick, abused and sexually exploited. They are at greater risk of dying from preventable diseases and are less likely than other children to be fully immunised (Bennell *et al.*, 2002:15). This has implications for all children. As immunisation coverage decreases, the herd immunity declines and all children become more susceptible to common childhood illnesses, which in the case of HIV infected children, can be fatal (Dorrington, Bourne, Bradshaw, Laubscher & Timaeus, 2001:28).

With limited resources and inadequate adult supervision, HIV/AIDS infected learners are more likely than to drop out of school, leaving them with fewer opportunities for growth and development. They are also denied the benefit of the monitoring and support of teachers and peers and nutritional support offered through the primary school nutrition programme, which targets poor children at schools (Heyzer, 2003:5).

#### **2.8.5 The impact of HIV on health services for children**

Studies of paediatric admissions in hospitals have shown a marked increase in HIV related admissions (Mann, 2001:26). HIV positive children spend an estimated 3.4 times longer in hospital and require multiple admissions. In 1997 and 1998, 20 per cent of paediatric admissions at Chris Hani Baragwanath Hospital were HIV related (Ryan & Deci, 2000:68).

Increases in paediatric admissions in general over the past few years are significant and entirely attributable to HIV/AIDS (Velas, 2001:28). In areas of the country with very high rates of infection, up to 75 per cent of beds in children's wards are occupied by children with AIDS related conditions (Anderson & Schatlander, 2002:73). As a result of the increased burden on health services, children suffering from conditions other than HIV will have to wait longer for access to a bed and it can be expected that there will be an

increase in mortality among HIV negative patients due to delayed treatment. As the epidemic progresses and more HIV positive people develop AIDS, the impact on the health sector will grow exponentially (Brown, 2003:49).

The most obvious costs in caring for HIV positive children are those incurred by the health care facility itself, but additional costs such as the cost to the parents for transport to and from hospital, reduced house income and the cost of outpatient visits need to be considered when calculating the overall impact of HIV on the child (learner) and service delivery on basis of current interventions offered to HIV positive children at health care facilities, acute health care costs are expected to double in the public sector by 2010. The estimated cost per year of treating an HIV positive child with the interventions currently available at public sector health care facilities is R17 000 (stage 4 of disease), R6 200 (stage3) and R1 300 (stage 1 and 2) (Cohen, 2000:21).

Government will be pressurised into increasing its expenditure on health services and the specific share of the budget allocated to the care of HIV infected children. At the same time, rationing of services will have to occur as projected expenditure requirement, which are not sustainable. HIV positive children are reported to being denied access to intensive care units in some provinces (Schneider, 2001:50). Many HIV positive children are denied access to medication on the assumption that the medication will do little to extend their life. In further attempt to deal with the epidemic, patients are being referred away from health facilities to more community-based programmes such as home-based care (Rugalema & Akoulouze, 2003:13). Home-based models of care have been found to be very effective in reducing rate of hospitalisation and length of stay in hospital, reducing the costs of HIV/AIDS on primary health care services, reducing the costs and providing support for the family and increasing compliances to treatment regimes (Johnson & Graham, 2004:17). It is not surprising then that this is being promoted by policy makers, but the existing health system lacks the infrastructure and resources to provide the necessary training and support to home-based care (Whiteside & Sunter, 2000:65).

Health care workers face difficult decision as hospitals move towards providing palliative care for children with AIDS. All of these factors are likely to have an impact on the psychological well-being of service providers and increase rates of burnout and incidence of job-related stress (Jacoby, 2003:26). The growing demand on health care service is exacerbated by an escalating TB epidemic, developing in the shadow of HIV. Currently, about half of all TB cases are thought to be attributable to HIV (Barnett, 2002:20). As HIV weakens the immune system, it makes people more vulnerable to opportunistic infections and to developing active TB. With greater number of HIV positive people developing TB, HIV positive and HIV negative children will be exposed to a greater number of potential sources of TB infection (Fassin & Schneider, 2003:96). The World Bank estimates that 25 per cent of the TB related health in HIV negative people in the coming years will be a direct result of the HIV/AIDS epidemic (UNAIDS, 2005:19). In the Western Cape, the number of TB cases continues to increase, mainly due to HIV/AIDS and each new case of TB represents a further drain on the health system (Williams, 2000:74).

The impact of HIV/AIDS on the health sector will also be felt through HIV related illness and death of health care workers while increasing the demand on the health care system, HIV simultaneously reduce the system's capacity to cope with the epidemic by killing health care workers, the majority of whom are women (Anderson & Scharlander, 2002:73). Rising rates of HIV infection among health care workers will lead to increased absenteeism, reduced productivity and greater spending on treatment, death benefits, staff recruitment and training of new personnel (Ellis, 2000:170). The burden of the HIV/AIDS epidemic will divert resources from other essential health care service and make it difficult to implement and maintain other key primary health care programmes (Keeton, 2002:24).

## **2.9 CONCLUSION**

In this chapter terms used in this research were defined, recent statistics on HIV/AIDS globally, and in South Africa was explored. It was necessary to

discuss the effect of HIV/AIDS on psycho-physical wellbeing of learners, HIV/AIDS related psycho-social problems that infected learners encounter.

The following chapter explores the support of HIV/AIDS infected learners.

## **CHAPTER THREE**

### **SUPPORT FOR HIV INFECTED LEARNERS**

#### **3.1 INTRODUCTION**

This chapter reviews the basic principles of supporting individuals, ways of supporting HIV/AIDS infected learners and the importance of support in groups and individually. The rationale for support of infected learners in schools, types of intervention, the structure of support, the role of counselling in helping children who are HIV/AIDS positive is described. It was also necessary to analyse effectiveness of support, general principles of support, factors affecting support of infected learners social and support theories.

#### **3.2 CONCEPTUALISATION OF SUPPORT**

There are a number of ways to approach a definition of support. Some of these are explored below prior to arriving at a composite definition for purposes of this research:

- It is a relationship. The emphasis here is on the quality of the helping relationship offered to the individual. Characteristics of a good helping relationship are sometimes stated as non-possessive warmth, genuineness and a sensitive understanding of the individual's thoughts and feelings (Achat, Kawachi, Spiro, Demolles & Sparrow, 2000:127).
- It involves a repertoire of skills. This repertoire of skills both incorporates and also goes beyond those of the basic relationship. Another way of looking at these skills is that they are interventions which are selectively deployed depending upon the needs and states of readiness of individuals. These interventions may focus on feeling, thinking and acting. Furthermore, they may include group work and life skills training. Another intervention is that of consultancy. This may deal with some of the problems "upstream", with the systems causing them rather than

“downstream” with individual individuals (Kivama, Vahtera, Elovainio, Lillrank & Kevin, 2002:17).

- It emphasises self-help. Helping is a process with the overriding aim of helping individuals to help themselves. Another way of stating this is that all individuals, to a greater or lesser degree, have problems in taking effective responsibility for their lives. The notion of personal responsibility is at the heart of the processes of effective helping and self help (Shariff & Neil, 2002:28).
- It emphasises choice. Mitchel and Shoda (1998:50) define personal responsibility “as the process of making the choices that maximise the individual’s happiness and fulfilment”. Throughout their lives people are choosers. They can make good choices or poor choices. However, they can never escape the “mandate to choose among possibilities”. Helping aims to help individuals with conduct disorders, depression and anxiety to become better choosers (Baron & Byrne, 1994:64).
- It focuses on problems of living. Helping is primarily focused on the choices required for the developmental tasks, transitions and individual tasks of ordinary people rather than on the needs of the moderately to severely disturbed minority (Farmer, Leandre & Mukherjee, 2001:49). Developmental tasks are tasks which people face at differing stages of their life span, for instance, finding a partner, developing and maintaining an intimate relationship, and adjusting to declining physical strength. The notion of transitions both applies to progression through the life stages, and to acknowledge that changes can be unpredictable and not necessarily in accordance with normative developmental tasks, for instance, being expelled from school, as contrasted with progressing well at school (Reid, 1999:23). The notion of individual tasks represents the existential idea of people having to create their lives through their daily choices. This is despite constraints in themselves, from others and from their environments. Though helping skills may be used with vulnerable groups like depressed and anxious individuals, helpers are mainly found in non-medical settings (James, 2001:99).

- It is a process. The word “process” denotes movement, flow and the interaction of at least two people in which each is being influenced by the behaviour of the others. Both helpers and supportees can be in the process of influencing each other (Abdullah, Young, Bitalo, Coetzee & Myers, 2001:79). Furthermore, though some of this process transpires within sessions, much of it is likely to take place between sessions and even after the contact has ended. What begins as a process involving two people, ideally ends as a self-help process (Garofalo, Cameron, Shari, Palfrey & Robert, 1998:90).

The American Psychology defines support as “Helping individuals towards overcoming obstacles to their developmental personal growth, wherever these may be encountered, and towards the optimal development of their personal resources”(Norem & Chang, 2001:47).

Thompson, Rudolph and Henderson (2004:9) define support as “People become engaged in support when a person, occupying regularly or temporarily the role of supporter, offers or agrees explicitly to offer time, attention and respect to another person or persons temporarily in the role of supportee.”

Cilliers, Viviers and Marais (1998:32) define support as a “Facilitative process in which the supporter, working within the framework of a special helping relationship, uses specific skills to assist young people to help themselves more effectively.”

### **3.2.1 Key terms of support**

Key terms of support within these definitions are ‘counselling’; “a facilitative process”; “special helping relationship”; “specific helping skills”; “assist individuals to help themselves”; “offers or agrees”; “explicitly”; and “focuses on problems of living”. These terms within the definitions of support, provide the nature and range of support practice, namely:

- support is not viewed simply as a means of providing help in the form of information, advice, or support, but as a complex, interpersonal interaction, which in itself promotes growth and change (O'Connor & Shimizu, 2002:74);
- meaningful change and help take place best when working within the framework of a warm accepting and empathic relationship. This serves to encourage those seeking help to express themselves more freely, and fosters their natural tendency to move towards positive growth and change (Siebert & Paul, 2003:80);
- specific helping skills include communication techniques, and specialised skills which are employed to help change feelings, thoughts or behaviour (Aspinwal & Staudinger, 2003:46);
- the most desirable and permanent help is self-help, where the individual accepts responsibility for changing to a more satisfactory way of living, and participates actively in the process (Dykema, Bergbower & Peterson, 1995:57); and
- support can only begin when the supporter has explicitly agreed to offer his or her services, and when the individual with problems has clearly and explicitly accepted that offer (Kendler, Gardner & Prescott, 2003:12).

Support is, therefore, considered as a process of helping individuals to change, not by taking over or providing solutions, but by creating favourable conditions for them to achieve their own insight, and to change from within. In this way they gain confidence in their ability to use their own resources, and are encouraged to assume self-direction and responsibility for their lives (Shariff & Neil, 2002:26).

### **3.2.2 Support in the context of this research**

For the purposes of this research, support is defined as:

“a process which aims to help individuals suffering from HIV/AIDS, who are mainly seen outside medical settings, to help themselves by making better choices and by becoming better choosers. The helper’s repertoire

of skills includes those of forming an understanding relationship, as well as interventions focused on helping individuals change specific aspects of their feeling, thinking and acting.”

From the foregoing definition of support, it would seem that the concept support can be viewed as a source of psychosocial coping assistance – a social fund so to speak from which one can draw upon when faced with stressors. For this study, the theoretical definition of support will be limited to perceived levels of functional social support, defined as a person’s subjective appraisal of availability and adequacy to the specific function that the social ties of an individual provide, and includes such elements as:

- informational support;
- social companionship;
- self-esteem; and
- tangible support (Western, Stimson, Mullins, Memmott, Baum, Johnston & Van Gellecum, 2002:158).

### **3.3 SOCIAL SUPPORT THEORIES**

The roots of the concept of social support are found in such nineteenth century sociologists as Alberti and Emmons (2001a:14), who established a link between diminishing social ties and an increase in suicide (Compton, 2001:84). As a concept, it has evolved over time starting with the terms “social ties,” as used by Kubzansky, Sparrow, Vokonas and Kawachi (2001:15), and “social system,” as described by Pretzer and Walsh (2001:24), to what is now social support, which has different dimensions to it and is expressed in different forms and different ways. It can come in the form of emotional support from family, friends and peers (Sinclair & Tertric, 2000:25), as well as from social interactions in the community (Wubbolding & Brickle, 2000:64), including support from professionals, and even from interaction with the environment (Ang & Hughes, 2001:164). Diene.; Suh, Lucas and Smith (1999:276) argued that social support results in a sense of achievement,

higher self-esteem, and control over people's work and their life, all of which affects their health and well-being. In many ways, both the giver and the receiver of social support benefit from this give-and-take process. According to Groenewald (2005:350), social support is a process of people negotiating meaning together through their interactions within relationships. Social support theorists have debated whether social support should be best understood in terms of:

- networks of personal relations,
- preventive or therapeutic commodities,
- interpersonal coping resources,
- personality characteristics (i.e., perception, appraisal),
- a social provision, or
- an interpersonal communication (Norem & Chang, 2001:47).

However, none of the above-related psychological and social problems alone captures the transactional dynamism that brings coherence to the interconnectedness among all these components of social support (Wigle & Sandoval, 2000:9). Allima-Brissett, Turner and Skovholet (2004:40) contended that whether support is measured in terms of structure or function, there is a distinction among the various types of support, i.e. emotional, informational, social companionship, and instrumental. England and Artinian (1996:74) argued that social support gives individuals the positive context within which experiences of stressful events are processed.

Kossuth (1998:7), on the other hand, made a distinction between social embeddedness, perceived support, and enacted support, defining social embeddedness as a state of connectivity, of being a part of social groups or of being effectively integrated within social networks. Perceived social support is seen as the cognitive appraisal of being reliably connected to others (Sheldon & Kaisser, 2001:30), while enacted support is the actual support received. It is this sense of assurance that Beck and Weishaar (2000:72) referred to as

one's satisfaction with social relationship, which has intrinsic, as well as instrumental, value (Gillespie, Birdthistle, Jones, Bundy, Hoffman, Pigozzi, Draxler, VinceWhiteman, Fouilhoux & Drake, 2003:80).

Symister and Friend (2003:23) have distinguished between perceived and received support, observing that the difference between perceived and received support is that the one is a cognitive type of support, or cognitive appraisal of what support is available to an individual, while the other is behavioural type of support, or actual support received (Bratter, 2000:36). Although it has been shown that healthy individuals who are socially embedded or those who perceive themselves to be socially supported are self assured, loved, accepted, and socially included (Davis, Nolen-Hoekena & Larson, 1998:61), it is also true that it is the actual support received or enacted during the times of crisis that makes a difference in the life of the person caught in the middle of the crisis situation.

According to Scheier, Matthews, Owens, Schultz, Bringes, Magovern and Carver (1999:29), it is the extent to which individuals can reliably count on their network of support to step in to provide the required support that defines perceived social support. The quality of the relationship between the person who gives and the person who receives is also important. It provides the social context within which social support takes place. There is reciprocity in the relationship between the person perceiving that support will be given and the person that is expected to give support (Ang & Hughes, 2001:70). Cohen *et al.* (1997:16) argued that the presence of extensive social ties and interactions did not necessarily translate in support being given.

Garofalo *et al.* (1998:92) contend that the socio-economic class of individuals determines both their network of support and the actual support. James (2001:14) also portends that social status is an important factor in determining the level of social support that people are likely to either perceive or receive. The lower the social class, the less the control the person has over his/her destiny (including the source of support), and the less the ability the person has to influence the events in their life, including the events that affect personal health (James, 2001:22).

Control of destiny involves access to a variety of things, including financial resources, power and prestige, and information (Mitchel & Shoda, 1998:58). A combination of all these things could lead to a feeling of mastery, self-efficacy, locus of control, predictability, desire for control, sense of and ability to control, hardiness, competence and better health (Sheldon & Kaisser, 2001:50). Social support increases overall positive affect and elevates senses of self-esteem, stability, and control over the environment. It is individuals with high feelings of control, who unlike those with low self-esteem, focus on active coping and on problem solving (Western *et al.*, 2002:158).

All of above has direct relevance to HIV/AIDS, especially in underserved populations and in underdeveloped communities where poverty undermines people's sense of mastery and control.

Adaptation to stress, or having a sense of coherence, is dependent on multiple factors in the social world, including, among other things, relationships with other people and also with the environment. These relationships give social support a context within which it is given and received as well as interpreted by both the person providing it and the one receiving (Achat *et al.*, 2000:30).

Compton (2001:84) considered the following three models of social support as important hypotheses:

- the moderator or buffering model,
- the direct or main effects model, and
- the mediating model.

As the above discussion suggests, the link between adherence and the perception that social support will be available as well as actually received is complex and hard to quantify (Kendler *et al.*, 2003:20). The most important thing, however, is that both perceived and received support are important determinants of adherence to any treatment regimen pertaining to any health condition (Thompson & Rudolph, 2004:14).

### **3.4 FACTORS AFFECTING SUPPORT OF INFECTED LEARNERS**

Factors affecting support of infected learners include disclosure, non-disclosure, and confidentiality.

#### **3.4.1 Disclosure and non disclosure**

In terms of the National Policy on HIV/AIDS, learners and educators are not compelled to disclose their HIV status to the school or institution or employer (27/1996). However, voluntary disclosure of a learner, student or educator's HIV/AIDS status to the appropriate authority is welcomed and this policy encourages that an enabling environment should be cultivated in which the confidentiality of such information is ensured and in which unfair discrimination is not tolerated (Beck & Miners, 2001:39).

The policy further states that unauthorized disclosure of HIV/AIDS related information could give rise to a legal liability. This means that any person, to whom any information about the medical condition of learner, student or educator with HIV/AIDS has been divulged, must keep this information confidential (27/1996). For instance the principal cannot inform his School Management Team or the School Governing Body about the status of whether the learner or the learners or the educator and even non-teaching staff.

Disclosure is a major challenge to the Education Department because, in the case of voluntary disclosure, it may be in the interest of that particular individual with HIV/AIDS if a member of the staff of the school or institution directly involved with the care of the learner or student, is informed of his/her status. An educator may disclose his/her HIV and AIDS status to the principal of the school or institution (27/1996).

#### **3.4.2 Confidentiality**

It involves the obviously private information people disclose to counsellors. This type of mutual trust relationship is kept intact by specific obligations that the confidante's contracts to uphold. Confidentiality regarding medical

information implies the principle of respect, and is a requirement dictated by traditional medical ethics (Henry, 2002:18).

Learners, parents and guardians are not obligated to report their HIV status to their school. The decision to disclose a learner's HIV status to school is personal and often based on the age of the minor. If the family chooses to inform school authorities, the child's right of privacy must be assured (27/1996).

Any information obtained regarding the HIV status of an individual connected to the school, shall not be released to third parties, except to those persons who are:

- named on an Authorization for Release of Confidential HIV related information form;
- named in a special HIV court order;
- as indicated in National policy for HIV/AIDS (27/1996) when necessary to provide healthcare to the individual (i.e., to the school physician and the school nurse);
- any employee who breaches the confidentiality of a person who is HIV infected shall be subjected to disciplinary action in accordance with applicable law and/or collective bargaining agreement; and
- to protect the confidentiality of an HIV infected individual, any documents identifying the HIV status of such individuals shall be maintained by the school nurse (or another authorized individual) in a secure file, separate from the individual's regular file. Access to such file shall be granted only to those persons approved named on the Information form of the Department of Health which allows Authorization for Release of Confidential HIV related information or through a special HIV court order. When information is disclosed, a statement prohibiting further re-disclosure, except when in compliance with the law, must accompany the disclosure (Department of Health, 2001:15).

### 3.5 GENERAL PRINCIPLES OF SUPPORT

There is a need to establish some principles which help to distinguish support from other activities in schools. The first is that support is something which the learner must be aware of is occurring and which must in some way be chosen. This does not imply that this requires that support can only be learner-initiated but rather that it should be invitational in nature (Riskind, Sarampote & Mercier, 1996:17). For example, the educator might say, "Would you like to talk about this?" There is an assumption in-built into support that the learner can change - it is an essentially optimistic, but not unrealistic, activity. The learner's needs are paramount in support rather than the needs of the school or the educator, although the learner may need to know the views and perceptions of others (Spreitzer, 1995:42). The support should aim generally to empower the learner and to develop a sense of control and autonomy. The relationship in which the support takes place should be:

- respectful (including an acknowledgement of and respect for the views and experiences of others different from ourselves);
- genuine on the part of the educator ; and
- aimed at demonstrating empathy (Cummings, 2002:4).

In addition, the support should include the full range of support interventions and be practically helpful to the learner. Flisher (2000:16) argues that a valid intervention is one which is "appropriate to the supportee's current state and stage of development and to developing practitioner-supportee interaction". To say that it is appropriate, is to say that it is:

- in the right category ;
- the right sort of intervention within the category;
- content and use of language are fitting;
- delivered in the right manner; and

- delivered with good timing.

Some of the issues being highlighted in this research have to do with a specialist level of work and it is essential to distinguish between the different levels of work in schools. Page (2001:46) distinguishes three levels of work in schools which are:

### **3.5.1 The immediate level**

This level of work is for all educators in the school and involves the use of first level support skills and an awareness of what support is. Support skills should be used to facilitate good communication as well as to acknowledge the emotional dimension of learning and living. Reasonable demands should be made to learners and educators. Educators should be able to work in the emotional domain, adapting to individuals and groups in the light of what is known, and providing reinforcement and support. Educators should also be involved in detecting signs of stress, depression and anxiety in learners and communicating this to others if it is appropriate. Page (2001:47) calls this an exploratory and screening function. This level of work may involve working with educators and other professionals (Davis *et al.*, 1998:561).

### **3.5.2 The intermediate level**

Here, Dinkmeyer and Sperry (2002:48) argue that the school is concerned to provide continuity of care, concern and relationship. It has to do with the co-ordinations of efforts and resources, including those outside of the school setting. It has also to do with the establishment and operation of systems which act as early warnings of learners who may need support and guidance. This means that systems of communication need to be established, monitored and reviewed. Rugalema and Akoulouze (2003:18) comment on aspects of provision at this level. He highlights the importance of good record keeping, "including recording interviews held with learners, by whom, when, for what purpose and with what result". Part of the co-ordination of resources includes knowing what type of training and expertise exist amongst the staff. Boyden and Mann (2000:38) comment that:

Successful practice involves adults who have had special training, qualities or experience (or more often all three) and include trained supporters, chaplains, matrons and nurses as well as some individual pastoral staff. However, support was often *ad hoc*, dealt with problems which had simmered unattended for too long, and was undertaken by educators who lacked training in support skills. Several educators who had received support training were not always in positions where such skills could be put to good use.

### **3.5.3 The specialist level**

This level demands training for the task and this expertise may reside within the school or outside of it. It also involves the identification of learners who may require this level of help. It may involve specialists in the running of groups as well as working with individuals (Sinclair & Tertric, 2000:25).

In the formation of a support policy, the levels of work and the training needs of the educators need to be determined. The provision needs to be evaluated and managed. Part of the ethical requirements of schools is to monitor and evaluate the nature of the provision. Wigle and Sandoval (2000:9) have found that it was clear that this was not a common activity in schools. Only two institutions in his research "had a systematic approach to evaluating the planning, processes and outcomes of the personal, educational and vocational guidance offered to learners". A responsibility should also comprise to ensure that staff is equipped to provide adequate support and guidance and this involves looking at the training and development needs of the staff (Brissette, Scheier & Carver, 2002:81).

Confidentiality is another ethical matter which the school needs to look into. A clear statement is rarely found on this issue and learners often receive very mixed messages on this. The school setting is a complex one to work in, regarding this issue. There also is a desire to protect learner privacy and at the same time legal requirements exist, which prevent the promising of total confidentiality to learners in certain areas of work, for example child abuse (Kossuth, 1998:26). What is important is that both staff and learners are aware of the limits of confidentiality in various settings and types of interview,

as well as being aware of what happens to information shared with educators and other professionals (Saudino, Pedersen, Lichtenstein, McClellan & Plomin, 1997:96).

Staff working in this area also needs professional support and a forum to debate some of the difficult professional and moral decisions which may occur. Barnard (1994:35) has found examples "of networks or groups of educators coming together to plan specific initiatives or to review aspects of a school's work".

Apart from managing the development of policy on ethical and professional support, there are many other management issues. The provision of private apartments for support and guidance work is important (Brenes, Rapp, Rejeski & Miller, 2002:219). Coatsworth and Duncan (2003:56) comment that "effective guidance was promoted where the physical environment was such as to encourage good relationships and a positive ethos, and where special accommodation for a range of guidance activities was readily available and of a good standard". The allocation of time is also important. Dossey (1994:15) notes large variations between institutions when he concludes that, "Institutions may like to consider reviewing the time allocated for guidance, on the basis of a closer identification of need."

Dossey (1994:16) has found that "responsibilities for planning the use of guidance resources were usually too widely dispersed to allow for effective management". The issue of managing, staffing, training and development of staff, and co-ordinating the communication between them, is central to the management task. Scheier *et al.* (1999:829) has identified the following management issues:

- a need to clarify the purposes of support and guidance, acknowledging the different purposes and different levels of work;
- a need to evaluate that provision, including the "learner voice" in that process; and
- a need to draw up and communicate policy in this area.

Wubbolding and Brickle (2000:64) have found that, "Generally speaking the greatest strength of the support lies in its pervasiveness ...There were, however, weaknesses in the provision of support. It was seldom co-ordinated and there were rarely policies relevant to support... finally, more attention needed to be given to analysing the outcomes of support, and relating findings to planning of provision. If schools are present to offer support of good quality they need to develop approaches which, in the light of their circumstances, achieve and maintain a proper balance between meeting the needs of the individual and of society; and between reacting to problems and taking the initiative."

### **3.6 BASIC PRICIPLES OF SUPPORTING INDIVIDUALS**

In a support relationship, the supporter should always respect the individual's right to reach his or her own solutions. Advice may be given for practical problems but this is a small part of what support is about. The most important contributions to effective support comprises; supporting the individual, respect for the individual, listening to the supportee, clarifying the supportee's needs and feelings and focusing on what the supportee has said in order to make it clearer to the supporter, and understanding the supportee's needs (Everson, 1996:113).

#### **3.6.1 Supporting the individual**

Effective helpers and supporters require both good facilitative and relationship skills so intensely as well as good training skills. The majority of HIV/AIDS infected individuals are affected that they require more active help to provide skills to move forward (Bateman, 2001:364). The helping relationship is central to this learning process in many ways, which include:

- strengthening the working alliance;
- helping assessment and individual self-assessment;
- assisting individual self-exploration and experiencing of feelings;

- providing the emotional climate for individuals to take risks and also look more closely at the consequences of their behaviour; and
- allowing individuals to be open about difficulties in implementing life skills.

Individuals are likely to gain most from helpers and supporters who both offer good supportive relationships and also impart skills effectively. The helping relationship supports an active approach to training and learning (Everson, Goldberg, Kaplan, Cohen & Pukkala, 1996:113). Support is utilised by reality supporters to maximise individuals' awareness, anticipation, and expectation of a positive outcome. Individuals with a failure identity require much support, particularly because they initiate their plans into action. They have learned to expect failure and do not relish the idea of risking more of it. Encouragement and support are essential if individuals are to commit themselves seriously to new behavioural patterns since individual commitment is often only as strong as the individual-supporter involvement (Norem & Chang, 2001:67).

Accepting individuals as persons of worth, seeking individuals' opinions and asking for their evaluations of their present behaviour, expresses faith in individuals' abilities to change and providing pause for successfully completing a plan of action are supportive. Encouragement and support not only increase individual motivation, but also serve to communicate feelings of worth to the individual (Wigle & Sandoval, 2000:5).

Feeling more worthwhile, individuals need not exert as much energy controlling perceptual errors in this particular station of their minds (Aspinwall & Staudinger, 2003:246), and the energy they once directed toward controlling for perceptual error may now be focused on living more effectively and responsibly (Farmer *et al.*, 2001:49).

### **3.7 SUPPORTING HIV/AIDS INFECTED INDIVIDUALS WITH DEPRESSION AND ANXIETY**

Support can be distinguished by the goal of the therapy. Some therapies such as long-term analytic support, aim to bring about fundamental change in the way the individual feels about himself or herself and relates to others.

Therapies such as crisis intervention and behavioural therapy aim at symptomatic improvement and the restoration of effective functioning of individuals affected by psychological illness or life crisis. Support aims to maintain adequate functioning in long-standing, intractable personality or psychological disorders (Kiecolt-Glaser, Page, Marucha, MacCallum & Glaser, 1998:218).

Support therapy is a brief, problem-focused therapy. Its principal goal is to achieve symptomatic improvement and enhance an individual's coping strategies. It also aims to help the individual with depression and anxiety *change more fundamentally as well*. Improvements in self-esteem and global functioning may partly explain why studies have found that support therapy reduces the risk of relapse in a number of HIV/AIDS infected individuals with depression and anxiety (Dorkenoo, 2001:23).

The goal of support is to help the HIV/AIDS infected individual with depression and anxiety:

- Firstly, to understand how dysfunctional thoughts (for example, unrealistic, negative and self-critical thoughts) contribute to unpleasant feelings and unhelpful conduct and behaviour; and
- Secondly, to find ways to overcome problems by modifying these thoughts (Kiecolt-Glaser *et al.*, 1998:218).

### **3.7.1 Respect for the individual**

In the process of experimenting with new ways of thinking and behaving, individuals are often unsure of themselves and tend to personalise everything. They need ongoing reassurance, both in the way the supporter speaks and acts, and that the supporter recognises and genuinely respects them for who they are, and for what they think and say, even if the supporter happens to disagree with them (Siebert & Paul, 2003:77).

It is sometimes more important for an individual to feel that his/her opinions and feelings have been taken into serious consideration, than to receive

solutions to problems, however relevant or logical these solutions may be (Allima-Brissett *et al.*, 2004:128). The supporter and helper must bear in mind that a generation gap, in prevalent and a growing dependence on the peer groups for setting standards. The supporter must be prepared to be accused of not understanding or "not being with it", and where this is valid, the supporter must acknowledge the fact and ask for co-operation in helping to bring him or her more up to date. On the other hand, if the supporter does not agree with a specific issue, he/she must clarify the issue, but also give his/her reasons why (Cilliers *et al.*, 1998:38).

### **3.7.2 Listening to the supportee**

Effective listening is the cornerstone of support. It provides the basis for making sense of the supportee's problem and helps him or her feel understood. Listening involves active attention by the supporter. It is not a passive or simple process. Effective listening involves listening to the supportee's words, recognising the feelings behind the words, taking note of body language, and the feelings behind silences. The feelings aroused in the supporter should also be identified (Pretzer & Walsh, 2001:330).

Effective listening requires resisting the temptation to interrupt the counsellee with solutions or advice. Interruptions, criticisms, too many questions, premature advice, and dismissing or belittling the presented problem, all undermine the supportee's discovery of his or her own solutions. Even experienced supporters can fall prey to these pitfalls. The supporter must listen to his or her own feelings to ensure that they do not interrupt the process of listening to the supportee. For example, if the supportee says something that makes the supporter feel uncomfortable he or she should avoid trying to deal with this discomfort by changing the subject or attempting to placate the supportee (Robinson-Whelan, Kim, Maccallum & Kiecolt-Glaser, 1997:45).

### **3.7.3 Clarifying the supportee's needs and feelings**

During the process of ongoing listening, the supporter should ask a few key questions to ensure he or she has understood the supportee correctly and to

draw the supportee out further. This questioning process is called clarifying. The questions may be open-ended (and encourage long answers) or closed (which are answered by "yes" or "no"). Clarifying questions should assist rather than interfere with the listening process. Open-ended questions are preferable as they can help supportees to elaborate on what they are saying. The supporter should never interrupt the supportee to ask questions (Diener, 2000:41).

An example of open-ended questions is: "How does that make you feel?" and of a close question, "Are you angry?"

### **3.7.4 Focusing on what the supportee has said in order to make it clearer to the supporter, and understanding the supportee's needs**

This is done by: reflecting, summarizing and problem-solving.

#### **3.7.4.1 Reflecting**

Reflecting is the process of communicating to the supportee how one, as the supporter, has understood the supportee's feelings and perceptions. Reflecting involves the supporter acting as a mirror. The supporter reflects back to the supportee what he or she has said. Reflections show that the supporter understands the individual's point of view, including both the content and the feelings behind what is being said. Reflecting helps the supportee feel understood and encourages the supportee to continue sharing his or her experience of the problem (Rugalema & Akoulouze, 2003:56).

Reflecting involves more than merely repeating what the supportee has said. It involves releasing those aspects of experience the supportee struggles to verbalise. It requires listening, attending to unexpressed feelings and putting them into words for the supportee. People are often not aware of their feelings. Reflecting can help them understand the feeling aspects of their experience (Baron & Byrne, 1994:66). In reflecting feelings the supporter must try to describe the feelings that he or she perceives as accurately and empathetically as possible. This is a difficult task, as the supporter's reactions may not match those of the supportee. Therefore the supporter must guard

against assuming or guessing the supportee's feelings and should carefully assess what the supportee's words, body language and tone of voice indicate (Everson *et al.*, 1996:67).

The supporter should not rush the supportee or interrupt with questions or premature advice as understanding takes time. In addition, the supporter needs to set aside the reactions or thoughts he or she might have about what should have been done or what might be done in the situation (Reid, 1999: 24).

The supportee's response is the best indicator of whether the supporter is accurate in his or her understanding. To be unsure is a natural part of the support relationship. In such an instance it is wise for the supporter to check his or her understanding and ask the supportee if it feels correct (Diener, 2000:34).

He or she may then elaborate on the experience more fully. In this way a bridge of mutual understanding is established. The essential point of reflecting is for the supporter to base reflections on the evidence he or she sees, hears and feels (Kubzansky *et al.*, 2001:11). An example of reflecting is: "It seems that you are angry!"

#### **3.7.4.2 Summarising**

Summarising draws on the understanding the supporter has developed by listening, clarifying and reflecting. The supporter shares those understandings and perceptions with the supportee. In this way the supportee should sense that someone else has heard things from his or her point of view and may promote a clearer understanding of the problem (Sheldon & Kasser, 2001:35).

Summarising entails linking reported experiences, events, reactions, feelings and ideas in order to define issues facing the supportee. As in reflecting, or summarizing, the supporter will not necessarily be complete or accurate. He or she needs to check that the summary seems right to the supportee and that he/she need to be prepared to change his or her attitude if necessary.

Creating a summary is a joint activity, involving both supporter and supportee (O'Connor & Shimizu, 2002:173).

Although the summary may work well, the supportee may reject or dismiss it because he or she is not ready to accept or listen to it. In this case it is better to work with what the supportee is willing to hear. Timing of the presentation of a summary is vital to successful support (Symester & Friend, 2003:127).

An example of summarising is: "You are angry, and it seems part of the anger is that the situation makes you feel helpless."

#### **3.7.4.3 Problem solving**

There are times in support where what is called for goes beyond listening, clarifying, reflecting and summarising. Sometimes a decision needs to be made or the counsellor needs to make clear plans of action to break free of the problem. Hopefully the supportee will reach the decision or action plan by himself. However, in reality the supportee often looks to the supporter to play a greater role in decision-making and the formulation of action plans (Ang & Hughes, 2001:170).

The supporter must not make decisions for a supportee but should enable the supportee to reach his or her own decisions. To make decisions for the supportee is ultimately disempowering. The supporter may give information but the decision, and its consequences, lies with the supportee (Diener & Diener, 1995:653).

#### **3.7.5 What individual support offers**

The majority of support that takes place in Europe, the United States of America and South Africa today probably occurs within the one-to-one arena of individual support (Kivimäki *et al.*, 2002:817). The particular therapeutic merits of individual support are:

- Individual support, by its nature, provides supportees with a situation of complete confidentiality. It is indicated therefore when it is important for supportees to be able to disclose themselves in privacy without fear that

others may use such information to their detriment. Some supportees are particularly anxious concerning how others, for example in group support, would react to their disclosures, and such anxiety precludes their productive participation in that arena. Similarly, supportees who otherwise would not disclose “confidential” material are best suited to individual support. As in other situations, transfer to group support may be indicated later when such supportees are more able and/or willing to disclose themselves to others (Sinclair & Tertric, 2000:25).

- Individual support, by its dyadic nature, provides an opportunity for a closer relationship to develop between supporter and supportee than may exist when other supportees are present. This factor may be particularly important for some supportees who have not developed close relationships with significant people in their lives and for whom group support, for example, may initially be too threatening (Barnett & Schueller, 2002:16).
- Individual support can be conducted to best match the supportee’s pace of learning. Thus, it is particularly suited for supportees who, due to their present state of mind, or speed of learning, require their supporter’s full individual attention. This is especially important for supportees who are quite confused and who would only be distracted by the complexity of interactions that can take place in other therapeutic arenas (Garofalo *et al.*, 1998:93).
- Individual support is particularly therapeutic when supportees’ major problems involve their relationship with themselves rather than their relationships with other people (Kendler *et al.*, 2003:120).
- Individual support may be particularly helpful for supportees who wish to differentiate themselves from others – for example, those who have decided to leave a relationship and wish to deal with individual problems that this may involve. Here, however, some conjoint sessions with their partner, friend and family may also be helpful, particularly in matters of conciliation (Groenewald, 2000:175).

- Individual support may also be the arena of choice for supportees who want to explore whether or not they should differentiate themselves from others - for example, those who are unhappy in their relationships with significant others but are not sure whether to work to improve the relationship or to leave it. The presence of the other person may unduly inhibit such individuals from exploring the full consequences of their choice (Pretzer & Wlash, 2001:46).
- It could be beneficial for supporters to vary their therapeutic style with supportees in order to minimise the risk of perpetuating the supportee's problems by providing an inappropriate interactive style. Individual support offers supporters an opportunity to vary their interactive style with supportees free from the concern that such variation may adversely affect other supportees present (Spreitzer, 1995:42).
- Individual support is particularly beneficial for supportees who have profound difficulties sharing therapeutic time with other supportees (Wubbolding & Brickle, 2000:65).
- Individual support may also have therapeutic merits, but for negative reasons. Thus, supportees may benefit from being seen in individual support who may not be helped from working in group support. Therefore, supportees who may monopolise a support group, may be too withdrawn within it to benefit from the experience, or who are thought too vulnerable to gain value from family support can often be seen in individual support, with minimal risk (Aspinwall & Staudinger, 2003:47).

Contra-indications for individual support are the following:

- Individual support may be contra-indicated for supportees who are likely to become overly dependent on the supporter, particularly when such dependency becomes so intense as to lead to supportee determination. Such supportees may be more appropriately assisted in group support where such intense dependency is less likely to develop, due to the fact

that the supporter has to relate to several other people (Bracken & Petty, 1998:42).

- Individual support, by its dyadic nature, can involve a close interpersonal encounter between supportee and supporter and as such, may be contraindicated for some supportees who may find such a degree of intimacy or the prospect of such intimacy unduly threatening and where the likelihood of overcoming this is poor (Everson, 1996:115).
- Individual support may be contra-indicated for supportees who find this arena too comfortable. Based on the idea that personal change is often best facilitated in situations where there is an optimal level of arousal, individual support may not provide enough challenge for such supportees. In this context, Kossuth (1998:28) has found that it may be unproductive to offer individual support to supportees who have had much previous individual support but who still require therapeutic help.
- Individual support may not be appropriate for supportees for whom other arenas are deemed to have greater therapeutic value. Supportees who are shy, retiring, and afraid to take risks, for example, are more likely to benefit from group support (if they can be encouraged to join such a group) than from the less risky situation of individual support (Saudino *et al.*, 1997:96).

### **3.8 SUPPORT IN GROUPS**

Group support offers a fundamentally different experience to the supportee from that of individual one-to-one support. In his research, Siebert and Paul (2003:75) have identified the following eleven factors which distinguish the curative factors operating in group support and provide a background to all its forms:

- The instillation of hope is central to all forms of psychological therapy, and to religion and medicine.
- Universality: one of the most significant learnings by members of groups is that they are not alone either in their experience or concerns.

- Imparting of information: although in the beginning, group members often expect that, as in school, they will be taught facts, they come to realise that this is of relatively limited importance.
- Altruism: group memberships often releases within participants previously hidden or forgotten capacities for helping others.
- The corrective recapitulation of the primary family group: groups can help members to work through and in some ways, heal hurts sustained in earlier life.
- Development of socialising techniques: participating in a group provides the opportunity of learning, and practising, different ways of relating to others in a live setting.
- Imitative behaviour: by watching others' behaviour and listening to them, group members can discover their own distinctive personal styles.
- Interpersonal learning: through interacting with others, members are often able to grow and change. Groups provide an opportunity for both emotional and cognitive understanding.
- Group cohesiveness is the result of all the forces acting on the members to remain in a group and is not a curative factor *per se* but a necessary precondition for effective change.
- Catharsis and ventilation of feelings are not in themselves sufficient for change, but both can be a significant part of the process and can therefore also be curative factors.
- Existential factors such as the need to take responsibility oneself, the fact of individual isolation, contingency, the inevitability of mortality, and the capriciousness of existence are all themes, which are often more easily tackled in group settings rather than in individual therapy.

Subsequently, Siebert and Paul (2003:76) have established what members of groups themselves saw as the most helpful factors. In order of importance, they are:

- discovering and accepting previously unknown or unacceptable parts of the self;
- being able to say what was bothering you as a person instead of holding it all in;
- other members honestly telling what they think of others;
- learning how to express personal feelings;
- the group's teaching a person about the type of impression they make on others;
- expressing negative and/or positive feelings towards another member;
- learning that individuals must take ultimate responsibility for the way they live their life no matter how much guidance and support they got from others;
- learning how individuals come across to others;
- seeing that others could reveal embarrassing information and take other risks and benefit from it, helped others to do the same; and
- feeling more trustful of groups and other people.

Group support provides a therapeutic and learning environment where many human problems can be worked on with good effect. Individuals, for whom a one-to-one helping relationship is essential, will not benefit from groups. Individuals who will probably not do well in groups, are those suffering from psychotic illness and severe depression, those who can only see their difficulties in psychical terms, the paranoid who are overly suspicious, the narcissistic who need all the attention for themselves, and the schizoids who are too cut off from other people (Achat *et al.*, 2000:130). Once individuals

have been helped to move from these categories, groupwork can often provide an important and potent ingredient in their return to well being. In essence, groups are more for interpersonal rather than intrapersonal development (Bratter, 2000:38).

It is often difficult to persuade potential participants that a group really is the most useful option and not a second best to individual therapy. The culture of individualism in societies is often strongly embodied in those with difficulties, especially interpersonal difficulties (Mitchel & Shoda, 1998:46).

The power and flexibility of group support is that it can be used to help participants over a whole range of concerns. There limited number of people who cannot benefit from group support, which can provide a forum of open and genuine communication (Scheier *et al.*, 1999:30).

### **3.9 RATIONALE FOR SUPPORT OF LEARNERS IN SCHOOLS**

Schools have a statutory responsibility to develop a curriculum which promotes the spiritual, moral, cultural, mental and physical development of learners at the school and of society, and prepare such learners for the opportunity, responsibilities and experiences of adult life (Wigle & Sandoval, 2000:7). Guidance plays a part in helping schools to fulfill this commitment. The aim is to contribute as fully and as positively as possible to the mental health of the learners in the school community and to do this in different ways, which is through:

- the curriculum,
- the community of the school; and
- one-to-one and group work (Beck & Weishaar, 2000:52).

Support interventions have a developmental function as well as a reactive one. Early in the development of support in schools, the task was seen as involving educators in working one-to-one with learners and was viewed as developmental in nature.

The objectives of support were related to:

- fostering self-acceptance in learners and not changing or remediating personality;
- developing control from within or fostering an internal locus of control; and
- helping learners to learn strategies and coping skills for situations which were difficult or important in terms of their impact on future life (Farmer *et al.*, 2001:49).

These aims have not changed, but there is a realisation that in a school context the work could play a more educative role. Kubzansky *et al.* (2001:13) have realized this, when he talked of the “art of giving individual guidance” without having to give it individually. It is interesting to see how many of the key figures in support progressed to writing in the widest sense about schools and their impact on individuals (Norem & Chang, 2001:61).

### **3.9.1 The educative function of schools**

Schools have a responsibility to develop learners personally and socially, which means that an educative function has to exist. However, personal and social development and sense of identity are learned in interactions with others. Individuals learn who they are in the context of a community and those involved in it (Badcock-Walters, 2001:8). Therefore, there is also the responsibility to explore the impact of the school on the personal and social development of the learners. This reflective or evaluative function involves exploring the possible impact of/ and contribution to personal and social development of practices in the classroom and other aspects of the school community. This generally incorporates interactions between educators and learners as well as between learners and learners (Coombe, 2003:18). It also includes wider issues of teaching and learning styles, as well as classroom and school climate. In addition, there is the welfare function: the responsibility to plan for and react to issues, which impact on learners' welfare and development. This is the area where support has traditionally been seen to play a part. It is helpful to distinguish these different aims but there is also the need to co-ordinate them and identify the links between them (Friedman,

Tucker, Schwartz, Martin, Tomlinson-Keasey, Wingard & Criqui, 1995:96). James (2001:16) states, "Generally speaking, the greatest strength of the guidance lies in its pervasiveness." It is important to see the task as one of identifying the different "strands of the web" rather than developing separate and unconnected practices. Guidance in the classroom is most successful where teaching and learning are of good quality. If this is the case, then co-ordination and management of provision become very important, as does exploring the reality of the school's provision.

The educative element of the school's function includes guidance in the curriculum as well as the wider field of affective education or education for the emotions. In terms of guidance in the curriculum, vocational and educational guidance is now a well accepted one (Ryan & Frederick, 1997:38). The curriculum is related to the different needs and ages of learners. It should also reflect the particular needs of learners in relation to their community and context. Much of this element can be planned in advance using frameworks which have been tried and tested, for example, the framework for vocational guidance of developing decision making, transition learning, opportunity awareness and self-awareness (Dinkmeyer & Sperry, 2002:26). It includes giving learners the personal and social skills without which they may require problem-based support, for example, helping learners acquire the skills of listening and responding appropriately to others, or developing the ability to express feelings and opinions. It also contains elements, which are in response to guidance needs, perceived as arising from particular themes in groups or individuals. This may include working on topics such as friendship or negotiation, as well as the experience and development of the ability to work in a group. Many of the issues which were responded to by educators on an individual basis, such as bullying, are now being acknowledged as issues which need to be dealt with in an educative way through the curriculum. Responding to these issues on an *ad hoc* basis is no longer adequate (Cohen *et al.*, 1997:65).

The time of vulnerability for many learners is at periods of transition. Diener *et al.*, 1999:76) call these "critical incidents". They are critical because they are

occasions when learners can affiliate to the school or become alienated. At these times, such as entry to school, transfer to new courses or transfer to new institutions, learners need support and this support needs to be in an organized form and have a curricular element. Robinson-Whelan *et al.*, (1997:45) has noted that, "All institutions understood the necessity of offering substantial guidance at these stages and most provided guidance that was overall sound in many respects." However, he has identified the subject or aspect of guidance in Grade 10 as often inadequate and he emphasises the importance of guidance at age 13. In providing effective guidance there is a need to plan a programme which is coherent and not merely a collection of one-off events. Guidance is most effective when it is continual and cumulative. The same themes will recur and yet will differ according to the age and stage the learners have reached (Symster & Friend, 2003:127).

### **3.9.2 Classroom climates**

Support requires an awareness of the appropriate methods in this field; for example, the ability to help learners to think for themselves or the ability to work in groups rather than as individuals (Abdullah *et al.*, 2001:80). Dykema *et al.* (1995:69) have identified three areas of weakness here, namely:

- not all educators involved are at ease with various aspects of content and approaches;
- over-reliance on commercially reproduced schemes and duplicated worksheets so that learners are not encouraged to think for themselves; and
- failure to achieve an appropriate balance between content and related personal, vocational and educational issues.

Educators need to be able to use a repertoire of teaching styles and to be able to choose consciously from them, being aware of the impact that each one has. There is considerable evidence to show that techniques such as co-operative learning do impact on learners' personal and social development (Shariff & Neil, 2002:69).

The creation of an appropriate classroom climate and the establishment of procedures are as important as the content and teaching format. In a study of girls' development Thompson *et al.* (2004:15) show that during adolescence, girls lose the ability to express their real feelings and opinions. They describe this as a loss of voice and argue that girls do this to avoid endangering relationships and that it has long term consequences for the development of women. As a result, they argue for the need to encourage individual girls to express difference and disagreement. This would suggest that procedures in the classroom, such as the negotiation of ground rules and rules for constructive controversy, are important. The following programmes of work are examples:

- Skills for Adolescence includes procedures and rules regarding the way learners listen to one another or demonstrate respect (Davis *et al.*, 1998:61); and
- The Elton Report on discipline in schools also emphasises the importance of learners' negotiating rules and procedures, as well as having opportunities for the expression of opinion (Kiecolt-Glaser *et al.*, 1998:218).

The classroom context, the procedures and the nature of interactions all impact on learner self-image and self-esteem. These are important elements in the school's contribution to personal and social development, as well as in motivation (Sheldon & King, 2001:16).

### **3.9.3 Self-development of learners**

Other processes, such as the development of self-assessment and the formation of action plans, facilitate the personal development of learners. In the one-to-one dialogues with learners, educators are required to use skills drawn from support. It is important to distinguish between drawing on support skills to make communication effective and conducting a support interview. The ethical constraints, the boundaries of the talk and the learners' choosing of that dialogue are all important differences between the two activities (Wubbolding & Brickle, 2000:64).

The reflective function is related to an exploration of the impact of the school on the personal and social development, as well as the mental health of the learners. This is to argue that the role of support is to promote healthy institutions as well as healthy individuals (Brenes *et al.*, 2000:25). Research has shown that schools can have a substantial impact on individuals' psychological development both in the present and in the future. Kubzansky *et al.* (2001:16) sums up much of his own and others' research in these words:

"It is no easy matter to create a happy, effective school and there are a variety of influences outside the control of the schools. Nevertheless, schooling does matter greatly. Moreover, the benefits can be surprisingly long-lasting. This is not because school experiences have a permanent effect on an individual's psychological brain structure, but rather because experiences at one point in an individual's life tend to influence what happens afterwards in a complicated set of indirect chain reactions. It is crucial to appreciate that these long-term benefits rely on both effects of cognitive performance (in terms of learning specific skills, improved task orientation and better persistence) and effects of self-esteem and self-efficacy (with respect to better attitudes to learning, raised parental expectations and more positive educator responses because individuals are more rewarding to teach)."

The Elton Report advocates an approach which reflects this position of developing schools as healthy environments personally, socially, and academically (O'Connor & Shimizu, 2002:84). Previously the disciplinary role of the school had largely to do with the reaction to incidents of bad behaviour (Sheldon & Kasser, 2001:35). The Elton Report has argued for the promotion of positive behaviour. It is a much more proactive and wide ranging approach, one which acknowledges the role of all in the school community and which shifts the emphasis to a concentration on developing positive behaviour rather than focusing on problem behaviours. Similarly, in the area of support and guidance, a more proactive and wide-ranging approach is needed. This should reflect the promotion of positive strategies to developing mental health

rather than a focus on reacting to problem situations (Western *et al.*, 2002:168).

In the same manner as Alberti and Emmons's work (2001:39) show how interactions in the classroom can impact on girls' development, there is an awareness of the impact of other aspects of school life on the learning and development of learners. The nature of learners' interactions with other learners is an example. Initiatives in child abuse and bullying, allied to an emphasis on children's rights, have alerted educators to what the experience of individuals is. The voices of individuals are being heard more clearly and the nature of their experience is being acknowledged more fully.

In reaction to above, educators and others have argued for intervention by educators and the co-ordination of approaches in the curriculum as well as in response to incidents. The task here then is to explore the school as a community and examine its impact on learners and educators (Gillespie *et al.*, 2003:84). It will involve educators in actively inviting learners to give feedback on the functioning and health of the school and its practices. This may engage educators in debates about educator-learner interactions and the values underpinning them, a difficult and controversial area for many to engage in (Sinclair & Tertric, 2000:23).

The welfare aspect of support and guidance is the area most focused on and developed in writing about support in school settings. Alberti and Emmons (2001:10) describe the school's role as that of being "a guidance community". The objectives in this area are to:

- aid learners in decision making and problem-solving;
- support learners in a constructive manner in times of difficulty ;
- monitor and detect learners who are at risk or under pressure;
- react in an appropriate fashion; and
- co-ordinate work within and outside the school.

The area will include a range of activities, *inter alia*:

- support when it is sought by learners;
- more focused guidance activities such as that involved in decision making of a predictable kind;
- support to react to crises, problems and transitions;
- more specialist support; and
- involve liaising with outside agencies and parents (Compton, 2001:84).

These activities require many and different skills and abilities. They also require practitioners to be able to distinguish between these different activities. Diener (2000:35) argues that there are six possible types of intervention between practitioner and supportee. By an intervention he means “an identifiable piece of verbal and/or non-verbal behaviour that is part of the practitioner’s service to the supportee.” The six categories again, are subdivided into two main types.

### **3.10 TYPES OF INTERVENTION**

This section deals with types of interventions for support of learners. These include those that are authoritative and those that are facilitative. These types of support will be discussed below.

#### **3.10.1 Authoritative**

In authoritative type of intervention, prescriptive, informative and confronting types can be mentioned (Flisher, 2000:39).

##### **3.10.1.1 Prescriptive**

A prescriptive support intervention seeks to direct the behaviour of the supportee, usually behaviour that is outside the practitioner-supportee relationship (Reid, 1999:24).

### **3.10.1.2 Informative**

An informative support intervention seeks to impart knowledge, information, and meaning to the supportee (Thompson *et al.*, 2004:65).

### **3.10.1.3 Confronting**

A confronting support intervention seeks to raise the supportee's consciousness about some limiting attitude or behaviour of which he is relatively unaware (Brissette *et al.*, 2002:67).

## **3.10.2 Facilitative**

In facilitative type of intervention, cathartic, catalytic and supportive types can be mentioned (England & Artinian, 1996:86).

### **3.10.2.1 Cathartic**

A cathartic support intervention seeks to enable the supportee to discharge, too painful emotion, primarily grief, fear and anger (Spreitzer, 1995:55).

### **3.10.2.2 Catalytic**

A catalytic support intervention seeks to elicit self-discovery, self-directed living, learning and problem solving in the supportee (Cilliers *et al.*, 1998:46).

### **3.10.2.3 Supportive**

A supportive support intervention seeks to affirm the worth and value of the supportee's person, qualities, attitudes or actions (Kendler *et al.*, 2003:89).

The first three categories are called authoritative because they are rather more hierarchical; the practitioner is taking responsibility for and on behalf of the supportee. The second three are called facilitative because they are rather less hierarchical, the practitioner is seeking to enable supportees to become more autonomous and take more responsibility for themselves (Shariff & Neil, 2002:45).

Barnard (1994:137) comments that "Traditional education and training have often omitted facilitative interaction altogether". Barnard (1994:137) argues that the skilled practitioner is someone who is equally proficient in a wide range of interventions in each of the above-mentioned categories; can move elegantly, flexibly and cleanly from one intervention to another as the situation and purposes require; is aware at any given time of what intervention he/she is using; knows when to lead the supportee and when to follow; and has a creative balance between power over the supportee, power shared with the supportee and the facilitation of power within the supportee.

The support interventions are helpful to work done in schools and as a framework for educator development. They can also highlight some of the problems of work in schools. Brackel and Petty (1998:46) detect confusion about the role and type of interventions that are described in schools as support interventions.

For example, wanting to change learner's behaviour because it causes problems for the school or is seen as unacceptable by a particular educator is not necessarily a prescriptive support intervention.

Dossey (1994:17) further describes the misuses of support in schools. He argues that support is not about personality change; it is not solely for those perceived as "deviant" and "disadvantaged"; it is not an opportunity to exercise subtle control or manipulation; nor is it probing into the learner's private world. Dossey (1994:18) comments on the lack of clarity between discipline and support, saying that "staff learners often perceived a clash between guidance and the need to enforce discipline".

### **3.10.3 The practice of support**

The practice of support involves assessment where extensive history is taken to establish the following:

- Does the HIV/AIDS infected individual have a longstanding susceptibility to depression and anxiety?

- Are there life circumstances, which contribute to the problem, such as family relationships, schoolwork or financial problems?
- Are there physical symptoms of depression and anxiety?
- What worrying and debilitating thoughts does the HIV/AIDS infected individual have?
- What are the behavioural symptoms?
- Enquire about specific situations, places or people that the HIV/AIDS infected individual tends to avoid because of depression and anxiety.
- Include substance misuse, physical illness and a major psychological disorder, which may cause the depression and anxiety. Enquire about depressive symptomatology such as, for example, sustained low mood, loss of the ability to enjoy life, suicidal thoughts and disturbed sleep (Dickson, McDonald & Roberts, 2002:238; Fleischman, 2003:253).

The practice of support, also, involves a detailed analysis of the feelings, thoughts and behaviours in collaboration with the HIV/AIDS infected individual with depression and anxiety. Typically the HIV/AIDS infected individual would keep a diary. Using this dysfunctional thought record, the supportee and supporter embark on a process of challenging negative automatic thoughts (Heyzer, 2003:34; Meless, Messele & Doringo, 2003:10).

#### **3.10.4 Types of questions**

Thought challenging questions to ask about negative automatic thoughts are:

- Is there good evidence to support this thought?
- Is there another conclusion which could be reached instead?
- Am I making a logical error when I think like this, in other words, am I:
  - jumping to conclusions?
  - using all or nothing thinking - events are either all good or all bad?

- only selecting the negatives?
- over-generalising?
- magnifying the negatives or minimising the positives? (Boyden, 2003:39).

### **3.11 THE STRUCTURE OF SUPPORT**

The supporter works with the supportee to challenge automatic behaviours and to find new ways of coping. Two columns can be added to the thought record – a “rational response” to the negative automatic thoughts and a “further action” to be taken (Kivimaki *et al.*, 2002:16).

Support is structured and collaborative. Each session follows a determined format – the supportee and supporter agree on an agenda for the session, which includes a review of the previous week’s homework. At the end of the session the supportee is invited to give feedback and supporter and supportee decide together on what tasks or homework the supportee will tackle during the following week (Siebert & Paul, 2003:75). Towards the end of the therapy the supportee is given greater responsibility in directing therapy. Ideally the supportee should continue the therapeutic exercises on his or her own after termination of therapy. The later stages of therapy often involve investigating a supportee’s underlying false assumptions. These are deeply set ideas that usually develop in childhood and may make the supportee more vulnerable to mental illness. For example, the belief that “I cannot cope on my own” may lead to dependent behaviour as well as depression and anxiety when relationships are under threat (Wigle & Sandoval, 2000:7).

Most supportees are helped when they are given useful information about the nature of their complaints. This might involve explaining the depression and anxiety cycles to the supportee and how these maintain the conduct disorders. If the disorders are severe or long-standing, specific interventions might be appropriate, which are:

- graded exposure to feared situations to overcome the avoidance;
- education and cognitive challenging to overcome unrealistic worries and fearful misinterpretations; and
- realisation techniques to help with the psychological symptoms (Gergen & McNamee, 2000:334; Rubak, 2005:46).

In supportees who see their difficulties as physical in nature and do not perceive a link to depression and anxiety, it is important to acknowledge their very real concerns. An explanation of how depression and anxiety may work through the body to produce physical symptoms, might lead to a discussion of their problems as well as to strategies and resources for solving these (Walter & Peller, 2000:32).

The essential principles of supporting HIV/AIDS infected individuals with depression and anxiety are:

- educate the individual regarding symptoms that may be experienced in the coming weeks;
- discuss coping strategies such as realisation and the use of support networks;
- the short-term use of hypnotics may be indicated; and
- it may also be helpful to encourage the supportee to talk through what had happened (Ellis, 2000:168; Isaacs & Stone, 1999:258).

Techniques utilised in supporting HIV/AIDS infected individuals with depression and anxiety are:

- **Activity scheduling** - This may be useful for helping depressed individuals. It is often used as the first non-medical intervention for treating supportees who are inactive and lack energy and drive. A list of pleasurable and useful tasks is scheduled for the supportee to do each day. The supporter offers gentle encouragement and praise for tasks accomplished (Nichols & Shwartz, 2002:18).

- **Graded exposure** - This is used to treat phobias. The supportee is gradually exposed to the feared situation or object, or several feared situations in ascending order of difficulty (Sexton, 1997:590).
- **Behavioural experiments** - These are used to test negative expectations and assumptions. For example the thought "if I am more assertive with my friends, they will like me less" can easily be tested (Wilson, 2000:205).
- **Relaxation training** - This is usually started in a quiet, calm environment. The supportee breathes deeply and tries to imagine the depression, anxiety and tension leaving his/her body as he or she breathes out. Tensing and relaxing muscles, music and mental imagery may also help the supportee to relax. Once supportees have learnt strategies that help them relax, they can apply them when they begin to feel anxious (Corey & Haynes, 2005:33).
- **Social skills training** - This aims to teach awkward or socially unskilled supportees how to behave appropriately in a variety of social situations. Assertiveness and conflict resolution skills can also be of great value and equip persons to cope more effectively with future crises (Gibson, Swartz & Sandenbergh, 2002:27).

From the foregoing paragraphs it is clear that support is a simple and practical way of helping individuals with a wide range of psychological difficulties and disorders. It can be used effectively by educators and primary health care workers to manage most common psychological difficulties and disorders of children and adolescents suffering from HIV/AIDS, with or without other forms of intervention. The following strategies of learning to live with the HIV/AIDS disease can be inculcated with supportee:

### **Positive Living**

Positive living means living with HIV/AIDS in such a way that a person takes control of his/her own physical, emotional, social and spiritual life. It means keeping a positive outlook and not giving up (Lazazus & Zur, 2002:29).

## **Accepting feelings**

Finding out that an individual is infected with HIV, can make him/her feel very angry and confused. Some people feel very sad, some go into shock and may feel numb, and others are very scared. Many people feel totally overwhelmed and helpless. It is important for an HIV/AIDS infected person to realize that he/she is undergoing a crisis, so these feelings are normal (Carr-Hill & Peart, 2003:64). They need to accept such feelings, because feeling this way, is part of the process of coming to terms with their HIV status. The strength of these feelings will lessen over time, but the majority of people may sleep badly, not feel like eating and feel tearful for a few weeks after being told they have HIV/AIDS. If these feelings strongly persist, they may need to seek professional help from a psychologist or physician (Mendel, 2002:16).

### **3.12 THE ROLE OF COUNSELLING IN HELPING CHILDREN WHO ARE HIV/AIDS POSITIVE**

Various studies have proved that good counselling has:

- assisted people to make informed decisions such as whether to have an HIV test;
- helped many other people living with HIV or AIDS to cope better with their condition and lead more positive lives; and
- helped prevent HIV transmission (Murdock, 2000:130).

However, many decision makers and service managers such as policy-makers in government ministries, directors of hospitals or heads of nongovernmental organizations (NGOs) are doubtful about the effectiveness of counselling (Department of Health, 2004:14). Their scepticism is a major obstacle to the development and provision of good counselling services.

The resulting inadequacies include:

- lack of policy approval for establishing counselling services;
- insufficient space or resources provided for counsellors;

- unreasonable demands on the time of counsellors;
- difficult access to the service for supportees;
- intimidating or inappropriate atmosphere within the counselling clinic;
- a lack of privacy and confidentiality ;
- no follow-up support for those infected with HIV and their families, spouses and partners. Disseminating the results of studies on the beneficial impact of counselling can help overcome the scepticism and strengthen the support given to counselling (Department of Education, 2001:16). For an effective counselling service, a number of things are needed, including:
  - careful selection of trainees who will be able to provide counselling services;
  - training that includes supervised placement after initial training and follow-up training after a period of work experience;
  - retention of trained counsellors, by providing them with sufficient space and reasonable working hours; sufficient administrative support, professional support and support from their colleagues;
  - the creation of appropriate settings for counselling, avoiding an environment which prevents supportees from freely expressing personal concerns; confidentiality for supportees and ensuring that informed consent is always given and counselling offered before an HIV test; and
  - referral systems that link counselling services with medical clinics and with a range of other services - such as social support , legal services and the supportive care available through religious communities – usually provided by NGOs (Freedman & Combs, 2002:55; Lewis & Osborn, 2004:48).

### **3.13 EFFECTIVENESS OF SUPPORT**

HIV counselling has been proved effective in various ways. An evaluation of the AIDS Service Organization (TASO) in Uganda has shown that it helps people accept and cope with the knowledge of being HIV-positive and furthermore encourages acceptance from families and communities (Ryan &

Deci, 2000:68). A Rwandan study has proved that HIV counselling can help people make decisions about HIV testing, as well as reduce HIV transmission. Yet, there is reluctance among some policy-makers and service managers to give counselling its proper due as a discipline in which trained practitioners can produce measurable, useful results. For this reason it is under-resourced and fully appreciated (Brown, 2003:64).

HIV counselling is a confidential dialogue between a supportee and counsellor aimed at enabling the supportee to cope with stress and take personal decisions related to HIV/AIDS (Wahab, 2005:50). The counselling process includes evaluating the personal risk of HIV transmission and discussing the ways to prevent infection. It concentrates specifically on emotional and social issues related to possible or actual infection with HIV and to AIDS (Ainsworth & Teokul, 2000:11). With the consent of the supportee, counselling can be extended to spouses, sex partners and relatives (family-level counselling, based on the concept of shared confidentiality). HIV counselling helps supportees in making their own informed decisions about their lives, and in giving practical information and suggesting follow-up visits for counselling.

Counselling should be a process involving a series of sessions as well as follow-up. It can be done in any location that offers peace of mind and confidentiality for the supportee. Two types of counselling, according to site are practiced. Clinic-based counselling provided in a formal session – in a hospital, health centre or clinic – by a trained professional, such as a doctor, social worker, nurse or psychologist. Community-based counselling is given in a non-formal environment, in a village or urban neighbourhood - by one community member trained in counselling to another community or family member (Miller & Moyers, 2005:267).

### **3.13.1 Pre-test counselling**

HIV counselling is often given in connection with a voluntary HIV test. Such counselling helps to prepare the supportee for the HIV test, explains the implications of knowing that one is, or is not infected with HIV, and facilitates discussions about ways to cope with knowing your HIV status. It also involves

a discussion of sexuality, relationships, and possible sex- and drug-related risk behaviours and how to prevent infection (Piot & Seck, 2001:10). It helps correct myths and misinformation around the subject of AIDS. Whenever resources permit, pre-test counselling should be made available to those who desire it. People who do not want or do not have access to pre-test, counselling should not be prevented from taking a voluntary HIV test, however. In contrast, informed consent is always required before an HIV test where the individual's name will be linked to the result. To allay anxieties while awaiting the test result, some individuals may seek support not only from their own families or knowledgeable community worker (Moursund & Erskine, 2004:44).

This is a kind of counselling people get which makes them decide whether they want to have the HIV antibody test. Some of the issues the counsellor will discuss with individuals are:

- Why the person decide to come for counselling
- What counselling is, and the role of the counsellor
- What his/her personal history is
- Whether s/he has any health problems
- What his/her risk of being HIV infected is
- What s/he knows about HIV /AIDS
- Information about HIV/AIDS, including the test procedure and what people who are HIV infected can do to make sure that they stay as healthy as possible for as long as possible.
- What alternative there is for solving your problems?
- Which issues they want to tackle first.

- What impact s/he thinks a positive, indeterminate or negative result would have on his/her life and how s/he thinks s/he would react to receiving them.
- The advantages and disadvantages for him/her to having the test.
- What kind of support system s/he has including who s/he would be able to tell if s/he tested HIV antibody positive.
- How s/he has coped with problems in the past (Rubak, Sandboek, Lauritzen & Christensen, 2005:305).

### **3.13.2 Post-test counselling**

Post-test counselling helps the supportee understand and cope with counselling objectives both prevention and care. A counsellor is a person trained in the skills of the job: listening to the supportee, asking supportive questions, discussing options, encouraging the supportee to make sense of the HIV test result. Here, the counsellor prepares the supportee for the result, gives the result and then provides the supportee with any further information required, if necessary referring the person to other services (Watson & Tharp, 2002:36).

HIV test results should always be given with counselling. The form of post-test counselling will depend on what the test result is. Where it is positive, the counsellor needs to tell the supportee clearly and as gently and humanly as possible, support and discussing with the supportee on how best to cope, including information on relevant referral services. Ongoing counselling will help supportees accept their HIV status and have a positive attitude to their lives (Amrhein, 2004:4).

Through ongoing counselling, the infected person may choose to invite a trusted family member to share confidentiality and participate in the counselling – enabling the family to start practicing family level counselling. But counselling is also important after a negative result. While the supportee is likely to feel relief, the counsellor must emphasize several points (Dinkmeyer & Sperry, 2002:26). Firstly, because of the “window period”, a negative result may not mean absence of infection and the supportee might

wish to consider returning for a repeat test after three to six months. Secondly, counsellors need to discuss HIV prevention, providing support to help the supportee adopt and sustain any new safer practices. This is the kind of counselling a person receives after s/he had the test (Leahy, 2002:418). During this session the counsellor will:

- divulge the test result;
- let the person express his/her feeling about being HIV antibody positive, negative or indeterminate. Help him/her to revisit the issues they raised during the pre test counselling session; including any plans they may have made;
- discuss any immediate problems and help them to decide on a plan of action;
- answer any questions they may have and provide them with useful information;
- discuss positive living; and
- give individual's positive information on what resources there are in their community to help them (Sexton & Alexander, 2002:239).

### **3.13.3 Voluntary counselling and testing**

VCT stands for voluntary counselling and testing. VCT is when a person chooses to undergo HIV/AIDS counselling so that they are able to make an informed decision about whether to be tested for HIV (Winslade & Monk, 2000:63). It believes that if many individuals get tested, even though they may not be sick, this could help lessen the amount of stigma associated with the HIV test. Also, if individuals find out at an earlier stage, that they are infected with HIV they should be able to:

- learn more about the virus and how it affects their body;

- look after their health so that they could stay as healthy as possible for as long as possible;
- get information and counselling about the way to live positively with the virus. This means learning to accept the fact that they are HIV – infected, seeking emotional support, eating a health diet, learning how to control the amount of stress in their lives, making sure they do not become re-infected and be able to plan for the future;
- learn to recognize the signs of opportunistic infections in order to get them treated promptly;
- find out about prophylactic drugs. These drugs do not cure HIV/AIDS, but can prevent us from getting some opportunistic infections that are common with people living with HIV/AIDS e.g. T.B. and some kinds Pneumonia;
- access to Nevirapene. This is a drug available at a number of hospitals and clinics that lessens the chance of a pregnant mother passing the virus onto her baby;
- get emotional support by seeking counselling and joining support groups;
- ensure that they do not infect anyone else or get re–infected themselves; and
- learn how to manage the stress in their lives (Corbett, 2002:37; O'Connor, 2001:88).

Once the test has been done, one will receive post-test counselling. This is the counselling during which s/he will receive her/his results. People who have good pre and post–test counselling are able to cope better with their results, are more likely to look after their health and protect others from infection. The counselling that one may have once s/he knows her/his result is known as ongoing counselling. Ongoing counselling helps one to live positively with HIV and provides her/him with support and guidance with regard to any problem that s/he may face (Lock, 1997:456).

#### **3.13.4 Counselling for behavioural change**

The availability of HIV counselling, even without HIV testing, may create a private environment for discussing sexual matters and personal worries. Counselling augments AIDS education by making HIV related information personally relevant. Counselling of this type for behavioural change has been successfully provided in the Medical Research Council project in western Uganda. Here, community based counselling in a small rural community increased condom use from 2 000 to 7 000 per month (Ginerich & Eisangart, 2000:477).

#### **3.13.5 Counselling for children**

In many towns, children who affected by the epidemic are increasing. Apart from those themselves infected with HIV, include children where one or both the parents are either living with HIV/AIDS or have died of AIDS. These children have special counselling needs, such as the emotional trauma of seeing their parents being ill or die, discrimination by other children and adults, and emotional worries about their own continuing illness. Older children may need counselling related to sexual issues, as well as about the avoidance of risk behaviour (Barnett & Schueller, 2002:29).

#### **3.13.6 Establishing the role of HIV counselling**

One-way counselling can be accorded its proper respect by conducting studies on its delivery, quality and impact. Research findings on counselling can help convince decision-makers and service managers to endorse and provide resources in support of counselling services (Carlson & Kjos, 2002:43).

In Uganda, TASO (The AIDS Service Organization) conducted a study on 730 HIV-positive supportees to whom it had given long-term counselling. Counselling appeared to help these supportees cope with their infection. Of the supportees sampled, 90% had revealed the fact of their infection to another person, with 85.3% telling their relations. The study also showed a high level of acceptance of HIV-positive people within families (79%) as

reported by the TASO supportees who had received regular counselling. After results were discussed at each hospital where TASO operated, the hospital managers provided more space for counsellors and encouraged doctors to refer supportees to TASO counsellors (Lamptey, Wigley & Carr, 2002:3).

In 1992, a study in Rwanda examined the impact of preventive counselling. It was shown that for the women whose partners were also tested and counselled, the annual incidence of new HIV infections decreased from 41% to 1.8%. Among women who were HIV positive, the prevalence of gonorrhoea decreased from 13% to 6%, with the greatest reduction in those using condoms. As a result of these findings counselling was recognized as a mainstream intervention and the funders of the study established a project for counselling and discordant couples in Zambia (Kiragu, 2001:15; Kelly, 2002:81).

### **3.13.7 Ongoing HIV/AIDS counselling**

Ongoing counselling is aptly named "the king of counselling" and takes place after having received test result. The aims of ongoing counselling are to:

- help in managing the impact that HIV on life and the lives of other people;
- encourage in taking control of health and taking charge of life;
- help in accepting positive results and live positively with HIV /AIDS;
- explore the advantages and disadvantages of telling others about ones positive status;
- assist in tackling problems;
- provide emotional and psychological support;
- help to strengthen support system;
- help one to plan for future; and
- explore issues around death and dying (Combs & Freedman, 1998:406).

### 3.13.8 The effect of stigmatisation on testing

HIV/AIDS-related stigma affects issues related to HIV testing including delays in testing, the effect of delay on further transmission of HIV, and individuals' responses to testing positive (Corbett, 2002:36). Early detection of HIV infection is important. Knowledge of HIV sero-positivity can lead to earlier treatment and improved outcomes. Knowledge of sero-positivity also can lead to changes in risk behaviours that can reduce or eliminate the risk of HIV transmission (Dorrington *et al.*, 2001:64).

Heyzer (2003:45) in his survey suggested that fear of being stigmatized by HIV/AIDS has some relationship to people's decisions about getting tested for HIV. One-third of survey respondents said that if they were tested for HIV, they would be very or somewhat concerned that people would think less of them if they discovered that they had been tested. In addition, 8% of people who had never been tested for HIV said that worries about confidentiality played a part in their decision not to have the test.

Studies provide evidence that stigma is associated with delays in HIV testing among individuals who are at high risk of being infected with HIV. In a study of gay and bisexual men who were unaware of their HIV status, two-thirds of the participants expressed a fear of discrimination against people with HIV and said it was a reason for not getting tested (Mohlala, 2002:7).

Early in the epidemic, HIV stigmatization was shown to influence the way in which at risk populations approached HIV testing. People at risk for HIV infection were more likely to seek testing that was offered anonymously (i.e., no names were recorded) than testing that was offered confidentially (i.e., names were kept in confidential files) (Pawinski & Lalloo, 2001:448).

HIV/AIDS-related stigma also influences individuals' responses to testing positive: It aggravates the psychological burden of receiving a positive HIV test. Earlier in the epidemic, there were reports of severe psychological responses to notification, including denial, anxiety, depression, and suicidal ideation (Tawfik & Kinoti, 2002:66). Over time, studies have shown a decrease in severe reactions to being notified of positive test results; however,

research continues to show that notification is associated with high distress. Distress is greatest immediately after notification and typically declines within two to ten weeks (Haacker, 2001:58)

Stigma also affects the care of HIV-positive individuals. After a person tests positive, he or she faces decisions that include how to enter and adhere to care and whether to disclose HIV sero-positivity to partners, friends, family, colleagues, employers, and health care providers. At each level, a decision to disclose sero-positivity individual to stigmatization and potential discrimination (Jennings, 2000:43).

### **3.14 CONCLUSION**

In this chapter the role of support for HIV infected learners was analysed and explored. It strongly emerged that there is a great need for these learners to be supported so as for them to achieve symptomatic improvement and enhance their individual's coping strategies.

The following chapter outlines the research design.

## **CHAPTER FOUR**

### **RESEARCH DESIGN**

#### **4.1 INTRODUCTION**

This chapter presents the research methods used in this study. It includes an overview and justification of using qualitative research, research design and sampling. The use of a interviews is taken as the most appropriate and practical technique in reaching the aims of this study, which are to:

- determine effect of HIV/AIDS on psychological well being of learners infected by HIV/AIDS;
- investigate the effect of HIV/AIDS on the physical well being of learners infected by HIV/AIDS;
- determine the effect of HIV/AIDS on the general functioning of learners affected by HIV/AIDS in schools; and
- determine the nature and extent of support these learners get.

#### **4.2 QUALITATIVE RESEARCH DESIGN**

Different scholars have provided various definitions and meanings of qualitative research. Merriam (1998:15) characterized qualitative research as an "umbrella" concept covering several forms of inquiry. This analogy helped explain the meaning of social phenomenon with as little disruption of the natural setting as possible, and in which the focus of the study is on interpretation and meaning. Smith and Glass (1987:27) regarded qualitative research as devoted to developing an understanding of human phenomena and experience, which helps explain "the persons involved, their behaviour and perceptions, and the influence of the physical, social, and psychological environment or context on them". According to Cresswell (1998:15)

“Qualitative research is an inquiry process of understanding, based on distinct methodological traditions of inquiry that explore a social or human problem. In the process of a study, the researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting.”

A comprehensive definition of qualitative research came from Denzin and Lincoln (1994):

“Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts – that describe routine and problematic moments and meaning in individuals’ lives.”

Qualitative research studies have many typologies and traditions. Denzin and Lincoln (1994:24) provided different approaches to qualitative study, which include case studies, ethnography and participant observation, phenomenology and ethnomethodology, grounded theory, biographical method, historical social science, participative inquiry, and clinical research. In addition, Gall, Borg, and Gall (1996) analyzed the above approaches of qualitative study and provide three major issues that focus on:

- **individual ‘lived’ experience** exemplified by phenomenological approaches, some feminist inquiry, and narrative analysis;
- **society and culture as** seen in ethnography and qualitative sociology; and
- **language and communication** expressed by sociolinguistic and semiotic approaches.

Qualitative research also has different variable characteristics and it provides ample advantages to research study. Foshay et al. (1999:56) stated the advantage of a qualitative or naturalistic method is the ability to ascribe meaning to a situation by studying things in context rather than in artificial isolation as happens in controlled experiments. Meanwhile, Sherman and Webb (1988:913) listed four important characteristics of qualitative research methods:

- events can be understood adequately only if they are seen in context; therefore, qualitative researchers immerse themselves in the setting;
- the contexts of inquiry are not contrived; they are natural. Nothing is predefined or taken for granted;
- qualitative research wants those who are studied to speak for themselves, to offer their own perspectives in words and actions. Qualitative research is an interactive process in which the persons studied teach the researcher about their lives; and
- qualitative researchers attend to experience as a whole, not in terms of separate variables.

The aim of qualitative research is, therefore, to understand experience as being unified.

The above characteristics of qualitative research were consistent with the values of qualitative research described by Borg and Gall (1989). They listed the following values:

- **phenomenology**: the researcher develops an "insider's" viewpoint from
- multiple perspectives;
- **holism**: the researcher perceives the big picture or the total situation rather than a few elements in a complex situation, as in quantitative research;

- **nonjudgmental orientation:** the researcher records a situation in qualitative terms without superimposing his or her value system, judgments, hypotheses, or preconceptions may distort what the researcher sees;
- **contextualization:** all information is considered only in the context of the environment in which it was gathered.

It seems obvious that these characteristics of qualitative research are appropriate for studying experiences of learners infected with HIV/AIDS. Marshall and Rossman (1999:2) affirmed that "qualitative research is pragmatic, interpretative, and grounded in the lived experiences of people". The researcher chose the qualitative research design because of interest in studying learner's perspectives of their experiences of HIV/AIDS. The qualitative research design provided a way to uncover problems and recommendations for HIV/AIDS infected learners. In such a case, experiments would have been unethical (Marshall, 1987).

#### **4.3 JUSTIFICATION FOR USE OF QUALITATIVE RESEARCH**

Two reasons account for this choice, firstly it is a type of formative research that could offer specialized techniques for obtaining in-depth responses about what learners infected by HIV/AIDS experience, how they live with the virus, problems they encounter because of being HIV positive, their feelings, and their needs and wants, as it is exploratory and interactive. Qualitative research enables the researcher to gain insight into the infected learner's reality. Secondly qualitative research provides a rich texture and context through which to learn about the infected learner as an individual without losing the rich descriptions of his/her attitudes and feelings and the essence of his/her experiences.

The research is investigative and exploratory, and the interview with the learner infected by HIV/AIDS was designed to encourage her to tell her stories. According to Balamontsou and McLeod (cited in Rampund, 1996:53), this is consistent with the idea that people make sense of and communicate their experiences through stories. Bruner (1990:42) explains that narrative or

story telling represents distinctive “way of knowing” quite different from the theoretical, propositional or paradigmatic knowledge that has historically been the trademark of the scientific community.

#### **4.4 THE PURPOSE OF THIS STUDY**

The purpose of this study was to find out more about the psychological and social support HIV/AIDS positive learners get. Through a qualitative design, this study examined and integrated the in-depth experiences one learner infected by HIV/AIDS. In-depth descriptions of experiences are provided through the inclusion of actual personal accounts or a case study. The case study was analyzed for common themes and patterns that were contributory to psychological and social support of infected learners.

A quantitative design was not chosen because this process would require the use of standardized methods and would limit the extensive and varied experiences of the respondents by forcing a fit into predetermined categories (Patton, 1990).

The qualitative design included the following components:

- purposive sampling;
- in-depth interviewing with the goal of obtaining exemplar events and detailed descriptions of experiences of learners infected by HIV/AIDS; and
- case studies reporting to richly portray each of the credible 'stories'; and,
- inductive analysis of the themes or common patterns that tie the individual experience of HIV/AIDS infected learners together and help to construct a framework which allows for better understanding of these experiences.

#### **4.5 DATA COLLECTION**

This section discusses the way the participants are selected and how the data was gathered, and how it was transcribed and analysed.

### **4.5.1 Sampling**

This research is purely qualitative and the purposeful sampling was used. The qualitative approach was used because, the researcher wanted to be able to:

- record and understand these learners in their own terms;
- observe natural, ordinary experiences of learners infected by HIV/AIDS; and
- generate detailed data about the learners that were studied and also to provide a contextual understanding (Baumgartner & Strong, 1994: 177).

There are different types of purposeful sampling; and network sampling is one of the types mentioned in Merriam (1998). The researcher decided to utilise network sampling. Patton (1990:182) argues that this strategy involves identifying cases of interest from people who know what cases are information-rich, that is, good examples for the study, good interview subjects. In purposeful sampling size and specific cases depend on the study purpose. The researcher used her network of friends who are managers of NGOs, social workers, health workers (both professionals and paraprofessionals) and colleagues to conduct network sampling. The researcher decided to approach a social worker that was working with street, abandoned, orphaned and neglected children. The interviewer requested the social worker for assistance, as it was difficult to get this kind of information at schools. Educators do not know which learners are HIV positive and they have to depend on whether parents are prepared to disclose their children's status or not.

### **4.5.2 Case study formulation**

Case studies were used as the method of investigation of the psychosocial support infected learners get. Case studies are a form of qualitative research as well as a methodology. Wolcott (1992:12) describes case studies as "an end product of field-oriented research," which means the end report of a case investigation. It is in this context that the case study method was selected for

this research. A Case study can be defined in terms of process and can be used to carry out investigation or inquiry of bounded systems or units of analysis selected for study. *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 (see Chapter 5). 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 for both interviewees. The case study included an in depth and thorough explanation of the respondents' personal experiences as told by the respondent/interviewee. The case studies were presented as a holistic and descriptive personal account of the individual respondents. Unique experiences of each of the respondents were provided through direct quotes and details of influential factors that played a part in their psychological, physical well being. Basic information on family background was contained in the case studies.

#### **4.5.3 Research instrument**

##### **4.5.3.1 Interview procedure**

Prior to the beginning of the interview, the participants were read procedure the research was going to employ. This procedure specified that confidentiality would be preserved during the documentation and reporting process, the identity of the respondent would remain confidential throughout the research project, the respondent was asked to select a pseudonym, which was used for the recorded interview, the transcription and the reporting process in this dissertation. It was stated that the interview tapes and transcribed documents would only be available to the transcriber and the doctoral committee of the University of North West (Vaal Campus).

Prior to the interview, the respondents were asked if they objected to the researcher taking handwritten notes. They were also told that they would receive a copy of the *verbatim* transcript. Respondents were asked to read the transcript and make the necessary corrections. They were also informed that they would receive their completed case studies. They were asked to correct it

for any inaccuracies and to make sure that the case studies accurately portrayed the information they provided and their experiences of being infected with HIV/AIDS. The researcher requested the respondents to return their comments within one to two weeks after receiving their case studies.

#### **4.5.3.2 Interview setting**

Participants were encouraged to select an interview setting that would be private, convenient and comfortable. Both respondents agreed to be interviewed at their home. The choice of home as a setting was convenient for both the interviewees as it provided them with privacy and comfort. Participants were asked to allow two hours for the complete interview. Participants were told that the interview would be transcribed and audio-taped and asked if they had any objections to this process. Both respondents agreed to be audio-taped.

#### **4.5.3.3 Interview guide**

The researcher opted for in-depth and semi-structured interviews which involve one-to-one interaction and are organized to encourage the respondent to express himself/herself freely about his/her experiences HIV/AIDS. In-depth interviewing focuses in considerable detail on the life experience and social behaviour of selected individual respondents. An open-ended interview was used to explore each of the participant's thoughts and feelings about their experiences of HIV/AIDS. In this open-ended interview, a group of questions was used to guide the interview. Respondents were not provided with a limited and predetermined set of responses to each question. Instead, respondents were free to respond in any manner they chose.

According to Patton (1990), open-ended interviewing is considered to be an effective way to obtain individual perspectives. Opening and non-threatening questions, such as the first question, "Would you tell me about yourself?" were included to help establish rapport and allow the interviewee to respond freely. In addition to developing rapport, the open-ended interview dialogue was selected because it assisted with enhancing the communication level between the respondent and the interviewer.

#### **4.5.4 Transcriptions and analysis**

Transcriptions were made of all the audio-taped interviews. The researcher compared audiotapes to transcripts and reviewed each transcript to ensure that it contained the *verbatim* recorded interview. These steps were important for the accuracy of the design and for the identification of emergent issues, which were to form themes.

Data collection and analysis are not independent processes in qualitative research design. While data collection actually entailed the process of interviewing, informal analysis of the respondents was also conducted during the interview. Handwritten assessment notes taken during and after the interview constituted part of the initial research design. Immediate review of audiotapes, *verbatim* review of the interview transcript and notes to the methodological log were additional analysis steps that intertwined with data collection. Thus, analysis was ongoing and occurred during the process of data collection.

Details of the interview setting and procedure, field notes/methodological log, transcriptions, case study development, case analysis follow.

#### **4.6 ETHICAL CONSIDERATIONS**

Due to the charged, and emotive nature of the HIV/AIDS phenomenon, certain ethical considerations assumed particular importance. Rosnow and Rosenthal (1996:32) note that the very nature of the aim of a phenomenological study, namely to access the individual's life world, is obtrusive. In this study, this obtrusiveness will further be exacerbated by the sensitivity of the topic under investigation. First and foremost, the researcher will have a responsibility to respect the rights, needs, values and wishes of the participants (Rosnow & Rosenthal, 1996:12). In order to protect the participants' rights, the following safeguards as listed by Cresswell (1994:23) are employed:

- the research topic and objectives will be expressed clearly in order to be well understood by the participants;

- each participant's consent will be requested to participate in the study;
- transcriptions, interpretations and reports will be made available to the
- participants if they wish to see them;
- in any decision-making process in the study, the researcher will consider the rights and protection of the participants; and
- the researcher will honour confidentiality. The participants will choose their pseudonym to be used in the texts to protect their anonymity. It is anticipated that the discussion of the experience of meaning in individuals with HIV may prove to be emotionally distressing for some participants. Participants, therefore, will be monitored and debriefed. If necessary the researcher will make recommendations for therapeutic interventions (Eagle, 1998:67).

#### **4.7 CONCLUSION**

This chapter presented a research design employed in this study the next chapter deals with analysis and interpretation of data collected by means of interviews.

## CHAPTER FIVE

### 5.1 INTRODUCTION

This chapter provides analyses and interpretations of a case of HIV positive learner Bulelani (not her real name). Her personal experiences were investigated through the following themes which are the:

- effects of HIV/AIDS on their psychological well being;
- effects of HIV/AIDS on their physical well being;
- nature and extent of support infected learners get; and
- effects of HIV/AIDS on their school performance.

The family background will be placed first, followed by *verbatim* transcription of the interview and analysis and interpretation.

### 5.2 CASE STUDY: BULELANI (MOTHER-TO-CHILD TRANSMISSION)

#### 5.2.1 Introduction

As indicated in the previous chapter the interviewer interviewed four people. These respondents included one infected learner, her cousin, her class teacher and her aunt (N=4). The interviewer had two interviews with the infected learner, Bulelani and her cousin Lebohang (not their real names). Each session lasted about two hours. Bulelani and her cousin Lebohang were interviewed simultaneously, because, when talking to the cousin earlier on, before the interview started, it was realised that the two were comfortable being together. Lebohang felt that Bulelani would speak freely in her presence. The other two respondents, the teacher and the social worker were interviewed individually.

### **5.2.2 Family background**

Bulelani is an eleven-year-old, grade six learner who was born in Evaton on 2 September 1993. Bulelani is the only child in the family. Bulelani's mother lived with her husband in Evaton after they got married. Bulelani's father became very ill and passed away in February 2001. His wife also became ill and passed away in July 2003. By the time Bulelani's mother was ill, she came to live in Zone 7 with her brother's family. Bulelani's mother brought her daughter along to stay in Zone 7, as there was no one to take care of her in Evaton.

Bulelani's uncle lives with his wife and their daughter who is the last-born in the family. He has two children, the first-born is married and has his own house and the other Lebohang, is still living with her parents. Lebohang completed her studies at Vaal University of Technology in 2004 and she is still searching for a job. Bulelani's uncle and aunt (on her mother's side) adopted her legally, after the death of her parents. Bulelani's uncle is working in a firm in Johannesburg and her aunt is a housewife. The family attends a church service every Sunday. They are all born-again Christians. They all live in a four-roomed house, which was left by her uncle's grandparents.

Bulelani knows that she is HIV positive - she overheard a conversation between a nurse working in a nearby clinic and her aunt talking about her status after being tested, without her consent. She was very ill in January 2004; and her aunt took her to the clinic where she was tested.

### **5.2.3 Progress Of conversation**

Here follows the transcription of the interview with Bulelani.

**Interviewer:** How did you feel when you heard about your HIV positive status?

**Bulelani:** I felt like screaming. I could not believe what the doctor had just said. The doctor was not even telling me, he was revealing my status to my aunt who is my uncle's wife. I felt as if the doctor would have told me and not

my aunt, I felt betrayed. I was very sad and frustrated. What came to my mind was what my friends were going to say when my status is revealed to them. I also thought of the teachers at school and people in our community. All the time the doctor was talking, I was hoping that he had made a mistake and that he was going to realize that before we left.

**Interviewer: How did you feel when you heard about Bulelani's HIV positive status?**

**Aunt:** Although I was expecting her to be, I really felt bad. I thought of her mother before she died. I was the one who was taking care of her. She was very ill and looked frail and very thin. I felt very sorry for this child who at her age was facing such hardship. I wished that the doctor would have made a mistake. I also felt as if the doctor would have revealed her status in her absence so that when I have dealt with this myself, I would find way of breaking the news gently to her.

**Interviewer: Were you expecting HIV positive or negative results when you were tested?**

**Bulelani:** I think I was expecting positive results, I knew that both my parents died of HIV/AIDS, especially my mother, although I was still young but I could sense it. No one told me what my parents were suffering from - I did not even bother to ask my uncle or my aunt, I knew they would tell me something else. I suspected that I could be HIV positive but I did not want that confirmed. In January 2004 when I was ill I had sores all over my body, my mother was like that when she started being sick.

**Interviewer: Were you counselled before you got tested?**

**Bulelani:** No, I was not counselled. The nurse asked my aunt a few questions about my health, such as, when did I start being ill? Have I been tested? Do I get sick more often? How did my parents die? The nurse then asked me if the sores are itchy.

**Interviewer: Did you notice any change in Bulelani's behaviour or health after the day she was tested for HIV?**

**Cousin:** Yes there was change in her behaviour, she is a lively person, but she was reserved for the whole of that week. We were also very worried as she could refuse to go out and play with her friends. She ate very little, sometimes she could not even touch her food, and she had lost her appetite. Her health deteriorated to an extent that she could not go to school for the whole of that week. By the end of the second week one could see that she lost weight.

**Interviewer: What did you do about this as guardians?**

**Aunt:** There was nothing we could do - we just waited for her to recover. We thought that taking her back to the clinic would make things worse.

**Interviewer: How do you feel about not being told that your parents had HIV/AIDS and that you are also infected?**

**Bulelani:** Bad, very bad, I wish they would stop treating me like a baby. I wish they would just sit down with me, tell me everything, I mean every little detail about my parents and how they contracted the disease. They talk about my life behind closed doors; it is as if I do not exist. Even when my uncle and my aunt have decided to take me to the doctor (this is what they usually do whenever my health deteriorates) they do not consult me. I wish that one of them could just advise me on what to do and what not to do so that I can adopt and maintain a healthy lifestyle.

**Interviewer: What could be your reason/s of not telling Bulelani that her parents died of HIV/AIDS?**

**Aunt:** We thought of telling her when she is at least sixteen, she is still very young to be told about those things. We feel that she should concentrate on her own life rather than thinking about her parents. I am concerned about the impact that disclosure may have on Bulelani's emotional health and I am also

afraid that the knowledge will negatively affect her will to live. How will Bulelani feel knowing that she is HIV-infected because of her parents.

**Interviewer: What do you think your adopted parents could talk to you about concerning your status?**

**Bulelani:** I sometimes become very ill because I have no appetite. I eat just a little bit of porridge in the morning and rush off to school. My aunt gives me R2, everyday to buy something at school during break. In the tuck shop at school they only sell sweets, chips and skhambane (quarter of bread with a little bit of chips, achar and mangola). With the R2 I have I could afford to buy skhambane but I do not always have an appetite, so I would stay the whole day without food. When I arrive home after school my aunt would give me something to eat, I would pretend as if I am full, I would say I bought skhambane at the tuck shop. Even in the evening at suppertime I do not eat I just have a little piece of meat and a little bit of cabbage and that would be enough. Not eating well (not that they do not cook healthy food, they try to for my sake) because of the lack of appetite, it makes me weak and I would become ill occasionally. This disturbs me with my studies. In a term I think I am absent from school for about a month because of ill health. I feel that if we could sit down as a family, we could come up with something that can improve my appetite. I also need information about the progression of HIV/AIDS in a human body, I need to know how much time I am left with, I would like to know if I can be able to progress up to the University. I know some of the questions they cannot answer, but I need to talk to someone about HIV/AIDS.

**Interviewer: Why are you not asking your teacher some of the questions, especially those that concern HIV/AIDS progression?**

**Bulelani:** I am scared, may be if I ask other learners will suspect that I am HIV positive. No one in our class talks about AIDS, except the teacher when she is telling us about what the acronyms HIV/AIDS mean.

**Interviewer: Do you ever talk about HIV/AIDS with Bulelani at home when you are relaxing?**

**Cousin:** No, no one ever talk about HIV/AIDS, I think we are afraid of how Bulelani would react.

**Interviewer:** **What are you supposed to teach learners about HIV/AIDS?**

**Life Orientation teacher:** I teach them Life Orientation. In this learning area I do not only concentrate on HIV/AIDS. It is just a small part of other aspects that have to be dealt with in this learning area. It depends in other years you have time to cover all the themes including HIV/AIDS, in some years you do not. Basically, I teach them what it means and how it is transmitted. That usually takes about two to three periods per year.

**Interviewer:** **Are they allowed to ask questions on the subject?**

**Life Orientation teacher:** Yes, they are but mainly questions should be based on what I have told them. We do not have time to discuss the topic generally and I feel some of the learners would not be comfortable with this as some of their relatives are HIV/AIDS positive.

**Interviewer:** **Is there a way that you can let these learners choose what they want to talk about concerning HIV/AIDS, that is accommodating their interests?**

**Life Orientation teacher:** I cannot just allow them to choose their own topic, you see, I plan for each day. In my planning I have to say what I am going to teach learners that day, now saying that I am going to depend on what they are interested in is not acceptable. Also I feel they are still too young to be told in detail how HIV/AIDS is contracted and all the other sensitive information around the subject. I think they will get some of the information from the nurses and the media.

**Interviewer:** **Why don't you tell the doctor or the nurse at the clinic about your lack of appetite?**

**Bulelani:** I can't, the doctor never asks me anything, he listens to what my aunt or my cousin is telling him. One thing they all tell me is that I am going to be better. My aunt knows that I do not eat well, she tries to force me to eat

sometimes and tries to feed me but *this does not help because I throw up*. My cousin would even beg me to eat, I also want to sometimes, but I just can't, I feel I am not given a chance to be part of what is happening in my life.

**Interviewer: What else do you wish you could talk about besides the progression of HIV/AIDS and your lack of appetite?**

**Bulelani:** I know that I am going to die. Whenever I see a person with AIDS at the clinic I think of death and I think of how my mother was before she died (*very thin, frail and very sick*). I do not always think of death or of my status for that matter, but I wish I could get more information on how to keep healthy so as to live longer. I know that exercise helps, I heard that from my Life Orientation teacher at school, but I have never exercised. I want to exercise, *when I am not sick I play a lot, in my mind I am trying to exercise. I wish I could get more information about the disease and how it affects people. I want to know about the stages of HIV/AIDS, I am dying to hear from other children of my age how it affects their lives. When they talk about it on TV I try to listen but it is always about medical stuff I do not understand.*

**Interviewer: Which learning areas involve HIV/AIDS at school?**

**Bulelani:** It is mainly Life orientation. The teacher does not tell us much about HIV/AIDS. *She asked us what we know about the HIV/AIDS. One of the learners told the teacher that what he knows is that it kills. The teacher told us that she did not know much about the virus but told us how people become infected. She mentioned three ways on how people can become infected, that is through Mother-to-child transmission (MTCT), through sex and through blood transfusion. These were just mentioned and not discussed I am still interested to know what and how exactly people become infected in these three ways. This year we were told that eating healthy and exercising helps in maintaining good health.*

**Interviewer: Do you eat healthy or exercise regularly?**

**Bulelani:** I do exercise although I cannot say regularly, I play a lot with my friends and most of the time we use skipping rope, but when I am ill it

becomes impossible to do so until I have recovered. I do not think I eat healthy though as most of the time I do not have appetite.

**Interviewer: What do you do about Bulelani's lack of appetite?**

**Aunt:** There is nothing we can do if she does not want to eat, I once bought her multivitamin tablets, I am not sure if they worked I do not remember monitoring her during that time. We just try to cook what she usually likes eating which is not healthy at all, "pap and meat" instead of vegetables.

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

**Cousin:** The class teacher is complaining, Buli is not doing well at all at school. Her books are very neat she takes pride in her work, however her performance is affected by her high rate of absenteeism like now she has been absent for two weeks and it is the time when other learners are writing tests for the end of the term. Buli also has a problem she says she lacks concentration in class as she is always thinking about her positive status.

**Interviewer: How is Bulelani in class?**

**Life Orientation teacher:** I think she would do well if her performance was not affected by her high rate of absenteeism, she also gets tired very easily, as a result it is difficult for her to complete tasks. I can say her performance is a little below average, but she was the best student in Grade one and two. Her performance started dropping last year when she started becoming ill.

**Interviewer: What do you do at school to help Bulelani catch up with her work after absence?**

**Life Orientation teacher:** We really do not have a strategy at school to help learners who have been absent from school. I personally try to explain what I am teaching that day thoroughly so that they at least get something, but to teach what one has taught two weeks ago in her absence is very difficult. I am thinking of what other learners are going to do when I am busy teaching Bulelani only.

**Interviewer: Is there a way that these learners that are frequently absent because of illness can be given extra classes to help them catch up?**

**Life Orientation teacher:** I think they may be given extra classes but we have done that at our school. We rely on them to take the initiative to ask others what has been done in their absence. The problem is when they do not understand what others are telling them or when those that were attending cannot explain thoroughly for them to understand.

**Interviewer: What do you do to help Bulelani at home with her school work?**

**Cousin:** There is nothing much we can do, it is the teacher's duty to see to it that learners are not only taught but also understand what they have been taught. We are not teachers, we are her relatives.

**Interviewer: Why are you not asking for help from other learners Bulelani?**

**Bulelani:** I am afraid to ask for assistance from other learners, I think may be they will laugh at me. I am not stupid I know myself but if you were not at school for a long time you lose out on important lessons and it is very difficult to catch up. I think other learners would say I am stupid if I ask them for help.

**Interviewer: Do you experience any discrimination in your area as a family because of her status?**

**Cousin:** No, people in our area do not know that Bulelani is HIV positive, the only people that know about her status are us as her immediate family and my boyfriend's family. We are not a socialising family, we do not usually go out with other people, we are always at home or when we are out we have gone to town. I sometimes take her along to visit my boyfriend's parents, one time she became ill when we were there, that is when I told them about her status. My boyfriend's mother was very supportive; she even accompanied us back home to make sure we were safe.

**Interviewer: Do you experience any discrimination at school Bulelani?**

**Bulelani:** Children at our school do not know that I am HIV/AIDS positive, but they always tease me about being thin. They call me "broom stick", because sometimes I feel very weak and I cannot play for a long time they do not choose me as their partner. My friends do not want to eat my food as they say I am going to infect them with what I am suffering from.

**Interviewer:** How do you deal with discrimination at your school?

**Life Orientation teacher:** We have not had any cases of discrimination at our school - if they are there they have not been reported. We have an HIV/AIDS policy that we do not use as there are not many HIV cases reported in the school. May be if cases of discrimination can be reported we can see what we can do.

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

**Bulelani:** No one, I do not want to tell my teacher about my status, in fact I do not want her to know. I feel if she knows she will treat me differently, or she will always see a person who is HIV positive and not just one of the learners. I also do not want to tell my friends, I do not want to lose them. No one in our school has ever come up and said s/he is HIV positive. I wish it was easy to do so without fear of what people would say.

**Interviewer:** Who have you told about Bulelani's status?

**Aunt:** No one, I do not want to tell people about Bulelani's status, even members of the family. I do not want people to spread rumours about our family. In our community if one member of the family is HIV positive they just say the whole family is infected.

**Interviewer:** What do you do with the money you save?

**Bulelani:** I would like to be an artist. I like drawing especially people, whenever I have money I would buy myself colouring pencils, drawing books, paintbrushes, colour paints and dolls. When I am not playing with my friends I am in the bedroom I share with my cousin, painting or drawing. I draw a lot

especially when I am ill and staying at home, bored and when I miss my mother. I also draw when something good or bad has happened to me.

**Interviewer: How do you feel when you cannot go to school because you are sick?**

**Bulelani:** Very frustrated, I would miss school, my friends and my teachers a lot, I would hope for a speedy recovery but that does not happen sometimes. I would be very excited when my aunt tells me to wake up and get ready for school after a relapse, I would feel like I am back to where I belong.

**Interviewer: Does drawing help you to relieve the frustration you experience when you cannot go to school?**

**Bulelani:** I think so; I forget about everything when I am drawing, I only think about what I want to draw, I hate being disturbed when I am drawing. It is as if I can tell my aunt and my cousin not to come to my room when I am drawing, but because they are always so concerned they come and ask me to come to the living room, when I am too sick they take turns to come and sit with me in my room.

**Interviewer: Have you seen Bulelani's drawings?**

**Cousin:** Yes, I have seen her drawings because we share a bedroom, she does not show her work to anyone but I do not think she is hiding it. She draws people mostly both old and young, sometimes her classroom or the house we are living in. Her drawings are about sad and happy people, children playing and so on. I never thought of asking her about her drawings, I would just pass a remark if the drawing was good or bad. I think she is an artist she draws very neatly; if she can get someone who is a qualified artist just to guide her she would be very good.

**Interviewer: How often does a nurse, a doctor or any health worker come to your school to talk to you about HIV/AIDS?**

**Bulelani:** They come once a year between August and September, an AIDS day is organised around that time at our school. We would celebrate AIDS day

the same way each and every year, a nurse telling us about AIDS how it is contracted, a person who is HIV positive would also speak and tell us how s/he contracted the disease and then it would be performances by learners in our school, then we would eat. The first year when this was organised in our school we moved around our area issuing out condoms, our principal told us that we have to do this to make people in our community aware that HIV/AIDS kills and they should use condoms.

**Interviewer: How often do you organise health workers, non governmental organisations to address learners on matters pertaining to HIV/AIDS?**

**Life Orientation teacher:** Yes, we can manage to do that once a year when we are celebrating the World AIDS day. We do not have time to organise these occasions, we are aware that they are very important for learners but at the same time we have to concentrate on teaching.

**Interviewer: Have you ever been counselled at school by a qualified counsellor or by your teacher?**

**Bulelani:** There are no qualified counsellors at school; we only have teachers and clerks. I was once very emotional in class, I think I was frustrated because I did not know how the sums we were given were done and other learners were quickly doing them and showing their work to the teacher, it was the work they were doing two days before I came to school after being sick. I cried because I did not know what to do. The teacher saw this, she called me and asked what the problem was, I told her the truth, she started telling me that it was not my fault that I did not know the work, she is going to help me with it and she is going to make sure that I am helped by one of my friends whenever I need help. We talked about this for about fifteen minutes; she was also trying to comfort me. I felt relieved after that and continued with my work.

**Interviewer: Did it help you to talk about your problem to your teacher?**

**Bulelani:** Yes, it helped a lot, I was very frustrated and I felt relieved after I spoke to the teacher about my problem. She even offered to help me, if I did not tell her what my problem was she would not have been able to help me.

**Interviewer:** Do you think you will be able to talk to her if you feel frustrated about your HIV/AIDS status?

**Bulelani:** No, I cannot talk to her about that, I do not want my teacher to know about my status.

**Interviewer:** But do you think if you were willing to talk about it, it would help?

**Bulelani:** Yes, I think it would help somehow, if she understands and if she knows anything about being positive.

### **5.3 ANALYSES AND INTERPRETATION**

The analysis and interpretation will be based on the following themes that are addressing the aims of this research, the themes are:

#### **5.3.1 Effects of HIV/AIDS on the infected learner's psychological well being**

- Psychological disturbance
- Change of behaviour or health after HIV positive status has been revealed
- Concern about what other people would say
- Hope for a negative status
- Fear of death

#### **5.3.2 Effects of HIV/AIDS on the infected learner's scholastic performance**

- Absenteeism and lack of concentration affecting performance

- Absence of strategy to assist learners who are absent frequently because of being ill.
- Lack of assistance with school work at home
- Loss of valued level of functioning
- Lack of assistance at school
- Fear of being discriminated or ridiculed
- Discrimination and lack of measures to deal with it

### **5.3.3 General support**

- Support from school
- Lack of counselling
- Lack of information on HIV/AIDS
- Lack of support from the community
- Fear of disclosing to friends
- Non disclosure of HIV status by parents
- Lack of communication between parents and infected learners about issues regarding HIV/AIDS

### **5.3.4 Analysis**

#### **5.3.4.1 Psychological disturbance**

Responding to the question about how she felt when her HIV positive status was revealed to her, the respondent indicated the following:

'I felt like screaming'

'I could not believe what the doctor had just said'

'I was very sad and frustrated'

Having parents that died because of HIV/AIDS seem not to have prepared Bulelani for the positive HIV results, this is what she said:

"I suspected that I could be HIV positive but I did not want that confirmed. In January 2004 when I was ill I had sores all over my body, my mother was like that when she started being sick"

Caretakers are also affected when children they are taking care of are diagnosed HIV positive, this is what Bulelani's aunt said:

"Although I was expecting her to be, I really felt bad. I thought of her mother before she died. I was the one who was taking care of her. She was very ill and looked frail and very thin. I felt very sorry for this child who at her age was facing such hardship. I wished that the doctor would have made a mistake"

Bulelani indicated that it would have been better if she her HIV positive status was not revealed in front of her aunt. Bulelani's aunt also felt that it would be better if Bulelani was not there when the doctor revealed her status, this is what they said:

"I felt as if the doctor would have told me and not my aunt, I felt betrayed. I was very sad and frustrated. What came to my mind was what my friends are going to say when my status is revealed to them"

"I also felt as if the doctor would have revealed her status in her absence so that when I have dealt with this myself, I would find way of breaking the news gently to her"

### **Interpretation**

The respondent indicated being frustrated, sad and not believing what the doctor revealed. It is indicated in the literature review that HIV/AIDS epidemic itself is an obvious source of psychological distress (see literature).

The respondent indicated that the death of both parents due to HIV/AIDS did not prepare her for a positive HIV status. It seems that infected learners whose parents died of HIV/AIDS experience more fears as they normally have a picture of their parents before they died.

Bulelani's aunt seem to have suffered psychological distress because Bulelani's HIV/AIDS status. It seems that caretakers and guardians of these learners are also not spared of the pain they undergo.

Both respondents feel that the positive HIV status would have been revealed to them separately, this seems to have evoked stress for both these respondents.

#### **5.3.4.2 Change of behaviour or health after HIV positive status has been revealed**

The respondent in this question indicated a change in Bulelani's behaviour and health after the disclosure of her positive HIV/AIDS - this is what the respondent said:

"Yes there was change in her behaviour, she is a lively person, but she was reserved for the whole of that week. We were also very worried as she could refuse to go out and play with her friends. She ate very little, sometimes she could not even touch her food, and she had lost her appetite. Her health deteriorated to an extent that she could not go to school for the whole of that week. By the end of the second week one could see that she lost weight"

#### **Interpretation**

The change in Bulelani's behaviour could be attributed to the emotional disturbances she experienced when her HIV status was revealed to her aunt.

#### **5.3.4.3 Concern about what other people would say**

The respondent seemed to be more concerned about what people would say, this is what she said:

'What came to my mind was what my friends are going to say when my status is revealed to them. I also thought of the teachers at school and people in our community'

'The doctor was not even telling me, he was revealing my status to my aunt who is my uncle's wife'

### **Interpretation**

The respondent indicated fears about what other people would say when they are informed of her HIV positive status. Fear of being discriminated against and prejudiced may cause Bulelani to be scared of what people would say. She is not sure how they are going to react to this.

#### **5.3.4.4 Hope for a negative status**

The respondent and her aunt both hoped for a negative status, this is what they said:

'All the time the doctor was talking I was hoping that he had made a mistake and that he was going to realize that before we left'

'I suspected that I could be HIV positive but I did not want that confirmed'

"I wished that the doctor would have made a mistake"

### **Interpretation**

The respondent indicated hoping for a negative status. This could also be a sign of disbelief and denial.

#### **5.3.4.5 Fear of death**

'I know that I am going to die. Whenever I see a person with AIDS at the clinic I think of death and I think of how my mother was before she died (very thin, frail and very sick)'

'I am sometimes afraid that maybe when death comes I would all alone at home. As a result I make sure that I hear them from the kitchen or dining room where they are. I do not want to be alone or to die alone'

'I know that I am going to die'

## **Interpretation**

The respondent indicated fears of death - this could be attributed to the fact that she has experienced both her parents getting ill everyday and eventually died. This could also be an indication of the fact that when she thinks about HIV/AIDS what comes to her mind is death.

### **5.3.5 Effect of HIV/AIDS on general performance in school**

#### **5.3.5.1 Performance affected by absenteeism and lack of concentration**

Responding to the questions about Bulelani's general performance in class, Bulelani and her cousin and the class teacher said:

'Her books are very neat she takes pride in her work, however her performance is affected her high rate of absenteeism like now she has been absent for two weeks and it is the time when other learners are writing tests for the end of the term'

'Buli also has a problem she says she lacks concentration in class as she is always thinking about her positive status'

'The class teacher says Buli gets tired very easily, as a result it is difficult for her to complete tasks'

'I think she would do well if her performance was not affected by her high rate of absenteeism, she also gets tired very easily, as a result it is difficult for her to complete tasks. I can say her performance is a little below average, but she was the best student in Grade one and two. Her performance started dropping last year when she started becoming ill'

## **Interpretation**

From these responses it can be deduced that Bulelani's performance is affected by high rate of absenteeism, lack of concentration in class and getting tired easily. All these factors are negatively affecting Bulelani's performance.

### **5.3.5.2 Absence of strategy to assist learners who are absent frequently because of illness**

The Life Orientation educator indicated not having a strategy at her school for assisting learners who are frequently absent because of illness, this is what she said:

'We really do not have a strategy at school to help learners who have been absent from school. I personally try to explain what I am teaching that day thoroughly so that they at least get something, but to teach what one has taught two weeks ago in her absence is very difficult. I am thinking of what other learners are going to do when I am busy teaching Bulelani only'

'I think they may be given extra classes but we have not done that at our school. We rely on them to take the initiative to ask others what has been done in their absence. The problem is when they do not understand what others are telling them or when those that were attending cannot explain thoroughly for them to understand'

## **Interpretation**

The Life Orientation educator indicated that they do not have extra classes for learners who are frequently absent because of illness, they also do not have a strategy to assist these learners to catch up. This could indicate that if these learners are not assisted at school to catch up, they could fail and end up dropping out of school.

### **5.3.5.3 Lack of assistance at home**

The respondents indicated lack of assistance towards Bulelani on her school work and her illness, this is what the respondents said:

'There is nothing much we can do, it is the teacher's duty to see to it that learners are not only taught but also understand what they have been taught. We are not teachers, we are her family'

'There was nothing we could do - we just waited for her to recover. We thought that taking her back to the clinic would make things worse'

#### **Interpretation**

Both respondents indicated that they are unable to help the infected learner with her schoolwork and that there is nothing they could do when she was ill. This indicates that these respondents lack information on how to help children with schoolwork. This could also be an indication that the school and the home do not work together to help these learners.

### **5.3.5.4 Loss of valued level of functioning**

The loss of valued level of functioning appeared to be a problem for Bulelani, this is what she said:

'I am afraid to ask for assistance from other learners, I think may be they will laugh at me'

'I am not stupid I know myself but if you were not at school for a long time you lose out on important lessons and it is very difficult to catch up'

'I think other learners would say I am stupid if I ask them for help'

#### **Interpretation**

Bulelani indicated loss of valued level of functioning regarding schoolwork as she used to be intelligent. She also indicated being scared of what other learners would say if she asks for assistance from them. The loss of

functioning could be very frustrating for the respondent, as she would struggle to do things she used to do with ease.

#### **5.3.5.5 Lack of assistance at school**

The respondent indicated not being helped to catch up with the work being a problem, this is what she said:

'She does not help me with catching up, she just tries to explain what she is teaching that day thoroughly'

I do not think she would have time to start all over again and teach me everything she taught others in my absence.

The teacher mentioned not having enough time for discussion of the topic of HIV/AIDS, she said about that:

'Yes, they are but mainly questions should be based on what I have told them.' 'We do not have time to discuss the topic generally and I feel some of the learners would not be comfortable with this as some of their relatives are HIV/AIDS positive.'

'Also I feel they are still too young to be told in detail how HIV/AIDS is contracted and all the other sensitive information around the subject.' 'I think they will get some of the information from the nurses and the media.'

#### **Interpretation**

Bulelani indicated not being helped by the teacher to catch up with the schoolwork as being a problem she feels that teachers might not have time to teach her again the work they have already done with the other learners. This will have a negative effect on this learner's performance.

The teacher mentioned not having enough time for discussion of the topic of HIV/AIDS in general in class she also indicated fears that some of the learners would not be comfortable with the topic of HIV/AIDS as some of their

relatives are HIV positive. This could deprive other learners' valuable information they need on HIV/AIDS.

#### **5.3.5.6 Fear of being discriminated or ridiculed**

The respondent indicated fear of being discriminated against, or ridiculed if she asks for assistance from other learners, this is what she said:

'I am afraid to ask for assistance from other learners, I think may be they will laugh at me. I am not stupid I know myself but if you were not at school for a long time you lose out on important lessons and it is very difficult to catch up. I think other learners would say I am stupid if I ask them for help'

#### **Interpretation**

The respondent indicated that she fears being discriminated against or ridiculed if she asks for assistance from other learners. She is also worried that other learners would say she is stupid. These fears will prohibit the learner from asking for help and deprive her of the assistance she could have got.

#### **5.3.5.7 Discrimination at school and absence of measures to deal with it**

The respondent indicated being discriminated against by her friends at school. The teacher indicated that cases of discrimination are not reported to them. This is what they said:

'Children at our school do not know that I am HIV/AIDS positive, but they always tease me about being thin. They call me "broom stick", because sometimes I feel very weak and I cannot play for a long time they do not choose me as their partner. My friends do not want to eat my food as they say I am going to infect them with what I am suffering from'

'We have not had any cases of discrimination at our school - if they are there they have not been reported'

## **Interpretation**

The respondent indicated being discriminated against by other learners at school. The teacher indicated that cases of discrimination are not reported to the school and thus they do not have a record of those cases. It is worrisome that these cases are not reported by learners as that would create a platform for educators to deal with discrimination and prejudice in the school.

### **5.3.5.8 Lack of counselling at the health centres and at school**

The respondent indicated not being counselled before being counselled and after, she also mentioned lack of counselling at school, this is what she said:

'No, I was not counselled. The nurse asked my aunt a few questions about my health, such as, when did I start being ill? Have I been tested? Do I get sick more often? How did my parents die? The nurse then asked me if the sores are itchy'

'There are no qualified counsellors at school; we only have teachers and clerks'

## **Interpretation**

The respondent indicated not being counselled before and after testing, she also indicated a lack of counselling at school. This is against the Department of Health mandate that all persons who are testing for HIV/AIDS should be counselled before the test to prepare them for the results, and after to help them.

### **5.3.6 Nature and extent of support infected learners get**

#### **5.3.6.1 Support from school**

The respondent indicated being assisted to understand schoolwork by the teacher, this is what she said:

'My school teacher assists me with school work, she makes sure that I am helped by one of my friends whenever I need help'

## **Interpretation**

It is impressive that the teacher helps Bulelani to understand the schoolwork when she is at school. Understanding the work would help to boost the learner's self esteem.

### **5.3.6.2 Lack of information on HIV/AIDS**

The respondent indicated lack of information regarding HIV/AIDS and the fact that she would like to know how other learners are affected by HIV/AIDS.

'I wish I could get more information on how to keep healthy so as to live longer. I know that exercise helps, I heard that from my Life Orientation teacher at school, but I have never exercised'

'I am dying to hear from other children of my age how it affects their lives. When they talk about it on TV I try to listen but it is always about medical stuff I do not understand'

## **Interpretation**

The respondent indicated lack of information regarding HIV/AIDS and lack of support groups for infected learners where she would understand how they are affected by HIV/AIDS. This lack of knowledge regarding HIV/AIDS can be attributed to the fact that talking about HIV/AIDS is a taboo in these communities.

### **5.3.6.3 Lack of social support**

The respondent indicated that Bulelani's HIV status has not been disclosed to members of the community, this is what she said:

'No, people in our area do not know that Bulelani is HIV positive, the only people that know about her status are us as her immediate family and my boyfriend's family'

## **Interpretation**

The respondent indicated that her HIV positive status had not been disclosed to other members of the community, hence there is a lack of support. Non-disclosure of an HIV status can deprive the infected of the valuable support they dearly need.

### **5.3.6.4 Fear of disclosing to friends and teachers**

The respondent indicated that she fears disclosing to teachers and friends, this is what she said:

'I do not want to tell my teacher about my status, in fact I do not want her to know. I feel if she knows she will treat me differently, or she will always see a person who is HIV positive and not just one of the learners'

'I also do not want to tell my friends, I do not want to lose them. No one in our school has ever come up and said s/he is HIV positive. I wish it were easy to do so without fear of what people would say'

## **Interpretation**

The respondent indicated fears disclosing to teachers and friends as she does not know what they are going to say. Fear of what people say and of what they think seem to be the major barrier to non-disclosure of positive HIV/AIDS status.

### **5.3.6.5 Non-disclosure of HIV status by parents**

"Bad, very bad, I wish they would stop treating me like a baby. I wish they would just sit down with me, tell me everything, I mean every little detail about my parents and how they contracted the disease. They talk about my life behind closed doors; it is as if I do not exist"

"We thought of telling her when she is at least sixteen, she is still very young to be told about those things. We feel that she should concentrate on her own life rather than thinking about her parents. I am concerned about the impact that disclosure may have on Bulelani's emotional

health and I am also afraid that the knowledge will negatively affect her will to live. How will Bulelani feel knowing that she is HIV-infected because of her parents”

### **Interpretation**

The respondent seems to be stressed by the fact that her parent's status has not been disclosed to her. There are several reasons why her aunt decided not to tell her about her parent's status. All these reasons seem not to be acceptable to Bulelani.

#### **5.3.6.6 Lack of communication between parents and infected learners about issues regarding HIV/AIDS**

“Bad, very bad, I wish they would stop treating me like a baby. I wish they would just sit down with me, tell me everything, I mean every little detail about my parents and how they contracted the disease. They talk about my life behind closed doors; it is as if I do not exist”

“I feel that if we could sit down as a family, we could come up with something that can improve my appetite. I also need information about the progression of HIV/AIDS in a human body, I need to know how much time I am left with, I would like to know if I can be able to progress up to the University”

“No, no one ever talk about HIV/AIDS, I think we are afraid of how Bulelani would react”

### **Interpretation**

The respondent indicated lack of communication regarding issues related to HIV/AIDS as one of the sources of stress. It seems difficult for the respondent to carry on with life, there are important things that she would like to communicate to her family. This lack of communication may have negative effects on the relationship.

## 5.4 FOCUS GROUP INTERVIEWS

### 5.4.1 Introduction

In this section data collected by means of focus group interviews will be analysed and interpreted. The interviews are written first then analysis and interpretation of data follows. Data is analysed and interpreted by means of themes.

### 5.4.2 Interview proceedings

**Interviewer:** How is being HIV positive affected you emotionally?

**Thandeka:** I feel like crying all the time, I cannot concentrate on my schoolwork. I am afraid to sit next to a person who is HIV positive not that s/he is going to re-infect me, but I just do not feel comfortable.

**Jabulani:** When I look at people who are HIV positive I feel sorry for myself. I think of what is going to happen to me in future and how is being HIV positive going to affect my life. It is when I see other people with AIDS that I think of my own status.

**Ubuntu:** I feel sad, and sorry for myself, sometimes I think I even feel pain in my heart. I always think of death as I know that people with HIV/AIDS do not live long.

**Aphiwe:** When my positive HIV status was revealed to me I cried, I was very disturbed emotionally. I think I have accepted that I am sick. I love my parents (which are both deceased) very much although sometimes I blame them for infecting me with this dreadful disease.

**Selina:** I feel very bad each time I look at my elder sister and brother I ask myself why me? Why is it not one of them who is infected? I was diagnosed HIV positive three years ago. I was very sick at the clinic they tested me and revealed my status to me and my mother. I think I am disturbed because I sometimes loose memory. My mother used to console me by saying that I am not the only one since my parents are also HIV positive.

**Interviewer: How is being HIV positive affected you spiritually?**

**Thandeka:** I am always praying it is as if God does not hear my prayers. I think this is a curse for me. I pray that God should heal me or just make this disease to go away.

**Jabulani:** I always plead with God to help doctors get a cure for HIV/AIDS before I become very sick like my father before he died. Sometimes I pray that God can take me so that I can find rest as I am sometimes suffering a lot.

**Ubuntu:** I always pray that God can intervene so that all people who are dying of HIV/AIDS can be healed by prayer. I do not pray only for myself I pray for others as well because if God does not heal all of us AIDS will still spread.

**Aphiwe:** I pray to God and plead with Him to heal me. God is my only hope, I trust Him. The prayer helps me as I feel I cannot just sit, do nothing and just slowly die. I arrive last year here at the shelter there are three babies who are already dead. When they arrived the house mother informed us of their status so that when we play with them we must be careful. It is sad to watch other children dying knowing that one day it is going to be your turn.

**Selina:** Everyday I ask myself whether this is because of God's wrath because if it is that is why He does not help us get a cure for AIDS. I also ask for forgiveness for the sins I have done. I feel that I should have done something very bad to evoke God's anger on me.

**Interviewer: How is being HIV positive affected you physically?**

**Thandeka:** Sometimes I do not even eat. We are aware of all the children who are positive in the shelter. When one of them is sick I become very worried. I think of my own health. I also think and dream about how I would be in my last stages of HIV/AIDS. When I am day-dreaming I see myself as thin as a rake and very frail. I wish I would have someone to take care of me. I do not think that our house mother would be able to take care of all of us.

**Jabulani:** There are times when I have sores all over my body, sometimes they take a long time to heal. Then there are times when I have shingles, I cannot even go to school during this time. Shingles are very painful.

**Ubuntu:** I do not sleep well at night. When this started it was because I used to think a lot about my condition, that I am living at the shelter while other children are living at their homes with their parents. I used to think about my status and what is going to happen to me in future. Now I do not sleep because I am afraid that I would die on my sleep. When one of us coughs, or is in pain I just toss and turn the whole night. I always think of what I would do if the other child can die while sleeping with me.

**Aphiwe:** My weight is gradually dropping I am now as thin as a rake. I do not eat well. It is difficult to sit and enjoy a meal my appetite has also decreased. My friends at the shelter know this. They would sit next to me at lunch so that I can share my lunch with them. The house mother sometimes forces me to eat and make sure that I finish my meal. This does not help as I would throw up.

**Selina:** I do not sleep at night I am afraid of dying in my sleep. Sometimes it is as if the bed is too soft then I would sleep seated on a chair. It is very difficult to do this as I can just fall off. I also have nightmares because of my illness.

**Interviewer:** How has being HIV positive affected your social life?

**Thandeka:** It has not affected my social life that much, I still enjoy hanging out with friends, but we cannot hang out until late we are afraid of being raped by people who are HIV positive and we cannot arrive after 8h00 at the shelter.

**Jabulani:** I do not think it has affected my social life I do not take myself as having a social life or being part of the society for that matter. I take myself as an outcast. I do talk to other children at school and at the shelter but most of the time I am just quiet. I do not think there is any point in chatting or playing with others I am not like them!

**Ubuntu:** I used to like playing with my friends at school, but I do not do that anymore. I do not even enjoy my friends' company I feel that they no longer

love me. I think they know that I am HIV positive. I also had friends at the shelter but when we fight they threaten me that they are going to tell everybody at school that I am HIV positive. They would then mock me and tell me not to play with them as I am going to infect them.

**Aphiwe:** I do not have time to play. After school I have to rush to the shelter to help the house mother with the house chores. I am the eldest and she relies on me on a lot of things. Even if there is nothing to be done at the shelter I do not think of going out to play with other children. I feel guilty.

**Selina:** It is difficult to enjoy the company of other learners who are not HIV positive at school. I think it is a way of protecting myself from them. I just sit and play alone. Because I am used to this at school I also do it at the shelter.

**Interviewer:** How is being HIV positive affect your scholastic performance?

**Thandeka:** I think my performance has been affected. When I think about my positive HIV status I see no point in pursuing my studies. I feel that we are all going to die of HIV/AIDS. It is only now that I still feel healthy in years to come I will also be sick and die.

**Jabulani:** I cannot concentrate at school, I always think of my status. My performance is poor in all the learning areas. I sometimes want to perform better but I just cannot. I think other learners are cleverer than I am. I am not always at school my poor attendance also affects my performance.

**Ubuntu:** My mind is not at school I am in class only physically I always think of my status. There are times when I am very sick. I do not perform well because of lack of concentration in class.

**Aphiwe:** I am always working at the shelter, we have so many chores and when others are sick we have to do theirs as well sometimes I do not have time to do my homework. At school I am tired and cannot concentrate especially when I am not feeling well.

**Selina:** I cannot concentrate in class my performance is becoming poor I do not have time to think about my studies. When I am very sick I have to absent myself. There are times when I do not attend school for a month. There is nothing I can do about this infect I have accepted that I am not like other learners whose only worry is to get good marks. I have my life to take care of.

**Interviewer:** How is being HIV positive affect your daily routine as a learner?

**Thandeka:** My daily routine is affected. Sometimes when I wake up in the morning preparing for school I realize that I have to go for check-up at the clinic. That usually takes the whole day. Then there are days when I am sick and cannot attend.

**Jabulani:** I cannot even plan for one day. I think it is true what they say that people who are HIV positive must live one day at a time! I can tell myself that I am going to do my homework in the evening only to find out that I am sick by then.

**Ubuntu:** There are days when I feel very tired that I cannot even do my class work. In these days I just sit and do nothing in class the whole day. My class educator understands as she was informed of my HIV positive status by the house mother. Even if I want to work like other learners I cannot it is really frustrating.

**Aphiwe:** I am on ARV's I have been told at the clinic that ARV's have side effects. Sometimes I feel nauseous after I have taken my medication. I cannot stay at school when I am like this. It can take me days feeling this way.

**Selina:** I cannot plan ahead, what I have to do depend on how my health is that day. My health is unpredictable. I am well today tomorrow I might be very sick to an extent of being hospitalized.

**Interviewer:** What has helped you to cope whilst living with HIV/AIDS?

**Thandeka:** To talk to other children about HIV/AIDS helps me to cope. We are friends here at the shelter. We help each other a lot although there are

times when we quarrel this happens when we feel that the house mother does not care for us, she is concentrating on other children who have just arrived.

**Jabulani:** I do not think I am coping nothing is helping me to cope. People like the house mother and my class educator try to comfort me sometimes when I am feeling down. This does not help but I just tell them that I am better.

**Ubuntu:** Being with other learners at school help me to forget about my status. Just watching them play or chat makes me feel better.

**Aphiwe:** My aunt visits me every month at the shelter. I get a chance of telling someone how I feel. She brings us fruit and sweets. She is working as a domestic worker. I always look forward to her visit. She told me that she cannot be able to live with me as she has four children of her own and two others who are her younger sister's. She does not earn much. She motivates me to be patient and work hard at school things will be better. Although I do not believe this I feel lucky to have her.

**Selina:** I do not think there is anything that makes me to cope. I live everyday as it comes. I think this is meant to be. I even feel that this is the burden I have to carry until I die.

**Interviewer: What support do you need from your school to cope with being HIV positive?**

**Thandeka:** I think we need to have people who are doctors, nurses, and psychologists to come and educate us about this disease. I think I still need more information on the late stages of the HIV/AIDS disease. People talk about HIV, there are programmes on TV but I still feel that we can talk about it in class more often.

**Jabulani:** At our school AIDS day is celebrated once a year, this when we get a chance of talking to people who have been invited by the school especially those who are HIV positive. I hope we can get a chance like this more often. I think this can help me in the sense that I will better understand HIV/AIDS and I will then be able to perform better in class.

**Ubuntu:** I wish I could get a chance to talk to other learners who are also HIV positive. I think we can be able to share our problems.

**Aphiwe:** I wish I could be able to tell my educator about my status. I am afraid to tell her, as I am not sure how she will react. She is a very knowledgeable person who could be able to advise me on problems I encounter.

**Selina:** I wish educators could be more understanding there are days when I cannot do schoolwork in class, I wish I could just be left alone. When I am absent no one tells me what others have been doing, I wish the educators could re-teach the work done in my absence.

**Interviewer:** What support do you need from other learners to cope with how the HIV/AIDS pandemic has affected your performance as a learner?

**Thandeka:** I wish they could be able to assist me with my work and stop talking bad about people who are HIV positive. I do not think I could be able to tell them that I am HIV positive. I wish I could be able to tell them how I feel when they are talking bad about infected people.

**Jabulani:** I wish they can help me with the activities in class. There are learners who do not want to help me. Others do not want me to be in their group. They say I am a slow learner. I wish they could just accept me as I am.

**Ubuntu:** They do not help me when I am struggling to understand something, I wish they could. When other learners realise that you are struggling to understand something they laugh or mock you. It becomes difficult to ask for their assistance.

**Aphiwe:** I need to be helped with all the tasks we do in class. I love soccer but I cannot play it at school. I do not have soccer boots like other learners and other learners do not allow us to play barefoot.

**Selina:** If other learners could pay me a visit at home when I am absent from school and keep me informed about the schoolwork I would be glad.

**Interviewer: What support do you need from the community to cope with being HIV/AIDS positive?**

**Thandeka:** People in the community should help out especially those who are working. There are times when we do not have school uniform, there are those who come and donate school uniform to the centre. We normally do not get the right sizes of trousers and shirts. There is a system that is used by our house mother that if you got a new trouser and shirt the previous year you won't get them the following year. She is trying to be fair but this does not work as we go to school wearing torn trousers and shirts. They should also not discriminate against people who are HIV positive.

**Jabulani:** I think there should be more shelters for children like us who do not have parents or anyone to take care of them. Our shelter sometimes becomes overcrowded until others decide to move to other shelters or back to the streets. Even if you feel you are not comfortable there is nothing you can do, I hate living in the streets I am not used to that life. I would rather stay in this shelter until I am older then I will decide what to do.

**Ubuntu:** I would love to stay in a normal home where there are few children a mother and a father. I think it is the members of the community who can give us a chance of a better life by adopting us. There are people who come and take us out to their homes for weekend. This happens very rare. I wish more people in the community can do this.

**Aphiwe:** I wish community members would help us out. We are about twenty in our shelter including five babies who are always sick. They need special attention. The house mother and the other woman (we call her aunty) do not seem to cope. There are days when we do not eat after school because they had a lot of work to do. This happens mostly when one of them has to take one or two of the sick babies to the clinic.

**Selina:** I need the community to just accept me and just love me.

**Interviewer: What else can be done to support learners who are infected with HIV/AIDS?**

**Thandeka:** I think it would be good if we can have food at home and at school.

**Jabulani:** We need to be taken care of - the government should also give us grants so that we can be able to lead a normal life.

**Ubuntu:** We need money for food, if we can be able to get a grant. I also need people within the community to take care of me even if they adopt me.

**Aphiwe:** There are social workers and retired nurses who can help us in the shelter there are times when I feel that if we had a nurse it would have been better. I cannot just go and approach them I am afraid.

## **5.5 ANALYSES AND INTERPRETATION**

Here follows analysis and interpretation of results. Themes will be written first then analysis and interpretation of each theme will follow.

### **5.5.1 THEME 1: Effect of HIV/AIDS on emotional well being of infected learners**

The infected learners indicated that they are affected emotionally. This is what they said:

'I feel like crying all the time', 'I feel sorry for myself', 'I feel sad, and sorry for myself', 'I always think of death', 'I cried, I was very disturbed emotionally', 'I feel very bad', 'I sometimes loose memory.'

These learners feel helpless and hopeless they seem not to be having any solution to the problem.

### **5.5.2 THEME 2: Effect of HIV/AIDS on infected learners' spiritual well being**

The participants indicated being closer to God. They pray occasionally for their health. The learners pray for their own health mainly and also for others:

'I pray that God should heal me', I do not pray only for myself I pray for others as well', 'I always pray that God can intervene', God is my only

hope, I trust Him', 'I always plead with God to help doctors get a cure for HIV/AIDS'

For one of these learners prayer makes her feel she has done something instead of doing nothing. This is what she said:

'The prayer helps me as I feel I cannot just sit do nothing.'

For the other participants HIV/AIDS is a punishment from God. This is what they said:

'I ask myself whether this is because of God's wrath'; 'I feel that I should have done something very bad to evoke God's anger on me'

There are learners who pray because they are depressed or need a miracle. This is what they said:

'Sometimes I pray that God can take me so that I can find rest', '...or just make this disease to go away.'

The implication is that all respondents became closer to God. They also realise that if they cannot find help on earth they can negotiate and bargain for a divine help.

### **5.5.3 THEME 3: Effect of HIV/AIDS on learners' physical well being**

Most learner participants indicated having difficulty to sleep at night. They indicated various reasons for this, this is what they said:

'I do not sleep well at night', 'I do not sleep because I am afraid that I would die on my sleep', 'I also have nightmares because of my illness', 'I do not sleep because I am afraid that I would die on my sleep', 'I also think and dream about how I would be in my last stages of HIV/AIDS.'

The participants are also having difficulty to eat. This is what they said:

'...my appetite has also decreased', 'Sometimes I do not even eat', 'My weight is gradually dropping.'

These participants also show signs of being affected physically. They said:

*'Then there are times when I have shingles', 'There are times when I have sores all over my body', 'I see myself as thin as a rake and very frail.'*

This is an indication of how severely affected these learners are by HIV/AIDS, they also show signs of being traumatised as one of them have nightmares.

#### **5.5.4 THEME 4: Effect of HIV/AIDS on infected learners' social life**

The learner participants' social life is affected. They indicated being afraid of being raped, not enjoying other children's company as they are not like them and discrimination. This is what they said:

*'...we cannot hang out until late we are afraid of being raped by people who are HIV positive', 'I do not think there is any point in chatting or playing with others I am not like them', 'I do not even enjoy my friends' company I feel that they no longer love me', '...when we fight they threaten me that they are going to tell everybody at school that I am HIV positive', 'I do not take myself as having a social life or being part of the society for that matter', 'I take myself as an outcast', 'They would then mock me and tell me not to play with them as I am going to infect them', 'I do not have time to play', 'I do not think of going out to play with other children I feel guilty', 'I think it is a way of protecting myself from them.'*

These learners seem not to enjoy life like other children who are not HIV/AIDS positive. They seem not to be able to make lasting friends as they have to protect themselves from others. They are living in fear of being attacked for being HIV positive.

#### **5.5.5 THEME 5: Effect of HIV/AIDS on learners' scholastic performance**

All respondents indicated that their scholastic performance has been affected. They indicated lack of concentration, lack of interest, being tired and not having time to think about studies as their reasons for their poor performance.

'When I think about my positive HIV status I see no point in pursuing my studies', 'I cannot concentrate at school, I always think of my status', 'I am not always at school my poor attendance also affects my performance', 'My mind is not at school I am in class only physically', 'I do not have time to do my homework.'

These learners show signs of being demotivated. This is a situation which can lead to them failing their grades and could eventually drop out of school.

#### **5.5.6 THEME 6: Effect of HIV/AIDS on learners' daily routine**

All respondents indicated that their daily routine is affected by mainly their health that is unpredictable. These learners indicated that they cannot plan ahead as being sick and going for check-ups usually disturbs their routine. This is what these learners said:

'Sometimes when I wake up in the morning preparing for school I realize that I have to go for check-up at the clinic', 'I can tell myself that I am going to do my homework in the evening only to find out that I am sick by then', 'There are days when I feel very tired that I cannot even do my class work', 'Sometimes I feel nauseous after I have taken my medication', 'I have to do depend on how my health is that day', 'My health is unpredictable I am well today tomorrow I might be very sick to an extent of being hospitalized.'

The learner participants are unable to enjoy life, play like all other children their age because they have to take adult roles at a tender age.

#### **5.5.7 THEME 7: Coping with being HIV positive**

Some of the respondents have developed ways of coping with the pandemic such as talking to other children about HIV/AIDS, being with other learners at school and relying on the support of relatives. There are however two respondents who seem not to be coping, they feel that there is nothing that can make them cope. This is what the respondents said:

*'To talk to other children about HIV/AIDS helps me to cope', 'I do not think I am coping nothing is helping me to cope', 'Being with other learners at school help me to forget about my status', 'My aunt visits me every month at the shelter. I get a chance of telling someone how I feel', 'I do not think there is anything that can make me to cope.'*

In a search for balance and normality within the abnormality of life where HIV/AIDS rages it is applauded that these learners are finding ways of coping. It is worrisome though that one of them has lost all hope and seems to succumb to the situation.

#### **5.5.8 THEME 8: Support from school, other learners and the community to cope with being HIV positive**

The respondents gave different answers on the support they need from school such as having people who are doctors, nurses, and psychologists to come and educate them about HIV/AIDS, getting a chance to talk to other learners who are HIV positive, being able to talk to educators about problems and having educators who are willing to re-teach the work done in their absence. This is what the respondents said:

*'I think we need to have people who are doctors, nurses, and psychologists to come and educate us about this disease', '...get a chance of talking to people who have been invited by the school especially those who are HIV positive', 'I wish I could get a chance to talk to other learners who are also HIV positive', 'I wish I could be able to tell my educator about my status', 'I wish educators could be more understanding there are days when I cannot do schoolwork in class, I wish I could just be left alone.'*

All respondents indicated that these learners need to be assisted by their peers with their tasks and with being visited at home when they are absent from school to keep them informed about the schoolwork. This is what they said:

'I wish they could be able to assist me with my work and stop talking bad about people who are HIV positive', 'I wish they can help me with the activities in class', 'I wish they could just accept me as I am', 'If other learners could pay me a visit at home when I am absent from school and keep me informed about the schoolwork.'

All learner participants indicated being in need of help from their community with assisting in the shelter, with adoption of children who are orphans, with donating necessities including school uniform and with visiting and loving them. The respondents indicated the following:

'People in the community should help out especially those who are working', 'They should also not discriminate against people who are HIV positive', '.....come and donate school uniform to the centre', 'I think there should be more shelters for children like us who do not have parents or anyone to take care of them', 'I think it is the members of the community who can give us a chance of a better life by adopting us', 'I need the community to just accept me and just love me.'

The responses indicate that there is a lot that can be done by schools, other learners and the community members to support these learners. These learners surely need the support of everyone within their communities to cope, without this support there is no hope for them.

## **5.6 CONCLUSION**

This part of the research dealt with analysing and interpretation of the data collected from a case study of a learner infected with HIV/AIDS and five learners also infected with HIV/AIDS who participated in a focus group interview.

The next chapter presents summaries, conclusions and recommendations of this research.

## CHAPTER SIX

### CONCLUSIONS, FINDINGS AND RECOMMENDATIONS

#### 6.1 INTRODUCTION

In this chapter a summary of the findings from the literature study as well as the empirical design and important deductions are presented. Recommendations for the practical implementation of these findings and for further research are also included.

#### 6.2 SUMMARY AND CONCLUSIONS

##### 6.2.1 Findings and conclusions from the literature study

In the literature study it was found that

- the Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS) have become the most common diagnosis among learners and that many schools in South Africa are likely to see a huge increase in the prevalence of infection and manifestation of this epidemic among learners over the next few years (see paragraph 1.1);
- HIV/AIDS wreaks havoc on the psychological health and mental functions of learners such as memory, concentration, and creativity. Behavioural efficiency and effectiveness, interpersonal relationships and personal productivity are also limited (see paragraph 2.4);
- because of the physical and psychological demands involved in coping with this dreadful disease, it is not surprising that physicians and psychologists have suggested that the experiencing of HIV and AIDS by an infected learner, will have a negative effect on his or her general functioning at schools (see paragraph 1.1);
- learners and educators are at risk of contracting HIV because of ignorance and lack of information on HIV and AIDS epidemic (see paragraph 2.2.3);

- that children who are suffering from HIV/AIDS need comprehensive support from schools, families, communities and society in general. That is why schools need to develop support systems which can help learners suffering from HIV/AIDS, cope with the disease (see paragraph 3.9); and
- having support groups is an important step in the direction of supporting learners and educators infected and affected by HIV and AIDS (see paragraph 3.8).

### **6.2.2 Findings and conclusion from the empirical investigation**

The empirical investigation revealed that:

- they are affected emotionally as they feel like crying all the time, sorry, sad, always thinking of death, disturbed emotionally and feel bad (cf. *Table 4.3*);
- for most of the participants HIV/AIDS made them to be closer to God as they pray occasionally for their health and for others. These participants get comfort in prayer. For the other participants HIV/AIDS is a punishment from God.
- their physical well being is affected. Most learner participants indicated having difficulty to sleep at night and to eat and also show signs of being affected physically.
- their social life is affected. They indicated being afraid of being raped, not enjoying other children's company as they are not like them and discrimination.
- their scholastic performance has been affected. They indicated lack of concentration, lack of interest, being tired and not having time to think about studies as their reasons for their poor performance;
- their daily routine is affected by mainly their health that is unpredictable. These learners indicated that they cannot plan ahead as being sick and going for check-ups usually disturbs their routine;

- they have developed ways of coping with the pandemic such as talking to other children about HIV/AIDS, being with other learners at school and relying on the support of relatives. There are however two respondents who seem not to be coping, they feel that there is nothing that can make them cope;

The respondents gave different answers on the support they need from school such as having people who are doctors, nurses, and psychologists to come *and educate them about HIV/AIDS*, getting a chance to talk to other learners who are HIV positive, being able to talk to educators about problems and having educators who are willing to re-teach the work done in their absence.

All learner participants indicated being in need of help from their community with assisting in the shelter, with adoption of children who are orphans, with donating necessities including school uniform and with visiting and loving them.

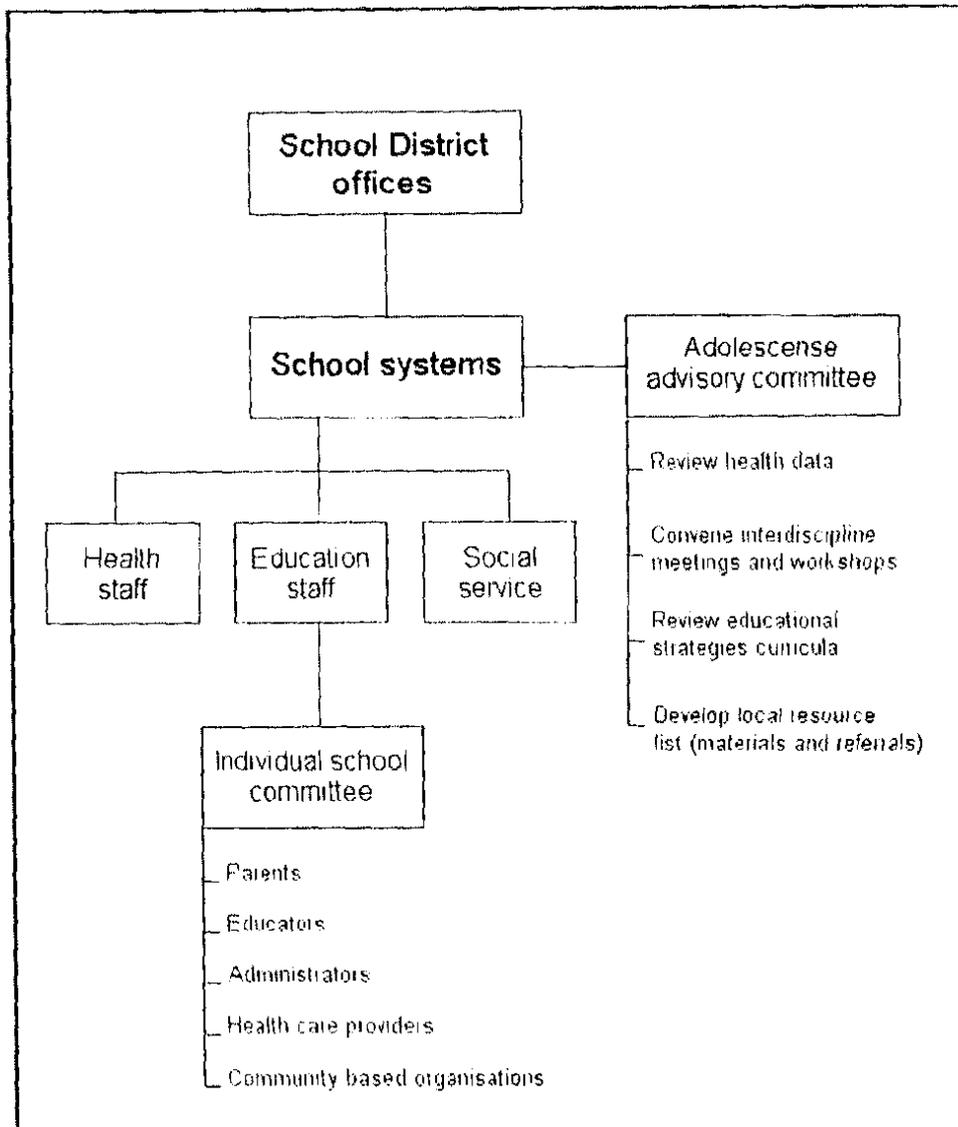
### **6.3 AN ECOSYSTEMIC SUPPORT PROGRAMME FOR HIV INFECTED LEARNERS**

Effective ecosystemic support programme for learners infected with HIV/AIDS at schools can play a major role in shaping the attitudes, opinions and the behaviour of learners infected with HIV/AIDS. A support programme for learners suffering from HIV/AIDS can be only effective and meaningful when it is socially founded on the socio-cultural values of all the social systems that constitute their environment. The environment in this regard forms their social context in the form of families, schools, community and societal systems, which are crucial for determining their experiences.

This section provides an ecosystemic support programme which schools can adopt and adapt in order to fight against this psycho-socially devastating pandemic with a view of reducing its impact on teaching and learning in schools.

The table below shows how parents (family systems), school systems, and community agencies can interact in their concerted effort to deal with the HIV/AIDS pandemic.

**An ecosystemic support programme for dealing with HIV/AIDS at schools (Donahue & Markman, 1999:3).**



- **Schools should have HIV/AIDS education teams** - Primary and High schools should establish HIV/AIDS education teams that include parents, learners, faculty members, and community experts in health,

HIV/AIDS, and adolescent development. To ensure high-quality programme strategies, these schools should be required to establish HIV/AIDS education teams with mandated participation from the school principal, along with parents, learners, school staff, and health experts. Programmes are more likely to be well received and understood by the community as a whole when the entire community has been involved in their development. While Department of Education school districts are in an ideal position to collect and disseminate information about HIV/AIDS issues and to assist schools in identifying model programmes, the school community itself is best suited to select specific strategies to affect a particular goal or objective. School-based HIV/AIDS education teams should give parents, learners, and faculty members a sense of programme ownership, which helps sustain the school's commitment to a programme over time.

- **Schools need to employ counselors** - Because of the high rates of HIV/AIDS infection in South Africa, it would be advisable that paraprofessionals be used. These paraprofessionals can be supervised by qualified counsellors and psychologists working in schools. Initially the supervisor's role would be to provide instruction, coaching, and feedback; raise the level of awareness of the supervisees in regard to areas critical to the counselling relationship; and process observations of group dynamics. Also, counsellor supervision and support should address these emotional incidents counsellors may experience.
- **The Department of Education should ensure that counsellors are trained** - More school counsellors/educators need to be trained, and previously trained school counsellors need their knowledge and skills updated. Department of Education officials could frequently monitor schools to make sure they are compliant with HIV/AIDS education as this education is an important prevention tool. Counsellor training should address the issue of what types of psychological experiences the counsellors may have when counselling HIV/AIDS infected learners.

- **Schools should ensure that needy learners are part of their School Nutrition Programmes** - HIV/AIDS has significant nutrition-related implications and consequences for infected individuals. In infected individuals, HIV contributes to and is affected by nutritional status. Consequences of HIV infection include inability to absorb nutrients from food, changes in metabolism, and reductions in food intake due to HIV-related symptoms. In turn, poor nutrition increases the vulnerability to, and the severity of, opportunistic infections. Poor nutrition can also reduce medication efficacy and adherence, and can accelerate the progression of disease. Poor health and malnutrition prevent children from attending school and from learning while there. The school counsellors therefore should ensure that needy and or infected learners are provided food rations in the form of mid-day meals.
- **HIV/AIDS and education** - School counsellors should be people who are knowledgeable, competent to provide good-quality basic education and skills-based prevention education, which is fundamental in reversing the spread of HIV/AIDS, particularly for girls. Girls are at greater risk of contracting the disease, bear a disproportionate share of its burden and comprise the majority of new infections globally.
- **The role of the government** - The government can play a role of ensuring that voluntary counselling and testing centres operate in an ethical manner in regard to all aspects of their operations, whether it is around confidentiality, advertising, staff training, and support and supervision services. Voluntary counselling and testing services should be accessible and affordable.
- **Voluntary counselling and testing** - VCT should be provided in schools by the counsellors or educators designated to counsel. The VCT should be followed by an ongoing counselling for both those that have been diagnosed HIV negative (to ensure that they remain negative), and those that have been diagnosed HIV positive (to ensure that counsellors provide information about 'responsible sexual

behaviour'). VCT offers a holistic approach that can address HIV in the broader context of learner's lives, including the context of poverty and its relationship to risk practice.

- **Adolescent HIV/AIDS prevention** - A network of education offices for adolescent HIV/AIDS prevention and care should be established to maximize coordination of resources across health and education, and support the development of high-quality interdisciplinary approaches for both school and community-based adolescent HIV/AIDS prevention programmes.
- **Schools should collaborate with other organisations especially those that are dealing with HIV/AIDS** - Government education departments should establish a Health/Education collaborative, a committee including health and education experts, to coordinate across disciplines and to advise on the development of adolescent HIV/AIDS prevention education programme development. Health/Education collaboration would establish a formal linkage between the health and education sectors at provincial level and would have to be dedicated to ensuring high-quality HIV/AIDS prevention education through communication and the coordination of resources. The collaboration would be comprised of health and education professionals who volunteer to participate and who are dedicated to coordinating existing resources within their own professional sector to ensure high-quality programme efforts. Members of the collaboration would work closely with the Department of education office of adolescent HIV/AIDS prevention, serving as advisors to that office and as links to institutional resources. Membership in the collaborative should be solicited from the professional health and education communities, as well as from the public departments of health and education.
- **School systems should establish a health and education HIV/AIDS advisory committees** – The HAC should include educational administrators as well as representatives from the public and private health care community. School governing bodies and school

management teams should tackle complicated and controversial issues as they review and improve their HIV/AIDS prevention education programmes. The public and private health care professionals should assist the school district to develop curriculum, programme, and services strategies by reviewing health data, undertaking risk-behaviour studies, and conducting a local health needs assessment. This assistance would ensure that the programmes and strategies proposed for classroom instruction and school-based services are appropriate to meet the needs of the learners. Reporting to the school district IDSO's, this advisory committee should consist of educational administrators and public and private health professionals who have volunteered to participate.

#### **6.4 CONCLUSION**

In this research it became clear that the culture of teaching and learning can never be realized in schools where HIV/AIDS is prevalent. The duty of schools should not only be to ensure that quality education is provided but, also, to support those infected with HIV/AIDS within these schools.

The researcher has often felt that if learners infected with HIV/AIDS were cared for, supported, respected, tolerated and accepted there would be fewer problems concerning their stigmatisation and discrimination in schools and this would lead to school environments that are more supportive and accommodating to learners infected with HIV/AIDS.

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## **ADDENDUM A**

### **INTERVIEW QUESTIONS: CASE STUDY**

How did you feel when you heard about your HIV positive status?

How did you feel when you heard about Bulelani's HIV positive status?

Were you expecting HIV positive or negative results when you were tested?

Were you counselled before you got tested?

Did you notice any change in Bulelani's behaviour or health after the day she was tested for HIV?

What did you do about this as guardians?

How do you feel about not being told that your parents had HIV/AIDS and that you are also infected?

What could be your reason/s of not telling Bulelani that her parents died of HIV/AIDS?

What do you think your adopted parents could talk to you about concerning your status?

Why are you not asking your teacher some of the questions, especially those that concern HIV/AIDS progression?

Do you ever talk about HIV/AIDS with Bulelani at home when you are relaxing?

What are you supposed to teach learners about HIV/AIDS?

Are they allowed to ask questions on the subject?

Is there a way that you can let these learners choose what they want to talk about concerning HIV/AIDS, that is accommodating their interests?

Why don't you tell the doctor or the nurse at the clinic about your lack of appetite?

What else do you wish you could talk about besides the progression of HIV/AIDS and your lack of appetite?

Which learning areas involve HIV/AIDS at school?

Do you eat healthy or exercise regularly?

What do you do about Bulelani's lack of appetite?

How is Bulelani's performance at school?

How is Bulelani in class?

What do you do at school to help Bulelani catch up with her work after absence?

Is there a way that these learners that are frequently absent because of illness can be given extra classes to help them catch up?

What do you do to help Bulelani at home with her school work?

## **ADDENDUM B**

### **FOCUS GROUP INTERVIEWS**

How is being HIV positive affected you emotionally?

How is being HIV positive affected you spiritually?

How is being HIV positive affected you physically?

How has being HIV positive affected your social life?

How is being HIV positive affect your scholastic performance?

How is being HIV positive affect your daily routine as a learner?

What has helped you to cope whilst living with HIV/AIDS?

What support do you need from your school to cope with being HIV positive?

What support do you need from other learners to cope with how the HIV/AIDS pandemic has affected your performance as a learner?

What support do you need from the community to cope with being HIV/AIDS positive?

What else can be done to support learners who are infected with HIV/AIDS?